Patient/Family Engagement in Acute Care Adverse Risk Reduction

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Disclosures

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Disclosure of Relevant Financial Relationship:
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Disclosure of Off-Label and/or Investigative Uses:
• I will not discuss off label and/or investigational use of any medications in my presentation.

What is Harm and Safety?

• 44,000 – 98,000 deaths per year from medical mistakes
  • (IOM report/rebuttals, Leape, 1999 & 2000)
• Today’s estimate: 400,000 deaths annually attributable to preventable AE’s
• 3rd leading cause of death (following cancer and heart disease)
Patient Safety: Status Check

- Analogy by Former Lt. General Patricia Horoho
- Jumbo jet of deaths per day
- Greyhound bus worth of deaths per day
- Terrible danger and cannot be ignored

- Nurses are the architect of patient safety

- 1 in 10 hospital admissions result in AE
- 2/3 rd have little to no harm
- ½ are preventable
- $17 BILLION /year (just inpatient setting)
Factors that Impact Patient Safety

- Human Factors
  - Multi-task NOT good
  - Safely handle 5-7 pieces of information
- Social Factors
  - Communication
  - Silencekills.com
- Organizational Factors
  - Resource allocation
  - Work arounds

WHY ENGAGE PATIENTS/FAMILY?

- Untapped Resource
- Relevance/Perspective
- Assure Cultural Sensitivity
- Design/Methods
- Funding expectation
- Outcomes

Patient Harm: Patient Engagement

Phase I: Spring 2015
Phase II: Spring 2016
Phase III: 2017

Increased Knowledge about Patient Engagement with Reduction in Harm
Phase I: Explore Patient Centered Interventions to Reduce Acute Care Harm

Team Members
• Tamara Odom-Maryon, PhD
• Beth Schenk, PhD, MH, RN
• Ruth Bryant, PhD (c), RN
• Kara Fitzgerald, BSN, RN
• Huey-Ming Tzeng, PhD, RN, FAAN

Collaborative Sites:
• Washington State University
• Kootenai Medical Center
• Providence St. Patrick (Missoula, MT)
  -- Level II Trauma Center
  -- Stroke Center
  -- 253 beds and over 600 nurses
• Providence Sacred Heart Medical Center
  (Spokane, WA)
  -- Level II trauma center
  -- Transplant center
  -- 650 beds and over 1,900 nurses

Phase I: Strategic Plan
2. Jointly explore and discover interventions that engage patients & family members in promoting patient safety in acute care settings.
3. Identify patient-centered interventions designed to decrease adverse events during hospital stays.
4. Adverse Events:
   • Hospital acquired pressure ulcers, hospital acquired infections, falls and medication errors
5. Model PCORI P2P
   -- Patient Centered Outcomes Research Initiative, Pipeline to Proposal

Patient Centered Outcomes Research Institute (PCORI)
• Nonprofit, nongovernmental organization
• Mandate: “...improve quality & relevance of evidence available to help ... make informed health decisions.”
• Designed to improve patient care & outcomes through patient-centered comparative clinical effectiveness research (CER)
• Goal: which of the many healthcare options available ... work best in particular circumstances.
• Involve patients, caregivers, clinicians, healthcare stakeholders with researchers throughout process
PSAP: Membership & Commitment

- Each site with representatives from patient/family and nurse category
- Nurses (1-3)
- Patients & Families (1-3)
- Hospital Staff (1) & Volunteers (1-2)
- Researchers (6)

Members invited to continue in Patient Safety Research Team

PSAP Meetings

- #1: Focus: Safety and Effective Messages
  - Comfort level in asking questions
  - Introduced: falls, PrUs, HAI, med errors

- #2: Focus: Possible Solutions and Research
  - Real life examples of harm
  - What is research?
  - Ideas of what could reduce risk in 4 areas
    - Patient education through communication
    - Education of patient and providers using technology
    - Empowerment of patient/family members
    - Advocate

PSAP Meetings

- #3: Focus: Introduce Intervention Ideas
  - IVN 1: SPEAK-UP (Empowerment)
  - IVN 2: App or iPad Education (Education w/ technology)
  - IVN 3: iEngaging (Bundled education/empowerment using technology; Specific to fall risk reduction)

- #4: Focus: Role Play
  - IVN 1: SPEAK-UP / MAPS
    - Nurse/ patient and Physician/nurse scenarios
  - IVN 3: iEngaging software
    - Two volunteers
Patient Engagement

• What does the literature say?

Where do we go next?

Need patient/provider input:
➢ How can we empower patients to speak up?
➢ What is required for clinicians to embrace the idea?

Patient Harm: Focus Groups

Phase I: Spring 2015
Phase II: Spring 2016
Phase III: 2017

Increased Knowledge about Patient Engagement with Reduction in Harm
Patient/Family Engagement with Reduction of Harm

• Specific Aims
  1. Explore attitudes and perceptions towards engaging patients in reducing preventable patient harm and safety risks among patients, family members, and health professionals.
  2. Explore attitudes and perceptions towards feasibility of the “Speak-Up/MAPS Intervention”
     • an approach to increasing patient/family engagement, and ultimately reducing preventable patient harm due to safety risks.

Phase II: Methodological Process

Round 1
Explore perceptions of patient engagement with reduction of harm
• Four separate focus groups at two sites = 8 focus groups
• Focus group data shared and reviewed by research team
• Weekly research team meetings to compare notes, discuss findings

Round 2
Discuss feasibility of the Speak-Up/MAPS Intervention
• 8 focus groups (constituents may change)
• Same process
• Summarized Round 1 findings & shared with Round 2 participants

Round 3
Explore perceptions and feasibility of Speak-Up MAPS
• Interdisciplinary subset of participants from Round 1 & 2
• Shared summary of all data
• Discussed feasibility, perceptions and intervention design from interdisciplinary perspective

Round I: Benefits of Patient Engagement with Reduction of Harm

Patients/Families
• We are all in this together
• Families can help prevent falls
• It’s important to understand what medications they are taking and what they do
• Family knows the patient so much better than staff, we can help fill in gaps.
• It requires good communication and trust

Notes
• Get a better health history, a baseline, what meds they take
• Help prevent falls serve as a sitter
• Families know meds better than patients
• Help calm and re-orient the patient
• Help prepare for discharge by planning ahead and asking good questions

“We spend time together; evenings don’t have to be so long. Talking things through, helping one another, preventing all of those things.”

‘I think it’s good to have someone else there. Sometimes you’re so busy, Communications is key, it helps in preventing all of those things.”

‘it’s good to have someone else there who can keep up with everything that’s happening; prevents all of those things. falls, meds, mix-ups.”

‘Understanding that safety is part of their treatment and care while they’re here and that they have a role to play in it.’
Round I: Benefits of Patient Engagement with Reduction of Harm

Physicians
- Help to direct course of hospitalization
- Can reinforce treatment plan with patient
- Very helpful if they have an up-to-date medication list
- Let us know about habits: alcohol, drugs, sleep
- Can ask about end of life issues at the right time for the family

Pharm/PT
- Work together toward goals
- Families can help explain wishes of patients
- Talking about new medications, clarifying what patient takes

“Supportive family members can really help reinforce what therapy tries to teach patients.”

“…finding ways to get patients and families to buy into these concerns about safety and having them be active participants.”

Round I: Barriers to Patient Engagement with Reduction of Harm

Nurses
- Lack of Time
- Gap in knowledge
- Families don’t feel this is their responsibility
- Families sometimes increase agitation
- Sometimes don’t support patient’s wishes
- Too many family members
- Disorientation, opiates, agitation
- Intimidation by caregivers

“Knowledge deficit is a barrier. We have a very short time with most patients and have to teach them so they can take them to do something they don’t know why.”

Round I: Barriers to Patient Engagement with Reduction of Harm

Patients/Families
- Lack of knowledge—what can we help with?
- What are risks?
- Unclear how much new staff knows about our family member
- Need excellent communication—doesn’t always happen, left in the dark
- Bad attitude among caregivers
- If we can’t be at the hospital, and what about people with no advocate?
- Lack of teamwork, it’s difficult to try and piece together everything that is happening

“…you can tell between people who care or don’t care. If you’re not going to call them, you’ll do it yourself.”
Round I: Barriers to Patient Engagement with Reduction of Harm

Physicians
- Don’t always help with very anxious people
- Lack of time it takes time to talk with all the family members
- Care is very complex families don’t always understand it
- When family is not aligned with desires of the patient, it can be a problem
- May not feel it’s their job it’s up to the professionals
- Intimidation

Pharm/PT
- Don’t feel empowered, feel intimidated to ask
  - Cognitive ability, orientation, education
  - Fear retaliation, don’t want to be burden

“…can get frustrating when you explain everything to one group of family, and then another set of family shows up, and then a third set…”

“I’ve reminded patients to use the call light to call, and they’re like, ‘Oh, I don’t want to bother the staff’.”

Round 1: What did we learn?

1. All caregiver groups and patients/families thought patient engagement with safety is an important idea, and worth understanding better
2. Different perspectives uncovered varying ideas:
   - Staff: Busy, notice knowledge gaps, acknowledge sometimes families complicate care
   - Patient/Family: Notice knowledge gaps, point out importance of attitude of staff, want to know what to do
3. First round built cohesion in groups-ready to explore more in Round 2

Round II: Methods

Discuss feasibility of the Speak-Up/MAPS intervention
- 8 focus groups (constituents may change)
- Same process
- Summarized Round 1 findings & shared with Round 2 participants

Specific Aim 2:
Explore attitudes and perceptions towards feasibility of The Joint Commission’s “Speak-Up” initiative combined with an advocate for patient safety as an approach to increasing patient/family engagement, and ultimately reducing preventable patient harm due to safety risks.

SPEAK-UP/MAPS
### Round 2 RNs: How would this role be:

<table>
<thead>
<tr>
<th>Helpful?</th>
<th>Not Helpful or Confusing?</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Lessen # of ?’s we get as we provide care…”</td>
<td>Potential for “…too many cooks”</td>
</tr>
<tr>
<td>Dedicated time to sit with patient/family</td>
<td>“…risk of giving too much or conflicting information about disease”</td>
</tr>
<tr>
<td>2nd person who will be able to negotiate/advocate…</td>
<td>“…family could get in the way asking too many questions”</td>
</tr>
<tr>
<td>Provide guidance if patient or family feels intimidated</td>
<td>Not needed with all patients</td>
</tr>
<tr>
<td>Top 10 list of questions to ask</td>
<td></td>
</tr>
</tbody>
</table>

### Round 2 MDs: How would this role be:

<table>
<thead>
<tr>
<th>Helpful?</th>
<th>Not Helpful or Confusing?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coaching</td>
<td>One more role or person to talk with</td>
</tr>
<tr>
<td>Reinforce that asking ‘?s is encouraged</td>
<td>Duplicative of existing roles</td>
</tr>
<tr>
<td>Build confidence in staff</td>
<td>“Inexperience could cause situation to be overstated or escalated…”</td>
</tr>
<tr>
<td>Not needed with all patients</td>
<td>“Advocacy groups can become obsessed with agenda…over-zealous.”</td>
</tr>
<tr>
<td>Patients with no family especially beneficial</td>
<td>“Duly ambitious…may create more burden for staff.”</td>
</tr>
<tr>
<td>“Anything we can do to help patients be informed and aware is good”</td>
<td>Many family members to keep informed</td>
</tr>
</tbody>
</table>

### Round 2: PT/Pharmacists: How would this role be:

<table>
<thead>
<tr>
<th>Helpful?</th>
<th>Not Helpful or Confusing?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Empowers patient &amp; family</td>
<td>One more person or role rather than using existing staff</td>
</tr>
<tr>
<td>Would have dedicated time to sit with patient/family</td>
<td>“Could be bothersome when staff really busy…”</td>
</tr>
<tr>
<td>Reduce intimidation or guide how to address</td>
<td>“Staff perceive they have extra questions to answer…”</td>
</tr>
<tr>
<td>“Suggest types of questions they could or should ask.”</td>
<td></td>
</tr>
<tr>
<td>“Time dedicated to do this rather than many other responsibilities.”</td>
<td></td>
</tr>
<tr>
<td>Permission…”should be asking ‘?s…”</td>
<td></td>
</tr>
</tbody>
</table>
Round 2 Patients: How would this role be:

**Helpful?**
- Empowering to patient and family
- Could coach patient/family in how to speak up
- “Reinforce and reaffirm patient/family role is to participate in care…”
- Could “orient” to hospital routine (bed alarms, NPO status, when ask for help mobilizing, etc.)
- Act as mediator
- Clarify processes, people, procedures

**Not Helpful or Confusing?**
- “Another layer”
- “…one more person coming into the room…”
- “…might be perceived by staff as criticizing them if we ask questions or make requests…”

Round Three

Attitude, perceptions and feasibility of Speak-Up MAPS

- Interdisciplinary subset from Rounds 1 & 2
- Consolidated data to create brief summary
- Shared with participants
- Feasibility, perceptions and intervention design from interdisciplinary perspective

Round 3: Feasibility of Role?
- Risk of duplication of roles (RN, MD, PT)
- Most nurses and PT already advocate...
- “ANM already rounds on patients and gathers lot of information and shares with staff…” (RN)
- “Terrific! Especially for patients without family.” (Patient/Family)
- “Don’t want staff to feel intimidated by us asking questions, though.” (Patient/Family)
Round 3: How would you react?
- "...if staff person stressed, could push them over the edge...still the right thing to do, though." (MD)
- "Might feel a little like being judged...but need to take ownership" (RN)
- "Adds extra burden, but right thing to do" (MD)
- "...would be helpful to have classes...not a priority when really busy..." (RN)

Round 3: Caregivers comfortable?
- "...heartened staff listening and being so open to patients/family asking questions"
- "Message has to be clear and simple..."
- "...if you see this...you need to speak up...knowing it is okay to speak up"
- Comfort level increased by knowing a person will help them with language

By end of Round 3:
- Large amount of data
- Strong support for idea of MAPS role
- Changed focus from SPEAK-UP to HRO to align with organizational efforts
- Unclear about best CER (Comparative Effectiveness Research Question)
- Would like to go forward...
Patient Harm: Coalition Building

Phase I: Spring 2015
Phase II: Spring 2016
Phase III: 2017

Increased Knowledge about Patient Engagement with Reduction in Harm

Next Steps: Pipeline to PCORI

- June, 2016: Submitted Letter of Inquiry to PCORI
- $50,000 grant to further develop research coalitions
- Yes-We were asked to submit Proposal
  - Due September 30, 2016
- Purposes
  - Build research team and Stakeholder Coalition
  - Details of Study Design
  - HRO-MAPS
  - Staff, Lay, Video
- Grant Period: 1-Oct 31, 2017
  - At end...ready to write full proposal for PCORI grant

College of Nursing