Patient and Family Involvement – experience from the Appropriate use of antipsychotics (AUA) project in LTC

Sept 2016
AHS: Patient/Family involvement

“Upstream” (planning)

Patient Engagement:
• include the patient/family perspective when planning health care delivery (AUA project implementation)

“Downstream” (clinical practice)

Patient Centred Care:
• implement practices that enhance the patient experience and improve key outcomes
• gain the patient/family perspective at the point of care
  • Inclusion
  • Responsiveness
  • Partnering

“Upstream”

“Downstream”
What are Antipsychotics?

• Medications designed to treat psychosis (hallucinations/delusions)

• VERY helpful/necessary for:
  – chronic mental health conditions (Schizophrenia; some types of depression, etc.)
  – Short term for distressing psychosis (e.g. delirium)

• Commonly used to ‘manage’ behaviours in people with dementia (chemical/pharmacologic restraint)
  risperdal; seroquel; zyprexa

• Clearly established evidence of harm when used for long-term in older people with dementia
  – Death: strokes/pneumonia; falls, decreased ability to communicate/engage
AUA: a project in 4 phases

Phase 1 (2012-13) Plan/Develop resources
- AUA Steering Committee
- AUA Guideline – Expert Advisory Group
- AUA Toolkit of resources – working group
- Outcome Evaluation working group

Phase 2 (2013-14) Start Small
- 11 Early Adopter Sites (EAS)
- Innovation Collaborative
- 50% reduction in residents on meds

Phase 3 (2014-15) Scale and Spread
- Provincial implementation to all 170 LTC sites in province (Innovation Collaborates and Education)

Phase 4 (2015-16) Sustainability
- Two additional LWs (Sleep and Delirium on Dementia)
- Trail resources in Supportive Living
## Summary: Family engagement in AUA

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<th>Project stages</th>
<th>Engaging family – project level – planning/feedback</th>
<th>Engaging family at site level in AUA project</th>
<th>Skilling LTC staff to engage family</th>
<th>Engaging family about antipsychotic use in LTC sites</th>
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<td><strong>Phase 1:</strong> AUA steering ctte</td>
<td>Family Advisor on AUA Steering committee</td>
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<td>Developed Staff module on engaging family and resources to use at site</td>
<td>Consent required in Guideline</td>
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<td>- AUA Guideline</td>
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<td>Developed: Family resources</td>
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<td>- AUA Toolkit (staff)</td>
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<td>- MyHealth.Alberta.ca</td>
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<td><strong>Phase 2:</strong> 11 EAS LTC sites</td>
<td>Family reps invited 3 family reps (posters, letters, interviews, etc.)</td>
<td>Media stories</td>
<td>LW#1 - med review steps LW#2 – why engage family? LW#3 – resources for family engagement</td>
<td>Engage in care-planning around responsive behaviours</td>
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<td><strong>Phase 3:</strong> 170 LTC sites</td>
<td>Family focus groups held to get feedback on the family resources (lead by PERG)</td>
<td>Letters phone calls Present to Family Councils</td>
<td>LW#1: stakeholder (families at site); med review, consent; MEASURE family engagement LW#2: FAMILY resources LW#3: meaningful activities</td>
<td><strong>AUA OUTCOME</strong> Evaluation: family reported improved resident Quality of Life, participate in medication discussions</td>
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<td><strong>Phase 4:</strong> Sustainability</td>
<td>Presentations made to family councils; Family advisor collaborated in planning LW content</td>
<td>Sites asked to invite family to LWs</td>
<td>LW#4: Sleep - decrease sleeping pills LW#5: prevent delirium</td>
<td>Encouraged sharing resources with family</td>
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<td><strong>SPREAD: EAS for Supportive Living (SL)</strong></td>
<td>Sites asked to invite family rep involvement</td>
<td>Letters Family Councils</td>
<td>LW#1, LW#2, LW#3, LW#4, LW#5</td>
<td>Planning engagement for provincial spread in SL</td>
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</table>
Site AUA Teams encouraged to “inform” about AUA project at site level – resources provided

Inform

Consult

Involve

Collaborate

Empower

AUA project team provincially
Family representatives “consulted” about resource development (beginning to involve/collaborate)

Care staff “collaborate” with families about antipsychotic use at point of care
Engaging Families in PLANNING

Strategy

• Encouraged sites to invite family to be on SITE implementation planning committee (phase 2)
• Project team engaged with family at project planning stage in developing resources for staff/families (phase 3/4)
• Offered family council presentations on antipsychotic medications (phase 4)

Lessons

• provide more support/direction for teams regarding family advisors
• GOOD collaboration; resources suitable to share with family (not many came to sessions)
• GOOD response to presentations made to family councils
Encouraging Patient/family centred care

Strategy

• Set expectation for obtaining consent in **AUA Guideline**
• Developed resources to support conversations about behaviours/antipsychotics
  – Pamphlets
  – Self-study module on how to have conversations

Lesson

• Not all clinicians ready to engage with family on prescription decisions (yet)
• Concern about maintaining safety in sites when behaviours put others at risk of injury
• Feedback from families: not all WANT to be involved in discussion “leave that to dr”
Family engagement: Lessons learned (so far)

• we are learning as we go AND trying to role-model and encourage good engagement in sites

• ‘easiest’ stage: involve families around care decisions (help with care-planning behaviours; use of antipsychotics)

• Look for the ‘interested’ family to engage in planning – respect their skills!

• Sitting on committees may not BEST way to use families (going to try more focus groups next)
Engagement Resources

Google: “AUA Toolkit” (external AHS webpage)

- Resources for staff to use to engage families about medication use/behaviours/consent

- Module for staff on engaging families in conversations about antipsychotic use

http://www.albertahealthservices.ca/scns/auatoolkit.aspx
Family resources on behaviours and antipsychotic use

MyHealth.Alberta.ca
Key success factors for AUA project

• Leadership support: province, zone, sites, units
• Care Team engagement: local efforts
• Measurement: local tracking/system monitoring
• Lots of communication (project bulletins, media releases) – story telling!!!
• Resources made available to ‘all’ on AUA Webpage – tools/strategies developed to help with local implementation
• Family engagement
Family Presence

Troy Stooke

• Resources for families to help negotiate “being present”
Families are more than visitors. They’re partners in care.
SUGGESTIONS FOR HOW PATIENTS, FAMILIES, ADVISORS, AND CITIZENS CAN ENCOURAGE FAMILY PRESENCE

AT THE POINT OF CARE
- Ask healthcare providers to use words that everyone can understand, not medical jargon. Ask that instructions are written down, and meeting materials are sent in advance.
- Request healthcare providers pay attention to concerns expressed by patients and families.
- Encourage practices that will enhance communication between patients, families and healthcare providers such as “NOD” (Name, Occupation, Duties) and “Teach Back” (e.g. “Can you tell me in your own words how you would explain what we’ve talked about, to a friend”).

ORGANIZATIONS
- Suggest that healthcare organizations update policies and practices to enable family presence, access, or rooming-in 24/7 (for the support person) versus visiting hours (for guests).
- Ask healthcare providers about practices that increase patient and family participation as partners in care. Some examples are:
  - *Shared decision-making* - a collaborative process that allows patients and their providers to make healthcare decisions together.
  - Family sharing the patient’s cultural, emotional and spiritual preferences
  - Family Presence at assessments, or hospital “rounds”, or care planning meetings
  - The opportunity (not the responsibility) for family to help with routine or comfort care
  - Staff support and guidelines for families to be present during difficult, painful or invasive procedures, during critical illness, as well as pre-and post-operatively.
- Find out how patients and families are acknowledged and included in conversations about care, safety, quality improvement, service planning as well as system design, research and evaluation.
- Discover the best ‘point person’ to have these discussions with. It could be a health care provider or manager, a patient representative, a patient/family advisory council, a patient experience department, or quality improvement team.

SUPPORT AND RESOURCES
- Find out about the ways your local healthcare organization listens to patients including the process for concerns or compliments and/or a patient and family advisory committee.
- Learn about other resources from the Institute for Patient- and Family- Centered Care such as the Family Presence Guide: Better Together Pocket Guide for Families.
- The Canadian Foundation for Healthcare Improvement has a full toolkit.
- Learn how Better Together can help you!
WHAT CAN PATIENTS AND FAMILIES DO?

ASK
- Get to know the names of the healthcare providers and what they do.
- Ask questions, clarify your assumptions, be respectful as you ask for information “Could you help me understand why...” or “How can I help?”

KEEP TRACK
- Use a notebook or the back of this document or whiteboard in the patient’s room to write down questions, answers, names, history, tests, observations, etc.
- Choose one person as the main contact to share progress with family and friends, and tell the doctors and healthcare staff as well as other family members.

CONTRIBUTE
- Families have important information that healthcare providers might need to know to provide good care. Find out when the care planning meetings and patient rounds will occur and ask to be present.
- Contribute your knowledge to planning care and the discharge plan.

ENSURE SAFETY
- Write down information about all medicines. This might include medication name, purpose, how often it is taken and how much.
- Ask for instructions in writing, in words you understand.
- Clean your hands.
- Speak up and tell the healthcare team if you are concerned about a change in your loved one’s well-being.

PROVIDE COMFORT
- Discuss if, and how, family members might help with routine care.
- Discuss opportunities for a family member to be present during critical illness, uncomfortable procedures, or just before and right after surgery.