The Need for Family/Resident Engagement in CC in Alberta

• National and provincial health care standards
  – Accreditation Canada
  – Continuing Care Health Standards effective January 2016 (revised June 2018)

• Provincial legislation
  – Resident and Family Councils Act (enacted 2018)
What We Did

• June 2017 – Focus Groups with ICCER members
  – 2 focus groups/discussions (Calgary and Edmonton)
  – 39 participants in total
• Applied an engagement framework to identify best practice processes
What We Did

• June 2018 – Focus Groups with ICCER members
  – 2 focus groups/discussions (Calgary and Edmonton)
  – 31 participants
• Revisited the draft framework
• Discussed opportunities to strengthen engagement strategies
Levels of engagement:
- **Direct care**
  - Consultation: Patients receive information about a diagnosis.
  - Involvement: Patients are asked about their preferences in treatment plan.
  - Partnership and shared leadership: Treatment decisions are made based on patients' preferences, medical evidence, and clinical judgment.

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**Organizational design and governance**
- Consultation: Organization surveys patients about their care experiences.
- Involvement: Hospital involves patients as advisers or advisory council members.
- Partnership and shared leadership: Patients co-lead hospital safety and quality improvement committees.

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**Policy making**
- Consultation: Public agency conducts focus groups with patients to ask opinions about a health care issue.
- Involvement: Patients' recommendations about research priorities are used by public agency to make funding decisions.
- Partnership and shared leadership: Patients have equal representation on agency committee that makes decisions about how to allocate resources to health programs.

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Factors influencing engagement:
- **Patient** (beliefs about patient role, health literacy, education)
- **Organization** (policies and practices, culture)
- **Society** (social norms, regulations, policy)
Continuum of engagement

Levels of engagement

Direct care (bedside) level
- Residents/families receive information about a diagnosis

Organizational design & governance level
- Health quality or internal surveys
- Face-to-face interviews, focus groups
- Social media, online forums
- Family onboarding working

Policy making level
- Discussing policies with residents/families
- Organize events with policy makers and residents/families
- Education sessions

Consultation
- Residents/families are asked about their preferences in treatment plan

Involvement
- Engagement workshops (e.g. sensitivity lunches)
- Family/resident involvement in board meetings
- Resident/family councils
- Resident/family surveys

Partnership and shared leadership
- Treatment decisions are made based on resident/family preference, medical evidence & clinical judgment
- Resident/family involvement in hiring committees
- Channel of communication between board & residents/families
- Resident/family involvement

- Ask residents/families to review new policies before implementation
- Share strategic planning with frontline staff
- Forums, meetings, etc. with government/policy makers

- Resident/family can provide reason/rationale for when they don’t agree with a policy/standard
- Resident/family on board committees, meetings, retreats
2018 Highlights

• Confirmation of experiences across engagement levels was consistent with all stakeholders.
• There tends to be more clarity for engagement at the direct care level across the continuum.
• Organizational and governance levels of engagement tend to emphasize factors contributing to consultation as there is a lack of processes for effective engagement beyond the direct care level.
2018 Highlights continued

• Lack of common understanding and definition of engagement limits organizational and governance levels of consultation. This prevents current approaches of engagement from being considered at the policy level.

• Awareness and consistent agreement that application of the continuum of engagement does not clearly define appropriate levels of engagement for all circumstances (i.e. shared decision making does not define appropriate engagement for all stakeholders in all circumstances).
Direct Care Level

Factors Influencing Engagement

Resident/Family
- Lack of availability and/or interest of residents/families
- Unrealistic expectations of residents/families on service & engagement
- Residents/families unable to understand medical terminologies
- Concern/fear of consequences to care in response to speaking up
- Language barriers
Proposed Solutions

**Resident/Family**
- Involve families in different ways (e.g. using technology)
- Build rapport & trust (e.g. social events)
- Tie meetings to social gatherings
- Use of family onboarding checklists
- Organize equipment demos with residents/families
- Pamphlets & orientation packages for residents/families
- Use plain language
- Educate residents/families about policies & standards
- Document resident/family responses to questions
Direct Care Level

Factors Influencing Engagement

Care Providers
• Staff too busy
• Staff image with families negative
• Staff resistant to change
• Language barriers
• Staff giving up power to residents/families
Proposed Solutions

Care Providers
• Person and family centered care questions included in recruitment interviews and evaluations (e.g. performance reviews)
• Person and family centered care education and supports to be provided to care providers
Factors Influencing Engagement

Organization
• Executive leadership has limited/no experience at front-line
• Management too busy
• No specific engagement team or strategies among staff
• No communication channel between leadership & residents/families
• Time & resource constraints (e.g. staffing levels)
• Lack of clarity on which topic(s) are most appropriate for engagement
• Lack of clear structure or processes to support engagement beyond direct care level
Organizational Level

Proposed Solutions

**Organization**
- Provide clarity & formalize the engagement process
- Provide sources of communication to staff & residents/families
- Appoint staff dedicated to engagement
- Include engagement in staff training
- Include residents/family in staff orientation
- Create “care fair” (e.g. demonstrate equipment)
- Create a “Buddy system” for staff when communicating with family (i.e. HCAs & RNs/LPNs)
- Change HCA role to include communication with families
- Create opportunities for shared decision making (e.g. allocation of fund raising proceeds)
Societal Level

Factors Influencing Engagement

Society
• Lack of understanding on what “engagement” means
• Current definition of engagement does not link clear process with evidence of impact/outcomes
• No common clarity for effective engagement
• No forum for collaboration between government & residents/families
• Funding constraints
• Lack of positive publicity for LTC in the media
Societal Level

Proposed Solutions

**Society**
- Organizations host interaction forums between government & residents/families
- Encourage families to lobby
- Increase fundraising activities
- Ask family members where to direct their donations
Conclusions and Next Steps

• Consensus on engagement strategies represents an evolving priority in CC to ensure care processes and practices result in person and family centered experiences in health care.

• ICCER will continue to support increased awareness and a shared understanding of engagement that supports CC in AB.
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