Updates & Innovations in Essential Conversations for the Health Care Team

Session Topic: **Essential Conversations: Talking to Adults Who Have Challenges in Articulating their Wishes in Medical Care**

Presenter: Camara Van Breemen

Wednesday October 15th, 12:00pm - 1:00pm

Agenda Item	Discussion
Introduction & Key Themes	**Introduction:** • The presentation focuses on communication strategies, inclusion, shared decision-making, and the ethical responsibility to ensure people with intellectual and developmental disabilities (IDD) are included in understanding and participating in decisions about their care.

Presentation Key points	❖ **Understanding Serious Illness and the Role of Advance Care Planning (ACP)**
	• **Definition:** Serious illness carries a high risk of death within a year, significantly impacts quality of life, and burdens both patients and families.
	• **Purpose of ACP:**
	  ○ Enhance quality of life and reduce psychological distress.
	  ○ Enable informed and values-based end-of-life decisions.
	• **Communication Principles:**
	  ○ ACP is an ongoing, cyclical conversation that deepens over time.
	  ○ Builds resilience and prognostic awareness for patients and families.
	❖ **Communicating with People with Differing Abilities**
	• Support individuals with different intellectual or verbal abilities to participate meaningfully.
	• Incorporate play therapy and non-verbal tools to interpret emotions and support understanding.
	• Conversations should be adaptive, repetitive, and inclusive, tailored to each person's communication capacity.
	❖ **Canuck Place "Zones of Health" Framework**
	• **Orange Zone:** Medically stable but at high risk of deterioration (e.g., organ decline, metastases).
	• **Red Zone:** Indicates critical instability or rapid decline.
	• Zones guide when to initiate or revisit ACP discussions.
	• Two key factors:
	  ○ Medical fragility (likelihood of sudden decline).
	  ○ Care stability (frequency of interventions and symptom needs).

❖ **Understanding Intellectual and Developmental Disabilities (IDD)**

- **Definition:** Significant limitations in intellectual functioning and adaptive behavior (social/practical skills).
- **Common conditions:** Down syndrome, autism, genetic disorders.
- **Challenges in Care:**
    - Difficulty distinguishing pain vs. emotional distress in non-verbal individuals.
    - Under-treatment of pain (e.g., limited opioid use).
    - Assumptions that individuals cannot participate in planning.
    - Limited integration between palliative and developmental care specialists.

❖ **Barriers and Inequities**

- Persistent discrimination and exclusion in palliative care.
- Clinicians may avoid difficult conversations due to uncertainty about communication.
- Evidence shows that people with IDD want information about illness and dying; open communication is appropriate and beneficial.

❖ **Rights and Ethical Principles**

- People with IDD and children have the right to:
    - Understand their condition to the best of their ability.
    - Know what to expect and prepare emotionally.
    - Share preferences and be involved in care decisions.
- Health teams must respect developmental levels and expressed preferences.

❖ **Assessing Understanding and Capacity**

- Individuals with IDD vary widely in awareness and communication ability.
- Assess both present awareness and capacity for future-oriented thinking.
- Avoid a binary view of “capable or not capable”; decision-making exists on a spectrum.

Spectrum of Involvement Example:

- Not able/willing to participate → Caregiver makes decisions.
- Shares opinions through caregiver.
- Participates with support.
- Has full control of decisions.

❖ **Legal vs. Trusted Decision-Makers**

- Legal guardians may not be the ones who know the individual best.
- Identify trusted allies (caregivers, support workers, nurses) who understand daily needs.
- Before ACP discussions:
    - Clarify who communicates best with the person.

	○ Determine who should participate in discussions. ○ Identify those who understand the whole care picture.
Group Discussion, Q&A	❖ **<u>Case Example: Dylan</u>** • **Profile:** 20-year-old with leukodystrophy, living between home and a care facility. • **Situation:** Multiple ICU admissions indicate he's in the orange/red zone. • **Ethical Challenge:** Balancing aggressive medical interventions with quality of life and family well-being. • **Lesson:** Care must prioritize comfort, dignity, and awareness capacity. ❖ **<u>Communication Approaches</u>** • Use visual aids (photos, drawings, diagrams). • Simplify explanations using familiar or symbolic stories (e.g., superheroes, family routines). • Ask concrete questions rather than abstract ones. • Focus on present choices (e.g., comfort vs. procedure). • Use assistive communication tools like *Beyond Words*. • Encourage life review and legacy work to strengthen connection and meaning. ❖ **<u>Broadening the Care Lens</u>** • Include all voices: patient, family, caregivers, and staff. • Allocate more time for relational discussions. • Use reflective tools like "Wish, Worry, Wonder" to balance hope with realism. • Explore trade-offs by identifying what makes a "good day" or what is intolerable. ❖ **<u>Reframing Critical Experiences and Trade-Offs</u>** • Replace "critical abilities" with "meaningful experiences" — what matters most to the person. • Reframe "trade-offs" as "setbacks" to make language more accessible to families. • Example prompts: ○ "What are three things that make life meaningful?" ○ "If your child had a setback, what would be worth trying?" ○ "What would cause more harm than good?" • Set clear endpoints for treatment trials and regularly revisit plans. ❖ **Ethical Decision-Making and Conflict Resolution** • When preferences differ between patient and caregivers: ○ Hold separate discussions to explore understanding, fears, and hopes. ○ Bring parties together to identify agreements and disagreements. ○ Clarify stopping points for care escalation. ○ Involve ethics, social work, or psychology teams when needed.

	❖ **Addressing System-Level Gaps**
	• Example: A patient with an M1 MOST form denied hospital transfer due to misinterpretation.
	• Kamara emphasized:
	  ○ M1 assumes access to full palliative support- if unavailable, use M2.
	  ○ Provide education for paramedics and clinicians on contextual MOST use.
	  ○ Regularly review and correct inappropriate documentation.
	❖ **Clinical and System Supports**
	• Connect Place offers:
	  ○ 24-hour consultation for youth and young adults with serious illness.
	  ○ Ethical and communication guidance for complex cases.
	  ○ Support for bridging pediatric and adult palliative systems.
	❖ **Overarching Key Takeaways**
	• ACP is relational, iterative, and context-driven; not a one-time event.
	• Avoid binary views of capacity; engagement is fluid.
	• Combine legal clarity with trusted relational insight.
	• Use creative, individualized communication strategies.
	• Integrate equity, empathy, and inclusion in every discussion.
	• Prioritize dignity, autonomy, and emotional safety for all patients.

Resources	• **Video link**