Not Just at the Bedside: Harnessing the Power of the Patient and Family Voice in Pediatric Educational Activities Outside of the Clinical Care Environment

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Disclosures

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Learning Objectives

• Identify ways in which using patient and family voices introduces vulnerability for participants and educational leaders
• Understand the value in hearing the other perspective (patient and provider) as a way of developing empathy
• Evaluate the variety of ways in which patient and family voices can augment training
• Create an outline for an educational experience using patient and family voices
Introductions
EXPERIENTIAL EXERCISE
WATCHING, LISTENING, LEANING IN

What does video **enable and invite** you to do as a:

- person?
- learner?
- teacher?
Facilitated Reflection Exercise: A Mom Speaks

Something always comes up. You do it again and again and again.
Facilitated Reflection Exercise

• How did this make you feel?
• What did you notice?
• What surprised you?
• If you were sitting next to this mom, what might you say in response to what you heard her say?
Facilitated Reflection Exercise

• How would you use this with trainees?
• How does this compare with your experience as providers?
• Are there strategies you might use to work with this mom?
Large Group Discussion

• How did the family “voice” via video enrich the discussion and learning of your group?

• Advantages/Disadvantages to videotaped vs live?

• How does this compare to other means of teaching?
EXAMPLES
Video Narratives

Sources

• Courageous Parents Network (curated by parents and providers)
• TED talks
• YouTube
• Podcasts (audio)

What should you watch for in selecting videos?

Advantages/Pros of using video in an educational setting

Disadvantages/Limitations
Written Narratives

• Example: “Liza’s Death” prework article

• Read as Pre-work
  – Challenges: Not everyone completes, not shared
  – Advantages: focus on discussion, more time to reflect

• Read Together
  – Challenges: Time, read aloud vs quietly
  – Advantages: shared experience
Patient-Provider Discussions

- Patient family as “expert”
- Power of Patient-Physician relationship
- Chronic disease patients when not acutely ill
- Topic Examples:
  - Adoption
  - Eating Disorders
  - NICU follow up
  - Cystic Fibrosis
  - Inflammatory Bowel Disease
  - Palliative Care/End of Life
Family Co-Facilitators

• Communications Workshops
  – Challenging Conversations
  – Role Play
  – Multidisciplinary
  – Turns in “hot seat”

• Remembering Together
  – Celebrating the lives of patients who have died
  – Parents and Caregivers
  – Preparatory Readings
Formal Presentations

• Family Advisory Council Grand Rounds

• Topic Examples:
  – Provider/parent partnerships
  – Modeling good communication and overcoming breakdowns
  – Parents engaged in quality improvements
  – Physicians as Patient/Providers as Parents
  – What I’d like my doctors to know
Formal Presentations

Grand Rounds: Matthew's Tips for Providers
Choosing and Preparing Families

• Provider and parent long standing relationship
• Parents/patients who’ve been able to reflect on experiences

• Setting the stage / Providing framework
  – Who will be in audience?
  – Timing
• Script
• Set questions
Preparing Learners

• Framing experience

• What we can learn

• What we can feel
  – Handling reactions
  – “When I heard _____, I began to feel/think about ______. I wonder if I feel that way because ________.”

• We are not responsible for others’ actions
SMALL GROUP DISCUSSION
Barriers/Obstacles/Vulnerabilities

• Please discuss at tables what barriers and obstacles might exist to using more patient/family voices in your teaching

• How might you overcome such obstacles?

• What unique vulnerabilities exist in this format?

• How might you provide for these vulnerabilities?
LARGE GROUP REPORT BACK
Benefits to Patients and Families

- Meaning Making
- Legacy Building
- Sense of Self-Efficacy
- Personal Validation
- Empowering Family Advocacy
- Humanizing of Medical System
CREATE YOUR OWN LEARNING ACTIVITY OUTLINE
Planning an Educational Session

• Plan format
  – Degree of interactivity
    • Discussion versus presentation
    • Panel?
  – Audience
    • Same level? mixed?
    • Number of people

• Preparation of learners and speakers
  – Is family known to the audience
  – Is there a longitudinal context
Creating a Learning Activity

• Choose a topic / Create learning objectives
  – What are the hardest things to teach? Can the family voice help?

• Format
  – Written and video narrative examples in packet
  – Grand rounds, panel, small group

• Discussion Prompts

• Resources / Preparation for Participants

• Contingency planning
CREATING A LEARNING ACTIVITY REPORT BACK
QUESTIONS?
What will you take away?
Make a Commitment

Your Name
Your Street Address
City, State 00000

In the next 2 months, I’m going to try...
Let’s Collaborate

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THANK YOU