The Struggle Is Real: Examining Communication Barriers and Strategies to Improve Informed Consent

Learning Objectives
At the end of this presentation, participants will be able to:
1. List and describe four communication barriers that may hinder informed consent.
2. Use the ART cycle to achieve mutual understanding during informed consent conversations.
3. Explain how to use PEARLS when responding to patient and family concerns.
4. Use the “chunk and check” method when participating in the informed consent process.

Difficult Healthcare Conversations
Observe: Bedside rounds, discharge summaries, patient handoffs, bad news, informed consent
Two central questions:
- What is the struggle? Mutual understanding
- What is the result? Errors, noncompliance, readmission, lawsuits, low enrollment
Two central goals:
- Make it easier and more effective by identifying verbal and nonverbal communication strategies
- Teach/train providers, patients, and their loved ones to use communication strategies

Current Focus
As the director of community engagement & the apheresis center for GenCure my focus is improving enrollment:
- Bone marrow registry
- Cord blood
- Blood/cadaveric tissue
- Clinical trials

Discussion Questions
What do you struggle with when consenting patients and their loved ones?
What is the result?
3 types of barriers

This program of research enabled me to identify 3 barriers providers experience during the consent and recruitment of patients and their loved ones:

- Provider, or Recruiter “you”
- Patient, Loved one, Donor “them”
- Context “situation”

Self- Barriers (you)

Characteristics and traits of the provider or recruiter that inhibit enrollment

- Anxiety
- Lack of confidence
- Lack of knowledge and expertise

Uninterested (them)

Patient or Potential donor lack of interest or concern; in their own world, distracted

- Rushing
- Emotional or info overload
- Fear

Mistrust (them)

Unease, active doubt, or suspicion that leads to unwillingness to enroll

- Cultural and religious differences
- Heard an inaccurate story from someone (i.e., family, friends, media, internet, etc.)

Misinformation (them)

Having false or inaccurate information that leads to unwillingness to enroll

- Tattoos
- Weight
- Sexual orientation
- Time & money
- Pain/needles/procedure
- Requires parent’s permission

Context Barriers (Situation)

Lack of infrastructure that supports patient recruitment processes:

- Clinical environment, waiting room, patient portal, visuals, research team approach
- Trained staff, language, communication strategies, inclusion criteria, prevent fall out
- Technology- tracking patient progress, history,
- Organizational culture- norms, confidence, buy in
How can you minimize the struggle?

5 Communication Strategies:
- Get Ready
- Grab Attention
- Use the ART CYCLE
- Convey Empathy Using PEARLS
- Chunk & Check

Get Ready
- Reflect: increase your own awareness
  - What personal barriers do you experience?
  - How does your appearance play a role in the recruitment process?
  - How does your culture influence the recruitment process?
  - What unintentional messages might you be sending with your body language?
- Prepare (who, what, when, where)
- Practice (anticipate questions, concerns)

Grab Attention
- Sit close
- Introduce self ask their name
- Explain what you are doing there
- Ask questions to get a conversation going- build rapport

Build Trust
- Use their name early in the conversation
- Be honest and admit when you don’t know something
- Refer back to their comments
- Focus fully on them

Use ART Cycles
- ASK, Respond, Teach) to overcome barriers:
  A: Ask what they know “What do you know about participating in research” OPEN QUESTIONS
  R: Respond “That’s right you could experience side effects we may not know about yet”
  T: Teach- identify what you want them to know and understand

Teach using “Chunk and Check”
- Identify bite size knowledge claims that can be chewed, tasted, and digested
- What are the 3 things you want them to understand after the consent discussion?
- Discuss 1 thing at a time pausing to check for understanding before moving on (teach back)
- Turn a monologue into dialogue
Convey Empathy using PEARLS

- Partnership: “Let’s work on this together”
- Emotion: “You say you’re frustrated”
- Apology & Appreciation: “I’m sorry that upset you”
- Respect: “I give you a lot of credit for getting through this as you have”
- Legitimization: “Most people in your position would feel the very same way”
- Support: “We are going to stick with you through this”

Communicate Confidence

- Eye contact
- Confident tone and speech rate
- Open body language
- Talk slowly and clearly
- Avoid vocal fillers and nervous gestures
- Use space

Recap

What communication barriers may hinder the informed consent process?

What communication strategies can you use to improve consent conversations?

How can you apply what you learned today when working with patients and their loved ones?