10/30 Interview Summary

Rae, Natalie, Justin

#1, Janene (neonatologist)

3 golden nugget quotes:

- 1. "If I'm the one breaking down, it takes the focus off the parents. It's about their relationship with the baby."
- 2. "The attendings tell parents to ignore the monitors and just focus on being parents, but I don't see how they can do that."
- 3. "I explain most of the risks, but parents don't really hear them."

Take-away: Janene wants to appreciate the parents' perspective, but her primary job is to care for the baby.

#2, Scott (dad)

3 golden nugget quotes:

- 1. "I looked at the numbers as soon as I got in the room. My wife looked at the nurse."
- 2. "We could say we were going to make the logical decision, but we knew if we looked at him, and saw that glimmer of hope, we wouldn't be able to help ourselves."
- 3. "You watch O2 drop 90 to 50, you know they have to resuscitate. You hear an alarm, then you ask, and find out what the alarm means. Most people learn what the numbers are like this."
- 4. "It's like skimming a textbook: you're reading the chapters, but not really understanding anything."

Take-away: Scott deals with his emotions by researching logical information, but doesn't have a structured way to learn about the NICU.

#3, Joan (nurse)

3 golden nugget quotes:

- 1. "Reassure the parents? I'm not sure I can reassure the parents, but I explain what we' re doing."
- 2. "If there is a mom who doesn't speak English, I put my hand on her shoulder so we have made that connection by the time we get an interpreter."
- 3. "The parents that were most traumatized were the ones who took their baby home, then had to come back."

Take-away: Joan cares a lot about connecting with the patient's parents.

#4, Liz (mother)

3 golden nugget quotes:

- 1. "Surprises about her health came up on a daily basis once we got home."
- 2. "We had to take a crash course in becoming a NICU nurse."
- 3. "Different teams gave us conflicting information, but our nurse gathered everyone for a care conference and got us all on the same page. She was our glue."
- 4. "We had to learn about metabolic processes, but I was ok with that. I wanted to learn"

Take-away: Liz wants to learn as much as she can, but she has to do so in an extremely high-stakes situation.

#5, Preemie Support Group

3 golden nugget quotes:

- 1. "I had a notebook and pen and it lived in my handbag. Anytime a nurse mentioned anything I wrote it down."
- 2. "It helped to write things down when I would finally get to see D.H. [da husband] because I could explain to him everything that had happened (since my brain was not on the remembering train)."
- 3. "After reading and understanding the types of monitors and machinery my baby may have needed at each stage, I felt much better knowing WHY these things were attached to our son when he was born."

Take-away:

Parents want to fully understand what's happening to their child, but there is so much information that it's difficult to keep track of it all.