Patient and Family Advisory Council
Thursday, Nov 12, 2020
5:15pm - 7:15pm
Zoom

Seattle Cancer Care Alliance
Fred Hutch · Seattle Children's · UW Medicine

Key Takeaways:

Pilot project logistics:

- Focus on patients and caregivers
- Leverage existing structures for communication such as white boards in patient's rooms to escalate concerns
- Upfront encourage staff and providers to welcome patients to bring up their safety concerns and that they are part of the team
- Preference to focus on the "how" to speak up and on the training to staff to receive the information in a positive way (eg. staff should always thank patient for raising the concern)
- Recognize negative risks: making the patient feel if they don't speak up they are unsafe or depleting their resources/energy trying to speak up for their safety
    - Needs to be very clear that providers are still ultimately responsible for patients safety

Reflections from participants:

<u>Has anyone here spoken up for safety while receiving care? How did that feel? What was the outcome?</u>

- **Participant One:** I felt like I could never relax because I needed to be on point at all times while receiving care. I would be nervous when taking premeds because I wouldn't be able to be on point to monitor my own care. There were two instances where **I felt resistance from the staff because the staff thought they were doing things right.** It was very traumatic, not just how it felt at the time but the effect it has 7-8 years later.
- **Participant Two:** My husband had his first transplant and was in infusion to receive a transfusion and fluids. He had a low-grade fever, which didn't allow for him to receive the transfusion. I couldn't take him home unless his fever went down, and he couldn't be admitted unless his fever went up. It was not charted that he did not received the transfusion or that he had a low-grade temp. **I felt bad about complaining and didn't know who to turn to even though I was well initiated to the system.**

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- **Participant Three:** When I have MRI's with contrast, I remind staff to use contrast that is not harmful on the kidneys**. I always feel like I should remind them, and I feel heard when I bring it up.**
- **Participant Four:** I ended up waiting on a stretcher in a hallway while I was neutropenic and had a fever of 105. I was fortunate to have my phone with me and contacted my husband and my nurse came to get me. She was very reactive and followed up with the provider and with me. However, **I never received any resolution or had anyone call to close the loop.** Speaking up for safety needs to be something that can be understood without exhausting the patient's energy or cause a negative reaction.
- **Participant Five:** While in the ED someone entered my room with a mobile chest x-ray, and I didn't have anything wrong with my chest. I was confused as to why I needed to have this chest X-ray. I remember feeling "handled" because they were used to confrontational patients in the ER. **I felt like I was not being listened to and they were just viewing it as a refusal and noncompliance.** Once they checked my MRN they realized that they had the wrong patient.

<u>What can we do to better prepare providers to receive patients speaking up for safety?</u>

- **Participant One:** Right from the beginning **it was communicated to me that I was part of my own team and if I felt something was not right, I should speak up.** Communication is always number one. Patients are scared and sick, but they need to know what is expected of them. If they feel like something is wrong, they need to speak up and the doctors need to be receptive when they do raise concerns.
- **Participant Two:** Terms like safety and medication errors may scare patients, but if you **make safety part of the everyday conversation it is more approachable.** Utilizing the boards in the rooms would be a great place to include safety information. Nurses do a great job of constantly explaining why they are doing something, and that simple step by step process creates trust and understanding. When staff use simple language, it can help to bring patients into the discussion.
- **Participant Three:** Build a vernacular around "care requires safety". **The focus on safety should demonstration how we care for and value patients.** It is important to have multiple perspectives, isolating patient or caregiver input only would leave you with an incomplete analysis. When thinking about what to choose and how to canvass, think about how that would impact the patient. It needs to be something that can be understood without exhausting the patient's energy or cause a negative reaction emotionally.

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- **Participant Four:** The nurse I had the first day of chemo is the one who taught me to speak up. The nurse told me to let her know if something didn't feel right or if I had questions. She told me **I should feel empowered to be my own advocate.** It was done in a very subtle, caring, and supportive way. The patients are a partner, but they are not responsible for making sure that an error does not occur.
- **Participant Five:** Infusion nurses were amazing trainers about safety and modeled it well with their communication with each other. They took the drama out of it showed me that feedback is part of the process. I always felt safe in that environment. They asked patients if what was happening was what they expected, this prevented undue surprise or fear. It is important to let patients know these are the types of things we can and should talk about**. Anytime a patient brings up any concern, clinic staff's response should be thank you,** it takes away the fear of reprisal.

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