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# Patient-Perceived Breakdowns in Care: Informing Clinician Responses

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# Disclosures

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# What is a patient-perceived breakdown in care?

- Any event in which something “went wrong” in care from the perspective of the patient or the family member
- In some studies, definition includes that event was preventable and resulted in harm (impact) to the patient
- Not all (in fact, most) patient-perceived breakdowns may not meet “traditional” definition of medical error

# Types of patient-perceived breakdowns

Type of breakdown	Total = 979 n (%)
Information exchange (insufficient information; providers not listening to patient; difficulty getting questions answered)	158 (16.1)
Medication-related (pain control), side effects, wrong meds, med admin	120 (12.3)
Access and relationship with provider (no/suboptimal access to provider; providers with rude manner)	100 (10.2)
Admission process (long wait on admission)	90 (9.2)
Team communication	65 (6.6)
Nursing care and responsiveness	63 (6.4)
Discharge (timing, arrangements, information)	56 (5.7)
Treatment (not available, too aggressive, not appropriate)	34 (3.5)
Diagnosis (delayed, no diagnosis, conflicting diagnoses)	33 (3.4)
Testing (not offered/available, delayed, denied)	21 (2.1)

# Some examples from the ICU of surrogate-DM difficulty getting information

“I didn't have a really clear idea of who to go to for information.”

“I thought there was little silos of information.”

“I had asked them multiple times for more information and paperwork. And they didn't give it to me.”

# Why are patient-perceived breakdowns in care important? (they are common)

Population	Clinical sites (n)	N screened	Breakdown reported, n (%)
Patients treated for cancer	3	416	93 (22.4)
SDMs of critically ill patients	1	70	32 (45.7)
Hospitalized patients	2	979	386 (39.4)

Mazor et al., J Clin Oncol. 2012 May 20;30(15):1784-90.  
Fisher et al., Patient Educ Couns. 2016 Oct;99(10):1685-93  
Fisher et al., J Hosp Med. 2017, (accepted for publication).

# Why are patient-perceived breakdowns in care important? (they are harmful)

- Impact of breakdowns in care (as reported by patients)
  - Physical harm (includes pain)
  - Emotional distress (worry, anger, frustration)
  - Damaged relationship with providers (care avoidance)
  - Need for additional medical care (prolonged hospital stay or re-hospitalization)
  - Provision of healthcare not in keeping with patient's preferences
  - Disruption to patient's or family member's life
  - Impaired decision-making ability
  - Financial costs to patient

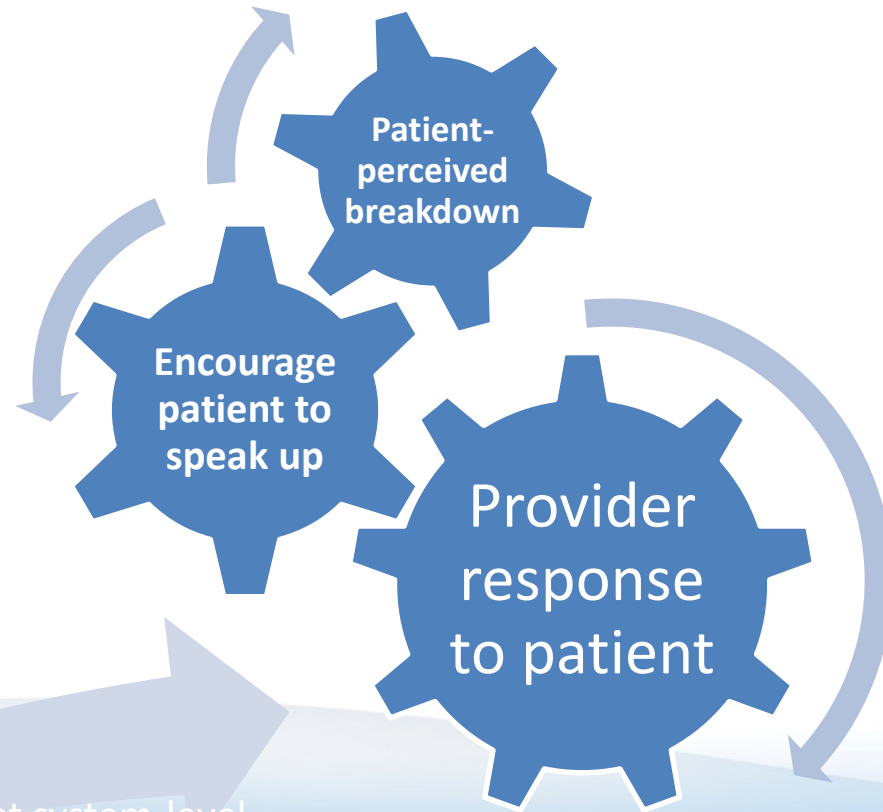


# Impact of patient perceived-breakdowns on decision making

“I’m responsible for his medical decisions when he’s in that situation. I need to have all this information. I need to not have conflicting statements constantly. You don’t know what to do.”

“I can't think of anything specifically that went wrong, other than her being intubated in the first place. My mom has always said she never wanted to be intubated.”

# How can patient-perceived breakdowns in care be used to improve healthcare?



Systematic reporting of patient-perceived breakdowns (HCAHPS)

Identify common breakdowns

Target system-level improvements

# How do patients want providers to respond?

“Now I understand. I get that. All you have to do is just let me know. Let me be on the same page.”

“It definitely helped that she was apologetic.”

Patients receive fully and satisfactory response in ~ 25% events

# How do providers frequently respond?

Limited response in ~ 50% events

“One of the nurses found a doctor to talk to me. But it wasn’t sort of a person who knew completely about her care. It just happened to be the resident who was on the unit at that time.”

Hostile or no response ~ 25% events

“When I questioned the doctor he got kind of belligerent with me.”

# Conclusions

- Patient-perceived breakdowns in care are common and harmful events
- Interventions to address patient-perceived breakdowns are needed to make healthcare more patient-centered
- Provider engagement will be required to effectively address patient-perceived breakdowns in care
  - Need to understand provider perspective of patient-perceived breakdowns in care and factors that influence their response
  - Develop interventions (communication skills training, apology training)

# Thank you.

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