Talking with Parents About Unexpected Birth Outcomes

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What Would You Tell the Parents? Case #1

- 37 year old G2P1 admitted to L&D for possible repeat cesarean at 37 weeks due to history of classical cesarean section.
- Pregnancy dating: Unsure LMP. Patient was out of the country and did not start prenatal care until 28 weeks of pregnancy, when first US was performed. Amniocentesis reveals mature FLM (fetal lung maturity)
- Surgery performed and 5 lbs. baby boy delivered without complications. Infant required resuscitation and NICU transfer, 10 days on ventilator and CPAP support. Infant went home after three weeks.
What Would You Tell the Parents? Case #1

- After the delivery, the obstetrician reviews the maternal medical record and realizes that among the three amniocenteses performed that morning, the wrong chart and thus the wrong fetal lung maturity value for this patient was read.

- The amniocentesis for this woman actually shows immature fetal lung indices.
What Would You Tell These Parents? Case #2

- 33 yo G3P2 with no comorbidities has been undergoing routine prenatal care for an uncomplicated pregnancy.
- During a visit fundal height noted to measure size less than dates at 34 weeks. The growth US ordered reveals head measurements in the 3rd percentile, overall growth in the 12th percentile.
- Ordering provider received report, but was out of the office on vacation, and contacted covering senior provider for an opinion on the report and suggesting to start antenatal testing and send patient for MFM consult.
What Would You Tell These Parents? Case #2

- Covering provider decided that additional testing was not necessary and that patient should have repeat growth US in 2-3 weeks.
- Patient presented to routine prenatal care visit 2 weeks later with an IUFD.
- Placental pathology consistent with abruption.
A Challenging Conversation

I WOULD RATHER TELL 18 PATIENTS THEY HAVE BREAST CANCER THAN TELL ONE PERSON THEIR BABY IS DEAD

- PROVIDER
Objectives

- Understand literature on Error Disclosure
- Describe the **challenges** around communicating with parents about unanticipated adverse birth outcomes
- Outline **critical communication skills** and other tools that can enhance communication with parents about adverse birth outcomes.
- **Practice** these communication skills (today and tomorrow)
Patient’s Perspective

- A study in 1996 showed that 98% of patients wanted to be informed of even minor errors. (1)

- Focus groups in 2002: patients wanted disclosure of all harmful errors
  - what happened
  - Why

- Emotional support and an apology. (2)

Physician Disclosure Practices

- A 1991 study published in JAMA, 76% of Medicine residents said they did not disclose a serious error to a patient and 46% did not tell their attending\(^{(1)}\).

- In 2002, a NEJM survey of physicians and members of the public showed only 30% had experienced disclosure or apology when harmful medical error occurred. \(^{(2)}\)

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2. Blendon RJ, DesRoches CM, Brodie M. Views of practicing physicians and the public on medical errors. NEJM. 2002
Physician Disclosure Practices

• Focus groups with IM & General Surgery physicians agreed that harmful errors should be disclosed but they “choose their words carefully” when talking to patients. (1)

• In 2003-04 surveys were mailed to medical and surgical physicians in WA, MO, and Canada with 4 scenarios depicting serious errors that varied by specialty and how obvious the error would be to the patient. (2)

## Table 2. Clinical Scenarios

<table>
<thead>
<tr>
<th>Type of Scenario</th>
<th>Description</th>
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<tbody>
<tr>
<td>Medical</td>
<td>You have admitted a diabetic patient to the hospital for a COPD exacerbation. You handwrite an order for the patient to receive “10 U” of insulin. The “U” in your order looks like a 0. The following morning, the patient is given 100 U of insulin, 10 times the patient’s normal dose, and is later found unresponsive, with a serum glucose level of 35 mg/dL (1.94 mmol/L). The patient is resuscitated and transferred to the intensive care unit. You expect the patient to make a full recovery.</td>
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<tr>
<td>Hyperkalemia (less apparent error)</td>
<td>You administer a new medicine with a common adverse effect of increasing the potassium level to an outpatient with hypertension. The patient’s baseline potassium level is normal (4.5 mEq/L). You order a repeat blood test to measure potassium level, to be drawn the next week, but forget to check the laboratory results. Two weeks after the patient begins taking this new medicine, the patient starts feeling palpitations and goes to the emergency department. In the emergency department, the patient experiences an episode of ventricular tachycardia, requiring cardioversion. The patient’s potassium level at this event is 7.5 mEq/L. The patient is hospitalized for 4 days, and makes a full recovery. The patient returns to your office for a follow-up visit. On reviewing the patient’s chart, you see the overlooked laboratory results, which showed the patient’s potassium level had increased substantially from 4.0 to 5.6 mEq/L. Had you seen this elevated potassium level earlier, you would have discontinued the new medicine and treated the hyperkalemia, likely avoiding the life-threatening arrhythmia.</td>
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<tr>
<td>Surgical</td>
<td>You are seeing a patient 3 weeks after elective splenectomy for ITP. The splenectomy was technically challenging because of the patient’s obesity, but seemed uncomplicated. At this follow-up visit, the patient complains of vague persistent LUQ pain. You send the patient for an abdominal x-ray film, which shows a foreign body consistent with a retained surgical sponge in the patient’s LUQ. You remember that the sponge count was correct at the end of the procedure. However, you also remember that you packed off a small bleeding vessel near the stomach with a sponge, and do not recall removing this sponge. When you review the postoperative records, you observe that a math error was responsible for a falsely correct sponge count. You believe a subsequent operation to remove the retained sponge is indicated, and expect the patient will make a full recovery.</td>
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<tr>
<td>Bile duct injury (less apparent error)</td>
<td>You are performing a laparoscopic cholecystectomy. In the informed consent before surgery, you explicitly told the patient that an open procedure might be required. A surgical device representative has asked you to try a new coagulation/dissection device. He mentions in passing that the tip of the device can get hot. You are dissecting with the new device, and the procedure is going smoothly. A surgical resident asks you a question. With the dissection device off, you look in the resident’s direction to answer the question. When you turn back to the operative field, you realize the tip of the dissection device is resting against the common bile duct, which has been burned. You did not realize that this new device could cause such tissue damage even when turned off. You convert the procedure to an open cholecystectomy and repair the injured common bile duct. The remainder of the procedure is unremarkable, and you expect the patient to make a full recovery.</td>
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**Abbreviations:** COPD, chronic obstructive pulmonary disease; ITP, idiopathic thrombocytopenic purpura; LUQ, left upper quadrant.
Physician Disclosure Practices

What Physicians would disclose about error

- Partial Disclosure (mention adverse events but not error): 56%
- Full disclosure (explicit statement that error occurred): 42%
- No disclosure (no reference to adverse event or error): 3%

Percent of Physicians agreeing
Physician Disclosure Practices

- Use word "error": 58% (Medical), 19% (Surgical)
- Specific details about error: 61% (Medical), 35% (Surgical)
- Explicit Apology: 41% (Medical), 21% (Surgical)
- Preventing Error: 52% (Medical), 16% (Surgical)
Physician Disclosure Practices

- In 2005, testing skills of General Surgeons while disclosing errors in simulations
- Each surgeon discussed 2 of 3 error scenarios (wrong-side lumpectomy, retained surgical sponge, and hyperkalemia-induced arrhythmia) with standardized patients
  - 65% took responsibility for error
  - 47% offered apology
  - 8% discussed how error would be prevented.

Chan DK, Gallagher TH. How surgeons disclose medical errors to patients: A study using standardized patients. Surgery. 2005
# How is birth different?

<table>
<thead>
<tr>
<th>Perceived as a positive experience</th>
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<tbody>
<tr>
<td>Perceived as natural and “perfect”</td>
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<tr>
<td>Two patients, one body</td>
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<tr>
<td>Family event</td>
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<tr>
<td>Multiple providers</td>
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<th>Highly anticipated</th>
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<td>Dynamic process, can go bad quickly</td>
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Empiric Research: Unanticipated Birth Outcome

- Parent interviews
  - N=27
  - Parents who experienced unanticipated birth outcome
  - Three geographic areas

- Provider focus groups
  - N=6 groups, 46 total provider participants
  - Mix of OB, Peds, nurses, midwives

- Supported by The Doctors Company Foundation
Patient reactions to communication

Patients reported feeling:

- Angry
- Sad
- Frustrated
- Scared
- Alone and/or “in the dark”
Patient Challenges

- High expectations
- Lack of explanation why
- Inconsistency in provider and institutional messaging
- Problems processing information
- Confusion about provider roles

- Feeling alone after birth and “left out of the loop”
- Self blame and shame
Patient’s changing emotions

Factors that may influence change

- Baby’s current health status
- Family/Friends
- Input from providers not involved in the event
- Resolution about why the event happened
- Acceptance that mistakes happen and everyone did the best they could
Provider Challenges

- Medical unknowns and changing storyline
- Transfer of care and information
- Many providers involved
- Extreme differences in perception of severity
- Two patient dynamic
- Communication with multiple family members
Provider Challenges

- Fear of litigation
- Own emotional response to event
- How to react to blame from patients
- Lack of feedback on how to improve communication
- Wording & nonverbal communication
- Consent in emergent situation
Quality of Actual Disclosures

- COPIC
- 3Rs (“Recognize, Respond, Resolve”) program for disclosure and compensation, 2007-2009
  - 837 Events
  - 445 patient surveys (55% response rate)
  - 705 physician surveys (84% response rate)
## Event Severity

<table>
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<tr>
<th>Event Description</th>
<th>Patient Assessment</th>
<th>Physician Assessment</th>
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<tbody>
<tr>
<td>Extremely serious (I might have died)</td>
<td>31%</td>
<td>7%</td>
</tr>
<tr>
<td>Very Serious (permanent injury)</td>
<td>25%</td>
<td>25%</td>
</tr>
<tr>
<td>Somewhat serious (injury that resolved)</td>
<td>28%</td>
<td>61%</td>
</tr>
<tr>
<td>Not at all serious</td>
<td>3%</td>
<td>6%</td>
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</table>
"I THINK THAT WHATEVER THE SITUATION IS, IT SHOULD BE LAID OUT AND PUT ON THE TABLE. HERE'S WHAT IT IS. HERE'S WHAT WE'RE DEALING WITH. AND ALL COMMUNICATION SHOULD ALWAYS BE UP FRONT, AND TO THE POINT, AND EASY TO UNDERSTAND, DELIVERED WITH SYMPATHY AND EMPATHY."

-PATIENT
Factors that helped patients

- Physicians taking time to talk to the patient or making themselves available
- Consistency in care and provider messaging
- Information/full explanation/diagnosis/next steps
- Social support
- Nurses
- Being with/seeing the baby
- Words of comfort/calming
- Sincerity/empathy
In Summary...

- **Patients need**
  - Truthful, accurate information
  - Emotional support, including apology when appropriate
  - Follow-up, potentially compensation

- **Health care workers need**
  - Help preparing for a disclosure
  - Emotional support

- **Process, not an event**
  - Initial conversation
  - Event analysis
  - Follow-up conversation
Step 1: Planning

- Most common failure – lack of planning
- Ensure you understand what happened
- Agreement on what will be disclosed (in consultation with RM)
- Plan roles for discussion if not alone
Step 2: Prepare

- Turn pager off
- Have someone cover for you
- Sit down when talking to patient
- If applicable have most recent update from NICU
Step 3: What does the patient know?

- Ask what they know so far and then really listen

- Empathic communication is curiosity about what patient is feeling
Step 4: What does the patient need?

- They want to be heard

- They won’t listen until they are heard. Address emotion first

- Acknowledge and validate emotion

- Be human: “shed the white coat”
Step 5: Initial Conversation

- Review of the facts (no speculation!)
- Avoid medical jargon
- Clear, honest communication of regret
- Steps to investigate event
- Who will speak to the patient next, and when
- Offer of support services to patient/family
- Close with sincere expressions of support, sympathy, concern
“I’m sorry” ≠ “Apology”

- “I’m sorry for what has happened to you” is always appropriate
- Do not blame “the system” or colleagues.
- Be careful of apologies that include “butts”
  - “I’m sorry, but if the physician had only called me...”
- “I’m sorry for what I did to you” appropriate only when unanticipated outcome due to clear-cut error or system failure
Communication Strategies

- Addressing uncertainty
  - Despite intensive investigation, it may be unclear if error occurred or whether error caused bad outcome
  - Just-in-time coaching for clinicians is key
    - Avoid understandable impulse to connect dots that can’t be connected
  - In some situations, may be best to share final results of investigation with parents even if uncertainty remains
    - Perceived absence of transparency powerful driver of litigation
when things go wrong
“At some point we must all bring medical mistakes out of the closet. This will be difficult as long as both the profession and society continue to project their desires for perfection onto the doctor”

“Facing our mistakes”
Disclosure is not now, and never will be, a risk management technique.

Disclosure is not intended to stop people from suing, or requesting compensation.

Disclosure honors the patient’s right to autonomy to make decisions about care.
Disclosure is also the only path to obtaining, maintaining, or regaining patient and family trust.

To increase the willingness of providers to disclose, the culture must shift to support provider and staff humanness.
References
References

5. Blendon RJ, DesRoches CM, Brodie M. Views of practicing physicians and the public on medical errors. NEJM. 2002
10. Shanafelt. Burnout and Medical Errors Among American Surgeons. Annals of Surgery • Volume 251, Number 6, June 2010