The Voice of the Patient

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Synopsis of a Medical Error

- Lewis, a healthy 120-pound boy, is prescribed a five-day adult course of the NSAID ketorolac tromethamine following surgery.
- Adequate fluid levels are not maintained.
- Three days after surgery, Lewis begins complaining of severe, unremitting epigastric pain.
- Nurses and residents fail to act upon increasing signs of instability.
- Parents’ request for an attending physician is not honored.
- Four days post-op, following 30 hours of deteriorating vital signs, including four hours of completely undetectable blood pressure, Lewis dies. He has not seen an attending physician for over two days.
- Autopsy shows a giant duodenal ulcer and 2.8 liters of blood and gastric secretions in the peritoneal cavity.
Failures in Care

- Unfamiliarity with pediatric dosing
- Unfamiliarity with medication contraindications/side effects
- Failure to consider the possibility of medication reaction
- Unwillingness to challenge incorrect orders
- Unwillingness to change the plan
- Failure to recognize the signs of sepsis and shock
- Prolonged inaction in the face of alarming symptoms (“clinical futile cycles”)
- Undue deference to hierarchy
- Unwillingness to intervene with someone else’s patient
- Delay in calling code
The Lewis Blackman Act

• All clinical hospital workers are identified by name, department, and status.

• Patients are provided written information about the role of students in the hospital.

• If asked, hospital staff must call a patient’s attending physician or provide the physician’s phone number to the patient.

• Hospitals provide a means through which patients can call directly for assistance if they feel they need to do so.
South Carolina Hospital Infection Disclosure Act

- Hospitals submit reports every six months on their hospital-acquired infection rates for specific clinical procedures.

- The health department validates the data.

- Each hospital’s infection rates are posted on the health department website.

- The health department advisory committee has equal representation from diverse interest groups, including business and consumers, and has latitude to expand the scope of reporting.
The Empowered Patient Coalition

Informing Patients
Building Partnerships

- Factsheets and Checklists
- Advocate Directory
- Patient Resources
- Report a Medical Event
- Publications & Videos
- Join Our Email List!

www.empoweredpatientcoalition.org
The Empowered Patient

Hundreds of LIFE-SAVING facts, action steps and strategies you need to know

Dr. Julia A. Hallisy
A GUIDE TO HOSPITAL CARE FOR PATIENTS AND FAMILIES

www.empoweredpatientcoalition.org
What Patients Need to Know

• The Basics: Documents, advocates, hierarchies, informed consent and medical records

• The Details: What to watch for from diagnosis to discharge
  The Diagnostic Process * Surgery and Anesthesia * Infection Control and Prevention * Medical Error Reduction * Discharge and Home Care

• How to Navigate the System: Communicating concerns and complaints in and out of the hospital

• Knowing When You Might Have a Problem: Signs and symptoms of medical conditions requiring prompt attention

• How to Track the Patient’s Condition: Keeping a patient journal
Your Healthcare Team – The Medical Hierarchy

- Attending physician
- Fellow
- Chief resident
- Senior resident
- Junior resident (second year resident)
- Intern (first year resident)
- Medical student
Climbing the Nursing Hierarchy

↑ Administrator on call

↑ Nurse manager or nurse supervisor

↑ Charge nurse

↑ Staff or bedside nurse

↑ Unlicensed assistive personnel

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Whom to call in the Hospital

- **BEDSIDE NURSE** for most concerns.
- **CHARGE NURSE** if the bedside nurse does not respond appropriately.
- **RAPID RESPONSE TEAM** if you have a medical emergency.
- **NURSE MANAGER OR NURSE SUPERVISOR** if the hospital does not have a rapid response team. Ask them to call someone to assess the patient.
- **ATTENDING PHYSICIAN OR HOSPITALIST** if you need immediate medical advice but the situation is not life-threatening.
- **ADMINISTRATOR ON CALL** if you have an emergency but have not been able to get help through the usual channels. (The administrator on call can be reached through the hospital operator.)
- **PATIENT RELATIONS DEPARTMENT** for help with hospital rules and policies.
- **SOCIAL SERVICES DEPARTMENT** for assistance in communicating with staff and scheduling family meetings.
Warning Signs of a Rapidly Declining Patient

- High or low body temperature
- Changes in heart rate (pulse) or respiratory (breathing) rate
- A drop in the patient’s blood pressure (it becomes much lower)
- Mental confusion or other change in mental state
- Decrease in amount of urine/urine darker in color, looks “concentrated”
- The patient states that something is wrong with them
- The advocate observes that the patient doesn’t look right
- The patient is short of breath or having chest tightness or discomfort
- Acute pain, especially in the abdomen
- The patient is very pale or breaking out in cold sweats

NOTE: A rapid and sustained change of more than 20% above or below the patient’s normal pulse or blood pressure rate is cause for concern. A change of more than 40% is reason to seek help immediately.
SBAR (Situation, Background, Assessment, Recommendation) is a standardized communication tool developed by Kaiser Permanente. Use SBAR for patients and advocates to quickly and accurately relay clinical information in a format that is familiar to health care professionals.

Available online at www.empoweredpatientcoalition.org/publications.
The Patient Journal

• 1) Personal Medical History
• 2) Healthcare Providers’ Contact Information
• 3) Visits by Doctors and Other Healthcare Professionals
• 4) Record of Diagnostic Tests and Studies
• 5) Record of Medical Procedures
• 6) Patient’s Condition & Care: Observations & Questions
• 7) Weekly Medication Record
• 8) 24-Hour Vital Signs Chart
The goal of this joint effort by Empowered Patient Coalition and Consumers Union Safe Patient Project is to capture a snapshot of the impact of medical events from the patient’s point of view.

This survey is designed to answer questions that are important to patients. We want the public to know that they can and must be the cornerstone to improving health care quality and safety and that their experiences are being counted...
Why we created a survey

• Patient frustration with the reporting experience

• Need for a place where the patient’s voice can be heard

• Desire to get a broad-brush picture of the patient’s experience of medical harm, which is very different from the provider’s

• Desire to ask questions not asked elsewhere
Patient Safety: The Scope of the Problem Today

- November 2010 study by Office of Inspector General for HHS finds that 1 in 7 hospitalized Medicare beneficiaries in Oct. 2008 experienced serious adverse events during their hospital stays.¹

- November 2010 study of ten North Carolina hospitals finds 18.1% rate of medical harm, with no change from 2002 to 2007.²


998 randomly selected patients from 16 Boston hospitals were interviewed following discharge

- 23% reported an adverse event that was not reported in the medical record
- 37.5% of serious, preventable events were not documented in the medical record (12/32)

The Problem with Root Cause Analysis

- The questions asked of the investigation tend to be too narrow.
- Findings are seldom collected, analyzed, and disseminated in an effective way.
- Recommendations are often limited.
- Recommendations are not usually followed up on.
- Patient input is rarely sought.

Breakdown of Reported Adverse Events
N=1411

- Surgical or procedure-related complications (365)
- Healthcare-associated infections (362)
- Other complications in diagnosis or treatment (360)
- Adverse medication events (252)
- Accidents or failure to supervise the patient (51)
- Complications of childbirth (21)

547 respondents / 1411 responses
Breakdown of Surgical and Procedure-Related Events
(365 respondents/576 responses)

- Post-operative infection (68.5%) - 250
- Other post-operative complication (44.1%) - 161
- Unintentional cut, puncture, or tear (16.7%) - 61
- Blood loss from surgery or procedure (10.4%) - 38
- Other anesthesia-related complication (7.1%) - 26
- Positioning injury (3.0%) - 11
- Wrong-site surgery or procedure (3.0%) - 11
- Anesthesia awareness (2.2%) - 8
- Foreign object left in patient (1.6%) - 6
- Wrong procedure (0.3%) - 1
- Procedure/surgery on wrong patient (0.3%) - 1
- Burn during surgery, not from a fire (0.3%) - 1
- Surgical fire (0.3%) - 1

Number (Percent) of Patients Reporting
Breakdown of Healthcare-Associated Infections and Pneumonia
(357 respondents/799 responses)

- Infection at site of surgery (45.1%) - 161
- Sepsis or bloodstream infection (42.9%) - 153
- Other infection following surgery (30.3%) - 108
- C. difficile or other intestinal infection (23.2%) - 83
- Urinary tract infection (15.1%) - 54
- Infection at site of central line, PICC line or port (13.2%) - 47
- Pneumonia that developed while on a ventilator (12.9%) - 46
- Infected pressure sore (decubitus ulcer) (12.6%) - 45
- Infection at site of IV (9.5%) - 34
- Other pneumonia (8.7%) - 31
- Aspiration pneumonia (from inhaling food or other substance) (6.4%) - 23
- Necrotizing fasciitis (flesh-eating bacteria) associated with surgery (3.9%) - 14

Number (Percent) of Patients Reporting
Pathogens Involved in Healthcare-Associated Infections/Infestations
(360 respondents/535 responses)

- MRSA or ORSA (antibiotic-resistant Staph aureus) (47.5%) - 171
- Clostridium difficile (c diff) (20.0%) - 72
- Don’t know (19.2%) - 69
- Staphylococcus not specified as antibiotic-resistant (15.0%) - 54
- VRE (Vancomycin-resistant Enterococcus) (9.4%) - 34
- Pseudomonas aeruginosa (7.4%) - 27
- E. coli (4.4%) - 16
- Candida or other yeast infection (3.9%) - 14
- MRSE (antibiotic-resistant Staph epidermidis) (3.6%) - 13
- Klebsiella (3.3%) - 12
- Other pathogen (1.9%) - 7
- Unspecified gram negative bacteria (1.9%) - 7
- Enterococcus not specified as antibiotic-resistant (1.9%) - 7
- Aspergillus or other fungus (1.9%) - 7
- Acinetobacter baumannii (1.9%) - 7
- VRSA (Vancomycin-resistant Staph aureus) (1.4%) - 5
- Enterobacter (1.1%) - 4
- Serratia marcescens (0.8%) - 3
- Streptococcus (Strep) (0.6%) - 2
- Mycobacterium Mucogenicium (0.6%) - 2
- Legionella (0.3%) - 1
- Scabies (0.3%) - 1

Number (Percent) of Patients Reporting
Breakdown of Adverse Medication Events
(252 respondents/495 responses)

- Patient was not given medication he or she needed to have (43.1%) - 86
- Healthcare providers did not recognize medication side effects (31.0%) - 78
- Medication prescribed for wrong purpose or at wrong dosage (23.0%) - 58
- Patient was prescribed or given contraindicated medication (21.8%) - 55
- Patient was not given adequate medication to control pain (20.2%) - 51
- Patient had reaction to med prescribed according to accepted use (17.1%) - 43
- Med was incorrectly administered (e.g., wrong route, late) (13.9%) - 35
- Medication prescribed to which patient was known to be allergic (11.9%) - 30
- Medications that should not be used together were given (9.9%) - 25
- Pharmacist filled prescription incorrectly (4.0%) - 10
- Patient suffered overdose or underdose related to PCA pump (3.6%) - 9
- Patient was given medication not prescribed for him/her (2.8%) - 7
- Patient suffered epidural or spinal anesthesia error (2.0%) - 5
- Generic drug had different effect from brand-name (0.8%) - 2
- Patient became addicted to pain medication (0.4%) - 1
Source of Medication Event (N=494)

- Prescriber: 79%
- Administration of drug: 10%
- Manufacturer or drug itself: 9%
- Pharmacy: 2%
Drugs Involved in Adverse Medication Events

N=271

- Antibiotics 23%
- Narcotic pain medications 19%
- Psychiatric medications including antidepressants and ADD drugs 12%
- Blood thinners (Heparin, Warfarin, etc.) 10%
- Drugs used in anesthesia 8%
- Steroid medications 6%
- Benzodiazepines (e.g., Valium, Ativan) 4%
- Diuretics 3%
- Sleep medications 3%
- Insulin 3%
- Other diabetes medications 2%
- NSAID pain medications 3%
- Heart medications 1%
- Chemotherapy medications 2%
- Acetaminophen (e.g., Tylenol) 1%

185 respondents/271 responses
Other Complications of Medical Treatment
(360 respondents, 923 responses)

- Delay in diagnosis or treatment (63.6%)
  - Number: 229
- Failure to rescue a patient who was getting worse (52.8%)
  - Number: 190
- Misdiagnosis (38.6%)
  - Number: 139
- Proper tests not ordered (31.9%)
  - Number: 115
- Test results lost, misplaced, or disregarded (15.3%)
  - Number: 55
- Pressure ulcer or bedsore (13.1%)
  - Number: 47
- Problem with IV or central line (excluding infections) (8.9%)
  - Number: 32
- Complications from not controlling blood sugar levels (6.4%)
  - Number: 23
- Laboratory or pathology error (6.4%)
  - Number: 23
- Medical equipment problem (6.1%)
  - Number: 22
- Ventilator injury or death (excluding infections) (5.6%)
  - Number: 20
- Pulmonary embolism, blood clot or DVT (5.3%)
  - Number: 19
- Blood transfusion error or reaction (2.5%)
  - Number: 9

Number (Percent) of Patients Reporting
Where Did the Event Happen?
(529 respondents/688 responses)

- Hospital: 90.6% (479 responses)
- Doctor’s/healthcare provider’s office: 9.1% (48 responses)
- Emergency department: 6.4% (34 responses)
- Long-term care facility: 5.5% (29 responses)
- Outpatient surgery center: 4.5% (24 responses)
- Home: 4.2% (22 responses)
- Nursing home: 3.6% (19 responses)
- Assisted living facility: 1.9% (10 responses)
- Laboratory (e.g., lab or pathology): 1.3% (7 responses)
- Psychiatric/behavioral health facility: 1.3% (7 responses)
- Pharmacy or drugstore: 0.8% (4 responses)
- Dialysis unit: 0.6% (3 responses)
- Freestanding birthing center: 0.2% (1 response)
Personnel Involved
(511 respondents/1361 responses)

<table>
<thead>
<tr>
<th>Role</th>
<th>Number (%)</th>
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<tbody>
<tr>
<td>Surgeon</td>
<td>287 (56.2%)</td>
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<tr>
<td>Other specialist MD</td>
<td>204 (39.9%)</td>
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<tr>
<td>Primary care physician</td>
<td>161 (31.5%)</td>
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<tr>
<td>Resident physician</td>
<td>149 (29.2%)</td>
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<tr>
<td>Hospital administration</td>
<td>130 (25.4%)</td>
</tr>
<tr>
<td>Nurse practitioner</td>
<td>85 (16.6%)</td>
</tr>
<tr>
<td>Other health professional</td>
<td>79 (15.5%)</td>
</tr>
<tr>
<td>Pathologist</td>
<td>76 (14.9%)</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>73 (14.3%)</td>
</tr>
<tr>
<td>Social worker</td>
<td>27 (5.3%)</td>
</tr>
<tr>
<td>Board-certified obstetrician</td>
<td>25 (4.9%)</td>
</tr>
<tr>
<td>Emergency Medical Responders</td>
<td>18 (3.3%)</td>
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<tr>
<td>Chiropractor</td>
<td>17 (3.3%)</td>
</tr>
<tr>
<td>Lay midwife</td>
<td>4 (0.8%)</td>
</tr>
<tr>
<td>Other (0.2%)</td>
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Summary of Findings

- 90% of reported events were in hospitals.
- Most complications were postoperative.
- The most common complication was infection.
- Doctors were implicated in nearly every case; nurses in about half; other personnel much less frequently.
- The most common problem in medical treatment was delay:
  - Delay in diagnosis or treatment
  - Failure to rescue
Deficiencies Highlighted by the Survey

- Poor diagnostic skills
- Inadequate communication
- Failure to understand the risks of treatment and medications
- Failure to recognize the danger of infection
- Failure to recognize medical emergencies
- Lack of compassion and humility
Factors Contributing to Adverse Events (N=547)

- Healthcare personnel did not listen to patient (347) 63.4%
- Patient was not properly monitored (316) 57.8%
- HC personnel did not seem concerned about patient (314) 57.4%
- HC personnel seemed untrained or lacking in necessary knowledge (310) 56.7%
- HC personnel did not communicate well with each other (294) 53.7%
- Medical procedures or tests were not performed carefully (287) 52.5%
- HC personnel seemed overconfident (283) 51.7%
- HC personnel did not follow sanitary procedure (272) 49.7%
- HC personnel did not seem familiar with the patient’s case (243) 44.4%
- HC personnel seemed overworked, rushed, or behind schedule (231) 42.2%
- Patient’s room not cleaned properly, environment not sanitary (206) 37.7%
- Lack of follow-up after discharge (178) 32.5%
- Doctor was slow to arrive (172) 31.4%
- HC personnel seemed fatigued (160) 29.3%
- Nurse did not respond quickly to the call button (154) 28.2%
- Premature discharge (143) 26.1%

Percent (Number) of Patients Reporting
Patient Outcome from Event
(511 respondents, 1307 responses)

- Death (other than suicide): 182
- Need for additional surgery or treatment: 174
- Post-traumatic stress or emotional trauma: 160
- Financial loss: 158
- Chronic pain: 127
- Long-term loss of function (change in appearance): 122
- Short-term loss of function (change in appearance): 107
- Disfigurement: 84
- Loss of bowel or bladder control: 47
- Brain damage: 43
- Not sure yet (for recent events): 42
- No injury – near miss: 21
- Other: 18
Effect of Event on Patient's Family and Significant Others

(469 respondents/1348 responses)

- Emotional trauma: 404
- Stress of caregiving: 235
- Financial loss: 211
- Loss of lifestyle: 188
- Guilt: 159
- Loss of employment: 79
- Loss of home: 28
- Little or no effect: 25
- Divorce: 19
Patient-reported outcomes from adverse medical events

- Patient slipped into a coma
- Loss of income
- Patient required long-term treatment
- Face paralyzed
- Anemia, chronic kidney failure
- Still living in severe pain
- Unable to return to full-time duty
- I lost many days of work
- Lost my ability to live in my home
- ...was blind for two years before death
- Died after nine weeks of isolation in a nursing home
Patient-reported outcomes from adverse medical events

• Kidney failure, diabetes problems
• Loss of function and ultimately death
• Excruciating post-surgical pain
• Multiple surgeries to correct problem
• Multiple ED admissions
• Had to leave the ED to summon help
• The event precipitated other events that led to death
• Two suicide attempts
• Loss of insurance
• Not able to live independently
Effect of adverse event on patient’s family

- Trauma, financial loss, depression
- Tremendous emotional stress
- Chronic pain and total lifestyle change
- Very troubled. I can’t describe the anxiety
- Financial, physical and emotional disaster
- Loss of insurance
- Horrible fear, upset, confused
- I have been made to feel like I wasn’t of concern
- I tried my best to shield my loved ones from the trauma
- Tragic. It tore my family completely apart
Effect of adverse event on patient’s family

- We will never be the same
- She had three small children at the time of her death
- It is difficult to capture the degree of emotional trauma
- Great emotional toll
- Extensive cost – loss of relationship and communication – isolation
- The pain and agony of seeing a wife/mother unable to care for her own needs
- It was devastating to watch him die a slow death
- It destroyed our lives
- Ended up my wife divorced me
- Devastation
How Did the Provider or Facility Respond?
(479 respondents, 1153 responses)

- Told patient/family that care was "appropriate" when it did not appear to be (41.3%)
- Denied responsibility (41.1%)
- Secretive or unwilling to include patient or family in evaluating the situation (37.2%)
- No response after request to investigate (28.8%)
- Individual providers who were involved were not available (25.9%)
- Tried to prevent patient/family from getting critical information (20.0%)
- Removed information or altered medical records (18.8%)
- Open, concerned, and transparent (12.7%)
- Apologized and took responsibility for incident (6.9%)
- Event was investigated and patient/family were kept informed (2.7%)
- Offered to compensate or otherwise make amends to patient/family (2.5%)
- Patient/family were interviewed as part of investigation of the event (1.9%)
- Patient/family were included as part of the investigating team (0.8%)
To what agencies or institutions did you report the event?

- Administration of facility where incident occurred
- Not reported
- State health department
- State licensing board
- Joint Commission
- Insurance company
- Medicare/Medicaid
- Ombudsman or Patient Relations
- FDA
- ISMP or ConsumerMedSafety
- Filed HIPAA or FIPPA complaint
- Canadian Minister of Health
- Canadian Health Authority
- ACGME
Were you satisfied with the response of the institutions or agencies to which you reported? (N=270)
Patient experiences reporting medical events

- Medical board allowed me to read my statement, but did not consider action.
- I never heard from them, other than it would be looked into, and the standard “Thank you, we will look into the matter, etc., etc., etc."
- All said that they could not prove that the doctor or hospital did anything wrong.
- Although there were two autopsy reports submitted, a significant amount of investigative data, and arrest records for the surgeon, the state medical board did not deem the case worthy of investigation.
- Received only letters stating "Investigation ongoing."
- No one replied.
- Inconclusive and secretive.
Patient experiences reporting medical events

The patient quality and safety department used my case to make certain changes that they felt were important and, ultimately, shared some of that information. I am told they also addressed other of the issues I felt were most important but no one was willing to share any information about those changes.

More than two years after the adverse event I was able to arrange what turned out to be a completely unsatisfying meeting with the physician who was the instrumentality of the catastrophe. She was accompanied by her attorney and only spoke two sentences during the entire hour-long meeting. The first was "I didn't go in to medicine to hurt people" even though no one suggested she had. The second was "I do feel bad about what happened to you" as though she had nothing to do with it.

At the end of that meeting I was prepared to go ahead with litigation. Ultimately I decided there was little to gain and much to suffer if I decided to litigate so I did not. I have looked for opportunities to share my story.
Thank you
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