The Voice of the Patient

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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 throws light on the darkest corners of the medical bureaucracy and abounds in practical advice for keeping yourself safe in the face of its sometimes alarming inconsistencies. If you are a patient or plan on ever being one, you need to read this book!”

Helen Haskell, President,
Mothers Against Medical Error

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
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
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
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)

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

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

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

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

- Hospital (90.6%)
- Emergency department (6.4%)
- Outpatient surgery center (5.5%)
- Rehab unit or long-term care facility (4.5%)
- Home (4.2%)
- Nursing home or health center (3.6%)
- Assisted living facility (1.9%)
- Laboratory (e.g., lab or pathology) (1.3%)
- Psychiatric/behavioral health facility (1.3%)
- Pharmacy or drugstore (0.8%)
- Dialysis unit (0.6%)
- Freestanding birthing center (0.2%)
Personnel Involved
(511 respondents/1361 responses)

- Surgeon (56.2%)
- Other specialist MD (39.9%)
- Primary care physician (31.5%)
- Resident physician (29.2%)
- Hospital administration (25.4%)
- Nurse practitioner (16.6%)
- Unlicensed assistive personnel (15.5%)
- Other health professional (14.9%)
- Pathologist (5.3%)
- Pharmacist (4.9%)
- Social worker (4.9%)
- Board-certified obstetrician (3.5%)
- Emergency Medical Responders (3.3%)
- Chiropractor (0.8%)
- Lay midwife (0.2%)
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
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 (more than 3 months): 126
- Disfigurement (less than 3 months): 107
- Short-term loss of function: 84
- Loss of bowel or bladder control: 47
- Brain damage: 43
- Not sure yet (for recent events): 42
- No injury – near miss: 21
- No injury – near miss: 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%) - 198 responses
- Denied responsibility (41.1%) - 197 responses
- Secretive or unwilling to include patient or family in evaluating the situation (37.2%) - 178 responses
- No response after request to investigate (28.8%) - 138 responses
- Individual providers who were involved were not available (25.9%) - 124 responses
- Tried to prevent patient/family from getting critical information (20.0%) - 96 responses
- Removed information or altered medical records (18.8%) - 90 responses
- Open, concerned, and transparent (12.7%) - 61 responses
- Apologized and took responsibility for incident (6.9%) - 33 responses
- Event was investigated and patient/family were kept informed (2.7%) - 13 responses
- Offered to compensate or otherwise make amends to patient/family (2.5%) - 12 responses
- Patient/family were interviewed as part of investigation of the event (1.9%) - 9 responses
- Patient/family were included as part of the investigating team (0.8%) - 4 responses
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.
Thank you
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