The Vanishing Patient: A case of discharge from the Post-Anesthesia Care Unit (PACU) Against Medical Advice (AMA)

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Case Objectives

1. Recognize reasons why parents might want to remove their child from the hospital AMA.
2. Discuss management strategies for parents who wish to remove their child from the hospital AMA.
3. Specify elements of discussion with parents to ensure the safety and care of their child.
4. Justify acceptable interventions if a parent is attempting to leave AMA:
   a.) to prevent discharge AMA from occurring, or
   b.) if it does occur, who to call if it is believed that a patient’s life is in jeopardy
5. Describe key elements of documentation within the medical record.

Case History

A six-year-old girl with colonic dysmotility is scheduled for cecostomy revision under general anesthesia. During the Nursing Assessment pre-screening telephone call, the patient’s mother demands that her child be designated a day surgery candidate.

It is important to note the patient’s complex medical history. Comorbidities include Noonan syndrome (heterozygous T266K mutation), brain malformation (associated TUBB2B gene mutation), craniofacial dysmorphism, sleep apnea, snoring, intermittent stridor, persistent hoarseness, autonomic dysregulation and cyanotic syncopal episodes of unclear etiology. Additionally, she has recently received an implanted cardiac Reveal monitor, in an attempt to differentiate between arrhythmias and seizures.
Questions:
What is Noonan syndrome? What implication does Noonan syndrome have for perioperative anesthesia management? What is the significance of her brain malformation and airway issues?

Case History (continued)

A chart review is undertaken by the Anesthesiologist on the afternoon prior to surgery. The child has a significant cardiac history. For her pulmonary stenosis she underwent a failed balloon dilatation, which was followed by a successful commissurotomy. She was left with residual moderate-to-severe pulmonary regurgitation and right ventricular overload. She has an absent right coronary artery. ECG shows right ventricular bundle block. For the recently diagnosed autonomic dysregulation she has been initiated on Florinef by her cardiologist. The clinical effects of her cerebral dysmorphology include complex partial seizures, left hemiparesis, hypotonia, frequent falls, cortical visual impairment and developmental delay.

In the past 6 months she has undergone 3 surgical procedures:

(1) Due to recurrent cyanotic fainting episodes at school (pulse-oximeter measurements 78-85%) she had a five-day hospitalization with extensive work up, resulting in the surgical implantation of a Reveal monitor. She was discharged to home postoperatively. On POD #2 she returned to the ER complaining of urinary retention. She was readmitted for further management, lasting four days.

(2) Approximately three months earlier, she underwent a laparoscopic-assisted cecostomy which required pre-admission for bowel prep and hydration, followed by a tenuous recovery. She was discharged on POD #6. The anesthesiologist for that case was consulted and reported a rocky postoperative course, thus recommending against day-surgery.

(3) Approximately two months earlier, she underwent removal and replacement of her cecostomy, secondary to granulation tissue. She was admitted one day prior to surgery for preoperative hydration. She was discharged on POD #1.

Multi-disciplinary discussions amongst the patient’s general surgeon, prior anesthesiologists, and the cardiac anesthesia consult team resulted in a decision that postoperative admission was really the safest disposition for this child.

Questions:
What is your own preoperative assessment of this child’s risk for anesthesia? Which ASA classification would you assign this patient? Are you satisfied with the consultations you have collected and would you seek additional studies prior to proceeding with this case? Would you admit this child for overnight observation?
**Day of Surgery**

On the day of surgery, the team is surprised that the patient is accompanied by her father. He had not been involved in the nursing preoperative assessment telephone conversations. However, he agrees to the revised plan for postoperative admission, signs the surgical and anesthesia consent forms, and states “just go forward”.

**Questions:**

Would you consider calling the child’s Mother on the day of procedure to relay your intentions? What are some different anesthetic options for this child? Our cardiac anesthesia recommendation was as follows: premedication (1 mg/kg midazolam combined with 5 mg/kg ketamine) via G-tube, cautious inhalation induction, general anesthesia with LMA, augment preload with a fluid bolus, use dopamine as needed, and admit postoperatively to the cardiac inpatient unit. Would you follow this advice?

**Operative and PACU Course**

The patient underwent an uneventful surgical procedure. Anesthetic management was remarkable in the sense that her mask induction was complicated by a severely obstructed upper airway, which was managed with an oral airway and PEEP, followed by LMA placement and assisted breathing. During emergence a similar obstructive respiratory pattern was observed. The patient arrived in the PACU, where the receiving Attending Anesthesiologist noted an obtunded child with intermittent airway obstruction and desaturations. For greater than two hours the child required stimulus for breathing, continuous oxygen delivery via humidified face mask, and frequent suctioning of secretions. The patient’s father became increasingly agitated and verbally abusive towards the PACU team, as his daughter’s recovery seemed to be making very slow progress. He insinuated that he should just go home, and made it clear that he was disgusted with the perioperative team. He soon refused the overnight admission. He finally demanded that the PACU nurse remove the patient’s intravenous catheter. He requested an AMA form, signed it, and hastily departed with his child. There was no opportunity to discuss risks of leaving and benefits of hospitalization. Our hospital’s AMA policy was unclear at that time, and collaborative recommendations for revision of the policy are currently in progress.

**Questions:**

What might be some specific reasons that this parent wished to leave? What management strategies might have been utilized, to calm the situation and solicit cooperation from the parent?
What alternative might be offered to a parent, to reach an agreement between parent and treating clinician(s), thus avoiding discharge against medical advice (AMA)?

Who should be involved in the discussion about leaving AMA, and what specific communications with the family should occur?

If a parent demands discharge AMA and you believe a child’s health is jeopardized, what interventions might be initiated to prevent an impending departure AMA?

If you believe a child’s health is jeopardized and a parent has already departed, then what interventions might be initiated?

What documentation should be placed into the child’s medical record?

Do insurance companies deny payment for patients leaving against medical advice?

**Discussion**

Approximately 500,000 patients (1-2%) elect to leave United States hospitals every year, against medical advice (AMA). This designation implies that a patient has departed the hospital before his/her treating physician has recommended discharge. This creates a significant challenge for healthcare providers. Such patients expose themselves to the risk of being inadequately treated for their medical conditions, frequently resulting in readmission or less commonly, death. Using a common childhood diagnosis as an example, asthmatics who were discharged AMA had a 4-times higher risk of readmission to the emergency department within 30 days and almost a 3-times higher risk of readmission to the hospital within 30 days. The ethical conundrum becomes a physician’s struggle with the desire to respect an adult patient’s wish to leave AMA (the patient’s right to autonomy) as opposed to doing what is best for the patient (acting with beneficence). Predictors of AMA discharge include adult patients of lower socioeconomic status, those with Medicaid or no insurance, younger age, a history of substance abuse, and male gender. When an unplanned discharge involves a minor (below the age of legal competence), the harsh reality is that children likely neither comprehend nor contribute to the final decision-making process of their parents / legal guardians. Unfortunately, they are a subset of patients whose health status may be most jeopardized, and are representative of a high-risk group for both morbidity and mortality.

Understanding why patients elect to leave hospitals AMA allows for earlier identification of those at higher risk and thus earlier intervention to prevent excess morbidity, mortality, and health care costs. If at any point during hospitalization a threat to leave AMA is vocalized, there has likely been a breakdown in the doctor-patient-parent relationship. A threat may indeed
mask an individual’s true feelings of anger, frustration, anxiety or depression. A family-centered approach to examining conflicts is suggested, with the goal of understanding the family’s rationale for wanting to leave. Specific complaints which are common when reviewing discharge AMA cases include global misunderstandings about a child’s medical condition, dissatisfaction with various medical teams, disagreement about current decision-making, unmet expectations surrounding a treatment plan, presumed delays in medical management, and personal factors, including unique stressors in the home.

If a controversy arises, it is paramount that basic education about risks and benefits of continued hospitalization take place. Allowing adequate time to ponder all available options is necessary. Meeting promptly with the family, listening to their concerns, and attempting to reach a compromise that is safe and acceptable for the patient is indicated. It is highly recommended that specific individuals engage in a group discussion to explore parental dissatisfaction. This might include the primary attending physician, a nursing supervisor and a social worker. Together the trio shall assess the patient’s health status. They should make efforts to solicit cooperation from the parent/legal guardian. They must clearly communicate the risks of leaving, consequences of no treatment, make every effort to continue current hospitalization, and establish a follow-up plan for the parents. If the family remains adamant about leaving, the group might discuss alternative treatment options for the future, and if appropriate, offer ambulance transfer to another facility that is acceptable to the family. It is important to recognize that a compromise that is acceptable to both parties cannot always be reached.

If a parent continues to demand discharge AMA or the patient has been removed AMA and his/her health status is jeopardized, immediate implementation of a pre-established protocol may be warranted. Various vehicles for doing so exist in most medical facilities. The option for calling hospital security, with the goal of blocking a discharge, may be simplest. Next, a designated child protection team and/or legal group may be called upon to implement an emergency protection order. Finally, consideration for contacting law enforcement via the legal office must be weighed, particularly if the child has already departed hospital property.

Managing an AMA discharge requires careful documentation within the medical record. First and foremost, informed consent prior to leaving AMA implies that a parent of the minor patient has reached the decision to leave in consultation with the primary physician, without coercion, and with a full understanding of risks, benefits, and alternatives of that decision. Next, the patient’s diagnosis, current care plan, and health status upon leaving AMA must be recorded. It is advisable to draft a complete summary of events preceding the discharge. Document the parent’s desire to pursue an alternative plan of care for their child, including any potential risk and/or consequence, and where this might take place (ie at a different medical facility, at
home, or within a physician’s office). Record the individual’s comprehension of the medical risks/consequences given the impending departure. Outline a plan for managing future medical problems which may arise after discharge AMA: this may be formulated with assistance from a Patient Relations or Social Services team. Consultation with an ethicist or psychiatrist may also be necessary in understanding legal requirements, particularly if a decision has been made to keep a minor patient hospitalized against the parent’s will. Record all steps taken, to communicate information to the patient/guardian, hospital security, legal team, and possibly law enforcement via the legal team. The process of undertaking a clear conversation with the patient/guardian about pertinent issues, followed by accurate documentation in the medical record, ensures the best care possible for the individual of record, and may reduce liability in the longer term.

The question periodically arises as to whom shall assume financial responsibility for patients who leave AMA. Is it primarily the insurance company, the hospital, or the patient who is paying the bill? Various surveys have been conducted throughout the United States with a broad array of answers (4). The beliefs of resident and fellowship physicians, attending physicians, and nurse managers differ markedly across institutions. A comprehensive review of select billing data from 2001-2010 was undertaken by the University of Chicago, which indicated that the predominant reasons for insurance coverage denial included the untimely submission of an original hospital bill, confusion about patient identity, and the potential for an extended utilization review (4). Their data indicated that the denial for payment had absolutely no association with the fact that a patient departed against medical advice. Based on this report, their institution has suggested targeted training for medical providers, regarding the need for specific conversations with patients/parents/guardians who are contemplating a departure AMA, to enforce the notion that it is highly unlikely that they will be held financially responsible for any payments related to that unsatisfactory hospitalization. It is a rather unique conversation that may need to take place in your own institution.

In closing, our hospital’s “Discharge Against Medical Advice Policy” was unclear at the time of our event. Ongoing collaboration and extensive recommendations for revision of the policy are currently being undertaken by the Boston Children’s Hospital Governance Committee.

References


