

NCPS De-identified Event: Informed Refusal

Nebraska Coalition for Patient Safety May 2023

Event

- A 50-year-old patient presented to a local hospital's emergency department at the direction of their cardiologist because of an elevated potassium level and abnormal kidney function tests.
- The ED Provider assessed the patient and encouraged them to be admitted for further investigation and correction of lab values.
- The patient refused to be admitted and chose to sign out of the ED against-medical-advice.
- As the patient began to drive away from the hospital, they suffered a medical emergency and ran into an oncoming car while still on the hospital's property.
- Local EMS was dispatched to the scene and staff from the ED also responded.
- The patient was taken back to the ED and efforts to revive them were not successful.

Additional Event Review Information

- ED staff was unsure if they if they could take the ED's gurney outside of the ED because of the organization's lacking/conflicting policies about medical emergencies outside of the hospital building but on their property.
- EMS staff had to use the ED's gurney to get the patient into the ED because the road's access to the building was partially blocked.
- The medical emergency event was not communicated to hospital staff.
- The medical emergency event was not reported up the chain of command in a timely manner.
- ED staff expressed concerns about the local EMS personnel's CPR skills and lack of teamwork.

Contributing Factor Categories:

Emergency situation

Immediate/proximal cause(s):

Human performance – Patient disregarded instruction

Categories of Causal Statements:

- Patient/Family Factors
- Rules/Policies/Procedures

Root Causes:

- Patient disregarded instruction
- Procedure/policy not followed
- Physical environment condition
- Did not communicate concern up the chain of command

Actions Taken to Avoid Future Events

- Communication process improved (with patient as well as with internal stakeholders and management)
- Education/training provided
- Informed patient/caregiver of error
- Consulted organization's legal to understand state law regarding informed refusal
- Consulted organization's malpractice insurance provider to understand their best practices guidance for informed refusal
- Policy/procedure revised for clarity

- It is estimated that as many as 2% of all United States hospital discharges (approximately 500,000 per year) are designated as against-medical-advice (that is, a patient chooses to leave the hospital before the treating physician recommends discharge). At disadvantaged inner-city populations this figure goes up to 6%. A study at a major academic medical center found that about 2.7% of patients left the ED against-medical-advice.
- Compared with patients discharged conventionally, readmission rates for patients discharged against medical advice are 20% - 40% higher, and their adjusted relative risk of 30-day mortality may be 10% higher.⁵
- Studies suggest that provider to patient communication has a direct influence on patient decisions to leave against-medical-advice and an against-medical-advice discharge may be averted if providers^{4.6.7}:
 - ✓ engage in meaningful interactions with active listening
 - ✓ verbalize and understand the patient's frustration
 - ✓ use de-escalation techniques to address why the patient wants to leave

- A variety of reasons for patients wanting to leave have been cited^{7,8}:
 - ✓ short staffing in the hospital setting or other limited resources
 - ✓ patients' needs related to work or family obligations
 - ✓ unrealistic patient expectations
 - ✓ frustration from either the patient, the staff, or both
 - ✓ cost of care or treatment
 - inconvenience of the time that the treatment may take
 - ✓ the expected pain and suffering that treatment may cause
 - ✓ inability to travel
- Informed Refusal needs to occur when a patient refuses a recommended medical treatment based upon an understanding of the facts needed to make a decision.

- Mitigating patient harm when AMA discharge is unavoidable requires the provider to ensure that⁸:
 - ✓ the patient is informed
 - ✓ all aspects of treatment have been explained
 - ✓ risks and benefits have been fully discussed
 - ✓ the potential outcomes of a lack of treatment are discussed and understood
 - ✓ the patient is competent to refuse care (e.g., not intoxicated, no mental illness, no dementia, cognition not impaired).
- Decisional capacity is essential to evaluate patients in the ED who wish to leave without being evaluated or treated.⁸ A variety of assessment tools may be used such as the MacArthur Competence Assessment Tool for Treatment.

General Tips for How to Best Handle the Situation When a Patient is Refusing Your Medical Treatment Recommendation⁹:

- Handle informed refusal as a natural extension of your informed consent process. (i.e., assess the patient's competence, provide verbal and written information in languages the patient can understand, and use the patient teach-back method).
- Listen. When a patient expresses resistance to your treatment recommendations, pay attention to what they're really saying. Follow the principles of shared decision making and patient-centered care to help them identify what is most important to them and pinpoint their concerns about your prescribed treatment.
- Take the patient seriously. No matter how trivial the patient's objection seems to you from a clinical viewpoint, don't minimize their concern. Practice active listening and ask probing questions to help you and the patient better understand the basis for their decision. You can express your disagreement but balance it with an acknowledgement of their viewpoint.
- Provide options. Patients may be feeling overwhelmed and out of control.
 Presenting them with options can give them some sense of urgency and reduce their fears.

General Tips for How to Handle the Situation When A Patient is Refusing Your Medical Treatment Recommendation (cont.):

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- Take your time. It is very important help a patient understand what they are refusing. The patient teach-back method can be particularly helpful in this situation; having the patient repeat the risks of refusal back to you can help verify their understanding.
- **Don't take it personally.** Remember, the patient is not rejecting you as a person or your authority as a provider. Encourage second opinions, be open to continuing the conversation, and be prepared to agree to disagree.
- Don't stop at the no. Just because they initially refuse doesn't mean that will be their final decision. If at all possible, give the patient time to digest the information you've provided, talk with family and friends, and weigh their options. Consider providing a method to receive, and respond to additional questions after the initial conversation (i.e. through a patient portal, voicemail line, or email).
- Check your state's regulations. Check with your state medical association or your malpractice carrier for state specific guidance since some state have specific laws on informed refusal.
- Document, document. All of the above steps should be carefully documented in the patient record. Document the specifics of each action and conversation, including copies of patient education materials you provide.

Could this happen in your organization?

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	Yes	No	NA	Action	
Has your patient care staff, including providers, received training in active listening and de-escalation techniques?					
During the de-escalation process are patients and family members given the opportunity to communicate all their emotions, frustrations, concerns, and questions in a private setting?					
Have your healthcare workers been trained to remain open- minded and non-judgmental, and to refrain from being defensive when dealing with a difficult patient?					
Is a post-event de-brief and review held after an against-medical- advice event to provide an educational opportunity to avoid potential future AMA situations?					
Does your organization have a policy/procedure which clearly outlines the required steps and documentation for Informed Refusal? Has your legal department reviewed the content?					
Does your organization educate all employees on patients' rights and responsibilities which includes the right to ask questions, be informed, be a part of decision making, and to refuse care or treatment?					
Have you considered utilizing a framework for making ethical decisions which relies on the principles of autonomy, beneficence, nonmaleficence, and justice. See the Four-box method.8					

Could this happen in your organization?

	Yes	No	NA	Action	
Does your organization have an emergency management policy which includes when and how to notify management of emergency situations or how to escalate a concern up the chain of command? See Joint Commission Emergency Management. EM.07.01.01					
Do you perform emergency management "practice drills" to ensure all persons know their roles and to improve upon any gaps discovered?					
Does your Emergency Department have a collaborative relationship with local EMS? Have you considered strategies to strengthen your teamwork? See 4 Tips for Better Relationships with Your EMS Provider.					

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