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### Abstract:

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# When a Patient Declines Curative Care: Management of a Ruptured Aortic Aneurysm

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The management of major vascular emergencies in the emergency department (ED) involves rapid, aggressive resuscitation followed by emergent definitive surgery. However, for some patients this traditional approach may not be consistent with their goals and values. We explore the appropriate way to determine best treatment practices when patients elect to forego curative care in the ED, while reviewing such a case. We present the case of a 72-year-old patient who presented to the ED with a ruptured abdominal aortic aneurysm, but refused surgery. We discuss the transition of the patient from a curative to a comfort care approach with appropriate direct referral to hospice from the ED. Using principles of autonomy, decision-making capacity, informed consent, prognostication, and goals-of-care, ED clinicians are best able to align their approach with patients' goals and values. [West J Emerg Med. 2013;14(5):555–558.]

## INTRODUCTION

The priority of traditional emergency department (ED) care is on the resuscitation and stabilization of the acutely ill or injured patient. The ED is a safety net for many patients with an advanced chronic illness who present with critical “crisis” and terminal events.<sup>1-5</sup> The traditional, aggressive ED approach may not suit the needs of such patients and optimal care plans are best tailored to patient goals and values.<sup>5,6</sup> ED clinicians caring for these patients may therefore have to rapidly adapt and shift their focus from a disease-directed resuscitation to comfort care, a challenging task for many ED clinicians who may feel unprepared and untrained for such scenarios.<sup>7-10</sup> We present the case of a patient with underlying chronic illnesses who presents to the ED with a “catastrophic” event and whose values are not aligned with resuscitative ED care. We then discuss a framework that may assist ED clinicians faced with the transition of a patient from a curative to comfort care-based approach.

## CASE REPORT

A 72-year-old female ex-smoker with a past medical history significant for hypertension, abdominal aortic aneurysm, severe chronic obstructive pulmonary disease, and lung cancer presented to the ED with progressively

increasing left-sided abdominal pain over 24 hours. The patient was tearful and anxious. Her vital signs included blood pressure of 150/90 mmHg, oral temperature of 36.5°C (97.8 °F), pulse 120 beats/minute, respiratory rate 26 breaths/minute, and 97% oxygen saturation by pulse-oximeter. She was adherent to her albuterol inhaler and labetalol regimen. Physical examination revealed a slightly distended abdomen with guarding and significant tenderness over the left lower quadrant. The rest of her examination, including bilateral pulses, was normal. A bedside FAST (focused assessment with sonography for trauma) examination was positive for free intra-peritoneal fluid. Computed tomography imaging revealed an 8 cm (transverse diameter) aortic aneurysm with evidence of contained rupture and displacement of abdominal organs by the large left sided peri-aortic hematoma (Figure). The patient informed staff that she was aware of her diagnosis and condition and had refused surgery 5 years prior. During her initial resuscitation, the patient had a discussion regarding operative management with the vascular surgeon and ED clinician. She again refused any major surgical interventions due to her concern that she could be ventilator dependent for some time, an outcome she felt was unacceptable.

Therefore, we present a framework for shared informed decision-making, exploring the pathway of our patient's

**Table.** Rapid Overall Goals-of-Care Conversation in the emergency department.<sup>12-15</sup>

Skill	Description
Determine the legal decision-maker	If patient unable to make decisions review any completed advance directives.
Communicate prognosis	Answer the two fundamental questions: “What is wrong with patient?” and “What will happen to her/him?” Summarize the “big picture” in a few sentences—use the word “dying” if appropriate Frame the discussion as “hoping for the best but planning for the worst.”
Use appropriate language	We want to ensure you receive the kind of treatment you want. Your comfort and dignity will be our top priority. Let us discuss how we can work towards your wish to stay home or pain-free or...
Elicit patient preferences with open ended questions	Knowing that time is short, what is most important to you? What are you expecting in the next few hours, days, weeks...? What kind of results are you hoping for? What do you hope to avoid at all costs? Have you seen or been with someone who had a particularly good death or a particularly bad death? Please tell me about it.
Make recommendations	Example, “According to what you want/what you want for [the patient], I would/would not recommend....”

transition from a curative (disease-directed) to a comfort care (symptom-directed) approach.

## DISCUSSION

The patient presentation as described above posed major ED management challenges/issues, such as:

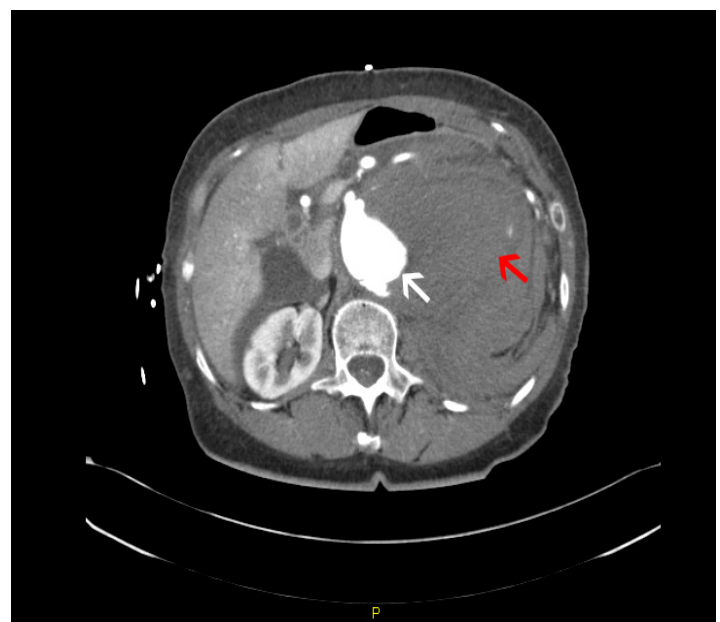
1. Does the patient have decision-making capacity, and is she able to fully understand the consequences of surgery refusal?
2. How does the ED provider hold a rapid goals-of-care discussion to elicit her values and concerns?
3. How does the ED provider shift approach and transition the patient from curative to comfort-based care?

### Issue#1: Refusal for curative care (surgery) and assessing decision-making capacity

We applied the ethical principles of autonomy and available guidelines for determining decision-making capacity and informed consent to assist our patient care.<sup>11</sup> *Autonomy* (self-determination) refers to a person’s ability to make his or her own decisions, including health-related choices, based on personal values and beliefs. For a valid, informed refusal (similar to informed consent) we consider the following: 1) the patient must have *decision-making capacity*; 2) information related to significant risks and magnitude of harm must be provided explicitly; 3) the patient must demonstrate comprehension of the information; and 4) refusal must be voluntary and without coercion.<sup>11</sup>

In healthcare settings, we assume that all adults have the medical decision-making capacity to accept/refuse a plan of care unless there is evidence in the history, behavior, or physical examination that suggests that this capacity has been significantly compromised. Decision-making capacity

is dynamic and decision-relative (a patient may be able to make a simple decision, but not a complex one).<sup>11</sup> A patient may only need a *low* level decision-making capacity to consent for a low-risk, high-magnitude-of-benefit procedure, but would likely need a *high* level of capacity when refusing the same. It is also important to note that “competence” is a legal term and determined by court (for example, a person may not be competent to handle their finances but still have medical decision-making capacity). Medical decision-making is obviously more challenging if the patient lacks decision-making capacity, and surrogates or healthcare proxies need to make inferences based on known patient values.<sup>11</sup>



**Figure.** Computed tomography of the abdomen and pelvis (large peri-aortic hematoma [red] with abdominal aortic aneurysm [white]).

Our patient demonstrated decision-making capacity to refuse surgical care based on her ability to: 1) receive information regarding her catastrophic vascular emergency; 2) deliberate and weigh the risks of the procedure itself and the procedure refusal, including imminent death; and 3) defend, as well as verbalize her choice based on her values and perceived quality of life.

### **Issue#2 Shared informed decision-making (goals-of-care ED discussion)**

Patient management is ideally based on a shared decision model where therapy is aligned to the patient's values. If deterioration is imminent or rapid, decisions are needed regarding the use of life-sustaining treatments (e.g., intubation for respiratory failure), and a focused discussion around goals-of-care must occur in the ED (Table).<sup>6,12,13</sup> Goals-of-care discussions aid in discovering where the patient wants to go and what he wants to avoid so we can then recommend the best treatment plan to achieve his objectives.<sup>13,14</sup> For example, advance directives (ADs) are documents that are completed by a patient when he or she *has* decision-making capacity and provide direction for care at a *future* time when the person may become unable to make such decisions, such as *instructional* directives (do-not-hospitalize or do-not-intubate) or *proxy* directive or designation of the durable power of attorney for healthcare. The key to understanding the patient's goals is the "why" behind a decision as opposed to the "yes" and "no" answers. Unveiling the patient's underlying refusal of care may be paramount to establishing trust and allowing communication in a timely manner.<sup>14</sup> Therefore, it is best to determine the overall concerns and goals before addressing specific issues such as cardio-pulmonary resuscitation.<sup>12,13,15</sup> The way we ask the patients questions often determines their responses. Clinicians must be cognizant of their language, tone, and presentation when discussing goals-of-care to patients. The framing effect may lead to adverse decision-making on behalf of the patient. The patient/family may feel abandoned if statements with a negative connotation are used. For example, "Do you want us to discontinue care or do you want us to stop aggressive therapy?" Emergency clinicians and all clinicians of the treatment team should use suitable language in the setting of end-of-life discussions in patients with a terminal chronic illness (Table).<sup>12,13,15</sup> The treatment team should present the patient with alternatives should the patient choose to forego the optimum plan.

Based on the goals-of-care conversation, we determined that our patient understood her prognosis and knew that she was going to die in a short period of time (hours to days). Her main concerns were receiving adequate pain control and being with loved ones for the remainder of her time. She expressed no fear of imminent death, but was fearful of dying "on the table-all alone;" and even if she were to survive the major operation, she expressed no desire to live "tied to machines."

### **Issue#3 Transition of the patient from curative to a comfort care approach in the ED**

A seamless shift from curative to comfort care-based

approach may be needed once patient goals are clarified. It is imperative to emphasize non-abandonment of the patient by expressed words and actions. Optimal symptom control and addressing the physical, as well as psychosocial and spiritual needs of the patient, is essential during this transition. These steps are best accomplished by involvement of a palliative care consultation team (if available) or an appropriate referral to hospice in the ED.<sup>12-16</sup> Hospice care is provided by a multidisciplinary team that includes a physician, nurses, social workers, chaplaincy support, home health aides, volunteers, and therapists. Members of the hospice team meet regularly to set patient care plans, discuss ongoing issues, and make regular visits to assess the patient for needed care and support services. Hospice care plans include the management of the pain and other distressing symptoms; provision of symptom and comfort-related medications, medical supplies and equipment; assistance with emotional, psychosocial, and spiritual aspects of dying; caregiver support and guidance on how to care for the patient; speech and physical therapy; short-term inpatient care when symptoms become difficult to manage at home for those actively dying or when the caregiver needs respite time; and bereavement care to the surviving family and caregivers for one year after patient death. Sometimes, based on the dying patient's wishes and needs, a safe disposition to home under hospice care may be possible from the ED.<sup>12-16</sup>

We optimized care for the patient's distressing physical symptoms of pain and anxiety with use of a continuous morphine drip and intermittent use of lorazepam.<sup>16</sup> The patient was moved to a private ED room while awaiting a hospital bed to ensure privacy to the family. All monitors were turned off to create a calmer setting. A timely and appropriate referral to hospice was made from the ED. Thirty-six hours after admission, the patient died in-hospital surrounded by her family and chaplain. Ongoing bereavement support was provided to family survivors as part of hospice services.<sup>16</sup> Both the staff and family expressed satisfaction with the quality of end-of-life care provided.

### **CONCLUSION**

When resuscitative care is not desired, a tailored approach is required for optimal ED management of the imminently dying patient. Therapy is thus aligned to the values and goals-of-care of the patient. Integrating basic palliative care principles into practice may assist ED clinicians in transitioning their patient from a curative to comfort care-based approach at end-of-life and support family at this challenging time.

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