

Code Status vs. Care Status

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Learning Objectives

- Articulate the difference between code status and a patient’s goals of care.
- Differentiate between the four domains required for a patient to have capacity.
- Discuss how implicit bias and cognitive underspecification contribute to poor communication between care teams.
- Examine financial and policy-related pressures contributing to increased ICU and hospital bed turnover.
- Identify factors than can make someone a vulnerable patient in the context of healthcare; discuss possible interventions to better care for vulnerable patients.

The Case

A 65-year-old African American man with metastatic squamous cell carcinoma (SCC of unknown primary site) was admitted to the hospital after developing increasing back pain. His work-up revealed a T10 burst fracture. In addition to his cancer, the patient had a past medical history of schizophrenia, developmental delay (not conserved), and COPD. He received neurosurgical treatment for the fracture, but had a complicated post-operative course: aspiration, respiratory failure, intubation, new deep vein thrombosis and pulmonary embolism, and infection. Eventually, the ICU team was able to extubate the patient, but he continued to require intermittent high flow oxygen or bilevel positive airway pressure (BIPAP) to maintain his oxygenation.

The palliative care team, which included an expert in medical ethics, was consulted to discuss goals of care with the patient, particularly regarding further cancer treatment and the possibility of placing a permanent feeding tube. Prior to his admission to the hospital, the patient resided in a semi-independent living facility, where he was cared for by a devoted caregiver and received other supportive services for his developmental delay; he had no family involved in his life. The patient shared with the team that he had been in nursing home settings/institutions in the 1970s and that he would never want to go back to one. His ultimate goal was to go home. After multiple lengthy discussions with the patient, his caregiver, the agency managing his services, and the hospital teams involved in his care, the decision was made to transition the patient home with hospice care, honoring his wish to go home to live as well as possible for as long as possible, but without burdensome treatments such as chemotherapy. The palliative care team and discharge planner worked with the social services agency to coordinate the transfer home, including acquiring appropriate equipment, training the patient's caregivers on use of the equipment, and arranging home hospice and caregiving services.

The ICU team continued to optimize the patient's respiratory status as they prepared for his eventual discharge home. On a Friday afternoon, his care teams felt that the patient would benefit from ICU care over the weekend to further improve his respiratory status and that he would likely be able to go home the following week with hospice. A timeline for the transition had not been established, given the complexity of the situation and the patient's clinical status. However, within hours of changing the patient's code status to "Do Not Resuscitate" (DNR) and after the palliative care team had left for the day, the patient was transferred out of the ICU to a medical/surgical floor. It is unclear who made this decision or why. With the transfer, he was given a new medical team. The patient was not rounded on by his new team of providers over the weekend. It seemed these new providers noted the patient's DNR code status and the plan to go home with hospice and felt no further interventions would be required.

Once outside of the ICU over the weekend, the patient's respiratory status deteriorated, reaching a level of severe oxygen desaturation. No one continued to emphasize to the patient the importance of BIPAP and other respiratory care to his ability to go home. In fact, the new medical team seemed to have not even ordered BIPAP or other non-invasive respiratory support measures for the patient. When a new medical team arrived Monday morning to receive sign-out report from the weekend team, they were unsure what to do about the patient's respiratory distress. They called the palliative care team for clarification about the plan of care. Once they understood the intended care, the Monday team attempted to improve the patient's respiratory status with all measures short of intubation. Unfortunately, they were not able to reverse the effect of the ineffective respiratory care from the weekend. The patient died in the hospital later that week; he was never able to go home as he had wished.

After the patient's death, a discussion was held between the neurosurgical teams (the patient's primary assigned service) and various providers about what DNR means and does not mean. To many, it meant the healthcare team was no longer needed because the patient was imminently dying, and so the team was going to focus its limited time and energy on patients who were "full code" which they equated with "full treatment."

The Commentary

By Rebecca K. Krisman, MD, MPH and Hannah Spero, MSN, APRN, NP-C

In approaching the patient safety errors and challenges this case illustrates, we will focus on cognitive biases at the [sharp end](#) and the latent conditions affecting the error chain. We hope to make conscious many of the unconscious mental models we carry with us as we go about our daily work caring for patients. If we are aware of the assumptions we make and the heuristics we use, we can question them, allowing us to deliver more informed and appropriate care. Furthermore, if our EHR systems and leadership support frontline staff, and we recognize the special challenges of care in the presence of unique environmental stressors and patient characteristics, patient safety will be enhanced.

Code Status, Not Care Status

The teams taking care of the patient in this case were methodical in trying to figure out what his wishes were and how to honor them, working with his caregiver (family surrogate) and social services agency, as well as inquiring directly with the patient. The goals of care conversations appropriately took place as the patient faced decisions about further interventions, such as feeding tube placement and biopsy of the esophagus to further delineate the type of SCC. A consensus developed that he would be best served by getting to go home, to enjoy his familiar environment, to listen to his music and to eat what he enjoyed. Because of the severity of his illness and his needs for around the clock nursing care at the time the decision was made to shift the focus of his care from full cancer treatment to going home, the transition couldn't be made right away.

Shortly thereafter though, the complexity of his needs and goals--to stay in the ICU for a couple of more days to improve respiratory status and fluid status enough to facilitate the eventual transfer home after intensive resource coordination-- was lost. Instead, the patient became a victim of an alternate translation of the original intent: "DNR, transfer out the ICU, we need the bed." With this interpretation, the decision about the focus of care appears binary, when really it is not. Full code/full care vs. DNR/comfort care or restorative vs supportive care path are not polar opposites. These binary heuristics represent attribute substitution, where we substitute a simple automatic intuitive judgment for a computationally complex or self-aware judgment.¹ According to Shah and Oppenheimer, we employ such heuristics to save time and energy.² This makes intuitive sense when we think about the sheer number of demands on our health care teams, but often falls short when considering the importance of patient-centered care and patient safety.

DNR or do not resuscitate orders technically mean only one thing. According to The American Medical Association's Council on Ethical and Judicial Affairs, "DNR orders only preclude resuscitative efforts

and should not influence other therapeutic interventions that may be appropriate.”³ Sadly, research shows that when a patient has a DNR order, not only do the attitudes of their physicians and nurses change, but the actual care deteriorates as well. Nurses call doctors less often, care is escalated less frequently, and doctors order fewer treatments and studies.^{4,5,6} This misunderstanding, that code status is not care status, is pervasive, even in health care providers who report that they have had education in this area.⁷ [Anchoring bias](#), or the tendency to rely too heavily on a single anchoring piece of information (in this case the DNR designation) when making decisions heavily influences health care providers as they go about their daily work. If patients knew they would be treated differently with a DNR order on their charts, would they consent?

Understanding Capacity

The palliative care team, ICU team, and social services agency established the patient’s capacity to make some, but not all, decisions during their goals of care discussions with the patient, caregivers, and others involved in his care. Based on the case submitted, his subsequent care team did not treat the patient as though he could make any decisions, nor respect the complex goals elucidated during multiple meetings. Unfortunately, this is not an uncommon phenomenon. When providers or other care team members see mental health diagnoses or developmental delay, they question the patient’s capacity.⁸ In some circumstances, depending on the severity of the mental illness/episode or developmental delay, a patient may not be in a condition to make decisions about their care. However, a diagnosis of developmental delay or mental illness alone do not speak to a patient’s ability to weigh care decisions and reason through options to a final choice.⁹ It is vital to ethical, patient-centered care that the entire healthcare team understand the components of decision-making capacity so that they do not deprive patients of their rights to make decisions about their care. In healthcare, decision-making capacity comprises four dimensions: Understanding, Appreciation, Reasoning, and Expression of a Choice.^{10,11}

- **Understanding** refers to one’s ability to comprehend the information presented to them. After presenting information about a patient’s condition and care choices, a provider should check the patient’s understanding by asking them to explain what they have just heard in their own words. There may not be sufficient understanding if the patient repeats back word-for-word what the provider has said. Asking them to explain it in their own words demonstrates information processing by the patient to understand.^{10,11}
- **Appreciation** involves the application of information presented to one’s own situation. The patient must show how the information and choices relate to them personally. For example, a patient may demonstrate appreciation by verbalizing the consequences to themselves by forgoing certain treatments.^{10,11}
- **Reasoning** refers to one’s ability to compare the treatment options available and compare their risks and benefits in a logical, rational manner. Reasoning can be explored with a patient by asking open-ended questions about how they came to their decision or why they decided to forgo the options

presented. It is important with this dimension to recognize that even if a patient's choice is not the one recommended by the care team, they can still have rational reasons specific to their own preferences for forgoing the recommended option.^{10,11}

- **Expression of a Choice** is one's ability to convey a clear and consistent treatment choice. Patients still retain the right to change their mind. This dimension refers to the patient's ability to come to a conclusion about the information presented and express a clear choice based on that information and the other required dimensions of capacity.¹¹

In this case, the patient's developmental delay and mental illness did not interfere with his capacity to make all decisions, as demonstrated in the holistic assessment by the palliative care team. It was a nuanced situation that required explicit communication with multiple parties to fully understand the patient's baseline and cognitive capabilities. As he began to decline outside the ICU, he should have been offered full information about BIPAP and other non-invasive treatment measures to improve his respiratory status so that he could fulfill his goal of returning home. As discussed above, DNR code status does not mean that care stops for the patient. Had this patient been informed that missing his breathing treatments or BIPAP would keep him from leaving the hospital, it is likely would have readily accepted treatment. Full respiratory care (short of intubation) should have been offered to this patient, as was decided on in the goals of care meeting in the ICU.

Communication Challenges

Cognitive Underspecification

Transitions of care and the handoffs between teams are rife with potential for miscommunication. And communication failures often lead to patient harm, as they did in the care of this patient. There are evidence-based resident-resident handoff tools being implemented, including the I-PASS bundle, and their use has been associated with a reduction in medical errors and adverse events.¹² The basic structure of the handoff is adaptable to other health care providers and situations.¹³

When clinicians receive an incomplete handoff or are distracted or time constrained during communication, their minds naturally fill in what is missing. Cognitive underspecification is defined by James Reason as a knowledge gap that we fill with our own explanation, informed by our own experiences, values, and beliefs, usually influenced by high frequency events.^{14,15} When incomplete communication takes place or there is failure to have a shared mental model around the meaning of specific terminology, clinicians are prone to errors of cognitive underspecification. In this case, the ICU team had one idea about what the patient's goals of care were, and when the receiving team heard an abbreviated version of these goals, they filled in the gaps with their own understanding and experience. This process continued with handoff after handoff, and left the patient being lumped into a category of care that did not reflect his actual goals.

The receiving team could have stated their understanding of the patient's goals and which monitoring, therapies, and interventions are in alignment with those goals—a sort of advanced read-back—instead of filling in “DNR/home with hospice” knowledge gaps with their prior experiences or assumptions of

what that type of care looks like. For this patient, the goal was to go home to a familiar environment, so for example, therapies directed toward improving the patient's respiratory status would need to be continued. If your mental model was that home with hospice meant "discontinue everything, except comfort focused treatment," you miss the reality that in order to meet his goal, his respiratory status needed continued monitoring and intervention. Further, the expectation of the ICU team was that his respiratory status would improve to the point where he could go home. In fact, it was thought that he could get well enough to receive chemotherapy, if that had been in alignment with his goals.

Elucidating and documenting specific patient goals like going home to enjoy loud music rather than relying on medical terminology shortcuts and emphasizing that providers don't always share a complete mental model of the terminology we use may help prevent harm. We need to bring awareness of our biases, and the latent factors that contribute to poor quality communication in general, such as fatigue, workload, interruptions and other distractions to our utilization of handoff best practices.

EHR, Burnout, and Time Pressure

One hope for EHR (electronic health record) systems had been that documentation would become clearer and more accessible, and perhaps in other countries this is the case.^{16,17} Unfortunately, documentation in the EHR has morphed from a tool for clinicians to communicate with one another and reason through their differential diagnoses, into a vehicle for billing, compliance, and defense against lawsuits.^{18,19} Clinical notes in the United States are four times longer than in other industrialized nations.¹⁹ Spending time searching through the EHR for useful information contributes to health care worker fatigue and burnout.¹⁹ The repurposed functionality of the EHR also leads to patient harm, as clinicians struggle to rapidly find the information they need to provide patient centered care.²⁰

A workaround to the burdensome EHR has been the reliance on, and subsequent growth of, the parallel documentation system of sign-out sheets. Sign-out sheets have long existed as a tool for handoffs and cross coverage at night.²¹ They are rule-less and can contain whatever the keeper of the document deems important in whatever notation seems most helpful. As the formal EHR serves clinicians and patients less and less, will this alternative one play a larger role? More research is needed. If patients now have easy access to notes in the standard EHR, will the parallel EHR be used even more regularly? This is potentially dangerous as fewer clinicians have access to the thoughts/data it contains. It is unclear what it contains, and on some level, maintaining it is yet another task keeping clinicians from the bedside. Other workarounds to the mainstream EHR include scribes and voice recognition software, as well as having ancillary staff work to the limit of their licenses to offload the documentation burdens on doctors and nurses. With the development of EHR, more clerical and administrative tasks fall on all healthcare providers, contributing to their fatigue and less available time at the bedside.

As mentioned above, inefficient time spent on EHR contributes to burnout. Part of burnout is the depersonalization of patients, which seemed to happen to this patient once he left the ICU. This contributes to a vicious cycle of worsening care and worsening job satisfaction for clinicians. It is impossible to discuss the harm that came to this patient without discussing the absence of enough time as a limiting factor for clinicians. It seems to be the elephant in the room in this case, and likely for many more instances of avoidable patient harm. If clinicians are task saturated and burned out, spending progressively more

energy on the EHR, than at the bedside, how can we not expect this outcome?

In the long term, we need reconfiguring of our EHR so that it is patient care centered, easily allowing identification of critical information and facilitating communication between care providers. Information technology should evolve to the point where secondary aims such as billing and compliance, are dealt with behind the scenes and not by overburdened clinicians. In the short term, one tool to counteract many of these identified risks to patient safety involves education and training, such as [AHRQ's TeamSTEPPs](#), which focuses on teamwork and communication. The mutual support emphasized in the training helps alleviate some of the time pressure clinicians face. Creating shared mental models of various clinical situations improves communication and efficiency.

Systemic Pressures on Patient Care

In this patient case, there are two systemic influences on patient care that likely affected the outcome for this patient: 1) financial- and resource-driven pressures on health systems, and 2) the challenges (and failings) of healthcare systems to care for vulnerable populations, including people of color and those with developmental delay or mental illness.

Pressures on Health Systems

While healthcare systems work continuously to adapt to a multitude of pressures, the care of this patient was likely impacted as a result of systemic decisions made to address financial and resource pressures. The pressure to turnover hospital beds quickly is not a new trend; it increases the number of patients who move through the system, which in turn supports hospital finances. For example, reimbursement models in programs like Medicare and Medicaid pay out a specific amount for a hospital stay based on the admitting diagnosis and what is the likely length of stay and care needs for that diagnosis.²² The ability of a hospital to get the patient discharged in less time than the determined “likely” length of stay could represent additional revenue for the hospital. At the same time, hospitals themselves, including staff, patient beds, and medical equipment, are limited resources. As such, health systems endeavor to ensure an appropriate level of care for each patient; a patient with an uncomplicated dog bite does not need ICU-level care while a patient with respiratory failure needs care escalated beyond their primary care clinic. Furthermore, healthcare systems are encouraged to always be ready situations in which demand for hospital care might increase, such as a pandemic, a natural disaster, or a mass casualty event.

The patient in this case needed ICU-level care to best support his respiratory status, but the weekend ICU team likely felt pressure to get patients out to lower levels of care in order to make room for other patients. Although his goal of care changed to reflect a supportive care focus, his original plan for discharge relied on continuing to receive intensive care. It is because he did not receive this level of care that not only did he not go home, but his length of stay in the hospital was extended, likely reducing the hospital's revenue margin. Hospital systems must work to strike a better balance between their systemic pressures and what is best for the care of individual patients. Cases such as this one should be reviewed by hospital systems, using root cause analysis or other quality improvement models, to create clearer policies and protocols for supportive and comfort care interventions.

Along with systemic pressures on care, pressures at the bedside may have impacted this patient's outcome. As was discussed with the neurosurgery and medical teams after the patient's death, there is a misconception in healthcare about the needs of patients with a code status of DNR. There is evidence that in situations of constrained resources in ICUs, patients are made DNR earlier and die sooner.²³ To make matters worse, many hospitals are experiencing staffing shortages and high burnout among nurses, further stressing their limited resources.²⁴ In this case, it was not just that a medical team did not understand the patient's care needs; the bedside staff caring for the patient did not receive adequate communication regarding the care plan. As hospital censuses increase and bedside staff take on more patients, a patient's perceived lack of needs, like in this case, may make them a lower priority. It is important as care plans change and when care is transferred that all members of the care team, bedside staff and providers, receive communication about plan of care. Had bedside medical surgical or ICU nursing staff been made aware of the need for intense respiratory interventions to facilitate a discharge home, they may have more readily advocated for the patient to receive these measures over the weekend or even questioned his discharge from the ICU. It is possible that a warm handoff to the oncoming shifts could have prevented this unfortunate outcome.

Vulnerable Patients

While healthcare must address its systemic pressures, it is also important to acknowledge that in this case, the negative outcome affected a vulnerable patient. The patient was an African American man with schizophrenia and developmental delay. At baseline, he required a caregiver and an agency to manage his other support services. He had no family or friends involved in his care. Decades of data demonstrate healthcare's systemic racism and the many barriers to care experienced by the black community and other people of color.²⁴ These groups also experience increased risk of early death compared to their white counterparts, even when adjusting for other socioeconomic factors.²⁵ Implicit bias may have impacted the clinicians that transferred this patient out of the ICU once the DNR status was ordered. It is important that we recognize the impact of our own implicit biases against different groups so that we ensure we provide equitable, patient-centered care, and begin to overcome the entrenched systemic racism in healthcare.

The patient's care over the weekend further demonstrated his vulnerable patient status, as evidenced by his inability to adequately advocate for himself. Environmental circumstances at the hospital prevented him from having someone at the bedside. At his goals of care meetings, he had his caregiver and services agency staff available remotely to advocate for him. The palliative care team continued to advocate for the patient by establishing a plan of care with the weekday ICU team to meet the patient's goals. Once the meeting was over, though, and the weekday provider services left, no one continued to advocate for this patient. The patient's cognitive delay and schizophrenia, along with his declining respiratory status, made him unable to reach out for assistance for himself. He needed someone to be his advocate over the weekend, and he had nobody. As a result, he was not able to fulfill his wish to go home.

Now more than ever, as the demands on healthcare workers reach new peaks and continue to change day-to-day, we must not forget the needs of our most vulnerable patients. We must adjust care and make even greater efforts to ensure they have adequate advocacy and services. In cases where hospital policies prohibit most visitors, a solution could involve visitation exceptions for a loved-one to advocate at the

bedside or more readily available access to hospital-based advocates, including vigilant rounding over the weekend. It is also the duty of providers and bedside staff to raise questions if the care given is not congruent with previously documented plans, like those for this patient. Systems could consider piloting new EHR flags to alert staff to the particular needs of a vulnerable patient. There are many possible solutions, but they must be implemented at a system-wide level to ensure no vulnerable patient falls through the cracks.

Take Home Points

- A patient with mental health conditions or developmental delay can still fulfill the four dimensions of capacity: Understanding, Appreciation, Reasoning, and Expression of a Choice.
- Care inconsistent with a patient's goals of care is a preventable harm. Patients at the end of life are often medically complex and their care may not become simpler when their goals no longer include cure or CPR. Becoming aware of the many biases we have and cognitive shortcuts we take can help us provide more comprehensive, patient centered care.
- DNR is a code status. It should not determine how a patient is cared for, unless they have a cardiac arrest.
- Warm handoffs between providers, including consulting services such as palliative care, can improve communication and prevent avoidable errors.
- It is important for providers and other members of the healthcare team to be aware of their vulnerable patients and act as their advocates, especially when there is no family or other caregivers at the bedside.

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