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A framework for assessing reasoning about controversial end-of-life clinical decisions.

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The Case

A 65-year-old man with metastatic hepatocellular carcinoma (HCC), status-post partial hepatectomy with later development of a large ventral hernia, presented to the hospital with worsening abdominal pain. He was receiving palliative chemotherapy with bevacizumab, an agent that slows the growth of metastatic HCC by suppressing the formation of blood vessels that carry oxygen and nutrients to tumors. Imaging studies revealed perforated diverticulitis. A goals-of-care discussion was led by the palliative care service; the patient and his designated decision-makers chose to pursue non-operative management of diverticulitis. The patient was initially treated in the intensive care unit with broad-spectrum antibiotics; his condition improved, and he was transferred to a regular inpatient bed for continued antibiotics and observation. Later in the hospital course, he required abscess drainage by an interventional radiologist. However, the patient’s condition worsened, and he suddenly developed diffuse peritonitis, signaling failure of non-operative management. Following his wishes, he transitioned to comfort-focused end-of-life care but remained in an inpatient bed.

Shortly after this transition, the patient became unresponsive. He was no longer able to ask for pain medications or answer nursing questions regarding pain. However, he showed non-verbal signs of pain including moaning, grimacing, rigid extremities, and head shaking. Intravenous hydromorphone with a typical basal rate on a patient-controlled analgesia (PCA) pump was ordered near the end of the day shift. The evening nurse acknowledged the order yet refused to start the drip as she was uncomfortable with any basal PCA rate. The resident physician on duty spoke at length with the nurse, but she refused to start the drip and said, incorrectly, that the pharmacist did not approve it. The resident ordered hourly opioid bolus doses instead; however, the patient did not receive enough medication to resolve non-verbal signs of pain.

The same nurse refused to start basal PCA dosing through two subsequent nights despite discussions with multiple physicians and the charge nurse, due to concern that the medication would hasten the patient’s death. This disagreement was extremely difficult to explain to the patient's loving significant other, who was unable to hear the nursing staff (due to deafness) and unable to read lips with masks in place. The patient’s family expressed anger, anxiety, and frustration that he remained in pain, stating that he "does not deserve a death like this." Nurse staffing was stretched very thin due to staffing shortages, so no other nurses could be assigned to help, and the night residents had to check the patient almost hourly to ensure that he was receiving episodic pain control. After several days of continued unresponsiveness and non-verbal signs of pain, the patient died. The palliative care team spent many hours with the family helping them to manage their grief and dissatisfaction.

The Commentary

By Mark Fedyk, PhD, Nathan Fairman, MD, MPH, Patrick S. Romano, MD, MPH, John MacMillan, MD, and Monica Miller, RN, MS, CCRN

The authors believe that the tragic circumstances of this case arose not out of any one person’s choice, but rather because of the multi-layer nature of decision-making about the patient’s care plan, and the absence of an applicable strategy for responding to what we might call an “order-of-reasons" problem. In the following sections, therefore, we propose a framework that can be used to resolve controversies that arise from an “order-of-reasons” problems, demonstrate how the proposed framework applies to the current case, and address several related conceptual and clinical issues related to reasoning about complex end-of-life care.

A Proposed Framework for Organizing Reasoning about Complex Cases

At least five categories of reasons are relevant when formulating and implementing treatment plans. Organizing these categories into a hierarchy creates a framework that can potentially be applied to clinical scenarios when competing reasons arise (**Figure 1**).

In most situations, the reasons listed at higher levels should take priority over those listed at lower levels. There will be exceptions, such as when patients ask for tests or medications that have no plausible expectation of benefit. Nevertheless, this hierarchy can function as a “center-of-gravity” for deciding which considerations should take priority over others when making decisions about how to deliver care.

Figure 1.

Informed Patient Preferences (PP)	The patient’s beliefs or desires, or those of the patient’s family or surrogate decision-maker(s) medical expertise, are paramount.[1] All care, to the extent that it is medically possible to do so, must be reconciled with reasons at care plan ought to be implemented without taking account of the patient’s preferences and en care plan are consistent with those preferences.[2,3]

Standard of Care (SOC)	Clinicians have strong reasons to take or avoid certain actions because they either constitute care or would involve departing from standard of care. Intuitively, unless a patient desires or must be treated according to prevailing standards of care.

Emergent Patient Safety Concerns (PS)	Normally standards of care and considerations of patient safety should be overlapping catego the institutional context,[6] limitations of medical expertise,[7] the patient’s own role in their care, patient’s illness, or their social context, can lead to circumstances where there are legitimate safety. That is: from time to time, cases will arise where exactly following current standards of course of action. It must therefore be part of all clinicians’ discretionary responsibility to obser and suggest or implement modifications to care that improve the patient’s safety. These are e concerns, and, though they may be rare, by their very nature they are distinct from standards The CUS framework, which is discussed below, is helpful tool for calling attention to an emerg

Institutional Policies and Practices (IPAP)	Institutional policies reflect formal commitments to different stakeholders about how institutional resources will be used.[11] With respect to potentially controversial interventions, such as abortion or end-of-life care, institutional policies represent promises to practitioners and patients about how resources maintained by the institution can and should be used where there may be reasonable disagreement about treatment. Institutional policies usually follow a logic of risk mitigation, and thus they can support clinical decision-making by clarifying “ceiling” or “floor” levels of risk that are appropriate in a particular context. In addition to providing direction about the use of institutional resources, institutional policies can offer guidance about how much risk to take when negotiating or implementing a care plan.

Personal Beliefs of Clinicians (PBOC)	Finally, some personal beliefs of clinicians might be *about* areas of professional clinical compe professional standards of care, insights or research on patient safety, or institutional policies a the form of pre-standing substantive moral commitments such as: *all patients, no matter their access to the best care*; *non-medically necessary abortions are morally wrong*; and, perhaps *to hasten death.* These are the “Personal Beliefs of Clinicians”.[12] We stress that PBOCs are justified, as they are often grounded in important moral principles and so clinicians may offer meaningful justifications for their PBOCs. This point is relevant be just not comfortable with that” as a means of rejecting some clinical intervention, their underly When this statement is not an emergent patient safety concern (PS) and halts a care plan tha reasons, it must take lower priority.

The middle three rows are highlighted because these three categories circumscribe a clinician’s professional competency and their regulatory environment. With that, this table allows visualization of the proposed framework: patient preferences come first as the highest priority, next professional standards and knowledge, and only then are clinicians’ personal beliefs relevant, as the lowest priority. As a prima facie rule, care plans should only be based on mixtures of “blue” and “green” reasons, and “orange” reasons should have comparatively little influence on the course of care.

Applicability to The Case

In this case, reasons at the level of emergent patient safety concerns (PS) or personal beliefs of a clinician (PBOC) took priority, when our proposed framework suggests that the more suitable order-of-reasons should have been:

Informed Patient Preferences (PP) **?** Standard of Care (SOC) **?** Emergent Patient Safety Concerns (PS) **?** Institutional Policies and Practices (IPAP) **?** Personal Beliefs of Clinicians (PBOC).

In support of this assessment, what appears to have happened is that the order to provide an opioid infusion was not acted upon because of either concern about patient safety or personal beliefs. Reasons at these levels may provide appropriate justification for not acting upon a physician order, but only when no overriding reasons come into play. In this case, the argument from a patient safety perspective may have been that providing any basal opioid infusion would be likely to hasten the patient’s death. The argument based on personal belief may have been similar: administering any basal opioid infusion would violate the nurse’s personal moral beliefs about not contributing to death, create a risk of legal liability, or otherwise cause moral distress for the nurse at the center of this case.

All the same, the physician’s order was consistent with standard of care:[13] with the loss of the ability to swallow, and given a pathophysiology that is well understood to be excruciatingly painful, continuous opioid infusions with bolus dosing as needed are appropriate palliative measures at the end of life. There is also no evidence that either the patient or his family would have preferred an alternative to this standard of care, and the case does not describe any hospital policy that would have contradicted this course of action.

Finally, this is a case where there is no middle ground — no obvious reconciliation of the competing reasons. For example, halving the opioid dose would not necessarily extend the patient's life, but it may have rendered the medication ineffective, and there are no effective alternatives to opioids in cases such as these.[14]

It may seem that an obvious reconciliation would have been for the hospital to rotate the nurse responsible for the patient to another assignment. But if the nurse's objections were based in what they sincerely believed to be emergent patient safety concerns, it would be a mistake for hospitals to have a general policy by which they respond to discretionary actions taken by providers on emergent patient safety grounds by *immediately* rotating the provider to alternative patients or services (though more on this option will be discussed below). Any such policy would effectively de-prioritize emergent patient safety considerations relative to hospital policy, depriving providers of an important area of discretionary responsibility and potentially leaving patients exposed to unsafe clinical circumstances.

When reconciliation of all relevant reasons by care team members is not possible, one should make care decisions according to a hierarchy that prioritizes some reasons over others.[15] This is just such a case: even though reasons held in good faith are presumed to have been the basis for the choices made and actions taken in the case, those reasons were not necessarily the *type* of reason that should have been given highest priority, given the clinical context. We believe this was a case where standards of care and informed patient preferences should have superseded other reasons, and that this case therefore serves as an example of an "order-of-reasons" problem: the wrong type of reason determined the course of care.

Approach to Improving Patient Safety

A Proposed Strategy for Ensuring Implementation of an Established Care Plan

When implementation of an established care plan is being blocked, as in this case, a strategy for diagnosing the cause of the block and overcoming it may be helpful. Components of this proposed strategy include:

1. Check for understanding of and consensus about the care plan among care team members, family members, and patients. A care plan represents a negotiated agreement that forms a basis for coordinated actions among everyone involved in the care of the patient, and so there must be a shared understanding – and ideally consensus – about the care plan. Lack of understanding of the care plan on the part of an essential member of a clinical team, for example, could cause them to block implementation. At this step, it is also valuable to double-check that the care plan is justified by sound PP, SOC, and IPAP reasons.
2. Assess and address gaps in knowledge and/or skills. If consensus about a care plan exists, and implementation of the care plan is still being blocked, or is threatened with blockage, the next step would be to address the basis in knowledge or training causing non-compliance with the care plan. For example, it could be that the case presents technical challenges relating to dosing or pharmacological interactions that should be addressed.
3. Reconfigure the care team. If the previous two approaches fail, and a member of a care team continues to fail to follow the care plan, clinical management must reconfigure the team. Clinical managers have an ethical duty to ensure that appropriate personnel are assigned so that a patient's

care plan can be implemented.

4. Escalate effort as needed. If all the other options have failed, clinicians should escalate their advocacy on behalf of the patient; raise the issue with successively higher levels of management until the problem is resolved.

Thus, in this case, the primary team of physicians, along with the palliative care team, could have recognized an order-of-reasons problem, and, if the actions described under #1 and #2 above were unable to permit implementation of the care plan, escalated their concerns about the care of the patient to the nurse manager of the unit.

Reconciling the Framework with TeamSTEPPS

The nurse in this case apparently believed that it was appropriate to refuse to implement the order for basal hydomorphone on patient safety grounds, highlighting the value of the CUS tool from TeamSTEPPS (Team Strategies & Tools to Enhance Performance & Patient Safety). CUS provides a simple script that a clinician can follow to communicate a patient safety concern.[11] It recommends that clinicians say, “I am **c**oncerned”, then “I am **u**ncomfortable”, and finally “This is a **s**afety issue” in order to call attention to, and potentially halt, some aspect of care that may be harmful to a patient. Having followed these steps, a clinician likely has grounds to refuse to participate in a care plan.

However, the CUS tool assumes that the clinician who uses it has adequate reason to be concerned about patient safety. As this case illustrates, end-of-life-care has complexities that make it difficult to determine how best to protect patients. The proposed framework above provides mechanisms for interpreting and appropriately weighting the reasons why a clinician may want to block the implementation of a care plan: PBOCs are not normally sufficient reason to refuse to follow an order justified by PP and SOC reasons. Similarly, PBOCs are also not normally sufficient to invoke the first step in the CUS tool. Saying “I’m not comfortable with this” with the intent to halt the implementation of a care plan, *with no intent to participate in good faith a follow-up dialogue*, *and where the statement is only based on PBOCs, is professionally and ethically inappropriate.*

Establishing a Context for Successful Utilization of the Proposed Implementation Strategy

Hospitals and nursing homes can promote successful utilization of the implementation strategy for care plans described above in two ways. First, education and professional training about end-of-life care can be strengthened if these efforts include guidance about how to overcome situations where all the relevant evidence and reasoning cannot be reconciled into a single, universally agreed-upon course of action. The hierarchical framework depicted in the table above may be helpful to include in this training, as it simplifies what kind of evidence is relevant when formulating a care plan.

Likewise, broader knowledge of the proposed framework can help providers who will be responsible for implementing the care plan predict the possibility of conflict, even moral distress, because the proposed treatment plan conflicts with some of their PBOCs. It is better if providers prepare in advance for the emotional burden that participating in such care plans can create, or otherwise be proactive about working with management to take themselves off the care team.

Continuing professional education must also include attention to basics. In this case, refusal to implement the physician's order for continuous intravenous opioid analgesia was inconsistent with well-established and widely recognized standards of care,[7,8] resulting in significant harm to the patient and family.[13,16] There is a robust program for educating nurses on end-of-life care, called the ELNEC (End of Life Nursing Education Consortium) project, developed by the American Association of Colleges of Nursing.[17] Hospitals should consider making such training a mandatory component of orientation or regular training for their nursing staffs.

Ethical decision-making should always involve giving, receiving, evaluating, and eventually acting on reasons for common actions. Ethical decision-making, that is to say, needs occur in a shared "space of reasons"[18] to be coordinated with the often-complex array of additional relevant considerations. Sometimes the strength of a feeling or the force of an intuition can seem dispositive of action, but this is usually both practically and morally incorrect.[19-21] Clinicians should be certain that they act for good reasons when carrying out their duties, but they also need to be certain that the reasons that are guiding their actions are recognized and shared by other members of the care team.

For this reason, standardized decision trees are a particularly valuable tool for helping to resolve ethical challenges. Tamang and colleagues describe a decision tree that was created to assist with determining next best patient care steps for patients at the end of life.[22] For example, had a standardized order set recommended by Tamang et al. been utilized in this case, the nurse might not have objected to performing the prescribed interventions, as knowledge that the physician's orders came from an evidence-based order set might have persuaded this nurse that implementing these orders was standard, accepted practice.

Using the Hierarchical Framework for Creating and Implementing Care Plans

While everyone professionally involved in delivering healthcare should recognize the *types* of reasons described in the framework depicted in the table above, the authors acknowledge that members of different professions and different disciplines may rank some types of higher or lower priority.[23] Exploring such different rankings in a nonjudgmental manner may lead to healthy and informative discussions. As discussed earlier in this Commentary, clinical decision-making occurs in a space of shared reasons — and the framework shown above may serve as a helpful device for organizing and simplifying reasoning about ethically complex or controversial healthcare, and thereby help to prevent "order-of-reasons" problems from arising.

Shared Decision-Making requires Shared Reasoning

Clinical decision-making is always a collective responsibility that involves *all* members of a patient's care team as well as the patient. Providers should always be proactive and explicit in communicating their reasons for making different clinical choices and recommendations, taking various actions, and rejecting plausible alternatives. This suggestion implies that care providers have a responsibility to continually educate themselves about standards of care, institutional practices, and patient safety challenges. Institutions have a corresponding responsibility to their clinicians to provide relevant education. Shared reasoning must have a strong foundation in clinical expertise.

Maintaining an awareness that shared decision-making requires shared reasoning is important because of the increasing division of labor in most healthcare organizations. Nearly all clinical effects flow from highly interdependent networks of clinicians, specialists, technicians, and even administrators, each of whom has jurisdiction over different and complex actions, and considerations of efficiency ensure there is little overlapping jurisdiction among the people comprising these networks. High levels of interdependence combined with few areas of shared jurisdiction will inevitably create situations in which an individual acts to halt implementation of a care plan, which appears to be what happened in this case. It is therefore important to have a framework that can be used to minimize individual vetoes of the care plan (see table above) and a strategy that can be used to fix situations in which implementation is blocked.

The complexity of health care can be a source of risk or harm to patients in other ways as well. For example, healthcare delivery can be a source of bad moral luck for patients; this term refers to outcomes for which a clinician may be held accountable even if they were caused by factors beyond the clinician’s control.[24] It is therefore appropriate in some instances for a clinician to exercise discretion and halt the implementation of a care plan — such as when legitimate patient safety concerns arise or when new information about patient preferences comes to light. In both cases, however, there must be a compelling reason to stop the implementation of a previously agreed upon care plan.

Conclusion

What is most troubling about this case is not that the nurse exercised a prerogative that is important for all clinicians to have, as the ability to halt clinical processes is an important safeguard of patient safety. Rather, the nurse did not articulate an evidence-based rationale for refusing the order, and the details of the case suggest that the patient and family suffered as a result of her refusal. No clinician should be able to halt the implementation of a care plan by saying “I’m not comfortable with this” and then failing to participate in the necessary deliberative follow-through; blocking the implementation of a care plan without an evidence-based reason for doing so is both professionally and ethically inappropriate.

The proposed framework presented in response to this case is intended to help us think about and critically evaluate the different kinds of reasons that could be given to support implementing or interrupting a clinical procedure. It provides examples of which reasons are justified (i.e., patient safety concerns, patient preferences, standards of care) and which reasons are less likely to be justified (i.e., respect for autonomy, religious freedom, or promotion of pluralism). To optimize patient safety and patient-centered care, health care organizations must have mechanisms in place to address controversies of the type described above, and to prioritize informed patient preferences and professional standards of care over personal beliefs of clinicians.

Take-Home Points

- It is appropriate to utilize a decision-making framework that establishes the following hierarchy (most important first) among the categories of factors to consider when creating and implementing care plans:
    - Informed Patient Preferences (PP)

    - Standard of Care (SOC)
    - Emergent Patient Safety Concerns (PS)
    - Institutional Policies and Practices (IPAP)
    - Personal Beliefs of Clinicians (PBOC)
- Patient preferences enable person-centered care when they are identified as the most important layer.
- Clinicians should be attentive to the types of reasoning they use in making clinical decisions, and make sure that the reasons they use to determine a course of care are shared among all members of a care team.
- “I’m not comfortable with this,” on its own, with no deliberative follow-through, is not a clinically valid reason for refusing to implement a treatment plan, as it does not represent a clearly articulated safety concern.
- When a clinician refuses to follow a care plan, the following strategy may be effective in overcoming the problem:
    - check for consensus about treatment plan
    - determine if the refusal is due to gaps in knowledge or understanding
    - reconfigure the care team as needed
    - if all else fails, then advocate for the patient by escalating the issue until the problem is resolved.

Mark Fedyk, PhD
Associate Professor
Betty Irene Moore School of Nursing
Department of Internal Medicine
UC Davis Health

Nathan Fairman, MD, MPH
Associate Clinical Professor
Department of Psychiatry and Behavioral Sciences
UC Davis Health

Patrick S. Romano, MD, MPH
Professor
Department of Internal Medicine
Department of Pediatrics
UC Davis Health

John MacMillan, MD
Clinical Professor
Medical Director, Hospice Programs
Department of Internal Medicine
UC Davis Health

Monica Miller, RN, MS, CCRN
Clinical Nurse
Medical Intensive Care Unit
UC Davis Health

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