

# “BUT DOCTOR, YOU HAVE TO DO EVERYTHING!” MANAGING END-OF-LIFE ETHICAL DILEMMAS IN THE HOSPITAL

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It is not surprising that residents often struggle to identify and manage ethical problems when they arise [1,2]. Assessing decision-making capacity, providing care at the end of life, maintaining confidentiality, and weighing issues of medical futility all can perplex the busy resident who is caring for several patients simultaneously.

Although the Accreditation Council for Graduate Medical Education has designated ethical clinical practice as a core competency of residency training [3], there is no literature in support of evidence-based curricula designed to meet this need. Because *clinical ethics*—the application of bioethical principles in the care of a patient [4]—is closely entwined with quality clinical care, training programs often attempt to address clinical ethics in, at best, a piecemeal fashion through didactics focused on communication, conflict resolution, and legal theory. Some residents may ultimately learn to manage clinical ethical dilemmas through prior experience or by seeking guidance from the hospital ethics consultation service, whereas many others may complete their residency without the confidence needed to respond effectively to these challenges in practice [5].

In attempt to aid physicians in navigating these difficult situations, a few authors have developed strategies for systematically examining and working through clinical ethical dilemmas [4,6,7]. These proposed systematic approaches vary somewhat in their individual components but are similarly designed to operate in much the same way as clinical problem solving. The methods all reflect the view that clinicians should approach ethical dilemmas as they do medical problems, with systematic data collection and analysis that can lead to a logical plan that is justifiable to all parties involved.

This article is the first in a series designed to illustrate the use of a systematic approach to managing ethical problems. Each article will highlight a specific approach and present a common clinical scenario that raises an ethical issue likely to be encountered during and after training. The intent of these “how to” articles is to demystify the topic of clinical ethics by providing a practical and accessible framework for thinking about, understanding, and working through clinical ethical dilemmas. The authors hope that these templates will serve as useful guides for both formal and informal teaching sessions with medical students and trainees.

In this first article, we present a case of an elderly hospitalized man who is at the end of his life and whose daughter and son are at odds over his care. Using a stepwise approach, we illustrate how the core ethical issue can be broken down into a series of steps or questions that help to order the resident’s thinking and allow for better communication with the family and, ultimately, a resolution that respects the patient’s values and preferences.

## Applying a Systematic Approach

### The Case: A Dying Man with a DNR/DNI Order

Mr. Kingston is an 89-year-old man with Parkinson’s disease, hypertension, renal insufficiency, and urinary incontinence. Six days ago, Mr. Kingston was brought to the emergency department (ED) after his son found him in respiratory distress. The ED physician noted that the patient was minimally responsive, afebrile, normotensive, tachycardic to 114 bpm, and tachypneic to 38 breaths/min. The physical examination was significant for left-sided rales. Laboratory tests were significant for a white blood cell count of  $17 \times 10^3 \mu\text{L}$  and a creatinine of 2.1 mg/dL. A chest radiograph revealed a left lower lobe consolidation.

Because Mr. Kingston had an advance directive authorizing his physician to issue a do not resuscitate/do not intubate (DNR/DNI) order, he was placed on bi-level positive airway pressure (BIPAP), given intravenous antibiotics, and transferred to the

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medical intensive care unit (ICU) for further observation. In the ICU, the patient's respiratory status stabilized, and he was able to be gradually weaned off BIPAP. After the full battery of testing, the ICU physicians concluded that Mr. Kingston's new worsened mental status was due to the pneumonia. His renal insufficiency was stable with a creatinine of 2 mg/dL. The ICU discharge plan was for antibiotics and supportive care.

On the day of Mr. Kingston's transfer to the medicine service, Dr. Romani—a second-year resident—finds the patient comatose and in mild respiratory distress off BIPAP. The patient's daughter has just arrived at the hospital and tells Dr. Romani that she "wants everything done" for her father. The doctor is concerned that this approach would conflict with the patient's advance directive, but she is unsure what to do next. Dr. Romani tells the daughter that she understands that she wants the best care for her father. She asks whether they could meet later in the day to discuss the daughter's concerns.

In this case, a clinical ethical problem has been identified by the resident responsible for a dying man's care in the medicine ward of the hospital. The daughter's request for care conflicts with the patient's advance directive and places the resident in the difficult position of either honoring the patient's wishes or satisfying the daughter's request.

Recognizing a clinical ethical problem is not unlike being presented with a chief complaint. Similar to evaluating chest pain and a chest radiograph in the workup of a patient with suspected pneumonia, the evaluation of a clinical ethical problem can be approached systematically, using a stepwise technique. Each step allows the physician to collect information that will help lead to an ethically justifiable clinical decision. In the following discussion, we illustrate how the resident might analyze and work through this dilemma using a systematic approach developed by Rhodes and Alfandre [7]. This straightforward method (**Figure**) can be applied during rounds or at the bedside to help identify and prioritize the relevant ethical principles and to provide direction for arriving at an ethically sound decision or course of action.

1. Collect all relevant data that should be evaluated in an attempt to resolve the dilemma.

This step is akin to gathering all the historical, physical examination, laboratory, and radiologic data

1. Collect all relevant data (medical and nonmedical) that should be evaluated in an attempt to resolve the dilemma.
2. Identify ethical principles and/or related ethical concepts involved, and explain how they relate to the case.
3. Consider whether principles conflict OR whether there is uncertainty about what a particular principle (eg, beneficence, respect for autonomy) directs you to do.
4. Formulate a question that reflects the dilemma.
5. Decide which principle should have priority and support that choice with factors relevant to the case, OR find an alternative clinical course of action that avoids the dilemma.
6. When uncertainty persists, determine whether there is missing information that would help in resolving the dilemma. Which information? How will it help?
7. Evaluate your decision by asking if it is what a consensus of exemplary doctors would agree to do.
8. Plan the practical steps that you should take, focusing on the details of the case and the future issues that you foresee.

**Figure.** Applying a clinical problem-solving approach to managing clinical ethical dilemmas. (Adapted from Rhodes R, Alfandre D. A systematic approach to clinical moral reasoning. *Clin Ethics* 2007;2:66–70. Reproduced with the permission of The Royal Society of Medicine, London.)

needed for analysis of a medical problem. To analyze an ethical issue, the physician needs to gather all medical as well as nonmedical information essential to arrive at a full understanding of the issues to be weighed in the case. Key medical information that is relevant in this case would include the patient's diagnoses, prognosis, baseline mental and physical function, and decision-making capacity.

It is also essential to determine whether the patient has a *health care proxy* (also referred to as a *durable power of attorney*), who is an agent appointed by the patient to make health care decisions should he/she lose the ability to do so. In addition, it is important to assess the presence or absence of family relationships and to determine, as best one can, the patient's previously stated wishes about his/her health care.

In an attempt to better understand the scope of the ethical dilemma before her, Dr. Romani takes a moment while in the company of Mr. Kingston's daughter to collect more information about her father's medical history and personal values. The daughter says that in his advance directive, her father appointed her brother, who lives with the patient, as the health care proxy. Five years prior to this hospitalization, a neurologist diagnosed the patient

**Table.** Ethical Principles: A Starting Point for Managing Clinical Ethical Dilemmas**Principles**

Respect for patient autonomy

Beneficence/caring

Nonmaleficence/minimize harm

Justice (fair allocation of resources)

**Ethical/professional issues for physicians**

Trust/fiduciary responsibility

Duty to provide care

Confidentiality

Truth telling

Duty to warn

Informed consent

Justified paternalism

Assess decisional capacity/assess surrogate

Conflict of interest

Medical futility

Advance directives

Nonjudgmental regard

Professional competence

Responsibilities to peers and institutions

Evidence-based practice

with Parkinson's disease, and 6 months prior he was diagnosed with mild dementia. During this time, the daughter notes that her father was unable to ambulate independently and used a wheelchair outside the house, but he still enjoyed reading, watching TV, and seeing his grandchildren.

The daughter says that her father decided on the DNR/DNI order last year after an extended hospitalization for pneumonia. Mr. Kingston's advance directive further states that he does not wish heroic measures if he has no reasonable chance of meaningful recovery.

The daughter, a health care administrator at a hospital a few hours away, reiterates her concern that more could be done for her father. She tells Dr. Romani that her father needs stronger antibiotics to fight the pneumonia, a breathing tube to help his breathing, and dialysis to help his kidneys. Based on Dr. Romani's assessment of the patient's present comatose mental status, she concludes that Mr. Kingston is unable to meaningfully and rationally participate in decisions about his medical care and, therefore, lacks decision-making capacity.

2. Identify the ethical principles and concepts involved, and explain how they relate to the case.

Dr. Romani decides she needs to speak with Mr. Kingston's son, the health care proxy and legally appointed decision maker for the patient. She is able to reach the son by phone and to discuss Mr. Kingston's case and the planned course of treatment. The son emphatically agrees with the ICU team's plan to continue the current supportive treatment regimen. He states that his father would not have wanted aggressive measures, and he agrees to comfort care for the patient. He says he will speak to his sister about her concerns and will join Dr. Romani later in the day when she meets with his sister.

The first step in analyzing a clinical ethical dilemma is to further characterize the situation in terms of the underlying ethical principles that apply and the possible related ethical concepts (eg, advance directives, confidentiality, informed consent) that may be involved. Deciding which ethical principles and/or concepts are relevant helps to bring the central controversy of the case into focus (**Table**).

The widely adopted approach to understanding ethical dilemmas by Beauchamp and Childress [8] attempts to distill ethical dilemmas down to the 4 main principles of medical ethics: respect for patient autonomy, beneficence, justice, and nonmaleficence. While this approach is valid and useful in many if not most situations, it is important to caution readers that reducing decisions to the 4 principles may fail to address some of the complexity inherent in many ethical dilemmas [9]. Nevertheless, reflecting on the 4 main principles is a useful starting point in analyzing a clinical ethical dilemma. Two of these principles clearly apply in the case of Mr. Kingston.

**Respect for patient autonomy.** This principle is a cornerstone of Western medical ethics. To ensure that his autonomous wishes were followed, Mr. Kingston had completed an advanced directive, which authorized a physician to issue a DNR/DNI order and authorized his son as his health care proxy to make decisions on his behalf in the event that he was unable to do so himself. Because a patient's preferences can change over time, the physician should confirm with the proxy that the advance directive is still representative of the patient's wishes. To respect Mr. Kingston's autonomy, the medical team should abide by the patient's previously stated wishes as directed by his son.

**Beneficence.** This principle directs the physician to act in the patient's best interests. In a patient lacking decisional capacity, it is more difficult to determine what the patient would have regarded as being in his or her interest. In this case, we can rely on the appointed health care proxy to decide what the patient would have wanted.

3. Consider whether principles conflict in this situation OR whether there is uncertainty about what a particular principle (eg, beneficence, respect for autonomy) directs you to do.

In this case, the health care proxy (Mr. Kingston's son) does not share the feelings of another close family member (Mr. Kingston's daughter) about the care of the patient, placing the principles of autonomy and beneficence at odds. Upholding the patient's autonomous choices, through either his prior advance directive or his current health care proxy, conflicts with the daughter's desires for more aggressive treatment for the patient. It is useful to acknowledge that in end-of-life care situations, the family members also are in need of care (beneficence in this case applies to the patient's close family members, not the patient). This concept of "treating the family" is a common element of managing palliative care in incapacitated patients. Because families are left to live with the decisions at the end of a loved one's life, it is important to seriously consider the concerns of all relevant family members.

Although it may be relatively uncontroversial to accept respect for patient autonomy and beneficence (for the patient) as the prominent and relevant ethical principles involved in this case, the principles themselves do not provide the tools to prioritize one over the other. The following 2 steps in this systematic approach help to overcome this problem.

4. Formulate a question that reflects the dilemma.

Once again, it is useful to think of the approach to clinical ethical decision making as being analogous to taking an evidence-based approach to clinical decisions. Just as formulating a focused clinical question guides a search for relevant, objective evidence, formulating a specific ethical question helps to focus the clinician on the particular facet of the dilemma that requires further investigation. The ethical question raised in this case might be stated as follows: "*What are the physician's obligations when a family disagrees about the prior stated wishes of an incapacitated family member?*"

5. Decide which principle should have priority and support that choice with factors relevant to the case, OR find an alternative clinical course of action that avoids the dilemma.

Prioritizing one relevant ethical principle over the other can be difficult and requires objective data analysis; a doctor's intuition is not enough. The physician must provide explicit and transparent reasons to support the choice that can be articulated to the patient, the family, and medical colleagues and that can be documented in the medical record. In some situations, an alternative clinical course of action may be possible that will avoid the dilemma.

In the case at hand, Dr. Romani is concerned about providing additional medical treatment that the patient may not have wanted. The ICU physicians and the health care proxy agree. The daughter appears to be the only one with concerns about the treatment plan. Dr. Romani would need a compelling reason to counteract Mr. Kingston's autonomous wishes to not have any heroic measures performed.

In thinking through all the elements of the case, Dr. Romani realizes that she is unsure whether the daughter's concerns represent her own personal values about her father's illness or Mr. Kingston's personal values. At the same time, she feels fairly certain, based on her discussion with the son, that Mr. Kingston would agree with the proposed treatment plan. She concludes that, without compelling reasons to override the patient's prior stated wishes, respecting the patient's autonomy takes precedence over beneficence, as the care the patient would have chosen is the care that has been proposed. Thus, the team should continue with comfort care including antibiotics, oxygen, frequent suctioning, and opioids for respiratory distress. To do otherwise would contradict Mr. Kingston's autonomous decisions. At the same time, Dr. Romani realizes it will not be easy to adhere to this treatment plan without the daughter's cooperation.

6. When uncertainty persists, determine whether there is missing information that would help in resolving the dilemma. Which information? How will it help?

It may become clear that additional information needs to be collected or that existing information needs to be reevaluated. This step sometimes operates like a feedback loop: the new information

changes the clinical ethical picture and brings the process back to the original step. When it does not, it may yield insight that will be useful in the analysis of the dilemma.

Later that day, Dr. Romani returns to the bedside with the health care proxy (son) to confirm whether there is any additional information he wishes to share with the medical team. Because Mr. Kingston's daughter is there, Dr. Romani starts a dialogue about the value of comfort care and its importance with dying patients. The daughter interrupts angrily, saying "I'm not ready to talk about this!"

7. Evaluate your decision by asking if it is what a consensus of exemplary doctors would agree to do.

This step is a consideration of what is the "ethical standard of care" [10]. Not unlike what is considered a basic standard of medical or surgical care, a physician's choices about any case should be evaluated according to how one would be judged by his or her peers.

Dr. Romani has been troubled about this case, so she decides to revisit it the next day during morning rounds. She is relieved to find that her 2 attending physicians agree with her evaluation and management of Mr. Kingston. They leave Dr. Romani to decide how to manage the dilemma going forward.

8. Plan the practical steps that you should take, focusing on the details of the case and the future issues that you foresee.

Many ethical dilemmas are rooted in inadequate doctor-patient or doctor-family communication [11]. Especially in end-of-life dilemmas, the stress of illness and dying can create tension that makes barriers to communication more likely to arise, even if there is an advance directive [12,13].

In these emotionally charged situations, the communication and interpersonal skills of the physician are called upon and often challenged. By becoming an effective and empathic communicator who is able to put the clinical and humanistic elements of doctoring in proper balance, house staff physicians will be better able to negotiate consensus to effectively address competing ethical priorities. Because the personal and professional values of a physician and the values of a patient or family member can conflict, it is important for the physician to respect the

patient's/family member's choices even if the physician disagrees. To do this, a physician must recognize the importance of simply letting patients or families articulate their values. Only by leaving space for this dialogue can the physician ensure that the concerns and values of patients and families are heard and understood [14]. In these situations, the physician would be well-advised to "don't just do something, stand there" [15]. Then, a more feasible plan that reflects important values of the patient and/or family can be formed.

Dr. Romani returns to Mr. Kingston's room the following morning and finds the patient with more labored breathing. Mr. Kingston's daughter, who is at the bedside, appears distraught. Dr. Romani decides to quietly observe. Thirty seconds pass as she is evaluating the patient's general condition, when the daughter says, "The last time I saw him, he was so strong." The doctor decides to remain silent. After a moment, the daughter says, "I didn't visit him as often as I should have."

Dr. Romani now suspects that part of the daughter's earlier concern may have been related to a sense of grief and loss and its associated guilt and regret. She also remembers an attending saying that you cannot solve a problem before understanding it. Rather than trying to "cure" the daughter's guilt, Dr. Romani focuses on the empathic response. She turns to the daughter and says, "I imagine it's hard to watch a parent so sick."

"But he's uncomfortable. Look how he doesn't say anything. Isn't there anything we can do?"

Attempting to discern and understand patient and/or family values is critical in managing ethical dilemmas. However, strong emotions on the part of the patient or family sometimes interfere with a physician's ability to understand these values. Physicians who are confronted with anger, scorn, irritation, or annoyance often find it difficult to maintain the empathic response necessary to understand their patients' needs. Awareness of the primary importance of this professional commitment can help a physician to react less to negative emotions. Furthermore, being mindful of one's own emotions in complicated ethical dilemmas can help the physician have more empathy for patients and thereby improve the therapeutic alliance [16].

What was once seen as conflict over goals between the daughter and the medical team becomes clearer

now as Dr. Romani realizes the daughter's sorrow for her father's imminent death. The tension that was building between the daughter and the medical team has been replaced, because of the physician's empathic response, with a bridge to communication.

"This must be so hard for you to watch," says Dr. Romani, remembering that an empathic response can be as simple as a reflection of what the physician sees and hears. "Your father is very sick—that's why he's not talking—but I want to reassure you that he's not uncomfortable. He is getting morphine to relax his breathing and manage his pain. This is part of the dying process and we are making him comfortable."

The tension in the daughter's shoulders releases and she says, "I know you are doing what he would have wanted. I guess I'm scared that I'm going to lose him... This is so hard for me. Thank you for listening."

The following day Dr. Romani schedules a joint meeting with the son and daughter. At the meeting, she allows time for the family's grief to be expressed, for the son and daughter to come to agreement about the plan of care, and to have all their concerns addressed. The son and daughter together agree to proceed with comfort care.

Following the meeting, Dr. Romani returns to the nursing station and places an order to titrate up Mr. Kingston's opioid drip for comfort. The patient dies 8 hours later in no acute distress, with the family at the bedside. One of the attending physicians joins Dr. Romani later in the day and praises her careful and effective communication techniques, her planning, and the resulting "good death" of her patient.

Although this case was successfully resolved by addressing the central conflict between the ethical principles of patient autonomy and beneficence, it is important to note the limitations of using a principlist approach. While giving the process structure, focusing solely on the fundamental ethical principles can divert attention from other relevant and important concepts (eg, empathy, countertransference) that require the clinician's attention [9]. For instance, while invoking patient autonomy, allowing a depressed patient to refuse antibiotics for lower extremity cellulitis may neglect the consideration that depression can be a cognitive distortion that limits a patient's ability to appropriately weigh the risks versus benefits in reaching an informed decision. Cases that involve subtle and complicated issues such as this or that become

untenable and fractious can sometimes be best managed by asking for the help of the ethics consultation service.

### Summary

Medical school provides grounding in the principles of medical ethics. There, students apply these newly learned principles to idealized cases, ones that often lack the complexity of clinical ethical dilemmas encountered in actual practice. However, within the hectic context of a busy residency program, these ethical principles may not be perceived as immediately relevant to residents who are struggling to manage ethical dilemmas. Lacking a conceptual framework to understand the dilemma, many residents end up confused and unsure of how to proceed.

A systematic approach to clinical ethical problem solving offers a clear, concise, and learnable framework that can create order within a complicated dilemma. Residents can rely on this general algorithm to prompt their thinking and to ensure that all relevant and necessary details have been identified and considered in the evaluation of the dilemma. Having a structural basis for assessing their intuitive convictions about an ethical dilemma also enables residents to articulate reasons for acting that are both transparent and explicit. Relying on a clear and directed thought process, one that is consistently used in other areas of medical decision making, can result in better communication with the patient as well as with colleagues and better documentation in the medical record.

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