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IssueBrief

October 2018

Act with integrity and fidelity:

Know the **SCOR**e when ethical stakes are high

Even when everyone agrees on the path forward, making end-of-life decisions can be agonizing, especially when the client cannot participate. Disagreements among and between family members and the health care team make these situations even more distressing and raise difficult ethical questions.

In the midst of this, case managers are ethically required to stand up for their client's best interest—not just in the abstract, but in the all-too-painful reality. Consider, for example, Jesse's story.

> *Jesse has been ventilator-dependent since he was born prematurely four months ago. The NICU physicians diagnosed him with bronchopulmonary dysplasia (BPD), and they believe a tracheostomy will give him the best chance at long-term survival.*
>
> *If he receives the trach, he will need to stay in the hospital for another six to 12 months before being discharged home. Both parents would need to be trained on tracheostomy care. At home, he would need 24-hour "awake care" to make sure he does not have any plugs that could quickly become fatal. The parents' insurance would cover only about 18 hours per week of assistance from a home health care aide. He would likely need to keep this status for three to six years.*

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The parents, Mariel and Fernando, consistently tell the health care team that they want "everything" to keep Jesse alive. At the same time, they do not want Jesse to receive a tracheostomy because they believe that he will "grow out of" the BPD. Fernando also mentions to the case manager that "God will make sure he heals," and Fernando does not want health care aides intruding on their privacy.

Walking into a situation like this and making the ethical choices can be profoundly challenging, says Michelle Baker, BS, RN, CRRN, CCM, chair-elect, Commission for Case Manager Certification.

"As case managers, we are fortunate to have the principles of the Code of Professional Conduct to help keep our ethical compass pointed at true north. The first four principles in particular emphasize our commitment to the public interest above our own personal preferences, and the imperative to always serve as the client's advocate" (see sidebar).

Unfortunately, having that "true north" doesn't make things any easier. "Clients and their family members bring their own values to the table—and sometimes they're not in agreement with one another," Baker says.

"Ethically supportable options"

Such challenges make practical ethics difficult for case managers and other members of the care team, says ethicist Laura Guidry-Grimes, Ph.D. assistant professor in the department of medical humanities and bioethics at the University of Arkansas for Medical Sciences (UAMS).

Dealing with end-of-life issues can be wearing and wearying for the health care team and for families. "Many of us have personally gone through this," says Guidry-Grimes, who also serves as a clinical ethicist at UAMS and at Arkansas Children's Hospital. The impact

The Code of Professional Conduct for Case Managers

Originally adopted in 1996 and updated in 2015, the Commission developed the Code of Professional Conduct for Case Managers to assure quality and protect the public interest. It includes broad principles—advisory in nature—and prescriptive rules and standards for professional conduct.

PRINCIPLE 1: Board-Certified Case Managers (CCMs) will place the public interest above their own at all times.

PRINCIPLE 2: Board-Certified Case Managers (CCMs) will respect the rights and inherent dignity of all of their clients.

PRINCIPLE 3: Board-Certified Case Managers (CCMs) will always maintain objectivity in their relationships with clients.

PRINCIPLE 4: Board-Certified Case Managers (CCMs) will act with integrity and fidelity with clients and others.

PRINCIPLE 5: Board-Certified Case Managers (CCMs) will maintain their competency at a level that ensures their clients will receive the highest quality of service.

PRINCIPLE 6: Board-Certified Case Managers (CCMs) will honor the integrity of the CCM designation and adhere to the requirements for its use.

PRINCIPLE 7: Board-Certified Case Managers (CCMs) will obey all laws and regulations.

PRINCIPLE 8: Board-Certified Case Managers (CCMs) will help maintain the integrity of the Code, by responding to requests for public comments.

Compliance with the rules and standards in the Code is an expectation for every board-certified case manager. Accepted throughout the industry, the Code provides the framework for all case managers to follow. Case managers who carry the CCM credential commit to providing ethical advocacy for their clients, putting the client's safety, privacy and autonomy first.

can be devastating, according to peer-reviewed research; it includes guilt, trauma, stress and increased risk for PTSD.[1,2]

She points to yet another challenge: agreeing on what constitutes "end of life." There's rarely a bright line marking the entrance to that final phase. Often, it only becomes clear after you fully understand the client's situation. Guidry-Grimes identifies four factors to consider in end-of-life situations that may create ethical dilemmas (see sidebar).

"We should ask: What are ethically supportable options? What steps are fair and respectful of the different perspectives and interests of the involved parties? And we should revisit resolutions, checking to see if there are any lingering moral concerns," counsels Guidry-Grimes. After all, she adds, resolutions are rarely perfect.

Put another way, case managers need to know the score.

Knowing the SCORe

The ethical considerations around end-of-life care can be ambiguous, but Guidry-Grimes describes a mnemonic—SCORe—for the four steps to dissect ethical situations and tease out the issues: the **S**takes, **C**onstraints, **O**bligations and **R**esolution.

End of life isn't a simple thing

Often, understanding whether a client is at the end of his or her life can be complicated. Guidry-Grimes offers four factors to consider in end-of-life situations—each of which may create ethical dilemmas.

The client's medical condition, including psychiatric disorders that may complicate matters, especially around consent. "Even if the patient lacks decision-making capacity, trying to medically benefit the patient over the patient's objections can be ethically troubling if it involves prolonged restraints or sedation; at the same time, involuntary treatment could also help the patient survive, be in less pain and regain the ability to make their own decisions," Guidry-Grimes says.

Resource limitations: Conflicts may arise when a client or family wants costly treatment options or scarce resources that the hospital is unwilling to provide. "In these kinds of cases, the team has to weigh considerations of just allocation of resources and what will be most beneficial to the patient long-term; it then needs to establish reasonable expectations as part of building therapeutic trust," she adds.

The social situation: A client might be incapable of making his or her own decisions but also have no willing or available surrogate decision-maker. At the other extreme, complex family dynamics can lead to arguments about goals of care. Outside of the hospital setting, the client's social situation might also make it difficult for them to access the resources needed, making adherence to a plan of care next to impossible. "It is not uncommon for patients to be unfairly judged for their non-adherence even when they have these obstacles," she says. "This is an area where your insights as case managers can be so incredibly important."

Decision-making: Even having an advance directive doesn't guarantee end-of-life decisions will be easy because documented wishes may be open to interpretation. "Even if it says the patient would not want 'aggressive' treatments if he or she were permanently unconscious, it might not be clear whether the patient is permanently unconscious or what treatments should count as 'aggressive.'" Case managers and other health team members may also encounter a client, parent or surrogate who requests comfort measures only, even though other medical interventions are available.

Each of these factors combines with the others in different ways, depending on the particular situation, to create an understanding of just what "end of life" entails. Identifying and understanding the ethical issues—much less resolving them—can be daunting. Case managers are up to the task.

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— LAURA GUIDRY-GRIMES, PH.D.
ASSISTANT PROFESSOR AND
CLINICAL ETHICIST

1 D. Wendler and A. Rid. "Systematic Review: The Effect on Surrogates of Making Treatment Decisions for Others." *Ann Intern Med* 154 (2011): 336-346.

2 E. Azoulay, et al. "Risk of Post-traumatic Stress Symptoms in Family Members of Intensive Care Unit Patients." *Am J Respir Cri Care Med* 171.9 (2005): 987-994.

Let's first look at each, then apply SCORe to Jesse's situation.

The **Stakes** may always be high, but they vary. They may include client preferences, family interests, resources, pain and suffering, professional integrity, resource allocation, the obligation to protect vulnerable persons, client autonomy—the list is as varied as clients are, she says.

Constraints include the obvious—laws and institutional policies and financial considerations (including insurance caps). But constraints also refer to the limitations of modern medicine. Perhaps there is no viable treatment. Or maybe the issue is access. Guidry-Grimes offers an example. "In Arkansas we have very few facilities that can take ventilator-dependent patients, and we have had patients waiting for over a year for a bed. This resource limitation can cause conflicts and impasses when it comes to the initial tracheostomy decision, especially if the team is divided on whether trach should even be offered."

Obligations include professional role-based duties, as well as parental and familial ones. But what are the client's obligations? "There could be societal obligations that have not been met, leading to a tragic and perhaps unfixable situation for this patient," Guidry-Grimes says.

Resolution, at least for case managers, comes down to principled advocacy. The client, says Baker, is always first.[3] "As case managers, we're often the translators and facilitators when clients and families make tough decisions. We're obligated to go with their choices in health care—even when they may not be the decisions we would make in the same situation. Sometimes, others make decisions that point in a different direction from *our* ethical compass. It's natural to feel that pull and strain, but it's part of our Code of Conduct to act with integrity and fidelity with the client and others."

Examining Jesse's situation through this framework illustrates the challenges.

- **What are the stakes?** These could include not only Jesse's life, but also his pain and suffering. Can the pain be managed medically and safely at home? His future is at stake: If the tracheostomy is the only way that Jesse could survive, then it is arguably in his interest to undergo the procedure to be given the opportunity to grow up. And, perhaps less obviously, Fernando's religious views are at stake. "It might be important to him to prove to God that he has faith in God's healing power."

- **What are the constraints?** One constraint is that the medical options are limited: If the family does not want the tracheostomy, then there is not much else the medical team can do to keep Jesse alive long-term. The team might be legally constrained: The parents have presumptive legal authority to make health care decisions for their son, so overriding them would likely involve a protracted legal battle.

- **What obligations must be met?** Both the health care team and the parents have the obligation to try to advocate for Jesse's interests. To fulfill this obligation, the health care team must help the parents in this decision-making, providing necessary information and supporting them as much as possible.

- **What is an ethically reasonable resolution?** So much depends on all the other factors, but this one is clear, she says. "An ethically reasonable next step would be to continue educating the parents on BPD and tracheostomies, so they can make an informed decision. If the father is mistaken that Jesse could grow out of BPD, then that needs to be addressed."

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> — MICHELLE BAKER, BS, RN, CRRN, CCM
> CHAIR-ELECT, COMMISSION FOR CASE MANAGER CERTIFICATION,
> MANAGER OF NETWORK OPERATIONS
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[3] Except in cases of medical neglect or abuse. In such cases, the case manager is required to contact the appropriate agency or authority, e.g., child protective services for pediatric cases.

Special pediatric concerns

Jesse's situation highlights issues that can arise when parents want to reject medical advice. Whether and when to override a parental decision is a "complicated and controversial topic," Guidry-Grimes says.

She cites the work of pediatric bioethicist Douglas Diekema—specifically, what he calls the Harm Principle. Simply put, when there is too much potential harm, the state should intervene. It doesn't clearly delineate which parental acts require intervention; rather, the point is to identify a threshold where outside intervention is needed to protect the child.[4]

It takes a compassionate, nuanced approach. "In Jesse's case, I hope conversation about intervening wouldn't start immediately," Guidry-Grimes says. Case managers have obligations, of course, to protect the vulnerable from undue suffering. But they first must understand the facts. The care team can best serve Jesse and his family by working with them to better understand their needs and desires.

"Don't call child protective services or seek a court order lightly," she cautions. "Take stock of our own values—be self-aware, self-reflective." The family must be treated with respect, she says.

Baker agrees, noting that case managers excel at dealing with complex and sensitive family issues.

"Case managers have special insight into who the patient is, their family dynamics and how a health care team operates. Part of advocating for the patient and their family is keeping the humanity in these conversations, helping everyone be empathetic and compassionate and kind. We can do right by these patients, their loved ones and each other if we keep our focus on the patient as a person in all of their complexity," Guidry-Grimes says.

Ethical backup: Use it

Case managers don't have to struggle with these issues alone. Guidry-Grimes encourages taking advantage of the hospital's ethics committee. "If we say this is outside of what is ethically reasonable, are we sure?" Having your employer organization's ethics committee review the situation—especially if you can do it confidentially—is often the wisest move.

"Call ethics early and often. Don't wait for a crisis, when legal is getting involved, when everyone is stuck. We can keep the sticking from happening," she says. The employer-based ethics committee can be a source of support for case managers in very trying times. And no matter how strong, ethical and resilient a case manager is, she or he will need support.

As case managers care for others, they must also care for themselves, Baker counsels.

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> — LAURA GUIDRY-GRIMES, PH.D. ASSISTANT PROFESSOR AND CLINICAL ETHICIST, UNIVERSITY OF ARKANSAS FOR MEDICAL SCIENCES, DEPARTMENT OF MEDICAL HUMANITIES AND BIOETHICS CLINICAL ETHICIST, ARKANSAS CHILDREN'S HOSPITAL

"As case managers, we, too, may be left with the emotional residue from ethical conflicts. The intellectual realization that we have followed professional ethical principles to advocate for the client may aid in healing, but it's critical that we take the time to process these experiences emotionally as well," she says. "We all rely on the Commission's Code of Professional Conduct as the touchstone for ethical principles, but we also need to practice mindfulness in these challenging situations—awareness and acknowledgement that what we're feeling is natural. Ground yourself in foundational principles, build relationships with trusted colleagues to test assumptions, and practice the self-care you need to nurture your capacity to be resilient." ■

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4 Diekema DS . "Parental refusals of medical treatment: the harm principle as threshold for state intervention." *Theor Med Bioeth.* 2004;25(4):243–264pmid:15637945

About the Experts

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As manager of network operations for Paradigm Outcomes, **MICHELLE BAKER** manages the employed workers' compensation catastrophic nurse case managers as well as program development and implementation. Her professional background includes a variety of clinical leadership roles, including director of nursing, director of rehabilitation and senior case manager. She earned her bachelor's degree in nursing from Towson State University. She has presented at the local, state and national levels on rehabilitation and workers' compensation topics since 2007. Her volunteer experience for the Commission includes service in the Role and Function Study, item writing/test development and item review. She has served as a Commissioner since 2016, serving on the Governance and Nominations, Finance and New World Symposium committees.

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