

## Standing by Our Principles in Times of Crisis

KELSEY GIPE, PH.D.

In the face of the novel coronavirus (COVID-19) pandemic, it is worth stepping back and reflecting on what a public health crisis may entail in terms of some of the foundational philosophical principles that undergird medical ethics. Real-life ethical decision making is a ‘balancing act’ where moral principles and moral considerations must be weighed in light of the type and particulars of the situation addressed. One classic and widely regarded text in bioethics is James Beauchamp and Tom Childress’s *Principles of Biomedical Ethics*. In it, the authors provide four main “clusters of moral principles” that ought to be considered and balanced against each other in the provision of medical care:

1. **Respect for autonomy**—a norm of respecting and supporting autonomous decisions.
2. **Nonmaleficence**—a norm of avoiding the causation of harm.
3. **Beneficence**—a group of norms pertaining to relieving, lessening, or preventing harm and providing benefits against risks and costs.
4. **Justice**—a cluster of norms for fairly distributing benefits, risks, and costs.<sup>1</sup>

These principles are of ethical importance regardless of whether we are operating under a crisis standard of care or conducting ‘business as usual.’ However, the way in which we apply these principles may shift depending on what external circumstances obtain.

### Respect for Autonomy: Providing Options and Honoring Patient Choices

In general, respect for a patient’s autonomy covers two primary domains. First, a patient’s autonomy may be respected by allowing the patient to make rational, informed choices involving their own medical care. This requires that the patient possess the capacity for reasoned decision making in line with their own values and goals. It also requires that the patient be provided with the information necessary to inform medical decision making. This involves not only providing the patient with facts, but also explaining and interpreting information in line with the patient’s level of medical literacy to promote understanding.

Another component consists in providing the patient with an appropriate range of options from which to choose. This means, for instance, that presenting a patient with end-stage cancer the option of either receiving aggressive drug treatment or foregoing treatment and focusing on comfort, when there is a new experimental (albeit promising) therapy undergoing clinical trials, would not demonstrate respect for the patient’s autonomy. This is because the clinician who refrained from making their patient aware of a potentially helpful clinical trial would be failing to provide a reasonable treatment option, thus limiting the patient’s ability to make a thoroughly informed choice. In crisis situations where there may be resource scarcity, the autonomy of patients may be constrained in a sense because *external circumstances* have necessitated narrowing the range of treatment options available to patients. Whether through immediate total lack of a given resource or the need to allocate resources in line with a crisis standard of care in the face of extreme scarcity, the treatment options available to a patient may be reduced. This is importantly different from a provider

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## The Ethicist Is In: Bedside Rationing

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### The Case:

Greg, an 86-year-old male, suffered a series of complications following a surgical procedure, including bowel perforation, severe infections, and the failure of multiple organs. Despite extensive medical intervention and additional surgeries, Greg's condition continued to deteriorate. He remained hospitalized on a ventilator and, due to neurological damage following a heart attack, became unable to communicate. As the months passed, Greg began requiring frequent transfusions of blood products to counteract bleeding from his gastrointestinal and urinary tracts. After clearly explaining that Greg was close to the end of his life and experiencing discomfort from procedures that were no longer benefitting him, Greg's physicians recommended to his wife, Naomi, that all aggressive treatments be stopped and that Greg be transitioned to end-of-life comfort care. Naomi remained adamant that Greg would want to continue the life-prolonging blood transfusions and other life support. Greg's supervising physician requested an ethics consultation asking whether it would be ethically appropriate to discontinue Greg's transfusions on the basis of conserving limited blood products for the use of other patients, who were more likely to benefit from those resources.

### The Ethicist:

The decision by a physician to withhold a beneficial medical service, such as a blood transfusion, from a patient because of the cost to someone other than the patient is called **bedside rationing**. Blood products are scarce resources that depend on donation, and shortages are known to occur. The ethical principle of justice requires that such medical resources be allocated prudently and equitably. An assessment of Greg's case indicated that the continued use of blood products was viewed as medically inappropriate by the treating team because they believed the transfusions offered Greg no benefit, extended his suffering, and used up resources that could be available to others. While it was clear why Greg's providers questioned the overutilization of blood products, it was also understandable that Naomi considered the continuation of the blood transfusions to be beneficial because they were keeping Greg alive.

As a general rule, bedside rationing by a clinician of a resource that may be prone to shortages, such as blood products, medications, ventilators, or a room in the ICU, is considered ethically inappropriate for several reasons. First, bedside rationing is not appropriate due to concerns that allocation decisions may be influenced by an individual provider's conscious or unconscious biases. If these important decisions are left to frontline providers, there is a potential that morally

irrelevant characteristics, such as ethnicity, age, gender, sexual orientation, socioeconomic status, personality, etc., may impact decision making, leading to patients with similar clinical problems being treated differently. Such a practice would not be ethically appropriate. Second, an individual treating physician may not have sufficient knowledge and training regarding larger resource supplies and demands to judge the absolute shortage of an essential medical resource. And, finally, in most situations, a clinician cannot accurately predict whether the resources, such as blood products, conserved by their decision to withhold a medical service, will be put to better use for another patient.

There are forms of bedside rationing that occur on a daily basis and are generally unproblematic. Providers commonly have to ration the time they spend with each patient. Every day physicians are called upon to use their medical knowledge, training, and experience to make recommendations from among a variety of options to treat those under their care. However, for larger decisions that apply specifically to rationing treatments for patients in critical conditions and/or at the end of life, relying on organizational guidance and system-wide policies may be more likely to support efficient, consistent, and just decisions when rationing is necessary. The hope is that biased or arbitrary rationing decisions can mostly be avoided

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# Standing by Our Principles

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purposely, intentionally, and ‘artificially’ narrowing the range of treatment options presented to a patient.

However, the narrowing of treatment options that may happen in a crisis does not preclude a clinician from demonstrating respect for a patient’s autonomy, by presenting available options and allowing the patient to choose in line with their own considered judgments, values, and goals. Suppose, for instance, that a vaccine is limited such that only members of the most vulnerable groups may receive it in line with an allocation scheme based on overall benefit to the population. By declining to present that vaccine as an option to a patient who does not belong to a prioritized vulnerable group, a clinician would not thereby fail to respect the patient’s autonomy. Decisions that limit the options available to patients in a time of crisis may be unfortunate and in the worst cases even tragic, but there is still room for providers to demonstrate respect for patient autonomy to the best of their ability, even in the midst of extreme resource scarcity.

## **Nonmaleficence: Avoiding Harm to Patients**

Nonmaleficence is perhaps the most well-known ethical principle in healthcare, a concept that extends at least as far back as the Hippocratic Oath. It is of course impossible in many cases to provide adequate care to a patient without harming them in some respect. For instance, performing surgery may cause trauma to the patient’s body in the service of healing, and many beneficial medications have accompanying side effects. Rather than placing an outright prohibition on harm, the principle of nonmaleficence requires us to avoid causing harm that would be disproportionate to the benefit provided to patients. Nonmaleficence is a principle that applies similarly under both ordinary and crisis conditions. Healthcare providers always ought to avoid disproportionately harming patients.

## **Beneficence: Benefiting Patients**

Beneficence involves aiming to treat patients in such a way that the benefits provided them outweigh potential harms. The scope of beneficence may vary between crisis and ordinary standards of care. In a health crisis, the public health perspective takes greater priority than it might otherwise. For instance, under ordinary circumstances in the American healthcare context, nearly all patients are to be treated on a first-come-first-served basis. In contrast, under crisis conditions, scarce resources may need to be saved for and provided to those who need them the most and/or who will benefit the most from receiving those resources. Setting

allocation priorities in a way that creates the most overall population-level benefit may be imperative in circumstances where many lives are at stake and life-saving resources are in short supply. However, it is important that priority setting is also tempered by appropriate attention to concerns regarding justice.

## **Justice: Treating Patients Fairly**

Justice is best understood primarily in terms of fairness. It is our duty in providing medical care to patients under all circumstances that we be sensitive to the need to treat patients fairly. We ought to protect vulnerable populations and do our best to refrain from reinforcing existing systems of oppression. These moral considerations are supported by legislation that prohibits “discrimination on the basis of race, color, national origin, disability, age, sex, and exercise of conscience and religion.”<sup>2</sup> Justice involves protecting patients from discrimination and treating them in accordance with objective medical criteria. As a rule of thumb, social or demographic facts about a patient are relevant only to the extent that they may impact the patient’s medical status and prognosis. In setting allocation priorities in a crisis situation where certain resources are or may become scarce, issues of justice grow especially salient. Systems for allocating scarce medical resources should treat each individual as fairly as possible and be structured so as not to disadvantage minority populations and vulnerable patients.

## **Holding On to Our Principles**

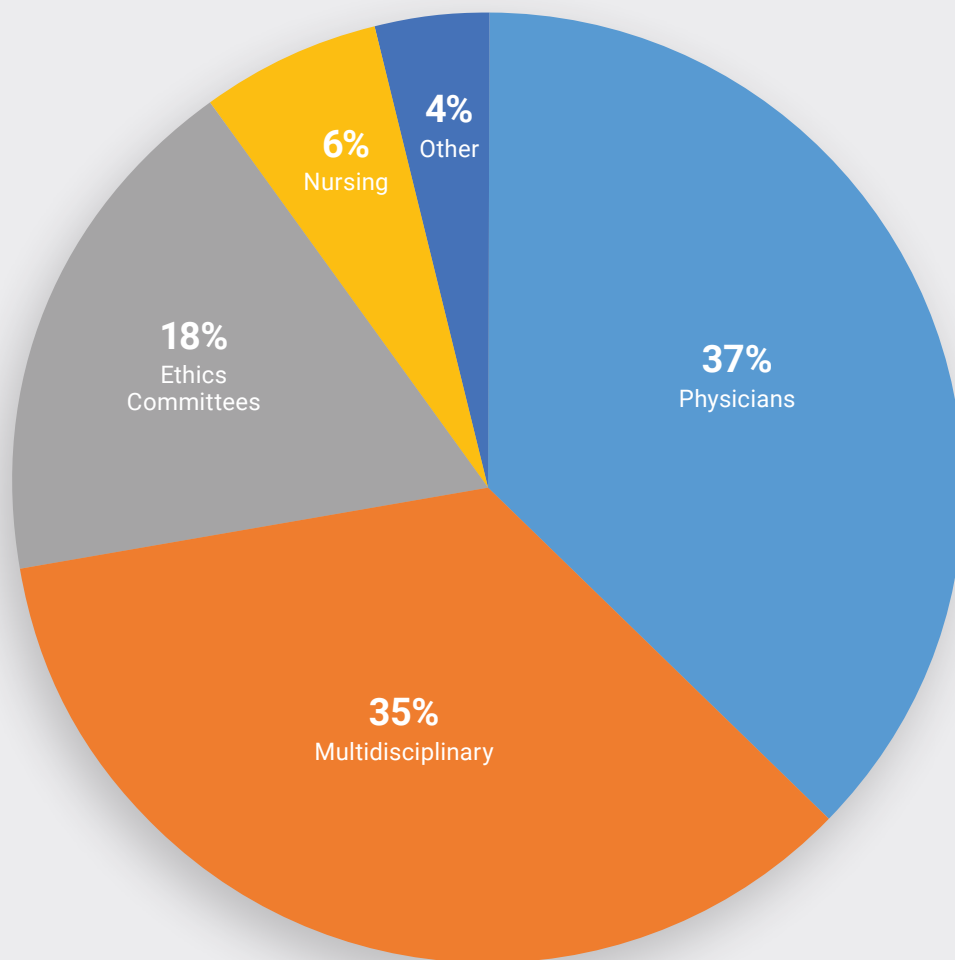
Public health crises have the potential to shake our understanding of the world, our professions, and even ourselves. It is essential in times of uncertainty and fear to hold onto and foster the things that matter most, including our sense of self and relationships with one another. Respecting the autonomy of others, avoiding harm, working to benefit others, and trying our best to treat everyone fairly are principles that can help to guide and ground us both personally and professionally as healthcare workers. The troubling events we are living through may remind us of the lines of W.B. Yeats, “Things fall apart; the centre cannot hold.” However, we have an antidote to such a dire prediction. By focusing on our established principles, we will continue to provide the best care possible to patients, whatever circumstances obtain.

1. Beauchamp TL and JF Childress. *Principles of Biomedical Ethics*. 8th ed. New York, NY: Oxford University Press; 2019.

2. U.S. Department of Health and Human Services, Office for Civil Rights. BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19). <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf> Published March 2020. Accessed April 6, 2020.

## Education Spotlight: 72 Bioethics Education Sessions in 2019

In 2019, the Program in Medicine and Human Values (PMHV) professional bioethics team conducted 72 education sessions. These presentations covered a variety of topics related to ethical issues in patient care and were delivered to providers across Sutter Health and beyond. Our webinars continued to remain hugely popular with clinicians and ethics committee members. Apart from care providers, our bioethicists spoke at community events and patient support groups. The program's faculty also presented at national and international meetings.



Dr. Lael Duncan

### WEBINAR SERIES UPDATE

## Effective Communication at the End of Life

As a part of our ongoing bioethics webinar series, PMHV hosted a live training class on “Communicating Treatment Options at the End of Life” on April 8. Our guest speaker was Lael Duncan, M.D., medical director of Consulting Services for the Coalition for Compassionate Care of California. Around 100 people from multiple health systems across California and other states attended the webinar, which provided a framework for communicating clearly and openly while assisting patients and their families with creating meaningful care plans. Dr. Duncan emphasized skills for understanding the patient’s healthcare priorities, while balancing hope and honesty, and engaging with patients and families during tragic situations. She also provided communication strategies, conflict resolution tips, and effective word choices for conducting productive end-of-life conversations.

# The Ethicist Is In

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*In most cases, an effective way to frame the question of ethical appropriateness is to ask whether the treatment is medically benefiting the patient, while taking into account the goals and values of the patient.*

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by removing such limited resource allocation decisions from the provider at the bedside working directly with the patient.

Decisions about withholding or discontinuing treatment, such as in Greg's case, regularly arise in medicine. In most cases, an effective way to frame the question of ethical appropriateness is to ask whether the treatment is medically benefiting the patient, while taking into account the goals and values of the patient. Greg could not express his wishes, but his wife, as his surrogate decision-maker, was committed to keeping Greg alive as long as possible. At the same time, Greg's physicians and other providers had become emotionally and morally distressed because they felt powerless to stop what they believed to be unnecessary, aggressive treatments. Physicians have the right to refuse treatment based on their duty to "do no harm," which applied in Greg's case, since he was experiencing suffering without compensatory benefit. However, it is often very difficult to follow through on such rights when doctors are opposed by distraught family members.

If an agreement with Naomi could not be reached through discussions, second opinions, or palliative care options, the Ethicist should remind the medical team that providers are not ethically and legally obligated to provide medical treatment that, in the physician's best judgement, qualifies as non-beneficial. Referring to policies that address this issue can be helpful to medical teams because they clarify a clinician's responsibility in withholding and withdrawing treatment. Organizational guidelines can also be helpful for patients and their families because the required process to be followed demonstrates that a decision to withhold or withdraw treatment from their loved one is not subjective and is standardized for the hospital.



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In Greg's case, a bedside rationing approach to halting his transfusions on the basis of conserving limited blood products for the use of other patients would not be considered ethically appropriate. Focusing on the fact that the blood transfusions and other aggressive treatments are no longer benefitting Greg is considered the most appropriate practice for determining the proper clinical and ethical plan of care.

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- Kersjes, E & Smith, L. How should decision science inform scarce blood product allocation? *AMA J Ethics*. 2019;21(10):E852-857.
- Smith, L, Cooling, L, & Davenport, R. How do I allocate blood products at the end of life? An ethical analysis with suggested guidelines. *Transfusion*. 2013;53:696-700.
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## **Summer Ethics Workshop**

### **Refining Your Communication Skills: Ethics In Action**

## **POSTPONED**

After careful consideration, the Program in Medicine & Human Values has decided to postpone this year's Summer Ethics Workshop, which was scheduled for Saturday, June 6. The health and safety of our attendees is of paramount importance to us. We look forward to continuing our annual tradition and expect to reschedule this educational workshop later in the year. Please visit our website for any additional information.