A Resource for Hospice and Palliative Care Leaders & their Organizations

Introduction

Without doubt, hospice and palliative care leaders and the organizations they serve face difficult ethical questions when faced with pandemic disease. Not only do such leaders worry about providing the best care as people near the final human milestone, but they also bear responsibility for employing a talented and passionate workforce. All of this is encapsulated by the challenges of daily business operations and the demands of corporate finance. While the challenges associated with pandemic disease are new to this generation, we might take comfort that "this has all happened before," to paraphrase Marcus Aurelius.¹ While new to us, this scene had played out in only slightly different ways countless times before we took the stage.

One of the most difficult ethical questions in healthcare is the fair allocation of scarce resources. The answers to these questions are made all the more difficult by timing; they never occur in the midst of calm and stability. Instead, the nature of "only having so much to go around" forces us to make difficult decisions that inherently benefit some people and exclude others at a time when lives and livelihoods are at stake. As you consider the suggestions placed within this document, keep in mind to whom your decisions are directed. While we have been conditioned to focus on the patient as the center of our work, the hospice and palliative care organizations have obligations to others as well, such as employees, referral sources, families and caregivers, corporate owners, and communities.² The purpose of this document is to:

- Assist hospice and palliative care leaders and organizations to (re)familiarize themselves with a small set of ethical concepts as they face resource allocation decisions.
- Introduce four principles of healthcare ethics and place them in the context of resource allocation.
- Guide leaders and their organization through a compact decision-making and discernment model, mainly as a means to raise attention to a handful of foundational questions central to the topic.

^{2.} Shanafelt, Tait, Jonathan Ripp, and Mickey Trockel. 2020. "Understanding and Addressing Sources of Anxiety among Health Care Professionals during the COVID-19 Pandemic." JAMA - Journal of the American Medical Association 323 (21): 2133–34. https://doi.org/10.1001/jama.2020.5893.



^{1.} Aurelius, Marcus. 2003. Meditations. Edited by Gregory Hays. New York: Modern Library.

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Four Ethical Principles: A Brief Reintroduction³

Autonomy

At its core, the principle of autonomy is concerned with a patient's freedom and capacity to make voluntary and informed decisions. But it's important to remember that as an employer facing pandemic disease in the community, the patient isn't the only person to consider. For example, an organization's clinical staff have an equal right to exercise autonomy, mainly as they assess personal risk and how that risk may impact their health. Over the last several decades, the bioethics community in the United States has overwhelmingly crowned the principle of autonomy as a first among equals. That is, for many people, the ability to exercise their autonomy is a right that takes precedence over other factors at stake. While unquestionably important, leaders and organizations should also approach autonomy from the point of view of the communities they serve. Must individuals always come first? Is the community's health and wellbeing ever more critical than a single person's? In the context of pandemic disease or other large-scale disasters, public health officials are often forced to weigh the value of a single life against the collective health of a community.

Question for Discernment: What is the best way to balance individual patients' needs while also caring for the local community your organization serves?

Beneficence

As healthcare providers, beneficence has to do with the clinician's (or the healthcare organization's) duty to provide services to patients that are beneficial. For most people engaged in the work of healthcare, "doing good" or "helping people" are common motivations underlying their daily activities. But interestingly, some people view this duty as a limited one. While the duty to prevent harm seems unquestionable and everpresent, clinicians regularly decide who they choose to serve. They do this based on insurance type, field nurse caseload, inpatient unit capacity, and the list continues.

Question for Discernment: Does mandating clinical staff to receive a vaccination for personal and patient safety the right thing to do if some of those clinical staff quit as a result? Does your decision change whether the number of employees who leave is 5% or 50%?



^{3.} McCormick, Thomas R. 2018. "Principles of Bioethics." 2018. https://depts.washington.edu/bhdept/ethics-medicine/bioethics-topics/articles/principles-bioethics.

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Nonmaleficence

As leaders, clinicians, and healthcare organizations focus on providing measurable benefits to the patients they serve, it is equally important to reduce or prevent harm and injury. Many recognize nonmaleficence from Hippocrates' maxim "first do no harm." As a hospice leader, it is essential to consider whether one's actions contribute to the Good or create a potential for harm.

Question for Discernment: Is being present at the patient's bedside at the time of death more or less important than minimizing the risk of clinical staff acting as a disease vector?

Justice

In the context of pandemic disease, justice focuses on the fair distribution of available resources, especially those that may offer protection or slow the spread of disease. As active participants in our country's healthcare system's stewardship, many leaders and organizations chose to prioritize particularly vulnerable populations. When something like PPE or vaccine is in short supply, the organization that possesses the "product" should first establish the distribution criteria. Beauchamp & Childress⁵ list six such criteria:

- 1. To each person an equal share
- 2. To each person according to need
- 3. To each person according to effort
- 4. To each person according to contribution
- 5. To each person according to merit
- 6. To each person according to free-market exchanges.

Questions for Discernment: Are some hospice or palliative care patients more important than others? Would it ever be appropriate to put a hospice's workforce before the hospice's patients? Are patients more important than the organization's long-term health and sustainability?

A Methodology for Discerning Issues Related to Allocation

It should go without saying that the hospice leader's time is better spent considering how to allocate scarce resources they have control over rather than what they do not have control over. There has been much debate amongst healthcare leaders about who to "give" or who to "prioritize" amongst their employees to receive a vaccine or other limited resources. Ask yourself, do you have control over how the vaccine is distributed? Thus

^{5.} Beauchamp, Tom L., and James F. Childress. 2019. Principles of Biomedical Ethics. Book. 8th Ed. New York: Oxford University Press.



^{4.} Miles, Steven H. 2005. The Hippocratic Oath and the Ethics of Medicine. Oxford University Press.

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far, this has typically been controlled by local health departments, not by hospice and palliative care companies. Maintain focus on the critical decisions in front of you. A fundamental question is this: Based upon my organization's values, what are my obligations?

Step 1: Identify What You Have Available To Allocate

Ask yourself: What do I have control over in the face of the current situation?

This might include how you choose to deploy available clinical staff or what clinical disciplines you send into the field first before others. When limited supplies like PPE are received, what is vital to distribute immediately and what should be held in reserve? Some hospice and palliative care organizations have chosen to shut down their operations as they "wait it out." You may or may not have the control to do this, and the implications are profound.

Ask yourself: What may I be able to influence?

You may influence how you encourage clinical staff to get vaccinated, but this is not something over which you have direct control. Clinical staff may choose to exercise their autonomy in ways that are surprising to you. That said, you can influence how clinical staff engages their patients in the community. Do you encourage clinical staff to "slog through it" or show courage and even enthusiasm to serve in difficult times that are also ripe for opportunities to lead by example?

Ask yourself: What can I not control.

This might appear to be obvious, but it isn't. Do you have direct control over how or when the government or state distributes vaccines? No. Do you have direct control over how many of your staff get the vaccine despite an organizational mandate? No. Do you have direct control over the reliable resupply of PPE? Likely not.

Step 2: Identify and Prioritize Your Obligations

As a leader, you have many "customers," both within your organization and in the community and beyond.

First, make a list of these obligations. To whom do we owe what? You may have obligations to employees (e.g., continued employment); to your patients (e.g., care and support at the end-of-life); to your referral sources (e.g., a specialized resource to care for patients with specific needs); to your local community (e.g., what will our actions reveal about our organization's values?).

Second, prioritize your list of obligations. Ask yourself which obligation is unquestionably non-negotiable to you and the organization. Likewise, what obligations are essential but are less critical to address during a crisis?



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Step 3: Identify What Else is at Stake

Beyond the ethical considerations surrounding patient care and your personal and organizational obligations as a leader, there are always additional factors that play a role in one's decision-making. Some of these other factors might include corporate finances, the organization's reputation, the sustainability of the organization's workforce, and even how to prioritize which hospice patients are served first and which can be triaged in other ways.

Step 4. Take Action

After practicing personal and corporate discernment, consulting with colleagues and customers, and even diving into the academic literature, take confident and proactive action. Choose a path forward.

Communicate that path to internal and external customers. Finally, maintain flexibility, exude confidence, and seek real-time feedback.

