

# Critical Ethics: How to Balance Patient Autonomy With Fairness When Patients Refuse Coronavirus Disease 2019 Testing

**OBJECTIVES:** A cornerstone of our healthcare system's response to the coronavirus disease 2019 pandemic is widespread testing to facilitate both isolation and early treatment. When patients refuse to undergo coronavirus disease testing, they compromise not only just their own health but also the health of those around them. The primary objective of our review is to identify the most ethical way a given healthcare system may respond to a patient's refusal to undergo coronavirus disease 2019 testing.

**DATA SOURCES:** We apply a systematic approach to a true clinical case scenario to evaluate the ethical merits of four plausible responses to a patient's refusal to undergo coronavirus disease testing. Although our clinical case is anecdotal, it is representative of our experience at our University Tertiary Care Center.

**DATA EXTRACTION:** Each plausible response in the case is rigorously analyzed by examining relevant stakeholders, facts, norms, and ethical weight both with respect to individuals' rights and to the interests of public health. We use the "So Far No Objections" method as the ethical approach of choice because it has been widely used in the Ethics Modules of the Surgical Council on Resident Education Curriculum of the American College of Surgeons.

**DATA SYNTHESIS:** Two ethically viable options may be tailored to individual circumstances depending on the severity of the patient's condition. Although unstable patients must be assumed to be coronavirus disease positive and treated accordingly even in the absence of a test, stable patients who refuse testing may rightfully be asked to seek care elsewhere.

**CONCLUSIONS:** Although patient autonomy is a fundamental principle of our society's medical ethic, during a pandemic we must, in the interest of vulnerable and critically ill patients, draw certain limits to obliging the preferences of noncritically ill patients with decisional capacity.

**KEY WORDS:** allocation of scarce resources; coronavirus disease 2019; patient autonomy; triaging

## CASE SCENARIO:

A 19-year-old male presents to an outside hospital emergency department after sustaining a gunshot wound to his abdomen and right hip, necessitating repair of his comminuted iliac fracture and an exploratory laparotomy with sigmoid colon resection and external iliac vein ligation. Several days after discharge, he returns with worsening abdominal pain and fever. He is transferred to the

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nearest tertiary hospital. Workup reveals an early post-operative small bowel obstruction. As per the hospital's emergency preparedness policy implemented during a public health crisis, coronavirus disease (COVID) test is ordered. The patient, however, refuses the test.

The patient would be admitted to a regular floor if negative or to a COVID ward if positive. Many patients who first present with COVID are admitted to the ICU. When they improve, they are transferred from the ICU to a COVID floor. Without testing, this patient would put staff and other patients on a regular floor at risk. Assigning this patient a bed on a COVID ward would compromise the transfer of an improving COVID-positive patient from the ICU to a COVID ward. With a patient who does not need intensive care in the unit, there would be one fewer bed available for the next COVID-positive patient waiting to be transferred to the ICU.

Over 10 million Americans have been diagnosed with COVID-2019 (COVID-19) to date resulting in more than 245,000 deaths in the United States (1). Although neither a scientifically accepted cure nor a Federal Drug Administration approved vaccine to prevent the disease has been reached, much more is now known about the behavior and spread of the virus than in the earliest days of the pandemic. In particular, overwhelming evidence exists that both the elderly and patients who are immunocompromized tend to suffer more severe and prolonged cases (2, 3). We also know that the virus is transmitted readily among people in close quarters and even via objects and surfaces used hours apart (4).

In the interest of public health, hospitals have enacted various institutional measures to minimize the spread of COVID-19. One such measure is the routine testing of patients before they undergo elective operations (5–7). As illustrated in our case scenario, some patients refuse COVID testing. Although this conflict has been explored in the United Kingdom through a legal lens (8), in the United States, the analysis has been limited to the psychiatric literature (9). These articles, although focused on their own scope of practice, do support our own anecdotal experience that addressing patient refusal for COVID-19 testing should be systematically addressed. As to the reasons why some patients with medical decisional capacity refuse testing, we can only speculate at this point. In our current political landscape, some opposition may be explained along party lines. Other hypotheses include buying

into various conspiracy theories and biblical interpretations of “being marked by the beast” (10). Whatever the underlying fear, this issue is particularly relevant to the care of vulnerable and critically ill patients who may contract the virus from unidentified carriers. Our article examines both clinical and ethical norms and options to answer the question: What is the most ethically appropriate response to a patient's refusal to undergo COVID testing?

## METHODS

An ethical dilemma presents us with at least two ethically viable but mutually exclusive options. When choosing one option, we must necessarily reject the other(s), although it is ethically incumbent on us to minimize, to the best of our ability, the negative effects of our choice. A systematic approach to evaluating these decisions is critical.

We use the “So Far No Objections” method to resolving ethical dilemmas developed and published by James Dubois and also used for the Ethics Modules of the Surgical Council on Resident Education Curriculum for surgical trainees (11). Following the method's prescription, we identify relevant stakeholders, facts, norms, and options and then we analyze the potential options by using the method's criteria. These criteria include ascertaining an option's necessity, effectiveness, least infringement, proportionality, and use of proper process. Definitions of relevant ethical concepts are anchored in our interpretation of classic bioethics based on Principles of Biomedical Ethics by Beauchamp and Childress (12) and are borrowed from the Glossary Section of the Center for Humanism and Ethics in Surgical Specialties (13) at Washington University in Saint Louis (Table 1).

## ETHICAL ANALYSIS

We begin our analysis by identifying all relevant stakeholders, facts, norms, and plausible options (Table 2).

### Stakeholders

The stakeholders include the patient, all providers, other patients at the same hospital, and patients at other hospitals with known COVID-19 disease who are awaiting transfer to a COVID bed.

**TABLE 1.**  
**Ethical Definitions<sup>a,b</sup>**

Ethical Concept	Definition
Ethics	Ethics is a systematic study of how we ought to act toward ourselves and others. The determination of what ought to be done, all things considered.
Autonomy	Autonomy is often used interchangeably with self-determination. Autonomous decisions are sufficiently independent from the will of others to be considered one's own decision. An autonomous person is sufficiently free from controlling interferences and from limitations to exercise responsible decision-making and to be responsible for outcomes.
Beneficence	Beneficence refers to actions that bring about valued effects for the recipients of the actions.
Nonmaleficence	Nonmaleficence concentrates on acting in ways that avoid harm. In patient care, prioritizing this caution results in the least pain or suffering possible from efforts to achieve a beneficial outcome.
Justice	Justice draws attention to the interests of everyone with a stake in the outcome of an action.

<sup>a</sup>Beauchamp and Childress (12).

<sup>b</sup>Center for Humanism and Ethics in Surgical Specialties (13).

**TABLE 2.**  
**Ethical Analysis Part 1**

Stakeholders	Facts	Norms	Options
1) Patient	1) More PPE is needed in taking care of COVID+ patients.	1) Patients' absolute right of refusal.	1) Allow the patient to refuse the test and wear maximal PPE around him but not transfer him to a COVID floor.
2) Other patients	2) Need for COVID unit beds is greater than availability.	2) Patients' relative right to preferred treatment.	2) Force the patient to undergo the test.
3) Hospital staff	3) COVID is easily spread in close quarters without physical contact.	3) Ethical access to care.	3) Transfer the patient to a COVID floor with assumed infection and observe all necessary precautions.
4) Patients at outside facilities awaiting beds in COVID units	4) A small bowel obstruction is an urgent surgical concern, but not an emergent one.	4) Just allocation of scarce resources. 5) Duty to protect the public.	4) Only offer care to the patient if he agrees to undergo appropriate testing.

COVID = coronavirus disease, PPE = personal protective equipment.

## Facts

Relevant facts include the need for more personal protective equipment when treating COVID patients, the easy transmissibility of COVID-19, and the reality that smaller, rural hospitals frequently await transfer of their COVID-19 patients to higher level of care at larger centers where COVID units tend to be filled to

maximum capacity (14). At this point in the pandemic, we also have strong evidence from the World Health Organization to show that healthcare workers exposed to COVID-19+ become infected at a high rate (15). Separately from a public health crisis, patients in the United States have the absolute right to refuse medical interventions as long as they are deemed to have medical decision-making capacity (16). Also relevant

is the fact that hospitals are bound by the Emergency Medical Treatment and Labor Act (EMTALA) to provide life-saving emergency medical care to all (17).

## Norms

Relevant norms begin with patient autonomy, which may be divided into positive and negative autonomy. Negative autonomy represents a competent patient's right to refuse care and is an absolute right, the violation of which constitutes battery (16). Patients may only be forced to undergo medically indicated treatments if and only if the patient is found to have no medical decision-making capacity. Positive autonomy, on the other hand, is not absolute and refers to patient preferences and requests for treatment measures that may or may not be indicated for their condition (18). A patient who is a Jehovah's Witness adherent, for example, may refuse blood transfusions, but may not demand to undergo elective surgery that would normally involve the administration of blood products. Although some surgeons may offer to operate on these patients, they are certainly not obligated to do so.

Ethical norms applicable to COVID-19 scenarios may be clarified by reference to the literature generated during the HIV pandemic, with the caveat that we pay careful attention to important differences between the two disease processes. Applicable similarities include the potential of death upon transmission and the pace with which the respective diseases' initial spread had overwhelmed hospitals across the nation. Notable differences include not only the potential complete curability of COVID-19 but also its much higher rate of transmissibility (19, 20). Although the magnitude of the current pandemic is still expanding to previously unknown proportions, a norm that we may build upon from the HIV literature is the evolution of testing from an opt-in approach to routine screening. With improved screening tests for antibodies, diminished social stigma associated with being HIV+, and expanding beneficial treatment modalities that reframed HIV as a chronic disease, HIV screening tests became a standard part of laboratory tests. In 2006, the Center for Disease Control endorsed HIV testing as routine, and a consensus recommending this practice formed that included the American Medical Association, the American College of Physicians, the Infectious Diseases Society of America, the Institute of Medicine, the American College of Obstetricians

and Gynecologists, and the American Academy of Pediatricians (21, 22).

Certain treatments, such as extracorporeal membrane oxygenation or convalescent plasma exchange, are only available at hospitals with higher levels of care. When we are able to closely match patients' needs for special treatment with availability of the corresponding treatment, we also maximize patient benefit on both the individual and the macro level. In an ideal situation, for example, we would have exactly as many ventilators available for use as we need. Whenever a ventilator is used by a patient to whom it is no longer beneficial, we are depriving a patient in need from the potential benefit through use of that ventilator. The field of organ transplantation has successfully pioneered ethical and practical algorithms for the allocation of finite resources (23).

When a patient or potential patient is in serious imminent and preventable danger, precedence both legally and ethically supports the restricting of certain liberties enjoyed by the person who may be the source of said danger. Examples include mandatory vaccinations in certain states and psychiatrists' duty to warn anyone who, in their professional opinion, might reasonably be considered to be the target of a patient's attack (14, 24). Businesses have the right to turn customers away if their mask-wearing policy is not practiced, and public schools may disenroll students who do not meet their health screening criteria for attendance. Additionally, elective interventions are routinely restricted to patients who have either insurance or the ability to pay.

## Summary of Ethical Framework

- 1) **Patients' absolute right of refusal:** In accordance with patient autonomy interpreted as a negative right, patients with medical decisional capacity have the absolute right to refuse care.
- 2) **Patients' relative right to preferred treatment:** In accordance with patient autonomy interpreted as a positive right, patients may ask for but not demand their preferred treatment. Competing imperatives include professional autonomy and hospital policies.
- 3) **Ethical access to care:** Both legally (EMTALA rule) and ethically, in the spirit of fairness in society and the constitutional right to life, emergency medical care must be provided to all in need. Semielective and elective interventions, however, are subject both to institutional conditions and to professional autonomy.
- 4) **Just allocation of scarce resources:** To maximize both beneficence and justice, ethical allocation of scarce resources is based on need and likely benefit.

- 5) **Duty to protect the public:** When a person's disregard for the safety of others is likely to lead to death or permanent disability of others, it is ethically appropriate, in accordance with the principle of nonmaleficence, to restrain the liberties of that individual in order to protect the life and physical integrity of members of the public.

## Options

- 1) Honor the patient's request to refuse COVID testing and continue to treat him as a presumed COVID-negative patient.
- 2) Physically force the patient to undergo COVID testing, similar to a patient without medical decision-making capacity.
- 3) Honor the patient's request to refuse COVID testing and treat him as a presumed COVID-positive patient, including transfer to a COVID floor (with the understanding that this option puts the patient at higher risk of COVID exposure/infection).
- 4) Explain to the patient the risk he poses to the hospital's staff and other vulnerable and critically ill patients and advise him to seek care elsewhere if he continues to decline testing.

## ETHICAL ANALYSIS OF OPTIONS

We analyze the ethical merit of each of the plausible options by applying the criteria enumerated in the So Far No Objections paradigm. As stated before, an ethical dilemma unavoidably violates an ethical norm. In order to compare the relative violations, the method uses the following criteria to evaluate each option (Table 3).

- 1) **Necessity:** Is the violation of the norm necessary when choosing this option?
- 2) **Effectiveness:** Is the violation of the norm effective in producing the outcome we intend to uphold by honoring the other norms?
- 3) **Least infringement:** Is the violation of the norm done with the least possible infringement of the norm?
- 4) **Proportionality:** Is the loss that results from violation of the norm in favorable proportion to the likely outcome when honoring the other norm(s)?
- 5) **Proper process:** Are we observing proper process when violating the norm?

### Option 1: Honor the Patient's Request to Refuse COVID Testing and Continue to Treat Him as a Presumed COVID-Negative Patient

The ethical norms met in this option are both the patient's positive and negative autonomy, in that the

patient is not required to undergo testing (negative autonomy) and he is receiving treatment at his preferred hospital (positive autonomy). Because the patient is undergoing prompt medical evaluation, the norm of ethical access to care is ensured. Because he is not being transferred to a COVID bed, we are also maximizing the availability of COVID beds to those with confirmed COVID infection, thereby assuring just allocation of scarce resources. The one norm necessarily violated—that is, the duty to protect the public—in this instance fails the criteria for justification of its violation. Although this option is effective at protecting the patient's autonomy and providing the patient's preferred treatment, the norm violated will likely result in a disproportional infringement on the rights and health of a great number of patients, staff, and potentially the greater public. It also does not observe proper process as it is in frank opposition to hospital policy.

### Option 2: Physically Force the Patient to Undergo COVID Testing, Similar to a Patient Without Medical Decision-Making Capacity

The ethical norms met in this option are ethical access to care, the duty to protect the public, and just allocation of scarce resources. Norms that are violated are the patient's positive and negative autonomy. This unavoidable violation very effectively achieves the outcome the norms upheld are protecting as a test result will readily guide our further actions for both the patient and in the protection of others. Furthermore, a COVID bed is only taken for this patient if in fact indicated, ensuring that scarce resources are allocated fairly. The violation of the patient's right to refuse care, however, in the medical ethical milieu of our society, may be considered the strongest, most inviolable norm. In fact, violating this norm in the case of a patient with medical decisional capacity constitutes battery both ethically and legally; this option, therefore, does not observe proper process.

### Option 3: Honor the Patient's Request to Refuse COVID Testing and Treat Him as a Presumed COVID-Positive Patient, Including Transfer to a COVID Floor

Norms met in this option are both positive and negative patient autonomy by allowing the patient to refuse testing while also receiving care at his chosen healthcare

**TABLE 3.**  
**Ethical Analysis Part 2**

	<b>Option 1</b>	<b>Option 2</b>	<b>Option 3</b>	<b>Option 4</b>
	<b>Allow the Patient to Refuse the Test and Wear Maximal Personal Protective Equipment Around Him But Not Transfer Him to a COVID Floor</b>	<b>Force the Patient to Undergo Testing</b>	<b>Transfer the Patient to a COVID floor With Assumed Infection and Observe All Necessary Precautions</b>	<b>In the Event of a Nonemergent Situation, the Hospital Should Reserve the Right to Only Offer Care If the Patient Undergoes Appropriate Testing</b>
Ethical norm(s) upheld	Patients' absolute right of refusal  Patients' relative right to preferred treatment  Ethical access to care  Just allocation of scarce resources	Just allocation of scarce resources  Duty to protect the public  Ethical access to care	Patients' absolute right of refusal  Patients' relative right to preferred treatment  Ethical access to care  Duty to protect the public	Patients' absolute right of refusal  Ethical access to care  Duty to protect the public  Just allocation of scarce resources
Ethical norm(s) violated	Duty to protect the public	Patients' absolute right of refusal  Patients' relative right to preferred treatment	Just allocation of scarce resources	Patients' relative right to preferred treatment
Necessity	Yes	Yes	Yes (for as long as COVID beds are scarce)	Yes
Effectiveness	Yes	Yes	Yes	Yes
Least infringement	No	No	No (for as long as COVID beds are scarce)	Yes
Proportionality	No	No	No (for as long as COVID beds are scarce)	Yes
Proper process	No	No	Partially	Yes

COVID = coronavirus disease.

facility. Ethical access to care is ensured for him, as well as protecting the public by treating the patient as presumed COVID positive. The norm violated is just allocation of resources. Importantly, however, this norm is only violated if there are other patients awaiting COVID beds and thus COVID beds in fact qualify as a scarce

resource. In a pandemic, this latter is a safe assumption. But as the virus eventually becomes less prevalent and fewer patients need either ICU or floor beds that are capable of safely housing COVID patients, this option might become more ethically appealing. For now, however, depriving a patient who is COVID positive of the

scarce resource of a COVID bed while simultaneously putting others around that positive patients at risk is in great disproportion to observing patient preference and certainly does not pose the least infringement. Although this option does not fully observe proper process as it does not require testing in accordance to hospital policy, it does more so align with the intent of the policy than either of the previous two options.

#### **Option 4: If the Patient's Condition Does Not Require Emergent Intervention, Then Educate the Patient About the Spread of COVID-19 and the Hospital's Obligation to Its Other Patients and Greater Community and Only Offer Further Care at This Hospital If the Patient Agrees to Be Tested**

This option meets the patient's right to refuse any care including testing and protects other patients at the hospital as well as staff. This option also ensures just allocation of scarce resources by not occupying one of the COVID beds without a confirmed positive test. Ethical access to care is ensured if and when the patient's condition does not require emergent, life-saving intervention. The only norm violated is the patient's preference to receive medical attention at his chosen hospital (i.e., his positive autonomy). This norm is the least ethically mandatory and thus causes the least infringement. Proportionality and proper process are also met as the patient's care is only tied to the nonburdensome condition of testing. Just as it is within patients' rights to refuse care, it is also within hospitals' rights to refuse providing care to patients with nonemergent conditions who do not accept the medical and/or institutional conditions of their care.

## **CONCLUSIONS**

After reviewing the ethics "pros" and "cons" of each plausible action plan, we find that Options 3 and 4 may be considered ethically viable under different circumstances. To reiterate, Option 3 transferring a patient who refuses COVID testing to a COVID floor with assumed infection and observe all necessary precautions. Option 4, on the other hand, involves educating the patient about the spread of COVID-19 and the hospital's obligation to its other patients and greater community and only offer further care at this hospital if the patient agrees to be tested.

In the case of a patient who is in need of emergency medical treatment, if that treatment is within our

scope of practice, then we are obligated to intervene without delay. In such instances, we may isolate the patient who is refusing COVID testing to a bed in the COVID unit with the assumption that he is positive for the disease. The same may be offered to patients refusing COVID testing who are not in need of emergent medical attention, if and only if there is an abundance of COVID beds, and no patients are currently awaiting transfer to a COVID bed whose care would be adversely affected by this wait. Option 3 is therefore appropriate for patients who are in need of emergency treatment and/or when COVID beds do not qualify as scarce commodities. Option 4, on the other hand, is most ethically appropriate when encountering patients who do not have an immediate, emergent need for medical intervention and therefore have time to seek care elsewhere. Option 4 observes all the proper processes and prioritizes the autonomous wishes of the presenting patient and the safety of others.

## **DISCUSSION**

Some precedents for turning patients away who refuse COVID testing do exist. In Utah, for example, a bill currently awaiting approval would allow nursing homes to discharge patients if they refuse testing. Several hospitals, including University Hospital of Nebraska and Boston Medical Center (BMC), have clear policies in place regarding refusal of testing. At BMC, if a patient refuses testing, then he/she is isolated in a private room without any outside privileges. Similarly, some inpatient psychiatric facilities mandate quarantining or social distancing of certain patients who refuse COVID testing.

A disheartening lesson we are learning during this pandemic is the unsystematic application of hospital policies and guidelines for triaging and treatment. Despite the robust ethically compelling approaches described in the literature, few institutions, if any, have managed to operationalize their institutional guidelines (25). As the pandemic rages on, we feel that as individual healthcare providers, we must continue to advocate for organizational fairness and transparency in order to maintain our patients' trust in the profession and abide by our collective social contract.

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