

ETHICS & MEDICS

JULY 2020 VOLUME 45, NUMBER 7

A Commentary of The National Catholic Bioethics Center on Health Care and the Life Sciences

■ Also in this issue: “An Alternative Perspective on Rationing Ventilators,” by Rev. Tadeusz Pacholczyk ■

DEPRIVED OF SPIRITUAL AND PHYSICAL NEEDS

Joseph Meaney



It came as a shock. My heart went into ventricular tachycardia (V-tach), a dangerous ventricular arrhythmia that can be fatal. My wife probably saved my life. She noticed that something was wrong—that I was not asleep but rather unconscious in bed—and she called for emergency help. The 911 first responders and emergency room doctors had to use defibrillators to shock my heart back into a normal beating rhythm.

Because of the COVID-19 pandemic restrictions, my wife was not allowed to accompany me to the hospital. But she was permitted into the emergency room waiting area, and doctors told her my situation was critical. The medical team could not figure out why my heart had two V-tach-induced cardiac arrests, one at home and one in the emergency room. The best explanation so far is a genetic condition called Brugada syndrome, which can be a silent killer. With the insertion of an implanted cardiac defibrillator (ICD) device, the chances of a future critical V-tach incident have now become vanishingly small.

I am very grateful for the advances in modern medicine that transformed what could have been a death sentence only a few decades ago into a highly manageable health issue. The technology, including a ventilator for a few hours, carried me through. None of that would have mattered, however, if my dear wife had not seen the problem and done exactly the right thing in a crisis. I went through an MRI (magnetic resonance imaging) scan of my heart to confirm that my cardiac function had returned to normal. It was unpleasant to be crammed into that MRI tube for an hour and told to hold my breath for long periods. The small ICD device was inserted in my chest without general anesthesia in day surgery, and it has a battery that should last up to sixteen years. My main life limitation now is a prohibition on playing full-contact sports like rugby or tackle football.

Denial of Sacraments

More fundamentally, however, I suffered a catastrophic failure in spiritual care. My religious liberty rights as a Catholic were gravely violated. I was not able to see a priest during my four-day

stay at the hospital, even though I tested negative for COVID-19 and my wife and I asked repeatedly for the sacrament of Anointing of the Sick. The ambulance took me directly to the closest hospital to my house. It is not a Catholic health care ministry. When my wife heard I was in critical condition, already in the emergency room, she asked for a priest. They did call a Catholic chaplain who came quickly, but she was a lay person. It was good for my wife to speak to her and for them to pray together, but this chaplain could not administer the last rites to me.

I improved so rapidly that, the next day, I was extubated and taken off the ventilator, and the intra-aortic balloon pump was pulled out of my femoral artery. I had a pleasant visit from another lay Catholic chaplain that day. He gave me a card with a prayer for spiritual communion, and we prayed together. He could not confess or anoint me, of course, and he did not have Holy Communion with him. I later received a phone call, but not a physical visit, from a priest associated with the hospital. Finally, the lay Catholic chaplain who had come to the emergency room paid me a final visit before I was discharged, and she prayed with me. Clearly, significant pastoral efforts were made for me, but hospital pandemic precaution policies made it impossible for me to receive what I needed most, the sacraments.

Our parish priest was willing to go to the hospital, but he told my wife that he had been refused admittance under their current highly restrictive policy on access to the hospital. My wife was not allowed visiting privileges either, although she was told that if I took a turn for the worse and was dying, she would be allowed in to see me. I emailed Philadelphia's Archbishop Emeritus Charles Chaput, and he responded in minutes. He would have come personally if allowed, but he was also blocked from the hospital. Chaput delegated a priest to look into the matter further, but I was discharged from the hospital before a priest's visit could be arranged for me. It was quick and simple for me to get the sacraments of Reconciliation and Anointing of the Sick once I was discharged and out of the hospital.

Fundamental Rights

I do not think some thoroughly secular people grasp the magnitude of the offense of denying a gravely ill or dying person the last rites of the Church. The sacrament of Anointing of the Sick, including holy viaticum, can literally make the difference between an eternal destiny in heaven or one in hell. If that Catholic belief is not respected, we enter the realm of religious persecution and grave violations of civil rights and religious liberty rights. It is unreasonable and unconscionable to have a blanket no-visitors pandemic policy that excludes clergy. They could certainly require priests to wear personal protective equipment and be trained in heightened

safety precautions to protect themselves and others. No urgent medical reason exists, however, to justify denying patients access to sacraments. Also, thinking that all chaplains are equivalent may just represent ignorance on the part of nonbelievers, but there is no substitute for a Catholic priest in the conferring of certain sacraments.

The National Catholic Bioethics Center (NCBC) collaborated with bishops in the United States to develop guidance for providing the sacraments in a way that is consistent with both canon law and public health directives.¹ We have heard terrible accounts from people who contact us for free individual ethical consults. People tell us of loved ones who died alone in hospitals without the benefit of the last rites during this pandemic. I have always felt strongly about this issue, but it is a very personal concern for me now.

The Church must demand that fundamental rights be respected. A crisis does not excuse human rights violations. Rather, it calls for greater accommodation of and compassion for believers in danger of death, who may need a priest even more than a doctor as they prepare to meet their Maker.

The Hippocratic philosophy of medicine regards the good treatment of the whole patient—body, mind, and soul—as a paramount goal. The foundational guideline for Western medicine, the Hippocratic oath, proclaims a physician's duty to avoid harming patients. This is indeed wisdom from the ancients that modern health care would do well to ponder.

Sleep Deprivation

After my V-tach episode, I spent four nights hospitalized: three in the cardiac intensive care unit (ICU) and one in a normal ward. Except for the first night, when I was heavily drugged, I hardly slept more than a few interrupted hours. This experience is not unusual. Almost everyone I know who has spent time hospitalized has commented to me on the sleep deprivation they suffered during their stay.

One ironic story happened to the father of a friend. His dad was in a Veterans Administration hospital with several patients to a room. The noise and disturbances prevented him from sleeping well. One night, after he had finally fallen into a deep sleep, a nurse roused him—just to give him a sleeping pill.

Several years ago, when my own father was in the hospital during his final illness, family members took turns spending the night with him in his hospital room. It brought great comfort to my dad to have loved ones at hand, especially since he was suffering from dementia but still recognized his wife and children. A vivid memory from that time was the total inability of my papa, or others in the room with him, to get a good night's sleep. Hospital staff came by for various reasons all through the night. Noises, lights, and even overhead announcements came at random, disruptive intervals. I was completely healthy but felt shattered from lack of rest each morning after managing to snatch only a few moments of sleep whenever I stayed overnight with dad. My father was critically ill. This lack of sleep certainly made his recovery even more difficult.

Sleep deprivation is a serious and well-documented health issue. The US Centers for Disease Control and Prevention estimates that more than a third of adult Americans between the ages of eighteen and sixty do not get the minimum of seven hours' sleep needed each night to prevent multiple adverse health effects.² Anyone who goes completely without sleep for twenty-four hours will typically start to experience a whole range of symptoms such

as impaired judgment, lack of ability to concentrate, coordination problems, short-term memory loss, irritability, and higher levels of stress hormones and blood sugar.³ These symptoms and others only worsen as an individual falls deeper into *sleep debt*, a medical term for all the hours below the minimum required for healthy living that someone with poor sleep patterns accumulates. Chronic lack of sleep can contribute to serious health problems like paranoia, depression, obesity, diabetes, and deadly cardiovascular diseases. Evidence already suggests that the COVID-19 pandemic has aggravated the insomnia many Americans face.⁴

Patient Needs Come First

Modern medicine seems to theoretically understand the importance of sleep for our health. But frequently hospital settings do not prioritize this vital need of patients. Studies estimate, for instance, that 75 percent of patients in the ICU manage to get only poor or very poor sleep. A major barrier to improving the situation comes from routine assessments and actions that occur at regular intervals in a hospital setting, whether the patient is asleep or awake.⁵ When I was in the cardiac ICU, a blood pressure cuff on my arm went off automatically every thirty minutes, day and night, squeezing my arm so tightly that it was very hard to sleep through it. Once I was awakened at 3 a.m. by a lab technician to draw blood. I simply could not believe this was a routine practice.

It is stressful enough to be in the hospital. It is uncomfortable to have catheters and IV lines in your body while monitors beep or flash around your bed. On top of all that, as a patient you can expect to be regularly awakened in the middle of the night or very early in the morning. This adds insult to injury and actively harms patients by depriving them of needed sleep. The health consequences of this problem raise it from the level of a nuisance—one that everyone complains about but puts up with—to a significant bioethics issue that must be addressed.

The ethics of Hippocratic medicine puts the doctor and other health professionals at the service of the patient. Clearly some medical policies ignore patients' need for proper sleep and prioritize instead the convenience and schedules of hospital workers. Much of the technology of modern medicine does not facilitate sleep either. One of the doctors who came to my bedside agreed that this is a common problem in hospitals and mentioned that some institutions have changed their policies to minimize disruptions between midnight and five in the morning. A few of my nurses were more attentive than others in doing assessments with the bare minimum of disruption, often by clustering some interventions and postponing others to promote more sleep. Sadly, however, this kind of compassionate attentiveness to what is best for the patients seems to be more of an exception than the rule.

Major reform is needed in this area. I slept almost twelve hours straight the first night I came home. Through successive nights, I made up much of the sleep debt I had accumulated in the hospital, and I felt noticeably better. Catholic health care ministries should develop a special interest in this area of hospital reform.

When St. Padre Pio founded a hospital, as part of the facility's inaugural tour he insisted to the medical staff that this hospital was for the good of the patients, not the doctors. The Catholic health care ethos is to follow the example of Jesus, the divine physician, and that clearly means putting the needs of patients ahead of what is most convenient or practical for hospital workers.



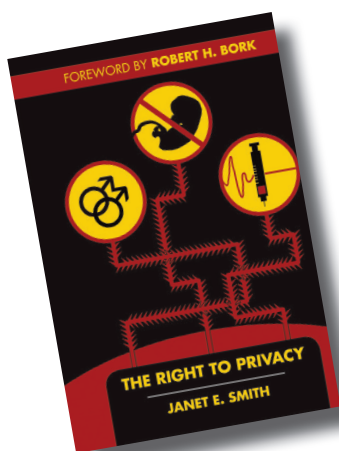
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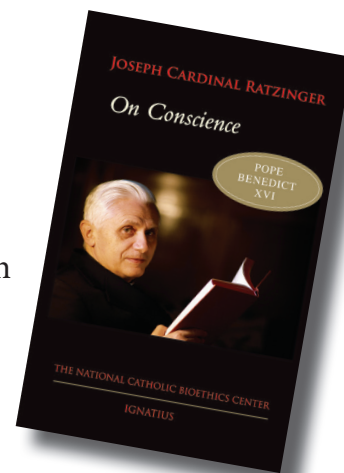
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Trying to facilitate healthy sleep for patients should rank far higher in the medical priorities than it currently does in too many hospitals. I experienced the problem firsthand, and the NCBC will be taking this issue seriously.

Time for a Reassessment

The COVID-19 pandemic has raised new religious liberty and ethical problems, while older ones, like sleep deprivation of hospitalized patients, persist. It was a great relief that the worst fears of hospitals' running out of ventilators for patients with COVID-19 and having to institute draconian medical triage policies did not come about in the vast majority of the United States.

The NCBC clearly stands against the universal use of do-not-resuscitate orders for any group of patients. Instead, each case must be evaluated individually to determine if a DNR order is ethically appropriate. We also reject any triage policy that would deny ventilator support to patients on the basis of anything other than objective medical criteria—that is, a determination that the patient is not expected to survive even with use of a ventilator.⁶ Similarly, taking a patient off a ventilator without his or her consent to benefit another patient could be ethical only if the first patient is no longer benefitting from the ventilator or is dying despite its use. Obviously, the problem arises only if a hospital does not have enough ventilators for all the patients who need them.

One positive byproduct of the pandemic for medical ethics was a surge in officially sponsored solidarity for the vulnerable in our society, especially the elderly and chronically ill. Most of the lockdown policies were justified by an appeal to slowing the spread of the disease and keeping our hospitals from being overwhelmed by critically ill patients. For the vast majority of younger and healthy

people, COVID-19 infection does not pose grave risks of death. Governments required social distancing and even isolation to benefit our frail and vulnerable brothers and sisters. This is commendable, except where human rights violations took place, like refusing access to the sacraments when they could be administered safely. It is also true that, when imposed for an extended period, shutdown policies carry large and increasing costs in human lives. Serious consideration has to be given as to when the costs can no longer be ethically justified.

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AN ALTERNATIVE PERSPECTIVE ON RATIONING VENTILATORS

Rev. Tadeusz Pacholczyk



The COVID-19 pandemic has resulted in a flurry of discussion around the question of how to allocate ventilators when the devices are in short supply. While creative responses are likely to help—such as ramping up ventilator manufacturing, double-tubing patients on one machine, repurposing other medical devices to serve as ventilators, or transferring patients out of urban settings to smaller hospitals that are not experiencing shortages—even these approaches may not ultimately suffice in the throes of a pandemic, and many health care systems have been actively looking ahead to the possibility of rationing.

In a March 2020 article in the *New England Journal of Medicine* (*NEJM*), Robert Truog and his collaborators proposed that we take tough choices about allocating ventilators out of the hands of frontline clinicians and hand them over to dedicated triage officers

or triage committees. This approach was offered as a way to protect clinicians: "Reports from Italy describe physicians 'weeping in the hospital hallways because of the choices they were going to have to make.' The angst that clinicians may experience when asked to withdraw ventilators for reasons not related to the welfare of their patients should not be underestimated—it may lead to debilitating and disabling distress for some clinicians. One strategy for avoiding this tragic outcome is to use a triage committee to buffer clinicians from this potential harm."¹

There appears to be a growing acceptance of the idea that triage committees should be able to take away a patient's ventilator without his or her consent; and patients and their families are clearly troubled at the prospect, as we all should be. The principle of subsidiarity reminds us that one should not withdraw those decisions or choices that rightly belong to individuals or smaller groups and assign them to higher authorities or larger groups. This mistake is made whenever important personal medical decisions are shifted away from physicians and their patients, for example, and handed over to insurance companies or hospital administrators.

When it comes to allocating limited medical resources in a COVID-19 crisis, subsidiarity implies that frontline clinicians, together with their patients, should be making these decisions, with ethics committees or triage committees serving only in an advisory, not a decision-making or adjudicating, capacity.

Subsidiarity is also relevant in emergency situations. For example, when a plane's engines flame out, the captain should not

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ETHICS & MEDICS

VOLUME 45, NUMBER 7

JULY 2020

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be sidelined in favor of having a remote landing committee bring the plane to a safe touchdown. Instead, passengers deserve a pilot with professional skills, instincts, and expertise, somebody who is fully invested in the critical task at hand. The pilot's personal involvement in the fate of his or her passengers mirrors the physician's accompaniment of his or her patients in a time of crisis.

When it comes to allocating limited medical resources in a COVID-19 crisis, frontline clinicians, together with their patients, should be making these decisions, with ethics committees or triage committees serving only in an advisory, not a decision-making or adjudicating, capacity.

When I bring up the Italian doctors' weeping, physicians I know say they do not see that happening here. A pulmonologist working in an intensive care unit in Florida said that it would be "the great exception" and stressed that "as a group we are used to making difficult decisions and are psychologically resilient."

The main goal during triage, moreover, cannot be to buffer clinicians or soften the angst of what are clearly difficult and challenging decisions. Nor is it to "save the most lives possible in a time of unprecedented crisis," as proposed in the *NEJM* article.² Nor is it to favor those with the best prospects for the longest remaining life, by relying on a utilitarian calculus that favors the young and the strong, as others have suggested.

Rather, the goal must be to make allocation decisions on the basis of evenly applied practices, as fairly as possible, across the spectrum of patients, without turning to biased quality-of-life assessments. Even in a pandemic, the first priority remains the provision of outstanding patient care.

Instead of offloading responsibility to a committee to "mitigate the enormous emotional, spiritual, and existential burden to which caregivers may be exposed,"³ as the *NEJM* article phrases it, clinicians can rely on several key ethical principles to help them navigate these complex decisions:

1. Ventilators should not be rationed on the basis of categorical exclusions such as a patient's age, disability (e.g., being paraplegic), or other secondary traits, but rather on the basis of clinical data, including likelihood of survival, organ function, and other clinically relevant medical data or test results. Various medical scoring tools can be used to objectively evaluate this information about a patient's status and to make comparisons among patients.

2. If two clinically similar patients arrive at the emergency room, a ventilator can be allocated to one patient rather than the other on a first-come, first-served basis, a lottery, or another randomized approach.
3. In general it is immoral to take away a patient's medically indicated ventilator without his or her consent and give it to another patient who may die without it.
4. In situations where a patient on a ventilator is clearly deteriorating, and where COVID-19 and its complications can reasonably be expected to cause the patient's death even with continued ventilator support, dialogue should be initiated with the patient or his or her designated health care agent to obtain consent to remove the ventilator. Obtaining free and informed consent helps resolve nearly every problematic angle of the ventilator rationing process. Scoring tools can be used to decide which patient's health care agent should be approached first. Attention must always remain focused on establishing and maintaining honest and open communication with the patient, family, and health care agent throughout difficult triage situations.
5. Patients who relinquish a ventilator in triage situations, or who cannot be given a ventilator because none are available, should receive not only suitable alternative forms of medical treatment and palliative measures to manage their discomfort, but also spiritual support rooted in their particular religious tradition. This includes visits from a pastor, minister, priest, and so on where final requests, last sacraments, and other needs can be attended to.

If rationing becomes necessary, these ethical considerations can help frontline clinicians to make responsible decisions and more calmly accompany each patient, including those particularly ill patients who may be facing their final days and hours in a health care facility.

Rev. Tadeusz Pacholczyk is the director of education at the National Catholic Bioethics Center in Philadelphia.

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