

Edmund G. Howe, "What We Should Learn from the COVID-19 Pandemic," *The Journal of Clinical Ethics* 31, no. 3 (Fall 2020): 197-208.

At the Bedside

What We Should Learn from the COVID-19 Pandemic

Edmund G. Howe

ABSTRACT

The COVID-19 pandemic may have left many of us needing closeness with others more than we have before. Three contexts in which we may especially need this closeness are (1) when we must triage and some but not all will benefit, (2) when families may be separated from loved ones who have COVID-19, and (3) when people for any reason experience shame. In this article I examine sources of present, harmful emotional distancing. I suggest how we might do better in each of these contexts due to what the COVID-19 pandemic can teach us.

This issue of *The Journal of Clinical Ethics (JCE)* features a special section on responses to the COVID-19 pandemic in New York City, written by clinical ethicists at two campuses of New York Presbyterian Hospital. As I write, the pandemic is far from over. But it is not too early to ask what we might learn from what we have

Edmund G. Howe, MD, JD, is Professor of Psychiatry and Director of Programs in Medical Ethics at the Uniformed Services University of the Health Sciences in Bethesda, Maryland; and Editor in Chief of *The Journal of Clinical Ethics*. The opinions or assertions contained herein are the private views of the author and are not necessarily those of the AFRR, USUHS, or the Department of Defense. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript. Conflicts of interest: none.

gone through already. Looking back may help us immediately and in the future. In this introduction to the fall 2020 issue of *JCE*, I will discuss three of the most taxing questions posed by the epidemic: (1) How should we triage patients who present to our emergency rooms? (2) What should we do when a patient's family members want to stay with their loved one, who is in the hospital with COVID-19? (3) How might we help all people, including clinicians, avoid feelings of shame in response to aspects of the pandemic?

The first question, How we can best perform triage? is the most difficult ethical question. In "The COVID-19 Crisis and Clinical Ethics in New York City," Joseph J. Fins and Kenneth M. Prager sum up: "If there is a lesson to be learned from the New York experience, it is to better anticipate the need for crisis standards of care and to prepare the legal landscape for that eventuality."¹ This difficulty extends further than might be imagined because the virus brings about secondary health problems.

An example of such a secondary health problem is the need for dialysis: Should we fully dialyze a few patients, and thus optimize their chances for survival, or should we provide a shorter, less efficacious course of dialysis to a greater number of patients, knowing that more patients will be likely to survive? This is discussed in "Phases of a Pandemic Surge: The

Experience of an Ethics Service in New York City During COVID-19,” a second article in the special section on COVID-19 in New York City, written by Barrie J. Huberman, Debjani Mukherjee, and colleagues.²

The second question I will address is: How we should respond to family members who want to stay with a loved one who is hospitalized due to COVID-19, when the hospital does not allow visitation? Later in this introduction to the issue, I will describe one hospital that resolved this dilemma for children who have COVID-19, and consider whether this practice should be expanded, and what it might suggest for family members in other clinical contexts.

This question regarding visitation by family members is spurred by the painful isolation that family members have experienced during the pandemic. Kenneth M. Prager and Joseph J. Fins capture this in a third article in the special section on COVID-19, “Meeting the Challenge of COVID-19: The Response of Two Ethics Consultation Services in New York City.” They write, “Ethics consultants were often crucial collaborators for their colleagues in the middle of the night, surrounded by 10 to 15 critically ill intubated patients in the emergency department, while the patients’ panicked relatives sat nervously in a (virtual) waiting room, anxiously expecting news of their loved one.”³

The third question I will consider is: How might we help all people, including clinicians, avoid feelings of shame in response to aspects of the pandemic? This pandemic brings about many different sources of shame, and the effects of shame on individuals and their quality of life can be singularly devastating. Feelings of shame can, for example, wholly devastate our self-esteem for the rest of our life. Some people feel shame, for instance, because they fear that they infected another person, and the person died as a result. Feelings of shame may be especially deep-seated when transmission could have been avoided, as, for example, when a caregiver could have quit working at a nursing home but did not. Others feel shame because, due to the COVID-19 epidemic, they lost their job.⁴

Careproviders are exceptionally vulnerable to such feelings of shame.⁵ They hope to heal their patients, but, due to COVID-19, this has not been possible, to an unusual extent. Fins and Prager write that clinicians were often expected by patients and families “to have remedies that we could not provide because of legal con-

straints regarding the New York State do-not-resuscitate (DNR) law. While we might have agreed with their ethical analysis we were constrained as well.”⁶

As Atul Gawande states in his book, *Being Mortal: Medicine and What Matters in the End*, when we are confronted with the fear that we may die, we tend to change what we care about, regardless of our age. Before we feel fear that we could die, we are usually preoccupied with everyday affairs. But once we believe we could die soon, we look to what we find most meaningful. Commonly, what we find to be most meaningful are the people closest to us and our relationships with them.⁷ The pandemic brings the fear that if we contract COVID-19, we could die. For some of us, this fear is triggered, for instance, whenever we merely cough.

As I consider possible responses to these three questions, there is common thread: we—meaning all of us, throughout the globe—may be better able to get through this pandemic with each other’s support. Working together to craft triage policies that are fair will make triage policies more possible to implement. Helping family members to stay in touch with their loved one, as much as is medically reasonable, may help them get through their loved one’s illness. And, if we are able to limit feelings of shame and reverse them once they occur, even in careproviders, we will be more able to give each other the care we need. We have limited control over this virus. We can, though, always be there for each other, as much as we can.

TRIAGE

There are many competing moral priorities at play when policies regarding triage are designed. I will consider three of these priorities to show how, even when they may seem to be mutually exclusive, they may be meaningfully combined. The three priorities are utility, justice, and enhancing quality of life.

Triage policy should be transparent, able to be understood by all, and fair. With these qualities, a policy might be acceptable to all or at least most people, even when they may not be among those who would benefit from the policy. One approach is a weighted lottery, which has been tried in Pittsburgh and appears to be effective. It was developed in the spring of 2020 by Bruce B. White, Robert Truog, and others, to allocate remdesivir.⁸ (In May 2020, a large clinical trial

found that remdesivir “slightly improved recovery time for hospitalized patients.”⁹ In June 2020, White reported that Pittsburgh hospitals had enough remdesivir to treat one in four patients who needed it.¹⁰ A weighted lottery is one way that disparate values—utility, justice, and quality of life—may be reconciled and combined in a way that most of us find acceptable.¹¹

To achieve both transparency and fairness may be extremely difficult. Complex algorithms may, for example, best achieve fairness, but due to their complexity may be difficult for most people to understand.¹² The triage algorithm in use in Pittsburgh may achieve wide support, even among those who will not themselves receive the treatment they need. At this time this report remains speculative.¹³

There are many views on how to best do triage. In general, they all involve what is best for large numbers of people, as opposed to what is best for the individual patient. To meet even one of the three priorities listed above—utility, justice, and quality of life—may be most difficult, as I will elaborate below.

Utility

For many people, utility is the starting point for planning the allocation of scarce resources. Many of us prioritize saving the most lives and/or maximizing the number of years that people will live. Even if we can agree that utility should be the primary ethical principle furthered by triage, how to do this in practice may remain wholly open to debate.

We need to agree, for instance, on who should be in the “first cut” to receive the scarce resource, and who should be in later, progressive cuts, as the need to further prioritize patients arises. It would seem that careproviders should be in the first group, since they are needed to treat others. Beyond this, there may be thorny challenges. For example, epidemiologists might receive higher priority than other careproviders because they may be able, to a greater extent, to help marshal limited resources.¹⁴ Should those who remove our wastes be next? We may want to prioritize them, so we do not risk undergoing a second plague.

Age as a Criterion

The degree to which age should be used as a criterion in triage decisions is controversial. Some see its use as a violation of the absolute sanctity of life, as well as a violation of the need

for absolute equality that follows from it. Practically, sometimes people who are older will do better medically than some people who are younger. Emotionally and ethically, some people feel we owe older people “back pay.” That is, some assert that, in addition to our need to respect aged people as persons, we owe them compensatory justice, that is, compensating them for what they have done in the past, regardless of what they can or cannot offer in the present.

These factors favor the use of age as a criterion: (1) Age is an objective determination. That is, it eliminates possible wrongs that may be caused by conscious or unconscious subjective bias. (2) We all age; thus, in this sense, there is equity. For example, a person who is 21 years old is prioritized to receive a treatment over a person 101 years old. Any of us could live to be 101. This is not the case with other characteristics, such as race, and, in most cases, gender. (3) We may see being able to live a full life as a priority. Most of us tend to grieve more when a child dies than when an older person dies.¹⁵

There are more nuanced limits associated with any use of age as a triage criterion. F.M. Kamm argues, for example, “if doctors think in terms of helping people based on expected life years they would have to help a sixty year old whose life would be extended 20 years by treatment in preference to a thirty year old whose life would be extended 15 years by treatment.”¹⁶

Keeping Families Together as a Criterion

If feelings are to be included as a criterion under the heading of utility, namely, as a good, a core concern in triage decisions might also be to give moral weight to keeping family members together. What people feel—for example, feeling anxious or feeling calm—is a good, since we greatly value what people feel. What people feel may be a basis, for example, for people in one country to believe that something is wrong, but for people in another country to believe is right—thus, in this regard, a basis for cultural relativity.

Concern for the importance of families’ feelings, even during triage, arose years ago, in 2005, after Hurricane Katrina hit New Orleans. At one inner city hospital there, some hospital staff brought family members, pets, and possessions to the hospital for safety during the flooding. But after days without power, air conditioning, and supplies, patients, staff, and their family members waited for rescue boats. (Their pets

were euthanized.) When the boats arrived, there were two options for triage: prioritize the rescue of patients or prioritize rescue to keep family members together. As the boats were loaded at the emergency room ambulance ramp, the hospital CEO asked doctors present “ ‘why the hell’ ” they were loading their own family members onto the boats when “ ‘We’re trying to get the patients out!’ ” One of the doctors explained, “ ‘Everybody’s a patient, including us.’ ”¹⁷ (The physician’s statement should be understood metaphorically: “everyone” was not a patient, but everyone was striving to survive. This raises the question: What meaning should “worst-off” have in this context and in similar contexts?) Even with assistance, the patients moved slowly; the boats would only stay until dark; the doctors wanted to get as many to safety as possible before the boats left.

It should not be a surprise that such sharp feelings and disagreement about prioritizing the rescue of family members emerged. This was especially the case because careproviders and their families were competing for space with patients and their families. Our feelings move us to keep families together. For example, we grieve deeply at the thought of young children who lose their parents.

There are some cons to this line of reasoning. If we assign higher priority to patients with family, we deny equal treatment to patients who don’t have family. Examples include those who wanted children but couldn’t have them and those who simply chose not to have children. A group for whom this source of injustice is especially troubling are those whose wishes to have children were obstructed by society. Although such obstruction is now changing, in the past this included people who were not able to adopt a child because they are gay.¹⁸

Justice

People of different races and ethnicities have been subject to societal injustice for centuries, and it continues. For this reason, members of these groups may have a greater claim to being assigned priority for COVID-19 treatment. Assigning priority to persons who have a lower socioeconomic status has been suggested as one way to address societal injustice.¹⁹ This was a component of the Pittsburgh weighted lottery. Such a “proxy criterion” might help more persons who are worse-off and may be a preferable way to assign priority, for this reason.

This might, to some, not adequately compensate members of our society for wrongs society has done to them in the past: African Americans and Native Americans. Greater benefits for these patients might be achieved by giving them increased priority.

An additional criterion for triage policy is that most people find the triage scheme acceptable. This need is morally objectionable to the degree that it risks being “ethical by majority rule.” This concern is solely pragmatic: people should find acceptable a triage plan that will affect them.

An approach that favors the worst-off may face barriers because those who are better-off may be less sensitive to the needs of those who are not well-off. This has always been a problem, and it is likely to be the greatest obstacle to implementing new applications of justice such as those described above. Although it is absolutely ethically wrong, it is an obstacle to better-off countries (including the United States) meeting the needs of worst-off persons throughout the world.

For example, there is a “10/90 gap” in research funding: only 10 percent of global health research funding is devoted to conditions that account for 90 percent of the global disease burden.²⁰ One problem is that, emotionally, people are less likely to feel committed to strangers than they are to family, friends, and others in their own country. Although this makes sense, these preferences affect the survival of strangers, and even though they are strangers, their life and health should be granted far greater moral weight than they often are. Thus, it seems appropriate that resources be assigned using objective measures rather than our emotions, as Peter Singer and many others have suggested.²¹

A Weighted Lottery

As mentioned above, a weighted lottery was used in Pittsburgh to allocate remdesivir to treat COVID-19.²² Doctors and ethicists created the policy to determine who should be accorded priority, and to what degree. For example, first responders were prioritized over very sick patients who were unlikely to recover. A weighted lottery of a different sort could be used to allocate resources among countries that are worse-off. Needs that could be accorded greater weight could include a country’s population and medical resources, relative to those of other countries that were less worse-off.

A starting consideration might be whether careproviders from a less-well-off country have means to protect themselves that are equal to the protections given to careproviders from a country with greater resources, such as the U.S., when careproviders from a wealthier country go to another country to help out. In the past this has not always been the case; careproviders from wealthier countries, including the U.S., have received multiple protections that careproviders from less-well-off countries did not.

Research

Research is another key utilitarian end. Research gains, such as vaccines, should help to prevent COVID-19 from spreading. Prevention is better than most cures. The use of a weighted lottery could help in the conduct of vaccine research. While members of one research arm would receive treatment and members of the other arm would not receive treatment, members of the two groups would be the same in other respects. Those who did not receive treatment would constitute a naturally created control group. To achieve greater equity for those who are studied, some of the ethical standards that are regarded as ideal may need to be compromised. One example could be pregnant women who have COVID-19.²³

Ideally, pregnant women—as for all research participants—should have sufficient time to reflect on whether they want to participate in research. It would be best to discuss their participation during a prenatal visit. But this would omit pregnant women who see a careprovider for the first time when they are in labor. Their medical needs may be different than the needs of women who received prenatal care; for example, they may not have been given vitamins, such as vitamin D, typically prescribed during prenatal visits. This may lead them to be more vulnerable to acquiring and/or becoming seriously ill with COVID-19. Greater equity might require accepting these women into a treatment protocol when they are in labor, although that is not an ideal time to ask someone to reflect on and decide about participation in research.

Quality of Life

A different but no less critically important question is which patients, if any, should be excluded from a weighted lottery (or whatever allocation scheme is adopted) based on the quality of life that others imagine the patients would

have in the future. When patients can discuss their future quality of life, their own views should prevail. When they cannot, however, their quality of life may be imagined based on the extent of their physical, cognitive, or emotional impairment. These impairments could include, for example, quadriplegia, cognitive deficits, dementia, and psychiatric illness (those with unremitting psychoses). The impairments may have further, possibly morally relevant subcategories. Dementia, for example, may be fixed or later get better, as when it is due to a stroke. Dementia may predictably worsen, however, when it is caused by an underlying illness such as Alzheimer's disease.

This is a critically important point that should be made initially: patients' quality of life may not be correlated, and thus may not be validly inferred, from the extent and severity of their deficits or limitations. Rather, their quality of life, for them and for those who care for them, if they need a caregiver, may surpass that of people who have no limitations. I think of a woman who loved her child and found exceeding joy and meaning in raising her. The child could not talk or walk, but could communicate only by banging a toy hard against the floor to show that she wanted something. I think also of a woman, who, for months, found joy and meaning sitting by her husband's side as he lay in bed in a coma. She would sometimes speak to him. As discussed in the next section, speaking to him may not have been as futile as it seems. But whether or not it was futile is not the point. The point is that what may seem to be a poor quality of life may be anything but to the patients and caregivers who are most affected.

It may be useful, in designing a weighted lottery that would include quality of life as a factor, to begin with those groups of patients that might be excluded, out of hand, from any consideration of triaged treatment. The reasoning would be that if patients who have many disabilities should be included in a weighted lottery, then perhaps other patients who have disabilities should be included. But if patients who have disabilities are to be excluded from consideration in a weighted lottery, who else should be excluded, and why?

One example of a "worst-off" group that could be considered for exclusion from triaged treatment might be patients who are in a persistent vegetative state, or in a minimally conscious state that has not yet been detected. These pa-

tients may have no awareness, or may have some awareness, or may not have awareness at the present time but possibly acquire it in the future, if their brain heals. At present, such determinations can take place only in a research setting. But some ethical questions still loom: for example, if patients are in a minimally conscious state, or could later be, and they have COVID-19, should they be in a queue for treatment?

Researchers have described how it may be possible to communicate with these patients if they have awareness. In the first research study, in 2006, researchers asked a patient who fulfilled the criteria for a diagnosis of a vegetative state to imagine playing tennis or moving around her home, and with the use of functional magnetic resonance imaging (MRI), compared the patient's reaction with that of healthy volunteers. The authors reported that "the patient activated predicted cortical areas in a manner indistinguishable from that of healthy volunteers."²⁴ In a more recent study, researchers asked subjects with severe brain injury to (1) imagine playing tennis or swimming, (2) answer a yes or no question, and (3) answer a multiple choice question.²⁵ Subjects' responses were detected, but not consistent, leading the researchers to conclude that larger studies with larger sample sizes are needed.

Based on who these patients are, or even on who they could become, it may be reasonable to include them in a weighted triage lottery. The latter group would include those who have not yet shown that they are aware, but who could have and show awareness at a later time.

In an article published in the *New York Times*, Joseph Fins and coauthors described a patient, "Maggie," who suffered a massive stroke during her senior year at college. She made cognitive progress over the next several years. The authors reported that magnetic resonance imaging showed that reconnections could be made and the brain could heal, even when it had been badly injured. This possibility suggests the importance of giving these patients optimal, ongoing, loving care.²⁶

If patients like Maggie are included in treatment queues, inclusion criteria may have to be rethought altogether. A new criterion to be considered, for example, could be whether or not patients would be likely or highly likely to return to their previous, pre-COVID-19 state. But realistically, at this point, it is unlikely that these patients would be included in a treatment queue.

The criteria used in triage decisions should be acceptable to most people, so what other factors in triage might be acceptable to most people? Most of us probably want to be able enjoy life, and not find it painful to continue to be alive. Thus, in general in these triage decisions, the benefits of staying alive should be seen as outweighing the burdens, even though the benefits might have to be inferred.

Most people want to have awareness. Some patients with dementia lack all awareness of their previous life, but seem to enjoy their present life. Should they develop a fatal illness such as a fast-growing cancer, and their health foreseeably go quickly downhill, how should they be positioned in a triage queue? Their position in the queue would probably not be high. Likewise, the child I described earlier, who could only communicate by banging a toy on the floor, might not be given priority for treatment for COVID-19. The elderly man in a coma, whose wife stayed by him and talked to him, probably would not be assigned a priority. There would be insufficient grounds to believe that their future benefits could be great enough to justify being assigned priority.

FAMILIES

Early in the pandemic, I was part of a discussion regarding whether the wife of a patient who was hospitalized with COVID-19 should be permitted to remain with him, isolated in his room, as she requested. I imagined the possibility of a fixed, semicircular perimeter that would form a barrier outside his single room, guaranteeing a "safe" six-foot distance. While this solution wasn't tried, the possibility raises the question of whether it should have been.

New Approaches at a Children's Hospital

This solution is not as farfetched as it may appear. St. Mary's Hospital for Children in Queens, New York, did something similar this spring. Benjamin Weiser, in an article in the *New York Times*, relates, "Ultimately, 20 mothers and two fathers have moved into St. Mary's, bringing pajamas, sweatpants, toiletries, vitamins, and laptops. Most now have been there for nearly three months, sleeping on recliners in their children's rooms and becoming immersed in their child's care." Weiser relates that one mother, whose six-year-old son was on "round-the-clock oxygen" said, "We just thought it was

going to be a two-week thing, but then they kept extending and extending.’²⁷

St. Mary’s Hospital allowed only one parent to join the child with COVID-19. Once there, the parent couldn’t leave and come back again. Feasibly, many parents would want to be able to do this. Many parents say, for instance, that they would give their life in a heartbeat for their child, and they seem to mean it. Risking contracting COVID-19 or death by being with their child would not seem to be a large risk for these parents. This raises the question of why a parent would be allowed to be with a child who has COVID-19, but an adult would not be allowed to be with an infected parent, or an older parent be allowed to be with an adult child. Perhaps these instances are not allowed because the risk to others that visitation poses is too great. Still, assuming that the risk could be fundamentally mostly avoided, it is worth noting a counter example: that a competent adult who is not suicidal can refuse lifesaving treatment. If an adult knowingly chooses to risk contracting COVID-19, then it does not seem to be going too far to respect that person’s autonomy and allow visitation with an infected loved one.

Such greater emphasis and priority on family members’ feelings for each other is common in some non-Western societies. For instance, this different emphasis on relationships and feelings is notable in sub-Saharan Africa and in China, Taiwan, Japan, and Korea.²⁸ Thaddeus Metz posited that such a relational preference “implies that a being warrants moral consideration only if, and because, it exhibits some kind of intentional or causal property with regard to another being.”²⁹ Bishop Desmond Tutu, speaking of a “typically African” standpoint noted, “We say, ‘a person is a person through other people.’ It is not ‘I think therefore I am.’ It says rather: ‘I am human because I belong.’ I participate, I share. . . . Harmony, friendliness, community are great goods. Social harmony is for us the *summum bonum*—the greatest good.”³⁰

Other Ways to Respect the Feelings of Patients’ Family Members

The example of St. Mary’s Hospital in Queens on parental visitation for children with COVID-19 suggests we might consider other ways that we can respect, to a greater extent, family members’ feelings. Each of the following examples involves a different way to interact with patients’ family members.

What to Say When a Child Dies Early On

A fetus may be stillborn and a newborn may die shortly after birth due to COVID-19, although both of these outcomes appear to be uncommon.³¹ In the past some clinicians believed they should encourage pregnant women to have an abortion when it was clear that the fetus would die, and to not provide life-prolonging treatment to a newborn who would soon die. These clinicians most likely thought this advice would spare mothers and parents greater and unnecessary grief. It has become clear, however, that a considerable subgroup of these parents would find great joy and meaning in seeing, holding, and bathing their child, for as long as they can, and retain these feelings after their baby has died.³² It may be even a considerable majority of these parents. They may find keepsakes of their baby to be a source of precious memories.³³ These experiences may move the parents to choose to try to have another child, when otherwise they might not try.³⁴

These possibly profound benefits for parents have led some careproviders to believe that even when parents initially refuse to see, hold, or bathe a child because they are aware that the infant will die soon, the parents should be asked again, later, whether they want to interact with their infant. They may change their mind. I suggest that careproviders who want to ask parents a second time if they want to interact with their infant to first ask whether it would be okay to do so, and say why they are asking. Careproviders can explain that the parents may later change their mind and choose to see, hold, and bathe their dying infant, and find the experience of loving the dying infant exceedingly meaningful. The parents may then be able to have memories of the infant that are precious to them, and they may later be able to consider trying to have another child, when they otherwise might not.³⁵

Performing a First Lumbar Puncture

Clinicians who perform lumbar punctures (LPs) or spinal taps on infants, to discern meningitis, must at some time perform their first LP on their own. Some clinicians choose not to tell the infant’s parents that this is the first time they will do a “solo” procedure, unless the parents ask. Even when parents ask, some clinicians may not disclose that this is the first LP they will perform on their own.

Should clinicians take the initiative to disclose to parents that this will be their first solo

LP, or should they tell parents only when parents ask, or should clinicians always lie about this? Some believe that, based on parents' extremely intense and involved feelings for their child, that clinicians should always lie about this, or at least lie somewhat, by saying that they have done "several" LPs on infants "alone" before, when in fact they have done an LP before under supervision.³⁶ This is a potentially perilous course. In principle, it gives clinicians tacit consent, in cases that suit their needs, to lie.

What to Say at Discovering Nonpaternity

Nonpaternity may be accidentally discovered during genetic testing. Before a genetic test will be done, when this is medically and practically possible, some clinicians will explain to a mother who is to be tested that there is a risk that such information may be discovered, so that she can choose not to have her child, her husband, or herself tested. If the father is not tested, testing cannot show biological nonpaternity. Other clinicians insist that if nonpaternity is detected, a mother must tell the child's father, and if she does not, the clinicians will follow up and tell the father themselves.³⁷

These practices may wholly differ when there is some medical reason to share the results of genetic testing. Some clinicians hold that since a mother in this situation engaged in an "indiscretion," she should suffer the consequences. I find this egregious. I relate these different approaches and express my personal views because such judgments can be so harmful. Those who have power, as careproviders may, who make such judgments may harm others to an extent that few others can. Other careproviders hold—as egregiously, or at least naïvely—that the father, learning he isn't biologically related to the child, will simply still love the child just as much, as the father would if the child had been adopted. Would that this were always so! The information may, on the other hand, destroy both the child's and the family's subsequent life.

It may be possible to respond differently in these situations. For example, it may be possible to not indicate that we have this incidental information. Even if we have access to this information and say that we won't share it, this may alert a father, for the first time, that it is possible to discern nonpaternity by this means. A father then may pursue genetic testing on his own, and it may decimate the family.

I have been informed of instances when staff who did genetic testing for another medical purpose chose not to mention that they had information regarding nonpaternity. I know of another case in which, at a parent's request, a careprovider deleted this information from the medical record. The family had previously cared greatly for each other, and with this action, their great caring for each other continued.

It is possible to imagine that, in these two situations, the families' relationships were optimal prior to testing and that, because the information was not disclosed, the optimal relationships were preserved. In these situations, should we consider not disclosing test results to a greater extent than we do now? Should we do more to help preserve families' fond feelings to a greater extent than we do now?

What to Say about a Body Left to Science

Family members may have concerns regarding what will happen to the body of loved ones who leave their body to science. This may be for the use of the body in an anatomy lab, for example in medical schools, or for research. One example is research that uses a deceased person's body to test the effectiveness of a new type of helmet that will protect a live person from head injury, for example, in the military. In this instance, how specific should clinicians or researchers be regarding the type of research? Family members may want more detailed information, but greater detail may be painful for family members to imagine.³⁸ They could, with more detailed information, choose to withdraw their consent for the body to be used in research.

The images that research brings up may haunt them. When we are asked about the specific intent of research with the body of a deceased family member, or even asked about the intent of more general research, should we give out this information?³⁹ The question of how much detail to provide involves possibly sparing loved ones discomfort, while denying them the opportunity, with the added information, to object if they want. When we need to make an important decision, we value information around the decision above all else. This rationale may provide us, in most contexts, with the better answer.

What to Say about Forensic Evaluation

A final example of the greater respect we could show to family members' feelings involves

the conduct of forensic examinations for the state. In the process of examining a patient, some clinicians will contact family members to obtain more information. While the information gained may benefit the patient, it might, on the other hand, cause harm. The information that family members provide may, for example, make a difference in whether a patient receives compensation for an alleged disability, or conceivably even get the death penalty for a crime the patient has committed.

Forensic examiners do not work for the benefit of the patient, but for the state, and they must inform the patient's family members of this. The ethical question is how much further, if at all, forensic examiners should go in informing family members. We could tell family members, even in a general way, of the harm that could be done by providing us with information about the patient. The likely consequences of this may be that the family members might not give us any information. Does respecting family members' feelings, not to mention their autonomy and personhood, warrant never receiving information that may further more just results from them? Dear although this price may be, it may.

Can Such Changes Practically Be Made?

This is a fair question. Changing the ways things have been done, and are currently done, isn't easy. In a recent issue of *JCE*, an attempt to make such changes is worth citing. Erin Talati Paquette and Lainie Friedman Ross, in their article "Abusive Head Trauma and Parental Participation in Pediatric Decision Making," challenge what has previously been the almost sacrosanct notion that parents who have abused their child should be precluded from participating in treatment decisions for their child.⁴⁰ Paquette and Ross state, "nuanced consideration of these issues requires careproviders to remain open to parental involvement in the decision-making process. . . . Parents are essential contributors to these deliberations." Such a nuanced approach opposes an all-or-none outcome.

The present discussion, spurred by COVID-19, is intended to relate why it is appropriate to respect family members' feelings to a greater extent than we may have in the past. It may have been just as "appropriate" to have respected feelings in the past, but we didn't perceive this. The fears evoked by the pandemic, as Gawande has told us, may help us now to see this. If this is the case, looking for such nuanced approaches,

as Paquette and Ross have, would seem to be the way we should go.⁴¹

When a Loved One May Be Able to Hear But Not Be Able to Communicate

In a recent study, Elizabeth Blundon, Romaine Gallagher, and Lawrence Ward report that patients who are dying may hear and presumably understand when they are spoken to, even when they are no longer able to communicate.⁴² It has been established in other contexts that we should watch what we say when patients are undergoing surgery or are in a locked-in state, as there is evidence they remember what is said, and later report what they have heard.⁴³ This new finding can be used to benefit our loved ones when they are dying.

We may find that we talk to our loved ones more when they can't talk back, even on the phone. For example, a man couldn't be with his mother during the time that she was dying, but he arranged for those who were caring for her to regularly hold the phone to her ear so that he could continue to speak to her. We can encourage family members to do as he did. This may add a different light to the case of the patient's wife who sat beside her husband daily, for hours, and talked with him as he lay in a coma, over a period of months. It may not at all have been in vain. The patient's wife may model for us the kind of caring to which we can aspire.

SHAME

There are many sources for the feelings of shame that people have felt during this pandemic.⁴⁴ People condemn themselves because they believe they passed the virus to another, because they lost their job, or, as careproviders, they could not save enough patients who had COVID-19. I would like to consider this last group, careproviders. They—like anyone else—are vulnerable to blaming themselves when there is even just a possibility they have failed.

One instance when it is all too common to blame ourselves is when someone we love takes his or her life. We may call the other person and find out we are too late. "I should have called earlier," we may tell ourselves. Forever. We blame ourselves for what our reasoning tells us we could have done, but didn't. Bernard Williams calls this "agent-regret."⁴⁵ Another example of agent-regret is when a truck driver kills a child who runs into the path of the driver's moving

truck. The driver is innocent, but is likely to feel at fault.

Similarly, careproviders may wrongly feel devastating shame when, it seems to them, too many of their patients have died due to COVID-19. These feelings of shame, unlike other feelings, may obliterate our self-respect, and the loss may remain throughout our entire life.⁴⁶

This feeling was expressed intensely by the physician David Hilfiker in his book, *Facing Our Mistakes*. Hilfiker describes how, in his rural practice in 1984, a patient he knew well had missed several menses and “felt” pregnant, but had four negative urine tests and no growth of the fetus. After more than two months, Hilfiker was worried that the fetus had died. He did not order an ultrasound because the patient would have to travel to have it, and her family could not afford it. Thus, Hilfiker performed a dilation and curettage (D&C), but found, to his horror, that the fetus was healthy and alive. He wrote, not at all to excuse himself, that mistakes are an inevitable part of everyone’s life and that they demonstrate our fallibility. He wrote, “But mistakes seem different for doctors. This has to do with the very nature of our work. A mistake in the intensive care unit, in the emergency room, in the surgery suite, or at the sickbed is different from a mistake on the dock or at the typewriter. A doctor’s miscalculation or oversight can prolong an illness, or cause a permanent disability, or kill a patient. Few other mistakes are more costly.” He continued,

We are not prepared for our mistakes, and we don’t know how to cope with them when they occur. . . . Doctors are not alone in harboring expectations of perfection. Patients, too, expect doctors to be perfect. . . . But the degree of perfection expected by patients is no doubt also a result of what we doctors have come to believe about ourselves, or better, have tried to convince ourselves about ourselves. . . . Unable to admit our mistakes, we physicians are cut off from healing. We cannot ask for forgiveness, and we get none. We are thwarted, stunted; we do not grow.⁴⁷

Hilfiker’s view, that we can grow after and in response to such experiences, is an important expectation that may be hidden to most of us. We might want to keep this in the back of our mind, available for a later “archeological dig.”

When careproviders feel this kind of shame, they need to be with others.⁴⁸ We can be these

others for colleagues, and, when we need to be with our colleagues, we should seek them out.

CONCLUSION

COVID-19 has raised many new challenges. This article earmarks a few. First is the need for triage to be fair and transparent enough to enable patients to accept it, even when they don’t “win” and receive a scarce resource, as they may in a weighted lottery. Second, given the agony that family members feel when they are isolated due to COVID-19, we may do more to respect their feelings in numerous contexts. Third, careproviders need others when they experience shame. As suggested by Gawande, when we fear death more, we need to be with others more.⁴⁹

M.T. Anderson wrote a partial biography of the Russian composer Dimitri Shostokovich, set during the Siege of Leningrad by the Army Group North of Nazi Germany, from September 1941 to January 1944. Throughout his life, the composer wrestled with his own beliefs and fears, which were in conflict with those of Russian society. Anderson wrote that Shostokovich’s life was a “tale of a utopian dream turned into a dystopian nightmare.” The author states that the biography is a story of how music “coaxes us to endure unthinkable tragedy.” He noted, “It can still comfort your suffering, saying, ‘Whatever has befallen you—you are not alone.’”⁵⁰ COVID-19 has been and will continue to be an unthinkable tragedy. We must create this kind of comfort for each other.

NOTES

I wish to thank Norman Quist for his many insights when reviewing the manuscript for this article.

1. J.J. Fins and K.M. Prager, “The COVID-19 Crisis and Clinical Ethics in New York City,” in this issue of *The Journal of Clinical Ethics* volume 31, no. 3 (Fall 2020).

2. B.J. Huberman and D. Mukerjee et al, “Phases of a Pandemic Surge: The Experience of an Ethics Service in New York City during COVID-19,” in this issue of *The Journal of Clinical Ethics* volume 31, no. 3 (Fall 2020). See also N. Polzin-Rosenberg, “One Ventilator Too Few?” *Hastings Center Report* 48, no. 2 (2018): 3-4.

3. K.M. Prager and J.J. Fins, “Meeting the Challenge of COVID-19: The Response of Two Ethics Consultation Services in New York City,” in this issue of *The Journal of Clinical Ethics* volume 31, no. 3 (Fall 2020).

4. M. Haller et al., “A Model for Treating COVID-

19-related Guilt, Shame, and Moral Injury,” *Psychological Trauma* (18 June 2020), 10.1037/tra0000742, doi:10.1037/tra0000742. Such guilt and shame may be present for decades after the initial guilt or shame causing event. See also R. Wille, “The Shame of Existing,” *International Journal of Psychoanalysis* 95, no. 4 (August 2016): 695-717.

5. T. Shanafelt, J. Ripp, and M. Trockel, “Understanding and Addressing Sources of Anxiety Among Health Care Professionals During the COVID-19 Pandemic,” *Journal of the American Medical Association* (7 April 2020): 2020;10.1001/jama.2020.5893, doi:10.1001/jama.2020.5893.

6. Prager and Fins, “Meeting the Challenge of COVID-19,” see note 3 above.

7. A. Gawande, *Being Mortal: Medicine and What Matters in the End* (New York: Picador, 2014).

8. G. Kolata, “Who Gets the Covid-19 Vaccine First? Here’s One Idea,” *New York Times*, 23 July 2020, <https://www.nytimes.com/2020/07/23/health/coronavirus-vaccine-allocation.html?action=click&module=Top%20Stories&pgtype=Homepage>. My thanks to Jack Drescher for this reference.

9. J. Beigel et al., “Remdesivir for the Treatment of Covid-19—Preliminary Report,” *New England Journal of Medicine* (22 May 2020): DOI: 10.1056/NEJMoa2007764.

10. Kolata, “Who Gets the Covid-19 Vaccine First?” see note 8 above.

11. Additionally, truth-telling and transparency regarding the goals of disaster preparedness, the decision-making process, and the principles and values that support both are required to build and maintain trust and demonstrate respect for persons. V.B. Satkoske, D.A. Kappel, and M.A. DeVita, “Disaster Ethics: Shifting Priorities in an Unstable and Dangerous Environment,” *Critical Care Clinics* 35, no. 4 (2019): 717-25, 719, doi:10.1016/j.ccc.2019.06.006.

12. In 2008, a multidisciplinary committee compared two mass casualty triage systems, START (Simple Triage and Rapid Treatment) and SALT (Sort, Assess, Lifesaving Intervention, Treatment/Transport), in a field mass casualty simulation. For pragmatic reasons, the literature lacked studies that evaluated the application of these algorithms in an actual mass casualty intervention. SALT indicated that it may have a higher accuracy rate and a lower over-triage rate than START. S. Silvestri et al., “Comparison of START and SALT Triage Methodologies to Reference Standard Definitions and to a Field Mass Casualty Simulation,” *American Journal of Disaster Medicine* 12, no. 1 (2017): 27-8, doi:10.5055/ajdm.2017.025503-AJDM_Papa_170003.indd27.

13. “Patients have accepted the results, even when they lost in the lottery and ended up being denied the drug . . . I speculate that is because we are very transparent about the reason and the ethical framework that applies to everyone who comes into hospital, whether that is the hospital president or someone who is homeless. . . .” Satkoske, Kappel, and

DeVita, “Disaster Ethics: Shifting Priorities in an Unstable and Dangerous Environment,” see note 11 above, p. 722.

14. “Given the choice between a physician and an entomologist, the team would have chosen having the latter, because more lives could be saved by preventing mosquito proliferation than could be saved with antimalarial care.” *Ibid.*, 722.

15. P. Singer, “Ethics and Intuitions,” *Journal of Ethics* 9, no. 3-4 (2005): 331-52.

16. F.M. Kamm, “Moral Reasoning in a Pandemic: Three things we need to get right,” *Boston Review*, 6 July 2020, <http://bostonreview.net/philosophy-religion/f-m-kamm-moral-reasoning-pandemic>.

17. S. Fink, *Five Days at Memorial: Life and Death in a Storm-Ravaged Hospital* (New York: Crown, 2013), 206.

18. Peter Singer suggests we should also include more people who will need our present resources in the future. He calls this “temporal impartiality.” Singer, “Ethics and Intuitions,” see note 15 above. See also C.S. Wareham, “Partiality and Distributive Justice in African Bioethics,” *Theoretical Medicine and Bioethics* 38, no. 2 (2017):127-44, 130.

19. H. Schmidt, “Health Care Rationing and End of Life Decisions: Who and How?” Institute for Communitarian Policy Studies Webinar, 20 July 2020, <https://compassionandchoices.org/take-action/staying-stronger-together/health-care-rationing-and-end-of-life-decisions-who-and-how-hosted-by-arena-stage/>.

20. F. Germa, “Pandemics, Ebola, and the Family Doctor,” *Canadian Family Physician* 62, no. 3 (March 2016): 203-5, 204.

21. Among others, Singer has raised the question what we owe, if anything, to people who are born in the future. A critical and practical question that speaks to this is what we should do in regard to research. Singer, “Ethics and Intuitions,” see note 15 above.

22. Kolata, “Who Gets the Covid-19 Vaccine First?” see note 8 above.

23. P. Buekens et al., “A Call for Action for COVID-19 Surveillance and Research During Pregnancy,” *Lancet Global Health* 8, no. 7 (2020): e877-e878.

24. A.M. Owen, “Detecting awareness in the vegetative state,” *Science* 313, no. 5792 (8 September 2006): 1402; doi: 10.1126/science.1130197.

25. J.C. Bardin et al., “Dissociations between behavioural and functional magnetic resonance imaging-based evaluations of cognitive function after brain injury,” *Brain* 134 (2011): 76982.

26. J.J. Fins, “The Civil Right We Don’t Think About,” *New York Times*, 27 August 2017, <https://www.nytimes.com/2017/08/24/opinion/minimally-conscious-braincivil-rights.html>. See also E.G. Howe, “New Ways to Cut through Ethical Gordian Knots,” *The Journal of Clinical Ethics* 28, no. 4 (Winter 2017): 257-68, 260.

27. B. Weiser, “After the Virus Came, 22 Parents Moved into their Children’s Hospital,” *New York*

Times, 10 June 2020, <https://www.nytimes.com/2020/06/10/nyregion/coronavirus-children-hospital.html>. My thanks to Norman Quist for alerting me to this reference.

28. T. Metz, "Harmonizing Global Ethics in the Future: A Proposal to Add South and East to West," *Journal of Global Ethics* 10, no. 2 (2014): 146-55, 146.

29. *Ibid.*, 148.

30. *Ibid.*, 149, citing Desmond Tutu, D. Tutu, *No Future without Forgiveness* (New York: Random House, 1999), 35. Metz writes that, typically, one's own harmonious or friendly relationships are a matter of importance to people from Africa. Metz, "Harmonizing Global Ethics in the Future," see note 27 above, p. 149. He states, "The aim of this article has not been to convince the reader that a harmony-based ethic is most justified, only that it must not be ignored when theorizing about normative issues facing the world." (p. 153) This view is one that is held by many in the U.S. See, for example, A.L. Carse, "Justice within Intimate Spheres," *The Journal of Clinical Ethics* 4, no. 1 (April 1993): 68-71. This is also referred to as relational autonomy. See M.R. Hunt and C. Ells, "Partners Towards Autonomy: Risky Choices and Relational Autonomy in Rehabilitation Care," *Disability and Rehabilitation* 33, no. 11 (May 2011): 961-7, doi: 10.3109/09638288.2010.515703.

31. P. Zimmermann and N. Curtis, "COVID-19 in Children, Pregnancy and Neonates: A Review of Epidemiologic and Clinical Features," *Journal of Pediatric Infectious Diseases* 39, no. 6 (2020): 469-77.

32. A.E.P. Heazell et al., "Stillbirths: Economic and Psychosocial Consequences," *Lancet* 387, no. 10018 (2016): 604-16.

33. C. Kingdon, E. O'Donnell, J. Givens, and M. Turner, "The Role of Healthcare Professionals in Encouraging Parents to See and Hold Their Stillborn Baby: A Meta-Synthesis of Qualitative Studies," *PLoS One* 10, no. 7 (2015): e0130059.

34. V. Daugirdaite, O. van den Akker, and S. Purewal, "Posttraumatic Stress and Posttraumatic Stress Disorder after Termination of Pregnancy and Reproductive Loss: A Systematic Review," *Journal of Pregnancy* (5 February 2015).

35. A. Lathrop and L. VandeVusse, "Affirming Motherhood: Validation and Invalidation in Women's Perinatal Hospice Narratives," *Birth* 38 (2011): 256-65.

36. This question also involves a concern regarding justice. Parents who would take initiative to ask would likely be those who are more informed or assertive, and so not telling those who don't ask would discriminate against those parents who are less informed or assertive. Those who do not ask may, however, not ask to not risk having greater anxiety.

37. D.C. Wertz, J.C. Fletcher, and K. Berg, *Review of Ethical Issues in Medical Genetics* (Geneva, Switzerland: World Health Organization, 2003), 48, <https://apps.who.int/iris/handle/10665/68512>.

38. A jurisdiction may require a family to additionally consent to the donation after their loved one

has died. Since the family must agree in any case, it may make sense for donors and their family to meet and then all agree—or not. When this happens, should specificity be greater?

39. Some believe that, to respect all persons adequately, society should gain consent prior to using the body of an unidentified homeless person for any purpose after the person has died.

40. E.T. Paquette and L.F. Ross, "Abusive Head Trauma and Parental Participation in Pediatric Decision Making," *The Journal of Clinical Ethics* 31, no. 2 (Summer 2020): 121-5.

41. S.A. Rasmussen et al., "Coronavirus Disease 2019 (COVID-19) and Pregnancy: What Obstetricians Need to Know," *American Journal of Obstetrics and Gynecology* 222, no. 5 (2020): 415-26.

42. E.G. Blundon, R.E. Gallagher, and L.M. Ward, "Electrophysiological Evidence of Preserved Hearing at the End of Life," *Scientific Reports* 10, no. 1 (2020): 10336, <https://doi.org/10.1038/s41598-020-67234-9>. Thanks to Norman Quist for alerting me to this reference.

43. One patient who had been in a transient locked-in state, for example, shared his irritation that, as he was listening to a sports event on television, a careprovider turned his television off when the score was still tied! He said too that he hated it when music was played that he abhorred, and later pleaded with careproviders that, in the future, they ask patients' family members what kind of music the patients liked. Some patients greatly fear that they will be awake enough during surgery to feel pain, but not awake enough to indicate it. They may refuse future surgery that they need for this reason.

44. Haller et al., "A Model for Treating COVID-19-related Guilt," see note 4 above.

45. A. McAninch, "Moral Distress, Moral Injury, and Moral Luck," *American Journal of Bioethics* 16, no. 12 (2016): 29-31, doi:10.1080/15265161.2016.1239790. See also B. Williams, *Moral Luck* (New York, N.Y.: Cambridge University Press, 1982), 27-8.

46. R. Karen, "Shame," *Atlantic Monthly*, February 1992, 40-70, 40.

47. D. Hilfiker, "Facing Our Mistakes," *New England Journal of Medicine* 310 (12 January 1984): 118-22, https://physicians.index.org/wp-content/uploads/2015/02/Hilfiker-Facing_Our_Mistakes-4-3-2013.pdf.

48. K.J. Van Vliet, "The Role of Attributions in the Process of Overcoming Shame: A Qualitative Analysis," *Psychology and Psychotherapy: Theory, Research and Practice* 82 (2009): 137-52.

49. K.M. Fitzpatrick, C. Harris, and G. Drawve, "Living in the Midst of Fear: Depressive Symptomatology among US Adults during the COVID-19 Pandemic," *Anxiety and Depression Association of America* (April 2020, revised 1 July 2020).

50. M.T. Anderson, *Symphony for the City of the Dead: Dmitri Shostakovich and the Siege of Leningrad* (Somerville, Mass.: Candlewick Press, 2015), 7. See also A.B. Ho and D. Feofanov, *Shostakovich Reconsidered* (London: Toccata Press, 2006).