

of communication, there is at least one new question that we have learned to ask at the end of a family meeting: “Do you want the chance to talk with him by phone or video?” In the past, we assumed families would come to see their loved ones. Or they wouldn’t. Either way, visits from family members were largely a realm of connection independent of us as clinicians. In the era of Covid-19, we become the mediators of this private interaction as well.

Mr. B’s family specifically asked us to connect to him by phone and not video. It was their voices that they hoped would have power: His wife wondered if hearing his family might help his recovery. “We’re hopeful for sparks,” she said.

They told us that he wouldn’t want them to see him “like this.” That was a visual wall they didn’t want to breach. Like our phone calls to families, this interaction would not have eye contact.

We connected his wife, son, and daughter by speakerphone, and the intern held it near his ear. The family could not see his room, his nasogastric

tube, his oxygen cannula, his intravenous lines. And he could not see his family. All we had were words.

“I know we had our days, but I love you, Dad. I do.” His son talked about how his dad taught him to be a father and a husband. There were silences between some of the son’s sentences, and I found myself wondering whether these were pauses or moments of crying. And I will never know.

“You came back from Vietnam without a scratch,” his wife said. “You can do this.” She ended with loud crying, which began suddenly and ended just as suddenly.

His daughter talked about how they were going to move him to Florida after he got home: “no more shoveling snow. . . . You’ve done enough of that.”

And finally, his wife said, “He’s ours now, but he’s God’s child.” This was as close to a recognition that Mr. B might die as his family could have at that moment.

All this took place over only five minutes. But I was struck by how open and intense this felt. Despite the fact

that we had never met this family and don’t even know what they look like, we were part of an intimate moment that we would rarely see in the past.

Both these versions of family connections—between families and clinicians and between families and patients—are now entirely digital. Stripped of their usual physicality, they have become all about words and pauses, talking and listening. As clinical communication, they run the risk of being disembodied and poor substitutes for our previous in-person interactions. But they are also intensely intimate moments that we have become a necessary part of. They force us to break through walls, to be even more present for our families and patients, and they allow us to bear witness to the strength and sadness and love that we might otherwise miss.

Acknowledgment

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Dying during Covid-19

by Bryanna Moore

Ma’am, I assure you I am not calling to try to convince you to ‘give up’ on your daughter and let the doctors ‘kill her.’ I’m not trying to push you to make any decisions. I reached out to you to try to gain some insight into what Madeleine¹ would say she wants to do, if she could speak to us right now.” I was on the phone with Madeleine’s mother. Madeleine was twenty-four years old. She had been an engineer. Now she was a cancer patient. Madeleine had end-stage acute myeloid leukemia and was intubated in one of our intensive care units (ICUs). She was dying. Her intensivist had re-

quested a clinical ethics consultation for potentially inappropriate medical treatment—in the world of clinical ethicists, routine stuff. Except that, in March 2020, nothing was routine anymore.

I had been on the phone with Madeleine’s mother for fifteen minutes, and she had sobbed throughout. Even through the phone, I could hear her splintering. She pleaded with me, “You won’t even let our family visit her together. If you really want to help my daughter, you will let us stay with her. Can’t you do anything? Don’t you have anything to say?” I was lost for words.

Should she, Madeleine’s father, and the rest of Madeleine’s loved ones have been able to visit her? Absolutely. Should we have lifted the strict Covid-19-related visitation policies? Absolutely not. I mumbled a feeble reply about passing along her request to the unit manager. Madeleine’s mother snorted. We both knew what the unit manager’s response would be.

I am confident that, in normal circumstances, Madeleine’s family’s bereavement would have been what experts call “complicated grief,” or persistent complex bereavement disorder. Now I fear it will be unbearable. This

is true of individuals and communities around the globe who know someone who is dying or has died during the Covid-19 pandemic. People are being prevented from attending funerals, crying together, and holding each other in a time where being able to do so feels more essential than ever. We are grieving in isolation—something that comes close to an oxymoron in many cultures, where mourning is a shared, social practice. A spike in Covid-19-related prolonged and complicated grief is itself a potential public health crisis. On the impact of the 1918 influenza pandemic, Nancy Bristow writes, “Though the country moved on, and expected the epidemic’s victims to move on as well, countless Americans continued to suffer their losses and their grief in the decades that followed, a reality likely made worse by their culture’s failure to acknowledge it” (see “It’s as Bad as Anything Can Be: Patients, Identity, and the Influenza Pandemic,” published in 2010 in *Public Health Reports*). The need for timely access to mental health services has rarely been more pressing.

The Covid-19 pandemic is therefore an opportunity to think creatively about ad hoc and post hoc bereavement efforts. In a 2004 *Palliative Medicine* article, Ian Yi-Onn Leong and colleagues note that bereavement and traditional mourning rituals were similarly truncated during previous epidemics. As discussed in the NPR story “Alternative Mourning Rituals Offer Comfort and Closure during an Outbreak,” in the wake of the Ebola crisis, a group of psychologists and counselors in the Dominican Republic of Congo developed an alternative burial program that helps families to find closure. There are lessons to be learned from their program, which has three steps: first, mourning family members gather at a place of their choosing, where counselors then introduce the program and give people the opportunity to ask questions about the virus and the death of their loved one. Second, as a substitute for the dances and songs that are traditionally part of burial parties, families come together

to share stories about the deceased, using photographs, prayer, music, and letters. Third, families are invited to create a living memorial where people can mourn and remember by picking a different yet special place for planting flowers and trees—a culturally crucial part of burials. During the Covid-19 pandemic, people are now live-streaming funerals; physicians and chaplains report using speaker and video chat functions to allow families to say goodbye to their critically ill loved ones and to deliver patients their last rites—the first wave of a new era of “e-mourning.” Short-term and sustained changes to mourning practices, meaning making at the end of life, is one way in which the pandemic may impact how we think about what it means to have a good experience with death.

The pandemic is also directly affecting patients themselves. Being provided with consistent, compassionate, culturally sensitive, and well-coordinated end-of-life care is often understood as part of a good death. Yet during much of this pandemic, health care practitioners have not been able to help facilitate a good death, so conceived. Physicians in epicenters such as New York and Italy report facing away from patients during consultations. Others have reported that the simple act of holding a patient’s hand and accompanying them in their final moments has become an ethical and logistical nightmare.

The pandemic has constrained the ability of palliative care physicians, chaplains, and social workers to do their work and is disrupting the timely transfer of patients to hospice care.

As Madeleine’s family spent very little time with her, their perception of her pain was very different from the clinical care team’s. The team felt that Madeleine’s pain could be better managed, but her family expressed some disbelief over the seriousness of her condition—it was hard for them to accept her terminal diagnosis with so little face-to-face contact. They expressed a desire to see her, but they had no choice or control over whether and how they could do so. Her family was given little time or space to say their

goodbyes. Madeleine’s family struggled to understand why their daughter’s experience should be affected by a condition that she didn’t have. This stonewalled decision-making.

Madeleine herself had no opportunity to participate in end-of-life planning, but even if she had, many of her wishes probably could not have been realized, given the contingency conditions in place. While some patients lack the cognitive awareness to appreciate these changes, others may experience serious and prolonged suffering because of them. Having adequate pain management, being accompanied at the time of death, exercising choice over the location and other circumstances, being able to determine who will be present, having time and space to say one’s goodbyes, not feeling like a burden, and leaving behind a meaningful legacy are also commonly identified features of a good death. Realizing these features of good end-of-life care can pose a challenge in the best of times; against a backdrop of inundated ICUs and makeshift morgues on the streets, the notion of a good death, so conceived, has seemed almost impossible.

These changes may result in efforts to revise existing accounts of what constitutes a good death in order to accommodate patients’ and families’ experiences at the end of life during a pandemic. The primary motivation for changing how we think about a good death in times of crisis is a psychological one—accepting that many, many people die a “bad” death during such times is a hard pill to swallow. Alternately, this experience may cement existing accounts of what constitutes a good death. This could result in increased recognition of the importance of good end-of-life care and bereavement support, which have been shown to aid grief processes and familial acceptance. In addition to normalizing unconventional ways of mourning, in the wake of the Covid-19 pandemic, we may see expansions to palliative care, chaplain, and social work services and a newfound awareness and appreciation of

opportunities to plan for and shape our experiences of dying.

Ultimately, Madeleine wasn't alone at the time of her death. When her physicians determined that Madeleine's death was imminent, her mother and father were allowed to stay with her.

I can imagine commentators saying something seemingly poignant like, "In the end, we all die alone." That may well be true. I don't really care. Because the modality of our dying matters to those who survive us. Is a good death

something we can recreate, or recapture, after the fact? Only time will tell.

1. The patient's name and some other details about the case have been changed to protect confidentiality.

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The Hang Up

by Laura Specker Sullivan

The call that March morning came like any other. A page from someone working in the medical intensive care unit (MICU), wanting to speak with a clinical ethicist about a problem he had. The page had just a name and a phone number, but the initial details are usually sparse.

Over time, I've gotten used to the uncertainty of making these calls—unless the name is familiar to me, I don't know the age, gender, or position of the person I'm calling or which of the seemingly endless lists of ethical questions I might encounter. Sometimes, the call is quick and relatively easy, and I'm relieved; sometimes, the call occupies my entire day.

As the ethicist on call, I needed to get back to the caller promptly—within fifteen minutes is what we tell people to expect. The first time I called the number, it rang and rang. Odd, I thought, to get a page from someone who wasn't now next to the phone. I waited five minutes and tried again. This time I reached someone.

"Hi, this is Laura with ethics," I said. "What can I help you with?"

"I've never called ethics before," the caller answered, identifying himself as a resident. "So I'm not quite sure how to do this."

"No problem. Tell me about the situation, and I'll help as best I can."

The resident proceeded to describe the patient. He had end-stage renal disease and heart failure and had been admitted to the hospital multiple times

over the past year for missing hemodialysis. He often comes to the emergency department after using cocaine and experiencing shortness of breath and is admitted to the MICU for hemodialysis.

The situation is familiar to me. Over the past year, our ethics service has had numerous consultations involving patients who use the ED for regular dialysis. Sometimes, they have access to outpatient hemodialysis that they forgo; other times, they've been "fired" from this kind of outpatient facility, and so the ED is their last option. In most of these cases, we're called because the patient is disruptive once admitted to the ICU and behavior plans haven't helped. One patient would hurl bodily fluids and catheters at clinicians; another punched a nurse in the face. In these cases, I can't help but feel that ethics is called as a last resort—the team has nowhere else to turn.

According to the Emergency Medical Treatment and Labor Act, these patients must be treated when they arrive in acute distress, even though they would be fine had they been attending their hemodialysis appointments regularly or following the plan laid out for them by their doctors. They're often described as "noncompliant," although ethicists have argued that we should not use this term. It's easy to blame these patients for their condition, especially when they're abusive to members of the hospital staff. The solution seems so simple—the patients could just go

to an outpatient hemodialysis facility regularly. Clinicians often suspect that patients come to the ED hoping to be admitted, knowing that they'll receive a bed and a hot meal.

"Has the patient been disruptive?" I asked, assuming this case would resemble those that had come before it. "Is there an issue when he's in the MICU?"

"No, he's not disruptive," the resident replied. "It's just that he comes in after using cocaine, and given scarcity with the coronavirus and ICU beds . . ." He didn't finish, but I could imagine what would come next: it seems like a waste of resources. Why help this man, who is sick of his own accord, and is taking up a hospital bed and clinician time, when we're anticipating a surge of Covid-19 patients in the coming weeks?

I took a moment to reply, somewhat taken aback. With disruptive patients, it's relatively easy to understand clinician distress, but this was just a normal patient with an addiction. Yes, he'll keep coming back and using hospital resources. So do all patients with chronic conditions that are difficult to treat, especially in the context of trying socioeconomic factors—such as the cost of transportation, the inconvenient location of many health care facilities, and the shortage of jobs—that make access to regular care challenging. That doesn't mean he doesn't deserve our care or our resources.

"I know it's frustrating to have someone keep coming back for the same thing," I said, "but if he's coming to the ED in acute distress, we have to treat him."

I wasn't sure what else to say. All my other consults about hemodialysis patients coming to the ED had been