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Not Dying Alone — Modern Compassionate Care in the Covid-19 Pandemic

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r. Wakam: I'm 5 hours into my ICU shift at a community hospital in Detroit when the results of another arterial blood gas return. My patient has been hospitalized for 3 days and is Covid-19—positive. Over the past 12

hours, his treatment has progressed from intubation, to prone positioning on 100% fractional inspired oxygen, to medically induced paralysis, and finally to bilevel ventilation. The results from the arterial blood gas are dismal: pH 7.19, pCO, 70.1, pO, 63.7, HCO, 26.0. He has already experienced episodes of profound hypoxia when we try to rotate him into a supine position, and his heart has begun to show signs of strain, with periods of atrial fibrillation with rapid ventricular response and nonsustained runs of ventricular tachycardia. A request to transfer the patient for extracorporeal membrane oxygenation (ECMO) is denied. It's 11 p.m., and I'm worried that my patient won't survive until morning.

I call the patient's wife to inform her about her husband's trajectory. The conversation makes her feel overwhelmed and helpless. She asks to come into the hospital to be with her husband, or at least see him through the door to his room. Unfortunately, I am told by the unit charge nurse that hospital policy permits no visitors for patients who have tested positive or are under investigation for Covid-19.

The fear of dying alone is nearly universal — a fact of which anyone who's taken care of a critically ill patient is acutely aware. So we sometimes go to great lengths to give patients just a little more time for family members to arrive and say their goodbyes. One aspect of the Covid-19 pandemic that has been particularly difficult is that instead of our usual promise that "We'll do everything we can to keep him alive until you get here," we find

ourselves telling families, "Because of hospital policy, we cannot allow visitors at this time." This conversation sometimes takes place at the doors to the ICU, over the phone, or in front of the hospital, as families beg to see their loved ones before they die. A seemingly simple request, which in other times would be encouraged, has become an ethical and health care dilemma.

It is 12 a.m., and I try to advocate for the wife with the nursing managers. To complicate matters, the wife admits that although she hasn't had any fever or cough, she has had a headache and a sore throat. With no clear policy in place for family members with symptoms, we call the hospital administrator at home, and he answers immediately: "No." Then there's a long back and forth about "extenuating circumstances" criteria, which allow a single visitor to come to the hospital. But since the wife could possibly have symptoms and has not been tested for Covid-19, the administrator decides she cannot visit. I telephone the wife and relay the final decision, and she rapidly cycles through stages of grief. Her initial anger and threats of a lawsuit quickly give way to pleading and bargaining — "What if I only spent 5 minutes and left?"

The problem is multifaceted. In many cases, family members have already spent time in close contact with the patient, which means they're reasonably likely to be infected with SARS-CoV-2 themselves. Moreover, there is a shortage of personal protective equipment (PPE), and using some on family members means consuming more of a scarce resource. And if the family members are currently uninfected, a visit to a ward full of patients with Covid-19 risks infecting people who lack proper training in PPE use.

This dilemma has led to some creative workarounds: nurses may hold the bedside phone up to the patient's ear or bring their personal smartphone into the room and hold it up while using Skype, WhatsApp, or FaceTime. But many nurses, owing to concern about HIPAA privacy rules, a heavy workload, or poor connectivity can't offer such communication with family. And even if a call does take place, families may be left feeling like they didn't get to say goodbye properly - and we are left feeling like there must be a better way.

My patient's wife arrives at the emergency department at 1:30 a.m., despite having been told she would not be allowed to see her husband. I go to meet her, and we discuss her husband's

continued decline. Unfortunately, in the middle of the conversation, a Code Blue rings from the overhead speaker for a patient in the ICU. I step away and find myself entering her husband's room, where CPR is already in progress.

After 90 minutes of CPR, epinephrine, and defibrillations, my patient still has not regained a sustained pulse. I somberly call time of death. One of the nurses in the hallway has been in contact with the wife throughout the process and has informed her of the death; she now has the wife on FaceTime so that she can see her husband. When she recognizes him in the distorted image, she lets out a wail of sorrow. She is in the midst of her final goodbyes when I have to excuse myself from the room: another patient with Covid-19 is deteriorating a few rooms over.

We, as residents, have spent much of our time these past few weeks in community ICUs around Detroit, one of the epicenters of Covid-19 in the United States, and have all experienced similar scenarios. We have witnessed more death in the past 3 weeks than in all our previous years combined. Unfortunately, similar stories are becoming more common and represent uncharted territory for many of us, as we try to maintain our humanity and patient-centeredness while managing these difficult situations.

We believe that the U.S. health care system can do better. As telehealth and virtual meetings become the new normal, so can telecommunication between isolated patients and their families. Perhaps setting up a tablet com-

puter facing the patient or repurposing a workstation on wheels logged in to a video chat would be a solution. Recently, some guidance has become available regarding difficult but necessary conversations related to Covid-19 and ways of bridging the physical distance we must maintain during the pandemic.1,2 Such efforts may not represent the evidence-based medicine we all strive to practice, but they capture some of the art of caring not just for patients, but also for their families and friends. National guidance would be beneficial, since existing Covid-19 management resources fall short. There may be no way for families to hold patients' hands or hug them while they're dying, but with the care and compassion of frontline health care workers, maybe we can harness creative solutions to help them feel some connection, while still keeping everyone safe.

Identifying details have been changed to protect the family's privacy.

Disclosure forms provided by the authors are available at NEJM.org.

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- 1. VitalTalk. COVID ready communication playbook (https://www.vitaltalk.org/guides/covid-19-communication-skills/).
- 2. Hollander JE, Carr BG. Virtually perfect? Telemedicine for Covid-19. N Engl J Med. DOI: 10.1056/NEJMp2003539.

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