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Before it is over: A family's experience with end-of-life care during COVID-related restrictive visitation policies

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Abstract

It is not uncommon in the American medical community that a personal narrative sparks a conversation about a controversial topic. In 1988 the Journal of American Medical Association published a narrative by a medical doctor which provoked a debate on euthanasia within the readership of the journal and the greater public. The testimony that I am presenting aims to invite a public dialogue on the harmful effects of restrictive visitation policies brought on by the COVID-19 pandemic. The story of my family's experience during the end-of-life care for my mother, a COVID patient, illustrates how urgent is the need to rethink the restrictive visitation policies so as to protect patients from unnecessary suffering. In order to battle pandemic-related stress and fatigue medical staff and families must work together to improve patient care.

Keywords

Family experience, end-of-life care, restrictive visitation policies, COVID-19

In 1988, the Journal of the American Medical Association (JAMA) published in its column "A Piece of My Mind" an anonymous piece by a medical doctor describing how they conducted an act of euthanasia consented to by the mother of a 20-year-old patient. Taking the form of personal testimony, the article "It's Over, Debbie" tells a story, possibly fictional, of a physician making a personal decision to kill his patient so as to relieve her of suffering caused by a terminal painful illness.¹ As the story has it, a gynecological resident had responded to a midnight call to help a patient who, as reported by her nurse, "was having difficulty getting rest." Although the doctor "had come to detest telephone calls, because invariably, I would be up for several hours and would not feel good the next day," they answered the call. Subsequently, the tired resident made it over to the patient's room wherein lay a twenty-year-old patient, obviously in pain, with her mother by the bedside. The patient addressed the doctor with the words, "Let's get this over with." After what seemed like a brief episode of decision-making at the nurses' station, the doctor reasoned that "I could not give her health, but I could give her rest," and administered a dose of morphine sulfate causing an apparently peaceful death of the patient, her mother still by her side.

Void of complex ethical deliberations, reviews of bioethical and legal literature or input from colleagues or an ethics committee, the article offers insight into a possible thought process of a tired night-shift doctor responding to a call regarding a distressed patient. The simplicity of the decision-making process is striking and largely centered on the sense of exhaustion of both the doctor and the patient. The only present family member,

the patient's mother, in this story figures as a speechless witness to her daughter's suffering and the supportive companion to her death who "stroked the hair of the now-sleeping patient."

The story brought on an avalanche of responses to the journal from the medical community and the public. Physicians, ethicists, leaders of medical associations, as well as terminally ill patients and their family members reacted to the account of the tired resident who stumbled half-asleep into one of the most important decisions of his professional life. JAMA's editor reported receiving over one hundred and fifty letters in response to the narrative.² The responses ranged from the demands for justice for the dead patient and polite invitations for a continued discussion on the contested issue of euthanasia in American medicine and culture, to opinions that explicitly took sides (for or against) in the euthanasia debate.³

I did not participate in this debate. I came across the article decades after the debate in JAMA had subsided, when I was a doctoral student of rehabilitation counseling and disability studies with an interest in disability bioethics. In my reading, the article gave an insight into what may have constituted good reasons for euthanasia in the eyes of a doctor who did not, for whatever reason, follow the ethical standards and end-of-life protocols prescribed by his profession. For me, this short story was a window into a physician's reasoning on the much-debated problem of euthanasia. I read this account almost exclusively as an early example of what would become in the 1990s in the US a robust public polemic on physician-assisted suicide and euthanasia.

The personal story that follows offers a simplified non-fictional account of the management of the end-of-life care of a COVID-19 patient—my mother—in the time of the pandemic-related restrictions on visitation. My hope is that, as was the case with the 1988 article, this brief personal account offers a starting point for a much-needed public conversation about the limits of restrictive visitation policies and the need for families and medical staff to work together, instead of apart or at odds, during a pandemic.

In the hospital where my mother was admitted for COVID pneumonia, the visitation policy for COVID patients allowed for two family members to visit with the patient one time only for 30 minutes in full Personal Protective Equipment (PPE). The conditions for the visit were that the patient and/or the family have consented to DNI/DNR code status, and that the comfort measures have commenced prior to the visit. In other words, in order to visit with my ill mother, I and/or she would have had to have consented to end-of-life care, and comfort measures must have commenced prior to the visit.

After speaking to my mother over Facetime, we both agreed to the DNI/DNR code status but refused to consent to comfort measures. In subsequent conversations with her hospitalist and her palliative care doctor via telephone, I reiterated the decision not to endorse the comfort measures without visiting with my mother first. I explained that our family needed to see her in person and speak with her in person in order to make this important decision which would involve removing her breathing support (bipap). Consequently, a visit was provisionally allowed for the following day, but, in compliance with the hospital's policy, only two members of our family could attend. 'Who should get a chance to see grandma, possibly for the last time?,' my children wondered.

We are a family of four, a family in which my mother and I have been parenting my two children together for two decades. My mother attended the birth of her grandchildren, she stayed home with them when they were ill, she attended their graduations, and helped with their homework. Every summer we took vacations together. As with many people, for my children, their grandma was an integral part of every aspect of their life. Like many retired people, my mother had put most of her energy into supporting the lives of her grandchildren. Under the pressure of the two-visitors-only policy, we begin to ask ludicrous questions like, 'Did she love one of them more?'; 'Did one of them love her more than the other?'; and 'Should neither of them go?' After agonizing about the decision for several hours, we got in touch with the doctors and asked them to have a hospital administrator decide which grandchild should attend the visit. The decision was not ours to make, we asserted.

The call for the approved visit came mid-morning. In the absence of the decision from the hospital administration about which grandchild would be allowed to attend, all three of us rushed to the hospital for our half-hour visit. We enjoyed our time together with mom. After the visit, I agreed for the comfort measures to commence and for the referral to hospice to be made. Later that day we made our way into her room again for an assessment by a hospice nurse. The assessment concluded that mom was unstable for transport to the local hospice in-patient facility, and we agreed that she would stay in the hospital. Soon after the assessment was completed and the hospice intake nurse left, the floor nurse educated us about the medicine regimen. The pattern would be an hourly comfort medication administration, whose dosing would vary depending on my mother's behaviors, that is, on how obvious it was that she was in pain or anxious. We wondered why one would wait for the call for comfort of a thirsty and air-hungry person in order to administer the comforting medicine, in the conditions when both the patient and the family have consented to the end-of-life care. 'Could she not be provided continuous comfort?,' I asked. Both the nurse and the clinical supervisor responded that the hospital's end-of-life-care policy calls only for providing patients with comfort through the process of natural death, which is achieved through a careful titration of appropriate drugs. The policy, they reiterated, does not allow the patients to be killed by high doses of medicine. Although they did not answer my question, I understood that the policy was protecting the patients from involuntary or voluntary euthanasia, like the one the tired resident described in the 1988 article. So, we agreed to the presented plan: to carefully titrate the medicine in order to achieve optimal comfort. In essence, this treatment approach reflected our family's values. But what followed did not evolve according to this plan.

Since no one asked us to leave after the hospice assessment was completed, we stayed in mom's hospital room overnight. To avoid being asked to leave, not one of us left the room for the remainder of the night; we did not drink or eat, and we used the bathroom adjacent to her room. We intended to be as quiet and unnoticeable as possible. The desire to be with our beloved family member trumped the sense of hunger, thirst, and sleepiness.

But our intent not to be discovered was in vain: this entire night and the following morning, my mother's comfort completely depended on our advocacy. The palliative care doctor and the nurses assigned to mom's care could not provide the appropriate comfort care without our assistance. We were the ones to notice that her IV ruptured twice, diminishing the delivery of comforting medicine and causing her great distress. We were the ones to call on the nurse to administer comfort medicine at the very first sign of my mother's discomfort, which had been progressively coming on sooner than the one-hour mark.

Finally, it was our advocacy that brought on a much-needed substantial increase of the dose after hours of high respiration rate that made my mother rather uncomfortable.

In order to accomplish the escalation in the dose, or perhaps more accurately, to ensure the proper titration of the medication for this patient, I demanded to see her palliative care doctor several times. After putting in the request, mom's nurse relayed the doctor's response to me: he was too busy with other patients and could not see me right away but would come by as soon as he could. An hour or so after my initial demand, the doctor phoned in. I was angry but managed to explain in great detail my mother's distress caused by the high respiration rate. Soon after our conversation, the doctor ordered that the titration time be shortened and he approved a larger dose of morphine. Simply put, if not for the family who ended up staying by her side much longer than the allowed visitation policy, my mother would have suffered greatly.

By the morning, probably due to the fierce advocacy regarding the escalation of the dose, our uninvited and unapproved stay by mom's bedside was clearly noticed by the nursing staff. At the start of the morning shift, I was summoned for a talk with the clinical supervisor who noted that we overstayed the visit and thus should leave soon. Due to the nature of her needs, mom too had to leave the floor, she added. The palliative care physician stopped by the room so I could sign discharge paperwork. At that time, he acknowledged and apologized for the delays in treatment caused by his being busy with other patients. As we were getting ready to leave the hospital, I could feel the nurses anticipate the relief that would come with our departure.

With much help from the hospice care staff, a transport was arranged swiftly. Now in a markedly less stable state than the day before, mom was moved to the hospice facility a few miles away from the hospital. By the time she was settled in the new facility and we reconnected with her there, my two children and I had not slept for over 40 hours. Like the doctor, the nurses, and my mother, we too were exhausted.

The restrictions in the hospice care facility required that we only visit with mom two at a time. The visitation hours were unlimited so we could take turns regularly, but sleeping in the room was forbidden to ensure that the PPE was worn by the visitors at all times. Mom spent the next day in no apparent discomfort with us by her side. As we took turns being with her, each of us caught up on sleep a bit. She passed away free of pain.

During the long hours filled with fear for the loved one's suffering and in between the bouts of assertive patient advocacy, I found myself thinking a lot about the article

"It's Over, Debbie." Although I have read it many times and have sometimes used it as a case study in my teaching, for the first time I appreciated the simplicity with which it foregrounded the role of exhaustion of patients, medical staff, and family members in the ethical decision-making processes and quality of patient care. Although exhaustion must not stop us from demanding the best quality of care for ourselves and our loved ones and should never serve as an excuse for hastily carrying out euthanasia, it should be recognized as an important factor in the process of patient care.

Undoubtedly, COVID-19 has made us all very tired and in need of rest. Visitation restrictions only make us all weaker in the face of pandemic-related fatigue. I see my mother's unnecessary suffering (even with our advocacy in place) as a result of labor shortages, overworking of staff, and compassion fatigue in otherwise competent and empathic nurses and doctors—all conditions common in the medical occupations but exacerbated by this pandemic. It is likely that the lax enforcement of visitation rules was also a result of the exhaustion of the floor nurses who cared for many critical patients while also worrying about their own personal health and safety. At the time when exhaustion is a common feeling in the body and the mind, we must rely on each other in order to find even a bit of the much-needed reprieve. Removing the visitation restrictions may be a good first step towards a better collective response to the challenges that the pandemic has put on end-of-life care.

In the absence of ethical deliberations, ethical consults, and legal analysis, it seems clear that no rest or comfort can come with restrictive visitation policies. Unlike the family member in the 1988 article, a passive witness to her daughter's suffering (perhaps an image of a next-of-kin's behavior desired by overtired residents on busy night shifts), many family members are active participants in end-of-life care of their loved ones. And, like the exhausted doctor who gets to make a split-second decision about what they think is the best care for his patient, family members can make decisions about the care of their loved ones. Even when exhausted, they are fierce advocates for the patient. When it is almost over, both comfort-seeking patients and tired doctors and nurses need the continuous presence of patients' families by the bedside.

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