

Losing Contact — Covid-19, Telemedicine, and the Patient–Provider Relationship

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February 2020 marked the end of young J.'s 7-year journey with a rare cancer that started at the age of 17 months. Over that time, his medical team had learned to anticipate his dad's thoughtful pauses as he absorbed information. We could predict when the need to advocate for her son would bring out the "dragon mom" in his kind mother.^{1,2} We witnessed our patient growing into an intelligent boy who loved monster trucks and had an engineer's mind like his father's. J.'s little brother was precocious and outgoing — which, in the end, made him well suited to delivering a eulogy. Their sister grew up in the hospital; as a toddler, she'd developed an obsession with hand sanitizer, having no idea that the rest of the world would soon follow suit.

Although the family's primary residence was not in Massachusetts, where we live and work, we were J.'s health care team, managing care in person or by phone regardless of the family's physical location. Had J. lived a bit longer, our remote interactions would have been enhanced by the telemedicine revolution incited by Covid. As his death approached and J. and his family remained in Boston, our long-term relationship allowed us to sensitively read the body language that conveyed emotion beyond words.

During J.'s final days of life,

we visited him and his family at his bedside. We sat on his bed, discussed death and fear, and wept together as J.'s parents asked the hardest questions of all: How will we know when he is gone from his body? Should we keep his favorite lion stuffy for our family or bury it with him?

J. died a few days after our visit and was mourned in one of the last in-person funerals of 2020. As they were hit by overwhelming grief, his family's life froze. Coincidentally, the entire world froze too.

The Covid pandemic brought dramatic changes to interactions between health care workers and patients. In the hospital, bustling energy was replaced by an eerie silence, borne of staff absences, visitor restrictions, and masked faces. Social distancing in waiting rooms precluded the sharing of experiences and empathy among patients and families. In the empty pediatric playroom, soundproof walls were no longer needed. Although the outside world is now returning to a time of full facial expressions and hugs, in the hospital those days may be gone forever. Hospitals' infection-control efforts during Covid — though necessary and additionally beneficial in reducing transmission of other infectious diseases — deeply affect the relationships between medical staff and patients. It is human to console patients and families,

holding their hands or offering hugs, especially when a long-time patient is dying. Personal protective equipment (PPE) limits nonverbal communication to eye contact alone.

Despite the upheavals in clinical settings, however, the pressures of Covid did result in some unanticipated positive changes. Widespread adoption of telemedicine allowed us to reach patients in the comfort of their own homes, reducing the financial impact of care for both patients and hospitals, easing travel burdens during periods of immense stress, enabling family members to participate in visits more easily, and reducing carbon emissions. It also geographically broadened access to expert care and reduced disparities in care that are intrinsic to our system — particularly benefiting patients who live in underresourced areas far from high-volume centers of excellence that are crucial for the treatment of rare diseases such as childhood cancers.

During the pandemic, with regulations allowing providers to see out-of-state patients virtually, patients could seek specialty care and meet new health care teams without traveling long distances.³ Families could then make informed choices about whether subsequent transfer of care or travel out of state was appropriate and possible in light of their loved one's diagnosis and circum-



stances, secure in the knowledge that all possible options had been explored. But instead of embracing the rapid growth of telemedicine as a benefit of the pandemic, states have, one by one, reinstated restrictions on providing telehealth care across state lines, thereby prohibiting its use for many of the patients who need it most.³

Through small computer cameras, telemedicine allows us to see each other's full facial expressions without risk of transferring infection, so we gather more emotional information than we could in an in-person encounter requiring PPE. We get glimpses of patients' lives — their pets, their art, their music, all the things outside their illness that make them who they are. Beyond permitting additional insight for the medical team, patients' ability to remain in their home environment may alleviate their anxiety, improve their comprehension of information, and increase their comfort with asking questions. Young patients may play in their rooms, and their parents can decide when it's appropriate to

draw them into conversation.

So it seems cruel that state-licensing restrictions are now being enforced more aggressively than ever, catching both clinicians and patients off guard. After many months of conducting televisits with our out-of-state patients, we are being told we cannot return phone calls to give medical advice to these patients, let alone conduct virtual visits with them. Such interactions are now considered “practicing medicine without a license,” and even if clinicians are not reimbursed for them, they open practitioners up to liability and consequences for their licensure. The pandemic has highlighted the fact that patients who travel for specialty care cannot have their out-of-state doctors view their results, comment on their scans, or return a phone call to answer medical questions. These prohibitions are causing more turmoil for people under particular stress, whose lives have been upended by illness. Many hospitals now require clinicians to ask about and document a patient's location as soon

as they answer the phone or log into a video platform — and to abruptly end the encounter if the patient is in a state where the clinician isn't licensed.

Clinical care teams recognize that continuity across state lines is crucial for high-quality care. Patients who are too ill to travel still deserve to receive care from clinicians they know and trust, especially in their final days and hours. To families living through these sacred but painful moments, state lines seem distant and arbitrary.

Critics argue that medical care is better when patients and their families are seen in person. But even if it weren't for the current hindrance of masks and PPE, this argument misses the point: often, the question is whether a televisit is better than no visit at all. We have precedent for ongoing interstate care: U.S. military physicians have long been allowed to practice medicine across state lines, and U.S. clinicians now have more widespread experience from the pandemic period. We believe this paradigm should be reinstated for specialty care and be made permanent.

When J. was diagnosed with a rare disease in a state where there were no relevant specialists, the experience was disorienting for his parents and his diagnosing doctor. At the same time, ongoing efforts to lower the costs of specialty care aim to reduce hospitalizations and visits. Why shouldn't we address both these sets of needs simultaneously by encouraging televisits with patients in states with clinician shortages? The past few years have taught us that health care inequity not only affects

groups lacking access to medical care but has negative effects on everyone. We believe policy regarding the provision of specialized health care across state lines should be driven by patients' and clinicians' shared goal of high-quality, equitable medical care for all.

It would be a devastating setback if the success achieved in caring for patients across state lines during the pandemic were negated by poorly informed and dated government policy. Personally, we were elated to be able to care for out-of-state patients by telemedicine and thought it would continue forever. We now feel even more restricted than we

did before the pandemic about communicating with such patients, as hospitals inform doctors and staff through new policies, lectures, and emails that doing so puts our licenses at risk. We know that rolling back specialists' telemedicine privileges will increase the financial burden on families and the health care system alike.⁴ It will also mean missing a rare opportunity to immediately expand access to care for life-threatening rare conditions for patients like J. throughout the United States.

Disclosure forms provided by the authors are available at [NEJM.org](https://www.nejm.org).

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