

Improving Patient Experience During the COVID-19 Pandemic: One Family's Reflections

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On March 11, 2020, the novel coronavirus disease 2019 (COVID-19) was declared a pandemic by the World Health Organization.¹ On March 13, 2020, a national emergency was declared in the United States concerning the COVID-19 outbreak.² Later that week, Mike Kueper, a 52-year-old previously healthy man and resident of the Indianapolis metropolitan area, became sick with what he would eventually learn was COVID-19. Prior to contracting the novel coronavirus, he had never had as much as an Emergency Department (ED) visit. He had never spent a night in a hospital. He and his sister, DeAnn Harvey, describe the events that followed.

DeAnn

As a 20-year veteran clinical child psychologist and mother of two teenagers, my first reaction to the governor's call for statewide lockdowns was that they sounded like an opportunity for time at home with my husband and children. I thought we would play games, watch movies, try new recipes, and get a much-needed reprieve from our hectic lives of sports schedules, homework, and social outings. Even a slowdown in my practice sounded good. Maybe I could finally finish those continuing education credits that were due for my upcoming license renewal. My greatest concerns about sheltering in place were about how I was going to structure my children's online learning while at the same time getting into my office to manage my patients via telehealth. Unfortunately, this relaxed feeling was short-lived.

On March 20, 2020, a few days after the lockdown started, my brother Mike developed high fevers. During a virtual doctor visit, he was told that it could be COVID-19 and to self-quarantine. Our discussions turned to jokes about his lack of taste or smell. We had dropped off soup for him from a new recipe my daughter had tried. My son joked that Mike was lucky that he couldn't taste it.

On the morning of March 28, my mother called to tell me that Mike needed to go to the ED. Because we needed to figure out which hospital would be the best for him and I didn't want my children to worry too much, I jumped in my car and drove to our church parking lot. In between calls to area hospitals, I began praying for his health and for guidance and

support from God. Mike, concerned about spreading the virus to the rest of the family, refused to let my parents or me drive him to the hospital.

Mike

I thought I had a regular cold, and then, once I had a temperature of 102 °F and night sweats, decided it was the flu. One night, I was so cold that I went to bed wearing winter gloves. After a virtual visit with a nurse, she said my symptoms did not sound like COVID, but recommended self-quarantine, just in case. On March 26, I noticed that my sense of taste and smell had disappeared completely, and it hurt to yawn or take deep breaths. By Saturday, March 28, I was getting sicker and was short of breath and very tired. My elderly parents wanted to drive me to the ED, but if it was COVID-19, I didn't want them near me. After getting advice from my sister, I called a local hospital and asked if I could come into the ED. The person on the phone said if I got there within an hour, they would be able to take me. When I arrived, an aide came out to my car, put me in a protective gown and mask, and walked me in. Walking even this short distance was tiring, and from this moment, things get fuzzy. I only have glimpses of the next few days. At first, I was put into a negative pressure room. I spent the night in there. I remember talking to a doctor who asked if I had a living will. He recommended that I go on a ventilator. I asked him, "Do you expect me to die?"

I remember him saying, "That is always a possibility."

DeAnn

Once Mike was admitted to the hospital, we didn't hear from anyone for about 6 hours, and I started to panic. I called people I knew who worked in the hospital, and my friend who is an intensive care unit (ICU) nurse agreed to track him down. He was indeed admitted to the hospital and was receiving oxygen. When I finally got to talk to him later that night, Mike had difficulty completing sentences because he was so short of breath. I told him not to use his energy, and that if they would let me, I would be there by his side. I promised him that he was going to get through this. Around 1:30 AM, I texted him goodnight. He immediately responded, "They are transferring me to the ICU." That was the last contact I would have with him for the next 17 days.

Mike

I don't remember much from the ICU, but I understand that it was touch and go at times. I knew I was on a ventilator, and I found out later that I was "proned" for up to 16 hours. Being on

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the ventilator was horrible, but what was even worse was that, once I was off the vent and alone in my hospital room, I had no idea how I got there. I thought I had been in a plane crash. I wanted to check my phone to see where I was flying in from but couldn't because I thought my phone had been hacked by terrorists. I had no idea what was real and what was not. It was extremely scary.

DeAnn

When I think about the doctor coming in to tell Mike they had to put him on the ventilator, my heart absolutely breaks. It hurts to think of him all alone, having to make this decision without any of his family there to support him. Neither he nor I wanted to think about it, but we knew there was the possibility that he would never come off the ventilator. We hadn't had a chance to hug him or even see him for days before his admission. If he didn't make it, we would never get one of his amazing "Uncle Mike" hugs again.

Our friend, the ICU nurse, made it a point to find out which nurse was assigned to Mike and made it a priority to gather information from that nurse daily, allowing our family to receive updates on Mike's status 2-3 times a day. In addition, the ICU physician was in daily contact with my parents: however, it was still excruciating not being able to be there. I spent a lot of time pacing the house, not eating or sleeping, checking my phone for texts, fielding texts and calls from friends and family. I was unable to do even simple household tasks, and left laundry, cooking, and my kids' online schooling to my husband.

Feeling so helpless, I turned to prayer. My close friends organized a daily prayer vigil at 7:30 PM each night in the church parking lot and my family and I did not miss a night until Mike came home from the hospital. It brought me comfort to have that connection each night. I also began, along with one of Mike's closest friends, organizing a meal train for the doctors and nurses in the ICU during both the day and night shifts. Interacting with those who were caring for him helped us feel closer to Mike. Because of the meal train, I became acquainted with two of his regular nurses, and they set up video chats on two occasions. Seeing him on the ventilator, so vulnerable, so ill, inspired the most difficult mix of emotions I have ever experienced. I was trying to just say anything that he would understand, hoping that he was hearing me. I told him, "We all miss you and love you. You are the strongest person we know and because of that, you will beat this!" I wish I felt as confident as I sounded.

Then, after 17 days, a miracle: he was taken off the ventilator and moved to the medical unit. Looking back, I think these are really the days that the presence of his family would have sped up his recovery. Mike was experiencing delirium and hallucinations as a result of illness, medications, and the time he spent in an induced coma. I wish I could have been there with him to be the one he asked if what he was experiencing was real or a hallucination. Then we could have laughed about it together; our family has always found that humor helps with healing.

Mike

I understand the purpose of the isolation, but it really did a number on my mind. I remember being in the ICU, having my catheter

taken out, not knowing what was happening or how I ended up in the hospital. I was so confused and was seeing people who were not there. One morning, I woke up thinking I was in my house and I had stolen the hospital bed I was in. I was panicking and scheming about how I might get this hospital bed back to the hospital before anyone noticed. As I mentioned earlier, I thought I was on a plane that had been taken over by terrorists who were using us COVID patients as biological weapons. Then I thought agents of the Federal Bureau of Investigation were coming to interrogate me and that they were also looking for my sister. To protect DeAnn, the next time someone asked me the name of my sister, I told them, "Maria" (the name of my sister who passed away in 1991) rather than DeAnn, who is very much alive. Another time, I thought my grandmother and cousin had died in a plane crash. My cousin is a state representative in Illinois, so once I got my phone to work, I checked his Wikipedia page to see if there was a death date listed.

When I was less confused, I found it's tough spending day after day lying in a hospital bed with no family member or friend to offer companionship, comfort, or clarity. Even though I was extremely weak and could barely walk, I was asking, daily, about when I was expected to be discharged. I had to get out.

One night, our friend the ICU nurse came into my room to sit with me and just talk. She spent about 30 minutes with me around 4:00 in the morning. It was wonderful. All I could think about was what a huge blessing it was. I don't think she knows just how much that meant to me. More often, I would report some symptom of confusion or insomnia, and a nurse would offer me medications for sleep or pain. I did not want any more drugs in my system. Human contact would have been a far better treatment.

I was reluctant to ask for help when I needed something, like a trip to the bathroom or some ice water. When I did press the call button, I had to wait for the busy nurse or tech to put on all the protective gear, and then, when they left, watch them take all the steps to disinfect and rid themselves of the gear that they had just put on. Even so, I was excited when it came time to take my vital signs or administer medications because that meant human interaction, however brief (and even if it was 4:00 AM). I wanted to bathe or change gowns and/or socks, but I opted to wear the same gown and socks for over three-fourths of the time I was there because I did not want to burden the staff.

Video chat turned out to be one of the best tools for creating connection. I may have sobbed a few times when talking to my parents on FaceTime, but just seeing their faces made all the difference in the world.

Finally, on April 21, 25 days after I was led into the ED, I was discharged. As we reflect on this experience, my family and I have some recommendations for hospitals and health systems trying to make patient experience a priority during this pandemic:

Kueper Family Recommendations to Improve Patient Experience for Those With COVID-19

- Adopt a more systematic approach to communicating with patient families, which would greatly improve the connection between them and healthcare personnel. This is espe-

cially important for families when the patient is critically ill, and especially in times when the patient is in isolation. We were fortunate in that we received updates from nurses and physicians several times a day. This was partly due to the relationships or connections with staff members that existed previously or developed over the course of Mike's stay. Staff members who became invested in Mike's progress became part of his hospital "family." Many people who have had a family member with COVID have not had this experience, nor did they have the opportunity to build relationships with the staff, which we felt were important to ensure good care and open and frequent communication with them and the patient. Therefore, we believe a more systematic approach toward communication (eg, "the team will call each day during multidisciplinary rounds at 11 AM,") would greatly improve the connection between families and healthcare personnel.

- Allow visitation under certain conditions even while the patient is in isolation. Visitation would have been especially helpful once Mike was more awake but isolated and delirious. We know that these policies are difficult to create and navigate but believe that there should be allowance for some visitation when there is a clear clinical benefit (eg, delirium). Because Mike had little human contact the week after he was taken off the ventilator (eg, contact limited to nurses coming in to take vitals, once daily doctor visit), he had to navigate the hallucinations and delirium on his own. Even one family member by his side who could provide frequent feedback on reality would have helped to resolve the feelings of agitation and fear that can accompany delirium.
- Schedule more video chats. Even when Mike was on the ventilator, we found video chats to be an important way to understand his experience and connect with him. Although we know such chats are difficult for clinicians to schedule, it greatly improved the experience for us.
- Reassure patients that caring for them is not a burden and they should not hesitate to ask for help. Being contagious and believing you are a danger to others is a terrible feeling. No one on staff said or even implied that they were afraid to care for him, but Mike felt "dangerous" to the staff and as such hesitated to "burden" the clinicians with requests (eg, going to the bathroom, having a change of clothes). It is time-consuming and difficult to don PPE and the amount of effort it takes to enter the room is immediately obvious

to the patient. Because of this, it is very important that the clinicians and staff reassure patients that it is part of the job and not a burden to come in and out of the room.

DeAnn

Having Mike alive and now home is an incredible gift. We are taking every chance we can to make up for the time that we could not see him and are so grateful for the hospital team that saved his life.

Mike

On April 21, I was discharged and sent home. Luckily, for about 2 weeks, I had a best friend, my brother, and DeAnn, separately, stay with me each night. This was a godsend as all made sure I was taking my medicine, eating, and doing my prescribed exercises. I am struggling with a long recovery. I used a walker for a while and had both a physical and occupational therapist visit me two to three times a week. I visit a neurologist for some of my symptoms that have not resolved, such as pain and atrophy in my right shoulder, hand tremors, and some numbness in my thighs. Thankfully, I was able to resume working from home, but even going up stairs causes me to become winded. I know that doctors don't understand this disease very well, and neither do I. Sometimes I feel discouraged about how much it set me back physically. I wish things could have been different—that I could have avoided this disease altogether or had milder symptoms. But I am so grateful to be alive and so thankful for the doctors and nurses, as well as for my family, who could not be there physically during the hospitalization but did everything they could do to help me. Because of their love and support, I survived.

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