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## Is this really happening? Family-centered care during COVID-19: People before policy

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## Is this really happening? Family-centered care during COVID-19: People before policy

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### Abstract

In the middle of a global pandemic, hospitals created policies for visitor restrictions to reduce the transmission of coronavirus to protect patients and staff and developed protocols allowing only one support person to call the critical care unit for patient updates. Late on a Tuesday afternoon, the Manager of Patient Experience received a phone call asking her to call Karri, the wife of one of our patients who was on a ventilator. Karri was struggling with updating her mother-in-law because she was very upset with the news she received, making it difficult to call her husband's mom. Karri asked the nurse on the phone if her mother-in-law could call in to get updates and was bluntly advised, "No we only allow one family member to call in to get updates." Although Karri understood the protocol, she wished it had been a different response. This narrative describes the feelings and emotions experienced by Karri, along with what the Middlesex Health did to put *people before policy* to reduce the suffering for Karri and provide family-centered care.

### Keywords

COVID-19, communication, family-centered care, critical care, virtual visits, family presence, visitor restrictions

### Introduction

At a time of uncertainty during a pandemic, hospitals around the world implemented policies that were potential barriers to family-centered care.<sup>1</sup> Visitor restrictions became a standard for all hospitals in an attempt to conserve personal protective equipment and reduce the transmission of coronavirus to protect patients and staff. Family presence at the bedside with regular communication with family members were strategies normally used to deliver family-centered care.<sup>2</sup> This article discusses how one hospital overcame these barriers, put people before policy, and provided family-centered care. This patient story will share the journey of the first admitted patient to test positive for COVID-19 at Middlesex Hospital, a community hospital in Connecticut that is part of Middlesex Health. Communication with loved ones is critical when there are visitor restrictions in place to limit the spread of the coronavirus. The narrative exemplifies how staff balanced family-centered care when caring for an acutely ill patient during a pandemic and reduced suffering for his wife and family.

### Patient Story

On March 8, 2020, the first patient tested positive for COVID-19 in Connecticut. Eight days later, Joe, a 48-year-old husband and father of two, went to a local COVID-19 clinic because he was fatigued and had a temperature of 102. He could not walk two steps without

having to stop to take a break. Joe went inside to be tested while his wife, Karri, waited in the car. About 20 minutes later, the nurse came to the car to let Karri know that they called an ambulance to bring Joe to Middlesex Hospital. A chest X-ray showed double pneumonia, and his symptoms were getting worse. This would be the last time Karri would see Joe awake for five weeks.

Karri followed the ambulance to the hospital with the expectation that she would be able to see her husband in the Emergency Department (ED). She waited for about 30 minutes, which felt like an eternity. A nurse then told Karri she would not be able to see him because of visitor restrictions due to COVID-19. Physical distancing was the principal mitigation strategy to reduce the transmission of the coronavirus.<sup>2</sup> Karri was told to go home and quarantine herself and her sons for two weeks. She was given a hospital phone number to call and was told that someone would call with an update. Karri left the ED feeling scared and devastated. She wondered, "Is this really happening to me?"

Later that evening, Karri was called by a nurse and told that Joe was receiving antibiotics for pneumonia, and he was getting oxygen with a mask to help him breathe more comfortably. His wife thought, "This is great. The antibiotics will help Joe, and he will be back home with us soon." Karri, however, soon received another call from an ED provider who told her that Joe's breathing was getting

worse and that they might need to intubate him if he did not improve.

The next day, Joe seemed stable. However, on March 18, just two days after being admitted, Joe got worse and agreed to be intubated. Joe called his wife to let her know. “We talked, cried, said our I love yous and said our typical see you soon,” Karri said. “We don’t hang up the phone with a goodbye, as it is way too final.” Joe and Karri did not anticipate that he would be intubated for very long.

Later that afternoon, Karri got a call from an intensivist. Joe’s intubation was successful, but his COVID-19 test had come back positive. The doctor educated Karri about the coronavirus and reassured her that the hospital would do everything it could to get Joe back home with his family.

### Visitor Restrictions

Karri soon developed a relationship with the staff members who worked in the hospital’s critical care unit (CCU). She spoke to the physicians every day and the nurses at least four times a day. It is important for hospitals to encourage family members to call as often as they would like to reinforce communication.<sup>3</sup> Middlesex Hospital had restricted visitors unless it was end-of-life or childbirth. To ensure that patients, the healthcare team and family members were not contaminated, all hospitals implemented visitor restrictions.<sup>3</sup> Although Karri understood why she was unable to visit, it was still hard. “Not being able to go to the hospital, hold Joe’s hand and tell him I am here, that everything is going to be alright and that I love him was the hardest thing I have ever endured,” Karri said.

Communication between the health care team and the family support person is so crucial, but even more so when there are visitor restrictions<sup>3</sup>. Each time Karri got an update, the providers and nurses were honest about his condition. She kept a journal of the conversations so that she could share accurate information with family and friends. The clinical team should provide clinical updates and allow the designated contact the opportunity to ask questions.<sup>2</sup>

“They provided me with updates and showered me with compassion, understanding and empathy,” Karri said. “They knew not being there was hurting me so much. They always asked me how my boys and I were doing.”

Joe had so many ups and downs during his 36 days in the hospital. One day he was improving, and the next day he was declining. “This is a marathon; not a sprint,” the doctors and nurses told Karri from the beginning.

### The Marathon

On March 24, Joe stopped breathing due to a mucous plug and required CPR. He was resuscitated, but Karri was scared and felt like her worst nightmare was coming true. “Is this really happening to me?” she thought. She wondered why she could not be with him. She understood there was a pandemic, but she was mad that the “stupid virus” was keeping her from the man she loved. She knew the hospital was not allowing visitors.

On March 31, Joe’s condition got worse. He was showing signs of organ failure, and the health care team was doing everything possible to save him. Joe spent time on his stomach to improve his breathing. Karri was told that the prognosis was not good. “I went into a very dark place,” she said. “I felt broken. I made myself believe I was going to lose Joe. The uncertainty was so awful and not being there was so terrible. I just cried in bed. I felt helpless. How do I tell our boys their dad is having a really bad day? This is so hard, so sad.” Karri knew she had to call Joe’s mom with this update, which would also be hard to do. She asked the nurse if her mother-in-law could be on the call list to get updates, and she was told “No, we only allow one family member to call in to get updates.”

### People Before Policy

Ultimately, there was light that came into the darkness. Karri received a call from the Manager of Patient Experience. She asked if there was anything she could do to help Karri and her family. Karri asked if Joe’s mom could be added to the contact list for updates. The Manager of Patient Experience advocated for Karri for an exception to the policy of only one support person calling for updates. This request was granted, and Joe’s mother was added as a contact to call. Karri was asked if Middlesex Hospital could do anything else to support her during this difficult time. Karri knew they were not allowing visitation, but asked, “Can I come see Joe? I want to tell him our boys are okay. We are not sick, and we need him to keep fighting.” Karri was told that the critical care leadership team would be asked and then she would be called back.

The Manager of Patient Experience advocated again for Karri; she knew what it would mean to Karri and Joe. Sometimes, the right thing to do is to not follow a policy and to put people before policy. Karri was allowed a short visit with Joe. “I jumped out of bed, got into the car and drove to the hospital,” Karri said. “On my way there, I thought to myself: ‘Oh my goodness, was I approved to see him to say goodbye?’”

## Compassionate Visit

Karri was greeted in the hospital lobby by a kind security guard who took her temperature and gave her a mask. The Manager of Patient Experience met Karri in the lobby and brought her up to the CCU. “She was so loving, supportive, caring and genuine,” Karri said. “She recognized that I could not stop crying and just put her hand on my arm.” Karri was so grateful for the chance to see Joe and tell him everything that she wanted to tell him, especially if it would be for the last time.

Karri was introduced to the CCU nurse manager. She also met the intensivist that was caring for Joe, who told her Joe was stable at that moment. “Those words just rang through me like the most beautiful sound that I have ever heard before. I practically lost my balance,” Karri said.

The nurse manager brought Karri over to Joe’s room. He looked so comfortable and so well taken care of. Karri was given two pairs of gloves and two gowns to put on. “I was so nervous and still crying,” she said. Joe’s nurse recognized this and came over and gave Karri the best hug that she had received in weeks. The nurse explained to Karri everything that Joe was hooked up to and then sat her down in the chair next to him and took Joe’s hand out from under the blanket for her to hold. “Oh, my goodness, holding Joe’s hand felt wonderful,” she said. “Seeing him in person, sleeping so peacefully helped me tremendously. I talked to him, told him jokes and stories from our boys, family and friends. I sang him our wedding song.” Soon, the intensivist came in and updated Karri that the dialysis was helping to improve Joe’s potassium level. Karri spent an hour with Joe, and before she left, she reminded him how much she loved him and that he needed to keep fighting and get home.

At this moment in time, the healthcare team provided them with family-centered care, which made everyone happy, including the staff. Karri left Middlesex Hospital feeling a little relieved. She saw how hard the health care team was working to help Joe. “Seeing with my own eyes the amazing, wonderful care they were giving Joe really helped me,” she said.

## Family Presence

Since there were visitor restrictions, the healthcare team needed to find ways to keep family members connected with the patients. This was important for the psychological and emotional well-being for Joe and his family. *Family presence* replaced *visitation* in the family-centered paradigm.<sup>2</sup> The hospital began offering daily virtual visits using Zoom so Karri and the boys could see and speak to Joe. Karri felt Joe needed to hear a familiar voice, and since visiting him was not an option, the virtual visits were the next best thing. “During this unprecedented time in our lives, this

process helped me so much,” Karri said “Not only was I able to meet and see his nurses, but I was able to talk to Joe, which was such an important process.” Karri was asked to share fun facts about Joe and to provide pictures so that the healthcare team could connect with Joe as a person.

## The Marathon Continues

Joe’s condition, unfortunately, took a turn on April 8. His tube got clogged by mucus, and it could not be cleared with suction. Joe required CPR and resuscitation again, and a new tube was inserted. “Thank goodness again for the quick thinking, intelligent, knowledgeable doctors and nurses,” Karri said. “They saved his life—my husband’s life...my boys’ father, again.”

Fortunately, after the second resuscitation, Joe remained stable. On Easter Sunday, April 12, Karri was participating in a virtual Zoom visit when the Ipad was turned on Joe. A miracle happened. Joe was awake and had been extubated from the ventilator. “What am I seeing?” Karri thought. “What am I hearing? Is Joe really talking to me? I was completely surprised, overjoyed and overwhelmed with emotions.” Having the virtual visit allowed Karri to see with her own eyes the miracle of Joe being awake on Easter, a day of resurrection. Karri screamed for joy, cried happy tears, and Joe cried too.

On April 16, Joe was transferred from the CCU to a medical unit. Joe’s nurse used Zoom so that Karri could witness this milestone. CCU staff members lined the hallway to cheer him on. This was a giant step toward getting Joe home with his family. “Joe’s doctors, nurses and all CCU staff worked together to find a way to save Joe’s life,” Karri said. “They won Joe’s battle of COVID-19. I will forever be grateful.”

## Next Transition

After 36 days in the hospital, 24 days on a ventilator, and two respiratory arrests requiring CPR, Joe transitioned from Middlesex Hospital and was brought to a long-term acute care facility for rehabilitation. Karri and her sons were invited to the hospital to greet Joe before he was placed into the ambulance. The hospital played the Rocky theme song over its intercom to celebrate Joe’s discharge. “When I heard the Rocky theme song start, I had chills all over my body because I knew what that meant,” Karri said. “Joe was on his way down to us. I could not contain my excitement. My boys stayed close to me, as I think they were pretty excited too. I knew in a few short minutes we were going to be able to hug Joe after five weeks of his long battle with COVID-19.”

As he was wheeled through the hospital, hospital staff lined the hallways to cheer Joe on. He thanked the staff for

everything they did. “Thank you for saving my life,” he said. As Joe moved closer to his family, Karri and their sons hugged him and cried with happiness. It was the first time the boys had seen their dad in five weeks. “The staff at this hospital prevailed,” Karri said. “They worked together tirelessly, selflessly to save Joe’s life during this unknown and uncertainty. For this, I will be forever grateful.”

### Reflection

This patient and family story about COVID-19 not only exemplified quality care and teamwork, but it also exemplified compassionate, family-centered care. The communication and trust between the healthcare team and Karri was outstanding. She received daily updates from both the physicians and the nurses. At a time when it was most needed for Karri and Joe, they allowed a compassionate visit so that Karri could be at Joe’s bedside. This was monumental for Karri. She was able to see her husband and sing their wedding song, and Joe’s condition improved after having this visit from his wife. Sometimes, the right thing to do is to put people before policy, to reduce suffering. Hospitals should evaluate each patient case scenario to see if this is feasible and appropriate.

Family photo of Karri, Joe and their sons, November 2018



At a time when no visitors were allowed, the hospital started using virtual visits so that Karri and their sons could communicate with Joe—both when he was on and off the ventilator. Hospitals should adapt virtual visits so that family presence can replace visitation in the family-centered paradigm.<sup>2</sup>The hospital celebrated Joe and the healthcare team by playing the Rocky theme song in its entirety, and staff members lined hallways during his discharge to a rehabilitation facility. Yes, this is really happening.

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Gratitude poster made by Karri and Joe’s family for the Critical Care staff

