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No visitors allowed: How health systems can better engage patients' families during a pandemic

Jennifer Schlimgen

Kahler Slater, jenniferschlimgen1@gmail.com

Amy Frye

AB Design Research LLC, amy@abdesignresearch.com

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No visitors allowed: How health systems can better engage patients' families during a pandemic

Jennifer Schlimgen, AIA, *Kahler Slater*, jenniferschlimgen1@gmail.com

Amy Frye, *AB Design Research LLC*, amy@abdesignresearch.com

Abstract

The ravages of COVID -19 and the no visitor policies that accompany it have forged a tectonic shift in the patient and family experience. This hit home for me with a recent family member health event and hospitalization, leading me to think “*we HAVE to do better!*” Why should hospitals and health systems care about family involvement during COVID-19?

Keywords

COVID-19, patient experience, family satisfaction, empathy, communication, dying, hospitalization, physical limitations, respect, visitation, human experience

The ravages of COVID -19 and the no visitor policies that accompany it have forged a tectonic shift in the patient and family experience. This hit home for me with a recent family member health event and hospitalization, leading me to think “*we HAVE to do better!*”

After sending our distressed COVID-positive mother in an ambulance from her home in assisted living, my sisters and I waited anxiously at our homes more than eight hours for an update from ER staff. Mom was eventually admitted to the hospital. After receiving only general information the next day from her hospitalist, in our desire to understand what was happening to Mom, we called the nursing unit staff workstation to request test results, something we have routinely been able to receive when we are physically present as a bedside visitor in the hospital. We were told by her social worker (the person we most frequently heard from, who was focused on preparing a discharge plan for Mom to go to a rehab center), that we were calling too often and we should wait for her care team to contact us. We waited FOUR DAYS over the first weekend for a phone call. We were beside ourselves with anxiety over what we could only imagine was happening to Mom.

Throughout her stay, communication with her caregiving team remained minimal. Messages went unreturned. We had more questions than answers. And we ached to see and talk to Mom in any possible way. The hospital's website and TV ads promoted the use of tablets for face-to-face video calls for patients to stay in touch with their families. When we tried to set one up, I called three times in one day and staff was never able to find a tablet to use. No one called back so we weren't able to even just talk to Mom on the phone.

As days and then weeks wore on, it appeared Mom was getting better from what we were being told. She had conquered all the medical challenges that came her way, but still had high inflammation rates in her blood test results, something no one seemed to have a good understanding of at that time. Three weeks after her initial ambulance ride, she was discharged to assisted living. Hospital staff reported at discharge that Mom was medically stable but weak.

We were shocked to hear from a hospice nurse the next morning that Mom was dying. The nurse hoped she was wrong, but she was right. Gratefully, the assisted living facility allowed the four of us to be with Mom, in full PPE, 24/7 until she died a week later. That time at her bedside was priceless for us. I can't imagine losing a loved one without the opportunity to say those long goodbyes that included initiating phone calls to friends and family who could not be in the room for the day and a half of that week, while Mom rallied through laughter and tears to say goodbye.

The Letter

My sister was my mother's healthcare POA, and as a scientist who taught in medical school for her entire career, she was not satisfied with Mom's medical story as we understood it. And so, several weeks after Mom died, my sister wrote a letter to the hospital President and the Chief Medical Officer, asking the unanswered questions about Mom's medical care and describing the communication challenges we'd experienced. To their credit, both welcomed my sister's inquiry, and following an initial call from the CMO to my sister, we scheduled a 45-

minute video call that included the hospital President, the Risk Manager and a physician who was following the daily evolution of COVID treatment protocols and had studied Mom's case in detail.

To my surprise, the hospital President began with great empathy, having very recently lost a family member of his own, by profusely apologizing for our experience as family members and for not finding a way to provide the connection our mother desperately needed. I had expected some level of defensiveness or maybe just the facts, but we received much more than that. The physician explained how our mother's care fit into the framework of what they had known about COVID treatment at the time of her hospitalization, as compared to what they knew at the time of our phone call (several months later). We learned that she actually died from the inflammation syndrome that followed COVID, which she had had for six weeks. This would have been treated with steroids if they had known then what they knew now. But the reality was, for patients over 85 (Mom was 92), they now also knew COVID was nearly always fatal, which was something we had not heard before. We also learned that Mom hadn't been contagious after her first 10 days of symptoms, which had not been understood earlier.

The President told us that my sister's letter had been impactful. It inspired action and made a difference in how they were communicating with families now. Staff had also been distressed to know that they weren't connecting well enough with families, so developed new protocols for how to do so. Daily calls were now being made to families during or just after morning rounds. He also admitted that he was fairly certain that someone or several people on the caregiving team must have known that Mom was about to die when they discharged her but didn't have the courage to tell us. He felt this was very wrong and was something they were working hard to improve. He felt the hospital had a moral duty to patients and families to be honest with them at these critical times. He ended with another heartfelt apology and thanked us for our feedback. The empathy, respect and information so freely shared made a world of difference to our family. That is really all that we wanted. It did not bring our mother back to us, but it did bring closure. I personally cannot imagine a better service recovery strategy than what transpired following the hospital's receipt of my sister's letter.

Why It Matters

Why should hospitals and health systems care about family involvement? There are many reasons. Families decide where patients will go for care and fill in critical information when patients cannot - on medical history, cognitive impairments, physical limitations and preferences. We advocate for them and comfort them and coordinate care after they leave the hospital. For family

members in this position, to not have real time access and information – is *agonizing*.

Based on previous patient experience research,¹ we also know that patients do better the more that family members are involved in their care and that, in turn, positively influences both clinical quality and financial performance of the organization. If you are not excelling at including family members in your patients' care, you can expect to see a significant dip in your patient experience scores, patient volumes and even philanthropic donations. These potentially stressful experiences are a BIG risk to your reputation, your relationships with your consumers and your community. There has to be a better way to involve families when we are not allowed to be physically present.

Never Waste a Good Crisis

What is the vision for the patient and family experience in this *new normal*? Whose job is it to communicate with family, under what circumstances and how often? What can the new protocol look like? I've been thinking:

What if we get creative with family engagement?

- **What if** family members became an essential part of each patients' care team as they often are when they are there in person? What kind of communication would be needed to make that a reality? As a self-declared expert in this area, having provided and coordinated care for multiple family elders for more than two decades, I see a future where checking in on a family member's health status is as easy as checking my weather app (something I compulsively do). I am a late adopter of technology and my families' ability varies greatly, even over simple popular platforms such as Zoom. It must be simple.
- **What if** each care episode started with a scheduled live care conference, where family members were briefed and had the opportunity to engage the caregiving team, clarifying assumptions, and asking questions?
- **What if** families were offered a virtual introduction to staff as shift changes occurred?

What if we get creative with technology?

- **What if** a provider could record a brief statement for the family on their cell phone at the end of their patient visit? Family members could listen or view, ask questions, and feel more actively engaged. Could the provider receive notifications when the family had questions or concerns? Likewise, could the family receive notifications when there is new information (an answer to the question or a new status update) waiting for them in the EMR patient portal?

- **What if** nurses and staff could also record their view of our family member's evolving status? The day-to-day observations, wisdom and data they have at their fingertips is of vital interest to families. The same is true for consulting specialists and therapists.
- **What if** family members could click an icon to request to talk to the patient? Often, patients are so weak or debilitated in the moment they are unable to navigate a telephone or tablet device themselves and need assistance. What if this were assigned to volunteers?
- **What if** nurses or staff could record a brief message from the patient each day? In the six weeks our mother had COVID, without the ability to see her firsthand, the main understanding we had of her status was the sound of her voice and the length of a phone conversation she could sustain, which varied from 50 minutes initially to 2 minutes towards the end of her hospitalization.

What if we get creative with communication?

- **What if** online EMR access provided real time posting of more complete information? For example, for Congestive Heart Failure patients (a pre-existing condition our Mom had for several years that was exacerbated by COVID), daily weights are not typically posted for family view in the EMR portal, even though they are taken and recorded for clinician's view. Anyone who manages this chronic illness for a family member, knows weight gain is a key indicator of an escalating heart failure challenge and something that should be watched closely. Could family members receive an automated notice when the EMR has been updated?
- **What if** a patient tracking system could automatically text family members with a virtual dashboard answer on questions like, "Is she in recovery? When will we hear from the surgeon?"
- **What if** each of these interactions was preserved in a running log, so anyone could go back to find the answer to a question previously asked or review a previous status update, like an email or text string?

While many of these technologically enabled connections might have been available at the time of our Mother's hospitalization, none were offered to our family at that time.

What if we find a way to ensure COVID positive patients aren't dying alone?

- **What if** you could predict PPE needs going forward and secure enough supply in the future to allow family to be with non-contagious patients? Although our mother continued to test positive for six weeks, she was not contagious after day 10 of her

symptoms. Being with our mother for the last week of her life made all the difference in the world to our family.

Perhaps my biggest personal lesson learned was this. When something doesn't sit right with you, *write the letter!* Feedback is a gift. It could help improve someone else's care experience and outcomes.

The one bright spot I am truly grateful for as we mourn the loss of our Mother is that one nurse in our mother's three-week hospital stay managed to help her call all four of her daughters - on Mothers' Day. What a blessing! We keep her and all those who cared for our Mother in our hearts. We know it is not an easy job, and we so appreciate the enormous risks they take personally at this time to provide that care every day.

References

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