



2021

How to address fear: A patient's perspective of seeking care during COVID-19

Rosie Bartel

Sydney Hoel

University of Wisconsin-Madison

Nasia Safdar

University of Wisconsin - Madison

Mary Jo Knobloch

University of Wisconsin-Madison

Follow this and additional works at: <https://pxjournal.org/journal>



Part of the [Quality Improvement Commons](#)

Recommended Citation

Bartel R, Hoel S, Safdar N, Knobloch M. How to address fear: A patient's perspective of seeking care during COVID-19. *Patient Experience Journal*. 2021; 8(3):13-16. doi: 10.35680/2372-0247.1604.

This Personal Narrative is brought to you for free and open access by Patient Experience Journal. It has been accepted for inclusion in Patient Experience Journal by an authorized editor of Patient Experience Journal.

How to address fear: A patient's perspective of seeking care during COVID-19

Cover Page Footnote

Conflict of interest: All authors report no conflicts of interest related to this article. This article is associated with the Patient, Family & Community Engagement lens of The Beryl Institute Experience Framework (<https://www.theberylinstitute.org/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: http://bit.ly/PX_PtFamComm

How to address fear: A patient's perspective of seeking care during COVID-19

Rosie Bartel, *bartel1949@gmail.com*

Sydney Hoel, *University of Wisconsin-Madison, smhoel@medicine.wisc.edu*

Nasia Safdar, *University of Wisconsin-Madison, ns2@medicine.wisc.edu*

Mary Jo Knobloch, *University of Wisconsin-Madison, mjknoblo@medicine.wisc.edu*

Abstract

This article is a narrative of one patient's experience during COVID-19. As a non-COVID patient, she shares her personal fears, the fears of others in her family and the fears of the healthcare professionals. These fears have made navigating the healthcare systems stressful for patients but also caused patients to avoid them completely. In some cases, this avoidance led to delayed diagnosis, missed diagnosis and death. When healthcare providers guide patients through the process of seeking in-person healthcare, the outcomes were more positive for everyone involved but especially for the patients and their care partners. The patient's voice is needed to help healthcare professionals understand their fears and how to provide the best healthcare for all.

Keywords

Patient experience, quality of care, COVID-19

After more than a year, the COVID-19 pandemic continues to sweep the globe. Initially, much attention was focused on the readiness of healthcare systems, development of vaccines, and healthcare employees' ability to handle the influx of patients with severe acute respiratory distress syndrome coronavirus 2 (SARS-CoV-2). Less attention was paid to the perspective of the non-COVID patient, but as healthcare employees became patients themselves, the patient experience – specifically, the realities of seeking care during the COVID-19 pandemic – has come into focus. I am sharing my own story of multiple interactions with the healthcare system over the past year, good and bad; the challenges of loss and navigating the healthcare system alone; and the strain I have witnessed on both healthcare workers and patients during the COVID-19 pandemic.

I am a patient in my 70s with extensive experience with the healthcare system. Over 11 years ago, I was the recipient of a new artificial knee and, along with it, a surgical site infection. The diagnosis was methicillin-resistant *Staphylococcus aureus* (MRSA) osteomyelitis. Since that time, I have undergone 58 surgical procedures and have been hospitalized well over 200 times - including visits for 12 unique septic shock events. As of today, I have had a total of 3 amputations (transfemoral, hip disarticulation, and hemipelvectomy) and still have low-grade MRSA bone colonization. In May of 2020, I found myself faced with an urgent health concern and close to developing sepsis, and despite knowing exactly what to do,

I found myself overwhelmed with fear. In the midst of the pandemic, I was unsure what going to the emergency department (ED) would mean for me. Finally, I decided to contact my infectious disease provider before going to the hospital. This helped me navigate the situation, and my provider created a positive patient experience for me. My husband and primary care partner were able to go to the ED with me. This helped me deal with my fears.

Little did I know that this experience would be just the tip of the iceberg. My husband had developed a backache in March just as the country was beginning to lock down. He went to his primary care physician about mid-March and was told that he probably needed more exercise. When getting more exercise seemed to add to the pain, I encouraged him to try a chiropractor. After five weeks of treatment that didn't seem to be helping, the chiropractor suggested that he get an MRI. On June 26, 2020, he finally got an MRI at 7:00 am. At 1:00 pm, his primary care provider asked him to come into the office to discuss the results. The MRI showed two kinds of bone cancer, which were secondary to another unidentified primary cancer. After CT scans and biopsies, he was told he had multiple organ terminal cancer, including pancreas, gallbladder, liver and upper GI, along with the two kinds of bone cancer and had less than six months to live. They offered him comfort chemotherapy. This chemotherapy could either help the pain or make it worse. By now, the bone pain was so unbearable that he decided to try this option. He received one dose of comfort chemotherapy and he

lived about one more week. On July 28, 2020, my beloved husband lost his short battle with cancer.

This loss profoundly shaped my subsequent experiences with healthcare during that year. When my husband had gotten sick, I was dealing with uncontrollable a-trial fibrillation (a-fib) and was in the process of discussing the placement of a pacemaker and having an ablation. After losing him, I was still struggling with a-fib. Finally, in November, I decided that medications were not helping, and it was time for the procedures.

On November 5, 2020, I went to the hospital without my husband and care partner or any other family member by my side. Originally, they told me they would place the pacemaker and do the ablation on the same day. However, when I arrived at the hospital, I discovered that the physician had changed his mind. That hospital experience was full of fear - my personal fear of being alone at a hospital for the first time in 45 years as well as the expressed fears of the healthcare professionals. Lots of errors happened during that first visit, and they were related to the fears of the healthcare employees. After this very stressful experience, I had to come back in five to six weeks. I returned for the ablation on December 10, 2020. It was so hard being alone, especially as an amputee who is wheelchair-bound. Although my second experience was better than the first, I was still very fearful.

The need for non-COVID-related care has persisted throughout the pandemic, both for patients like me, receiving acute care, and for patients with chronic or ongoing medical conditions that need consistent interaction with the healthcare system. However, we are not seeing this reflected in care-seeking trends. Numerous institutions are reporting a reduction in emergency department (ED) visits for common issues such as heart attack and stroke.^{1,3} Across the United States, some ED volumes have dropped to 50% of normal.⁴ Patients may be foregoing care for their child due to fear,² but self-perceived urgency is a strong motivator for patients to seek medical care through an ED.⁵ However, in the context of COVID-19, it can be overwhelming to make the decision to go to the ED. In my case, I knew from experience that if I did not address my infection, I would most likely develop sepsis and even septic shock. One such sepsis event resulted in a Flight for Life trip and coma for 6 days. I understood the risks. My life was in danger, and yet I was paralyzed by the possibility that going to the hospital may put my life in greater danger by being exposed to COVID-19.

COVID-19 exposure is just one fear affecting care-seeking behaviors, but it is a powerful one. Patients interviewed as part of a Human-Centered Design intervention from a community hospital in California indicated that they believed that hospitals are “infection reservoirs” and are

“crawling with COVID-19.”⁴ As patients with medical concerns contemplate seeking care, it appears their concerns for contracting COVID-19 rival, and often exceed, their concern from their present health issues. Along with these concerns are those that seeking care for non-COVID issues could take providers away from more important tasks and result in resources being taken from other patients. This was the experience my husband felt when he was looking for help from his primary care physician for his backache in March of 2020. Patients have expressed concerns of “bothering the doctor” and being “selfish” for bringing up their own health concerns.¹ These are the exact words my husband used after his first doctor appointment. This fear is likely still prevalent among many patients and may result in patients avoiding the care they need.

As the COVID-19 situation unfolded, media outlets provided graphic details of hospitals being overwhelmed with COVID-19 patients and front-line healthcare workers describing the extraordinary circumstances. This, combined with the severe shortage of ventilators and PPE, painted a clear picture to patients: health systems are not equipped to provide adequate care. This portrayal often likened the worst-hit hospitals to “war zones,” and that imagery has stuck with patients. Similar to me, patients still wonder, “Is it even safe to go to the hospital?” with others expressing concerns about taking resources away from critically ill patients, not having masks to protect themselves or their healthcare providers, long wait times, and even that they may be turned away if they do not have the virus.⁴ When I went to the ED, the complete opposite was true. I was the only patient in a large ED. The hospital was relatively empty, because there were only COVID-19 patients and extreme emergencies being treated at that time. I received the emergency care I needed but refused to stay because I was afraid that I could bring the virus home to my family.

Even pre-COVID-19, this fear was a source of anxiety that all too often deterred patients from seeking care.^{6,7} The palpable perceived risk to the patient, their loved ones, their healthcare providers, and other patients creates a major barrier to seeking care.

We know that fear is not unique to patients. Numerous articles and countless personal stories have emerged chronicling experiences from the front lines of the healthcare system.^{1,11-14} Providers fear for their own safety daily. Simply showing up to work constitutes an acknowledgement of what is possibly the most imminent mortal risk they have ever experienced.¹³ This risk also extends beyond the workplace to family members, friends, and others. Coupled with these personal fears are stressors experienced in what, until recently, were known as ‘routine care.’ Now, healthcare workers must rely on coworkers to assist in donning gloves, gowns, glasses, caps, masks,

visors, shoes, and shoe covers.⁵ They must perform their once familiar medical exams and procedures through smudged and fogged eye protection, muffled voices, and a lack of the facial expressions that are so important for reassurance and communication.¹¹⁻¹³ These difficulties affect both healthcare workers and patients, who no longer feel connected to their healthcare providers.

This constant experience of fear from an external threat, in this case COVID-19, has been described as incidental fear — fear that arises independent of the immediate context. It has been shown that the presence of incidental fear can compromise one's ability to empathize with others' suffering.¹⁵ In light of this, healthcare providers must be aware that their capacity for empathy may be diminished in the context of fear. I definitely experienced this when I was completely alone in the hospital. Healthcare professionals were so emotionally drained because of their personal fear that they couldn't focus on giving quality care.

There are several things to consider when thinking about this from the patient perspective. Provider-patient relationships have been shown to be a critical factor in patient adherence to lifestyle changes and medications.⁸⁻¹⁰ PPE may hinder the development of patient-provider relationships.¹¹ I experienced miscommunication during my pacemaker procedure because the physician had an accent and I have a hearing loss. Even with hearing aids, I still depend on some reading of lips, which is made impossible by masks.

While virtual visits are a good alternative to in-person care in some situations, the learning curve required of patients to navigate technology may represent an additional barrier to care. For my family, telehealth was a good place to start when I developed my infection, but greater medical attention at the ED was needed in order to provide correct and complete diagnoses.

Patient fear may also have been amplified by the knowledge (spread by media, public health, and health systems) that if hospitalization is needed, visitors may not be allowed, even for end-of-life situations. This has been proven true in many healthcare facilities and in most countries. The thought of being totally alone when sick or dying is a terrifying one that has profound effects on both patients and healthcare providers.¹¹ Once my husband knew he had terminal cancer, he had one request. That request was to die at home in his own bed so his family could be with him.

Who is currently telling the story of the patient? While it is not appropriate to compare the fear between individuals, it is safe to say that as patients, we have less of a voice to express it. There is a common thread that runs between all of us, and it is the fear presented by this novel virus. We

must help all patients to understand that everyone cares about them - even from behind the provider's face shields and respirators. We are all worried and anxious; we all feel vulnerable. Acknowledging these fears is the only way we can provide adequate care going forward.

Patients like me have done the math. We may be more fearful of our medical condition than COVID-19. Yet, if we do not feel cared for, we will not seek care. It is up to all of us to acknowledge the shared fears that affect us all, however, we must never forget that patients have fears too. The true cost of this pandemic will not only be the deaths due to COVID-19, but it will also include the immeasurable number of preventable deaths that are the result of fear.

References

1. Rosenbaum L. The Untold Toll — The Pandemic's Effects on Patients without Covid-19. *N Engl J Med*. 2020 Apr 17;382(24):2368–71.
2. Liao JM, Pronovost PJ, Navathe AS. To Re-Open Health Care, Leaders Should Address Patient Fear. *NEJM Catal Innov Care Deliv*. 2020 Jul 9;1(4):6.
3. Garcia S, Albaghdadi MS, Meraj PM, Schmidt C, Garberich R, Jaffer FA, et al. Reduction in ST-Segment Elevation Cardiac Catheterization Laboratory Activations in the United States During COVID-19 Pandemic. *J Am Coll Cardiol*. 2020 Jun 9;75(22):2871–2.
4. Wong LE, Hawkins JE, Langness S, Murrell KL, Iris P, Sammann A. Where Are All the Patients? Addressing Covid-19 Fear to Encourage Sick Patients to Seek Emergency Care. *NEJM Catal Innov Care Deliv*. 2020 May 14;1(3):12.
5. Coster JE, Turner JK, Bradbury D, Cantrell A. Why Do People Choose Emergency and Urgent Care Services? A Rapid Review Utilizing a Systematic Literature Search and Narrative Synthesis. *Acad Emerg Med Off J Soc Acad Emerg Med*. 2017 Sep 24;24(9):1137–49.
6. Taber JM, Leyva B, Persoskie A. Why do People Avoid Medical Care? A Qualitative Study Using National Data. *J Gen Intern Med*. 2015 Mar;30(3):290–7.
7. Kannan VD, Veazie PJ. Predictors of avoiding medical care and reasons for avoidance behavior. *Med Care*. 2014 Apr;52(4):336–345.
8. Cameron C. Patient compliance: recognition of factors involved and suggestions for promoting compliance with therapeutic regimens. *J Adv Nurs*. 1996 Aug;24(2):244–50.
9. Osterberg L, Blaschke T. Adherence to Medication. *N Engl J Med*. 2005 Aug 4;353(5):487–97.
10. van der Laan DM, Elders PJM, Boons CCLM, Beckeringh JJ, Nijpels G, Hugtenburg JG. Factors associated with antihypertensive medication non-

- adherence: a systematic review. *J Hum Hypertens*. 2011 Nov;31(11):687–94.
11. Cunningham CO, Diaz C, Slawek DE. COVID-19: The Worst Days of Our Careers. *Ann Intern Med*. 2020 Jun 2;172(11):764–5.
 12. Castelletti S. A Shift on the Front Line. *N Engl J Med*. 2020 Apr 9;382(23):e83.
 13. Earnest M. On Becoming a Plague Doctor. *N Engl J Med*. 2020 May 20;383(10):e64.
 14. Crosby SS. My COVID-19. *Ann Intern Med* [Internet]. 2020 Aug 11 [cited 2020 Oct 14]; Available from: <https://www.acpjournals.org/doi/10.7326/M20-5126>
 15. Richins MT, Barreto M, Karl A, Lawrence N. Incidental fear reduces empathy for an out-group's pain. *Emotion* [Internet]. 2019 Dec 19; Available from: <https://pubmed.ncbi.nlm.nih.gov/31855012/>