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## Is it fair to compare? A patient and family experience of two healthcare systems and neurosurgical teams within a two-week period

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### Cover Page Footnote

I'd like to acknowledge our son, Ian, who through the years, has taught our family the definition of strength, endurance, and courage. My passion for staff education and patient experience took root from those early seeds planted in the NICU. This article is associated with the Quality & Clinical Excellence lens of The Beryl Institute Experience Framework. (<http://bit.ly/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: [http://bit.ly/PX\\_QualityClinExc](http://bit.ly/PX_QualityClinExc)

## Is it fair to compare? A patient and family experience of two healthcare systems and neurosurgical teams within a two-week period

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### Abstract

As the mother of a 28-year-old son with cerebral palsy and hydrocephalus, and as a healthcare consultant focused on patient experience and professional development, I have a unique perspective and skill set. Recently he experienced symptoms that included an excruciating headache, neck pain and lethargy. Fearing his ventriculoperitoneal shunt had malfunctioned, he went to the emergency room and was later admitted on the neuro inpatient floor for a three-day hospitalization. His original shunt had been placed in 1991, and he never had an issue with until August 2018. While in the hospital, he was informed that he was no longer shunt-dependent and that his headaches were a result of a pulled muscle in his neck, which would eventually resolve itself. He was discharged from the hospital with over-the-counter pain medicine for his neck pain and sent home. Thirteen days later, he was admitted to a different healthcare system, where the condition was quickly identified as hydrocephalus due to a shunt malfunction; neurosurgery was emergently performed, resulting in a six-day stay. These two hospitalizations, in such a short amount of time, provided completely different patient and family experiences, not to mention completely different clinical outcomes. When the patient satisfaction survey arrived in his mailbox following both hospitalizations, his survey answers were drastically different. This article will share examples of how healthcare professionals can positively impact the patient and family experience, even when the medical outcomes are not optimal, and how those interactions can positively impact patient satisfaction scores.

### Keywords

Patient experience, patient- and family-centered care, quality of care, health literacy, healthcare, communication

### History

As a premature infant in 1991, my son, Ian, spent 93 days in the NICU. His twin brother spent 186 days in the NICU and died just before his first birthday. At birth, Ian weighed 2 lbs 4 oz and was 12 inches long. Shortly after birth, he experienced a grade III brain hemorrhage resulting in hydrocephalus; a ventriculoperitoneal (VP) shunt was placed on the right side in the back of his skull. The shunt tubing went from the back of his head, near his right ear, alongside of his right neck and down into his abdomen. A shunt revision occurred four weeks after the original shunt and was never revised or replaced again. In addition to the VP shunt, Ian has cerebral palsy (CP) affecting his legs, feet, gait, stability, balance and endurance. As is the case with many former NICU graduates, Ian has an unnaturally high tolerance for pain. This characteristic, combined with his quiet and stoic personality, sometimes results in missed opportunities for better pain management and a complete understanding of his chronic conditions.

In 2018, (with the past 27 years non-eventful regarding the shunt), Ian had an aggressive sneezing fit in the middle of the night at his residence. The final severe sneeze forced

his head down and to the left, at which point he heard a “clicking pop sound” close to his right ear, felt the tubing tug and snap near his neck, and experienced an excruciating pain near the shunt location behind his right ear, with extreme pressure and pain immediately radiating up to the top, right center of his head. Over the next few hours, the headache subsided to a dull, throbbing sensation that stayed with him for days. Additionally, he felt like he “pulled a muscle” in his neck, making it painful to turn his head to the right. Three days later with the pain continuing, the patient went to the closest emergency room, and was later admitted to their Heart & Neuro Vascular Care Unit. A series of x-rays and CT scans was conducted. The x-ray showed a one-inch break in the tubing near his right ear, around the area of his neck pain. Surgery was scheduled for the next morning, but later postponed to the afternoon, so additional x-rays and CT scans could be taken for comparison purposes. At the same time, the neurosurgeon used a long syringe, inserted it into the shunt to extract fluid but nothing came out. The neurosurgeon indicated that since fluid was not present, the shunt was not working and therefore, Ian was no longer shunt dependent. The headaches continued at the hospital, but not as severe as the initial extreme pain and he consistently rated his pain around three to four on a ten-point scale. After a review of the tests and scans,

**Figure 1. Image taken on 17 Aug 2018, the day of discharge from the hospital**



surgery was postponed again and rescheduled for the next morning as they settled on a wait-and-see approach. After reviewing the final sets of x-rays and CT scans (Figure 1) the next morning, the surgeon determined release was appropriate; even though the headaches and neck pain continued, Ian was discharged that evening. His discharge paperwork stated he should follow up with his primary care physician within two weeks and take ibuprofen as needed for mild pain. His total length of stay was three days.

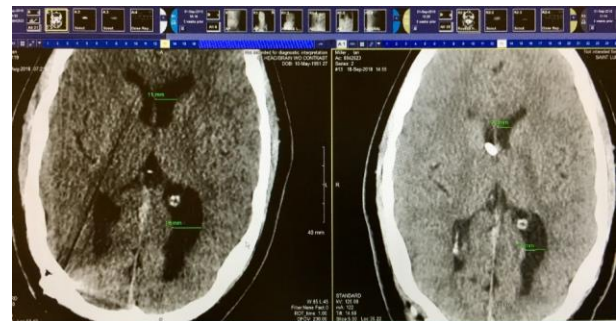
As the headaches continued over several days, Ian became increasingly lethargic and missed several consecutive days of work. Thirteen days after his initial discharge, he had an appointment with a new neurosurgeon, who was associated with a different hospital in the city.

During that appointment, the physician's assistant reviewed the x-rays and CT scans that had been taken from the inpatient stay two weeks earlier and compared them to previous scans obtained from the children's hospital 15 years before, which had been taken during a routine follow-up visit. The most recent x-ray from two weeks earlier showed that the VP shunt had pulled partially out of its original placement and showed a one-inch separation or break of the tubing in the neck area, just below the right ear, exactly where the patient heard the clicking pop sound. The tubing had snapped and separated during the sneeze. The comparative CT scans (from 15 years earlier and two weeks earlier) showed a marked change in the size of the ventricles, with the increase showing additional fluid buildup. Ian was told that he was still shunt-dependent and that his shunt had failed. He was immediately admitted to the Neurosciences Institute with surgery scheduled for the following morning.

By the next morning, Ian was in considerable pain, as pressure in his brain continued to increase. He was more lethargic, swollen in the face and neck area, and sensitive to light and sound. During surgery, the team replaced the entire shunt system with new tubing, catheter and pump, removing all original shunt apparatus, and using all of the original locations for the new shunt. The post-surgery x-ray and CT scans looked positive. Overnight, however, he

was in unbearable pain and the morning CT scans showed that his ventricles were enlarged again, due to fluid build-up. The shunt revision failed, and a second surgery was scheduled immediately. The shunt was relocated to the upper right frontal area. The follow-up x-rays and CT scans looked positive. The next morning, Ian felt and looked better, and he began his recovery process. Because of his existing conditions of CP, gait and mobility issues, recovery was challenging and took longer than anticipated. His length of stay was six days. At his follow-up appointment sixteen days after surgery, Ian's conditioned showed improvement and his CT scan showed a decrease in the ventricle size. (Figure 2)

**Figure 2. Comparing CT scans: On the left, 14 days before the surgery; on the right, 16 days after the surgery, at the follow-up appointment.**



### Comparing patient experiences at two different healthcare systems

It is a rare opportunity when a patient has the chance to be treated for the exact same condition by two different healthcare systems and surgical teams within a very short amount of time. While the intake process differed, his condition was described to both teams in the same way: severe headache, pressure, and neck pain. Both teams used the same set of x-rays and CT scans for their initial diagnosis. The patient's initial presenting condition was the same, yet the plan of care, the patient and family experience, the staff interactions and communication, and the outcomes could not have been farther apart.

Patient confidence in the physician's abilities depends not only on clinical excellence, but also on how he is able to communicate the clinical diagnosis and the plan of care. Effective communication is conveyed not only through words, but through body language, tone of voice, utilizing an ability to listen and respond. Words matter, but how you say them matters, too. In the article *Ethics & Etiquette in the Neonatal Intensive Care Unit*, the authors list the ten essentials of etiquette-based neonatal care from the parents' perspective, including recommendations on scripting for conversations with parents in crisis. The authors conclude that although these guidelines may seem

**Table 1. Comparing experience at two different health systems – Admission Process**

Admission Process	Experience #1	Experience #2
	Ian went to the emergency room at 2:00 pm on a Wednesday afternoon and waited in the lobby for an hour before triage. After triage, he waited in the lobby for another hour before being moved to a room in the emergency room. He stayed there until 11:45 pm, when a room was ready for him on the Heart & Neuro Vascular Care Unit. He arrived to his room after midnight. The whole process almost ten hours.	Ian was informed during his doctor’s appointment at 3:30 pm that they had admitted him to the hospital. He was told to go to the Neurosciences Institute, located at the hospital next door. He was met by the intake specialist, who called for a wheelchair transport who took him directly to his room. The whole process took less than 45 minutes.

like common sense, simple rules of etiquette are not always applied in the hospital at large. “A physician who can remember a patient’s hemoglobin level can also remember a patient’s name. These guidelines do not require the system to change; they require the physician to change.”<sup>1</sup>

At both hospitals, the majority of provider-to-patient interaction was with the nurse. Bedside rounding occurred at each change of shift, where the two nurses were in the

room discussing the Ian’s care and the plan for the next 12 hours. While the process was the same at both locations, he experienced a different level of care from each.

Exceeding expectations, not just managing expectations, and certainly not falling below expectations, is what hospitals say they strive for with each patient interaction. The last personal interaction that a hospital has with a patient is during the discharge process, sitting on the bed,

**Table 2. Comparing experience at two different health systems – Neurosurgeon**

Neurosurgeon	Experience #1	Experience #2
Body Language	The surgeon stood at the end of the bed, arms crossed, legs in a wide stance. His bedside manner was authoritarian. He did not express any overt concern for Ian or discuss his ability to find a solution.	The surgeon sat down in the post-op waiting room and stayed at eye-level with us after surgery. When standing, his hands were behind his back, at his side or active as he used them to emphasize the communication. When asked about the stiffness or pliability of the shunt tubing, the surgeon used the cellphone charging cable as his example, explained its approximate size, flexibility and discussed the material from which it was made. His bedside manner was one of concern for Ian, inquisitive, and determination to find a solution.
Communication style	The surgeon did not talk specifically to Ian or ask him questions; he spoke “at” us. On a number of occasions, he interrupted and talked over us.  When I mentioned that Ian had been a preemie twin, the surgeon pulled out his phone and showed pictures of his twins and talked at length about their shunts, without asking (or knowing) about the fate of our other son. He asked no questions of our previous experience, even though he was eager to share about his NICU experience.	Each time the surgeon entered the room he asked Ian what had changed, what did his head feel like, where did it hurt?  Our perception of the amount of time the surgeon spent explaining the situation and checking for understanding was that he would stay until every question was answered. There was never a rush for time.
Specific comments from the neurosurgeon to the patient	<ul style="list-style-type: none"> <li>• “I haven’t done this in a few years.”</li> <li>• “This isn’t rocket science. VP shunt revisions are not a big deal. Most kids have 15, 20 or more revisions by the time they’re your age.”</li> <li>• “We did this on a young woman a few years ago; she got an infection and died.”</li> <li>• “There is no right or wrong answer, but you need to make a decision about surgery.”</li> </ul>	<ul style="list-style-type: none"> <li>• “Even though I’m not on-call this weekend, the nurses will call me directly about you. The other surgeons don’t know about you and I’d rather handle this personally. I’ll be coming in each morning to round on you.”</li> <li>• “I only get 1/3 of my information from the x-rays, scans and reports; I’m relying on you to give me the other 2/3. You’ll need to tell me exactly what you’re feeling, what changes and where it hurts.”</li> <li>• “Tell me what has changed since I saw you last.”</li> <li>• “What other questions do you have for me?”</li> <li>• “What else can I answer for you?”</li> </ul>

**Table 3. Comparing experience at two different health systems – Neuro Unit Team**

Neuro Unit Team	Experience #1	Experience #2
Nurse / staff interaction	<p>The nurses on the Heart &amp; Neuro Vascular Care Unit were pleasant; unfortunately they were habitually unresponsive to requests for pain medicine, heating pad, pillow, menu, etc. Each call button request required follow-up call button reminders, as the nurse would forget. This happened on each shift, with each nurse.</p> <p>Only about half of staff who entered Ian’s room introduced themselves by name or role.</p>	<p>The entire team on the Neurosciences Institute floor was focused on Ian’s healing. The housekeeping staff, nursing assistants, registered nurses, rounding surgeons, food service staff, occupational and physical therapists and everyone else who entered his space were kind, quiet and totally competent. They always knocked first, introduced themselves and asked if they could do xyz (turn on the lights, take his vitals, look for a good IV spot, etc), and then asked “Is there anything I can bring you?” before they left the room.</p>
Alarm fatigue	<p>During the first overnight, Ian and his father’s sleep were interrupted every 20 minutes with an alarm, because his IV tube was crimped each time his elbow bent. He needed to use his call button each time to inform the nurse of the alarm. On several instances, he rang the call button twice as a reminder while the alarm continued to ring. In the morning at shift change, the new nurse was informed of the constant beeping and interruption of sleep; she immediately straightened and immobilized his arm with a towel and tape. Problem solved, albeit eight hours too late.</p>	<p>We did not notice any unnecessary beeping or buzzing during the entire length of stay. On the two occurrences when Ian got out of bed without warning, his bed alarm went off, bringing staff to his room within seconds to check on his safety.</p>

going through the discharge paperwork. This is the hospital’s last chance to leave a lasting impact on the patient’s experience. Studies show many hospital’s discharge paperwork is incomplete and lacks key components<sup>2</sup>:

- Hospital course and treatment missing up to 22%
- Discharge medications missing up to 40%
- Completed test results missing 33% - 63%
- Pending test results missing 65%
- Follow-up plans missing 43%

**Hearing the patient’s story: (Ian’s story)**

During my time at the second hospital, I received excellent care. I feel they met their goal of respectfully serving me and doing everything to alleviate the pain I was in. During my doctor’s appointment, the physician’s assistant was very kind and attentive when listening to the descriptions of my symptoms. I was particularly impressed that, before seeing me, she had taken the time to read my case files from the previous hospitalization, as well as my time at the children’s hospital. I felt she was very well informed and, while startled that I was to be immediately admitted, I trusted her judgment. She was capable and very courteous to me throughout.

The neurosurgeon spoke directly to me, in a relaxed, calm manner, meeting with me every day during my stay. He

met with my family before the surgery to describe the procedure and asked if we had any questions. He made sure that we were all in agreement about the operation before he went forward, including informing us of all possible complications, given the magnitude of the surgery (it was brain surgery, after all). I feel he was very concerned with my well-being, and I was particularly struck by how he instructed the nurses to call him directly, even if he was off work. I wasn’t expecting that level of interest.

Everyone, including the nurses, nurse assistants, lab technicians, food service and housekeeping staff, was helpful and introduced themselves upon entering my room, taking care to explain the various procedures they would need to do each time. They were kind and considerate, always knocking on the door before entering the room. At night, they came in quietly and kept the lights off when possible. They seemed happy to see me and also happy in their jobs.

Overall, they went above and beyond in terms of my patient satisfaction. I left with a solid plan of care. The surgeon met with me one last time before discharge and discussed how to identify adverse symptoms and when to return if they progressed to a dangerous point. He scheduled a follow-up in two weeks. I left with a feeling that my needs had been more than met.

**Table 4. Comparing experience at two different health systems – Discharge**

Discharge	Experience #1	Experience #2
Discharge process	Based on the statements by the nurse, the expectation was that discharge would occur in the midmorning time frame, after the surgeon had an opportunity to see Ian in person. Throughout the day, we inquired about the timing of the surgeon’s visit; the nurse would page, but never got a response. At 5:30 pm, we were informed that the surgeon had been in the OR and would not be coming in. The nurse was instructed to discharge him. Ian was released around 6:00 pm without ever seeing the neurosurgeon. The discharge process took more than eight hours, many hours past the expected length of time.	The night before the day of discharge, we were informed that he would be released the next morning. The neurosurgeon and the physician’s assistant rounded around 9:00 am and answered all of our questions, explaining next steps. At 10:00 am, the nurse went through discharge paperwork. By 10:30 am, Ian was loaded in the car and heading home. The discharge process took approximately two hours, and met our expectation of what we had been told to expect.
Discharge paperwork	<p>Eleven pages long, with general information, suitable for any patient:</p> <ul style="list-style-type: none"> <li>• Hospital’s name, location and phone number</li> <li>• Patient’s name, DOB, MRN#, Visit date (starting date only, no discharge date)</li> <li>• Medication list (take ibuprofen as needed for mild pain) Continue taking home medications</li> <li>• My After-Hospital Care Plan                             <ul style="list-style-type: none"> <li>○ Name of primary care physician, phone number</li> <li>○ Doctor instructions: (blank, no information)</li> <li>○ Discharge to: home</li> <li>○ Patient condition at discharge: stable</li> <li>○ Diet: healthful diet</li> <li>○ Resume activities: as tolerated</li> <li>○ Doctor’s instructions: (again, left blank)</li> </ul> </li> <li>• General follow up care: with primary care provider in two weeks</li> <li>• After you leave the hospital: general information on suicide, home health, DME</li> <li>• Acknowledgement form</li> <li>• Information sheet on general neck/back pain, non-specific to patient</li> <li>• General handouts: talk to your provider about medications, follow up care, call 911, when to seek medical care</li> </ul>	<p>Seven pages long, filled with important, patient-specific information:</p> <ul style="list-style-type: none"> <li>• Primary diagnosis</li> <li>• Name, location and phone number of hospital</li> <li>• Name of surgeon, office location and phone number</li> <li>• Admission information/date</li> <li>• Discharge information/date</li> <li>• Next steps (pharmacy order and detailed follow up appointment instructions)</li> <li>• Physician instructions specific to the patient: when to call the doctor, when to call 911</li> <li>• Information about providing feedback</li> <li>• Medication instructions</li> <li>• Prescription</li> <li>• Detailed instructions for patient’s post-op wound care and suggested activity level</li> </ul>
Confidence in what to expect once home	The discharge paperwork was reviewed at the bedside with the nurse. Ian was discharged to home with incomplete paperwork, void of any specific directions from the neurosurgeon. The information sheet on neck pain was not relevant to his specific issue. To be sent home, listed as stable, with no follow-up care directions, seemed negligent and impersonal. We had no confidence in Ian’s ability to transition safely to the home environment, or to manage his care.	The discharge paperwork was reviewed at the bedside with the family by the neurosurgeon, the physician’s assistant and the nurse. Information on signs of concern were clearly stated in writing and verbally. The staff used teach-back method to determine Ian’s comprehension of the information.

**The consumer’s ability to make informed decisions**

Had we known that a potential neurosurgery loomed in his immediate future, he would not have chosen to go to the emergency room at the first hospital. While that hospital’s reputation in the community is positive, they are not known for their advanced neurosurgical department. It just happened to be the most convenient emergency room

located near the patient’s home. This was a hard lesson learned for our family.

As consumers of our own healthcare, we each have the right to ask questions of our providers and understand the answers they offer. If we do not feel comfortable with the situation, we have the right to ask for changes in the care plan. Unfortunately, when you are in an emergent situation, the pressure to make decisions quickly without all the answers can feel overwhelming to a patient and

family, causing anxiety and creating additional stress. In the emergency room of the first hospital, we felt as if the neurosurgeon was quickly moving toward a shunt revision or replacement surgery for the next morning. We were becoming increasingly uncomfortable with this particular procedure being performed at this particular hospital, knowing there were two other hospitals within ten miles known for their neurosurgery departments. I asked the surgeon to convince us that we were in the right place for this procedure. The neurosurgeon answered, “A shunt revision is not rocket science; they are not a big deal.”

While our son was still in the emergency room of the first hospital, we considered our options of alternate hospital locations. As a certified patient experience professional (CPXP), I utilized all the resources I could acquire on short notice and with limited wireless connectivity; taking the following steps to help make informed decisions:

- Accessed [www.medicare.gov/hospitalcompare](http://www.medicare.gov/hospitalcompare) to compare the HCAHPS<sup>3</sup> patient satisfaction survey scores from several hospitals in nearby vicinity
- Contacted three close friends who were physicians in the area for advice and recommendations
- Spoke directly to the neurosurgeon about our concerns, asking specific questions about the quality of care our son would receive there versus another hospital in the area

The information obtained from this search left our family feeling troubled. There was no obvious reason to ask for a transfer to another hospital, yet we felt like our son’s needs were not being met. Despite our gut feelings telling us otherwise, we remained at the first hospital for the next three days.

### **The lasting impact of compassionate communication**

Thirteen days after the first hospitalization, we were sitting in the appointment room of Ian’s new neurosurgeon, when the physician’s assistant came in apologetically. After introducing herself, and describing her role, she sat down right in front of Ian, at eye level, and smiled; recognizing the amount of pain he was in, she asked him how he was feeling. She emphasized how sorry she was that we experienced a 20-minute wait, but she indicated that she had spent the time reading his NICU chart from 1991, focusing on his initial brain hemorrhage, hydrocephalus and shunt surgery. It was clear that not only had she reviewed his past medical history, but she referenced key points of his past throughout the conversation. To help illustrate the patient’s current situation, she displayed on the computer the x-ray from the previous hospitalization showing the breakage in the shunt tubing near his neck and explained that the pain he was experiencing was related to that breakage. She also displayed two CT scans,

for a side-by-side comparison. One was the most recent, from two weeks prior, and the other was from a 2003 well-visit appointment to his pediatric neurosurgeon’s office at the children’s hospital. Looking at both scans and seeing the obvious difference in ventricle size between the two images was shocking; that visual aid was the first time we fully understood the seriousness of the situation. After all questions had been answered, the physician’s assistant very quickly transitioned the conversation to the next step, which was hospital admission and surgery. Without mincing any words, she said that they had already admitted Ian to the hospital, and he would be going into surgery the next day, as soon as they could fit him into the schedule. While feeling shell-shocked by the unexpected news, there was extreme comfort in knowing a plan was in place with competent providers at the helm, ready to move forward.

The physician assistant’s communication style:

- She introduced herself and explained her role
- She apologized for the length of wait time
- She sat at eye-level and spoke directly to Ian
- She explained what she had done to review his history
- She showed comparative images of his ventricles, illustrating the size difference
- She conveyed compassion, kindness and competence
- She had a plan and helped him quickly shift gears

### **The impact effective communication can have on a patient’s confidence in his provider**

The first time we met the neurosurgeon at the second hospital was in the operating room prep space, minutes before Ian’s surgery. He introduced himself and spoke directly to Ian, explained the procedure, the expected length of time and the expected outcomes. He encouraged us to ask questions. Even though we had never met him, our perception of the neurosurgeon’s style and manner and his apparent competence as a clinician were based on his ability to communicate effectively and relate personally to Ian. Following surgery, he met with us, explaining the procedure and what his expectations of outcomes were, and again provided the space for questions. When it became apparent a second surgery would be required the following day, the neurosurgeon met with us very early the next morning. He knew we were disappointed and apologized. He provided the time to discuss what had happened and what the new plan was. His ability to effectively communicate and connect with us on a personal level, even within a short amount of time, led to a feeling of trust and confidence in the physician. Following the second surgery, the neurosurgeon informed us that he would be rounding on Ian each morning, until discharged day, regardless of whether he was on-call. We saw him for the next six days, and left the hospital feeling 100% confidence in the neurosurgeon and the facility.



The neurosurgeon's communication style:

- He introduced himself
- He explained Ian's diagnosis and the plan of care using plain language and checked for understanding
- He offered unlimited time for us to ask questions
- His personality exuded kindness and concern, as well as competence
- He made Ian feel like his priority
- He sat at eye-level when able
- He used a prop (cell phone charging cable) to help explain the shunt tubing
- At the follow-up appointment three weeks later, he had a shunt and tubing available in the room for Ian to hold and feel, to help our understanding of how the equipment works

### Defining the patient experience

What defines a positive patient experience? While a beautiful facility, renovated rooms, nice view from the patient's window, soft color palette and consistent navigational signage are important, what moves the patient experience needle significantly from negative to positive is system-wide clinical excellence delivered by every member of the hospital staff, who are universally committed to understanding the patient's and family's perspective, and working towards the patient's goals of getting better and going home.

As consumers, we make choices everyday based upon the quality and price of any given product, the efficiency of the service, the interaction with the service providers and the atmosphere and culture of the environment. Healthcare is no different; the consequences of one bad patient experience in a hospital will most likely be reflected in the consumer's activation of their power of choice. Next time, the patient will probably choose to go elsewhere if the entire team hasn't been educated on the importance of positive patient experience, as well as the consequences of a bad patient experience. Moreover, many of those dissatisfied patients will share their story with their friends and family, usually via social media. What used to be a singular event that ended when the patient mailed their satisfaction survey or a complaint letter to the hospital and waited for a response is past. Hospital evaluation has now become a viral, instantaneous shout out to the hospital's surrounding community through social media and other fast-time resources. Hospitals no longer have the luxury of putting up a billboard on the highway that says We're Number One. They have to prove it every day, on every shift, with every patient encounter.

### Summary

The age of your child does not matter. As a parent, you never get used to seeing your child in pain. The realization that you have little to no control over their healthcare emergency forces every parent to immediately wish that they could magically trade places with their child. Try as you may, and often under tremendous time pressure, you do the best that you can, attempt to research the situation, ask the right questions of the team, and hope for the best outcomes. However, sometimes nothing can be done to alleviate your child's painful experience. This patient's experience ended on a positive note. Following the second surgery, the patient remained in the hospital for six days and was discharged to his parent's home to recover for another week. At the time of this publication, the shunt is functioning fully.

### About the author

Laura Miller is a certified patient experience professional (CPXP) and the mother of the patient in this article. She is a healthcare consultant who supports hospitals and healthcare organizations in their efforts to engage the patient and family in quality improvement processes and projects. Laura is an educator and nursing content writer who trains healthcare professionals throughout the country on the topics of improving the patient experience, improving the provider to patient communication, supporting families in crisis, exploring the voice of the patient panel, and more. Her passion for improving the patient experience is driven from decades of parenting a child who has had complex medical care needs throughout his life. Her passion for staff training is driven from seeing the positive, lasting impacts to the patient experience that can be made from the exposure to quality professional education.

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