Noah's Story: Please Listen

By Tanya Lord, MPH, PhD

Communication in healthcare—provider to patient, patient to provider, and provider to provider—is at the heart of improving quality and patient safety. This is the story of my son Noah, whose experience with the healthcare system 13 years ago inspired me to work toward making positive changes in hospital care. His story is interspersed below with my present-day commentary about what I now understand about how poor communication contributed to his death. I hope Noah's story inspires patients, families, and providers to communicate as effectively as possible and helps other patients and families avoid harm.

January 25, 1995
Boston, Massachusetts
Noah was born healthy and happy, but as an infant and toddler he did not babble or verbalize in the way that was expected.

1997
Boston, Massachusetts
Noah's speech development continued to be somewhat delayed, which was determined to be due to periodic hearing loss caused by multiple ear infections and chronic fluid in both ears. He was referred to an otolaryngologist in Boston who recommended placing tubes in Noah's ears to allow fluid to drain. The doctor also considered whether Noah might have sleep apnea for which he would recommend removing his tonsils and adenoids. A sleep evaluation determined that Noah did not have sleep apnea, and therefore only tubes were necessary. They were put in place during uneventful surgery.

Noah's surgeon and I were in sync and communicating well. Noah's surgery in Boston was successful, and his symptoms began to diminish.

1999
Cherry Hill, New Jersey
Two years later, we were living in New Jersey. Noah was 4 years old and enrolled in a Special Education preschool, and his speech was improving. He again began having ear infections, and in the spring of 1999 we visited an otolaryngologist in Philadelphia. At the initial appointment, the nurse asked me if Noah snored. That week he had a cold and was snoring, so I answered yes. The nurse asked about sleep apnea, and I told her that a previous evaluation found he did not have sleep apnea. The otolaryngologist told me that Noah's tubes had fallen out. He thought Noah should have another set inserted and have his tonsils and adenoids removed. We left the office with an appointment for surgery several weeks later.


Noah Lord

This was the beginning of our communication problems. I knew from the otolaryngologist in Boston that Noah did not have sleep apnea. I did not, however, understand the connection between sleep apnea and snoring. I answered the nurse's question truthfully, without understanding the type of snoring the nurse was looking for. The otolaryngologist read the intake form filled out by the nurse and assumed that because I had mentioned snoring, Noah must have sleep apnea, which would be improved by removing his adenoids and tonsils.

Friday, June 4, 1999
Voorhees, New Jersey
I talked with my mother about the surgery, and she reminded me about my own childhood history of ear infections and that with only my adenoids removed, the problem had resolved. I also remembered that when the physician in Boston talked about the possibility of surgery he had explained that the adenoids are near the Eustachian tubes and could have contributed to Noah's ear problems by pressing on and restricting adequate flow through the tubes, leading to retained fluid and ear infections. Tonsils were not a factor in Noah's symptoms. I did not want him to have unnecessary surgery, so one week before the scheduled surgery, I requested another appointment with the otolaryngologist. I told him that Noah had stopped snoring and reminded him that in Boston we had determined that he did not have sleep apnea. I also told him my own history and that I really wanted him to remove only Noah's adenoids. The otolaryngologist told me that the tonsils still should come out. He felt that they were large, might be a problem in the future, and while Noah was already having surgery, he might as well have his tonsils removed, too. Otherwise, Noah might be back in 6 months, and it would be cruel to subject him to general anesthesia twice in one year. The physician in Boston had said that Noah had large tonsils but that this was not an indication to remove them. I lacked confidence in my own opinion and agreed to the scheduled surgery against my own judgment.

At the time, I knew a breakdown in communication had occurred and tried to rectify it. The surgeon did not recognize that the snoring was no longer an important symptom and continued with the initial plan without giving serious thought to what I was saying. I didn't feel comfortable with the scheduled surgery, but I wanted to trust the physician and reassured myself that the surgery was routine. Wanting to make the best decision for my son, I continued with the original plan despite the fact that Noah did not have obstructive sleep apnea or other symptoms that would indicate his tonsils should be removed.

Friday June 11, 1999
Philadelphia, Pennsylvania
Noah's surgery was done as an outpatient procedure in a children's hospital and was reported to be uneventful. We were told that he would be discharged when he was able to drink fluid. In the recovery room, he was vomiting and refused to drink anything. We were told that the vomiting was caused by the anesthesia and would go away soon. We were discharged home.

Another form of miscommunication occurred at this point. It wasn't clear to me why Noah was being discharged. I had been told one thing would happen, but something else happened. I did not question why Noah was discharged before he'd had anything to drink. The nurses had decided that Noah was vomiting from the anesthesia, were confident that it would stop soon, and that he would be fine being sent home. It is not clear if this information was communicated to the surgeon.

Saturday, June 12, 1999
Cherry Hill, New Jersey
At home Noah continued to vomit, had developed a slight fever, was constantly making small coughing sounds, and continued to refuse to take anything by mouth. I put him in pull-up diapers because he was too weak to get to the bathroom, but he had stopped urinating. I telephoned the on-call resident five times that day to report on Noah's worsening condition. Each time I called, I asked the same questions and was given the same answers. The residents thought Noah was vomiting because he was in pain and not able to take any oral medication. They recommended Tylenol suppositories, 5 every 6 hours, and said that he would start drinking once the pain was better. They asked me if Noah was vomiting blood. Thinking that vomited blood would look bright red, I told them no. They never explained that blood that had been swallowed and vomited would look like coffee grounds, which is what it looked like. Noah continued to vomit and refuse anything by mouth throughout the night.

Here we missed an opportunity for a care provider to listen effectively and communicate important information. Calling five times between early morning and late evening was a clear signal that I knew something was very wrong with Noah. Throughout that day, I spoke to a succession of providers who were either new to the case or did not recall my previous phone calls. Although I had to repeat my concerns and answer the same questions, I assumed my concerns were being heard clearly and understood. I believed they were giving me the best advice,

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and there didn't seem to be anything for me to do but continue to care for Noah and try to get him to drink. I had been awake for 48 hours before making the first call and did not understand that vomited blood can look like coffee grounds or that not urinating is an important symptom. Under these conditions, it is likely that information and the urgency of the situation was lost. Providers can improve communication in these situations by listening carefully, sorting through what they are hearing, and asking the right questions to elicit the most accurate response. Also, there is a limit to the usefulness of telephone communications and a time for physical re-examination.

Sunday, June 13, 1999
Extended Emergency Department
Philadelphia, PA

I talked to the covering otolaryngologist by phone three times during the morning and finally asked if I could bring Noah in to be seen. We arrived at the emergency department (ED) around 11 a.m. Noah was evaluated by different clinicians. I wasn't sure who they all were, except for his surgeon who consulted by telephone. It was determined that Noah was severely dehydrated and was admitted to the Extended ED where he could be observed for up to 23 hours. He was given intravenous fluids, medication to stop the vomiting, and morphine for pain. He still refused to take anything by mouth and continued to cough. He did not seem to be getting any better. He couldn't stand to have us touch or hold him, and my concern for his condition increased as hours passed with almost no information and no visit from his surgeon. I asked at the nurses' station several times about Noah's symptoms, his lethargy, pain, and refusal to drink. The nurses in that part of the ED were filling in from other areas and were not familiar with post-operative or emergency patients. At one point, an older clinician poked his head into the room and asked how Noah was doing. I answered that he wasn't doing well and he said, "Okay," and left without entering the room. At no point during the stay in the extended ED was Noah's surgical site assessed.

Communication with our family and the care Noah received clearly took a turn for the worse at this point. None of the clinicians took responsibility for Noah's care. The ED attending saw Noah as a surgical patient and, therefore, did not make sure that Noah's surgical site was assessed. Though the surgeon was consulting by phone, he assumed that Noah was the ED's patient and did not see himself as responsible for caring for him. Noah was treated for dehydration and not as a post-operative patient. There were otolaryngologist residents involved in Noah's care, but it was unclear who was responsible for assessing and monitoring his surgical site. The nurses providing information to the surgeon were not ED nurses. and they lacked experienced in identifying the acuity of Noah's condition. The information they relayed to the surgeon, therefore, was flawed. At no time in the Extended ED did I feel comfortable with the care Noah was receiving. I did not know what was wrong, but I knew that he was not okay and was not getting better. The care in the ED was not at all patient centered, and no thought was given to partnering with us to help understand Noah and provide the best care possible. I was clearly concerned, and there was little being done to address those concerns. Along with faulty communication, there were examples of poor quality of care because the clinicians were not able to look beyond Noah's primary diagnosis of dehydration and see him also as post-operative.

Monday morning, June 14, 1999
Extended ED to Home
Cherry Hill, New Jersey

The surgeon told me by phone that Noah was dehydrated and that he was going to be discharged with a PIC-line. A visiting nurse would come to our home to hook up the fluids. A nurse came in a couple hours later and told me again that Noah was going home and a visiting nurse would come to our home at 6 p.m. to hook up the fluids. She asked me to sign a paper, which I thought was my consent to have the nurse come to the house. I sat with Noah who was still coughing, not eating or drinking, extremely lethargic, and appeared to be in a lot of pain. He was no better; I thought that he actually was getting worse. After a couple of hours I went to the nurse's station, told them I was very concerned about my son, and asked them to please contact a doctor with whom I could discuss Noah's condition. The nurse informed me that Noah had already been discharged and therefore there was no one she could call. The paper I had signed was not a consent form but Noah's discharge papers. Not knowing what else to do, I called my husband and we took him home.

I have learned since then that the hospital's discharge protocol was not followed that morning. Noah should not have been discharged without having been seen by an ED physician, not before the care team did rounds. He should not have been discharged until I fully understood and agreed with the plan. The surgeon had no responsibility to discharge Noah, but the nurse wrongly assumed that the surgeon suggestion for fluids at home was also a discharge order. When the attending did come to Noah's room, he was informed about the discharge. Later he told me that he did not understand why Noah had been discharged without a discharge order and assumed that I had wanted to leave and insisted on being discharged. I saw no improvement in Noah and was concerned that he was not getting the attention he needed. My ability to voice my concerns was hampered by exhaustion, concern for Noah, and lack of understanding of hospital procedures. Had I been told that Noah was being discharged, I would have refused to sign the paper and would have insisted on seeing a physician. Had providers listened to me and followed established protocols, Noah would have remained in the hospital.

Monday afternoon, June 14, 1999
Cherry Hill, NJ

Noah continued to continued to cough and refused to drink, eat, or take anything by mouth. About 3 or 4 hours after we got home, I helped Noah to the bathroom, at his request. When it was time for his Tylenol suppositories, I helped him lie on the couch. He lifted his head, his eyes got huge, and he said quietly "Mommy?" He then began to cough and bleed profusely from his mouth and nose. I screamed for my husband to call 911. The blood came so fast, it began to block his airway. At the time I was a trained lifeguard and knew how to preform CPR. Noah stopped breathing. I was able to clear his airway and got him breathing three times before a clot blocked his airway completely. I was not able to clear his airway, and he died before the EMTs were able to get to our home.

In addition to poor quality of care, a series of miscommunications and lack of partnering with me, or practicing patient-and-family centered care contributed to this tragic outcome. It is the provider's responsibility to ensure that patients and/or family members have sufficient understanding and information. What is obvious and well known to a provider may not be known to the patient or families, such as my not understanding what vomited blood looked like or that I was signing discharge papers.

It remains unclear what actually caused the fatal hemorrhage. The surgeon speculated that the eschar covering the surgical site released prematurely, possibly because of the severe dehydration. There was no way to determine if other factors such as surgical technique were a root cause. The risk of post-tonsillectomy hemorrhage is about 1 in 1,500; fatalities are very rare. Bleeding is a signal to seek medical care. Had Noah still been in the hospital, the blood clots could have been cleared, the bleeding stopped, and it is unlikely that the hemorrhage would have been fatal. Though it is suspected that Noah had begun bleeding before the hemorrhage, this was not documented or observed, partly because of lack of complete assessments.

July 1999
Cherry Hill, New Jersey

During the weeks following Noah's death, only his surgeon would return our calls. We had so many questions and no answers. The surgeon continually said he did not understand what had happened to Noah. A neighbor told us about Compassionate Friends, a national support group for bereaved parents, but nobody from the hospital offered any help or suggestions.

Because Noah's case was sent directly to risk management, the social-work staff was not informed of his death. My family received no child-loss support services or recommendations. A decision was made internally to have only Noah's surgeon contact our family, given that he had an established relationship with us. The hospital did not necessarily intend to close off other avenues of communication, and there was no consideration of how this choice would appear to our family. We felt shunned and excluded from discussions that hospital staff members might be having about Noah. The hospital's decision about follow-up communication also did not take into account the enormous burden that was being placed on the surgeon. Responding effectively to a family that has just suffered a sudden and traumatic death takes some training and understanding. The surgeon, who was also suffering, was constantly putting himself into the path

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of a grieving mother experiencing and expressing a spectrum of emotions. A third-party professional could have mentored and mediated the conversations between the surgeon and me to minimize the additional angst created by continued unproductive conversations. The people who had the answers were hiding behind the doors of the hospital, where I was no longer welcome.

November 2010
Philadelphia, Pennsylvania

Ten years later, I had a master's degree in public health and was finishing a PhD with a focus in patient safety. Noah's death had forever changed my family, and I wanted to be involved in improving the system that had failed us. When I began presenting Noah's story to medical students and other clinicians, I contacted the hospital. This time the doors were thrown wide open. I was invited to come and learn what had changed in the last 10 years. I also was given the opportunity to meet and forgive the clinicians who had taken care of Noah. This time, many of my questions about what had happened and what went wrong were answered , and the hospital acknowledged many of the memories and concerns that I had about Noah's treatment.

It is never too late to do the right thing. In hindsight, there was not one single event that caused Noah's death. Unfortunately his death was an example of how people working in a flawed system sometimes do not provide the best care to patients. The obvious lessons from Noah's story are about the poor communication that occurred throughout his care and following his death. But there are some subtle, equally important lessons to be learned about the value of partnering with patients and their families even after an error or adverse event has occurred. Whatever the circumstances of a child's death, the parent's well being should become the top priority for healthcare providers even while everyone is trying to determine what happened. There are hospital and community services for every type of loss, and these need to be provided to a family suffering the loss of a child.

As time went by, the hospital missed another opportunity. When I visited many years later, they might have realized that I was a prime candidate to serve on a patient-and-family advisory council. I was passionate and eager to learn and did not harbor anger toward the hospital. Providing an outlet for that energy and passion would have benefited everyone. Let patients be part of the solution. This is a different way to look at patient/family centered care. Patients and families are valuable partners when care is going well and just as important when things don't go as planned.

Communication is at the heart of an accurate diagnosis, patient and staff satisfaction, patient safety, and even reducing malpractice risk. In 2005, faulty communication was associated with approximately 70% of all hospital sentinel events (Joint Commission, 2007), and in 2010 it was shown that there were no significant improvements in communication. Improving communication is not the same as changing procedure methods, redesigning processes, or implementing typical patient safety interventions. Effective communication depends on the culture of the institution as well as on individuals concerned. The hospital culture has to be one of openness to questions whether they are from a co-worker or patient. As simple and basic as it may sound, culture change is perhaps the most difficult thing to accomplish. Speaking, listening, cultural sensitivity, and literacy skills can be taught, but communication begins with a basic respect for the person receiving care and an understanding of how important it is to listen and to leave assumptions at bay. ▌

***Tanya Lord** was a special education teacher when Noah died. After his death she read The Institute of Medicine's report* To Err Is Human *and realized that the errors responsible for her son's death were not unique. This created a desire and determination to better understand and work towards improving health care. Currently she has completed a master's degree in public health and a PhD in clinical and population health research and is completing a post-doctoral fellowship. Lord shares her personal and professional experiences in presentations and workshops for medical staff and students focusing on the importance of effective communication with patients before and after an error. She also is a co-founder of The Grief Toolbox (www.thegrieftoolbox.com), which offers tools to help those along the grief journey. Lord may be contacted at Tanya.Lord@umassmed.edu.*

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