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Immortalization: Placement of a Percutaneous Endoscopic Gastrostomy Tube and Tracheostomy in a Neurologically Devastated Patient

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Introduction

Making Ethical Decisions: Stories from Surgeons

Narrative Inquiry in Bioethics Editors

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Abstract. Surgeons share their challenges and dilemmas in making ethical decisions in these twelve personal stories. The three commentary articles draw out the lessons the stories address. The commentators come from diverse backgrounds including sociology, bioethics, nursing, and surgery.

Key Words. Decision-Making, End-of-Life, Informed Consent, Medical Uncertainty, Moral Distress, Patient-Surgeon Relationship, Surgical Ethics, Technological Imperative.

Four principles—respect for autonomy, beneficence, nonmaleficence, and justice—have gained special currency within contemporary medical practice (Beauchamp & Childress, 1979). These principles are constantly in the background of the stories in the following narrative symposium even when the authors do not explicitly express them. It is clear from reading these narratives that the surgeons who provided our stories have a strong desire to offer their patients (and patients' families) respect and that they desire to do good and avoid harms. It is also clear that surgeons do not always know how achieve these aims when confronted with unusual patient requests, uncertain prognoses, competing goals, and other challenges regularly presented to them.

The Call for Stories

The call for stories asked surgeons for stories on their engagement of ethical issues in their clinical practice or research, and expressed special interest in stories about:

... conflicts between patient requests and clinical judgment, interactions with device manufacturers, social justice challenges, the boundaries between research and innovative surgery,

tension between surgical training and practice, medical errors disclosures, or any other specific ethical challenges individuals have faced in their work as surgeons.

As with other calls for stories, authors we asked to consider the following when sharing their stories:

- What about your experience was positive? What was negative? Was anything surprising?
- What could have been done differently to improve your experience?
- What would you want to tell future surgeons, people who find themselves in a similar position, patients, or policymakers?

They were asked to refrain from the use of heavily technical medical jargon and to focus on the issues they thought most important.

The call was sent out on various listservs, posted on NIB's webpage, and sent to colleagues and experts to distribute.

Response

We received many good proposals and invited 15 people to send full stories—13 of whom sent finished stories. The 12 stories selected for the print

edition were sent to commentators. The additional story can be found in our online-only version of the journal (on Project MUSE) as a supplemental story.

Commentary Articles

Christine Grady, Chief of the National Institutes of Health Clinical Center's Department of Bioethics, draws out the prominence that uncertainty plays in these stories. Uncertainty affects communication with patients and families, informed consent, causes moral distress, raises concerns about offering treatment that may be futile or even inappropriate, and generates confusion about the limits of professional responsibility. She says, "Surgeons are prototypically confident in their recommendations. Yet, these surgeons poignantly describe uncertainty. Sometimes the uncertainty leads to careful reflection, taking a stand, or changing practice, and sometimes it lead to moral distress." She concludes that the surgeons who wrote these stories share valuable insights with us and remind us that though "imperfect they are quite extraordinary."

Renée Fox, renowned medical sociologist and Annenberg Professor Emerita of the Social Sciences at the University of Pennsylvania, notes several major themes in these narratives: end-of-life issues; the struggle to be inclusively empathetic; social justice; and medical uncertainty, which can be exacerbated by disagreement among colleagues. Of particular note is the fact that so many of the stories deal with "decisions that surgeons are called upon to make when they are caring for patients in disastrous conditions, or who are terminally ill." She also makes special note of the fact that many themes and moral discussions special to surgery are not found in these narratives such as the fact that surgeons must cut into a living person, any acknowledgement of medical errors (which was a topic specifically mentioned in the call for stories), nor was there any mention of the importance of the surgical team or the possible discord that can arise within this team. She wonders why these 'gaps' exist in the collection of stories and calls for more work to be done to draw out these missing ideas.

Christian Vercler, an assistant professor and co-chair of the clinical ethics program at the University of Michigan Health System, brings his own experience as a plastic surgeon to bear on these stories. He makes note of the fact that the relationship between surgeon and patient is different from other medical encounters because the nature of surgery inflicts pain (even if it is for the good of the patient), is "irreducibly personal," and crossing the gap of knowledge between the surgeon and the patient or patient's family is challenging and difficult.

Conclusion

This narrative symposium is offered in the hope that these stories will lead to better discussions between surgeons and their patients or patients' families and to greater respect and dialogue between medical colleagues who may disagree about various treatment options. We also wish to express our interest in publishing qualitative research aimed at investigating surgeons' perspectives on those issues that did not come up in this symposium.

References

- Beauchamp, T. L. & Childress, J. F. (1979). *Principles of Biomedical Ethics*. New York: Oxford University Press.

Personal Narratives

Patient vs. Self in Surgical Practice

Ana Berlin

When I first graduated from surgery residency and entered into practice as an attending general surgeon, I felt like I was no stranger to ethical challenges facing surgeons. In fact, it was, and still is, precisely the difficult decision-making so often encountered in general acute care surgery that drew me to my

chosen field. I have found that I thrive on the dilemmas regularly encountered on general surgery call; diagnostic dilemmas, ethical dilemmas, and treatment dilemmas are the stuff of life in acute care surgery. The quintessential case is that of the patient who has been dying for weeks, or even months, but whose sub-acute decline has gone unrecognized by the generalist, oncologist, or other-ist taking care of him or her, until an acute event—typically an intra-abdominal or vascular catastrophe—prompts surgical consultation. In these situations, often at odd hours and in less than ideal surroundings, I break into my role of patient and family counselor, determining the decision-makers and stakeholders, and delving into a process of narrative inquiry to elucidate the patient's goals of care. Often, I need to break bad news . . . and then offer hope for a better—more humane, more comfortable, more peaceful—way of death. As one of my fellow trainees once put it, one of my most important skills as a surgeon is my ability to “glide the plane down for a soft landing.” My general surgery education, coupled with specialized training I have specifically sought out in ethics and palliative care, has prepared me well for these situations.

What I was less well prepared for as I entered into practice was a different sort of ethical dilemma, the one that plays out not on the wards, but in the academic halls and offices and homes and hearts of surgeons. It is the tension between obligations to the self (be it personal, academic, or other commitments) and the patient. No doubt surgery residency provides fertile ground for honing one's sense of self-sacrifice, and, to a lesser extent, work-life balance. But my first week on call as an attending at a large academic medical center had me in for some big surprises. The sentinel event that signaled a new reality occurred on the day following a long string of nights on call. During that last overnight, I had taken on an ICU patient whom I had been asked to evaluate for an intestinal obstruction. My impression was that the patient did not have a mechanical blockage, but rather a functional reason for her bowel to be distended beyond its normal capacity, almost but not quite to the bursting point. Although she had no signs of impending

catastrophe when I examined her one last time at the end of the day, I knew that she would need careful attention overnight so as not to miss a red flag indicative of deterioration in her condition. So, before going home, and looking forward to a good night's rest, I telephoned the on-call surgical attending. I reached out to him as a courtesy to let him know that the residents, who remain in-house for 24 hours a day, would be assessing the patient every six hours overnight. My hope was that the attending, having heard about the patient and her context from me, would be better poised to react to a report from the residents if a change were to develop. The reaction that ensued opened my eyes to the fact that my understanding of patient ownership had been completely misguided; contrary to the attending group practice model I was familiar with from residency training, the culture among attendings at my new institution was one of strict individual patient ownership, 24/7, on call or not. Should a problem with my patient develop, it would have to be me who would come in overnight and take her to the operating room, even though I was not “on call.”

Although in retrospect I think my family and I had been hopelessly naïve, at the time, we didn't feel adequately prepared to handle the uncertainty and commitment required by the demands of my new position. Yet it appeared there was no choice but to flex and give in. Sometimes this has meant internal handwringing about how to manage a patient knowing that—although we learn that “the patient must always come first”—in reality, weekend plans, a sick parent or child, a rapidly approaching grant deadline, a conference call, or important academic meetings do have to be juggled and weighed along with clinical and hospital system factors. Sometimes it has meant learning that physiology is thankfully forgiving, and that an appendectomy can be delayed several hours in order to accommodate other demands. Sometimes it has meant opting for surgical intervention sooner in the course of a patient's illness, because of the greater inconvenience of a late failure of more conservative management. Sometimes it has meant taking on a patient as a “favor” to the on-call surgeon

(and also to the patient), because the surgeon on call is stretched beyond capacity and perceives no option but to manage the patient in a suboptimal manner due to limited resources of time and energy. Of course, this means that other commitments are set aside. . . .

Indeed, when we speak about balance in surgical careers, it is often understood, or assumed, that we mean balance between one's "career" identity, and one's "noncareer" identity. The fact that these are construed as two distinct entities is interesting in and of itself. But what often goes unrecognized is that there are other career obligations that can also get in the way of optimal devotion to a patient. Whether it be clinical demands, such as multiple simultaneously sick patients (a not altogether uncommon occurrence), or academic demands, there is no doubt that being a surgeon involves keeping many balls in the air, and would be overwhelming at times even if it took place in a vacuum, isolated from the rest of everything we call "life." But just what are the limits of one's professional responsibility to a patient? What constitutes a justifiable exception to that responsibility? No one teaches young resident trainees just how to perform that calculus, despite the fact that once in practice, it is next to impossible to escape.

According to the American College of Surgeons' webpage on "surgical career lifestyle issues," after completion of training, the average general surgeon can expect to work 50–60 hours per week, excluding time designated as "on call"; solo practitioners can expect to be on call "as much as all the time", compared to once a week for members of a large group. Increasingly, young surgeons, particularly women, are seeking part-time positions, to help ease the burden of balancing clinical and other commitments, whether they be personal or academic. But part-time positions can be hard to come by, and many job applicants are faced with similar responses from department chairs and administrators. "A part-time employment model is not one we think works well for clinical faculty." This is understandable, given the multiple and frequently unexpected demands imposed by clinical practice, as I have outlined above. More often than not,

part-timers end up working nearly just as hard as their full-time colleagues, but getting paid much less. But how is being a part-time surgeon any different from being an academic surgeon, when it comes to that element of "protected time"? Academic practice typically involves splitting one's effort into a percentage of clinical time and academic time. Ideally, the academic time is protected from clinical obligations, by contractual coverage agreements and the like. In practice however, it is extremely rare for this "protected academic time" to be guaranteed. This creates a fallacy in which the academic surgeon must operate, squeezing in academic pursuits between rounds, clinic, the OR, and the various emergencies and intangibles that regularly occur. So, in answer to those who would declare part-time surgical work impossible, I would simply argue that it is no less possible than it is to be an academic surgeon. It is not easy, but it is an "employment model" that has prevailed for quite some time.

Thankfully, it is not all calamity and woe in the field of academic surgery. I have come to value many aspects of this the primary patient ownership approach to patient care. I enjoy the control, autonomy, continuity of care, and accountability that being a "solo practitioner" involves. I know that I am more attuned to the details of my patients' clinical courses and recoveries, and am thus poised to learn more from the experience of caring for them as a result. When patients suffer complications, although one yearns in part to be able to "pass it off to the next guy," there is a better part of oneself that thrives on overcoming the challenge and emerging stronger on the other end. Most of all, I have found that my relationships with my patients, which I always considered to be strong and gratifying, have flourished under the umbrella of near-total personal responsibility and ownership. In fact, I am not alone: according to the 2013 Medscape General Surgeon Compensation Report, 38% of surgeons list "gratitude/relationships with patients" as the most rewarding aspect of their job—the greatest percentage among all other possible responses. It is easy to understand why so many surgeons cling to this time-honored practice model. As my colleagues

and I discuss ways in which to improve our system, I find myself ambivalent, even to a degree holding back against change, since I know I will miss some of the rewards of the current model that I have come to appreciate.

I do believe that these conflicts will have systems-based solutions in my lifetime. More and more, we will shift practice models from the individual solo practitioner mold to more modern, flexible group practice and team-based models. But these models require a great deal of trust in our colleagues, and bring on ethical challenges of their own, particularly when it comes to accountability for outcomes. Narrative inquiry in ethics and qualitative research are valuable for defining how we understand and grapple with these ethical dilemmas. Hopefully, openly sharing how we as surgeons experience and process these dilemmas will not only shed valuable light on the necessity for change, but also guide our path to practice patterns that will be more humane and effective for practitioners and patients alike.

Consenting for Novel and Dangerous Surgical Procedures with Minimal Supporting Evidence

Michelle J. Clarke

Frank¹ was a 19-year-old man referred to me after a workup for back pain led to the discovery of a large, aggressive tumor in his sacrum. The tumor wrapped around the nerves controlling bowel, bladder, and leg function. We performed a needle biopsy and learned that the tumor was an angiosarcoma, an extremely aggressive and usually deadly form of cancer. However, the tumor was unique in that it *theoretically* could be

cured if removed in one piece. But, to do so would necessitate sacrificing the nerves, leaving the patient irreversibly incontinent, lacking sexual function, and confined to a wheelchair.

Once we knew the diagnosis, Frank came to the office with his family to discuss treatment options. He appeared terrified and was almost silent through the appointment, deferring most questions to his parents. Due to the speed of tumor growth, we discussed palliative therapy, conventional treatment, and the one-piece or “en bloc” surgery, which was new and unproven for his disease. Based on the remarkable tumor growth we noted during the work-up, with palliative treatment the patient would likely survive for less than six months. Conventional treatment, in which surgery is done to remove part of the tumor while sparing the nerves to bowel and bladder function, was known to have a high rate of recurrence and death. Further, this tumor didn’t respond well to radiation and chemotherapy, so chance of survival was limited, although his life might have been extended for a short period. Thus our conversation turned to the novel “en bloc” procedure.

The en bloc procedure offered a hope of long-term survival unlike the other options. However, this came with an enormous cost. The surgery itself would be planned to occur over three days with five separate surgical teams and a very real chance of major complications or death. Nerves to bowel and bladder would be cut, irreversibly leaving the patient without sexual function, and completely incontinent with a urinary catheter and colostomy. Walking was expected to be disrupted or potentially impossible due to the nerve resection. We went to great lengths over the course of many visits to describe the impact of the surgery on the patient’s function, and the impact on his quality of life. To make matters more challenging, as this procedure was so new and the tumor so rare, research did not yet exist to quantify his likelihood of long-term survival.

Personally I was very uncomfortable with the situation. From a medical standpoint, the surgery offered was the best distillation of research and professional experience. En bloc surgery offered the best—if not the only—chance for survival in

¹ Name changed to protect privacy.

this young man. Additionally, having treated many spine-injured patients I was aware that many patients with similar deficits led happy and productive lives following an emotional and physical adjustment period. However the surgery was also extreme. I worried that we would not be able to accomplish the goal of a one-piece resection and would accidentally spill some of the tumor, creating all of the deficits but no survival benefit. Frankly, I thought there was a 25% chance that would happen, which was explained to the family preoperatively. Were we overreaching our abilities and making a dying patient's life worse by proceeding?

Second, I was uneasy about the social situation. The patient's family was very supportive, traveling with him to all appointments and assisting with his care. The patient himself usually deferred all scheduling to his mother, which wasn't entirely unusual for such a young man. However it was difficult to grasp how much the patient understood of his disease or supported the plan. We attempted to delve more deeply into his thoughts, including without his parents present, but got only short answers, which revealed little. While the family appeared to have accepted the diagnosis and wanted to get to the business of treatment, the patient seemed to me to still carry the shock of his recent cancer diagnosis. Pushed by the rapid tumor growth, we were limited in how long we could wait for him to become a more active participant, if he ever was to do so. Throughout, family remained consistently in agreement to proceed with aggressive treatment. When asked if he wanted surgery, the patient simply said "yes" and signed the consent form.

Surgery itself could not have gone better. The procedure was an enormous undertaking, with world-class surgeons from urology, orthopedics, plastics, general surgery, and neurosurgery working for almost 40 hours to deliver the tumor in one piece and reconstruct Frank's spine and pelvis. We were ecstatic. The possibility that this young man had been cured of a rapidly fatal disease was fantastic and the doubt whether we were doing the right thing washed away.

On his first postoperative visit the patient started talking. In fact, we could barely get him to stop

talking long enough to discuss his healing. He came alone and reported that he and his parents were working on remodelling a house so that he could move about in his wheelchair. It was notable that he was having trouble standing due to weakness, but he was positive that with continued exercise it would improve. I had some misgivings about that last statement, but his turn-around was so remarkable I thought that it might just happen. We suggested some specific physical therapy, which was steadfastly refused, saying very suddenly that, "I have a right to refuse any medical treatment." At the time it seemed like a slightly odd statement, but we rolled with that as the patient was correct, and the therapy certainly wasn't a medical imperative. I was so pleased he was talking and participating in his care, I saw it as a positive sign: Frank was exerting some control on a situation he had previously had little control over.

Then things went downhill. Because of his lack of mobility, Frank was at risk of pressure ulcers. Despite a stint in rehabilitation in which this was emphasized, Frank was also asserting his control over therapy by not following pressure-ulcer prevention recommendations. He was also refusing to come back for follow-up appointments, and was bitter that surgery was "done to him." He returned at the six-month mark, and a pressure ulcer had grown so deep that his pelvic bones were visible. The ulcer was scant millimeters away from connecting to the surgical cavity. While he had been following with a local physician for wound care, we were fearful that this ulcer would extend to the surgical site, as an infection of the bone graft material holding his spine and pelvis together would be disastrous. Allowed to worsen, the patient we had so proudly cured of aggressive cancer might well require bilateral leg amputations or simply die of a preventable infection.

The best chance of stopping this process would be a plastic surgery procedure in which a flap of leg muscle would be flipped over the ulcer to allow it to heal. It would have been from the patient's weak leg, and he still held out hope he could one day be strong enough to walk. Frankly, I had given up that hope and just wanted him to survive. When offered

surgery, he very clearly said no. His parents did not accompany him and he refused requests by the team to speak with them. To respect the patient's desire for control, we provided him with options: palliation, continued local treatment, and our vastly preferred surgical option. The patient was released to continue wound care with his local doctor as he wished. We have unequivocally stated we are available for any issues that may arise regarding tumor or wound, but the patient has chosen not to return.

The experience with Frank has made me reconsider our consent process. Unfortunately, this case combined a shocking diagnosis with a time-critical decision. While we were willing to allow patient and family to mull over treatment options, the tumor itself had little patience, and if curative surgery was to be attempted the window for treatment was small. Following this case, one addition to our preoperative counseling in patients where we anticipate major functional loss will be a psychological evaluation. We hope that this will help the patient quantify the impact the functional loss will have on their quality of life, and whether they feel such a price is worth paying. As a different patient once said to me, "you described the outcome perfectly, but I was so scared it seemed trivial. The realization that I had cancer overwhelmed all other things."

It is difficult to quantify the upside of an unproven surgery. Even if we had solid evidence to provide a patient with the statistical likelihood of success, it is difficult to imagine many people choosing Cancer over Cure. Despite being very graphic about the negative consequences of surgery, I have yet to see a patient refuse. Perhaps it is the unique nature of the rare tumor, which holds the possibility of "cure" that makes surgery so irresistible. When the opposing certainty is death, the chance to be cancer-free seems worth the sacrifice.

Finally, while I strongly feel that the patients are fully informed before giving consent to such large procedures, I do doubt that they reach a balanced choice due to the overwhelming fear and emotion tied to their decision. While the surgical team can describe the technical components, risks, and probable outcomes, it is impossible for us to apply this very dry information to a particular patient's life

goals. Often the patient is so focused on fighting their disease that these previously important goals lose their importance and are not articulated even with questioning. Sadly, once treatment and convalescence are successfully completed, and cancer is no longer something to be fought, these now unattainable goals resurface. As with other life-changing physical injuries, there is a grieving process with the loss of function that many patients are able to work through and ultimately lead productive and happy lives. From a surgeon's perspective however, the nadir of this process often occurs at the termination of surgical follow-up. In Frank's case, the impact of the surgical deficits on his life has been overwhelming, and he consistently states that he wishes that he had never consented to the procedure, despite the certainty he would not have survived without it. It certainly leaves me questioning whether such treatment is worth it.

I hope that Frank is one of those patients who is in the midst of grieving and will ultimately succeed in completing this part of the healing process. It would be a thrill for me and the team to hear of his adventures years down the road, as I think he is willful enough to make a dent in the world. I can only hope that the opportunity we gave him to make that dent didn't set him back so far he can't achieve it. There is little I feel we could have done differently in this case, although I do regret operating. The memories of the impact we had on Frank will give all of us pause, and hopefully allow us to help our future patients to choose the treatment path which best suits them.

May of 1973

William Doscher

It was May of 1973. I was a Chief Surgical Resident at the Montefiore Hospital and Medical Center in the Bronx, New York. In six weeks, I would complete five years of surgery training and be qualified to sit for Board Certification.

There were four color-coded surgical services at Montefiore. If my memory serves me correctly Red stood for Blood, Green stood for Money, Orange stood for Stool and Purple which stood for Imperial, as it was Dr. G's service, who was the Chief of Surgery. The Head and Neck and Vascular services had no nickname unless "pain" was considered one. I was the Chief Resident on Purple, which was a difficult service to run, as it was the largest and most diverse service in the Surgical Department. It also included the entire full time faculty (many of whom were very senior and heavy hitters), the transplant service and the ward service. I had ten senior and junior residents working for me. In short, the Purple service posed quite a management problem, especially considering how many patients were in hospital at the same time on Purple. Furthermore, at this time—1973—Chief Surgical Residents were on call 24/7/365 and were totally responsible for their services. This was particularly so for the ward service where patients without their own surgeon or the ability to pay for one were admitted. This meant I was the surgeon for every ward patient with the only caveat that I had to notify the service attending of the day what my plans were especially if I wanted to take a patient to the operating room (OR). It was the obligation of the service attending to be in the OR at the time a ward patient (or service patient to use the more common appellation) was having a procedure.

I had been on Purple since the beginning of May and, to be honest, was getting tired and worn with these demands at the end of a brutal year. Still, the Purple service was under control as I had learned how to organize and not take "no" for an answer: at least from a fellow resident.

I was making rounds early one morning when the senior resident who had been on call the night before took me to see a man in his thirties who had been admitted through the emergency room (ER) with a diagnosis of appendicitis. This diagnosis had been made, as it usually was in 1973, with a minimum of laboratory work and no CAT scan, but with a good history and physical examination (including a rectal). This evaluation yielded an accuracy rate of approximately 85%–90%, which

was totally acceptable. I reviewed the lab work and examined the patient. As far as I was concerned, it was a textbook case that required operative intervention within a reasonable number of hours. I tracked down the service attending (not always an easy task) personally before he started his operative schedule, as it was the best way to get cooperation while demonstrating the need for urgent action. In all fairness, Dr. S. came to see the patient without a problem. However, after examining the patient—somewhat superficially in my opinion—he told me that the patient probably had gastroenteritis and did not need surgical intervention. He left to go to the OR. My senior resident and I looked at each other in disbelief.

I had never been in a position where I had a patient whose well being and possibly his life was in my hands but had no way to care for him as I could not book him for the OR without a service attending. The structure of a surgical residency then somewhat resembled a medieval guild system with the residents at the bottom of the heap with little recourse once a guildsman had spoken. In general, nobody wanted to hear your complaints at any level of authority. Unfortunately, the system has not changed that much to date, as residents are still dependent on the attendings to actually do cases.

While I considered myself widely read in history and the humanities, I had had no formal training in ethics but I did know that I had a personal responsibility to care for the gentleman with appendicitis even though I could have taken cover under Dr. S.'s diagnosis. It was just wrong and I could feel it in my gut but the pressure to do nothing was great as I realized that perhaps my residency could be in danger if I went over Dr. S.'s head.

I made a decision: right or wrong. I found Dr. G. and explained the situation to him. "Where is the patient", were his only words. After examining him, his next statement was, "Where is Dr. S.?" I told him he was in the OR. The Chief marched into Dr. S.'s OR while he was actually doing a case (something not done when the discussion is to be confrontational) made eye contact and again his only words were, "You have a case to follow." I obviously or maybe not so obviously was right behind or next

to the Chief. “If looks could kill . . .”—I don’t think I need to say more.

I do not remember ever speaking to Dr. S. again. Certainly, the Chief and I never discussed the matter again. I finished my residency and was recommended to sit for the American Board of Surgery.

In the era of my training, residents received no instruction in ethical behavior or humanism. Hospitals had no Ethics Committee or Ethics consultation. We all functioned under a personal sense of morality without discussion or perhaps Dr. G’s silence in this instance was a sign of moral approval as it was he who signed my paper work for the Board.

I do not remember my mental status when I left the hospital that day but I hope I felt as I now counsel my residents—“When you leave the hospital you should not feel guilty.”

Death Perception: How Temporary Ventilator Disconnection Helped my Family Accept Brain Death and Donate Organs

Thomas B. Freeman

Acknowledgements. I would like to thank my niece for the clear articulation of her feelings that prompted the need for this manuscript. I would also like to thank Howard S. Tuch, MD, Charles E. Wright, MD, and Dorothy E. Vawter, PhD for their compassionate and insightful reviews from the palliative care, organ procurement and ethics perspectives, respectively.

The night of my nephew’s closed head injury in Boston, I was on call as a neurosurgeon at Tampa General Hospital. I was therefore not shocked at first when my telephone rang at four o’clock in the morning, but I soon understood the severity of the tragic news. The next half hour was a blur of frantic phone calls and devastating decisions leading to surgery to remove a subdural hematoma

from my nephew’s head, even though he was only two brain stem reflexes away from brain death.

I thought that my experience as a neurosurgeon would somehow help me. However, when my sister-in-law asked me if this was just like the other tragic closed head injuries that I had seen in 26 years of practice, my answer was very simple: this was the only severe closed head injury I had ever seen—in my family. At this point, I was no longer a neurosurgeon. I was an uncle. My nephew’s closed head injury overwhelmed both his brain’s capacity to survive and my entire family’s ability to think rationally or objectively while grieving so intensely.

It is in this context that we were asked to consider organ donation. The appeal for organ donation is one of altruism. My nephew’s parents agreed that organ donation would be an important way to honor their son’s life, allow him to make one final contribution to save the lives of several patients, and help to bring peace to the family.

I will never forget, however, my niece’s distraught response. She is altruistic by nature, but was tremendously conflicted by the choice to donate her own brother’s organs. At this point, all discussions about organ donation stopped until we could understand the source of her conflict. Since she did not have legal authority regarding the final decision, some family members wondered if organ donation should be allowed if she could not come to terms with the choice. She felt isolated, because she was the only person in the room who was experiencing conflict. As a neurosurgeon, I have always advised other families in this situation that they may have more peace if they can make such decisions unanimously, regardless of who has the ultimate legal authority for decision-making. This helps bring healing to the family, eliminates disruption of family values and unity, and reduces possible feelings of guilt.

I asked my niece what she was feeling. She stated something that I had never heard before as a neurosurgeon. She had listened to the words that her brother was brain dead, but she felt that he was somehow still alive, since he was breathing on a ventilator and his heart was beating. She felt powerless due to her inability to do anything more for

him. She also wanted to be there when her brother “died,” which she would recognize by the cessation of his heartbeat. She would not abandon her brother.

I searched for a way to respect my niece’s wishes and her legitimate request, while preserving the ability to proceed with organ donation. Solving this conundrum proved to be a pivotal part of the beginning of both her mourning process and acceptance of his death.

As an uncle, I experienced the clear dissociation that modern medicine creates between medical care and the natural human process of recognizing and accepting death. My family observed the subtle difference between a deep coma and brain death. They noticed that my nephew’s color had changed when his temperature dropped to 94° F before the heating blanket was placed. They perceived the decrease in muscle tone when he stopped breathing faster than the ventilator rate. Outside of that, there was no significant difference in his appearance when he was “alive” or “dead.”

In spite of heroic measures and superlative surgical and medical care, his closed head injury progressed unremittingly until he became brain dead 36 hours later. The diagnosis of “brain death” was pronounced to the family. Accepting the death of someone who is still breathing and whose heart is still beating seems to violate a basic understanding of what constitutes life. It takes an unnatural leap of faith to understand brain death cognitively based on the word of a complete stranger, rather than experientially based on direct observation. What was inadvertently deprived from my niece was the experience of participating in her brother’s last living moments by actually being present at what she perceived to be her brother’s death. Instead, organ donation would only permit her to understand that he was considered to be legally dead because his status corresponded to a set of defined indicators.

I believe that experiential learning (such as learning to ride a bicycle) is far more powerful than cognitive learning, and lasts a lifetime. It brings true meaning to any thought, and encourages deep understanding. Physicians may understand medical care, but we must also empathize with the grieving process of families as they learn through

experience about the death of a loved one. I therefore sought to find a way to allow my niece to have the experiential understanding of her brother’s death, so that she could more effectively grieve and accept his passing. Without this, organ donation would not have been acceptable as an option for our family.

Like most people, my niece understood that if her brother’s heart stopped beating, then he was dead. But judging life and death by the heartbeat is a historically recent event. The electrocardiogram and stethoscope are less than 200 years old. Modern television dramas further reinforce the concept of death as an event demarcated by cardiopulmonary resuscitation, which only occurs in a small minority of cases in real life. As a physician, I also knew that the act of breathing is something that everyone intuitively recognizes as the most obvious marker of life, as mankind has known throughout history. When we were taught as medical students the “ABC’s” of cardiopulmonary resuscitation, we learned that the control of a patient’s airway and breathing take priority over maneuvers to restore cardiac function. The airway is protected by the gag reflex, which is the strongest reflex in the human body. Childbirth is complete when the newborn takes its first breath. It is written in the bible that God “breathed life” into all living things. The Hebrew word for breath is the same as that for spirit. It is the loss of the automatic ability to breathe that we intuitively understand correlates with death, and we associate life with the process of breathing.

When organ procurement teams ask for organ donations after a declaration of brain death, they may deny families the chance for emotional closures derived from experiencing and participating in the final moments of their loved one’s life. No family member of an organ donor typically sees either the last breath or heartbeat.

I therefore made a very simple suggestion to my niece. I asked her if she would want to be with her brother when the ventilator was temporarily disconnected. My niece understood that in this way she could be present for her brother’s final breath, and participate in his death by being at his side when he stopped breathing. I let her know that

the alarms would be turned off, there would be a quiet and reverent atmosphere in the room, and the family would be with her for support as well as to say good-bye. In other words, I offered her the opportunity to be present at her brother's death, focusing on his breathing.

Based on my experience as a neurosurgeon, I discussed with the treating team how this would be done in a manner that would fulfill the goal of viable organ donation, while simultaneously increase the probability of obtaining consent from all family members and minimizing stress and conflict for my niece. This process was only to be done after brain death was officially declared by the physicians according to standard legally defined criteria, and if doing so would not jeopardize the organ donation process for medical reasons. The ventilator was to be reconnected when the oxygen saturations began to fall. My nephew did not require high levels of positive end-expiratory pressure (PEEP), so the risk of sudden cardiac death with temporary discontinuation of the ventilator was reasonable.

My niece agreed that this would help her to accept and understand the finality of his death, and to have closure. One of the nurses in the ICU tried to undermine the process, telling other family members that this was going to jeopardize all organ donations. However, I knew that temporary ventilatory disconnection is reasonable and is a routine part of nearly all brain death examinations. It could be done easily and peacefully in the ICU, without urgency or any special arrangements. In comparison, donation after cardiac death does not allow for recovery of the heart, and is performed urgently in the operating room.

When the time came, my niece, all of the other family members and a very close friend chose to be present. By now, we had all spent 36 hours facing the inevitable, and we were with my nephew before and after he was declared brain dead. We had already had the opportunity to say good-bye. However, when the ventilator was disconnected, the reaction was the same for everyone, including me. For the first time, we all experienced directly that my nephew was truly dead. Sadness filled the room. Everyone touched his chest and felt his

heartbeat. We experienced that he was dead because he was not breathing, even though his heartbeat was maintained artificially. By the time that the oxygen saturation dropped to below 90% and the ventilator was reconnected, everyone had both experienced and understood the reality of this tragedy in our family. We cried together. Closure was final.

Later, at the funeral, each one of us chose to throw a shovel of dirt on the coffin. This ancient tradition was also created to help the grieving process by making the burial real and final in an experiential rather than a cognitive manner. This helps mourners begin the transition from grief back to life. Such rituals are essential in aiding the grieving processes for family and community. Similarly, the ritual of disconnecting the ventilator or even participating in the entire brain death examination may help the family understand and accept the death.

There is an overwhelming shortage of organs for donation purposes, and numerous patients would benefit from a more effective organ donation process. Why do families refuse to support such a clearly charitable act that would honor the legacy of their loved one? Do they, like my niece, feel conflicted if they interfere with letting nature take its course? Do they, also like my niece, not believe in the reality and finality of brain death? Has the medical professions' historically recent focus on brain death as the only absolute definition of death created an ambiguous reality for families when they experience death of a loved one in a modern hospital setting?

In my hospital, specially trained individuals help families with the organ donation consent process because approximately half of families ultimately refuse to permit donation of a loved one's organs and increasing the consent rate provides a significant opportunity for increasing the number of donors. Like my niece, many families I've encountered also do not understand or accept brain death. Even among those families that do choose to donate, many do not understand or accept brain death but agree to donate for altruistic reasons. Many are confused about when a patient has died, or believe that death only occurs when the heart stops. Post-traumatic stress symptoms are prevalent in

family members of intensive care unit patients, and may be exacerbated by their participation in end-of-life decisions without truly understanding if life has actually ended. There is therefore a clear need to help other families like mine understand brain death from an experiential perspective in order to help them have closure, minimize guilt and post-traumatic stress, and finally, increase the rate of organ donation.

It is my belief that the simple, no-cost act of silent and reverent temporary ventilator disconnection (and possibly participation in the entire brain death examination as well) will help the most sensitive and vulnerable members of other families understand brain death, and overcome feelings of abandonment, survivor guilt, denial, misplaced loyalty to a loved one, and other types of conflict that may stem from organ donation. I believe that this action will therefore also help other families consent to organ donation, just as it did for my family. Of equal importance, helping family members recognize the end of a loved one's life in an experiential manner can speed their progression of mourning from denial, protest, bargaining and despair back to acceptance, healthy grieving and recommitment to life, just as it did for my niece. Though my nephew died, my niece helped all of us find a way to heal. I am grateful to her for teaching me this important lesson. I am sure the organ recipients would be grateful too, if they only knew.

Operating in a Contemporary Safety Net

Jason D. Keune

It is summer, and I have just started my fourth year of general surgery residency, having just returned from two years in the lab. My “lab years” were spent as a Scholar-in-Residence of the American College of Surgeons. The scholarship that I engaged in included obtaining an MBA and a Graduate Certificate in Professional Ethics. The

ethics component was self-designed with help from an advisor, and was made up of graduate courses in political theory, healthcare financing law and bioethics. To say that I was reflective as I returned to the clinical rotations of the fourth year of residency would be understated.

During this two-year period, I did not operate. I did do some clinical work during this time, but there wasn't anyone in town willing to hire a partially-trained surgeon to do anything operative. I ended my third year of residency very happy with my technical skills, and was not sure just how these skills would survive a two-year hiatus. The challenge, as I thought of it then, would be to return to clinical rotations with this insecurity in mind and try to gain insight into just how rusty my skills were in a short period of time, and rectify them. I was in for a surprise.

I felt a chill of trepidation when I discovered that the rotation that had been selected for me to return to was one in which I would be assigned to operate on and care for a low-income population of uninsured or underinsured patients with surgical problems—with minimal attending supervision. The patients were referred from the Federally Qualified Health Centers in town. The rotation had arisen from altruistic roots. The surgical service, provided at a large, academic urban hospital, was established when the city's last remaining public hospital closed its doors for surgical patients. The service was an upright attempt to provide surgical continuity for this population. As I started the rotation and performed my first surgeries in two years with very minimal supervision, I realized that I would be participatory in what sums to a thoroughly unjust healthcare system. I would be caught in a swirl of humanitarian justice celebrated and a focus on a justice that seemed to fall short of a mark.

The indigent hospital itself managed the clinic with a full complement of staff befitting a contemporary surgical clinic, albeit with a rather rudimentary computer system. The recordkeeping mechanism in our surgical office, however, was done without administrative assistance. We occupied a small room amongst the academic surgical offices at our home institution. The chief resident sat at a large

desk, the intern at a smaller desk, and the medical student had a chair and a laptop. The recordkeeping mechanism tracking who needed surgery, who had had surgery, and who needed follow-up on pathology was maintained by all members of the team. It involved one labyrinthine Excel spreadsheet, with multiple tabs, and a complex color-coordinated scheme of organization. The team would scan the entire thing on a daily basis to make sure nothing would be missed.

When it came time to schedule a patient for the operating room, it was my responsibility as a chief resident to get an attending to “cover the case”, which amounted to finding an attending who agreed, at the bare minimum, to be present for the “critical portion” of the case. If the case was complex or very difficult, an attending surgeon would have to be sought who would scrub in and help perform the procedure. Not every attending would cover a charity case—the reasons why were not forthcoming. One surgeon would scrub every case he was asked to cover, stating that he felt every patient should have the same chance at the best treatment. Another would come to the room, but sit along the wall and review manuscripts as we operated, there to grant reassurance, and answer questions, but not, presumably, to direct the overall decision-making. All patients with breast cancer were seen, and operated on by one very dedicated breast surgeon with a humanitarian bent.

I, therefore, performed excisions of subcutaneous masses, all kinds of hernia repairs, cholecystectomies and other general surgery procedures on an ample number of patients without the supervision that I would’ve had with any insured patient. The norm for the insured was full operative participation by the attending physician. Did I hurt anyone? I don’t think so. I lost some sleep worrying about being good enough for my patients, and certainly the experience was a pressure-cooker—but was the system trying to squeeze excellence from a stone?

The system was set up to serve a disenfranchised community and the surgeries we performed were as good as the patients would have received anywhere in our city. However, the fact that I was not yet fully trained, gave me pause. Did I have the proper insight to evaluate whether the surgery was performed as

well? I hadn’t operated for a two-year period—did I even have the insight to determine whether my skills were rusty? Surgery is a very hierarchical system of training and complete independence is not usually granted until training is complete. On the other hand, the attending surgeons who allowed their name on the charts of the patients I operated on independently knew me well, and in agreeing, perhaps granted me independence on these procedures in the spirit of trust. Why were these patients getting me, an incompletely trained surgeon, for their surgery, while others in our community were able to have their surgeries performed by fully trained professors and surgical experts? Certainly my colleagues in other medical specialties were already practicing without supervision, as their training is shorter, and other countries have different, often shorter, training requirements for surgeons.

Are these not humans before us, equal humans deserving of some notion of justice, though? The answer was clear: these patients are underprivileged and seemed to have no other way of getting access to surgical care. My brain started wrapping itself around this problem. Was I unhappy with the arrangement because of the larger system, or was it the local response rather than the more global problem? Was I unhappy because I was made to become involved with it first-hand? What would happen if I were to try to change the system?

The argument was that some surgery is better than no surgery; these patients would go untreated otherwise. To me, this seemed to fall short of any measure of real justice. At the 1966 convention of the Medical Committee for Human Rights, Dr. Martin Luther King said, “Of all the forms of inequality, injustice in health care is the most shocking and inhuman.” Having felt these words as truth for years prior to the experience I write about, I could not sign on to this argument. So, to succeed in my residency program, I disengaged morally just enough to do the highest quality job possible.

To my knowledge, this practice pattern ended in 2012 with the dissolution of these surgical services. The hospital itself, which hosted our clinic space, dissolved completely in 2013 under Chapter 7 bankruptcy. The patients that were previously seen in the

setting described now present to the two academic hospitals in our city through a federally-funded health program, which reimburses at rates that put the patients into the mainstream. The program is a Center for Medicare and Medicaid Services Section 1115 demonstration project, which covers only a percentage of the total number of uninsured residing within the city limits. It is a bridge measure that is intended to exist until more comprehensive coverage (namely, Medicaid expansion or universal or single-payer healthcare) becomes available.

A little more than a year after this experience, I entered a hospital elevator, busy on another rotation. A large man wearing sweats looked at my face and exclaimed, "Hey! You were my doctor, my surgeon." A few moments passed as we looked at each other (I didn't recognize him), until he said "My hernia's back, doc." I didn't know what to say, since the surgical service had ended, and there was not yet a replacement.

I regard this as a specific example of a much deeper problem that plagues humans worldwide: healthcare is a resource-intensive activity. Here, the nuances of the breakdown of healthcare resources affected me in a very personal way that perhaps only a surgeon-in-training can experience. By being compelled to participate physically in an unjust system of healthcare, I became disengaged from the problem and delivered the best care I possibly could. Whether I remain disengaged will be uncovered as I start an elective surgery practice in the same city; many of the choices I make now are shaped by my experience with this moral problem.

I Am Not Sure?

Paul E. Levin

It was a beautiful Friday morning, a few weeks into the summer. My schedule appeared lighter than usual and I even envisioned leaving work a bit early. Maybe a challenging bike ride before

dinner. I was sitting in the chairman's office having our weekly meeting. One of our junior faculty members called . . . he needed help. He was on call and a 32-year-old pregnant woman with a displaced femoral neck fracture had just been transferred to our emergency department (ED). Ms. B tripped in her kitchen last evening. She was unable to stand and was brought to the local ED by ambulance.

My colleague was concerned that he wouldn't be able to successfully reduce the fracture. The long-term prognosis of the hip joint depended on a successful reduction of the femoral neck fracture. In addition, there was an ongoing debate in the orthopaedic literature related to the urgency of operative care to prevent osteonecrosis of the femoral head. I reviewed the x-rays, didn't anticipate a problem and let him know that I would come to the operating room (OR) to assist. "No", he responded, "I am not comfortable caring for this patient". I immediately left the office, went to the hospital and assumed care of the patient. Clearly, my plans for a bike ride were gone, but I had the opportunity to help a woman in need of expert orthopaedic care.

Ms. B had been admitted to the obstetrical service. She was a 32-year-old woman of Haitian descent who had recently immigrated to the United States. She had very limited English comprehension and her primary spoken languages were French and Creole. She was alone, in a hospital in a foreign country. She was 24 weeks pregnant with her first child and had no other co-morbidities. Her pregnancy had been progressing uneventfully.

When I first met Ms. B she was lying on a stretcher in an observation unit on the obstetrical floor. She appeared frightened. Two orthopaedic residents were present and obtaining consent for surgical repair of the hip. In their minds there was nothing to discuss, the patient had a displaced femoral neck fracture and needed to have surgery immediately. In their minds, no other options were available and obtaining consent would be straightforward. I introduced myself, sat down on a lab stool by the bed and began a conversation. I needed to meet the patient, understand who she was and discuss treatment. I am not sure that obtaining an informed consent is ever "straightforward" when

a doctor is explaining to a patient that they require emergency surgery. This discussion surely would not be easy or straightforward.

We utilized a telephone interpretation service. Every question and response required the transfer of the handset between the patient and physician. Ms. B was in pain and frightened. She immediately expressed concern about her pregnancy and her baby. I arranged for her to meet all of the physicians who would possibly be involved in her care and the care of her baby. Each consultant could explain their area of expertise and potential involvement in the care of Ms. B and her child. She met and had an opportunity to talk with the obstetrician on call, a maternal fetal medicine (MFM) fellow and a neonatologist. I supplied the orthopaedic information. I explained the severity of the injury, the risks of osteonecrosis either with or without surgery as well as concerns over non-union and traumatic arthritis of the hip. Undoubtedly, in a healthy 32-year-old woman who wasn't pregnant, early surgical intervention would be the most appropriate management in hopes of preserving a normal hip joint. We also discussed the possibility of treating her without surgery. She would be administered pain medication, which were known to be safe during pregnancy, and allowed to begin to ambulate with a walker or crutches. I explained potential problems without surgery and what options would be available to treat any problems that developed with her hip after the child was born. Of course, hip fractures in pregnant woman are very rare, and as a result treating a pregnant patient with a hip fracture non-operatively would be associated with unknown risks. Normally, when treating a femoral neck fracture without surgery the pain quickly resolves, patients do not require prolonged use of narcotics and are rapidly able to sit in a chair and ambulate with walkers. If Ms. B's pain couldn't be controlled she could possibly require prolonged use of narcotics and remain immobile. Surely, neither one of these outcomes would be ideal in a pregnant woman.

The MFM fellow discussed the possibility that the stress associated with surgery could cause Ms. B to go into premature labor. She reported that the risk

of premature labor was approximately 5%. My subsequent discussions with a MFM attending placed the risk of premature labor in non-abdominal surgery at less than 1%. The fellow was also concerned over the necessity of fluoroscopic imaging for the surgical intervention and a slight increased risk of developing childhood leukemia when a fetus is exposed to ionizing radiation. The neonatologist described the potential complications for a child when born after 24 weeks of gestation.

The discussions with the involved physicians, all utilizing the telephone interpreter service lasted two hours. I remained seated next to Ms. B, my hand on top of hers, during the discussions. After the consulting physicians had each explained their areas of expertise as it related to Ms. B and her pregnancy, I reviewed the orthopaedic management. The patient looked at me, afraid and confused and said she wanted to do what was best for the baby. She then asked me, "What should I do?" I remained silent for a bit, mulling over what I had just learned; 5% risk of premature labor with a 24-week pregnancy, radiation risks, complications related to premature birth, as well as complications of a femoral neck fracture with and without surgery. Finally, I replied. "If you weren't pregnant I would hope to have you in the operating room as soon as possible. But, you are pregnant and I am not sure". Ms. B replied that she wanted to do what was best for the child and didn't want an operation. I assured her that I respected her choice and I would continue to care for her. I promised to return the next morning and we could continue our discussion. I also believed that it was likely she would subsequently elect to undergo surgical intervention.

I left, very troubled. Did I deliver expert orthopaedic care? Was I wrong for replying, "I am not sure"? Did we share too much information? Did we unnecessarily scare Ms. B? We clearly had to inform her of all of the well-known complications, as well as any complications that may have significant long-term implications. Withholding information with the intention of having the patient select the treatment that you believe is best is an infringement on autonomy and the basic guidelines of an appropriate informed consent discussion. Should I have

made a definitive recommendation? Should I have recommended surgical repair? Should I have said, let's be cautious, care for your hip fracture without surgery and address any problems with your hip after the baby is born? It was very likely that with non-operative treatment she would have a poor outcome and require a total hip arthroplasty (THA). THA in young individuals like Ms. B are associated with their own set of long-term problems. Of course, bearing a very premature child could also have long-term implications for the new mother and her child.

To make my self-reflection and personal angst worse, two of my senior partners who I had known for thirty years called me on my cell to question my care of the patient. In fact, they were furious. They had spoken with the orthopaedic residents involved in the care of Ms. B and were informed that I didn't insist that the patient have surgery and accepted the patient's decision for non-operative care. In my colleague's minds, I was simply wrong. They believed that it was my responsibility to tell the patient that she had to have surgery and by not insisting on surgical intervention I had destined Ms. B to be "crippled for life". They both also believed that patients actually want doctors to tell them what to do, and patients do not want to be given choices without a definitive recommendation from the doctor. In reality, I truly didn't know what to do!

Guiding patients in times of medical uncertainty can be emotionally taxing for patients, family members and physicians. From the perspective of a physician and the patient it is easier and more comforting if the doctor knows the "right" answer, and advises the patient what to do. It is also reassuring for everyone involved to be able to do something, as opposed to "nothing". Superficially, this approach may seem correct; the doctor has trained to treat diseases and surely the doctor would know the best way to cure the disease. But, the patient surely knows themselves, their personal values, and morality and how they wish to lead their lives better than a doctor meeting them for the first time. Determining the "best" treatment requires an incorporation of the information supplied by the patient and the doctor. I surely could tell Ms. B the

best treatment for a displaced femoral neck fracture when the displaced femoral neck fracture wasn't attached to a unique individual who was pregnant with her first child. As I recounted the events in my mind, I was comfortable that I had approached the situation appropriately. Ms. B needed to understand that all of the available options of treatment had their own set of risks. Undeniably, if I could guarantee successful surgery without complications related to the initial injury, surgery or to the pregnancy, surgical intervention was preferable. Obviously, I couldn't give that guarantee.

I have a strong belief in the principles of autonomy, shared decision-making and patient centered care. I have always taught my students that it is our responsibility to help our patients make appropriate medical decisions for their particular circumstance, but we don't always have the "right" answer. Being honest with our patients and being cognizant of the limitations of medical science are the best ways to be beneficent and non-maleficent physicians. Spending the time to carefully, comprehensively and objectively teach our patients and help them develop an understanding of the issues being addressed and debated is the foundation of shared decision making. If we believe our patients are making unwise or foolish choices we need to be persuasive and even suggest an opinion from another physician. When the treatment options are fraught with uncertainty, each with significant complications, it is our professional responsibility to guide our patients, and ultimately care for them in a manner which feels "right" to the patient. Physicians cannot and should not bear the burden of always knowing what to do.

Follow-up

The day following admission Ms. B. decided that she would prefer to proceed with surgical repair of her hip. She received the necessary preoperative dosing of steroids to expedite pulmonary maturation in the fetus. The most experienced x-ray technologist was present to perform the necessary fluoroscopic imaging and additional lead shielding was placed to limit x-ray exposure to the fetus. The surgical

repair of the hip fracture proceeded uneventfully and the pregnancy was carried to full term. Ms. B. bore a healthy son. Unfortunately, one and a half years following the injury the patient has developed signs of osteonecrosis of the femoral head and is considering total hip arthroplasty.

Whisper Before You Go

John K Petty

David came with a bang.¹ A momentary prelude from a dysphonic chorus of pagers announce “Level 1 Pediatric Trauma—MVC ejected” before the abrupt crescendo of the trauma bay doors opening. He is maybe two. Maybe three-years-old. It is hard to tell when a child is strapped in, strapped down, nonverbal, intubated, and alone.

The flight team speaks for him, “Four-year-old boy improperly restrained in a single-vehicle crash into a ditch. He was partially ejected. He was unresponsive and pulseless at the scene. He got CPR and code drugs, and they got a pulse back. Emergency medical service (EMS) took him to the nearest hospital where they needled his chest, called for air transport, and scanned him up. He has been shocky for us since we picked him up. Glasgow Coma Scale (GCS) has been three the whole time. They said his head scan showed subarachnoid hemorrhage.”

With the words of the flight team as background narrative, we get about doing our thing—hopefully more method and less madness. Bang, bang, bang! Check the tube. Vital signs. IV fluids. Place a chest tube. Hang the blood. Quick X-ray. Neuro exam—nothing. Get him off the board. Warm him up. Place the orogastric (OG) tube. Bang, bang, bang!

The neurosurgery resident opens the CT scans from the other hospital. The brain and cervical spine scans show a disaster: some swelling and bleeding in the higher brain, but the worst damage is in the lower brain, brainstem, and top of the spinal cord. I have heard a neurosurgeon describe this pattern before as “internal decapitation.” Such language never makes it into the patient’s chart. For David the last two words of the neurosurgery consult note will eventually read, “Prognosis grim.”

He remains unstable in the trauma bay. Inaction is death. We ultrasound his heart, abdomen, and pelvis. He has fluid that shouldn’t be around his heart. He is dying of the neuro injury we cannot control, but the pericardial fluid might be giving him shock, and we can control that. We can’t ignore the fluid. Shouldn’t ignore it. At least, wouldn’t ignore it. So, we bang up to the operating room. Squeezing blood. Spiking fluid. Oxygen tank and crash cart. Up we go.

In the operating room, we do much and we do well. We release the fluid around the heart and find it was CPR, not heart injury that put it there. In the pericardial flash we get a view of the cardiac athlete, pounding like the 26th mile of the marathon. We explore the abdomen and find it swollen but innocent of an injury that would take his life. We place our lines and tubes as the neurosurgeons place theirs. If nothing else, we will be able to measure what lies ahead.

“Good work, team,” and we bump the door on the way to the pediatric intensive care unit (PICU).

The care in the PICU is more Apache brave than Gaelic knight—more bottles, fewer scissors. The curtains and carpets mute the tones. Our efforts continue, but I get a word that David’s father has arrived. He is sitting in a small, private waiting room off of the main PICU waiting room. The PICU staff colloquially refer to this as “the bad news room.” I take a seat next to a solitary man who is having the worst day of his life. His worst day so far.

“I am Dr. Petty, and I am one of the doctors who is taking care of your son. I am very sorry about what has happened. Maybe you can tell me a little bit about what you understand is going on, and I’ll tell you what I know.”

¹ Details of this story and names have been changed to protect patient confidentiality.

He tells me that his wife was driving David back from her sister's house, just the two of them. He doesn't know what happened, but he got a call from the other hospital about the crash. His wife was badly hurt. He heard that David had died, but they got him back. Both were transferred up to the trauma center. His wife was still in the operating room, and he wanted to come see David.

"Is David going to be Okay?" he asks through tears.

"I don't think so," I tell him in a soft voice. I do my best to explain to him in simple terms a situation that is irreducibly complex. I try to explain the brain injury, the CT scan, the neurological exam and the neurosurgical nihilism. "I don't think that David can survive this, and there is a chance that he has already died, even though his heart and lungs are still working. I try not to overload this poor man, when he is already overwhelmed. I try to let him know that the next couple days are going to be crucial to determine the extent of the neurological damage and to see if he responds to our treatments. "It is good that you are with, David. We want you to be with your son as much as you can," I share with him. I put a hand on his shoulder and let him know that we will bring him back to be in the room with David soon, but what he will see is going to be very different from the last time he saw his son.

Brain injuries vex us all. This most intricate, most wonderful organ defies the schemas of those of us who are simple-minded. How could anyone hope to account for every pruned branch or lost root of this electric rainforest when injury strikes? And yet, we dare not leave a parent alone in "the bad news room." A snowdrift may be formed by the microscopic lattice of billions of unique frosted hexagons, but the schoolchild who wakes in the winter morning wants simply to know if school is canceled or not. "Is David going to be Okay?"

Over the first couple days, David's brain injury shows its insidious nature. Very often the measured pressure of the injured brain starts high and then becomes higher as the swollen brain swells further. If we have treatment for brain injury at all, it is a treatment of swelling. David's case is unusual in that intracranial pressures are not high and do

not change much. It is the delayed swelling of the brain that often converts a devastating brain injury into a lethal one. David's brain injury is devastating and devastatingly stable. He is unresponsive. He does not move. His eyes are lifeless and still. At one point, he has lip twitching that we discover to be seizures. He is but a lip twitch from death. He has come to the line, but he will not cross it.

One day bumps to the next—morning rounds, evening rounds, pages in between. My moments with David's father are sometimes brief and sometimes long.

"David is not doing well," I tell him. "I am sorry, but he can't survive this. . . . We are going to have to make some hard decisions."

His eyes fall. He tells me that he can't make any decisions about stopping. He can't without his wife. She has her own injuries, her own recovery, her own trauma. She bears the regret of the driver. I tell him that we do not have to decide today. He will talk to her.

"Is David going to be Okay?"

In the days to come, I go to her bedside to meet with her and her husband. I try to explain what has happened. Her eyes fall like her husband's. She asks how we can be sure. In the days that have passed since the injury, the bleak opinions on David's prognosis have clarified and consolidated. MRI, neurosurgery, neurology, EEG, intensivist, nurse, and surgeon all concur. "I wish I that I had good news for you. I am sorry," I share with her. We ask and answer a few more questions, but it already feels like too much. "We are going to have to make some hard decisions," I say as we finish, "but I can see that today is not the day."

As the days slip away, David remains unchanged. The stillness of his status quo is a dynamic equilibrium of the thousands of care decisions that we make for him in the pediatric ICU. We continue to care for David, and we try to care for his parents, too. We arrange for his mother to come on a stretcher to spend time with him, to see. Amidst the care and the consolations, we ask for their help in making decisions for their son. "We are going to have to make some hard decisions." I continue to visit her and talk to him, but they seem to be more

passive, more avoidant. Who could possibly blame them, as I only have sad news to share, and I make requests of them that no parent wants to face? As the days of indecision lean on, the decisions for David become harder. What about antibiotics? What about another transfusion? What about more seizure medications? What about this arrhythmia? What if his heart stops? Are we doing the right thing? The decisions and the doing begin to weigh on all of us who are caring for David, as we collectively wonder if we are indeed caring for him. All of us—parents, physicians, nurses, family members—are spending in emotion and being paid in guilt.

David's cardiac arrhythmias defy indecision. I plead with his parents that I believe that they are David's way of telling us that it is time for him to die. "I know that it is hard, but it is Okay to let him go." Even at a moment like this, they are unable to decide to let him go. In the end, they tell us that they will be understanding of David's death. They tell us that they trust us to do what needs to be done for him. They could not tell us to stop, but they give us permission to do what we think would be best for David. In this, we could take some of their guilt feelings and put them on ourselves. It is a privilege to care for a boy like David. He died without a whimper.

From Impatience to Empathy

Stephanie Pierce & Kavita Shah Arora

We gave J.H. a label the first time we met her, as many often do—"Uncooperative." She was a patient with autism and intellectual delay who had presented to the emergency department (ED) with vaginal bleeding. After receiving the gynecology consult request from the emergency medicine physicians, we were already mentally formulating our recommendations based on the information they told us over the phone. "Does not cooperate with exam,"

"no acute surgical intervention is currently warranted," and "recommend outpatient follow-up."

When we arrived in her room, she was sitting in the hospital bed surrounded by a protective shield of caregivers from her group home. We introduced ourselves as the gynecology team but it was obvious that J.H. could not communicate verbally. Upon speaking with her caregivers we learned that she had Cowden syndrome, a genetic disease that confers significantly increased risks for several types of cancer including endometrial, thyroid, and breast cancers. J.H. had also been having heavy vaginal bleeding, which was difficult for her caregivers to manage, and this was the reason she was brought into the emergency department. After attempting to gain as much information as we could from the caregivers, we started to perform an abdominal exam, which made J.H. extremely agitated. We quickly stopped the exam and the caregivers helped to calm J.H. We remember our mixture of emotions—bewilderment at the agitation and commotion in the exam room full of people, frustration at not being able to complete our exam fully, and annoyance that this "difficult patient" was taking up our limited time between surgical cases. Thankfully, these knee-jerk reactions were quickly replaced by feelings of concern for the patient and the realization of how frightening an experience this must be for her—being in a strange place with white walls and unfamiliar people, unable to communicate her thoughts.

J.H.'s mother, her surrogate decision-maker, was not at the hospital that day but the caregivers told us that she had expressed a strong desire for her daughter to have a prophylactic hysterectomy due to her lifetime risk for developing uterine cancer as well as a permanent solution to the bleeding concerns. What had initially started as a simple ED consult was now turning into a complex question. The ethical and legal dilemma was obvious—whether to perform a major surgery that would irreversibly sterilize a patient who could not consent on her own behalf in order to minimize the potential risk of cancer later in life. While medical management could improve the bleeding and potentially reduce the risk of cancer, frequent exams would be necessary

to ensure that the medication was working and that premalignant changes were not occurring in J.H.'s uterus. However, based on our experience in the emergency department, J.H. would need anesthesia for such exams and it was doubtful the medications would completely normalize her elevated risk of uterine malignancy. We knew that in order to address this question, we would need to see J.H. again along with her mother to have a frank discussion about the risks and benefits of such a decision, and so we made plans to see her in our outpatient clinic.

Several days later, J.H., her mother, and the group home caregivers arrived in the office. Anticipating a complex discussion, we had requested a representative from the hospital ethics committee to join us at the visit. We didn't know what to expect meeting J.H.'s mother for the first time but as we sat in the room talking, it was obvious that she was truly trying to act in her daughter's best interest. Similarly, it was touching to watch the faces of the caregivers from the group home as they nodded in solidarity with J.H.'s mother, also clearly wanting what was best for her and supporting her mother in this difficult decision. J.H., meanwhile, seemed content to sit silently with us during the discussion, surrounded as she was by people who cared deeply for her well-being.

After extensive partnership with the ethics consultants, legal department, social work, J.H.'s mother, and the group home, we decided that due to her risk for developing uterine cancer and difficulty tolerating surveillance exams, a prophylactic hysterectomy would be a reasonable solution that was truly in her best interest and well within the medical standard of care. Our team performed the surgery and she recovered well. One of the best parts of this experience was watching so many people come together on J.H.'s behalf to ensure that we were doing our best for her, both in examining the ethical ramifications of our decisions when planning her surgery as well as helping her to have a smooth hospital stay and recovery. We have a feeling that if she were able to talk with us she would agree with the decisions made, but it is still unsettling that we will never know for sure.

Although we initially saw her only as a difficult and uncooperative patient, this experience forced us to reexamine our own biases. We remember J.H.'s agitation in the emergency room, which was likely her only way to express the anxiety she felt. Although the hospital atmosphere is familiar to us as physicians, for our patients this is often a foreign and uncomfortable experience filled with uncertainty, and we hope to use this experience to remind ourselves to address those feelings with patients in the future. We thought back to how many other times we were impatient or too easily dismissed someone with whom we did not communicate well, whether due to an intellectual delay, psychiatric disorder, cultural difference, or simply differing personalities. Our team will certainly take these lessons with us into future interactions, working together with family members to make responsible decisions and continuing to learn about empathizing with patients in whatever situation they may be. A surgeon's need for efficiency and precision does not need to run counter to the ability to provide humanistic and compassionate care; rather, the rapport we built with J.H.'s mother at the outpatient consultative visit allowed us to provide empathetic and patient-centered care while simultaneously leading to efficient and organized care. Most of all, we realized that the very fact that J.H. could not communicate her own desires was all the more reason to not be frustrated, but instead consider the measures that we would desire if we were in that situation, and to listen to the wishes of those who knew her best.

Operating Through Hatred

Andrew G. Shuman

“You’re not cutting my ***ing neck. The cancer is in my ***ing mouth.”
While many patient encounters are memorable, Mr. K’s introduction to the head and

neck surgical oncology clinic is indelibly imprinted into the minds of all of the clinicians present on that certain autumn morning. This was, quite simply, a man who resonated hate. He was rude and disruptive. He insisted on an expedited workup “without any waiting.” He questioned the ethnicity and nationality of his care providers. He told me, in no uncertain terms, that he did not appreciate my Jewish heritage—the swastika tattooed on his bicep underscored the point. He bragged about his recent incarceration for armed robbery. While my colleagues and I were tempted to simply refuse to assume his care, Mr. K had a bad problem—his recurrent tongue cancer required a major operation in order to offer him any hope for cure.

Mr. K initially received an abbreviated course of radiation at an outside institution, which was limited by his non-compliance. While one might debate the wisdom of this decision in retrospect—in general, surgery is preferred for his type of tumor—the die was already cast. A heroic attempt at surgical salvage was now his only curative option. He previously sought care elsewhere . . . only to be fired by this original surgeon when Mr. K physically threatened him in the outpatient office during preoperative consultation. [It was the doctor’s fault for insulting him in the first place, Mr. K maintained . . . and no charges were filed.] We were, indeed, his last resort. Other than his recurrent cancer, Mr. K was robust; he was in his sixth decade, physically fit, and on the whole, fairly healthy. In the classic surgical lexicon, he was a reasonable surgical candidate. But was it reasonable to operate on such a person?

I remember thinking, at the time, about our obligation to care for such an individual. Of course, being a medical professional carries with it many obligations, including a judicious assumption of personal risk. And, working in a tertiary care center begets the responsibility to assist referring clinicians in the management of difficult cases. Although professional obligations certainly have their limits, defining their bounds is decidedly more difficult. Paramount is creating an atmosphere of mutual trust and acceptance. Naturally, this was easier said than done in regard to Mr. K.

Perhaps against our better judgment, we agreed to operate under the condition that he abide by strict behavioral ground rules, on our terms. We agreed upon the extent of the necessary operation (which indeed involved cutting his ***ing neck, much to his chagrin and reluctant acceptance). Mr. K promised to follow instructions for postoperative care. He assured us that he would not swear or yell (again). And, in the presence of hospital security, who reinforced our institutional policies regarding patient behavior, he guaranteed that he would not be verbally or physically violent or inappropriate, and would not make disparaging comments to other patients or staff. It seemed, at least, that we had an understanding.

Needless to say, these rules were broken shortly after he awoke from surgery. I vividly remember being summoned from the OR when he threatened to murder his impressionable and terrified nurse a few days later, who would not acquiesce to his unreasonable demands. From that point onward, hospital security was deployed to his room regularly, and anything resembling a potential weapon was safeguarded. Any semblance of a mutual doctor–patient bond was shattered. At this point, everyone’s goal was simply to get Mr. K home.

My visceral reactions to his behavior, while intense, were not unexpected, and fell in line with those of the entire team of clinicians caring for him. His antics brought his healthcare team together in collective unity (and condemnation). However, my surgical colleagues and I also felt somewhat guilty and responsible. While surgeons can choose to assume some degree of inherent personal danger in caring for a violent and angry patient, we also put the safety and soundness of the entire perioperative team in jeopardy, without necessarily seeking their input. But once we had decided to operate, like it or not, his well-being was also our collective responsibility.

What made caring for Mr. K so difficult after surgery was just how dependent he was on the very individuals he despised. His need for frequent dressing changes and suctioning made it difficult to remain emotionally detached and impassive; clinicians were regularly hunched eye-to-eye with

him. But his inherent humanity and vulnerability were difficult to ignore, as was the innate desire among doctors and nurses to help a troubled person in need. The paradox was painfully evident each passing day, even if the glare in his eyes made it that much more challenging to complete the necessary tasks. It is a testament to the entire team that he recovered and was soon ready to return home. His eventual discharge was heralded by little more than relief by all of us.

It was his sudden death that really shook me. When Mr. K passed away at home a week after surgery, I experienced an entirely unexpected emotion—grief. Despite having mourned the passing of many patients in my nascent career, few affected me like this one. I still wonder why . . . was it shame related to my unabashed counter-transference? An intrinsic sense of professional failure? Concern that his personality led us to compromise his care? Sorrow for this poor, hateful and lonely man? Some complex permutation of them all?

We never found out why he died; his estranged family refused an autopsy. Mysteries remain. Why was he so angry? What happened? Did we do something wrong? Even years later, I still have not yet fully come to terms with my very mixed emotions related to my role caring for this troubled man, and these questions persist.

“Just Because You Can—Doesn’t Mean You Should”

Mindy B. Statter

As Albert R. Jonsen stated, “The technological imperative begins to rule clinical decisions: if a technology exists, it must be applied. Patients . . . are moved to higher and higher levels of care, finally becoming enmeshed in a tangle of tubes that extinguish their identity and needs as persons.” In this case the conflict created by the parental demand for the utilization of

technology, extracorporeal support in a neonate will be explored.

I was consulted in the care of a newborn with a right-sided congenital diaphragmatic hernia (CDH). In this anomaly the diaphragm, the muscular partition that separates the abdomen and the thorax, forms incompletely, and the viscera migrate up into the chest compressing the developing lung, shifting the mediastinum and heart and compressing the contralateral lung. The resulting lung maldevelopment is termed pulmonary hypoplasia. The maldevelopment of the lungs in CDH is variable with the most severe forms resulting in neonatal death. This congenital anomaly is associated with 55% survivability; the poor prognosis is due to the pulmonary hypoplasia. In addition to pulmonary hypoplasia, there is the association of pulmonary hypertension with CDH. Pulmonary hypertension is a condition where the vascular resistance in the lung is high with reduced blood flow within the lung. The physiologic consequence of pulmonary hypertension is hypoxemia, oxygen deficiency in the blood, and reduced oxygen delivery to all organs. Unlike severe pulmonary hypoplasia, pulmonary hypertension is reversible. When an infant with CDH is born and deteriorates due to respiratory failure it can be difficult to determine whether the respiratory failure is due to pulmonary hypoplasia or pulmonary hypertension. Extracorporeal membrane oxygenation (ECMO) is indicated in the management of reversible respiratory and, or cardiac failure. In the case of neonates with CDH, ECMO addresses the reversible component of the respiratory failure, the pulmonary hypertension. The respiratory failure due to severe pulmonary hypoplasia is not reversible; ECMO is not indicated. There are established criteria to guide the determination of which infant is a candidate for ECMO. Depending upon the ECMO center, the stringency can vary.

In this case, the baby had significant respiratory failure with impairment in both oxygenation, hypoxia, and ventilation—the elimination of carbon dioxide, hypercapnea. The neonatologist spoke with the mother who stated that she wanted “everything done” including ECMO in the management

of her baby. When the neonatologist consulted me to put the baby on ECMO I expressed my concern that this infant had irreversible respiratory failure due to pulmonary hypoplasia. And simply from a technical aspect, I could not guarantee that ECMO would “work”. When an infant is “cannulated” for extracorporeal support, cannulas are inserted to allow for the drainage of blood into the ECMO circuit, the blood oxygenated and the carbon dioxide is cleared, and the blood is then returned to the infant. The majority of diaphragmatic hernias are on the left and when the CDH is on the right side, the right heart may be compressed by the viscera in the chest, and venous drainage into the ECMO circuit may be impaired. When this is encountered, the next step in the management algorithm is to fix the hernia—reduce and return the viscera within the chest to the abdomen and eliminate the visceral compression of the right heart. The neonatologist shared my concern and also reiterated that this baby’s mother wanted “everything done”. I had little uncertainty as to the etiology of the respiratory failure in this baby. In meeting the mother’s demands I then suggested that the hernia be repaired first, and if there was improvement in the hypoxia and hypercapnea, then give the baby the benefit of the doubt that there is a component of reversibility to the respiratory failure and then proceed with ECMO cannulation. The neonatologist agreed with this suggested plan.

I then went to talk with the baby’s mother. I explained my concerns that based on the profound hypercapnea on the arterial blood gases that the baby’s respiratory failure was due to pulmonary hypoplasia and not reversible with extracorporeal support. She insisted that her baby be put on ECMO. I then explained the operative algorithm and repeated my concern that the baby had significant pulmonary hypoplasia which would not be responsive to extracorporeal support. I explained that the endpoint for extracorporeal support would be two weeks and at that time an attempt would be made to wean the baby from extracorporeal support. The failure to wean to conventional ventilator or oscillator support would confirm severe pulmonary hypoplasia.

The baby underwent right CDH repair and had no native diaphragm, a poor prognostic sign, and required placement of a prosthetic patch to construct a partition between the thorax and the abdomen. There was a very diminutive lung in the right chest. The oxygen saturation and hypercapnea only improved marginally and after brief intraoperative consultation with the neonatologist, I then cannulated and put the baby on full ECMO support. After 2 weeks on extracorporeal support, the baby failed weaning from ECMO. When we discussed withdrawing extracorporeal support, with the knowledge that the baby would subsequently soon die, the baby’s mother insisted that it be kept on ECMO until her pastor returned from an undisclosed location. The baby remained on ECMO for an additional 2 days after the delineated endpoint and when the extracorporeal support was terminated, the infant died within several minutes, as expected with pulmonary hypoplasia.

As a pediatric surgeon I am obligated to respect parental autonomy, be beneficent, be nonmaleficent, and exercise distributive justice. When obtaining informed consent from the baby’s mother, I felt an imbalance in the fiduciary relationship between surgeon and patient. Inherent in this relationship is the trust that the patient has in the surgeon and the confidence that the surgeon will act responsibly and respect the patient’s autonomy and their preferences. It is the parent that has to sustain the loss of the child and live with the guilt of decision making, and therefore, needs to feel that everything possible was “done” to save their child. In this case I was concerned that the mother may not be making an autonomous, informed, decision because without this invasive intervention she feared that her child may die. I also felt that this mother, in exercising her autonomy, was making demands and viewing me as simply a technician. The adage, “Just because you can, doesn’t mean you should” popped into my mind with regard to the use of technology in this case.

This mother had only one prenatal care visit during her pregnancy, where she learned that the fetus had a significant congenital anomaly, a congenital diaphragmatic hernia. Most obstetricians then refer

the mother to a pediatric surgeon for prenatal consultation to discuss the anomaly, and the postnatal management options, including ECMO. I felt that there was a missed opportunity during the antenatal period to educate this mother about her fetus in a more relaxed environment with the advantage of time. Instead, I was having this complex discussion, involving the delivery of “bad news” in the patient’s room, post-partum, separated from her newborn infant, with the added pressure that the infant was unstable due to respiratory failure. I respect the mother’s autonomy, however, in terms of her reproductive autonomy she has an obligation of beneficence to her fetus, and this includes prenatal care.

Based on the available data, which included confirmation of the diagnosis of CDH on post-natal imaging, examination of the infant on conventional ventilatory support, and the arterial blood gas results, I made a judgment that the baby was not an ECMO candidate; the probable cause of the respiratory failure was severe pulmonary hypoplasia which is irreversible. I felt strongly, and with a great degree of certainty, that the use of extracorporeal support was not indicated in this case but that I had to acquiesce to the demands of the mother. In balancing the risks and benefits to the baby, I felt that I was not being beneficent, but maleficent – doing harm to the baby during this prolongation of life on extracorporeal support. I also felt that the mother had an unrealistic perception of outcome. The baby had sustained significant initial post-natal hypoxia, and if the baby would have survived after extracorporeal support, there remained the possibility of neurological impairment affecting development.

In terms of distributive justice, I felt that this was not an appropriate use of a limited technological resource. And when utilizing ECMO there is also dependence upon the use of blood products and when there is restricted availability of certain blood components this has an impact throughout the hospital.

I also felt strongly that the neonatologist should have discussed the management of this patient with me prior to agreeing to the mother’s demands. The

management of the baby with CDH involves a care team and there should be discussion of the therapeutic options and consensus among the members of the team prior to discussion with the parents, especially in the utilization of limited technological resource. I felt that multiple assumptions had been made by the neonatologist, the first that the baby was an ECMO candidate, the second that an ECMO circuit was available, and the third that I would simply perform the cannulation as directed. As a result of this experience, in my discussions with neonatologists and pediatric intensivists that request ECMO support, I now provide the analogy of the patient with organ failure referred for transplantation—their candidacy for transplantation is determined by a team prior to simply listing the patient as a recipient. Similarly, the infant or child with respiratory failure must be first evaluated to determine their candidacy for ECMO prior to making a commitment to the utilization of this limited technology, and prior to making promises to parents.

When utilizing extracorporeal support or any limited resource technology, the goals of the therapeutic intervention need to be delineated including the duration of the therapy. In addition, the goals need to be incorporated into the best interests analysis for the patient, weighing the benefits and burdens of the intervention. In this case the surgeon’s perspective of the patient’s best interest differed from the mother’s perspective. I was cautious not to convey any degree of uncertainty because of the concern that it may be viewed conversely as hope. The value of the intervention has a different meaning for the parent. I was conflicted by my role as the surgeon with the goals of being beneficent, but views the utilization of technology, extracorporeal support, in this case, as futile. It is imperative that each case be individualized not only to respect the autonomy of the parent, and the best interests of the infant, but to reassess the probabilities of outcome particularly as surgical innovations and technologies evolve. And there should be clarity and consistency in the discussions among the physicians and in the discussions with parents.

Immortalization: Placement of a Percutaneous Endoscopic Gastrostomy Tube and Tracheostomy in a Neurologically Devastated Patient

Anji Wall

On a Monday morning during the late summer of my second year of residency, I received a consultation request for placement of a percutaneous endoscopic gastrostomy (PEG) tube and tracheostomy (trach) in a 20-year-old male who suffered a near drowning. This unfortunate young man, SB, had been out in a paddleboat, fallen off, and was submerged underwater for about twenty minutes. He was eventually rescued from the water by an off-duty police officer and underwent six minutes of CPR after which he had return of spontaneous circulation. He was intubated in the field for respiratory failure, and transferred to our facility for further management. He was found to have extensive anoxic brain injury complicated by several brain infarcts. He had lost his gag, corneal and cough reflexes, but was initiating breaths on the ventilator, meaning that he did have brainstem function and was, therefore, not brain dead.

At the time I was consulted, SB was almost two weeks into his hospitalization. He had not regained any further neurologic function and had deteriorated significantly from pond water pneumonitis. The palliative care team had been consulted two days before to assist in discussions with the family regarding goals of care given this patient's dismal neurologic prognosis. In their initial discussion with palliative care, SB's parents expressed the sentiment that "every opportunity for recovery should be provided." This is what eventuated the emergency general surgery (EGS) consult. In order to continue moving forward with this patient's care, he would need a permanent airway and feeding access.

Two days after the EGS consultation, it was not clear where the trajectory of SB's care was headed. Palliative care again met with his parents. He mother stated that she could "never make the decision to stop treatment." She further said that she was supposed to die before her son and could not live without him. That sentiment solidified the family's decision to want to move forward with a PEG and trach.

From a timing perspective, a trach was more pressing than a PEG because SB had been on a ventilator for two weeks. Therefore, a trach was placed the following day. The patient was quickly weaned from the ventilator to trach collar. The family was happy that he was breathing on his own, but this happiness soon faded when they saw that his neurologic function had not changed. At that point, the palliative care team asked SB's family what they would want to do if he were to need ventilator support again. The parents agreed that this would be a step backwards in his recovery and they would not want this to be done, so a do not intubate (DNI) order was placed.

That day another important theme entered into the conversation with palliative care. One of SB's friends had died in a car wreck a month earlier. He told his brother at that time that it was a "blessing" that his friend died quickly and did not suffer. The family kept thinking about this conversation and they noted several times that SB would not want his life prolonged. However, they ended the conversation with a desire to move forward with PEG placement as they knew that he would need it long term.

About a week after trach placement, the EGS team was then asked to reevaluate SB for PEG placement as the family wanted to get him home and be able to care for him there. While a PEG tube was technically feasible, a few members of the team, including myself, had reservations about going forward with this procedure because of the implications that it had for SB's long-term survival given his dismal neurologic prognosis. We felt as though we would be merely prolonging SB's existence and his family's suffering without providing

any therapeutic benefit. After a discussion with the palliative care team, the EGS attending decided that it would be reasonable to do this procedure because the family wanted to get the patient home, and this would help accomplish that goal.

SB was discharged four days after PEG placement. His mother was “proud” of being able to care for him, and pledged to do so for “as long as he needs.” I followed along with his progress over the next several months. He did not regain further neurologic function. He did, however, develop several infections from pneumonia to clostridium difficile colitis. He eventually died at home from one of his infections.

Reflections

This case demonstrated to me the complexity of decision making when a tragic injury happens to a young, otherwise healthy person. These situations are devastating to families because they are unexpected and often unfixable. As this case unfolded, several interventions were offered that would increase the quantity but have no effect on the quality of the SB’s life. I knew that this patient would not regain meaningful function, that he would be dependent on others for the rest of his life, and that he would eventually die from an infection or blood clot given his functional status. I was also told that this patient would not want to exist in his current state. However, rather than working with his family to help them accept the situation and implement SB’s wishes, the medical providers continued to offer therapeutic interventions that led us down a treatment rather than palliative pathway. I would like to focus on how we could have done a better job in changing the conversations with SB’s family to help them navigate this devastating situation in a way that was consistent with SB’s wishes

“Every opportunity for recovery should be provided”

In their first interaction with palliative care, SB’s family was of the mindset that everything should be done to aid with his recovery. In discussing goals of

care, the family’s goal was clearly for SB to recover. This was a rather nebulous goal. In order to further the discussion at that meeting, there should have been more investigation into what the family felt an adequate or “good” recovery would look like. Were they expecting him to return to how he was prior to the accident? Or, would they accept minor improvements in neurologic function as adequate recovery (e.g., regaining brainstem reflexes)? I think that a discussion of the family’s vision of recovery at this point in his hospitalization would have set the tone not only for possible reassessment of expectations but also for the trajectory for his management. It would have given us a better framework for future conversations.

The mother could “never make the decision to stop treatment”

The next conversation with the palliative care service was in some ways opposite to the initial discussion in that rather than giving SB an opportunity to recover, the family was now unable to make a decision to stop interventions. They were relating the sentiment that maybe he would not recover, but they did not want to be in the position to make the decision to stop treating him. This is a common progression among family members when faced with decisions like the ones in this case. No one ever wants to make a decision to stop treatment. No one wants for their loved one to die. When the family opened up the conversation to the fact that they did not want to make the decision to stop treatment, there was an opportunity for the palliative care team to discuss limiting additional interventions as well as putting time limits on the current treatments.

“A good death”

In conversations with palliative care after SB’s trach, the family brought up the patient’s perception of a good death. He had described the death of his friend as good because he died quickly without suffering. The family was sure that SB would not want to continue in the state that he was in. However, they were now on a therapeutic trajectory that would allow him to continue to live, and possibly

even go home. While there was near certainty about what the patient would want done, the family could not bring themselves to do this. When there is a disconnect between the decisions that are being made about a patient and his known preferences, I believe that it is the job of the medical team to push the conversation to be about the patient's wishes as the ultimate driver of decision making. This was not done and the conversation ultimately put the family's preference to continue forward with interventions above SB's preferences. I think that this conversation should have focused on the question of how to care for SB given his perception of a good death as quick and without suffering rather than on the family's desire to move forward with aggressive interventions.

Reservations of the surgical team

At this point in the case, the surgical team was brought back in as consultants for PEG placement. We had not been part of the ongoing discussions between the family, the MICU team, and the palliative care team. However, the decision was ultimately made between these parties to proceed with PEG placement. There was disagreement among members of the EGS team as to our role in this case. Were we technicians or consultants? I think that we should always function as consultants to make thoughtful decisions about patients but others on my team were of the opposite mindset that the decision to do a PEG was already made and we just had to execute the procedure.

My bias is that when a surgeon intervenes on a patient, it is essential that he or she is doing so for a medically indicated reason and with a mutual understanding of the risks, benefits and alternatives. One thing that I could have done better in this case is insist that the surgical team was involved in the palliative care discussions throughout SB's hospitalization. This would have allowed us to have a seat at the table when it came to detailed discussions regarding PEG placement. So, rather than questioning a decision that was made after weeks of discussions, we could have been part of the conversations that led to this decision.

Who did we do this for?

At the end of many discussions among the EGS, MICU and palliative care team, we did place a PEG tube. It ultimately came down to the family's inability to make the decision to stop aggressive interventions and let SB die. One of the themes that arose late in the palliative care discussions is that the PEG and trach would enable the family to bring SB home and care for him there. The ability to do this was a source of pride for his mother who felt that in some way she was regaining control of the situation. Although he did make it home, SB never made a neurologic recovery. He remained completely dependent on his family for care and he ultimately died of an infection. I believe that pushing for SB's continued survival was more in line with the family's inability to let him die rather than a reflection of what he would have wanted done. After SB had these procedures done and had left the hospital, I could not help but think that we did all of this to SB for his family and not for him.

Lessons learned

I cannot comment on what the quality of his or his family's life was during the months that SB had at home. It must have been a trying time to watch SB exist as a person without any meaningful interaction with those around him. I often wonder if, in hindsight, the family would have made the same decisions. We allowed them to push forward with interventions, despite both our and their reservations. There were several opportunities to allow them to make the decision to change the trajectory of SB's care to a focus on comfort and a good death, which from all indicators would have been his choice.

I still question the utility of placing the trach and PEG tube in this patient. I am not sure that it was the right thing to do and I am quite sure that I would not do it again if given the choice. One of my co-residents describes trach and PEG procedures as "immortalizing patients". And, in this case, it is a good description. We suspended this patient in a state of neurologic devastation for months, knowing that he would not have a meaningful recovery.

We allowed his family to slowly suffer through the concomitant grief of losing a loved one and having to care for a completely dependent individual. Rather than being remembered as the vibrant 20 year old that he was prior to the accident, he would be remembered in his neurologically devastated, dependent state. In some ways, I feel that in offering the interventions that we did, we deprived him of the one thing we could have provided in this tragic situation: a good death.

Care of the terminal patient: Are we on the same page?

Lauren Wancata

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In surgical training a “service” or care team consists of sick patients admitted to the hospital and the medical team caring for the patient. Each service consists of an attending physician, a chief resident, a senior resident and junior residents structured as a hierarchy. The chief was gone for the week. As a senior trainee I would be the acting chief—a role I had assumed many times before this month. To prepare for the week of his absence, I read through each patient’s chart, and the chief and I discussed each patient—diagnosis, procedures, and plans.

One was a 41-year-old male with cancer—he was young, but a patient like him was not uncommon at my institution. He originally came in through the emergency department with abdominal pain and difficulty with urination. His admitting medical team started the work-up for his symptoms—blood tests, a CAT scan, and consults to other physician services with specialized knowledge. He eventually underwent endoscopy with biopsies of his stomach and placement of stents into his ureter and kidney for his urinary issues. With return of the biopsies, he had a diagnosis—cancer. He required additional

procedures, including the placement of stents into his bile ducts, as they, like his ureter, had become affected by the cancer. The next step was staging the cancer to determine his treatment options. Our surgical service was consulted for a diagnostic laparoscopy with washing—we would take a look inside his abdomen with a camera and obtain a fluid sample to be sent to the pathologist for review, the standard of care for this type of cancer. When the camera was placed nodules were seen—a sample of the nodules and the fluid were sent to a pathologist and determined to be positive for cancer: metastatic disease, stage IV. A special feeding tube was placed into his small intestine to aid in nutritional support, as he had already lost a significant amount of weight, and improving his nutrition would be imperative for any further treatments. Following this operation, oversight of his day-to-day care was taken on by our surgical service, and he had been under our care for a period of time before I rotated onto the service for the month.

What was the plan for his care in the hospital, and what was his long-term plan? His cancer could not be surgically removed due to the extent of its spread within his body. He had recently undergone another CAT scan due to an elevation in his white blood cell count (this elevation was a sign of possible infection) and a thoracentesis, a procedure to remove some of the fluid that was collecting around his lungs. Nephrologists (kidney specialist) had been consulted due to his declining kidney function. Throughout the days, his tube feeds, his source of nutrition, would often be turned off due to bloating and feeling full.

Each morning, I rounded with our team, and we would see how he was doing. We would discuss how his night went, and make a plan for the day. He was a man of few words, but his wife was always at his bedside, to support him, listen to updates and keep track of his progress. She had worked at the hospital and had seen a wide range of patients. She would ask about his kidney function, his tube feeds, and his labs. But, she never asked about his prognosis. I would leave his room each day with the unnerving feeling that the patient, family members and care team were not on the same page. Yes, we all wanted him to get better and to leave the hospital.

But, was he really going to get better? What defined better? Did the patient and his family really know the extent of his disease and his prognosis?

Towards the end of my week as chief, I started to ask if they had any other questions. It had been a few weeks since his operation. Was there anything that they wanted to discuss or ask me about? At the same time, I was asking myself, “what should I even say to them?” Members of my team asked if we should consult other services, such as oncology or palliative care? I had been contemplating the same things.

The weekend that followed was the turning point. He went for his standard dialysis run, as his kidneys couldn’t do the work for him anymore. During his dialysis session I received a page that he had developed sudden respiratory distress and needed the emergent placement of a breathing tube. This was done, and he was transferred to the ICU. Maybe with a few more minds on the ICU team caring for him they would be able to make him better. But what were we trying to make better? Were we trying to improve his short-term health to get him out of the ICU. Or were we trying to improve his long-term health, to treat his cancer. Or both?

As I stood in his room, I talked to his wife about his goals of care. Our conversation was very brief. It was already an eventful day, and I felt all confidence leaving my body as our short discussion continued. Did I even know what I was talking about?

His lungs improved, and the breathing tube was removed the next day. I asked him to talk with this wife about what he wanted. If his lungs failed again, did he want the breathing tube? This was a needed conversation. Whether or not they had this conversation, I’m still not sure.

At the start of the new week, our chief resident was back. I was able to stay behind on rounds to talk with the patient and his wife. I wanted to be there, in case they had questions or needed clarification. Still, we never discussed his prognosis and goals.

Again, he experienced respiratory failure, and again, a breathing tube was placed emergently. He required maximum support on the breathing machine. He was given pressors, medicine given to artificially keep his blood pressure up, as it was

dropping to dangerously low levels. Strong antibiotics were started. Urgently, tubes were placed to drain fluid from around his lungs and from his gallbladder.

A family meeting was held. Family members and friends gathered to discuss how grave the situation was. “What is the plan?” was the thought that kept running through my head. What are we doing? I knew his cancer was extensive, and he had very few options for treatment. His chance for long-term survival was poor. With the severity of his other medical conditions, he would not be able to safely receive chemotherapy. I knew this and the oncologists confirmed it. In the family meeting, we discussed making him DNR (Do Not Resuscitate). The concern from the medical team was that he was already unstable on maximal medical support—if his health declined further, would measures such as CPR offer any benefit? It’s an ever-present question in these situations: would the experience of CPR being performed on a loved one be traumatic, or would it be the final act a family needs to prove to themselves that they did all that they could for their loved one and honored what they believed to be the wishes of that person? Some family members agreed with the DNR status. His wife, however, kept repeating that he was “a fighter” and would want to “fight this.” Because of this, he remained “full code,” and full support continued. But what was he fighting for? He had incurable cancer. Was he fighting to cure his cancer? Was he fighting to get off of the ventilator? Was he fighting to go home and enjoy his last few days there? I don’t know and will never know.

I never asked. I was too scared. I lacked confidence. What would I say? I am still in training and far from an expert in any of these matters. How do I counsel a patient on his diagnosis and the life decisions he will have to make? Was this even my responsibility? I felt a sense of failure, I was a physician, I could do better. I needed to do better.

“He is improving.” These were the words his wife would hear each day on rounds. And yes, he was getting better, if you looked at the numbers. His oxygen requirements had come down from 100% to 70%, but this was still high. The amount of medicine

he was requiring to keep his blood pressure up had decreased. He still required continuous dialysis for his kidneys.

One afternoon the nurse asked if I could come in and talk with her and his wife, as she was trying to explain a few things about his care and would appreciate my input. His wife was sitting in a chair and I sat on a stepstool next to her. First, his cancer, it was extensive, metastatic. There were limited treatment options and very limited chances for survival. The pressors, the amount needed was less than before, but still necessary. Continuous dialysis, his kidneys could not function on their own. Whether the function would come back remained unknown. The ventilator, the extra oxygen he needed was still at 70%. Yes, it was better than 100%. But, normally we breathe 21% oxygen. To have the breathing tube removed he would need to be alert, require minimal extra support from the ventilator and prove to us he could breathe on his own. His nutrition, poor. The nurse made sure we talked in lay language and not doctor language. I could see that her face changed. I don't know if the details were finally making sense, or if she was simply accepting the true gravity of her husband's situation. While working at the hospital she had seen many patients on a ventilator. It was a life she would not want to live and made sure her family knew her wishes. As I left the room, the nurse whispered "good job" with a comforting squeeze of my arm. I disagreed. Was the plan of *doing everything* really true to my oath of beneficence for my patient and his family?

As the days continued and his condition remained critical, realizations regarding his prognosis became even more apparent. He was transitioned from full code to DNR, and finally to withdrawal of life-supporting interventions. On the day when he was finally made "comfort care", life-sustaining medications were stopped, powerful narcotics were started to help make him comfortable and family and friends gathered around his bedside. I made my way close to his wife, placing my hand on her shoulder. As she turned her head to see whose hand it was, she embraced me, both of us with tears in our eyes.

He died soon after.

People often ask why I am embarking on the career path that I have chosen, integrating surgery and end of life care. Patients like him and the countless others that I have cared for in my short career have brought me to be unsatisfied with the care I am providing. Should I have pursued other treatment options for him? Should I have had that conversation with him and his wife? Was this part of my role as a trainee? Once we become a physician, is it then automatically our responsibility to inform patients about these things, even if we don't have all of the knowledge and experience ourselves? Do we continue medical care in the acute phase when a patient has a terminal disease? As much as we want to save our patients, death is a natural force. How can my patient have a "good death"? How do I move forward in my training and future career with these questions and with a lack of answers?