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Even In An Emergency, Doctors Must Make Informed Consent An Informed Choice

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When a stroke is suspected, a daughter is pressured to consent to her father's treatment without fully understanding the risks.

BY CINDY BRACH

My dad is a wonderful man. In his working years, he was a tax accountant who served on the board of the Bronx River Neighborhood Center and shared his passion for tennis by teaching young men who lived in the South Bronx to play. He retired early to introduce others to meditation and other stress reduction methods that he had found helpful, and he ended up as a volunteer community mediator.

In October 2013, just a few months after giving up playing tennis, my eighty-eight-year-old father was diagnosed as having stage 4 prostate cancer. He responded well to the hormone treatments, but by May 2014 his prostate had gotten so large that he had difficulty peeing. Although he liked saying, "I don't like to brag, but I have a HUUUGE prostate," this condition had become dangerous: The blockage began to cause kidney failure.

My dad's urologist gave him two choices. He could either live with a catheter (a tube inserted into his bladder) for the rest of his life, or he could have surgery to trim his prostate to create a channel for the pee. After hearing that sporting a catheter would end his ping-pong career and that he'd only have to spend one night in the hospital, my dad overcame a long-standing fear of germs and elected to have the surgery.

Since my mother's immune system was shot from having chemotherapy for lymphoma, my twenty-year-old son and I were the ones who accompanied my dad to the hospital. I am not a clinician, but I have worked for the Agency for Healthcare Research and Quality for almost twenty years, and I felt well equipped to be my dad's health care proxy. He checked into the ambulatory surgery unit early in the morning and was soon taken away for the surgery.

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Complications After Surgery

Immediately after the surgery, my dad's urologist told us that it had gone well. The following morning, however, he informed us there was too much blood in my dad's pee. My father had to stay in the hospital an extra day so they could flush the blood out while the catheter was still in place.

On his third day in the hospital, my father was pronounced ready for a "voiding trial." They pumped a liter of fluid into his bladder, removed the catheter, and waited to see if he could pee. However, my dad felt no urge to go. Even after drinking cup after cup of water and sitting with a handheld urinal for several hours, he couldn't get anything out.

It was early that afternoon when I noticed that he was having some difficulty speaking. He was clearly trying to say something but couldn't come up with the words he was searching for.

I pointed out the problem to the urology nurse practitioner. "Dad, what are you trying to do?" I asked him.

"Well, I'm trying to..." His words trailed off. "You see, I'm making an effort... I'm really..." He couldn't say, "I'm trying to pee."

The nurse practitioner suggested that we call the stroke team. While I didn't think my dad had had a stroke, I knew I might be attributing the symptoms to other health issues, which frequently happens to stroke victims in hospitals. So I agreed, and the nurse called in the stroke team.

Strong-Arm Tactics

Fifteen minutes later half a dozen neurology residents were swarming around the room. One of them performed the standard stroke assessment—how many fingers do you see, squeeze my fingers, hold your arms out and don't let me push them down, and so on.

The next thing I knew, they were rolling my dad out the door on a gurney.

"Where are you taking him?" I asked.

"To the ER to give him tPA," the lead resident answered, as they wheeled him down the hall. I knew what tPA was: Tissue plasminogen activator (tPA) is a stroke treatment drug that busts up clots that block the flow of blood to the brain. But I was not convinced that my dad was having a stroke.

"But I haven't consented," I called after them.

"This is an emergency!" they replied.

I stood my ground. "I'm his health proxy. You're NOT giving him anything without my consent, and I haven't consented!" That stopped them.

“You’re right,” the resident said, backpedaling. “Could you come with us while I explain?”

As I trotted to the elevator with them, the resident explained that my father had had a stroke, that there was medicine they could give to break up the blood clot, but that there was a short window of time in which the medicine could be administered.

How could they be so sure he’d had a stroke? I wondered to myself. Did they know my dad had been too shaky on his feet to take a walk that morning, that he had not eaten until the nurse made him have a yogurt midmorning, and that he later threw up his lunch? Did they know that he hadn’t slept much the past two nights? Could it be that his full bladder was causing his kidneys to go toxic again?

I’d seen my dad get fuzzy when he had a bladder infection—maybe that was the problem. Or maybe the exhaustion from trying to pass the “voiding trial” and the worry about the pain he’d feel if they had to put the catheter back in were affecting my elderly father.

Maybe I’d watched too many episodes of the medical drama *House*, but it seemed as if the doctors hadn’t ruled out other possible causes of my dad’s symptom. They hadn’t asked me anything about his history other than the time of the onset of symptoms. I was worried that these neurologists in training might see a stroke where there wasn’t one because that’s what they were looking for.

“Why are you so sure it’s a stroke?” I asked the lead resident. “Was there anything other than the language problem?”

No, the resident answered, there was nothing else.

On the way to the emergency department (ED), we stopped for my father to get a CT scan to make sure he wasn’t already bleeding into his brain, which is a contraindication for administering tPA. All I had heard thus far was how tPA could reverse stroke symptoms—no one had told me about any potential downsides. I asked the stroke team about the risks from tPA if my father was not having a stroke. I was told there was a small risk (on the order of 1 percent) that tPA would cause him to bleed into his brain, which could either kill him or leave him severely impaired. No one bothered to mention that the risk of a catastrophic brain bleed from tPA was even greater if he was in fact having a stroke. Or that there was a risk of a noncatastrophic brain bleed.

The CT scan showed no bleeding. As we moved quickly on to the ED, I was pressed for my consent to give my father tPA.

“It’s the standard of care!” the resident kept hammering at me. “We’re running out of time.”

I repeated that I had not consented and proceeded to call my mother. She and I were both my father’s health care proxies. While I was on the phone explaining the situation to my mother, a senior neurology resident interrupted me to make sure I *really* understood that time was running out. I put my mom on speakerphone so she could hear what the senior resident had to say, which was what I’d already been told: that tPA would break up the clot, that tPA was the standard of care, and that it was critical for my father to get the medicine right away.

I took my mother off speakerphone so we could discuss the decision, but the senior resident insisted that I give her a decision right then. I gave her the response I'd often given my children when they pestered me for an immediate answer, "If you need an answer now, the answer is no."

On the phone, my mother gave her opinion. Maybe it was just that tPA had received good press coverage, she said, but she wanted my dad to get the medicine. So I consented. It was barely within the three-hour treatment window when they administered the drug.

Shortly after receiving the drug, as my dad was being wheeled up to the neurology unit, he sat halfway up with outstretched arms, shook violently, and then lay back down. "He's having a seizure," someone cried, at which point he seized a second time.

My father had suffered from an intracranial hemorrhage—he had bled into his brain. Throughout the rest of that night in the neurology intensive care unit, he shook uncontrollably, didn't appear to understand us, and couldn't communicate at all. Tears streamed down my face.

What had I done? Had my mistake been to allow them to give him the tPA? Or had it been in questioning its administration in the first place and losing valuable time? Why, despite being an expert on health literacy who was developing training modules to improve informed consent in hospitals, was I unable to come up with the questions to get the information I needed to make a truly informed choice in a timely manner?

My dad trusted me to make good decisions for him, and I felt I had let him down. I also felt the hospital staff had let me down.

Health care systems can and must do a better job. What would have served me and my family during my father's emergency was better communication and a care team geared to helping us reach a treatment decision.

Improving Communication

Clinical trials have shown, on average, more benefit than harm for the average patient meeting specified stroke criteria when tPA is administered within three to four hours of the first symptoms. The earlier the patient receives the medicine, the better the results. This creates both intense time pressure and the illusion that there is no time to spare for conversations. But if clinicians can communicate effectively and efficiently, the time can be found.

Doctors are the experts in medicine. Patients and their families are the experts in themselves and their bodies. The neurology residents who evaluated my father for stroke should also have been asking me questions. They should have asked about what my father was normally like, whether he had ever experienced symptoms like this before, if I knew of anything that might account for his current symptom, and other questions to gather more evidence about his condition.

Had the residents taken more seriously my doubts about whether my dad had had a stroke and my concerns about the treatment, they might have told me that they had checked my father's blood sugar level, and that there was a second symptom of stroke they hadn't told me about. Instead, valuable time was wasted, and I was left confused and in turmoil.

There is a growing expectation that doctors should be effective communicators. Medical schools have begun to teach communication skills, especially since the United States Medical Licensing Examination started testing those skills with the use of simulated patients in 2004, and the communication skills component of the exam was enhanced in 2012. Additionally, the results of surveys of patients' experiences of care—which include questions about how well doctors and nurses respect, listen to, and explain things clearly to patients—are being used in determining hospital payments. But we still have a long way to go. Hospital leaders need to make it known throughout their organization that clear communication is an institutional priority.

Every discussion of possible treatments should cover the risks, harms, and benefits of all the options—including the option of doing nothing. This is a basic tenet of informed consent, which unfortunately many hospitals do not observe. Hospitals have been cited by the Joint Commission for failing to have appropriate informed consent policies in place, but little attention has been paid to whether they adhere to the policies they have established.

In my dad's case, the residents should have educated me about the natural progression of stroke and the chances that the stroke would resolve on its own, that the symptoms would persist or increase, or that the stroke would kill him. They should have taken me through a similar risk-benefit discussion of tPA and explained the chances that my father would improve, stay the same, get worse, or die.

Risk communication is notoriously difficult. One method used to simplify the task is a visual representation of the risks and benefits of a treatment versus other alternatives. Since my father's emergency, I've considered whether something like this would have helped me.

One challenge is making such illustrations unbiased. My research found two graphics showing the benefits and risks of tPA, but both were criticized by Jigneshkumar Gadhia and colleagues in a review article published in 2010 in *Stroke* for presenting a distorted view of the risks and benefits. Furthermore, these types of graphics are complex and can be difficult to understand, even for patients with high health literacy, as noted by Jasmir Nayak and colleagues in a 2015 article in *Patient Education and Counseling*.

Another problem is that the graphics show the aggregate results of clinical trials. For graphics to be meaningful communication tools, they need to depict the risks and benefits for each patient as accurately as possible. Some work has been done to tailor risk-benefit calculations to patients using data from stroke registries and to present these data to patients and families. This would not only have given the residents treating my dad more precise guidance, but it would also have allayed my concerns that the treatment they recommended was dictated by a rule of thumb instead of my father's particular situation.

Translating the results into easy-to-understand graphics remains challenging, however. Testing these tools with diverse patients, including those with limited health literacy, will be essential.

Making Informed Consent An Informed Choice

Some people would argue that stroke treatment is not an area that should be subject to shared decision making. They would say that the science is clear and that a doctor's objective should be to obtain consent as quickly as possible to increase the likelihood of a good outcome. Some patients and family members would indeed prefer to abdicate the decision to clinicians. That is their prerogative.

Evidence should never be used as a cudgel to pressure patients to consent to treatments they don't fully understand.

But I believe that patients and family members have a role to play, even when decisions must be made quickly. The claim that "it's an emergency" does not exempt clinicians from engaging patients and families and explaining the situation in an understandable way so that if consent is given, it is truly informed. Evidence should never be used as a cudgel to pressure patients to consent to treatments they don't fully understand.

Different people will be prepared to take different risks. Some people will feel better if they avail themselves of a chance for a full recovery, even if the treatment involved is risky. Others will feel worse if they gave their consent for something that ended up killing their loved one. There will always be bad outcomes, and how patients and their families feel when they occur matters. After all, patients and families have to live with the consequences.

The informed consent process has to be more than chasing down a signature for a form. To empower patients and families to make informed choices, health care organizations must build supportive systems. For example, hospitals could maintain a library of high-quality decision aids, which are tools designed to facilitate shared decision making and patient participation in health care decisions. Even the most dedicated doctors will have difficulty engaging patients and families in shared decision making without the support of their institutions.

Making Engagement Part Of The Protocol

Hospitals' "door-to-needle time"—the time between when a stroke patient arrives and when tPA is administered—is now a quality metric. There has been a major push to increase the number of stroke patients who receive the drug quickly. Protocol dictates that when a stroke is suspected in the hospital, a stroke team is called to evaluate the patient. If the patient meets the criteria for tPA, a CT scan is done, and if there are no signs of a brain bleed, tPA is administered.

To turn informed consent into informed choice, patient and family engagement has to be integrated into this protocol. It could dictate, for example, that while the patient is being evaluated, a member of the stroke team lets family members know that a decision may have to be made quickly and asks if any other relatives should be involved in the decision.

The protocol could also specify that during the CT scan, the family be briefed about the results of the evaluation, the purpose of the scan, and the upcoming decision about whether to administer tPA. The next step would call for the doctor to sit down with the patient and family and use a personalized decision aid to elicit their goals and preferences. After discussing the benefits, harms, and risks of the options, including the option of no treatment, the doctor would check that this information had been understood. The final step would be that the doctor helps the patient and family make a choice. Everything could be accomplished in a short amount of time if the process was streamlined and clearly delineated.

Simply having a policy in place that doctors must obtain informed consent is not sufficient. To make sure that patients and families are appropriately included in decision making every time, roles need to be specified (for example, who is going to explain the results of the stroke assessment), logistics need to be worked out (for instance, where there is a place to talk, or how family members who are not on site will be contacted if cell phones don't work in the ED), and staff members have to be trained (for example, how to use decision aids, engage patients and families in the decision-making process, and check their understanding of the information they've been given).

In addition, adherence to policies about patient and family inclusion has to be monitored. And when policies are not followed, these failures should be studied to determine where the breakdown occurred and what corrective action is needed.

Epilogue

My father was lucky. He got back most of his functioning after the brain bleed, although he can only play ping-pong sitting down and can no longer go out for a walk by himself because he is at risk of falling or getting disoriented. The doctors are pleased with the outcome, but I am displeased that they did not explain the risks before I gave consent. The health care system needs to hardwire patient and family engagement into the informed consent process, even in emergencies.

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When the residents gave my father a stroke diagnosis, I needed someone to serve as an unbiased interpreter of the evidence, to recognize my knowledge of this particular patient, and to ask about our values and goals. I needed someone to acknowledge that we faced a hard decision, that there were no guarantees, and that it was ultimately our choice. Anything less violates the principles of informed consent and the dignity of patients and families.

Policy Checklist

The issue

Clinicians must ensure that patients and families fully understand the risks, harms, and benefits of all treatment options available to them, but often they fail to do so and neglect to engage patients and families in shared decision making. Hospitals must hardwire patient and family engagement into informed consent protocols, even when decisions must be made quickly.

Resources

Agency for Healthcare Research and Quality. AHRQ Health Literacy Universal Precautions Toolkit, 2nd ed. <http://www.ahrq.gov/literacy>

Agency for Healthcare Research and Quality. CAHPS Health Literacy Item Sets. <https://www.cahps.ahrq.gov/surveys-guidance/item-sets/literacy/index.html>.

Agency for Healthcare Research and Quality. Guide to Patient and Family Engagement in Hospital Quality and Safety. <http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/guide.html>

Agency for Healthcare Research and Quality. The SHARE Approach. <http://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/index.html>

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Fleisher L, Raivitch S, Miller SM, Partida Y, Martin-Boyan A, Soltoff C, et al. A Practical Guide to Informed Consent. <http://www.templehealth.org/ICTOOLKIT/html/ictoolkitpage1.html>

Informed Medical Decisions Foundation. Advancing Shared Decision Making. <http://www.informedmedicaldecisions.org/>

Knox L, Brach C. "Primary Care Practice Facilitation Curriculum, Module 10: Mapping and Re-Designing Workflow. <https://www.pcmh.ahrq.gov/sites/default/files/attachments/pcpf-module-10-workflow-mapping.pdf>.

Minnesota Shared Decision-Making Collaborative home page. <http://msdmc.org/>

Ottawa Hospital Research Institute. Patient Decision Aids. <https://decisionaid.ohri.ca/AZinvent.php/>

Related reading

Volk R, Llewellyn-Thomas H, Stacey D, Elwyn G, editors. "The International Patient Decision Aid Standards (IPDAS) Collaboration's quality dimensions: theoretical rationales current evidence, and emerging issues." BMC Med Inform Decis Mak. 2013;13(Suppl 2). <http://bmcmmedinformdecismak.biomedcentral.com/articles/supplements/volume-13-supplement-3>