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Narrative Matters

A Nurse Learns Firsthand That You May Fend For Yourself After A Hospital Stay

Following her husband’s stroke, it falls to a registered nurse and nursing school dean to coordinate care and manage her recovering spouse’s transitions among several hospitals and home.

BY BETH ANN SWAN

At 9:45 on the evening of Tuesday, April 26, 2011, the phone rang in our home in suburban Philadelphia. When I answered, I heard the voice of my husband Eric’s colleague, who was with him in Chicago on a business trip. They wouldn’t be flying home that evening, he told me. Had they missed the plane? “Not exactly,” he answered. Eric was in the emergency department of a hospital near O’Hare International Airport. He had collapsed while boarding the plane to Philadelphia.

In an instant, we were thrown into the unreal world of medical “care coordination” and “transition management.” There would be no easy way for us to get Eric from a hospital there to a hospital here and then to home. And along the way there would be gaps in the care Eric received—gaps so large they were more like chasms. We just didn’t know it yet.

Chicago

What had felled Eric was a brain stem stroke, which had caused what is known as Wallenberg’s syndrome. The stroke had blocked an artery on the right side of his neck, depriving part of his brain of the blood it needed. A formerly healthy fifty-three-year-old male, Eric now was far from home, hospitalized with a serious stroke.

My thoughts were racing. Thank goodness he wasn’t alone, thank goodness the stroke happened before the plane took off, and thank goodness I’m a registered nurse who works at a world-renowned academic health center where I have friends and resources.

My first call was to the president of the academic health center in Philadelphia where I work, who is himself a neurologist. He immediately started working to get Eric into the best stroke center in Chicago. Next I called my mother to come stay with Eric’s and my thirteen-year-old daughter. By midnight I was running around the house packing a suitcase, with no idea how long we’d be in Chicago.

The next morning I left the house at 5:00 to fly to Chicago. I cried all the way to the airport. How was I going to get Eric transferred from the community hospital where he was at that moment to the Chicago academic health center with specialized stroke care, and then get him home?

I arrived at Eric’s bedside at 11:30 a.m. on April 27. Although a bed was waiting for him at the stroke center, it took me until 5:30 p.m. to get Eric into a hired ambulance. By 6:30 p.m. he was in the neurologic intensive care unit at the Chicago academic health center. As his wife, I wanted to cry. Instead I put on a brave face and became his care manager.

Illustration by Brett Ryder
Eric spent ten days hospitalized in Chicago. He couldn’t swallow, and he couldn’t walk. He had rapid, involuntary eye movements, called rotary nystagmus, that made him look like a cartoon character with his eyelids going round and round in circles. He also had a drooping right eyelid; pupils that were different sizes; double vision; numbness on the right side of his face and in his left arm and leg; and other neurologic issues.

**What Went Well, What Didn’t**

During Eric’s ten-day hospitalization, he was cared for by a team of more than fifty health care professionals and students. He was asked to repeat his story over and over, and although information was passed along from shift to shift, like the whispered game of telephone, inaccuracies inevitably cropped up. It was up to him, as the patient—with my help—to correct them.

Eric also experienced a series of micro transitions in Chicago, as he moved from the neurologic intensive care unit to the step-down unit, and then to the general care unit. Thankfully, during these internal transitions, communication and handoffs went smoothly.

But the later macro transition from the academic health center in Chicago to an acute rehabilitation hospital in Philadelphia was challenging. There was no communication about the handoff between the two facilities; neither had a system to handle this type of complicated transfer. I don’t know why, given that such situations are hardly unique. But everything was left to us, the ill patient and his wife. Basically Eric was going from a group of fifty caregivers to one—me—to handle his interstate transfer.

My first challenge was getting a copy of Eric’s complete health record from his hospitalizations in Chicago, along with copies of all of his imaging studies. It took many conversations and phone calls until I was finally given paper records to carry back to Philadelphia by hand. Who knows if electronic health records might have been a possibility?

My second challenge was to locate an acute rehab unit bed in a hospital that would be available on the day and at the time when Eric needed it, with the timing a moving target.

My third challenge was to get approval from our health insurance company to transfer Eric from a hospital bed in Chicago to an acute rehab hospital bed in Philadelphia.

From the moment Eric fell ill, the goal was to get him hospitalized back home in Philadelphia. Even so, a social worker first met with us to discuss planning for Eric’s discharge only five days before he was transferred.

The transfer process would have difficulties, especially because Eric couldn’t walk. At about $10,000, hiring an air ambulance was prohibitively expensive. To fly on a commercial airline, Eric would need to be able to transfer himself with assistance from a wheelchair to an airplane seat.

In addition, managing this city-to-city transition would require complex care coordination and transition management on our part, as well as tenacity and the micromanagement of dozens of details. How, I wondered, do others in similar circumstances—especially people without my nursing knowledge, familiarity with hospitals, and professional contacts and resources—navigate this kind of complexity?

At 1:15 p.m. on May 6, Eric and I flew out of Chicago. We had copies of Eric’s health records, which included a hospital discharge summary, the list of medications he was taking at the time he was discharged, and his imaging studies. This handoff consisted of an envelope given to us by a resident physician.

We arrived in Philadelphia at 4:15 p.m., where we were met by an ambulance I’d arranged for through my work contacts. The ambulance transported Eric to the acute rehabilitation hospital, which we reached at 5:30 p.m. No one in Chicago ever contacted us to see if Eric had made it safely to the rehab hospital.

**The Shock Of Rehab To Home**

Eric continued to improve during the next twelve days. With intensive physical therapy, occupational therapy, and a variety of other therapies, he progressed from a wheelchair to walking with a walker, and then to being able to go up and down stairs. Although he continued to have double vision and problems with balance, coordination, and a constellation of other symptoms, on May 17 Eric was ready to go home.

Everyone was thrilled. But neither Eric nor I was prepared for what lay ahead.

As we soon discovered, I would be managing the care he would receive from six or more primary and specialty health care providers and services, as well as coordinating Eric’s various care needs at home. Keeping everything straight would prove to be a herculean task that required determination and persistence, to say nothing of the ability to navigate the after-hospital world filled with lengthy to-do lists. I would frequently find myself talking to answering machines, not getting callbacks, and yearning for answers from a human being.

This next, extremely complex home phase began when we were handed a ten-page report with Eric’s rehabilitation discharge instructions. The report listed the five medical personnel with whom Eric had to have appointments: a physical therapist, whom he was to see as soon as possible; a neurologist, a primary care doctor, and a vascular physician, all of whom needed to be seen within two weeks; and a rehab physician, to be seen within three weeks.

Because Eric was taking a blood thinner, he was required to have his blood drawn weekly; the first draw would need to be the next day, May 18. But the report didn’t say where to go or with whom to make the appointment.

Eric also was given seven prescriptions, along with twenty-nine pages of printed information about them; five pages of instructions dealing with home
Looking Back
My most striking discovery during the year following Eric’s hospital and rehab stays was that his outpatient care involved no registered nurses. While he was in a hospital, if I had a question about anything, I had 24/7 access to one of Eric’s registered nurses. Yet the help we needed in navigating the outpatient setting was as intensive as the care that registered nurses had delivered during his hospitalizations. After he was discharged, we were on our own. Yet not a day went by when we weren’t performing some activity that dealt with coordinating care and managing transitions among all of Eric’s doctors and other providers. We had no identified point of contact, no phone number, no e-mail address to use for support or guidance. No one was knowledgeable about Eric’s comprehensive care plan, and no one had or provided expertise in coordinating his still-complicated care once he was home.

As a patient’s wife, I would have welcomed having an RN as a point of contact. As a nursing school dean, I know the evidence demonstrating that registered nurses are critical to the operational and financial success of health care delivery systems. Their education, knowledge, skills, and competencies are as much an asset in outpatient settings as they are in hospitals.

I also know that nurses have the expertise to bridge care transitions and are critical to coordinating care across all settings. The Care Transitions Intervention developed by Eric Coleman at the University of Colorado uses “transitions coaches,” primarily nurses and social workers, who first meet patients in the hospital and then follow up through home visits and phone calls. Another proven transitional care model, developed by Mary Naylor and colleagues at the University of Pennsylvania, employs advanced practice nurses to coach patients and their caregivers, coordinate follow-up care plans, and provide regular home visits and round-the-clock support by phone.

Although these models have been adopted by hundreds of hospitals, it is frustrating that they aren’t more widely utilized. Fortunately, one of the reform strategies in the Affordable Care Act, the formation of accountable care organizations, should spur health systems to adopt these models and other techniques to better manage posthospital transitions and care management. Accountable care organizations are expected to deliver coordinated, efficient, and effective care by accepting responsibility for the cost and quality of care delivered by a group of providers.

The wheels are already in motion. As it stands now, the Centers for Medicare and Medicaid Services has established thirty-three quality measures for accountable care organizations, some of which deal with the patient-caregiver experience. The data to construct the measures are already being collected in a survey, the Consumer Assessment of Healthcare Providers and Systems, conducted by the Agency for Healthcare Research and Quality.

But will these measures go far enough to capture the actual, full experience? I hope information is available on the details. For example, the patient-caregiver experience is a broad measure that includes how well doctors communicate; it implies a verbal exchange or discussion of information. In our case, technically, we were “communicated with,” but the communication was far from adequate.

There seemed to be an assumption that we could manage the complexities of Eric’s care on our own.

And that phone call saying we had an unpaid balance of $23,312 in Chicago? After making multiple calls, I discovered that the community hospital had incorrectly recorded Eric as having Medicare Part A and no other insurance. But the hospital informed me that its error was our problem. It would take at least thirty days to correct the bill, and in the meantime the hospital said it couldn’t reverse the collection notice. We continued receiving calls to our home. The calls stopped on June 23 when the matter was finally resolved; in fact, we owed just $3,076.

Arrghh!
May 17 was a wonderful day—Eric was home at last. But it was also the day we entered the Twilight Zone.

When we arrived home, we found a voice-mail message telling us that we were “being placed in collection” for not paying a bill in the amount of $23,312 owed to the community hospital in Chicago where Eric had spent twenty hours. The mail box was jammed with hospital and ambulance bills. How, I wondered, can we reengineer the delivery of health care so that it is as timely and efficient as the medical billing process?

The next day, May 18, our new aggravations continued as we tried to find a lab to draw Eric’s blood that day and then to schedule his follow-up appointments. What about the neurologist appointment required in two weeks? The next available appointment was in October. The vascular physician appointment needed in two weeks? The next available appointment was in July. I started calling on members of my professional network to get appointments for Eric within the prescribed time frames.

Each office where we scheduled an appointment asked that we bring all of Eric’s Chicago records and imaging studies. This was another problem. We’d given all of that information to the rehab hospital here in Philadelphia—and it had lost everything. I needed, again, to gather all of the records and imaging studies from Chicago.

Friends, family, and the hospital staff were all very helpful. They worked with the insurance companies, the hospital, and the rehab center to get Eric’s records and imaging studies. As a result, Eric was able to obtain his records from the hospital and rehab center. This was another problem. We’d given all of that information to the rehab hospital here in Philadelphia—and it had lost everything. I needed, again, to gather all of the records and imaging studies from Chicago.

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Providing patients with written instructions before they’re discharged from a hospital might be considered a type of handoff, but it’s not a measure of patient care being coordinated or of a patient’s transition being managed. That’s especially true when there’s no attempt to be sure that the patient and family understand how to follow up properly on the care instructions.

For years, numerous national reports have called for patient-centered care, yet health care organizations haven’t achieved measurable or sustainable change in that area. A 2011 Institute of Medicine report, *The Future of Nursing: Leading Change, Advancing Health*, also called for care that is centered on the patient and further recommended reconsidering the roles of health professionals, including registered nurses, to transform current practices dealing with care coordination and transition management.

True coordination and management are made up of dynamic processes requiring ongoing communication between patient and provider and among multiple providers. Patients and their families need to participate actively in these processes at all stages, including needing to know what to do if conditions worsen when they are home.

**Looking Ahead**

Patient-centered care has to be more than a trendy phrase. Experiences such as my family’s offer real-world guidance on what’s needed to get it right.

We need to ensure that patient-centered care is understood to be a long-term relationship in which patients have a specific point of contact with their team of providers. That team member must be accountable to those patients and responsible for coordinating their care. There must be contingency plans making clear who patients are to get in touch with when their identified point of contact isn’t available.

Additionally, patients and their families need access to information around the clock. This could be accomplished in small practices with a designated on-call provider who has access to the practices’ electronic health records, or by call centers staffed by registered nurses with access to the records.

We need to acknowledge that true patient-centered, team-based care coordination covers all of a patient’s micro and macro care transitions, all parts of the hospital setting, and the move from hospital to home.

At the heart of this coordination is assessing patients’ and families’ readiness to manage their care and their capability to do so. We should never assume that they can do it all on their own.

When people are in hospitals, they’re sick and vulnerable. That doesn’t necessarily change on the day they’re discharged. How can we expect not-yet-well people to suddenly begin managing all of the complex medical and personal issues that just the day before were being handled by an entire team of trained professionals?

We have to figure out a way to handle these patient transitions in a kind, sensible, thorough, and realistic way. Registered nurses seem to me like the group with the right training for the job, but I also believe that getting it done properly is more important than which profession does it. The bottom line: We need patient care and transition systems inside and outside of hospitals that work efficiently. Until they do, patients run the risk of falling into a terrible abyss of uncertainty as they go out the hospital door.

Beth Ann Swan (bethannswan@gmail.com) is dean and professor at the Jefferson School of Nursing at Thomas Jefferson University, in Philadelphia, Pennsylvania. She and her husband, Eric, express their gratitude to their colleagues and the many great health care professionals who supported them after Eric’s stroke.