Caregiver Viewpoint

From the Other Side of the Stethoscope

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All the world may be a stage,
But men and women are not merely patients.
All of us, in our time, will play many parts...

I am a primary care physician who recently had the opportunity to play a different role when my 96-year-old aunt was hospitalized for a cardiac issue. Though she lives in a neighboring state >2-hour drive away, my wife and I are her support network. Acting as her support and guardian angel during her hospitalization, I saw how fraught with risk a hospital stay can be.

(Spoiler: this story ends well.)

At noon on a Thursday, we received a phone call from the home health aide, telling us that my aunt was on the way to the hospital by ambulance. The aide could not tell us what had happened, or even what hospital. A flurry of frantic phone calls over the next hour determined that she had just arrived in a nearby Emergency Department (ED) with a rapid heart rate problem. I spoke with the ED nursing staff, faxed them a copy of her medical proxy and Advance Directive, packed a suitcase, and hit the road. My wife stayed home to be a communication center for extended family and to make sure my office knew I was going to be out for several days.

I arrived in time to accompany my aunt from the ED to her room on the cardiac care floor. No physician in the ED was available to talk to me about her medical status, but the nurse told me she had arrived with a fast heart rate and chest pain, got some medication through intravenous that slowed her heart down to normal, and that the purpose of what he hoped would be a short hospital stay was to make sure her rhythm and rate stayed normal and to see if her heart had been damaged by the stress, causing a heart attack that might require other testing or treatment. He answered our questions well.

Events during this admission illustrate both the powerfully good and the dishearteningly bad aspects of hospital care.

The nurses and the hospitalists were polite and attentive. They introduced themselves and described their role. They made eye contact. They evidenced care and compassion. Though obviously busy, they never seemed rushed, impatient, or frustrated. They solicited and answered our questions and said “I don’t know” where appropriate. They were obviously good at what they did, inspiring comfort and confidence, but it was also apparent that they worked in a system where doing the right thing was harder than necessary.

• I gave contact information multiple times (6) although I witnessed it being entered into the computer 4 times.
• The advance directive I faxed to the ED vanished. I gave them a second copy the night of admission and reviewed its contents with the hospitalist, but her discharge summary said there was no advance directive.
• Important aspects of her health and social context were not transmitted from person to person: she lives alone with family 2 hours away; she plans to age in place at home; although independent for bathing, ambulating, and toileting, a visiting nurse puts out her medicines weekly because she cannot remember to do so; and her family manages her finances. She cannot leave the apartment alone to do errands. Although this information was provided 3 times, the first evening and several more times the next day, it was apparently not available to clinical staff.
• She arrived on the floor too late (5:00 pm) for the evening meal and had not been fed in the ED. Three clinical staff commented on this. Two took her order for dinner. It still

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took several prompts from me before a sandwich and beverage were produced.

- I asked when the cardiologist would be making rounds the next morning because I wanted to be there. They made a notation in her chart to call me when he arrived. That did not happen, and he and I played phone tag for several hours.

I arrived the next morning after the cardiologist had gone. He had not called me when he was there because he could not find my contact information. He explained she had had a small heart attack without significant damage, probably a result of the rapid heart rate, and suggested that her blood pressure medication can be changed from nifedipine to a β-blocker to help prevent recurrent atrial fibrillation and heart damage from a rapid rate. He recommended anticoagulation with oral coumadin to prevent strokes, a known risk for patients with atrial fibrillation. After I explained that she lived alone, could not handle her medications independently, was at high risk for falls, and could not get frequent blood tests to assess the coumadin dose, he agreed that it made more sense to lower her risk for stroke with daily aspirin, a less effective but safer approach.

Several hours later, the hospitalist of the day (not the one who had admitted her the evening before) came in for morning rounds. Like every member of the clinical team we had met the day before, she was delightful, competent, and caring person—but had to be brought up to speed. When she said they would be starting her on coumadin to prevent strokes, I pointed out that the cardiologist and I had decided that aspirin was a more appropriate approach. After discussing the home situation (which should have been in the chart in notes), she agreed. I asked about the results of the laboratory: normal except for mild renal impairment of the β-blocker and rapid rhythms with a different blood pressure medication and reduce the risk of stroke with daily aspirin. All that was needed was the report of the ECG (done 2 days earlier to help assess her cardiac function and guide treatment). It was not until mid afternoon that the report of the (normal) ECG reached her chart. At that point, a nurse came in to review her discharge instructions and medications. I asked that we receive a copy of the hospital record for her stay and was told initially that I would have to request that during the week through medical records, but when I persisted, they gave me a form to sign and said the record would be sent. (It arrived within a week, but contained many errors and inconsistencies.)

The discharge nurse had never met us before and did a good job going over the paperwork done by the hospitalist; although it was obvious, she did not realize that my aunt was essentially homebound and managed at home only because of a structured support system, which was never mentioned in the discharge process. My aunt sat there, smiled and nodded at the instructions she did not understand, and dutifully signed where she was told to sign. By the time she was dressed and we were in my car, it was too late to go to her usual pharmacy, and the hospital did not provide enough medications at discharge to cover until we could get to her pharmacy, so we had to find and use a pharmacy with extended weekend hours.

The hospital offered to enroll her in their fairly robust post-discharge program, and my aunt would have said yes although it would have been duplication of the services already in place. The hospital had no process in place to communicate the discharge process to the existing community services, so my wife and I served as the conduit.

That all occurred several months ago. My aunt has done well. She feels fine and has no cardiac symptoms other than more fatigue. She tells us that the hospital did a wonderful job and the staff treated her well. I sent a letter to the nursing staff, commending and thanking them for their excellent care. I sent a separate letter to the hospital administration, pointing out that the staff had been fantastic, but that they were being undercut by a system that made their lives harder and put patients at risk. I enumerated a list of information and communication issues and suggested that a group of patients, clinicians, and support staff be charged with improvement. I have been pleasantly surprised by the response. Within 2 weeks, I received 2 letters with detailed discussions of the issues I had raised and a nice card from the nursing director thanking me on behalf of her staff for the kind words. I have also had (at their initiative) 2 long conversations to discuss options for improving communication with patients and especially family, and an invitation to join them for some meetings to work on this.

My take home from this experience is the following:

- Medicine is complex, and there are countless opportunities for errors and missed opportunities.
• The people working in healthcare are overwhelmingly hard working, competent, conscientious, and caring but also overwhelmed by the job.
• The system is terrible, especially in areas of communication and information management.
• No patient should be left alone in a hospital (or at an office visit if there are serious issues to be addressed). I shudder to think of what might have gone wrong if I had stayed home and called once a day. The more ill the patient is, the more important this becomes.

• A polite letter acknowledging the hard work and good people and carefully listing issues that need to be addressed can be powerful.

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None.

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