Caregiver Perspective

"Observation Days" in a Kafkaesque Hospital Setting

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My 82 year old mother came to live with me two years ago. She had had Type II diabetes for several decades, and had developed weakness and gait disturbances (loss of balance and falls) in the past few years. She has a degenerative brain disorder, progressive supranuclear palsy, often mistaken for Parkinson's disease in its early stages, and had fallen numerous times, before coming to live with me, and while in my house. Her bones must be made of rubber because she never broke a hip, just developed nasty looking bruises, and, she refused to use a cane or walker. That can't go on forever, and one day she fell, got up, fell again, said she was fine, but did not get out of bed.

It took me a day to call the doctor, two more days for an appointment, and me finally realizing that she needed a hospital, not an office visit with the doctor. I had grown accustomed to her falls, and was stunned when our local hospital told me that she had a broken neck, a C-2 fracture, and needed to go to a larger hospital. They took her there by ambulance and I followed in my car. By 3:00 PM, we were at the ER of a big city hospital. Eight hours later, at 11:30 PM, she was still in the ER and I told the staff that I needed to go home, and would return the next day. When I came the next day, I found her in room 624, in a bed, in a hospital gown, wearing a wrist identifier. A nursing assistant was feeding her lunch. It was Saturday of a three day weekend and everything was pretty much on hold, but I visited every day of the weekend, asking about everything, talking to anyone who was there, writing notes, and generally making my presence known.

Three days later, the Tuesday after Labor Day, the case worker dropped a bombshell, "Your mother is not an inpatient, she was never admitted to the hospital."

Kafka? No. Rhode Island 2009.

This is not only happening in Rhode Island. Hospitals have the right to categorize care as outpatient "observation days". The procedures are billed as outpatient services (Medicare Part B); you get to pay for the patient's "room and board". Even worse, the seven days of care (in my mother's case) do not meet Medicare's requirement for a 3 day hospital stay – neces-

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sary for coverage of the care she will need in a Skilled Nursing Facility (she has a broken neck).

If the hospital labels the stay "outpatient" or "observational" you are out the $30,000 of Medicare benefits she could receive if the stay had been labeled as "inpatient". I've told this story to the staff at one Representative and two Senators' offices. None of them had heard of this. "That's a new one on me," said one staff member.

Mind you, my mom was in a bed, in a room, receiving meals, nursing care, insulin, physical therapy, a CT scan of her head, a full body CT scan, an ultrasound of her ovaries, two rectal exams, and I'd know more if I ever got to see a discharge summary. Oops! There ain't gonna be a discharge summary – she was never admitted.

Here's the latest from the streets: if you or a loved one is in the hospital, you must verify that the patient has been admitted as an inpatient. The hospital is not required to inform you that you or your loved one is on "observation status". You will find out after the transfer to the skilled nursing facility and Medicare informs you that the hospital stay was not "inpatient" and does not qualify for coverage at the skilled nursing facility. It is a lot to chew on: seven days in a hospital bed does not equal "inpatient care." The hospital is not required to tell you about the observational status. You are only allowed to appeal this categorization while the patient is in the hospital, but if the hospital doesn't inform you about the "observational status", you are not going to be able to appeal the decision. You've just lost Medicare coverage of the care required for an 83 year old woman with a broken neck.

Maybe I should calm down a bit. Perhaps this financial/administrative stuff is just a fight over who pays? So, how *was* her medical care? My answer is, "I don't know". No doctor ever took responsibility for her care (she was an outpatient). Everyone was well-intentioned, but I don't know who decided she needed an ultrasound to examine a cyst on her ovaries, or whether the ultrasound was necessary, and who is going to pay for it. That doesn't fit my definition of responsible medical practice.

Yesterday, a nice, empathetic young doctor met with me to review her condition. When I asked how my mother's diabetes is being managed, the doctor replied, "she's on her home meds". That must mean they've stopped injecting her with insulin (at home we managed the diabetes with oral meds), "Oh yes." Five minutes later, I go to my mother's room, and the nurse is injecting my mother with insulin. The doctor later apologized to me for misinforming me; she didn't know that my mother was being treated with insulin.

Ten months have passed since these events. I never received any summary describing medical care, treatment, or procedures during her "observation days" and no doctor or nurse ever contacted me to find out about her status. The hospital administration gave me a day or two to find a skilled nursing facility (telephone calls from my Congressman and Senators ensured that the hospital continued to care for my mother until I found a place for her). We were lucky to find a wonderful facility, with a place available, but because my mother had not been admitted as an inpatient in the hospital, she did not qualify to have Medicare pay for her stay in the skilled nursing facility. At this stage of her recovery, she wore a collar to support her neck and she received physical therapy. Her walking ability had deteriorated, either as a result of the fall, or the pain, or the awkwardness of the neck collar. I never had a chance to talk with a neurologist or neurosurgeon about this. She could no longer walk unassisted, and I lost interest in the why of it. It took two assistants to help her to the bathroom, get dressed and eat. By December, her brain deterioration led to her transfer to a dementia unit. By February, we had used up her assets to pay for her care, and she qualified for Medicaid.

The story of her "observation days" became part of the larger story of caring for a loved one with a degenerative brain disease, a new and painful world for me, a constant heartache. Her neck healed, and the collar was removed. She now lives in a dementia unit and I visit her several times a week. She always

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recognizes me, and sometimes, asks to come home. As this situation progresses, my feelings about the events around her "observation days" recede, replaced by each new day's questions and concerns.

Most people I've spoken to are not aware that a patient can be in bed in a hospital room, and not be an inpatient, and that the hospital does not need to disclose this to the patient or his/her family members. A recent article in Bloomberg News, suggests that the use of observation day status is a reaction to Medicare auditors challenging hospitals for admitting patients who do not require hospitalizations (Armstrong, 2010). In order to avoid penalties for hospitalizing someone unnecessarily, a hospital might care for a patient on "observation status". As with other federal systems, guidelines and checklists are available to govern this decision. Apparently, my mother did not require hospitalization according to the Medicare guidelines (I never saw a copy of the criteria), and one can imagine an error in the algorithm or checklists resulting in such a conclusion. Could it be true that an 83 year old diabetic woman with a broken neck doesn't need to be hospitalized? The neurosurgeons decided that she did not need surgery, but I was not equipped or prepared to take care of her in my house, and prevent further injury to her neck and spinal cord. Ultimately, the skilled nursing facility was the appropriate place for her, but placement took several days, and evaluation of her neck injury was a necessary step in the process. In response to a letter from me, the Rhode Island Department of Health investigated events and wrote to me, stating, "the hospital was found to be in compliance with state and/or federal regulations. There were no deficient practices or standard of care issues identified."

The initial decision to categorize my mother's care as "observational" might have been an innocuous attempt to work with the Medicare bureaucracy, but it resulted in a loss of Medicare coverage of my mother's care at a skilled nursing facility. With regards to my mother's individual experience I may have an opportunity to appeal the decision to deny Medicare coverage for the skilled nursing facility, except that the skilled nursing facility did not submit her stay for coverage, anticipating the denial. I am working with them to push the paperwork through the process, but new wrinkles seem to emerge at every turn. On a more general note, it seems that others have had similar experiences and are making their voices heard. There's even an advocacy group working on this issue, the Center for Medicare Advocacy and they've kept me posted on events at the national level. I learned that Congressman Courtney (D, Conn) has introduced a bill, H.R.5950 -- Improving Access to Medicare Coverage Act of 2010 that will count observation time as inpatient time if a Medicare beneficiary is hospitalized for more than 24 hours, for observation stays after January 1, 2010 (Open Congress, 2010).

In addition to the enormous financial consequences of the decision to categorize my mother's care as "observation days", we encountered a lack of accountability that led to unnecessary tests and procedures, and inadequate communication between the hospital and myself. The "observation status" meant that no one took responsibility for her care, no discharge summary was required, and for some reason, there was no requirement that the hospital discuss treatment decisions with me. At the very least, this led to chaos, eroding my trust and confidence, and alienating me, the person responsible for her care. At the worst, harm was done, or opportunities missed to help my mother recover with comfort and dignity.

REFERENCE

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