4-1-2000

Is Incapacity a Permanent Thing?

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by
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Ms. H. K., an 82 year old retired nurse, was taken to her local hospital after a neighbor found her lying outside her house, confused and unable to move her left leg. The ER physician stabilized her fractured femur, then her primary care doctor transferred her to a tertiary care hospital because he felt her condition was too complex to be handled by their facility.

She remained confused after arrival at the city hospital, and her only known relative, a niece, was appointed surrogate decision- maker. The patient's hospital course was rather stormy. She was found to have pneumonia and evidence of a non-Q wave MI (heart attack), and she developed extensive skin ulcerations on her left leg. The ulcerations were thought by the medical team to be due to a combination of chronic venous stasis and pressure damage incurred while she had lain on the ground for several hours.

A conservative treatment regimen was followed, in keeping with the niece's statement that "Aunt Hattie wouldn't have wanted a lot of stuff done to her in this condition," and the patient remained in the hospital for the next three weeks. Slowly, her pneumonia cleared and she showed no further signs of cardiac ischemia. Physical therapy was started and she was transferred to an extended care unit. She did not appear very motivated and did not interact very much with most staff members. She did have better rapport with certain nurses and therapists, and they reported that she was becoming less confused; other staff had not seen much change.

After two weeks in extended care, the medical team decided the patient had reached maximum benefit and planned for discharge; the surrogate agreed immediately to nursing home placement. The social worker went in to inform the patient, even though she did not believe the patient would fully comprehend the discussion. Ms. K. immediately became agitated and refused nursing home placement. She repeatedly said, "I won't go anywhere but back to my own house." In discussing the need to regularly change the dressings on her legs, she said, "I can do it." Extensive discussion ensued, as the niece indicated that no one in the family could provide the care she would need, and home health services would be intermittent at best. The patient could not do all her own care, though she could transfer independently and feed herself. The medical team and the surrogate favored transfer to a nursing home, contending that the patient had been incapacitated for decision making since admission and was now obviously "not thinking straight" in making such an "unreasonable" request. Several nursing staff members held that she had recovered enough to make her own decisions. After two days' impasse, a geriatrics consultation was obtained.

The geriatrics consultant framed the following questions to determine the patient's capacity:

1. What was the patient's functional level and mental status prior to her injury?
2. What is her current mental status?
3. Does she understand her current medical condition and the extent of her need for assistance?
4. Does she understand the potential consequences of her decisions?

It is important to know the patient's prior status. If she was previously entirely functional, it is a medically reasonable assumption that she might recover back to baseline. The corollary assumption, of course, is that if a patient is demented or incapacitated at baseline, there is little hope of an event such as this having a better-than-baseline outcome. In Ms. K.'s case, the niece and a neighbor agreed that she had been a little cantankerous, but was definitely functioning normally prior to her fall.

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In spite of the current controversy, the consultant found that no one had attempted any formal assessment of her mental status, relying instead on assumptions based on their informal observation of her through her hospital stay. When the consultant assessed the patient, he found her alert, oriented to person, place, and situation, but not to time. She had said it was "a Tuesday, around October 20, 1999" (a date about two weeks after her fall) rather than the actual date of Wednesday, November 10, 1999, five weeks post-accident. She missed two more points on the Folstein Mini Mental Status Exam, one on recall and one because she refused to try to draw pentagons. The consultant assessed this as a minimally abnormal score, and attributed her deficits to explainable circumstances.

"The Folstein MMSE is not by itself an adequate tool to assess mental status, and certainly not to assess decision-making capacity,"

but it is a very handy bedside evaluation tool when circumstances do not permit full testing. Of 30 possible points, a score of 20 or less represents certain impairment, and 28 or more in most cases would be normal. Between 21 and 27, the scores are in a "gray zone" in which case situational variables must be considered.

To answer the final two questions, the consultant spent time interviewing the patient personally about her level of understanding, and her perceived reasons for her decision. He determined that her main concern was that "She's trying to get me off in a home so she can get my house." She expressed at least a passing knowledge of her medical diagnoses, though she contended that "I don't think I really had any kind of heart attack. Surely I would know if I did." She also stated, "Yes, I know it may be hard to change these bandages, but I'll just keep them clean, and they won't need changing so often." The consultant confronted the patient with the possible consequences of inadequate nursing care, the worst of which he described as possible infection of her leg ulcers which could go so far as to require amputation. The patient said, "Well, I'll never let anybody cut off my leg, and if I die, I die."

During the doctor's interview with the patient, the social worker made contact with two of her neighbors to find out more about her recent interactions with her niece and others in the community. She learned that the patient had frequently had conversations with these neighbors and that whenever the topic was related to late-life care issues, Ms. H.K. had often repeated that she planned to die in her own home. "As long as I have any say-so, my niece won't get her hands on this house. Neither she nor her mother before her would ever help take care of our parents, and this is all they left me. I won't let her have it." The neighbors also supported the patient's contention that the niece did mention at times that she would love to get a chance to get control of the property.

Ultimately, the consultant concluded that the patient had regained her decision-making capacity. He noted that, while her decision was somewhat short-sighted and quite problematic in terms of her care needs, it was based on life-long habit patterns and certain actual facts, and that she did have an adequate understanding of potential consequences. The patient was discharged to her home with maximum available home health services, and with special attention from the home health social worker. The social worker eventually found that a few of her neighbors and members of her church were willing to assist her, though her family members were not. She continues a very slow recovery at home with this arrangement.