A Daughter's Duty

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Rosa Torres (not her real name) was a 72-year-old woman with advanced congestive heart failure, chronic obstructive pulmonary disease, and severe chronic pain caused by degenerative joint disease. Over the previous 12 months, she had become bed- and chair-bound because of shortness of breath. Before this, she had been able to get around her apartment with a walker but could not go out without assistance. She had been prescribed numerous medications, including long-term treatment with narcotics for pain. Her native language was Spanish, but she had lived in the United States for 40 years and spoke English fluently. Despite early dementia, she remained oriented and capable of making her own decisions.

Until recently, Ms. Torres had lived with her daughter, Angela Hernandez, who also had extensive medical and mental health issues. They were both patients of Dr. Stevens, a family physician with a large panel of geriatric and nursing home patients. Since becoming their physician 4 years before, Dr. Stevens had regularly seen Ms. Torres, who was usually accompanied by Ms. Hernandez. They discussed advance care planning on multiple occasions, and Ms. Torres continued to desire aggressive treatment, including cardiopulmonary resuscitation and intubation. She had been widowed 15 years before and had no living siblings. Her late husband had sexually and physically abused Ms. Hernandez, who was being treated for depression and post-traumatic stress syndrome by a local psychiatrist. Ms. Hernandez was quite isolated—her teenage son had substance abuse and legal problems, she had few friends, and she was not part of a faith community. Ms. Torres had another daughter on the East Coast, who was estranged from Ms. Torres and Ms. Hernandez.

During a recent hospitalization for weakness and confusion, Ms. Hernandez and Dr. Stevens had agreed that she was no longer able to meet her mother's care needs at home, so Ms. Torres had been discharged to a local nursing home under the care of Dr. Stevens. There, she conflicted with staff and frequently refused medications and treatments. Ms. Torres strongly wished to return to Ms. Hernandez's home, saying it was "a daughter's duty" to care for her aging parent. She called Ms. Hernandez many times each day begging to be taken home. Ms. Hernandez felt extremely guilty over the situation and eventually moved Ms. Torres to a private home with a paid live-in caregiver. Visiting nurses felt the care-giving arrangements were inadequate and expressed concern about her safety. Ms. Hernandez "fired" the visiting nurse service after an agency social worker visited. Dr. Stevens considered consulting Adult Protective Services but opted to make a home visit first.

Before the home visit, however, Ms. Torres was admitted to the hospital in respiratory failure. She was placed on a ventilator, treated for pneumonia, and stabilized after 2 days. She refused to return to a nursing home, and at her insistence (and that of Ms. Hernandez), she was discharged to a different private home with a different paid live-in caregiver. She agreed to a hospice consultation. The hospice nurse and social worker felt her living arrangements were unsafe and declined admission to hospice until a better in-home care plan was in place. Ms. Torres and Ms. Hernandez declined visiting nursing services. She was readmitted to the hospital within 24 hours because of mental status changes.

Her mental status quickly returned to baseline, and she initially agreed to placement in another local nursing home under the care of Dr. Stevens. At the time of transfer she protested, saying that she was "not ready to leave the hospital yet" and

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that she "never agreed to *this* nursing home." Nursing and transport staff cajoled her into going as planned. On arrival at the nursing home, however, she became extremely agitated; she said that she had been "tricked" and "forced to go there against [her] will" and that she refused to stay under any circumstances. The charge nurse called Dr. Stevens and put him on the phone with Mr. Torres. He told her that he was frustrated that she was not going along with their agreement and that she was leaving him with few options, but she remained firm in her refusal to stay at the nursing home. The nursing home staff sent her back to the hospital, where a mental health crisis counselor triaged her and concluded that she was not delusional or sufficiently impaired to qualify for involuntary placement.

At this time, Dr. Stevens requested that her admission be deemed medically unnecessary, raising the possibility that Medicare benefits for her readmission would be denied, making the patient responsible for the bill. A meeting was convened with Ms. Torres, Ms. Hernandez, Dr. Stevens, social services, and the hospital's utilization/compliance officer. During the meeting Ms. Torres told Dr. Stevens, "Something's different. You don't love me any more." Ms. Torres eventually agreed to nursing home placement. Because no local nursing homes would accept her at this point, she was admitted to a facility in a different community under a different physician's care. A few days after transfer, Ms. Hernandez visited the nursing home and, without notifying the staff, Dr. Stevens, or her mother's new physician, took her from the facility and moved her into another private home. A day later, Ms. Torres was once again brought to the emergency department by ambulance because of acute mental status changes. Dr. Stevens was called to admit her. He now requests an ethics consult.

How should Dr. Stevens respond?

Question

The seemingly irrational behavior of Ms. Torres may call into question the psychiatrist's judgment that she still has decision-making capacity. How should the physician negotiate lingering questions about her ability to make decisions about her care?

Response

Larry Lawhorne

A fundamental issue in this case is the determination of decision-making capacity. We are told that she is fully oriented and capable of making her own decisions but are provided very little information to support this conclusion. A psychiatric consultant has suggested a diagnosis of mild dementia but preserved ability to make decisions for herself. The primary care physician's agreement with the consultant's assessment, therefore, becomes pivotal here. If her physician agrees that she is capable, every effort should be made to prevent the recurrent episodes leading to hospitalization. Avoiding recurrent and possibly preventable hospitalizations not only saves Medicare dollars but also decreases her risks for iatrogenic events, delirium, and deconditioning. Such an effort will require that the diverse elements of the patchwork health care delivery system work in concert to tailor an individualized plan for Ms. Torres. If the physician does not agree with the consultant psychiatrist's assessment, the probate court should be petitioned for limited guardianship.

Primary care physicians, by virtue of relatively frequent encounters with patients under a variety of circumstances, potentially are best positioned to assess their patients' decision-making capacity. However, the physician should use a systematic approach[1] if such an assessment can be counted on to be helpful in situations such as the one described for Ms. Torres. First, is there effective communication between physician and patient? In this case, language barriers do not seem to be an issue, but subtle differences in phrasing and emphasis and cultural differences related to health beliefs and the sick role may lead to misunderstandings or an inability to reach consensus about the probable effect of treatment and placement decisions on outcomes.

Once effective communication is taking place, the next question is: does she understand her medical circumstances? Does she have the best description that can be provided of her diagnoses, the functional consequences of the diagnoses, and prognosis? Next, does she understand her choices for addressing her diagnoses and their functional consequences? Treatment options and placement options go hand in hand in this case, with the placement option the sticking point. Her reference to her "daughter's duty" may be a critical point here. Based on the available history, Ms. Torres came to the Unites States at the age of 32 and may have brought with her a strong belief that families take care of their own.

The final components of the physician's assessment of the decision-making capacity of Ms. Torres concern her ability to understand the consequences of her choices and whether her choices are consistent from day to day and consistent with past decisions, beliefs and values. Many people with mild dementia have preserved decision-making capacity in a number of domains, including what medical treatment they want and where they want to live. If the primary care physician agrees with the psychiatric consultant that Ms. Torres can make decisions for herself, the physician should work with the hospital's social services and discharge planning coordinators to prevent Ms. Torres from "falling through the cracks." Each component of the health care delivery system has clearly delineated roles and responsibilities; however, sometimes the transition of care provided by one component then another is neither smooth nor coordinated. The hospital's role and responsibility are to provide the personnel and materials necessary to diagnose and treat her acute medical problems and to assist her in securing appropriate health care services after the hospitalization. Securing these services often includes advice about and help with placement in a nursing facility, advice about and referral to visiting nurses, or advice about and referral to a hospice provider.

Each of these three providers can deliver services only if the patient or the patient's decision maker wants the service. Sometimes, we fail to explain adequately the purposes and scope of the service choices that are offered, to define explicitly what the treatment goals are, and to estimate as best we can what the prognosis may be. In addition, we often fail to elicit from the patient what her expectations are and how her expectations and our predictions may differ. Adult Protective Services (APS) has a responsibility to help keep Ms. Torres safe but is also very protective of her right to make decisions about how and where she lives. It is unlikely that APS will intervene if she has been assessed to be capable of making decisions for herself.

On the other hand, people with mild dementia that is complicated by a mood disorder or a preexisting personality disorder or who are overwhelmed by social or financial problems may not be capable of making their own informed decisions. In such cases, and this may be one of them, the probate court should be petitioned to help resolve the issue. If the physician believes that decision-making capacity is impaired, he/she should work with the hospital's social services department to identify a petitioner who will seek limited guardianship for placement decisions only. The petitioner should request that someone other than the daughter be appointed guardian.

From a practical perspective, resolution of the situation described here will most likely require the court appointment of a limited guardian who will make decisions about placement and require the services of a person skilled in case management. The case manager can help the guardian choose the site of care that is most likely to support the treatment and monitoring services that Ms. Torres needs to achieve her best level of physical, cognitive, and psychosocial functioning. The need for a guardian should be reassessed periodically and every effort should be made to understand and incorporate her values and health beliefs into decisions about placement and into decisions about the manner in which health care services are delivered.

Question

Even if she still has decision making capacity, her decisions repeatedly conflict with agreed-on plans of care, in ways that endanger her welfare. How should the physician try to resolve those conflicts?

Response

Gregg VandeKieft

The behavior of Ms. Torres tests the limits of her caregivers' patience, skill, compassion, and professionalism. Medical professionals want to provide care that serves their patients' best interest. Most physicians accept that "best interests" sometimes take a back seat to an autonomous patient's contrary wishes. However, her actions conflict so drastically with what seems to be in her best interest that questions about her ability to make rational decisions are inevitable.

Assuming, however, no significant impairment in decision-making capacity, one's response to this situation can emphasize either conflict or engagement. This case certainly has multiple conflicts: between patient and physician, daughter and physician, patient and hospital/nursing home, daughter and hospital/nursing home, and potentially between physician and hospital/nursing home. The most important conflict, however, is between the patient and her daughter. Ms. Torres seems to be manipulating the health care system by manipulating her daughter, Ms. Hernandez—primarily via guilt. One can easily imagine that this is a lifelong pattern and that Ms. Hernandez must be dealing with enormous internal conflict. Ms. Hernandez's motives in aiding her mother's seemingly self-destructive behavior are also unclear: is she being a dutiful daughter, is her behavior a passive-aggressive means of punishing her mother. . . or both?

Given Ms. Torres's debilitated and vulnerable condition, one might expect her to turn her care planning over to her daughter, or that Ms. Hernandez could easily convince her mother to "play along." However, sick people possess a paradoxical moral authority. "To experience serious illness is to be struck by a sense of disability and powerlessness. . . . However, if the sick affect the healthy in deep and powerful ways and if to be sick is to occupy a well-defined social role that creates reciprocal role responsibilities in others, then the sick person is ironically also in a position of great power."[2] Familial and cultural factors also play a substantial role in defining the power structure within relationships. Thus, to better understand the family conflict, and to be able to mediate some of the conflicts between Ms. Torres and the medical team, one needs to engage the patient and her daughter and learn something of their story.[3]

Someone with whom Ms. Torres and Ms. Hernandez have a trusting relationship should explore the conflicts between them, as well as Ms. Hernandez's feelings about her mother's charge that she "failed to perform her duty." Dr. Stevens could be an appropriate candidate, given his long-standing relationship with both women. However, he may no longer be able to muster sufficient objectivity and empathy to work with them. Either way, the interviewer should have expertise in family dynamics, because there seems to be a long family history of manipulative behavior. An inexperienced interviewer or armchair psychotherapist could exacerbate the family conflicts and miss opportunities to negotiate a shared treatment plan. People who might facilitate this process include a hospital chaplain or clergy from Ms. Torres's own religious community, a social worker, or a mental health professional. The interdisciplinary expertise provided by an ethics committee consultation might also help sort out the complex issues.

"Difficult" and highly vulnerable patients stimulate a strong emotional response from physicians and other health professionals. Varying levels of counter-transference play a part, and physicians may act out their own issues unawares. A patient's refusal to follow recommended care may be perceived, even subliminally, as a personal rejection and may intensify the emotions involved. "Self-awareness is critical because of the pervasive role emotions play in the decision-making process and the process of communication. Unfortunately, medical education does not emphasize the art of cultivating self-awareness."[4] Dialogue with colleagues and other caregivers involved in Ms. Torres's care may be valuable. The process of reflection and dialogue will lessen the likelihood that the physician will act in a "knee-jerk" manner and sever the relationship, or take other actions or say things that adversely affect the relationship or hinder the opportunity to achieve a mutually satisfactory outcome.[5–7]

Given the recent experiences with placement in private homes, Ms. Hernandez's decision to remove her mother from the nursing home placed Ms. Torres at great risk. Doing so without the knowledge of Dr. Stevens or the nursing home staff seems deceptive or, at best, an impulsive response to a domineering parent. During the hospitalization that concludes the case presentation, Dr. Stevens and hospital staff should engage Ms. Torres and Ms. Hernandez to ascertain their goals for care—individually and as a family—and establish a care plan with clear expectations and boundaries. If Ms. Torres communicates better in Spanish, the hospital should offer professional interpretive services to assure accurate translation of medical terms and concepts, to assure that Ms. Hernandez's biases do not magnify or distort the language barrier, and to spare Ms. Hernandez the pressure of serving as medical translator. During the patient's hospitalization or nursing home stay, APS can be notified of the previous actions that placed her at risk, but as an inpatient or a nursing home resident, she will be deemed to be in a safe environment and no actions will be taken as long as she remains in that setting. At discharge, however, APS can be asked to monitor the situation and intervene if Ms. Hernandez attempts to move her out of the nursing home again. Legal and ethical considerations then come to bear on the extent to which a vulnerable elderly person may be placed at risk, and whether placement in a safer environment should be mandated.

The time and energy required by patients and families such as Ms. Torres and Ms. Hernandez are incredibly draining and can lead to "compassion fatigue." However, finally achieving a mutually satisfactory care plan and seeing the patient and family benefit from those efforts can be very rewarding. Just as the journey, rather than the destination, may define any passage, so the process of communication, reflection, and cultivating self-awareness in the service of one's challenging patients may be a defining event in the physician's professional development. Although such difficulties are seldom welcome they are, as Ms. Torres might say, "a doctor's duty."

Question

Given that Ms. Torres' repeated hospitalizations are largely preventable and caused by decisions made by her and her daughter, what are the limits of the hospital's moral obligation to bear the costs of her unnecessary hospitalizations?

Response

Leonard Fleck

This is a very complex case. I would construe one of the central moral questions this way: does the hospital have a moral obligation to provide Ms. Torres with a hospital bed when her medical condition as such does not dictate that she be in a hospital bed? I do not believe such an obligation exists in this case. That, however, suggests a follow up question. Does the hospital nevertheless have an obligation to "do something" by way of meeting Ms. Torres' needs and protecting her best interests? That is, would the hospital be open to justified moral criticism if the hospital simply discharged Ms. Torres, saying in effect, this is not our problem? To this question I would give an affirmative answer, discussed below.

Although the case raises important questions of competency, discussed by another commentator, I shall assume for the sake of my discussion that Ms. Torres has expressed an autonomous, competent choice to remain in the hospital. Does that autonomous choice generate a moral obligation on the part of the hospital to respect that choice? I argue that it does not.

There are limits to what respect for patient autonomy requires. First, patients may not demand (as a moral right) that physicians provide them with medical care that simply represents bad medicine, such as antibiotics to treat a common cold. Second, respect for patient autonomy does not give patients a right to demand medical care for which they have no just claim, when honoring their claim requires us to violate the more compelling claims of others to that health resource.

Ms. Torres is not occupying an intensive care unit bed, where such competing claims are more readily apparent. She is occupying an ordinary acute care bed, which we will assume for the sake of argument is not in short supply. This means that no one else's just claim to that bed is being denied because she is occupying it. Still, that does not give her a moral right or a just claim to that bed. Medicare may justifiably refuse to pay the hospital for Ms. Torres' continued hospital stay once she no longer needs that level of care. That means that the hospital itself will have to absorb the cost of Ms. Torres' care from its charity care budget, and the eventual result may be that resources are unavailable for meeting other patients' more compelling needs. Hospital charity care budgets are under intense pressure. In the past, hospitals have been able to sustain large charity care efforts by, in effect, over-billing patients who were very well insured. These days, however, managed care organizations and other insurance payers are demanding discounts from hospitals in exchange for guarantees that more patients will be sent their way. That has severely eroded charity care budgets. Consequently, hospitals need to prioritize access to those charity care dollars. This is itself a serious moral issue. Patients with serious and urgent health needs who can benefit substantially from access to timely hospital care are patients who will have the strongest moral claim to those charity care dollars. It is very far from obvious that Ms. Torres' belongs in that category.

Does our analysis up to this point warrant the broad conclusion that the hospital has no moral obligations with respect to Ms. Torres? No. Even if she has no rightful claim to the charity budget, the hospital has continuing moral obligations with respect to the protection of her best interests. At a bare minimum, the hospital must protect Ms. Torres from harm. Thus, the hospital would be open to justified moral criticism if Ms. Torres were simply discharged again to the care of her daughter with the attitude "we will just hope for the best," when there is no reasonable basis for hope in this regard. Thus, the hospital continues to have a moral obligation to keep working with Ms. Torres, her daughter, and relevant agencies to establish safe and stable arrangements for her postdischarge care. Strategies for accomplishing this are discussed by other commentators.

What if such plans still don't work, and Ms. Torres ends up back in the hospital yet again? Even if she has no just claim to a hospital bed, the hospital would still have an obligation to protect her best interests. The moral problem is how to do that in a way that also protects the hospital's obligations to the more rightful claims of other patients drawing on its charity care budget. Solving this problem may require some creative financing. Perhaps, for example, hospital administrators could propose a deal to Medicare. If Medicare pays the hospital what would otherwise be paid to a skilled nursing facility, then the hospital will accept that as payment in full. That figure may be close to the actual marginal costs of the hospital for Ms. Torres, minimizing demands on charity care resources. And, as long as the hospital is not looking at 100% occupancy by needy acute care patients, the justice issue there is negated as well. This would not be a morally perfect solution, but it would be "good enough" given the complexity of the circumstances in this case.

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