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## Was My Patient Fortunate or Forsaken?

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As I teach the first year medical students in the course, "Patient-Doctor Interviewing, I am often asked, "How do you care for patients who do not care for themselves?" One particular patient comes to mind when I respond to the students.

A couple years ago, I became involved in the care of a woman who challenged the ideas and ideals of her healthcare team each day. Lorraine was a paraplegic woman who had extensive decubitus ulcers and was admitted to Massachusetts General Hospital (MGH) to improve care of these wounds. Apparently, the visiting nurses would no longer agree to provide home care because she had been difficult to manage and noncompliant with her treatment. Her boyfriend and family were unable to provide the aggressive care she needed.

First, she had been refusing to turn in bed to relieve pressure from her wounds, and she had refused to quit smoking. The plastic surgery service said that they would be unable to provide potentially curative therapy involving debridement and flap placement because these treatments depend upon a patient's cooperation and compliance. As a physician, I knew the wounds were severe. Any treatment options were heroic and would likely fail, even with a cooperative patient. The most reasonable expected medical outcome would be a prolongation of the patient's life for a few years. I was certain that her difficulty complying with medical treatment would worsen her medical prognosis.

I believe that noncompliance with medical treatment is complex and stems from deeply rooted instinctual desires and needs that are in conflict with one another. These behaviors are deeply seated and guided by feelings such as loss of control of one's environment, denial of and rebellion toward illness, mistrust of others, and inability to comprehend the long-term effects of refusing treatment. Lorraine's behavior revealed that she was a master at finding ways to feel "in control."

Lorraine was physically and emotionally destitute. She tried to fill her insatiable needs by manipulating the people around her. Unfortunately, such lifelong, ingrained internal depravity cannot be erased by the late arrival of valiant effort. It was from this point in Lorraine's life that our healthcare team tried to "pick up the pieces."

Lorraine was immature and fought each day to get what she wanted without regard for the consequences. Most of the time, she wanted more pain medication or to go outside and smoke. In the opinion of the healthcare team, both of these requests were contraindicated in any plan to improve her medical condition. The questions the team asked themselves were: How much pain medication is too much? When the nursing staff is uncomfortable with the care they are being asked to provide, how do you go about deciding which

care is appropriate? What may healthcare workers justifiably refuse to do? Should a patient like Lorraine, who exhibits self-destructive behavior, make her own choices, and should we accept them? I am not sure we found answers to all of these questions, but we did learn to work together and to support each other.

Lorraine exhibited such masterful and cunning drug-seeking behavior, I knew she must have spent a lifetime perfecting her approach. When we decided not to increase her pain medication any further, she decided otherwise. She would wait until late at night and insist on seeing the covering nighttime physician about her pain. Initially, this approach was successful, until the physicians caught on and signed out to each other that she was not to receive any additional pain medication overnight. Her next ploy was to say she had vomited up her meds (often at night) so she could receive an extra dose. After a while we detected this scheme and stopped giving the extra pain medication dose. Finally, she was found with her pain pills broken down in a spoon. She was confronted, and her pain medications were rotated and changed to liquid form. We required that she be observed when she ingested each dose of pain medication. I can imagine that this regimented program provided daily discomfort for the nursing staff, whose main goal is to advocate for and to build a trusting relationship with patients.

When I think about patient advocacy and the physician's role in a patient's care, I again reflect on the sessions with my medical students. During the last year, we had a very intense but productive session about taking care of patients whom you do not like or whose moral values you do not respect. Some students didn't think they could care for such patients objectively, while other students thought that to be an enlightened physician meant transcending such conflicts and being able to care for all patients equally, irrespective of their core values.

We talked about aligning our goals with that of the patient's. I shared my "litmus test" with them. If I can sleep at night, I have done my best. If I toss and turn, I probably still need to work things out with my patient the next day. I did lose a few nights of sleep when caring for Lorraine. Was I her advocate? Did I do my best in looking beyond the actions to see Lorraine for who she was and what she needed? The engraved words of Dr. L.J. Henderson on the classroom wall continually advise me: "When you talk to a patient you should listen, first, for what he wants to tell you, secondly, for what he does not want to tell, thirdly, for what he cannot tell." Was I giving Lorraine the benefit of the doubt? A chance to rise above? I know that changing the mind of an adult is not only difficult, but, at times, impossible. You must use what you learn from listening to adult patients to correct and challenge misunderstandings. If you see any slight change, continuing to build the relationship is key. If thoughts and behaviors persist, then it is better to move to the next issue. With Lorraine, I searched for ways to sort out the truth from the dysfunction.

I tried to develop a relationship with her. She was conversant at times. We liked some of the same music, old classics. We spoke of her music frequently as it played in the background on her radio. She responded to my questions with compliance or complaints. Not a day went by that she did not complain of pain. I searched for ways to provide a holistic treatment plan and to move Lorraine forward, including adequate nutrition, daily activity, and prevention of iatrogenic complications. Various consultants were addressing many of these issues, but I carefully reviewed each aspect to make sure nothing was missed. With the help of the nurse practitioner, Grace, I had plastic surgery evaluate and debride her wounds again. In addition, psychiatrists and social workers were involved to help Lorraine deal with her illness.

I listened to see if there was something she could not say. Solutions never came, just more questions. Why did I become a doctor? When faced with a challenging patient like Lorraine, the answer is not always clear. Idealistically, the doctor is a healer, compassionate and empathetic. Was it compassionate to give her pain medication because she complained of pain, or should I "do no harm" and withhold pain medication from an obviously sedated patient? Was it empathetic to listen to her complaints each day and sit back and do nothing, or should I challenge her with my words to expect more from herself and to coerce her to do more than she was willing to do? Through time, one consistent principle became clear to me. Lorraine was set on a path of self-destruction from which there was no return. Although at times she did allow some care, ultimately she was unable, for whatever reason, to hold to a course that might allow her wounds to heal.

Was Lorraine impaired by the large amount of narcotics she was taking? Should treatment be forced on

people for their own benefit? Lorraine was actually coherent on an unbelievably large amount of opiate narcotics, and she still complained of pain. In my limited experience, such patients become super-sensitized to pain. With more medication, they seem to have more pain instead of less pain. The idea of narcotic rotation was often presented to Lorraine. Like any other addicted patient, her psychological and physical dependence on these medications would not allow her to agree to a rotation of these medications, medications on which she had come to rely that were now failing to address her problem. I still wonder if we had forced her to rotate her narcotics earlier whether it would have made any difference. I am beginning to believe that forced narcotic rotation may be some patients' only chance at reversing their self-destructive course. This type of treatment plan would entail a forced change of medication against the patient's wishes. When is it reasonable to force such things on a patient? Clearly, if a patient is in imminent danger and lacks insight, the decision is clear. However, when the outcome of treatment is less certain, and the patient has the apparent capacity to make decisions, it is less clear.

As Lorraine continued to refuse care, psychological evaluations were done to see if she had the cognitive capability to make decisions and to determine if she was mentally impaired by depression or suicidal ideation. Each evaluation was the same. She was medically and legally capable of making her own decisions. Thus, we had to respect her refusal of treatments and procedures that we knew could make her better, and allow her to set a course that would lead to her demise. Ultimately, she chose to move toward that fate by changing her code status to "do not resuscitate."

Her refusal of treatment and her decision not to be resuscitated was difficult for her to handle, and appeared almost equally difficult for the nursing staff and healthcare team. This difficulty was not only because of Lorraine's young age, but also because of the unspoken idea that "this could have been prevented."

As a physician, I often feel the weight of the outcome on my shoulders. I am very familiar with the anguish that coincides with perpetually questioning your motivations and actions regarding a complex patient's well-being and care. The feeling of failure, or the thought, "if only I had done more, or tried harder," can be overwhelming. In situations like caring for Lorraine, these feelings are bound to distress caregivers because of the "love-hate" factor that is inevitably added to relationships with such multifaceted patients. Lorraine had made such poor choices that no healthcare team member could go away from the situation without a smoldering scar.

I repeatedly assured myself that we had done everything possible. I made a decision to dedicate much of my time to supporting the healthcare team who had gathered around this woman. My hope was that I could lighten their burden of responsibility by clearly validating the decisions they made and by consistently reassuring staff that they were doing everything possible.

The time came when I would have to "muster up" the strength to go see Lorraine. Her persistent nagging complaints were almost too much to bear when I knew each of her many needs were being tended to daily by several people. With every visit, I knew it would be a struggle to "enforce the rules." I would set a plan before entering the room to be less swayed by her manipulative behavior.

In the end, I knew I could have another physician who knew Lorraine take over her care, which I did. I felt a sense of despair about Lorraine's decisions and the way that she had isolated the staff who had worked so hard to care for her. I think these feelings stemmed from her unending request for pain medication. I view addiction as separate from the person, and despise where the cycle of addiction brings people. With Lorraine, I felt that her addiction played a large role in the choices she made. As with many addicted patients, there is a point of no return, when addiction irrevocably claims its victim. My recusal from her case was based on the loathsome feeling I have toward the terminal cycle of addiction. I was not upset with Lorraine, but I could no longer deny the strength of her disease.

Lorraine often told me that each day she would make herself get out of bed. This made her feel like she was moving forward. I knew, when she stopped getting out of bed, she had given up hope. The fight was over. By that time, her medical prognosis had become quite grim. Questions continued to arise. How do you assess a patient's quality of life and ensure the best quality possible? When do you make demands? When do

you give way? The simple answer is that there is no simple answer. Each question on each day requires evaluation by a team of people who know the details.

When I went to the floor to see Lorraine, I always saw a group of individuals from different backgrounds and of different ages providing compassionate and thoughtful care. Not a day went by that her team did not agonize about each decision, each dressing change, and each pain medication she received.

I remember a particular day that Lorraine was feeling better than usual. She had gone to the hospital salon and had had her hair done and her eyebrows waxed. She was sitting by the nurses' station in her wheelchair "chatting it up." She was talking to the nurses and making jokes. Her enjoyment when visiting with the staff was obvious and tangible. Their relationships had become meaningful. That day, it became very clear to me that Lorraine was receiving the best care that she would allow. She was maintaining the best quality of life possible for her at that moment.

I believe that indifference and neglect result in the worst quality of life and the worst care of patients. In the last months of Lorraine's life and throughout her prolonged hospital stay, she was never treated with indifference or neglect. I don't think that there is any way to figure out why Lorraine made the choices she made. What I do know is that Lorraine received commendable care during her stay, and that her caregivers made sure that her dignity remained intact each day until her last.