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Case and Analysis

Family Loyalty as a Cultural Obstacle to Good Care: The Case of Mrs. Indira

Shahla Siddiqui

ABSTRACT

What is the responsibility of the physician when a capacitated patient assigns decision-making authority to a surrogate who does not act in the patient's best interest?

THE CASE

I first met Mrs. Indira when I was on consultation a number of months ago. It was the end of the day and I was annoyed when the phone rang and the junior surgeon requested that I go see a complicated patient for an anesthetic evaluation for a leg amputation. Each of these consults can take up to an hour and I was already exhausted.

The patient, Mrs. Indira, was in an isolation room due to her contagious infection—which would mean wearing protective gear (another five minutes gone!). The overwhelming stench of putrid flesh accosted me as I entered and tried to smile under my mask. She was a small, shy little Indian woman, in obvious pain, lying on her hospital bed, looking lost and worried. Her black hair belied her physiologic age, which seemed much more advanced. She smiled in a timid manner at me, recognizing me to be a doctor. "Hi Mrs. Indira, I am here to speak to you about your operation," I said, trying to sound cheerful. She remained silent as if she was assessing the situation and sizing up the threat. Fear was written all over her face. I had been told that she understood English perfectly, and so I didn't feel I needed a translator, however, I may have gotten it wrong. So I repeated myself, slowly, "I need to discuss with you the surgery, do you know about it?" Silence again.

I persisted, giving her my first name, my designation, my professional field, and also explaining how I had been asked to come see her. I was squirming inside and as uncomfortable about the interview as she was. I felt I needed to break the ice, and frankly I had nothing else to say, and so I rattled on. She avoided looking at me and pretended to focus on the glass of water at her bedside.

"Mrs. Indira, the surgeon has asked me to speak to you about the risk from anesthesia during your surgery. Can I please discuss this with you?" Again no response. I really wanted to tell her she was high risk: she had cardiac disease, diabetes, and renal failure. She needed an above-knee amputation from her sepsis, and she was already pretty sick. Without all this, she would surely die. She also needed to decide fairly quickly.

But yet something about her fear kept me from unloading all this on her without her active engagement. "Mrs. Indira. . . ." I felt like I was addressing a stubborn school girl. "Do you want surgery?" I asked.

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"Ask my daughter," she said softly, without looking at me directly. I had been told she had three daughters who did not visit her very frequently, as there was a wedding in the family very soon.

"I will discuss this with your family, but I need to let you know all the risks and benefits of the procedure. In the end the decision is yours," I replied. "I, I cannot decide. You ask my daughter." Again the silence, and then she shut her eyes as if dismissing me. That was the end of our encounter. She had made up her mind to defer her decision to her daughter, for whatever reasons, and there would be no discussion about it.

I silently left the room, puzzled and frustrated. I felt that she did have an opinion, that she was afraid, and that she wanted someone from her family, someone familiar to her, to help her cross this difficult journey with her and to guide her. And so she did what many women from the Subcontinent do, she let her fate rest with a loved one, trusting them to make a decision for her, that would be in her best interest. I was also aware that, as a mother of the bride, she didn't want to burden her daughter at such an auspicious time by agreeing to a risky operation. Her pain and suffering was obvious, and, being educated, she probably knew that surgery was her best option, without which she might die.

I called her daughter on the phone, having documented the patient's refusal to discuss the anesthesia risks. This daughter was the one getting married in a week's time, and sounded busy and hassled. I introduced myself and explained why I had called. I told the high risk of the surgery, about the anesthesia, and the chance of a stormy postoperative course. I highlighted the risk of deferring surgery, as the mother might deteriorate from her sepsis.

She replied, "You know I am really busy, we have a wedding next week in the house. I cannot have the surgery done before the wedding you know, in case of complications. Who will deal with that? My mother knows all this and agrees."

COMMENTARY

The ethical question here is, should a physician accept surrogate decision making when directed by the patient (driven by cultural or moral obligation or loyalty), and what happens when this decision is clearly not in the patient's best interest?

Autonomous Decision Making and Family Loyalty

The influence of family loyalty on autonomous decision making has not been well explored in the literature.[1] In this case, we see a mother who is willing to put up with excruciating pain for the sake of not disturbing her daughter's wedding. Her own autonomy is tempered with feelings of responsibility (duty) towards her offspring. This self -sacrifice is not uncommon in both Western and Eastern families.[2] Might values such as loyalty influence autonomy to the extent that true choices are not standalone and unrelated? Should medical professionals take such choices at face value and disregard the nuances of such decision making? Individual independence is a cherished virtue and important in human development, but the boundaries of each individual merge at times with that of other beings and relationships. These shades of influence can affect autonomous decision making heavily.[3]

Individuals may have mental capacity, as my patient did, but her seemingly "unwise" choice of deferring her decision to her daughter did not stem from lack of understanding or lack of insight. It probably stemmed from a need to leave the burdensome decision of surgery to her daughter, whose plans she did not want to disturb. Her own safety and relief took a back seat to her need for loyalty and solidarity with her daughter's happiness. In the face of such self -sacrificial behavior, what are the goals of care for the healthcare team? What of the doctor-patient relationship, which is based on a covenant of trust and the best interest of the patient?

Relational Autonomy and a Surrogate's Responsibility

Feminist theory requires an examination of the context of the situation to come to a moral conclusion.[4] It asks how a deed affects the person, the family, and those depending upon one another. In this case, in the mother's mind, her decision for surgery could potentially disrupt her daughter's happiness. But is this a misplaced belief? Could Mrs. Indira be persuaded that the surgery might result in a better outcome before the wedding, relieve her suffering, and prevent her untimely death?

If a patient willingly transfers her autonomy to a surrogate, what responsibility does the physician have to respect the decision? Does the principle of best interest dictate that the doctor override the decision and persuade the patient to undergo surgery for her own good? Is that likely the better option?

Cultural Influences

It is a challenge for physicians to balance, in a diverse society, cultural factors that influence a patient's responses to medical issues, such as healing and suffering, in the physician-patient relationship.[5] In this case, often a female patient from sub-

continental India, Pakistan, or Bangladesh will relinquish her decision-making rights to her family members, especially those responsible for her care and financial support.

Cultural diversity may affect the reception of "bad news," advanced directives, and end-of-life care. Often families wish to shield patients from news of possible risks, and, at times, patients may refuse to hear such information.[6] Is a patient exercising his or her autonomy by giving up this right?

In this case, the patient's traditional role may have been to be docile, and she may have been accustomed to having others make important decisions for her. Should the decision that is made for her be a bad one, this cultural practice may hinder the delivery of beneficent medical care.

MALEFICENT DECISION MAKING BY FAMILY MEMBERS

Without judging the motivations behind Mrs. Indira's daughter's decision to defer surgery, it seems that the patient's best interest was ignored. Mrs. Indira's trust that her daughter would reach a feasible decision was overriding her concerns regarding her own safety. (Perhaps she thought that her daughter would defer the surgery, and she agreed with this decision, even at the expense of her own health.[7]) What is the role of a doctor in this close-knit family dynamic? Being a patient advocate, physicians at times find themselves to be in conflict with family members when a patient's care is compromised. This usually happens when the said patient has no mental capacity.[8] However, in cases such as this, when a patient willingly allows a family member to make a maleficent decision about her care, what steps should a physician take? Is there any legal recourse in such situations?

THE PHYSICIAN'S MORAL DILEMMA

As a result of all these factors, a physician may feel moral distress in the care of such a patient. If Mrs. Indira had left the decision to her physician, would it be easier to go ahead with surgery? Is there a conflict of values between the family and the physician? A physician may feel obliged to go along with a patient's family (as a result of the patient's desire to delegate the decision to surrogates), even though it may be an unwise decision. Others may feel that the "wrong" decision must be overridden, in the best interest of the patient.[9] But performing a surgery (fraught with inherent risks) without the permission of the patient and relatives is not possible. These frustrations can cause immense moral distress amongst clinicians.[10]

THE RESOLUTION OF THE CASE

The physicians tried to persuade the daughter to agree to surgery on the phone and also tried to engage the patient. However, Mrs. Indira continued to be passive and her daughter refused adamantly not to allow surgery until after the wedding. On the day before her wedding, Mrs. Indira deteriorated to the point of becoming comatose with septic shock, and her daughter finally arrived in the intensive care unit, and relented and agreed to the very high-risk amputation. The patient did not survive the operation, as her condition had become much worse and her organ failure had escalated due to the delay.

NOTES

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