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Complexities in Caregiving: Comforts, Cultures, Countries, Conversations, and Contracts

Shenbagam Dewar and Rajan Dewar

ABSTRACT

Providing medical care and planning for a procedure such as amputation may have different cultural contexts, based on patients' country, comfort, and contract with their physician. These contexts may create complexities for physicians as they interact with patients and caregiving relatives. Issues such as the personal choices of a caregiving relative may appear to unduly influence the decisions behind complex healthcare choices. We consider several possible scenarios in the background of the complex case presented in "Family Loyalty as a Cultural Obstacle to Good Care: The Case of Mrs. Indira," in this issue of *JCE*.[1]

The patient-physician relationship dynamic sometimes evolves into a complex situation, leading to unsatisfying experiences for those who provide healthcare and those who receive it. In providing care for those who cannot make their own decisions, the involvement of a third party, such as a family member, while necessary, may introduce conflict, which is typical of a multipartite decision-making process. One such narrative is the case of Mrs. Indira, in this issue *of The Journal of Clinical Ethics*.[2] In our consideration of this case, we analyze Mrs. Indira's situation as third-party, blinded reviewers, and try to ask and answer various questions through imagined scenarios that may have led to the outcome described in the narrative. We feel that in such complex circumstances, many other factors, such as culture, country, and the clinician's role, may all add varying degrees of complexity, which may lead to incongruent decision making.

Briefly, as narrated in the article, Mrs. Indira is a presumably elderly (or middle-aged) woman, with a gangrenous foot that needs amputation. The anesthesiologist, while in the process of evaluating Mrs. Indira for a surgical decision (above/below knee amputation), was referred to a daughter by the patient, and a surrogate decision for going to immediate surgery was unduly influenced by the daughter's impending wedding. Due to postponement of the surgery, the patient developed further complications and died. The cultural influence of surrogate decision making, and a bias towards maintaining a wedding date to the peril of the patient's death, is elegantly described by the author in this article.

Both in the Eastern and the Western world, individuals and patients may make very surprising choices, sometimes in shocking contrast with the expectations of physicians. Shared decision mak-

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ing is a new concept of managerial medicine developing in Western countries, where clinicians objectively provide evidence to patients.[3] Patients (and sometimes families) will make choices based on the data they receive from their careproviders. Computer algorithms and models are now being tried and deployed to facilitate their decision-making processes. The effectiveness of the algorithms and models in individual circumstances is still open to further, extensive study. Ideally, even in current practice, careproviders should objectively present data and facilitate patients' decision-making processes. Making decisions, such as evaluating the risks and benefits of amputation, the timing of the amputation, and the social events influencing the timing, present complex scenarios.

CHOOSING TO DIE RATHER THAN TO LIVE AS AN AMPUTEE

Did Mrs. Indira choose to avoid amputation deliberately, and perhaps consciously or subconsciously choose to die?

Life as an amputee is not easy. Even in Western countries—where citizens are protected by acts such as the American with Disabilities Act (ADA)—it is only in recent decades that life for disabled persons has become somewhat bearable. The ADA has ensured inclusivity for disabled individuals, with the provision of mobility-assisting devices, and the construction of many facilities that will not restrict activities of daily living. In low-middle-income countries and even in advanced economies such as Singapore, such provisions may not be taken for granted. Life as an amputee would be very challenging for an elderly person with limited resources and possibly in a strained family relationship. Thus, if Mrs. Indira lived by herself and would face serious dilemmas regarding her care in a post-amputation setting, she may have been reticent in her response to her doctor about a decision to have surgery. She may have used her daughter and her daughter's wedding as a ruse; the true, deeper reason might very well have been to avoid life as an amputee.

These reactions are not uncommon, even in Western countries. In a case report and review by Bhuvaneswar and colleagues, the news of the possibility of amputation is often received by patients with a typical grief response, in which they undergo a phase of denial and depression.[4] During this phase, patients often refuse to engage in a discussion of this possibility with their physicians. Something like this may have been the case for Mrs. Indira. Perhaps part of her response might have been bargaining: "I am too tired; I don't want to go through the procedure." Was Mrs. Indira's citation of her daughter's impending wedding such a bargaining tool?

We have previously described common practices of surrogate decision making on behalf of Indian women.[5] This may be especially prevalent among elderly women who are past child-rearing age. Sometimes this may be a fatalistic reaction, as in the case of Mrs. Gandhi, as described by Dewar and colleagues.[6] A recent review covers broader cultural aspects of lifestyle and growing old among Indians.[7]

The psychological needs of a patient requiring amputation in India or South Asia has not been studied in depth. One study of amputees, focusing on males, all of them requiring amputation due to military service, reported that psychological interventions played a major role in improving depression, body image, and so on.[8] Such interventions should be planned from the day of preparing a patient in the discussion of amputation (such as the pre-surgical evaluation stage). In the United States, in most tertiary care hospitals, this is done actively by physician-support staff—social workers and psychologist who engage the patient. This includes making a visit to the patient's home to evaluate the post-amputation readiness of the residence.

INDIRECT PHYSICIAN CONTRACTS AS IMPEDIMENTS TO ENGAGING PATIENTS

Another often overlooked, complex factor in physician-patient interaction is the nature of contracts with "third-party" physicians. In the case of Mrs. Indira, an anesthesiologist is conflicted about her role and the patient's decision-making process. Anesthesiologists engage with patients for brief periods of time (most of it is established when the patient is unconscious) to cover pre-surgical evaluation, to provide anesthesia care during the procedure, and to handle immediate post-operative recovery. Often times the direct caregiver, whom the patient identifies with as the careprovider, is the surgeon. Thus, the patient establishes a stronger, long-term, and direct contract with the direct caregiver—the surgeon. The role of the anesthesiologist is often relegated to secondary caregiving responsibilities. Brief and quick encounters with "second-degree" physicians (indirect contracts), such as anesthesiologists, often are not enough to establish the much-needed, deeper psychosocial rapport that is required to engage in dialogue and counseling towards making decisions such as amputation.

We have previously described that three physician specialties have such complex, indirect con-

tracts with patients: anesthesiologists, radiologists, and pathologists.[9] Such indirect contracts can sometimes create certain conflicts and impediments in providing medical care. Teamwork among physicians is often required. (In the case of Mrs. Indira, this might be the surgeon and the anesthesiologist, along with a psychosocial counselor.) But this is very challenging to execute—to make optimal, congruent decisions in complex clinical situations, due to various limitations, in both Western and Eastern countries. In the case of Mrs. Indira, it led to conflicts in decision making, not only between the anesthesiologist and her patient, but also caregiving family members.

THE UNPREDICTABLE NATURE OF SUB-ACUTE AND CHRONIC HEALTH CONDITIONS

Decision making in acute settings, such as life-threatening emergencies, administration of cardiopulmonary resuscitation, or intubation, is sometimes easier than decision making for chronic health conditions. In the case of Mrs. Indira, the lack of immediate threat of complications possibly gave a false assurance to the care team, and presumably to the patient and her family members. Thus, in an alternate scenario, in which Mrs. Indira's daughter has a forthcoming wedding and her mother is involved in an acute event—such as a stroke, an accident, or a myocardial event—it might be easier to decide that an emergent surgical procedure is necessary, and it might be acceptable for events such as weddings to be postponed. However, when it is tough even for physicians to predict an outcome in a situation involving chronic illness, it is even more difficult for patients and family members to make healthcare decisions in the context of important life events such as weddings.

In an excellent review of this complex subject, Susan Watt compared two patients: Mr. Arthur, who has to make a decision about an acute health condition, and Mrs. Arthur, who has to make a decision about adjusting medication for a chronic condition.[10] Interestingly, and as could be imagined also in Mrs. Indira's case, it was more difficult for Mrs. Arthur to make a decision regarding her chronic condition. Ironically, Mrs. Arthur (an imaginary patient, probably in a Western context) struggled with making a decision while planning around her niece's wedding. Watt's article nicely illustrates that making a decision about the treatment of a chronic illness (such as for Mrs. Arthur and Mrs. Indira) is more complex than it is for making decisions about an acute illness. In addition, the case of Mrs. Indira shows how personal/cultural scenarios such as weddings, as influencers of healthcare-related decisions, are not unique to Eastern cultures, but also are important factors throughout the world. It may appear that the daughter of Mrs. Indira acted with narrow and self-interested intent, but there may have been other nuances that influenced her decisions about her mother's health.

RACE, CULTURE, AND COUNTRY-OF-ORIGIN IDENTITY INFLUENCE PHYSICIAN-PATIENT RELATIONSHIPS

Comedian Russell Peters jokingly remarks that if he could choose, he would want to have a doctor who is "Black" and came from "the hood," because that doctor would be a survivor who had proved he could rise up against all odds, to become a doctor.[11]

Consciously choosing a healthcare provider or a patient based on race and ethnicity is likely an uncommon practice. There have been some cases in which doctors have declared conflicts, and have withdrawn from providing medical care, based on faith: for example, a gynecologist who refuses to provide termination of pregnancy because he/she has pro-life beliefs.[12]

COMPLEX RACE RELATIONSHIPS ARE EXHIBITED IN SUBTLE WAYS IN COSMOPOLITAN ENVIRONMENTS

While there is absolutely no indication that a race/ethnic difference played any role in the relationship between Mrs. Indira and her treating anesthesiologist, anecdotal evidence indicates that such factors exist in similar situations. In a country such as Singapore, a very vibrant, diverse culture exists. There are conscious and unconscious biases and prejudices that exist at various levels between patients, their family members, and, less commonly, physicians.

Whether physicians exhibit such bias is less reported and possibly reflects their training and the value they ascribe to the care for human life (the Hippocratic Oath), irrespective of external factors. However, such constraints are not binding on patients. Can a conscious or unconscious bias by an Indian patient toward a Pakistani doctor in a Singaporean healthcare institution provide a substantial barrier to the establishment of a rapport, which could hinder an optimal decision-making process?

As discussed in a very recent article by Paul-Emile and colleagues in the *New England Journal of*

Medicine, patients in the U.S. may request the reassignment of a physician (even if it is based on race!), and usually their requests are considered by the healthcare facility.[13] Regulations facilitating or precluding such actions are hard to imagine, especially in other parts of the world. But physicians should be cognizant of such unconscious bias in the patients whom they care for, and try to accommodate their patients' bias without prejudice. This is with the moral intent of doing the right thing to heal the sick, even at the cost of hurt pride. After all, being a physician and providing care is a noble assignment.

NOTES

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