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ETHICS CASE

Consequences for Patients and Their Loved Ones When Physicians Refuse to Participate in Ethics Consultation Processes

Commentary by David S. Seres, MD, ScM

Sarah is a 17-year-old girl currently in the intensive care unit (ICU) of a large academic medical institution. She was diagnosed with an aggressive soft-tissue sarcoma a few years ago and has been receiving treatment from her oncologist, Dr. Hunter, who is a senior member of his department at the institution. Despite Dr. Hunter's best efforts and Sarah's participation in multiple experimental therapies, she has been getting progressively worse and is now visibly cachectic and in pain. Dr. Hunter can think of no further conventional chemotherapy options.

Sarah's parents are very concerned for their daughter's well-being, and they have for many years generously donated to the institution's oncology department. Over the years they have also formed a close relationship with Dr. Hunter.

The ICU physicians taking care of Sarah during her current admission determine her cancer to be at a very advanced stage, with imaging confirming metastatic lesions in her lungs, liver, and bones. Due to her progressive wasting and pain, they feel that comfort care is indicated. However, when this option is discussed with Sarah's parents, they say that this is absolutely not an option for them. Following this tense interaction, it becomes clear to the medical care team that Sarah's parents only trust Dr. Hunter and will not consider options discussed with them by other clinicians.

The house staff contacts Dr. Hunter to communicate their impression that Sarah should be transferred to palliative care, hoping that he will be willing to discuss the transfer with the family. To their surprise, Dr. Hunter disagrees, telling the house staff that "we need to make sure her parents feel like we took care of her until the very end." Dr. Hunter also argues that the longer the house staff is able to keep Sarah alive, the more likely it is that an unconventional therapy option might present itself. He refuses to discuss the option of palliative care with the family.

When this situation is discussed the following day during multidisciplinary rounds, one of the ICU nurses tells the team that she knows Dr. Hunter has a close personal relationship with Sarah's parents. She also informs the medical care team that the parents are known benefactors of the institution's oncology department. After confirming these claims, the house staff feels that Dr. Hunter's financial and personal ties to the family are clouding

his judgment—and, as a result, negatively influencing Sarah's medical care. They initially hesitate to call for an ethics consultation because Dr. Hunter is such a powerful and well-respected figure at the institution. Ultimately, however, they call for an ethics consultation because they strongly feel that Sarah's current medical care is inappropriate.

The hospital's ethics committee requests Dr. Hunter to appear before the committee in order to discuss the potential conflicts of interest he might have in the case. However, Dr. Hunter refuses to do so, arguing that he never called for an ethics consultation and is under no obligation to participate. He also argues that, even if *he* had called for an ethics consultation, he would be under no obligation to share the committee's recommendation with the family if he disagreed with it, much less convince them that this was in Sarah's best interest.

Commentary

Sarah's case illustrates multiple dilemmas related to the function and role of an ethics committee (EC), including the means by which the EC interacts with members of the clinical team, the authority of the EC, and the impact of the patient's family's status as institutional benefactors on clinicians' decision making or EC members' recommendations. The case hinges on Dr. Hunter's unwillingness to participate in the ethics deliberation process and includes concerns about possible conflict of interest.

Structural Roles in Ethics Committees

Often, the structure of an EC includes a clinical ethics consultation team (or an individual consultant) and a larger deliberative body. The former should, of course, be highly skilled at performing ethics consultations. Standardization and credentialing for clinical ethics consultants is being discussed at a national level, and health care organizations should establish policies to determine who is allowed to perform ethics consultations [1].

The consultants. Most ethics consultations are performed by an individual consultant or small subcommittee or team. The conversations are often quite intimate. Limiting the number of participants to prevent deliberations from feeling confrontational might be desirable, but consultants must also take care not to exclude stakeholders who can be substantially affected by decisions and outcomes of deliberations. The decision that the EC made to summon Dr. Hunter to appear before the committee might have contributed to or even caused Dr. Hunter's refusal to participate. A request to appear before the EC has a punitive or confrontational feel, no matter the intent. Perhaps the family and Dr. Hunter had been approached multiple times about the issues raised in the ethics consultation and were therefore primed for a fight.

The deliberative body. The larger EC should function in a deliberative and advisory role and have a multidisciplinary membership that includes multiple clinical specialists, legal

experts, and administrators. Many deliberative bodies draw as well from members of the community and former patients or their family members. Clinical specialists represented might include medical practitioners, nurses, social workers, patient services representatives, spiritual care practitioners, and others, depending on specialists' availability, interest, and expertise. The EC should reach out broadly for membership, as practitioners in disciplines such as nutrition, physical therapy, occupational therapy, and speech pathology, to name a few, are frequently exposed to ethically challenging situations and can make excellent contributions to the EC.

It is advisable that the larger EC be given authority to present policy recommendations for adoption by the health care organization through the medical board or another administrative body. But it is critical that the EC not be seen as a punitive or authoritarian body. Ethics consultation is best performed as a consensus-building or facilitation process or as mediation [1].

In addition to setting policy, the larger EC is often very helpful in advising the consulting team about how to address complex or novel situations. A situation such as presented in our case, for example, might be brought by the consulting team to the full EC for advice, given the political complexities of the involvement of a powerful doctor and donor family.

To be able to serve in the role of intermediary, the EC and consultation teams must be known for impartiality and must serve in an advisory role. When consensus cannot be built, which is not infrequent, laws and policies might specify who should be allowed to be a decision maker. In these situations, the ethics consultation might only have the effect of reassuring a distraught medical staff that everything possible has been done to resolve clinical or ethical complexities.

How Should the Ethics Consultation Proceed in this Case?

Acknowledge staff members' moral distress. It is clear that this case has generated moral distress among some members of the staff. This is likely caused, in part, by medical orders to pursue treatment they find morally objectionable, which can seriously influence morale over the short and long term, and perhaps even patient care. Unresolved situations such as this create discord, necessitate staff shifting, and have even resulted in collective actions such as sick-outs (the taking of paid time off—"sick days"—for protest, in lieu of a formal strike). Another concern, judging by staff members' comments about Dr. Hunter's conflict of interest, is that Dr. Hunter appears to be seen by some as less trustworthy. When ignored, conflicts of interest tend to undermine trust in an organization or person and add to the urgency the EC might feel to resolve this situation. Moreover, assumptions about different stakeholders' motivations can be a source of bias, misunderstanding, and misperception that needs attention from an ethics perspective, too. Addressing these issues with the staff, perhaps in a meeting separate from the patient and family, is an important opportunity for the EC to try to influence the

culture and morale at the health care organization. While easily overlooked, this step should be of primary importance for the EC.

Outreach to Dr. Hunter. The EC in this case might be well served to look to its membership for someone with an existing relationship with Dr. Hunter and have that person reach out to him for a one-on-one conversation. The request should be couched in nonthreatening terms that avoid any hint that the EC has any intention of embarrassing or undermining Dr. Hunter or infringing on his relationship with Sarah or her family. Ideally, such a request should be made in a way that would appeal to the common ground between Dr. Hunter and the EC: a desire to do well by Sarah, her family, and the hospital. In this case, the consultation team might indicate to him both an awareness of escalating tensions surrounding Sarah's care and a desire to solicit his insights. The consultation team's offer to serve as intermediary to help avoid further conflict, rather than to push a decision-making agenda, should be explicit.

Further attempts at communication, as outlined below, are warranted.

Address Dr. Hunter's intransigence. Dr. Hunter's refusal to meet with the committee or consultation team might seem to present a significant barrier for the ethics consultant. Generally speaking, ethics consultation should be available at the request of anyone involved in the care of the patient, without regard to others' willingness to participate. For cases in which practitioners, family members, or even surrogate decision makers refuse to participate, ethics consultants should attempt to assess situations in which they're not yet involved while attempting to find creative ways to secure an invitation to become involved.

More challenging could be situations in which a primary physician attempts to block an ethics consultation or refuses to communicate the recommendations of the clinical ethics consultant to the patient or family, as Dr. Hunter has done. As mentioned, ethics consultation is available to everyone and so no one should be able to prevent others from accessing one. Ideally, these situations can be prevented by the EC positioning itself as a mediating, rather than punitive, body.

But once situations have arisen in which recommendations—or even the fact that an ethics consultation was requested—are kept from the patient or family or other key stakeholders, they should be dealt with on a case-by-case basis according to institutional policy. In general, a situation in which actual harm might come from withholding the findings of the EC should compel the overriding of the primary physician's refusal to divulge, and the EC might even be compelled to seek assistance from organizational leadership in communicating with the obstructing clinician. There is not enough information provided in this case to know whether there was a risk of harm from not divulging the EC's findings. One could imagine a similar situation in which a

young patient is disagreeing with her parents about goals of care, the choice to forgo further life-prolonging therapies is deemed reasonable by the EC, and the patient's choice might be respected if the EC could weigh in. But the EC must be circumspect in judging the value of its own recommendations. Again, an in-person, one-on-one, nonconfrontational approach to communicating with the primary physician is recommended in this situation.

Address possible conflicts of interest and bias. The donor status of the family should be considered as a potential source of bias in clinical and other types of decision making. Access to medical treatment should be equitable for all, regardless of patients' or their families' financial support of an organization. In this case, while the consequences might be significant and cannot be ignored, ethics consultation might be considered part of the medical care. The EC will have to take great care to act as it would in any other matter and avoid being inappropriately influenced by the family's donor status.

On the other hand, given the longevity of the relationship between Dr. Hunter and the family, his behavior might in fact express respect for the family's desires. Because his reaction takes the form of an unwillingness to meet with the team, the information that would allow assessment of his reasons is incomplete. There is a lack of evidence in this case; jumping to conclusions should be avoided. The assumption that his reaction stems from a conflict of interest could reflect a bias on the part of the staff or the EC. The EC should develop strategies for acknowledging and mitigating potential bias created by conflicts of interest.

Preventing Conflicts in the Future

One of the roles recommended for ECs is that of education [1]. One of the most effective means for an EC to function is to try to prevent the escalation of disagreements [2] through ongoing training for staff in dealing with conflict. Beyond teaching clinicians the skills to deal with conflict, it is important to teach ethics committee members to recognize their own emotional reactions and to look for help dealing with high-stakes situations.

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