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Specters, Traces, and Regret in Ethics Consultation

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As clinical ethics consultants, we inevitably participate in cases that haunt us long after our formal involvement ends. With patients, families, and careproviders, we are moral agents who are culpable for our interactions and our recommendations. When we consult, we weave ourselves into the story of the case. In doing so, we influence the path of the story and are altered by the encounter. The standard way to write an ethics case is to focus on a particular ethical issue, rather than the role of the consultant in the case and the impact of the case on the ethics consultant. There are times when no good solution exists, when organizational or legal constraints seem insurmountable, and/or the consultant is unable to bring about the result that she or he desires.

Although we need to discuss patients' ethical dilemmas for their own sake, we must also share the affective nature of complex situations. In trying to act with integrity, we strive to recognize our shortcomings and to improve our practices. Having the courage to write about these cases is important for helping new people in the field, because these expositions highlight the personal and professional risks of ethics consultation. Sharing haunting cases may improve the practice of clinical ethics consultation by addressing the character and professional development of consultants.

Ethics consultants influence how cases play out, if in no other way than to bring greater understanding of individual and professional values, fostering decision making. While clinical ethics consultants may encourage others to courageously express and negotiate values, consultants also risk harming others and being harmed themselves.[1]

To practice ethics consultation well, we invest ourselves in the devastating circumstances of others, and we genuinely want to assuage suffering by facilitating critical reflection and trying to improve outcomes. Emotions and facts play an important role in the dynamics that we must understand. To communicate effectively, we should recognize the ambiguity, sorrow, uncertainty, and lack of closure inherent in many consultations.

We must not allow haunting cases to paralyze us. Rather, being haunted should foster our further professional growth. To whatever degree that these special cases influence our activities by means of paralysis,

growth, or anxiety, it is clear that there is an affective component that extends beyond our professional activities. We return to our families and social circles, where grief can linger from the interactions borne of tragic and frustrating cases. Given the small community of bioethicists in any given geographic area, it is easy to feel isolated, as there are few colleagues with whom to confer or debrief in a confidential manner.

For this special section of *The Journal of Clinical Ethics,* we present a set of haunting ethics consultations, told by experienced clinical ethics consultants. Authors were asked to focus on their role and the challenges they faced as consultants during and after the consultation. Although each story raises unique challenges, there are several overarching themes. Each case calls into question who can or should make healthcare decisions, and most cases include a question of the patient or decision-maker's capacity to make decisions. These cases go beyond being tragic; they touch on uncertainty, lack of power, and unclear professional boundaries. These are elements that contribute to the complexity of many consultations.

Clinical ethics consultation is haunting for several reasons. First, the ethical issues that are presented are often challenging in themselves, and it is stressful to help others negotiate them. Second, often the ethics consultants judge when and how to intervene. This involvement is not always beneficial, and may occasionally cause harm. Third, consultants experience moral distress and uncertainty similar to the distress and uncertainty experienced by those they help. Fourth, like the patients with whom we work, we often feel powerless to facilitate positive change, as tragedy and suffering are pervasive or organizational constraints seem intractable. Finally, once we begin consulting, our values are part of the complex dynamics, and are either incorporated constructively or stumbled over on the road to clarity.

In the first case in this special section, Denise M. Dudzinski recounts the story of a woman who requested the amputation of her arm because of a regional pain syndrome. This case prompted Dudzinski to reflect on the moral distress encountered by a consultant and its impact on professional integrity. The patient appeared rational, yet the actual request she made was not reasonable by medical standards, as it was unlikely to alleviate her pain. The patient suffered and had few good therapeutic options. The case prompted Dudzinski to consider when an ethics consultation is appropriate and how the consultant's own interests play into the decision to become involved in informal consultations. The case prompts consideration of professional boundaries and integrity.

In the second case, by Joy D. Skeel and Kristi S. Williams, the patient made decisions that may not be in his best interest. The patient's decision-making capacity was in question, and the patient himself was labeled "hateful." The consultant found herself mediating between medical services (medicine, psychiatry, nursing) as well as between the patient and healthcare providers. In the end, the case leaves questions about the power to help and perhaps prompts regret that something more effective was not attempted.

In the third case, by Paul J. Ford, the patient had limited and sporadic cognitive function. The designated decision makers were at odds with the medical team on what would be best for the patient and what would be acceptable medical practice. The consultant was stuck in a process that protected various interests, but this process was neither expedient nor smooth in assisting a satisfactory conclusion. The case leaves questions about the reactive nature of consultation and the need to try to break out of processes that exact a heavy cost for all parties.

In the fourth case by Jeffrey Spike, the presumed decision maker had significant conflicts of interest. The infant patient had severe neurological damage, from which he would not recover. The consultant was forced to balance a number of competing visceral reactions to an incarcerated mother who was in chains at her baby's bedside. Was the mother, who allegedly hurt the baby, entitled to see him? The consultant found that many caregivers had already decided that the answer should be no. The consultant resisted being persuaded by consensus, but was sympathetic to the caregivers' anger and desire to protect the vulnerable child, as well as the mother's love for the child. The nurses, consultant, and mother all experienced grief and distress. The consultant had to carefully consider his own and others' affective responses to be effective. He was haunted by uncertainty and powerlessness long after his involvement in the case ended.

In the final case by Richard M. Zaner, parents were faced with a complicated pregnancy with a greatly uncertain prognosis. The 22-week-old fetus might have had spina bifida, suggested by ultrasound and alpha-

feto protein tests. The physician thought the mother was angry at the suggestion that therapeutic abortion was an option. In speaking with her, Zaner discovered a more subtle source of distress: the mother was astounded that this profound decision was to be made before the age of viability, without adequate clinical information. Was she also reacting to *how* the clinicians communicated with her? Zaner reflects on the familiar haunting of moral decision making when the possibility for a devastating "mistake" is so immense and the patient's vulnerability is so great. He describes the kind of haunting that is at the very foundation of clinical ethics consultation.

Haunting cases are not unique to ethics consultation. They exist in many areas of medicine. In particular, they are common with surgical interventions. When candidacy for surgery is discussed in patient management meetings, it is not uncommon to hear people say, "This case looks like another Mr. Smith. . . . none of us want that," or, "Remember Mrs. Jones? We still don't know why surgery failed to work." These anecdotes are not only cautionary, but also a sign of being troubled by outcomes and processes. They are not a warning to "remember this type of procedure failed," but an attempt to give voice to an inchoate experience that remains mysterious, anguishing, and puzzling. We invite readers to reflect on the following cases, which describe challenges in systems, practice, and personal involvement that haunt clinical ethics consultants.

NOTES

1. M.J. Bliton and S.G. Finder, "Traversing Boundaries: Clinical Ethics, Moral Experience, and the Withdrawal of Life Supports," *Theoretical Medicine* 23 (2002): 233-58; R.M. Zaner, "Listening or Telling? Thoughts on Responsibility in Clinical Ethics Consultation," *Theoretical Medicine* 17, no. 3 (1996): 255-77.