Complex Ethics Consultations

Cases that Haunt Us

Edited by

Paul J. Ford and Denise M. Dudzinski
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A book on “Cases that Haunt Us” is a summons to realism in clinical ethics. Since the origins of bioethics in the 1970s, and since its turn into the clinical world in the 1980s, bioethicists have fretted over theories, principles, and methods. They have explored the theories that philosophers have created to think about and resolve ethical problems, filling pages with explanations of deontology and consequentialism. They have argued over the definitions and priorities of autonomy, beneficence, and justice. They have delved into antique methods, such as casuistry, and devised new ones, such as Rawlsian reflective equilibrium. In all of these efforts, ethics appears as a rational activity, striving to define, analyze, and resolve a problem. Certainly, some approaches, such as narrative ethics, discount the claims of excessive rationality, and casuistry disclaims the value of rational deduction. Still, bioethicists, particularly those who engage in clinical consultation, have hoped to be “solvers” of problems.

In the opening days of bioethics, one of its founders, Dan Callahan, called for the construction of a discipline that employed philosophical logic and explored “the unfettered imagination, the ability to envision alternatives, to get into people’s ethical agonies . . . and sensitivity to feelings and emotions.” Still, in its conclusions, bioethical thinking should reach “reasonably specific and clear decisions in the circumstances of medicine and science.”

“The circumstances of medicine” do present a basic problem to philosophical ethics. “Reasonably clear and specific decisions” are often confounded by the tragedies of death and disability, by the uncertainty of diagnosis and treatments, and the complexity of cases that include not only a patient and a doctor but a surrounding family, religion, money, hospital, and many other social structures. Indeed, the very notion of a “case” is perplexing. Its etymology is properly from the Latin word *casus*, which literally means “an event, an occasion.” We know that any event, say a birthday party, is not simply a gathering between walls for a few hours. It radiates out into the lives of many people before and after the instant occasion. But another Latin word, *capsa*, becomes *cassa* and *caja* in the Romance languages and “case” in English. This “case” means a box or a container, as in “briefcase” or

“suitcase.” The coincidence of words is suggestive: bioethicists try to fit the almost infinite complications of an event into a box, where they can be studied in hopes of reaching a judgment about how they relate to each other. Of course, medicine and law do exactly the same. Their cases are defined and circumscribed sets of facts put into boxes drawn by the parameters of statutes or of pathophysiology. The process of reaching a conclusion, whether it is made by judge or physician, requires that complexity be put into order.

The clinical ethicist works with the same paradigm. However, something may be missing from that paradigm. At the heart of many ethical cases lies genuine paradox. The fine British moral philosopher, Stuart Hampshire, wrote a book titled *Morality and Conflict*. He confessed to a significant shift in his thought about morality. He once believed that “the basis of morality is found principally in powers of mind that are common to all mankind . . . improvement of human life is to come from improved reasoning . . . Slowly, I have come to disbelieve that reason, in its recognized forms, can have, and should have, that overriding role . . . I argue that morality and conflict are inseparable: conflict between different admirable ways of life and between different defensible moral ideals, conflict of obligations, conflict between essential, but incompatible interests.”

The ethicist is very likely to encounter conflict at the heart of a case, and the conflict is often irreconcilable. A judicial decision can slice through the conflicts of law, and physician can leap into the uncertainties of diagnosis. An ethicist may have to simply stand before irreconcilable conflict of principle. Indeed, we often speak of ethical dilemmas in which either conflicting answer to a question makes equal sense. We speak of ethical “perplexity,” unconsciously evoking the ancient meaning of that word, “tangled in a net.” In common conversation, people often say that moral problems are unsolvable. We ethicists may bristle at that statement because if it is true, we would seem to be superfluous. We may answer that the difficult problems are compounded of unclear thinking and missing information. We will resolve them once we resolve those issues. This answer is correct, but not always.

It does not respond to the kinds of cases reported in this book. It does not respond to the cases of conflict over “different admirable ways of life, different defensible moral ideals, conflicts of obligations, of essential but incompatible interests.” It does not address the elements of consultation that the authors report in this book. These cases are filled with Hampshire’s conflicts of obligations and of interests. As I read their sensitive stories and reflections, the cases of my own 30 years as a consultant floated back into my memory. Almost every case echoed in my own experience. As I now reflect on their stories and on my career as consultant, I believe that, in addition to the conflicts pointed out by Hampshire, the moral experiences encountered by ethics consultants demonstrate two ineradicable features of moral

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life not often discussed in moral treatises. They are the embedding of the moral problem in time and the density of the human crowd that surrounds it. The dimension of time and of a space filled with people is, I think, common to moral life in general. It is vividly present in the activities of ethics consultation in clinical medicine.

In my immature days as a scholar of ethics, ethical problems appeared in my books as timeless moments: whether or not to tell a lie, whether or not to save a threatened life. Also, these ethical problems existed in the conscience of the one who must choose, or between several persons debating right and wrong. When I entered the world of clinical medicine, ethical problems suddenly were swept into a temporal sea, moving, changing, sweeping to an ever-receding horizon. Cases concerned persons with a developing illness, an immanent crisis, a constantly shifting physiological picture, and deepening emotional responses. I was surprised by the clinicians’ oft uttered phrase, “We should give this some time.” For me, ethics was timelessly true.

In this book, many stories involve time. Macauley and Orr tell of a “quick” decision to withdraw life support from a neonate; Woodrum and McCormick, in contrast, are distressed by how long a case “drags out.” Diekema and Spike ponder the problem of deciding prematurely or tardily. Sarah Shannon speaks of “slowing down the train” that speeds to a decision, often so fast that significant features of the case are blurred or missed. Many other chapters show the case evolving in time. Time, in medicine, may not “heal all,” but certainly, it is the theater in which ethically relevant features, such as seriousness of disease, futility of treatment, hope of cure, all are played out. Bioethicists, such as those who write these chapters, have discovered that ethical problems are not static, and, much to their own moral distress, they and others often miss the opportune moment (if there is one).

The second intractable feature of moral decisions, as they appear in a clinical ethics consultation, is the density of the human crowd surrounding the patient. The ethical problem is not a proposition isolated in the mind of one or two actors – it dwells within a pressing crowd of persons, each with a distinct and rich store of interests, understandings, emotions, and personal histories. I realized, on my introduction into the world of medicine that I was no longer a priest in a confessional, which I had been for some years. The ethical experience of confession and counseling is a closed, private one. I now found myself in a hospital room, the patient in the bed, the doctors and nurses at bedside, the family waiting anxiously outside, and many other unseen participants, such as the hospital administrators, the insurers, the legal counsel, the ministers, and congregation of a church. Each of these participants views the case differently, some perhaps drastically so.

Many of the cases in this book describe the ways in which that crowd affects the consultation. Pinkus, Smetanka, and Kottkamp show a child attempting to control her treatment amid the powerful influences of family, doctors, and lawyers. Ford’s patient is also caught in this crowd. Bioethicists often propose themselves as
mediators and facilitators, but often, the crowd is so dense and the interests of its members so intense that mediation is futile. We try to thin out the crowd, narrow down the participants to “appropriate” ones, but sometimes fail. When some in the crowd are strangers in belief and culture to the providers and the ethicists, the negotiation becomes even more difficult. Those in the crowd may stand with banners of deeply held principles on which they will never compromise. Ohnsorge and Ford, Rosell, and Weise present versions of this story. The density of the crowd surrounding the patient puts ethics into a maelstrom of conflicting values.

These two features of moral reality make for difficult, indeed, haunting cases. They haunt in two ways. In a troubling but less profound way, they linger in the memory. We cannot get out of our heads the face of a dying child whose parents disagree over her treatment; we cannot erase the distress of an immigrant family caught in a system they do not understand. But more problematic, these hauntings are an indefinable presence dwelling in the house of bioethics. It is important for bioethicists to acknowledge that presence and to know they cannot exorcize it. It is a presence that, despite its ghostly form, puts realism into their work. They should be conscious that, often enough, they are working around, or helping others to work around, irreconcilable conflict. They should continue their task of helping unravel an ethical conflict with humility, remaining sensitive to the idea that the perplexity they encounter when they begin may still be present when they conclude their best efforts.

We modern folk, particularly those of us who revere science and scientific thinking, may be troubled by this feature of ethics. We do want to draw “reasonably specific and clear” answers out of confusing questions. We want to believe that we can devise a method of logical analysis for an ethical problem. We want the “boxes” of our cases to be uncluttered, well-sorted containers of facts and principles. Our patron philosopher, although he is unacknowledged in contemporary bioethics, may be Baruch Spinoza, who strove to create an “ethics according to geometric methods.” Short of that desire for clarity, what can we ethicists do in the face of our haunting ghosts of irreconcilable conflict, the rush of time, and the density of crowds?

Professor Hampshire has a suggestion that may salve our conscience. At the end of his book, he notes that “in . . . life, the practical need is often for sensitive observation of the easily missed features of the situation, not clear application of principles . . . We have no pressing need for satisfactory total explanations of our conduct and way of life. Our need is rather to construct and maintain a way of life of which we are not ashamed and which we shall not, on reflection, regret . . . and which we respect.” 3 The clinical ethicist will often observe and point out to others “the easily missed features of the situation.” This is not, in the complex world of contemporary health care, a negligible contribution. In the last analysis, however,

3. Ibid., p. 168.
the ethicist, the patient, the family, the physicians, and the nurses should come away from an ethical dilemma with a resolution of which they are not ashamed, if not with “a satisfactory total explanation of conduct.” They can respect the fact that thoughtful, compassionate, honest attention has been given to a deeply troubling, perplexing human problem.

The moving stories and the thoughtful reflections in this book do, as I said earlier, summon us to realism about moral life and moral decisions within medicine. Read in isolation, they may convince some that the bioethicist’s life is difficult and futile. However, these authors are obviously not discouraged. They are encouraged by the resolutions that result from thoughtful, compassionate attention a case often brings. They are gratified by the relief that comes to all participants when the tension of an ethical crisis, if not extinguished, is at least relaxed by their sensitive, wise involvement.

Fortunately, ethics is not, as Pullman, Singleton, and Templeton note in their concluding chapter, all hard cases. It is an amalgam of centuries of thought about the moral life of humans, broadly accepted moral principles of modern bioethics, and the collections of many cases. The “hard cases” appear within that broader perspective. The emotional discomfort and the intellectual puzzlement of these cases do not undermine the experience of respect, beneficence, compassion, and justice that bioethicists and, indeed, all providers of care can view as a guide to their professional endeavors. In this way, “respect,” not “regret,” will mark the life and work of this new profession.

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Acknowledgments

The idea for this book arose during a dinner with our mentor Richard Zaner at a conference. We identified the need for sharing cases that emphasize the affective component of ethics consultation. Richard Zaner’s influence can be seen throughout many aspects of this work, and we are greatly indebted to him. That conversation prompted us to present several panels discussing haunting cases and to edit a special section of the *Journal of Clinical Ethics (JCE)*. We continue to be grateful to those at *JCE* who fostered the publication of the original cases that are included, with revision, in this book. We are especially grateful to Norman Quist, Randy Howe, Mary Gesford, and Leslie LeBlanc. We would like to thank those at Cambridge University Press who believed deeply in the text as this project transformed into a book. They include Richard Barling, Pauline Graham, and Rachael Lazenby and, more recently, Nicholas Dunton and Katie James.

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