

Introduction

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The first edition of *Complex Ethics Consultations: Cases that Haunt Us* in 2008 did not anticipate that “cases that haunt us” would become part of the bioethics lexicon. Variations of this phrase have become regular themes in papers, panels, and conversations. The phrase acknowledges the complex, unpredictable, and uncontrollable circumstances typically encountered in ethics consultation. It also engages the affective, moral, and professional complexities and doubts ethics consultants’ experience. Now, when we talk about a *haunting case*, it invites a confessional style of reflection marked by candor and humility. The speaker places trust in the listener, asking for grace, forgiveness, compassion, and assistance. Witnessing each other’s achievements as well as missteps has helped our practice mature, fostering a kind of guild where new consultants take solace in the fact that respected senior ethics consultants also experienced loss, grief, and bewilderment. The cases in the first edition remain relevant and remain unchanged for those purposes. We added a new chapter in each section. New authors reflect on what has been learned since publication of the first edition. The concluding chapter has also been substantially revised.

Many things have changed in 15 years. The *Core Competencies in Healthcare Ethics Consultation* were updated, with yet another revision in the works. Ethics consultants can now become certified in healthcare ethics consultation (signified by the Healthcare Ethics Consultant-Certified [HEC-C] credential). Bioethicists played pivotal roles during the COVID-19 pandemic, influencing policy and practice at national, state, and regional levels. Staff moral distress captures more of our time and attention. Our practices have changed for the better, as clinical ethicists examine the privileges they previously neglected to acknowledge and challenge. New authors in this edition look back on the 2008 cases with attention to inclusivity and equity, providing important framing and context. It is astounding that so many of the cases in the 2008 volume are still familiar in contemporary practice.

We invited seven respected colleagues to read and reflect on one section of the book, providing new insights about how ethics consultation has evolved over 15 years. Each section includes four original cases and a new chapter with further reflection. Each new author was asked to answer four questions: (1) What are the most powerful lessons that remain relevant in today’s practice of ethics consultation? (2) How might the consultations be carried out differently today? (3) How would you appraise the presence or absence of equity, diversity, and inclusion in case discussions and reflect on their impact on the quality of the ethical analysis and reflections and (4) In the future, how should ethics consultation better address affective components of clinical ethics practice? These authors help us critically differentiate practices to be commended from those we can set aside in favor of greater incisiveness, compassion, and inclusion, welcoming the voices of historically marginalized patients, families, and ethicists.

Lucia D. Wocial, PhD, RN, FAAN, HEC-C reviews the cases in Part I, “Starting at the Beginning: Prenatal and Neonatal Issues.” Wocial implores clinicians and ethics consultants to “take a deep breath and pause,” resisting the pressure to make rapid decisions in the midst of value uncertainty. All ethics consultants have felt this pressure, and we often need to take a few deep breaths ourselves before encouraging the team and family to do the same. Wocial highlights the importance of helping the team convey the care and concern they have for parents struggling with end-of-life decision-making for neonates, “When parents feel that the team cares *about* their baby and *for* them as parents, trust is fostered.”

Nneka Sederstrom, PhD, MPH, MA, FCCP, FCCM reviews the cases in Part II, “The Most Vulnerable of Us: Pediatrics.” Reflecting on both the practices of the treating teams and ethics consultants, she highlights the need to trust the family and to “uplift the child’s voice sooner,” especially when children have experience with the treatments in question, as Susie did in “Susie’s Voice.” Sederstrom points out that we continue to miss opportunities to truly understand the patient’s and family’s values. She reminds us of the perils of failing to do so. She also describes the vital role empathy plays in antiracism and reducing bias in patient care. True empathy replaces defensiveness with curiosity, humility, kindness, and gentleness.

Maya Scott, MSW, LICSW reviews Part III, “Diversity of Desires and Limits of Liberty: Psychiatric and Psychological Issues.” Regarding Chapter 9, “Helping Staff Help a ‘Hateful’ Patient: The Case of TJ,” she highlights the harm of ascribing the dread and apprehension we feel to the patient with monikers like the “hateful patient.” Bias and unjustified assumptions can infuse our unfiltered and uninformed perception of patients, masking our own racism, ableism, classism, etc. Scott writes that in reviewing the chapters in this section, “[she] grappled with experiences of human suffering, the powerlessness we feel when we are unable to help, our own shame-based reactions to some of the anger that we feel when we are pushed to our limits, the cumulative impact of the trauma that frontline and consulting teams absorb, and the overreaches of power.”

Crystal Brown, MD, MA considers Part IV, “Withholding Therapy with a Twist.” End-of-life decision making has been and is likely to continue to be a frequent subject of ethics consults. In the years since publication of the first edition, ethics consultants have come to work side by side with palliative care professionals. Brown encourages such collaboration as she emphasizes the necessity of skilled communication to navigate end-of-life decisions and elicit patient, family, and clinician values. Brown highlights the value of feminist ethics in attending to lived experiences while also revealing and expanding the loci of power.

Mahwish U. Ahmad, MD, MPH, HEC-C reviews Part V, “The Unspeakable/Unassailable: Religious and Cultural Beliefs.” She echoes the advice of many authors, advocating empathy and “taking the time to listen without judgment as the gateway to addressing cultural value conflicts, creating trust between the patient and the hospital team/ethicist.” Ahmad writes that she empathizes with Bena, a pregnant, unmarried adolescent who asks her doctor to withhold information about her pregnancy from the women accompanying her in order to evade the risk of ostracism from her community. Listening without judgment may be one of the best ways to respectfully interact with people from cultures with which we are less familiar. Clinicians’ concerns about truth-telling are balanced against Bena’s needs and values, even when counterintuitive from the perspective of clinicians who are unfamiliar with her culture. Ahmad also reflects on the

changing transplant landscape over the past 15 years, where the appeal of *narrative* gains force through social media. Social media means unrelated donors are more easily enlisted.

Kaarkuzhali B. Krishnamurthy, MD, MBE reflects on the cases in Part VI, “Human Guinea Pigs and Miracles: Clinical Innovations and Unorthodox Treatment.” Krishnamurthy notes the importance of conflicts of interest when considering whether to abide by a request for amputation from a patient with complex regional pain syndrome, even when no one recommends surgery. She asks ethics consultants to be more explicit when examining conflicts of interest, such as instances when surgeons factor in potential litigation when deciding whether to proceed with surgery. Today, we also see more patients and families favoring herbal remedies, and Krishnamurthy highlights the unfavorable terms used by healthcare providers for the surrogates in such circumstances: difficult, abrasive, bully. She reminds us of the ethics consultant’s role in dispensing with such terms and seeking to understand the beneficence motivating the surrogate’s request.

Ruchika Mishra, PhD reviews Part VII, “The Big Picture: Organizational Issues.” The organizational structure of a hospital impacts bedside decision making, and Mishra notes that working in teams tends to reduce organizational missteps and encourage an inclusive culture. “[M]any health care organizations across the country are focused on creating a culture of speaking up to reduce opportunities for errors and ensure pathways to quickly identify and rectify issues.” The thoughtful incorporation of bedside realities in hospital policy can provide an additional support structure for staff. Proactive policy development can give staff practical strategies to fairly address complex patient care issues. Persistent bed and staff shortages post pandemic give Chapter 28, “Who’s That Sleeping in My Bed?” more contemporary import, as complex discharges arise more frequently in ethics consultations. Looking to the future, Mishra writes, “There has been a steady forward movement in terms of identifying and addressing potential ethical problems before they take root; actively soliciting diverse perspectives; supporting a team approach; improving transparency; and extending available educational opportunities.”

We are grateful to these seven authors for helping us view the 2008 cases in the changing light that time and enlightenment bring. They have given us the gift of insight and wisdom by encouraging readers to embrace change, even when it comes with some trepidation. They also help us discern when we should stand true, as we did 15 years ago, despite contemporary pressures toward expediency.

The identities and clinical and/or social details of patients and colleagues have been changed to protect their privacy while preserving the narrative. We extend our deep gratitude to the patients, clinicians, families, authors, and colleagues. Their sensitivity to ethical issues and commitment to the well-being of everyone in their care have made all the difference.