Introduction

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Clinical ethics consultation is a deeply affective activity. Fundamentally, ethics consultants are trusted to help in complex clinical cases to assist patients and clinicians when values differ. The stakes are high, with loss and trauma being inevitable. Consultants influence which losses occur and who suffers additional traumas. As such we are active moral agents who are influential, but minor, characters in clinical cases. A "case" in our understanding encompasses the intricate relationships and interactions between treating teams, patients, and families.

Fifteen years ago Paul Ford and Denise Dudzinski recognized that the affective component of clinical ethics consultation was rarely discussed, and decided to gather cases that were published as Volume 1 of *Complex Ethics Consultations: Cases that Haunt Us*. At the time, asking clinical ethicists to offer reflections on cases that left them with emotional residue was a leap of faith. The usual ethics case format provided ethical analysis and discussion of professional issues without attending to the impact on ethics consultants; "cases that haunt" are situations that have left poignant imprints that consultants carry with them throughout their careers. This book allowed for heightened awareness in the clinical ethics community for the emotional residue left after doing this work day after day and week after week. The importance of Volume 1 is such that it has been designated a required text for candidates applying for the Healthcare Ethics Consultant-Certified credential.

So why revisit this format? Because it is still relevant. Ethics consultations have become more complex as medical science has evolved. There are more treatment options to consider, and patient–physician interactions are given less and less time for discussion and shared decision-making. Although sources of education and information have become more easily accessible due to technology and social media, health literacy has not significantly increased. As a society we recognize the inequalities embedded in our healthcare systems due to insurance barriers, lack of access to care geographically, structural imbalances for vulnerable populations, and a host of other factors. All these challenges lead to greater potential for unresolved moral residue and regret as clinical ethicists are called in to untangle the morass of decisions that have been and still need to be made.

And why now, fifteen years later? It is exactly the magnitude of the changes in clinical medicine that makes this next volume of cases relevant. New treatments, including gene therapies and immunomodulation, have revolutionized a host of diseases that used to be considered lethal. But while medical science has grown and evolved, access to care has not kept pace. Barriers persist, leading to lack of equity in how these new resources are distributed. Appreciation for the ways in which cultural diversity and humility should be incorporated in healthcare systems has not yet resulted in structural changes that would

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welcome and include people of all communities. This became more apparent during the COVID-19 pandemic. Finally, there are new voices within the clinical ethics community who should be heard and who will, we hope, serve as catalysts for ongoing change and growth within the field.

This book contains reflections by clinical ethicists concerning cases that have deeply affected them. The "haunting aspects" of ethics consultation are not standard in other texts. Each case has left substantial emotional residue on the authors. Taking the time to reflect on and share impact improves practice and gives consultants fortitude to invest in case after case. Integrating the lessons from haunting cases into future practice should avoid the pitfall of unreflectively applying unusual circumstances (exception to the rule) to more usual cases while also avoiding an urge to dismiss the lessons altogether. Additionally, the well-being and career longevity of ethics consultants can be enhanced by allowing emotional processing.

Many cases within this book suggest approaches to address emotional aspects of the cases. For instance, author Frolic highlights a kind of mindfulness that she employs to center herself (Chapter 33). Ethics consultants borrow coping mechanisms employed by our colleagues in social work, nursing, and chaplaincy who have toolboxes that encourage and guide consultants in processing their involvement in life and death cases day after day.

In the need to protect confidentiality, some details of cases have been altered or made vague. In doing so the authors have been attentive to keep true to the specific context while still leaving ambiguities about potential identities. The primary focus of each chapter is the story of the ethics consultant(s), and the authors have not changed the details of their experiences.

Pedagogical Utility

The brevity of each chapter is conducive to instruction in classrooms, ethics committee educational sessions, clinical education, and self-study. The goal of the book is to socialize ethics consultants to the common experience of suffering, satisfaction, and instruction prompted by affective reflection as part of consultative processes. It is also designed to help individuals to deeply reflect on challenging situations to develop new skills and methodologies in ethical analysis. Most importantly, we hope to reassure ethics consultants that they are not alone in their work. Experienced and novice consultants alike will recognize the affective impact described in these cases.

Distinguishing Volume 1 and Volume 2

Although this book is a second volume of *Complex Ethics Consultations: Cases That Haunt Us*, it stands on its own, comprised of brand-new cases that demonstrate the evolution of the practice of ethics consultation. We are pleased to have influenced the field by introducing an enduring theme in professional seminars related to the affective impact of ethics consultation. Volume 2 introduces new voices and perspectives. In addition, this volume inspired the editors to publish a second edition of Volume 1 to look back on cases published in 2008 by introducing seven new commentaries. The first volume includes a concluding chapter suggesting educational activities that is not repeated in the current volume to avoid redundancy. Volume 1 and 2 are intended to be complementary and to enrich one another.

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Equity, Diversity, and Inclusion

The themes of equity, diversity, and inclusion feature prominently in this volume as our field tries to welcome and learn from voices that have been absent. This volume includes authors who have been historically underrepresented in academia and healthcare, including authors of color and from a variety of countries of origin. As a result of increasing diversity, we learn how to address justice and equity more comprehensively and with greater humility. In addition, there is a section of each chapter that prompts the author to explicitly reflect on these themes.

Selection of Cases

The content of this book was largely driven by an open submission process in which we received more than ninety proposals, a far greater number than we expected – a pleasant surprise. We share our gratitude for all who submitted proposals, and we concluded with thirty-three. In the end, the volume is not an exhaustive overview of haunting clinical ethics cases. Rather it provides important reflections and, when possible, juxtaposes contrasting cases, for instance between life-sustaining therapy being withdrawn or being maintained.

Chapter Topics

The book begins with perinatal challenges, capturing heartbreak and courage around the time of birth. As one might expect, the volume features several COVID-19 cases. Part I includes two such cases (Neely and Weber). Both cases resulted in a C-section moving forward after initial declination. In contrast to this, Mendola describes a recommended C-section not going forward because of maternal objection. Finally, Wimberly and Ellis provide a case related to the implantation of long-term birth control at the time of a C-section in a patient without decisional capacity and with substantial developmental disability. This section offers differing scenarios with the theme of C-section and consent-creating.

Part II involves cases about patients who range from ten years of age to young adults. The first case (Lanphier and Fanning) concerns an end-of-life discussion in the pediatric intensive care unit (PICU) involving a school-aged patient with a fatal genetic disease whose parents have refugee status and do not speak English. The remaining three are adolescent cases with variations in the disposition of the patient and the involvement of institutions.

Part III explores cases of difference and disability, and how the system does or does not care for those with disabilities fairly. Kagel's reflections are particularly poignant in relating her own experiences in navigating the system as a person who is deaf (Chapter 11). The cases in this section highlight various concerns of marginalization and discrimination in healthcare for those who have differences of behavior, function, and ability.

Parts IV and V explore end-of-life decision-making, often in the intensive care unit with high technology interventions. The majority of clinical ethics consultations involve end-of-life decisions in some way or another. In each case there are variations in the circumstances that include technology, social conditions, and assumptions about the efficacy and the goals of medical technology. One case involves a medical interpreter

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(Mayer, Chapter 13); another a young adult being treated in a children's hospital for a COVID-19 related illness (Paquette, Frader, and Patel, Chapter 14).

Part VI deals with cases within the context of pandemic responses. It was inevitable that a call for haunting cases would evoke some stories about pandemic response. Not only were there severe visitation restrictions and anguishing resource allocation decisions, there was also widespread ideological disagreement about the existence, severity, and receptiveness to treatment among patients, families, and healthcare workers. In addition, Carr's case (Chapter 23) deserves mention in that it relates to a Native Alaskan newborn from a rural area of Alaska with few resources. This chapter could have been placed in multiple parts of the text, including in Parts I and II. Finally, several chapters from earlier in the text also occurred in the context of COVID-19, particularly the labor and delivery cases in Part I as well as Part IV.

Part VII is dedicated to cases of complex disposition issues. Even though some of these cases resonate with earlier sections about end of life, the cases in Part VII focus on where these cases happen, and the challenges faced in placement, disposition, and long-term stays. Ethicists are called on to help with complex admissions and discharges. Sometimes there seems to be no possible plan for discharge, and only for continuous surgeries (Sankary and Morley, Chapter 28), or a need for a team to better understand the sacrifices of families that have been invested in excellent care at home (Krishnamurthy, Chapter 29). Additionally, the question of how to keep people safe in the hospital and upon discharge is vividly addressed in relation to the patient who swallows foreign objects (Kolmes, Tabari, and McLean House, Chapter 26) as well as the case of a patient at high risk of aspiration (Funke and Gish, Chapter 27). The question of who takes on which risks features prominently, as well as what it means to have the capacity to make risky choices.

Clinical ethics consultants provide professional guidance on organizational and public health cases. Policies and procedures substantially influence patient care and help to ensure fairness. DiDiomenco, Correoso-Thomas, and Zatulovsky (Chapter 31) highlight the tension when there are differences of opinion about whether to receive care at home or at a skilled nursing facility. Although they discuss a single instance, this is a wide-ranging challenge influenced by legal risk as well as reimbursement. Dudzinski and Kirkpatrick (Chapter 32) provide a powerful reflection on normothermic regional perfusion (NRP), addressing the limits of institutional reach when there are multiple organizations with power to decide how and when to employ the technology. Frolic (Chapter 33) gives a powerful reflection on the early legalization of medical aid in dying in the Candidian context, regarding an institutional "consciences" objection to the practice. In each case, there are broad organizational stakes.

Final Observations

Each chapter has a uniform format to allow the reader to quickly identify the domains being addressed and also to efficiently and more easily identify the differences as well as similarities amongst the cases. The chapters are divided into five parts: 1. Case Narrative; 2. Haunting Aspects; 3. Equity, Diversity, and Inclusion; 4. Professional Reflections/Lessons; 5. Case Outcome/Conclusion. A list of discussion questions at the end of the cases are intended to prompt small group discussion as well as for individual reflections. In this way a chapter can be easily assigned to a class, to a continuing medical education

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session, or to an ethics committee session with a natural set of questions to guide an hour of education. As clinical ethics consultation continues to professionalize, it is important for experienced ethicists to share the cases in which they struggle and the ways in which they have tried to offset negative emotional effects on their practices.

We extend gratitude and admiration to every author for sharing their doubts, disappointments, and emotional challenges in being a clinical ethics consultant. The work is difficult and rewarding. We need each other. We hope this volume assures readers that they are never alone and that they deserve support and care.

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