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# Shared Decision Making in Adult Critical Care

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*From Dr. Jaffa:*

For Zach, who first taught me to share, especially in all of our decisions. For Florrie and Colby with whom I share all of myself, and everything else.

*From Dr. Hwang:*

For Julia, Theo, Janice, and our families.

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## Preface

Decisions about life, quality of life, and death are routine in critical care practice. To promote the ethical principle of patient autonomy, clinicians often find themselves incorporating their medical expertise into value-laden conversations with patients and families of incapacitated patients – with regard to whether clinical care plans are consistent with patients’ wishes, or the best approximation thereof.

Guiding patients and families through these shared decisions can be difficult, not necessarily because of detailed technical knowledge needed to understand how interventions work in the intensive care unit (ICU), but because of the uncertainty of what ICU interventions might achieve at any given time for a certain patient and the challenges of conveying difficult news to overwhelmed patients and families – whether that news is certain or uncertain. ICU teams are generally large and multidisciplinary, and although the complexity of such conversations warrants a clinician with expertise and compassion guiding them, it is not infrequent that these conversations are led by clinical trainees who build close relationships with patients and families, but who may not have a wealth of experience from which to draw.

In this context, our hope is that all critical care clinicians – but especially students, trainees, and those early in their independent careers – will find this easy-to-read book on shared decision-making in ICUs to be both useful and practical. The first four introductory chapters of this book cover some basic principles that apply to a wide variety of scenarios – assessing what types of decision are appropriate opportunities for shared decision-making, how involved a patient’s family wishes to be in decisions, how best to present quantitative information, and how to optimize family discussions. The middle 11 chapters cover specific, common clinical scenarios in critical care that require clinicians to weave together their basic medical knowledge with shared decision-making approaches. These chapters are all case based and provide recommended frameworks for approach. The reader will find that some core principles are repeated throughout these chapters, but also that the chapter authors highlight key references and statistics that may help clinicians in planning their discussions with patients and families. A fair number of these chapters are neurologic in nature; this fact admittedly in part represents our editorial bias as neurointensivists, but also is an acknowledgment that the degree of neurologic recovery is often a key factor in goals-of-care decisions made in critical care.

This book ends with a few chapters on a potpourri of related topics – advance directives, care of the unbefriended patient, and incorporating

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palliative care consultants into the ICU. We have also included a chapter on how researchers grapple with the difficult question of how best to measure “success” for ICU shared decisions. One could potentially argue that the final chapter on discussions regarding brain death is perhaps a bit outside what one considers a truly “shared” decision – because death by neurologic criteria is still legal death. Yet, communicating such a concept to families is challenging in its own right, and many principles that apply to shared decision-making conversations apply in brain death conversations as well.

We note that the chapters in this book were nearly all written before the onset of the worldwide novel coronavirus disease-2019 (COVID-19) pandemic. The concerns during the height of the pandemic – that ICU resources even in resource-rich environments would possibly need to be widely rationed, that hospitals needed revised protocols for determining code statuses for patients with COVID-19, and that prolonged strict visitor restriction policies were necessary – became multiple barriers to our field’s standard methods of promoting shared decision-making. Some of the principles of this book are preserved whether one is having discussions with families in person or via phone/video conference; others require significant flexibility. We acknowledge as well that still others may be profoundly affected by the risk COVID-19 presents to clinicians themselves (i.e., how a clinician discusses offering cardiopulmonary resuscitation for COVID-19–positive patients with a poor chance of survival).

Our hope is that, by the time this book is published, the risk of virus transmission will be lower than it was in the spring and summer of 2020 and the families that we all depend on so much will be at ICU patients’ bedsides with increased frequency. But even if that is unfortunately not the case, we hope that this book is a reminder – especially to those entering the practice of medicine amid a pandemic – that shared decision-making is not merely an optional approach to be practiced by clinicians when convenient, but that the principle of incorporating patient’s values into decisions that ideally require knowledge of them is an immutable tenet of ethical and high-quality critical care practice.