

## Chapter

## 1

## When Does Shared Decision-Making Apply in Adult Critical Care?

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Shared decision-making in medicine has been defined by multiple professional societies as “a collaborative process that allows patients, or their surrogates, and clinicians to make health-care decisions together, taking into account the best scientific evidence available, as well as the patient’s values, goals and preferences.”<sup>1</sup> This definition incorporates several important ethical principles simultaneously; it acknowledges the importance of patient autonomy. Patient autonomy incorporates a patient’s personal values and respects the degree to which he or she might wish to be involved in a decision about his or her own medical care.<sup>2</sup> It also recognizes the critical role of clinicians as experts in actively advising patients about the benefits and risks of their available treatment options and in designing treatment plans to align with patients’ ultimate goals and preferences.

### 1.1 Challenges with Practicing Shared Decision-Making in Critical Care

At its core, the practice of shared decision-making centers on informed collaboration and mutual deliberation between clinicians and patients.<sup>3</sup> In emergency department and critical care environments, there are multiple barriers that prevent collaboration and mutual deliberation with patients from occurring easily. Patients and families are often meeting clinicians for the first time, with relatively little time to build trust. Important decisions often must be made in a time-sensitive manner. Many patients, especially in intensive care units (ICUs), lack capacity to participate in or make decisions. Those patients who do have capacity may nevertheless have significant communication barriers, such as being mechanically ventilated. Clear and specific scientific evidence regarding benefits and risks may not exist for many important decisions that need to be made. However, despite these recognized barriers, clinicians in emergency rooms and ICUs must strive to practice shared decision-making to the best degree possible when situations call for it, because of its strong ethical justification.

Cambridge University Press

978-1-108-73554-4 — Shared Decision Making in Adult Critical Care

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For a patient to demonstrate the “capacity” to make choices related to the direction of their medical care, he or she must have the ability to (1) integrate information about their illness and treatment, (2) consider the nature of various alternatives and their consequences, (3) rationally question all information that is presented, and (4) communicate a decision that is consistent with their own personal values.<sup>4</sup> Intubated patients may use communication boards if they remain awake on minimal amounts of sedation, although aphasic patients may require additional assessment and teamwork with speech pathologists to delineate a means for clear communication.<sup>5</sup> Advances in technology may even allow for patients with neuromuscular weakness or locked-in syndrome to communicate via eye-gaze systems and newer devices such as brain-computer interfaces. However, in the ICU, the patient’s being unable to participate in collaboration and mutual deliberation is more often the rule rather than the exception.

When an ICU patient is unable to participate in shared decision-making, advance care planning documentation may already exist that can provide insight to a patient’s preferences.<sup>6,7</sup> However, most adults in the United States do not have a completed advanced directive. For those who have completed one, the details have often not been shared with their families or the persons they have appointed to be responsible.<sup>8</sup> Even the most clearly delineated advanced directives are generally unable to cover every possible situation that may occur and often only address concerns related to extreme medical futility.

These limitations in pre-existing care planning for incapacitated patients more often than not require that surrogate decision makers enter into the clinician-patient relationship as partners to help decide on important aspects and directions of emergency and ICU care. However, even if a proper surrogate (or surrogates) is identified, the process of surrogate decision-making can be fraught with challenges.<sup>9</sup> A surrogate may happen to not be an adequate judge of what a patient’s wishes would have been in any specific situation, whether the surrogate realizes it or not. Several studies have revealed surrogates to be imperfect predictors of patient preferences, overestimating their desire for life-prolonging interventions.<sup>10,11</sup> Surrogates may also incorporate their own preferences and personal factors in decision-making, aside from simply exercising substituted judgment on behalf of the incapacitated patient.<sup>12</sup>

The fact that ICU clinicians work with surrogate decision makers on a daily basis does not necessarily mitigate the practical challenges with shared decision-making outlined in this chapter. Because this book discusses general strategies for approaching many of these practical challenges and outlines considerations in certain common specific scenarios, it is prudent to briefly review examples of ICU situations in which shared decision-making may apply and those in which it may not.

## 1.2 Situations in Which Principles of Shared Decision-Making Apply in ICUs

Hundreds of decisions are made daily in the ICU, many of which patients and families may only be aware of if participating in bedside rounds or if constantly at the bedside. Which ICU decisions warrant collaboration and deliberation?

The shared decision-making approach is most relevant regarding those care decisions that are truly affected by a patient's individual preferences, goals, and attitudes toward acceptable quality of life. Conditions where uncertainty exists regarding both survival and functional recovery routinely warrant collaboration and deliberation among clinicians and patients/surrogates to explore treatment options that are based on scientific evidence in the context of the patient's perceived preferences.<sup>13</sup> However, every admission to an ICU can be considered an opportunity for clinicians to initiate discussions with patients and their families regarding patients' goals of care, as well as preferences and values, especially before medical emergencies occur, where a patient might later be rendered incapacitated. Importantly, routine decisions in patient care that are not typically value laden – such as which laboratory tests to order, which antibiotics to use to treat a urinary tract infection, etc. – can and should be made in general by treating clinicians based on consensus best practices and evidence-based implementation.

Table 1.1 provides examples of health-care decisions encountered in the critical care unit that are ideal for the practice of shared decision-making.

**Table 1.1** Examples of decisions appropriate for shared decision-making<sup>1</sup>

1. Whether to undergo decompressive hemicraniectomy in a patient with malignant stroke and cerebral swelling.
2. Whether to pursue ongoing weaning efforts at ventilator facility or transition to palliative care for a patient with advanced chronic obstructive pulmonary disease having failed several attempts at ventilator weaning in the ICU.
3. Whether a patient's quality of life is sufficiently satisfying that she or he would want life-sustaining treatment when a life-threatening event occurs.
4. Whether to initiate renal replacement therapy in a patient with significant volume overload who has terminal cancer.
5. Whether to implement extracorporeal membrane oxygenation in a 90-year-old patients with loss of consciousness owing to pulmonary embolus while on the golf course.

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Several chapters of this book address potential challenges with the overall processes of shared decision-making in ICUs, and others discuss specific common clinical scenarios, such as the ones presented in Section 1.2 and Table 1.1 and suggest approaches for using available outcome data to guide individualized discussions with patients and surrogates. Implementing shared decision-making in critical care scenarios can be complex and time consuming, and – despite clinicians’ best efforts – situations can at times result in intractable conflict with patients and families that may be challenging and frustrating to resolve. In the face of these and other challenges, we hope that this book will help to provide a framework to aid readers in their own best efforts to collaborate and deliberate with patients and families when moments arise that call for shared decisions.

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