Compelling Ethical Challenges in Critical Care and Emergency Medicine

Andrej Michalsen
Nicholas Sadovnikoff
Editors

Springer

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Foreword

I am delighted that Drs. Andrej Michalsen and Nicholas Sadovnikoff asked me to write the Foreword to this volume on *Compelling Ethical Challenges in Critical Care and Emergency Medicine*. These two medical specialties have always been at the tip of the sword when it comes to ethical challenges in the practice of medicine. In reflecting back over the past few decades, I am struck by the extent to which thinking about ethical issues has evolved. As recently as the 1980s, few physicians sought advice or counsel when faced with challenging ethical questions, and when they did, it was almost always from senior physician colleagues in their field.

As reflected in the essays contained in this volume, the focus of ethical decision-making has shifted away from considering physicians to be the only experts to recognize the importance of deliberation among teams, between professionals, and especially with patients and their families. At a time when moral distress and burnout are becoming a true threat to the viability of our profession, the essays in this volume serve to remind us how a robust ethics service can support clinicians caring for critically ill patients. They also provide valuable advice on how honest prognostication can help patients and families make difficult decisions, how to use advance directives and surrogate decision-makers when patients cannot make decisions for themselves, and how to apply principles for supporting genuine shared decision-making with patients and families.

The fields of emergency and critical care medicine are developing to the point where the biological functioning of essentially every organ system can be artificially supported and maintained. Technologies for supporting the many and varied functions of human body will soon reach the point where biological death as we know it will become virtually optional, such that patients will die only when we cease to support the functions that are sustaining them. As emergency and critical care practitioners assume the burden of caring for these patients, we are being forced to address fundamental existential issues: what are the goals of medicine, when does continued treatment become disproportionate in terms of suffering and cost, and how do we educate our patients and society to the reality of the limits of medicine?

Most of all, however, this volume should remind us how important it is to keep our moral compass firmly in front of us, directing us to the true north of wise and compassionate care, not only for our patients, but also for ourselves.

June 2020

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Preface

Practitioners of medicine are frequently called upon to make moral decisions. Those who practice in the most acute care settings, such as in emergency departments (EDs) and intensive care units (ICUs), find themselves in such situations more frequently, and typically with less time within which to act, than in most other specialties. When this occurs, they call upon an ethical framework within which to decide what is the "right" or "good" thing to do for a given patient. For most practitioners, though, such a framework is largely intuitive, guided by experience and perhaps some rudimentary didactic education during their training. They may seek guidance from textbooks of bioethics, only to find the instruction to be more theoretical and academic than practical. They may seek advice from colleagues only to find that they, too, are lacking in ethical training or expertise. It is for those practitioners in the acute care setting of EDs and ICUs that we humbly offer this volume as a practical resource. We do not purport to provide solutions for all imaginable ethical challenges. Rather, we seek to identify compelling ethical challenges currently faced in the high-acuity care setting and to offer suggestions and potential approaches that might be of practical value at the bedside.

As experienced practitioners of critical care and emergency medicine (both in the prehospital and in-hospital settings), bolstered with additional training in medical ethics, we, the editors of this collection, hope to provide an assemblage of chapters that comprise a broad representative sample of ethically difficult scenarios commonly faced in EDs and ICUs

We first acknowledge that we remain challenged by questions that have existed for decades. Not uncommonly, for instance, whether from fear of litigation or simply aversion to conflict, clinicians can find themselves continuing life-sustaining interventions in an elderly patient with multiple organ failure and a dismal prognosis, simply because the surrogate decision-maker insists that "everything" be done, claiming that is what the patient would have wanted. Should our respect for autonomy extend so far as to exclude our clinical judgment of a foreseen poor outcome in such cases? Does the institutional culture accommodate the possibility of overriding the patient's wishes or surrogate's instructions?

Similarly, consider the situation of a patient who comes to the emergency department in coma after attempting suicide by overdose, but his reason for doing so was his diagnosis of stage IV metastatic cancer with a prognosis measured in weeks to months, and no further therapies to be offered. Must he be treated as we do most patients with suicide attempts and resuscitated to then be treated for his suicidal depression? On the contrary to the patient's wishes as such a resuscitation might seem, can the emergency physician withhold such interventions?

Finally, there can be no disputing that the advent of more and increasingly complex and exotic medical technologies has allowed many lives to be saved or at least prolonged, but with each advance come new and vexing questions. We must now face, for example, the ICU patient who is fully awake and cognitively intact on extracorporeal membrane oxygenation (ECMO), for whom no cure, device, or transplant is possible; this patient must be told that ECMO will now be withdrawn – how are we to meet such an ethical challenge? How do we plan even to approach such a conversation?

By calling upon a broad, diverse, and international cadre of authors, we have sought to aggregate a shared understanding of a practical bedside approach regarding ethical challenges, in an effort to answer the question, "What constitutes ethically appropriate care for a particular patient at a particular stage in the course of his/her treatment?"

As editors, we would like to thank all authors for their time and their expertise they devoted to this book, resulting in a comprehensive and stimulating "state of affairs" regarding present ethical challenges in emergency and critical care medicine. Furthermore, we are indebted to Andrea Ridolfi, Milano, from Springer Nature – Clinical Medicine Books, for his continuous obliging support of this project: *Grazie mille!*

I would like to express my sincere gratitude to my "ethics mentors" for their prudent leadership and their sustained encouragement: Robert D. Truog, Charles L. Sprung, J. Randall Curtis, and Uwe Janssens. Moreover, I would like to thank my wife, Joanne Vincenten, and our daughter Anna for their patience, prudence, and all their encouragement in the months this book took shape [AM].

I would like to acknowledge all the contributors to my education in medical ethics at the Harvard Center for Bioethics, but in particular Bob Truog, Dan Brock, and Millie Solomon, who all taught me to reach a little deeper into moral thinking. I must also thank Martha Jurchak for her longstanding and ongoing tutelage in the practical application of clinical ethics. Finally, I cannot thank enough my wife, friend, companion, and mother of our children, Dr. Marcie Rubin, for her patience, tolerance, and love [NS].

Tettnang, Germany — Andrej Michalsen
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Part I

Introduction

How Ethics Can Support Clinicians Caring for Critically Ill Patients

1

Aimee B. Milliken and Nicholas Sadovnikoff

1.1 Introduction

As a field, clinical ethics has made significant progress in the past 50 years. There is evidence, however, that ethical conflict and uncertainty are still major contributors to challenges faced in critical care and emergency department (ED) practice, resulting in stress on clinicians and potentially detrimental impacts on patient care. Additionally, as technology continues to progress and evolve, so do the ethical questions that arise. In this chapter, we begin by providing a brief background on clinical ethics. Then, using clinical vignettes, we examine the ways in which the tools of ethics can help the bedside clinician, and where there may still be gaps.

1.2 Background

Ethics and ethical questions are at the basis of health-care practice [1–4]. Indeed, many authors have argued that every interaction between a clinician and patient is ethical in nature [1] arising from the fact that the health professions exist to provide a public good, namely the promotion of health, prevention of illness, and alleviation of suffering. These goals serve as the foundation for professional codes of ethics [2–4] which represent nonnegotiable ethical standards for practicing clinicians.

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Given the fundamentally ethical nature of health care, questions about what is "right" or "good" for a particular patient are commonplace, as are professional disagreements about the answers to these questions. This is particularly true in the intensive care unit (ICU) and ED environments, where the pace is fast and decisions must be made quickly, often without time for lengthy deliberation. These questions serve as the foundation for clinical ethics, which is concerned with ethical issues that arise in the care of patients [1].

Many authors have highlighted the fact that clinicians tend to feel underprepared for the ethical challenges they face in practice. This is, in part, due to the fact that clinical ethics is traditionally not a major focus of nursing education [5, 6] or medical training [7]. In 2006, Carrese and Sugarman argued that "deficiencies exist in bioethics knowledge and performance among practicing clinicians and trainees; therefore, bioethics education is needed for learners at all levels" [1]. Nevertheless, ethics education remains an underemphasized area of many health-care training curricula, and this can translate into discomfort and distress in the care of complex patients.

Research has extensively documented clinician perceptions of excessive or inappropriate care [8, 9], challenges with interprofessional communication, and conflict between the family and medical team [10] as contributors to moral distress, which has been defined "the embodied response … of an individual to a moral problem for which the individual assumes some moral responsibility, makes a moral judgment about the appropriate ethical action to be taken but, due to real or perceived constraints, participates by act or omission in what he or she regards as moral wrongdoing" [10]. Over time, these stressors, and the experience of moral distress, in particular, have been connected to burnout, attrition, compassion fatigue, detachment, and the development of dehumanizing attitudes toward patients in physicians and nurses [11–13]**.**

Thus, in this chapter, we endeavor to examine the way the tools of ethics can help clinicians facing ethically challenging situations. The following vignettes highlight cases in which a decision with significant ethical implications must be made. Many of the issues introduced in these cases will be addressed in greater detail in later chapters in this volume. For each case, we review general ethical frameworks and consensuses that clinicians can turn to for guidance. We also highlight challenges with the prevailing frameworks, and areas where there is still work to be done.

1.3 Vignettes

Vignette 1: Autonomy, Paternalism, and Shared Decision-Making

A 60-year-old woman with uncontrolled diabetes presents to the ED with an infected foot ulcer, concerning for gangrene, and evidence of early systemic sepsis. An amputation below the knee is the definitive way to manage this infection; however, when the ED physician presents this option to the patient,

she refuses. Her father and sister have had amputations, and she feels their quality of life is not one that would be acceptable to her. The physician knows that without surgery, the patient will most likely develop septic shock and die. He feels uncomfortable with the thought of allowing a relatively young person with a treatable condition, to refuse treatment because that refusal will result in her death.

Generally, it is accepted in contemporary clinical ethics that a patient with decision-making capacity has the right to make decisions for themselves about medical treatments and the plan of care, even when their decisions do not align with the medical team's recommendations [14, 15]. This argument has at its basis the ethical principle of autonomy, or "self-rule" [14], which holds that the patient's values and preferences should be central in decision-making. A focus on autonomy as the guiding ethical principle in clinical decision-making is particularly common in North America [16]. This deference to autonomy has not always been the case, however, and historically, decision-making in medicine was conducted paternalistically. In a paternalistic style of decision-making, a clinician "substitutes one's own judgment for that of another person and decide(s) in place of that person for his/her best interest" [17]. In other words, the judgment of the clinician is central, and the role of patient preferences comes secondary to what the clinician judges to be the right decision. Contemporarily, there are cultural and geographic differences in the primacy of autonomy in decision-making. For example, some authors have noted a paternalistic approach to decision-making is still more common in European countries [16] though this is not a general assessment.

The pure-autonomy approach is limited, however, and can lead to patients and families feeling left to make decisions on their own, without expert guidance. Over-reliance on autonomy as the guiding principle for decision-making may additionally lead to situations where patients or their surrogates request care that clinicians view as potentially inappropriate or even harmful. Furthermore, a pure-autonomy approach to decision-making is often limited in the case of surrogate decision-making, where the patient's advance directives may be unknown or impracticable. Many authors have highlighted the limitations of surrogate decision-making, citing individuals' propensity to change their minds over time [18] and the inaccuracy of surrogates in predicting what their loved one would want [19].

In an effort to address some of the aforementioned limitations, shared decision-making has been recommended by multiple critical care societies [16]. This model of decision-making has been defined as a "collaborative process that allows patients, or their surrogates, and clinicians to make healthcare decisions together, taking into account the best scientific evidence available, as well as the patient's values, goals and preferences" [20].

Thus, in this case, a shared decision-making approach could allow the ED physician caring for the patient to explore her refusal. In an effort to respect her autonomy, he could probe the values that underly her decision, and inquire more

about her understanding of the intervention. The patient has prior experience with people who have undergone amputation, so this may be a crucial factor in her refusal. In addition to understanding her values and preferences, the physician can ensure that the medical situation is accurately conveyed to her, that his recommendation is clear, and that she has an adequate understanding of what she is refusing and the likely consequences of that refusal. The patient may have misconceptions or misunderstandings that, if corrected, could alter her decision. If time allows, he could explore whether there are important people in her life that could help her think through this high-stakes decision as a form of autonomy support. Assuming the patient retains decision-making capacity throughout the process, ultimately the choice to undergo surgery or not is up to her, but the physician caring for her can work to ensure that the decision is informed both by an understanding of accurate clinical information and by her prior experiences, her values, and her preferences.

Vignette 2: Proportionality, Potentially Inappropriate Treatment, and Cultural Considerations

A 68-year-old patient from a Middle Eastern country is admitted to an American hospital for cardiac surgery. He had multiple comorbid conditions preoperatively and understood that the risks of surgery were high. Postoperatively he developed a sternal wound infection that resulted in dehiscence of his incision and ultimately removal of his entire sternum. He was persistently ventilator- and dialysis-dependent and never regained consciousness after the procedure. After weeks of attempting to treat the infection unsuccessfully, the medical team believes that he will not survive, and recommend transitioning the focus of his care to comfort. The patient's family objects, citing their religious beliefs. They want the team to "do everything," and to leave the outcome in "God's hands." There is significant distress among the medical and nursing staff as they believe the patient is suffering but want to be respectful of the family's religious and cultural views.

The ethical principle of proportionality requires that clinicians assess the relative benefits and burdens of proposed interventions [21]. There is no ethical obligation for clinicians to offer interventions that are assessed to be overly burdensome, without a high degree of likely benefit [22]. Indeed, it could be argued that clinicians are obligated *not* to offer such interventions as an extension of non-maleficence, or the duty to avoid harm [14].

Nevertheless, requests for aggressive treatment, particularly at the end of life, are well documented in the literature [23]. In the early 1990s, this trend gave rise to the concept of futility, arising from technological advances in critical care that enabled the prolongation of life beyond what had ever been historically possible. This technological capability quickly became the genesis for questions about requests for the

initiation or continuation of treatment that clinicians judged to be "futile." One early definition of futility proposed that "when physicians conclude … that in the last 100 cases a medical treatment has been useless, they should regard the treatment as futile. If a treatment merely preserves permanent unconsciousness or cannot end dependence on medical care, the treatment should be considered futile" [24]. Many authors, however, challenged this and other notions of futility as ambiguous and subjective [25], giving rise to frameworks and preventive ethics approaches to the problem, focused on resolving disputes over treatment between patients/families and clinicians [26].

In 2015, the American Thoracic Society, American Association of Critical Care Nurses, the American College of Chest Physicians, the European Society for Intensive Care Medicine, and the Society of Critical Care Medicine released a joint policy statement. In it, the groups advocated for the use of "potentially inappropriate" rather than "futile" to describe treatments that "have at least some chance of accomplishing the effect sought by the patient, but clinicians believe that competing ethical considerations justify not providing them" [23]. They further argued for reserving the word "futile" for rare situations of physiologic futility, in which the intervention cannot accomplish the intended physiologic goal, and recommended a conflict resolution process for managing intractable disagreements [23]. Today, many hospitals have developed this sort of conflict resolution process, and data suggest that these processes may improve end-of-life care and mitigate conflict [27].

Cultural and religious views are important considerations in cases of disagreement about potentially inappropriate care. Some evidence has shown that individuals who are more religious may be inclined toward preferring more intensive care and life-prolonging treatment [28, 29]. Additionally, physicians' religiosity may have bearing on preferences toward limiting treatment at the end of life [30] although there is evidence to suggest that there is widespread agreement among clinicians internationally regarding not offering cardiopulmonary resuscitation when not medically indicated [31]. The clinician's understanding of the cultural and/or religious basis for certain treatment preferences may help patients and families to feel heard and understood, which in turn may engender a willingness to consider a wider variety of treatment recommendations [32].

The team caring for the patient in this vignette could begin by acknowledging the difficult position the family find themselves in and exploring the meaning behind their request to "do everything." This is a common directive given by grieving families; however, the specifics behind this request must be elucidated. For example, the team may work toward "doing everything" to keep the patient comfortable and relieving suffering as he approaches the end of life. The family may also benefit from engagement with individuals from their religious community if it is different than that of the practitioners involved, as in this case. Ideally, such an individual can help guide the family through the decision-making process and serve as a cultural broker between them and the clinical team [33]. While respecting cultural and religious preferences is essential, the clinical course also may reach a juncture where further medical intervention no longer has the potential to benefit the patient. If not

already initiated, at this point the medical team can begin conversations about withholding the escalation of interventions or withdrawing current interventions with the family, on the basis that they are causing more harm than good.

Vignette 3: Interprofessional Teamwork and Communication
A 70-year-old woman is admitted to an oncology unit with advanced cancer. She quickly becomes deconditioned, unable to feed herself, and non-interactive. She is cachectic and has a large sacral pressure ulcer. The nursing staff feel strongly that this patient should have her care transitioned to a focus on comfort; however, the patient's oncologist is not in agreement. He argues that the patient was a "fighter" and has not tried immunotherapy. He offers this to the family and they readily accept. The nursing staff are frustrated because they "know where this is heading," but do not feel as though the oncology team is listening to them.

The literature is rife with evidence about communication and teamwork challenges among members of the multidisciplinary team in the critical care and ED environments [34]. Although communication challenges are not always framed as ethical issues per se, poor communication and inadequate collaboration have been identified as major sources of moral distress [35] and even as contributors to medical errors [36]. Recent data suggest that there are differences in the way critical care physicians and nurses view the scope of their respective moral obligations, which may further hamper teamwork and give rise to conflict [37].

In light of these challenges, authors have highlighted the importance of interprofessional shared decision-making (IP-SDM), which is a collaborative process that allows for the "exchange of information, deliberation, and joint attainment of important treatment decisions" among an interprofessional team, including physicians, nurses, and other clinicians [38]. This model is particularly important where there are disagreements about the plan of care as it can highlight gaps in fact information that may be drivers of differing perspectives. For example, the nurses may have information about the patient's values or goals that the medical team has not heard, and the medical team may have information about the treatment and prognosis of which the nursing staff have not been made aware. Furthermore, IP-SDM can lead to "better-reasoned and more robust decisions" about the treatment plan [38].

Ethics consultation is one way of facilitating this type of communication, particularly in cases that are especially fraught or characterized by conflict. Ethics consultation services, and other ethics-related resources, can provide mechanisms that foster interprofessional communication around moral issues. Some authors have described "moral spaces" as a metaphor for the time, structures, and processes that facilitate this type of conversation around ethical issues and challenging clinical scenarios [39, 40], all of which can create a more robust sense of teamwork and collaboration.

In this case, the nursing staff may advocate for the convening of an interdisciplinary team meeting, where they can raise their concerns about the plan of care with the rest of the medical team, including the oncologist. If this attempt is unsuccessful, or if there are still concerns after the group meets, an ethics consultation may prove useful in helping the group sort out their disagreement, ensuring that all viewpoints are heard and that the plan of care reflects a robust consideration of the relevant stakeholder perspectives.

1.4 Conclusion

As these vignettes highlight, ethical frameworks have evolved in the past several decades in ways that can be practically useful for clinicians and that have been corroborated by research and scholarly work. Progress toward the model of shared decision-making and a greater sensitivity to cultural nuances can help clinicians ally with patients and families when making difficult choices about the plan of care. A heightened attention to the proportionality of care, the movement toward defining and avoiding potentially inappropriate treatment, and an increasing presence of palliative care in the critical care environment are all trends that can aid clinicians navigate ethically challenging situations with patients, particularly at the end of life. Finally, efforts to strengthen interprofessional teamwork and communication, particularly in situations of conflict, can support the development of a more ethical climate in ICUs and EDs. All that said, work remains to be done in the dissemination and uptake of existing tools and frameworks, and additional research is needed to optimally equip clinicians at the bedside. New technology will continue to give rise to new questions, but the tools of ethics can help clinicians navigate these challenging new scenarios.

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2 Patients and Teams Caring for Them: Parallels Between Critical Care and Emergency Medicine

Spyros D. Mentzelopoulos

2.1 Introduction

Emergency and intensive care of severely and acutely ill patients with medical or surgical pathology (including trauma) constitute a significant healthcare, societal, and financial burden. Furthermore, the pertinent and greatly diverse clinical scenarios may be associated with multiple ethical challenges. For example, frail, elderly patients with multiple comorbidities tend to visit the emergency department (ED) and/or get hospitalized more often during the last 2 years of their lives [1]. However, and especially in the presence of time constraints imposed by a life-threatening condition (e.g., cardiac arrest, septic shock), it may be difficult or even impossible to determine the level of emergency and/or intensive care (e.g., "fully supportive" vs. "palliative") that will accord to patient's values, preferences, and best interest. In such cases, the "sanctity of life" may prevail over patient autonomy, and this can result in "disproportional" resuscitative interventions [2, 3].

Medical ethics has evolved from a paternalistic to patient-centered and family-centered model [2–5], whereas a continuously evolving resuscitation and critical care science may offer increasingly effective treatment options [2, 3]. The ED and intensive care unit (ICU) constitute integral parts of the continuum of care of severely/critically ill patients. Major ethical issues and/or "conflicts," potentially involving all principles of bioethics (Box 2.1), and ensuing in the ED due to "time-sensitive" treatment decisions [2, 3, 6], may need to be subsequently addressed in the ICU. In the current chapter, these problems are reviewed and potential solutions are proposed, in the context of similarities, differences, and interdependence between the ED and ICU settings.

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Box 2.1 Definitions[a] of the principles of bioethics

- *"**Autonomy**: respect for the right of self-determination;" "Honesty[b]: accurate and transparent communication to the patient/family of the best research evidence, and clinical judgment including uncertainties."*
- *"**Beneficence**: the selection of beneficial interventions for the patient after assessment of the risk-to-benefit ratio."*
- *"**Non-maleficence**: avoiding harm or inflicting the least possible harm in the course of achieving a beneficial outcome."*
- *"**Dignity**: comprises "being human," "having control," "relationship and belonging," and "maintaining the individual self"; regarding resuscitation and post-resuscitation care, dignity means avoiding disproportional interventions and an "end-of-life" contradicting patient's preferences."*
- *"**Justice**: means fair and equal distribution of benefits, risks, and costs; pertains to the equality of rights to healthcare, and the legal obligation of healthcare providers to adhere to appropriate care and allocation of burdens and benefits."*

[a]Expert consensus-based and recently published in [2]
[b]Principle introduced and defined in the context of respect for autonomy (see [2])
Following slight "style change," this text extract was reused with permission from [2]

2.2 Initial ED Care and Triage for ICU Admission

ED patients can be classified according to the intensity of care they require as: Level 0 – regular patients with no need for additional monitoring or ICU care; Level 1 – need for additional monitoring (e.g., continuous electrocardiography), clinical interventions, clinical input or advice, or need for critical care outreach support; Level 2 – need for monitoring and frequent interventions for single-organ organ dysfunction, or need for invasive monitoring for preoperative optimization; Level 3 – need for life-sustaining treatment (LST) in an ICU (e.g., advanced respiratory support, or support for dysfunction of at least two organs).

ED Level 3 patients should be considered for (1) immediate initiation of LST, which may include cardiopulmonary resuscitation (CPR); and (2) direct ICU admission, according to their estimated probability of recovery, patient and/or next-of-kin acceptance of LST continuation, and ICU bed availability [7]. In prior studies, besides "*bed availability*," the major determinants of ICU admission decisions were "*hospital admission diagnosis (including comorbid conditions), acute illness severity and reversibility (including the indication for surgery), patient's age, functional status, and wishes, and ICU physician's experience and perception of the patient's quality of life*" [8, 9]. Following hospital admission, certain initially Level 0–2 patients with a complicated clinical course and/or a sudden deterioration may also be considered for ICU admission, usually according to the aforementioned criteria/factors [8–10].

Compared to all patients provided ICU admission according to healthcare systems' needs for using resources wisely, the ED subpopulation triaged for ICU admission (either while in the ED or later on during hospital stay) may include more

frail, elderly patients with multiple comorbidities, patients with a higher disease severity (e.g., Acute Physiology and Chronic Health Evaluation II score of >15 points), and patients with chronic, debilitating diseases, or hereditary/genetic anomalies [2, 8–10].

2.3 Ethical Challenges in the ED and ICU Settings

In acute and potentially life-threatening illnesses and injuries, delays in treatment decisions may have a substantial impact on patient outcomes. Therefore, ED and ICU ethical practice challenges may be associated with the need for (1) immediate decisions with no available time window (e.g., should CPR be started in a patient with cardiac arrest?); (2) urgent decisions with a limited time window of ≤6 h [2, 11] (e.g., administration of a potentially beneficial intervention such as tranexamic acid to limit traumatic hemorrhage [12]; or stabilization of a vertebral fracture and/or evacuation of an epidural hematoma in a trauma patient; or decompressive craniectomy for malignant infarction of the middle cerebral artery [11]); and (3) nonurgent decisions with a time window of 6–24 h (e.g., renal replacement therapy in a frail, elderly patient with acute kidney injury).

Major ED/ICU ethical practice challenges (1) may be related to the application of the bioethical principles; (2) may ensue during the acute phase of patient care or after the patient's cardiorespiratory stabilization, as well as during ongoing/prolonged ICU care; (3) may depend on applicable legislation and healthcare system organization; and (4) may be associated with the conduct of clinical research (Table 2.1) [2, 3, 8–11, 13–18].

2.4 Vulnerable ED and ICU Patients

ED/ICU patients with or without chronic comorbidities can be considered as vulnerable when they (1) experience an acute and/or life-threatening condition necessitating immediate/prompt therapeutic interventions and/or LST and (2) lack capacity to decide on available treatment options. Decisional incapacity means inability to understand essential information about the diagnosis and related treatment options and their consequences, reason about a treatment option in terms of weighing risks and benefits against other options, and express and substantiate a choice [13].

In both the ED and ICU setting, acute illness per se (e.g., brain injury, septic, hemorrhagic, or cardiogenic shock), sedatives and analgesics that are given to ameliorate discomfort/pain, and chronic comorbidities (e.g., dementia) may contribute to impairment or loss of decisional capacity. In the absence of immediate access to any recorded preferences or an authorized, surrogate decision-maker (SRDM) [19], ED physicians may have to treat vulnerable ED patients with a life-threatening condition under a presumption of patient consent [4, 9, 20, 21]; this "immediate necessity" [2, 22, 23] is consistent with the "*patient's health and well-being constituting*

Table 2.1 Major ethical challenges of emergency and critical care practice, and pertinent, time-sensitive differences

Ethical dilemma	Associated ethical imperatives and societal/ healthcare system characteristics	Major difference between ED and ICU settings
During the acute phase (no therapeutic window) Is the patient capable of decision making/ consenting to treatment? [11] Patient cannot decide: Is there are liable substitute decision maker? Should LST be started to prevent or treat CA?[a] Should only palliative treatment be given? Patient AD(s) available: is/are they valid? When should LST/CPR stop? Should family members be present during resuscitation? Do patient clinical status/comorbidities justify LST in ICU [8–10]? Should the patient receive advanced treatment (e.g., ECMO) [2]? Is there immediately available/reliable information on AD/ACP?	Respecting patient preferences/bodily integrity (autonomy/honesty; dignity); respecting family preferences (family autonomy); benefiting without harming (beneficence/nonmaleficence); equal access to best-quality care (justice)	In the ICU (as opposed to the ED), there is frequently adequate time [2, 13] to (1) determine the patient's decisional capacity [14]; (2) to reach an appropriate substitute decision maker [14]; (3) to obtain informed consent for indicated interventions as required [2, 3, 14, 15]; and (4) to interpret any available AD(s) [2, 3, 14] ICU setting frequently associated with availability of information about the patient's prior medical history and quality of life, preferences, and current clinical status and prognosis
After patient stabilization and during ongoing/ prolonged ICU care Do patient clinical status/comorbidities justify LST/ICU [8–10]? Should the patient receive advanced treatment (e.g., ECMO)? When should LST be withheld and/or withdrawn? How should the patient/family be involved in decision-making?[b] Should the family be present during non-emergent and emergent ICU care? Are treatment goals adjustable to patient clinical course/prognosis? Should ethics consultation be sought?	Equal access to best-quality care (justice); benefiting without harming (beneficence/ nonmaleficence); respecting patient preferences (autonomy/honesty; dignity)	ICU setting may be associated with an already ongoing and/or completed decision-making process [2, 4]

Healthcare system		ICU setting frequently associated with more time available to reach an appropriate substitute decision maker and request an informed consent
Do patients have equal access to the best-quality of care?	Equal access to best-quality care (justice); emergency/critical care organization/disaster area emergency/critical care organization[c]	
Can VIPs be treated without disrupting the care of others? [16, 17]		
Disaster areas: should patients be triaged for treatment feasibility? [18]		
Emergency/critical care research		
Can a valid informed consent be obtained? [2]	Respecting patient preferences (autonomy/honesty) versus benefiting the patient (beneficence)[d]	
Can consent be presumed, waived, or deferred? [15]	Respecting patient preferences (autonomy) versus benefiting the patient (beneficence); country-specific legislation	
Does potential benefit outweigh potential risk? [2]	Benefiting without harming (beneficence/nonmaleficence)	
Is the benefit-to-risk ratio equal among societal groups? [2]	Avoiding harm (nonmaleficence) versus provision of accurate information about the research-associated risk-to-benefit ratio and about research interventions administered to the patient prior to their death (honesty)	
Should the patient's family be informed about the research, in case the patient dies before consent can be requested?		

ED emergency department, *ICU* intensive care unit, *CPR* cardiopulmonary resuscitation, *CA* cardiac arrest, *AD(s)* Advance Directive(s), *ACP* advance care planning, *LST* life-sustaining treatment, *ECMO* extracorporeal membrane oxygenation, *VIP(s)* very important person(s)

Definitions for Ethical Principles are provided in the text

The Associations between Clinical Dilemmas/Practice Issues and Ethical Principles are analyzed throughout the text

[a]Regarding life-threatening situations, patient consent is presumed, unless there is immediate access to (or knowledge of) a patient's AD against CPR (see also text)

[b]This should include a shared decision-making process (see also text)

[c]In disaster areas, specialists such as neurosurgeons may not be available, and certain neurosurgical patients may not be treated to prevent waste of scarce resources [18]

[d]Clinical research may evaluate new and potentially beneficial interventions, or even routine practices (e.g., epinephrine use during CPR) with a still unclear risk-to-benefit ratio

the physician's first consideration" [23]; respect for patient autonomy can be applied later on by shared decision-making [4]. In contrast, ICU physicians frequently obtain access to or information about patient preferences, before having to make a resuscitation decision. Furthermore, Do-not-attempt CPR (DNACPR) orders and/or LST limitation (or even withdrawal) decisions may already be in place, as a result of a preceding shared decision-making process [4].

Consent issues are addressed in detail in Chapter 4. Briefly, presumed consent for an evidence-based and indicated, life-saving intervention favors beneficence over autonomy, applying the *"ethical default of preserving (the sanctity of) life"* [2]. However, regarding research, presumed consent cannot simply replace preenrollment consent. In research, acceptable alternative consent models include deferred consent [2, 22, 24], exception to informed consent with prior community consultation and the option for potential, prospective participants "*to opt out by the wearing of 'NO STUDY' bracelets*" [22].

In the absence of "immediate necessity" for treatment [22, 24], a valid, free, and informed consent must be obtained before a patient receives a health-related, therapeutic or research intervention [2]. Consent validity depends on (1) patient or proxy decisional capacity and proxy's actual knowledge of patient's preferences [2, 13, 15, 22]; (2) therapeutic or investigational intervention complexity [22]; (3) timely, honest, and accurate physician description/delineation of expected intervention-related benefits, possible adverse effects, and alternative treatments [2]; (4) acute illness-related time constraints (e.g., need for urgent evacuation of an expanding epidural hematoma [11]); and (5) physical (e.g., pain due to trauma) and emotional distress [4, 15].

2.5 Challenges Associated with Surrogate Decision-Makers

As a safeguard for the autonomy of a vulnerable incapacitated ED/ICU patient, consent for therapeutic (e.g., LST) or research interventions must be sought from and provided by an SRDM fulfilling criteria of and acting as a "*legally designated representative*" [2–4, 13, 15, 19, 22, 24]. Depending on country-specific legislation, SRDM can be a patient's family member or a person holding a durable power of attorney as regards healthcare-related decisions [2, 3, 13, 19, 25].

An SRDM should decide according to the patient's wishes, substituted judgments, and best interests [26]. However, several authors have cast doubt upon an SRDMs' ability to provide a valid consent for interventions under conditions of emotional stress related to their loved one's acute/life-threatening condition [15, 26]. Therefore, in the absence of specific time constraints, it is recommended that patient values, goals, and preferences be carefully elicited from SRDMs, and under conditions of emotional support by and partnership with the care team [4, 13].

Additional SRDM-related challenges are detailed in Chapter 4. Briefly, SRDMs may feel uncertain about their capability of decision-making [27]. Conflicts between decision-makers (including SRDMs) may have impact on patient outcomes [2, 28].

SRDM participation in ICU end-of-life decision-making may be associated with later SRDM post-traumatic stress disorder, which in turn, if severe, may be related to anxiety, depression, and a worse quality of life [20]. Lastly, the aforementioned challenges may prove substantially more difficult to address in an ED setting, where prompt SRDM decisions, consistent with patient preferences are needed.

2.6 Family Presence During Patient Care and Resuscitation

Recent guidelines on family-centered care in the ICU suggest (evidence level, 2D) that families be offered open or flexible presence at the bedside according to their preferences, while concurrently motivating ICU staff to work in partnership with families to improve family satisfaction [5]. However, unrestricted or flexible family presence may be (1) viewed by ICU staff as impediment to practice and an increase in their workload; (2) stressful to family members due to the patient's critical condition, or to patients worrying about the emotional burden placed on their loved ones but being unable to communicate their thoughts and feelings due to ongoing invasive mechanical ventilation and an indwelling tracheal tube; and (3) associated with an increase in staff's burnout levels [5]. Conversely, family presence has been associated with (1) improved outcomes, when coupled with an educational program; and (2) increased family satisfaction, without changing staff satisfaction [5].

Family presence during resuscitation is supported by current guidelines [21]. This practice varies considerably among different countries [29], and may be easier in the out-of-hospital rather than the ED/ICU setting [2]. Pertinent concerns include potential psychological trauma to family members (e.g., due to patient's visible bleeding), performance anxiety/distraction of the resuscitation team, and fear of medicolegal problems [2]. In the out-of-hospital setting, a cluster-randomized, family-presence trial and a subsequent 1-year follow-up study revealed that family presence did not adversely affect resuscitation, reduced the frequency of family members' post-traumatic stress disorder, anxiety, depression, major depressive episode(s), and complicated grief, did not increase resuscitation team stress, and did not cause medicolegal problems [2, 30]. Essential prerequisites for successful family presence may include dedicated healthcare policies resulting in specific resuscitation team training, a designated assistant explaining ongoing resuscitative interventions to family members, and comprehensive post-resuscitation debriefing by a qualified healthcare provider [2]. Recently reported, pragmatic ED–family presence issues included inadequate staffing levels and resuscitation room physical space and lack of endorsement of family presence by medical staff [31]. In a retrospective study concerning the in-hospital setting (including the ICU), the family presence was associated with shorter duration of resuscitation [32], which in turn may be associated with lower survival to hospital discharge. Results of recent studies show high variability in healthcare professionals' attitudes toward family presence (from "positive" to "negative") and its practice (from "routinely allowed" to "not allowed") across different countries worldwide [29].

2.7 Advance Directives (AD), Advance Care Planning (ACP)

ADs are instruments relaying information about a person's values and medical/surgical treatment-related goals and preferences in the event the person concerned becomes incapable of decision-making [2]. ADs are based on autonomy and can be formatted as a living will, durable power of attorney, and the legal status of preferences [33]. Living wills (or instruction directives) specify the type of care a person would accept or refuse under various conditions [33]. As an example for the case of critical illness and associated decisional incapacity, living wills may pertain to resuscitation (e.g., DNACPR directive), LST (e.g., mechanical ventilation, renal replacement therapy), and palliative end-of-life care. The durable power of attorney refers to the appointment of a healthcare proxy agent to make treatment decisions on behalf of the person concerned [3, 33]. The legal status of preferences is a written or oral general statement not covering specific treatments and conditions but indicating, for example, whether a person wishes to participate (or not) in decision-making [33].

Substantive components as to the validity and applicability of an AD include the person's mental status and freedom of choice at the time of drafting, absence of AD revocation, conformity to applicable law, legally binding status, clarity without ambiguity aimed at covering a broad spectrum of diseases, timing of drafting and subsequent reviewing, and potential changes in a person's preferences due to scientific progress achieved since AD drafting [2, 14]. Specific ADs for common degenerative diseases such as dementia might be associated with improved clarity and applicability.

Among elderly decedents, living wills were associated with increased frequency of preference for limited care or solely comfort care, and increased consistency between desired and actually delivered intensity of care [34]. However, ED patients with end-of-life documents refusing specific interventions only (e.g., DNACPR) should not be automatically excluded from ICU admission, and their care should not be restricted based on extrapolating what their wishes might be from a DNACPR order. The American College of Emergency Physicians endorses goals-of-care discussions, which in the stable patient include the steps of preparation, establishing patient's/SRDM's level of knowledge of the acute illness, assessing patient/SRDM willingness to receive information, providing the information, responding to patient/family emotions, establishing the goals of care, making medical recommendations, and summarizing the plan based on the discussion [35]. The American College suggests ICU admission of ED patients if ICU care can offer unique benefits (through LST) that accord with patient's values and goals [35]. Establishing goals of care promptly may be impossible in ED patients requiring emergency interventions (e.g., thrombolysis for life-threatening pulmonary embolism) followed by LST in an ICU. In such cases, beneficence may supercede autonomy.

Unintended consequences of "isolated" DNACPR decisions may include inappropriate CPR, undue delay, and emotionally stressful discussions around DNACPR, and unjustified withholding of other indicated treatments, or even standard

diagnostic tests and monitoring [2]. Therefore, a holistic approach integrating DNACPR preferences into ACP has been recently advocated [2]. Regarding ACP, a definition based on the synthesis of two recent consensus definitions reads as follows: "A process that enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate. The main objective of ACP is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious, chronic and/or acute/life-threatening illness."

Recent research results have been positive for ACP. A systematic review of 55 randomized trials reported that ACP was associated with increased frequency of ADs' completion and congruency between patients' preferences and actually delivered care. Five randomized controlled trials evaluating ACP programs have reported favorable results on the frequency of hospitalization and mortality, improved communication/awareness of participants' treatment preferences, improved concordance of patients' preferences with actually administered CPR, more frequent selection of comfort care and forgoing LST/CPR, and reduced emotional/psychological stress of family members and greater patient/family satisfaction [2]. In addition, in the out-of-hospital setting, completed and immediately available physician orders for LST (POLST) forms may inform treatment decisions for collapsed/unconscious patients with or without pulse [36].

2.8 Shared Decision-Making

ICU admission and initial stabilization should be followed by a shared decision-making process defined 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*" [4]. As per current guidelines [4], during shared decision-making, clinicians should (1) establish partnership with SRDMs; (2) provide emotional support; (3) assess SRDM's understanding of the medical situation; (4) honestly/transparently explain the patient's health/physical problems and the pertinent prognosis [2]; (5) highlight the presence of options of treatment strategies (e.g., initial trial of full support followed by comfort care only); (6) explain principles of SRDM decision-making and assess SRDM's role preference; (7) explain benefits/risks of indicated interventions; (8) elicit patient values, goals, and preferences; (9) deliberate with patient/SRDM; and (10) reach a decision. Processes should be modified as required to meet specific patient/SRDM needs [4].

ACP and shared decision-making are intended to safeguard patient autonomy and dignity and concurrently promote beneficence/non-maleficence. On the other hand, these ethical practice interventions are complex, resource-demanding, and require specifically oriented and supportive governmental policies, legislation, and healthcare system organization. Shared decision-making is further discussed in Chapters 6 and 7.

2.9 Equal Access to Best-Quality Care

Fair allocation of LST resources is challenging and may raise issues of clinical judgment subjectivity as regards prognosis, and ethical integrity of criteria applied for DNACPR/LST decisions [2, 10]. Factors such as patient age, comorbidity, frailty, prior DNACPR orders, race, ethnicity, religion, recent immigration or refugee status, and socioeconomic status should not, but still may, impact access to high-quality ED/ICU or even ward-level in-hospital care, as well as palliative care [2, 3, 10, 29, 35].

The combination of advanced age, frailty, chronic comorbidity, and a DNACPR order can result in unjustified exclusion from ICU admission to effectively treat reversible pathology such as pneumonia causing respiratory failure [35]. Similar scenarios can apply for patients with debilitating diseases (e.g., multiple sclerosis) or those with chronic or hereditary or genetic diseases/anomalies [2]. Conversely, ethnic groups such as "very recent" North American immigrants of Asian/African origin may be more likely to receive disproportionate LST due to more frequent, clinician-directed decision-making, cultural and religious differences, and difficulties in accessing palliative care compared to long-standing residents [37].

ED (or even ICU) care of "very important persons" (VIPs) may be associated with breakdowns or even temporary disruption in the care of other, non-VIP patients [16]. VIPs may demand prioritization, preferential care over others, and even contraindicated and potentially harmful treatments [17]. Such conditions and VIP attitudes contradict beneficence/non-maleficence and justice [17]. VIPs' care is routinely expedited by ED directors [18]. Conversely, VIPs may be under undue pressure from their entourage (e.g., athletic team representatives, agents of actors, etc.), and this may compromise their freedom of choice and autonomy [17]. In addition, VIPs may require special protection of their privacy [17].

Disaster conditions present unique ethical ED challenges. Normally, and by local triage protocols, all patients visiting an ED are treated, with prioritization and possible ICU admission partly depending on the urgency/severity of their condition. In contrast, in major disaster areas, the triage dilemma is who can be treated or not according to "a field hospital's resources" [18]. According to the American College of Emergency Physicians, by definition in a disaster situation, "*natural or man-made destructive forces overwhelm the ability of a local/regional healthcare system to meet a mass casualty-induced demand*" [18]. For disaster situations, the World Medical Association states that "*physicians should set an order of priorities that will save the greatest number of lives and also minimize morbidity*" [18]. In disasters, physicians' shift to "utilitarian-based ethics" may be justified.

2.10 Dignity and End-of-Life Care

In the context of severe, acute illness with poor prognosis and ongoing ICU care, dignity primarily pertains to the patient's right to avoid disproportional interventions (e.g., extracorporeal life support) and an end-of-life care that does not accord

with patients' wishes. DNACPR orders and ACP should achieve protection of dignity and ensure efficacious end-of-life comfort care while avoiding the controversial and rarely practiced (but recently more widely legalized) physician-assisted death (PHAD) and euthanasia [2, 3]. In the absence of a written DNACPR order, the patient's relatives might best be asked: "*what was important in the life of your loved one?*"

In post-resuscitation care, withdrawing/withholding of LST may be conducted in the context of shared decision-making and/or a very low probability (e.g., <3%) of neurologically favorable survival [2, 4, 13, 21]. Withdrawing/withholding LST is based on clinical evidence for the disproportionate use of life-sustaining measures [2]. In contrast to PHAD, withdrawing/withholding LST does not correspond to the active infliction of death. However, the distinction between allowing a patient to die after withdrawing LST and deliberate termination of life remains unanswered. Many physicians believe that a ventilator-dependent patient is allowed to die after withdrawing LST when further treatment is no longer appropriate because the underlying patient's condition or severe organ failure causes death. Others regard withdrawing LST as the immediate cause of death, as most patients die within 30 minutes following its application [2]. Physicians must anticipate the distressing symptoms and provide sufficient comfort throughout the dying process. Anticipated administration of sedatives and opioids in adequate doses does not seem to shorten the dying process [2]. Guidelines for withdrawing LST have been recently published [38]. Current European guidelines on withdrawing/withholding LST are consistent with palliative sedation and analgesia to reduce patient awareness of intolerable symptoms, alleviate pain, and suffering, but do not support the hastening of death by using sedatives and analgesics [2, 13].

2.11 Emergency/Critical Care Research Issues Besides Consent

This topic has been reviewed in detail elsewhere [2]. Briefly, research involving incapacitated patients should result in minimal risk exposure, while also providing a prospect of possible benefit [2, 22]. The risk-to-benefit ratio should not differ among societal groups. If certain groups bear more research burden, they should also enjoy more research-related benefits [2]. Benefit should not be confined to privileged groups or residents of nonparticipating countries [2]. Furthermore, the dignity of research subjects should be respected, and subjects/SRDMs should be involved in the research processes to the extent of their ability (e.g., given the option to be present during investigational interventions or offer their opinion/advice about the protocol) [2]. Participants' privacy and personal data must be protected. Furthermore, investigators should apply research protocols in a transparent manner and should readily share results with the communities/groups of the research participants [2].

2.12 Conclusions and Future Directions

ED and ICU clinical practice is associated with a broad spectrum of challenges pertaining to the application of all the principles of bioethics. Although similar in nature, ED challenges are more difficult to address in the presence of time constraints imposed by a collapsing patient needing immediate intervention for stabilization. Regarding vulnerable patients, current evidence supports ACP, family-centered care, family presence during resuscitation, and shared decision-making as safeguards of autonomy, but also of beneficence/non-maleficence. Regarding equality of access to best-quality care, substantial progress is needed. PHAD and euthanasia remain controversial and rarely practiced. Current research regulations foster low-risk emergency/critical care research in North America and Europe while concurrently including provisions to safeguard autonomy and the well-being of vulnerable patients.

Further progress regarding ED/ICU ethical practice could be achievable through the following actions/initiatives:

- Continuing efforts to reach multilevel, international consensus regarding the most efficient and appropriate application of the principles of bioethics.
- Specific governmental policies providing legal, financial, and healthcare systemic/organizational support for evidence-based interventions, such as ACP, family-centered care, and shared decision-making.
- Compulsory pre-graduate education of healthcare providers in the field of bioethics.
- Education programs for the public, and promotion of ACP in the community.
- Continued support (e.g., from governmental or nonprofit organizations) of research aimed at optimizing the quality of ethical practice.

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Part II

Goal of Therapy, Teams and Patients

Indication and Prognostication

3

Armand R. J. Girbes

3.1 Introduction

The ultimate goal of any medical treatment is the benefit for the individual patient. This requires, on the one hand, to be aware of what is considered as a benefit by the patient, and on the other hand, what can be obtained and at which price by medical treatment. The latter requires a wide medical expertise [1]. Several aspects of medical treatment are furthermore important to acknowledge. First, the expected outcome of medical treatment is never 100% certain, and second, it is accompanied by risks and side effects of different degrees [2]. Third, and perhaps most importantly, although treatment outcomes in medicine have tremendously improved over the past century in terms of the outcomes of diseases, medicine remains an imperfect science, and in the end, all patients will die. Finally, predicting the outcome of patients admitted to the intensive care unit (ICU) can be very difficult for individual cases, and physicians as well as nurses perform badly [3, 4]. It is of note that in the end, there is finally only one who will know the truth, and that is time. This may seem very obvious but refers to the fact that it should be considered as useful to take some time. It will allow making a complete diagnosis, and determining with more certainty the reversibility of failing vital organ systems. Moreover, it gives extra time to the patient and the family to make up their mind on their thoughts and wishes, especially concerning the extent of life-prolonging treatments and the quality of life thereafter – and at which efforts and sacrifices. Overall, this approach will take away the sense of being forced into rushed decisions under (time) pressure, both for the patient with his/her beloved ones and the treating team. Patients can die only once, and death is irreversible.

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3.2 Patient-Centered Indication and Prognostication

Patients are admitted to the emergency department (ED) or the ICU because of an imminent or present life-threatening condition with failure of vital organ systems. The decision to admit a patient to the ED or ICU is an important one since treatment there can make the difference between life and death at that moment. Ideally, the patient is admitted for a relatively short-term treatment period that will reverse the life-threatening situation so that the patient can be discharged in a better condition. Reversibility of the life-threatening disease or condition is therefore a keyword for consideration at the moment of admission. However, once going into a sequence of medical treatments – usually then in an ICU – implies the risks of being confronted with unforeseen side effects, a longer treatment period than foreseen and unwanted consequences of a decision taken earlier at admission. Having the option to make the correct prognostication of the outcome at the time of admission would be of help. Scoring systems developed in the past, like the Acute Physiology And Chronic Health Evaluation (APACHE) or the Simplified Acute Physiology Score (SAPS) may be of help to predict the outcome in patient populations, but they are not suitable to predict outcome in individual patients. Moreover, the area under the receiver operating characteristic curve – a measure to express the ability of the model to discriminate patients who will survive from those who die – is 0.70–0.80 at best [5]. Moreover, in a recent study in patients with septic shock participating in clinical trials, we have shown that factors not measured at baseline were of more importance for survival than those measured, including, for instance, the severity of illness scores [6]. This underscores how difficult it is to predict an outcome. Taken into consideration that at the moment of admission the patient is in a life-threatening situation, there is always a pressure of time. Therefore, if the reversibility of the medical situation is not unequivocally clear and/or the wishes of the patient are unsatisfactorily defined, starting a treatment that will buy time should strongly be taken into consideration. This will also allow the possibility to discuss the situation of the patient in a multidisciplinary way, thus avoiding that a single physician would take the decision to withhold or withdraw life-sustaining treatments without further consultation of other physicians and nurses [7, 8].

The decision to admit a patient to the ICU in the first place can be a difficult one. Notwithstanding the fact that the decision should be taken on the basis of medical expertise and the will of the patient, a factor that may play a role is that in situations where patients may die, the clinician is also confronted with the fact that humankind – including physicians and nurses – is mortal. All clinicians who have worked long enough, especially in EDs and ICUs, have seen or lived a situation where a clinician could not accept that the patient was in fact at the end of his/her life.

An example, that I will never forget, is the liver transplant surgeon who was confronted with uncontrollable bleeding during surgery. The patient had been hypotensive for a long time, with extremely low hemoglobin values, and at a certain moment it became unmistakably clear to the anesthesiology team that the patient was (brain-)dead. The anesthesiologist repeatedly mentioned this to the surgeon, but the surgeon answered, “Wait a minute, the bleeding has almost stopped!”

This example is by no means meant as a caricature, yet it confronts us with the difficult experience to have to accept that some patients will die, despite all efforts. Although difficult to study scientifically the impact of such feelings of clinicians on decisions to continue treatment, it seems reasonable to assume that they do matter.

3.3 The Gap Between Attainable and Desirable Outcome

On the one hand, at the time of admission or thereafter during the ensuing treatment, it may become clear which outcome will be attainable for the patient. The maximum attainable outcome should then be put into perspective with the minimum desirable outcome, as determined by the patient. If the minimum desirable outcome is unattainable, then further treatment in an ED or ICU becomes, metaphorically speaking, "a search for the pot of gold at the end of the rainbow." If the desired outcome that is sought for cannot be achieved, a gap exists between the maximally attainable and the minimally desirable outcome (Fig. 3.1). Obviously, to understand which outcome is achievable at best requires medical expertise. The physician should, therefore, be well aware of the nature and severity of the acute disease or injury as well as of the concomitant diseases – and the reversibility of the factors that brought the patient to the ED or ICU. As a rule of thumb, the patient cannot be restituted into a better situation than he was before the present (imminent) organ failure unless the patient had not been treated optimally before. To assess the latter, it is important to realize that this also requires knowledge of the previous (chronic) diseases and the options to improve the respective care.

As an example, a patient with congestive heart failure with dyspnea at minimal effort who would not have used any medication and would not have had an adequate workup or a treatment plan regarding reversible causes may significantly benefit from chronic state-of-the-art treatment. The same holds true for patients with severe chronic obstructive pulmonary disease, who do not use an appropriate medication or still smoke cigarettes, or who suffer from untreated pulmonary hypertension. If

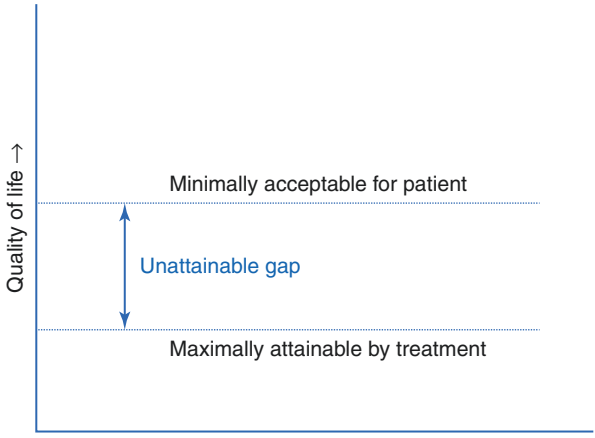

Fig. 3.1 The difference between what is the maximally attainable and the minimally acceptable outcome for the patient is "the unattainable gap"

the ED or ICU physician were not aware of these reversible factors, it might inappropriately be decided not to admit the patient because of a "bad" general condition.

Physicians and nurses can be wrongfully convinced of a bad outcome of patients, not in accordance with data from the literature [3, 9]. The outcome of elderly patients may be better than expected, and age alone should not be the reason for suspicion of a bad outcome [10]. National or local guidelines may also inappropriately deny critical care services for patients [11], underscoring the fact that physicians should be careful to refuse admission to the ICU in individual cases, *a fortiori* when not all aspects of the disease(s) and general condition of the patient are known.

On the other hand, the wishes of the patient need to be inventoried. What did the patient think of his/her quality of life before the onset of the condition that led to ED or ICU admission? And what would the lower limit be that the patient considers worthy to live? Of note, the patient may require some time to find that out. And it is not uncommon that the patient is not in a state to express his/her will in the acute situation or even in a more chronic situation [12]. Nor do surrogates estimate the putative will of the patient sufficiently well [13]. Nowadays, more and more patients will have statements regarding a do-not-resuscitate-order (DNR) or any other treatment limitations. At first, this may seem to ease the situation and the decision as to an admission. However, the ER or ICU physician should be aware of the possibility that the information given to the patient regarding treatment limitations may not have been given by an expert in the field. Consequently, the patient and his/her family might have taken a different decision if truly well informed.

As an example, a previously healthy patient with Guillain–Barré Syndrome (GBS) was admitted to our unit because of progressive respiratory failure. Previously, an inexperienced physician in the ED had discussed with him the DNR orders. As the patient stated that "he did not want to end-up as a plant," he denied any resuscitation actions, including defibrillation or cardioversion for ventricular tachycardia. It took me 2 h of discussion with the family and the patient after his admission to the ICU to reverse this expressed wish that was mainly based on insufficient knowledge on the frequency and reversibility of severe cardiac arrhythmia in patients with GBS and their general outcome.

The information provided or not provided plays an important role in the decision-making of the patient and the family regarding the extent of treatment. If the patient is or becomes incapacitated, it may take some time to collect all available and required information in order to make a well-balanced decision. Several sources should be used, including if ever possible the general practitioner or at least the physician who knows the patient best [14]. Evaluating the result of intensive care treatment in the first days to determine reversibility has been advocated in specific groups of patients where it is well-known to be difficult to determine the outcome [15]. A decision to deny admission to the ICU carries a high self-fulfilling prophecy [16]. Furthermore, studies have shown that when physicians estimate the mortality risk >90%, it is a more powerful predictor of ICU mortality than any other indicator of the severity of the disease. In other words, once the treating team has assessed the survival chances to be very low, the patient is very likely to die indeed. Therefore, given the uncertainty regarding any outcome prediction, some modesty and patience of physicians seem appropriate.

3.4 The Will of the Patient

In order to respect the autonomy of the patient, it is of utmost importance to be aware of the patients' will. Patients may have very personal reasons not to extend their life anymore. It is the autonomous right of the patient to refuse each and every medical treatment, and physicians should not impose a specific treatment on them. It appears important, however, to be informed about the patient's motives and inducements and the potential role of external factors or influences, such as the feeling to be a burden to family and friends as well as a temporary depression due to a lifetime event, such as the death of a beloved person. Another consideration, which may come to the mind of the patient and the family, is how the end of life will be experienced when the treatment in the ICU is not successful in terms of survival. Fear of pain, death, and the unknown may influence a patient's decision. As best as possible, internal and external influences need to be addressed and clarified. Reassurance and information by an expert about the possibilities and impossibilities in the ED or the ICU as well as dying with dignity and free of pain is generally highly appreciated by patients and their families in this context.

Explanation of statistical chances and risk of dying may be difficult to handle. As an example, potentially complicated elective heart surgery carries a mortality risk of 4%. This may be considered not a high figure. What is often not appreciated, however, is the fact that this number is about "everything or nothing." In such cases, rational statistical data do not count anymore. Playing with dices can serve as an explanatory example to clarify the limitation of statistics for such cases. Proposing to throw two dices with a sum of 3, 4, 5, 6, 7, 8, 9, 10, 11, or 12 that will give one million Euro may seem attractive. But if the consequence of throwing the sum of 2 (i.e., one and one with each dice) is that all family members will be killed, the assessment will be totally different. The chance of throwing two with two dices is, however, only 1/36 = 2.8%, yet it becomes clear to everybody, that it is an unacceptable risk and bet, because it is about all or nothing.

Overall, the quality of adequately patient-centered intensive care is not only reflected by high survival rates or low rates of hospital-acquired infections, but also by good palliative and human care. This is of special importance for those patients who will die in the ICU.

As an important caveat, the discourse on indication and prognostication is embedded in a context of sufficient resources for adequate ED and ICU structures and processes. In the case of a significant shortage of resources, the discourse would necessarily be very different. This is, however, beyond the scope of this chapter.

3.5 Summary

The decision to admit or not admit a patient to an ED or ICU should be the result of medical expertise regarding the reversibility of the acute condition that led to the failure of vital organ systems, in accordance with the will of the patient. Since not all information as to the extent of treatment may be available in the acute situation, admitting the patient for a time-limited trial may be advisable. This holds especially

true in an ED where physicians may be confronted with patients they have never seen before and the available documentation is limited. Ideally, different scenarios have been discussed previously and electively, with the involvement of the patient and the family. However, this is often not the case. Therefore, taking time is important and can be used to collect all required information while also observing the effect of treatments implemented in the ED or the ICU. Since a patient can only die once, the ethical challenge is not only to make the best decision for the patient but also at the right moment and based on the best information possibly attainable.

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Consent, Advance Directives, and Decision by Proxies

4

Annette Robertsen, Susanne Jöbges, and Nicholas Sadovnikoff

4.1 Introduction

Patient autonomy is a prominent ethical principle in the practice of medicine. This right to self-determination can be exercised by a competent patient through the process of informed consent (IC) or refusal, or it can be extended, if the patient lacks decision-making capacity (DMC), through an advance directive (AD) or a designated surrogate. A properly informed patient with full DMC can not only make decisions personally, but is the only one who can make such directives. In most Western countries, such decisions are binding for the health care team, and to override them constitutes a violation of law. However, DMC in acutely ill patients often is compromised, either due to effects of the acute condition or to preexisting cognitive impairment [1]. In such instances, the ethical obligation remains to respect their autonomy. How can that be achieved in emergency departments (EDs) and intensive

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care units (ICUs)? Are ADs helpful in guiding the decision-making process? What is the role of a designated surrogate decision-maker such as a person assigned a power of attorney?

In this chapter we will address the legal basis as well as the ethical challenges and possible solutions regarding these issues.

4.2 Legal Bases

Physicians and allied caregivers need to have knowledge of the legal framework in which medical decision-making is conducted in their jurisdiction. This requires a basic knowledge of the laws as they are written (statutory law) and the way in which they have been applied in legal precedent (common law). In situations regarding issues such as informed consent, emergency consent, best-interest standards, ADs, and proxy decision-making, clinicians must be cognizant of the precise legal standards applied in their jurisdiction, as these vary from country to country and even from region to region (state, province, department, county, Bundesland, etc.), and to adapt their practice accordingly.

4.3 Informed Consent

The process of obtaining IC is an extension of the fundamentals of the physician–patient relationship, focusing on the patient's autonomy and well-being. Beauchamp and Childress have parsed the components of a robust consent process into three categories as follows [2]:

1. Threshold elements
   (a) Competence/capacity
   (b) Voluntariness
2. Informational elements
   (a) Disclosure
   (b) Recommendation
   (c) Understanding
3. Consent elements
   (a) Decision
   (b) Authorization

4.3.1 Decisional Capacity or Competence

The first threshold element that must necessarily be present for a robust consent process to take place is decisional capacity of the patient. Importantly, while there can be a legal distinction between the terms "capacity" and "competence," for the purposes of informed consent, the terms may be considered interchangeable.

A prerequisite for an informed consent process is decision-making capacity. Decision-making capacity is a person's capacity to make a choice and is dependent on the following abilities [3, 4]:

1. Comprehension: the ability to understand facts related to diagnoses, risks, and benefits of treatment and of foregoing treatment, as well as to potential other options of care.
2. Appreciation: the ability to recognize how the facts are relevant to the person.
3. Reason: the ability to compare information and infer consequences of choices.
4. Choice: the ability to make and to express a choice.

Decisional capacity must be evaluated related to the specific situation and the specific question at hand.

4.3.1.1 Assessing Capacity

Decision-making capacity is generally assumed to be present unless there is a reason to believe otherwise. However, in the setting of acute illness, one must carry a high index of suspicion for concomitant cognitive dysfunction. It is the duty of the physician to evaluate a patient's decision-making capacity. An individual's capacity may fluctuate with changes in his/her condition, and impaired decisional capacity is sometimes linked to reversible conditions. Some patients may be able to make simple decisions, but lack the capacity to make more complex decisions. The *degree* of capacity demanded may be calibrated to the gravity of the proposed intervention. The capacity necessary to give consent for phlebotomy may be less compared to what would be required to consent for an abdominal aortic aneurysm repair. Although clinicians often view capacity as a continuum, from a legal perspective, patients either do or do not possess it. The rigor of the assessment should be accordingly proportionate to the gravity of the situation [5].

The use of directed clinical interviews or a formal capacity assessment tool has been proposed, as intuition-based evaluations by clinicians are fallible [6, 7]. Physicians tend to overestimate a patient's capacity when structured approaches are not used [7]. In cases where sufficient uncertainty is present and when time permits, psychiatric evaluation may be indicated as this is often regarded as the "gold standard" of capacity evaluations. However, in the setting of the ED or the ICU, this is often logistically impractical, and clinicians must proceed with a healthy degree of concern as to the possibility of impaired decision-making capacity in acutely ill patients.

4.3.1.2 How to Proceed When Patients Lack Capacity

In most jurisdictions, the physician in charge has the decision-making authority for emergency interventions when the patients lack capacity and there is no surrogate decision-maker available. When there is no one to represent the patient's previously stated preferences, the ethical and legal principle that applies in most jurisdictions is "the patient's best interest." It is left to the judgment of the clinician as to how to proceed to further the patient's best interest, and in general this involves employing invasive therapies such as intubation, mechanical ventilation, and cardiopulmonary resuscitation in order to sustain life.

When available, however, a named proxy (such as a health care agent or a durable power of attorney) has the authority to consent or refuse on the patient's behalf. In such cases, the patient's autonomy is respected, as it is presumed that the named proxy decision-maker will appropriately represent the patient's previously articulated wishes. In the absence of such a proxy, dialogue between the care team and the patient's family members or close companions may be helpful to enable the determination of the patient's goals and preferences. Physicians have an ethical and legal obligation to take into account individual patients' goals, values, and wishes. The wishes of an incapacitated patient can be reconstructed in two ways: through implementation of advance directives or through cooperation with proxies [8]. Thus, a diligent exploration of the patient and his/her relevant values should include inquiring as to the existence of designated proxy decision-makers as well as the existence of any advance directives. It is worth noting that the legal weight of written advance directives may vary substantially from one jurisdiction to the next. Therefore, it is incumbent upon the clinicians to be familiar with the statutes that prevail in their locality.

4.3.2 Voluntariness

The term voluntariness signifies that the patient is making a decision free of coercion and is considered a mandatory "threshold condition" without which no consent process is valid. Coercion may take the form of either threat or enticement, but in either case the influence of coercion nullifies the legitimacy of a consent.

4.3.3 Information

The informational component of the IC process must at a minimum include a discussion of the indications for and description of the intervention, the desired benefits, the potential risks, and possible alternative treatments, including doing nothing, and their attendant risks. The granularity of the description may be calibrated according to patient considerations, including the patient's intellectual capacity and the patient's own preferences. The ethical standard of detail would be one that the patient can comprehend and recapitulate. Manipulation, in which the information provided to the patient is incomplete, selective, or even false, with the goal of getting the patient to endorse a certain plan, is a gross violation of the process of information disclosure and is highly unethical.

4.3.4 Documentation

Documentation can be made by a signature of a patient with capacity or by an authorized proxy agent on a consent form, or with a note by the physician in the medical record if there is no proxy agent or the agent is not physically present. Again, specific local legal requirements may apply.

4.4 Advance Directives and Power of Attorney

4.4.1 Advance Directives (ADs)

An advisable way to exercise the right to self-determination is to create an AD. Some prefer to take ownership over such a planning process themselves, while others prefer to make plans guided by their physician. Even though many countries have developed AD legislation to enable citizens to influence what happens to them with regard to treatment in the event of incapacity, still relatively few people take advantage of this opportunity.

There are several different terms used under the broad category of ADs:

The terms *Advance Directive (AD) or Living Will* refer to a written document in which a person describes his or her wishes and preferences, in particular what treatments he or she would refuse under certain specified circumstances. Different templates for AD documents exist [9, 10]. Criteria for valid ADs differ by country. Personal descriptions of what matters most (wishes) may go hand in hand with more formal statements about the refusal of specific interventions in specific circumstances (instructions).

4.4.1.1 Physician's Orders for Life-Sustaining Treatment (POLST)

POLST are orders signed by the provider and patient or surrogate to direct current care across settings, generally utilized in the last stages of life [11, 12]. The POLST can be helpful for emergency services, nursing homes and EDs to decide in critical situations and to respect the wishes and values of the patient [11]. The POLST can include wishes for treatments and limitations thereof (full treatment, limited intervention, comfort care, do not hospitalize).

4.4.1.2 Advanced Care Planning (ACP)

"Advanced care planning enables individuals to define goals and preferences for further medical treatments and care, to discuss these goals and preferences with family and health care providers, and to record and review these preferences if appropriate" [13]. ACP focuses not solely on the documentation but also on the process of creating an individual plan for specific situations (lack of capacity, critical illness, end-of-life). Often ACP results in a written AD or the appointing of a designated surrogate decision-maker, as with conferring a power of attorney (POA) or assigning a health care agent (HCA) or both. ACP's main focus is on facilitating conversations about goals and to explicitly address death and dying. ACP may help patients and families better understand what the different options involve, understand nuances, perhaps reduce fear, and offer the opportunity for the patient to be protected from inappropriate or unwanted treatment, thereby contributing to peace of mind.

4.4.2 Durable Medical Power of Attorney for Health Care

A durable/lasting power of attorney (POA) for health and welfare refers to the appointment of a trusted person to make decisions on patients' behalf should they

lose capacity. In some jurisdictions, the appointee is classified as a health care agent (HCA). An alternative is to ask a judge to appoint someone as a court-appointed guardian.

4.4.3 Are ADs Valid, Applicable, and Legally Binding?

In many jurisdictions, ADs are legally binding in principle. However, the treating team still needs to evaluate them for applicability and validity (Fig. 4.1). It is paramount to realize that a capable patient can always overrule or retract an AD.

Applicability: Applicability means "does the content match the situation at hand?" Quite often, the actual clinical situation during the course of critical illness does not match the scenarios described in the AD. Nevertheless, even when not fully applicable, an AD may provide valuable information about the patient's preferences to clinicians.

Validity: Validity refers to whether the formal requirements of ADs, as stipulated in the respective jurisdictions, are fulfilled (signed, updated, etc.) [14, 15].

Legal binding rights: Whether ADs are legally binding when applicable and valid, or only regarded as a start for best interest discussions, differs by country. It is beyond the scope of this chapter to go into details regarding the legal spectrum; however, some selected comments as to the variability of legislation and practice can be found in Table 4.1 [16–18].

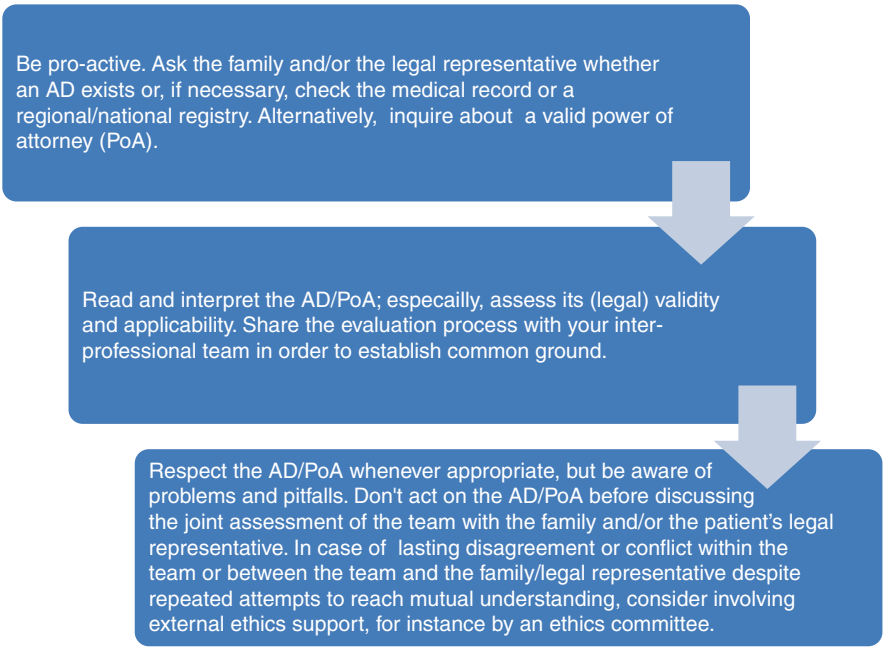

Fig. 4.1 Recommended steps before acting on an advance directive (AD)

Table 4.1 Laws and legal issues with regard to consent, advance directives, and end-of-life issues: world-wide variation

Country	Legislation	Comment
Argentina	Law on Death and Dignity 2012: Legal recognition of ADs	Relational approaches such as ACP are more in line with the culture than a narrow focus on ADs
Australia	ADs are legally binding. Laws on AD vary by state	An increasing numbers of Australians have ADs. 15% of citizens have participated in ACP
Belgium	Law on AD passed in 2002 ADs are legally binding	Most public debate is around euthanasia, not other ADs
Brazil	No legal framework	No public debate regarding how patients can express wishes in the event of incapacity
Canada	Interpretation of laws regarding consent in end-of-life; after *the Rasouli case* 2011	In some provinces in Canada, physicians need consent from families to withdraw life-sustaining treatment even when continued treatment is judged to be non-beneficial
Columbia	Law on AD passed 2018	There has been some public attention and debate on the matter. Columbia is also the only Latin American country where euthanasia is legalized, though still a Catholic and conservative society
Denmark	Refusals of life-sustaining treatment in "living wills" legally binding since 1998	Long traditions for "living will," but only 2% of the population have them. Physicians are obliged to ask for them/ check with the national registry. It is not known whether physicians actually do ask
England and Wales	Mental Capacity Act passed 2005	If valid and applicable, ADs are legally binding. There are public interest and debates on end-of-life issues
France	French law in 2005 (Leonetti's law), on end-of-life care and patient's rights. Revised in the Clayes–Leonetti law in 2016	End-of-life law developed to strengthen patient's right to oppose unreasonable obstinacy and to delineate good medical practice. Communication with families, collegial discussions, and consensus-seeking are emphasized in France. The drafting of an AD was made a right in 2005. Physicians had to take ADs into account, but ADs were not legally binding. Changed in 2016, AD became legally binding
Germany	New German Laws on ADs in 2009	An AD is legally binding if it accurately matches the situation. No requirement for regular updating
Greece	No legal framework. ADs are not legally binding	Intensivists do not ask about ADs. There is no public debate on the issues related to capacity or consent
Hong Kong	No specific AD legislation AD not legally binding	ADs are rare. Physicians are encouraged to ask about ADs. If they exist they are likely to be followed. A government campaign is underway to increase citizens' attention on the topic
Italy	Law 219/2017 – Provisions for informed consent and advanced directives	Despite long-term public debate and the Catholic church's influence, the law passed giving Italians the right to write AD including wishes to refuse nutrition and hydration. ADs are legally binding

(continued)

Table 4.1 (continued)

Country	Legislation	Comment
Israel	The Dying Act 2005 AD legally binding	The Dying Act was created by medical, legal and religious representatives after years of professional and public debate. It recognizes that neither the value of life nor the principle of autonomy is an absolute value
Netherlands	Legal recognition for (negative) treatment directives, Laws on Contract for Medical Treatment 1995	Since 2002, citizens can request euthanasia through an AD. First euthanasia case that triggered criminal investigation was an AD case in 2016. Euthanasia does not play a role in ICUs
Norway	No specific AD legislation AD have no legal force	No public attention on how patients can express wishes in the event of incapacity. Recent years increased professional focus on ACP
Switzerland	Revision of the Swiss Civil Code 2013	Mandatory for medical staff to act according to the patient's AD
USA	Patient Self-Determination Act 1990 intended to help patient avoid unwanted medical interventions and requiring institutions to inquire about the presence of AD	Long legal traditions to protect the right to self-determination. ACP established in many states; 18% of Americans have written an AD

ACP advance care planning; *AD(s)* advance directive(s)

4.5 Ethical Challenges and Solutions in the Context of Emergency Medicine and Intensive Care

There are many dimensions to consider when reflecting on the challenges regarding IC and ADs that arise in the very time-sensitive context of acute, life-threatening conditions seen in the ED and the ICU. We highlight some of them here:

4.5.1 Emergencies

Emergency situations by their very nature involve a risk of autonomy being compromised due to many factors including time limitations, incomplete medical information, and lack of access to documentation of the patient's previously articulated wishes, preferences, or goals. Major interventions such as life-sustaining therapies may be started prior to the opportunity to conduct proper ethically based decision-making processes.

Potential solutions:

- Recognize that autonomy is at risk of being compromised in the context of medical emergencies [19].
- In emergency situations, physicians need to manage each patient's unique situation in the most ethically sound manner possible. It is important to be attentive to how the patient perceives the situation and to their emotional reactions [20].

- Ask for ADs and establish as soon as possible an interpretation of ADs in collaboration with family, proxy, and the treatment team.
- Reassess on regular basis the medical, ethical, and legal justification for continued life-sustaining therapies or other treatments.
- Consider consulting ethics resources – individuals within the institution whose familiarity with such challenging scenarios may allow for a richer discussion and appreciation of the ethically sound courses of action.

4.5.2 Barriers to Informed Consent in the ED/ICU

Informed consent processes serve to protect the patient's right to autonomous self-determination as well as to build trust between the physicians and the patient and family through transparent communication. The judicial and ethical obligation to engage in an informed consent process applies to ICU and ED decision-making alike. In the ED and ICU environment, however, informed consent processes can be difficult to operationalize or take on a low priority as multiple barriers for a formal informed consent process exist, both avoidable and unavoidable. Physicians in the ED and ICU are at risk of making wrong assumptions about patient's capacity, and regardless of removal of barriers and proper assessment efforts, assessments may either overestimate or underestimate a patient's actual decision-making capabilities. It can be highly problematic for a patient to be deprived of his or her right to self-determination because he or she erroneously is assessed not to have decision-making capacity, or to have only partial capacity.

On the other hand, physicians may sometimes wrongly assume that patients have capacity, which may put such patients at risk of voicing choices that in no way reflect their authentic preferences, values, and beliefs.

Potential solutions:

- Identify and remove avoidable barriers to involving patients in their own medical decision-making.
- Be aware of the pitfalls and problems with regard to capacity assessments.
- Develop a consistent practice of involving patients in decisions whenever possible, even when involvement may occasionally be limited [21, 22].
- Establish empathetic communication processes.
- Promote ethics education for the patient care teams regarding the concepts of autonomy and paternalism.

4.5.3 UN Convention on the Rights of Persons with Disabilities

Autonomy and self-determination are widely protected human rights. The United Nations Convention on the Rights of Persons with Disabilities (UN-CRPD, 2006) has produced policies of particular relevance for physicians in ED and ICUs. Disability is defined by the UN-CRPD as physical, mental, intellectual, or sensory

impairments which in interaction with various barriers may hinder the full and effective participation in society on equal basis with others. The UN-CRPD challenges the very concept of decision-making capacity and emphasizes that all patients are equal right bearers and have the right to receive treatment on equal basis [23]. Appropriate support and removal of barriers significantly improves the ability of patients to participate. They also emphasize that subjective quality of life of disabled persons is often high compared to the assessments and judgments of medical personnel. Caution should be exercised to ensure that value judgments by physicians and medical teams should not guide important decisions.

Potential solutions:

- Capacity assessments should not be guided by assumptions that a patient lacks capacity based on their disability. Nor should capacity be assumed in the context of depression, mental disorders, or delirium in the ICU. Careful assessment of decision-making capacity should be carried out with attention to concomitant medical issues and disabilities, but with an understanding that these do not necessarily constitute barriers to autonomous decision-making.

4.5.4 Lack of ADs and Consequences for the Extent of Treatment

Unfortunately, only relatively few patients have advance directives. Physicians and families are therefore often left without the guidance of the patient's expressed wishes when difficult situations arise and decisions need to be made; this is particularly challenging with life-and-death decisions. With the capabilities of modern life-sustaining technologies, and absence of information about what a patient wants, many physicians tend to feel they must apply all available treatments to keep the patient alive.

When no AD exists, the goal for all involved parties should be to understand what options are most in line with the patient's values. Empathic communication with family, friends, and proxies should be pursued to determine to the best extent possible the wishes of the patient. Sometimes disagreement or disputes within families may arise over what the patient would have wanted. There is also the risk that families in decision-making processes may overrule a patient's values, preferences, beliefs, or wishes by replacing them with their own.

When patients are without proxies and without ADs, they are even more vulnerable. No consensus exists on whether there is a need for involvement of a legal representative, clinical ethics committees or a court, or if decisions can be left to the physicians alone [24, 25].

Potential solutions:

- Include talking about wishes and values in medical care in every day practice.
- Promote a reflective ethical climate in ED and ICUs with ongoing discussion about appropriateness of medical therapies to avoid over- and undertreatment. Consider engaging palliative care teams or ethics resource support.
- Engage, communicate with, and support families on an ongoing basis throughout the ED and ICU stay. Explain to them their role of helping physicians to determine

what the incapacitated patient would want done, a process that can be demanding and involve doubt.
- Increase awareness of citizens about available options to anticipate decisions in event of incapacity.

4.5.5 Availability of ADs

ADs can be a helpful and important tool. It can be a relief to have access to an AD both for the family and for the staff. Others have argued that ADs are too problematic and often fail to achieve their goal [26, 27]. ADs are vulnerable to be challenged or subjected to interpretation. ADs often contain notable ambiguities, requiring the reader to interpret whether the patient's actual condition matches one classified as unacceptable in the document.

When uncertain, physicians may overrule an AD and act on their assessment of the patient's best interest. To do so the physician needs to have very good reasons that make sense to all involved parties. In other cases, individual physicians may have conscientious objections related to the instructions expressed in the AD. In such cases, physicians should consider transferring responsibility to a provider willing to carry out the AD's guidance.

Finally, there is the fundamental challenge of "past-self versus present-self" [28]. What matters to the "present-self" is likely to be different from what mattered to the "past-self" when the patient prepared the AD. As a result, the decision may be contrary to their present interest and preferences. Humans' capacity for change and ability to adapt to disability is frequently underestimated. On the other hand, a will actually written down in an AD can be an expression of something strongly held and not likely to change. To determine the relative weight of the AD in the setting of the current circumstances can be a complex task.

Potential solutions:

- If there are plausible wishes and values documented in an AD sort out exactly what treatments the patient did not want.
- Both citizens and health care professionals need to be aware of pitfalls and problems even when an AD exists.
- Empathic communication about goals of therapy and individual values between the team and family/proxy should be established.
- Ethical reflection about the conflict between respect for autonomy and paternalism in team conferences can be helpful. Utilization of the institution's ethics resources may facilitate such discussions.

4.5.6 How to Make an Ethics-Based Decision

The optimization of quality in medicine is a highly sought-after goal today. The question is: How is good quality defined? One widely embraced definition is that quality care involves optimizing the medical outcomes that matter to patients. It can be seen

that this embraces both the technical goal of the treatment and the goals of the patient in terms of quality of life. From our discussion above we can posit that good quality care in high acuity settings needs to be conducted within a solid and thoughtful ethical framework. This implies not only the use of the right interventions and technologies, but recognition that there are no "one size fits all" solutions for either utilizating life-sustaining therapies or withholding them. It requires an exploration of each patient's individual circumstances and prognosis, as well as goals and preferences, as best as they can be determined. While the special high-acuity decision-making faced in the ICU/ED may favor an immediate action in a patient's best interest, the principle of respect for autonomy must always be maintained in the foreground, with a willingness to withdraw potentially burdensome life-sustaining treatments as facts, both medical and patient preference-specific, become more clearly elucidated.

Potential solutions:

- Decision-making needs to reflect the fundamental ethical values of the medical profession.
- Team conferences during active cases and debriefings after challenging cases can be utilized to promote an ethically enlightened team culture.
- Consider including palliative care and/or ethics services in challenging cases.
- See patient and family as a unit and explore their values and relationships, while resisting the tendency to project the medical team's own values on the decision-making.

4.6 Conclusion

Autonomy is protected by health laws and human rights and is one of the core principles in medical ethics. Nevertheless, in the ED and ICU it can be challenging both for patients to exercise their right to self-determination and for physicians to respect this right or to determine the weight to give autonomy compared to other ethical considerations, in particular a concern for the patient's best interest. Empathic communication with a patient's family or proxy is needed to successfully navigate these ethically challenging scenarios. While ADs have their clear limitations and shortcomings, they are better than no instructions at all. The option for patients to craft an AD in order to buttress their right to medical self-determination deserves more public attention and widespread adoption.

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Cultural Diversity

5

Victoria Metaxa and E. Wesley Ely

5.1 Introduction

The definition of culture has long been a controversy, and the term is used in a variety of ways. One commonly used definition is:

> *"[Culture] is that complex whole which includes knowledge, beliefs, arts, morals, laws, customs, and any other capabilities and habits acquired by [a human] as a member of society."* [1]

Both within- and cross-border population flow, such as migration, has led to increased diversity within the societies. This diversity results in the coexistence of differences in behavior, traditions, and customs – in short, a diversity of cultures. UNESCO's governing body, the General Conference, adopted the UNESCO Universal Declaration on Cultural Diversity in 2001, recognizing the concept of diversity as a factor in intellectual, emotional, and economic development but also as an ethical imperative, inseparable from the respect for human rights [2].

Many parts of the world are no longer homogenously cultural or religious entities. Latinos represent nearly 13% of the US population, in Canada there are approximately 1,000,000 Chinese, whereas only 18% of the 1.1 billion Muslims live in the Arab countries [3]. It follows that in the multicultural societies of today, people value different things, believe in different authorities, follow different customs but

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most importantly differ on what things they count as right or wrong, permissible, or impermissible. How then can one believe that their own view is superior to another? How can we judge the ways of others and assume that we hold the only right answer? Is there is a universally binding, common morality upon which all right-thinking people would agree?

There are two predominant ethical theories that attempt to answer these questions: moral (cultural) relativism and moral objectivism. The former posits that there is no absolute right answer to moral questions because morality is relative to culture or society; the moral values that people hold depend on the culture in which they live or were raised. In contrast, moral objectivism holds that there are universal, moral truths which are unchangeable and also that these truths give us the appropriate authority to make decisions that are in line with the best path for humanity. For example, Beauchamp and Childress claim that the four key principles (autonomy, beneficence, non-maleficence, and justice) represent a "set of universal norms shared by all persons committed to morality" [4]. Irrespective of any cultural diversity, this "common morality" binds all rational persons, and no culturally particular norm can be justified, if it is contradictory.

It is important for clinicians to realize that they may operate within one of these two belief systems but that they may be caring for patients who hold the opposite one (e.g., a physician who believes that quality of life is more important than just being alive, caring for a patient that values the sanctity of life above all). In such circumstances, and especially around sensitive and important areas such as end-of-life care (EOLC), it is imperative to develop a manner of care and decision-making that respects the patient's beliefs while at the same time does not jeopardize the clinician's right to practice in accordance with their conscience and the respective legal stipulations.

5.2 Caring for Critically Ill Patients

The potential for conflict due to cultural diversity is higher in emergency departments (EDs) and intensive care units (ICUs), which are the places that provide specialist care to patients with life-threatening injury or disease. As many as 11% of ED [5] and 40% of ICU patients will not survive their hospital admission [6], with more than 70% of deaths in ICUs being preceded by some form of limitation of life-sustaining treatment [7]. Research has shown, especially regarding the ETHICUS studies, that patients and physicians with different religious, cultural, and ethical backgrounds adopt different approaches, even within the same region [7–9]. Diverse perspectives, particularly around emotional topics such as death and dying, demand good communication and understanding between the involved parties, namely clinicians, patients, and their families/surrogates. ICU clinicians are often ill-prepared to provide supportive care to dying patients and their families, especially when the latter are unable to clearly express their wishes because of cultural or language barriers. When communication regarding EOLC is not culturally sensitive, there are missed opportunities for understanding patients' and families' needs, leading to patient and family distress [10]. Communication challenges

and conflict can occur with relatives from ethnic minority groups around critical medical decision-making, communication of bad news, and the more practical aspects of caring for the patient. Incongruent beliefs about the causes and treatment of an illness, language difficulties, strong religious beliefs, and ethnocultural values are often described as the root causes of the tension [11].

Especially around end-of-life decision-making, the impact of patient's religion, race, and ethnicity has been clearly described: Non-white patients are less likely to have a Do-Not-Attempt-Resuscitation (DNACPR) order than white ones, even after adjusting for possible confounding factors [12]. Clinicians in North America and northern European countries may be more likely to support DNACPR and limitation of life-sustaining treatment than their colleagues in southern Europe and the Middle East; there appears to be a gradient of less aggressive to more aggressive end-of-life care practices from northern to southern Europe and in Great Britain when compared to the United States [12]. In a landmark study, Sprung et al. found that withholding life-sustaining therapy occurred more often than withdrawing if the patients were Jewish, Greek Orthodox, or Muslim [3]. Withdrawing occurred more frequently than withholding if patients were Catholic, Protestant, or had no religious affiliation [8]. Finally, advance care planning was more common in patients who identified themselves as white and who had higher levels of income and education and less in non-white patients that also had less trust in the (US) health-care system [13].

Special mention is warranted for the much-contested topics of physician-assisted suicide (PAS) and euthanasia. The former (which is an outpatient prescription for lethal medications to be administered by the patient) is legal in Switzerland, Japan, Albania, and parts of the Unites States (Washington, Oregon, Vermont, New Mexico, Montana, and California), whereas both (PAS and euthanasia) are legal in the Netherlands, Belgium, Colombia, Canada, and Luxembourg [14]. Religiosity and educational status have both been found to correlate with attitudes toward PAS and euthanasia, with higher religious affiliation and lower educational status being linked with opposition toward these two practices and preservation of the idea that actively "intending" the death of a patient via active administration of lethal medications is not a part of good medical practice by physicians [14]. Interestingly, cultural and religious perspectives seem sometimes to be far too complicated to predict individual preferences regarding euthanasia. Individual views often reveal no clear-cut positions anchored in "nationality," "culture," or even "religion"; rather, attitudes are formed on a personal level which represents the specific political, social, and existential situation of the individual [15]. Attempts to openly address this thorny topic have demonstrated the diversity in opinions. Temperate, explorative publications that present the issues from the perspective of ethicists and health-care professionals [16] come in contrast with the clear declarations against intentional ending of a patient's life as part of a health-care professional's activities [17]. The ethical debate appears to be prevalent in North America and Northern Europe but does not feature in other parts of the world, where these issues are not only illegal but also morally unacceptable. In 2016, there was an appeal to the World Medical Association to approve PAS/Euthanasia, which was rejected. Caution is warranted, as organizations should not attempt to force societies or countries to approve practices that violate their ethics and laws [18].

5.3 When Cultural Diversity Leads to Conflict

In the emergency setting, especially when the patient has lost decision-making capacity without previously voicing wishes regarding the extent of treatment, family members frequently participate in EOLC discussions. They are asked to act as proxy decision makers in highly emotional, life-and-death situations, at a traumatic time and with incomplete understanding. Adding to the equation the potentially different cultural backgrounds, it is no surprise that conflict may arise. Reasons identified include lack of awareness by families of culturally diverse backgrounds as how to communicate their cultural needs with the clinicians; over-optimism, unrealistic expectations, and lack of understanding of EOLC concepts; and physician avoidance to engage in discussion for fear that the family "might not understand" [10].

As conflict is a source of considerable moral distress both for health-care professionals and family members [19], a model that enables congruent treatment decisions was proposed. This model was termed *shared decision-making* and has been endorsed by major critical care professional organizations as a way to reach consensus and hence avoid conflict [20, 21]. According to their recommendations, clinicians share information about the relevant treatment options and their risks and benefits, whereas surrogates communicate patients' values, goals, and preferences that are relevant to the decision at hand. Clinicians are advised to tailor the decision-making process to each individual case, respecting the (cultural) background of the patient and the family members, establishing trust and eliciting their values, wishes, and preferences [21, 22]. However, shared decision-making does not mean that the patient or family have the right to demand any treatment, with the physician being obliged to provide it. On the contrary, it aims to harmonize medically appropriate decisions with the patient's values, goals, and preferences, thus reducing potentially inappropriate treatment and conflict.

When there is a legal framework to guide EOLC decision-making, then clinicians can respond easier to treatment requests that spring from cultural beliefs but differ from their own. For example, in countries where cessation of brain stem function is legally recognized as death by neurological criteria, a request to perform cardiopulmonary resuscitation on a patient with confirmed absence of brain stem reflexes can easily be refuted. Equally, when an intervention is considered *futile*, the clinicians are not expected to provide it [23]. After decades of debate around the term, a statement issued by the biggest professional bodies of Europe and North America has defined futile interventions as ones that cannot accomplish the intended physiologic parameters. Example given is that of a clinician who refuses to perform CPR on a patient with signs of irreversible death or one who declines to prescribe inappropriate antibiotics when not indicated [23].

Another source of conflict might arise when the clinicians' own cultural background does not allow them to provide a requested intervention. The moral objection to the provision or disclosure of information about legal, professionally accepted, and otherwise available medical services is termed *conscientious objection*. An example would be a request to withdraw life support by the family of a sedated septic patient who is being cared for by an orthodox Jewish physician who

objects to the removal of continuous forms of life support (e.g., mechanical ventilation). In such cases, the existence of an institutional mechanism that respects diverse values of both the patients and the ICU clinicians, without depending solely on the individual provider's decisions, is paramount. Furthermore, the accommodation of a clinician's conscientious objections should not impede the timely access to medical services or create excessive hardship for other clinicians [24].

However, there will be occasions where every attempt to reach a commonly acceptable decision will prove impossible, and some patients and families will object to any decisions to limit or withdraw life-prolonging interventions proposed by the treating team. It is important clinicians are not compelled to act against their understanding of professional obligations, as such a behavior would compromise medical professionalism. These decisions are more complicated when treatments have at least some chance of accomplishing the effect sought by the patient, but clinicians believe that competing ethical considerations justify not providing them. These treatments are described as *potentially inappropriate* by a recent multi-society statement and commonest examples include the limitation of life-sustaining treatment when prognosis is uncertain [25]. Apart from recommending the implementation of strategies in order to avoid intractable treatment conflicts, the statement also proposes a practical resolution process for the rare cases, where the differences between the treating team and the patient/family are insurmountable. In these cases, culture-sensitive communication and advocation of the treatment plan is advised, which may consist of multiple meetings between clinicians and patient surrogates. If conflict continues to exist, then the following steps might be proven helpful:

- An outside, second medical opinion
- Interdisciplinary, institutional committee – ethics committee consultation
- Expert consultation – mediation
- Appeal to the appropriate judicial authority of the country

Before each step, the patient and/or their surrogates need to be informed of the process intended to be followed by the clinicians, and an option to transfer the patient to another institution willing to continue their care should always be offered. When time-critical decisions are required (in an ED or ICU), and all the steps of the recommended process cannot be followed, then clinicians are advised to base their judgments on their best understanding of their professional obligations. A universal algorithm that would guide clinicians through the ethical minefield is impossible to implement – tailored guidance is necessitated according to each country's moral and legal framework.

Irrespective of the cultural background, one opinion should not prevail over another. As Pellegrino said, "the physician–patient relationship, like any ethical relationship, is a reciprocal relationship. In the justifiable concern for patient autonomy, we must remember that the physician is a moral agent, as well as the patient. When the two are in conflict, the patient's wish does not automatically trump the physician's" [26]. However, and despite the multi-society guidance, "real-world" decision-making remains fraught with uncertainty and moral conflict. Physicians'

approach aims at achieving the outcome that they believe to be in the patient's best interests – often the withholding or withdrawal of life support, when meaningful recovery is unlikely [27]. Cultural diversity and the lack of a clear legal framework further contribute to the impasse, which can potentially lead to clinician burnout, family distress, and reduced quality of care [18, 28].

5.4 Conclusion

Cultural diversity is a common characteristic of many societies, and this is more evident when issues related to death and dying are concerned. In EDs and ICUs, the cultural diversity that exists both among patients/families and between clinicians influences EOLC discussions and sometimes creates moral and legal conflict. Individual patients, surrogates, and clinicians may approach these discussions with different expectations and preferences, often influenced by geography, religion, societal norms, and culture. A number of Critical Care societies have published guidance on the prevention and management of conflict, which involve timely expert consultation, referral to ethics committees, continuous and open communication with patients and their surrogates. A universal, "one-size-fits-all" algorithm that will facilitate the resolution of all conflict remains, unfortunately, an elusive goal. For the existing statements to gain general acceptance in pluralistic societies, the input of clinician, patient, and other stakeholder groups is paramount. Until then, cultural diversity will continue to be a potential source of conflict in EOLC decision-making.

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Interprofessional Shared Decision-Making

6

Andrej Michalsen and Hanne Irene Jensen

6.1 Introduction

Emergency and intensive care medicine clinicians help patients and their family members navigate difficult phases of their lives. Most critically ill patients are admitted to emergency departments (EDs) and/or intensive care units (ICUs) with a curative goal of treatment. This is generally achieved by acutely stabilizing vital functions threatened or disrupted with medications and/or mechanical devices. The primary goal is that the organ systems return to self-sufficient function and that the patients regain at least their *status quo ante*. Many patients now survive severe illnesses and injuries that would have led to their demise only a few decades ago. However, quite regularly patients die in the ED, in the ICU, and even in prehospital emergency care due to an assessment that life-sustaining treatments are not (or no longer) indicated or not (or no longer) seen as appropriate [1–4].

The ethical challenge discussed in this chapter is how to reach important clinical decisions within the team. Important decisions often touch on patients', families', and clinicians' values, goals, and preferences, and such decisions will have a substantial impact not only on the patients and their course of treatment but also on the families and the clinicians involved. Shared decision-making between the team and the patient/family is the focus of Chap. 7.

ED and ICU physicians, nurses, and allied healthcare professionals, hereafter referred to as the ER and the ICU team, respectively, not only treat patients, but they

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also focus and coordinate the input of other disciplines and professions involved. Therefore, they have become a prime source of information, guidance, and care for patients and their families. This expansion of tasks entails the responsibility for informed and thoughtful decision-making as to medical, logistical, sometimes legal, and certainly ethical issues.

Notwithstanding many realms of success, current treatment in EDs and ICUs still faces several challenges to high-quality patient- and family-centered care that have not yet been fully appreciated or addressed. For instance, improved intensive care treatments have resulted in more patients surviving with reduced quality of life. This entails trade-offs for many patients, their families, and the ICU teams that need to be addressed [5–7]. Furthermore, healthcare expenditures for emergency and intensive care medicine are notably high in some countries and regions, in significant part due to frequent usage by specific subpopulations – especially aging populations – and their growing demands for medical care. Finally, the humane and interpersonal aspects of care have often not kept pace with the remarkable technological advances over the recent years, risking transforming medicine into a trade without the understanding that quality care needs far more than apparatus and algorithms [8].

In the context of present challenges, including those outlined above, well-functioning ED and ICU teams that incorporate communication, collaboration, and shared decision-making are important for high-quality care. Unfortunately, successful teamwork is often hampered by discord concerning prognostication, disagreement about indication for treatments, insufficient knowledge about patients' goals of care, a poor working environment, and, perhaps most prominently, a lack of effective communication, collaboration, and decision-making within the team. These deficiencies result in team conflicts, demoralization, moral distress, burnout, medical errors, suboptimal patient care, and poor family support [9–14].

In order to help overcome or best prevent such untoward outcomes, these deficiencies should be addressed through better interprofessional communication and collaboration, specifically through improved interprofessional shared decision-making (IP-SDM).

6.2 Definitions and Evidence Base

IP-SDM is defined as a collaborative process among clinicians that allows for team involvement in important clinical decisions, taking into account the best scientific evidence available and the combined expertise of clinicians involved as well as the patient's values, goals, and preferences [15]. Exemplarily, important clinical decisions can relate to complex medical or surgical procedures as well as to the goals and extent of treatment.

The terms "interprofessional" and "interdisciplinary" communication and collaboration imply that there are several professions and disciplines, respectively, working together with the same patient to arrive at and implement a mutually endorsed plan.

Several publications document variation in the approach to treatment decisions in the ICU and the ER, especially concerning complex clinical and ethical issues. Although there is considerable variability between different countries and legislations, recent studies suggest there is similar variation within countries or even among clinicians within individual hospitals. Indeed, the perspective of an individual healthcare provider may be one of the most important factors in decision-making [1, 15–19]. A key goal of IP-SDM is to move from individual to team decisions when important clinical issues are at stake.

In a recent systematic review as to the benefit of implementing IP-SDM in ICUs, a search in three common databases, MEDLINE, CINAHL, and Cochrane, only yielded four studies between 1975 and 2017 for final analysis. Overall, the quality of the evidence in these studies was very low. Taken together, however, they corroborate the notion that adequate interprofessional communication and IP-SDM allow reaching a durable decision regarding the extent of treatment, thereby reducing the suffering of patients and the discord within the team [15]. The review identified only a relatively small amount of research. Therefore, the following three recommendations regarding the implementation of IP-SDM are based primarily on expert opinion and need to be viewed as conditional recommendations. Furthermore, the recommendations are extended to ED teams, as they face similar challenges as do ICU teams regarding IP-SDM.

6.3 Recommendations

Recommendation 1
ED and ICU clinicians should consider engaging in an IP-SDM process in order to promote the most appropriate and balanced decisions.

Conceptually, decision-making can be executed on four different levels, going from individual decisions by one clinician to fully shared decision-making by a group of clinicians (Table 6.1) [20].

Clinical decisions are a daily practice for ED and ICU teams. The decisions are often appropriately made by individual clinicians (level 1), or perhaps after brief discussion with other members of the team (level 2), for example, decisions such as which antibiotic to use. For slightly more nuanced issues, such as when to administer vasopressors or whether to call for an immediate surgical procedure, a more extended discourse among clinicians may be undertaken (level 3). Complex decisions, however, with potentially far-reaching consequences for patients, families, and clinicians (level 4), such as the intensification or the limitation of life-sustaining treatments, may warrant the consideration of IP-SDM [15, 20]. The four levels are intended to provide a conceptual guide to the process of decision-making, rather than to serve as rigid or mutually exclusive approaches. Furthermore, the need for an urgent clinical decision may prevent the application of IP-SDM but may at the same time establish the need for a team debriefing later.

Table 6.1 Levels of interprofessional collaboration in decisions [modified from 20]

Name of level	Definition	Example	Appropriate use
Individual decision (level 1)	A clinical decision is made without involvement of another type of healthcare professional	The choice of an antihypertensive medication for a given patient with a known medical condition	A clinical decision is made by one healthcare professional according to known practice guidelines that are applied to a specific patient in an unambiguous clinical situation
		While being suctioned by a nurse, a patient suddenly reverts to a fatal cardiac rhythm; and the nurse immediately starts CPR while calling for a physician	In an emergency situation when other healthcare professionals are not available
Information exchange (level 2)	Relay of information from one healthcare professional to another, to be used by one healthcare professional for decision-making purposes	Relaying information about the patient's most current vital signs in a way that informs a unilateral decision to obtain an X-ray to rule out pneumonia	Sharing information about a patient or family member by a healthcare provider. This information may be unknown to others and might prove useful in their practice
		A description of the clinical factors and physiological underpinnings behind the decision not to continue antibiotic treatment	Explaining the reasoning behind clinical decisions that were made by other team members not involved in the decision-making process
Deliberation (level 3)	A two-way flow of information with some discussion, yet a decision is not made with shared decision-making	During rounds there is a discussion of nursing and medical considerations as to why a specific patient should or should not be isolated, tested, and treated for presumed *3-MRGN* infection. The physician then decides regarding these three issues	The patient is assessed independently by different healthcare professionals who come to their own conclusions about patient care. These conclusions are then discussed. A final decision is made by one of the providers
Shared decision-making (level 4)	Each healthcare provider presents their information, a deliberation takes place, followed by a joint decision by participating providers	A patient with several chronic diseases is admitted to the ICU, and is presently in multi-organ failure. The prognosis is very poor. A 3-day trial period is conducted without any improvement. After joint discussions among the ICU team and involvement of the family, a decision is made to change the treatment goal to comfort care only	Complex patient care decisions where different healthcare providers can contribute their expertise to a decision. A discussion is held between the stake holders, and a joint decision is made and followed. The decision may involve ethical dilemmas, where no decision is totally correct or incorrect

Ideally, the appropriate level of interprofessional decision-making will be the level that produces the best decision for the individual patient and ultimately leads to the best patient, family, and team outcomes. IP-SDM is a process that incorporates the entire interprofessional ED or ICU team and, when appropriate, consultants and others involved in the patient's care. The underlying maxim is to transform individual clinicians into team members who are empowered and involved.

While it addresses some of the same important issues, IP-SDM is distinct and separate from shared decision-making with patients and their families. The latter describes *processes between the teams and the patients and their families* and has been widely elaborated upon [21–23]; the former delineates the *processes within a team* and has only recently been described in depth [15]. There is often overlap in the process of shared decision-making with patients and families and the process of IP-SDM, and there is also overlap in the composition of the groups involved in these two processes. However, it may be helpful to separate them conceptually. Frequently, discussions within the team will influence discussions with the patients and/or families and vice versa. Generally, first the ED or ICU team should arrive at a joint decision about medically reasonable treatment options as outlined earlier, and these options should then be discussed with patients and/or family members, in principle using a shared decision-making process [15, 22, 23].

When making such important clinical decisions, each healthcare provider's level of involvement in IP-SDM may be influenced by many different determinants, such as their individual judgment regarding the patient's prognosis, their experience and expertise, their hierarchical status in the ED/ICU or hospital, their personal and cultural values as well as the work climate [9, 10, 13, 16, 24, 25]. Importantly, a lack of recognition of value differences within the team in the context of complex clinical decisions can lead to unbalanced decisions and distress among clinicians [9–11, 15, 26, 27].

Perhaps the most practical rationale for implementing IP-SDM is the premise that making use of the combined expertise and knowledge of all team members involved can lead to better-reasoned and more robust decisions. If a particular decision is contrary to one of the team member's reasoned assessment or contrary to his or her professional or religious values, then open deliberation and IP-SDM may be essential in order to ensure high-quality team functioning as well as individual clinician well-being.

Recommendation 2
Clinicians and hospital administrators should implement strategies to accept and foster an ED or ICU climate oriented toward IP-SDM.

Successful IP-SDM depends on appropriate interpersonal skills as well as on a good ED/ICU climate. Organizational theory and research have shown that work units' climate and culture exert an important influence on outcomes, such as unit performance [28]. Many diverse factors can impact on the climate- and

culture–performance relationship, especially quality of management, adequacy of staffing and resources, effective leadership, and a robust safety and ethical climate [8–11, 15, 26, 29]. For ICUs, there exists at best limited evidence that specific interventions to improve the work environment will lead to improved organizational performance or patient outcomes. Overall, however, skilled communication, true collaboration, and effective decision-making are recognized as imperative in establishing and sustaining healthy work environments. This will in turn increase the likelihood that team members engage in IP-SDM.

Consequently, we propose that ED and ICU clinicians as well as administrators should reflect on and foster the situations in which the effort is made to seek and incorporate the perspectives of the whole team in the decision-making process.

Recommendation 3
Clinicians should consider incorporating the basic principles of the VALUE TEAM-template as an explicit structural approach to respectful communication when implementing IP-SDM.

Many clinical decisions depend on multiple individual clinicians, often from different disciplines and professions and with potentially conflicting approaches. Therefore, IP-SDM relies upon basic principles of respectful communication. Using a structured approach for such communication may reduce communication failures, improve information transfer, and increase the acceptability of treatment decisions as well as the job satisfaction for the ICU team.

We recommend incorporating the newly designed "VALUE TEAM-template," based on the previously validated VALUE-template [30], as a systematic approach to support IP-SDM within the interdisciplinary ED or ICU team; this involves several elements as aids for respectful communication (Table 6.2). Occasionally, the need for external advice regarding ethical or legal matters may arise and should be sought by the applicant(s), either from ethics consultants or from institutional legal counsel.

Table 6.2 The VALUE-TEAM-template [reprinted with permission from 15]

V	Value statements from all of the members of the interprofessional team, including, among others, physicians, nurses, physiotherapists, clergy, psychologists, and ethicists
A	Acknowledge emotions
L	Listen to each other
U	Understand the team members as integral persons, including their commitments to patients and high-quality patient care
E	Elicit the expert suggestions of team members and make use of their specific expertise
T	Tie the decision to the best evidence available
E	Elaborate on the patient's values, goals, and preferences
A	Address diverse opinions and seek consensus among team members
M	Make the best decision weighing reasonable medical options with the patient's goals and the quality of life he/she would want to achieve after their stay in the ICU

6.4 Conclusions

High-quality care for patients and their families in EDs and ICUs requires optimization of interprofessional collaboration and communication to achieve sound and durable team decisions. Therefore, clinicians should consider utilizing an IP-SDM model that allows for the exchange of information, deliberation, and joint attainment of a treatment decision in a structured manner – as outlined in the recommendations above. IP-SDM is neither intended to be used for routine and straightforward decisions nor intended to promote any specific clinical decision; it rather provides a range of explicit approaches to the process of decision-making within the interprofessional team. Ultimately, fostering the quality of ED and ICU team decisions and work environments will improve outcomes for patients, family members, and clinicians.

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Shared Decision-Making With Patients and Families

7

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7.1 Introduction

Patients and families generally wish to be involved in important medical decisions through a process known as "shared decision-making." Shared decision-making (SDM) is a process of communication between clinicians and patients or family members that involves the following steps: (1) discussing the nature of the decision to be made; (2) exchanging relevant medical information and information about the patient's values; (3) checking for understanding of information; (4) discussing preferred roles in decision-making; and (5) achieving consensus about the treatment course most consistent with the patient's values and preferences [1]. This approach to decision-making is different to paternalism, in which the physician makes the clinical decision with mere patient or family assent, and to informed choice, in which the physician only provides information and the patient or family makes the

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final decision after receiving this information. In this chapter, we will see that involving patients and/or family members in SDM in the emergency department (ED) and the intensive care unit (ICU) can be a challenging task, specifically when patients lack decision-making capacity, when family preferences for decision-making vary, and when emotional distress is high. We also describe strategies to help clinicians to better involve patients and families in decision-making. Interprofessional shared decision-making within the team is the focus of Chap. 6.

7.2 The Relevance of Shared Decision-Making

SDM is a central component of patient-centered care in the ED and the ICU. SDM must be consistent with ethical principles and with patients' and surrogates' preferences. The American College of Critical Care Medicine defines shared decision-making 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" [2]. In the ED and the ICU, difficult choices arise, and important decisions are made. Clinicians offer their expertise, scientific knowledge, and experience to improve their patients' health status, yet they still need to involve the patients and/or their families to ensure that the decisions made are respectful of the patients' values, goals, and preferences.

7.3 Shared Decision-Making in Critically Ill Patients

Patients in EDs and ICUs are some of the most vulnerable in any acute hospital. The change from a healthy individual occurs prior to the patient's arrival in an ED or an ICU and marks a fundamental change. The traditional consent model for medical treatment is often shortened, and ED or ICU physicians may have to adopt a paternalistic approach. The issues surrounding this area are discussed in Chapter 4 of this book.

Shared decision-making in critically ill patients can be challenging because patients and ED/ICU physicians usually have no established relationship, and decisions can be time critical. Achieving agreement as to the extent of treatment requires a balance of respect for autonomy and beneficence and/or management of resources. The emotional stress of the emergency situation on the patient and the fact that the baseline mental status is unknown to the clinicians often make it difficult to determine competency for decision-making, especially in cases of refusal of treatment [3].While patient autonomy is central, physicians may sometimes give priority to their own professional judgment to achieve the best possible outcome for patients. In the specific context of the ED, recent qualitative research shows specific emotional and logistical challenges to SDM, such as difficulty building trust, the challenges of uncertainty, lack of follow-up care, and the physical space of the ED [4].

7.4 Families in the ED and the ICU: Shared Decision-Making in a Context of High Emotional Distress

Patients in the ED and ICU very often lack decision-making capacity, and clinicians must turn to their families to learn about their values. Thus, families are no longer simple visitors in the hospital: They play important roles and should be considered by the ED and ICU teams as active partners. As defined by the American College of Critical Care Medicine [2], the term "family" should be used in its broadest sense to include "all individuals whom the patient considers family, whether related or unrelated to the patient, including those with whom the patient has a significant relationship and those who provide support to the patient." Ideally, the patient should choose which of his relatives should be involved. When this is not possible, the surrogate will help clinicians identify those individuals.

As all families are unique, there is a spectrum of role preferences, ranging from letting the physician decide to assuming responsibility for the final decision. Families often describe one of their roles in the ED or the ICU as being the patient's "historian" (inform the team of the patient's prior medical status, history, and wishes) and "facilitator" (translating, explaining, and interpreting information for both the patient and the team) [5]. Families can help the team understand the patient as a person and thus help the team respect that person by proposing adapted care. Sharing valuable information with the team is perceived as an important role, sometimes as the only role they want/are able to endorse.

Preferences for decision-making can vary. Some families may want to leave the physician decide independently, and this choice must be honored. For others, participating in the deliberation process is important: listening to the team's expertise and recommendations, sharing their opinion, asking questions, but leaving the decision to the medical team. Indeed, some families do not want to share the burden of decision-making with the clinicians. Others however may want to feel part of the decision itself, sometimes going as far as actually making the decision.

Cultural context impacts on these possible roles: For example, family responsibility for the decision to withdraw life-sustaining treatment is possible in the United States, whereas in France, this responsibility can only be the physician's. In a study from the United States [6], concerning value-laden decisions (resuscitation preferences), 10% of surrogates preferred to decide independently, 45% preferred to decide after considering the physician's recommendations, 40% preferred shared responsibility, and 5% preferred the physician decides either after considering the family's opinion or independently. A study from France shows that only 39% of ICU physicians had actually involved family members in decisions. A desire to share in decision-making was expressed by only 47% of family members, and only 15% of family members actually shared in decision-making [7].

Adapting the decision-making process to the family's preferences is thus fundamental, and guidelines must be adapted in order to have meaning in each specific cultural context.

7.5 Impact of Shared Decision-Making on Families' Well-Being

A qualitative study investigated which physician and nurse behaviors families find supportive and which behaviors increase the family's burden. Timely communication, open discussion about families' roles, facilitating family consensus, and providing adapted emotional support are helpful. Behaviors that made families feel excluded or increased their burden included postponing discussions about treatment withdrawal, delaying withdrawal once scheduled, placing the full burden of decision-making on one person, withdrawing from the family, and defining death as a failure [8].

In many studies, participation in care, discussions, and decisions is listed among the factors that increase family satisfaction [9]. For some families, however, sharing in decisions can result in substantial psychological burden: In a study from France, families involved in ICU end-of-life medical decisions presented higher risk of developing posttraumatic stress symptoms 3 months after the patient's death [10]. A systematic review found that at least one-third of the surrogates report negative emotional effects lasting months, and sometimes years, after making treatment decisions for others, including stress, guilt, and doubt about whether they made the right choice [11]. These results raise questions as to how family members are involved and what specific factors during the SDM process are associated with increased psychological distress. Future research is necessary to develop ways to increase support and reduce this burden [12].

Involving the family in the decision-making process raises further complex challenges. First, in the ICU, families suffer from high levels of emotional distress, such as symptoms of anxiety, depression, and acute stress [13]. They may experience feelings of vulnerability and guilt as well as daytime sleepiness that can impair their ability to make decisions that are in the patient's best interests. Second, not all patients discuss their wishes with their family. Family members may feel at a loss and not able to correctly describe their loved one's goals and preferences. Third, the family members may have difficulty shifting their perspective from what they want to what they believe the patient wants. This can also be true in other decisional contexts, such as organ donation. Families may defend their own best interests rather than the patient's [14, 15]. Fourth, obstacles to shared decision-making include difficulties experienced by families in understanding the information they receive: Studies have shown that families only understand half of the information given by the physician [15], and they may also unconsciously make decisions without clearly understanding what is at stake. Last, clinicians may sometimes be concerned that families pressure the patient to adopt their own preferences, thus violating the patient's autonomy. In situations of potential coercion or manipulation, clinicians may need to discuss with patients in private their goals and family dynamics in order to adapt decision-making to the patient's preferences: Some may wish to be free of family influence, while others may prefer to adjust to their family's position, thus requiring that clinicians consider the patient's *and* the family's mutual interests [16].

An interesting qualitative study shows that SDM can be a struggle for families [17]. Indeed, they may experience significant emotional conflict as they wish to act in accordance with their loved one's values but without feeling responsible of the patient's death. They fear that their lay involvement may be a barrier to a chance of recovery. Additionally, they have their family's well-being at heart, and involvement can increase the risk of tensions or conflicts [18].

7.6 Team-Centered Challenges

SDM challenges are not only family-centered. Other challenges remain and concern the ICU team. Research has shown the importance of quality communication. The manner in which the physician conveys the information may influence the choices made by the patients and the families. Shared decision-making assumes that the ICU staff can convey their knowledge in a simple and readily understandable manner that nevertheless allows the patient or family to grasp the nuances and consequences of each decision, without feeling any pressure. Among others, timing of the decision is also important. Rapid progression of a life-threatening illness can lead to rapid decision-making and insufficient time to build a trusting relationship with the family members.

7.7 Strategies to Improve Shared Decision-Making

7.7.1 Family Conferences: The VALUE Approach

Discussing end-of-life issues can be testing. The Society of Critical Care Medicine family-centered guidelines recommend that "routine interdisciplinary family conferences be used in the ICU to improve family satisfaction with communication and trust in clinicians and to reduce conflict between clinicians and family members" [19].

Using a structured approach to communication, such as the "VALUE" mnemonic, will help enhance clinician-family communication [20]. This proactive communication strategy encourages clinicians to prepare the meeting beforehand, as interdisciplinary and interprofessional involvement in family conferences is important and all clinicians have a role to play. During the conference itself, clinicians are encouraged to:

- value family statements
- acknowledge family emotions
- listen to the family
- understand the patient as a person
- elicit family questions

This strategy includes active listening, expressions of empathy, and making supportive statements around nonabandonment and decision-making [21]. This

mnemonic was used as part of an intervention to improve clinician-family communication in the ICU and, combined with a bereavement brochure, has been shown to significantly decrease family symptoms of anxiety, depression, and posttraumatic stress 3 months after the patient's death [22].

Effective communication with family members not only provides support for families and decreases their stress but will also improve decision-making for the critically ill patient. Once again, clinicians should tailor their approach to communication to each family's preferences by multiplying informal conversations and organizing formal conferences. This will enable families to experience SDM not as a "one-shot" but rather as a process that is responsive to their needs and emotions.

As communication is both complex and fundamental, the family-centered guidelines [19] also recommend that "ICU clinicians receive family-centered communication training as one element of critical care training to improve clinician self-efficacy and family satisfaction."

7.7.2 Support for the Family

The primary aim for facilitating a shared decision approach should be team collaboration [23]. When all invested parties – including, but not limited to physicians, nurses, social workers, and psychologists – are involved in SDM, the burden of decision outcomes is dispersed among those collaborating and does not fall on one person. Better collaboration between members of the ICU team encourages the development of collective competence and enhances job satisfaction, logically producing improved care and subsequently improving patient and family outcomes.

Family/patient-orientated facilitating techniques include developing confidence and trust (e.g., through patient activation), rapport with providers, and a trusting and positive patient-provider relationship. Language concordance between the provider and the patient is also imperative. Different professionals could intervene as facilitators, such as chaplains [24], social workers, nurses and physicians – as long as they are familiar with the ICU environment and have benefited from advanced training in communication.

In fact, the intervention of an ICU communication facilitator or specifically trained nurses can help to specifically reduce family distress and intensity of end-of-life care. Facilitators' roles are to support communication between clinicians and families, to adapt communication to family needs, and to mediate conflict. In an American study [25], families who benefited from the intervention of a facilitator experienced decreased symptoms of depression at 6 months, while families who didn't had increased symptoms. Symptoms of posttraumatic stress disorder were also lower with the intervention at 6 months. For decedents, the intervention was associated with reduced length of stay in the ICU and hospital. Facilitators may be a valuable resource and can help clinicians address issues that might be overlooked or unaddressed in the busy hospital setting. In another American study [26], a family-support pathway was instituted in which the trained nurses met with families in the interventional group on a daily basis (emotional support and communication

needs) and arranged clinician–family meetings within 48 h after enrollment and every 5–7 days thereafter. The study showed that this family-support intervention did not significantly affect the surrogates' psychological distress; however, the surrogates' ratings of the quality of communication and the patient- and family-centeredness of care were better and the length of stay in the ICU was shorter with the intervention than with usual care.

7.7.3 Dealing With Discordance and Conflict

Discussing uncertainty about prognosis can be challenging for clinicians, although it is a central part of their work. Disagreement, and moreover conflict, between physicians and families over end-of-life decisions can lead to significant stress for everyone involved and can considerably hinder SDM. Research had revealed that such conflicts are prevalent in the ICU. In a multicenter international study [27], 27% of clinicians reported at least one conflict between themselves and families in the preceding week. Conflict is harmful in that it is associated with adverse outcomes both in clinicians (burnout) and in families (anxiety, mistrust). However, when correctly identified and managed, conflict can have positive effects, such as helping families move forward through a distressing experience.

Discordance about prognosis can be problematic in the context of SDM, and it is important to understand its causes. In a multicenter American study [28], physician-family discordance about prognosis occurred in over 50% of situations. Interestingly, discordance was related to misunderstandings by families about physicians' assessments of patients' prognoses and differences in beliefs about patients' prognoses. It is thus important that physicians regularly check with families about their perceptions of prognosis before engaging in SDM. Providing adapted emotional support (aimed to alleviate guilt, for example) and discussing religious or spiritual beliefs are strategies that have shown to be beneficial.

7.7.4 Mediation

Mediation is the process by which someone tries to end a disagreement by helping the two sides talk. It is a new area for clinical disputes, although has widespread use in other areas of conflict resolution. In the United Kingdom, the National Health Service Resolution (website resolution.nhs.uk) uses mediation to resolve clinical negligence claims. The results include nonfinancial remedies, which otherwise would not have been available to the claimant. In the recent case of Charlie Gard – a controversial case about an infant boy born with mitochondrial DNA depletion syndrome for whom the medical team and the parents disagreed about whether experimental treatment was in the best interests of the child [29] – the judge stressed repeatedly how he considered that the parties should have tried mediation first. International experience is there, with a Canadian Elder Law report demonstrating that 90% of participants found the process of mediation helpful, even if the dispute

was not settled. Overall, mediation has been found to be cheaper, faster, and with a high chance of success (60–90%) [30]: It allows for the preservation of relationships rather than the destructiveness of litigation.

7.8 Conclusion

Throughout this chapter, it has been shown that shared decision-making is a complex personalized process that necessitates constant adaptation to the patients' as well as to the family members' needs and preferences. High-quality communication is a prerequisite to SDM, focused on the patient's and family's understanding of the medical situation, evaluation, and re-evaluation of the family's preferred role for decision-making and, last but not least, adequate emotional support. Some families may choose to formally be part of decision-making, thus taking on decisional responsibility, whereas others may choose to remain at a distance of medical decisions. R. J. Curtis and R. Burt have developed an alternative approach called "informed assent" that avoids putting family members in the difficult position of feeling responsible for the outcome [31].

Communication strategies have been tested, and recommendations have been published that are valuable tools for clinicians. However, one size does not fit all, and within every individual clinical circumstance, clinicians must strive to develop an approach to SDM that is adapted to each specific patient and each specific family. Last, one must remember that actively listening to the patient and the family is, without doubt, the first step to SDM.

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Part III

Extent of Treatment

Emergency Medicine and Critical Care Triage

8

Joseph L. Nates and Charles L. Sprung

8.1 Introduction

Triage is a common process in modern medicine. Initially a military process of sorting injured patients in the field with origins in the Napoleonic wars, it has become a daily process performed by nurses and physicians in emergency departments (EDs), intensive care units (ICUs), rapid response teams, and others throughout the entire healthcare system. Triage can be divided into three: primary, secondary, and tertiary. Primary triage is performed at the scene mainly during natural or civilian disasters and or military confrontations. It usually occurs far away from the civilian hospitals, and its successful implementation demands to have an infrastructure capable to reach the injured, perform triage, and then transport the victims to a healthcare facility capable to manage them in a timely fashion. Secondary triage occurs on arrival to the healthcare facility where the patients are treated, and decisions are made as to whether a patient needs an operation or a transfer/admission to the ICU. This is done mainly in EDs. Tertiary triage occurs after admission when victims need to reach the highest level of care (e.g., need to remain in the ICU with daily re-evaluations, but resources are insufficient). Triage is mostly associated with military events, epidemics, mass civilian trauma events, and natural disasters – but most importantly, when supply is less than demand. All these situations present different

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challenges to the different providers involved in the decision process and management of the event and victims (Table 8.1). Specific challenges referring to the allocation of scarce resources during pandemics are discussed in Chap. 16.

In the past 15 years, several task forces have provided a better understanding of the triage process and have made important recommendations [1–3]. Task forces from the European Society of Intensive Care Medicine and others have created guidelines to handle mass events and the allocation of scarce resources during these extremely complex situations [4]. A task force of members from the American College of Emergency Physicians (ACEP) and Emergency Nursing Association (ENA) has also made recommendations regarding the use of five-level triage systems in the United States [5].

Triage is a complex task that requires knowledge, training, and experience. Moreover, having all the required skills does not guarantee an accurate triage. Wide variability performing triage in EDs has been demonstrated using interactive triage

Table 8.1 Challenges performing triage in the emergency departments and intensive care units

1. Large patient volumes or demand > supply
2. Insufficient triage education
3. Lack of triage protocols
4. Lack of triage team/team leader
5. Inadequate infrastructure to manage large patient volumes
6. Triage variability
7. Inadequate triage processes
8. Inability to predict outcomes
9. Lack of accuracy triaging (a) Over-triage (b) Under-triage
10. Lack of accurate early warning systems and/or failure to implement them
11. Inefficient patient flow management
12. Overcrowding
13. Insufficient staffing
14. Insufficient number of hospital beds
15. Insufficient number of intensive care unit beds
16. Bottlenecks
17. Patient care delays
18. Disposition delays
19. Misutilization of resources
20. Discharge delays (delays in triage out)
21. Ethical dilemmas (a) Practitioner's bias (b) Failing to respect patient's autonomy (c) Failing to fairly distribute resources (d) Lack of adherence to principle of beneficence
22. Inadequate legal protection for the practitioner performing triage

simulators [6]. Process variability seems to be the rule also in ICUs [7, 8] and among hospitals [9]. Triage decisions are made taking into account several factors such as written criteria, available resources, tools used to prioritize, or environmental factors. The general process for critically ill patients was delineated in the mid-1990s [1]. The task force of the Society of Critical Care Medicine (SCCM) recommended to include six key features in the process*:* evaluation of the patient, determination of urgency, assignment of a priority level, consideration of resources available, documentation, and disposition. However, these elements alone are not enough to make a decision. We lack the ability to accurately predict the future. Scores developed to evaluate the severity of illness have been proposed in triage but lack broad support for their implementation [2]. In addition to the severity of illness, other factors that need to be taken into consideration are age, admission diagnosis, the number of ICU beds available, and operative status [10]. However, again, using age and severity of illness scores as factors to take a decision have been shown to be misleading, and calls have been made to change these triage practices [11]. Other important components for triage include the need for an organized system, oversight, absolute adherence to the known ethical principles, the inclusion of palliative care, and legal protection [4].

8.2 Triage in the Emergency Department

The actual triage process involves the primary triage functions of collecting the relevant information and performing assessments and reassessments based on physical examination and vital signs. The healthcare provider assigns acuity, prioritizes and creates a rapid disposition plan. Needed emergent interventions are performed. However, personnel in the ED also carry out other activities while performing triage, which can affect the entire process. Although there seems to be variation as to by whom and how to perform triage [2], in most cases, nurses perform the first triage on arrival to the EDs. In a national survey in 87% for Swedish EDs, it was shown that patients arriving via ambulance were triaged by a nurse in 99% of the EDs studied, but in 46% of them, there was no use of any triage scale [12]. This seems to be also true in other countries and using different triage instruments [13].

8.2.1 Triage Scales

Multiple tools to perform triage have been developed, and these are used to perform the assessment of acuity and time to intervention. The most popular instruments have been the Australasian Triage Scale (ATS), The Canadian Triage and Acuity Scale (CTAS) which is based on the ATS, the Manchester Triage System (MTS) used in Great Britain and, after some modifications, in Germany, as well as the Emergency Severity Index (ESI) used in the United States since the 1990s [13]. The validity and reliability of these tools are extremely important. However, many of these tools have been used without validation and translated from their original

languages (e.g., MTS). One of the externally validated and translated instruments (ESI) has shown high validity and reliability in the German language [14]. In a recent review of the most used instruments and their validity and reliability, the CTAS was found to be the best performer (interobserver reliability $k = 0.68–0.89$, and hospital mortality correlation and resource utilization, $p < 0.01$), followed closely by the ESI [13]. Based on these results, the CTAS seems to be the most appropriate tool at this point, although, it is still in need of further development.

8.2.2 Patient Flow and Overcrowding

Increasing volumes of patients have become a reality in daily medical practice. Consequently, these large volumes and the logistical challenges that these numbers impose onto the healthcare system have created patient flow inefficiencies with overcrowding of EDs, hospitals, and overwhelming institutional services [15]. Patient flow inefficiencies have become one of the most serious hospital and patient care problems in the United States, leading to multiple initiatives to reduce suboptimal care and potential harm [16, 17]. The Institute of Healthcare Improvement (IHI) has been a leader addressing this problem. To achieve an improvement in hospital-wide patient flow, they recommend a multilayer and very comprehensive approach that includes: lean management approach, quality improvement initiatives, operational/industrial engineering with advance data analytics/systems analysis to improve elective surgery scheduling, and focusing attention on reducing critical services demand by relocation of care to cheaper alternatives [17].

A recent study in five representative Australian emergency departments tried to answer whether scribes would improve physician performance [18]. The investigators found a definitive impact on improving physicians' performance by 15% and reducing patients' median length of stay by 19 minutes ($p < 0.001$). Interestingly, the greatest advantages were noted by placing scribes with senior doctors at triage. Some studies, though, that had also shown improved physicians' performance, have yet failed to demonstrate benefit in regard to throughput [19]. Others have been able to demonstrate benefits regarding patient throughput, productivity, and patient satisfaction [20]. However, a recent meta-analysis failed to show advantages in the length of stay or time to disposition [21]. The only potential advantages found in the study were an increased number of patients seen in an hour with increased revenue and physician/patient satisfaction. These results indicate that adding scribes to the team could be a useful strategy to improve physicians' performance and throughput.

Triage liaison physicians have been found to reduce the length of stay by 36.85 minutes (95% CI, 51.11–22.58 minutes). Another intervention that has shown to be effective is fast-tracking, or the process of developing an alternative pathway for patients with minor complaints, which in some studies reduces the length of stay by a median of 27 minutes [15]. The list of interventions with the potential to improve patient flow and reduce overcrowding is long. In Table 8.2,

Table 8.2 Interventions to improve triage and patient flow in the emergency department

Triage team and protocols	1. To have a triage system, protocols and triage team 2. To have a senior physician assisting triage 3. To coordinate work with triage liaisons 4. Advance triaging, having nursing protocols to initiate earlier interventions (e.g., ordering labs, radiographs)
Supporting systems	1. Having: (a) Electronic health records (b) Electronic tracking boards (c) Computerized Physician Order Entry (CPOE) 2. Point of care testing capability and dedicated radiology staff 3. Having scribes 4. Having *full capacity protocols* (ability to relocate patients in temporary areas once emergency room reaches capacity) 5. Streaming (cohorting patients by complaints following specific pathways and tailored care)
Organizational changes	1. Implementing: (a) Rapid assessment zones (b) Short stay units (c) Medical assessment units 2. Using bedside registration 3. Adjusting staffing needs 4. Having coordinators 5. Performing Patient Flow Analysis (PFA)

we enumerate the most important interventions to take into consideration when attempting to improve the processes, patient flow, and length of stay in the emergency department.

8.3 Triage in the Intensive Care Unit

Not all ICUs have an organized triage service or admission policies. Some ICUs handle the admission process by assigning the responsibility of referred patients to whoever is on call. Others have organized and dedicated admitting services that deal exclusively with the new arrivals. Although there is no consensus, organized triage teams led by a senior and experienced physician and following structured protocols seem to be more effective and efficient [2, 15].

Most recently, a task force from the SCCM published the most comprehensive document published to date addressing ICU admission and triage. It provides evidence-based recommendations addressing most of the scenarios we encounter frequently in daily practice [2]. The SCCM guidelines offer not only guidance for admitting patients to the ICU but also triaging in a wide range of scenarios. Additionally, they also provide a guide to approach the most frequent ethical dilemmas we confront when making triage decisions in patients regarding end-of-life care (EOLC). As it is not possible to discuss the entire subject in this chapter, we highlight some of the most important challenges identified by the task force.

8.3.1 Under- and Over-Triage

The lack of an accurate assessment of any patient can lead to underestimating his illness with harmful results for the patient. This situation leads to principally appropriate care delivery (for the underestimated disease) usually associated with poorer outcomes. The opposite, over-triaging, has mostly deleterious consequences for the system, leading to overutilization of ICU beds with reduced capability and access to others more in need of the resources offered in the unit. Under-triage has been associated with increased mortality, regardless of whether triage was performed before arrival to the hospital or afterward [2, 22]. In a recent study, almost half of all the U.S. trauma patients who died in EDs were triaged to non-trauma centers [23]. Interestingly, sex and demographic disparities were identified, with female and highest household income zip code patients being less likely to be triaged to a trauma center (OR 0.83; 95% CI, 0.70–0.90 and OR 0.54; 95% CI, 0.43–0.69, respectively). Given that females have a lower trauma-related death rate than males, it is possible that the injuries in this group were underestimated or indeed were less severe. At the same time, patients with higher socioeconomic status may have been injured close to their homes and far from the inner cities were trauma centers are usually located.

8.3.2 Logistical Challenges/Patient Flow Inefficiencies

We usually assume that patients accepted for admission to the ICU are admitted in a timely fashion. However, patient flow disruptions associated with several hospital inefficiencies such as lack of adequate intrahospital transportation can lead to harmful delays. Transfer delays from the ED to the ICU above 6 h have been associated with increased mortality [2]. A more recent study, investigating the impact of ward to ICU transfer delays, showed increased mortality in patients with admission delays above 6 h (33.2% vs. 24.5%, $p < 0.001$) [24]. In addition, the investigators also showed that for every hour of delay, there was an associated adjusted 3% increase in the odds to die ($p < 0.001$). Table 8.3 highlights some of the potential interventions to improve triage in ICUs.

8.4 Rapid Response Teams/Early Warning Systems

With the rising popularity of the rapid response services (RRS), units have expanded their triage role from a simple passive receptive process, in which patients are screened only when referred for admission consideration or evaluation by a critical care consultant, to a more active role reaching out beyond the walls of the ICUs. RRS not only respond to calls from relatives and worried nurses in the wards, but these teams have also become screeners of patients at risk identifying deteriorating patients much earlier. At the same time, early warning systems provide an additional

Table 8.3 Interventions to improve triage and patient flow in the intensive care units

Triage team and protocols	1. To have intensive care unit (ICU) admission and discharge policies with specific criteria for both 2. To implement an organized triage system with a triage team led by an experienced physician and advance practice providers or experienced ICU nurses 3. To have prioritization protocols for admission 4. To have prioritization protocols for discharge (Triage Out) 5. To have Surge and other Full Capacity protocols (ability to admit or relocate patients in designated temporary areas once the intensive care unit reaches capacity)
Supporting systems	1. To have the capability to manage critically ill patients in the emergency department in case of admission delays due to bottlenecks 2. To have a robust institutional electronic health record 3. To have a real time electronic dashboard to track patients in the emergency department, the operating room, and other ward services
Organizational changes	1. To have a robust outreach program with: (a) Rapid response systems(e.g., nurses, respiratory therapists) and (b) Early warning systems 2. To have a ward consulting service 3. To have intermediate or stepdown medical units for admission or discharge of less critical/improving patients 4. To have performing improvement programs with industrial engineering support and patient flow analysis

layer of support for a more efficient and earlier detection of any signs of decline leading to earlier triage. A recent systematic review failed to show definitive evidence of improving outcomes at this stage, though [25].

8.5 Ethical and Legal Challenges

One of the most important challenges for the practitioner is to make unbiased decisions. Multiple preconceived beliefs affect the judgment of the practitioners at the time of triage. Whether it is the patient's age, sex, the presence of cancer, ethnicity, socioeconomic status, and others, these play an unconscious role affecting the triage officer's decision [2]. Age, for example, has been used to deny access to critical care resources despite evidence that older patients' survival is not determined by age but rather by the admission diagnosis and severity of illness. A similar situation has occurred with cancer patients, where access to critical resources has been limited despite that their short-term outcomes are similar to the other critically ill patients, and at the same time that their long-term outcomes continue improving remarkably over the years. Fairly distributing available resources should always be part of the process, maintaining the principle of *distributive justice* [3].

Another ethical challenge in emergency situations is respecting the principle of *autonomy*. Respecting the wishes of the patients is not always possible. Balancing their demands appropriately without letting particular privileged individuals impose

their influence, which occurs with celebrities or any other so-called very important person [26]. Alternatively, *autonomy* is lost when patients arrive unconscious without relatives to be triaged and treated. In this situation, triage officers, and other medical personnel in need to make decisions for the patients, not always chose the patient's preferred option (e.g., transfusing a Jehovah witness because no one knew of the patient's religious beliefs, or resuscitating a patient that had an unknown advanced directive against it).

The principle of *non-maleficence* ("do no harm") can be put in question when we under- or over-triage patients consequently increasing their risk for or causing harm. Our ethical responsibilities do not end with not causing harm: Rather, we should actively prevent it (the principle of *beneficence*) [27]. Even allowing overcrowding negatively affects our triage capabilities leading to poorer outcomes. We should ask ourselves whether we are doing enough in this regard, whether we are acting to reduce the factors leading to worse outcomes, or just complaining about them. These challenges bring us to the principle of *justice* and fairly distributing our critical medical resources. Attempting to save one life at all cost, and in the process allocating a disproportionate amount of resources, may hurt many others. Our goal should always be to match the resources available to the needs of the triaged without any bias and just considering that the benefits outweigh the downsides, adhering to the principle of *beneficence*. The use of transparent and well written policies vetted by ethics and legal advisors can mitigate any public distrust or even decision errors in the "fog of war."

The fear of making questionable or difficult decisions, which could lead to litigation after a disaster situation, can become a serious ethical and practical dilemma for the triage officer [2] – and one that would be impossible to resolve in real-time. Physicians' fear to be taken to court in emergency situations is associated with real consequences. In certain cases, physicians have lost their licenses or even been accused of murder like in the case of Dr. Anna Pou following the New Orleans disaster caused by Hurricane Katrina in 2005 [28]. In that case, 200 patients and hundreds of healthcare providers were trapped in Memorial Medical Center Hospital, surrounded by up to 10 ft. of floodwaters with no electricity, exposed to extremely high temperatures, and rationed food, water, and medications, among many other [29]. While completely isolated from the rest of the world (the entire city of New Orleans was evacuated) and extreme conditions, the practitioners had to make very difficult decisions. The triage process used was very rudimentary. For example, they gave intravenous fluids to those patients who opened their eyes; those who did not open their eyes did not receive care. Dr. Pou and two nurses were arrested and charged with second-degree murder after events that occurred during the storm.

We are bound by many ethical principles but without enough legal protections for physicians in emergency situations. The Good Samaritan laws, which prevent practitioners from liability when acting in good faith during emergency conditions, do not apply to staff on duty in a hospital. In 2001, the Centers for Disease Control developed the Model State Emergency Health Powers Act that addressed healthcare

providers' liability in emergency situations such as epidemics or bioterrorism. This document was used by legislators in numerous states to pass bills with similar provisions. However, the American Civil Liberties Union and others have expressed concerns about the power this legislation gives the government against individuals' freedom and challenge these resolutions (e.g., quarantine power).

In real situations, following principles such as the *principle of rescue* or *non-abandonment* exposes healthcare providers to increased risks and liability without real legal protections as described previously. In the case of Dr. Pou, she stayed in the hospital's hellish conditions caring for numerous critical and dying patients for 4 days. In the aftermath, her efforts were rewarded with murder charges and civil suits that have destroyed her life. Clearly, there is a need for medical societies to be more engaged in the development of proper legislation and guidelines protected by law for this type of situation. But there are other aspects of this principle we also overlook, the financial burden of rescuing patients leading to rationing and the clash between principles, *non-abandonment*, and *distributive justice*. We are obligated to find alternative solutions to rationing. However, innumerable ICUs around the globe maintain an insufficient capacity to provide care for all those needing it in the respective institutions (e.g., insufficient ICU-to-hospital-beds-ratios). Some of our actions conflict with many of the ethical principles we usually invoke, clearly indicating the ethical and moral complexities of triaging and the responsibilities assigned to any triage officer.

8.6 Other Human-Related Challenges: Variability and Scarce Resources

Hurricane Katrina made evident the extension of the lack of preparedness at a city-wide scale. Dr. Pou's personal account of the events highlighted the multilayer deficiencies in the disaster plans associated with the poor government and medical responses observed in New Orleans in 2005 (e.g., lack of education, lack of training) [30]. The disaster plans were not only inadequate for the local, regional, and national levels (e.g., communication systems, hospital evacuations, etc.) but also these plans did not prepare anybody for the necessary triage challenges they encountered. The public, which plays an important role in disaster situations (e.g., supporting evacuations), was also unprepared and uneducated. The role of the community has been noted by Nates in his description of the successful management of the external and internal disaster that occurred at the Houston Memorial Hermann Hospital in 2001, 4 years before Katrina [31]. The public response and direct participation were essential components in the evacuation without fatalities of the 570 patients hospitalized at the time. Yet, despite the warning and the lessons learned in Houston, the New Orleans disaster plans were not revised-with worse consequences. In the case of Katrina, the public, the press, and the government turned against those who actually cared for the needed, an important lesson to consider when performing triage in emergency situations. When considering these two disasters and a few

others, Nates and Moyer concluded that more than the lack of knowledge, the failed emergency responses are the result of "inaction and poor implementation of the necessary measures to prevent, contain, or mitigate the impact of natural disasters on the populations exposed" [32].

As we can learn from these internal disaster examples, physicians are fully responsible for the "triage out." Deciding who to treat or transfer out can be as difficult or more than accepting patients. The physicians are not protected at the same extent than the military or firefighting personnel who in most cases just follow orders or rigid protocols [30]. The physicians carry not only most responsibilities and emotional burden but also the legal consequences.

A factor that although omnipresent seems to be ignored is practice variability [7]. Rathi et al. have clearly demonstrated the significant variability that exists among practitioners performing triage [33]. In a multicenter, multinational, randomized triage study, they found that following published and well-known guidelines or even guidelines-based algorithms did not reduce triage variability at the time to prioritize critically ill cancer patients' ICU admission. They also found poor agreement among practitioners. Well beyond the actual triage process, individual variability imposes additional challenges that have not been well characterized or taken into consideration at the time to develop protocols. These findings have significant medicolegal implications, indicating that two or more practitioners performing triage, regardless of the level of urgency, will probably make different decisions. Consequently, regulating the implementation of protocols or guidelines can become challenging.

Finally, the study of Rathi et al. was performed in developing countries [33]. Triage in geographical areas with fewer resources such as in developing countries is not different in principle-there is just less to offer (e.g., the city of Houston was able to absorb over 250,000 evacuees from Louisiana during Katrina, something that very few places in the world would be able to match, if at all) [32]. The variability and their challenges seem to be exactly the same as in the United States [7].

8.7 Conclusions

Triage is a complex medical decision-making process. It is very challenging in daily practice due to the innumerable factors that physicians need to take into consideration to make a triage decision, most of which are not available to them in real time. Before admission or afterward, all the prediction models remain too inaccurate to be used in individual cases, real-time or prospectively. Daily hospital triage activities should be driven by an organized team with clear and transparent protocols and led by a triage officer. Basic ethical principles should always be maintained. We should continue refining our current triage scales and severity of illness scores as well as developing legislation to protect healthcare workers providing services in disaster conditions. More research and education are needed to address current knowledge and practice gaps.

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Usage of Cutting-Edge Technology: ECPR

9

Lionel Lamhaut and Alice Hutin

9.1 Introduction

Cardiac arrest (CA) is a major public health issue. In adults, it is mostly due to cardiovascular diseases and is one of the leading causes of mortality in industrialized countries [1]. Despite attempts to improve different links of the so-called "chain of survival" for the victims of CA, survival rates after out-of-hospital CA (OHCA) remain very low, between 5% and 10% in most countries [2, 3]. Actions aimed at improving these low rates include prevention measures against cardiovascular risk factors, increasing CPR awareness and skills by bystanders, widespread dissemination of automatic external defibrillators (AEDs), emphasis on early defibrillation, and improving professional cardiopulmonary resuscitation (CPR). After failure of conventional CPR to obtain return of spontaneous circulation (ROSC), extracorporeal CPR (ECPR) is a highly invasive therapy in the management of refractory CA employed to increase patient survival rate. However, access to ECPR, timing to implement ECPR, and patient selection are some of the questions yet unanswered. The role of extracorporeal membrane oxygenation in the treatment of diseases primarily affecting the function of the lungs is discussed in Chap. 10.

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9.2 The Concept of ECPR

Frontiers of medicine have evolved in major ways over the past decades. Over time, the criteria for definition of death have evolved. For example, a few decades ago, a patient presenting with OHCA was considered dead. Rescue teams then learned to provide artificial ventilation and Peter Safar created the "ABC of resuscitation" [4]. The first two letters, A for *airway* and B for *breathing*, signify maintenance of a patent airway, the ideal form being thought to be a secure endotracheal tube and provision of ventilation and oxygenation via said airway. Incidentally, recent publications on this subject have questioned the advantage of endotracheal intubation over bag-mask ventilation or supraglottic airway ventilation during resuscitation of cardiac arrest [5, 6], and to this day, this remains an unresolved question. In practice, the answer depends on local health-care systems and algorithms for the management of OHCA; there is probably no "one solution fits all." The third letter, C for *circulation*, was traditionally achieved by external chest compression. Despite its numerous limitations and marginal effectiveness, the importance of circulation over airway management is such that applying compressions-only CPR is taught to the general public, according to the guidelines for first responders. The classical "ABC" protocol in terms of priority has thus become CAB [7]. The limitations of restoring the circulation by external chest compressions can now be overcome with the implementation of ECPR. Indeed, animal studies have shown that ECPR results in much better organ perfusion than cardiac massage, especially in prolonged CPR, while increasing the likelihood of ROSC [8]. The real question is no longer "should we switch to ECPR?" but "when should we employ ECPR?"

Conventional CPR aims to obtain ROSC [7]. Indeed, until recently, when ROSC was not achieved after a certain time, no other treatment was considered and patients were pronounced dead, be it at the scene or in the hospital. In the absence of ROSC, treatment of the cause of CA was difficult and neurological evaluation was impossible. Even with the achievement of ROSC, neurological damage due to anoxic brain injury can be very severe and the risk increases with the duration of CPR and the associated low flow time.

In this setting, there are two important treatment goals: maintaining cerebral perfusion despite a non-beating heart and preventing secondary cerebral lesions. ECPR is considered today as a second-line therapy for the treatment of refractory cardiac arrest with potentially reversible etiology [9, 10]. Beyond the objective of ROSC, ECPR restores adequate perfusion to organs; priority is placed on the brain with the idea that better cerebral perfusion during prolonged CPR leads to better neurological recovery after cardiac arrest. Indeed, ECPR allows time to evaluate the brain and treat the cause of CA (especially myocardial infarction or pulmonary embolism) independently of heart function. The device is implemented through cannulation of the femoral vessels in order to provide organs with satisfactory blood flow, especially the heart and the brain. The venous cannula drains blood from the vena cava, drawn by a pump (replacing the heart), which then delivers the blood to the systemic circulation via the arterial cannula after it has passed through the oxygenator/CO_2 remover (replacing the lungs) [8].

Thus, ECPR allows life to be possible, at least temporally, without a beating heart. This concept had long been utilized in the setting of cardiothoracic surgery, but now has evolved in the emergency setting during the management of CA. In this situation, ECPR leads to a change in the criteria for declaration of death, which are no longer dependent on the arrest of the heart, but rather on cessation of cerebral functions. The challenge then becomes how to identify the irreversible cessation of cerebral function. Apnea testing, the gold-standard test for total brain failure, requires significant modification when systemic CO_2 is being regulated by the machine [11].

It should be recognized that the use of ECPR is not without risk. In some cases, the patient survives neurologically intact, but with severe irreversible heart failure dependent on extracorporeal circulation, without any long-term therapeutic options (i.e., heart transplant). The ethical decision-making when it comes to withdrawing a therapy that has become "a bridge to nowhere," yet with the patient awake and cognizant of the circumstances, is extremely complicated. ECPR services must be prepared for such eventualities and have policies and/or guidelines in place to support the patient, family, and medical team facing such challenges.

9.3 Challenges Regarding the Implementation of Prehospital ECPR (Fig. 9.1)

The number of ECPR cases reported around the world has increased exponentially in the past 20 years, going from zero in the late 1990s to more than 1300 in 2015 [12]. Survival rates in selected patients are relatively favorable despite prolonged resuscitation, with 20–30% achieving good neurological outcomes [12–14]. These numbers are somewhat startling when compared to global OHCA survival rates. Indeed, it can seem contradictory to have better survival rates in the situation of very severe CA when conventional CPR has failed. These survival rates apply to very specific patient subpopulations, however, for whom the chain of survival works extremely well through its very first link, as most – if not all – of these patients would have been declared dead after a certain duration of conventional CPR.

9.3.1 Inclusion Criteria

Although the number of ECPR cases has increased substantially, precise indications for ECPR are still lacking and consensus relies on expert opinion as there are no results yet from randomized controlled trials on the subject. In most ECPR programs, "ECPR candidates" are patients with witnessed CA, with no-flow duration of less than 5 minutes, and refractory ventricular fibrillation. Age limitations differ between programs around the world, usually around 65–70 years of age, but one

Fig. 9.1 Prehospital ECPR in the street of Paris

must keep in mind that it is not the chronological age, but the existence of comorbidities (or their severity) that constitutes the real limit.

Concerning the CA itself, it is important to note that variations in inclusion criteria come from the current absence of reliable monitoring techniques for intra-arrest cerebral activity. Many centers focus on criteria such as initial cardiac rhythm and time to first bystander CPR. These factors are classically known as being predictive of ROSC, however, it may not be appropriate to choose these cardiac factors for the purpose of neurological prediction. In current medical practice, several ECPR centers concentrate on criteria more directly linked to cerebral activity such as "signs of life" (gasp, breathing movements, spontaneous movements, pupillary reactivity) [14]. The presence of these signs shows the existence of cerebral activity or at least brain stem activity.

Furthermore, it is obviously impossible to obtain informed patient consent after CA. As conventional CPR is usually implemented without consent – or with presumed consent – in this emergency situation, so should be the ECPR. Both treatments can be discontinued when prolonging them seems unreasonable, for instance,

due to the identification of severe chronic illnesses, very old age, or a valid previously expressed "do not resuscitate" instruction by the patient. Otherwise, in the absence of ROSC with conventional CPR, ECPR has become the subsequent step, in specific situations, as described earlier. Clearly, ECPR can result in a difficult experience for patients and especially for their families, as hospital length of stay can be prolonged and many complications can occur [15]. However, experience has shown that well-informed families rarely criticize maximal treatment implemented in this situation when it seems congruent with the patient's wishes.

9.3.2 Accessibility with Regards to Time Limits

The management of cardiac arrest itself varies in different settings across the world. In some places, resuscitation takes place in the field with advanced cardiac life support delivered by highly qualified paramedics or physicians. In other places, patients are very rapidly taken to the hospital with ongoing CPR. In the same manner, access to ECPR, when it exists, depends on local facilities and protocols.

Time is actually the most limiting factor governing the access to ECPR. Most centers around the world agree that prolonged low flow is clearly a negative prognostic factor and most experts recommend that the ECPR should be implemented within 60 minutes after cardiac arrest [16]. Although this time frame can seem long on paper, in the reality of OHCA, this "golden hour" is quickly consumed when adding up extraction time from the site of the cardiac arrest, transportation time to the hospital, and implementation time; having the patient under ECPR within 60 minutes can pose a daunting challenge. One must also keep in mind the necessity to ensure both high-quality CPR throughout and secure working conditions for rescue teams during high-speed transportation. Therefore, some centers have developed "prehospital ECPR." In this model, ECPR is brought to the patient and implemented on the site of the cardiac arrest [17] (Fig. 9.1). The patient is then transported to the hospital once the pump has been activated and satisfactory flow achieved to ensure brain perfusion. Early results seem encouraging in terms of feasibility, outcome, and safety [14, 17].

9.3.3 Distributive Justice and Equality of Care

Experts largely agree as to the value of ECPR for refractory cardiac arrest. However, ECPR is not yet considered standard of care, although many urban areas in industrialized countries are working to create dedicated pathways. Unfortunately, in countries where prehospital basic life support is poorly developed, ECPR is not a realistic priority. However, within one country or one region, it would seem important from an ethical standpoint to be able to treat all patients medically equally. When an area decides to implement an ECPR program, attention should be directed to ensure

equality of care for all patients suffering cardiac arrest with the same prognosis within that area. Such decisions are political as much as medical and need to be undertaken with more public health data than is available today for ECPR. The lack of uniformity in the access to ECPR is due to many factors. These include a finite number of skilled practitioners, limited quantities of equipment, and the challenge of providing equal access to ECPR implementation without unreasonable delay. Training in and implementation of ECPR by emergency physicians and intensivists in addition to cardiac surgeons would broaden the accessibility to ECPR in urban and potentially in rural areas. Secondary transfers, even over long distances, of patients under ECPR have been described. While ECPR implementation can be achieved in an emergency department, a cardiac catheterization suite, or an intensive care unit (ICU) [12, 14, 18] as mentioned earlier, ECPR implementation can also take place in the field, with the team being dispatched to the CA patient, even quite far away from an in-hospital ECPR facility (Fig. 9.1). Moreover, due to the increased availability of equipment requiring less sophisticated expertise, patients on ECPR can be treated in general ICUs, as opposed to in the specialized units which were previously required with cardiothoracic surgeons, intensivists, and perfusionists immediately available. If needed, patients can then be transferred to ECPR referral centers, especially as weaning from ECPR and decannulation may require specific surgical skills.

9.3.4 Costs

As with many other "cutting-edge" treatment modalities, ECPR is very expensive; the costs for one patient are estimated at approximately $125,000 per ECPR in the United States [19]. Ideally, ECPR should be dedicated to selected patients for whom neurologically intact recovery after CA is realistic. The objective is for patients to go home, return to work, and not be a burden to society. Patients with an unfavorable course frequently die within the first 24–48 h after implementation of ECPR from multi-organ failure. While some patients survive, but with major disabilities, the percentage of these patients seems lower than for patients achieving initial ROSC without ECPR [16].

A recent cost effectiveness study has shown positive results regarding this intervention with a calculated cost utility for ECPR of approximately $56,000 per quality-adjusted life year gained [19]. This compares favorably with many other currently widely accepted therapies.

9.3.5 Organ Donation

Several countries have allowed organ explantation in patients still in cardiac arrest, so-called non-heart-beating donation (NHBD) [20]. These are patients without ROSC deemed to be without any hope for good neurological survival. The decision as to whether the patient should be a candidate for ECPR or for organ donation is challenged by the short time frame in which the decision must be

made. Things are made yet more complicated by the aforementioned absence of formal eligibility criteria for ECPR. For example, using bystander report information to determine whether there was a "no-flow time" of greater than 5 minutes to judge whether a patient should be considered for cure versus organ donation would clearly be ethically fraught [20]. One option would be to implement ECPR in patients for whom the neurological prognosis is unknown, i.e., unclear no-flow time or non-shockable rhythms, to allow time to evaluate patients over several days after cannulation. Some of these patients will progress to brain death and become potential organ donors, whereas others may achieve neurologic recovery. Some series have shown that organs from ECPR patients reach early good functional recovery and may be of better quality than those from NHBD patients [21]. From a practical standpoint, ECPR also provides time for families of CA patients to digest the often unexpected bad news, offering the opportunity to consider carefully what the patient would want done.

9.4 Conclusions

The treatment of refractory CA has been significantly improved with the emergence of ECPR, initiated in the field or in the hospital. ECPR is clearly the only effective known treatment after failure of conventional CPR for patients to survive neurologically intact. However, several core issues, such as selection criteria, means of provision, equitability of access, and justification of costs, await further clarification before ECPR can be recommended for widespread implementation.

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Usage of Cutting-Edge Technology: ECMO

10

Onnen Mörer and Michael Quintel

10.1 Introduction

Extracorporeal membrane oxygenation (ECMO) is a fascinating, potentially life-saving technology that can be used to support the lungs and is especially indicated in patients with severe (reversible) respiratory failure when conventional therapies fail [1]. ECMO can be applied either as a rescue therapy or as a tool to reduce the invasiveness of the mechanical ventilation to avoid further lung damage. Today, despite the lack of widely accepted evidence demonstrating a clear benefit, ECMO is implemented for a broad spectrum of indications from acute severe hypoxemic respiratory failure due to pneumonia to bridging to transplantation in patients with chronic lung diseases. Thus, ECMO therapy is used at the extremes, offering a "last" option to avoid a fatal outcome, however, with a high inherent uncertainty with regard to the true outcome. Unavoidably, this implies recurrent difficult decisions about its most appropriate utilization and a wise application with regard to its limitations.

This chapter addresses some of the ethical challenges related to the usage of ECMO in the context of vague evidence overall, a lack of defined and generally accepted indications as well as problems related to patient consent, the variable national supply, reimbursement structures, and finally the limitation of life-sustaining therapies. ECMO can also be applied to support cardiac function in critically ill adult and pediatric patients suffering from organ failure refractory to conventional therapies [1]. This chapter focuses on the use of ECMO for pulmonary support and the ensuing ethical challenges; the usage of ECMO for cardiac support is not the topic of this chapter, but it is discussed in Chapter 9.

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In patients where the underlying pulmonary disease process substantially impairs the gas exchange, ECMO can replace the native lung function partially or completely. For this purpose, blood is drained from the venous system and circulated by a pump through a semipermeable membrane to facilitate oxygenation and carbon dioxide removal. Thereafter, it is reinfused into the venous system (= venovenous or VV-ECMO), in rare cases into the venous and arterial system to further improve oxygenation (VV/VA hybrid ECMO). Venous access is enabled via cannulas placed into large vessels.

During the last decades, ECMO has evolved from a life-saving therapy available and used only in very few centers per country to a technique potentially available in every intensive care unit [2, 3]. The technical development facilitating the clinical usage of this "cutting-edge technology" is impressive, although complications directly attributable to it are still substantial [4]. The development of transportable systems led to the worldwide setup of mobile ECMO teams that can retrieve and transport patients safely to experienced centers, where otherwise the transfer would have been extremely dangerous or even impossible [5].

Recent technological progress facilitated a broad use of ECMO in more and more hospitals and led to a dramatic increase of its application worldwide. Unfortunately, this growth was much faster than the increase in knowledge about the clinical usefulness and associated ethical challenges. While ECMO is widely used now in daily routine, questions for whom, how long, and in which setting it should be used are still matters of debate. The evidence for proper indications and applications of ECMO besides its use as a true rescue therapy is rather weak – as is the knowledge of potential limits of this invasive procedure. In Germany, a nationwide initiative that clearly defines the demand and the rules on how to apply ECMO is missing, although the recently published national guidelines might support decision-making [1].

The lack of evidence-based and generally accepted indications is of major concern as it might lead to under-usage (not every patient with a clear indication gets access to this technique), over-usage (use of a costly technique in vain), and even harmful (usage in patients who would benefit from a less invasive therapy) application consuming a reasonable amount of resources that can only be spent once. The current literature reflects an open discourse about ethical questions and concerns, discusses the benefits and risks of the technique, and deals with the problem of getting access to the therapy and the resulting allocation of resources in recent years [6–13].

10.2 Acute Respiratory Failure Due to Potentially Reversible Causes

The initiation of ECMO for respiratory failure can either be based on the goal of functional organ recovery of the native organ buying "time to heal" (bridge to recovery) or on buying time to enable organ transplantation (bridge to transplant, BTT) [14]. Another option, "bridge to decision" (BTD), has been

suggested for patients with an uncertain prognosis [14]. The discriminative power adding this third goal seems questionable, though, since the likelihood of recovery is usually difficult to assess at ECMO initiation. If the recovery of the patient's native organ function becomes highly unlikely ("bridge to nowhere"), the remaining option is to discontinue ECMO and to change the therapeutic goals from cure to palliation.

In the intensive care setting, long-established therapeutic concepts are often offered and applied to patients with astonishing confidence despite the lack of clear and proven evidence. This also holds true for ECMO therapy. Although ECMO is broadly used worldwide, conclusive evidence from high-quality, properly powered, randomized controlled trials (RCTs) is lacking [3, 15–18]. The demand for RCTs is obvious, but hampered by a seemingly insurmountable problem, the ethical dilemma of trying to create evidence regarding a life-saving technique for patients at a very high risk of non-survival without this technique.

As reflected by DeMartino and colleagues, **"***the threads of controversy fuse ethics and knowledge in a seemingly inescapable knot***"** which is characterized by the following problems [19]:

- Randomization to an experimental (ECMO-) arm without exactly knowing the risks and their incidence.
- Exposure to an experimental (ECMO-) arm with little knowledge about its efficacy, but loaded with potentially life-threatening risks.
- Randomization to conventional (non-ECMO) therapy in which a high percentage of patients might die ("randomization to death").

Early studies on the use of ECMO for the treatment of ARDS included an RCT in the United States in the 1970s showing poor survival and high complication rates [18]. Another RCT was not conclusive due to the technical limitations of ECMO and the invasiveness of the conventional therapy applied [17]. Two important recent trials, the CESAR [16] and the EOLIA [15] trial, will be briefly described.

In the CESAR trial [16], patients with ARDS were, once randomized to ECMO, transferred to one single ECMO center or, when randomized to conventional therapy, stayed in the hospital of admission. The observed outcome in the treatment arm was significantly better than in the control arm. However, not all patients randomized to the intervention arm were actually treated with ECMO, whereas the ventilation scheme in the control arm was not standardized. Therefore, at least a part of the positive findings might be more attributable to the fact that these patients were treated in an ARDS center than to the effects of the ECMO therapy itself. Of note, three patients died during transportation. The design excluded the ethical burden of potentially treating two patients next to each other, one of them receiving a potentially life-saving therapy and the other one "simply" being treated conventionally. The design, however, created a large bias making a conclusive interpretation of the findings difficult. Nonetheless, the study was predominantly perceived as favoring ECMO and after its publication, especially in combination with the first H1N1 pandemic, a marked and sustained increase in the use of ECMO could be observed

worldwide, although data that would really allow weighing the risks against the potential benefits had not been provided.

The very recent EOLIA trial [15], comparing ECMO with conventional therapy, allowed crossover in order to overcome the issue of withholding a potentially life-saving tool due to randomization. However, this led to the fact that 28% of the patients randomized to the conventional arm received ECMO as well. The trial was stopped by the data safety monitoring board for "futility," not expecting that the predefined 10% absolute mortality difference between the groups could be reached. EOLIA clearly showed a trend in favor of early ECMO use (mortality 35% in the ECMO group compared to 46% in the control group, relative risk, 0.76; 95% confidence interval, 0.55–1.04; $P = 0.09$), especially if taking into account the secondary endpoints and the benefit from crossover in the most severely compromised patients. Therefore, some name it "the most positive negative trial,", whereas following the generally accepted rules of evidence, it was simply negative.

Both studies required tremendous efforts to be conducted, however, they added important knowledge and some evidence to recommend ECMO in predefined stages of ARDS; a recent meta-analysis even derives a positive signal in favor of ECMO [20, 21]. At this stage, though, the evidence for applying an invasive, potentially life-saving, yet at the same time potentially harmful therapy is still low – and unlikely to be improved by a classical RCT. Strictly speaking, the lack of evidence for ECMO should lead to classify the technology as experimental. Subsequently, it should only be used in research settings and/or as an off-label measure. National and international efforts are needed to increase the knowledge defining the role of the technology more adequately. As RCTs are no realistic option, researchers and clinicians might use careful case documentations in registries that accrue real-life data (comparable to data regarding treatments in oncology, for instance). With such registries, large-scale observational data of actual clinical practice could be gathered that might help to answer clinical questions and help to solve the ethical challenges.

However, with a technology already used lavishly worldwide, such structured information might be difficult to obtain. The momentum to create valid structured scientific confirmation before spreading a new technology into daily routine has passed, and with it the chance to avoid the widespread application of a therapy not fully elucidated.

10.3 Acting with Informed Consent: A Difficult Task for Acute ECMO Initiation

Being applied as a rescue measure, the wishes and preferences of the patients can rarely be assessed directly since they are mostly incapacitated when ECMO is being indicated. Moreover, even if of sound mind, time pressure would preclude most of them from an adequate risk–benefit assessment required for a valid informed consent process.

When consent cannot be obtained and ECMO will be applied as a rescue therapy for acute respiratory failure, it is usually justified stating that "doctors should provide medical treatment that is in the patient's best interests and is immediately necessary to save life or avoid significant deterioration in the patient's health"[22]. This approach assumes that "*once the clinical situation has been stabilized, a formal, if retrospective, consent discussion can be held with the option of withdrawing the life-sustaining interventions or therapies being given full consideration if consistent with the patient's previously expressed preferences*"[23]. But even if consent could finally be obtained directly from the patient, it has to be kept in mind from the beginning that "retrospective" in this context might mean after weeks or even months of extensive ICU therapy.

Adequate and valid advance directives, that would help guide decision-making, are not as frequently available as needed and elucidating the patient's presumed will by speaking with the next of kin is often difficult or impossible in an acute situation. Thus, the discussion to place an invasive and costly therapeutic procedure is usually made under the assumption that clinical deterioration and potential death do not represent a reasonable option. As in many emergency situations, then, the obligatory process for obtaining informed consent, ensuring the patient's autonomy, may get overruled by time constraints owed to the urgency of the decision-making [12].

In summary, informed consent to establish ECMO for acute respiratory failure, based on an autonomous well-informed decision, is usually impossible to achieve. Even assessing the patient's presumed will through the next of kin is – under most circumstances – hardly attainable as the full range of consequences induced by the initiation of ECMO in a timely manner is difficult to grasp.

10.4 ECMO Programs: Ensuring Access to Therapy on a National Level While Avoiding Uncontrolled Use

A marked increase of ECMO use has been observed during the last decade, partially explainable by the H1N1 epidemic in 2009, the results of the CESAR trial in 2008 (see above) and by the fact, that technical developments led to ECMO systems easier to handle [2]. Questions needing an answer in this regard comprise the following:

- How is the demand for ECMO centers ascertained?
- Is the number of available centers sufficient to cover the demands?
- Is the volume of patients treated per center sufficient to ensure clinical expertise?

A broad and fundamental ethical discussion about the (unequal) distribution of healthcare facilities and access to health care worldwide is beyond the scope of this article. With regards to ECMO, though, and at least focusing on the situation in Europe, the strategic concepts on how ECMO therapy is offered vary remarkably. Some countries have addressed this issue in a "top down" manner, estimating the

national needs and defining and setting up a number of hospitals within a network that provides the estimated number of treatments. In contrast, in other countries, such as Germany, the setup of ECMO centers and teams was driven by the dedication, competency, interest and capacities of those responsible for each single ICU. It cannot be denied that economic considerations, related to the reimbursement of ECMO, have been a strong incentive for establishing this technology in some facilities. To date, it is evident that without a national concept about implementation and provision of ECMO therapy, multifactorial forces cause uncontrolled genesis of self-appointed centers – independent from regional requirements, quality, and volumes that fulfill the real needs of the society.

For example, in the United Kingdom, 5 ECMO centers are run currently (population 53 millions), in Sweden 1–2 centers (population 10.2millions), in France considerably more than 20 centers (population 67.1million), while in Germany 85 departments officially announce ECMO capacities in a national ARDS register (population 85 million) [24, 25]. Based upon the incidence of severe respiratory failure, Combes et al. estimated an incidence of up to 10 ECMO cases per million population per year [26]. Postulating that the percentage of patients requiring ECMO should be comparable in the countries named above, the actual supply obviously varies considerably. This might limit access to the therapy in some countries, whereas in others, the number of places for treatment will lead to treatment volumes that are at risk to undercut the minimum number of cases per year per center with a considerable risk of losing expertise. A recent international guideline (Germany, Austria, and Switzerland) as well as a position paper from an international group of experts defined the structural and personal prerequisites for an ECMO center and also the minimum number of 20 patients treated per year in order to ensure the quality of care [1, 26]. Combes et al. proposed a network of hospitals that should be covered by one ECMO center located at a tertiary referral hospital taking care of an estimated population of two to three million of inhabitants [26].

10.5 Decision to Withdraw ECMO Therapy

In a retrospective analysis, DeMartino et al. found that at the time of requests to withdraw therapy in 62 ECMO patients (26% of all ECMO cases during the observation period), none of these patients were able to take part in the decision-making [19]. Despite survival rates of about 65%, the estimated number of patients where ECMO had to be withdrawn due to the loss of a curative therapeutic goal was certainly noteworthy – although the exact number was not obtained.

Offering a therapy despite a high likelihood of a fatal outcome is often based on weighing individual chances against statistical probabilities and strongly hoping for a good outcome for the single individual case [19]. However, this approach necessarily requires the readiness to withdraw that therapy once the chance of bridge to recovery has turned into a “bridge to nowhere.” The exact point in time, though,

when ECMO is no longer indicated or no longer in accordance with the patient's values, goals, and preferences, is often difficult to define. Especially in patients with severe and chronic organ failure on ECMO, the assessment that there is no realistic hope for recovery, will often be difficult and rather rest on eminence than on clinical evidence. So far, there are only weak prognostic variables to estimate the chances for recovery. Assuming a patient would even accept permanent respirator dependency, it might be extremely difficult to make a prognosis as to whether and when conventional non-ECMO ventilation alone might be sufficient. The actual lack of mid- to long-term "implantable" "ECMO-like" supportive devices creates necessarily an "all or nothing" situation that requires thoughtful ethical decision-making in a complex setting.

With a number needed to treat of six patients treated for one extra survivor and a low disability rate at 6 months, the authors of the CESAR trial concluded that ECMO likely can be considered to be cost-effective [16]. With average total costs of 73,979 pounds for ECMO patients compared with 33,435 pounds for those undergoing conventional therapy, the costs per quality-adjusted life-year (QALY) of ECMO were predicted to be 19,252 pounds. With a predicted additional 0.03 QALYs at 6 months [16], lifetime QALYs gained were 10.75 for the ECMO group compared with 7.31 for the conventional group. A more recent Canadian analysis suggests that veno-venous ECMO for ARDS is likely cost-effective for young adult patients with severe ARDS and should be considered on a case-by-case basis in patients who have a high likelihood of a good long-term functional outcome, but should be limited to expert high-volume ECMO centers [27]. Another Canadian study suggests that high in-hospital therapeutic costs of ECMO use notwithstanding, ECMO likely is cost-effective as costs of the survivors after discharge are moderate [28].

Nonetheless, continuous reassessment of the therapeutic goal with regards to survival and best achievable outcome in terms of quality of life should help align the medically achievable goals to the values and wishes of the patient. Thereby, the respective medical decision regarding the adequate indication to provide, continue, or stop ECMO therapy should preferably be based on interprofessional shared decision-making leading to an interdisciplinary and interprofessional consensus [7, 29].

10.6 ECMO as a Bridge to Lung Transplantation

Lung transplantation is a potential option for patients with acute or chronic respiratory failure, most frequently related to advanced chronic obstructive pulmonary disease, idiopathic pulmonary fibrosis, cystic fibrosis, emphysema (α1-antitrypsin deficiency), idiopathic pulmonary arterial hypertension, or graft failure of the primary transplant (re-transplantation). In the end stages of these diseases, ECMO therapy might be considered for patients requiring respiratory support while waiting for an appropriate organ.

Candidates for lung transplantation (LTx) are patients with chronic end-stage lung diseases in the absence of other treatment options who meet the following criteria [30]:

- High risk of death (>50%) within 2 years if LTx is not performed.
- High likelihood (>80%) of surviving at least 90 days after LTx.
- High likelihood (>80%) of 5-year posttransplant survival after hospital discharge.

This precludes transplantation in situations, where the patient has a little to no chance of survival with or without LTx.

Bridging to lung transplantation is seldom an option for patients who receive ECMO as a rescue measure for acute respiratory failure. In view of shortage of transplantable organs, it is easy to understand that transplantation centers indicate lung transplantations with great hesitation in these cases. Nevertheless, there are now a growing number of reports on ECMO being used for bridging to LTx, especially in the United States [31, 32], and numerous centers have meanwhile experience in taking care of these patients. Therefore, ECMO could be regarded as reasonable bridging strategy to lung transplantation for individual patients under specific conditions, especially provided acceptable one-year survival rates [33]. Nevertheless, a thorough assessment of the indication and contraindications are pivotal before initiating ECMO as a bridge to transplantation in order to offer a reasonable perspective for the patient.

10.7 ECMO in Brain-Dead Potential Organ Donors

With the increase in ECMO prevalence, there will be also an increase in the number of patients with unfortunate neurologic complications such as intracranial hemorrhage and ischemic strokes, which can result in brain death of the ECMO patient. Organ donation might be considered in these patients, especially since there is a high demand for organs. Due to the critical illness, the organ quality of ECMO patients for donation seems questionable. Thus, brain death ECMO patients are still seldom considered as organ donors. However, a recent French analysis compared 64 donors on ECMO with 10.805 donors that did not receive ECMO [34]. After matching these patients (non- vs. ECMO donors), there was no significant difference in 1-year kidney and liver graft survival and function between recipients. Thus, with proper evaluation and selection, organs from donors who received ECMO can be used with successful outcome. From an ethical point of view, the situation seems comparable to the conventional reasoning for organ transplantation. The main differences are related to the fact that under ECMO conditions, the time from decision to organ retrieval might be prolonged owed to the peculiarities of brain death diagnosis on ECMO, and might thus create a considerable burden for the relatives, even if the consent is not questioned.

More recently, the initiation of ECMO with the sole purpose of preserving organ function in brain death patients has been proposed. In cases of consent for organ donation, ECMO offers options for an optimal organ donor management in order to avoid organ loss, since brain death is often accompanied by hemodynamic and

multi-organ instability. Although there is little evidence concerning transplant success with regard to graft survival and function, some reports suggest that ECMO might sufficiently sustain organ function. An analysis from the United States, in which ECMO was used to enable organ donation after cardiac death, the number of kidneys transplanted increased significantly by 24% [35].

Although transplant programs are usually set up under conditions of high standards with established systems of quality control, the special aspects using ECMO as a bridge to perform organ donation in already (brain-) dead patients raise specific ethical questions [10]. The whole process needs a thorough advanced planning including the implementation of standardized protocols that cover these circumstances.

10.8 Conclusions

During the last decade, ECMO has become a therapeutic option for various clinical scenarios in critically ill patients. Today, this cutting-edge technology is used broadly for a wide range of clinical situations and various indications. However, ECMO therapy needs a profound (re-) assessment to define its place in the medical management of respiratory (and cardiac) failure. It seems crucial to ensure that this technique is used to save lives and provide best possible care, leading to an outcome with acceptable "quality of life" in patients suffering from severe respiratory failure and to avoid treatments finally interfering with the natural process of dying. Although research answering the key questions regarding the appropriateness, initiation, and management of ECMO is desperately required, the chances to gain evidence as to the full range of (potential) ECMO indications are limited. The extremely fast increase in its worldwide use has also increased the number of ethical dilemmas with an invasive technology offering life-saving potential, but also carrying life-threatening risks. A national and international research agenda in combination with large data base registries to provide long-term, large-scale observational data of actual clinical practice would create the base to answer upcoming clinical questions and support ethical decision-making. However, at this stage, this seems quite unrealistic. For daily care at the bedside, a team approach "that optimizes communication about the nature and purpose of ECMO while encouraging realistic outcome expectations not only with the family and the patient but also within the team, aligning patient and family understanding of, and proactively mitigating the moral distress of providers involved in complex ECMO cases" actually represents the only practical, faithful, and appropriate solution [19].

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Limiting Life-Sustaining Therapies

11

Diederik van Dijk, Carole Boulanger, Gavin Joynt, Andrej Michalsen, and Jan Bakker

11.1 Introduction

Decisions regarding the extent of treatment and specifically the decision to initiate, withhold or withdraw life-sustaining therapies in a prehospital setting, in the emergency department (ED) or the intensive care unit (ICU), may be straightforward at times; the patient will either clearly benefit from these therapies or clearly not. However, for many critically ill or injured patients, there is no sharp cutoff between foreseeable benefit and untoward suffering in light of often scarce information, time

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constraints, and ill-known patient wishes. Even if the benefits of life-sustaining treatments are undisputed at the time of their implementation, later, the side effects, for instance, pain, anxiety, and confusion, may ultimately change the balance of benefit and harm of the treatment. Therefore, considerable communicational, ethical, and legal challenges may arise regarding the limitation of life-sustaining therapies.

Specifically, the following issues warrant clarification:

1. Under what circumstances is limiting life-sustaining therapies permissible, advisable, or even imperative?
2. Who should decide on limiting life-sustaining therapies?
3. How can life-sustaining therapies be limited?

11.2 General Considerations Regarding the Extent of Treatment

Legal systems, societal norms, and personal value systems vary across the globe. In addition, the acceptance and implementation of limiting life-sustaining treatments vary not only between countries, but also within the countries and populations – and even between physicians within the individual ICUs [1–5]. Despite these variations, there is general agreement that medically each and every diagnostic and therapeutic procedure needs an indication, i.e., a reasoned assessment that it will benefit the individual patient in his/her present state of health. Measures that are not or no longer indicated for an individual patient in a specific situation should be withheld or withdrawn – or at least thoroughly reassessed. This holds for life-sustaining treatments as well – unless such limitation is legally prohibited [6].

Ethically, the four principles of non-maleficence, beneficence, respect for the patient's autonomy, and (distributive) justice might serve as a general guidance for how ED and ICU teams need to orientate the extent of treatment [7]. However, these principles need to be weighted and prioritized for each individual patient; they may not all be realizable – and they may even be in conflict. For example, the principle of non-maleficence is potentially violated by invasive treatments such as central venous catheterization, immobilization, intubation, and ventilation as they necessarily inflict harm; however, they may have to be applied in the EDs and ICUs for the sake of beneficence. The justification for violating the principle of non-maleficence is that the (intended) benefit of these measures usually outweighs the harm, so that no "net harm" will be caused.

Major challenges relate to satisfying the principles of beneficence and respect of autonomy. It may be difficult to clearly determine the individual short- and long-term benefit of a diagnostic or therapeutic measure. To a certain extent, this is the result of a prognostic uncertainty that pertains to medicine in general. More importantly, though, the assessment of a tolerable degree of suffering, favorable outcomes, and acceptable quality is in the eye of the patient rather than that of the treating team. Therefore, complex medical decisions, for instance those relating to

risk-prone therapies or the limitation of life-sustaining therapies, should be arrived at by shared decision-making, both within the team and between the team and the patient and/or the family or the legal representative, respectively [8, 9]. When an irresolvable conflict of opinion between patients or their representative and the treating team occurs, in most European countries medical judgment prevails, and neither patients nor family can coerce the treating team to implement measures that are not or are no longer indicated [10]. This approach is often called "paternalism." The present chapter leaves no space to explore this matter more deeply. Nevertheless, in this approach, the respect for patient autonomy does not make the patient the sovereign. His or her rights regarding the extent of treatment are seen more as a defense right (against coerced procedures) than a claim right (to force the treating team to perform procedures that they consider not indicated) [10, 11].

How conflicts are resolved may be dependent on the moral and legal rights of families or spokespersons when a patient is incapacitated and no applicable advance care directive is available. In many European countries, family members are not legal representatives of their loved ones *per se*, unless they are authorized by the patient ahead of time in a legally valid way or if they were appointed by a court. In other countries or cultures, families or clans do have the right to legally speak for their loved ones and sometimes overrule medical judgment. This represents another potential cause of conflict within an ED or ICU team or between the treating team and the family.

Finally, the inappropriate prolongation of scarce and costly treatment with life-sustaining therapies may be the result of some physicians invoking the rule of rescue, i.e., prolonging the life of an individual patient at all (human and material) costs, but without regard to the low odds of meaningful recovery. Especially in resource-limited circumstances or settings, this use of scarce resources may well violate the principle of distributive justice [12, 13].

11.3 Withholding Versus Withdrawing

Generally, Western ethical and – in many jurisdictions, legal reasoning strongly holds that there is no difference between withholding and withdrawing life support, and that either may be applied with the same justification [14, 15]. Notably, withdrawing life-sustaining treatment is prohibited by law in Israel. Legal permissibility notwithstanding, not all medical practitioners agree that withholding and withdrawing are ethically equal, even from a more theoretical background [16, 17]. For example, a majority of ICU physicians in the Middle East and Asia view these as ethically different [18]. This is reflected in the lower rate of withdrawal compared to withholding life support in corresponding regions [1]. Medical teams as well as patients and families frequently perceive withholding easier to accept emotionally compared to withdrawal. It is important to address the various elements of these emotions, such as feelings of being overwhelmed, guilt or fear of suffering, when deciding on limiting life-sustaining treatments.

11.4 An Intensity- or Time-Limited Trial with Life-Sustaining Treatments

There is often prognostic uncertainty whether the potential benefits of life-sustaining treatments will outweigh the associated burdens. At the same time, patients and/or surrogates may be overwhelmed by the illnesses or injuries they are faced with, and therefore, they may be unable to make rapid, but thoughtful decisions as to the extent of treatment. To not initiate potentially beneficial (life-sustaining) treatments, only because of fear that it might not be feasible or ethically permissible to withdraw them later would appear unjustified. The risk of such a decision could be avoided by a formal process of initiating a treatment in the ED or the ICU that is limited from the start.

One option is an intensity-limited ICU treatment, i.e., to admit a patient to the ICU, but to formally agree to withhold certain components of ICU treatment from the beginning. A good example is to provide noninvasive ventilation, but to withhold invasive mechanical ventilation should it be required. Although this approach may reduce the chance of survival, its primary goal is to reduce the burden of the ICU treatment for the patient.

Another option is a time-limited treatment. This provides more time to assess a patient's chance of a meaningful recovery according to his or her wishes and values. A time-limited ICU trial establishes an agreement between the healthcare team and the patient or his/her surrogates to apply intensive treatments, as required by the underlying condition(s), for a fixed period of time. When the time limit is reached, the curative treatment goal is upheld if the patient has responded positively to therapy, otherwise the therapeutic goal is changed from cure and care to comfort care only [19, 20]. Setting an appropriate time period for the trial is difficult. It has been suggested that 3–7 days would be appropriate for hypoxic-ischemic encephalopathy, end-stage cardiac failure, and other similar conditions, while 1–2 weeks might be required for conditions such as stroke [20]. A recent review suggested a time limit of at least 24–72 h for acute conditions in patients potentially facing the end of their lives [19].

11.5 Under What Circumstances Is Limiting Life-Sustaining Therapies Permissible, Advisable, or Even Imperative?

Both a medical indication and the patient's informed consent are imperative for any medical procedure. If one of these two constitutive elements is not given or is no longer valid, then the procedure in question must be withheld or withdrawn (unless these limitations are prohibited by legal stipulations in the respective jurisdiction).

Decisions on indications (or the lack thereof) rest with the medical teams, who need to take the patient's values and wishes into consideration. There is no general agreement as to whether non-indicated treatments can be limited against a patient's wish [2, 6, 10]. For many physicians, though, limitation would still be permissible. When patients and families appear to insist on potentially inappropriate treatments,

Table 11.1 Abbreviated assessment of the conditions for implementation or limitation of life-sustaining therapies

Treatment medically indicated	Treatment consented by patient or proxy	Implementation/ continuation	Limitation
YES	YES	YES	Usually n.a.
YES	NO	NO	YES
NO	YES or NO	NO	YES
NO	Demanded	NO	YES[a]

n.a.: not applicable
[a]Unless prohibited legally

repeated meticulous communication attempts, mediation, and even support by an ethics committee may be needed [11]. If a patient does not or no longer consent to a treatment, implementation or prolongation of this treatment is illegal; withholding or withdrawing is then imperative. A short assessment of the conditions for implementing or limiting life-sustaining therapies is shown in Table 11.1.

Limiting life-sustaining therapies should lead to a change in the goal of treatment from cure and care to comfort care only. Since this decision is far-reaching and irreversible most of the time, end-of-life decision-making is best achieved by consensus. This in turn is best achieved by shared decision-making both within the team and between the team and the patient/family [8, 9]. In individual cases, it may be appropriate to include other stakeholders in the decision-making process such as physicians from other specialties involved in the care of the individual patient, the patient's general practitioner or clergy.

Obviously, all elements of potential benefit and harm need to be addressed during decision-making, for instance, the patient's health status before admission, his/her treatment goals, short- and long-term prognoses beyond discharge, and the degree of suffering due to the ED/ICU treatment.

Consensus between the team and the patient/family (or the legal representative, respectively) needs to rest on truthful communication eliciting the patient's beliefs, values, and wishes as well as deliberating about the benefit and harm of the medical procedures in question. For many reasons, ED and ICU patients often lack decision-making capacity, and therefore, the patient's values and preferences must be elucidated in alternative ways, for instance, via advance directives (as valid in some countries) or family/surrogate "substituted judgment," that is based on their understanding of the patient's values and preferences. The ultimate decision is the result of a potentially quite complex process that involves the healthcare team at large as well as the patient or – much more frequently – the patient's family or other surrogate decision-makers.

Overall, it is often not easy to recognize the appropriate moment to be "suspicious enough" to re-assess the effectiveness and appropriateness of an intended or ongoing therapy. Therefore, the healthcare team should recognize triggers that may indicate the need for deliberations regarding end-of-life discussions beyond regular assessments during daily care. Commonly accepted, recognizable factors

Table 11.2 Suggested practical triggers for the initiation of end-of-life decision-making (adapted from [21])

Expected duration of patient survival
• May consider when survival is expected to be between 1 and 3 months
• Should consider when survival is expected to be expected to be up to less than 3 months
• Must consider when survival is expected to be less than a few days
Presence of multiple organ failure
• Should consider when three or more organs have failed for >3 days
• Must consider when three or more organs have failed for >7 days
Severe brain injury
• Should consider with predicted poor long-term outcome (dependent daily living)
• Must consider with predicted very poor long-term outcome (minimally conscious state)
Should always be considered when the healthcare team's opinion is
• The patient has a non-survivable injury (any terminal underlying illness)
• The patient is receiving non-beneficial therapy

that may trigger end-of-life discussions include a limited expected length of survival, severe neurological injury, multi-organ failure, and conditions demonstrating unresponsiveness to adequate therapy in an ED or ICU (see Table 11.2) [21]. This list is far from exhaustive, and clinicians should always be alert to circumstances when end-of-life discussions may be appropriate. Interestingly, advanced age and a severe illness in isolation were not recommended as appropriate triggers for end-of-life discussions for the healthcare team. This was explained by the recognition that severe illness may still be reversible and that outcomes in elderly patients, especially when measured in terms of quality of life, are not universally poor [21]. It should be recognized that the patient and his/her family may trigger end-of-life discussions as well, and such requests should be honored as if initiated by physicians or other members of the healthcare team.

Overall, decision-making at the end of life is a clinical skill with a large ethical and moral dimension and it has been shown that a good ethical climate within an ICU appropriately facilitates discussions and decision-making regarding the extent of treatment and the limitation of life-sustaining therapies [22].

11.6 How to Withdraw?

Once the decision is taken that life-sustaining therapies will be withheld or withdrawn, further treatment should focus on ensuring patient comfort and dignity. Effective limitation of life-sustaining therapies requires a multi-professional

approach to ensure a smooth transition from care and cure to comfort care only. This includes both adequate medical symptom control and support of the spiritual and emotional requirements of the patients and their families. Despite the likely extensive prior deliberations, the transition may still be perceived to be sudden and unexpected, especially by the family. It should be recognized that the timing of the withdrawal of life-sustaining therapies can be influenced to a small degree by clinicians in order to allow some time for patients and their families to experience a decent farewell.

When appropriate, all drugs and procedures that do not support the new therapeutic goal of comfort care should be discontinued. There is no need for gradual tapering of drugs such as vasopressors or antibiotics. On the other hand, drugs that help symptom control should be initiated or the dose increased until the intended effect is reached [23]. Especially, it should be remembered that there is no objective "maximum dose" for analgesics (Fig. 11.1). Whether patients need to be "terminally extubated" or whether only the ventilator settings need to be adjusted to "normal environmental conditions" (fiO_2 = 0.21, PEEP = 0) remains debatable. Most likely, procedures should be determined by the experience and best practice of the respective ED or ICU medical team in a way that maintains patient comfort and dignity [24–28]. There has been extensive debate regarding the withdrawal of fluids and nourishment during end-of-life care. In principle, an awake patient should receive fluids and nourishment orally according to his/her request. As there is no medical need for caloric intake at the end of life, in all other circumstances fluids should be administered as required for symptom control, whereas nutrition should be discontinued [27, 28].

As to the comfort needs of the patients and their families, a number of measures can be taken to facilitate the transition to comfort care, alleviate discomfort and stress as well as prevent post intensive care syndrome – family [29]. These measures include, but are not limited to, transferring the patient to a separate room in the ED or ICU to allow for unimpeded access for family; accepting religious rituals as long

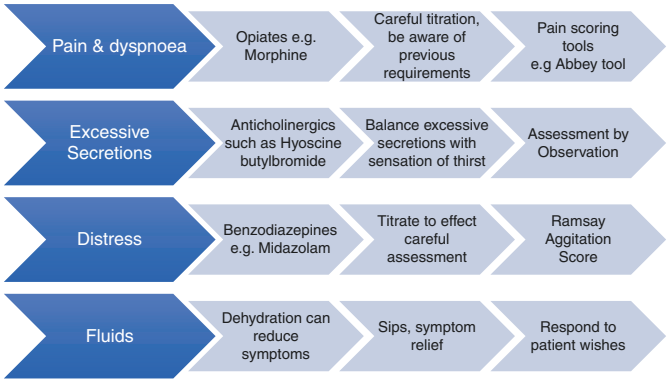

Fig. 11.1 Measures to increase comfort after the transition to palliative care

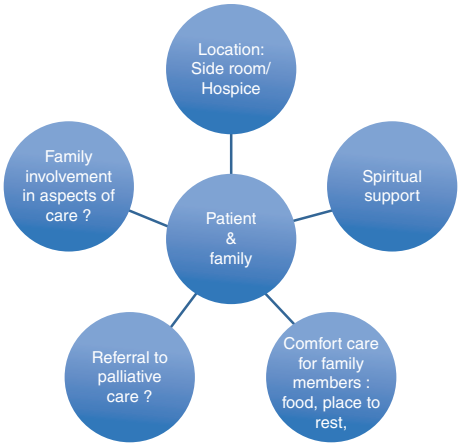

Fig. 11.2 Logistical considerations for supporting transition to palliative care: Careful consideration of the practical elements around location, family involvement, and support required can ease the transition and allow focus on the patient

as they do not impede medical care or other patients' well-being; and asking for palliative care consultation, if needed (Fig. 11.2) (see also Chap. 12).

Regarding documentation, it is recommended that a dedicated form for all treatment limitations be readily available under all circumstances. This form should document the reasons for treatment limitations (e.g., preexisting poor quality of life, prognosis, or patient preference), the persons who were involved in the decision-making (e.g., the patient himself, substitutes, intensivists, referring physicians, or a general practitioner), and the exact nature of the treatment limitations (e.g., removal or withholding of invasive mechanical ventilation and renal replacement therapy) [30].

11.7 Conclusions

Decisions to limit life-sustaining therapies are – implicitly most of the time – rooted in religious beliefs, cultural molding, societal norms, and the professional self-image of physicians, nurses, and other healthcare professionals as well as traditions and laws of the respective societal environment. Therefore, they are rarely generalizable or transferable globally. Nevertheless, implementation or prolongation of life-sustaining therapies without proper medical indication or against the patient's wishes and preferences is inappropriate and possibly illegal (in most legal systems). Therefore, life-sustaining therapies need to be withheld or withdrawn in a subpopulation of ED and ICU patients. In reality, such limitations imply the transition from cure to comfort care and correctly precede patients' deaths in many instances. End-of-life care has become an important task in modern care for critically ill patients – and it should be fulfilled with good ethical reasoning, prudence, and compassion.

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Advancing Palliative Care in Intensive Care and Emergency Medicine

12

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12.1 Introduction

Both the emergency department (ED) and the intensive care unit (ICU) can be daunting environments for patients and their family members. In these settings, patients with serious, life-limiting illness or injury often find themselves surrounded by unfamiliar faces, inundated with questions and overwhelmed by diagnostic testing and medical interventions. For many patients, critical illness or injury can lead to the inability to communicate one's own personal health preferences about care. When patients lack decision-making capacity, family members must field questions and make decisions about the medical treatment their loved one is to receive. Of the questions asked of patients and their family members, most focus on the history of present illness, and communication largely revolves around the proposed plan to stabilize and treat the patient's medical condition. Questions about values, goals of care, and treatment preferences may not have been addressed in the past and the acuity of the patient's illness often overshadows any attempts to discuss quality of

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life, symptom management, or emotional and spiritual needs. The failure to address these key components of care opens the door to medical interventions and potential consequences that patients and their family members may not have desired. Thus, many patients, even those who choose to receive life-sustaining treatments, may be left without a holistic assessment of their needs. One approach to remedying these deficiencies in communication involves incorporating the principles of palliative care into routine practice in the ED and the ICU.

Palliative care, also known as palliative medicine, focuses on improving the quality of life for patients with serious illness and their family members. Improvements in quality of life are achieved by control of symptoms, management of stress, and provision of emotional and spiritual support. Palliative care also involves addressing essential concepts with patients and their family members, including exploration of what "quality of life" means to them as well as delineation of their goals of care and treatment preferences. Any clinician can provide palliative care, in which case it is referred to as primary palliative care. Specialty palliative care is provided by individuals with advanced training in palliative medicine. There are many potential benefits related to the receipt of palliative care. In the ED, efforts to enhance palliative care have been associated with improved quality of life at 12 weeks [1], reductions in hospital length of stay [1, 2], and fewer ICU admissions [3]. In the ICU, palliative care has been associated with reductions in ICU length of stay [4] as well as higher family member satisfaction with care [5]. Despite these findings, there is still significant room for improvement in the implementation of palliative care in these settings. In this chapter, we discuss strategies to advance palliative care in the ED and the ICU. Ethical challenges addressed include variability in decision-making at the end of life as well as conflict between the patient, family members, and clinicians.

12.2 Advancing Palliative Care in the Emergency Department

The ED can be a hectic environment where it might seem impossible to thoroughly address a patient's values and treatment preferences. However, the delivery of palliative care in the ED is not only possible, it is of critical importance. In the ED, patients with serious, life-limiting illness often find themselves at a crossroads in their care, where they may feel torn between a desire to receive medical interventions focused on quantity of life and a desire to maintain an acceptable quality of life. Clinicians in the ED have a unique opportunity to help patients and their family members navigate this difficult terrain. To be able to seize this opportunity, education and training in palliative care should be required for all clinicians in the ED. This training should include basic principles of palliative care as well as education about the role of specialty palliative care. One core component of education should include the ability to recognize palliative care needs, specifically to be able to quickly identify individuals who would likely benefit from palliative care. The development of screening systems based on prespecified criteria such as age and/or comorbidity have significant potential to help prevent missed opportunities to

align patient preferences with their medical care [6]. Systems that capitalize on the electronic health record, especially those that integrate prior records of advance directives or living wills, may further streamline the process of identifying patients who would benefit most from palliative care [6].

The delivery of palliative care at the end of life is also an important skill for clinicians in the ED. In certain situations, when a patient has a critical condition that is not survivable or if the patient had previously delineated goals that do not include specific medical interventions, a decision to withhold or withdraw life-sustaining treatments or forgo resuscitation efforts may be made in the ED. This decision should involve the patient when possible or the patient's legally authorized surrogate decision-maker as well as the interdisciplinary team. In many circumstances, these decisions are made by the ED physician [7] with a little input from the nursing staff [8] or family members [8–11]. This may be ethically problematic when decisions to resuscitate the patients or withdraw life-sustaining treatments vary significantly from clinician to clinician, implying specific biases in decision-making [12]. Whenever possible, clinicians in the ED should make an effort to explore the patient's values and preferences and then use that understanding to inform recommendations for the patient and/or their surrogate decision-makers. In addition, clinicians should actively engage in interprofessional shared decision-making by including all clinicians involved in the patient's care, including physicians and nurses as well chaplains and social workers [13]. Protocol-driven comfort care orders and policies to guide the limitation of life-sustaining therapies should be utilized. When high-quality end-of-life care cannot be delivered in the ED, it is reasonable to pursue admission to acute care or the ICU in order to ensure that a patient's quality of dying can be optimized.

12.3 Advancing Palliative Care in the Intensive Care Unit

Unlike the ED, the ICU often affords more time to engage in conversations with patients and their family members. In many instances, patients are unable to participate in medical decision-making in the ICU, thus family members must serve as decision-makers for patients, substituting their own judgment for the patients or acting in the patient's best interest when the patient did not have previously articulated preferences for care. Multidisciplinary, proactive family meetings in the ICU may help improve communication between the treating team and the patient's decision-makers and can facilitate conversations about palliative care [14, 15]. Communication about prognosis is a core component of high-quality palliative care and prognosis should be addressed in these family conferences. Many patients will not survive their critical illness or injuries, so helping patients and their family members understand both short- and long-term prognosis can create opportunities to discuss the patients' preferences should their condition deteriorate despite critical care interventions. Depending on the clinical scenario, it may become apparent that life-sustaining interventions will not allow the patient to achieve their goals of care. When this occurs, a change of focus from attempts to cure disease to efforts

to manage distressing symptoms and provide supportive, holistic care may reduce suffering. As aforementioned, such far-reaching decisions require input of the entire interdisciplinary team [13]. In some cases, discussing a change of focus may generate conflict between members of the medical team and the patient and/or family member. The early involvement of palliative care clinicians in family discussions can help the ICU team navigate challenging situations and help prevent intractable disagreements when conflict arises about the plan of care [16].

Although routine family conferences are recommended [15], they often do not occur [17]. This failure of communication may lead to prolonged ICU stays and lower satisfaction with care in the ICU [4, 5]. To avoid these undesired outcomes, clinicians in the ICU must find ways to enhance their primary palliative care skills. Training programs that hone family-centered communication skills are needed, specifically programs that focus on factors associated with higher family satisfaction with care, including allowing the family ample time to speak, discussing symptom management, and being empathetic and supportive [18–20]. Clinicians in the ICU must also be able to recognize situations where it would be appropriate to consult specialty palliative care. Specialty palliative care clinicians should not be consulted in an effort to abdicate the primary team's responsibility to engage in difficult conversations with patients and their family members. The existing number of specialty palliative care clinicians is not sufficient to allow their involvement in the care of every seriously ill patient [21]; therefore, ICU clinicians need to develop strategies that will facilitate identification of those most likely to benefit from specialty palliative care. This might include patients with prolonged ICU stays, a high likelihood of not surviving their ICU or hospital stay or severe symptoms including intractable pain or dyspnea. Another potential indication for specialty palliative care involvement includes the management of complex psychosocial needs of patients and/or family members. The electronic health record, or at least the availability of prior health records, can be an important tool to assist clinicians in identifying patients at high risk of poor clinical outcomes who might benefit from earlier family meetings or involvement of specialty palliative care. Tools currently in development that use an app-based format to combine information from the electronic health record with family-reported needs have the potential to advance palliative care in the ICU [22].

In addition to efforts made by individual ICU clinicians to improve their communication skills and promote palliative care in their own practices, medical centers have a responsibility to develop a standardized approach to palliative care that meets the needs of their institution and patient population, while also adhering to guidelines that promote evidence-based practices for patient- and family-centered care in the ICU [15, 23]. This includes engaging clinicians in educational sessions about current recommendations and establishing consensus among ICU providers, specifically related to the practice of end-of-life care. This approach can contain consistent elements across ICUs within an institution (e.g., comfort care protocols), but should also account for aspects of palliative care that are unique to specific ICU settings, such as neuro-critical care units [24]. By establishing a framework, individual centers can reduce undesired variability in practice patterns

and provide more consistent, high-quality palliative care to patients and their family members.

12.4 Conclusions

In this chapter, we reviewed strategies to advance palliative care in the ED and the ICU. We addressed the role of high-quality primary and specialty palliative care in confronting and preventing ethical challenges in these settings, including variability in decision-making at the end of life and conflict between the patient, family members, and clinicians. In these environments, critical decisions are made about the medical care a patient receives, and those decisions can have lasting effects on a patient's quantity and quality of life as well as long-term psychological consequences for patients and their family members. By applying the principles of palliative care, clinicians can align medical interventions with the goals and preferences of patients and their family members, enhance management of symptoms, including pain and dyspnea, and provide emotional and spiritual support. At the end of life, it is important that patients and their family members recognize the option to receive care focused on symptom management, especially when ongoing life-sustaining interventions are not expected to achieve the patient's goals of care. Early and supportive palliative care discussions in the ED and ICU can attenuate distress for patients, families, and caregivers.

Several potential strategies may be employed to advance palliative care in the ED and ICU (Fig. 12.1). To apply these principles, clinicians in these environments need training in primary palliative care, and they also need to know when it is most appropriate to involve specialty palliative care clinicians. Although there is no "gold standard" for palliative care training, there are many valuable tools and resources available to clinicians and institutions [25]. To facilitate the delivery of palliative care to those who are most likely to benefit, systems must implement screening tools that utilize the electronic health record as well as patient- and family-based user technologies to identify patients with palliative care needs. Health-care organizations should recognize the potential benefits of developing consensus on key elements of palliative care, specifically end-of-life care, and make every effort to achieve consistency around core measures of high-quality palliative care.

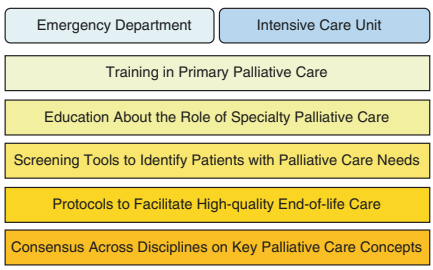

Fig. 12.1 Potential strategies to advance palliative care in the ED and ICU

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Organ Donation and Transplantation

13

Dale Gardiner and David Rodríguez-Arias

13.1 Introduction

An ethical organ donation and transplantation program regarding deceased donors would balance the needs of the organ recipient with the needs of the organ donor and his or her family. This chapter will explore the ethical challenges in trying to achieve this balance, paying particular attention to the impact organ donation can have on end-of-life care in critical care and emergency medicine.

Utilitarian language is often used to justify organ donation by emphasizing the benefit to organ recipients. There is certainly good in the utilitarian benefit of saving lives. Organ transplantation is one of the great medical success stories of the last 70 years and tens of thousands of lives have been saved as a result. Just as the space race had spin-off benefits to science, the drive for success in transplantation has driven other advances in medicine such as surgical skills, immunotherapy, and machine technologies. These advances have historically been led, almost exclusively, by members of the transplant community. Even the creation of organ donor registers owes more to the efforts of those waiting for transplants or who have received an organ, rather than to advocacy from those desiring to donate.

The last 20 years have witnessed the rise of a different movement, the emergence out of intensive care units (ICUs) and emergency departments (EDs) of a clinical donation community: physicians and nurses who champion donation. In many countries, a lay donation community of donor family networks and charities has

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grown, whose purpose is to offer emotional support to each other and also to promote organ donation within society. What is different in these donation communities, compared to transplant communities, is the language. Donation communities often use Kantian language, such that the moral imperative to donate arises from a desire to respect the end-of-life interest of the dying person to donate.

Most ICUs and EDs in the United Kingdom (UK) and Spain see deceased organ donors, not organ recipients. Therefore, what appears to have resonated and driven increases in the donation in our two countries were messages that put the preferences of the donor or those of his or her family ahead of those of the recipient. Has organ donation become a *right* at the end of life?

That dying and deceased people might have a right to become organ donors can be argued on the basis of two different principles: respect for the individual and individual benefit. The idea of respecting peoples' preference to become deceased organ donors presumes that interest to be a donor survives after death. This argument necessitates that health-care professionals try and ascertain the actual preferences of their patients toward organ donation. This is a challenge where a person has not expressed a preference in life and the preference must be inferred by families on the basis of their knowledge of the person's personality or the preference to donate is *presumed* in law by a failure to opt-out.

An alternative, less commonly expressed, justification for considering organ donation as a right is that organ donation itself *benefits* individuals and their families. An example of a benefit might be the creation of positive memories and legacy of the individual after death, and the potential for organ donation to positively impact on family grief. Importantly, the net benefit for an individual, that is, absence of harm and measurable individual benefit, is not an uncommon reason to support interventions without explicit consent, including vaccination, and participation of incompetent subjects in biomedical research with minimal risk. If the absence of harm and individual benefit are occasionally considered key for allowing non-consented interventions, these two factors become critical tests to justify organ retrieval from people who have never expressed a preference to become a deceased organ donor.

There has been much written about achieving a good death. While there are barriers to achieving a good death in an ED or ICU (e.g., suddenness of the event leading to admission or technology), intensive care can achieve a "good death" as judged by families. Yet failure in this area of care can result in a syndrome known as "complicated grief," an area of investigation in intensive care in its infancy. Good end-of-life care may reduce the incidence of complicated grief and more likely result in a good death [1].

In the first part of this chapter, we offer arguments suggesting that organ donation can involve important benefits, not only for the society, but also for the individual whose organs are donated, in terms of better end-of-life care. In the second part, we provide arguments suggesting that organ donation also involves potential risks that threaten optimal end-of-life care. Finally, we will conclude with suggestions regarding how an ethical balance can be found.

13.2 Organ Transplantation Can Foster Good End-of-Life Care

The Institute of Medicine defines a number of characteristics of a "good" death [2].

A good death should be one that is:

- In general accordance with the patients' and families' wishes.
- Free from avoidable death.
- Free from avoidable suffering for patients, families, and caregivers.

Have the increase of donations and the growth of a donation community within critical care and emergency medicine fostered good end-of-life care, and "good" deaths?

Only a few years back, the following scenario would have been very unusual in one of the author's (DG) ICU. An unsurvivable, 95% burns patient was admitted from the ED to an ICU side room solely to allow the patient's family to attend the hospital and say goodbye. There was no organ donation opportunity in this case. The patient was admitted, despite substantial logistic obstacles, to allow good end-of-life care and achieve, if possible, a good death. Yet this case and similar ones now occur frequently. What changed? Critical care bed capacity is still as stretched as it always has been in the UK. There was never any question about this patient surviving. Culturally, though, intensive care admission practice has changed. Previously, only patients who could physically benefit from intensive care, who had a chance for survival, were admitted. Now, end-of-life care is regarded as an acceptable reason in the UK for admission to the ICU despite a prognosis of no meaningful recovery.

13.2.1 General Accordance with the Patients' and Families' Wishes

The relentless focus of the donation community in the UK, of giving moral weight to the end-of-life wishes and needs of the dying, is impacting on the end-of-life care on other non-donation patients in ICUs and EDs. If one is willing to admit and explore a patient's wish to donate, then one should be willing to admit and explore other end-of-life wishes. If one is willing to delay the withdrawal of life-sustaining therapies for 24 h to allow donation to occur, then one should be willing to wait 24 h for the family to fly in and attend from afar.

ICUs and EDs in the UK were assisted in this shift by a new legal framework. "Best interests," according to the Mental Capacity Act (2005) and the Case Law that preceded it, are broader than "medical" best interests; broader than the physical or physiological benefit the patient might receive from intensive care. When a patient lacks capacity there is a legal duty to consult with those close to the patient to ascertain the patient's wishes, preferences, feelings, beliefs, and values. But how should this be interpreted when exploring donation potential?

The growth of Donation after Circulatory Death (DCD) has been particularly prominent in the UK and Spain, and both countries are world leaders. To reassure the medical profession regarding the legality of procedures to allow controlled DCD – a deceased donation which follows the withdrawal of life-sustaining treatment and the confirmation of death using cardiorespiratory criteria – the Departments of Health in England and Wales published legal guidance in 2010 [3]. This guidance restated that best interests extend beyond physical care to values, wishes, beliefs, and that it might be in the person's interests to donate:

- By maximizing the chance of fulfilling donors' wishes about what happens to them after death.
- By enhancing the donor's chances of performing an altruistic act of donation.
- By promoting the prospects of positive memories of the donor after death.

The legal guidance was not explicit that the individual expressed their donation preference in life and allowed for family interpretation of that expression:

> "If the person has not expressed views about organ donation directly, clinicians should attempt to determine what the person would have wanted had they been able to make the decision themselves. This should be based on what is known about their values and other matters which would have been important to them. The person's family may be able to give a view on what the person would have wanted based on their knowledge and experience of them as a person [3]."

What is interesting about this guidance is there is no mention of the recipient's need for organs as carrying any legal imperative. The legal guidance emphasized that the justification for deceased donation arose from the principles of both respect for the end-of-life wishes of individuals and individual benefits that might arise by donation to the individual and his or her family.

13.2.2 Free from Avoidable Death

Another part of The Institute of Medicine's definition of a good death is "one that is free from avoidable death." While organ donation is well known for saving lives, in the UK there have been anecdotal cases of donation saving the life of the donor! Rather than having withdrawal of life-sustaining treatments implemented in the ED, because the family had agreed to organ donation, it was delayed and the patient was instead admitted to the ICU. In rare but memorable cases, a few patients recovered and had better than expected outcomes – some even making full recovery. Manara and colleagues in Bristol, concerned about too early, and therefore wrong, neuro-prognostication in EDs, introduced a protocol for devastating brain injury that required intensive care admission for these patients [4]. This led to a UK Faculty of Intensive Care Medicine and Royal College of Emergency Medicine consensus statement being published in 2018, which recommended that intubated patients in the ED with devastating brain injury will require admission to critical care for a period of observation unless the extent of comorbidity grants no overall benefit regardless of potential neurological recovery [5].

In Spain, there are reported cases of patients being transferred to the hospital for uncontrolled donation after circulatory death (patients who unexpectedly have a cardiac arrest in the community and after failed resuscitation are transferred to a donation hospital), who experienced total recovery despite the fact that the ongoing interventions they were receiving on the journey to the donation hospital were strictly intended to preserve their organs. According to Mateos-Rodríguez and colleagues, "if these individuals had not been included in the donation protocol, resuscitation would have stopped after 30 minutes and the patients would not have survived [6]."

These are two examples of how organ donation benefits the wider critical care and emergency medicine patient populations and is fostering safer end-of-life care practices. Another example is the area of diagnosing death. When the organ donation community asked the whole medical community what the earliest time was after cardiorespiratory arrest one could safely diagnose death to allow DCD, the answer in the UK was, "5 minutes" – and this became a criterion for death in all patients in the UK, not just organ donation patients [7]. This allowed the growth of UK DCD, but it also made the diagnosis of death safer for *all* UK patients where case reports of prematurely diagnosing death (before 5 minutes and outside of donation contexts) had occurred to disastrous effect [8].

13.2.3 Free from Avoidable Suffering for Patients, Families, and Caregivers

> "We will never forget the support and love you and your team showed to us all.
> You made the journey a little easier."
> (Family feedback from a UK non-proceeding donation after circulatory death patient in September 2014.)

Pursuing a good death that is free from avoidable suffering for patients, families, and caregivers and acting in general accordance with the patients' and families' wishes are universal values for potential and non-potential donors alike. When pursued synergistically, even when donation does not occur, and there is no "silver lining donation effect" one can still be thanked by families for the care one has delivered. Such "thank-you feedback" should be valued as high, if not higher, than feedback from proceeding donor families. This should be the litmus test for knowing if one is delivering world-class end-of-life care.

A key person for supporting improvements in the family experience of end-of-life care in intensive care and ED environments has been medical leads and specialist nurses for donation. In countries such as Spain, where most transplant coordinators are intensivists, relationships of trust with the family can be developed before there is an organ donation approach. The transplant coordinators are often considered the best person to communicate bad news to a family because they all have received specific training about communication and are selected into their role because of their skill and empathy. Achieving excellent standards in end-of-life care to potential donors and their families could explain lower rates of family opposition against donation in Spain than in other countries.

With the above exploration, it should therefore not be surprising that it is the organ donation community in the UK that currently runs the only national course for critical care trainees on the safe diagnosis of death, end-of-life family communication, and ethical decision-making. As one anonymous delegate said in 2018, "The reputation of this course precedes it, not only for the organ donation content, but partly because this may well be the only formal ethics/communications skills training an intensivist gets" [9].

The focus from the organ donation community is on promoting Kantian values of respecting the end-of-life wishes of the deceased. Such endeavors have led to increasing numbers of donors and changed emergency medicine and intensive care culture in end-of-life care. Organ donation has taught clinicians in these clinical areas better ethics – and this is resulting in better end-of-life care for all patients. Organ transplantation is fostering good end-of-life care.

13.3 Organ Transplantation Can Threaten Good End-of-Life Care

The way patients are treated in the last moments of their lives determines not only the quality of their death as outlined above, but also the manner, place, and time of their deaths. These latter factors can affect the viability of organs for transplant. Such a tight link between end-of-life practices and organ retrieval implies that decisions on maintenance or withdrawal of life-sustaining therapies can be more or less conducive to transplant outcomes. Conversely, the possibility of an impending organ donation can alter the way patients are cared for in the last moments of their lives, in order to facilitate optimal organ recovery. This can create a moral tension because the optimal care of a patient may not be compatible with the optimal chance of obtaining the organs and vice versa. Hereafter, we will explore the two areas we consider at the highest risk for organ transplantation threatening good end-of-life care: conflicts of interest and the use of potentially disrespectful and potentially harmful practices.

13.3.1 Conflicts of Interest

When individuals are simultaneously being considered as patients and as potential sources of organs, professionals who deal with them are faced with conflicts of interest that may threaten the interests of potential donors. In their common statement, the *American Thoracic Society*, the *International Society for Heart and Lung Transplantation*, the *Society of Critical Care Medicine*, the *Association of Organ and Procurement Organizations*, and the *United Network of Organ Sharing* recommend:

> "If real or perceived conflicts arise between the goals of providing optimal end-of-life care and the goals of procuring organs, delivery of quality end-of-life care should take priority. Organ procurement does not necessarily conflict with the provision of palliative care at the end-of-life. Because interventions intended to preserve organ function may respect the patient's donation preferences, even invasive interventions may be consistent with patient-

centered end-of-life care. However, real or perceived conflicts may arise. Such incipient conflicts ought to be resolved through maximal attention to the patients' expressed preferences for end-of-life care. Patients or their surrogates should be informed of how certain end-of-life treatment strategies may affect opportunities for donation before their initiation" [10 (pp. 104–105)].

A conflict of interest occurs when the judgment that a health professional makes about what should be their primary interest, that is, their patients' safety and respect, might be influenced – consciously or not – by a secondary interest (helping organ recipients) [11]. Importantly, pursuing a secondary interest is not in itself wrong or bad; it only becomes inappropriate when the primary mission of the profession is subordinated to the achievement of that secondary goal and compromised by it. What is at stake here is not only the welfare of patients and their respect, but the credibility of the professional. Conflicts of interest do not necessarily lead to inadequate or harmful practices, but they are a favorable breeding ground for unprofessional practices that may end up undermining the trust society gives to professionals. A classic often used example of conflicting loyalties is health professionals involved with patients awaiting transplantation, who are simultaneously caring for another seriously ill patient whose death could save the life of the patient awaiting transplantation.

Guidelines and recommendations worldwide are intended to prevent professionals who will participate in organ retrieval and transplantation from being involved in the care or in end-of-life decision-making for those who may become candidates for organ donation [12–14]. For instance, the *House of Lords of the European Union Committee* has stated that prioritizing donors' interests may have the effect of losing opportunities for donation [15]. Nevertheless, it claims that health professionals owe primary loyalty to their patients, and only have subsidiary duties to the potential recipients of their organs [15].

In Spain, the majority of transplant coordinators are critical care or emergency physicians who hold responsibilities for identification and evaluation of potential donors, support for the maintenance of potential donors in critical care, and the approach to families for organ donation [16]. Their access to potential donors and their authority in the ICU prevents loss of donors due to non-detection or lack of staff motivation in maintaining donor candidates until brain death is confirmed and the family is approached about organ donation. When transplant coordinators are also ICU physicians who have participated in the treatment of the patient, their contact with the families provides them a chance to promote family satisfaction and trust in the medical institution – factors that facilitate the request for retrieval. However, their advantageous position also makes them face some conflicts of interest. In some Spanish regions, hospitals pay health professionals involved in the donation process bonuses for the successful facilitation of organ donations [17]. Spanish transplant authorities have claimed that variable – rather than fixed – compensation for professionals is more conducive for organ donation [18] and that such incentive bonuses "could stimulate a more continuous and dedicated search for donors" [19]. Still, the question must be raised of whether these professionals' judgments about the best interest of patients (some of which have expressed no preference regarding organ retrieval) and the best interest of their families are biased. There is no evidence

suggesting that professionals' economic incentives, in Spain or elsewhere, have indeed undermined the interests of potential donors or their families. One possible way to address whether organ retrieval is interfering with end-of-life practices is to compare the rate of withdrawal of life-sustaining treatment in hospitals before and after introducing a DCD program.

In all professional domains, the subordination of a primary interest to secondary interests degrades the very nature of any profession, which might not only harm or wrong individuals, but also damage the trustworthiness of the profession itself. Conflicts of interest can have a negative impact on medical reputation and on the professional practice of medicine. This is particularly worrisome for transplantation medicine, the long-term success of which depends on public trust for people to allow the retrieval of organs. Recognizing the existence of conflicts of interest is a necessary first step to try and prevent their most deleterious effects.

Outside of Spain and the UK, a 2015 Canadian publication "Ethics Guide for Donation Physicians" provided an important distinction in managing conflicts of interest, between disclosure and institutional trustworthiness [20]. Automatic and insensitively timed disclosure of a donation physician's role may be potentially harmful to a family, especially when the motivation to disclose is professional protection rather than information sharing of relevance to a family's donation decision. Putting the onus on the family to determine whether a role disclosure represents a conflict of interest and whether they should be concerned about this, might cause confusion and mistrust, given the grief and stress the family is already under. What was recommended is that a physician who is both a treating intensive care physician and a donation physician should disclose his/her role as a donation physician as soon as donation conversations begin with the family [20]. The guide posited that the essential patient protection for inevitable conflicts of interest was not disclosure, but institutional trust, created by implementing appropriate and clear role boundaries.

13.3.2 Potentially Disrespectful and Potentially Harmful Practices

The process of organ donation could compromise the interest of donors either by failing to protect them from the forms of harm that would be avoided if the patient fails to become an organ donor or by failing to respect their preferences [21]. The concepts of protection and respect deserve to be distinguished, as potential donors can be disrespected without being harmed and harmed without being disrespected.

In opt-out countries, like Spain, individuals who are presumed to be candidates for organ donation may undergo a number of non-consented interventions. For instance, using cardiac compression and commencing extracorporeal membrane oxygenation (ECMO) without consent in uncontrolled DCD, or maintaining non-beneficial mechanical ventilation in catastrophic brain injury patients until brain death can be determined, increase the chances that some patients will get more interventions than wished for. While these interventions cannot be beneficial for the patient, it is doubtful, given the patient's severe coma or confirmed death, that this could be perceived as physically harmful by them. Still, these interventions might extend the length of the dying process or artificially interfere with family grief. This

would suggest that the intervention could, therefore, be harmful to the family, but only disrespectful for the patient. Such conclusions are controversial and do not necessarily accord with concepts of bodily integrity. A more serious risk is that the patient might evolve into a chronic condition such as a persistent vegetative state as a result of the maintenance of non-beneficial life-sustaining therapies.

Prospective donors can be harmed – without necessarily being disrespected – if, as evidence suggests, the use of sedatives paradoxically slows the dying time in controlled DCD [22], and whenever potential donors deliberately authorize interventions that may threaten their health, their well-being, or even their life [23].

In those countries where DCD is practiced there have been discussions regarding the determination of the moment of death. The determination of brain death usually is very strictly stipulated by institutional protocols. In some countries, death by circulatory criteria is also well-defined. The moment circulation stops, preferably monitored by an intra-arterial line, the no-touch period starts. This period is necessary to rule out auto-resuscitation. After the period stipulated, typically 5 minutes, death is declared. In this specific circumstance, it is important to understand that the brain damage after circulatory arrest in DCD happens, because no resuscitation attempt is made – not because it is impossible. So, the determination of death due to circulatory criteria is based on the fact that brain circulation has ceased permanently, but not irreversibly. Irreversibility, however, will ensue within a short time.

From the view of lay relatives, the concept of circulatory determination of death is much more accepted than the concept of brain death. Therefore, the ethical dilemma of DCD donors not being irreversibly brain dead is more a professional problem than a public issue.

In DCD, interventions focused on prioritizing organ retrieval may involve some risks to wrong the experiential interests of the donors to have a "good death". These risks include unduly shortened life (if the organ donation request is made either by the donor or the family before rather than after a decision is made to withdraw life support), suboptimal end-of-life care if the use of anesthetics is feared as potentially hastening death, and actual pain as a result of accidentally restoring brain functioning by introducing organ preservation techniques, such as ECMO. The discussion on whether or not death itself is a harm for patients who are beyond any chance of meaningful survival with an acceptable quality of life is a question that we cannot address here.

Organ preservation and donor management will alter the end-of-life care that dying patients in critical care and emergency medicine receive. Therefore, organ transplantation can threaten good end-of-life.

13.4 Conclusion

The starting position of our chapter was that an ethical deceased organ donation and transplantation program should balance the needs of the organ recipient with the preferences of the organ donor and his or her family. We explored aspects of the organ donation process at the end-of-life that might foster or threaten end-of-life

care and a good death in critical care and emergency medicine. The solution to achieving this ethical balance is not easy, but the responsibility is clearly with the organ donation and transplantation communities and their wider healthcare and research colleagues to work together so that good end-of-life care for donors is achieved while simultaneously increasing the number and quality of deceased donor organ transplants.

We have a concluding suggestion to help both communities. If the language of the donation community leans toward Kantian ethics to justify their approach, and the transplant community toward a utilitarian language, then perhaps the language of *rule utilitarianism* is a useful framework for professionals to reach an acceptable balance. Such a moral framework would compel health professionals to categorically respect certain rules about respecting and protecting donors because honoring these rules leads to the greater good.

From our chapter we propose three rules:

1. The exploration of organ donation for all patients dying in ICUs and EDs should be pursued, as organ donation might improve end-of-life care and can honor the ideal of a "good death"
2. Organ donation must never compromise a "good death" and
3. All parties should seek to build institutional trustworthiness based on the respect and the protection of potential organ donors, and the minimization of conflicts of interest.

Organ transplantation from deceased and living donors is one of the great medical success stories of the last 70 years. Let us ensure that in 70 years hence when perhaps there is no longer organ donation and organs are either grown or manufactured, historians will write of the organ donation and transplant community that they did not unduly compromise the fundamental interests of dying patients even as they saved thousands of lives.

Disclaimer Dr. Gardiner is National Clinical Lead for Organ Donation for NHS Blood and Transplant, UK. The views expressed in this chapter are his own.

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Part IV

Disproportionate Care

Disproportionate Care, Ethical Climate, and Moral Distress

14

Bo Van den Bulcke and Dominique Benoit

14.1 Introduction

This chapter focuses on clinicians' perspectives on disproportionate care, moral distress, and the structure of the ethical decision-making climate concept. The authors discuss how disproportionate care is perceived, empirically measured, and sometimes accepted as part of everyday clinical practice when end-of-life decisions must be made. The need for more open and honest dialogue, along with active leadership, mutual respect and trust within the interdisciplinary team to mitigate the moral distress and improve the ethical climate, remains a consistent theme in the actual health-care landscape.

The initial goal of intensive care medicine is treating previous comparatively healthy patients suffering from organ dysfunction(s) until full or partial recovery. However, since the past decades, there is an increasing referral of patients with chronic underlying comorbidities or poor quality of life to intensive care units (ICUs) with an increasing ICU use in the last month(s) of life [1]. Clinicians and families are challenged to make decisions regarding whether life-sustaining therapies should be withdrawn or withheld [2, 3]. During this complex and uncertain process, an interprofessional team, where clinicians act together in a coordinated way, is crucial to fully appreciate the patients' context and work toward holistic planning, including a common goal setting and shared decision-making [4, 5].

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Despite this interprofessional context, respectively 73% of European and 87% of Canadian critical care physicians declare that they frequently admit patients with poor outcome expectations, indicating that this complex process is not handled well. Non-beneficial treatments are not only associated with higher costs for hospitals but also with reduced quality of life near end-of-life processes and lower perceptions of quality of care by patients and families [6, 7]. Moreover, the daily ethical challenge to consider whether life-sustaining therapy is perceived as appropriate or disproportionate *(non-beneficial, "futile")* frequently leads to clinicians' moral distress [8–12].

Moral distress occurs when an individual's moral integrity is seriously compromised, either because one feels unable to act in accordance with core values or obligations, or attempted actions fail to achieve the desired outcome [13]. This "inability to act" is particularly prevalent among ICU clinicians where ethical decision-making is part of everyday clinical practice [14]. For example, the application of prolonged life-sustaining treatments with little hope of survival is a repeated source of moral distress for the ICU clinician. Each time a similar morally distressing situation occurs and is not resolved, the level of residual moral distress rises. In addition, it is well known that clinicians experience professional burnout or fatigue as a consequence of repeated experiences with moral distress and/or unresolved ethical issues [14–16]. Together with moral distress, burnout is linked to poor clinician well-being, job dissatisfaction, and job leave [12–16]. The detrimental effect of clinicians' burnout, including unprofessional behavior and declined empathy, has negative effects on patient care (e.g. reduced patient satisfaction and higher rates of medical errors) [17–20]. Together with interventions focusing on individual clinicians' resilience to alleviate moral distress, cultivating a good ethical climate is a fundamental step to influence clinicians' attitudes and integrity [21]. Each clinician's way of thinking and feeling should be taken into account when addressing morally complex issues. In this chapter, we are focusing on the relations between disproportionate care, ethical climate, and moral distress.

14.2 Disproportionate Care and Ethical Climate

Perception of disproportionate, mainly excessive, care is common in the ICU. Different large multicenter studies are showing similar results. In the APPROPRICUS Study, we found that 27% of the clinicians working in ICUs in Europe and Israel perceived the care as excessive in at least one of the patients they had to take care of on the day of the study (almost 93% as excessive care). A similar prevalence was subsequently found by Anstey et al. in California [6]. Beside ICU-related organizational factors, such as hospital hierarchy pressure or financial advantages, team and communication factors, such as decision-making attitude or poor team communication, are perceived by team members as fundamental causes of excessive care [7]. While doctors ascribed prognostic uncertainty [6, 7] as the main reason to continue excessive care, nurses charged physicians with a lack of initiative and poor intra- and extra-team communication [4–6]. Unifying nurses'

and physicians' points of view regarding moral distress is necessary to encompass an interdisciplinary team perspective [5].

In particular, the ethical climate, defined as "individual perceptions of the organization that influences attitudes and behavior and serves as a reference for clinicinas' behavior", should be recognized as an important factor that contributes to the level of moral distress [5, 6]. The European and US DISPROPRICUS Study (Disproportionate care in ICUs), discussed in the following paragraphs, was specifically aimed at integrating a team perspective, regarding ethical climate and moral distress, and analyzing the perception of disproportionate care by clinicians in relation to individual patients' situations [4–7].

14.3 Results of the DISPROPRICUS Study

For this study, disproportionate care was defined as "care which is perceived by clinicians as disproportionate ('too much' or 'too little') in relation to the expected prognosis of the patient in terms of expected survival or quality of life or to the patients' or relatives' wishes" [22, 23]. The main objectives of the DISPROPRICUS Study were to (1) to examine the incidence, time of onset, and duration of (perceptions of) disproportionate care and the accompanying degree of moral distress among doctors and nurses in Europe and the United States during a 28-day period; (2) to assess whether perceptions of disproportionate care are informative about the patient's 1 year prognosis and in which circumstances these perceptions are informative; (3) to assess how the first two objectives are affected by the ethical climate prevailing in the unit; and (4) to determine the relation with intent to leave.

14.3.1 Measurement of Ethical Climate

In the context of this study, a 35-question self-assessment instrument was first developed through a modified Delphi method that created a theoretical framework for ethical decision-making. The tool was subsequently validated in 68 ICUs in 13 European countries and the United States. The ethical decision-making domains included within the ethical decision-making climate questionnaire (EDMCQ) are interdisciplinary collaboration and communication, leadership by physicians, and ethical climate. Although moral distress can manifest in many ways, the EDMCQ allows us to specifically identify aspects of the ethical climate domain as factors related to moral distress due to decision-making in ICU care (Fig. 14.1).

14.3.2 Patient's Level

The hypothesis of the DISPROPRCUS Study was that perceptions of excessive care in better climates would be more informative about the 1-year outcomes compared to poorer climates because the better the climate, the more nurses and physicians

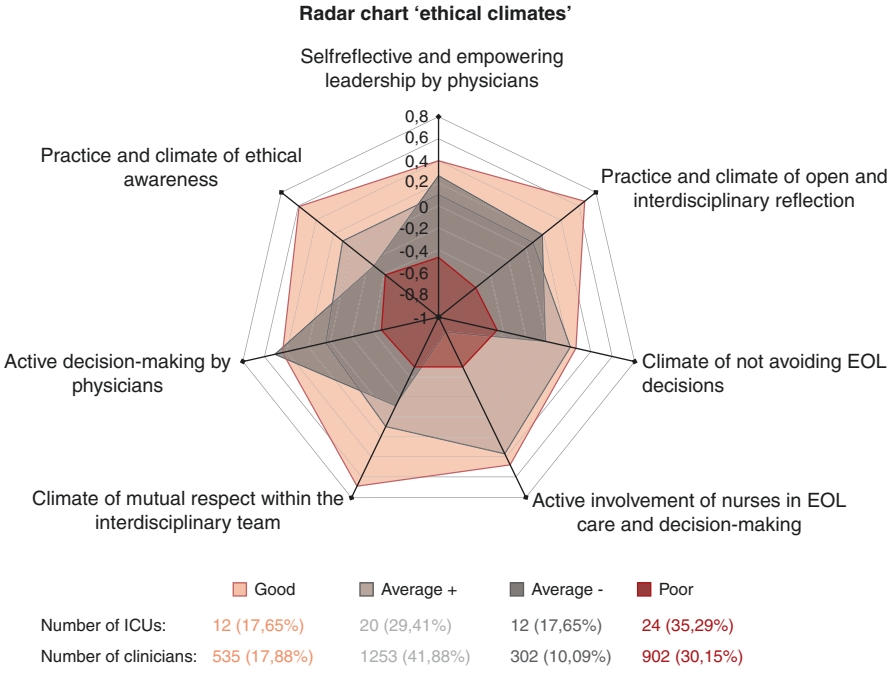

Fig. 14.1 Radar chart ethical climates. Reproduced with permission from [22]

share knowledge, experience, emotions, and values. After clinicians completed the EDMCQ, daily anonymous perceptions of disproportionate care ("too much care" vs. "too little care") for each patient were collected over a 28-day period. The primary patient endpoint of this study was death, not living at home or a utility score of ≤0.5 on the EuroQoL-5D questionnaire at 1 year. Secondary endpoints were time from identification of patients receiving excessive care according to at least two different clinicians until treatment limitation and death. Throughout different ICUs, the course of 1761 patients (96% required organ support) was examined. Of these, 181 (10.3%) had concordant perceptions of excessive care by at least two clinicians. This subgroup of patients was more likely to reach the primary composite endpoint in ICUs with a good ethical climate (100%) compared to those with a poor ethical climate (85.9%) ($p = 0.02$). Patients with concordant perceptions of excessive care were also more likely to have a written treatment limitation decision in ICUs with a good ethical climate. However, the latter observation was lost after adjustment for different case-mix, hospital, and country characteristics. The median time until death was significantly shorter for patients with concordant perceptions of excessive care in ICUs with a good ethical climate (5 days, interquartile range 2–18 days) compared to a poor ethical climate (14 days, 7–30 days) ($p < 0.05$). It is also important to highlight that the probability of achieving the combined endpoint at 1 year in patients without concordant perceptions across all climates was 55.5%.

This indicates that a substantial percentage of patients admitted to the ICU is, in fact, palliative, but is not acknowledged as such.

These results highlight the urgent need for improving advance-care planning (before ICU admission), admission triage, and end-of-life decision making in the ICU, more specifically via ethical climates favoring interdisciplinary reflection and collaboration and early involvement of palliative care [5, 7]. This may benefit the quality of care and especially end-of-life care.

14.3.3 Clinicians' Level: Intent to Leave and Burnout

Another objective of the DISPROPRICUS Study was to assess the relationship between the quality of the ethical climate in the ICU and intent to leave after taking the country, ICU, and clinician factors into account. The author group hypothesized that the better the quality of ethical climate in the ICU was, the lower the intent to leave would be among clinicians [23].

More than half of US physicians are affected by burnout, depression, and anxiety problems [16–20]. Large international nursing studies confirm the rates of intent to leave and actual job turnover. Many physicians seem to retreat to the world of "prognostic uncertainty," in which everything remains possible so that waiting seems the best and safest option. However, in this way, physicians may fail to recognize that this "wait and see" strategy is often perceived by the team as an alibi for physicians to avoid having to make a decision and causes moral distress among the team members [6, 13, 17]. To deal with this clinical uncertainty, clinicians should speak about their moral distress more openly. Prevention tools aimed at mitigating moral distress and burnout, such as resilience and mindfulness, tend to focus on the individual clinician. Hence, integrating those tools with a greater focus on being respectful, self-aware, and reflective as a team is a necessary step to reduce burnout and intent to leave the job [5, 22–26].

Recent findings help us to focus on the impact of different factors of the ethical climate on clinicians' intent to leave [23]. The experienced differences in the quality of ethical climate between units, hospitals, and countries, despite comparable staffing levels, competencies, and patient mix, highlight the importance of a good ethical climate [23]. Even after adjusting for clinicians' ICU and country characteristics, the risk of intent to leave was lower in clinicians working in ICUs in a good, average$^{(+)}$ and average$^{(-)}$ climate compared to clinicians working in ICUs with a poor climate (with a $p < 0.05$ for all comparisons). The most important independent ethical climate factors associated with an intent to *not l*eave were mutual respect within the interdisciplinary team, open interdisciplinary reflection, and not avoiding end-of-life decisions by physicians. Clinicians working in countries with a higher Big Mac Index (i.e., the cost of a Big Mac in 120 different countries as retrieved from the World Bank website), clinicians at younger age and clinicians working in ICUs with higher mortality, were independant factors signifcantly associated with a higher intent to leave.

14.4 Future Perspectives

Apart from our ethical basic health-care principles as beneficence, non-maleficence, respect for autonomy, and distributive justice, we should learn to invest more in creating a different principle, the ethical environment as such [5]. A critical key to learning from experience is the ability to openly and honestly discuss the risks, concerns, and even failures that inevitably occur in any complex ethical issue. Such respectful honesty requires courage, especially if people are afraid that they will be punished for speaking up [6, 8, 22, 23]. A safe, respectful climate and culture of self-reflection and open communication does not come naturally in ICU settings [27]. Physicians should use their leadership to actively create such an environment and should facilitate ethical discussions. To improve they should be more closely involved in interdisciplinary decisions, and a critical engagement should be supported at the organizational level. Moral distress can thus be both a challenge and an opportunity and might lead to increased team reflection, a better mutual respectful understanding and collaboration, thus generating better patient and family care [9–13]. Since patients and surrogates are often unaware that their prognostic estimates differ from those of physicians, recent findings highlight the importance of improving prognostic communication and understanding [25]. The author group found a disagreement between clinicians and patients/surrogates about the appropriateness of treatment for one-third of ICU patients [25]. This disagreement was associated with prognostic discordance and lower patient/surrogate satisfaction. Patients/surrogates who reported inappropriate treatment also reported lower satisfaction and trust in the ICU team. Further longitudinal studies concerning the ethical climate could focus on including patient and family perceptions and possible significant relations with different factors of the ethical climate. Adding qualitative results (e.g., interdisciplinary discussion groups with the patient' and surrogates' perspectives) could help answer the question as to which level of care is appropriate – and how to achieve it.

This future research is needed, but challenging because it stimulates ethical awareness and reflection among clinicians and therefore confronts them with their own responsibility in the decision-making process of patients at the end of their lives. It makes them aware that a change in culture starts at the bedside and with themselves, rather than coming from the top. Culture starts with the leaders' integrity and emotional intelligence. Senior and junior physicians remain key players since they have to install a safe EDM climate, however, they are no longer the only player in the decision-making process. Clinicians should consider an interprofessional shared decision-making model that allows for the exchange of information, deliberation, and joint attainment of important treatment decisions [28].

14.5 Conclusion

Altogether, the results of the DISPROPRICUS Study suggest that improving the quality of the ethical climate in ICUs may favor the identification of patients receiving excessive care and the subsequent end-of-life decision-making process. This

may benefit the quality of end-of-life care in ICUs and reduce the intent to leave the job in clinicians [5, 22, 23]. Future studies could include qualitative results concerning the specific ICUs' needs, using EDMCQ, and other climate measurements to improve ethical environments, with a focus on reducing (the perception of) excessive care and its consequences for the patients, relatives, clinicians, and society.

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Part V

The Way Ahead

15 To Treat or Not to Treat: How to Arrive at an Appropriate Decision Under Critical Circumstances

Andrej Michalsen and Nicholas Sadovnikoff

Health-care delivery is an intricate and complex process performed with an abundance – and perhaps sometimes an excess – of medical, financial, societal, cultural, religious, and legal conditions and stipulations. Despite the many external factors, the core focus of health care needs to be maintaining or restoring the health of individuals as well as populations. Emergency and intensive care medicine play a crucial role with regard to this task, as they can help patients and their family members navigate extraordinarily difficult phases when their life, limb or organs are at risk. Most patients are admitted to emergency departments (EDs) and/or intensive care units (ICUs) with a curative or restorative goal of therapy. Owing to remarkable technological progress, notable gains of evidence and treatment guidelines, as well as considerable education of ED and ICU clinicians during the last decades, this goal can be achieved more often and more successfully than ever before in many countries of the world.

To begin with, however, resources for health care as well as the rates of health-insured citizens are very unevenly distributed across the world's societies and populations, with striking variation not only between continents and countries but even within countries and regions [1]. Subsequently, access to health care is by no means equal for all in need. Second, this inequality notwithstanding, demands and claims as to health-care delivery seems to have risen remarkably – perhaps especially in aging populations – as if everybody were entitled to immediate and sustained "healing of all wounds" via the latest technology. And as in today's world misfortune appears to be unfashionable in most societies, treatment failures in health care

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become construed as man-made, and specifically (and more perniciously) caused by clinicians. Conversely, the resources allotted to health care do not seem to follow these increasing demands. Third, despite elaborate treatment regimens properly administered, still between 15% and 30% of patients in ICUs do not survive their illnesses or injuries, often after decisions that further life-sustaining treatments are not indicated or not seen as appropriate [2, 3]. Fourth, the assessment as to when or how long the application of life-sustaining treatments in EDs or ICUs is appropriate as opposed to when it only prolongs undue suffering for the patient and the family can be complex and conflictual [4]. Although agreement has been reached as to a number of principles of end-of-life care (EOLC) [5], there is still a large variation worldwide [6, 7]. Recent evidence suggests it is plausible that the most important source for this variability of EOLC actually is not the country or the region of where the care is rendered but rather the practice variability of individual physicians [8]. Fifth, improved intensive care treatments have resulted in more patients surviving with reduced quality of life. This entails trade-offs for many patients, their families, and the ICU teams that need to be addressed [9].

Given all these challenges and obstacles regarding health-care delivery that arise not exclusively but with great frequency in EDs and ICUs, would clinicians not understandably be discouraged to take decisions as to the extent of treatment, joining in with Hamlet's lament, "The world is out of joint, oh cursed spite / that ever I was born to set it right?"

Perhaps it is helpful for the process of decision-making to first remind ourselves of the ethical base and the factual prerequisites of medical reasoning and acting. The former has been exemplarily depicted by Beauchamp and Childress as the widely known four principles of biomedical ethics [10]; the latter are the known two columns of indication and informed consent, which support our actions [10, 11]. While it needs to be clear that medical indications are only formulated by clinicians (and in most legal systems ultimately by physicians), indications in a broader sense need to take the patients' wishes into account, otherwise a truly informed consent would not be granted.

First of all, however, three important caveats need to be mentioned: (1) The four ethical principles alluded to above represent widely accepted convictions; they are not universally acknowledged and may need to be adjusted to local circumstances or stipulations; however, it is important to institute a set of reasoned ethical rules on which to base medical acting, (2) In medical emergencies or under prevailing scarcity of information, immediate remedy, often leading toward a time-limited treatment trial, is usually justified [12] (3) Indications may need to be changed or altered in the course of an illness or an injury, and consent can be revoked at any time.

Second, ahead of all important clinical decisions, it is prudent to deliberate all relevant diagnostic and therapeutic options pertinent to each individual patient within the treating team at large. Making use of the combined expertise and knowledge of all team members involved can lead to better-reasoned and more robust decisions. A good ethical climate within an ED or ICU will help to achieve such interprofessional shared decision-making – a poor ethical climate will not [13, 14].

Third, the clinical decision regarding the contents, the extent, and the goal of treatment then need to be discussed with the family (perhaps the family-at-large) and/or the patient's legal representative, occasionally with the inclusion of other stakeholders. The goal of such shared decision-making in the context of family meetings is to arrive at a medically sensible treatment goal that integrates the patient's wishes and values [15]. Requests for potentially inappropriate or disproportionate care need to be handled with respect but firmness [16, 17]. The integration of palliative care concepts into intensive care may help foster an understanding of when the goal of therapy ought to be changed from curative care to comfort care only, and may thus also help to facilitate good quality end-of-life care [18, 19].

Fourth, when they do not survive, critically ill patients succumb to their illnesses or injuries, in the majority of cases, despite the admirable efforts of the team. Every death is a loss, a loss of a unique person with a distinctive narrative of life, but clinicians should not regard the death of a patient as their personal failure, a team failure [2, 3], or a source of despair. Rather, "What shall he fear who fears death not?" (Friedrich Schiller, *The Robbers*).

To meet compelling ethical challenges ultimately requires a clear understanding of what *not* to do in the course of caring for patients and their families. To this end, a triumvirate of renowned clinical ethicists has provided us with a respective list of eight things they would abstain from doing with regard to end-of-life care in the ICU [20]. Among others, these include not providing a non- or no longer beneficial treatment, not intentionally allowing ongoing pain, anxiety, dyspnea, or other forms of suffering, and not making an end-of-life decision and implementing it without discussing it with the patient and/or family as well as other medical team members.

To take decisions and meet ethical challenges under critical circumstances, a number of which we have explored in the preceding chapters, requires not only a firm knowledge of the relevant medical principles and practices but also a stout mind and a well-developed set of so-called soft skills – namely, respectful leadership with persistence in communication, cooperation, and consensus-building within teams, across the borders of professions and hierarchical levels, and with patients and families.

In summary, the question – we propound – is not whether to treat or not to treat in critical circumstances. Rather, the question is to what extent and with what goal to treat – and how to adjust these two determinants when need arises to do so.

The aim of treatment and care needs to be their appropriateness such that the nature of the ensuing measures neither encompasses more nor less than the matter requires (after Immanuel Kant).

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Part VI

Epilogue

Epilogue: Critical Care During a Pandemic – A Shift from Deontology to Utilitarianism?

16

Andrej Michalsen, Marco Vergano, Michael Quintel, Nicholas Sadovnikoff, and Robert D. Truog

16.1 Introduction

On March 11, 2020, the Director-General of the World Health Organization, Tedros Adhanom Ghebreyesus, officially declared COVID-19, caused by the coronavirus SARS-CoV-2, a pandemic. Originating from China in December 2019, this pandemic spread with almost unprecedented speed across the world over the following weeks and months, taking an equally unprecedented toll of infection of hundreds of thousands of citizens. However, there was a remarkable variation regarding the distribution between and within regions and countries as well as the impact in terms of incidence, prevalence, basic reproduction number, and case fatality rate [1–3]. In response to the pandemic, public health measures taken by provincial and national governments, such as decreeing social distancing, contact restrictions, and curfews,

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have had an impact on the way of life of millions of people to a degree hardly experienced in Western democratic countries since World War II. At the time of the writing of this chapter, the pandemic appears far from subsiding and continues to spread or spread again swiftly into populations around the world.

As is characteristic for mass casualty scenarios, the COVID-19 pandemic has led to a discrepancy between the need for medical care and the ability of the healthcare systems to provide such care, but on a strikingly more pronounced and perilous scale. Especially with regard to emergency and intensive care medicine, the demands regarding personnel and material clearly have exceeded the relevant capacities in many areas, including exhaustion of reserves and supply chains. The situation has been aggravated by the fact that – at the time of this chapter being written – no proven specific treatment is available, leaving only symptomatic and supportive measures. This has resulted in an enormous requirement for critical care personnel as well as a remarkable consumption of pure space and resources, such as personal protective equipment, pharmaceuticals, and ventilators [4–6].

During its course, the COVID-19 pandemic has raised a number of important general societal questions, among which are the following: To what extent and for how long can civil rights be restricted in order to mitigate the spread of a disease? How will societies act (or react) when its members cannot be equally protected or attended to medically? And how can societies (better) prepare for epidemics and pandemics in the future?

16.2 Challenges for Emergency Medicine and Critical Care in Epidemics and Pandemics

For emergency medicine and critical care, four challenges are of prominent concern:

1. How to sustain or recruit and train personnel for the tasks to be performed – and how to protect and/or restore their physical and mental health?
2. How to procure and/or maintain the equipment needed for safe care of patients?
3. How to allocate scarce resources among the patients in need?
4. How to explain the decisions and measures by necessity taken to ourselves as professionals as well as to patients and their families who cannot be offered limited resources? And how to deal with the potential mental sequelae?

Specifically during the COVID-19 pandemic, the allocation of scarce critical care resources, in particular full ventilatory support (and potentially also noninvasive ventilation), has emerged as an enormous medical and ethical challenge.

16.3 Allocation of Resources in Critical Care

16.3.1 When Resources Are Not Scarce

As long as resources are not scarce, resource allocation needs to be based on medical grounds and widely accepted ethical maxims. The former mainly comprise indication and informed consent, and the latter are conventionally represented by the four renowned ethical principles [7–9]. Allocation decisions need to be taken for every patient individually, observing the necessity of fair distribution of resources. Limitations of certain therapies may apply, but they refer to the fair assessment of benefits and risks for the individual patient as well as to his/her wishes.

16.3.2 When Resources Are Scarce and Cannot Meet the Demand

When resources become scarce despite all institutional efforts, however – referring to, among others, personnel, pharmaceuticals, equipment, nutrition, transportation capacities, or reinforcements in general – the treating teams need to selectively allot the resources available and hence must make prioritization decisions. The focus of care, then, must shift from patient-centered deontology to population-centered utilitarianism, or at least some modification thereof. Clearly, this shift needs to result in fair processes using clinically informed decisions about scarce resource allocation, and this may include preparing, adapting, conserving, substituting, reusing, and reallocating resources. In some jurisdictions, legal stipulations may direct the allocation of resources and may even overrule medical evaluations.

Medical societies in several countries have published recommendations regarding the allocation of scarce critical care resources during the COVID-19 pandemic [9–16]. They partially build on recommendations related to former (and sometimes recurring) epidemics or on general triage principles [8, 17–19]. They are also based on distinct ethical values, formulated more or less explicitly within the societies' statements and other related publications [5, 10–22]. Nonwithstanding the differences between the various healthcare systems as well as local cultural and societal norms, several values and recommendations are shared among the statements regarding crucial issues. For others, however, there is no consensus.

16.4 Ethical Values for Alloting Scarce Healthcare Resources

Three core ethical values appear uncontested: treating patients equally; maximizing the benefits achievable in the context of scarce resources; and giving priority to those with the best odds of success when the limited resources are applied to them.

Each and every patient is of equal value, and there should be no difference in allocating scarce resources between patients with COVID-19 and those not infected, but afflicted by another illness or an injury. As each patient deserves a fair chance of receiving medical care, all prioritization decisions should in principle be centered on the individual patient. However, the odds of success when applying a scarce resource will not be distributed equally among all those in need. Therefore, those with higher odds of success, as defined by transparent and reasoned medical and ethical criteria *ex ante,* should receive priority for the interventions necessary. Medical determinants that have a negative impact on the prognosis, i.e., the odds of treatment success, need to be described and integrated into the decision-making process [5, 12, 13, 16–21]. "Operationalizing the value of maximizing benefits means that people who are sick but could recover if treated are given priority over those who are unlikely to recover even if treated and those who are likely to recover without treatment" [5]. However, neither chronological age alone, nor the social value, religion, or wealth of a person, should determine his/her chance to benefit from scarce resources. Clearly, the rule of rescue – "the powerful human proclivity to rescue a single identified endangered life, regardless of cost, at the expense of any nameless faces who will therefore be denied health care", does not have a place under the conditions of scarcity [23, 24].

Whether maximizing benefits means saving *more lives* – usually measured with mortality predictions – or saving *more years of life* (in all surviving) – involving inclusion of comorbidities – is disputed. Saving more lives is more frequently advocated, but attempts are being made to adopt allocation algorithms that combine both concepts [21].

A fourth ethical value, promoting and rewarding reciprocity, i.e., giving priority to healthcare workers and research participants when other factors are equal, has not met the same degree of endorsement, as it raises concerns that those making the rules may be protecting themselves. However, keeping the necessary workforce healthy and alive will benefit others in need, and therefore this potential value deserves intensive further deliberation [5, 10, 11, 13].

16.5 Time and Decision-Making Process of Prioritization

In clinical practice, there are two primary times for prioritization decisions: (1) before scarce resources must be allotted – during the COVID-19 pandemic, the decision to start intensive care (life-sustaining) treatments, especially ventilatory support; and (2) once scarce resource allotment has already been implemented – that is, the decision whether to continue or withdraw such treatments. The former describes a "*contentio ex ante*," and the latter a "*contentio ex post*" for scarce resources. Withholding and withdrawing are mostly assessed as equally justified for the same individual. The specific question in the COVID-19 pandemic, though, is whether it is justified that one patient be removed from an ICU bed or a ventilator for the sake of another patient who has a higher likelihood of successful ICU and

ventilator treatment. In principle, the same criteria and rules for allocation should apply for both times. Some institutions have elected to commit a minimum time-limited trial of critical care before a patient would have such resources withdrawn. However, there is no concordance as to this difficult question [5, 12, 13, 15, 16, 20, 21, 25–27], and, again, legal stipulations may direct this particular decision.

Irrespective of at what point in the course of a patient's illness prioritization decisions must be made, they are complex and challenging. They will bear grave consequences for "denied" individual patients – in favor of "selected" others. Such decisions – and related measures, such as quarantine – can contribute or lead to conflicts, moral distress, and burnout among staff as well as to emotional distress, signs of depression, and complicated grief among patients and their families [28–33].

On the societal level, rationing can lead to a loss of trust in the healthcare system or even the civil order. A failure to plan for scarce resource situations may lead to the inappropriate application of crisis standards of care, inadvertent loss of life, and prioritization decisions being made inadequately or even unnecessarily; therefore, healthcare systems' "duty to plan" is paramount in a pandemic [30]. Hence, it is of the utmost importance that prioritization decisions not be taken as discretionary decisions, but taken thoroughly, consistently, proportionately, and transparently as to rules based on medical assessment and ethical values. Furthermore, these decisions need to be re-evaluated regularly and over a length of time adapted to the course of the disease.

Unless impeded by medical urgency, these serious decisions should be taken according to the principles of interprofessional shared decision-making in order to assure that all relevant professions and specialties are involved in the process and that the rules and recommendations are followed [34]. To alleviate the treating teams from the difficult prioritization decisions, the formation of independent triage officers and triage committees has been advocated and operationalized [5, 21, 27]. Whether this suggestion is widely advocated and attainable remains to be seen.

16.6 Recommendations[1] for Fair Allocation of Scare Medical Resources in Critical Care During the COVID-19 Pandemic

Based on ethical principles and values as well as on experience and guidelines related to epidemics in the past, the following recommendations have been formulated (Fig. 16.1):

[1] These recommendations are primarily formulated for high-income countries; in middle- and low-income countries, the availability of a nurse, electricity, intravenous fluids, and supplemental oxygen may already constitute scarce resources. The fairness of the allocation, however, does not depend on the resources specifically scarce, because there may not be an option for a swift (re-) supply. Rather, the process to arrive at proportionate and consistent prioritization decisions needs to be fair – under normal circumstances as well as during health crises.

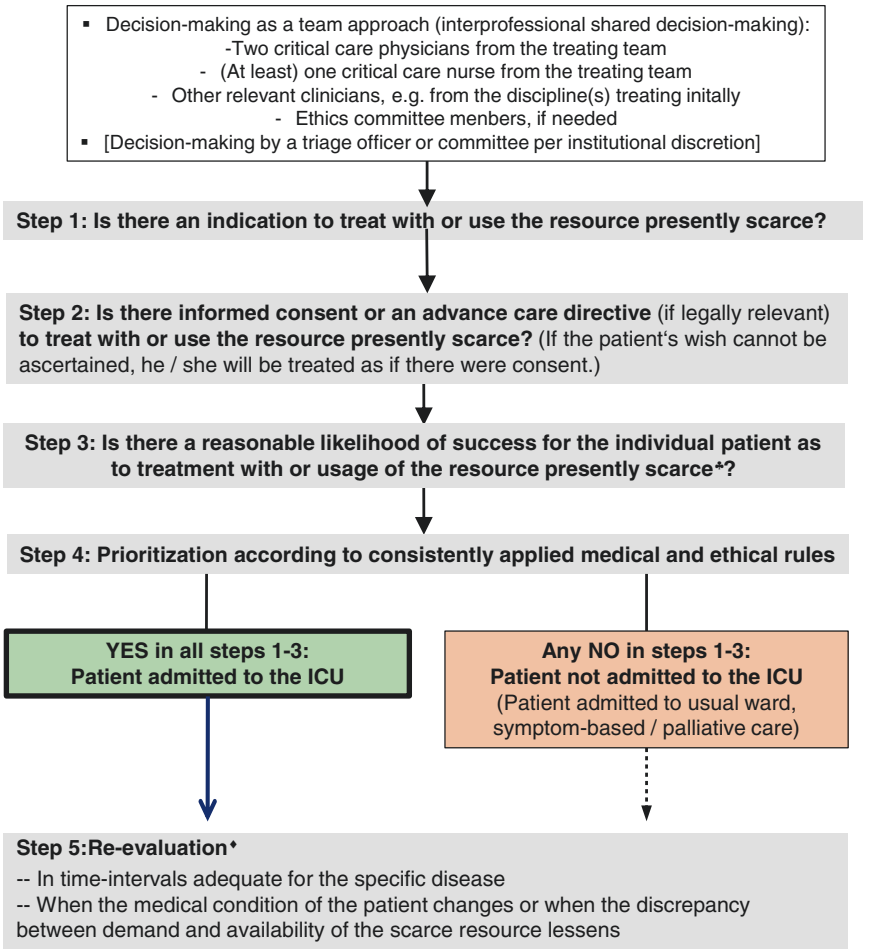

Fig. 16.1 Fair allocation of scarce medicial resources in critical care

1. The appropriateness of critical care, and especially ventilatory support, is assessed for every patient in need (not only those afflicted by the pandemic). Exceptionally invasive or resource-consuming procedures, such as renal replacement therapy or extracorporeal membrane oxygenation, need to be scrutinized meticulously. If critical care is not indicated, the patient will not be admitted to an ICU (or another high-care unit, for instance inside the emergency department).
2. The patient's informed consent is obtained or verified. If necessary, advance care directives need to be elucidated and honored. If there is no valid consent, the patient will not be admitted to an ICU. If the patient's wish cannot be ascertained, he/she will be assessed further as if he/she had consented.
3. Once the need for critical care treatment has been determined, the clinical likelihood of its success is assessed at least daily, according to reasoned and transparent criteria known at the time. Specifically, indicators for low odds of success are monitored. While success primarily focuses on survival, long-term outcomes and sequelae – as assessed by the patient and the family – are also taken into consideration.
4. Admission to an ICU and/or implementation of ventilatory support does not follow the usually applied "first-come first-serve rule." Rather, either patients are admitted to an ICU or admittance is withheld, according to their odds of success.
5. Decisions to change the goal of therapy from cure to comfort care only are considered for each and every patient they may apply to (not only for those afflicted by the pandemic) and are taken without delay.
6. Patients so affected will not be admitted to an ICU or will be discharged from the ICU where they are situated, even if this does not follow the usual protocol.
7. All prioritization decisions are re-evaluated regularly in adequate time intervals, and especially when the clinical status of the patient or the availability of resources changes.
8. The decision-making process follows the principles of interprofessional shared decision-making. If needed, local or regional advisory bodies, such as ethics committees or consultants, will be engaged.
9. After deliberation and decision-making within the treating team, the prioritization decisions will be explained to and discussed with the patient (or his/her legal representative) and the family in a transparent manner – if possible according to principles of shared decision-making [35] – and then documented appropriately.
10. To help navigate difficult decisions or phases, psychosocial support is always available to all patients, families, and team members.

Whether patients already on ventilatory support may be removed from the ventilator to provide it to others in need who have a higher likelihood of success remains debatable – especially from a legal standpoint. However, maintaining a patient on a ventilator despite very low odds of survival has a serious impact on the overall availability of ventilators and may deny appropriate care to other patients with clearly better odds of survival [5, 12, 13, 15, 16, 20, 21, 25–27].

Some clinicians do indeed advocate a complete shift from patient-centered to population-centered care with even more emphasis on minimizing opportunity costs. Clearly, decisions during pandemics are required for the entire population, not only for patients in hospitals [36, 37]. *In extremis*, very sick patients cared for outside a hospital might have to be counseled as to whether being admitted to a hospital and triaged there would really serve their best interest. Home care and mobile care teams, supplying oxygen, pharmaceuticals, and nutrition as needed, could avoid unnecessary transportation and decrease the pressure on hospitals. "This approach would limit hospitalization to a focused target of disease severity, thereby decreasing contagion, protecting patients and health care workers, and minimizing consumption of protective equipment" and other scarce resources as well [37].

16.7 Conclusion

In health crises such as the COVID-19 pandemic, many resources may become scarce. Although all patients still need to be given a fair chance to receive medical care, the treating teams need to selectively allot the resources available and hence must make prioritization decisions, according to reasoned medical and ethical rules formulated *ex ante*. As a result, the focus of care might have to shift from patient-centered deontology to population-centered utilitarianism. The pertaining decisions are complex and challenging, and they should be taken according to the principles of interprofessional shared decision-making whenever possible.

The values and recommendations deliberated upon and formulated in this chapter refer to the COVID-19 pandemic. However, they could serve as a model for ethically reasoned allocation decisions for future healthcare crises due to epidemics, pandemics, or other disasters.

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