International Library of Ethics, Law, and the New Medicine 77

Laura Miller-Smith
Ásdís Finnsdóttir Wagner
John D. Lantos

Bioethics in the Pediatric ICU: Ethical Dilemmas Encountered in the Care of Critically Ill Children

Springer

International Library of Ethics, Law, and the New Medicine

Volume 77

The book series *International Library of Ethics, Law and the New Medicine* comprises volumes with an international and interdisciplinary focus. The aim of the Series is to publish books on foundational issues in (bio) ethics, law, international health care and medicine. The volumes that have already appeared in this series address aspects of aging, mental health, AIDS, preventive medicine, bioethics and many other current topics. This Series was conceived against the background of increasing globalization and interdependency of the world's cultures and governments, with mutual influencing occurring throughout the world in all fields, most surely in health care and its delivery. By means of this Series we aim to contribute and cooperate to meet the challenge of our time: how to aim human technology to good human ends, how to deal with changed values in the areas of religion, society, culture and the self-definition of human persons, and how to formulate a new way of thinking, a new ethic. We welcome book proposals representing the broad interest of the interdisciplinary and international focus of the series. We especially welcome proposals that address aspects of 'new medicine', meaning advances in research and clinical health care, with an emphasis on those interventions and alterations that force us to re-examine foundational issues.

More information about this series at http://www.springer.com/series/6224

Laura Miller-Smith · Ásdís Finnsdóttir Wagner · John D. Lantos

Bioethics in the Pediatric ICU: Ethical Dilemmas Encountered in the Care of Critically Ill Children

Springer

Laura Miller-Smith
Pediatric Critical Care Medicine, Children's Mercy Hospital Department of Pediatrics
University of Missouri-Kansas
Kansas City, MO, USA

Ásdís Finnsdóttir Wagner
Pediatric Critical Care Medicine, Children's Mercy Hospital Department of Pediatrics
University of Missouri-Kansas
Kansas City, MO, USA

John D. Lantos
Children's Mercy Hospital Bioethics Center and Department of Pediatrics
University of Missouri-Kansas
Kansas City, MO, USA

ISSN 1567-8008 ISSN 2351-955X (electronic)
International Library of Ethics, Law, and the New Medicine
ISBN 978-3-030-00942-7 ISBN 978-3-030-00943-4 (eBook)
https://doi.org/10.1007/978-3-030-00943-4

Library of Congress Control Number: 2018968385

This Springer imprint is published by the registered company Springer Nature Switzerland AG
The registered company address is: Gewerbestrasse 11, 6330 Cham, Switzerland

Contents

1 Introduction 1
References 4

2 Epidemiology of Critical Illness in Children 5
2.1 The Changing Face of Pediatric Critical Illness 5
2.2 History of Illness in Children 6
2.3 Childhood Illness and Death in the United States in the 21st Century 8
2.4 How Children Die in PICUs 9
2.5 Implications of the Changing Nature of PICU Treatment 10
References 11

3 The Historical Foundation of Pediatric Critical Care 13
3.1 Early Efforts to Understand Respiratory Physiology 14
3.2 Humane Societies Develop to Advocate Resuscitation 15
3.3 From Tracheostomy to Endotracheal Tubes 16
3.4 The 1952 Copenhagen Polio Outbreak and the Development of Positive Pressure Ventilation 18
3.5 The Strange History of Neonatal Intensive Care 20
3.6 The Physician's Role in Alleviating Pain and Suffering: The Birth of Anesthesia 21
3.7 Complex Surgery and Modern Technology 24
3.8 The Development of Formal PICUs 26
References 27

4 Shared Decision Making and End-of-Life Discussions in the PICU 29
4.1 The Dreaded Conversation 29
4.2 Conversations About Withdrawal of Life Support Are a Modern Phenomenon 30

4.3 Narratives About Loss and Grief 31
4.4 Physicians' Emotional Responses to End-of-Life Discussions 35
4.5 Key Communication Skills 37
References 41

5 The Difficulty with Determining Whether Someone is Dead 45
5.1 Confusion About Brain Death 45
5.2 The Language of Brain Death: A Morass of Semantic Inconsistencies 47
5.3 Mistrust of Death Declaration Throughout History 48
5.4 A New Means to Declare Death 50
5.5 Controversies in the Definition of Death 51
5.6 The Legalization of Brain Death and Its Connection to Organ Donation 53
5.7 Whole Brain Criteria 54
5.8 Brainstem Criteria 57
5.9 Higher Brain Criteria 58
5.10 Testing to Confirm Brain Death 59
5.11 The Duty to Be Accurate with Brain Death Testing 61
5.12 Circulatory Determination of Death 62
5.13 Role of the Family in Determining Death 64
References 66

6 Intractable Disagreements About Futility in the PICU 69
6.1 Rare, but Distressing, Disagreements 69
6.2 Futility and the Ethos of Pediatric Critical Care 73
6.3 Why Do Parents Want Treatments that Doctors Believe to Be Futile? 74
6.4 Past Attempts to Understand and Resolve Intractable Disagreements 75
6.5 Futility and Symbolic Treatment 77
6.6 Legal Issues 78
6.7 Religious Beliefs and Medical Futility 82
6.8 Futility and Cross-Cultural Misunderstandings 86
6.9 Can We Think About Futility in the PICU in New Ways? 88
References 89

7 Chronically Critically Ill with Technological Dependence 93
7.1 Shifting Lines in the Sand 93
7.2 Defining Pediatric Chronic Critical Illness 94
7.3 Resources to Appropriately Care of PCCI Patients 96
7.4 PCCI and Parental Role 97
7.5 The Home Care of Technology Dependent Children 100

7.6 Unique Issues that Arise with Cardiac Assist Devices 102
7.7 The Subjective Experience of Technology Dependence 104
7.8 VAD as Destination Therapy 105
7.9 Withdrawal of Chronic Technology 106
7.10 The Challenges Ahead 107
References 108

8 Critical Care Resource Utilization 111
8.1 Tough Roles and Tough Decisions 111
8.2 Day-to-Day Decisions on Allocation 112
8.3 Ethical Approaches to Resource Allocation 115
8.4 The Need for Polices Regarding Critical Care Resources 119
References 123

9 Pediatric Organ Donation and Transplantation 125
9.1 The Growing Need for Organ Donation 125
9.2 Pediatric DCDD and DNDD 126
9.3 Does the Pediatric Donor Benefit from Organ Donation? 128
9.4 Dead Donor Rule 131
9.5 Challenges with Decoupling Donation from Death 134
9.6 Ethical Issues with Transplant Candidate Selection 135
9.7 Children as Living Donors 138
References 143

10 Moral Distress in the PICU 147
10.1 The PICU Is a Cauldron of Moral Distress 147
10.2 Defining Moral Distress 148
10.3 The Impact of Moral Distress 149
10.4 Some Problems with Current Conceptions of Moral Distress . . . 150
10.5 Moral Distress and Conscientious Objection 151
10.6 Moral Distress and Medical Futility 153
10.7 Moral Distress and Mission 153
10.8 Exit, Voice and Loyalty as Responses to Moral Distress 155
References 158

11 Conclusion 161

Chapter 1
Introduction

Abstract This chapter provides a brief introduction to the ethical issues that arise in the pediatric critical care setting.

This book calls for thoughtful attention to the complex ethical environment of the pediatric intensive care unit (PICU). In PICUs, doctors and their multi-disciplinary partners, parents, and children together face heart-wrenching and complex ethical challenges. Over the last few decades, we have developed amazing new ways to save the lives of critically ill children. We have seen the deployment of rapid response teams, advances in mechanical ventilator strategies, the expansion of extracorporeal CPR, and the use of artificial hearts (Gazit 2010; Zaritsky 2004). We have developed protocols for organ donation after cardiac death, clarified the criteria to meet brain death (Nakagawa et al. 2011), and worked to maximize the opportunities for organ transplantation. These advancements, while drastically impacting the number of lives saved, have also introduced new questions about appropriate ethical boundaries.

Technological progress, legal scrutiny, and bioethical reflection have all changed the ethical terrain in the PICU. Today, most children who die do so after a shared decision between doctors and parents to withhold or withdraw some potentially life-prolonging modality of treatment. Most end-of-life decisions and most PICU deaths take place among children with complex chronic conditions (Edwards 2012). These children and families are in the PICU with vast accumulated knowledge and experience about medical technologies and health care bureaucracies. They understand the wonders of modern medicine, but they are also acutely aware of the deficiencies of modern health care systems. They know that the technology can be wonderful or horrible and that it needs to be guided by firm ethical principles. They most likely have had both positive and negative experiences with both medical technology and health care professionals. They are empowered in unique ways because of all that they have learned. But they are also vulnerable in unique ways because of all that they have experienced.

There has been much research on the ethics and the techniques of end-of-life care for children. Today, we have more nuanced understandings than we did even a decade ago of the factors that make for effective or ineffective doctor-patient and doctor-

L. Miller-Smith et al., *Bioethics in the Pediatric ICU: Ethical Dilemmas Encountered in the Care of Critically Ill Children*, International Library of Ethics, Law, and the New Medicine 77, https://doi.org/10.1007/978-3-030-00943-4_1

parent communication. We have come to a new and more sophisticated appreciation of the complex process of shared decision making (Weise 2017). We strive for a middle ground between unbridled physician paternalism and unfettered parental autonomy (Morrison and Madrigal 2012). We recognize how important it is for doctors, nurses, and parents to work together to figure out what is best for a particular child and particular family. We have come to a better (but by no means non-conflictual) comprehension of medical futility. We understand the processes by which decisions are made.

This understanding is not always intuitive, and requires a dedicated focus to educating practitioners on how to navigate this challenging terrain. Fifteen years ago, Burns and colleagues suggested that, in order to help professionals on the front lines of pediatric critical care, we should encourage formal discussions of tough cases, more interdisciplinary dialogue and collaboration, and better research on successful strategies for shared decision making (Burns et al. 2001). Sahler and colleagues advocated for case-based pedagogy about difficult ethical decisions in the PICU. They wrote, "Teaching about EOL care does not require a new and separate curriculum but rather taking better advantage of the many teachable moments provided by caring for a dying patient" (Sahler et al. 2000). There are many opportunities for education within the PICU, but the process must be deliberate, not passive.

While parents and pediatricians share many concerns, such as a child's suffering or a child's anticipated quality of life, parents also have other concerns, such as the importance of prayer, faith, and intuition. These are areas of experience that pediatricians do not always consider in the decision-making process. For instance, parents' beliefs about clinical findings may be influenced by faith and so may differ from those of the pediatricians. This kind of disconnection can lead to misunderstandings and mistrust (Michelson et al. 2009).

Institutional constraints can also cause communication problems. Parents stress the importance of continuity of care and long-term trusting relationships with individual clinicians, but relationships in the PICU are short term and non-continuous. Attending physicians change often, consultants come and go, and, as a result, parents often receive conflicting messages about their child's diagnosis, prognosis, and treatment options (Michelson et al. 2013). Kruse and colleagues describe the results of these institutional arrangements: "Families are often forced to process information given in brief encounters laden with medical jargon. Providers are likewise challenged to balance conflicting obligations to disclose poor prognosis and continue to provide hope…. Families may confide their desires and fears to bedside nurses more often than they do to physicians" (Kruse et al. 2017).

Sometimes, it seems that doctors, nurses and parents are engaged in a complex dance in the PICU. As children get sicker, and difficult ethical decisions begin to loom large, doctors and parents try to sort out their respective responsibilities to play certain roles and advocate for certain values. Michelson and colleagues report that physicians may "give parents the 'illusion' of being decision makers." At the same time, a physicians' belief that they themselves are the ultimate decision makers may also be an illusion. In fact, decisions may be more collective than individual, and may involve many doctors, nurses, and family members, all trying to reach a consensus about what is best for an individual child (Lantos 2017).

As technology advances and research on communication and ethics becomes more sophisticated, opportunities for teaching have diminished. Work-hour restrictions for residents and fellows have led to a teaching environment where in-depth, case-based discussions are often an unattainable luxury (Ofri 2004). Residents and fellows may avoid important family conversations in order to perform concrete tasks ahead of their work-hour deadline, never gaining skills for the complex dance.

This book provides a readable, realistic, and holistic approach to addressing some of these problems. It is written by three pediatricians, two of whom are pediatric intensivists and all of whom have significant experience in clinical bioethics. The three of us have worked together for many years at a quaternary care children's hospital in Kansas City. We have collaborated in the clinical care of critically ill children and in discussions about the ethical issues that arise in their care.

One of the themes of the book is the diversity of ethical challenges in pediatric critical care. Many children admitted to the PICU stay for a short time while they are treated for an unexpected acute emergency. Many others are admitted post-operatively after a cardiac or orthopedic or neurosurgical procedure. These children seldom have life-threatening complications. Increasingly more common, though, are children admitted to the PICU with a complex, chronic condition. Nationwide, these children now comprise over half of admissions to the PICU. For many of them, the PICU has become their de facto medical home and the pediatric intensivist has become, in essence, their primary care doctor. The PICU doctors and nurses develop a very different sort of relationship with these children and their families than the relationship that exists among patients and families who are in the PICU only once and only for a day or two. This book aims to capture some of the complex ethical demands of these longer relationships on the work environment of the PICU and the professionals who work there.

We discuss common issues that arise in critical care, such as medical futility, end-of-life decisions, organ donation, and the determination of death. We do so with attentiveness to history and with a recognition of the importance of self-reflection. We do not offer simple formulae for difficult ethical dilemmas. This book is not about answers. Instead, we hope to encourage doctors, nurses and other staff who work in pediatric critical care medicine to reflect upon the complex ethical challenges they face in working with the children and families in their care.

Ultimately, the central ethical issues of pediatric critical care turn on how we approach the intertwined issues of hope and despair. PICUs offer hope where once there was none. But we cannot always offer hope, and should not be expected to do so. Some children are dying and their parents need to understand the limits of medical technology. Doctors and nurses need to be honest, in a compassionate manner. Detailed studies of hope, despair, honesty, and doctor-parent communication conclude that honest disclosure of even bleak information may have a positive effect on parents' sense of hope. Instead of hope that their child will survive, it is hope that that they can rely on an honest relationship with their doctors through a difficult course, even if their child does not survive (Mack et al. 2007). By carefully examining the ethical issues in this book, health care provides may find ways to build more honest, helpful, and meaningful relationships that improve care for critically ill children.

References

Burns, J.P., et al. 2001. End-of-life care in the pediatric intensive care unit: attitudes and practices of pediatric critical care physicians and nurses. *Critical Care Medicine* 29 (3): 658–664.

Edwards, J.D., et al. 2012. Chronic conditions among children admitted to U.S. pediatric intensive care units: Their prevalence and impact on risk for mortality and prolonged length of stay. Critical Care Medicine 40(7): 2196–2203.

Gazit, A.Z., S.K. Gandhi, and C.C. Canter. 2010. Mechanical circulatory support of the critically ill child awaiting heart transplantation. *Current Cardiology Reviews* 6(1): 46–53.

Kruse, K.E., et al. 2017. Challenges to code status discussions for pediatric patients. *PLoS ONE* 12 (11): e0187375.

Lantos, J. 2017. To whom do children belong? *American Journal of Bioethics* 17 (11): 4–5.

Mack, J.W., et al. 2007. Hope and prognostic disclosure. *Journal of Clinical Oncology* 25 (35): 5636–5642.

Michelson, K.N., et al. 2009. Parental views on withdrawing life-sustaining therapies in critically ill children. *Archives of Pediatrics and Adolescent Medicine* 163 (11): 986–992.

Michelson, K.N., et al. 2013. End-of-life care decisions in the PICU: Roles professionals play. *Pediatric Critical Care Medicine* 14 (1): e34–e44.

Morrison, W., and V. Madrigal. 2012. "My way or the highway" versus "Whatever the family wants"—intensivists reject both extremes. *Pediatric Critical Care Medicine* 13 (5): 612–613.

Nakagawa, T.A., et al. 2011. Guidelines for the determination of brain death in infants and children: An update of the 1987 task force recommendations. *Critical Care Medicine* 39 (9): 2139–2155.

Ofri, D. 2004. Residency regulations–resisting our reflexes. *New England Journal of Medicine* 351 (18): 1824–1826.

Sahler, O.J., et al. 2000. Medical education about end-of-life care in the pediatric setting: principles, challenges, and opportunities. *Pediatrics* 105 (3 Pt 1): 575–584.

Weise, K.L., et al. 2017. Guidance on forgoing life-sustaining medical treatment. Pediatrics 140(3).

Zaritsky, A. 2004. Extracorporeal cardiopulmonary resuscitation: Ready for prime time? *Pediatric Critical Care Medicine* 5 (5): 495–496.

Chapter 2
Epidemiology of Critical Illness in Children

Abstract This chapter defines the scope of pediatric critical illness. To understand the impact of ethical dilemmas among our patients, it is necessary to describe the patients being affected. Death among children has changed from a common reality, to a rare event. Within the United States, the mortality rate among children fell from 100 in 1000 births in 1900, down to 5.9 deaths among 1000 births in 2015. Within the PICU setting, mortality rates average among 2–3%. However, while deaths are few, these patients frequently have chronic medical conditions which make decision-making quite complicated. Children are increasing more technology dependent. When children do die, it is frequently requiring parental decisions upon withdrawal of that technology. The ethical issues that arise from PICU settings are increasingly around the chronically ill ICU patient that has arisen from advancements in modern medicine.

2.1 The Changing Face of Pediatric Critical Illness

I am on-call as a PICU attending physician on Christmas morning. The holiday season is evident throughout the unit. Walls are adorned with decorations. Patient rooms have crafted images of snowflakes made from the children's footprints, reindeer from handprints, or other such projects that allow parents to feel that their child has been a part of the holiday season. Hospital volunteers come door-to-door delivering gifts to those who will not be leaving the unit in time to celebrate at home. Doctors have made every effort to get those who can be safely discharged out of the PICU and, if possible, out of the hospital so they can celebrate the holiday with their families. So the patients who are still in the unit are the sickest of the sick.

As I make rounds, I reflect upon the patients who will spend the holiday in our unit. Usually, we have some patients who are post-op after scheduled major surgeries. Most of the time, those patients do well. They need to be stabilized for a day and then are transferred back to the surgical floor. There are minimal scheduled surgeries around Christmastime, so there are few straight forward post-operative patients. We usually have a few trauma patients, otherwise healthy children who were injured and

L. Miller-Smith et al., *Bioethics in the Pediatric ICU: Ethical Dilemmas Encountered in the Care of Critically Ill Children*, International Library of Ethics, Law, and the New Medicine 77, https://doi.org/10.1007/978-3-030-00943-4_2

admitted through the emergency room. The number of admissions for trauma always goes down when the weather gets cold, so we have even fewer of those patients today. There are a couple of babies with severe bronchiolitis. There will be more when winter fully sets in and we hit the peak of RSV season. There is one child with epilepsy whose seizures couldn't be controlled at home. He is now stable and will probably go home tomorrow.

Still, a lot of patients remain in the unit. They are the kids with complex chronic conditions (CCCs). They are admitted to the PICU often and, when admitted, they stay a long time. They are different from the other patients, the ones with more acute problems.

Most patients with an accidental injury will stabilize pretty quickly and be discharged from intensive care. On average, kids who are admitted after surgery will only be in the PICU overnight. When children get a serious infection, they usually either die quickly or recover fully. But, in each group, some neither die nor recover. Instead, they develop chronic conditions that leave them closely tethered to advanced medical support. On this Christmas morning, those patients stand out.

Chloe has a tracheostomy and is dependent upon mechanical ventilation. Her resource-limited single mother cannot care for her at home, so she has been in the PICU for months and will likely be here until at least Valentine's Day. Max has a single ventricle congenital heart lesion. He is between palliative surgeries, and he is too unstable to be safely discharged. Tonya is an ex-preemie who developed severe lung disease. She is on ECMO and has not shown any signs of lung recovery. But she is awake, and bonding with the bedside nurse. We wonder how long we will be able to keep her on ECMO but nobody, including her parents, wants to stop. Ibrahim is on a ventricular assist device, playing with his newly opened gifts, waiting for a call that the needed heart is available for transplantation.

These patients, the ones with CCCs, make up an ever larger proportion of the kids we care for in PICUs. This is a group of patients who is starkly different from the patients in the early days of pediatric critical care. That is, in part, because critical care in decades past could not deliver the sickest-of-the-sick into a chronically ill state. And it was in part because there were just not enough PICU beds, and the ones that were available were used mostly for kids with acute illnesses or for post-operative recovery. Now, we have more beds than ever in the PICU and they are almost always full. And we have the knowledge and technology to sustain children for a very long time. The epidemiology of childhood illness, including critical illness, has changed dramatically over the last 50 years. Our PICU on Christmas morning illustrates this change.

2.2 History of Illness in Children

Many people take it for granted today that most children will be healthy and that few will die during childhood. It is easy to forget just how common illness and death used to be for children. To remind ourselves of that reality, we need only to

read old medical textbooks about childhood illnesses. Shulman recently reviewed some of those old textbooks. He quotes an 11th century Arabic text describing the many infectious diseases that struck children (Shulman 2004). He cites an English publication from 1544 entitled "The Boke of Chyldren" that described, in detail, such childhood illnesses as "Aposteme of the brayne, Scalles of the heed, Styfnesse of the lymmes, Bloodshotten eyes, Diseases in the eares, Cankre in the mouth, Quynsye or swelling of the throne, Coughe, Feblenesse of the stomake and vomytyng, Fluxe of the belly, Wormes, Small pockes and measels, Fevers and Consumption" (Shulman 2004; Bowers and Phaer 1999). Death was a frequent outcome from these illnesses and there was little that doctors could do to save children. Epidemiologists estimate that, in the 18th century, about half of children died before their fifth birthday (Roser 2017). As recently as 1900, approximately 30% of children in the United States died before turning one-year-old.

Some children were at particularly high risk. In 1629, a Reverend Higginson took his family from England to New England. Long ocean voyages were treacherous and his children all died on the boat. In big cities, epidemic disease was rampant. Between 1762 and 1771, London was struck by a series of outbreaks. During those years, about two out of three children in London died before their fifth birthday, most before age 2. Measles, scarlet fever, diphtheria, and pertussis outbreaks periodically devastated cities. In 1772, measles killed 900 children in Charleston, SC. Between 1822 and 1847, scarlet fever killed 4874 New York City children (Shulman 2004).

With good sanitation, clean drinking water, immunizations, and antibiotics, we now rarely see these kinds of death rates from infectious disease. Today's killers—congenital anomalies, malignancies, and traumatic injuries—were certainly around at this time but accounted for a smaller proportion of childhood deaths than did infectious disease. In the 19th century, it was perilous for a child to be admitted to the hospital. L. Emmett Holt, Sr., spoke about this in his 1898 presidential address to the newly formed American Pediatric Society. He noted a 50% mortality rate for children admitted to hospitals in New York City at that time. Many died of nosocomial infections and he called for better hygiene and antisepsis (Shulman 2004).

Over the course of the 20th century, advances in public health and the development of new medical technology dramatically reduced the rate of childhood mortality. There are now only 5.9 deaths in childhood per 1000 live births, a mortality rate well below 1%. In the early 20th century, the rapid drop in childhood mortality was due to public health measures, including immunizations. In the later part of the 20th century, the continued drop in childhood mortality is attributable to intensive care (Fingerhut and Kleinman 1900).

Today, most people never experience a childhood death among their loved ones. Childhood death is no longer the horrible but not unexpected event that it once was. Instead, it is seen as something that should never occur.

2.3 Childhood Illness and Death in the United States in the 21st Century

Currently in the United States there are about 45,000 deaths in children per year. Approximately half of these deaths occur prior to 1 year of age. Among infants, the leading causes of death include congenital malformations and chromosomal abnormalities, prematurity and related problems, sudden infant death syndrome, and accidents. With older children, the leading causes of death include accidents, suicide, and homicide (Murphy et al. 2017). Children who die from trauma—whether intentional or unintentional—often die prior to arrival to a medical facility or in the emergency department.

The majority of patients admitted to PICUs today will survive their critical illness. Overall mortality rates for all PICU admissions in the United States are less than 3%. In the UK, mortality rates are similar (Sands et al. 2009). Burns et al. published data on how patients died in five geographically diverse US teaching hospitals in 2010. There were 227 deaths among 9516 admissions, giving a mortality rate of 2.39%. Almost two-thirds of patients who died had significant chronic or preexisting conditions. Patients had an average length of stay of 5.7 days prior to death. Of the deaths in the PICU, a younger age still predominates as is reflected in childhood mortality rates as a whole (Burns 2014). In the UK study, the median age of non-survivors was 3.1 years (Sands et al. 2009). This number is lower at centers with larger cardiac representations, with other studies reporting a range of 0.8–2.3 years.

Although the majority of critically ill children survive their PICU hospitalization, a growing number of patients will now be discharged from the hospital with increased morbidities. The Virtual PICU Systems (VPS) is an international database that collects data from over one hundred PICUs to improve quality, provide benchmarking with peers, and establish best practices in pediatric critical care. VPS looks at multiple variables surrounding PICU management and outcomes, including the overall disability of patients at admission and again at discharge. Although some data is missing, the rate of being "normal" is reported at 18.8% at admission and falls to 17.3% at discharge, with an increase of mild overall disability from 5.1% at admission to 6.4% at discharge, and of moderate overall disability from 7.4 to 7.8%. Severe overall disability is shown to remain constant at 2.7% (Virtual Pediatric Systems 2017). Although children are saved, they not infrequently leave the PICU with new medical problems.

The Survivor Outcomes Study reviewed 129 survivors from a larger tertiary medical center's PICU. The study showed that both morbidity and mortality continued to increase following discharge. Although the initial number of patients studied was low, and patients were lost to follow-up, the trajectory is reflective of what many intensivists fear for their patients—that life for some patients may become more challenging post-discharge. This study found that mortality increased from 3.9% while in-patient, to 7.8% at 6 months after discharge and 10.4% at 3 years. Additionally, having a new morbidity was 5.2% at discharge, increasing to 6.5% at 6 months and 10.4% at 3 years (Pinto et al. 2017). Certainly, these chronic medical issues

encountered increase the likelihood of subsequent hospitalization, with more of these patients presenting back to the PICU. Another study by Hartman and colleagues primarily investigated the rate of readmission and/or death following discharge from an ICU setting: the unplanned readmission rate for children following ICU care was two and a half times higher than as previously described for all hospitalized children, and a third of these admissions included more time in the ICU setting (Hartman et al. 2017).

The children who survive through discharge have a higher risk of mortality in the future (62 per 10,000-person years), which is two and a half times higher than for US children 1–4 years old and 5 times higher than for children 5–14 years old who have not been hospitalized in a PICU (Hartman et al. 2017). A recent 2017 review of the MarketScan database found that 71.7% of patients admitted to PICUs had a comorbidity, with the top three underlying conditions of children with ICU admissions being neurologic (19.2%), cardiac (16.8%), and respiratory (13.9%). Burns et al. demonstrates that this level of complexity is correlated with PICU mortality, showing that two thirds of patient deaths occurred in patients with chronic or preexisting conditions (Burns 2014). Again, even for these children with complex medical conditions, it is more likely than not that they will survive to discharge. But in what state are they discharged? And how will they do post-discharge? How well have the families been prepared? Advances in pediatric critical care have led to significant decreases in mortality, but with these advances have also come significant long-term sequelae and health complications on which patients and families must be counseled.

These statistics reveal how rare childhood death has become. Children who are admitted to the PICU are all critically ill, but intensive care is so effective that most survive. Children with respiratory failure are now routinely kept alive by mechanical ventilation. Children with severe sepsis receive antibiotics, fluids, vasopressors, and, if necessary, dialysis or ECMO (Hartman et al. 2013). Most kids who are admitted to the PICU go home again. But, for children with CCCs, each severe illness and PICU admission leads to an inexorable decline in their baseline health status. That, in turn, leads to more frequent acute illnesses and more frequent admissions to the PICU. Given this vicious cycle, it was not surprising that our PICU population on Christmas morning was made up largely of children with CCCs. We intensivists now provide a medical home for these children. We learn to recognize the names and faces of these children, the patients who bounce back to us often.

2.4 How Children Die in PICUs

In addition to increased efficacy of PICU care, another big change has been in the way that children die. Broadly speaking, the "mode of death" can be categorized as falling into one of three categories. Some children die in spite of receiving all available life-sustaining therapy, including mechanical ventilation, vasopressors, and cardiopulmonary resuscitation. Others are declared brain dead. A third group has some form of life-sustaining treatment withheld or withdrawn.

The study from the UK reported modes of death. They found that 55% of children died following withdrawal of life-sustaining technology. Another 10% died after a plan not to escalate the intensity of treatment. Twenty-four percent of children who died were declared brain dead. Only about 10% of children who died had CPR at the time of death (Sands et al. 2009). The majority of deaths follow a deliberate decision made with the family about limiting or withdrawing technology.

In the Burns study, 70% of deaths followed withholding/withdrawal of life-sustaining treatment. Sixteen percent were declared dead by neurological criteria. Only 14% of deaths followed unsuccessful CPR (Burns 2014). Lee and colleagues showed that, among 1263 deaths in 30 PICUs in the United States in 2004–2005, 23% of deaths were from brain death. Among the remaining deaths, 85% of patients had some limitation placed prior to death (Lee et al. 2010).

A recent study from the Hospital for Sick Children in Toronto, Canada, reveals a similar trend toward fewer deaths, but more deliberation and planning surrounding the process. Between 1998 and 2012, the percentage of hospital patients with palliative care team involvement before death increased from 10 to 73.9%. Similarly, the percentage of a "no CPR" order for patients prior to death increased from 31.4 to 87%. More patients were also noted to have died on a general patient ward, indicating that families were choosing for death to occur outside of the PICU environment. These findings demonstrate "that it has become more common for families of patients with life-limiting conditions to plan and discuss goals of care prior to death" (Roth et al. 2017). This is a drastic change from years past, when deaths occurred acutely in children, and there was less ability to deliberate about how death would occur.

2.5 Implications of the Changing Nature of PICU Treatment

Most PICU patients survive to discharge. But most patients who die in hospitals die in the NICU or the PICU. Most deaths in PICUs today follow deliberation, discussion, and decisions to withhold or withdraw some form of life-sustaining treatment. Thus, critical care doctors often need to have discussions with parents about limiting treatment. Families are now being asked to clearly understand our prognosis for their child and balance that with their perception of their child's current and future quality of life. Personal values of family members and healthcare workers are also at play. Doctors need to explain things clearly to parents and then help the parents clarify their values, goals, and preferences for treatment. These discussions and decisions have the potential to introduce stress, controversy, and ethical dilemmas into the dying process.

The ethics surrounding the provision of medical therapies to children in a PICU are complex. Questions arise frequently about the appropriateness of prolonging

life for children with complex, chronic, technology-dependent conditions. More and more, PICU doctors must initiate discussions with families about how they view a good death or what they think of their loved one's quality of life.

In this book, we write about different ways to think about and talk about these issues. How do we work and communicate with families? How do we integrate their values into our views of best medical practice? The development and application of new technology and medications puts pediatric ICUs on a blurry line between standard medical care and medical research. How do we keep our balance on this line, while always considering the best interest of our patients? We can change the trajectory of major medical problems, but at what cost? The advancement of possible medical interventions may be occurring at a rate faster than our ability to educate upon and to learn about such ethical and moral dilemmas.

Lack of knowledge regarding important ethical concepts, how they apply in the critical care setting, and how to navigate through difficult situations could impact the type of care provided to our vulnerable patient population. In addition, ethical dilemmas faced by healthcare workers contribute to moral distress and compassion fatigue, again potentially contributing to compromised quality of care for our patients and decreased longevity for professionals in healthcare careers. The purpose of this work is to educate pediatric critical care healthcare providers on ethical principles surrounding common critical care situations, with guidance on how to navigate through these dilemmas.

References

Bowers, R., and Phaer, T. 1999. *Thomas Phaer and the Boke of Chyldren* (1544). Tempe, AZ: Arizona Center for Medieval and Renaissance Studies, Arizona State University.

Burns, J.P., et al. 2014. Epidemiology of death in the PICU at five U.S. teaching hospitals. Critical Care Medicine 42(9): 2101–2108.

Fingerhut, L.A., and J.C. Kleinman. 1989. Trends and current status in childhood mortality. United States, 1900–85. *Vital and Health Statistics* 3(26): 1–44.

Hartman, M.E., et al. 2013. Trends in the epidemiology of pediatric severe sepsis. *Pediatric Critical Care Medicine* 14 (7): 686–693.

Hartman, M.E., et al. 2017. Readmission and late mortality after critical illness in childhood. *Pediatric Critical Care Medicine* 18 (3): e112–e121.

Lee, K.J., K. Tieves, and M.C. Scanlon. 2010. Alterations in end-of-life support in the pediatric intensive care unit. *Pediatrics* 126 (4): e859–e864.

Murphy, S.L., et al. 2017. Deaths: Final data for 2015. *National Vital Statistics Report* 66 (6): 1–75.

Pinto, N.P., et al. 2017. Long-term function after pediatric critical illness: Results from the survivor outcomes study. *Pediatric Critical Care Medicine* 18 (3): e122–e130.

Roser, M. 2017. *Our world data*. Available from: https://ourworldindata.org/child-mortality.

Roth, A., et al. 2017. General paediatric inpatient deaths over a 15-year period. *Paediatrics & Child Health* 22 (2): 80–83.

Sands, R., et al. 2009. Characteristics of deaths in paediatric intensive care: A 10-year study. *Nursing in Critical Care* 14 (5): 235–240.

Shulman, S.T. 2004. The history of pediatric infectious diseases. *Pediatric Research* 55 (1): 163–176.

Virtual Pediatric Systems. 10 March 2017. Available from: http://www.myvps.org/.

Chapter 3
The Historical Foundation of Pediatric Critical Care

Abstract The history of pediatric critical care is laid out within this chapter. It demonstrates how the development of medicine for critically ill infants and children has been advanced by those who were willing to push boundaries. Critical care required the development of medical technology that some questioned as being cruel and certainly experimental. Others pushed against stigmas of who was worth saving. Certainly issues of resource allocation, and where and by whom care should be delivered, has been present since the beginning. Understanding the history of pediatric critical care, and understanding that questions of ethical permissibility have been present since the beginning, helps create a framework for understanding the ethical questions and dilemmas of today.

A historical view is necessary to understand the ethical challenges posed by modern technologies in today's pediatric critical care environment. Over centuries of growing understanding of human anatomy and physiology, people have struggled with many of the same ethical issues we face today. But the development of the panoply of medical technologies and therapeutics that now allows us to save children who, until quite recently, would certainly have died from their illnesses means that we now have a different idea of what is or is not a terminal illness and how to think about the "natural" course of diseases among infants and children.

Many of the advancements that are now lifesaving for critically ill children developed from practices that were once considered unjustified, even ethically or morally questionable. As we discuss later in this chapter, at various points in history, anesthesia and pain control were thought to be a "curse" to humanity, tracheotomies were deemed futile, surgeries performed on hearts were improper, treatment of premature babies required "freak shows" for financial support, and physicians were ostracized from their profession for interventions we rely upon today. Critical care medicine evolved on a thin line between the "right" and "wrong" thing to do. At each stage, it was difficult to know exactly where that line should be drawn, or which activities fell squarely on one side or the other. Many advancements in critical care have required that we push the envelope in ethically dubious ways. Advancements save lives but may often accompanied by worry that we may be pushing things too far, committing

L. Miller-Smith et al., *Bioethics in the Pediatric ICU: Ethical Dilemmas Encountered in the Care of Critically Ill Children*, International Library of Ethics, Law, and the New Medicine 77, https://doi.org/10.1007/978-3-030-00943-4_3

moral wrongs along the way. This chapter is less a complete history of the medical advancements required for pediatric critical care development than a history in anecdotes—stories of how the advancements we now rely upon carried the same moral questions that we wrestle with today.

3.1 Early Efforts to Understand Respiratory Physiology

Many historical accounts trace the emergence of critical care, and its pediatric counterpart, to the use of intermittent, positive-pressure, mechanical ventilation (IPPV). This technology was first applied on a large scale to save polio patients during outbreaks of the disease. Lessons learned in the treatment of polio led to the creation of ICUs as a way to group patients and clinicians in one location within the hospital. But long before the days of iron lungs, innovators in science and medicine were exploring the possibilities of resuscitating those deemed incurable. Understanding the role of respiration would be required for any resuscitative efforts. Although breathing was clearly a requirement for life, the exact role of the lungs remained elusive to physiologists and physicians until quite recently.

The concept of assisted respiration dates back to early in human history. A biblical source of the concept of mouth-to-mouth resuscitation comes from the Book of Kings: "And he went up and lay upon the child, and put his mouth upon his mouth, and his eyes upon his eyes and his hands upon his hands … And the flesh of the child waxed warm … And the child sneezed seven times, and the child opened his eyes." (Bible). There were centuries of experimentation and exploration into the relationship between breathing and life. Galen, the famous Greek scientist, recognized the connection between respiration and circulation in the second century (Baker 1971). Very slowly, investigations continued intermittently among those who sought to better understand human physiology.

In the 16th century, the great Italian anatomy professor Vesalius experimentally applied positive pressure ventilation in animals with the use of bellows and a hole in their airway, an early attempt to perform a tracheotomy: "But that life may be restored to the animal, an opening must be attempted in the trunk of the trachea, into which a tube of reed or cane should be put; you will then blow into this, so that the lung may rise again and take air." (Slutsky 2015; Vesalius). In the 17th century, Robert Hooke again explored this concept, sustaining the life of a dog this way for hours. Hook aspired to apply this knowledge to his fellow man: "I shall shortly … make some other experiments, which, I hope, will thoroughly discover the genuine use of the respiration; and afterwards consider of what benefit this may be to Mankind." (Baker 1971; Slutsky 2015). Even though the desire was there long ago to intervene in respiratory failure, attempts to do so were sporadic, and largely viewed as unorthodox and futile.

3.2 Humane Societies Develop to Advocate Resuscitation

By the mid to late 1700s, it was clear that stimulation to the lungs through some form of assisted ventilation could be used to resuscitate a dying person. The field of midwifery had been using mouth-to-mouth breaths to stimulate breathing in a newborn with great success. It would take time for this development to be translated to saving the life of older persons. While carbon dioxide and oxygen were discovered around this same period, it was not known what roles these gases played. It was also unclear what should be used to stimulate the lungs—air from mouth-to-mouth ventilation seemed beneficial as the air was warm and humidified, so therefore tobacco smoke was a frequent substitute. Bellows, with their ease of administration, were also used.

During this time period, drowning was a leading cause of death. Anecdotal reports of drowning victims being resuscitated led some physicians to want to intervene. Most other physicians, however, generally considered it beneath them to sully their hands with resuscitation. They perceived their job to be curing illness, not experimenting on the dead. These professional views reflected prevailing societal attitudes. One commentator noted, "People still adhered to the Prejudice that it was degrading to touch those who had died an Unnatural Death." (Trubuhovich 2006). Additionally, some viewed reanimating those who had died as inhumane or cruel. Certainly there were those whose attempts at resuscitation may have gone too far. Mary Shelley's story of Frankenstein's monster reflected some of the ethical concerns that people had about trying to resuscitate the dead. Shelley may have been influenced by her family experience. Her own mother, Mary Wollstonecraft, had attempted suicide, and commented upon her rescue: "I have only to lament, that, when the bitterness of death was past, I was inhumanely brought back to life and misery." (Williams 2007). Then, as now, there was controversy about when, exactly, death became irreversible.

For those who saw drowning as a scourge worth fighting, efforts would have to be made at the societal level, not from within the hospitals or medical academies. "Humane societies" appeared across Europe, and much later in the United States, to deal specifically with resuscitation. In 1767, The Society for The Recovery of Drowned People was formed in Amsterdam. The highest priority was quick removal of the multiple victims found within the city's canals. Ladders, poles, and other devices were installed throughout the city, with instructions that included mouth-to-mouth resuscitation. However, pulmonary resuscitation was on par with other measures, such as body warming and tobacco fumigation. The society was credited with saving approximately 150 lives within its first 4 years (Trubuhovich 2006).

Success of the society prompted other cities to consider similar measures. Two London doctors, appealing to laymen to help them further their belief that these early resuscitation methods were beneficial, created the "Humane Society for the recovery of persons apparently drowned," still in existence today as the Royal Humane Society. To encourage the general public to intervene in lifesaving efforts, they offered financial rewards: 2 guineas to anyone attempting a rescue in the Westminster area of London, 4 guineas to anyone successfully bringing someone back to life, and 1 guinea to anyone (frequently a pub owner) allowing a body to be treated within

their home (Royal Humane Society History 2018). When scams began with falsified rescues to claim these monetary prizes, rewards were changed to medals.

The first award from this London society was for the rescue of a 14-month-old boy on July 12, 1774. He had wandered from his mother while she was drinking tea with some other women in a shop, and fell through a trap door into an aqueduct leading to the Thames River. A waterman heard the mother's distressed cries and ran through the neighborhood to an area where he could rescue the boy. Approximately 7 min elapsed from when the child was first submerged until he was removed from the water. He was brought back to the women and his mother. The story was reported in the Society's annual report:

> The women upon the strictest examination affirmed, that the child was to all appearance dead; its eyes were fixed, it lay breathless, and void either of motion or pulse.
>
> They shook, and beat it on its back for some little time, and laying it upon a counter in the shop, rubbed his belly and chest with dry salt; the friction was scarcely continued three minutes before the child began to gasp, and give other signs of returning life, which encreased [sic] till they were enabled to pour some salt and water down its throat.
>
> This excited a vomiting, by which the child threw up a considerable quantity of water and mud from its stomach, and in a few minutes more it was restored to the joyful arms of its mother.
>
> In the course of the evening it had two or three convulsive fits, but these were of short duration, and returned no more.
>
> The person who had taken the child out of the water ran for Mr. Boyse, one of the Medical Assistants to this Society: he not being at home, his journeyman went to the house, but he found the child pretty well recovered.
>
> The waterman had the reward promised by the society. (Royal Humane Society History 2018)

The story still feels familiar to us today. The story of a near fatal drowning, where we still rely upon families and first responders to be trained in emergency response and cardiopulmonary resuscitation in order to maximize the outcomes of patients. Over the years physicians would fortunately realize their important role in providing ongoing resuscitation efforts to these patients near death. While centuries ago these societies presented recommendations on how to perform resuscitation, the Royal Humane Society now defers recommendations to medical societies and focuses on rewarding the rescuers for their brave efforts.

3.3 From Tracheostomy to Endotracheal Tubes

Tracheostomy is an ancient concept. It is recorded in the Hindu book of medicine and passed down in oral tradition from approximately 2000 BC. The concept was documented in Egyptian writings 500 years later. The Talmud describes using a reed to cannulate the trachea of a newborn. Avicenna, a Muslim philosopher and physician (980–1037 AD), described using a silver or gold cannula for tracheal intubation. It was certainly appreciated that airway obstruction could lead to death, and a hole

through the throat could overcome such an obstruction. However, this could only be used for acute illnesses that could be quickly relieved, as performing sustained artificial respirations was not an option. Between 1500 and 1833, however, there are 28 cases in literature of successful tracheotomy on humans.

George Washington was not one of those cases. In December 1799, he lay on his death bed in Virginia. He struggled to breathe, shifting his position frequently in attempts to relieve his air hunger. Three physicians attempted to provide some relief. "One of the physicians present at the scene was aware of tracheostomy but was disinclined to perform it, especially on such an important personage, because he believed the procedure to be futile. As a result, George Washington died from fully preventable suffocation due to an upper airway obstruction caused by bacterial epiglottitis." (Szmuk et al. 2008). It is quite likely that substantial blood-letting also played a role in his death.

Fortunately, not every physician considered tracheotomy unworthy of pursuit. French physician Armand Trousseau performed tracheotomies on approximately 200 patients suffering from diphtheria (Szmuk et al. 2008). However, many shared Washington's physicians' concern about the true utility, while others butchered the trachea unnecessarily. It was recognized that in order to assist respirations an alternative was needed.

The concept of futility, applied to a medical intervention now commonly used, is striking. Then as now, it was difficult to differentiate between innovative therapies which might have been beneficial from those that were truly futile. That debate continued, and still continues, as doctors began studying intubation and ventilation of premature babies, extracorporeal membrane oxygenation for respiratory failure, and artificial hearts for children.

The pediatric patient would provide a prime example of this attempt at application, as the primary group inflicted by diphtheria with its associated airway obstruction. Two contemporary pediatricians, Frenchman Eugène Bouchut and American Joseph O'Dwyer, would independently seek strategies to overcome the airway obstruction without using a tracheotomy. Bouchut presented data to the French Academy of Sciences in 1858 from seven cases of patients with diphtheria, where a metal tube was placed orally through the glottis. He was met with much criticism and disdain. The attitude of the Academy was heavily swayed by Armand Trousseau. Trousseau, the leading expert on tracheotomy, believed that if done carefully, a tracheotomy was safer and more effective than endotracheal intubation. While true for him, most physicians did not share his skills. Bouchut was also hampered by the construction of his metal tube. It was not curved and had sharp edges that caused pain among the patients. Embarrassed by this experience, he would abandon his efforts to advance the concept of intubation without tracheotomy (Sperati and Felisati 2007).

Other physicians also recognized the need for intervention into the severe respiratory failure seen in pediatric patients with infectious airway obstruction. Dr. Joseph O'Dwyer, in New York, was also treating patients with diphtheria and croup. Completely unaware of Bouchut's experiences, he also developed new equipment and the procedure for orally intubating the airway of children. Like Bouchut, he received harsh criticism from colleagues (Fuhrman 2011). With softer and more blunted tubes

than his counterpart, O'Dwyer presented a means of using one's finger to hold the epiglottis and use the finger as a guide to introduce the tube into the airway. He reported that this was generally well tolerated by his patients. Pediatricians in New York would eventually be convinced by his case reports. It would become accepted that non-surgical intubation was to be considered as a lifesaving maneuver among children with infectious airway obstruction.

3.4 The 1952 Copenhagen Polio Outbreak and the Development of Positive Pressure Ventilation

Although tracheotomy and subsequent laryngeal tracheal intubations were gaining more acceptance, it was typically reserved for emergent, acute, and quickly reversible illnesses. A primary obstacle was how to provide ventilation, as it still required a human-operated bellow system at this time. While opportunities for invasive ventilation were certainly explored, noninvasive ventilator strategies were more palatable to the medical community. Unfortunately, the negative pressure ventilators, such as the iron lung, had significant pragmatic issues with implementation. They were large, expensive, and cumbersome for providing nursing care, preventing use among large populations of patients. Without the ability to apply even non-invasive support to large numbers of patients, the efficacy of treatment was difficult to prove. The polio epidemic would provide an opportunity for advancements that could be more widely applied, and the patient population on whom its benefits could be observed (Slutsky 2015).

In the 1950s there was an outbreak of polio in Copenhagen. As was typical in such outbreaks, the rate of bulbar paralysis and mortality was high. At Blegadam's Infectious Disease Hospital, a hospital of about 500 beds, there were 3,000 admissions with polio over 5 months at the end of 1952. At the epidemic's peak, the hospital was admitting 50 polio patients per day. Within the first month of this epidemic, mortality was an astounding 87%. As H. C. A. Lassen, the hospital's chief physician, would state in an article published the following year, "I do not want to dramatize the state of affairs existing in the middle of August 1952, but it certainly was desperate! Nearly all our patients with bulbar poliomyelitis had died!" (Lassen 1953). You can feel the anguish of a physician trying to do the best for all of his patients, with very limited resources: "We had to improvise; we had to find ways to avoid the impossible situation of having to choose which patient to treat in the available respirators and which patient not to treat. Every single patient should have his chance and an equal chance of survival." (Lassen 1953).

The hospital decided to bring in an anesthesiologist consultant, Bjorn Ibsen, to assist in guiding treatment. The hospital had only seven ventilators on hand: one full tank (or "iron lung"), and six cuirass respirators, which fit just around the thorax. This number of ventilators was hardly enough to support the up to 70 patients a day needing assisted respiration. Ibsen immediately proposed using intermittent positive

pressure ventilation (IPPV) for patients who were developing respiratory failure. The only way to deliver IPPV was to perform a tracheotomy and to ventilate by hand (Slutsky 2015). Lassen initially rejected pursuing this approach—the hospital had tried tracheotomy in the late 1940s during a less severe epidemic, with horrible results. Lassen was skeptical about trying again. But it worked. Ibsen developed clinical criteria to determine which patients would be given the tracheostomy and then receive IPPV by hand-bagging.

There were many pragmatic issues to overcome. As patients required hand-bagging, the administration closed the medical school and nursing school and the students provided ventilation by hand. Each day required 600 nurses, 250 medical students, and 27 technicians to support these patients (Fuhrman 2011). In order to use this staffing effectively, patients were cohorted together, essentially creating intensive care units. The success of this practice spread quickly throughout Europe, where tank respirators ("iron lungs") were limited in availability. In the United States, however, practice did not sway away from tank respirators until the mid-1960s, as many more of these "iron lungs" were present (Baker 1971).

Lassen was obviously worried about potential judgment from the medical community. Perhaps they were seen as too daring with their treatments:

> I am quite aware that we may be under suspicion of having used tracheotomy and bag-ventilation too freely! Yet in 40% where tracheotomy and bag ventilation had been the final therapeutic measure, treatment had begun with postural drainage or in a respirator. In all these cases we had to resort to tracheotomy and bag ventilation as a more radical therapy because of alarming symptoms of suffocation. (Lassen 1953)

But they saved hundreds of lives and were able to reduce the previous 87% mortality rate to below 40%.

Their experience gave rise to the concept of the intensive care unit. A few years after the epidemic, two anesthesiologists who had personally hand-ventilated these polio victims in Copenhagen would immigrate to the United States and establish the respiratory ICU at Massachusetts General Hospital (Grenvik and Pinsky 2009). Similar scenarios occurred elsewhere of physicians with polio expertise creating intensive care units.

The Copenhagen experience speaks to the role of resource utilization in critical care settings. The scenario is one that any emergency room or critical care practitioner fears today—a mass epidemic that utilizes all available resources. But these are precisely the issues that all ICUs must be prepared to deal with, or at a minimum know what strategies they will use to overcome these issues. With recent large natural disasters within the United States, and fears about migrating infectious agents such as SARS or Ebola, the lessons from the polio outbreaks are relevant today. It is important to cohort patients in order to use resources efficiently. It is also crucial to try new treatments, if they seem plausible, in order to save lives with limited resources. Lassen summed up this approach and its results: "We were now in a position to treat every single patient requiring respiratory aid. In this manner, we avoided being put in the dreadful situation of having to choose." (Lassen 1953).

3.5 The Strange History of Neonatal Intensive Care

As an official pediatric subspecialty, neonatology preceded pediatric critical care and contributed to its practice and knowledge base. For most of history, the newborn was treated by the delivering obstetrician. Virginia Apgar, the creator of the neonatal Apgar score, argued that the infant deserved someone specifically devoted to their well-being. The care would shift from the obstetrician to a pediatrician in the 1930s.

Prior to that time, there were physicians who began to take on the high mortality rate among premature newborns in Europe, particularly in France. Pierre-Constant Budin was an obstetrician who made these high-risk babies his life's work. In the late 1800s, he stressed breastmilk feeds, by gavage if necessary, higher hygiene standards, and education of mothers. One of his colleagues, another French obstetrician named Étienne Stéphane Tarnier, developed the first incubator, a glass-lidded wood box that held a water bottle to warm the infant. This application would decrease the mortality rate of infants by 28% over 3 years at the maternity hospital where he worked and utilized this technology (Philip 2005).

At the turn of the 20th century, there appeared to be minimal interest in the United States at prioritizing the health care of premature infants. Seen as weak, they were not a patient population thought worthy of healthcare resources. In spite of successes seen in Europe, many hospitals were unwilling to use the new technology. Incubators, purchased breast milk or specially created formulas, and the high number of care providers needed to support this care created an expense deemed to be unwarranted. In order to introduce lifesaving incubators and feeding strategies for infants in the United States, physician Martin Couney would have to find alternative locations, and probably more importantly, alternative funding strategies. One could argue that the first intensive care units for infants in the United States began as a sideshow, with Couney starting an exhibition of premature infants at Coney Island in 1903. One survivor of this early sideshow NICU discussed her experience with her daughter, as recorded by the StoryCorps Organization and recounted by National Public Radio:

> Lucille Horn was one of them. Born in 1920, she, too, ended up in an incubator on Coney Island.
>
> "My father said I was so tiny, he could hold me in his hand," she tells her own daughter, Barbara, on a visit with StoryCorps in Long Island, N.Y. "I think I was only about 2 pounds, and I couldn't live on my own. I was too weak to survive."
>
> She'd been born a twin, but her twin died at birth. And the hospital didn't show much hope for her, either: The staff said they didn't have a place for her; they told her father that there wasn't a chance in hell that she'd live.
>
> "They didn't have any help for me at all," Horn says. "It was just: You die because you didn't belong in the world."
>
> But her father refused to accept that for a final answer. He grabbed a blanket to wrap her in, hailed a taxicab and took her to Coney Island — and to Dr. Couney's infant exhibit.
>
> "How do you feel knowing that people paid to see you?" her daughter asks.

> "It's strange, but as long as they saw me and I was alive, it was all right," Horn says. "I think it was definitely more of a freak show. Something that they ordinarily did not see." (Storycorps: Lucille Horn and Barbara Horn 2017)

The infants' care was funded by the twenty-five cent admission fee paid by gawkers and onlookers. Subsequent exhibitions took place at the 1933 New York and 1939 Chicago World's Fairs. Couney's exhibitions were known to be kept clean, with high attention paid to his young patients. He employed nurses and other physicians at an enviable staff to patient ratio. He employed wet-nurses who were kept on a strict and healthy diet to provide optimal nutrition for the infants. He stressed that his facility was a small hospital and, if the term had already been coined, would likely have pressed the idea that it was the first neonatal intensive care unit. In spite of the high standard of care, however, the fact that these infants were placed on display for funds left many in the medical field dubious of Couney's intentions, and the exhibit was threatened to be closed on many occasions. With that being said, he claims to have saved the lives of 6,500 infants (How one man saved a generation of premature babies 2016; Prentice 2016).

A pediatrician who helped run his Chicago exhibit would later be called the father of American neonatology, Julius Hess. The first in-hospital NICU in the US would be opened in 1939, about 15 years before the first designated PICU. At that time, there was no mechanical ventilation. Instead, NICU care consisted of incubators for temperature control, gavage feeding, and supplemental oxygen. Neonatology would contribute to the pediatric critical care field through gained knowledge in respiratory support, development of nutritional formulas, blood sampling of small children, and vascular access. Additionally, it would set a precedent for the successful structure of a group of physicians in a specific geographic area providing care to critically ill children. The success of modern-day neonatology has also contributed to the current state of pediatric critical care with complex chronically ill patients who need intermittent critical care as they age.

The reluctance, or outright refusal, to take care of a specific patient population offers lessons that will likely continually be important for health care workers to learn. Historically, there have always been patients for whom medical treatment has been viewed as futile. Are trisomy 13 and 18 patients like the premature patients in Couney's days, with parents searching for hospitals willing to pursue treatment? Or are there patients whom we should truly not be offering therapeutic interventions—-due to resources, or due to what we perceive to be in their best interest?

3.6 The Physician's Role in Alleviating Pain and Suffering: The Birth of Anesthesia

The development of anesthesia and the field of anesthesiology were also paramount to the advent of critical care. Not only did the development of analgesics, anxiolytics, and paralytics allow for significantly more complex surgeries to occur, these

medications and knowledge of their use are required for modern-day critical care. Additionally, anesthesiologists' experiences in the operating room contributed to further expertise in intubation and artificial ventilation. Prior to the mid-1800s, surgeries had to be relatively limited in their complexity and duration, due to the inability to adequately control pain. It may be surprising to some physicians today that the development and use of anesthetics was frowned upon in its advent, even considered immoral. As data on the use of ether in animals emerged, physicians debated its necessity for surgery or midwifery:

> Pain is doubtless our great safeguard under ordinary circumstances; but for it we should be hourly falling into danger; and I am inclined to believe that pain should be considered as a healthy indication, and an essential concomitant with surgical operations, and that it is amply compensated by the effects it produces on the system as the natural incentive to reparative action. (Farr 1980)

And

> Pain during operations is, in the majority of cases, even desirable; its prevention or annihilation is, for the most part, hazardous to the patient. In the lying-in chamber nothing is more true than this: pain is the mother's safety, its absence her destruction. (Farr 1980)

One surgeon, in his sarcastic comments, mocked his colleagues for objecting to the use of anesthetics, noting that their objections were not medically based, but rather due to some questionable view of morality:

> Scarcely, however, is this glad and glorious discovery announced and acted upon, than another new, and, if possible, still stranger discovery, is broached and anxiously promulgated: namely, that in cutting the living flesh of man, the surgeon's knife does not, after all, produce any very remarkable or very important amount of pain, and that immunity from this pain during operations would be, perhaps, an evil rather than a good to humanity – a calamity rather than a blessing. (Farr 1980)

As Nicholas Greene states in his article on the obstacles to the development of anesthesia, there was a notion that pain came from God, and man should not intervene:

> So long as pain was regarded as a manifestation of divine justice, nothing serious could be done to alter its course, for to do so would be to tamper with the will of God, and action incomprehensible to an individual living in the Dark Ages, no matter how enlightened (i.e. heretical) he might have been by contemporary standards. Before anesthesia could be discovered, pain had to be regarded as a normal manifestation of response to physical stimulus, not as something visited on man by spirits or divine beings. (Greene 1971)

Because of those questioning the moral justness of anesthesia, there were likely many "first" human surgeries that took place with ether that were not reported. Perhaps also not surprising, it was outside of the field of surgery, in dentistry, that the use of anesthetics began to take off. William T. G. Morton would be the first to receive credit for its use, although others would later claim they preceded him in its use.

Morton was a dentist who contributed substantially to this development. Pain was the limiting factor for patients consenting to denture placement, and seeking to increase this procedure, he experimented on himself and animals extensively with

ether in his own home. One day, a man came to him with severe tooth pain. Morton extracted the tooth under ether, with the patient experiencing no pain or recollection of the event. The patient was not aware that ether would be used, nor that the use of ether was rather experimental. There was nothing remotely similar to the notions of "informed" or "consent" that we require today. But this man's joy in having his suffering relieved without additional pain likely suppressed any concern about not being told of the ether beforehand (Robinson and Toledo 2012).

Word spread quickly of this breakthrough. Morton, hoping to extend his finding beyond dentistry, approached Henry J. Bigelow, a surgeon at Massachusetts General Hospital, about using ether in his operations. Bigelow with the assistance of Dr. Morton would provide the first witnessed surgery under anesthesia shortly thereafter: the removal of a large vascular neck tumor in 1846 with the use of ether. While there were subsequent reports of physicians who had used ether for both dentistry and surgical operations prior to this event, Morton and Bigelow did so in a way that garnered societal recognition as the first surgery under general anesthesia (Robinson and Toledo 2012).

The next 150 years would see periods of trial and error with various inhalational anesthetic gases and means to deliver them. From the first glass flasks with a mouth piece to deliver ether and copper kettles to vaporize drugs, modern-day anesthetic machines would ultimately be developed. But supporting drugs were required as surgeries became more complex. Anesthesiologists would spend much effort developing drugs that could be given in an intravenous form to balance the doses and side effects of inhaled drugs. In doing so, they would garner much experience with the respiratory and cardiovascular effects of these drugs. Analysis of these experiences led to appreciation of the benefits and risks, information that we use daily in the PICU.

Anesthesiologists, and their knowledge, were paramount to the start of critical care. To this day, the subspecialties comingle. While the discipline of pediatric critical care is specifically a pediatric subspecialty, there are many who also train in anesthesiology. There are clear benefits to having a deep understanding of airway maneuvers, ventilation strategies, and sedation strategies. Critical care could not be the field it is today without the field of anesthesia.

The story also highlights a shift away from viewing pain and suffering as being a desirable part of the human condition, to now a physical manifestation that we must control. But we have also seen the pendulum in critical care perhaps swing too far, now having knowledge of long-term sequelae from excessive drug exposure. Perhaps too much pain relief can be a bad thing; perhaps some suffering is indeed part of the human condition. The degree that patients feel pain or potentially suffer within the walls of the PICU can indeed be a primary source of distress for all parties involved. We likely look at suffering through a modern lens; some may feel that any suffering may be too much. But is complete abatement the right approach? And how do we counsel families when we perceive a child's suffering to be too much, but beyond our ability to control? The role of the physician in pain control has changed greatly over the past 150 years, and there remain questions about the right approach.

3.7 Complex Surgery and Modern Technology

New applications of respiratory support and anesthetic regimens opened doors for pediatric general and cardiovascular surgeons, whose fields were also progressing rapidly, and whose patients would be a large component of soon-to-develop pediatric intensive care units. Prolonged and complicated surgeries, within all surgical subspecialties, could now be undertaken. But these patients would need more time to recover, and dedicated staff and monitoring to ensure they were recovering appropriately. The advancements in surgical correction of congenital heart lesions highlight the relationship between surgical progress and the development of pediatric critical care. They also highlight how pioneers in these fields had to directly challenge the accepted norms of their colleagues and communities, performing procedures and interventions that were deemed radical and inappropriate.

Any attempt of a surgeon to operate on the heart was considered prohibited for many years. Dr. Theodor Billroth, a famous European surgeon, stated in 1882 that "a surgeon who tries to suture a heart wound deserves to lose the esteem of his colleagues." Billroth equated pericardiectomy to "surgical prostitution." (Braile and Godoy 2012). Following Billroth's admonition, most surgeons considered it taboo to attempt surgical intervention for congenital heart disease. This was true even though such heart disease had been recognized as a fatal pathologic lesion for hundreds of years. But the development of technology to allow more accurate diagnosis of congenital heart disease led to changes in this taboo. The stethoscope, developed in the early 1800s by Laennec, (David and Dumitrascu 2017) allowed accurate diagnosis of many heart anomalies. Fluoroscopy and radiology improved diagnosis even more. Cardiac catheterization would also be an important contributor to achieving accurate diagnoses prior to surgical intervention.

The first cardiac catheterization was performed experimentally by German physician Werner Forssmann. Cardiac catheterizations had been performed experimentally on animals, but when Forssmann requested permission to expand this testing to humans, he was flatly denied. Unable to let go of his conviction that this diagnostic tool could be largely beneficial, he experimented upon himself, with self-catheterization done multiple times over his lifetime starting around 1930. While his work certainly contributed to improved treatment of cardiac disease, it primarily brought Dr. Forssmann disdain from his colleagues and community. He was not only forced from his institution, but also had to change fields to urology. Although his work was initially perceived as a dangerous and useless stunt, he would be later be recognized for his efforts, receiving a Nobel Prize in 1956. Forssmann's work was also pivotal to the monitoring to be done in cardiac catheterization labs and was the forerunner of invasive pressure monitoring now necessary in the modern-day ICU (Puri et al. 2009).

Diagnostic cardiac catheterization would be key to the advancements in the diagnosis and treatment of congenital heart lesions. By the 1950s, Helen Taussig, who could be considered the mother of pediatric cardiology, would use fluoroscopy and ECG to diagnose congenital heart disease. She corroborated her findings on autopsy.

She had already published her findings in The Atlas of Congenital Heart Disease in 1947 (Braile and Godoy 2012). Robert Gross of Children's Hospital of Boston had already performed the first intervention on congenital heart disease with ligation of a patent ductus arteriosus in 1938 (Gross 1939). Taussig herself would push for further advancements, but initially struggled to find a surgeon willing to continue this work. She ultimately collaborated with Alfred Blalock on the next major surgical advancement: the creation of a left subclavian artery to pulmonary artery shunt, used to improve the life of a child with severe cyanosis from tetralogy of Fallot (Blalock 1947). The Blalock-Taussig shunt, still used today, had enormous success and broadened the frontier of congenital heart surgery.

The story of cardiopulmonary bypass, and its impact on surgeries and eventually critical care, highlights the field's dependence on technology. Intricate and complex surgeries required surgeons to open the heart itself, while still maintaining oxygen delivery to the body. Cardio-pulmonary bypass made this possible.

Interestingly, the first mention of attempting to oxygenate (or rather aerate as oxygen had not been discovered) the blood outside of the body came in the mid-1600s from Robert Hooke, who proposed to see if allowing "the Blood to circulate through a vessel, so as it may be openly exposed to the fresh Air, will not suffice for the life of an animal." (Baker 1971). The lack of the ability to keep the blood from clotting, however, prevented much headway in this field, as heparin would not be discovered until 1916 (Ancalmo and Ochsner 1990). Work had been done, however, on discovering ways of "bubbling" in oxygen to blood, in addition to work on infusing and circulating fluids and blood. By the time John Gibbon entered the medical field around 1930, the background was set for him to devote his career to developing a heart-lung machine. On May 6th, 1953, he completed a surgical repair of an atrial septal defect on cardiopulmonary bypass (Braile and Godoy 2012; Passaroni et al. 2015). The use of cardiopulmonary bypass would allow surgeons to operate on children with more extensive lesions and challenging physiology. Eventually this technology, in the form of extracorporeal membrane oxygenation (ECMO), would be applied to children within the PICU itself who struggled with cardiopulmonary dysfunction from a multitude of etiologies. ECMO would allow the same concept of bypass to be applied over longer periods of time to critically ill children.

But, as with much of what we do, ECMO is not without significant risk of complications. Doctors today struggle to decide whether there are patients who are too sick to benefit from ECMO. Much discussion and debate focuses on how the risks of ECMO should be weighed against the benefits for each individual patient who might be a candidate. Over the years, ECMO has evolved from a therapy that was used only to rescue a few patients with carefully selected reversible illnesses to a salvage opportunity for even those with a dim prognosis. The more we do, the better we become. But the more we do, the more often we end up with patients whose treatment seems to do more harm than good. Some will still die from either their disease or complications from ECMO. Just as George Washington's physician looked at him and tried to decide if tracheostomy was worthwhile or "futile," we frequently battle this type of decision making with modern technology within the PICU.

3.8 The Development of Formal PICUs

The first pediatric intensive care unit was opened in 1955 in Sweden, and a few other units followed during the next decade. Most of these first units were run by pediatric anesthesiologists, although the unit at Hospital St. Vincent de Paul in Paris was directed by a neonatologist. A pediatric unit was opened in Melbourne, Australia, at the Royal Children's Hospital in 1963. The United States was also developing pediatric specific units for higher acuity patients. Future US Surgeon General C. Everett Koop opened a post-surgical recovery unit for infants in 1956 at Children's Hospital of Philadelphia. An anesthesiologist colleague of Koop, Dr. John Downes, would create a formal pediatric ICU in 1967. Two years prior to that, the first American unit had opened its doors at Children's Hospital of the District of Columbia, under the direction of pediatrician Cheston Berlin. Interestingly, Berlin did not realize that he was establishing the first patient care unit of its type within the United States. He and his colleagues recognized only that there was a patient need that they could address with a specific complex care unit (Epstein and Brill 2005; Downes 1992).

Over the next decade, PICUs were rapidly appearing across the world. Over this time, a transition occurred from mostly anesthesiologists directing the management of these units to pediatricians taking control. Future decades would see an additional change for PICUs. Although initially solely in academic centers and freestanding children's hospitals, PICUs are now found in many community hospitals. According to the American Hospital Association 2014 annual survey, there are over 400 PICUs in the United States, providing over 4,000 beds (Health Forum 2015). And as any pediatric critical care health care worker can attest to, the demand for these beds continues to grow.

The initial PICUs emerged out of different perceived needs, with some units initially intended to treat post-surgical critical illness, with other units focusing on acute respiratory failure, frequently from infectious issues. It became clear, however, that the technology focused in these units could be used to treat critical illness of multiple etiologies. With this shift to critical care being medical, not just surgical, units were more frequently managed by pediatricians. The knowledge and expertise needed to provide pediatric critical care became more in-depth, requiring further specific training. Fellowship training first began in the 1970s at multiple institutions. Doctors recognized the need for training program in pediatric critical care. In 1984, the American Academy of Pediatrics created a section of critical care. This led to recognition of pediatric critical care as a sub-specialty within pediatrics. In 1987, the American Board of Pediatrics first offered board certification in pediatric critical care. There are now over 500 pediatric critical care trainees in the United States. The Society of Critical Care Medicine (SCCM) in 1983 defined what constitutes a pediatric intensive care unit, and developed a pediatric subsection (Epstein and Brill 2005).

The progression from the first PICU in 1955, to the recognition of the field as a unique subspecialty in the 1984, seems rapid, but it occurred after hundreds of years of experimentation and exploration into the physiology and possible treatment

of critical illnesses. It is an exciting time for pediatric critical care, as cutting-edge technology and knowledge is applied to more and more children, although the field remains speckled with many of the same ethical questions that have been a part of its history since the beginning: how do we differentiate novel approaches to care from research? How do we provide informed consent about the care we provide, when we may not yet fully understand the risks? What is our obligation to keep society informed of our progress, and receive support for the work we do? How do we fund this care which utilizes expensive technology, and how do we allocate resources when scarce? Pediatric critical care sits directly on the cusp of these questions, and must continue to do so as we push the field forward.

References

Ancalmo, N., and J. Ochsner. 1990. Heparin, the miracle drug: A brief history of its discovery. *Journal of the Louisiana State Medical Society* 142 (9): 22–24.

Baker, A.B. 1971. Artificial respiration, the history of an idea. *Medical History* 15 (4): 336–351.

Bible, Kings II, 4, 34–35.

Blalock, A. 1947. The use of shunt or by-pass operations in the treatment of certain circulatory disorders, including portal hypertension and pulmonic stenosis. *Annals of Surgery* 125 (2): 129–141.

Braile, D.M., and M.F. Godoy. 2012. History of heart surgery in the world. 1996. *Revista Brasileira de Cirurgia Cardiovascular* 27 (1):125–136.

David, L., and D.L. Dumitrascu. 2017. The bicentennial of the stethoscope: A reappraisal. *Clujul Medical* 90 (3): 361–363.

Downes, J.J. 1992. The historical evolution, current status, and prospective development of pediatric critical care. *Critical Care Clinics* 8 (1): 1–22.

Epstein, D., and J.E. Brill. 2005. A history of pediatric critical care medicine. *Pediatric Research* 58 (5): 987–996.

Farr, A.D. 1980. Early opposition to obstetric anaesthesia. *Anaesthesia* 35 (9): 896–907.

Fuhrman, B.P. 2011. *Pediatric critical care*, 4th ed, xxviii, 1740 p. Philadelphia, PA: Elsevier Saunders.

Greene, N.M. 1971. A consideration of factors in the discovery of anesthesia and their effects on its development. *Anesthesiology* 35 (5): 515–522.

Grenvik, A., and M.R. Pinsky. 2009. Evolution of the intensive care unit as a clinical center and critical care medicine as a discipline. *Critical Care Clinics* 25 (1): 239–250.

Gross, R.E. 1939. Surgical management of the patent ductus arteriosus: With summary of four surgically treated cases. *Annals of Surgery* 110 (3): 321–356.

Health Forum, L. 2015. *American Hospital Association Hospital Statistics, 2015 (2014 Survey Data)*. Chicago, IL: American Hospital Association.

How one man saved a generation of premature babies. BBC Magazine, 2016.

Lassen, H.C. 1953. A preliminary report on the 1952 epidemic of poliomyelitis in Copenhagen with special reference to the treatment of acute respiratory insufficiency. *Lancet* 1 (6749): 37–41.

Passaroni, A.C., M.A. Silva, and W.B. Yoshida. 2015. Cardiopulmonary bypass: Development of John Gibbon's heart-lung machine. *Revista Brasileira de Cirurgia Cardiovascular* 30 (2): 235–245.

Philip, A.G. 2005. The evolution of neonatology. *Pediatric Research* 58 (4): 799–815.

Prentice, C. 2016. *The Man Who Ran a Carnival Attraction That Saved Thousands of Premature Babies Wasn't a Doctor at All*. Smithsonian.com, 2016.

Puri, N., V. Puri, and R.P. Dellinger. 2009. History of technology in the intensive care unit. *Critical Care Clinics* 25 (1):185–200, ix.

Robinson, D.H., and A.H. Toledo. 2012. Historical development of modern anesthesia. *Journal of Investigative Surgery* 25 (3): 141–149.

Royal Humane Society History. January 20, 2018. Available from: http://www.royalhumanesociety.org.uk/html/history.html.

Slutsky, A.S. 2015. History of mechanical ventilation. From Vesalius to ventilator-induced lung injury. *American Journal of Respiratory and Critical Care Medicine* 191 (10): 1106–1115.

Sperati, G., and D. Felisati. 2007. Bouchut, O'Dwyer and laryngeal intubation in patients with croup. *Acta Otorhinolaryngologica Italica* 27 (6): 320–323.

Storycorps: Lucille Horn and Barbara Horn. November 20, 2017. Available from: https://storycorps.org/listen/lucille-horn-150710/.

Szmuk, P., et al. 2008. A brief history of tracheostomy and tracheal intubation, from the Bronze Age to the Space Age. *Intensive Care Medicine* 34 (2): 222–228.

Trubuhovich, R.V. 2006. History of mouth-to-mouth rescue breathing. Part 2: The 18th century. *Critical Care and Resuscitation* 8 (2): 157–171.

Vesalius, A., *De humani corporis fabrica*, 1543.

Williams, C. 2007. "Inhumanely brought back to life and misery": Mary Wollstonecraft, frankenstein, and the royal humane society. *Women's Writing* 8 (2): 213–234.

Chapter 4
Shared Decision Making and End-of-Life Discussions in the PICU

Abstract Communication with parents about end-of-life decisions is one of the most challenging but crucial aspects of a pediatric intensivist's role. Making decisions for dying patients was physically, emotionally and morally easier when patients were less complex and less dependent upon technology, and when physicians felt justified in making unilateral decisions. Now these decisions are more complex. They require parents to comprehend complicated medical scenarios. They also require the incorporation of the family's values and goals through the shared decision making process. When these conversations go poorly, it can lead to compromised care for the child and increased moral distress among all involved. This chapter will describe these issues, in addition to pieces from a large body of research suggesting that such conversations require skills that can be taught and can be learned. Healthcare providers have a duty to hone these skills. In doing so, they will improve the experience of parents in the death of their child, decrease moral distress and burn-out within the PICU, and most importantly, improve the care provided to our patients.

4.1 The Dreaded Conversation

Conversations between PICU doctors and parents about end-of-life decisions for a dying child are among the most difficult conversations that people can have. Not only is the topic itself difficult, but the nature of intensive care can be generalized to mean different possibilities. One is that the patient's illness is acute, and the patient has spent little time within the PICU. The parents will not have gotten to know and trust any one particular doctor. The doctor may have never met the parents before. Thus, in many cases, these are conversations between strangers about an issue that is common for the doctor but unimaginable, unexpected, and totally unique for the parents.

The other possibility is that the patient has been chronically struggling with complex medical decisions for quite some time. The parents have likely made a slew of decisions with various physicians, attempting to reach some stability for their child. Perhaps they have also dreamed of a day that their child would be cured. But for these

L. Miller-Smith et al., *Bioethics in the Pediatric ICU: Ethical Dilemmas Encountered in the Care of Critically Ill Children*, International Library of Ethics, Law, and the New Medicine 77, https://doi.org/10.1007/978-3-030-00943-4_4

families, the discussion about end-of-life decisions has likely not been unexpected or unimaginable, but perhaps dreaded for a long time.

The conversations take place when the team of PICU professionals, including the pediatric intensivist, has collectively decided that they have reached a turning point in the treatment of a child. They believe that further efforts to cure the child's disease or even to prolong the child's life are more likely to only cause pain and suffering than they are to be beneficial. Put simply, they believe that the child is dying.

The parents have likely been afraid of this conversation since the moment that their child was admitted to the PICU. Such conversations are now part of collective societal experience. They are frequently portrayed on television and in the movies. Most parents, when told that the doctor wants to have a family meeting, will have some inkling of what is coming. But they will dread the conversation. They will likely have been living with the hope that treatment would be effective and that everything would turn out okay.

The conversation, then, is one in which the doctor's goal is to convince the parents that they must give up the hope that their child will survive and recover. In all likelihood, that is the parents' central hope, the most important hope, and perhaps the hope that has given the parents' lives meaning while their child was undergoing intensive care treatment. It may not be the only possible hope. The doctor may have to reframe expectations—and talk about the hope that their child will not be in pain or that the child's life will have had meaning.

This is extremely difficult territory for doctors (or other health professionals) to successfully navigate. To do so, they need to understand what it might mean for parents to accept the painful reality that their child is dying.

4.2 Conversations About Withdrawal of Life Support Are a Modern Phenomenon

There is something both ultra-modern and deeply unnatural about the conversations in which parents are asked to authorize the withdrawal of life support. They are ultra-modern in the sense that they only became necessary because of the advent of intensive care. Before that, children died without the need for anybody to make a decision to allow them to die. In those days, before mechanical ventilation and dialysis and ECMO and LVADs and vasopressors, death happened in spite of our best efforts to treat and cure children.

With the advent of intensive care and, in particular, the introduction of these life-support technologies, we can keep dying patients alive for weeks or months. We can do that even when there is no hope of recovery. These new technological capabilities mean that death is almost always preceded by a conversation about end-of-life choices and by decisions to withhold or withdraw one or many life-supporting technologies (Burns et al. 2014; Meert et al. 2015). Put another way, death seldom just happens anymore.

The decision by parents to authorize the withdrawal of life support and allow their child to die is extremely unnatural. The decision is necessary, in part, because of the societal choices that we have made about the roles of parents and doctors. Not all societies approach these problems the same way (Collins et al. 2006). In the United States, ethical arguments that emphasize autonomy and shared decision making mean that parents must not only accept the loss of hope but also must explicitly endorse a plan in which life-sustaining treatments are withheld or withdrawn. That is something that is extremely difficult for most parents to do.

In many other countries, a different approach is preferred. Parents are not asked to make the decision. Instead, the decision falls to the doctors. For example, Lago and colleagues report that, in Brazil, parents are rarely involved in decisions to withdraw life support (Lago et al. 2005). Moore and colleagues reviewed end-of-life practices in Australia and compared those with reports from other countries. They concluded that "North American and British parents appear to be involved in decisions regarding withdrawal and limitation of treatment more often than parents in other countries" (Moore et al. 2008).

In this chapter, we will try to understand the best way to facilitate shared decision making for end-of-life decisions by first presenting some narrative accounts of the ways that parents deal with the realization that their child is dying. We will then review literature on how doctors deal with the emotional challenges of caring for dying children and communicating with their parents. Finally, we will make some recommendations for how conversations about such topics might be considerate of the challenges that parents face in these situations.

4.3 Narratives About Loss and Grief

Parents who have lost children have written eloquently about their emotional experiences in facing such tragedies. A common theme in many parent memoirs is the way that profound grief distorts their thinking. The knowledge that their child is or might be dying, and the responsibility that they feel to be a good parent in such circumstances leads them to feel out of touch with day-to-day realities. The overwhelming importance of their presence and the decisions that they must make for their critically ill child seems to overtake their ability to think about or do ordinary things.

An example of this is Vicki Forman's book about her experiences after giving birth to extremely premature twins (Forman 2009). The book starts with a description of her inner emotional state:

> I learned about grief during this time. I learned that no matter the true temperature, grief made the air crisp and cold; that it caused me to drive slowly, carefully; there was very little I could eat. I learned that I didn't notice things until they flew out at me and that most stories and books and news articles were unreadable, being accounts not of the events themselves, but of me…I learned that a heart could stop and start a dozen times a day and that my throat felt so sore and tight I often had to swallow air simply in order to breathe. The world receded; everything took place in slow motion and was viewed as if down the wrong end of a very

> long telescope. So much was unfamiliar that if I was asked my name, I had to think for long moments…The stages of grief were slippery, I found, the boundaries melded, the order mixed up, confused.

Aleksandar Hemon wrote about what it was like to be the father of a daughter who was diagnosed with a life-threatening brain tumor (Hemon 2011). He calls his memoir "The Aquarium" because he felt, during the time when his daughter was sick, as if he were in an aquarium, isolated and looking out at all the people who were going on with their "normal" lives. He writes,

> One early morning, driving to the hospital, I saw a number of able-bodied, energetic runners progressing along Fullerton Avenue toward the sunny lakefront, and I had a strong physical sensation of being in an aquarium: I could see out, the people outside could see me (if they chose to pay attention), but we were living and breathing in entirely different environments. Isabel's illness and our experience of it had little connection to, and even less impact on, their lives. Teri and I were gathering heartbreaking knowledge that had no application whatsoever in the outside world and was of no interest to anyone but us…When people who didn't know about Isabel's illness asked me what was new, and I told them, I'd witness them rapidly receding to the distant horizons of their own lives, where entirely different things mattered. After I told my tax accountant that Isabel was gravely ill, he said, "But you look good, and that's the most important thing!" The world sailing calmly on depended on platitudes and clichés that had no logical or conceptual connection to our experience.

Raymond Carver's short story, "A Small, Good Thing," captures the way that a child's sudden critical illness can tear a gaping hole in parents' lives (Carver 2017). The story captures the sense of before-and-after that many parents describe. It starts with a mother, Ann, planning a birthday party for her healthy son Scotty's eighth birthday. She visits a bakery and orders a cake decorated with spaceships. Then, tragedy strikes. As Carver describes it:

> The birthday boy was walking to school with another boy. Without looking, the birthday boy stepped off the curb at an intersection and was immediately knocked down by a car. He fell on his side with his head in the gutter and his legs out in the road. His eyes were closed, but his legs moved back and forth as if he were trying to climb over something. His friend dropped the potato chips and started to cry.

The boy walked home but then passed out on the couch. He was taken to the hospital where he remained unresponsive. The parents, sitting at Scotty's bedside, review their lives. The father thinks:

> Until now, his life had gone smoothly and to his satisfaction — college, marriage, another year of college for the advanced degree in business, a junior partnership in an investment firm. Fatherhood. He was happy and, so far, lucky — he knew that. So far, he had kept away from any real harm, from those forces he knew existed and that could cripple or bring down a man if the luck went bad, if things suddenly turned. His left leg began to tremble…He tried to deal with the present situation in a rational manner. He closed his eyes and ran his hand over his face.

Neither mother nor father can eat or sleep or think of anything else except Scotty, their eight years together with him, and what it might mean to be suddenly without him.

Many parents cling to magical beliefs that what is happening to them cannot be happening. When Hemon was first given his daughter Isabel's diagnosis, his mind turned to irrelevancies rather than truly comprehending the enormity of the news that he was receiving,

> [The doctor] showed us the MRI images on his computer: right at the center of Isabel's brain, lodged between the cerebellum, the brain stem, and the hypothalamus, was a round *thing*. It was the size of a golf ball, Dr. Tomita suggested, but I'd never been interested in golf and couldn't envision what he meant. He would remove the tumor, and we would find out what kind it was only after the pathology report. "But it looks like a teratoid," he said. I didn't comprehend the word "teratoid," either—it was beyond my experience, belonging to the domain of the unimaginable and incomprehensible, the domain into which Dr. Tomita was now guiding us.

Lorrie Moore describes a similar experience when told that her baby had a Wilms tumor. She describes what it felt like when the ultrasound results came back (she writes in the third person, with herself as "The Mother"):

> "What we have here is a Wilms' tumor," says the Surgeon. He says "tumor" as if it were the most normal thing in the world.
>
> "Wilms'?" repeats the Mother. Among the three of them here, there is a long silence, as if it were suddenly the middle of the night. "Is that apostrophe ***s*** or ***s*** apostrophe?" the Mother says finally. She is a writer and a teacher. Spelling can be important—perhaps even at a time like this, though she has never before been at a time like this, so there are barbarisms she could easily commit and not know.
>
> "S apostrophe," says the Surgeon. "I think. A malignant tumor on the left kidney."
>
> Wait a minute. Hold on here. The Baby is only a baby, fed on organic applesauce and soy milk — a little prince! — and he was standing so close to her during the ultrasound. How could he have this terrible thing? It must have been her kidney. A fifties kidney. A DDT kidney. The Mother clears her throat. "Is it possible it was my kidney on the scan? I mean, I've never heard of a baby with a tumor, and, frankly, I was standing very close." She would make the blood hers, the tumor hers; it would all be some treacherous, farcical mistake.
>
> "No, that's not possible," says the Surgeon.

The reason for these parents' denial is clear. As Hemon writes,

> How can you possibly ease yourself into the death of your child? For one thing, it is supposed to happen well after your own dissolution into nothingness. Your children are supposed to outlive you by several decades, during the course of which they live their lives, happily devoid of the burden of your presence, and eventually complete the same mortal trajectory as their parents: oblivion, denial, fear, the end. They're supposed to handle their own mortality, and no help in that regard (other than forcing them to confront death by dying) can come from you—death ain't a science project. And, even if you could imagine your child's death, why would you?

While the reason for parents' magical thinking is clear and understandable, the implications are less clear. How can parents make good decisions for their children if they cannot even accept or acknowledge the diagnosis and if, by their own admission, their thought process is distorted by denial, grief, and magical thinking?

Some parents turn to religion. In Carver's story, the parents, by their own admission, were not religious people. Nevertheless, they felt an overwhelming impulse

to pray for Scotty. Carver describes a conversation between Scotty's mother and father. The mother says, "'I've been praying. I almost thought I'd forgotten how, but it came back to me. All I had to do was close my eyes and say, "Please God, help us—help Scotty" and then the rest was easy. The words were right there. Maybe if you prayed, too,' she said to him." The father replied, "'I've already prayed. I prayed this afternoon—yesterday afternoon, I mean—after you called, while I was driving to the hospital. I've been praying.'"

Others turn away from religion. Hemon writes, "We stayed away from anyone who we feared might offer us the solace of that supreme platitude: God. The hospital chaplain was prohibited from coming anywhere near us."

The messages of these narratives are clear and challenging for doctors who must engage parents in discussions about end-of-life decisions. Parents whose child is critically ill and possibly dying live in an altered reality. They cannot be expected to think or behave or act like "normal" parents. How, then, should doctors and nurses talk to parents when the parents are likely to be in this altered state? The conversations cannot and should not be entirely rational. They need to be based on the understanding that parents are in a strange and almost unimaginable place. Doctors will need to accept the likelihood that parents will engage in magical thinking. Some parents will crave prayer and ritual, others will abhor those practices.

There have been a number of studies of parents' perceptions of the process of shared decision making. Xafis and colleagues conducted a meta-analysis and synthesis of the published literature on discussions of end-of-life decisions (Xafis et al. 2015). They note, first, that parents don't know what to expect. Some described the experience as one of "being in unknown territory." In several studies, parents lamented the fact that the treating doctor had not provided more information. They felt their unfamiliarity with the events that were occurring and their lack of information made it difficult for them to make decisions. Parents wanted to know more about the intensive care unit and the specific treatments that their child was receiving. They were confused by medical jargon. One parent said, "No one really explained it to my satisfaction because I did not and still do not understand. And I would like to understand it in layman's terms. It was what you were gonna do for her" (Meert et al. 2008). Some studies reported that some parents thought the withdrawal of treatment was reasonable while others could never agree. Xafis and colleagues write, "Withdrawal of treatment was not considered appropriate by all parents, but some parents accepted that a decision to withdraw treatment was the right decision, especially when they felt that no other treatment options were available." They report that many parents are deeply conflicted and the conflicts create "extreme emotional strain."

Latour and colleagues studied parents of children in Dutch PICUs (Latour et al. 2011). Parents described the first days of their child's hospitalization as ones in which they were bewildered and felt that they were living "in a mist." Parents reported a sense of unreality. They felt the emotional intensity of the experience but felt powerless to do anything to help their child. They were grateful when the staff helped them participate in their child's care.

Importantly, there is a common element in many of the memoirs. The parents feel isolated. They all long for a connection with another understanding person. That longing provides a clue as to the best approach for doctors to take as they try to guide parents through these difficult situations. The conversations are ultimately about both the facts of the child's situation and about the doctor's commitment to be there for the parents and to not abandon them as their child is dying. Unfortunately, the doctor's own emotional responses may inhibit his or her ability to do this.

4.4 Physicians' Emotional Responses to End-of-Life Discussions

An essential component of the physicians' experience in pediatric critical care is that it involves intense relationships with parents who are facing deep and difficult personal tragedies. The challenge for physicians is to remain compassionate and emotionally available to parents and families while, at the same time, keeping enough emotional distance to remain objective and technically competent (Jellinek et al. 1992). Physicians must integrate the facts about a child's situation and their understanding of the parents' needs with their own feelings about what is going on. This is especially important, and especially difficult, when the doctors are having emotionally charged discussions about a child's quality of life or chance for survival.

In such situations, the facts themselves are often complicated. The prognosis can be unclear, the choice of treatments not always straightforward, and the risks high. For the doctor who, after all, wants to be in control of the situation, the complexity of decisions can lead to feelings of inadequacy. Sometimes the facts suggest that all the options are bleak and the doctor, like the parents, may feel very sad.

It is often difficult to explain to parents the uncertainties that doctors have about prognosis, or the complicated ways in which prognosis for survival may be different from prognosis for recovery. Parents make conflicting demands on the doctor. They want honesty and transparency, but they don't want doctors to take away hope. Sometimes, the news that the doctor brings causes parents to get angry at the doctors or walk away from discussions. These strong emotions can be frightening or frustrating. Parents may not show up for scheduled family meetings, leading doctors to conclude that the parents just don't care. In fact, they may not show up because they care too much and fear that they will have to deal with the sad news that their child is dying.

All of these responses, by both doctors and parents, are understandable. But they can all test a doctor's capacity to remain empathetic, to communicate honestly, to be sensitive to parents' needs, and to maintain their own emotional balance. Jellinek and colleagues studied PICU fellows in order to better understand what they call "the dark side" of being a physician in the PICU (Jellinek et al. 1993). They characterize the dark side as the common feelings of "their own high expectations, fallibility, anger, sense of loss, frustration, limited control, and the need to work closely with

tense, grieving families." They note, "It is not easy to find a place on the continuum between empathy and detachment. Too much closeness can be costly. Intensive care interweaves the joy of saving a life with the profound sadness when a child dies or is severely impaired." Similarly, DeCourcey writes, "If we allow ourselves to become overwhelmed by emotions, it is impossible to care for these critically ill children and their families, but if we attempt to restrain our emotions, we lose the very reason that many of us enter the medical profession in the first place" (DeCourcey 2017).

Jellinek and colleagues offer some suggestions for how PICU doctors might deal with the dark side. They suggest small group discussions in which PICU doctors can talk about their feelings about patients, families, and their work. These meetings should include both junior and senior physicians, so that the junior physicians can see and come to better understand how their role models deal with difficult feelings. These researchers stress the importance of follow-up with families of patients who have been discharged or died. This follow-up, they suggest, "provides a longitudinal perspective to the work and to one's emotions. Without follow-up, (physicians) only see patients and families in times of crisis and have to guess about the long-term effect of their interventions… Seeing positive outcomes and hearing gratitude rather than imagined anger will help manage the dark side."

The challenges of providing care and of communicating with parents can be morally distressing and emotionally exhausting. This moral distress and exhaustion sometimes leads to the phenomenon that has been termed "burnout." The term "burnout" was first used in the mid-1970s to describe physical and emotional exhaustion typified by negative self-concepts, negative job attitudes, and a loss of concern and feeling for clients (Freudenberger 1974). Other terms to describe the phenomenon include depersonalization, a loss of idealism, becoming jaded, and developing a negative attitude towards work, colleagues, and clients (Orlowski and Gulledge 1986).

In the PICU, burnout has been associated with the complex social dynamics around care for the sickest children, especially when families appear to have an unrealistic view of their child's condition and prognosis and communication breaks down (Levi et al. 2004). This communication breakdown and discrepant views of the child's prognosis can lead to moral distress (see Chap. 10). Moral distress can lead to a constellation of symptoms that have been called "burnout syndrome," or BOS.

BOS consists of three different symptoms: (1) emotional exhaustion, (2) depersonalization, and (3) reduced sense of accomplishment (Maslach et al. 1996). Burnout is common among PICU healthcare providers. Studies show that nearly three-quarters of PICU physicians and one-third of PICU nurses will experience BOS at some point in their careers (Garcia et al. 2014; Moss et al. 2016). Many more have some of the symptoms. The symptoms can be similar to those of post-traumatic stress disorder. People have nightmares. They are anxious. They second-guess their decisions.

BOS has consequences for both individuals and for the quality of care in PICUs. When more doctors and nurses have BOS, the frequency of medical errors increases (Shanafelt et al. 2010). Patient satisfaction goes down (Williams et al. 2007). There is a higher rate of turnover among PICU staff (Cimiotti et al. 2012). If BOS among PICU staff is not addressed, then patients could be harmed as a result.

Crowe and colleagues offer suggestions for ways that physicians can recognize and prevent BOS (Crowe et al. 2017). For some doctors, a program of "supervision," as commonly used in the training of psychotherapists, can help (Gold 2004). Crowe writes, "Supervision creates protected space for the professional to attend to a colleague on a regular basis to confidentially discuss the emotional effects of caring for patients and clients. Negative cognitive patterns such as 'only I can help' or 'it's all my fault' can be explored, with the aim of gaining insight into the physician's reactions and needs" (Crowe et al. 2017). Physicians need to take appropriate time off in order to build and nurture their own resilience (Zwack and Schweitzer 2013). All these things can help physicians to have the inner resources to engage parents in the emotionally draining conversations surrounding end-of-life decisions.

4.5 Key Communication Skills

There are specific skills that PICU physicians can learn in order to help them deal with parents' stress and their own feelings about difficult conversations. Janvier and colleagues reviewed the literature and drew upon their own experiences as neonatologists to develop a checklist of six things that doctors might remember as they go into these discussions (Janvier et al. 2014). They even suggested a mnemonic for the six: SOB-PIE. The first is to be clear about the Situation that is triggering the discussion. Is the discussion necessary because there has been a crisis and a decision needs to be made urgently? Or is it a discussion in which the doctor is doing some preliminary preparation of the parents in order to inform that the situation is not so good? In the first case, the doctor would not need to specifically address the question of whether it is time to withhold or withdraw life-sustaining treatment. Instead, the goal of the conversation is to convey concern that, if things don't change, the child might not survive. Parents appreciate doctors' honesty, especially when honesty is tempered with the possibility of hope.

The second thing that Janvier and colleagues recommend is for doctors to give their own Opinion. This is controversial (Ho 2008). Some models of shared decision making suggest that doctors should not give their opinions so that they do not bias or coerce the parents (Kon 2010). Blumenthal-Barby and colleagues discuss this issue and come to the same conclusion as Janvier et al. (Blumenthal-Barby et al. 2016) They write that, in the process of shared decision making, the physician should "share his or her clinical experiences about outcomes and explain fully his or her concerns about how using all available technologies may not be in their child's best interest." Furthermore, they note, the doctor "has to call it the way that he sees it and do and say what he thinks is right and most helpful." They conclude that non-directive counseling is, in situations like this, an abdication of responsibility rather than a sign of respect for parental autonomy. They caution that any advice that the doctor gives, based on his own values and preferences, should be given sensitively and in a way that invites parents to agree or disagree. They conclude, "Families want physicians to give their recommendation. This request should be viewed as an opportunity to delve

further into parental values and preferences. Thoughtful recommendations carefully tailored to each family's specific medical and social situation may be quite helpful."

The third reminder in the Janvier mnemonic is Basic human interactions. This is a reminder to be considerate. Invite the child's primary nurse to the meeting. Parents rely on nurses for emotional support. Inform the parents that they may invite anybody else that they want to the meeting. The doctor should introduce himself or herself, even if they've met the parents before. Parents meet so many people. They may not remember everyone. It might help to give the parents a business card with the doctor's name, phone number, and email address. Sit down in a private place. Take time. Tolerate silence. Parents need to absorb difficult information and process it before they are able to ask questions. Those questions will be key to assessing whether they understand the situation and the doctor's recommendations.

The "P" stands for Parents. All parents have a story. The child may be their first or their tenth. When this child joined their family, it may have been long planned and long desired or it may have come as a surprise. Some parents had picked out a name for their child long ago. That name will likely be a meaningful part of the story and give hints about larger family dynamics. Each parent and each family is different. They will have a different history and may have different values with regard to survival and survival with disability (Saigal et al. 2000). Time spent getting to know the parents will save much time in the future as the interactions with them become even more stressful.

The fifth consideration is important in and of itself but also because it should be fifth and not first. That consideration is to give the parents appropriate Information. Doctors often think that information should come first. That is a mistake. There is simply too much information and the information can be given in too many different ways. It is impossible to know what information to share and how to share it without understanding the situation, creating a space for respectful and basic human interactions, listening to the parents, and being prepared to share an opinion or recommendation. The information to be given, then, ought to be guided by the parents' response to the doctor's recommendation.

There have been many recent studies of different ways to give information and about how decisions can be shaped by the way information is framed. Haward and colleagues have shown that parents are more likely to choose treatment if they are told the chance of survival rather than the chance of death (Haward et al. 2008). Kakkilaya and colleagues showed that a visual aid showing statistics pictorially improves mothers' understanding of probabilities (Kakkilaya et al. 2011). In giving information, doctors should strive to be as neutral and understandable as possible. This is different from simply not making a recommendation because the biases and opinions can be hidden within different ways of communicating. Thus, physicians can shape decisions in a non-explicit and subtle way. There is no absolutely neutral way to present information, but neutrality is an ideal towards which we should strive in presenting information about outcomes.

The final component of the Janvier SOB-PIE mnemonic is Emotions. Everybody involved in discussions about the possibility of withholding life-sustaining treatment feels strong emotions. Parents love their children. Doctors are passionately

committed to saving lives. Doctors may feel guilty about things they did or did not do that might have made the situation worse. Parents may be angry at doctors. These strong emotions make conversations difficult, but the conversations are even more difficult if the emotions are not acknowledged. Janvier et al. write, "Knowledge and intelligence do not counter powerful emotions. In fact, most big decisions in life are not purely rational: which partner to choose, whether to have children, where to live, etc. Parents not only make decisions with their heads, but also with their hearts: love, guilt, regret, and tolerance of uncertainty will affect their decision" (Janvier et al. 2014). They cite Charland, who used the example of Dr. Spock on the television show *Star Trek* to suggest how inhuman it would be to make decisions in an unemotional and purely rational way (Charland 1998). We often judge a person who doesn't show the proper emotions to be "in denial" or even incompetent to make decisions. Emotions are clearly crucial to an appropriate parental response to tragedy. It is equally crucial that doctors acknowledge the parents' emotions and validate them.

Even more difficult, doctors need to be aware of their own emotions. For some, this awareness comes easily. For others, it takes practice. For almost everyone, it is difficult to be in the grip of strong emotions and find the right balance between emotional responsiveness and the detachment that is sometimes necessary to make good decisions. Osler counseled doctors to strive for equanimity, or imperturbability. He wrote, "Imperturbability means coolness and presence of mind under all circumstances, calmness amid storm, clearness of judgment in moments of grave peril, immobility, impassiveness. It is the quality which is most appreciated by the laity though often misunderstood by them; and the physician who has the misfortune to be without it, who betrays indecision and worry, and who shows that he is flustered and flurried in ordinary emergencies, loses rapidly the confidence of his patients" (Osler 2017).

This Oslerian model of "detached concern," by which the physician can intellectually perceive the suffering of her patients but doesn't feel anything herself, has been touted by medical educators for generations as the ideal model of the compassionate physician (Blumgart 1964; Suchman et al. 1997).

Recently, Halpern has criticized this model of detached concern. She advocates, instead, that clinicians learn to be aware of the emotions that each patient evokes because, she argues, those emotions are clues as to what the patient might be feeling (Halpern 2003). She gives an example from her own clinical practice as a psychiatry consultant:

> The medical team called for psychiatry to consult on a patient with Guillain-Barré syndrome who was depressed and refusing treatment. When I first came into the patient's room, I noticed a flicker of interest in his eyes as he greeted me. He was completely paralyzed from the neck down. He greeted me by struggling to whisper a few words through his tracheotomy tube. The nurse gently adjusted his tube. I felt uncomfortable viewing his immobile body splayed on the bed, hearing him struggle.
>
> I spoke to him in a quiet, gentle way. As I spoke, he became withdrawn, literally looking away to end the conversation. I felt ashamed at imposing on him. Yet, when I thought about the shame, which led me to retreat, I wondered if this shame was also an emotion that came from resonance with him. Here he was, a powerful man, now suddenly paralyzed and exposed to all of his caregivers. My gentle approach to him clearly backfired—did he sense pity? I

> tried to change my tone, to see how he responded. I asked him, directly and assertively, what was bothering him about how we were treating him. He looked right at me and then began an angry tirade about how disrespected he felt. This engagement was the beginning of an effective therapeutic alliance.

The crucial difference between imperturbability/equanimity and Halpernian empathy is that, in the latter, the clinician is exquisitely aware of what she is feeling, of how her feelings arise because of her response to the patient, and of the clues that those feelings give to how the patient is feeling. It is the very opposite of detachment. Halpern suggests that clinicians can learn to be aware of their feelings and, in doing so, will be able to use those feelings to be better at understanding what their patients are feeling. She writes, "Empathy is an experiential way of grasping another's emotional states. Empathy is a 'perceptual' activity that operates alongside logical inquiry. So long as physicians continue to exercise their skills of objective reasoning to investigate their empathic intuitions, empathy should enhance medical diagnosis rather than detract from it. Further, empathy enhances patient-physician communication and trust, and therefore treatment effectiveness."

Halpern acknowledges that there are three barriers to cultivating empathy as a way of improving communication. First, she notes, anxiety interferes with empathy. Anxiety arises for two reasons. First, physicians are under enormous time pressure. If they take the time to listen carefully and feel deeply, they may become less efficient and therefore be perceived as less skilled. Second, powerful emotional responses can, themselves, create anxiety. Doctors sometimes worry that, if they let themselves feel sadness or anger, they will be overwhelmed by these emotions and lose the professional detachment that Osler advocates. Of the former, Halpern suggests that taking good histories saves time and improves the quality of care. Of the second, she writes, "The culture of detachment needs to shift, encouraging physicians to acknowledge and seek support for their own emotional needs."

A second barrier is that physicians don't acknowledge or value emotions. They see them as getting in the way of good medical care, rather than as an essential element of such care. This belief can only be changed by their teachers and role models. Experienced physicians who are excellent communicators should stress the need for good communication, and talk about the ways that one can learn the skills to become better at communication (Vanderford et al. 2001).

A third barrier to empathy arises when doctors or patients feel things that have been categorized as "negative emotions." Physicians who feel angry with patients, for example, learn to suppress those feelings. Psychiatrists, on the other hand, learn just the opposite. They are taught to pay attention to counter-transference, that is, the negative feelings that they have toward patients that may give them a clue as to what the patients are feeling.

Winnicott, in a classic article, compared the doctors' feelings in such situations to those of a mother who loves her baby but also, at some moments, feels hatred toward the baby. He writes, "A mother has to be able to tolerate hating her baby without doing anything about it. She cannot express it to him. The most remarkable thing about a mother is her ability to be hurt so much by her baby and to hate so much without paying the child out" (Winnicott 1949). The same might apply to

doctors dealing with angry or hateful patients or parents. We inevitably hate them back. We can be aware of those feelings without acting on them. Winnicott suggests that such awareness is key to being responsive to the patients' needs without being overwhelmed by our own unacknowledged emotions.

Communicating with parents about end-of-life decisions is one of the most difficult, emotionally stressful, and important things that a PICU doctor does. Caring for dying children was easier when there was less life-sustaining technology and decisions about withdrawing it did not have to be made. It was easier when the model of decision making leaned more toward the unilateral and paternalistic approach by which doctors made decisions without including the parents. That world is gone. The technology of intensive care is with us to stay. Parents want to be involved in decision making and have the right to be involved. But not all parents are alike and each parent may want to be involved in their own way (Gillam and Sullivan 2011).

Many factors influence parental responses to discussions of treatment withdrawal. These include their previous experience with death and end-of-life decision making for others, their personal observations of their child's suffering, their perceptions of their child's will to survive, their need to protect and advocate for their child, and the family's financial resources and concerns regarding lifelong care.

The most important finding in a large body of research about difficult conversations and difficult decisions is that such conversations require skills that can be taught and can be learned. Doctors and nurses who want to become better communicators can improve their skills (Schaefer et al. 2014). Doing so will increase their ability to be empathic, will decrease burnout, and, most importantly, will improve the quality of care for children in the PICU.

References

Blumenthal-Barby, J.S., et al. 2016. Should Neonatologists Give Opinions Withdrawing Life-Sustaining Treatment? *Pediatrics* 138 (6): e20162585.

Blumgart, H.L. 1964. Caring for the Patient. *New England Journal of Medicine* 270: 449–456.

Burns, J.P., et al. 2014. Epidemiology of Death in the PICU at Five U.S. Teaching Hospitals*. *Critical Care Medicine* 42 (9): 2101–2108.

Carver, R. 2017. *A small good thing.* August 27, 2017. Available from: http://www.classicshorts.com/stories/sgthing.html.

Charland, L.C. 1998. Is Mr. Spock mentally competent? Competence to consent and emotion. *Philosophy, Psychiatry, Psychology* 5: 67–81.

Cimiotti, J.P., L.H. Aiken, D.M. Sloane, et al. 2012. Nurse Staffing, Burnout, and Healthcare-Associated Infection. *American Journal of Infection Control* 40 (6): 486–490.

Collins, N., D. Phelan, and E. Carton. 2006. End of life in ICU–Care of the Dying or 'Pulling the Plug'? *Irish Medical Journal* 99 (4): 112–114.

Crowe, S., et al. 2017. Grief and Burnout in the PICU. *Pediatrics* 139 (5): e20164041.

DeCourcey, D.D. 2017. Saying Goodbye. *JAMA Pediatric* 171 (5): 417.

Forman, V. 2009. *This Lovely Life*. Boston, MA: Mariner Books.

Freudenberger, H. 1974. Staff Burn-Out. *Journal of Social Issues* 30: 159–165.

Garcia, T.T., et al. 2014. Prevalence of Burnout in Pediatric Intensivists: An Observational Comparison with General Pediatricians. *Pediatric Critical Care Medicine* 15 (8): e347–e353.

Gillam, L., and J. Sullivan. 2011. Ethics at the End Of Life: Who Should Make Decisions About Treatment Limitation for Young Children with Life-Threatening or Life-Limiting Conditions? *Journal of Paediatrics and Child Health* 47 (9): 594–598.

Gold, J.H. 2004. Reflections on Psychodynamic Psychotherapy Supervision for Psychiatrists in Clinical Practice. *Journal of Psychiatric Practice* 10 (3): 162–169.

Halpern, J. 2003. What is Clinical Empathy? *Journal of General Internal Medicine* 18 (8): 670–674.

Haward, M.F., R.O. Murphy, and J.M. Lorenz. 2008. Message Framing and Perinatal Decisions. *Pediatrics* 122 (1): 109–118.

Hemon, A. 2011. *The aquarium: A child's isolating illness*, in New Yorker.

Ho, A. 2008. Relational Autonomy or Undue Pressure? Family's Role in Medical Decision-Making. *Scandinavian Journal of Caring Sciences* 22 (1): 128–135.

Janvier, A., K. Barrington, and B. Farlow. 2014. Communication with Parents Concerning Withholding or Withdrawing of Life-Sustaining Interventions in Neonatology. *Seminars in Perinatology* 38 (1): 38–46.

Jellinek, M.S., et al. 1992. Facing Tragic Decisions With Parents in the Neonatal Intensive Care Unit: Clinical Perspectives. *Pediatrics* 89 (1): 119–122.

Jellinek, M.S., et al. 1993. Pediatric Intensive Care Training: Confronting the Dark Side. *Critical Care Medicine* 21 (5): 775–779.

Kakkilaya, V., et al. 2011. Use of a Visual Aid to Improve Counseling at the Threshold of Viability. *Pediatrics* 128 (6): e1511–e1519.

Kon, A.A. 2010. The Shared Decision-Making Continuum. *JAMA* 304 (8): 903–904.

Lago, P.M., et al. 2005. Life Support Limitation at Three Pediatric Intensive Care Units in Southern Brazil. *Jornal de pediatria* 81 (2): 111–117.

Latour, J.M., et al. 2011. A Qualitative Study Exploring the Experiences of Parents of Children Admitted to Seven Dutch Pediatric Intensive Care Units. *Intensive Care Medicine* 37 (2): 319–325.

Levi, B.H., et al. 2004. Jading in the Pediatric Intensive Care Unit: Implications for Healthcare Providers of Medically Complex Children. *Pediatric Critical Care Medicine* 5 (3): 275–277.

Maslach, C., S.E. Jacksonm, and M.P. Leiter. 1996. *Maslach Burnout Inventory*. Palo Alto, CA: Consulting Psychologists Press.

Meert, K.L., et al. 2008. Parents' Perspectives on Physician-Parent Communication Near the Time of a Child's Death in the Pediatric Intensive Care Unit. *Pediatric critical care medicine* 9 (1): 2–7.

Meert, K.L., et al. 2015. End-of-Life Practices Among Tertiary Care PICUs in the United States: A Multicenter Study. *Pediatric Critical Care Medicine* 16 (7): e231–e238.

Moore, P., et al. 2008. Withdrawal and Limitation of Life-Sustaining Treatments in a Paediatric Intensive Care Unit and Review of the Literature. *Journal of Paediatrics and Child Health* 44 (7–8): 404–408.

Moss, M., et al. 2016. An Official Critical Care Societies Collaborative Statement: Burnout Syndrome in Critical Care Healthcare Professionals: A Call for Action. *Critical Care Medicine* 44 (7): 1414–1421.

Orlowski, J.P., and A.D. Gulledge. 1986. Critical Care Stress and Burnout. *Critical Care Clinics* 2 (1): 173–181.

Osler, W. 2017. *Aequanimitas*. 28 Aug 2017. Available from http://med-cat.livejournal.com/353670.html.

Saigal, S., et al. 2000. Parental Perspectives of the Health Status and Health-Related Quality of Life of Teen-Aged Children Who Were Extremely Low Birth Weight and Term Controls. *Pediatrics* 105 (3 Pt 1): 569–574.

Schaefer, K.G., et al. 2014. Raising the Bar for the Care of Seriously Ill Patients: Results of a National Survey to Define Essential Palliative Care Competencies For Medical Students and Residents. *Academic Medicine* 89 (7): 1024–1031.

Shanafelt, T.D., et al. 2010. Burnout and Medical Errors Among American Surgeons. *Annals of Surgery* 251 (6): 995–1000.

Suchman, A.L., et al. 1997. A Model of Empathic Communication in the Medical Interview. *JAMA* 277 (8): 678–682.

Vanderford, M.L., et al. 2001. Communication Challenges for Experienced Clinicians: Topics for an Advanced Communication Curriculum. *Health Communication* 13 (3): 261–284.

Williams, E.S., L.B. Manwell, T.R. Konrad, et al. 2007. The Relationship of Organizational Culture, Stress, Satisfaction, and Burnout With Physician-Reported Erro and Suboptimal Patient Care: Results from the MEMO Study. *Health Care Management* 32: 202–212.

Winnicott, D. 1949. Hate in the Counter-Transference. *International Journal of Psychoanalysis* 30: 69–74.

Xafis, V., D. Wilkinson, and J. Sullivan. 2015. What Information Do Parents Need When Facing End-of-Life Decisions for Their Child? A Meta-Synthesis of Parental Feedback. *BMC palliative care* 14: 19.

Zwack, J., and J. Schweitzer. 2013. If Every Fifth Physician is Affected by Burnout, What About the Other Four? Resilience Strategies Of Experienced Physicians. *Academic Medicine* 88 (3): 382–389.

Chapter 5
The Difficulty with Determining Whether Someone is Dead

Abstract Parents need certainty that, when their child is declared dead, there has not been any mistake. As discussed within this chapter, the fear of death being declared prematurely is inherent to human nature. However, the complexities of modern medicine have made the concept of death and when it occurs even more complex. The chapter reviews the history leading to the development of the Uniformed Declaration of Death Act, and its recognition that death may be declared following either loss of neurologic function or loss of circulatory and respiratory functions. While the construct of brain death addressed a growing critical care problem of the permanently and severely brain injured patient on technological support, it also introduced many other ethical questions about what it means to be dead. These ethical concerns will be reviewed. It is paramount that physicians understand the medical standards used to define death, but also appreciate the questions and concerns parents may raise about this difficult topic.

5.1 Confusion About Brain Death

Jahi McMath was a 13-year-old girl who tragically suffered an in-hospital cardiopulmonary arrest following a tonsillectomy and adenoidectomy in 2013. The arrest caused a severe anoxic brain injury. She would subsequently meet criteria for brain death. This diagnosis was determined by experts at the hospital where she was an inpatient and later confirmed by neurological consultants brought in from outside that hospital. Her family refused to accept that she was dead. They sought a court order to prevent Oakland Children's Hospital from removing the technology that they claimed was keeping Jahi alive and that doctors claimed was merely sustaining her body (Luce 2015).

The dispute raises many ethical, legal, and spiritual problems. Is the determination of death something to be done by doctors? Judges? State legislatures? Religious authorities? What does it mean to declare somebody dead while their heart is still beating? What should we call a person who meets criteria for brain death? A corpse?

L. Miller-Smith et al., *Bioethics in the Pediatric ICU: Ethical Dilemmas Encountered in the Care of Critically Ill Children*, International Library of Ethics, Law, and the New Medicine 77, https://doi.org/10.1007/978-3-030-00943-4_5

A dead body? A perfused cadaver? In this chapter, in conformity with current medical standards (and legal standards in most states), we will talk about "Jahi's body" rather than about "Jahi."

Jahi's family ultimately found a facility in New Jersey, a state where families may legally object to brain death, that would accept her body in transfer. That facility agreed to continue mechanical ventilation. With financial assistance from the Terri Schiavo foundation (Levs 2014), Jahi's body was moved to the New Jersey medical facility. In order for the body to be transported, a death certificate was issued by the California state coroner.

Once Jahi's body was in New Jersey, a gastrostomy tube was placed and a tracheotomy was performed. Jahi's body continued to be supported on a ventilator and by tube feedings. Her family intermittently posted updates on their blog and on Facebook. Jahi's body went through puberty and began menstruating. The family posted videos that, they claimed, demonstrated some purposeful movements and responses that were not merely spinal reflexes. They claimed that she was able to follow commands and that she had taken breaths on her own (Lupkin 2014). Both of these activities, if they actually occurred, would invalidate the diagnosis of brain death. Experts disagreed, however, about whether the reports of the McMath family or the videos that they posted were accurate or reliable.

In June, 2018, five years after her anoxic event, Jahi's heart stopped beating. Her New Jersey death certificate, her second death certificate, listed the cause of death as bleeding secondary to liver failure (Goldschmidt 2018).

On February 20, 2016, a deadly and horrific mass shooting took place in Kalamazoo, Michigan. Six people died and multiple others were injured. Six people died. One of the victims was a 14-year-old girl, Abigail, who was shot in the head. Discussion of her condition in the media highlighted the struggle and confusion that our society faces with the current status of declaration of death.

The day following the shooting, an NBC News outlet would quote a state police officer as saying, "The girl squeezed her mother's hand as doctors were preparing to harvest her organs." This statement, perhaps fueled by other offhand comments, would spread across the news and social media. Multiple headlines appeared stating that the young lady was "brain dead" and was actively being taken for organ retrieval when she began to move. Others stated that her hand-squeeze prevented doctors from being able to start the organ donation process. The NY Daily News published the following:

> She was initially declared deceased, information that was passed along to law enforcement and then members of the media during the shooting aftermath, when her heart stopped, but Abigail miraculously squeezed her mother's hand before doctors could contact Gift of Life Michigan to start the organ donation process. (Hensley 2016)

Anyone who is involved with the determination of death in ICUs likely shudders at the confusion that this sentence instills. Was she declared dead by cardiac criteria or by the neurologic criteria required for brain death? What was the timing and involvement of the organ procurement organization? Who is responsible for this confusion? Physicians want society to have faith in their ability to declare death.

It was unclear, in the way that this story was reported, whether there were faulty medical practices here or just faulty journalistic ones.

At a press conference about the case that was held on February 23rd, the girl's parents and one of the physicians tried to clarify what happened. CBS News reported the clarification:

> [Dr.] Lane-Davies said Abigail's heart beat stopped during attempts to save her life, but it was restored. An organ donation service was contacted with her parents' permission, though she was never declared medically brain dead, he said. Additionally, her parents reportedly had requested conversations about organ donation to begin, knowing how grave her situation was, although they always remained hopeful. (Kalamazoo Victim 2016)

This information, unlike the headlines of a not-brain-dead girl going for organ donation, helped clarify the sequence of medical events. Those events, decisions, and conversations seemed appropriate given the nature of her injuries and her parents' preferences. But those events did not get reported as widely as the original story. The clarifications were less newsworthy than the original tale.

The original, horrific story can still be found on social media sites today, among other stories, as part of a list used to question physicians' ability to declare death on the basis of neurological criteria. Such stories stoke widely held fears that doctors are overly eager to declare people "brain dead" in order to procure organs for transplant.

5.2 The Language of Brain Death: A Morass of Semantic Inconsistencies

The language used to discuss brain death is full of inconsistencies. Newspaper reports, medical journals, and legal proceedings talk about providing "life support" for people who have been declared dead. The haphazard use of language can lead to misconceptions about how death is determined and when it is declared. This confusion gets even worse during the process of testing to determine whether brain death has occurred. If someone has had one set of tests indicating that they have died, but have not yet had the confirmatory tests, are they dead? The risk of potential errors is particularly frightening to families when the life of a vulnerable child is on the line.

Critical care health care professionals have an ethical obligation to communicate concisely and accurately about death. We must follow professionally endorsed protocols for determining brain death. If it is determined that a patient meets criteria for brain death, we should pronounce them dead. We should also recognize that public skepticism surrounding declaration of death is nothing new. Brain death is just the latest development in a controversy that has been going on for centuries.

5.3 Mistrust of Death Declaration Throughout History

The fear of being buried prematurely (taphephobia) is probably as old as the human species. The fear was fed by the fact that medical practitioners sometimes have difficulty in deciding who is dead, or when, precisely, death occurs. Galen (130–190 CE) warned of avoiding early internment, particularly when the cause of death was "hysteria" (Polizzotto and Martin 2006). His advice should have been heeded centuries later by the family of an Iranian girl, who likely suffered from "hysterical paralysis" (or a conversion disorder) after refusing to go work on the family's tobacco farm one morning. Her case is reported by Agutter and colleagues. After the girl collapsed onto her bed and appeared lifeless, she was declared dead. In spite of warnings from an elder in the community who reported seeing subtle movement, the girl was buried one day following her "death." Ongoing concerns that she was alive led to the burial site being dug up a few days later. New findings of scratches on her body and its positioning would confirm that she had indeed died trying to escape from her grave (Agutter et al. 2013).

To avoid this type of tragedy, many medical experts became more conservative in the criteria they used to determine that death had occurred. Some would declare death only in the presence of putrefaction, rigor mortis, or decapitation. This likely contributed to the widespread practice of waiting several days after death before proceeding with burial. George Washington reportedly stated on his death bed that he should not be buried until a three-day period had passed. There were many who shared his concern. One way to address the concern was through creation of "waiting mortuaries," which were created in Europe to hold dead bodies while waiting for death to be beyond any doubt, and avoiding premature burial (Waiting Mortuaries 1896).

Industrialization and urbanization would make it challenging to continue to delay burials. In cities, there were many deaths each day in a small geographical area, making it difficult for mortuaries to keep bodies above ground for long periods of time. Furthermore, with the risk of contagious illnesses spreading, public health authorities recommended that bodies be buried quickly. In the 19th century, quick and less formal burials increased in frequency, fueling a significant increase in taphephobia.

Edgar Allan Poe's short horror story "The Premature Burial" epitomized the fear of being buried alive and highlighted the ongoing uncertainty about how to define the moment of death. Poe wrote,

> To be buried while alive is, beyond question, the most terrific of these extremes which has ever fallen to the lot of mere mortality. That it has frequently, very frequently, so fallen will scarcely be denied by those who think. The boundaries which divide Life from Death are at best shadowy and vague. Who shall say where the one ends, and where the other begins? (Poe 2010)

Many people dealt with such fears by specifying precisely how their deaths should be declared. Alfred Nobel, in the same will he used to create the Nobel Prizes, put rules in place for his physicians regarding his death. He stated that following his final breath, he wanted his veins "opened" to ensure his death, with the declaration to be made by "competent Doctors." Nobel's concerns persist. There was a recent report

of a 75-year-old woman whose fear of premature burial was so profound that, like Nobel, she made her daughter promise to have her wrists cut. Her physicians allowed her family to witness the cutting of her veins in the morgue (Polizzotto and Martin 2006). While this was believed to be physiologically unnecessary by the physician, it was done to meet the emotional needs of a patient and her family.

The practice of autopsy added to societal fear about premature declaration. Without a specific grace period between death and performance of an autopsy, some worried that they could have a fate perhaps worse than being buried alive—being surgically opened and having organs removed. Ambroise Paré, a famous French barber-surgeon from the 16th century, wrote that "in this century it happened that a great anatomist. … I say great and famous. … then a resident in Spain was ordered to open the body of a woman believed to be dead of suffocation of the womb. At the second cut of the razor the woman began to move and show other signs that she still lived. … the good master had to leave the country… And being exiled, soon after died of grief which was certainly a great loss for the Republic" (Paré 1968). Many believe this was fateful mistake made by renowned anatomist Vesalius, who revolutionized medicine with his detailed descriptions of human anatomy. In addition to being a notorious grave robber (in those days, before refrigeration, the study of anatomy relied on the dissection of relatively "fresh" corpses), he may also have committed the atrocity of performing an "autopsy" on an alive patient.

Multiple other accounts exist of autopsies and dissections performed upon the living. In the mid-1600s, Anne Green was sentenced to death after being found guilty of murdering her premature infant. She was sentenced to death by hanging. After 30 min, she was removed from the gallows, placed in a coffin, and transferred to the home of a professor of anatomy for dissection. When her coffin was opened, she was visibly breathing. She was resuscitated by inducing coughing, rubbing her hands and feet, and giving her warm liquids. She reportedly was sent home two days later, and went on to live for an additional 15 years. Luckily, she did not remember being hanged or the events that followed (Dossey 2007).

A major technological advance, in the early 19th century, helped physicians to be more precise in determining whether someone had died. The stethoscope, invented in 1819, improved doctors' ability to confirm he absence of a heartbeat. Dr. Eugene Bouchut would win an Academy of Science prize for "the best work on the signs of death and the means of preventing premature burials" in 1846 for suggesting the use of the stethoscope in declaring death (Gardiner et al. 2012). Bouchut proposed that listening for a minimum of two minutes without an appreciable heartbeat could be diagnostic of death. When this timeframe was questioned, it was lengthened to five minutes. This two to five minute waiting period has continued to be relevant, as it is still the generally applied time used in organ donation after circulatory determination of death (DCDD), at least within the United States.

In spite of the stethoscope, there are still occasional errors in the diagnosis of death. These errors are not limited to the distant past, but have occurred in modern times. In 1964 in New York, a pathologist was grabbed around the throat by the body

on which he was beginning to incise; the "corpse" lived, but the pathologist died of a cardiac arrest.

The modern equivalent of early burial or autopsy may be fear of premature organ harvesting for donation. One study on societal views and obstacles to donation found that many people fear they will be declared dead prematurely in order to take their organs. One individual, when asked about their concerns with organ donation, responded: "How fast is the decision made? Are you really dead? Who makes the decision?" (Corlett 1985).

Advancements in technology over the next century would assist physicians in declaration of death, but would also bring complications. If the stethoscope oiled the cog of accurately pronouncing death, then the concept of brain death would throw a wrench in it.

5.4 A New Means to Declare Death

Advancements in critical care in the late 20th century created a new and troubling subset of patients: those with catastrophic brain injury, no ability to breathe on their own, no perceived likelihood of any significant recovery, and whose hearts were still beating. Before mechanical ventilation, such patients would simply have died. With mechanical ventilation, they could be maintained alive. But did doctors have to continue ventilation? If not, was it because such treatment was futile? Or because such patients were not really alive?

In the 1950s, Molaret and Goulon coined the term "coma dépassé" to describe patients who physicians felt would never regain consciousness or the ability to breathe independently (Mollaret and Goulon 1959). These cases were viewed as the epitome of medical futility. Many doctors and theologians argued that it was ethically permissible to withdraw life support from such patients (though that wouldn't be legally tested in the United States until the case of Karen Ann Quinlan in 1976). But were these patients dead?

The use of our terms "alive" versus "dead" implies that a person must be in one category or the other, and that the transition between the two takes place at a discrete moment. But we are learning what Poe knew over a century ago, "The boundaries which divide Life from Death are at best shadowy and vague" (Poe 2010). Medical advancements are making them ever more so. The technology of pediatric intensive care setting has become so advanced that the process of dying can be slowed. This lack of natural progression makes it challenging for families and health care providers to actually see physical markers of death; to see the difference between a patient who should be considered alive and one who is dead or who is dying. The active process of dying can be extended over days or weeks. During that time, patients have a heartbeat and pulses. They are warm. They make urine. Their chest rises and falls with each puff from the ventilator. It is not surprising that many family members think they are alive.

5.5 Controversies in the Definition of Death

The best place to start when determining what it means to be dead is to determine what it means to be alive. From a basic biological standpoint, the term "living" is applied to things that (a) are made of cells; (b) obtain and use energy; (c) grow and develop; (d) reproduce; (e) respond and adapt to their environment; and (f) have different levels of organization. These characteristics apply to bacteria and viruses, as well as to plants and animals. From a simplistic biological point of view, presence of all of these factors corresponds to "life" and absence of any one characteristic qualifies as "not alive."

But there are difficulties with these basic qualities when applied to higher level organisms. Some humans (e.g. people with infertility, post-menopausal women) lack the ability to reproduce. But we would never use that criterion alone to assert that they were dead. Instead, we apply these criteria to the species as a whole, not to each individual member of the species. But what if this criterion were applied in reverse? Because an entity can reproduce, must it be alive? Such questions could be asked in relation to any of the criteria used to determine the difference between life and death. If one or more of these criteria can no longer be met, does that constitute death of the organism? Is it the case that a human being who can be fed and use that harnessed energy, who continues to grow, and who can gestate a fetus must be alive?

Today, in the United States and in many other countries around the world, the category of "alive" takes other factors into consideration. An important component in determining whether an organism is living or dead is the presence of different levels of organization. These levels of organization must be integrated into one system that supports the whole organism. Some degree of action at the cellular, tissue, or organ level is not enough. It is not enough that the cells of an organ may be functioning if those cells do not interact with other cells around them to provide a function. By this view, there is a certain threshold of cellular functioning required to allow tissue to function; a threshold of tissue function to allow organ functioning; and a threshold of organ function to say an organism as a whole is functioning. These integrated activities must come together to achieve the basic fundamental needs of the whole organism.

The basic fundamental needs go back to the criteria of being deemed a living thing described above. The integration of systems allows us to capture energy through eating and digestion, and then deliver important nutrients throughout the body, with subsequent excretion of waste. Likewise, the integration of the lungs and heart allow the delivering of oxygen to cells throughout the body, and control of these systems arises from the brain. But is every piece required to make up the whole human? Are certain organ systems required more than others? And what percentage of function of these organs, or of the whole, is enough for the person to be alive?

These two views of "life" and "death" are polarizing. Some scholars and bioethicists assert that "the functioning of the brain, by itself, has nothing to do with whether the human beings are alive or dead, any more than any other individual organ." They go on to state that humans who suffer massive neurological injury, even if by

decapitation, are "not dead as long as their bodies continue to function as an organism with the aid of technological intervention" (Miller 2012). These scholars provide physiologic examples to support this argument. One example is the ability of a brain-dead patient to gestate a fetus until delivery. Another is the ability of individuals who have been declared brain dead to fight infections and heal wounds. Similarly, such people can continue to digest food and to grow. These are signs that the multiple levels of organization are still present and integrated enough to support the fundamental biological functions of a living organism.

A counterargument to this biological argument focuses on the difference between the brain and other organs, a difference that comes down to ideas of what makes a person a person. The brain is different from the kidneys, lungs, or heart. The brain determines who we are as individuals. The brain's primary functions cannot be replaced by a machine or a transplant (or, if, in some future time, brain transplants were possible, we would think of them as creating a new person). Failure of other organs can be treated with dialysis, mechanical ventilation, or ECMO or ventricular assist devices. All may be treated by transplantation. Such replacement therapies do not fundamentally change a person. A patient can have renal failure, and in fact can undergo complete nephrectomy with dependence on dialysis, and we would not debate either whether they should be considered alive or whether they should still be thought of as being themselves. Likewise, patients who are supported on ECMO are not considered dead.

If the brain has remained unharmed, there is never a question in the PICU whether the child has fundamentally changed as a person. It is not until the brain has had extensive injury that health care workers and families alike begin to wonder if the child, as the person he or she was, is still there. Consciousness and self-awareness cannot be replaced. Many would argue that these are the characteristics that are paramount to defining personhood and that brain death may not be the death of the organism but it is the death of the person. Drs. Baker and Shemie make this argument. They state, "The capacity for consciousness and self-awareness is uniquely synonymous with human life and personhood, and its absence is necessary and sufficient to identify that death has occurred" (Baker and Shemie 2014).

Perhaps the real issue is a semantic one. We are discussing two different types of changes to the human condition. One is the loss of personhood. The other is the loss of the functioning biological organism. We are attempting to apply the term "death" to both.

Perhaps consciousness and awareness are the true litmus test for disintegration of the organism. If those higher brain functions are the ultimate of our systems' integration, and are functions that cannot be replaced technologically, then their loss is indication that death has occurred, regardless of technological support of specific organ and tissue function. This viewpoint supports the now medically accepted standard that brain death criteria are appropriate markers for death determination.

5.6 The Legalization of Brain Death and Its Connection to Organ Donation

Historically, there was a need to accept (or completely reject) the concept that neurological criteria could be used to determine death. As discussed earlier, catastrophic brain injury patients, fully supported on mechanical ventilatory support, were a growing patient population that needed to be addressed. The medical advancements that were being made allowed for these patients to be sustained for long periods, and theoretically, indefinitely.

Additionally, similar issues would be raised by another evolving medical advancement: solid organ transplantation. A later chapter will more directly discuss the issues surrounding organ transplantation. Here, we address only its role in catalyzing discussions about brain death. Organ transplantation and the drive for societal acceptance of brain death determination are closely linked. While many will argue that the discussions around severe irreversible brain injury constituting death were occurring regardless of the possibility of organ donation, the trajectories of these topics would inevitably intersect. We would see this intersection played out with the events surrounding the first heart transplantation.

Christiaan Barnard transplanted the first human heart on December 3rd, 1967, from a donor, Denise, who had suffered a catastrophic and non-survivable brain injury following a car accident. No laws were yet in place allowing determination of death with neurological criteria, so the donor was taken to the operating room, where artificial respiration was stopped. The medical examiner had been asked to be present in the operating room to declare the donor's death prior to harvesting the heart for transplantation. By initial reports, this went without difficulty (Brink 2009).

Later reports told a different story. In 2006, Barnard's brother revealed that Denise's heart did not stop on its own. Instead, she was given a high dose of intravenous potassium chloride (Alivizatos 2017). Had they actually waited until the heart stopped beating completely on its own, the heart may not have been viable to transplant. The heart was placed in a 53-year-old man with coronary insufficiency and heart failure. The patient initially did well, and the surgery was deemed a success by surgical colleagues, even though the recipient succumbed to pneumonia 18 days post-transplant (Brink 2009).

Regardless of this individual outcome, cardiac transplant was now a possibility. But having to wait to withdraw support, and hoping that the patient would die in a timeframe that would not lead to irreversible damage to the transplantable organ, seemed likely to worsen outcomes. For the success of transplantation, it would be better to retrieve organs while they remained well perfused and oxygenated, that is, while the heart was still beating.

The same year as Barnard's heart transplant, a committee was formed at Harvard Medical School to address questions about brain death. Publishing their recommendations in JAMA (A Definition of Irreversible Coma 1968), the committee members made clear their acceptance of neurological criteria to determine death and recommended standards for how testing of these criteria should be done. It should be noted

that their work embraced the whole-brain notion of death, outlining the clinical findings and ancillary studies that would allow such a diagnosis. They proposed that patients should be considered brain dead if they had no response to external stimuli, no cranial nerve function, no spontaneous respirations, and no extraneous causes for these symptoms. The committee recommended two examinations at least 24 h apart.

Three months later, in February of 1968, a bill was introduced in the US Congress to "establish a commission to assess and report on the ethical, legal, social and political implications of medical advances." (Levin et al. 1993) This was the first step for the United States government to address the question of death determination, and how neurological criteria could be considered. The President's Commission would eventually release recommendations about brain death in the form of proposed legislation for state governments. The commission called this the Uniform Declaration of Death Act (UDDA).

The UDDA would establish the accepted US definition of death, which has not been altered, although perhaps disputed, since 1981. The President's Commission recognized that either cardiopulmonary or neurological determinants could be used in the determination of death. The act states:

> An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.
>
> It further states that the entire brain must cease to function, irreversibly. The "entire brain" includes the brainstem as well as the neocortex. The concept of "entire brain" distinguishes determination of death in this act from "neocortical death" or "persistent vegetative state." These are not deemed valid legal or medical bases for determining death. (President's Commission 1981)

The UDDA's declaration about the "entire brain" ceasing to function was not then, nor is it now, without controversy. Much discussion occurred then and continues to date about the appropriate criteria to use to determine death. There exist three standards proposed for determining that the brain has been damaged significantly enough that loss of personhood has occurred, and death can be declared. These are the whole brain, brainstem, or higher brain criteria.

5.7 Whole Brain Criteria

The whole brain criteria require that "all" clinical functions of the brain be lost, including the cortex, diencephalon, and brainstem. Whole brain death criteria require that a patient have irreversible loss of function of both the brainstem and the cerebral cortex. Loss of neocortex, with the inability to integrate information from the environment and inability to interact in return, can certainly be interpreted as the loss of personhood. Many would view this as a loss of themselves. The brainstem controls flow of information into the higher brain, so its loss plays an important role in the loss of personal function and identity seen in severe brain injury. But additionally,

it is the area that controls many essential basic body functions, including heart rate, blood pressure, breathing, swallowing, and wake/sleep cycling. Therefore, when the whole brain criteria are used, the concept of brain death has been accepted by many societies as appropriate for determination of death.

A benefit of whole brain testing is the availability of additional ancillary testing to confirm the diagnosis. A flow study demonstrating complete lack of perfusion to the brain, or a completely silent electroencephalogram, can provide much reassurance to a healthcare team and to families about the irreversible nature of brain injury. These ancillary tests can be helpful when parts of the clinical exam cannot be performed (such as in patients with severe facial injuries or with high spinal cord injuries) or when there are medications/toxins that cannot be cleared. In these instances, relying on the above mentioned ancillary testing is in essence resorting to whole-brain criteria. After 15 years of using brainstem criteria in their national guidelines, because of these issues and concerns among health care providers, Poland changed their brain death guidelines to be consistent with whole brain criteria (Bohatyrewicz et al. 2009).

There are those experts who will argue that brain death is the only way that a human dies, and that loss of cardiopulmonary function merely serves as an indicator of impending death. It is known that within 15–20 s of cardiopulmonary arrest, measurements of cerebral electrical signaling are lost. Prolonged arrests beyond 30–40 min result in severe anoxic injury to the brain with subsequent swelling and herniation should the patient be resuscitated. For some experts, it is during this time period when death occurs. Whole brain death is loss of personhood and loss of the integration of biological function (regardless of technologies' abilities to support individual organ systems). Cardiopulmonary failure, with either the inability to resuscitate or decision to not attempt to, is an indicator of impending brain death that will quickly ensue. It is through this mechanism that some believe cardiopulmonary loss constitutes as death.

Whole brain death as a concept is not without its critics. Some argue that "whole" brain death should be just that: complete loss of ALL brain functions. Schif and Fins state "the diagnosis of brain death has at its core an unambiguous and fundamental biological model: all neurons within the cerebrum—the cerebral hemispheres and associated subcritical structures within the basal ganglia, thalamus and other subsystems—along with those in the within the brainstem are dead" (Schiff and Fins 2016). But as thorough as brain death testing attempts to be, it cannot completely account for all cellular function within the brain.

A major source of concern is from the hypothalamic-pituitary axis which provides hormone regulation within the body. It is known that some hormone regulation has been seen in patients declared brain dead. There have been reports of some patients maintaining fluid and sodium balance without evidence of diabetes insipidus (DI), the well-publicized story of a brain-dead girl who has gone through puberty, and stories of a brain dead woman continuing to gestate and deliver a fetus. These are markers of functioning of the hypothalamic-pituitary system, with the posterior pituitary controlling plasma osmotic pressure through arginine vasopressin secretion, and the anterior pituitary controlling multiple metabolic/endocrine functions through growth

hormone, thyroid-stimulating hormone, luteinizing hormone-releasing hormone, etc. Clinical markers for DI are not a part of brain death testing, nor are measurements of hormones released from the pituitary. A meta-analysis of publications including information on both brain death and presence of diabetes insipidus found that of 1878 brain-dead patients ranging in age from 2 months to 89 years, 925 (49%) were reported to have DI. Among pediatric patients, 145 (52%) of 279 had DI (Nair-Collins et al. 2016). So for approximately half of brain-dead patients, there is evidence that posterior pituitary continues to demonstrate some function. The anterior pituitary function is more difficult to quantify through literature search, although it is known that hypothyroidism is not universally demonstrated in brain-dead patients. It is clear that the hypothalamus-pituitary axis remains at least partially intact in some patients declared brain dead, which stands in contrast to the "entire brain" requirement set forth by the UDDA.

The counterargument can be made on two different fronts. One could take the physiological argument that the pituitary gland is not completely part of the brain. Embryologically, the anterior pituitary differs from the brain in that it develops from ectoderm. It is different from the tissue that forms the brain. While the posterior pituitary is composed of neuro-ectoderm, it forms in a way that protects it from the remainder of the brain. It is supplied by unique vasculature that branches off of extradural portions of the carotid arteries, and therefore the blood flow is not compromised from increased intracranial pressure. The pituitary also is nested in a bony structure, the sella turcica, with additional presence of dura matter, the diaphragm sellae, forming a roof. These structures also may protect the pituitary from high pressure. Because of these anatomical differences, the pituitary gland is not exposed to the same pressures and blood flow limitations that the cortex and brainstem may see following a traumatic or hypoxic injury. Therefore, one cannot say that if the pituitary has some preserved function, that it is indicative of the extent of injury for the rest of the brain. Because of this, it has been argued that pituitary function should not be considered among the "entire brain" functions required by some definitions.

The other defense is that the endocrine functions supplied through the pituitary gland do not rise to the level of things that we are think are essential to determine personhood. Making this argument is a return to the basic biological theory that all functions of the organ systems are of equal importance. Function of the pituitary can be supported through hormonal replacement and fluid control, and we would be hard pressed to use its presence or absence to determine the difference between life and death. Pituitary function can be medically replaced, and its innate function is not required to make a person who they are. While it makes for an interesting academic discussion, practically it is irrelevant to whether we accept someone as being alive or dead.

5.8 Brainstem Criteria

The brainstem criteria focus on the fact that the brainstem is responsible for consciousness as well as control of circulation and respiration, and is therefore the only area significant in the discussion of death. It is essentially our body's mainframe, controlling the functions that we have historically always used to define death. If we can declare someone dead due to loss of cardiopulmonary function, then we should be able to declare someone dead when we know the part of the brain that controls those functions is permanently severely damaged. The ventilator, plus any additional medicinal support, is masking what would have naturally occurred. Therefore, if there is no likelihood that these functions will return, the patient should be declared dead.

Some argue that the loss of brainstem function alone should be the primary driver to determine brain death. The UK, Canada, and India use the brainstem criteria. The United Kingdom Academy of Medical Royal Colleges reconfirmed in 2008 that "irreversible cessation of the integrative function of the brain-stem equates with the death of the individual and allows the medical practitioner to diagnose death" (Academy of Medical Royal Colleges 2008). Their report continues to extensively outline the criteria to support a diagnosis of brain death. In practice, the clinical diagnosis is clearly very similar between both brainstem and whole brain etiologies.

The exam laid out by the Academy of Medical Royal Colleges is quite similar to what the typical practice is within the United States. Additionally, the majority of patients who would progress to death by brainstem criteria have the same underlying etiology as those who progress to death by whole brain criteria within the United States. The cause of death is typically either a massive supratentorial lesion (masses, bleeding, or severe edema) leading to herniation and brainstem compression, or alternatively, diffuse anoxic brain injury leading to loss of both cortical and brainstem function. Rarely are there patients who have a primary brainstem lesion, such as a tumor or hemorrhage, while the cortex has preservation of blood flow. These patients would qualify as being in a coma in the United States, as compared to potentially meeting criteria for brain death in the UK or other countries with similar criteria. The physician would, however, need to be confident that the lesion resulted in *irreversible* loss of brainstem function, and this caveat could be enough to further limit the number of patients who would be treated differently in the different health care settings. One leading expert on brain death has concluded that while there may be theoretical difference between the practices, there is no clinical difference in application, citing that no case has been found of a patient who met brainstem death criteria but then recovered (Wijdicks 2012; Varelas 2016).

5.9 Higher Brain Criteria

Higher brain criteria were proposed based on the idea that if consciousness and cognition are what truly identify us as humans and individual beings, then significant damage to the cortex is adequate and justifiable in determining death. The higher brain criteria would incorporate patients with other disorders of consciousness.

Coma and vegetative state are two states of consciousness that practitioners could have the most difficulty in differentiating without completing the complete brain death testing. In both conditions, the patient is unresponsive to any stimulation without presence of any intentional action, although there remains enough function that some reflexes will remain present. Vegetative state, also called "unresponsive wakefulness," can be differentiated by the presence of some periods of eye opening, either spontaneous or in response to stimulation. This eye opening does not correlate to normal diurnal sleep-wake cycles. Both of these states of consciousness are typically transient, but any progression to some degree of recovery or to brain death occurs over a significantly variable period of time. Some patients will remain clinically unchanged over months, with a general acceptance that the term "persistent" may be used if no clinical change is seen within 1 month from the initial insult. But because of the variation in the time shown to recovery, the term "permanent vegetative state (PVS)," which implies irreversibility, should not be used until greater than 3 months from a non-traumatic injury, and 1 year from a traumatic etiology.

Even when the term "permanent" has been applied to patients in an unresponsive wakefulness state, there have been accounts of recovery months to years after that diagnosis is made. These rare but moving stories show that we lack the prognostication specificity to determine the irreversibility required to label these states as death. Studies have shown up to ~40% of patients have received a diagnostic error in their physician differentiating PVS from a minimally conscious state (MCS) (Childs and Mercer 1996). MCS occurs when a patient demonstrates some receptiveness to environmental stimulus. This may manifest as something that appears very simple, such as fixing and tracking an object, up to more complex activities such as giving gestures or verbalizations to communicate yes, no, or other preferences. These patients demonstrate both some awareness and higher level cognition that would never qualify as death. But physicians cannot accurately and consistently distinguish between PVS and MCS (Schnakers et al. 2009).

Higher brain criteria also stand most starkly against the biological viewpoint of death. Whole brain death criteria posit that cellular death is so severe, if not complete, that integration of basic cellular function to support higher functions is lost. This is clearly not the case in higher brain criteria, where complex functions are still retained. Many patients in a coma or with PVS are able to support their own respiratory and circulatory functions to the extent that they remain off technological support other than artificial fluids and nutrition. This adds a significant layer of complexity, as the patient would only progress to cardiopulmonary cessation if feeds were held.

Terri Schiavo was a young woman who was in an irreversible persistent vegetative state following a severe anoxic brain injury in 1990 in Florida. A protracted

court battle between her husband and parents, spanning from 1998 through 2005, would escalate to the attention of then President George W. Bush and be brought to the federal courts. The case was never about whether or not she was dead already, but whether or not her feeding tube could be removed with cessation of fluids and nutrition. However, the strong societal outcry to the case makes it clear that the higher brain criteria will not be accepted as a marker of death (Darr 2004; Marks 2004; Mueller 2009). It was very clear from this case that many in our society would view this life as one worth living, either for themselves or their loved ones. Many have significant and understandable difficulty seeing a breathing human being, with intermittent reflexive movements, as dead. Even if the technology existed that would accurately diagnosis complete and irreversible loss of awareness, if that patient is still able to maintain basic physiologic functions to sustain their body with little interventions other than gavage feeding, society is unlikely to accept that as defining death. Instead, it is not uncommonly viewed that death results from starvation and severe dehydration. We are far more willing to accept the notion that it is ethically permissible to allow that patient to die through cessation of artificial fluids and nutrition, especially if that is consistent with values the patient has previously expressed. It is not perceived by laypersons that death has already occurred. Because of these issues, while theoretically still presented by some as a justifiable means to declare death, the higher-brain standard will not hold up in modern society.

5.10 Testing to Confirm Brain Death

The UDDA states that standards should be adhered to for the use of neurological determination of death. While internal medicine could, and would, rely heavily on the criteria as laid out by the Harvard Committee, the pediatric community recognized early that there were issues applying the Harvard Committee guidelines to the pediatric population. In order to use neurological criteria, pediatric specific standards would need to be established. The neurological and critical care sections of the American Academy of Pediatrics, the pediatric section of the Society of Critical Care Medicine, and the Child Neurology Society created a workgroup, which in 1987 published its first iteration of brain death criteria (Report of Special Task Force 1987), with revisions published in 2011 (Nakagawa et al. 2011). The pediatric guidelines have been used in practice now for many years, and reflect the medical standard to which the UDDA definition refers. Not to use these guidelines would be breaking from the UDDA requirement, and is frankly poor medical practice for something that requires much accuracy: the declaration of death. It behooves the pediatric intensivist to be well versed with these standards, and to practice them with diligence.

The 2011 consensus statement on brain death testing in the pediatric population outlines the required prerequisites to testing, components of exam, and needed documentation. Prior to testing, the physician must ensure certain clinical expectations have been met:

(1) Factors that may impact the neurological exam must be corrected, specifically hypotension, hypothermia, or metabolic derangements.
(2) Sedatives, analgesics, neuromuscular blockade, and anticonvulsive agents should be discontinued in an appropriate timeframe prior to the exam so that no neuro-suppressive effect is present.
(3) Brain death testing should be deferred for 24–48 h (or longer if necessary) from cardiopulmonary resuscitation or acute brain injury as neurological functioning may be unreliable proximate to these events.

Clearly, brain death testing requires planning. Anecdotally, much of the distress incurred surrounding the testing stems from inadequate planning. Tests done prematurely, before a sedative has been cleared or before a metabolic derangement has been identified, demand re-testing. Re-testing brings doubt and uncertainty to the process; it is best to wait and do it right the first time. When reviewing the recommendations, however, not every threshold is clearly defined. For example, it is accepted that an abnormal sodium level has the potential to impact the neurological exam, but what is the appropriate range to which the sodium should be corrected? And should a phenobarbital level be non-detectable, or merely below a certain threshold? It is left to the discretion of the physician or institution to set some of these boundaries, as it is not clearly defined within the guidelines. It will benefit the process if agreed upon criteria are set forth within an institution's PICU to assure a standardized practice, and to minimize confusion among health care team members and potentially families.

Brain death is determined by a clinical exam. The exam must be completed twice, separated by at least 12 h and performed by two separate physicians. The first exam demonstrates that clinical findings are consistent with brain death, and the second exam confirms this, with declaration of death immediately following. The components must be the same in each examination:

(1) Coma—the patient must have loss of consciousness, vocalization, or any volitional activity
(2) Loss of brainstem functions
    a. Mid-position of fully dilated pupils, unresponsive to light
    b. Absence of movement of bulbar muscles, including facial or oropharyngeal
    c. Absent gag, cough, sucking, or rooting
    d. Absent corneal reflexes
    e. Absent oculovestibular reflexes
(3) Apnea—the patient must have complete loss of respiratory effort through formal testing with $PaCO_2 \geq 60$ mm Hg and ≥ 20 mm Hg change above baseline $PaCO_2$
(4) Flaccid tone and no spontaneous movement or induced movement, excluding spinal reflexes

The specifics to conducting each of these exams are described within the text, and while not described here, should be known and reviewed by the intensivists

(or neurologists) performing the exam. Again, any question into how the exam was performed will bring question to the accuracy of the exam's findings.

A change in 2011 from the previous guidelines includes the need to perform the apnea test during both examinations (Nakagawa et al. 2011). During this exam, the patient is first provided 100% oxygen and adequate ventilation to normalize the CO_2 about 5–10 min before the formal test. A blood gas should be obtained to document the initial PCO_2 level. The patient is then removed from the ventilator, either to a self-inflating bag or to a T-piece on the endotracheal tube. Remaining on the ventilator in a pressure support/CPAP mode is not recommended. The patient is observed for ideally 10 min for any sign of respirations. At the end of that period, or sooner if the patient is becoming desaturated or hemodynamically unstable, an additional blood gas is obtained to document a PCO_2 $\geq$60 mm Hg and a change of $\geq$20 mm Hg above the original level. If the patient shows signs of respirations at any time, the test is inconsistent with brain death, and brain death cannot be declared. If the patient's blood work does not demonstrate the necessary CO_2 changes, the test is inconclusive and should be repeated if the patient is clinically able. If the patient does not breathe and the CO_2 changes are documented, then the test is consistent with brain death.

Not every patient is able to have an apnea test. Some clinical findings, such as a high cervical cord lesion, could be the cause of apnea and therefore unrelated to brainstem functioning. Other patients are too unstable to be tested—either due to tenuous respiratory status or hemodynamic instability. In these situations, an ancillary test should be used to help support the clinical diagnosis. Again, the ancillary test is not what is used to determine brain death, as brain death is a clinical diagnosis, but it can help alleviate the uncertainty from an apnea test that cannot be completed. Ancillary studies may also be used if other parts of the exam cannot be done. An example may be severe traumatic facial/ocular injuries that make some of the brainstem testing difficult to complete. Ancillary studies may also be useful when a drug effect cannot be ruled out, as some patients with either renal or hepatic injury cannot clear certain medications. Ancillary studies include radionucleotide cerebral blood flow studies or electroencephalogram (EEG). Unfortunately, neither have the sensitivity or specificity to alone diagnose brain death, and are therefore only supportive of the clinical exam (Nakagawa et al. 2011).

5.11 The Duty to Be Accurate with Brain Death Testing

Deaths in the PICU are a relatively uncommon event compared to the adult ICU. The mortality rates in PICUs average about 2.5% compared with 10–30% in the adult ICU setting, and certainly not all of these are deaths determined by neurological criteria (Estupinan-Jimenez et al. 2015). Thus, not every PICU trainee will have robust exposure to and experience with applying brain death criteria. Pediatric critical care fellows in the United States report a median of five exposures to brain death testing over their three years of training, with some trainees reporting only performing one

exam (Ausmus et al. 2018). This limited exposure also results in attending physicians who are less prepared to accurately apply the guidelines.

Multiple studies have looked at variation in practice among providers. While most of the data comes from adult practice, given the relatively decreased incidence of pediatric deaths, we can likely extrapolate that the pediatrician experience is not much different. A study of adult practitioners looking at 226 brain-dead organ donors, found that only 45% had complete documentation of absence of brainstem reflexes and motor responses. The authors found that overall, only 45% of practitioners strictly adhered to the adult American Academy of Neurology guidelines for brain death testing (Shappell et al. 2013). Considering the distrust that has been present for eons about physicians accurately diagnosing death, the particular recent scrutiny of brain death testing, in addition to the UDDA mandate that we use "accepted medical standards," this performance rate is inadequate. Pediatric critical care physicians should feel obligated to know and follow the guidelines set forth by the multi-society committee on brain death determination.

A major criticism for the definitions set forth by the UDDA is the use of the term "irreversible." The term appears in both the neurological and circulatory criteria for death proclamation. For the former, the primary issue is that of prognostication and current medical knowledge. Do we know enough currently to accurately say when a patient has no likelihood of neurological recovery? There have been cases of physicians declaring brain death, with patients subsequently having return of some brainstem functioning (Joffe et al. 2009; Webb and Samuels 2011). Scrutiny of the cases, however, typically identifies some deviation from what we now accept as standardized criteria. Patients were declared dead prematurely because the exam was performed too closely to re-warming after hypothermia, and/or sedating medications (such as phenobarbital) were still present in the body (Machado 2010; Lang 2011; Wijdicks 2011). The published cases have not cast enough doubt on the irreversibility of brain death for us to forsake the concept, but have only confirmed that the examinations must be done very carefully. Brain death continues to be largely accepted, as it results in the loss of personhood, and if artificial technology were not applied, would also result in disintegration of the body. However, as an author of the UDDA stated in 2001, the concept of brain death is "well settled, yet still unresolved" (Capron 2001).

5.12 Circulatory Determination of Death

While much controversy has focused on brain death, another set of practices regarding the determination of death are equally controversial. It is intriguing that long-accepted means of determining death on the basis of loss of cardiopulmonary function are being questioned. The reason for concern comes down to the implementation of protocols for organ donation after cardiac (or circulatory) determination of death, DCDD. Following the legal acceptance of brain death, organ donation following declaration of death using neurological criteria was the primary source of organ donation in

most countries. However, with the ongoing need to find more donors, protocols were put into place to allow for donation from patients following withdrawal of medical technologies and pronouncement of death based on loss of circulation. These protocols dictate that as long as a patient is declared dead within a specific timeframe, typically 30–60 min following removal from medical technological support, viable organs may be retrieved for transplant. Protocols typical state that when a patient is declared dead, the transplant team will wait 2–5 min after declaration to ensure the heart does not begin to beat again, and then retrieval of organs may commence (Ethics Committee and Society of Critical Care Medicine 2001). These protocols introduced more doubt for some into when we can truly say a person is dead.

The controversy focuses on the question of irreversibility. It becomes up to the practitioner to decide when asystole should be considered irreversible. Certainly the underlying cause of arrest plays a role, but it is not uncommon for a physician to be unaware of the underlying etiology during the resuscitation, particularly in the emergency room. But we are frequently able to reverse lack of circulation. While not common, autoresuscitation can be seen for many minutes after cessation of cardiopulmonary resuscitation, with the longest case report being 7 min after loss of circulation (Hornby et al. 2010). It should be noted that there are no documented reports of autoresuscitation when CPR is not attempted. The possibility of autoresuscitation, however, highlights the fact that there is a period of reversibility. Cardiopulmonary resuscitation started during this time for many children can result in return to spontaneous circulation, reperfusion, and reintegration of organ systems.

For in-hospital witnessed arrests, approximately one-third of patients will survive to hospital discharge (Jayaram et al. 2014). Out-of-hospital arrests portend a less favorable outcome, dependent on the period of time lapsing prior to initiation of CPR. For witnessed arrests, the period of time it takes for return of spontaneous circulation (ROSC) impacts the likelihood of survival, with one review showing survival to discharge at 44.1% if ROSC occurs within 15 min, but falling to 15.9% if ROSC occurs after 35 min (Matos et al. 2013). This data is intended to stress that even at the time of loss of circulation, the "irreversibility" required by the UDDA definitions of death may not be yet achieved. What has the largest impact on this irreversibility is the decision, by physician or family, to perform or not perform CPR.

The concept of using extra-corporeal membrane oxygenation (ECMO) to rescue from cardiopulmonary arrest (extra-corporeal cardiopulmonary resuscitation or ECPR) proves the point that circulation can be artificially restored in many situations. A patient who cannot respond to standard resuscitation measures can be placed on ECMO to provide the circulation of oxygenated blood. ECPR has been employed in the pediatric patient population now for over a decade, for witnessed or imminent arrest situations. The goal is to restore circulation to preserve support of organ systems, while the underlying cause of the instability is treated. ECPR is generally avoided in patients whose underlying cause of arrest is not treatable, or in patients whose arrest has been prolonged and end organ damage is likely already significantly life-limiting. Additionally, there may be patient anatomical reasons that would make ECMO support impossible to achieve. These types of exclusion factors, in addition to this treatment modality being newer to practice, have limited the patient population

to whom the advanced (and risky) therapy is offered. However, in theory, for many patients at the time of declaration of death as determined by loss of circulation, circulation can be restored. We will see this issue play out in its relationship to donation of organs after circulatory death (DCDD) in a future chapter.

5.13 Role of the Family in Determining Death

It is true that some hold to cultural, religious, or personal views about when life begins and when it ends. Differences have been seen culturally in how certain countries have chosen to adopt and implement the concept of brain death. Japan, for example, rejected the concept of brain death for many years. Japanese culture sees death not as single point in time, but a process in which the family is an active participant.

Drs. Yang and Miller state that "death represents an ambiguous and gradual process with disintegration of both the physical and spiritual existences…. From the perspective of the nature worshiper, brain death is too specific and artificial" (Yang 2015). Likely because of this juxtaposition between the concept of brain death and the Eastern cultural view of death, brain death legislation was not adopted in Japan until 1997. It would take two more years before a patient would be declared by those criteria.

Japanese law requires that brain death is diagnosed only when organ donation will occur. Additionally, it requires that the individual has expressed acceptance of this form of the death and willingness to donate organs, and the family must agree with this decision (Bagheri 2003). Interestingly, the initial law prohibited physicians from declaring children under the age of 15 brain dead. However, in 2009 a revision was enacted reversing this policy, and the first pediatric patient was pronounced brain dead in 2011 to facilitate organ donation. A Japanese newspaper published a statement from the family stating, "If we can believe that even part of his body remains alive somewhere, we will feel somewhat healed from the pain and sorrow of having lost him" (2011). It will be interesting to see how cultural views on death change as the need for organ transplantation increases. It does remain concerning to some that how we define death is so closely tied to organ donation.

Legal precedent within the United States primarily supports the physician in stating that surrogate consent is not required to perform brain death testing. Although the physician will likely benefit from having a collaborative understanding with the family when undertaking brain death testing, and it may benefit the relationship to wait until the family is receptive to accept the results of the test, recent cases confirm that consent should not be required for a clinical exam. This was seen in a 2016 ruling in Virginia regarding a 2-year-old female who had anoxic brain injury progressing to brain death following choking on a popcorn kernel. The parents sought to prevent the apnea testing from being completed. While the Circuit Court ruled against the family, they also blocked the hospital from performing the test, giving the family

time to appeal to the State Supreme Court. The child was declared dead, with details not reported, prior to judicial resolutions (Richer 2016). The Nevada Legislature, in response to some cases brought to its State Supreme Court, approved Assembly Bill 424 in 2017 that explicitly states that determination of death is a clinical decision not requiring consent.

One important aspect of the McMath case presented earlier was the assertion from the family's attorney that it should be up the family to decide when a child has died. Perhaps similar to the Japanese decision, some in the United States also believe that a family's belief system should give them some control over how death is determined. In a 2014 editorial in the LA Times, the attorney Christopher Dolan again made that assertion:

> Those who attack [the mother's] decision and who are 'pro-choice' on the issue of abortion should think hard about the fallout from their insistence that the family's personal and private decision about when life ends can and should be overridden by doctors or the state. The same rights that support the choice made by [the mother] also support contraceptive rights and abortion rights. (Dolan 2014)

Some philosophers and ethicists have also argued that the determination of criteria for death should be left to individuals and their caregivers. Some have given the experiences of New Jersey and New York, where families are permitted to refuse the brain death declaration, to support this idea. Although exemptions from brain death are allowed in those states, they are rarely used (Son and Setta 2018). The majority of the public seems to accept the idea that the loss of brain function is the loss of person. What is the harm of allowing the rare family who disagrees with that the opportunity to see the end of their child's life play out as they see fit? Others will ask where, then, does the line exist? Can a family choose to deny that cardiorespiratory cessation is death, and demand their child's body not be buried or cremated? Can a family insist upon indefinite use of extracorporeal membrane oxygenation support? The likelihood of these situations and demands occurring frequently, or being demanded for a long period of time, is likely very rare. Most families are willing to accept the reality of the loss of their child, although for some it may take days of compassionate conversation and time to allow them to come to terms with that truth.

For the pediatric intensivist practicing at the bedside, it is important to know what the legal definition of death is within their society, and hold true to that practice. But there should be acknowledgment of where there are ambiguities or lack of agreement. An understanding of the natural human inclination to want certainty with death determination should prod the physician to be clear in the communications and explanations, as well as understanding of any doubts that may arise. Most of these questions from families can be overcome with time and communication. Due diligence must be paid to being consistent with existing standards of care, particularly with declaration of brain death. The pediatric intensivist should also consider being part of active conversations on how we define and determine death, and how much control we accept parents having in the process. Perhaps it is time for the UDDA to be revised, as concerns about the use of "entire" and "irreversible" may no longer be consistent with our practice of medicine. We have come a long way from the days of "waiting mortuaries" for us to be certain about death; but it is clear that we still have a long way to go.

References

Agutter, P.S., et al. 2013. Hysterical paralysis and premature burial: A medieval Persian case, fear and fascination in the West, and modern practice. *Journal of Forensic and Legal Medicine* 20 (3): 133–135.

A definition of irreversible coma. Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death. 1968. *JAMA* 205 (6): 337–340.

Academy of Medical Royal Colleges. 2008. *A code of practice for the diagnosis and confirmation of death*.

Alivizatos, P.A. 2017. Fiftieth anniversary of the first heart transplant: The progress of American medical research, the ethical dilemmas, and Christiaan Barnard. *Proceedings (Baylor University Medical Center)* 30 (4): 475–477.

Ausmus, A.M., et al. 2018. A needs assessment of brain death education in pediatric critical care medicine fellowships. *Pediatric Critical Care Medicine* 19 (7): 643–648.

Bagheri, A. 2003. Criticism of "brain death" policy in Japan. *Kennedy Institute of Ethics Journal* 13 (4): 359–372.

Baker, A., and S.D. Shemie. 2014. Biophilosophical basis for identifying the death of a person. *Journal of Critical Care* 29 (4): 687–689.

Bohatyrewicz, R., et al. 2009. Reversal to whole-brain death criteria after 15-year experience with brain stem death criteria in Poland. *Transplant Proceeding* 41 (8): 2959–2960.

Brink, J.G., and J. Hassoulas. 2009. The first human heart transplant and further advances in cardiac transplantation at Groote Schuur Hospital and the University of Cape Town—With reference to: The operation. A human cardiac transplant: An interim report of a successful operation performed at Groote Schuur Hospital, Cape Town. *The* Cardiovascular *Journal of* Africa 20 (1): 31–35.

Capron, A.M. 2001. Brain death—Well settled yet still unresolved. *New England Journal of Medicine* 344 (16): 1244–1246.

Childs, N.L., and W.N. Mercer. 1996. Brief report: Late improvement in consciousness after post-traumatic vegetative state. *New England Journal of Medicine* 334 (1): 24–25.

Child Organ Transplants Still Faces Hurdles. 2011. The Japan Times 2011 07/28/2017. Available from: https://www.japantimes.co.jp/news/2011/04/28/national/child-organ-transplants-still-face-hurdles/#.WocauGcUWUk.

Corlett, S. 1985. Public attitudes toward human organ donation. *Transplant Proceeding* 17 (6 Suppl 3): 103–110.

Darr, K. 2004. Terri Schindler Schiavo: An update. *Hosp Top* 82 (2): 28–31.

Dossey, L. 2007. The undead: Botched burials, safety coffins, and the fear of the grave. *Explore (NY)* 3 (4): 347–354.

Dolan, C. 2014. *McMath attorney: Jahi's family aren't fools; they deserve better than ignorant attacks*. LA Times.

Estupinan-Jimenez, J.C., et al. 2015. Mortality risk factors in critical post-surgical patients treated using continuous renal replacement techniques. *Revista Espanola de Anestesiologia y Reanimacion* 62 (4): 184–190.

Ethics Committee and Society of Critical Care Medicine. 2001. Recommendations for nonheart-beating organ donation. A position paper by the Ethics Committee, American College of Critical Care Medicine, Society of Critical Care Medicine. *Critical Care Medicine* 29 (9): 1826–1831.

Goldschmidt, D. 2018. *Joahi McMath, California teen at center of brain-death controversy, has died*. CNN.

Gardiner, D., et al. 2012. International perspective on the diagnosis of death. *British Journal of Anaesthesia* 108 (Suppl 1): i14–i28.

Hensley, N. 2016. *'My daughter is not dead': Mother of Abigail Kopf—Youngest victim of Kalamazoo attack—Says teen is fighting for her life*. New York Daily News.

Hornby, K., L. Hornby, and S.D. Shemie. 2010. A systematic review of autoresuscitation after cardiac arrest. *Critical Care Medicine* 38 (5): 1246–1253.
Jayaram, N., et al. 2014. Hospital variation in survival after pediatric in-hospital cardiac arrest. *Circulation: Cardiovascular Quality and Outcomes* 7 (4): 517–523.
Joffe, A.R., et al. 2009. A 10-month-old infant with reversible findings of brain death. *Pediatric Neurology* 41 (5): 378–382.
Kalamazoo victim, 14, a "strong-willed" survivor. CBS News, 2016.
Levs, J. 2014. *Terri Schiavo family joins fight over Jahi McMath*. CNN.
Luce, J.M. 2015. The uncommon case of Jahi McMath. *Chest* 147 (4): 1144–1151.
Lupkin, S. 2014. *Why Jahi McMath's mom is sure her daughter isn't brain dead*. ABC News.
Lang, C.J. 2011. There is no reversible brain death. *Critical Care Medicine* 39 (9): 2205–2206 (author reply 2206).
Levin, D.L., et al. 1993. Brain death in the pediatric patient: Historical, sociological, medical, religious, cultural, legal, and ethical considerations. *Critical Care Medicine* 2 (9 Suppl): S337–S339.
Machado, C. 2010. Are brain death findings reversible? *Pediatric Neurology* 42 (4): 305–306 (author reply 306–307).
Marks Jr., T.C. 2004. Terri Schiavo and the law. *Albany Law Review* 67 (3): 843–847.
Matos, R.I., et al. 2013. Duration of cardiopulmonary resuscitation and illness category impact survival and neurologic outcomes for in-hospital pediatric cardiac arrests. *Circulation* 127 (4): 442–451.
Miller, F.G., and R. Truog. 2012. *Death, dying, and organ transplantation: Reconstructing medical ethics at the end of life,* vol. ix, 196 p. Oxford: Oxford University Press.
Mollaret, P., and M. Goulon. 1959. The depassed coma (preliminary memoir). *Rev Neurol (Paris)* 101: 3–15.
Mueller, P.S. 2009. The Terri Schiavo saga: Ethical and legal aspects and implications for clinicians. *Polskie Archiwum Medycyny Wewnetrznej* 119 (9): 574–581.
Nair-Collins, M., J. Northrup, and J. Olcese. 2016. Hypothalamic-pituitary function in brain death: A review. *Journal of Intensive Care Medicine* 31 (1): 41–50.
Nakagawa, T.A., et al. 2011. Clinical report-guidelines for the determination of brain death in infants and children: An update of the 1987 task force recommendations. *Pediatrics* 128 (3): e720–e740.
Paré, A. 1968. *The collected works of Ambroise Paré*, 1173 p. Pound Ridge, N.Y.: Milford House.
Polizzotto, M.N., and P. Martin. 2006. Buried alive: An unusual problem at the end of life. *Journal of Palliative Care* 22 (2): 117–118.
Poe, E.A., and S. McKowen. 2010. *The premature burial.* In *The stories of Edgar Allan Poe,* vol. vi, 334 p. 2010, New York: Sterling Pub. Co.
President's Commission for the study of ethical problems in the medicine and biomedical and behavioral research: Defining Death. 1981. Government Printing Office, Washington, D.C.
Report of special task force. Guidelines for the determination of brain death in children. American Academy of Pediatrics Task Force on Brain Death in Children. 1987. *Pediatrics* 80 (2): 298–300.
Richer, A. 2016. Girl, 2, dies; was focus of fight over brain death test. AP News.
Schiff, N.D., and J.J. Fins. 2016. Brain death and disorders of consciousness. *Current Biology* 26 (13): R572–R576.
Schnakers, C., et al. 2009. Diagnostic accuracy of the vegetative and minimally conscious state: clinical consensus versus standardized neurobehavioral assessment. *BMC Neurology* 9: 35.
Shappell, C.N., et al. 2013. Practice variability in brain death determination: A call to action. *Neurology* 81 (23): 2009–2014.
Son, R.G., and S.M. Setta. 2018. Frequency of use of the religious exemption in New Jersey cases of determination of brain death. *BMC Medical Ethics* 19 (1): 76.
Varelas, P.N. 2016. Brainstem or entire brain-based declaration of death: Is there a difference? *Practical Neurology* 16 (2): 85–86.
Webb, A.C., and O.B. Samuels. 2011. Reversible brain death after cardiopulmonary arrest and induced hypothermia. *Critical Care Medicine* 39 (6): 1538–1542.
Wijdicks, E.F., et al. 2011. There is no reversible brain death. *Critical Care Medicine* 39 (9): 2204–2205 (author reply 2206).

Wijdicks, E.F. 2012. The transatlantic divide over brain death determination and the debate. *Brain* 135 (Pt 4): 1321–1331.

Waiting Mortuaries. 1896. *Hospital* (Lond 1886) 21 (532): 158.

Yang, Q., and G. Miller. 2015. East-West differences in perception of brain death. Review of history, current understandings, and directions for future research. *The Journal of Bioethical* Inquiry 12 (2): 211–225.

Chapter 6
Intractable Disagreements About Futility in the PICU

Abstract Much distress may be felt within the PICU setting regarding the impression that "futile," or "inappropriate" care is being provided. While a clear definition of futility remains elusive in the medical community, efforts have been made by critical care societies to differentiate between appropriate therapeutic options from potentially inappropriate and inappropriate treatments. Inappropriate treatments should not be offered. However, it can be challenging to know when some benefit is worthy of pursuit (such as a "slow code" for the sake of the family). Families may have cultural or religious values which may translate into a treatment having benefit to them. Healthcare workers typically are most concerned when issues surrounding futility lead to intractable disagreements. These issues seem to occur rarely in pediatric critical care settings, but can lead tension with consequences to medical care. However, intractable disagreements about medical treatments are most frequently resolved through excellent communication. Understanding the values and information that underpin parents' requests is the first step to resolution and may reveal that a therapy is not truly without some benefit.

6.1 Rare, but Distressing, Disagreements

Controversies about perceived futility, or potentially inappropriate treatments, are common in the PICU. Intractable disagreements, however, seem to be quite rare. Of course, it is difficult to know how often "intractable disagreements" arise because discussions of the issue often conflate two phenomena that should be disentangled. The first is a discussion between doctors and parents about whether further treatment is futile. Such conversations are fraught with tension and may lead to controversy. Usually, the controversy can be resolved and does not lead to an intractable disagreement. The subset of cases in which the controversy cannot be resolved and an intractable disagreement results ought to be the focus of debate and discussion.

It is difficult to know precisely how often discussions about futility take place. They are so much a part of the day-to-day life in a PICU that they are not documented or categorized, but we can estimate.

L. Miller-Smith et al., *Bioethics in the Pediatric ICU: Ethical Dilemmas Encountered in the Care of Critically Ill Children*, International Library of Ethics, Law, and the New Medicine 77, https://doi.org/10.1007/978-3-030-00943-4_6

We know that the majority of deaths in the PICU follow decisions to withhold or withdraw therapy (Naghib et al. 2010; Sands et al. 2009). This is also true in other ICUs (Verhagen et al. 2010; Varelas et al. 2009; Bertolini et al. 2010). Such decisions are made only after a discussion between doctors and parents. Parents usually do not immediately agree, nor are they asked to. Instead, agreement is reached only after there has been adequate time for questions, dialogue, reflection, second opinions, and negotiation (White et al. 2007). Luce describes how the process works. Doctors in the ICU, he writes, "discuss the nature and likely outcome of a given illness, explore the ramifications of forthcoming decisions, determine patient values, confirm that patients or families understand the information provided them, discuss preferred roles in decision-making, and achieve consensus about treatment courses that are most consistent with patient values" (Luce 2010). Since these conversations are frequent, some controversy is also likely to be frequent.

Some studies estimate the frequency of such controversies. Studdert and colleagues studied futility controversies in one PICU in Boston. They focused on patients who were in the PICU for at least a week. Over 11 months, there were 110 such patients and there were 55 controversies involving 51 patients (Studdert et al. 2003). Most often (60% of the time), when disagreements occurred, they were between professionals and the family. Less often (39%) there were conflicts within the medical teams. One controversy was within a family. Most conflicts were about poor communication and disagreements over the care plan for the child. They do not report how those controversies were resolved.

Vemuri and colleagues surveyed 21 PICU directors in the United Kingdom about futility. They asked those directors to estimate the number of patients in their PICU on one particular day for whom the doctors thought that further treatment was futile. Of the 111 patients in the PICU on that one day, "care was felt to be appropriate in 88 of these cases (79%), futile in nine cases (8%), and inappropriate in 14 cases (13%)" (Vemuri and Playfor 2006). They defined futile treatment as treatment that "will not have the desired outcome or accomplish its intended goals (no physiologic effect)." They defined inappropriate treatment as treatment that "would be extremely unlikely to be beneficial, is extremely costly, or is of uncertain benefit." Futile and inappropriate cases were most commonly patients with preexisting chronic conditions who were admitted with respiratory failure. These authors also do not report outcomes. Forbat and colleagues report that, in a six-month period in one children's hospital, there were 136 individual episodes of conflict about medical futility in a PICU in the UK (Forbat et al. 2016). It is odd that none of these studies report statistics on how often the controversies or conflicts become intractable or irresolvable.

In contrast to these common and (presumably) commonly resolved controversies about futility, there are some intractable disagreements. An intractable disagreement occurs when discussions have taken place, but deep and seemingly irresolvable disagreements remain. Health professionals find ongoing treatment ethically problematic and the family finds withdrawal (or withholding) of treatment ethically unacceptable. In such situations, both health professionals and patients/families face unpalatable choices. Family members could accede to the doctors' assessment and recommendations, abandon all hope for their loved one's survival, and grudgingly go

along with the recommendation to withdraw life support. Alternatively, the health professionals could ignore their moral qualms and continue to provide treatments that they believe are useless or even harmful. In the worst-case scenario, families could challenge the doctors in court, seeking a legal injunction that would compel doctors to continue treatment.

The judgment that a disagreement has become "intractable" is somewhat arbitrary. The process of discussion about treatment choices is often emotionally complex. Miscommunication, frustration, anger, and stress are common and somewhat expected. It is hard to know when or whether continued discussion will eventually lead to an agreement that both doctors and families endorse or, instead, when the disagreement becomes irresolvable. It is also hard to know which side should compromise. So "intractability" has a volitional element as well as a descriptive one. A disagreement becomes intractable when both sides decide that they are no longer willing to seek a mutually acceptable compromise.

A recent report from Massachusetts General Hospital (MGH) tried to quantify the number of "intractable disagreements" among adult patients (Robinson et al. 2017). The authors studied all admissions to that tertiary care center between 2007 and 2013. Overall, there were almost 287,000 admissions. Of all ethics consultations made during the study timeframe, 134 (42.7%) were about conflicts over DNR status. In 45/134 (34%) cases, the ethics consultation led to an agreement to implement a DNR order. In the remaining 89 cases, the surrogate (or patient) refused the DNR order. In 22 of those refusals, the doctors abided by the wishes of the surrogate and no DNR order was written. But in 61 cases, a DNR order was written. The surrogate accepted the DNR order in 42/61 (69%), However, in 19/61 (31%) the surrogate persisted in requesting CPR. In spite of that request, and consistent with that hospital's policy, CPR was not provided in these 19 cases. Thus, among adults at MGH, intractable disagreements occurred in 19/287,000 (0.007%) admissions and 19/332 (6%) cases that led to ethics consultation. In a study of the role of ethics consultation in resolving seemingly intractable disagreements, Casarett and Siegler found, as did the researchers at MGH, that most disagreements about DNR orders were resolved with further discussion (Casarett and Siegler 1999).

There are no such systematic reports in pediatrics. But a report about "intractable disagreements" from PICUs in two Texas hospitals illustrates the difficulty in deciding when a disagreement has become intractable (Okhuysen-Cawley et al. 2007). The report describes five cases that arose in the PICUs at the two hospitals. The report does not specify the time frame over which such cases arose. Instead, the report focuses on controversies that are described as intractable. But in three of the cases, the parents eventually agreed to withhold or withdraw life support. In a fourth, the parents never explicitly agreed to withdrawal of mechanical ventilation, but the doctors informed them that the child would be extubated and the parents remained at the bedside, and did not object when extubation took place and the child died. According to the authors, "They reiterated their appreciation of the physicians' efforts on behalf of their child…and accepted their child's death calmly when it occurred." In the fifth case, the doctors agreed to continue treatment and the child remained in the PICU for six months, had multiple surgical procedures, and was discharged to home. He died

at home two years after discharge. It would seem that, in each of these "intractable" disagreements, an agreement was eventually reached.

A report from the Royal Children's Hospital in Melbourne examined communication about decisions to withhold or withdraw life-sustaining treatment in 50 consecutive deaths (Stark et al. 2008). The authors found that life-sustaining treatment was withdrawn in 86% of cases. The decision usually followed multiple family meetings. There was only one case (2%) in which the medical team considered continued life-sustaining treatment to be futile but the family disagreed. The patient died while receiving maximal treatment. In other words, the doctors compromised their views that treatment needed to be stopped.

A number of detailed case reports in the medical literature describe seemingly intractable disagreements and, in most of those cases, an agreement was eventually reached (Leeuwenburgh-Pronk et al. 2015; Frader et al. 2010). In one such case, a prenatal assessment revealed a fetus with a giant omphalocele. The mother went into labor at 25 weeks. The doctors told the family that this condition was incompatible with life and that they would provide only palliative care after birth. The parents objected to this plan and wanted everything done. As described by the authors, "The mother said, 'This is wrong. You can't just let her die. Please try to save her life. Do everything that you can.' The father said, 'We are calling a lawyer. We demand that you do something to help our baby!'" (Feltman et al. 2014). In this case, further discussion with the family led to better understanding and eventual agreement. Once the surgeon met with the family and explained that an operation would not be feasible at that gestational age, the parents changed their mind, and told the doctors, "We don't want our baby to suffer if she can't survive."

Another case report described a two-year-old girl who had suffered perinatal asphyxia at birth (Paris et al. 1990). The infant underwent a gastrostomy at the age of one month, a Nissen fundoplication at four months, and a tracheostomy at seven months. She had intermittent episodes of aspiration and uncontrolled seizures. She was discharged after 14 months with 24-h home nursing care. During the next several months she was repeatedly hospitalized for pneumonia and septic shock. On multiple occasions, the doctors recommended palliative care. The mother had continued to demand that everything possible be done to ensure the child's survival. Finally, after a meeting with the hospital ethics committee, the doctors informed the mother that they would not readmit the child to the PICU or implement mechanical ventilation. The mother went to court. The court appointed a guardian ad litem for the child who sought a second opinion from a specialist at another hospital. That doctor and hospital were willing to accept the child in transfer. The baby was transferred, treated, and survived for years.

These cases all suggest that even the most intractable disagreements can often be resolved, even if the process of reaching a resolution is sometimes protracted and emotionally stressful for everybody involved. They also highlight an important feature of intractable disagreements. These do not usually arise because a doctor suggests to parents that further treatment may be futile. They don't even arise, necessarily, when parents disagree with the doctor's recommendation. Instead, they arise

because doctors decide that further efforts at discussion or negotiation are themselves futile.

In the next section, we speculate about the reasons why futility controversies sometimes lead to seemingly intractable disagreements and why those disagreements might be so deeply troubling to PICU health professionals.

6.2 Futility and the Ethos of Pediatric Critical Care

Futility controversies that lead to intractable disagreements cause a great deal of moral distress in PICUs (Epstein and Hamric 2009; Hamric and Blackhall 2007). They are one of the most common reasons why doctors seek ethics consultation (McDougall and Notini 2016; Thomas et al. 2015). After all, futility controversies arise only after attempts at communication have broken down. In those situations, "Patients become confused, medical professionals become frustrated, and there is further compromise of the doctor–patient relationship" (Grossman and Angelos 2009). Such confusion, frustration, and compromise are stressful.

But there are many stressors in the PICU. Most do not lead to such high reported levels of moral distress. It is not obvious why futility controversies should be so uniquely stressful in the environment of the PICU. It may be that intractable disagreements about futility are particularly troubling because they challenge intensivists about an issue that is particularly sensitive for those health care professionals who care for the sickest children. In futility controversies, the parents are asking the doctors and nurses to do everything possible to keep their beloved children alive. Doctors and nurses generally like to keep children alive. PICUs were created to treat cases that were once thought to be untreatable. ICUs push the boundaries of feasibility. Professionals who work there dare to dream that such previously untreatable conditions can be successfully treated, that dying children need not die, that anything is possible.

Perhaps the ethos of the PICU explains why PICU professionals find futility cases so frustrating. It is the essence of an intensivist's professional expertise to know what is possible and what is not. PICU doctors face the constant temptation of hubris. They try to save the lives of children who are at the brink of death. They need to believe their efforts are neither inhumane nor a thinly disguised form of experimentation but are, instead, judicious clinical judgments about the use of technologies in ways that have a reasonable or at least plausible chance of succeeding. Thus, when intensivists reach the point where they think that all reasonable efforts have failed and that further treatment is futile, they expect others to respect their unique expertise in making such judgments.

Intensivists understand that parents may not believe them at first. But they hope that they are skilled enough at compassionate communication to help parents understand why it is time to redirect treatment towards the amelioration of suffering and the facilitation of a pain-free death. When they fail, when parents reject their carefully arrived at assessments of futility, and when they then feel forced by the law

or hospital policy or an ethics consultant to defer to parental wishes and to continue interventions that are not only unlikely to achieve their intended goal but may cause pain and suffering to a dying child, they see this as a serious challenge to their professional integrity.

6.3 Why Do Parents Want Treatments that Doctors Believe to Be Futile?

Parents who have a critically ill child in the PICU live in a world of grief and fear. When a child is admitted to the PICU, parents fear that death is imminent. They don't have the knowledge, experience, or expertise to judge when the seemingly horrendous treatments that are part of intensive care are working as they should. They hope that their child can be saved, but they also fear that intensive care will cause pain and suffering that they are helpless to prevent. They cannot trust their own moral impulses. They become uniquely dependent upon the expert clinicians to help them understand what is going on.

Numerous memoirs by parents document the emotional challenges of seeing their children hooked up to machines and intravenous drips, intubated and suffering. Parents must steel themselves to bravely stick by their children while every fiber of their being screams out that they should rescue their children from the terrible fate of intensive care treatment. Novelist Lorrie Moore captured this feeling in a short story about a mother at the bedside of a child in the PICU:

> How can it be described? How can any of it be described? It is a horror and a miracle to see him. He is lying in his crib in his room, tubed up, splayed like a boy on a cross, his arms stiffened into cardboard 'no-no's' so that he cannot yank out the tubes. There is the bladder catheter, the nasal-gastric tube, and the Hickman, which, beneath the skin, is plugged into his jugular, then popped out his chest wall and capped with a long plastic cap. There is a large bandage taped over his abdomen. Groggy, on a morphine drip, still he is able to look at her when, maneuvering through all the vinyl wiring, she leans to hold him, and when she does, he begins to cry, but cry silently, without motion or noise. She has never seen a baby cry without motion or noise…

That powerful image of a baby in a Christ-like suffering and unable to express his own agony, captures the ambivalence that many parents feel. The mother, knowing that she put him there, feels powerless and angry. She wants to comfort her crying baby. Moore goes on,

> She would crawl up and lie beside him in the crib if she could. But instead, because of all his intricate wiring, she must lean into cuddle and sing to him.

But sing what song? Pray for what relief? And to what God? This sort of treatment, after all, is the answer to the prayers that parents have prayed since the beginning of time. But, now, Moore chooses a song of peril and flight. The song the mother sings, the prayer she offers, comes not from traditional liturgy, but from a 1960s pop song

that had been written about urban decay and became an anthem for soldiers during the Vietnam War…

> We gotta get out of this place, if it's the last thing we ever do. (Moore 1998)

Parents in the PICU quickly learn that their own instincts—instincts about what is good or bad or what it means to be a good or a bad parent—are useless. Parents have no normal against which to measure their child's progress. They need to trust the doctors and trust the technology. They need to hope that the payoff for all the pain and suffering will be a cure for their ailing child.

Then, sometimes, for reasons that are inevitably opaque to the parents, the doctors tell them that the treatments are no longer working, that it is time to stop. When that happens, parents may feel doubly betrayed—first, by their own instincts that told them that the treatment was inhumane from the outset, and second by the promises that were implicitly made to them when the horrible invasive treatments were begun in the first place. Those implicit promises were that it would all be worth it, that the gains would be worth the pains. For some parents, their agreement to withdraw life support is tantamount to acknowledging that it was all for naught. It would be a natural impulse for parents in these situations to find it difficult to accept that they've hit the wall, that further treatment will only prolong the dying process, and that there is not more hope for cure.

Thus, for both health professionals and parents, futility controversies challenge some essence of their being. For doctors, it challenges their idea of what it means to be a good doctor. Similarly, for parents, it raises questions about what they owe their child and what it means to be a good parent.

6.4 Past Attempts to Understand and Resolve Intractable Disagreements

There have been so many discussions of ways to think about and resolve seemingly intractable disagreements about futility. Thirty years ago, Blackhall wrote a groundbreaking article about a competent adult who was dying of leukemia but who nevertheless wanted CPR (Blackhall 1987). The patient had severe osteoporosis. CPR would likely cause multiple rib fractures and would have almost no chance of being even temporarily effective. Blackhall suggested that it would be appropriate for doctors to refuse to perform CPR even though a competent adult patient had requested it. Blackhall rejected the notion that doctors always have to abide by the expressed wishes of competent adults. She wrote, "In cases like these, in which CPR offers no conceivable benefit and much possible harm, I believe that patient autonomy cannot be our only guide." Non-beneficial CPR, she wrote, should never have been offered.

Blackhall's article unleashed an avalanche of scholarly writing. There are now thousands of articles and at least two books about futility controversies (Rubin 1998;

Schneiderman 2011). In all this writing, the professional world seems to be evenly split over the question of when or whether doctors should ever be permitted to override the requests of patients or families for a potentially life-prolonging treatment (Helft et al. 2000). Many writers have agreed with Blackhall's approach and suggest that there are limits to our obligation to respect patient autonomy. To counter autonomy-based claims, proponents of policies that would allow health professionals to make unilateral decisions to withhold treatment posit that health professionals also have rights. In particular, they have a right to refuse to administer or prescribe a treatment that they think will be of no benefit. Others suggest that the imprecision of clinical assessments of futility and the value-laden nature of such decisions both suggest that we should err on the side of empowering patients, not doctors, to make the final call on whether or not such treatments should be provided.

In judging these claims, the devil is always in the details. Can we define futility narrowly enough to apply only to situations in which the treatment will be completely ineffective? (Cotler and Gregory 1993). If the definition of futility is too narrow, it will apply only to a tiny number of cases. But if the definition is too broad, then it may cover cases in which treatment is not, strictly speaking, completely futile. A useful definition is very elusive (Truog et al. 1992). Futility seems to be not one thing but many things (Lantos et al. 1989). Some writers break futility down into subsets, and differentiate "quantitative futility" from "qualitative futility" (Zawacki 1995). By this approach, quantitative futility could be determined from data showing that a particular treatment could achieve its intended goal less than 1% of the time. Qualitative futility, by contrast, is based not much on the success rate of a particular treatment but on a judgment about the quality of life of the patient (Manara et al. 1998).

Five societies representing practitioners of critical care medicine (American Thoracic Society, American Association of Critical-Care Nurses, American College of Chest Physicians, European Society of Intensive Care Medicine, and Society of Critical Care Medicine) created a 2015 consensus statement on the provision of inappropriate treatments. They differentiate between "inappropriate treatments" and "futile treatments," specifying that "futile" should be applied only to the rare circumstances when a treatment has no possibility of achieving a physiologic goal. Futile treatment should not be provided. Most intractable disagreements surround "inappropriate" or "potentially inappropriate" treatments, which have "at least some chance of accomplishing the effect sought by the patient, but clinicians believe that competing ethical considerations justify not providing them" (Bosslet et al. 2015). The Society of Critical Care Medicine Ethics Committee's also issued a consensus opinion that the goal of ICU care should be to provide therapy for those with a reasonable expectation of being able to survive outside of the acute care setting, and who will also be able to perceive the benefit treatment. When a treatment cannot achieve this goal, it should be considered "inappropriate" (Kon et al. 2016). However, it is recognized that this decision is value laden, and should be determined on a case-by-case basis.

The boundary is inevitably blurry between futile treatment, burdensome treatment, inappropriate treatment, and treatment that is simply not cost-effective. The boundary is similarly obscure between futility judgments, judgments about quality of life, and

decisions based on resource allocation (Cranford 1994). With these concerns in mind, many writers have argued that futility is just a smokescreen, an attempt to cover up judgments about quality of life or decisions about resource allocation in the more acceptable language of professional integrity (Veatch and Spicer 1992; Gatter and Moskop 1995).

6.5 Futility and Symbolic Treatment

Two decades after Blackhall's article, another article appeared that advocated a very different approach. Truog, a pediatric critical care physician, described a case in which he performed CPR on a dying child even though he knew that it would be futile (Truog 2010).

The child was two years old. He had been born with a large frontal encephalocele. After surgery, he was neurologically devastated. In spite of repeated attempts to get his parents to agree to redirect care toward comfort and palliation, the parents continually requested that "everything be done" to keep their son alive. One day, the parents brought the child to the ER in full cardiac arrest. Truog directed the team to attempt resuscitation. Their efforts went on for 15 min, at which point, with no return of spontaneous circulation, the child was pronounced dead.

Truog describes how the father held his dead son's body tenderly. The father noticed all the puncture wounds and bruises from the failed attempts at placing lines and said, "I want to thank you. I can see from this that you really tried; you didn't just give up and let him die." Truog notes how distressing it was to provide CPR in these circumstances. One nurse "had to fight back the urge to vomit."

Truog was aware that the professional community was divided about the ethics of such efforts. He noted that, even among the teaching hospitals affiliated with Harvard Medical School, "Some have policies that permit clinicians to refuse to provide non-beneficial CPR, whereas others explicitly reject this approach and insist on agreement between the clinicians and the patient or family before CPR is withheld." This was true not just at Harvard but around the country. There is a patchwork of futility policies, little uniformity among them, and very few reports showing how often the policies are invoked or what outcomes follow (Johnson et al. 1997).

Given this disagreement, he concluded that there are times in which such resuscitation efforts, even when futile, show "that our hospitals are invested in treating patients and families with respect and concern for their individual needs." Sometimes, he writes, "providing non-beneficial CPR can be an act of sincere caring and compassion."

This paper stimulated many letters to the journal. Hanto and Ladin argued that "physicians are obligated first to the patient's best interest and only secondarily to the family's interests" and that Truog and his team betrayed this obligation (Hanto 2010). Fine accused Truog of violating Kant's second maxim—that persons should be treated as an end and never merely as a means to an end (Fine 2010). Sadovnikoff suggested that Truog was deliberately deceiving the family about the chance that

resuscitation would be successful (Sadovnikoff 2010). On the other side, Henrikson supported Truog's approach as a way of providing closure for the family (Henrikson 2010). Choma and colleagues saw such resuscitation efforts as a compassionate way of reassuring others who witness such efforts, including family members and other patients, of doctors' commitment to life (Choma 2010).

6.6 Legal Issues

The law addresses futility through both case law and statutory law. Cases can come before the courts in three ways. One is for the parents to file a lawsuit seeking a restraining order to prevent doctors from withholding or withdrawing life-sustaining treatment. The goal in these cases is to force doctors and hospitals to keep the patient alive. Alternatively, hospitals may seek a court judgement to support their proposed action, as was seen in two recent cases in the UK (discussed below.) Another way that cases can come before the courts is for family members to sue doctors, after a patient has died, for withholding or withdrawing life support. Such cases usually do not result in published opinions, so it is hard to know how common they are. Pope and Kemmerling recently reviewed some of the key legal cases in this area (Pope and Kemmerling 2016). Most of the cases involve adults, not children. Generally, when the cases involve children, and parents seek a court order for continued treatment, the courts grant the parents' wishes. This is true even if the children are brain dead (Caplan 2013), anencephalic, or are hospitalized in states that allow unilateral determinations of futility (Moreno 2007). That was true in the first intractable futility controversy to garner public attention (Paris et al. 1990). It has been true in a number of other cases since (Paulus 1985), including one involving a child with anencephaly in which the court ordered mechanical ventilation (U.S. District Court 1993), and a number of cases in which a child met neurological criteria for death and the parents wanted mechanical ventilation to continue (Nevada 2015). In at least one case, the court sided with the parents, even though a death certificate had already been completed (Luce 2015).

Only a few states have statutes that address futility controversies. In 1999, Texas enacted a law regulating end-of-life decisions. It provided a due process mechanism for resolving medical futility disputes (Fine and Mayo 2003). The legislative initiative that led to the law was unique. A few years earlier, in 1996, a group of Houston hospitals developed a common futility policy (Halevy and Brody 1996). The policy called for a hospital ethics committee to resolve disputes about futility. Patients or their proxy decision makers would be given three days' notice of the ethics committee meeting. If the ethics committee supported the doctors' recommendations, then life-sustaining treatment would be discontinued immediately. An odd feature of the policy was that, "If the institutional review process agrees with the determination of medical inappropriateness, intra-institutional transfers of the care of the patient to another physician to provide palliative care are allowed. However, intra-institutional

transfers to another physician to provide the intervention that has been judged by the institutional review committee to be medically inappropriate will not be allowed."

Some states have enacted laws to help resolve these conflicts. Texas has a law, the Texas Advanced Directives Act, that outlines procedures to resolve futility controversies (Kapottos and Youngner 2015). Virginia enacted a similar law, the Virginia Health Care Decisions Act, in 2018 (Virginia House Bill 226 (2018), amending Virginia code§32.7-127 and Virginia Code§ 54.1-2990). California has a comprehensive law about health care decisions that discusses medical futility and that specifically empowers doctors to refuse to provide a treatment if providing the treatment would violate their conscientious beliefs or when they believe that the treatment would be ineffective. But the law does not define "medically ineffective." Nor does it prescribe any specific procedural approach or safeguards for resolving such conflicts.

Even where there are laws, those laws may not determine the outcome in particular cases. Instead, laws merely define the framework for discussion. This becomes clear in controversies about stopping mechanical ventilation in patients who meet neurological criteria for death. In those cases, the law is usually clear. The patients are dead. Nevertheless, parents can successfully challenge the law and courts will sometimes order mechanical ventilation to be continued, or as in the recent UK cases, discontinued.

As stated above, two recent cases (Charlie Gard and Alfie Evans) highlight differences in approach between the UK and US court systems. They also reveal the hesitancy that institutions have to allow disputes to progress beyond the hospital walls, as the media scrutiny for these cases was intense and harsh.

In 2017, the case of Charlie Gard rose to international awareness. He was a boy diagnosed in his first year of life with a progressive and neurologically devastating genetic disorder called encephalomyopathic mitochondrial DNA depletion syndrome (MDDS.) Charlie spent months hospitalized at Great Ormond Street Hospital (GOSH), intubated and ventilated with profound neurological depression. The parents found a physician in the US using an experimental nucleoside therapy for a different mitochondrial depletion syndrome, MDDS with a TK2 mutation. In that patient population, the nucleoside therapy resulted in a 4% increase in life-expectancy (Paris et al. 2017). However, the specific genetic variant did not have the same neurologic involvement as in Charlie's case, and the drug had not been shown in even rodent models to effectively cross the blood brain barrier. GOSH physicians considered whether to provide this experimental treatment, but in the interim as the treatment was considered, Charlie experienced weeks of intractable seizures and the healthcare team decided that the experimental intervention was futile (Birchley 2018). Additionally, they believed that keeping Charlie intubated and ventilated was causing undue suffering, and that life-sustaining technology should be discontinued. They argued that this was in Charlie's best interest. The parents disagreed.

GOSH appealed to the Family Division of the High Court to hear the case, and the court allowed the hospital to stop providing life-sustaining therapy. The family pleaded their case to the Court of Appeal, and subsequently the Supreme Court and the European Court of Human Rights; the case was dismissed from these courts without overturning the original decision. The parents gave up their opposition when

the US physician, who initially offered the nucleoside treatment, came to London to examine the boy and his most recent MRI. Seeing Charlie's current situation, he withdrew the offer. He did not think there was any likelihood of improvement. The Family Division of the High Court set a deadline for the healthcare team and the parents to agree upon a time and location of removing technology. When this was not achieved, he was transferred to hospice, separated from mechanical ventilation and died shortly thereafter, on July 28th 2017 (Hammond-Browning 2017).

In December 2016, Alfie Evans was admitted to Alder Hey Children's Hospital in Liverpool, England, following a new onset of seizure activity. He was found to have a degenerative neurological disease, although the exact diagnosis remained elusive. He progressed to a minimally conscious state, and by September of 2017 the hospital petitioned the courts to withdraw ventilator support. Again, similar to Charlie's case, the healthcare team argued that continuing life sustaining technology was not in the child's best interest. The legal battle progressed in a similar manner through the Family Division of the High Court, with appeals made to the Court of Appeal, Supreme Court and European Court of Human Rights. The original decision, in support of the hospital, was again upheld. Following seeking support from the Pope during a visit to the Vatican and Rome, the Italian government issued Alfie a certificate of citizenship so that he could receive treatment there, likely a tracheostomy and feeding tube. The request to be transferred was denied by the court (Schuklenk 2018). Alfie died on April 28, 2018 following withdraw of technology days earlier.

These cases force us to look more carefully at the role of parental authority and its limitations. Current ethical standards support that parental authority is derived from a parent's desire to advance the welfare of their child. Parents may make decisions for their children because they are presumed to be the best surrogate at deciding what is in the child's best interest. But there are times when it becomes clear that a parent is not operating in a child's best interest. There are certainly times when a parent is clearly neglectful or even inflicting harm upon their child. But what about clearly loving, responsible and doting parents, such as Charlie's and Alfie's? Are there times when they may be unwittingly operating against their child's best interest? Both hospitals believed that the parents' pursuit of ongoing therapy was causing undue pain and suffering for the boys. Perhaps the parents' unreasonable hope for a cure led to a bias that prevented them from fairly weighing the benefits and risks for their child. A parent who is unwilling to accept the possibility of death for their child will understandably seek any possible treatment strategy, and may not be able to understand when the likelihood of success crosses the line between very unlikely to be successful to futile. For Charlie Gard's case, many healthcare providers agreed that the experimental treatment which the parents sought fell into the latter group. For Alfie, there was also consensus among the providers at his hospital that further treatment was unreasonable. (International scrutiny of the cases would indicate, however, that reasonable healthcare providers at other facilities did not agree—at least based on what was read in the media's description of the cases.) These cases are the epitome of intractable disagreements, with completely different assessments on what is in a child's best interest.

The United Kingdom already had judicial precedence on the approach to these types of disagreements from the Court of Appeal in *Wyatt v Portsmouth NHS Trust* in 2000:

> The judge must decide what is in the child's best interests. In making that decision, the welfare of the child is paramount, and the judge must look at the question from the assumed point of view of the child. There is a strong presumption in favour of a course of action which will prolong life, but that presumption is not irrebuttable. The term "best interests" encompasses medical, emotions and all other welfare issues. (Hammond-Browning 2017)

The duty of the court is to decide what is in the child's best interest. UK precedent is to usually favor the medical opinion of the physician in making these decisions. While the parents are important to decision making, they do not have an absolute right to demand treatments that a physician believes are not in the child's best interest. US courts, on the other hand, focus on parental authority or autonomy over best-interest claims (Birchley 2018). The Jahi McMath case is an excellent example (discussed in Chapter "The Difficulty with Determining Whether Someone is Dead") where even in the case of brain death, a legally accepted construct, the court would not overturn parental authority.

It can be argued, though, that the cases should not have been decided by either parental authority claims nor best interest claims. In Charlie's case, it is perhaps reasonable that seeking an experimental unproven therapy across the ocean is not in Charlie's *best* interest, but would it actually hurt him (or anyone else?) Shah et al. argue that the harm principle should be applied (Shah et al. 2017). This principle, best articulated by Diekema (2011), evaluates the threshold for state intervention, believing it should only occur when providers believe the parental actions would result in significant harm to the patient. In theory, applying the harm principle would allow parents more latitude in pursuing treatments. For Charlie and Alfie, the physicians would have to prove that there would be more harm to the patients in treatment than in their death. Considering the argument that Charlie and Alfie were too neurologically impaired to experience benefit from life, some have extrapolated that they may not have been able to experience suffering either. It is hard to know from our viewpoint outside of their PICU walls. Considering both families were willing to travel abroad, without state financial assistance, to healthcare systems willing to provide the treatments they sought, there was likely not any societal harm to consider either.

There are many reasons why the controversies are difficult to resolve. Parents are facing the loss of child, and may believe the healthcare team is giving up too soon. Doctors feel that their professional expertise and integrity are threatened. Doctors may also feel they are being asked to cause harm to their patients. The controversies touch on religious beliefs about the value of life or the value of suffering. There are deep-seated issues of trust and mistrust, age-old concepts about what it means to be dead or dying, economic issues in the ways that we finance health care, and ingrained cultural beliefs about the value of individual autonomy or about distrust of professional experts. Add to all these issues the inherent ambiguities of communication, especially in emotionally stressful situations, and it is not surprising that there are often ongoing controversies.

6.7 Religious Beliefs and Medical Futility

Richard Miller, a theologian, wrote a book entitled *Children, Ethics, and Modern Medicine* (Miller 2003). To write the book, he spent time as a participant-observer in two different PICUs, one in the Midwest and one on the East Coast. He did his observations throughout the 1990s. He focused on children, he says, because of the inadequacies of the paradigms that were evolving in adult medicine. For adults, he correctly noted, "the norm of respect for autonomy has general priority to the norm of beneficence" (p. 2). Adults may refuse treatments—or perhaps demand them—even if those treatments are not in their interests. With children, he notes, "Providers may often act in ways that subordinate respect for autonomy, such as it is, to the value of patient benefit" (p. 3). One chapter in the book discusses medical futility. He calls the chapter, "A Fighter, Doing God's Will: Technologically Tethered, Retaining Fluids, On Steroids, Sedated, and Four Years Old." It is a great title.

The chapter tells the story of Billy Richardson (a pseudonym) who has Hurler syndrome. Until the 1980s, Hurler was an untreatable and relentlessly progressive neurodegenerative disease. Over the last three decades, two new treatments have become available—enzyme replacement and bone marrow transplantation. Both treatments slow the rate of neurodegeneration, but neither is a cure. In one recent study, the average life expectancy for children who did not get a transplant was 6.8 years. For those who received a transplant, it was 8.6 years (Moore et al. 2008). Death after a transplant is mostly related to complications of the transplant. In one study of 258 children with Hurler who were transplanted, 64 (25%) died within five years. Of those "60 (were) from a transplant-related cause (11 viral infection, 11 multi-organ failure, 10 graft-versus-host disease, 6 hemorrhage, 4 idiopathic pneumonia syndrome/diffuse alveolar hemorrhage, 1 sepsis, 1 fungal, 13 other, and 3 from disease progression after graft failure). In 4 patients, the cause of death was unknown" (Boelens et al. 2013).

At age four, Billy had many of the complications that are common in this disease. He was developmentally delayed. He had renal insufficiency requiring dialysis. He had undergone a bone marrow transplant at the age of 13 months, but the transplant had failed to engraft. His disease had progressed relentlessly. Now his parents sought another bone marrow transplant.

Many hospitals thought Billy was too old to benefit and turned down his parents' request for a second transplant, but one agreed to try. The doctors there believed, and told the parents, that the procedure was risky and the chances of success were low. That is borne out by the literature. Success rates are lower for a second transplant. Mortality rates are higher. Sometimes, though, the procedure is successful. The doctors did not consider the procedure to be experimental. It was not part of a formal research protocol. Nevertheless, as Miller notes, doctors would sometimes say things like "That's how we learn about things so that the next group of patients will benefit," or "We're trying to push the envelope" (p. 159).

Billy's second transplant was more successful than the first. The transplanted bone marrow engrafted. Soon after, though, Billy developed many post-transplant

complications, including graft-versus-host disease, sepsis, and multi-system organ failure. He remained for weeks in the PICU on mechanical ventilation, vasopressor support, and dialysis. With each passing day, his chances for survival seemed lower. As one doctor noted, a few weeks post-transplant, "The current situation is ominous and he has significant probability of dying. It would be in Billy's best interest to withdraw support and give him DNR status if his respiratory condition does not improve after the high steroid course. This situation was mentioned to the family. They…do not wish DNR status or withdrawal of support" (p. 156).

Miller delves deeply into the case. He interviews the parents, doctors, and nurses involved. His write up captures, in its length and detail, the sense of weary overreach and internally contradictory frustration that characterizes so many futility cases. There were multiple ethics committee meetings regarding Billy and his family. In those meetings, doctors disagreed about his chances for survival. One oncologist said, "It was a gray area clinically. We can't say we've had 80 patients like Billy and they've died. We couldn't say he's going to die and it's in his best interest. Uncertainty is the proper premise here" (p. 159).

Billy's parents, Michelle and Kyle Richardson, described themselves as Christian. Furthermore, they said that their religious beliefs were central to their lives. They grew up in different Protestant denominations but eventually joined the same Presbyterian church. Kyle was an active member of the church's men's group. Michelle was also active in the church and had well-developed beliefs about God and the ways in which God works in the world. The parents' views about what should be done for Billy were based on their religious beliefs. His mother said, "God is present. Definitely. That Billy is still here says something for God's presence. He's guiding according to his will, which may not be what we want. God is here, orchestrating, allowing us to go through all this. It's his will. We may not like it. That is ultimately what is good for Billy."

By their view, God is all powerful and God is everywhere active in day-to-day human life. All that happens is necessarily a part of God's will. If Billy survives, that is attributable to God. If Billy dies, that is, too. In their view, God works things out on his own schedule and in his own time and it would be sacrilegious to interfere.

The parents did not think that God would necessarily heal Billy. They acknowledged that they, themselves, had no idea of what God's plan for Billy, or for themselves, might be. A nurse reported that Dad was overheard telling Billy that it would be ok to let go, and to die. Michelle told others that they were hoping Billy—or God—would make the decision for them. By acting on these beliefs, the Richardson parents are standing at a contested border between medicine, law, politics, and religion. The PICU is a stage upon which modern dramas of egalitarianism, empowerment, faithfulness, and ideas about professionalism play out in gut-wrenching, emotionally draining, and distress-inducing ways.

Because Miller is a theologian and not a physician or a bioethicist, he critically examines the religious philosophy that Billy's parents use to justify their actions and their decisions. He categorizes their theology as "not far from one strand of Calvin's piety and theology." Like Calvin, they believed that God has a direct, causal hand in human affairs. By this view, nothing, including natural law, can restrain the divine

will. Miracles are always possible. Miller has a deep respect for their beliefs. He sees that their deep faith allowed and energized them to provide tireless care for Billy. "They saw their love as mirroring divine *hesed*, God's steadfast, covenantal love, within a cosmic order that would reward the just" (p. 154).

Nevertheless, he makes a powerful argument that they have misunderstood Calvin's theology in important ways. He writes, "According to Calvinists, we are to accept gracefully and respond charitably to contingencies over which we have no control" (p. 161). Billy's parents, he suggests, refused to heed the limits of human willfulness. "The pursuit of goodness," he claims, "cannot violate natural patterns and processes that provide structure and coherence to everyday life" (p. 161).

Note what Miller is doing here. He is not arguing that doctors should override the parents and unilaterally withdraw life support (though he may think that that is the right thing to do). Instead, he is acknowledging that we should respect the parents' right to live their lives, and care for their children, based on their own understanding of the meaning of life and our purpose on earth. But he is challenging their theological understandings and making the sort of argument that tends not to occur in either medicine or bioethics today, an argument that the parents' religious beliefs are either mistaken or flawed. In doing this, he adds an important new interpretation of what is at stake in many intractable controversies about futility.

Miller shows that the root of the controversy is not, as is often assumed in the medical and ethics literature, about the epidemiology and prognostication in severe illness. The parents do not rely on studies showing that, in such circumstances, the chances for survival are extremely low. Controversies are not, in short, about the traditional goals of medicine. Instead, they are about fundamental theological beliefs and about the duties and obligations of a deeply faithful person when faced with a test of that faith. The parents also are not in denial or unwilling to accept death. At some points in the story, they seem to long for Billy's death, but it has to happen without their input or complicity.

Miller eventually comes to the conclusion that a great wrong was done to Billy. "At times," he writes, "religion must bow to common morality, and in pediatric medical contexts, that means honoring a patient's basic interests." We must do that, Miller argues, out of a proper understanding of what faithful Christianity demands, "Billy reminds us that there is what Thomas Aquinas calls an order of charity in which natural patterns, processes, and regularities have their own integrity and value." (p. 161). By that order, we (that is Kyle, Michelle, and the doctors) are demanding too much of Billy and demanding it in a way that ultimately leaves him unprotected against painful and medically unnecessary treatment.

Miller sees this as a situation in which they are avoiding parental responsibility by waiting for Billy to decide if he was ready to die or not. "The idioms of faith allowed them to defer their role as guardians for their son's basic interest. The burden of decision was put on his young shoulders, relieving them of that responsibility." That interpretation by Miller doesn't seem quite right. Kyle and Michelle did not think that it was Billy's decision, any more than they thought it was their own. Instead, they believed that it was all in God's hands.

Margaret Mohrmann is a physician and a theologian. She is thus in a unique position to respond to the medical issues, the bioethics issues, and the theological issues in Miller's case report. She wrote a thoughtful response to Miller's case (Mohrmann 2006).

Mohrmann begins by agreeing that Billy's case was one in which further treatment was likely to be useless. "As presented, Billy's medical situation seems the very definition of futile: everything being done appears only to prolong his dying, with no reasonable hope of recovery—and, even if he were to miraculously regain the ground lost with the second transplant, there would be no hope of preventing his early death from the underlying disease." This is the sort of situation in which many doctors and bioethicists would conclude, as Miller did, that our beneficence-based obligation to protect Billy's interests would demand of us that we stop the interventions that are violating those interests. We need, as Miller says, to protect Billy from the painful and unnecessary treatment because his parents are unable and unwilling to do so.

But what, Mohrmann then asks, about Billy's spiritual interests? She raises questions about the meaning of Billy's intervention. Mohrmann points out that the disagreements in this case and cases like it "may also and often be fundamentally about our divergent understandings of who God is and how God acts with us, specifically in relation to our suffering" (p. 145). Mohrmann pushes farther on this line of thought, and questions what our duties to care for Billy might be at this point. To be clear about the question she is asking, she notes, "It is clear that Billy's treatment is futile, his death inevitable; he does not have an open future. We are told that Billy is in no pain; there is no indication that he is suffering or even aware of what is going on. What, then, constitutes Billy's physical, intellectual, and emotional welfare? In what sense is it on behalf of *Billy's* welfare that he is either kept on life support or taken off and allowed to die?"

She concludes that questions about Billy's interests, or his welfare, or his rights are essentially unknowable, and that trying to know them leads to the inevitably ambiguous and ultimately futile task of trying to disentangle the interests of parents from those of their children. "The inseparability of interests is apparent when we consider that the futures of children and their parents are, in many key senses, interdependent. We say that children are our future, but we are just as surely theirs, a truth which complicates every child's right to an open future" (p. 147). As a result of this recognition of the inevitable intertwining of interests, she is less willing than Miller to say that the Richardson parents' choices flow from a focus on their own interests rather than Billy's. She writes, "I suspect that Miller's apparent certainty that Billy's parents and the medical staff are wrong to continue their aggressive treatment does not come from a reflective calculus about Billy's basic interests. Although that is the language invoked in the discussion, Miller does not tell us which of Billy's basic interests are at stake or how they are being violated or disregarded; he does not show us his moral discernment of and deliberation about them. Instead, he shows us Billy and lets us feel, as he does, the horror of the situation."

Mohrmann concludes that the dilemmas raised by this case cannot be solved by the traditional languages of bioethics. We make a category error when we conceptualize the dilemma as an ethical problem. Instead, it (and, perhaps, many other futility

cases) is fundamentally a spiritual problem. She writes, "(Billy's) welfare is beyond our grasp, unaccessable, unless we choose to adopt his parents' religious language and speak of keeping him alive because it is good for him that he serve God that way or, with a different but no less religiously warranted perspective, speak of letting him go because it will be good for him to move on to his eternal life with God…. Spiritual interests…may be all the interests Billy has left."

Billy's case, Miller's interpretation, and Mohrmann's analysis offer important lessons for health care professionals who struggle with these issues. They don't offer answers. Instead, they suggest that we may be asking the wrong questions. There are at least two interlocking dramas playing out at once. One is the medical-technological drama in which the vast armamentarium of life-saving interventions that we call critical care medicine are pitted against the infinite variety of things-gone-wrong that we call disease. Can the doctors save Billy? Will the new treatments work? What does it mean to call an outcome such as Billy's a success? Or a failure? When is it appropriate to declare victory, or hang out the white flag of surrender? That drama has been the focus of most futility discussions.

But the story of the Richardson family also makes clear that there is an altogether different drama playing out at the same time. That is the drama of people trying to come to some deep spiritual understanding of their purpose on earth—as doctors, nurses, or parents. Does Hurler disease exist for a reason? If not, or if so, what does that say about God? If God allows such diseases to exist, and also allows us as humans to develop treatments for those diseases, do we have an obligation to use those treatments gratefully and humbly, even if the outcome is not what we would wish? In the second drama, the terms and the evaluative markers that seem relevant in the first drama fade into irrelevance. Life and Death are in God's hands. We can only do the things that we can do to show our faith and witness God's actions. When we contrast these different dramas playing out, it becomes clearer why obtaining consent for limitations of treatment can become difficult—physicians think they are seeking parental understanding, and parents may feel they are being asked to forsake their religious views and become complicit in the death of their child.

6.8 Futility and Cross-Cultural Misunderstandings

Another famous case that sheds light on the meaning of medical futility is the subject of a full-length book. Anne Fadiman's *The Spirit Catches You and You Fall Down* tells the story of a Hmong family, the Lees, whose daughter, Lia, has epilepsy. Most of the book is about the clash of cultures between the Hmong family and their American doctors about the meaning of epilepsy and the implications of their different views for decisions about whether Lia was getting proper treatment. But a chapter near the end deals with the issue of medical futility and of a conflict between the Lees and their doctors.

At that point in the story, Lia had suffered massive brain damage as a result of septic shock. The resident who admitted her described her this way, "She was very hot

and febrile, her eyes were partially rolled back into her head, and she was breathing irregularly and way too fast. She wasn't making anything in the way of purposeful movement." Another doctor said, "She seemed to be in pain. She was struggling. I kept thinking, 'God, it can't go on like this. She is going to die any minute'" (p. 172).

Her mother brought funeral garments to the hospital for her to wear—a black hat, a black jacket, and a high-waisted appliqued skirt. The Lee family requested that her central line be removed, and all medication stopped. The doctors agreed, thinking that this meant that the Lees had accepted the fact that Lia was dying. But that was not the case. In fact, the Lees did not accept that fact, but they believed that the medication that Lia was receiving was making her worse.

After the central line and all the other lines were out, the Lees told the doctors that they wanted to take her home. The doctors told the Lees that she was going to die. The Lees did not accept that but could not explain to the doctors that they believed that they could take better care of her at home. There were a lot of misunderstandings. At one point, the Lees simply picked Lia up and tried to walk out of the hospital with her. The doctors called security to stop them.

This was an unusual sort of futility controversy. The doctors thought that the child was going to die. The parents didn't accept the prognosis, but also did not think that treatment in the hospital was helping Lia. Their belief was that they could take better care of her at home. The doctors, not surprisingly, disagreed, and would let her go home only if the Lee family acknowledged that she was likely to die there. The Lees were confused by the doctors' willingness to talk about the inevitability of death. As Fadiman notes, "In the Hmong moral code, foretelling a death is *strongly taboo.* It is an unpardonable insult to say to one's aged grandparent, 'After you're dead…' I asked several Hmong people I knew how they would feel if a doctor told them their child was going to die. 'A doctor should never say that!' one replied" (p. 178).

As one person involved in the case noted, "I'm not surprised. All those verb tenses. Lia will die. Lia might die. Lia has a 95% chance of dying. If the parents thought that (the doctors) were saying Lia *should* die, maybe they were right. A lot of people thought that if Lia was comatose and couldn't communicate and the only sensation she could feel was pain, it would be better for her if she did die" (p. 178).

Lia eventually left the hospital with a temperature of 104. She had an irregular breathing pattern, an inability to cough up or swallow her won secretions, and a prognosis of imminent death. When she got home, her parents boiled up some herbs and washed her body. Within days, her temperature was normal, her breathing was regular, and her swallowing and gag reflexes returned. Lia began to take baby formula by mouth, without coughing or choking.

Over the next many years, Lia's parents took excellent care of her. "Whenever they brought her into the clinic, Lia was always well-groomed, well-dressed, and immaculate. Just *immaculate*. It was very impressive." (p. 214) "Lia's black hair was shiny, her skin was soft and fine, her lips were still pink and shaped like a Cupid's bow. She smelled delicious. There were times when Lia seemed more like a pet—a golden retriever, perhaps, with strokable fur and a tractable disposition" (p. 217).

What do these two futility cases—Lia Lee and Billy Richardson—have in common? In both, the issue was only partly about specific treatments. The deeper,

underlying disagreements were about the meaning of illness and the meaning of ongoing treatment. These disagreements often reflect cross-cultural misunderstandings. Intractable disagreements about futility tend to occur more frequently among families from disenfranchised subpopulations. For example, in the paper cited above describing five cases of futility controversies in two PICUs, all five of the patients were from minority groups. Three were African-American, one was Mexican-American, and the fifth was from Turkey. Furthermore, in all of the cases, the focus was on something other than CPR. The treatments in question were mechanical ventilation, dialysis, vasopressors, and surgical procedures.

Those deep disagreements do not lend themselves to the sort of solutions that many have suggested for intractable disagreements, solutions that presume that everybody shares a common language and a common morality. In both cases, imposing a solution would have solved a short-term problem but may have exacerbated a longer-term problem of trust between the community of medical professionals and certain parental communities. Instead, they may require an approach that is more similar to that taken by Miller and Mohrmann, an approach that delves into the deeper meanings of illness and treatment, of life and death and love and responsibility than is common in clinical settings today.

6.9 Can We Think About Futility in the PICU in New Ways?

Old ways of thinking about futility seem to have led to an impasse. There are powerful arguments on both sides, with no bridge between the two. When disagreements become intractable, the only solution seems to be to declare one side the sad winner and the other side the angry loser. But what if the clash is seen as something other than an absolute battle of rights? Perhaps we're missing an essential element of what is going on. Perhaps it isn't really a power game, in which one side has to disempower the other in order to exert its own power. Perhaps, instead, such cases require us to think more deeply about what is really going on. The two detailed case descriptions above suggest some directions that such rethinking might take us.

Frader and Michelson note that the roots of such conflicts go deep. They write, "For many reasons, some having to do with theology, some with secular philosophy, and some with complicated historical, social, and political factors, different individuals and groups attach different meaning to the continued application of medical technologies, even in the absence of patient consciousness" (Frader and Michelson 2007). They fear that, given those complexities, policies like those in the Texas Advance Directives Act, which legally protect physicians who override family demands for care, dangerously substitute formal bureaucratic procedures for caring and compromise. They suggest that we need fewer policies and more emphasis on tolerance and empathy for others, "including others we do not like or with whom we disagree."

Janvier and colleagues come to similar conclusions. They write, "Parents and healthcare providers may have different values regarding the provision of life-sustaining interventions. However, parents base their decisions on many factors, not just probabilities. The role of emotions, regret, hope, quality of life, resilience, and relationships is rarely discussed. End-of-life discussions with parents should be individualized and personalized" (Janvier et al. 2014).

Morrison and Madrigal offer some clues as to how to do this. They point out that futility controversies tend to focus on a fairly narrow range of treatments. Some treatments are never offered. They write, "In our experience, the healthcare team is often comfortable never mentioning therapies that they think have no chance of helping (e.g., for most dying patients, there is no need to inform a family why extracorporeal life support is not being considered…)" (Morrison and Madrigal 2012). As a result, futility controversies usually focus either on DNR orders or on continued mechanical ventilation, rather than on the many other treatments that might be provided but that are never even discussed.

Morrison and Madrigal conclude that, in actual practice, pediatric intensivists learn to find a middle ground. They aren't willing to do absolutely everything possible or to give into every parental demand, but neither do they tell the parents that it is "my way or the highway." Instead, "Pediatric intensivists today prefer a collaborative approach with families, one that avoids staking out adversarial positions in cases where there is disagreement about the best course of action in a child's care. Approaching such disagreements with a desire to understand and acknowledge a family's position and offering support to the family before, during, and after a death is far preferable to attempting to push them to change their minds more rapidly than they are prepared to do."

We endorse this approach. It may lead to some cases in which health professionals experience moral distress because they are continuing to provide treatments that they see as non-beneficial. But with careful, honest communication, the number of cases that lead to intractable disagreements can probably be reduced. and as noted above, it is pretty low already.

References

Bertolini, G., et al. 2010. End-of-life decision-making and quality of ICU performance: An observational study in 84 Italian units. *Intensive Care Medicine* 36 (9): 1495–1504.

Birchley, G. 2018. Charlie Gard and the weight of parental rights to seek experimental treatment. *Journal of Medical Ethics* 44 (7): 448–452.

Blackhall, L.J. 1987. Must we always use CPR? *New England Journal of Medicine* 317 (20): 1281–1285.

Boelens, J.J., et al. 2013. Outcomes of transplantation using various hematopoietic cell sources in children with Hurler syndrome after Myeloablative conditioning. *Blood* 121 (19): 3981–3987.

Bosslet, G.T., et al. 2015. An Official ATS/AACN/ACCP/ESICM/SCCM policy statement: Responding to requests for potentially inappropriate treatments in intensive care units. *American Journal of Respiratory and Critical Care Medicine* 191 (11): 1318–1330.

Caplan, A. 2013. *Death, brain death, and life support*, January 18, 2017. Available from: http://www.bioethics.net/2013/12/death-brain-death-and-life-support/.
Casarett, D., and M. Siegler. 1999. Unilateral do-not-attempt-resuscitation orders and ethics consultation: A case series. *Critical Care Medicine* 27 (6): 1116–1120.
Choma, D.P., K.L. Cavanaugh, and J.P. Dwyer. 2010. Is it always wrong to perform futile CPR? *New England Journal of Medicine* 362 (21): 2036; author reply 2036–2037.
Cotler, M.P., and D.R. Gregory. 1993. Futility: Is definition the problem? Part I. *Cambridge Quarterly of Healthcare Ethics* 2 (2): 219–224.
Cranford, R.E. 1994. Medical futility: Transforming a clinical concept into legal and social policies. *Journal of the American Geriatrics Society* 42 (8): 894–898.
Diekema, D.S. 2011. Revisiting the best interest standard: Uses and misuses. *Journal of Clinical Ethics* 22 (2): 128–133.
Epstein, E.G., and A.B. Hamric. 2009. Moral distress, moral residue, and the crescendo effect. *Journal of Clinical Ethics* 20 (4): 330–342.
Feltman, D., et al. 2014. Is treatment futile for an extremely premature infant with giant omphalocele? *Pediatrics* 133 (1): 123–128.
Fine, R.L. 2010. Is it always wrong to perform futile CPR? *New England Journal of Medicine* 362 (21): 2035; author reply 2036–2037.
Fine, R.L., and T.W. Mayo. 2003. Resolution of futility by due process: Early experience with the Texas advance directives act. *Annals of Internal Medicine* 138 (9): 743–746.
Forbat, L., et al. 2016. Conflict in a paediatric hospital: A prospective mixed-method study. *Archives of Disease in Childhood* 101 (1): 23–27.
Frader, J., and K. Michelson. 2007. Can policy spoil compassion? *Pediatric Critical Care Medicine* 8 (3): 293–294.
Frader, J., E. Kodish, and J.D. Lantos. 2010. Ethics rounds. Symbolic resuscitation, medical futility, and parental rights. *Pediatrics* 126 (4): 769–772.
Gatter Jr., R.A., and J.C. Moskop. 1995. From futility to triage. *Journal of Medicine and Philosophy* 20 (2): 191–205.
Grossman, E., and P. Angelos. 2009. Futility: What Cool Hand Luke can teach the surgical community. *World Journal of Surgery* 33 (7): 1338–1340.
Halevy, A., and B.A. Brody. 1996. A multi-institution collaborative policy on medical futility. *JAMA* 276 (7): 571–574.
Hammond-Browning, N. 2017. When doctors and parents don't agree: The story of Charlie Gard. *Journal of Bioethical Inquiry* 14 (4): 461–468.
Hamric, A.B., and L.J. Blackhall. 2007. Nurse-physician perspectives on the care of dying patients in intensive care units: Collaboration, moral distress, and ethical climate. *Critical Care Medicine* 35 (2): 422–429.
Hanto, D.W., and K. Ladin. 2010. Is it always wrong to perform futile CPR? *New England Journal of Medicine,* 362 (21): 2034–2035; author reply 2036–2037.
Helft, P.R., M. Siegler, and J. Lantos. 2000. The rise and fall of the futility movement. *New England Journal of Medicine* 343 (4): 293–296.
Henrikson, C.A. 2010. Is it always wrong to perform futile CPR? *New England Journal of Medicine* 362 (21): 2036; author reply 2036–2037.
Janvier, A., K. Barrington, and B. Farlow. 2014. Communication with parents concerning withholding or withdrawing of life-sustaining interventions in neonatology. *Seminars in Perinatology* 38 (1): 38–46.
Johnson, S.H., et al. 1997. Legal and institutional policy responses to medical futility. *Journal of Health and Hospital Law* 30 (1): 21–36.
Kapottos, M., and S. Youngner. 2015. The Texas advanced directive law: Unfinished business. *American Journal of Bioethics* 15 (8): 34–38.
Kon, A.A., et al. 2016. Defining futile and potentially inappropriate interventions: A policy statement from the society of critical care medicine ethics committee. *Critical Care Medicine* 44 (9): 1769–1774.

Lantos, J.D., et al. 1989. The illusion of futility in clinical practice. *American Journal of Medicine* 87 (1): 81–84.
Leeuwenburgh-Pronk, W.G., et al. 2015. Are we allowed to discontinue medical treatment in this child? *Pediatrics* 135 (3): 545–549.
Luce, J.M. 2010. A history of resolving conflicts over end-of-life care in intensive care units in the United States. *Critical Care Medicine* 38 (8): 1623–1629.
Luce, J.M. 2015. The uncommon case of Jahi McMath. *Chest* 147 (4): 1144–1151.
Manara, A.R., J.A. Pittman, and F.E. Braddon. 1998. Reasons for withdrawing treatment in patients receiving intensive care. *Anaesthesia* 53 (6): 523–528.
McDougall, R.J., and L. Notini. 2016. What kinds of cases do paediatricians refer to clinical ethics? Insights from 184 case referrals at an Australian paediatric hospital. *Journal of Medical Ethics* 42 (9): 586–591.
Miller, R.B. 2003. *Children, ethics, & modern medicine*. IN: Indiana University Press.
Mohrmann, M.M. 2006. Whose interests are they anyway? *Journal of Religious Ethics* 34: 141–150.
Moore, L. 1998. *Birds of America*. New York: Alfred Knopf.
Moore, D., et al. 2008. The prevalence of and survival in mucopolysaccharidosis I: Hurler, Hurler-Scheie and Scheie syndromes in the UK. *Orphanet Journal of Rare Diseases* 3: 24.
Moreno, S. 2007. *Case puts Texas futile-treatment law under a microscope*. Washington Post.
Morrison, W., and V. Madrigal. 2012. "My way or the highway" versus "whatever the family wants"—Intensivists reject both extremes. *Pediatric Critical Care Medicine* 13 (5): 612–613.
Naghib, S., et al. 2010. Mortality in very long-stay pediatric intensive care unit patients and incidence of withdrawal of treatment. *Intensive Care Medicine* 36 (1): 131–136.
Nevada, S.C.O. 2015. In re Aden Hailu. *Nevada Advanced Opinion* 89.
Okhuysen-Cawley, R., M.L. McPherson, and L.S. Jefferson. 2007. Institutional policies on determination of medically inappropriate interventions: Use in five pediatric patients. *Pediatric Critical Care Medicine* 8 (3): 225–230.
Paris, J.J., R.K. Crone, and F. Reardon. 1990. Physicians' refusal of requested treatment. The case of Baby L. *New England Journal of Medicine* 322 (14): 1012–1015.
Paris, J.J., et al. 2017. The Charlie Gard case: British and American approaches to court resolution of disputes over medical decisions. *Journal of Perinatology* 37 (12): 1268–1271.
Paulus, S.M. 1985. In re L.H.R. *Issues in Law and Medicine* 1 (3): 233–236.
Pope, T.M., and K. Kemmerling. 2016. Legal briefing: Stopping nonbeneficial life-sustaining treatment without consent. *Journal of Clinical Ethics* 27 (3): 254–264.
Robinson, E.M., et al. 2017. After the DNR: Surrogates who persist in requesting cardiopulmonary resuscitation. *Hastings Center Report* 47 (1): 10–19.
Rubin, S. 1998. *When doctors say no: The battleground of medical futility*. Indiana: Indiana University Press.
Sadovnikoff, N. 2010. Is it always wrong to perform futile CPR? *New England Journal of Medicine* 362 (21): 2035; author reply 2036–2037.
Sands, R., et al. 2009. Characteristics of deaths in paediatric intensive care: A 10-year study. *Nursing in Critical Care* 14 (5): 235–240.
Schneiderman, L.J. 2011. *Wrong medicine: Doctors, patients, and futile treatment*. Baltimore, Maryland: Johns Hopkins University Press.
Schuklenk, U. 2018. Bioethics culture wars—2018 edition: Alfie Evans. *Bioethics* 32 (5): 270–271.
Shah, S.K., A.R. Rosenberg, and D.S. Diekema. 2017. Charlie Gard and the limits of best interests. *JAMA Pediatrics* 171 (10): 937–938.
Stark, Z., J. Hynson, and M. Forrester. 2008. Discussing withholding and withdrawing of life-sustaining medical treatment in paediatric inpatients: Audit of current practice. *Journal of Paediatrics and Child Health* 44 (7–8): 399–403.
Studdert, D.M., et al. 2003. Nature of conflict in the care of pediatric intensive care patients with prolonged stay. *Pediatrics* 112 (3 Pt 1): 553–558.
Thomas, S.M., et al. 2015. Not just little adults: A review of 102 paediatric ethics consultations. *Acta Paediatrica* 104 (5): 529–534.

Truog, R.D. 2010. Is it always wrong to perform futile CPR? *New England Journal of Medicine* 362 (6): 477–479.

Truog, R.D., A.S. Brett, and J. Frader. 1992. The problem with futility. *New England Journal of Medicine* 326 (23): 1560–1564.

U.S. District Court, E.D.V. 1993. Alexandria Division. In re Baby K. Fed Suppl 832: 1022–1031.

Varelas, P.N., et al. 2009. Withdrawal of life support in critically ill neurosurgical patients and in-hospital death after discharge from the neurosurgical intensive care unit. Clinical article. *Journal of Neurosurgery* 111 (2): 396–404.

Veatch, R.M., and C.M. Spicer. 1992. Medically futile care: The role of the physician in setting limits. *American Journal of Law and Medicine* 18 (1–2): 15–36.

Vemuri, G., and S.D. Playfor. 2006. Futility and inappropriate care in pediatric intensive care: A cross-sectional survey. *Paediatric Anaesthesia* 16 (3): 309–313.

Verhagen, A.A., et al. 2010. Categorizing neonatal deaths: A cross-cultural study in the United States, Canada, and The Netherlands. *Journal of Pediatrics* 156 (1): 33–37.

White, D.B., et al. 2007. Toward shared decision making at the end of life in intensive care units: Opportunities for improvement. *Archives of Internal Medicine* 167 (5): 461–467.

Zawacki, B.E. 1995. The "futility debate" and the management of Gordian knots. *Journal of Clinical Ethics* 6 (2): 112–127.

Chapter 7
Chronically Critically Ill with Technological Dependence

Abstract More and more children are surviving through PICU discharge. But discharge may be following a prolonged hospital course, and they may leave with a new slew of medical conditions, sometimes including dependence upon medical technology. This is the pediatric chronically critically ill child. While a definition of pediatric chronic critical illness (PCCI) is not clearly defined, the data supports that it is a cohort of patients that pediatric intensivists are increasingly manage. This chapter addresses the ethical issues that arise with pursuing life-saving measure that result in chronically critically illness, provision of appropriate resources for these conditions, in addition to ethical concerns regarding withdrawal of technological support.

7.1 Shifting Lines in the Sand

A few years ago, I sat down with parents of a young infant with extremely complex congenital heart disease. Our talk was during the child's protracted postoperative stay in the PICU. Preoperatively, the surgeons had not been optimistic about the chances that their palliative surgical correction would be successful. They had discussed this in transparent detail with the parents and, after careful consideration, the parents decided that it was worth trying. The parents stated, however, that if their daughter did not do well, they would want to change their focus to comfort measures.

Unfortunately, their daughter was not able to separate from bypass in the operating room. She came to the PICU on ECMO support. Her parents saw this as the very outcome that they had dreaded the most. They were clearly frustrated, feeling their wishes had not been followed. They felt that, since their daughter could not survive without what they considered to be "heroic" life-support measures, they did not want the doctors to make continued efforts to prolong her life. In their view, she was now "stuck" on ECMO support.

The surgeons saw things differently. They felt that postoperative ECMO support was essential for children who remained unstable after a major heart operation and that such postoperative support was really a part of the complex operation and

L. Miller-Smith et al., *Bioethics in the Pediatric ICU: Ethical Dilemmas Encountered in the Care of Critically Ill Children*, International Library of Ethics, Law, and the New Medicine 77, https://doi.org/10.1007/978-3-030-00943-4_7

recovery. This is a commonly shared philosophy. It was, in fact, part of the preoperative consent. They had hope that the patient would soon be able to separate from ECMO support.

The parents continued to press their point that they had requested that we not use heroic measures. They insisted that, even while on ECMO, their daughter should have a do-not-resuscitate order. Should an event occur on ECMO, they said, we should not attempt resuscitation. Such an event would, in their minds, would be their daughter's way of telling us to stop.

The little girl developed renal failure. We discussed with the family whether they would object to adding a dialysis circuit to the ECMO circuit for continuous renal replacement. They didn't object. They were told the kidney function could potentially return. In their mind, this didn't feel like the acute deterioration that would be their daughter's way of saying stop. After all, they asked, what was one more machine when she was already on cardiopulmonary bypass?

A couple of weeks passed, enough time for them to normalize the hectic therapy being offered to their daughter. The surgeons were correct—she was able to come off ECMO support. But she continued to struggle. She continued to require dialysis so a peritoneal catheter was placed. She was unable to come off of mechanical ventilation. Her surgeon wanted her to have a tracheostomy.

It was at that point that I, as the intensivist on service for the week, sat down with them to discuss possible next steps. Would they ever consider a tracheostomy with long-term mechanical ventilation as an option for their child? The mother looked puzzled and exhausted. She said, "We used to have a clear line in the sand that we would never cross. But with each decision that has been made, that line has been moved. It has been moved so many times. We now look back and wonder how we ever made it to this place where we never thought we would go or wanted to go. We are so far past our line. But how could we say "stop" now. That would make it seem like all her suffering up to now has been for nothing."

7.2 Defining Pediatric Chronic Critical Illness

An increasing number of children have their critical illness stabilized with modern intensive care medicine. Sometimes, however, we can stabilize the children, stop the progression of their illness, but cannot restore them to a state of good health. Thus, although survival rates following pediatric ICU admission continue to improve, we have an increasing number of children who require prolonged high-tech medical therapies. Many will never return to their previous baseline of health.

In some cases, like the one described above, this limbo between good health and death is the outcome that parents fear most. Initially, parents' darkest fear is that their child will die. To avoid that, they often consent to medical or surgical interventions that offer hope of saving their child. Over time, fears of having to witness the death of their child begin to dissipate. Those fears are replaced by a new and sometimes darker reality. They, their child, and their family will now live their daily lives in

a way they previously never conceived. The consequence of our rapidly advancing medicine is that we have created a new status for medically complex children: the chronically critically ill child.

Chronic critical illness among adult patients has long been recognized and discussed. The term was first used by Girard and Raffin in 1985. The authors asked the key question in the title of their article: "To save or let die?" (Girard and Raffin 1985) Over the past few decades, the syndrome of chronic critical illness in adults has been analyzed by multiple authors. Adult chronic critical illness (ACCI) has been defined as "a syndrome of persistent multisystem dysfunction that arises when critical care interventions support patients through the acute phase of a life-threatening critical illness but cannot return them to a state of good health and function" (Shapiro et al. 2017). There is general consensus that a long stay in the ICU and prolonged mechanical ventilation with tracheostomy are components of ACCI. The ACCI syndrome is also frequently characterized by neurological injuries, endocrine and metabolic disorders, multi-organ dysfunction, and predisposition to infections, particularly from decubitus ulcers. What is specific to the typical ACCI is that the major risk factor is age. It is seen as a consequence of the impact of modern medical advances on the natural progression of disease among the elderly.

Adult CCI has a large impact on patients and the healthcare system. Five to ten percent of adult patients who acutely require mechanical ventilation will go on to develop ACCI. The mortality from ACCI is high. Of the adults who develop CCI, 50–90% are dead within a year (Marcus et al. 2016; Nelson et al. 2010). Such patients are expensive. In the United States alone, they cost the health care system more than $20 billion per year, and utilize between 20 and 40% of ICU beds and associated resources (Marcus et al. 2016; Nelson et al. 2010). Many intensivists question whether it is appropriate to continue to aggressively treat these patients (Girard and Raffin 1985).

We now see the pediatric equivalent of ACCI. But the chronically critically ill pediatric patient is different from the adult CCI patient in many respects. The patient disease processes and demographics are considerably different among children, making it difficult to determine when a child has transitioned from the acute to chronic stage of critical illness. Some pediatric illnesses are naturally prolonged in their acute stage, and prolonged therapeutic dependence is expected. Examples may include prematurity with bronchopulmonary dysplasia, or a single ventricle patient undergoing and recovering from first stage palliation—standard care for these patients takes months. The typical course of acute illness and treatment in some pediatric diseases is more prolonged than in most adult diseases. We expect the acute phase to last for weeks to months, making it difficult to decide when to consider the disease chronic. The implications are important if CCI is seen as a marker of a very poor long-term prognosis.

Age is also an important difference for adult versus pediatric patients; decisions around critical illness may be less about how we see the child dying, but rather how we see the child living. Many patients have complex congenital conditions that would have been fatal just a few years ago. Today, however, we can now treat these children in ways that lead to long-term survival. But that survival is often associated with

long-term dependence upon medical technology. Sometimes, that technology-dependent state can last for years.

A key difference, then, between pediatric chronic critical illness (PCCI) and ACCI is that many PCCI patients survive for many years. Namachivayam investigated mortality rates of PCCI patients with varying underlying conditions from PICUs in Australia and New Zealand. In children whose initial PICU length of stay was greater than 28 days, the overall 5-year survival was 65.5% (Namachivayam et al. 2015). Unlike in ACCI, PCCI cases are not ones in which we are merely prolonging a patient's death. Rather, we are allowing for a life that may not have previously been an option. Questions inevitably arise about the child's quality of life given the burdens of long-term dependence on technology.

Another related difference between ACCI and PCCI is that children are often readmitted to the PICU for intercurrent illnesses. ACCI patients have a very high mortality rate during their initial admission and immediately following discharge. The discharge from the initial hospitalization is frequently to a long-term acute care or skilled nursing facility, which may manage that patient until their death. Pediatric patients have fewer community resources to provide medical support. Skilled nursing facilities are scarce in most regions. For this reason, the only options for these patients are to remain in the PICU or be discharged to home (Peterson-Carmichael 2012). It is not uncommon for a PCCI patient to be deemed too medically fragile to be safely taken care of at home, but not critically ill enough to be utilizing PICU resources. These patients tend to be discharged home, then readmitted to the general pediatric floor or the PICU. Their doctors and parents, meanwhile, strive to find the right environment to provide optimal monitoring while not misusing resources. They also try to balance what is best for the patient with what is best for the family. Some of these patients would likely benefit from skilled nursing facilities to help with the transition from hospital to home. However, very few such facilities for children exist and many families live too far from existing facilities to use them.

7.3 Resources to Appropriately Care of PCCI Patients

Although the number of children with PCCI is increasing, the resources available to take care of them outside of the PICU are decreasing. There has been a deliberate political and economic decision to move away from residential care facilities for children in the United States. The reasons for this move are ethically defensible and were a response to the overuse of residential facilities to house children with intellectual disabilities. In 1977, 36% of residents of state medical facilities were under the age of 21 (Friedman et al. 2014). During this time, children were institutionalized for behavioral, psychiatric, and sometime genetic diagnoses. Many had Down syndrome. Since that time, laws have been passed and guidelines have been developed that mandate or recommend that these children be preferentially placed into home settings. The intent of such laws and policies is good. The home setting, if

one is available, is a better place for children to live. Their long-term outcomes will be better if they are cared for at home than if they are institutionalized.

One example of such a law is The Olmstead Act of 1999. It states that persons with disabilities should be provided "appropriate and reasonable" accommodations for community-based care. Another is the Department of Health and Human Services' Healthy People 2010 program. That program specifically stated that it aimed to "reduce to 0 the number of children 17 and younger living in congregate care facilities." The American Academy of Pediatrics endorsed the Healthy People 2010 program, but made clear that it did not support the goal of working toward "zero" children in congregate care facilities, recognizing that there are still some patient populations that are well-served by these facilities.

Responding to these laws and policies, doctors and administrators have shifted resources from residential facilities to outpatient services and home care. While this approach certainly benefits numerous children who are indeed best suited to be cared for at home, it ignores the growing complex pediatric chronically critically ill population who may need chronic care facilities.

It is important to differentiate the medically complex children who have significant need for skilled nursing care from those patients who primarily carry behavioral or psychiatric diagnoses. The distinction is complex because some children with PCCI also have psychiatric and behavioral problems. The collective pediatric health care community should be advocating for care facilities to support medically complex patients as they transition to out-of-ICU care. These resources may include step-down units within hospital settings, acute rehabilitation centers that can handle technology such as ventilators, or skilled nursing facilities for longer-term care. The pediatric intensivist has an important perspective in this discussion, and knows the value of these resources. Unfortunately, intensivists' voices are rarely heard in these policy discussions because they don't directly affect the care of patients actively in the PICU. We are learning more, however, about its impact on our ability to safely discharge patients.

7.4 PCCI and Parental Role

With an increasing number of children being discharged home who require daily support with medical care, the parents are taking on a new role in their child's life. They need to perform many of the tasks that used to be performed only by highly trained and skilled health professionals. Parents must coordinate care between multiple subspecialists, manage and provide a slew of medications, start and stop treatments like gavage feeds, or provide physical or occupational therapies at home. When their children have home nursing, the parents may become both supervisors and educators since many home health care nurses do not have the specific skills needed to care for technology-dependent children. It is not uncommon to hear parents describe how they teach home health nurses to do tracheostomy changes or provide

adequate bag-ventilation for their child. These parents have become experts in much of their child's medical management, however, that role can create a novel sort of ethical conflict.

Home care for PCCI children places enormous demands on parents. Those with the ability to meet those demands and to learn the skills and techniques of pediatric critical care medicine are able to interact with doctors and nurses as peers. Along with developing technical skills, they also develop an enhanced ability to engage in the process of shared decision making regarding their children's medical care. Furthermore, because of the nature of the care, the parents provide care both at home and during the times when their child is hospitalized in the PICU. The traditional division of roles between doctors, nurses, and parents disappears. Parents become part of the health care team, but, of course, they are also still the parents. Parents' involvement in this manner can create tension between them and the healthcare team. Some conflicts between intensivist and parent will morph into a disagreement between healthcare providers, but the parent continues to have parental authority. Power struggles occur in a way that is different than among acutely ill patients and parents.

Henderson and colleagues captured some of this tension when querying healthcare providers and parents about chronic critical illness and frequent ICU admissions (Henderson 2017). One parent gave the advice:

> Listen to the parents. We told [the staff], "Don't suction past a certain point. She will gag. She will throw up." That advice was not heeded. She threw up all of her feedings because she was suctioned too deep….So listen to the people who take care of her on a regular basis and know exactly what is going on with her.

Physicians also recognize the tension between physicians and parents in determining roles. As one physician described:

> Some colleagues really embrace the idea that parents know a lot about what's going on with their children. For other colleagues it's important to them to maintain the role of expert, so maybe they aren't as good at listening as they could be. (Henderson 2017)

Most intensive care doctors were not trained to take care of these chronically ill children. At times, caring for the chronically critically ill patients may feel more like providing primary care. But it is a modern reality that there are often many such children in the PICU. A PICU doctor may bounce back and forth between providing traditional intensive care to a number of acutely severely ill children whose care is more typical of what a PICU doctor has been trained to provide, and providing care to PCCI patients. It is tricky to balance the responsibilities that these two types of patients demand. Consciously or subconsciously, bias may impact how those patients are prioritized. This is true for other disciplines as well. As one nurse stated:

> We don't have time. We have a really sick patient and a baby that is not as critically sick but still needs developmental care. You feel you have one child you can pay attention to, and the other is on autopilot. Which is unfair. But that's reality in the ICU.

Or as one physician described:

> Because I was a fellow in critical care, I wanted to be doing procedures. The last thing I wanted to do was have to figure out why one of these kids that had been there for years is running a fever at 3 o'clock in the morning. (Henderson 2017)

Since PICUs will be taking on more and more chronically critically ill patients, doctors and nurses will have to adapt. Some such adaptations include changes to fellowship training. Many programs now explicitly address the challenges of communicating with parents of PCCI children (Marcus et al. 2016). Additionally, some units designate "primary" nurses and physicians who can provide consistency in care and communication for families.

Daily workflow issues may also need to be altered for the chronic patient. Not every PICU patient needs to have vital signs every 2 h and to be awoken at 4 a.m. for lab work. In acute illness, these workflow decisions make sense. But as the focus changes to more long-term goals such as weight gain, developmental growth and recovery, units should demonstrate flexibility to allow an alteration to these schedules. Lessons may be learned from the NICU where doctors and nurses have always cared for both acutely ill neonates and those who were less acutely ill but still not stable enough to go home.

Additionally, it may be beneficial to lay out specific expectations of roles, and delineate clear boundaries for all parties (Marcus et al. 2016). An example may be that while in the hospital, staff may decide that a parent may not adjust their child's ventilator but can administer some medications. For PCCI patients, doctors and families may need to have meetings at the time of admission to clarify roles and boundaries. Such meetings could prevent tension from evolving during the child's PICU stay. A focus of such meetings might be on the process for making decisions. This is important to clarify because doctors make many different decisions for PICU patients every day. One study estimated that an intensivist makes over 100 discrete decisions each day, an average of 9 decisions per patient (McKenzie et al. 2015). Such decisions might include considerations about whether a patient should be intubated, whether to start vasopressors, or what adjustments to make in medication doses.

Parents might expect to be included in these decisions. By contrast, PICU doctors may be used to making most of these decisions by themselves. Doctors may think of each decision as discrete. Parents, however, experience the series of decisions as one continuous process in which each decision influences the next decision. Parents have expressed recurrent worry about each decision, reflecting upon previous decisions and anticipating the next (Lipstein and Britto 2015). To work in harmony with these parental perceptions, physicians and healthcare providers should change the way they talk about decisions with parents. This change would shift the focus of decision making from discrete events to the longitudinal trajectory for a patient. This shift will lead to framing decisions within the context of the patient's big picture and will

help parents see how choices must be consistent with a commonly agreed upon goal of treatment (Marcus et al. 2016).

7.5 The Home Care of Technology Dependent Children

Many chronically critically ill children have a lifelong dependence on medical technology. More and more children are being maintained long term on support such as tracheostomy with or without mechanical ventilation, ventricular assist devices, gastrostomy tubes, tunneled central vascular lines, and dialysis catheters. Children are frequently being discharged from the hospital on these chronic technological therapies. While some children must still remain in the ICU or the hospital, other children may use more transportable technology that allows discharge to either home or a less intensive hospital setting. To see the implications of these technologies, we will discuss the issues that arise around tracheostomy and invasive ventilation as an example of how critical care technology is spilling out of the PICU settings into outpatient venues.

Many parents now care for ventilator-dependent children at home. There has been a 55% increase in children requiring long-term ventilation between 2000 and 2006 (Benneyworth et al. 2011). In 2003, more than 4800 children were estimated to receive a tracheotomy each year in the United States (Lewis et al. 2003). Today, the number is probably at least twice that high. The vast majority of these patients will be discharged home or to long-term care facilities, depending on regional availability of these resources (Lewis et al. 2003).

Some patients with tracheostomies also require mechanical ventilation. But even among patients who will not be on a ventilator at home, surgical decannulation typically occurs many years following initial placement. A study from Zurich that examined patients with tracheostomies from 1990 through 2009 found that the mean time to decannulation was 28 months (de Trey et al. 2013). A 2016 study from Texas Children's Hospital found that the median time from tracheostomy to decannulation was 5.3 years (McPherson et al. 2017). Therefore, many of these children are home with tracheostomies, with or without a ventilator, for prolonged periods of time. One of the trade-offs for the ability to improve the survival rate among critically ill patients has been to accept a degree of dependence on technological support. The benefit of tracheostomy is that it can allow a child to be liberated from the hospital setting and return home. While at home, these children require monitoring, tracheal suctioning, and caregivers who are trained to give CPR.

Living at home with tracheostomy, with or without mechanical ventilation, has significant risks and costs. Children with tracheostomies are at risk for sudden acute events. These include sudden tracheal occlusion from mucous, accidental decannulation, equipment failure, and infections or bleeding from tracheal site. Parents or caregivers must be able to provide day-to-day care for their children and to medically stabilize their child should an emergency arise.

Moral distress arises from the concern that we may be asking parents to take on responsibilities that they are not prepared to handle. When a child accidentally decannulates himself at home and the parent fails to rescue the situation, the guilt may be felt heavily upon the parents' shoulders. Healthcare professionals are prepared to deal with these acute life-threatening events differently than parents are. When these events occur in the hospital, there are more resources at hand than there will be at home. Teams work to ensure the parents are as prepared as possible to take on these challenges when outpatient. Hospital discharge is frequently delayed as the health care team strives to ensure that the family is adequately educated and experienced in providing the care that their child will need when healthcare professionals are not around.

Socioeconomic factors influence health outcomes in many settings. Cristea and colleagues quantified the effect of median household income upon mortality in children on home mechanical ventilation. They evaluated 94 patients over a 27-year period. They analyzed outcomes for two groups of children, those with higher socioeconomic status (SES) and those with lower SES as determined by the average annual income of families in the patients' zip codes. The study demonstrated a statistically significant association between mortality and living in an area with a lower average household income (Cristea et al. 2015). Although the study does not elucidate the discrete reasons for this association, it suggests that children in poor families may be at higher risk when they go home on medical technology.

Some obvious issues could be contributing to the increased mortality rate among children in families with lower SES. Setting up medical technology such as mechanical ventilation through tracheostomy in a home setting imposes a large demand on the family and the community for resources. The household must be equipped with a sure source of electricity and a backup plan for power loss. The house must have space and be organized to accommodate the needed equipment. This study from Cristea gives some credence to the moral distress surrounding committing children to long term tracheostomy with ventilation, when parents may be struggling to get the resources they need to support the child safely at home. Social work involvement with families should begin even prior to tracheostomy placement to ensure families are aware of the resources required, and to begin working on plans to ensure that support is there.

Carnevale et al. highlight both the benefits and the multiple distresses that may arise from having a child at home on ventilator assistance. Parents reported significant concerns related to finding needed resources, having financial stability as jobs may have to change, and living in isolation from others. Additionally, there was a struggle with normalizing the life and home environment, and worrying that others were devaluing their child's life. There was strain placed on marriages and on the emotional well-being of the patient's siblings. Parents also reported a continual feeling of the presence of death, or worry of imminent death.

In spite of the stresses that are associated with home care for technology-dependent children, parents also reported that they never felt there was a "free choice" when the other options were either the death of their child or years in the hospital. Although parents may report wondering if they made the right choice, these feelings were

resolved when they considered the alternative. Although there were many difficulties, most parents reported the struggle was worthwhile (Carnevale et al. 2006).

Knowing the challenges that children and parents will face with pursuing tracheostomy with or without mechanical ventilation, many healthcare professionals feel distress over moving towards that intervention. This distress is worsened when the child also has severe neurological impairments. In such situations, many doctors question if the risks accrued by the family and the utilization of resources are worth it.

Wilfond reflected upon his own experiences with these decisions with provision of advice on how to navigate conversations with families (Wilfond 2014). He notes that, while health professionals might feel moral distress in caring for such patients, they should not let their own moral qualms drive the decisions. He shows that broad societal decisions to not provide life-sustaining health care for patients with severe disabilities is not consistent with our current legal and ethical position within the United States. He advocates a detailed discussion with parents and even, in some cases, directive counseling and recommendations to not pursue tracheostomy or long-term ventilation. However, at the end of the day, the medical team must decide if there is an absolute contraindication to tracheostomy based on medical information and local standard of care. If no absolute contraindication is agreed upon, the family should have the option to pursue that goal.

7.6 Unique Issues that Arise with Cardiac Assist Devices

Other technologies may raise issues similar to those raised by tracheostomies and home ventilators. Ventricular assist devices in children, such as the Berlin EXCOR ventricular assist device, are associated with a variety of unique challenges. How can we develop and test technology specific to critically ill children? How do we decide who receives the technological support? How is this technology applied in the end-of-life care for children?

For decades, doctors have sought ways to provide mechanical support for adults with end-stage heart failure who are not candidates for transplantation. The National Institutes of Health created an artificial heart program back in 1964, allocating $160 million towards the program (DeMartino et al. 2017). The FDA approved a left ventricular assist device for short-term bridge to transplant in adults in 1994 (Rose et al. 2001). The first artificial heart intended for destination therapy was implanted in 1982. It supported a patient for 112 days (DeMartino et al. 2017). Over the 1990s, work was done expanding this application to chronic use. The REMATCH trial, published in 2001, evaluated the impact on 129 adult patients with end-stage heart failure using devices for long-term support. The rates of survival at one year were 52% among VAD patients as compared to 25% in patients who were medically managed, a 48% reduction in death. The respective numbers at two years were 23 and 8% (Rose et al. 2001). This data led to FDA approval for use of VADs as destination therapy in adults. But it was not clear whether there was a role for this sort of device in children.

The Berlin EXCOR was developed in Germany to support small children with failing hearts. The initial Berlin EXCOR experience in the early 1990s had a high mortality, with only 35% of patients surviving the hospital discharge (van Manen 2017). The patient cohort receiving therapy were "patients with profound cardiogenic shock refractory to conventional therapy." This was not a randomized trial. There was no control group. But these were patients who were likely to die. The only therapy for such children at the time was extracorporeal membrane oxygenation (ECMO). ECMO is cumbersome and risky. It can only be provided in an intensive care unit and can only be provided for a limited amount of time, on average a few weeks.

With continued development, the VAD was performing well for children in Europe by 2000. In the United States, there were no options for children with severe heart failure other than ECMO. Centers began petitioning the FDA to allow for compassionate use of the device for their patients. There were approximately 100 cases prior to 2007 granted compassionate use status. Then, as part of a formal study, doctors collected prospective data on 204 patients between 2007 and 2010. At one year, 75% of these patients had survived: 64% were successfully transplanted, 5% were awaiting transplant, and 6% had recovered and separated from the device. The major complication from the device was neurological injury, occurring in 29% of patients. Neurological injury was the primary cause of death (Almond et al. 2013).

We have now learned a lot about the risks, benefits, and appropriate management of children on the Berlin EXCOR VAD. It is now approved by the FDA. Still, the path to its development required parents to accept a significant but unknown level of risk. It is thus emblematic of a common situation that we face in the PICU. We often try interventions for which the consequences are not fully known. We seek parental consent, but, given all the uncertainties, it cannot be a truly informed consent. Neither we nor they know what we are all getting into, but when a child's life is on the line, we are all willing to try very risky things if there is even a small chance of benefit. When we do so, we have an obligation to collect data and report results as was done with the Berlin EXCOR. It is not always possible to do a prospective randomized trial but high quality, observational data can answer many questions about the risks and benefits of innovative technology.

One of the reasons why randomized trials are difficult to design and conduct is because the technologies themselves are evolving rapidly. The facts that we give today about long-term outcomes may not be relevant in six months or a year. As an example, we are learning more information rapidly about the use of implantable cardiac assist devices in larger children. These devices can allow for discharge from the hospital setting. These are the devices commonly used in the adult arena. Unlike the Berlin, the pump for these devices is implanted internally, with a drive line connecting to an external computer controller with a power source. This technology allows the child to be discharged from the hospital, but still with their life being tied to continuous technological support. There are strong efforts underway to create similar implantable devices for smaller children as well.

7.7 The Subjective Experience of Technology Dependence

What does it mean for anyone, but particularly a child, to be dependent upon a cardiac assist device? Is it different from being dependent on more familiar technologies such as mechanical ventilation or renal dialysis? Van Manen evaluated the experiences of six school-aged children in Canada who were living outside the hospital on VAD support (van Manen 2017). The study gives a lovely insight into the lives of technology-dependent children. These children were able to give an account of how they experience living outside of a hospital while being supported by a machine that they need to stay alive. They are very much aware of how unnatural the experience feels:

> The actual device, inside of my chest, sometimes makes a hum, or like a kind of a buzz, and if I put my hand right into my chest I can feel the vibration of it. In a really quiet room, I can hear it. Sometimes, during these times, I just can't help but think that I don't want it anymore. That I just want it taken out. That I am just done with it all.

They struggle with explaining their technology to those around them:

> When people ask me about the bag? I sometimes say, "My heart is in my bag." But then people don't understand that. So I end up saying, "well, there is a mechanical device in my heart, in the left ventricle, and what is in my bag is the remote and the batteries that keep me going 24/7. (van Manen 2017)

But while the device may not be natural, it does allow them to return to normal child behaviors that their chronic illness would not allow them to do otherwise. Without the device, they would likely have either died, or would be captive within the PICU walls unable to experience any part of a "natural" life. With the device, important pieces of a child's life can return to "normal." One child explains:

> I go out with my friends. None of them are VAD trained per se. They do know to call my mom and an ambulance if it suddenly fails. It certainly is not as safe as living in the hospital. But having some independence. It's just a risk we are willing to take.

And from another child:

> After they gave me the VAD in the hospital, I was allowed to go home. I asked my friend to come over and play. We had so much fun. I almost forgot that I now had a VAD. (van Manen 2017)

But at the same time, there will always be indications that the child is not like another child. And always a lingering fear that suddenly the device could fail with catastrophic results.

> Last night I was just sitting there, just relaxing, and paying attention to my breathing and trying to fall asleep listening to its churning motor sound when I started thinking, started worrying about it stopping. I wonder how it might all end? I think about what might happen if it simply stopped. (van Manen 2017)

Technology can simultaneously allow a child to resume a normal pattern of life, while also keeping them distinct from their peers. It may also be intrusive—periodically reminding them of life's fragility and the potential for their death.

7.8 VAD as Destination Therapy

For most children, and their families, now experiencing life with a VAD, there is an end point. The typical experience is that a VAD will be a bridge to transplantation. At some unexpected moment, "the call" will come that a heart is available. The child will be able to separate from the life-saving technology, although will transition to the chronicity of immunosuppression. A few children will also use the VAD as a bridge to recovery, and be able to have the device removed and resume normal life. Although using a VAD for a finite duration is the norm, there is an increasing subset of patients who will be placed on a VAD as destination therapy. For these children, there is no plan for transplant. The goal is to support their cardiac function with a VAD indefinitely.

The largest group of children who use VAD as a destination therapy are children with Duchenne Muscular Dystrophy (DMD) with dilated cardiomyopathy. Historically, DMD patients died from respiratory failure. With advances in technology for respiratory support, including invasive and noninvasive ventilators, patients survived longer to experience the next complication: dilated cardiomyopathy. Now, ~40% of DMD patients will die from heart failure in spite of medical management (Fayssoil et al. 2010). DMD patients may not be cardiac transplant candidates due to concern for increased risk of transplant if there are other significant co-morbidities related to DMD.

In 2012, the first two case reports of the use of VADs for destination therapy for muscular dystrophy patients were published from Italy. The therapy was deemed successful as the adolescents were able to be discharged home to resume their normal activities (Amodeo and Adorisio 2012). Since that first report, this group has reported upon an additional 5 patients. All patients survived to discharge home. At the time of reporting, three patients had died: one from a pulmonary infection at 45 months on VAD support, one from tracheal bleeding from a tracheostomy at 29 months, and one from a cerebral hemorrhage after 14 months (Perri et al. 2017). While pediatric patients who are offered VADs for destination therapy may benefit from the additional years added to their life, this benefit can be at a high cost on their quality of life and quality of death. Many families refuse such therapy. All should be adequately informed of the risks and burdens before a VAD is implanted.

A recent case report from Purkey et al. describes a teen with Becker Muscular Dystrophy and a decision to use a VAD while a decision was being considered as to whether the child was a candidate for heart transplantation (Purkey 2017). The patient ultimately was deemed to be a candidate for a transplant, but he elected to not pursue heart transplantation and to stay on mechanical left-ventricular assist support. He was pleased using his current status as his "destination:" the quality of life was satisfactory to him. At the time of publication of the article he had accrued over 2100 days on VAD support. He continued to require frequent cardiology visits with twice monthly laboratory monitoring and echocardiograms every three weeks. In addition, he sees pulmonary, psychiatric and neuromuscular specialists. He has been re-hospitalized over nine times during that time period. He has also

experienced medical declines separate from his cardiac function, with progressive skeletal weakness that has left him wheelchair bound. But, barring a sudden event with his device, it is not likely to be heart disease that will cause his death; it will likely be another complication such as respiratory failure, infection, or hemorrhagic event associated with his anticoagulation. Because early death is still a reality for him, palliative care services were introduced to him and his family early so they could still make plans for end-of-life issues. This end-of-life planning will now require decisions about whether and how the device will be de-activated (Purkey 2017).

The case illustrates some of the problems that are on the horizon for patients with PCCI and technology dependence. As we develop technology to replace each failing organ system, we will also have to think in new ways about end-of-life decisions and the considerations that should guide choices about the withdrawal of life-supporting technology.

7.9 Withdrawal of Chronic Technology

The de-activation of technological support can be emotionally difficult for all involved, including patient, family and health care members. But the moral distress experienced should not indicate lack of ethical or legal permissibility in this matter. Legally and ethically, there is no difference between a decision to withdraw a therapy and a decision not to start it in the first place (Rady and Verheijde 2014). Emotionally, of course, there is a big difference.

In any situation in which a patient or parent may consent to or refuse the initiation of a technological therapy, they may choose to have it discontinued. This applies to support such as mechanical ventilators, dialysis treatments, artificial nutrition, pacemakers, and ventricular assist devices. A patient cannot be required to rely on artificial support to maintain an essential function a body cannot provide for itself. The patient's clinical situation may change, making what was acceptable to the patient and family before no longer acceptable now.

Some have tried to make the argument that pacemakers and VADs are more similar to a transplanted organ that becomes a part of the patient's body, that it is a "biofixture" and cannot be stopped. Those who worry about stopping things like a pacemakers, implantable cardioverter defibrillators, or implanted ventricular assist devices argue that internalization makes it different than an external device such as ECMO or a ventilator. They may also argue that it is the duration of care—that if a pacemaker has been present for years, it has become part of the patient. These arguments have not sustained scrutiny by bioethicists or legal experts. Neither internalization nor duration of therapy makes technology innate to the human body. This technology never becomes integrated into the individual the way a transplanted heart valve or organ may. It will likely, however, become increasingly difficult to make such distinctions as biotechnology advances. As Daniel Sulmasy states, "It is critically important… that we begin thinking seriously and carefully about what makes an intervention a part of the patient, rather than a treatment that is extrinsic to the patient's

self, even if it is located inside the patient's body. The rapid pace of technological progress assures us that these sorts of questions will continue to surface in clinical practice. Ethics, as the most practical branch of philosophy, must be prepared to keep pace with these challenges" (Sulmasy 2008).

It is our moral duty to engage with the patient and family, not just about the initiation of technological support, but also about the longitudinal responsibilities and decision making that will come with it. Rizzieri et al. put forth recommendations on approaching conversations and planning when using VADs for destination therapy, but this advice could be heeded for most, if not all, technological support or chronic medical therapies (Rizzieri et al. 2008). The authors advocate for using an early palliative care type approach with prerequisite conditions which must be met:

(1) Involvement of the full multi-disciplinary team, including early involvement of palliative care specialists
(2) A concise plan of care for anticipated device-related complications
(3) Careful surveillance and counseling for caregiver burden
(4) Advance-care planning for anticipated end-of-life trajectories and timing of device deactivation
(5) A plan to address the long-term financial burden on patients, families and caregivers (Rizzieri et al. 2008).

This type of conversation up front will ensure the family and patient are as adequately informed about the intervention being taken as possible. Additionally, it frames the decisions and planning in a longitudinal manner, anticipating long-term goals and outcomes. It is also transparent with caregivers about the risks, including medical, emotional, and social that they are taking on, and allows those risks to be anticipated and addressed early in the course. By bringing the full multidisciplinary team into the conversation from the beginning, it provides the family with the continuity of care they will need in both inpatient and outpatient settings.

7.10 The Challenges Ahead

Most PICU patients will survive their intensive care stay. Many will leave the PICU and the hospital with a number of chronic health problems. These chronically critically ill children will require frequent medical interventions and will often return to the PICU. For some of these patients, their support will involve artificial technological support. This is the reality of modern pediatrics and a new challenge for pediatric intensivists.

Pediatric intensivists cannot limit their role to the care of critically ill children only while those children are in the PICU. Instead, they should be advocates for high-quality home care or long-term care for medically fragile children. In order to safely discharge such children, intensivists must work with home health care agencies, discharge planners, politicians, and payors to ensure that resources are available both within the PICU and also within the community at large to support this growing

population of chronically critically ill children. Attention should be paid to ensuring that families are well supported in their decision-making around choices to prolong life with the use of chronic technology.

The availability and success of technologies, which can sustain life but do not cure the child's underlying disease, create challenges in obtaining informed consent. We must be clear with parents that the risks and benefits of interventions such as tracheostomy or the insertion of a VAD go well beyond the risks and benefits of the surgical procedures. We must be sure that parents understand what life with that technology will mean for the patient and their family over the weeks, months, or years after the child is discharged. Such discussion and planning for life with technology must be had prior to its placement. Such discussion should also address the difficult questions that will inevitably arise about discontinuing such therapies and a discussion of what death might look like and feel like if it follows a decision to turn off and withdraw technological support. Families need information, time for processing the information, and emotional support as they enter the world of chronic critical illness with their child.

References

Almond, C.S., et al. 2013. Berlin heart EXCOR pediatric ventricular assist device for bridge to heart transplantation in US children. *Circulation* 127 (16): 1702–1711.

Amodeo, A., and R. Adorisio. 2012. Left ventricular assist device in Duchenne cardiomyopathy: Can we change the natural history of cardiac disease? *International Journal of Cardiology* 161 (3): e43.

Benneyworth, B.D., et al. 2011. Inpatient health care utilization for children dependent on long-term mechanical ventilation. *Pediatrics* 127 (6): e1533–e1541.

Carnevale, F.A., et al. 2006. Daily living with distress and enrichment: The moral experience of families with ventilator-assisted children at home. *Pediatrics* 117 (1): e48–e60.

Cristea, A.I., et al. 2015. Median household income: Association with mortality in children on chronic ventilation at home secondary to bronchopulmonary dysplasia. *Pediatric Allergy, Immunology, and Pulmonology* 28 (1): 41–46.

de Trey, L., et al. 2013. Pediatric tracheotomy: A 30-year experience. *Journal of Pediatric Surgery* 48 (7): 1470–1475.

DeMartino, E.S., et al. 2017. Ethical analysis of withdrawing total artificial heart support. *Mayo Clinic Proceedings* 92 (5): 719–725.

Fayssoil, A., et al. 2010. Cardiomyopathy in Duchenne muscular dystrophy: Pathogenesis and therapeutics. *Heart Failure Reviews* 15 (1): 103–107.

Friedman, S.L., et al. 2014. Out-of-home placement for children and adolescents with disabilities. *Pediatrics* 134 (4): 836–846.

Girard, K., and T.A. Raffin. 1985. The chronically critically ill: To save or let die? *Respiratory Care* 30 (5): 339–347.

Henderson, C.M., et al. 2017. "Stuck in the ICU": Caring for children with chronic critical illness. Pediatric Critical Care Medicine.

Lewis, C.W., et al. 2003. Tracheotomy in pediatric patients: A national perspective. *Archives of Otolaryngology—Head and Neck Surgery* 129 (5): 523–529.

Lipstein, E.A., and M.T. Britto. 2015. Evolution of pediatric chronic disease treatment decisions: A qualitative, longitudinal view of parents' decision-making process. *Medical Decision Making* 35 (6): 703–713.

Marcus, K.L., C.M. Henderson, and R.D. Boss. 2016. Chronic critical illness in infants and children: A speculative synthesis on adapting ICU care to meet the needs of long-stay patients. *Pediatric Critical Care Medicine* 17 (8): 743–752.

McKenzie, M.S., et al. 2015. An observational study of decision making by medical intensivists. *Critical Care Medicine* 43 (8): 1660–1668.

McPherson, M.L., et al. 2017. A decade of pediatric tracheostomies: Indications, outcomes, and long-term prognosis. *Pediatric Pulmonology* 52 (7): 946–953.

Namachivayam, S.P., et al. 2015. Five-year survival of children with chronic critical illness in Australia and New Zealand. *Critical Care Medicine* 43 (9): 1978–1985.

Nelson, J.E., et al. 2010. Chronic critical illness. *American Journal of Respiratory and Critical Care Medicine* 182 (4): 446–454.

Perri, G., et al. 2017. Left ventricular assist device as destination therapy in cardiac end-stage dystrophinopathies: Midterm results. *Journal of Thoracic and Cardiovascular Surgery* 153 (3): 669–674.

Peterson-Carmichael, S.L., and I.M. Cheifetz. 2012. The chronically critically ill patient: Pediatric considerations. Respiratory Care 57 (6): 993–1002 (discussion 1002-3).

Purkey, N.J., et al. 2017. Long-term pediatric ventricular assist device therapy: A case report of 2100+ days of support. *ASAIO Journal*.

Rady, M.Y., and J.L. Verheijde. 2014. Ethical challenges with deactivation of durable mechanical circulatory support at the end of life: Left ventricular assist devices and total artificial hearts. *Journal of Intensive Care Medicine* 29 (1): 3–12.

Rizzieri, A.G., et al. 2008. Ethical challenges with the left ventricular assist device as a destination therapy. *Philosophy, Ethics, and Humanities in Medicine* 3: 20.

Rose, E.A., et al. 2001. Long-term use of a left ventricular assist device for end-stage heart failure. *New England Journal of Medicine* 345 (20): 1435–1443.

Shapiro, M.C., et al. 2017. Defining pediatric chronic critical illness for clinical care, research, and policy. *Hospital Pediatrics* 7 (4): 236–244.

Sulmasy, D.P. 2008. Within you/without you: Biotechnology, ontology, and ethics. *Journal of General Internal Medicine* 23 (Suppl 1): 69–72.

van Manen, M.A. 2017. The ventricular assist device in the life of the child: A phenomenological pediatric study. *Qualitative Health Research* 27 (6): 792–804.

Wilfond, B.S. 2014. Tracheostomies and assisted ventilation in children with profound disabilities: Navigating family and professional values. *Pediatrics* 133 (Suppl 1): S44–S49.

Chapter 8
Critical Care Resource Utilization

Abstract Allocation of resources is frequently thought to be an issue in third world countries who may regularly struggle with limited resources. Resource allocation, however, may be frequently encountered within critical care units. The seemingly simple struggle with limited beds or limited medication supply can regularly require providers to make allocation decisions. Additionally, critical care units are always faced with the possibility of a sudden surge of patients through unanticipated mass casualty or natural disaster. The healthcare team and institution should have knowledge surrounding ethical frameworks for allocation of limited resources. The chapter discusses various mechanisms for decision making surrounding allocation of scarce resources for physicians, hospitals and policy makers.

8.1 Tough Roles and Tough Decisions

In August 2008, a devastating hurricane named Katrina struck the southeastern United States. Hurricanes are not uncommon, but typically have a less severe outcome. Perhaps this resulted in complacency in some, and many were caught off guard by the destruction that resulted from both the storm and the subsequent flooding. New Orleans, in particular, struggled with rescuing and providing resources for citizens stranded within the surrounding area. In her book *Five Days at Memorial,* author Sheri Fink discusses the struggles encountered in some of New Orleans' health care systems with allocation of medical treatment to those who were stranded within hospitals and nursing homes (Fink 2013). While both the book and media reports from the time focused primarily on adults, specifically the elderly, one must remember that critically ill infants and children were impacted as well. Fink recounts the experience of one neonatologist at Memorial Medical Center in New Orleans, in a situation where no critical care provider anticipates being:

> The babies waited for the Coast Guard helicopters in the covered tunnel, their incubators plugged into a power outlet supplied by a hospital generator. A neonatal specialist wearing green scrubs paced from the holding area to the helipad, growing increasingly worried as time passed. The babies were hot; one was having complications that might require urgent surgery. The neonatologist, Dr. Juan Jorge Gershanik, looked down at the water surrounding

L. Miller-Smith et al., *Bioethics in the Pediatric ICU: Ethical Dilemmas Encountered in the Care of Critically Ill Children*, International Library of Ethics, Law, and the New Medicine 77, https://doi.org/10.1007/978-3-030-00943-4_8

> Memorial and imagined what it would be like if all power went out. The children would be goners. It would be a death sentence. He felt like he was in a movie. (p. 89)

Dr. Gershanik approached the head of internal medicine to discuss using the small number of helicopters that were arriving at the hospital for his patients. Most of the pilots, while willing to rescue the elderly patients, were uncomfortable taking the critically ill neonates. The helicopters were unable to handle the technology these sick babies required, such as incubators and ventilators. There were no plans in place, the infants were without the resources they needed, and Dr. Gershanik had to make decisions quickly. He approached the pilot and helicopter with two of the sickest babies, taking them out of the incubators. He gave one to a nurse to hold, and took the other himself:

> Gershanik decided to take the risk. He climbed into the seat next to the pilot and cradled a six-week-old preemie wrapped in blankets in his arms. "Baby Boy S" had been born at twenty-four weeks with severely underdeveloped lungs and still weighed less than a kilogram. Gershanik dispensed rapid puffs of oxygen with squeezes of the reinflating bag, attempting to replicate the work of sophisticated machine that sent oscillating waves of oxygen into the baby's lungs… As soon as they lifted off, Gershanik grew afraid. A cold draft circulated through the helicopter, and he tried to shield the baby with his body. It was getting dark. He could easily, without knowing it, dislodge the tiny tube in the baby's windpipe… Did I make the right decision?
>
> For a moment, Gershanik considered the larger reality, the competing priorities that had emerged as waters suffocated an entire city. He was only doing what is ingrained in a doctor – advocating for his own patients – but now he saw that the struggle to save lives extended far beyond the two critically ill neonates in the helicopter, or Memorials' entire population of sick babies or even the whole hospital, much as it had seemed like the universe when he was back there. (pp. 94–95)

No critical care provider wants to be in those shoes. We are trained to quickly make medical treatment decisions in acute scenarios—when to intubate, what vasoactive agent to start, etc.—but not routinely trained in how to advocate for and allocate resources in disasters. We certainly must prepare for those potential catastrophic events, but literature and experience shows that critical care team members are also dealing with scarce resources on a more regular basis. This chapter will examine some of the ethics principles that should be used to guide these decisions.

8.2 Day-to-Day Decisions on Allocation

Many of us in modern healthcare systems would like to think that resources are relatively unlimited. This differs significantly from some developing nations where concerns about distribution of resources occur on a daily basis, including staff shortages, lack of necessary equipment, and inadequate funding to provide care to all of those who are in need. In those countries, difficult decisions regarding triage and resource utilization are made either according to written policy or through experience and unwritten cultural norms. These decisions ideally take into consideration

what is best for society as a whole, considering how resources can be used to help the most people. In systems such as in the United States, our practice is to focus on what is best solely for the patient, and we may not think about how these decisions impact the hospital and greater community.

If you look closer at our daily work, however, critical care providers make decisions about use of resources on a regular basis. This includes allocation of PICU beds, use of more limited technology such as ECMO pumps, and even distribution of medications that are currently on short supply. When the hospital has an extreme shortage of a certain antiepileptic medication due to a manufacturing issue, who gets it? Is it most just and equitable to continue normal practice until it runs out, or do you organize a multidisciplinary team to decide which patient would be best served by its use, and make others switch to a different medication or go without?

What if there is only one ECMO pump left in the hospital, and an infant is being born in the Fetal Health Center with diaphragmatic hernia and the surgeons are concerned about possible the need for ECMO. Simultaneously, a transfer request comes on a 17 year-old girl with severe respiratory failure on full ventilator support in a hospital without ECMO capabilities. Do you preserve the option for ECMO for the infant already in your hospital but not yet born and refer the teenager to an adult facility, or transfer in the patient because she needs the support now and deal with the infant's potential needs later? In many instances requiring acute decision making, it comes to the physician to decide who gets said resource. It is important to be able to allocate those resources appropriately and consistently.

Physicians, however, struggle with the thought of rationing resources. While some admit that allocation of scarce resources is part of their ethical obligation towards society, others argue that it is their professional obligation not to participate in rationing (Scheunemann and White 2011). There is a varying degree of ambivalence among physicians, with a systematic literature review on publications between 1981 and 2007 revealing a range of 9–94% in physician willingness to participate in rationing (Strech et al. 2009). Ward and colleagues conducted a survey in 2008 among adult intensivists revealing 61% of intensivists believe that they do not ration care and that they "provide every patient all beneficial therapies without regard to costs" (Ward et al. 2008). Even so, rationing is unavoidable within the ICU setting and physicians routinely ration their time and decide which patient to see first, how much time they spend with a particular patient, and how they balance work obligations with their family responsibilities (Scheunemann and White 2011).

Limitations on bed availability in ICUs is a common source of rationing decisions. When there is a patient who needs an ICU bed, and no bed to be offered, a rationing decision must be made. Physicians may not realize that they are doing so. Research on rationing of adult intensive care services has revealed that patients are sicker on both admission to and discharge from the ICU during times of bed shortages, their length of ICU stay were shorter, and fewer patients were admitted for monitoring. This suggests that in times of ICU bed shortages some patients are denied a potentially beneficial treatment to accommodate sicker patients. A review of over 10,000 adult ICU bed triage decisions throughout North America, Hong Kong, Israel, and Europe

also showed that 15% of those patients that were denied admission to the ICU were explicitly denied because of bed shortages (Scheunemann and White 2011).

Recent articles have specifically discussed the approach to allocation of pediatric ICU beds. In an article from Drs. Rubin and Truog, they discuss the challenge with "untangling the concepts of rationing and inappropriate treatments" (Rubin and Truog 2017). In their hypothetical scenario they describe limited bed availability, and one physician believes that patients receiving "futile" care are monopolizing resources that could be used on children who could better benefit from treatment. In working through this dilemma, the authors compare the two concepts of futility and rationing. They further clarify that rationing "requires a selection of the best distribution of limited resources based on a comparison of the needs of two or more patients or populations of patients, in situations in which all of the treatments are desired and may have some value in improving the health of the patients involved" (Rubin and Truog 2017). In other words, rationing is a deviation from our standard practice that is specific to unique circumstances. On the other hand, limiting futile or inappropriate treatments should be standard of care. Something being "futile" is not dependent upon availability. Something being "futile" is not dependent on someone else needing the resources. In rationing, all patients have the chance of benefiting to some degree. With futile treatments, the individual cannot benefit. The authors argue that institutional polices must be made for both (1) withdrawing/withholding futile or inappropriate treatments and (2) rationing of PICU resources, and the policies should be independent of one another.

In the article *Who Should Get the Last PICU Bed?* the contributing authors again discuss how to balance bed allocation between children already admitted to the unit, who have a low likelihood of survival, and children who will need surgical corrections of survivable lesions, but will require critical care management during recovery (Wightman et al. 2014). One of the authors advocates for using the AMA Council on Ethical and Judicial Affairs approach, taking into account five factors: (1) likelihood of benefit to the patient, (2) impact of treatment in improving the quality of life of the patient, (3) duration of benefit, (4) urgency of treatment, and (5) the amount of resources required for successful treatment. When patients are considered equal using these factors, then "first come, first served" approach is endorsed (Wightman et al. 2014; American Medical Association 1995). Another author contributes that "there is a concomitant need for explicit institutional guidelines that empower clinicians to make ethically defensible, transparent decisions about resource allocation" (Wightman et al. 2014). In short, physicians need to understand the ethical approaches to resource allocation, and their institutions need to have policies that support and defend their providers through these tough decisions.

Polices and plans must also be put in place by communities, cities, and states. Critically ill children will need to be triaged prior to hospital arrival whenever our emergency response systems are stressed by a particular event or outbreak. These issues were brought to the forefront due to the challenges encountered responding to the 9/11 terrorist attacks in New York, hurricane Katrina in New Orleans, as well as the 2009 Pandemic Influenza A/H1N1 outbreak (Kissoon 2011). These are very real occurrences that do not happen infrequently and just in the months prior to writing

this chapter, we have had hurricanes ravage through Texas, Florida, and Puerto Rico while a deadly mass shooting took place in Las Vegas, Nevada. Although to date there has not been an emergency in North America that has overwhelmed intensive care capabilities on a system wide basis, we must recognize that we may not be so fortunate in the future. Plans must be put in place by hospitals, cities, states as well as on a national basis of how best to prepare for these catastrophes.

The issue of allocating scarce medical resources has challenged physicians and policy makers throughout history and shocked society at times when it was felt to be done unjustly. This includes prioritizing soldiers over civilians for the use of penicillin in the 1940s, and Seattle committees using prognosis, current health, social worth and number of dependents to allocate dialysis machines in the 1960s (Persad et al. 2009). The importance of fair, sound, and feasible allocation criteria cannot be overstated and public trust, or at least acceptance, of any allocation procedure is imperative. There are several ethical principles that must be considered when planning for resource allocation and rationing of potentially beneficial treatments (Persad et al. 2009; Antommaria et al. 2010, 2011).

8.3 Ethical Approaches to Resource Allocation

Egalitarianism is the idea of giving everyone equal chance or equal opportunity for the scarce resource in question. While a lottery system is the best example of an egalitarian approach, it pragmatically quite challenging to implement in an ICU setting. Proponents of this strategy argue that it can be a quick method of allocation, it does not require significant knowledge of the patients, and it resists corruption. Disadvantages of the lottery allocation is that it ignores several morally relevant considerations, such as if a patient's illness or injury is beyond saving and thus giving the scarce resource to a person unlikely to benefit from it (Persad et al. 2009; Antommaria et al. 2011). The type of egalitarianism that is most frequently employed in healthcare is queuing, or "first come, first served". The American Thoracic Society supports this approach as a form of natural lottery (Persad et al. 2009). A benefit of this approach is that it protects preexisting doctor-patient relationships such that if a patient is already under your care there is ethical justification to maintain that relationship. So if a patient is already admitted to the PICU receiving technological support, they would not be displaced if a more severely ill child was in need (Persad et al. 2009; Antommaria et al. 2011).

Prioritarianism seeks to prioritize treatment towards a vulnerable population or those that are worst off. Treating the sickest first is also referred to as the "rule of rescue" and is based on our powerful impulse to save those patients that are facing imminent death, regardless of the cost of treatment or chances of benefit. This is the typical allocation method used in emergency rooms and large part of the allocation method used by the United Network for Organ Sharing in designating recipients for organ transplantation. The main criticism of this method of prioritization towards those that are the sickest ignores the impact or likely benefit of the intervention.

Some patients may be so sick that they are unlikely to benefit from the treatment, and thus a valuable resource has now been used up without benefitting anyone in the long run. This is why, for instance, the sickest first prioritization is modified during battlefield triage to also evaluate the patient's ability to benefit from treatment such that patients are selected for treatment if they are among the sickest *and* will likely survive because they are treated first (Scheunemann and White 2011; Persad et al. 2009; Burns and Mitchell 2011).

The "life-cycle principle" is another example of prioritarianism. This criteria advocates for prioritizing the young over those who are old as the younger generations have not yet had the opportunity to live through all the various stages of life. Proponents of the life-cycle principle do not argue that one generation is worth more than the other or that they are more useful when compared to other generations. Rather, they seek to give all people an equal opportunity for a full life, thus prioritizing the young who have not yet had a chance to do so. Some have referred to this as the "fair innings" perspective. A variation of the life-cycle principle prioritizes not just based on age but also based on how much society has invested in a particular person. This method would therefore prioritize an adolescent or young adult over an infant or child because of how much has already been invested in the patient's life in addition to how many years they have left to live. Just like treating the sickest first, the life-cycle principle ignores the prognosis of the patient and their likelihood to benefit from the treatment, thus potentially not utilizing the scarce resource optimally. Additionally, critics note the discrimination against older patients (Scheunemann and White 2011; Persad et al. 2009; Burns and Mitchell 2011).

Utilitarianism aims to maximize the benefits for as many people as possible on a societal level. Typically this translates to saving as many lives as we can which seems straightforward, but it can also refer to saving as many life-years as possible. This would mean saving a 10 year old who has decades ahead of him in yet-lived life-years rather than two elderly individuals in their 90s who are nearing the end of their life span. Going purely off number of years left-to-live, however, is not straightforward either as quality of life is felt to play an important role. Some have thus advocated for the use of quality-adjusted life years (QALYs) as a metric to use when evaluating and quantifying the likely benefit related to particular treatment. Allocation of the scarce resource can then be directed to maximize QALYs (Scheunemann and White 2011; Persad et al. 2009; Burns and Mitchell 2011).

Critics of utilitarian strategies and policy argue that this strategy is unfair towards those who are older. Focusing on QALYs ignores differences in quality of life that occur over time. There is also no consideration for how many people benefit from saving a certain amount of QALYs; i.e. whether 100 QALYs distributed between 2 people or 10 different individuals. Additionally, they also feel that the value of the individual is ignored and thus other potential societal benefits are ignored as most societal functions and responsibilities (including caring for children) are carried out by those who are older. Despite these criticisms, QALYs are used to guide decision making by the National Institute for Health and Clinical Excellence in the United Kingdom and to determine whether a particular treatment is cost-effective. Using cost considerations for clinical decision making in the United States remains a politically

charged discussion which in turn makes QALYs seldom considered (Scheunemann and White 2011).

Societal value criteria is a method of allocation in and of itself and supporters of this criteria argue that those patients that are contributing more to society should receive the scarce resource in question over those patients that are not contributing significantly. As mentioned above, there was significant public outcry in the 1960s after the public found out that societal value was being used to appropriate dialysis treatments for patients in renal failure such that professionals, church goers, and heads of households received priority over others (Scheunemann and White 2011; Persad et al. 2009). Critics state that this method of evaluating societal worth and value is inherently subjective, disregards different cultural values, and many even go so far as calling it ethically indefensible. The United States Congress eventually agreed with this outcry and passed legislature to guarantee dialysis to all patients through Medicare (Scheunemann and White 2011).

Still, some would argue that societal worth and contribution has to be considered in certain extreme cases such as large outbreaks or disasters, where the contribution of a particular individual has significant societal impact, such as a healthcare provider or a vaccine factory worker during an influenza outbreak (Scheunemann and White 2011; Persad et al. 2009; Antommaria et al. 2010; Burns and Mitchell 2011). This is sometimes referred to as the "instrumental value criteria", "narrow social utility" or the "multiplier effect". This shift of resources towards a particular field or personnel, such as public safety officers during times of unrest or sailors during a shipwreck, is not necessarily based on their inherent personal worth to society. Rather, we are hoping that by saving these individuals that they in turn can save others and thus "multiply" the resource they were given (Burns and Mitchell 2011). Critics point out, however, that this policy discriminates against children who are not employed and underestimates their value as society's hope for the future. It is also challenging to decide what personnel is essential and how many you need to carry out the required task which can make planning impossible. Finally, immunizations can allow health care workers to remain at work throughout a pandemic, but if we are truly allocating critical care resources, the recovery time for a particular health worker to return to work in time to aid others is likely to be too long to justify prioritization (Scheunemann and White 2011; Antommaria et al. 2011; Burns and Mitchell 2011).

Finally, *conservation of resources* is another criteria for consideration when allocating scarce resources. This particular strategy focuses on maximizing the available resources for as many people as possible such that resources are utilized in an efficient manner. Therefore, it gives priority to those patients that require smaller amounts of treatments compared to those that require extensive use of the scarce resources, such as fewer days on ventilator or shorter courses of therapy (Antommaria et al. 2010; Burns and Mitchell 2011).

Physicians, policy makers, and ethicists generally agree that individually none of these principles are adequate as they all miss an important consideration in some manner (Antommaria et al. 2011). Several policies and theories have been formed based on hierarchical arrangement and combination of individual principles to provide instruction on how resources are best allocated during times of true scarcity.

Examples of such policies include those for organ donation by the United Network for Organ Sharing (UNOS), World Health Organization's (WHO) endorsement of disability-adjusted life-year allocation (DALY), and the complete lives system.

The DALY allocation is similar to the United Kingdom's QALY criteria mentioned above in that it incorporates quality of life measures and disability when allocating scarce resources. Additionally it prioritizes those that are young as well as those that have instrumental value for society at large. This type of allocation seeks to maximize future benefits of society and productivity (Persad et al. 2009). The "complete lives system" was advocated by Persad et al. in 2009 as an alternative for just allocation of scarce resources. This system prioritizes the young who have not yet had an opportunity to live a full life but modifies that principle to prioritize teens and young adults over infants and young children due to magnitude of societal and personal investments in their education and upbringing. The "complete lives system" also considers prognosis, utilitarianism and finally instrumental societal value and lottery (Persad et al. 2009; Antommaria et al. 2011).

The UNOS policies weigh different criteria depending on what organ is being allocated and include criteria such as patient's time on waiting list (egalitarianism, queueing), severity of illness (prioritarianism), and prognostic information (utilitiarianism) among other criteria. UNOS explicitly recognizes that many patients will die before receiving an organ since rationing is necessary (Scheunemann and White 2011; Persad et al. 2009).

In 2014, the OPTN/UNOS Pediatric Transplantation and Ethics Committees updated their statement on allocation or organs for pediatric patients. The change officially came following the case of Sarah Murnaghan, a then 10-year-old girl with cystic fibrosis, who was dying awaiting lung transplantation. Her parents vehemently and publically questioned the organ allocation process, which precluded Sarah from being able to receive a donation from an adult donor. Although much thoughtful medical deliberation had gone into the allocation rules in place, the case tugged at the heart strings of the nation. Capitalizing on the human desire to rescue a child, the family started a media blitz and took legal action. A judge ordered suspension of the allocation rules, and seven days later Sarah had adult lungs transplanted. The organs quickly failed, and she was supported on ECMO until an additional set of adult lungs could be transplanted (McCullough 2018). The 2014 changes from the OPTN/UNOS committee recognized that "many stakeholders in transplantation feel particularly sympathetic to the needs of children." They justified changes to their allocation policy with the following concepts: (1) the Prudential Lifespan Account, which justifies prioritizing the young because of their increased contribution to healthcare/insurance resources, (2) the Fair Innings Argument, stating that every person deserves to live a full life, (3) the "Maximin" Principle, which gives priority to the most disadvantaged group, and (4) the concept of utility, measured by (some degree) of improved graft survival in younger patients (O.P.a.T 2014). In spite of multiple medical set-backs along the way, Sarah is alive and reportedly doing well today.

8.4 The Need for Polices Regarding Critical Care Resources

None of these policies are specific to utilization of critical care resources during times of surges in critically ill patients and fail to consider situations unique to the critical care environment. Policy makers on both the micro and macro level felt the need for such policies in light of continuing stressors on the system, whether it be through national pandemics, environmental disasters, or terrorist activities. Answering the call from the governments of Canada and US, in 2008 the American College of Chest Physicians (CHEST) Task Force for Mass Critical Care published its suggestions of how critical care resources can by extended to the adult population during a surge of critical illness for whatever reason (Devereaux et al. 2007, 2008; Rubinson et al. 2008). They suggested using an emergency mass critical care (EMCC) approach to increase by threefold the capabilities for critical care for as much as 10 days during times of significant public health emergencies. This involves delaying or canceling nonessential or non-urgent care while paying particular attention to immediately life-saving measures. Additionally, during times of crisis there should be a shift towards optimization of population outcomes, rather than those of a particular individual, by directing resources towards those patients most likely to benefit from them (Devereaux et al. 2007; 2008; Rubinson et al. 2008).

Initiation of triage and rationing of scarce medical resources should be done in cooperation with local and regional public health departments and medical emergency operations command. Potential triggers include lack of critical equipment, lack of critical infrastructure, inability to transfer patients, lack of specialty care and inadequate staffing. Additional conditions required include a declared state of emergency or incident of national significance and maximal efforts at conservation, adaptation, substitution and reutilization of resources (Devereaux et al. 2008).

The triage process itself should follow several important principles. First, hospitals must cooperate and be uniform in their approach to resource allocation. They must exhaust all other options including reaching their surge capacity or transferring patients to other institutions with greater capacity. Second, limitations of intensive care should be proportional to resource limitations. Third, allocation of critical care resources need to occur uniformly, transparently, and be based on objective medical criteria. Fourth, rationing of intensive care resources applies equally to withholding and withdrawing life-sustaining therapies, and finally, those patients that are not eligible for critical care shall continue to receive care through general medical support or palliative care (Devereaux et al. 2008).

Once these criteria are met, patients admitted to intensive care units must require ICU specific interventions such as mechanical ventilation or inotropic support. Those patients needing observation only should be diverted to other areas of the hospital. Additionally, in order to determine which patients are most likely to benefit from ICU care, the 2008 CHEST guidelines suggest using exclusion criteria based on severity of illness and underlying chronic condition. Thus, patients will be excluded from ICU care if they are at high risk of death and are unlikely to survive long-term, and thus unlikely to benefit from critical care resources (Devereaux et al. 2008).

They chose the Sequential Organ Failure Assessment (SOFA) score as a measure of patient's critical illness primarily based on its ease of calculation when compared to other scoring systems and validation across breadth of critical care conditions. A minimum of 80% risk of mortality was chosen as cut-off for exclusion from critical care resources. This could be met by a SOFA score >14 at any time, SOFA score >4 for at least five days with a rising or flat trajectory, and any patient with at least six organ system failures. Exclusion of critical care services based on chronic illnesses includes conditions such as metastatic malignant disease, end-stage heart failure, terminal liver disease, advanced untreatable neuromuscular disease, profound cognitive impairment, or patients over 85 years of age (Devereaux et al. 2008).

This triage system is based on the principle of equitable allocation of limited resources based on objective medical data rather than subjective decisions by health care personnel, leaders, or patients themselves. Therefore there is limitation of individual autonomy, rights and/or liberty when it conflicts with societal goals to minimize mortality or clinicians duty to provide medical care (Kissoon 2011; Antommaria et al. 2011). Transparency is emphasized, both on governmental and institutional level, as open communication should take place within the community in order to reach public agreement and support. Lastly, this triage system relies on utilitarianism and maximization of benefits to the population as a whole. When the objective data does not clearly differentiate between two patients, these guidelines recommend a "first come, first served" queueing for allocation of critical care resources (Devereaux et al. 2008).

The 2008 CHEST guidelines, however, were admittedly limited in their scope and did not include provisions for critically injured children, other vulnerable populations, nor mass critical care delivery in the developing world. In response, a pediatric focused EMCC (PEMCC) Task Force of 44 experts across a variety of fields was convened and they published their recommendations in Pediatric Critical Care Medicine in 2011 (Kissoon 2011). This task force recommends similar strategies for planning and preparation in pediatric hospitals as those suggested for adult hospitals, and additionally that non-pediatric hospital be prepared to care for children as well as adults, as children may be disproportionately affected (Kissoon 2011).

In contrast to the 2008 CHEST Task Force which was able to provide objective recommendations for triage of scarce resources for critically ill adults, the PEMCC Task Force was not. This is in large part due to the lack of a validated scoring system for critically ill children and subsequent reliance on expert opinion to determine prognosis and potential benefit from critical care support (Kissoon 2011; Antommaria et al. 2011). The SOFA score used by the CHEST Task Force has not been validated in pediatrics and pediatric scoring systems, including the Pediatric Index of Mortality and the Pediatric Risk of Mortality, are both complex in their calculation and also not applicable at the time of admission as predictors of individual mortality (Antommaria et al. 2011). Further research is necessary to develop objective scoring systems to aid with triage of critically ill children.

The PEMCC Task Force explicitly rejects any discrimination against children based on age and specifically rejects prior suggestions that resources be prioritized towards individuals between the ages of 15 and 40 years of age as in the "complete

lives system." Rather, the PEMCC suggests that in conditions where triage of critical care support must be done, resources should be allocated to critically ill patients based on their need, benefit, conservation of resources, and lastly lottery or queuing. Furthermore, they discourage any allocation based on the "complete lives system" or social factors such as gender, race, religion, ethnicity, sexual orientation, or ability to pay (Kissoon 2011; Antommaria et al. 2011).

The PEMCC Task Force also identifies the unique challenges, needs, and vulnerabilities of critically ill children, both from a physical health standpoint (i.e. hypothermia) as well as psychosocial standpoint in regards to their development and psychologic response. Family centered care may often meet the psychosocial needs of children, and is thus emphasized whilst recognizing that it may at times conflict with the needs of individual children (Kissoon 2011; Antommaria et al. 2011). Both the PEMCC Task Force and the CHEST Task Force emphasize the continued medical care of those patients not eligible for critical care support, and if curative therapies are not provided, those patients should receive palliative care. The CHEST Task Force emphasizes that euthanasia is never acceptable whilst the PEMCC Task Force considers it outside its scope to determine if euthanasia is justified in extreme circumstances (Kissoon 2011; Devereaux et al. 2008).

Since the initial CHEST Task Force guidelines were published in 2008, the Task Force has reconvened and revised its recommendations to include special populations such as those with disability or chronic medical conditions, pediatric patients as well as critical care delivery regardless of global location (Christian et al. 2014a, b; Biddison et al. 2014). These 2014 CHEST Task Force guidelines continue to suggest the careful use of inclusion and exclusion criteria to divert critical care resources towards those most likely to benefit from their use as "likelihood of medical benefit is the most ethically sound basis for triage" (Biddison et al. 2014). This includes exclusion of patients with low probability (<10%) of survival such as those with severe trauma, severe burns, severe and irreversible neurologic event, severe prematurity of <24 weeks gestation, and cardiac arrest. Additionally, both pediatric and adult patients with metastatic malignancies, hematologic malignancies with poor prognosis, end-stage organ failure with expected survival <1 year, and severe/advanced immunocompromised state such as drug-resistant AIDS should be excluded from critical care admission. They also exclude adults with very advanced age and children with congenital anomalies where expected survival is under 1 year (Biddison et al. 2014).

The challenges in accurately estimating the potential benefit to each individual patient are recognized again. This can be due to both inconsistencies when those estimates are based on clinical judgement alone, as well as lack of reliable scoring tools to predict mortality for individual patients. The previously used SOFA score has been found to vary in its ability to predict survival depending on the population, and thus cannot be used uniformly as exclusionary criteria across all adult patients. The 2014 CHEST Task Force emphasizes the importance of objective triage tools or scoring systems to provide prognostic information for individual patients and recommends that prognostic scores should be able to reliably predict mortality with

a starting threshold of >90% mortality. However, there are no such scoring tools currently available (Biddison et al. 2014).

The threshold of 90% mortality as exclusion criteria for ICU admission may have to be adjusted up or down depending on available resources in order to provide care to as many as possible. Also, reassessment of patient condition every 72 h is recommended and if at that point the patient meets exclusion criteria for ICU care, then consideration should be given to withdrawal of life-sustaining therapies. Most ethicists agree that withholding and withdrawing life-sustaining therapies is ethically equivalent, however, withdrawal of life-sustaining therapies due to triage conditions represents a significant alteration in standard of care and thus must be carefully considered when necessary (Kissoon 2011; Biddison et al. 2014). Other alterations from standards of care in crisis situations where emergency mass critical care has been implemented also includes limiting therapies that are considered extraordinarily expensive or consume tremendous amounts of resources in terms of staff or equipment. This may include advanced therapies such as inhaled nitric oxide, prone-positioning, high-frequency oscillatory ventilation, and extracorporeal membrane oxygenation (Biddison et al. 2014).

The 2014 CHEST Task Force points out the near complete lack of data and evidence behind their recommendations for triage of critical care services and suggest that critical care triage should be avoided if at all possible. Instead, mass critical care strategies should be implemented, and hospitals and communities should be prepared to react at a moment's notice. They again emphasize the ethical theories of justice and utilitarianism combine to provide the most equal system that provides benefit for the maximum number of patients possible (Biddison et al. 2014): There are deep moral tensions that arise when we try to balance egalitarian and utilitarian principles with our desire to respond to those in need and individual autonomy (Scheunemann and White 2011). This applies equally to times of sudden surges in critical care patients through natural disasters, terrorism, and pandemics; as well as to the day-to-day activities of critical care physicians struggling with chronic ICU bed shortages that require careful allocation to those in need.

Sprung and his colleagues also demonstrated the challenges and inconsistencies amongst ICU physicians in balancing equity and efficiency when it came to allocating ICU beds amongst current and prospective patients. Physicians seem willing and able to make broad generalizations about triage and want explicit guidelines for the triage process, however, they are less willing to make specific decisions about individual patients or accept concrete suggestions for how these guidelines should be structured (Sprung et al. 2013). These issues surrounding critical care triage will undoubtedly remain a challenge the critical care community as we continue to address daily shortages and also prepare for critical care surges of more massive proportions that could outpace our current capabilities.

References

Antommaria, A.H., J. Sweney, and W.B. Poss. 2010. Critical appraisal of: Triaging pediatric critical care resources during a pandemic: Ethical and medical considerations. *Pediatric Critical Care Medicine* 11 (3): 396–400.

Antommaria, A.H., et al. 2011. Ethical issues in pediatric emergency mass critical care. *Pediatric Critical Care Medicine* 12 (6 Suppl): S163–S168.

Biddison, L.D., et al. 2014. Ethical considerations: Care of the critically ill and injured during pandemics and disasters: CHEST consensus statement. *Chest* 146 (4 Suppl): e145S–e155S.

Burns, J.P., and C. Mitchell. 2011. Resource allocation and triage in disasters and pandemics. In *Clinical ethics in pediatrics: A case-based textbook*, vol. xiv, p. 248, Cambridge: Cambridge University Press.

Christian, M.D., et al. 2014a. Introduction and executive summary: Care of the critically ill and injured during pandemics and disasters: CHEST consensus statement. *Chest* 146 (4 Suppl): 8S–34S.

Christian, M.D., et al. 2014b. Triage: Care of the critically ill and injured during pandemics and disasters: CHEST consensus statement. *Chest* 146 (4 Suppl): e61S–e74S.

Devereaux, A., et al. 2008a. Summary of suggestions from the task force for mass critical care summit, January 26–27, 2007. *Chest* 133 (5 Suppl): 1S–7S.

Devereaux, A.V., et al. 2008b. Definitive care for the critically ill during a disaster: A framework for allocation of scarce resources in mass critical care: From a task force for mass critical care summit meeting, January 26–27, 2007, Chicago, IL. *Chest* 133 (5 Suppl): 51S–66S.

Ethical considerations in the allocation of organs and other scarce medical resources among patients 1995. Council on Ethical and Judicial Affairs, American Medical Association. *Archives of International Medicine* 155 (1): 29–40.

Fink, S. 2013. *Five Days at Memorial: Life and Death in a Storm-Ravaged Hospital*. New York: Crown Publishers.

Kissoon, N. 2011. Task force for pediatric emergency mass critical care. *Pediatric Critical Care Medicine* 12 (6 Suppl): S103–S108.

McCullough, M.A. 2018. Historic adult-to-child lung transplant saved their daughter, who's now a thriving teen. The Inquirer.

Organ Procurement and Transplantation Network. (2014). Ethical principles of pediatric organ allocation. Available from https://optn.transplant.hrsa.gov/resources/ethics/ethical-principles-of-pediatric-organ-allocation/.

Persad, G., A. Wertheimer, and E.J. Emanuel. 2009. Principles for allocation of scarce medical interventions. *Lancet* 373 (9661): 423–431.

Rubin, M.A., and R.D. Truog. 2017. What to do when there aren't enough beds in the PICU. *AMA Journal of Ethics* 19 (2): 157–163.

Rubinson, L., et al. 2008. Definitive care for the critically ill during a disaster: A framework for optimizing critical care surge capacity: From a task force for mass critical care summit meeting, January 26–27, 2007, Chicago, IL. *Chest* 133 (5 Suppl): 18S–31S.

Scheunemann, L.P., and D.B. White. 2011. The ethics and reality of rationing in medicine. *Chest* 140 (6): 1625–1632.

Sprung, C.L., et al. 2013. Triage of intensive care patients: Identifying agreement and controversy. *Intensive Care Medicine* 39 (11): 1916–1924.

Strech, D., et al. 2009. Are physicians willing to ration health care? Conflicting findings in a systematic review of survey research. *Health Policy* 90 (2–3): 113–124.

Ward, N.S., et al. 2008. Perceptions of cost constraints, resource limitations, and rationing in united states intensive care units: Results of a National survey. *Critical Care Medicine* 36 (2): 471–476.

Wightman, A., et al. 2014. Who should get the last picu bed? *Pediatrics* 133 (5): 907–912.

Chapter 9
Pediatric Organ Donation and Transplantation

Abstract Organ donation and transplantation is an important component of pediatric critical care. In the United States, over 100 children die annually while listed for organ transplantation, while others are too sick to be listed. The pediatric intensivist strives to ensure one of her patients is not among those, through both excellent clinical care and through advocating for organ donation. However, the intensivist must be aware of some of the ethical concerns that are present with organ donation. With donation after circulatory determination of death (DCDD) there continues to be question of when death has actually occurred, with many arguing that Uniform Declaration of Death Act's definition of death may not have been achieved at the time of organ harvest. This would violate the Dead Donor Rule, that only organs may be harvested from dead patients. Additionally, there are practices within organ donation that are viewed as treating the patient as a means to an end, other than their own well-being. While many argue this is an altruistic goal we should all share, others argue that it should not be imposed upon a pediatric patient. Organ allocation also has ethical concerns, about selection criteria for appropriate recipients to ensure we are being the best steward of a valuable and limited resource. These allocation decisions may impact our patients awaiting transplantation. Organ donation and transplantation serves the greater good of patients and society, but we must recognize some the ethical concerns to ensure each patient is being treated with respect.

9.1 The Growing Need for Organ Donation

There are an increasing number of pediatric patients being placed on the waiting lists to receive solid organ transplantation. Unfortunately, there are a limited number of organs available, and the numbers of donors per year is rather stagnant, not increasing at the same rate as the waiting list grows. Some of these patients with end-stage organ disease may be awaiting transplantation in the critical care setting, requiring attentive medical management. But the potential donors are also our patients, requiring equally attentive management in their end-of-life care. This chapter will address actual and

L. Miller-Smith et al., *Bioethics in the Pediatric ICU: Ethical Dilemmas Encountered in the Care of Critically Ill Children*, International Library of Ethics, Law, and the New Medicine 77, https://doi.org/10.1007/978-3-030-00943-4_9

perceived ethical barriers encountered with organ donation and transplantation, with discussion on how to navigate what may seem to be potentially conflicting goals.

As of 2017, there were over 116,000 patients in the United States actively listed to receive an organ for transplantation. Nearly 2000 of those were infants and children 17 years of age or less. The largest need is for kidney transplantation, followed by liver and then heart. The number of pediatric patients transplanted from the list varies from 61.4 to 80.6%, with the likelihood of receiving a transplantation increasing with recipient age. While patients may be removed from the list due to medical stability or recovery, they may also be removed because they are deemed too ill to survive transplantation or due to death while waiting. In 2017, 6289 deaths occurred while on the list, with 126 of those being children less than 18 years of age. Additionally, 58 children were removed from the list due to clinical decline as they were thought to be too sick to transplant (U.D.o.H.a.H.S. 2018). The presumption is that these children also died. Infants have the highest wait list mortality due to size limitations and organ availability (Workman et al. 2013). Physicians, nurses and other healthcare workers, who have committed their careers to providing care to critically ill children, will very likely recognize that advocating for organ donation will benefit a demographic of patients they are aiming to cure.

However, the same healthcare team that is hoping for the offer of a life-saving organ for their patient may also be taking care of patient whose death is imminent. The patient may soon be declared brain dead, or perhaps die following the decision to withdraw technological support. Either way, the parents will have the predictable question of "what happens next?" The team recognizes that they must help parents navigate through not only the uncertainties of a future without their child, but also the practical decisions that must be made. Organ donation has become part of those required discussion points. The healthcare team must create processes and strategies that allows them to best care for both of these patient populations, without biases impacting the parent's decision to consent to donation of their child's organs.

9.2 Pediatric DCDD and DNDD

Organ donation, or at least the discussion thereof, has become an expected component of end-of-life decision making for patients. Pediatric living donation is rare (and will be discussed more thoroughly later in the chapter) making donation from pediatric donors almost exclusively a decision at the time of their death. The United Kingdom, through its National Institute for Health and Care Excellence (NICE) clinical guideline on organ donation, states that "organ donation should be considered as a usual part of 'end-of-life care' planning." (N.I.f.H.a.C. 2017). Likewise, the United States' Centers for Medicaid and Medicare Services mandates that hospitals with donation programs notify the organ procurement organization of all potential donors. Ensuring that patients or surrogates are offered the opportunity to donate has become a responsibility of the hospital and health care team. In the United States, this occurs in collaboration with the local Organ Procurement Organization (OPO).

Pediatric donors have the potential to follow two different procedures for organ donation, based on how their death was determined: Donation after Neurologic Determination of Death (DNDD) or Donation after Circulatory Determination of Death (DCDD). With DNDD cases, the patient is declared brain dead following accepted medical standards. Specifics on determinants of brain death are discussed in Chap. 5. Following declaration, while the body is still supported, the family is given the opportunity to donate organs. The donor may then be taken directly to the OR on full medical technology for organ retrieval, minimizing tissue ischemic time.

DCDD donations are strikingly different. Patient families are typically approached about donation potential following their decision to withdraw medical technology, but prior to the death of the child. Once consent is obtained, the timing of withdrawal is determined by when a receiving surgeon/transplant team can procure the organ(s). Technology, typically mechanical ventilation, will be stopped. This is usually done in the operating room itself, or within close proximity. Death must occur by loss of circulation within a set time frame, typically between 30 and 60 min depending on institutional or OPO policy. When circulation is lost, the physician will declare death with a subsequent observation period, typically of 5 min as advocated by the Institute of Medicine in 1997 (I.o.M.C.o.H.C. 1997) but with much variation among institutions and internationally. Should no return of spontaneous circulation occur during that waiting period, organ procurement may occur.

By many accounts, DNDD is the more desirable path towards donation. DNDD allows for transplantation of the most viable organs, as the major solid organs can be maintained with full circulation and ventilator support. This allows time for recovery from insufficiency of organ function that occurred from the initial insult. For example, a patient dying from traumatic brain injury may also have organs with contusion or hemorrhage that will recover to full viability in the time it takes to declare brain death and place organs for transplantation. Additionally, it allows time to find the optimal recipient. The organs do not go through a period of anoxia seen with DCDD, preserving post-transplant function, and allowing for transplantation of those organs which are most susceptible to anoxic injury. Donation after brain death is also widely considered less burdensome to the family. There is no decision to be made about withdrawing life-sustaining therapy, as the decision to donate typically occurs after death has been declared: the child dies, the family consents to donation, and stopping the ventilator and medication is done at the time of organ removal.

With DCDD cases, although the goal is that the family has decided to withdraw support independently from any consideration of organ donation, the timing of withdrawal, and therefore the timing of death, is coupled with donation. While parents may set deadlines for how much time they will allow to transpire prior to withdrawal, many are willing to wait until the organs are placed and receiving surgeons are available. Therefore, the final decision about removing medical technology is tightly linked to the subsequent step of organ donation. The goal of end-of-life care shifts its focus from being solely upon the patient and their family, to including the goal of maximizing the outcome from transplantation. This paradigm highlights the struggle that some practitioners experience with organ donation.

9.3 Does the Pediatric Donor Benefit from Organ Donation?

Some believe that seeking organ donation conflicts with the health care provider's primary responsibility to only seek what is in the patient's best interest. In cases where a patient has previously expressed interest in organ donation, the conflict is laid to rest. In pediatric patients who may have never reached capacity to make those decisions, there is inherent tension. When are the providers, or the patient surrogates, foregoing their responsibility to pursue the best interest of the patient in preference of the best interest of the recipient, or of society as a whole? The issue is further complicated by some donation processes which may theoretically bring harm to the donor.

Organ donation does not serve the patient. The only potential benefit to the organ donor is that of beneficence for another human being. For pediatric donation, the donor will not be able to, or have been able to, appreciate that benefit. Uncommonly, a more mature pediatric patient may have the capacity to request organ donation, either as a theoretical possibility or as part of their own end-of-life planning. In these situations, organ donation may be serving their goals of being an altruistic individual who helps save the life of others. Most pediatric donors have not reached this level of understanding, nor have they had the opportunity to engage in this conversation. Therefore, organ donation serves the needs only of others: the transplant recipient and potentially the donor's family.

Organ donation can certainly be a benefit to the donor's family. Many see this step as a potential silver-lining to the horrific loss a family has experienced. Organ donation can allow the family to feel a sense of altruism, and to a degree that many people do not have the opportunity to obtain. They have the ability to be a part of saving the lives of others. Additionally, the family may benefit from knowing that their child's life has not ended "in vain." They may believe that their child is given the opportunity to make a significant impact on society, which they may not have been able to do during their shortened lives.

Organ donation benefits society through distributive justice. It is valued by society to know that there are mechanisms in place that will allow rescuing of a suffering member, who is in need of a valuable and limited resource. The sense of duty to rescue others within a community is an important component of a functioning society. It is the reason news viewership increases during challenging rescues of a child in a well or a soccer team stuck in a cave. We watch as a large number of resources are provided to a specific individual or small group. Why do we not question this resource allocation? While we hopefully want well for the specific individual, we also want to know that resources would likewise be spent on ourselves should a harrowing situation arise. Knowing that this is how our society functions, we will be more likely to give back and contribute in a meaningful way. Organ donation fulfills this duty to rescue. A society where gifts of organs and tissue are given to others confirms that we live in a community which takes care of one-another. But we must have confidence that these altruistic acts do not come at too high of a cost.

So that is now the question: If organ donation does not benefit the donor, does it cause harm? If a patient is donating organs following death declared by neurological criteria, then death has already occurred while the body is still receiving medications or treatments that are being used specifically to maximize organ donation potential. For example, performing a bronchoscopy specifically on a brain-dead patient to determine suitability of lungs for donation will not benefit that patient, but it (or any potential consequences) will not harm the patient because he has already died. If the lungs can be optimized for donation, and therefore result in the survival of another human being, it is thereby justified. But what if the patient is not yet dead when interventions are being sought that are specific for organ donation?

This is exactly the conundrum encountered with donation after cardiac declaration of death, or DCDD. Some DCDD protocols will require, or at least the organ procurement organization will request, interventions upon the patient prior to their declaration. Examples of this may include a bolus of heparin that requires a beating heart to circulate. While the heparin will prevent thrombosis in the vasculature and organs to be transplanted, and therefore benefit the recipient, it does not benefit the donor. It can, however, theoretically place the donor at risk for hemorrhage in the last stages of their life. Additional requests have included placement of an arterial line for exact timing of both warm ischemic time of the organs and of death. There may be a request to initiate a peripherally acting vasoactive medications to improve organ perfusion. Again, while this may increase likelihood of the organs being accepted by a transplanting surgeon and benefit the recipient, putting an alive patient through a procedure or medication that does benefit them, and could possible result in iatrogenic harm, has been argued to be ethically unacceptable.

In the adult patient who may have preemptively vocalized their desire to donate organs, you can ethically justify these risks because they are balanced with honoring the patient's autonomy and values, and these interventions maximize the opportunity for the latter. But in the pediatric patient, are we really serving their best interest, or the understandable desire of their parents to have some good come from tragedy? Hoover et al. in 2014 did a qualitative analysis of interviews with parents surrounding their experiences with DCDD. One parent stated, "I mean she meant a great deal to us, and I loved her with everything in me, but I wanted her to be able to make more of an impact on somebody else's life by being able to donate, something that would save somebody, you know?" Another parent stated, "That was largely my reasoning for organ donation, because I was going to make sure that something good could come out of a tragedy." (Hoover et al. 2014). Some worry that statements like these indicate that parents are using the child as a means to an ends (Overby et al. 2015). Subconsciously, this bias may impact providing consent for interventions that do no benefit the child (arterial or venous catheters, heparin blouses, etc.) or even impact the timing of withdrawal of technology. Instead of timing the withdrawal of technology to be the optimal time for the patient, or even for the family, it is now the optimal time for unknown organ recipients.

The counter argument is the parents or surrogates are the best at predicting what the patient would want for themselves had they been able to grow and mature to full capacity. They would most likely take on the values that are reflected by their family;

if the parents would want organ donation, then we assume that the patient would most likely also desire this. The parents, knowing their child's own values and beliefs, may be the best to speculate on what their child would want, even if it deviates from what they would choose. Indeed, this was another factor highlighted in Hoover's study on parents' decision making. One parent who consented to DCDD stated "I think this is what she had wanted me to do for her." And a mother who declined for her adolescent son reported "… had he never said anything about that, I would have done it, and I would have felt fine with it. But then again he said that [he did not want to donate] and I don't think that I could have lived with, you know, with that decision." (Hoover et al. 2014). We use this same rationalization for most interventions we do on our critically ill patients. We allow parents to consent for their children to have tracheotomies, or to be placed emergently on ECMO, or to receive experimental treatments. There are potential risks and harms to these interventions, but we allow parents to take on those risks for their children to achieve a desired end. Why can't organ donation be such a desired end, when the fate of their child has already been decided?

The other argument made by De Lora is that DCDD is based in the best interest of the pediatric donor, "the interest of posthumously being regarded as an altruist individual who helped to save the lives of others." (De Lora 2015). He states that the act of donating organs may be a way of rescuing an individual from an existence without significance. A child who has not lived long enough to have a significant life accomplishment may do so through the act of donation. But not everyone expresses the inherent interest in being an altruistic individual, particularly when it is balanced with potential harm to themselves. This is reflected in what a parent (or any adult) would choose for themselves. Studies have shown a wide variation on willingness or interest in organ donation among adults. Numbers as low as 48% in Greece (Georgiadou et al. 2012) and up to 80% in the United Kingdom (Webb et al. 2015) have been reported of adults willing to consent to donation. Individuals with full capacity (although perhaps with incomplete information on the process) do not indicate that this a universally sought-after interest. It is, therefore, likely inappropriate for us to assume that all our pediatric patients would inherently want this.

Of course, there are those who see organ donation as being inherently good, and perhaps a good that trumps other competing interests. Organs are indeed a very limited resource, and organ donation will save another human being's life. While an individual may have personal religious, or spiritual reasons for wanting their body fully intact following death, most religions do not consider this a necessity. Therefore, the burial or cremation of a life-saving resource can be seen as an injustice to society. Some cultures, in fact, have decided to institute an "opt-out" policy regarding organ donation.

Spain adopted a policy of presumed consent back in 1979 (Matesanz et al. 2011). If there is no clear evidence of refusal from a patient, then it is presumed that they would want organ donation. Spain, at 40 donors per million population, is the international leader in donation (Matesanz et al. 2017). Other countries, including recently Wales in 2015, have moved towards a similar policy (Noyes et al. 2017; Kendall-Raynor 2016). Individual states within the US have also considered legislation to change to

an "opt-out" system, although this legislation has not passed. In "opt-out" systems, families of donors still have the potential to refuse, and those refusals are respected. Because of that, many argue that the differences between opt-in and opt-out policies are not entirely different. At the end of the day, the family still gets to decide. It is, however, likely other co-existing factors that play into Spain's success. A big contributor may be the increased knowledge about and awareness of organ donation within a society that accompanies such a policy.

These types of programs may not explicitly seem to impact pediatric patients, as the pediatric donor has not had the opportunity to vocalize a desire to opt-in or opt-out at all. In almost all situations, the parents are speculating upon what their child would want, or they are just applying their own values. Opt-out systems, however, could potentially impact pediatrics through an increase in available organs overall, as organs from adults can be transplanted into teenagers and larger children. This increased overall availability can shift allocation practices and increase access of children to life-saving organs.

9.4 Dead Donor Rule

It is accepted that organ donation should not be causative of death in a patient. Some worry that DCDD violates this dictum. As discussed in a previous chapter, the definition of death in the United States is laid out in the Uniform Declaration of Death Act (UDDA) that highlights that death, both by circulatory and neurological criteria, requires irreversibility. However, with modern medical technology, circulatory arrest may not be irreversible for many minutes, certainly within 30 min. Although the ultimate outcome of the patient following return of spontaneous circulation after a 30-min cardiopulmonary arrest may be less than ideal, it is still possible for lack of circulation to be reversed. Therefore, if organs are removed from a patient who has had lack-of-circulation for a period of time during which circulation COULD have been reversed, but the organ retrieval is what makes lack-of-circulation irreversible, is the donation itself the cause of death?

In 2007 a medical story played out in Aurora, Colorado, that would be later recounted by multiple news agencies. It's the type of story that brings bittersweet tears to the eyes of those who hear it. The sadness of something lost, the beauty of something gained, and the sense that a miracle brought goodness from tragedy. A newborn girl, Addison Grooms, was born with a severe brain injury that was not considered to be compatible with life. Her parents agreed to donation of organs after their planned withdrawal of medical technologies. As her mother would later state, "The reality was Addison was not going to live … As difficult as that was to hear, this opportunity [to donate] provided us with a ray of hope." (Nano 2018). The heart was transplanted into another Colorado baby, a 5-week old male born prematurely with congenital heart disease and would likely have died without the gift of an organ. At 21-months of age, the baby's mother reported that "He's just a crazy little kid who loves to play and swim and throw rocks." (Nano 2018).

On first blush, it may be surprising for some to hear that this story and the two other cases reported with it, would stir much debate within the organ transplantation community. These donations pushed the envelope on what is accepted within DCDD cases. Following loss of circulation, the patients were observed for as little as 75 s for possible autoresuscitation prior to beginning organ harvest (Boucek et al. 2008). The standard practice in the United States was a minimal 5-min observation period, which was already in stark contrast with some cultures worldwide who suggest up to a 20-min observation period. While the 75 s period was likely pivotal to the survival of function of the myocardial tissue, it was creeping precariously closer to a period of potential spontaneous return of circulation. Return of spontaneous circulation has been reported up to 60 s following death declaration (Boucek et al. 2008). If spontaneous return may occur, then the loss of circulatory function may not yet be irreversible. Therefore, if the loss of circulation is not irreversible, then by the definitions put forth by the UDDA, some would argue that death has not yet occurred. Further, if the harvesting of organs is what made the loss of circulation irreversible, then those who very strictly interpret the "irreversibility" component of the UDDA may conclude that the donation of organs is what caused the patient's death. This is in direct violation of the Dead Donor Rule.

The Dead Donor Rule (DDR) is the ethical norm that organs shall not be removed from a donor prior to their death. This norm has been widely accepted, frequently without any legal statute in place, for many decades. It is based on the same principle that opponents to euthanasia utilize: a physician should not cause the death of their patient. It has appeared self-evident to many that removing vital organs, and subsequently causing the patient's death for the benefit of another, is violation of the doctor-patient relationship. Many find value in the DDR as a protective barrier between end-of-life issues and organ donation, preventing the organ donor from being used as a means to benefit another, a direct violation of Kantian ethics. To do so would not be in the donor's best interest and would be devaluing them as a human being.

Some, although very few, argue that the Dead Donor Rule should be abandoned. Truog and colleagues advocate for eliminating the DDR (Truog et al. 2013). The argument is that brain death is not valid because the patient is able to maintain integrated functioning of organs and homeostatic balance for years, if not indefinitely, as long as they remain supported medically. Additionally, he is troubled by the compromise that organs may be harvested as soon as 2 min following loss of circulation, although irreversibility has not yet been lost. In short, he calls the compromises we are willing to make during the processes of DNDD and DCDD ethically acceptable "medical charades." However, instead of arguing that organ donation should be halted altogether because of these concerns, he argues that the principles of autonomy and non-maleficence should prevail. We should honor people's decisions to donate organs, even if it is prior to their death. Since the patient's death is imminent through withdrawal of therapies, the organ donation would not be adding additional harm (Truog et al. 2013). Changing this practice, as Dr. Truog recognizes, would require changes to our existing laws on homicide. Considering the challenges within the United States for physician assisted suicide to be legalized, it is hard to

imagine that retrieving vital organs from living patients will be allowed anytime soon on consenting adult patients, much less for pediatric patients.

Interestingly, it is a bit unclear what the general public's view point is upon the DDR. Many have made what seems to be a reasonable assumption that society at large would not accept the concept. Magnus et al. claim that, in regards to abandoning the DDR, "whatever the merits of the arguments for it as a philosophical position, it is far out of touch with … public opinion." (Vernez and Magnus 2011). One survey conducted in 2014 seems to counter that argument. An internet survey of over 1000 participants was conducted, giving hypothetical scenarios of organ donation from a patient with irreversible coma, but not brain death:

> Jason has been in a very bad car accident. He suffered a severe head injury and is now in the hospital. As a result of the injury, Jason is completely unconscious. He cannot hear or feel anything, cannot remember or think about anything, he is not aware of anything, and his condition is irreversible … Although he will never wake up and cannot breathe without the support of the machine, Jason is still biologically alive.
>
> Before the injury, Jason wanted to be an organ donor. The organs will function best if they are removed while Jason's heart is still breathing and while he is still on the breathing machine. If the organs are removed while Jason is still on the machine, he would die from the removal of organs (in other words, the surgery would cause Jason's biological death). (Nair-Collins et al. 2015)

Seventy-one percent of individuals surveyed stated that it should be legal for Jason to donate organs in this type of scenario, 67% said they would want to donate their organs in this type of scenario, and 72% said they would be willing to donate their loved ones organs in such a scenario, as long as the expressed desire to do so was clear (Nair-Collins et al. 2015). Responses, however, were not always consistent when verbiage was changed, possibly reflecting some confusion among participants, or a struggle to deal with competing issues. Either way, there does seem to be some willingness from society to, at a minimum, engage in these conversations.

Pediatric cases are not discussed in this survey. When the emotions of the loss of a child are at hand, it may seem less likely that a parent would agree to donation of organs in a child that is still biologically alive. No surveys exist on this subject. One story from parents following a failed attempt at DCDD, however, sheds light on how some parents may view the rules surrounding the norm that organs may only be retrieved following death:

> On January 13, 2008, a dying but not dead organ donor was brought to the OR and prepped for withdrawal of support in the first time in the hospital's history. Holley and Paul layer in their daughter's bed and played Jaiden's favorite Miley Cyrus song as the breathing tube was removed. They held their daughter and waited … Though her gasps were irregular, Jaiden did not stop breathing entirely. After an hour her heart hadn't stopped beating, and, in this situation, the hospital protocol called for the patient to be returned to the intensive care unit. The chance to donate her organs was over. Jaiden continued to take shallow breaths into the next morning, and then her heart finally stopped. She was legally dead. "It was so hurtful that she died so soon after," [her mother] said, disappointed that her organs died with her.… [Her father] had a hard time understanding why, if Jaiden was going to die anyway, she could not have been put under general anesthesia, undergone surgery to donate her organs, and then been pronounced dead. (Sanghavi 2009)

The story is gripping, and the parents' viewpoint warrants consideration. However, we are far away from throwing in the towel on the dead donor rule. While there are certainly physicians and philosophers who see our requirements for death declaration as being artificial constructs, and therefore reasonable to allow families to make decisions that the father above would have been willing to make, most agree that to abandon the dead donor rule would undermine society's faith in health care and be devastating to organ donation programs.

Rather than abandoning the DDR, the more practical take-home message from Jaiden's story is the importance of being very clear with families about the requirements for DCDD, and the possibility that their child will not meet those requirements. Parents who consent to DCDD, and then have children who cannot donate, may experience a secondary loss. They may have transferred all their previous hope in the recovery of their child to the hope of their child saving the lives of others. Should this fail, there is additional grief experienced. All efforts should be placed in fully informing the family about the time frame and expectations and providing further emotional support following the donation attempt.

9.5 Challenges with Decoupling Donation from Death

With the definition of neurological determinants of death by the Harvard Committee in 1968 being so closely linked with a concurrent need for organ donors, determination of death and organ donation have been associated for decades. Additionally, medical societies urge that organ donation be normalized as part of end-of-life discussions. For pediatric intensivists, who traditionally desire to take ownership of discussion surrounding end-of-life planning with their patients, it may feel necessary or appropriate for them to discuss the possibility of donation with their patients' families.

Even as the normalization of organ donation as an end-of-life issue is encouraged, others simultaneously stress the importance of the healthcare team striving to separate decisions surrounding end-of-life from the decision to donate. On one hand, we are asked to ensure that the opportunity to donate organs exists for every patient. On the other, we are asked to ensure that the possibility of organ donation is not influencing end-of-life planning. This can be a challenging line to walk.

The approach of parents and guardians for consent for organ donation can be a difficult conversation to navigate. Hospitals, in association with the local organ procurement organization (OPO), may have agreed on various rules to guide these conversations to maximize the organ donation conversion rate. In some facilities, it may rest with the healthcare team to be the first to mention organ donation. In other facilities, it is agreed that organ donation may only be first mentioned by a designated requestor, or one who has gone through formal training about how to approach families about this topic. There are benefits and potential issues with either approach. The former process allows the pediatric intensivist, who in the modern era focuses on transparent and shared decision making, to honestly put forth a potential

next step for the patient and family. However, some worry that it may be perceived as the physician putting the needs of potential recipients ahead of her patient. The latter process allows a separate entity, who has expertise in communication surrounding organ donation, to approach the family. This ensures that the physician remains perceived as focusing solely on the care of the patient. But the reality is that the physician and the designated requestor are commonly having conversations about the family approach outside of the room. The timing of the approach is also closely controlled. Many hospital agreements with OPOs clearly outline when the OPO will be called about a patient and when they come on site. They frequently review patient data prior to a patient's death to determine eligibility, and ensure they are available to enter the room once brain death is declared. Following an effective request process has demonstrated an increase in consent for organ donation. When families are approached at an appropriate time, and given full information from a knowledgeable source, they are more likely to agree to donate (Siminoff et al. 2013). Even when physicians do not mention organ donation, purportedly uninvolved from the family perspective, they are actively engaged in the conversation.

Should we pretend to families that end-of-life decision making and organ donation are completely separate, or should we attempt to educate families, and society at large, on how they go hand-in-hand? Is it deceptive and secretly patronizing to imply in actions to a family that conversations about organ donation do not occur until after death, when the OPO has been contacted long-before death occurs, and is likely on site at the hospital at the time that death is pronounced? Attempting to decouple organ donation from end-of-life issues may be step in the wrong direction. Rather, it may be important for healthcare teams to normalize organ donation as an important part of end of life discussion. Additionally, trust should be built with families over their time in the ICU setting that helps ensure them that the physician can be trusted to engage in these conversations with them, without compromising the care of their loved one.

9.6 Ethical Issues with Transplant Candidate Selection

Although the decision to list a patient for transplantation will ultimately be the responsibility of the transplant team, the pediatric intensivist may play a role in helping to sort through prognosis and eligibility. They will also have to alter their medical management as well as communication with the family dependent upon whether a critically ill patient is deemed a suitable candidate to pursue transplantation. Understanding factors that determine such eligibility can be important for all members of the team. Medical co-morbidities such as neurological injury or genetic disorders, in addition to significant social concerns that may impact follow-up and compliance, can factor into a patient's candidacy for transplantation.

A decision which can translate as life-or-death to the patient and their family is clearly fraught with emotional distress, and the decision-making process feels different from the "shared decision making" model that is becoming standard in many

pediatric intensive care units. While parents' views and values regarding transplantation and its impact on long term quality of life must clearly be taken into consideration before listing a child for transplant, this decision is far more unilateral than the majority of medical decisions we encounter. Turnbull describes this shift in decision making in her narrative regarding a child who is removed from the cardiac transplantation list following severe neurological injury, and the parents' reaction:

> When the decision was relayed to Sam's parents, they expressed sadness, frustration, and above all, anger. They had been deeply involved in the decision to pursue heart transplant for him as well as the decision to have a VAD placed to support him until the transplant could take place, and they felt that their decision-making capabilities as parents had been unexpectedly taken away when they were not involved in the decision of his no longer being a candidate for transplant … Angry and filled with grief, his parents were forced to shift their goals for him to those of comfort only, as no other path forward was available. (Turnbull 2015)

And, the mother of young girl with renal failure from a genetic disorder with developmental delay describes the day she was told that her daughter would not be listed for transplant:

> I am afraid to look over at Joe because I suddenly know where the conversation is headed. In the middle of both papers, he highlighted in pink two phrases. Paper number one has the words, "Mentally Retarded" in cotton candy pink right under Hepatitis C. Paper number two has the phrase, "Brain Damage" in the same pink right under HIV. I remind myself to focus and look back at the doctor. I am still smiling.
>
> He says about three more sentences when something sparks in my brain. First it is hazy, foggy, like I am swimming under water. I actually shake my head a little to clear it. And then my brain focuses on what he just said.
>
> I put my hand up. "Stop talking for a minute. Did you just say that Amelia shouldn't have the transplant done because she is mentally retarded? I am confused. Did you really just say that?"
>
> The tears. Oh, the damn tears. Where did they come from? Niagara Falls. All at once. There was no warning. I couldn't stop them. There were no tissues in conference room so I use my sleeve and my hands and I keep wiping telling myself to stop it.
>
> I point to the paper and he lets me rant a minute. I can't stop pointing to the paper. "This phrase. This word. This is why she can't have the transplant done."
>
> "Yes."
>
> I begin to shake. My whole body trembles and he begins to tell me how she will never be able to get on the waiting list because she is mentally retarded. (Belkin 2012)

But as Turnbull goes on to describe with the first mentioned case, the health care team is dealing with the ultimate of limited resources. With thousands of people dying each year awaiting the availability of an organ, it is appropriate that thoughtful consideration is given to whom will be the best candidate for each organ available. We must be good stewards of this rare gift. What is the best use for each individual organ? While the story is tragic for "Sam" and his family, we reconcile it with the likelihood that the heart he would have received was able to prolong the life of another child. But was that child more "worthy?"

Some of the frustration regarding this stewardship role is that the standards for appropriate stewardship are not clear, and significant variation exists in how that

role is handled. In 2004, OPTN/UNOS officially stated that patients with disabilities should not be excluded from consideration for being listed for transplant because of that disability (N.W.G.o.D.a. 2004). In 2007 they gave further clarification that those with cognitive delay deserve a comprehensive evaluation to fully inform the listing decision (Allee 2007). While these statements make it clear that patients should not be automatically ruled-out for transplantation due to neurologic impairment, it does not mean that neurological impairment is not a relative contraindication.

There is appropriate concern that those with cognitive delays may not be able to communicate with or receive information from the transplant team. While children may have parents/guardians who take control of their medical management, it does require their understanding and cooperation, particularly as they may mature. Additionally, there are concerns that neurodevelopmental delay will bring a myriad of other medical comorbidities that will complicate the post-transplant course. For example, children with severe neurological disability may have a predisposition to more respiratory or skin infections, which could be devastating in an immunocompromised patient. So while children should not be automatically be ruled out for transplantation, some degree of neurological disability may appropriately prohibit transplantation. However, due to the murkiness surrounding the issue, the ISHLT removed "mental retardation" from their list of relative contraindications to heart transplantation in 2016 (Mehra et al. 2016). So how are individual transplant centers handling this issue?

There are discrepancies between institutions on how candidacy is determined when neurological diagnoses co-exist. Research done by Richards et al. in 2009 demonstrated this variability. A survey regarding decision making for neurologically delayed children was sent to all active pediatric solid organ transplant programs in the United States. They found that among 88 programs within 45 hospitals, 21% of programs reported that neurodevelopmental delay was "irrelevant" to the listing process. That is contrasted with 21% of programs that report severe delay is an absolute contraindication and 19% of programs that say profound delay is an absolute contraindication. Two programs use moderate delay as an absolute contraindication. When given a specific scenario about an infant assessed as being profoundly delayed, missing all major milestones at 20 months of life, where the parents are requesting solid organ transplantation for organ failure, 59% of programs said they would list the infant and 32% said their program would not (Richards et al. 2009). Clearly, programs are approaching this topic differently.

If long-term survival graft and therefore patient survival can indeed be correlated with neurodevelopmental delay, then it is medically appropriate to consider this as part of transplant consideration. There is very limited data on long-term survival among patients with cognitive impairment following solid organ transplantation. There is short-term data from heart, renal and lung programs that does not seem to indicate a difference in graft survival (Wightman et al. 2014, 2016, 2017; Goel 2017). However, this comes from a retrospective look at patient data, where the most severely delayed children have likely already been selected out of the patient populations. One could conclude that this data indicates transplant programs are

already appropriately selecting transplant candidates based on neurological criteria. More research is needed on long-term outcomes.

If it does become evident that cognitive delay does not impact outcome, then using this as an absolute or relative contraindication becomes ethically questionable. Stewardship means responsible use and management of something entrusted to your care. But to what end? Is survival of the organ, and therefore the patient, the primary endpoint of this stewardship? One could argue that the organ donated is a gift to society. It is given by the donor not to one specific patient, but rather to the betterment of society as a whole. Society, through an organization such as UNOS, then gifts the organ to a specific patient. Society could then be the most desirable steward and could decide if certain requirements should be met for the allocation to be appropriate.

Should an individual be expected to be able to give back to a society that has given a life-saving gift? This is indeed a very slippery slope of deciding worth in societies where multitude of values are at play. When social factors, which do not directly impact medical outcomes, are considered there is a risk that discrimination will occur. Excluding cognitively delayed children, if there is no evidence that it would impair graft survival, could be interpreted in the United States as a violation of the Americans with Disabilities Act, which protects disabled individuals from discrimination. As a society, the United States learned much from the days when dialysis was allocated by a "God Committee" who chose candidates based on age, marital status, number of dependents, net worth, income, education and occupation (Levine 2009). We as a society reached consensus that these are not the parameters that we want decisions to be based upon for allocation of medical resources. Instead, as with expansion of Medicare in the 1970s to give universal access to dialysis, UNOS follows the ethical directive that allocation should be solely based on medical indications.

Pediatric intensivists, having great knowledge of their patients' current status and ability to help prognosticate about future health, can provide important information to transplant programs on those patients who are awaiting transplant within the walls of the PICU. Importantly, though, transplant programs within the US are required to have multi-disciplinary teams that work together to evaluate candidacy. So while the intensivist has a voice, and should understand the issues at hand, they are definitely not solely responsible for these decisions. However, they may have to be actively involved in communication with family and PICU staff about morally distressing situations when tough decisions are made.

9.7 Children as Living Donors

Thus far in this chapter, we have discussed organ donation after death, either following death by cardiac determination or death by neurologic determination, along with organ allocation. These are the situations more likely to be encountered in the PICU setting. However, PICU professionals may also occasional encounter situations of living donation of organs or tissue, most likely in taking care of an organ or tissue recipient. Living donation has its own unique ethical issues to consider.

Organs for transplantation, as discussed earlier, remain a scarce resource and are of limited supply. One option to overcome the shortage of some organs is advocating for living donation. Single kidney and partial liver donations are amenable to living-donation. Reviewing the UNOS database, in 2016 38% of kidney donors in the United States were living. Only 4% of liver gifts were from living donors. Single- or lobar-lung donation from living donors has decreased in frequency, likely due to changes in allocation, with no living donors over the last 4 years in the United States. When reviewing the breakdown of the age of living donors, there is only a smattering of pediatric donors. According to data from the U.S. Organ Procurement and Transplant Network, 82 minors have become living donors since 1988; this includes 4 children under 1 year of age and 17 children between the ages of 1 and 10 years old, with most of these younger patients being "domino donors", that is, donating their organs following receiving a transplant themselves (i.e. heart-lung transplant recipient with cystic fibrosis donating a heart to another patient) (U.S. Organ Procurement and Transplantation Network 2018). Living pediatric donation cases have been the rare exception in unique situations, but have not been normalized.

A systematic review of international guidelines, position papers and reports on kidney donation from minor living donors reveals a general consensus that living kidney donation among minors should be avoided (Thys et al. 2013). They found that in the majority of documents reviewed, minor status is considered an absolute contraindication. Other documents, however, stated that some circumstances may allow for exceptions. One example is a minor wanting to donate to an identical twin. The American Medical Association takes this latter stance, specifically saying that minors "need not be prohibited from acting as sources of organs, but their participation should be limited." (Thys et al. 2013). The identical twin exception is clinically quite relevant. Reports of twin-to-twin kidney transplants have been noted since the 1950s when three sets of teenage twins were permitted to donate kidneys to their identical twin following judicial rulings (Delmonico and Harmon 2002; Ross et al. 2008). The court rulings were based on the perceived profound negative psychosocial impact that the death of one twin would have on the other, thus outweighing the physical and medical risks of donating a kidney. Pediatric living donors are rare under 10 years of age, but a case report of a 7-year-old identical twin serving as a kidney donor to her sister sites the same judicial reasoning (Kim 2003). Between 1987 and 2000, there were 60 minors who were live kidney donors. Seven of these donors/recipients were identical twins and had excellent outcomes (Delmonico and Harmon 2002; Ross et al. 2008).

The US Live Organ Donor Consensus Group argues, however, that if strict criteria are followed, minors may serve as living donors and the American Academy of Pediatrics supports this as ethically permissible. A risk/benefit assessment must first be undertaken and include both the donor and the recipient. The donor's interests should be promoted, and the donor should be respected as an end on his/her own, not just as a means or an organ source. Children with cognitive disabilities have thus often been prohibited from serving as living donors as they are unlikely to reap the psychological and emotional benefits of organ donation if they lack the understanding

to comprehend the purpose of organ donation and if they are unlikely to ever do so (Delmonico and Harmon 2002; Ross et al. 2008).

Serving as an organ donor is never in the donor's medical best interest. Those in favor of prohibiting minors from becoming living donors argue that the procedure involved is medically intrusive with inherent risks and purely of benefit to someone else. Additionally, they argue that it allows for abuse of power by surrogate decision makers as children could not possibly refuse such a request from a parent or a family member (Workman et al. 2013; Delmonico and Harmon 2002; Ross et al. 2008). However, supporters of minors serving as living donors feel that a complete prohibition to minors donating disregards the psychological and emotional benefits that the child may experience from organ donation (Workman et al. 2013; Delmonico and Harmon 2002; Ross et al. 2008). This includes improved self-esteem, hero status within the family/community, increased parental attention as family member is no longer ill, and assurance that all has been tried if transplant fails (Delmonico and Harmon 2002; Ross et al. 2008). Additionally, the decision-making capacity of minors is considered in many other circumstances such as research, genetic testing, reproductive health, and postmortem organ donation and thus should also be considered when it comes to living organ donation (Workman et al. 2013).

Because of these complex and confounding issues in pediatric living organ donations, the AAP has published their recommendations and what conditions must be met for children to become candidates for living organ donation: (1) Both the donor and the recipient must be highly likely to benefit. This means that the donor and recipient should be intimately related such that the psychological benefit to the donor is considerable. Also, the likelihood of transplant success should be high to reduce the psychological distress that occurs if the transplant fails. (2) The medical risks to the donor should be very low, suggesting that they should be restricted to donating kidneys although rare exceptions for older adolescents and liver segment donations are possible. (3) All other possible adult or cadaveric transplant options should be exhausted first and the pediatric donor should only be considered as a last resort. (4) The minor child must agree to donate without coercion and this must be established by an independent donor advocate that assists the donor understand the process while also protecting and promoting the donor's interests and well-being. (5) The psychological and emotional risks to the pediatric donor should be minimized by adequate age-appropriate preparation and inclusion in the decision-making process (Delmonico and Harmon 2002; Ross et al. 2008). The transplant team must obtain the child's assent in addition to parental consent. Additional considerations including ethics consultation, psychiatry evaluations, and/or court involvement may be necessary for the very young child whose parents wish to consider for organ donation.

Similar to solid organ donation, children can also donate hematopoietic stem cells for various immunologic, genetic, hematologic and oncologic diseases in siblings or sometimes other family members. The first successful pediatric bone marrow transplants were reported in 1968 for patients with severe combined immunodeficiency (SCID) and Wiskott-Aldrich disease (AAP Committee on Bioethics 2010). Sources of stem cells include bone marrow, peripheral blood following stimulation by granulocyte colony-stimulating factor (G-CSF), and umbilical cord blood. It is generally

accepted that the medical risks to the minor donor are modest with few serious complications.

As with solid organ transplant, HLA-matching of donor and recipient is important to minimize risk for graft versus host disease in the recipient, thus often looking towards siblings of children needing bone marrow transplantation. Umbilical cord blood can be obtained from the HLA-matched sibling and poses no additional risk to the infant as long as the mode of delivery or cord sampling is not modified to maximize the quantity of stem cells collected. Several medical societies have voiced strong opposition to modifying deliveries to augment cord blood collection. Parents, however, have gone through great lengths to find suitable stem cell donors for their children, including searching national cord blood banks and public donor registries as well as sometimes private cord blood banking of their own infant's umbilical cord blood for later use.

So called "savior siblings" have also made national and international headlines when parents have intentionally conceived another child with the purpose of curing an older child via stem cell transplant. The 1990 case of Marissa Ayala was the first publicized story of a savior child. Faced with their teenage daughter Anissa's need for life saving stem cell transplant, Abe and Mary Ayala decided to have another child with the hope that the child would prove a match to Anissa. Although the chances were low, Marissa matched her sister perfectly and her cord blood along with bone marrow sampling at 14 months of age was used to provide the bone marrow transplant to her sister (AAP Committee on Bioethics 2010; Quigley 2011; Dulaney 2013). Over 20 years later, the sisters describe their relationship as incredibly close and Marissa denies any regrets at the decisions surrounding her conception or participation in curing her sister (Quigley 2011; Dulaney 2013).

The advancement of in vitro fertilization (IVF) and preimplantation genetic diagnosis (PGD) has furthered the creation of savior siblings, as parents can now deliberately implant an embryo that is both without the genetic condition causing the disease (if known) and also an adequate HLA match to its older sibling to provide stem cells. The first reported case of such a child was that of Adam Nash in 2000 who, following a prolonged legal battle, was conceived via IFV and PGD to provide umbilical cord stem cell donation to his sister Molly Nash who suffered from Fanconi anemia. Molly was subsequently cured from her disease and tolerated the transplant well (AAP Committee on Bioethics 2010).

Since Marissa Ayala and Adam Nash, many other savior siblings have been created. Some critics pose moral and ethical objections to IVF and PGD due to the creation of excess embryos that are then destroyed. Others may consider PGD when used to avoid the birth of a child with a serious life threatening illness but oppose PGD when it is exclusively used to procure an HLA-matched sibling. The concern is that the child is then solely used as a means/donor for the ill sibling and not as an ends in themselves which all children should be. The counter-argument acknowledges the use of the child as a means, but argues that this is ethically permissible as long as this is not the child's sole use. Anecdotal evidence suggests that these children are loved for their ability to save their sibling and become a valuable member of the family which is an end in itself (AAP Committee on Bioethics 2010).

Jodi Picoult's novel My Sister's Keeper, which later became a movie, garnered savior siblings, and the extremes that parents are willing to seek in order to save their children, national attention. The novel describes the fictional tale of one such savior sibling, Anna, who was conceived to save her older sister Kate suffering from leukemia. After initial umbilical cord blood donation, Anna has continued to serve as a stem cell reservoir for her sister and at the age of 13 she is told she will now have to donate a kidney to Kate who has developed renal failure. Desperate to stop her parents from forcing the donation, Anna seeks help from a lawyer:

> There is way too much to explain – my own blood seeping into my sister's veins; the nurses holding me down to stick me for white cells Kate might borrow; the doctor saying they didn't get enough the first time around. The bruises and deep bone ache after I gave up my marrow; the shots that sparked more stem cells in me, so that there'd be extra for my sister. The fact that I'm not sick, but I might as well be. The fact that the only reason I was born was as a harvest crop for Kate. The fact that even now, a major decision about me is being made, and no one's bothered to ask the one person who most deserves it to speak her opinion. There's way too much to explain, and so I do the best that I can. "It's not God. Just my parents," I say. "I want to sue them for the rights to my own body." (Picoult 2004)

The novel provides a fictional example of a child that is put through unwanted medical procedures; although a plot twist explains that it is actually Kate that asked Anna to refuse the donation as she is ready to die while Anna wanted to donate her kidney to her sister. Real-life examples also exist including a younger sister being asked to provide stem cell donation to an older brother who had sexually assaulted her; or biological siblings of an adopted child being approached for stem cell donation when there was no relationship or likely psychological benefit for the children from the donation (AAP Committee on Bioethics 2010). In order to avoid such controversies, the AAP has recommended a similar approach to hematopoietic stem cell donation as for living solid organ donation amongst minor donors. This includes adherence to specific criteria: (1) Screening may be performed simultaneously for multiple family members but adult donors are preferred over children and older siblings are preferred to those that are younger. Similarly, children with cognitive disabilities should be considered particularly vulnerable. (2) A strong positive personal relationship must exist or be anticipated in the case of young children. (3) There must be a possibility that the recipient will benefit from the transplant to minimize the negative psychosocial harms when a sibling dies following transplant. (4) Attempts should be made a minimizing the risks to the donor, including clinical, emotional, and psychosocial risks. (5) Parental permission and donor assent should be obtained. Due to the conflicts of interest that exist for both parents and transplant teams, the AAP recommends similar Donor Advocate as in living solid organ donation where the rights, understanding, and emotional wellbeing of the donor are promoted (AAP Committee on Bioethics 2010).

Critics of the AAP recommendations raise concern for invasion of parental rights and authority for decision making for their children as the stem cell procurement is within the realm of parental decision-making authority due to its modest risk profile (Revera and Frangoul 2011). Additionally, they state that requiring a child's assent for the procedure is not necessary as parents regularly expose their children to similar

risks either through sports activities, recreation, travel, or work. The benefits reaped through the emotional and psychological effects should not be shadowed by minimal to modest physical risk (Revera and Frangoul 2011). In general, however, these types of support systems are already in place at most, if not all, transplant sites to ensure adequate protection for donor children. Even when a young child initially refuses to donate, often with exploration of their reasons, possible fears, and emotional state, the child can be brought around and supported through the process with age appropriate explanations and guidance. The AAP guidelines are meant to be quite deferential to parental authority yet provide safe-guards in those cases where it may be necessary (Ross 2010).

The pediatric critical care health care team is pivotal to the success of organ transplant programs, both with their role in supporting patients and families through the possibility of organ donation and also in supporting other patients and families through the transplantation process. The primary issue for the pediatric intensivist is the balancing the expectation of stewardship, or duty, to various entities: the duty to serve our own patients, particularly those at the end of their lives; a perceived duty by many to advocate for transplantation to benefit the a special demographic of critically ill children; a duty seen in pediatrics, more so than in adult medicine, of respecting and honoring the family's wishes for their dying child; and a duty to ensuring that one of the most rare resources be managed in a way that optimizes its benefits.

References

AAP Committee on Bioethics. 2010. Children as hematopoietic stem cell donors. *Pediatrics* 125: 392–404.

Allee, M.R.a.S., M. 2007. *Report of the OPTN/UNOS Ethics Committee to the Board of Directors.* Richmond, VA: OPTN/UNOS (Editor 2007).

Belkin, L. 2012. *Denying a transplant to 'retarde' child?* The Huffington Post.

Boucek, M.M., et al. 2008. Pediatric heart transplantation after declaration of cardiocirculatory death. *New England Journal of Medicine* 359 (7): 709–714.

Delmonico, F.L., and W.E. Harmon. 2002. The use of a minor as a live kidney donor. *American Journal of Transplantation* 2 (4): 333–336.

Dulaney, J. 2013. *Born to save her sister's live, Marissa Ayala, now 23, will graduate from CSULB.* Press Telegram.

Excellence, N.I.f.H.a.C. 2017. *Organ donation for transplantation: improving donor identification and consent rates for deceased organ donation*. 2011 October 13, 2017. Available from: https://www.nice.org.uk/guidance/cg135.

Georgiadou, E., et al. 2012. Attitudes and behavior toward organ donation in Greece. *Transplant Proceedings* 44 (9): 2698–2701.

Goel, A.N., et al. 2017. *Heart transplantation in children with intellectual disability: An analysis of the UNOS database.* Pediatric Transplantation 21(2).

Hoover, S.M., et al. 2014. Parental experiences and recommendations in donation after circulatory determination of death*. *Pediatric Critical Care Medicine* 15 (2): 105–111.

Kendall-Raynor, P. 2016. Organ donation opt-out law is saving lives in Wales. *Emerg Nurse* 24 (4): 6.

Kim, C. 2003. Children as live kidney donors for siblings. *Virtual Mentor* 5 (8): 240–242.
Levine, C. 2009. The Seattle 'god committee': A cautionary tale. Health Affairs Blog.
De Lora, P. 2015. DCDD and children: A defense of the "best interests" standard. *American Journal of Bioethics* 15 (8): 21–22.
Matesanz, R., et al. 2011. Spanish experience as a leading country: What kind of measures were taken? *Transplant International* 24 (4): 333–343.
Matesanz, R., et al. 2017. How Spain reached 40 deceased organ donors per million population. *American Journal of Transplantation* 17 (6): 1447–1454.
Mehra, M.R., et al. 2016. The 2016 international society for heart lung transplantation listing criteria for heart transplantation: A 10-year update. *Journal of Heart and Lung Transplantation* 35 (1): 1–23.
Nair-Collins, M., S.R. Green, and A.R. Sutin. 2015. Abandoning the dead donor rule? A national survey of public views on death and organ donation. *Journal of Medical Ethics* 41 (4): 297–302.
Nano, S. 2018. *Doctors debate when to declare organ donors dead*. FOXNEWS.com.
Noyes, J., et al. 2017. Family attitudes, actions, decisions and experiences following implementation of deemed consent and the Human Transplantation (Wales) Act 2013: mixed-method study protocol. *British Medical Journal Open* 7 (10): e017287.
Organ Procurement and Transplantation Network. U.D.o.H.a.H.S. July 25, 2018. Available from: https://optn.transplant.hrsa.gov/data/view-data-reports/.
Overby, K.J., M.S. Weinstein, and A. Fiester. 2015. Addressing consent issues in donation after circulatory determination of death. *American Journal of Bioethics* 15 (8): 3–9.
Picoult, J. 2004. *My sister's keeper*. New York: Atria Books.
Quigley, R. 2011. *Born to save her sister's life: Marissa was conceived simply to save her cancer stricken sister… and said she has never looked back.* Daily Mail.
Revera, G.H., and H. Frangoul. 2011. A parent's point of view on the american academy of pediatrics policy statement: children as hematopoietic stem cell donors. *Pediatric Blood & Cancer* 56: 515–516.
Richards, C.T., L.M. Crawley, and D. Magnus. 2009. Use of neurodevelopmental delay in pediatric solid organ transplant listing decisions: inconsistencies in standards across major pediatric transplant centers. *Pediatric Transplantation* 13 (7): 843–850.
Ross, L.F. 2010. In defense of the American Academy of pediatrics policy statement-children as hematopoietic stem cell donors. *Pediatrics* 125 (2): 392–404.
Ross, A., Thistlethwaite, R., and The AAP Committee on Bioethics. 2008. *Minors as living solid-organ donors.* Pediatrics 122: 454–461.
Sanghavi, D. 2009. When does death start. *The New York Times Magazine 2009*. New York:The New York Times Company.
Services, I.o.M.C.o.H.C. 1997. *Non-heart-beating organ transplantation: Medical and ethical issues in procurement.* Washington, DC: National Academies Press.
Siminoff, L.A., A.A. Agyemang, and H.M. Traino. 2013. Consent to organ donation: A review. *Progress in Transplantation* 23 (1): 99–104.
Thys, K., et al. 2013. Could minors be living kidney donors? A systematic review of guidelines, position papers and reports. *Transplant International* 26 (10): 949–960.
Transplantation, N.W.G.o.D.a. 2004. *Individual and family disability survey: final results*. Bloomington, IN: The ArcLinkIncorporated.
Truog, R.D., F.G. Miller, and S.D. Halpern. 2013. The dead-donor rule and the future of organ donation. *New England Journal of Medicine* 369 (14): 1287–1289.
Turnbull, J.M. 2015. Responsible Stewards of a Limited Resource. *Hastings Center Report* 45 (4): 7–8.
U.S. Organ Procurement and Transplantation Network. 2018. *Living donors recovered in the U.S. by donor age*. https://optn.transplant.hrsa.gov/data/view-data-reports/national-data/ (last accessed August 12th, 2018).
Vernez, S.L., and D. Magnus. 2011. Can the dead donor rule be resuscitated? *American Journal of Bioethics* 11 (8): 1.

Webb, G., et al. 2015. Factors affecting the decision to grant consent for organ donation: A Survey of adults in England. *Transplantation* 99 (7): 1396–1402.
Wightman, A., et al. 2014. Prevalence and outcomes of renal transplantation in children with intellectual disability. *Pediatric Transplantation* 18 (7): 714–719.
Wightman, A., et al. 2016. Prevalence and outcomes of liver transplantation in children with intellectual disability. *Journal of Pediatric Gastroenterology and Nutrition* 62 (6): 808–812.
Wightman, A., et al. 2017. *Prevalence and outcomes of heart transplantation in children with intellectual disability.* Pediatric Transplantation 21(2).
Workman, J.K., et al. 2013. Pediatric organ donation and transplantation. *Pediatrics* 131 (6): e1723–e1730.

Chapter 10
Moral Distress in the PICU

Abstract Moral distress is ubiquitous in PICU settings, impacting team members from all different disciplines. Distress arises from the critical nature of the patient's illness, with many children facing either death or living with life-long disability. Values used for decision making vary widely among patients' families and multiple team members, leading to tension about "right" and "wrong". Additionally, differences in experiences among parties contribute to difficulty arriving at conclusions along the same timeline. Although many know when they feel moral distress, it can be difficult to define. This chapter examines current thinking about moral distress, how it may arise from questions surrounding ethical permissibility of treatments and variations in values. Moral distress can impact clinical care and the well-being of healthcare professionals, leading to burnout. Strategies on mitigating moral distress are offered, although recognizing some degree of distress should be expected and may be beneficial.

10.1 The PICU Is a Cauldron of Moral Distress

PICU professionals frequently experience moral distress. The roots of this distress lie in troubling realities of the work of caring for children with life-threatening illnesses. Children admitted to the PICU are all critically ill. Some are acutely ill and will quickly get better, but many have complex chronic diseases for which there is no cure. Some of these children will die during childhood. It can be challenging to prognosticate about the certainty of a patient's death during their PICU stay. At some point during a patient's course, however, healthcare professionals and parents may wonder if PICU treatment is only an ongoing struggle to delay the inevitable. Many children will be dependent, for variable time-periods, on half-way technologies; interventions that are stabilizing but not curative. They are phenomenally effective at preserving physiological stability but, in many cases, they do not go beyond that to treat the underlying causes of that physiologic instability. Many are invasive, painful, and burdensome. These costs are presumed to be outweighed by the chance of survival, but what if survival can no longer be guaranteed, or even expected?

L. Miller-Smith et al., *Bioethics in the Pediatric ICU: Ethical Dilemmas Encountered in the Care of Critically Ill Children*, International Library of Ethics, Law, and the New Medicine 77, https://doi.org/10.1007/978-3-030-00943-4_10

There comes a point for both health professionals and parents when they come to believe that stopping ongoing intensive care treatment may be preferable, even if the outcome is death. But not everybody arrives at that conclusion at the same time. The timing of this realization is influenced by an individual's experience and values. Intensivists are typically confident in their resources and abilities. Parents are typically very hopeful for their children. "Giving up" on these beliefs can cause a personal conflict; refusal to "give up" on these beliefs can cause conflict with others.

The stressful situation is compounded by the fact that PICU treatments are provided by multidisciplinary teams of health professionals. Nobody can do the job alone. Each individual is an expert in their own narrow field, but they may not have the big picture. Some team members or even parents may not have all the information needed to understand how one piece of treatment relates to the overall care. These gaps in knowledge can lead to a phrase not infrequently heard with the PICU walls: "what are we even doing?" Excellent PICU care requires constant clear communication among many members of the health care team about very delicate topics and constantly evolving clinical realities.

Communication is even more complicated because the people who work in the PICU and the families of children who are hospitalized there come from different cultural and religious traditions. Illness and death may mean different things to different people. Family structures, organizational hierarchies, and expectations about doctor-family communication may differ. Some of the professionals have decades of experience working in the PICU. Some are just out of training. Both the health professionals and the parents bring emotional baggage from their own lives, including prior cases or other family members' illnesses.

Taken together, these factors make PICUs a cauldron for moral distress. If, as an experiment, one wanted to design a situation in which people would experience moral distress, one would likely come up with something like the PICU.

10.2 Defining Moral Distress

All that said, moral distress is not an easy concept to define, identify, evaluate, or ameliorate. The concept has a decades-long history in the academic literature of nursing, philosophy, psychology, and professionalism. It has been defined in many ways. Each definition has been subject to extensive critiques. Given this conceptual confusion, it is even controversial whether moral distress is a good thing, a bad thing, or something in between. Field and colleagues note that, "with changes in societal beliefs, advances in technology and the increase in provision of care by multidisciplinary teams… moral distress is inevitable. Its elimination is unlikely to be possible or appropriate" (Field et al. 2016). If it is a bad thing, it is not clear how to minimize it. If it is a good thing, it is not clear exactly how.

The concept of moral distress was first formulated by Jameton who described it as a feeling or set of feelings that arise when "one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action"

(Jameton 1984). By Jameton's formulation, moral distress was a phenomenon that arose among the more powerless people within an organizational hierarchy and was a result of that powerlessness. His original focus was on nurses and their particular forms of institutional powerlessness. His solution, then, was to empower nurses to speak out and to develop institutional procedures to ensure that their voices were heard (Jameton 1990). Others hold similar views (Crippen 2016).

Since Jameton's original work, the concept of moral distress has been expanded beyond nursing and organizational power hierarchies to include all health professionals and broader societal constraints on action. Peter, for example, notes that moral distress involves "a challenge that arises when one has an ethical or moral judgment about care that differs from that of others in charge" (Peter 2013). Kelly links moral distress with challenges to one's moral integrity. Moral integrity is preserved, she writes, when one can maintain "a valued professional identity". Moral distress manifests itself when "one's behavior is inconsistent with strongly held moral beliefs" (Kelly 1998). By these views, the constraints on right action are seen to go beyond those that exist as a result of power structures within a single institution.

Framed in this way, moral distress is closely tied to the concept of conscientious objection to certain practices (Catlin et al. 2008). Both rely on a view that each individual can perceive what is right, and that it is inappropriate to require individuals, as part of their professional role, to violate their own beliefs and values.

10.3 The Impact of Moral Distress

It is understandable that some view moral distress as something to be eliminated. Growing research demonstrates the impact of moral distress on individual care providers, healthcare teams and institutions. The short-term emotional impact on providers can be profound. Physicians and nurses report feelings of anger, frustration, and guilt when they have moral angst about their provision of care. They additionally can have physical manifestations, including increased headaches, fatigue and sleep dysfunction. Those experiencing moral distress may avoid work and certain patient care duties.

Instances of moral distress can also accumulate into what is described as moral residue. Moral residue is described as lingering feelings that remain in an individual (or even collectively in a work environment) even after the situation has resolved. Repeated episodes of believing you have violated your own moral integrity can have a powerful impact on your personal identity. The impact can build overtime, described as the crescendo effect (Epstein and Hamric 2009). Overtime, unresolved moral distress and moral residue can result in high staff turnover for hospitals, and for the individual, can lead to a shortened careers and burnout.

Moral distress has been described as an ethical root cause of burnout (Dzeng and Curtis 2018). Burnout is discussed in additional detail in Chap. 4. The term "burnout syndrome," or BOS, was first used in 1974 by Herbert Freudenberger to describe exhaustion experienced by public service workers, as it was believed to

be the consequence of professions where one is using themselves as a tool to help others (Freudenberger 1980). Maslach and Johnson in 1986 defined the syndrome of "emotional exhaustion, depersonalization and reduced personal accomplishment" occurring in those who do "people work" (Maslach 1986). Maslach went on to develop a scale for measuring BOS among clinicians (the Maslach Burnout Inventory), looking at three domains of emotional exhaustion, depersonalization and low personal accomplishment (Maslach 1996). BOS has been linked to decreased clinician health and well-being and significant job turnover. It has been correlated with rates of depression in healthcare providers. Equally concerning is the evolving evidence that impacts our patients as well, as burnout correlates with increased risk of medical error and decreased provision of quality care (Dewa et al. 2017; Shanafelt et al. 2010). There seems little doubt that burnout is a problem.

Does moral distress lead to burnout? Multiple studies have verified this correlation. Larson et al. performed a cross sectional study of NICU and PICU professionals, examining levels of moral distress, burnout and uncertainty (Larson et al. 2017). There results showed a moderate correlation between moral distress and depersonalization on the Maslach Burnout Inventory. Moral distress was more frequently reported among nurses who felt uncertain about the benefits of the therapy they were providing. Fumis et al. looked at adult critical care providers, including physicians, nurses, and respiratory therapists, and were able to correlate moral distress with all three elements of the Maslach Burnout Inventory: emotional exhaustion, depersonalization and diminished personal accomplishment (Fumis et al. 2017). Moral distress does appear to contribute to the development of BOS among all subspecialties. However, while there is significant evidence that burnout must be mitigated in critical care, and in healthcare in general, does it naturally follow that the answer is through eradication of moral distress? The next sections evaluate the claim that moral distress is inherently unhelpful and unnecessary, and look more closely at its role in critical care.

10.4 Some Problems with Current Conceptions of Moral Distress

Conflicts about futility between doctors and nurses, and also between different doctors, are, no doubt, common in PICUs. However, the concept of moral distress may lead to a misunderstanding of these moral controversies. The central problem is that, in its fundamental formulation, the concept of moral distress imagines that the conscience of an individual is generally right and that the "institutional constraints" are generally wrong. Thus, an individual who feels that he or she is being inappropriately prevented from doing the obviously right thing is obviously right. The individual may conclude that their moral distress is a clear indication of someone else being unethical. But, in real life, it is rarely so simple. Often, one professional may perceive that a patient is dying and that the obviously right thing is to withdraw

life-support. Another professional, looking at the same case, may think that there is a chance that continued life-support will be beneficial. Or one professional may think that the interests of the patient should always take priority over the educational needs of trainees. Another may strike a different balance and claim that we must prioritize education of the next generation of professionals. It may not be obvious who is right.

The possibility that, in many case, different professionals will have different perceptions of what is right suggests ways that many descriptions of moral distress are wrong. First, these descriptions assume that every (right thinking) individual will come to the same conclusion about what is the right thing to do. Otherwise, one person's moral distress would be simply be the mirror image of another person's deeply held moral conviction. If, as in the example above, one doctor or nurse believes that continuing life-support and medical treatment is appropriate, but another health professional disagrees, then there is no course of action that would not cause moral distress. If treatment continues, one would experience moral distress. But if life-support were withdrawn, the other would experience it. There is no obviously correct default solution in such situations.

A second, related, flaw in many descriptions of moral distress is that it is based on the idea that "institutions" impose moral constraints. But the moral constraints imposed by institutions are really the beliefs of the people in those institutions. It is not clear that empowered people hold one set of beliefs and disempowered people hold another set. Instead, in controversial cases, people up and down the power hierarchies may hold a range of beliefs. This is true whether the institution is a PICU, the hospital in which the PICU is located, or the society in which the hospital is located. The tough cases are those in which there is a difference of opinion about what choice is the best choice, rather than an impersonal set of constraints on choice by people whose convictions are assumed to be morally correct.

Seen in this way, moral distress is an inevitable consequence of moral pluralism. The alternative to moral distress, then, would not be moral comfort for everyone. Instead, one alternative would be a severe draconian imposition of one set of values. Moral distress could be eliminated by narrowing the circumstances under which people's conscientious beliefs and philosophical disagreements could be discussed and taken seriously. Another alternative, which would eliminate moral distress would be to create a completely amoral society. These alternatives are inconsistent with our societal values, leading us to conclude that moral distress should be expected and cannot be eliminated.

10.5 Moral Distress and Conscientious Objection

Comparing the two concepts of moral distress and conscientious objection sheds light on the similarities and limitations of both. One major limitation is that both rely on a view of individual professionals as people who have a robust set of internal values. Only such people would experience the violation of those values as a challenge to both personal and professional integrity (Wicclair 2017). This view is likely most

accurate in situations in which a medical practice violates a specific religious belief, as in the case of abortion for Catholics. In such situations, respect for conscientious objections empowers individuals to act on their values by opting out of participation in certain procedures. As in situations of moral distress, this can empower individuals who might feel trapped by circumstances into becoming complicit in practices that violate their beliefs. But many people do not have such strong moral grounding. Instead of relying on religious doctrine, they rely on their feelings and intuitions about right and wrong. The difference is important. A religious doctrine is specific and prescriptive. It tells someone what is permissible or impermissible. The individual does not have to make a moral judgment. People without allegiance to a specific religious doctrine must decide for themselves, in each situation, whether to trust their feelings, to overcome their feelings, or to find a different professional venue in which to work.

These concerns play out in an ongoing debate about the proper scope of conscience clauses. For which specific practices should professionals be excused on the basis of conscience? Are there conscience claims that conflict with professional obligations to such a degree that professionals should not be permitted to opt out? Stahl and Emanuel argue that "(P)rofessional associations should resist sanctioning conscientious objection as an acceptable practice" (Stahl and Emanuel 2017). They argue that professionals have obligations to provide care that meets "the standards of the profession". If they are unable to meet those obligations, then they should not work in that profession. Shucklenk agrees with this view. He writes, "The very idea that we ought to countenance conscientious objection in any profession is objectionable. Nobody forces anyone to become a professional. It is a voluntary choice. A conscientious objector in medicine is not dissimilar to a taxi driver who joins a taxi company that runs a fleet of mostly combustion engine cars and who objects on grounds of conscience to drive those cars due to environmental concerns. Why did she become a taxi driver in the first place? Perhaps she should have opened a bicycle taxi company instead" (Schuklenk 2015).

These same sorts of arguments might apply to moral distress. One professional might feel moral distress from continuing life-sustaining treatment for a critically ill patient. Another might feel moral distress at the idea of giving that patient morphine and withdrawing life-support. One might think that the parents should be allowed to make the decision. Another might feel that the parents' authority should be overridden if they are not acting in the child's best interest.

These sorts of considerations suggest that moral distress is not simply a result of situations in which the individual is right, and the system is wrong. They may more often be situations in which nobody is quite sure what is right or wrong. In some of these situations there may not be one "right" decision, but rather a myriad of ethically permissible choices from which to choose. If that is the case (with regard to either conscience or moral distress), then the solution cannot simply be to empower everyone to assert their professional identity and maintain their integrity by opting out of activities or procedures that they find troubling. Instead, policies should aim toward helping people shape their professional identity to conform to communally shared norms.

10.6 Moral Distress and Medical Futility

The concept of moral distress is closely tied to debates about medical futility. Many of the situations that generate moral distress in ICUs are situations in which families are demanding more treatment than doctors or nurses believe to be appropriate. For example, Wocial and colleagues, writing about moral distress in the PICU, state that it arises when "…physicians believe the child will not survive his/her ICU experience" and there is no discussion among health professionals or with the family about "placing limits on interventions that offer marginal benefit, or merely prolong the suffering of a child" (Wocial et al. 2017). These researchers report that the patient may be subjected to unnecessary and painful additional medical interventions as a result of this lack of communication. This causes moral distress for the team members who are physically providing the interventions. They perceive that the right thing to do would be to withdraw life-support and provide palliative care, but they are prevented from doing so. They are prevented by both the parents' preferences and, in some cases, by the attending physicians' unwillingness to engage the parents in discussions that might help them understand the need to redirect care away from life-prolongation and towards palliation.

Epstein and Delgado also related moral distress to medical futility. They describe a case in which a patient is dying of sepsis and multisystem organ failure. The patient does not have a DNR order. The nurse suggests to the resident that he call the family. He does, and they come to the hospital. While the family is on the way, the patient develops unstable ventricular fibrillation and the nurse, resident, and code team start CPR. When the family arrives, the nurse suggests to the resident that he go talk to the family about stopping CPR. Instead, he chooses to continue resuscitation efforts, and says that he is continuing so that the interns can learn how to do chest compressions. The nurse is deeply distressed and, eventually, announces that she will no longer participate in what she views as a sham resuscitation (Epstein 2010).

Just as there are debates about the nature of moral distress or the proper scope of conscience clauses, so there is a debate about medical futility. We reviewed this debate in Chap. 6. For the understanding of how it relates to moral distress, we only note that the debate about medical futility is a clear example of the ways in which professionals might disagree about what is the right or wrong thing to do in any morally complex situation.

10.7 Moral Distress and Mission

Every organization must have a primary mission. A central task for any successful organization is to define its mission and then to build its internal systems so that it can fulfill that mission.

Moral distress may arise in PICUs because of confusion or disagreement about the mission of the PICU or because PICUs have multiple missions that sometimes

conflict. For example, the PICU at the University of Pittsburgh defines its mission as follows, "(T)o provide exemplary care for critically ill patients, conduct cutting edge research related to life-threatening acute medical problems, and to train the leaders of tomorrow in the field of critical care medicine" (Burns 2014). These different goals will not always be harmonious with one another. At Integris Children's Hospital in Oklahoma, the PICU mission is "to make a positive difference in the lives of children and their families by providing supportive and compassionate health care throughout all stages of life" (Watson 2017). That mission sounds very different than the mission of the PICU in Pittsburgh. Imagine a doctor or nurse who was trained in Pittsburgh going to work in Oklahoma. They might experience moral distress because the values that they learned in Pittsburgh as essential values for a PICU professional are somewhat different than the values that guide professionals at Integris. At the Alfred Health hospital ICU in Australia, the mission is "to provide best possible patient outcomes through the practice of excellent, evidence-based, compassionate and consistent team-oriented intensive care medicine. In every situation, the wishes of the patient and the hopes of those around them will be balanced with the likelihood of success and suffering. Our practice will include dignified end-of-life care if treatment becomes futile" (Hartman et al. 2016). This statement acknowledges, in ways that the others do not, that even excellent care has limits and that it is an important part of the mission to recognize those limits. Clearly, each of these mission statements includes multiple missions, the fulfillment of any of which could, in some circumstances, conflict with the fulfillment of others. And each of them is somewhat different from the others, which could lead to similar conflicts or confusion among professionals.

Complex organizations function best when the people who work in those organizations understand the mission and share the values behind the mission. Thus, a health care professional whose primary interest is patient care may not feel comfortable working in an institution in which research or teaching are prioritized. A professional whose goal is to do research will be unhappy in a unit that prioritizes patient care over the development of new knowledge. A person whose primary commitment is to the relief of suffering may not be comfortable providing painful treatments that prolong life.

Studies of PICU professionals illustrate the ways in which these conflicting missions lead to moral distress. In 2012, Thomas and colleagues interviewed 25 health care professionals who worked in PICUs about their experiences of moral distress during resuscitations (Thomas et al. 2016). Their study included attending physicians, residents, advanced practice nurses, bedside nurses, and respiratory therapists. They began by asking these professionals to describe "a memorable resuscitation". They purposely did not focus on moral distress.

Many of the memorable resuscitations were memorable precisely because the respondents were experiencing some moral distress. One described the mismatched expectations of professionals and families. She said, "I will never forget this distraught mother yelling at all of us that we were giving up on her child, and we were not doing enough during the code to save her son…how is it that families fail to see that we are doing everything possible for their child?" Another said, "This code clearly was not going well…and we all knew he was going to die, but I did not want

to be the one to 'end it'. So…we continued to code this child, when in reality you know the child is gone". A PICU fellow remembered the following events, "I've definitely done that 'continuing' resuscitation by pushing code doses of pressors and fluids after active CPR where I thought it was wrong and not a good idea".

The researchers identified several themes in these responses. One was that individuals simply did their jobs, and nobody focused on the big picture. In these situations, professionals were acting as technicians rather than as moral agents. As a result, their sense of professional integrity was challenged, and they wondered what made them continue efforts at resuscitation.

Another common theme was that different people had different ideas of what "resuscitation" actually meant. A nurse summarized her understanding of this variability: "There are different codes, right? The chemical code, the long code, the family code, the algorithmic code". Intensive care involves ongoing treatment with modalities that are part of resuscitation, including mechanical ventilation and vasopressors. In that environment, it is not clear what a do-not-resuscitate order really means unless it is clearly delineated in advance.

A third theme focused on uncertainties about role responsibilities, coupled with a sense that there was often ineffective leadership. Many of the professionals in this study spoke about the need for a team leader who explicitly takes the responsibility to direct and regulate team dynamics and who understands, and helps others understand, the patient's "big picture".

Prentice and colleagues found similar dynamics at play (Prentice et al. 2016). They did a systematic review of the literature on moral distress in NICUs and PICUs. They conclude, "The primary causes of moral distress in these studies were perceived disproportionate care, considered not in a patient's best interests and a perceived inability on the part of the healthcare professional to advocate for the child…The underlying causes relate to the ethical climate within the unit—the dynamics that occur between individual healthcare professionals and the organisational structures within which they work". These researchers go on to speculate about the impossibility of eliminating moral distress and the need, instead, to differentiate helpful from unhelpful moral distress. They write, "It must be asked whether, in our pluralistic world with uncertain outcomes, the elimination of moral distress is even desirable. The answers to some difficult ethical dilemmas are often not black and white and should cause some distress and unease in both healthcare professionals and parents. It is hard to navigate between 'doing too much' and 'not enough'. How much moral distress is necessary, so that we continue asking ourselves the right question and challenging ourselves when there are new treatments available?" (Prentice et al. 2016).

10.8 Exit, Voice and Loyalty as Responses to Moral Distress

Assume that moral distress in PICUs is inevitable. Also assume that moral distress is deeply troubling for individuals. How can we then think about moral distress in

a way that doesn't view it as a problem to be eliminated but, instead, views it as a phenomenon that must be managed? The solution may be to imagine that there is a theoretical optimum level of moral distress that allows for individual beliefs, that rewards and reinforces professional behaviors that are consistent with organizational mission, and that leads to excellent care and a healthy moral climate within each PICU. A model for thinking about moral distress might come from the fields of economics, sociology, and organizational psychology.

In 1970, economist Albert Hirschman wrote a book about a different sort of moral distress. His book, *Exit*, *Voice*, *and Loyalty: Responses to Decline in Firms*, *Organizations*, *and States*, Hirschman (1970) examines a situation that at first seems to be quite different from the situations that give rise to moral distress in PICUs. Hirschman starts by examining situations in which there are "lapses from efficient, rational, law-abiding, virtuous or otherwise functional behavior" (p1). His analysis focuses on business and government organizations, but it can be applied to very different sorts of situations. His real concern is not on economics, per se, but on the features of complex organizations that allow those organizations to provide services to their members.

Hirschman reviews some puzzling economic analyses that show how organizations can thrive even when they engage in "a wide range of irrational and inefficient behavior" (p11). Such behavior, he notes, is tolerable for a while. But, eventually, it can become too much, and then it leads to "an absolute or comparative deterioration of the quality of the product or service" (p4).

Hirschman's analysis applies these ideas to corporations or states. Corporations exist to provide services to their customers. The customers can vote with their wallets. They either buy the corporation's products (loyalty) or they buy the products of a competing corporation (exit). Government provides services to their citizens. Citizens cannot really vote with their wallets. They cannot stop paying taxes if they don't like what the government is doing. However, they can leave the country (exit), or they can try to change the government (voice).

What does this have to do with moral distress? The relevant analogy here is that a health professional who is feeling moral distress is dissatisfied with the situation they are experiencing within their work environment. To put it in Hirschman's terms, moral distress occurs when health professionals perceive the behavior of their organization as irrational or inefficient. They may perceive that we are "wasting resources" by providing futile care to dying patients. They may perceive that, instead of fulfilling the central mission of medicine, we are betraying that mission. The framework of moral distress conceptualized the irrationality or inefficiency in moral terms rather than in Hirschman's economic ones. But Hirschman's work suggests that a better way to think about it might be to meld moral concepts and economic ones. Moral distress is a measure of the overall "moral economy" of a hospital, health system, or unit. And the options that are available to deal with moral distress map onto Hirschman's framework of exit, voice, and loyalty.

Exit occurs when someone decides that they can no longer work within a particular moral, political or economic circumstance. They may say things like, "The things that I am being asked to do here are morally intolerable". They may perceive no

possibility of change. They simply don't belong in that organization because there is a fundamental conflict between their own values and the values of the organization.

Voice refers to the empowerment of individuals to change the organization. They speak up, express their concerns, and may find that many others within the organization share their concerns. Exit, according to Hirschman, is an essentially economic solution. In a free marketplace of labor and ideas, someone can find a different workplace. Presumably, this will be one in which there are fewer conflicts between the institutional ethos and the person's values. Voice, by contrast, is a political solution. In a functional political environment, each voice matters, and the organization can be reshaped to better reflect the values of the people who work there.

Loyalty can arise as a result of exit or voice, or in the absence of either. A person can either find a workplace to which they can be loyal, change their current workplace in ways that allow loyalty, or change their own values so that they no longer feel a conflict between their own values and those of the organization.

Each of these solutions maps onto the solutions that may be proposed to the problem of moral distress in PICUs. Some people simply cannot work in the pressure cooker environment of intensive care. They find the everyday work there to be too morally troubling. For them, the solution is to exit and go work someplace else. The people who stay, then, are more likely to develop loyalty to the values of the unit in which they work. People who are loyal also perpetuate the values of the unit because they believe them to be the correct values.

Voice is the trickiest solution. Sometimes, even the most loyal employees experience moral distress. Often, this arises because new technologies raise new questions or because new people bring different values to the unit. It may arise because the unit encourages people to speak up when they have moral concerns. PICU leaders should provide venues in which people can speak to one another about troubling cases and troubling practices. These conversations may help to either allay distress, or to identify areas where practice must change. To encourage "voice" is challenging, but necessary. People must set aside time. Skilled facilitators may be required to draw out people who might be reticent to express their views. Discussions about morally distressing situations may themselves be emotionally difficult. And, in the end, such discussions might lead some individuals to understand that, for them, the best solution is to exit and find less morally distressing work elsewhere. For others, these open conversations may renew faith in their PICU team and help build loyalty.

In the end, moral distress is always a reflection of conflicts about values. Some of these conflicts can be resolved. Others may fester. If left unaddressed, wide-spread distress can affect the overall moral climate of a unit or institution, and can lead to staff burn-out. However, the answer cannot be to eliminate moral distress. The idea that there is an optimum level of moral distress seeks to find the appropriate middle ground between a PICU in which nobody is empowered to express their feelings and one in which everybody holds a different set of moral commitments. Moral pluralism is valuable, and although it will result in tension during times of difficult decisions, it overall can contribute to improved dialogue about how we approach the best care for our patients.

References

Burns, J.P., et al. 2014. Epidemiology of death in the PICU at five U.S. teaching hospitals. *Critical Care Medicine* 42 (9): 2101–2108.

Catlin, A., et al. 2008. Conscientious objection: A potential neonatal nursing response to care orders that cause suffering at the end of life? Study of a concept. *Neonatal Network* 27 (2): 101–108.

Crippen, D. 2016. Moral distress in medicine: Powerlessness by any other name. *Journal of Critical Care* 31 (1): 271–272.

Dewa, C.S., et al. 2017. The relationship between physician burnout and quality of healthcare in terms of safety and acceptability: A systematic review. *British Medical Journal Open* 7 (6): e015141.

Dzeng, E., and J.R. Curtis. 2018. Understanding ethical climate, moral distress, and burnout: A novel tool and a conceptual framework. *BMJ Quality & Safety* 27 (10): 766–770.

Epstein, E.G., and S. Delgado. 2010. Understanding and addressing moral distress. *The Online Journal of Issues in Nursing* 15(3).

Epstein, E.G., and A.B. Hamric. 2009. Moral distress, moral residue, and the crescendo effect. *Journal of Clinical Ethics* 20 (4): 330–342.

Field, D., J. Deeming, and L.K. Smith. 2016. Moral distress: An inevitable part of neonatal and paediatric intensive care? *Archives of Disease in Childhood* 101 (8): 686–687.

Freudenberger, H.J., and G. Richelson. 1980. *Burn-out: The high cost of high achievement*. 1st ed. xxii, 214 p. Garden City, N.Y.: Anchor Press.

Fumis, R.R.L., et al. 2017. Moral distress and its contribution to the development of burnout syndrome among critical care providers. *Annals of Intensive Care* 7 (1): 71.

Hartman, M.L., et al. 2016. Salivary biomarkers in pediatric metabolic disease research. *Pediatric Endocrinology Reviews* 13 (3): 602–611.

Hirschman, A.O. 1970. *Exit, voice, and loyalty: Responses to decline in firms, organizations, and states*. Cambridge: Harvard University Press.

Jameton, A. 1984. *Nursing practice: The ethical issues*. Englewood Cliffs, NJ: Prentice Hall.

Jameton, A. 1990. Culture, mortality, and ethics. Twirling the spindle. *Critical Care Nursing Clinics of North America* 2 (3): 443–451.

Kelly, B. 1998. Preserving moral integrity: A follow-up study with new graduate nurses. *Journal of Advanced Nursing* 28 (5): 1134–1145.

Larson, C.P., et al. 2017. Moral distress in PICU and neonatal ICU practitioners: A cross-sectional evaluation. *Pediatric Critical Care Medicine* 18 (8): e318–e326.

Maslach, C., and S.E. Jackson. 1986. *Maslach burnout inventory: Manual*. 2nd ed. v, 34 p. Palo Alto, Calif. (577 College Ave., Palo Alto 94306): Consulting Psychologists Press.

Maslach, C., S.E. Jackson, and M.P. Leiter. 1996. *Maslach burnout inventory manual*. 3rd ed. iv, 52 p. Palo Alto, Calif. (577 College Ave., Palo Alto 94306): Consulting Psychologists Press.

Peter, E. 2013. Advancing the concept of moral distress. *Journal of Bioethical Inquiry* 10 (3): 293–295.

Prentice, T., et al. 2016. Moral distress within neonatal and paediatric intensive care units: A systematic review. *Archives of Disease in Childhood* 101 (8): 701–708.

Schuklenk, U. 2015. Conscientious objection in medicine: Private ideological convictions must not supercede public service obligations. *Bioethics* 29 (5): ii–iii.

Shanafelt, T.D., et al. 2010. Burnout and medical errors among American surgeons. *Annals of Surgery* 251 (6): 995–1000.

Stahl, R.Y., and E.J. Emanuel. 2017. Physicians, not conscripts—Conscientious objection in health care. *New England Journal of Medicine* 376 (14): 1380–1385.

Thomas, T.A., et al. 2016. A qualitative study exploring moral distress among pediatric resuscitation team clinicians: Challenges to professional integrity. *Pediatric Critical Care Medicine* 17 (7): e303–e308.

Watson, R.S., et al. 2017. Epidemiology and outcomes of pediatric multiple organ dysfunction syndrome. *Pediatric Critical Care Medicine* 18 (3_suppl Suppl 1): S4–S16.

Wicclair, M. 2017. Conscientious objection in healthcare and moral integrity. *Cambridge Quarterly of Healthcare Ethics* 26 (1): 7–17.
Wocial, L., et al. 2017. Pediatric Ethics and Communication Excellence (PEACE) rounds: Decreasing moral distress and patient length of stay in the PICU. *HEC Forum* 29 (1): 75–91.

Chapter 11
Conclusion

Abstract The chapter briefly summarizes the greater concepts within the book.

The story of pediatric critical care is a remarkable one. It can sometimes make you stop in wonderment, struck by the tremendous growth that has occurred and our ability to support and treat the sickest of children. We, the providers of critical care, are on a fast-paced journey—a journey that is fraught with triumph and danger, joy and fear, certainty and confusion. We are not alone in our journey. Every day we bring patients and families with us, as we explore the possibilities and pitfalls of modern day medicine.

The PICU is the final common pathway for most children who have either an acute life-threatening illness, or significant exacerbation of a chronic medical diagnosis. Patients in PICUs come from all medical and surgical subspecialties, with many different kinds of illnesses, and probably just as important, many different life experiences. Doctors, nurses and others who care for these critically ill children must quickly adapt to specific nuances of each situation. They must deal with sudden crises, emotional stress, and difficult decisions about withholding or withdrawing life-support. They must focus on optimizing communication with families, even when parents may be angry, anxious, depressed, or grieving. This book summarizes and analyzes some of the ethical issues that arise in this cauldron of medical and emotional intensity; issues that come at a particular juncture in the history of pediatric critical care medicine, and will likely continue to be pertinent in years to come.

Three decades ago, when the field was in its infancy, doctors focused primarily on stabilizing children with acute critical illness. Most children admitted to the PICU stayed for only a few days. Some were victims of trauma. Some were post-operative patients. Some had a life-threatening infection. Generally, in those early days, these children either got better quickly or died. Today, as a result of careful research and training, pediatric critical care medicine has become much more successful at saving children who, not so long ago, would have died. Although fewer children die today,

L. Miller-Smith et al., *Bioethics in the Pediatric ICU: Ethical Dilemmas Encountered in the Care of Critically Ill Children*, International Library of Ethics, Law, and the New Medicine 77, https://doi.org/10.1007/978-3-030-00943-4_11

many of the survivors are left with complex chronic health problems, a situation that leads to new ethical challenges. In this book, we provide a context and a framework for special considerations in the chronically critically ill pediatric patient. Many intensivists were trained more specifically for more acute illnesses, and must adapt to this new framework of critical illness becoming more chronic.

Our ability to provide lifesaving care to an increasingly complex patient population has also changed the manner in which pediatric death takes place. An increasing percentage of children who die have had complex chronic health conditions for a long time. Discussions with the parents of these children are different from discussions with parents of previously healthy children who have an acute and unexpected life-threatening illness. Parents of chronically ill children know the health care system. They frequently have been in the PICU before. If they have only been in the PICU once, it may have been for weeks to months. Often, they have participated in discussions about end-of-life decisions. If those discussions have not taken place, they have most likely considered their idea of the worst-case scenario, based on what they have seen transpire around them. Rather than being an isolated unexpected decision, a decision about limitations in support is the culmination of a protracted course; decision after decision that has led to this moment in time.

Such parents are part of the health care team in a way that other parents are not. While modern western medical culture values the shared-decision making process, the savvy parents of chronically ill children bring a new level of complexity to these discussions. Dealing with their children's complex illnesses, some families know for quite some time that they might be faced with end-of-life decisions, and they dread them. These discussions with families are difficult challenges for physicians and other health care providers. The shared decision making model provides an opportunity for parents and physicians to meet in the middle between paternalism and autonomy, and ideally reach a mutually agreeable decision. However, shared decision making often means dealing with different belief systems, backgrounds, and values within the PICU environment.

An admission to the PICU remains a stressful event for both the patients and their families. The parents, families, caretakers, and the children themselves are thrown into the whirlwind of emotions created by critical illness. Uncertainty, frustration, and fear mix with relief, sadness, hope, and despair. To help parents through such stressful times, health care team must provide parents with the necessary information to make an informed choice for their child. They must balance honesty with kindness. They must be realistic about hope. And they must try to do so with empathy and an understanding of the emotional roller-coaster the parents are riding.

Dealing with these emotions as well as their past experiences, parents must make decisions for their children with the guidance of their physician and health care team. Some decisions of medical care are so simple, such as which antibiotic to choose for a pneumonia, they may not necessarily be discussed in depth with the family. More difficult decisions involve asking families to make decisions about truly complex and ethically challenging issues, such as tracheostomies, surgical interventions, advance directives, and end-of-life decisions, since many physicians in North America and Europe rely heavily upon shared decision-making. There may be times, however,

when decisions must be made about distribution of scare resources (such as heart transplants) or about unproven experimental therapies. There may be instances when it is not appropriate for the decision to be the parents'. A duty of the pediatric intensivist is to apply best knowledge and evidence to know when a therapy is inappropriate to offer. These decisions, though, may lead to difficult conversations.

Intractable disagreements continue to arise in the PICU, particularly when healthcare staff, including physicians and nurses, perceive the patient's prognosis and burden of ongoing therapy differently from the way parents' perceive it. This disconnection can cause a great deal of moral distress and angst within the PICU. Most often these disputes occur when communication and negotiation between the parents and the health care team have broken down. Better communication, deeper understanding of parental values that are affecting their decisions, and education of the health care team can go a long way toward resolving this kind of problem. A collaborative approach where an understanding can be reached is the preferred method of trying to resolve these disagreements.

Although more pediatric patients are surviving their critical illness through ongoing technological advances and improvements in critical care delivery, that survival may come with technology dependence or profound neurologic impairment and increasing medical complexity. Parents often become experts in managing their child's condition as we have moved away from residential facilities, sometimes making a make-shift intensive care unit in their home. With the assistance of home nursing, these children can often be cared for at home, though they remain at risk for sudden life threatening events and frequent hospitalizations. The economic burden of having a child with medical complexity and technology dependence can also be significant and creates another layer of challenges for these children and their families. With ongoing technology support, the discontinuation and withdrawal of such support can be emotionally difficult, though from an ethical standpoint there is no difference between withholding and withdrawing of life sustaining therapies. We need honest and open discussion with families at the time that chronic technological support is initiated about what the future may hold. And we must consider palliative care, advance care planning, and anticipated socioeconomic burdens in our discussions with families.

In spite of all of our best-efforts, there will come a time when a pediatric patient cannot be saved. Not only should pediatric critical care focus on restoring health, when health cannot be restored, it should focus on providing the best death. In theory, this should not be complicated, but the medical community has struggled with the diagnosis of death since the beginning of time. Today, the ethical challenges surrounding death remain a key issue in ICU ethics. The relatively novel definition of death by neurologic criteria outlined by the Universal Declaration of Death Act is mistrusted by some families and not accepted by all religious or cultural groups. Controversies also surround death by circulatory criteria, particularly when considering the reversibility of the diagnosis and its link to organ donation. Some have also argued for abandonment of the Dead Donor Rule when it comes to organ donation, arguing that patient autonomy should prevail and allow for organ donation if the patient or surrogate decision maker so desires. However, making these changes

would require substantial changes to the laws surrounding homicide and euthanasia in this country. Critical care physicians must address these challenges and uncertainties. They must be familiar with the laws and regulations in their particular communities as they differ between countries, as well as between states.

Family, community, societal, and hospital resources may be stretched thin at various times, and although we hope that we live in a society where all patients can be treated equally, pediatric intensivists are frequently engaged in triage of their available resources. Whether it is the latest drug shortage, a recent IV fluid shortage related to the natural disaster in Puerto Rico, the last ECMO pump in the hospital during the influenza season, or a shortage of rooms available within our units, we must make decisions as to which patients gets which resource. These decisions become more complicated during times of local or national crises where hospitals may become isolated and there is a mass surge in patient volume. Several suggestions for triage have been developed, but as we would inevitably provide sub-optimal care to certain patient populations, the emphasis must be on re-establishing usual care, having ample preparation for such events, and minimizing the actual time spent in triage mode.

All of these ethical challenges continue to occur on a regular basis within our pediatric intensive care units. They often cause significant emotional and moral distress among health care providers. They can contribute to job dissatisfaction and burnout among critical care physicians and nurses. This reality may lead to a strong impetus to attempt to eliminate moral distress; this is not practical. The moral distress that is frequently encountered in pediatric critical care is a natural consequence of pushing boundaries forward in a morally pluralistic society. The array of viewpoints on what is right and wrong is an asset to critical care—it forces us to have ongoing conversations about what is in the best interest of our patients and how that can be achieved. The only way to eliminate distress is for us all to share only one viewpoint. Without dialogue, we would be at high risk of sharing the wrong viewpoint. Instead of eliminating moral distress, we must learn to manage it. We must take deliberate action to give voice to all members of the team, to communicate openly, and find resources to support our colleagues through challenging situations.

Ethics is a daily component of the work we provide in pediatric critical care. It is all around us—sometimes glaring and sometimes opaque. How we educate ourselves on the topic and how we approach the various problems impacts the moral climate in which we work. It impacts families, and how they are able to cope and understand their child's illness or death. It impacts our team and their ability to handle moral distress. It impacts us personally, and our ability to have longevity in the field to which we have committed so much of ourselves. Most importantly, it impacts our patients and the quality of care they receive. We have a duty to uphold the best interests of our patients, but always be cognizant of the personal and societal values that are at hand. Having a frame of reference and a deeper understanding of these challenges is important as we provide critical care to our increasingly complex patient population.