Families in the Intensive Care Unit

A Guide to Understanding, Engaging, and Supporting at the Bedside

Giora Netzer
Editor

Springer

Families in the Intensive Care Unit

Giora Netzer
Editor

Families in the Intensive Care Unit

A Guide to Understanding, Engaging, and Supporting at the Bedside

Springer

Editor
Giora Netzer
Division of Pulmonary and Critical Care Medicine
University of Maryland School of Medicine
Baltimore, MD
USA

ISBN 978-3-319-94336-7 ISBN 978-3-319-94337-4 (eBook)
https://doi.org/10.1007/978-3-319-94337-4

Library of Congress Control Number: 2018954771

© Springer Nature Switzerland AG 2018
This work is subject to copyright. All rights are reserved by the Publisher, whether the whole or part of the material is concerned, specifically the rights of translation, reprinting, reuse of illustrations, recitation, broadcasting, reproduction on microfilms or in any other physical way, and transmission or information storage and retrieval, electronic adaptation, computer software, or by similar or dissimilar methodology now known or hereafter developed.
The use of general descriptive names, registered names, trademarks, service marks, etc. in this publication does not imply, even in the absence of a specific statement, that such names are exempt from the relevant protective laws and regulations and therefore free for general use.
The publisher, the authors, and the editors are safe to assume that the advice and information in this book are believed to be true and accurate at the date of publication. Neither the publisher nor the authors or the editors give a warranty, express or implied, with respect to the material contained herein or for any errors or omissions that may have been made. The publisher remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

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

To my family that planted my roots, nurtured me, and guided me upwards; and to my family that nourishes and grows me yet.

Foreword

Margaret Atwood once wrote [1]:

> I would like to give you the silver
> branch, the small white flower, the one
> word that will protect you
> from the grief at the center
> of your dream, from the grief
> at the center. I would like to follow
> you up the long stairway
> again & become
> the boat that would row you back

In the ICU, we enact these beautiful metaphors hourly—trying to pull patients back from the sadness and sometimes horror of death and suffering.

In doing so, we increasingly partner deeply not just interprofessionally but with patients' families. This partnership involves an often unnatural intensity, and an interdependency that can develop within minutes and hours. That interdependency evolves as we work to save the patient's life or to recognize that it is not within our power to save—or that the patient would not want their life saved at the cost that must be imposed by our limitations.

Partnership at this level requires honesty and frankness. It means understanding what our partner can do at any given moment, but also what cannot—ought not—be asked of them.

This is a book to help us, as clinicians, understand what our patients' families may experience. It provides us a set of tools to understand the ways in which the ICU experience can reshape—and, yes, can deform and scar—family members. It can help us understand the ways in which the ICU experience may limit a family's ability to be their best self. It can help us learn what our partners are going through.

The authors of this book provide insights into what we may be doing that might make things worse for our partners, the families of our patients. They demonstrate that there are pervasive system issues that at best benignly neglect the needs of families—but sometimes may not be so benign.

The authors teach us paths forward, from broad philosophies of care to simple tips for engaging the family in bedside physical therapy. They suggest ways in which we can more effectively partner with families to transform critical care. There is much to learn here, and I hope dog-eared copies of this book will be found at ICU work rooms and nursing stations for years to come.

Ann Arbor, MI, USA Theodore J. Iwashyna, MD, PhD

Reference

1. Atwood M. Selected poems II: 1976–1986. 2nd ed. New York: Mariner Books; 1987.

Preface

After 12 days at my mother's bedside, I had reached the end of my rope, physically and emotionally. She'd had three craniotomies and was spiking a fever, and the neurosurgery resident arrived to perform the lumbar puncture. I walked out of her room in the intensive care unit (ICU), trying to figure out how to hold back the sobs welling up inside me. "Would you like a cup of coffee?" a nurse asked. It wasn't long before a Styrofoam cup of burnt, terrible machine coffee steamed in my hand. It was the greatest cup of coffee I had ever tasted.

That moment was miraculous even as it was unremarkable. A wise and caring nurse had reached out to a fellow human being who was suffering and poured a helping of pure and selfless kindness. This small act helped me more fully understand that while the hurt of families in the ICU was deeper and more jagged than I had realized, the power of a simple gesture of support and kindness was more powerful than I could have imagined.

My mother returned home a week later to begin her recovery. However, when I came back to the ICU, filled with gratitude, I brought with me an awareness that changed the way I viewed every facet of critical care. Now as I look at family faces in the waiting rooms, it reminds me of being there as a loved one—nauseous from days of junk food, bleary from sleep deprivation, and distraught and exhausted from the whirlwind of it all. Seeing them takes me back to being at my mother's bedside, anxious and waiting for cardiologists, cardiac surgeons, neurosurgeons, and ICU physicians. It was a raw epiphany that opened me to a truth I could now personally understand and relate to the feelings of those sitting across from me. I could no longer cloak myself in a white coat to escape the now-obvious truth that if I were to truly care for critically ill human beings in their totality, I owed their loved ones the same dedication I was giving them.

This realization brought to mind the words of the Chassidic philosopher Rebbe Nachman of Breslov [1]:

> *As the hand held before the eye conceals the greatest mountain, so the little earthly life hides from the glance the enormous lights and mysteries, of which the earth is full, and he who can draw it away from before his eyes, as one draws away a hand, beholds the great shining of the inner worlds.*

The science of today's ICU medicine is dazzling. We practice in a fortunate era, using technology and evidence to take better care of our patients than any time in history. At the same time, it's easy to lose sight that this is a human endeavor. Those for whom we care are individual souls, not bags of organs and collections of maladies. They and their families have entrusted us with this most precious thing, their very being. To save lives and ease suffering, our minds and efforts make our work in the ICU the highest calling. But kindness must be integral to this, elevating it from the noble to the sacred. We then illuminate the world around us.

For those of us in healthcare and research whose lives have been touched personally by critical illness, we are transformed. We want to see the ICU made human, not only for our patients and their families but for ourselves as well. But this endeavor requires more than just good intentions.

Our first task is to recognize that families are suffering with their loved ones in the ICU. But this, in and of itself, is not enough. We need to know how this suffering occurs and how it impacts their abilities to advocate and make the often difficult decisions frequently encountered in the ICU. Only then can we best create and assess the potential interventions that might support and guide them. Then will come the changes in the way we engage and work with families.

This book seeks to do these things: for us to describe what families are going through, what mechanisms may be driving their suffering, how we rise up to this great and noble challenge now, and how we may continue to rise up to meet it.

Baltimore, MD, USA Giora Netzer, MD, MSCE

Reference

1. Buber M. Tales of the Hasidim. New York: Schocken Books; 1991.

Acknowledgments

For me, the Hippocratic Oath's exhortation to honor one's teachers has been a delight, as I've been blessed with so many superb mentors throughout my path in medicine, including Thomas Shaffer, Gregory Tino, John Hansen-Flaschen, John Hess, Dale Needham, Anthony Harris, Michael Terrin, and Chuck Callahan. Jason Christie guided and launched me on my path and continues to generously provide his wisdom. I've tried to pay it forward. It's been my honor to work with amazing mentees, whose work, ideas, and talent have made so much exciting research possible. Thank you: Tessy Paul, Ann Parker, Xinggang Liu, Michael Dallman, Aaron Hess, Majid Afshar, Matthew Barrett, Sahar Mansoor, Mario Fusaro, Jona Ludmir, Niki Leiter, Danielle Glick, Stephen Biederman, and Sara Viola. I'm especially grateful to Don Sullivan, together with whom I developed the core concepts guiding my work on families.

Jack Iwashyna has been a collaborator, guide, foil, and friend since our time as residents. Jack's mark is apparent throughout this book; I am indebted to his thoughtful comments and guidance in its structure and approach. I hope the book's introduction conveys just how inspirational working with Judy Davidson has been—she's my ICU family hero, as is Sam Brown, who brings great grace and rigor to thinking about humanizing the ICU. Mark Mikkelsen has led the charge in addressing the challenges of ICU survivors and their families, and I'm fortunate to work and think with him.

My thanks to the Division of Pulmonary and Critical Care Medicine at the University of Maryland School of Medicine, where I work with some terrific friends and researchers, as well as the Department of Epidemiology and Public Health, whose work studying older caregivers has helped to inform my own work. I am grateful to the leadership of the University of Maryland Medical Center and the University of Maryland Medical System for their support in improving family-centered care across its ICUs. I'm honored and proud to be a member of the Society of Critical Care Medicine. The Society of Critical Care Medicine has taken a leadership position in advocating for patient- and family-centeredness in critical care with its state-of-the-art guidelines, and also the well-being of survivors and families after the ICU with its THRIVE Initiative (where Adair Andrews has worked tirelessly to make the world a better place).

For me, the inspiration to write a book about family comes from the love of my own. Thank you to my parents for their selflessness and my sister for her bravery. My wife and partner, Alison, and my children, Hannah, David, and Jacob, breathe life into my soul each day.

My thanks to Andy Kwan at Springer Press for his enthusiasm and vision for this project and also to Prakash Jagnnathan for his efforts in making it possible.

Contents

Contributors

Andre Carlos Kajdacsy-Balla Amaral Department of Critical Care Medicine, Sunnybrook Health Sciences Centre, Toronto, ON, Canada

Interdepartmental Division of Critical Care Medicine, University of Toronto, Toronto, ON, Canada

Bree Andrews Section of Neonatology, The University of Chicago Medicine Comer Children's Hospital, Chicago, IL, USA

Department of Pediatrics, The University of Chicago, Chicago, IL, USA

Arunmozhi Aravagiri Division of Pulmonary and Critical Care Medicine, University of Maryland School of Medicine, Baltimore, MD, USA

Sarah J. Beesley Division of Pulmonary and Critical Care, Department of Medicine, University of Utah School of Medicine, Salt Lake City, UT, USA

Pulmonary Division, Department of Medicine, Intermountain Medical Center, Shock Trauma Intensive Care Unit, Murray, UT, USA

Chris Benda Intensive Care Unit Patient-Family Advisory Council, Intermountain Medical Center, Murray, UT, USA

Waqas Bhatti Division of Pulmonary and Critical Care Medicine, University of Maryland School of Medicine, Baltimore, MD, USA

O. Joseph Bienvenu Psychiatry and Behavioral Sciences, Johns Hopkins University School of Medicine, Baltimore, MD, USA

A. Doran Bostwick Division of Pulmonary and Critical Care, Department of Medicine, University of Utah School of Medicine, Salt Lake City, UT, USA

Samuel M. Brown Pulmonary and Critical Care Medicine, Intermountain Medical Center, Murray, UT, USA

Center for Humanizing Critical Care, Intermountain Healthcare, Murray, UT, USA

Pulmonary and Critical Care Medicine, University of Utah School of Medicine, Salt Lake City, UT, USA

Intermountain Medical Center, Shock Trauma Intensive Care Unit, Murray, UT, USA

Jaime E. Bruce Middle Tennessee State University, College of Behavioral and Health Sciences, Murfreesboro, TN, USA

Monroe Carell Jr. Children's Hospital at Vanderbilt, Department of Child Life and Volunteer Services, Nashville, TN, USA

Morgan Bunting School of Medicine, Division of Gerontology, University of Maryland-Baltimore, Baltimore, MD, USA

John G. Cagle University of Maryland, Baltimore, School of Social Work, Baltimore, MD, USA

Delia Chiaramonte University of Maryland School of Medicine, Center for Integrative Medicine, Baltimore, MD, USA

Sal Colianni ARDS Patient, Northbrook, IL, USA

Christopher E. Cox Department of Medicine, Division of Pulmonary & Critical Care Medicine, Duke University, Durham, NC, USA

Program to Support People and Enhance Recovery, Duke University, Durham, NC, USA

Judy Elisa Davidson University of California, San Diego Health, San Diego, CA, USA

Samantha Gambles Farr Surgical Intensive Care, University of California, San Diego Health, San Diego, CA, USA

Kimberley Haines Western Health, Australia and New Zealand Intensive Care Society Research Center, Monash University, Clayton, VIC, Australia

Negin Hajizadeh Center for Health Innovations and Outcomes Research (CHIOR), Hofstra Northwell School of Medicine and Northwell Health, Manhasset, NY, USA

Scott D. Halpern Department of Medicine, Palliative and Advanced Illness Research Center, Philadelphia, PA, USA

Center for Health Incentives and Behavioral Economics at the Leonard Davis Institute of Health Economics, University of Pennsylvania School of Medicine, Philadelphia, PA, USA

Joanna L. Hart Department of Medicine, Palliative and Advanced Illness Research Center, Philadelphia, PA, USA

Center for Health Incentives and Behavioral Economics at the Leonard Davis Institute of Health Economics, University of Pennsylvania School of Medicine, Philadelphia, PA, USA

Christiane S. Hartog Department of Anaesthesiology and Intensive Care Medicine, Charité – Universitätsmedizin Berlin, Berlin, Germany

Ramona O. Hopkins Pulmonary and Critical Care Medicine, Intermountain Medical Center, Murray, UT, USA

Center for Humanizing Critical Care, Intermountain Healthcare, Murray, UT, USA

Psychology Department and Neuroscience Center, Brigham Young University, Provo, UT, USA

Catherine L. Hough Division of Pulmonary, Critical Care and Sleep Medicine, Harborview Medical Center, University of Washington, Seattle, WA, USA

Truong-Giang Huynh Medical-Surgical ICU, University of California, San Diego Health, San Diego, CA, USA

James C. Jackson Center for Critical Illness, Brain Dysfunction, and Survivorship (CIBS), Vanderbilt University Medical Center, Nashville, TN, USA

Department of Psychiatry, Vanderbilt University School of Medicine, Nashville, TN, USA

Research Service, Department of Veterans Affairs Medical Center, Tennessee Valley Healthcare System, Nashville, TN, USA

Stuti J. Jaiswa The Scripps Research Institute, La Jolla, CA, USA

Suzette Jernigan Burn ICU, Burn Special Care, University of California, San Diego Health, San Diego, CA, USA

Erin K. Kross Division of Pulmonary, Critical Care and Sleep Medicine, Harborview Medical Center, University of Washington, Seattle, WA, USA

Simon Lasair Compassion Research Lab, Faculty of Nursing, University of Calgary, Calgary, AB, Canada

Deborah Linehan University of Maryland Medical Center, Department of Respiratory Care, Baltimore, MD, USA

Jason H. Maley Massachusetts General Hospital, Harvard Medical School, Boston, MA, USA

Jennifer L. McAdam School of Nursing, Samuel Merritt University, Oakland, CA, USA

Kathleen McCue Children's Program, The Gathering Place, Cleveland, OH, USA

Janet Marty Mendis NICU, University of California, San Diego Health, San Diego, CA, USA

Mark E. Mikkelsen Medical Intensive Care Unit, Penn Presbyterian Medical Center, Philadelphia, PA, USA

Critical Care Section, Perelman School of Medicine at the University of Pennsylvania, Philadelphia, PA, USA

Giora Netzer Division of Pulmonary and Critical Care Medicine, University of Maryland School of Medicine, Baltimore, MD, USA

Department of Epidemiology, University of Maryland School of Medicine, Baltimore, MD, USA

Jetina Okereke Division of Pulmonary and Critical Care Medicine, University of Maryland School of Medicine, Baltimore, MD, USA

Robert L. Owens Pulmonary, Critical Care and Sleep Medicine Division, University of California San Diego, La Jolla, CA, USA

Thomas Patterson University of California, San Diego Department of Psychiatry, San Diego, CA, USA

Neethi Pinto Section of Pediatric Critical Care, The University of Chicago Medicine Comer Children's Hospital, Chicago, IL, USA

Department of Pediatrics, The University of Chicago, Chicago, IL, USA

Margaret A. Pisani Yale University, New Haven, CT, USA

Nilu Rahman Child Life Department, Johns Hopkins Children's Center, Baltimore, MA, USA

Nicole Roeder Yale University, New Haven, CT, USA

Julie Rogan Medical Intensive Care Unit, Penn Presbyterian Medical Center, Philadelphia, PA, USA

Eileen Rubin ARDS Foundation, Northbrook, IL, USA

Henry J. Silverman University of Maryland Baltimore, Baltimore, MD, USA

Shane Sinclair Compassion Research Lab, Faculty of Nursing, University of Calgary, Calgary, AB, Canada

Kristina Stepanovic Center for Critical Illness, Brain Dysfunction, and Survivorship (CIBS), Vanderbilt University Medical Center, Nashville, TN, USA

Joanna L. Stollings Department of Pharmaceutical Services, Vanderbilt University Medical Center, Nashville, TN, USA

Steffanie A. Strathdee University of California, San Diego Department of Medicine, San Diego, CA, USA

Julie Van Center for Critical Illness, Brain Dysfunction, and Survivorship (CIBS), Vanderbilt University Medical Center, Nashville, TN, USA

Avelino C. Verceles Division of Pulmonary and Critical Care Medicine, University of Maryland School of Medicine, Baltimore, MD, USA

Michael E. Wilson Pulmonary and Critical Care Medicine, Mayo Clinic, Rochester, MN, USA

Donald L. Zimmerman Healthcare Management, University of New Orleans, New Orleans, LA, USA

Chapter 1
An Introduction and Overview of Why Families Matter in the Intensive Care Unit

Giora Netzer

Defining Family

Ab ovo, please note that the term "family" is defined and used inclusively to reflect what makes us human and wonderful. The definition for family used here and throughout this book is that used by the Society of Critical Care Medicine's 2017 guidelines on family-centered care [1]:

> Family is defined by the patient or, in the case of minors or those without decision-making capacity, by their surrogates. In this context, the family may be related or unrelated to the patient. They are individuals who provide support and with whom the patient has a significant relationship.

Thinking About and Naming the Challenge

Traditionally, we have viewed the task of engaging families in the ICU as one of communication. This model emphasizes the need to improve *our* efforts at communication (the transmitter) but assumes the existence of a normally functioning receiver (the families). Observational data make a clear association between the quality of perceived communication and families' psychological state, including anxiety, depression, and post-traumatic stress disorder (PTSD) [2–5]. However, early, multicenter studies employing the logic of increased communication with families all failed to improve families' or their loved ones' outcomes [6–9]. Superficially addressing one symptom of a complex pathophysiology was not going to cut it.

G. Netzer
Division of Pulmonary and Critical Care Medicine, University of Maryland
School of Medicine, Baltimore, MD, USA
e-mail: gnetzer@som.umaryland.edu

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_1

Broadly, families living the nightmare of their loved one being close to death are barraged with high-intensity emotions. They are stressed, anxious, and depressed [10, 11]. Many have PTSD before even leaving the ICU [12]. Sleep deprivation further torments them [13]. Unable to process these insults, they may turn to maladaptive coping, further exacerbating their suffering [14]. Thinking about the possible death of their loved ones further deteriorates their social problem-solving skills [15]. Presented with data, they suffer the same biases we all do in daily life but now with greater consequences [16, 17]. As they gather together, families grapple with the agonizing process of having to speak for their loved one in a unified voice, despite often being wracked by disagreement [18].

The challenges faced by families after their ICU stay, caring for survivors of critical illness or mourning their loss, was defined in 2012 [19]. This definition recognized the psychological morbidity incurred during the ICU course on family members as they returned home. However, the suffering of families while still in the ICU was not discussed (speaking with Judy Davidson, it seems the authors intended it to encompass both during and after the ICU; if I encroached inappropriately on this term, I am truly sorry). Additionally, what family members experienced seemed to extend beyond just suffering described in this syndrome, to also include obstacles to cognition, threatening their ability to advocate and care for their loved ones.

We termed this constellation the Family Intensive Care Unit Syndrome (FICUS) (Fig. 1.1) [20]. While FICUS may not have been the catchiest acronym, we hoped to capture the symbolism of the *Ficus carica*, the fig tree. Just as illness and suffering are shared by all people, the *Ficus* tree plays an important role across the world's

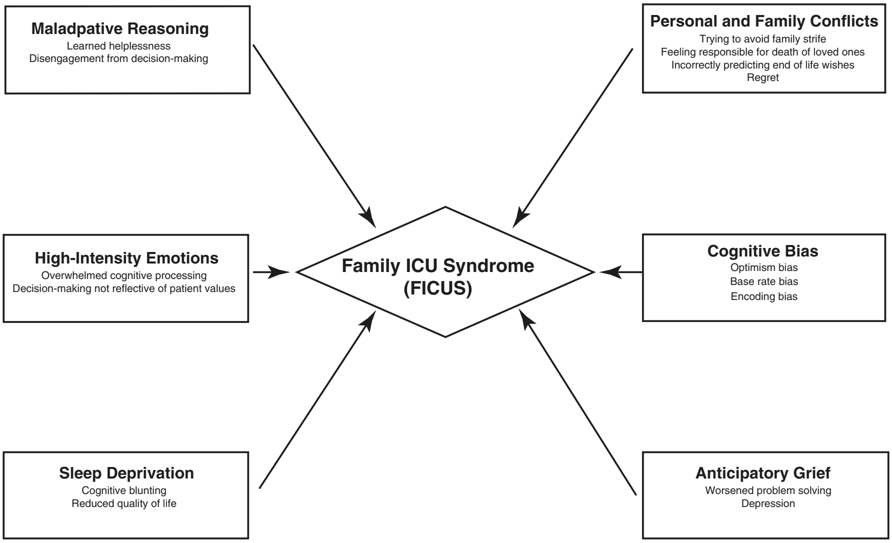


Fig. 1.1 Family ICU syndrome conceptual model. (Reprinted from Netzer and Sullivan [20] with permission of the American Thoracic Society. Copyright © 2018 American Thoracic Society. The *American Journal of Respiratory and Critical Care Medicine* is an official journal of the American Thoracic Society)

religions, from its multiple appearances in the Pentateuch and New Testament, to the Quran (including Sura 95, “The Fig”), and to Buddha’s enlightenment under the Bodhi tree (itself a fig).

Harnessing the Best of our Human Instinct

At the time, putting these thoughts to text, the task seemed overwhelming. I looked at prior negative studies that worked to support families, the enormous hurt of families, and I sometimes despaired. But being at the bedside, caring for patients in the medical ICU, and meeting with their families reminded me of the most important variable, though perhaps the hardest to measure: love.

It’s said that more than the calf wants to suckle, the cow wants to nurse [21]. A parent’s instinct is to give. Families have a natural instinct to protect those they love [22]. They ask us what they can do to help [23]. The first time I read Judy Davidson’s theory of facilitated sensemaking, I was simply struck; this approach both encourages and nurtures the instinct to give. By communicating with and caring for families, valuing their presence, and engaging them in bedside activities, we help them to make sense of the situation and their new role [24].

Previously, I had felt uneasy as I tried to reconcile my two worlds. Outcome-driven medicine was the thesis; all efforts should be directed toward rigorously tested processes that improve outcomes. The antithesis, in my mind, was my humanistic concern for families and their well-being. But as data accumulated, engaging families at the bedside was very clearly recognized as the synthesis. Doing so both improved the families’ lot while helping their loved ones do better clinically (Fig. 1.2).

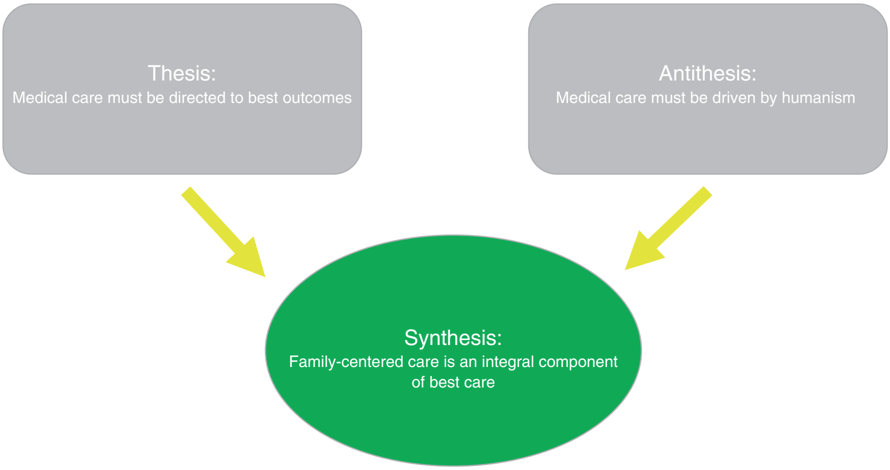


Fig. 1.2 Family engagement: synthesizing the best in ICU care and caring

Family Engagement Improves Patient Outcomes

In short, putting families to work helps our patients while simultaneously bringing meaning and coping to the families themselves. For example:

- Families can increase rates of early mobilization, reducing the length of mechanical ventilation and ICU length of stay [25, 26].
- Liberalizing family presence at the bedside reduces ICU delirium [27].
- With families joining bedside rounds, ICU throughput improves [28].
- When parents participate in care in the neonatal ICU, their infants gain more weight and are more likely to breastfeed at discharge [29].
- Families participating in care have reduced anxiety levels [30].
- Families can keep an ICU diary, reducing their loved one's PTSD symptoms [31].
- Families are far more effective at detecting errors and adverse events than hospital safety systems [32].

We Need Families for the Health of ICU Survivors and of our Community as a Whole

As Jack Iwashyna predicted, survivorship is indeed the defining challenge of critical care in the twenty-first century [33]. A large proportion of ICU survivors require family caregiving for the activities of daily living [34, 35]. Moreover, families are key determinants in whether the physical limitations incurred during critical illness result in disability [36]. In one example, the support provided by families, both instrumental and emotional, is significantly associated with the degree of recovery after stroke [37]. In the United States, (conservatively) 200,000 older survivors are our neighbors [38], not even counting younger survivors. Given the role that families play in caring for our ICU patients after discharge and modifying their post-ICU trajectories, as ICU clinicians, we must recognize that caring for families in the ICU is caring for the community itself [39].

Family Engagement Is Good for Us as a Healthcare Team

While we embrace the ICU for its energy and excitement, burnout is a significant problem among ICU providers [40]. When families are unsupported, conflict is more likely; that conflict, in turn, further increases burnout risk [41, 42]. As Joe Bienvenu points out [43], an intervention of targeted communication with families reduces staffing burnout as well [44]. In this sense, engaging families may benefit us as much as it does our patients and their loved ones.

This Book as Springboard

Critical care medicine is a relatively young specialty. Our focus on family-centered care and the science of what happens to families in the ICU is even younger. In collecting ideas for this book, I am honored that this dynamic group of contributing clinicians, families, and researchers has created a nidus for further thought, debate, and research. It's my hope that these pages also provide both better understanding and care for our patients' families in ICUs today. This approach to care is a win-win-win for our patients, our patients' families, and ourselves.

References

1. Davidson JE, Aslakson RA, Long AC, et al. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. Crit Care Med. 2017;45(1):103–28.
2. Azoulay E, Pochard F, Kentish-Barnes N, et al. Risk of post-traumatic stress symptoms in family members of intensive care unit patients. Am J Respir Crit Care Med. 2005;171(9):987–94.
3. Majesko A, Hong SY, Weissfeld L, White DB. Identifying family members who may struggle in the role of surrogate decision maker. Crit Care Med. 2012;40(8):2281–6.
4. Studdert DM, Mello MM, Burns JP, et al. Conflict in the care of patients with prolonged stay in the ICU: types, sources, and predictors. Intensive Care Med. 2003;29(9):1489–97.
5. Teno JM, Fisher E, Hamel MB, et al. Decision-making and outcomes of prolonged ICU stays in seriously ill patients. J Am Geriatr Soc. 2000;48(5 Suppl):S70–4.
6. Burns JP, Mello MM, Studdert DM, Puopolo AL, Truog RD, Brennan TA. Results of a clinical trial on care improvement for the critically ill. Crit Care Med. 2003;31(8):2107–17.
7. Curtis JR, Nielsen EL, Treece PD, et al. Effect of a quality-improvement intervention on end-of-life care in the intensive care unit: a randomized trial. Am J Respir Crit Care Med. 2011;183(3):348–55.
8. Daly BJ, Douglas SL, O'Toole E, et al. Effectiveness trial of an intensive communication structure for families of long-stay ICU patients. Chest. 2010;138(6):1340–8.
9. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT principal investigators. JAMA. 1995;274(20):1591–8.
10. Choi J, Sherwood PR, Schulz R, et al. Patterns of depressive symptoms in caregivers of mechanically ventilated critically ill adults from intensive care unit admission to 2 months postintensive care unit discharge: a pilot study. Crit Care Med. 2012;40(5):1546–53.
11. Pochard F, Darmon M, Fassier T, et al. Symptoms of anxiety and depression in family members of intensive care unit patients before discharge or death. A prospective multicenter study. J Crit Care. 2005;20(1):90–6.
12. Paparrigopoulos T, Melissaki A, Efthymiou A, et al. Short-term psychological impact on family members of intensive care unit patients. J Psychosom Res. 2006;61(5):719–22.
13. Verceles AC, Corwin DS, Afshar M, et al. Half of the family members of critically ill patients experience excessive daytime sleepiness. Intensive Care Med. 2014;40(8):1124–31.
14. Sullivan DR, Liu X, Corwin DS, et al. Learned helplessness among families and surrogate decision-makers of patients admitted to medical, surgical, and trauma ICUs. Chest. 2012;142(6):1440–6.
15. Glick DR, Motta M, Wiegand DL, Range P, Reed RM, Verceles AC, Shah NG, Netzer G. Anticipatory grief and impaired problem solving among surrogate decision makers of critically ill patients: A cross-sectional study. Intensive Crit Care Nurs. 2018; Epub ahead of print.

16. Leiter N, Motta M, Reed RM, et al. Numeracy and interpretation of prognostic estimates in intracerebral hemorrhage among surrogate decision makers in the neurologic ICU. Crit Care Med. 2018;46(2):264–71.
17. Zier LS, Sottile PD, Hong SY, Weissfield LA, White DB. Surrogate decision makers' interpretation of prognostic information: a mixed-methods study. Ann Intern Med. 2012;156(5):360–6.
18. Schenker Y, Crowley-Matoka M, Dohan D, Tiver GA, Arnold RM, White DB. I don't want to be the one saying 'we should just let him die': intrapersonal tensions experienced by surrogate decision makers in the ICU. J Gen Intern Med. 2012;27(12):1657–65.
19. Davidson JE, Jones C, Bienvenu OJ. Family response to critical illness: postintensive care syndrome-family. Crit Care Med. 2012;40(2):618–24.
20. Netzer G, Sullivan DR. Recognizing, naming, and measuring a family intensive care unit syndrome. Ann Am Thorac Soc. 2014;11(3):435–41.
21. Schottenstein Edition Talmud Bavli. Vol Pesachim Volume 3. 1st ed. Brooklyn: ArtScroll Mesorah Publications; 1998.
22. McAdam JL, Arai S, Puntillo KA. Unrecognized contributions of families in the intensive care unit. Intensive Care Med. 2008;34(6):1097–101.
23. Zimmerman BA. A piece of my mind. Patient's sister, seeking job. JAMA. 2013;309(19):2003–4.
24. Davidson JE, Zisook S. Implementing family-centered care through facilitated sensemaking. AACN Adv Crit Care. 2017;28(2):200–9.
25. Rukstele CD, Gagnon MM. Making strides in preventing ICU-acquired weakness: involving family in early progressive mobility. Crit Care Nurs Q. 2013;36(1):141–7.
26. Lai CC, Chou W, Chan KS, et al. Early mobilization reduces duration of mechanical ventilation and intensive care unit stay in patients with acute respiratory failure. Arch Phys Med Rehabil. 2017;98(5):931–9.
27. Rosa RG, Tonietto TF, da Silva DB, et al. Effectiveness and safety of an extended ICU visitation model for delirium prevention: a before and after study. Crit Care Med. 2017;45:1660.
28. Muething SE, Kotagal UR, Schoettker PJ, Gonzalez del Rey J, DeWitt TG. Family-centered bedside rounds: a new approach to patient care and teaching. Pediatrics. 2007;119(4):829–32.
29. O'Brien K, Robson K, Bracht M, Cruz M, Lui K, Alvaro R, da Silva O, Monterrosa L, Narvey M, Ng E, Soraisham A, Ye XY, Mirea L, Tarnow-Mordi W, Lee SK, FICare Study Group, FICare Parent Advisory Board. Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial. Lancet Child Adolescent Health. 2018;2(4):245–54.
30. Skoog M, Milner KA, Gatti-Petito J, Dintyala K. The impact of family engagement on anxiety levels in a cardiothoracic intensive care unit. Crit Care Nurse. 2016;36(2):84–9.
31. Parker AM, Sricharoenchai T, Raparla S, Schneck KW, Bienvenu OJ, Needham DM. Posttraumatic stress disorder in critical illness survivors: a metaanalysis. Crit Care Med. 2015;43(5):1121–9.
32. Khan A, Coffey M, Litterer KP, et al. Families as partners in hospital error and adverse event surveillance. JAMA Pediatr. 2017;171(4):372–81.
33. Iwashyna TJ. Survivorship will be the defining challenge of critical care in the 21st century. Ann Intern Med. 2010;153(3):204–5.
34. Im K, Belle SH, Schulz R, Mendelsohn AB, Chelluri L, Investigators Q-M. Prevalence and outcomes of caregiving after prolonged (> or =48 hours) mechanical ventilation in the ICU. Chest. 2004;125(2):597–606.
35. Griffiths J, Hatch RA, Bishop J, et al. An exploration of social and economic outcome and associated health-related quality of life after critical illness in general intensive care unit survivors: a 12-month follow-up study. Crit Care. 2013;17(3):R100.
36. Iwashyna TJ, Netzer G. The burdens of survivorship: an approach to thinking about long-term outcomes after critical illness. Semin Respir Crit Care Med. 2012;33(4):327–38.
37. Tsouna-Hadjis E, Vemmos KN, Zakopoulos N, Stamatelopoulos S. First-stroke recovery process: the role of family social support. Arch Phys Med Rehabil. 2000;81(7):881–7.

38. Iwashyna TJ, Cooke CR, Wunsch H, Kahn JM. Population burden of long-term survivorship after severe sepsis in older Americans. J Am Geriatr Soc. 2012;60(6):1070–7.
39. Netzer G, Davidson JE. Creating patient- and family-focused care in the intensive care unit. In: Zimmerman DO-H, editor. Person-focused health care management. New York: Springer; 2017.
40. Moss M, Good VS, Gozal D, Kleinpell R, Sessler CN. An official critical care societies collaborative statement: burnout syndrome in critical care health care professionals: a call for action. Am J Crit Care. 2016;25(4):368–76.
41. Embriaco N, Azoulay E, Barrau K, et al. High level of burnout in intensivists: prevalence and associated factors. Am J Respir Crit Care Med. 2007;175(7):686–92.
42. Burghi G, Lambert J, Chaize M, et al. Prevalence, risk factors and consequences of severe burnout syndrome in ICU. Intensive Care Med. 2014;40(11):1785–6.
43. Bienvenu OJ. Is this critical care clinician burned out? Intensive Care Med. 2016;42(11):1794–6.
44. Quenot JP, Rigaud JP, Prin S, et al. Suffering among carers working in critical care can be reduced by an intensive communication strategy on end-of-life practices. Intensive Care Med. 2012;38(1):55–61.

Chapter 2
Family Voices from the Intensive Care Unit

Eileen Rubin and Sal Colianni

Eileen Rubin, JD, is an acute respiratory distress syndrome (ARDS) survivor and founder of the ARDS Foundation, the largest critical care patient- and family-advocacy organization. She has worked to increase ARDS awareness among the public. Her activities include providing a patient voice and leadership in the American Thoracic Society and the Society of Critical Care Medicine, contributing to national guidelines, and engaging in Patient-Centered Outcomes Research Institute-sponsored research.

It is difficult to think of the intensive care unit as anything but an awful place. It is traumatic for patients and it is traumatic for their loved ones. No one asks to be there; for patients, it is because they are critically ill, and for families, it is because their loved one is so sick. Most people are unfamiliar with protocol, procedure, terminology, and proper behavior. I have experienced being both a critical care patient and also a family member of a critical care patient. In 1995, when I was 33 years old, I spent 9 weeks in the hospital with acute respiratory distress syndrome, a syndrome that causes widespread inflammation in the lungs as well as many other medical complications. At the time I was in the ICU, ARDS had a mortality rate of over 50%. Of those 9 weeks in the hospital, 8 were on the ventilator and 4 were in the ICU, mostly in a drug-induced coma. And in 2011, my father found himself in another ICU, diagnosed with acute lung injury. Though my parents and siblings were familiar with having a loved one in ICU, I was not. I knew right away that being on the other side of the bed was a completely different experience than being a patient, and even though there are many similarities, there are a tremendous number of aspects that make it more difficult, frustrating, and completely overwhelming.

E. Rubin (✉)
ARDS Foundation, Northbrook, IL, USA

S. Colianni
Philadelphia, PA, USA

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_2

In October, 2011, my father, 77 years old, had terrible ear pain. He was flying home from Florida the next day, so he visited the clinic at the pharmacy, where they said his ear was clear. Over the next few weeks, his ear and throat pain continued to worsen; he developed a constant cough and grew weaker. Multiple physician visits did not yield a diagnosis. Three trips to the emergency room and two inpatient admissions followed. A diagnosis of interstitial lung disease was entertained, and he was discharged home on steroids after the second hospitalization.

By Thanksgiving Day, he was in terrible condition, so weak he was barely able to stand. During the holiday weekend, someone always needed to be with him. Then, on Monday morning, my father sat up on his bed at 5:30 am and said twice, “I cannot get up.” My mother tried to help him but he slid right down the side of the bed. Paramedics took him to a local stroke center.

In the emergency room, we were frustrated by the delay in administering aspirin that was ordered after his electrocardiogram. The decision was made to transfer my dad to another hospital in the network.

My father was taken by ambulance to and admitted into the other hospital’s intensive care unit. My father was in the ICU for about 3 1/2 weeks. The ICU was an open one, without visiting hours. Family was able to come and go freely. Shortly after admission, the ICU staff became familiar with our family. They were helpful and friendly. When we met the attending intensivist, unfortunately, he was cold and aloof with my father, my mother, and our family. We felt he was not very forthcoming with information and that we were bothering him when we asked questions. By later in the week, his attitude changed and we felt more comfortable with him in charge of our father’s care. His attitude seemed to change as my father’s condition grew worse. From a former patient perspective, it was unfortunate that my father was unable to view this physician as a kind man, generously offering information with a more gentle attitude.

The nursing care was excellent. The nurses were kind and attentive, answered questions, and tried to make us as comfortable as possible. Nurses always introduced themselves to my father and to family. They answered questions, answered the call button quickly, and reacted to any situation appropriately. There was also a continuity of nursing care, as often my father had the same nurses on different days and most nurses worked 12 h shifts, long enough for us to get to know them and for them to get to know us. From a family perspective, the nurses seemed to have a vested interest in the care, comfort, and survival of my father.

They knew he had pneumonia but the antibiotics and steroids were not working. He had to have a procedure done involving his lungs and his heart. The day before the procedure, two of the doctors sat in a private room with my mother and now, as my sister had flown in from Arizona, all four of my father’s children, and they thoroughly explained the two-part procedure to us. They answered all of our questions and took as much time as we needed to repeat explanations. Although we were very worried, we felt comfortable with the surgeon and intensivist from the floor, who would also be present at surgery as they removed some of the uncertainty family feels when a loved one is going into surgery. The next day, after seeing my father off to surgery, our family waited in the surgical waiting area. Because his surgery took longer than anticipated, we asked that his status be checked, which was done without complaint. A diagnosis of cryptogenic organizing pneumonia was made.

My father's condition seemed to be getting worse. His voice was raspy and he was desperate to leave the hospital. He kept saying, "They are trying to kill me, get me out of here!" When I told him that I could not take him out, he said with anger, "You're a lousy daughter!" He told he to call my older brother for him, which I did. On the phone, he begged my older brother to come to the hospital and take him home, repeating to him that "they were trying to kill him!" My father also kept asking my mother and sister to get him out of the hospital. He never asked the nurses, but of course, in his state of delirium, he felt that they were in on the plan to kill him. The time when a patient is experiencing this sort of delirium is one of the most upsetting times for the family. It seems like there is nothing we are able to do to make anything better for my father. Because we could not give in to his demands, he reacted with anger and frustration. During this time, my father also had moments of pure sweetness, which happened when he told my sister, "Tell Mom when I get out of here, I am going to marry her!" But the other moments were so disturbing and felt so real. We could see his anxiety, his fear, and his frustration.

If there were any suggestions of how we could help him through this time, we were not given this information. But we felt that doctors and nurses were doing everything that they could, adjusting medications and trying to make him more comfortable, to lessen the delirium. When my father was reintubated again, it felt like a relief. He was again deeply medicated and no longer able to talk. As a former patient, I recall vividly the time when I was suffering from delirium. I remember not only how I felt but also how upset my family was, fearing I had suffered from brain damage. I also knew that there were two family members who saw me during that time who could never come back to visit me in the hospital afterwards because of how terrible I looked. When my father was intubated again, I felt extremely guilty; admittedly I felt a strong sense of relief but at the same time, the feeling of guilt was overwhelming.

The following day, they extubated him again. All day though, my father was declining. Later that day, we were told that he was losing blood, and, at some point, a nurse told us to go to the waiting room. My brothers showed up and all five of us waited for hours without information. In a small, private room to talk, three doctors told us that my father had already gone through eleven units of blood and they felt that surgery was the only option. They also said they did not believe that he would survive surgery. We saw our father for a few seconds before he was taken to surgery. We waited in the ICU waiting room for 5–6 h. The surgeon who performed the original surgery spoke to us. He admitted that he must have done something during the original surgery to cause the bleeding. He was very honest and comforting to our family and we had no anger or animosity.

The days after that surgery were among the most difficult for us as a family. We all had to forgo sleep, meals, showers, our work responsibilities, and our own spouses and children for days. But from that day forward, we started to see an improvement in my father. He was started on large amounts of steroids. A few days later, when they were getting near the time to extubate him, they told us that he had been receiving different medications and hopefully his delirium would be reduced, which it was. He spent another week in the ICU, a total of about 3 1/2 weeks, and was stabilized, extubated, and moved to a cardiac step-down unit. From there, he spent 2 more weeks in the hospital inpatient rehabilitation.

During the time in the ICU, my father's survival was a constant concern for his family. We worried that he was uncomfortable. We also felt exhausted all the time. We could not sleep but we were never fully alert. My mother, when she ate, had every meal in the hospital, often in my father's hospital room. Sometimes, she had a meal in the waiting room. Occasionally, she went down to the hospital cafeteria. The rest of us often missed meals or ate fast food and, likewise, had too many in the hospital. Prior to discharge, the staff at the hospital arranged for him to see a visiting nurse, a physical therapist, an occupational therapist, and a speech therapist at home, which was extremely helpful.

My mother stopped working while my father was sick. She had a part-time job as a travel agent. My sister, a public defender in Arizona, took off time from work and flew into town to stay while my father was ill. I was working part time as a criminal defense attorney and did not work during this time. My older brother, a busy real estate attorney, cut his hours drastically, coming to the hospital several times within a day. My younger brother, an executive at a real estate company and also an attorney, also cut his work hours drastically and was at the hospital several times each day as well. My father, who managed real estate properties, was unable to work and therefore, both my brothers needed to attend to his work during and after his hospitalization.

The expenses associated with a loved ones stay in ICU are beyond just the parking expenses. For our family, with four or five cars coming from different locations at different times each day, they began to add up. The ICU vouchers to reduce the parking rate helped a bit. Also, after discharge, my mother needed help to care for my father at home. This cost for a home health aide was $200 a day, for 9 days.

After discharge, my mom's new role was as a constant caregiver. She was unable to go back to work because she needed to be home all the time. Since my father was older, his recovery was slow. Family members and friends would come over to visit and also give my mother a break, but the reality was that all of the responsibility of being a caregiver fell on her. She had to schedule and make sure that my father was ready for his therapy appointments. She had to keep track of all of the medication that he was taking, including what to take, the time, and amount of medication. She also was responsible for filling and refilling medication. It was her responsibility to schedule and get my father to doctor appointments after his hospitalization. In addition, she had to make sure that the house had the types of foods that my father could eat, since he was on a specific diet after his hospitalization. At night, she always worried if he needed to get up to use the bathroom. Would he be able to get up? Would he fall? She knew she would be unable to get him up if that happened.

After spending 7 weeks in the hospital, 3 1/2 of them in ICU while my father was ill, my family believes that ICU clinicians talking to the patient's family should provide as much information as possible, along with full explanations of medical procedures, equipment, terminology, and the diagnosis. Even when a family thinks they know what is going on, they should make sure they actually understand everything. Many people describe themselves during this time as feeling like a deer in headlights. They might appear to comprehend what is happening, but in reality, all of the information being offered is mixed in with all of their anxiety, concern, fear, and uncertainty. And as the days go on, their mind is also affected by a lack of sleep, lack of a proper diet, mounting stress, and all of the other responsibilities they need to attend to but no longer can. Sometimes caregivers do not go home, even to shower and take their daily medications.

Having information makes it easier for the family to cope with their loved one's hospitalization. To be kept in the dark is never good, even if the news is not good news. Clinicians should also be more sensitive to what a family has been through, especially when dealing with prior hospitalizations or experiences with medical professionals, that led up to the ICU admission. In our family's case, there were four bad experiences where my father was put through a revolving door of hospitalizations, treated enough to go home, but he never received a diagnosis and continued to deteriorate. During these earlier visits and hospitalizations, doctors seemed to be putting a Band-Aid on a bullet wound in order to discharge him. Those prior experiences definitely affected our family, even when facing new doctors in the ICU. We approached with greater apprehension and uncertainty.

Finally, even though my father's ICU staff was overall excellent, those same doctors, nurses, and others often spoke about medical issues in front of my father. They only called our family out of his presence on two occasions to have a conversation. Even if a patient is in a medically induced coma, medical staff should never have these discussions about the patient, that do not include the patient, in front of the patient. No one can know the effect conversations like that have. Patients need to be treated as people. Clinicians should always remember that when they are walking into the ICU, they are going to work. When a family walks into the ICU, they are walking into the unknown. This environment is foreign to them and is filled with uncertainty, anxiety, and fear. But working together, the ICU can be a more comfortable place for patients and families alike.

In 2012, Deb Colianni developed pneumonia that progressed to the acute respiratory distress syndrome (ARDS). She was intubated and received mechanical ventilation, also requiring neuromuscular blockade for 21 days. Additionally, she required hemodialysis for treatment of acute renal failure. She and her husband, Sal, have shared their story and have also contributed to the Society of Critical Care Medicine's 2017 Guidelines for Family-Centered Care.

Deb was away for a few days at a college graduation at Johns Hopkins in Maryland, with family and friends. When she returned home, she was very tired and exhausted and thought it was her fibromyalgia acting up. This was a Saturday and Deb stayed home from work for the week, which wasn't unusual as it's happened before. The week progressed, she was not feeling any better, and we started thinking that maybe this was something more serious. On Sunday morning Deb woke up feeling very weak, unable to walk, and seeing things and colors; we immediately went to our local hospital.

When we arrived at the emergency room, the nurses were going through the questions as to what was going on. As soon as they took her blood pressure, it was 50/30 and it was evident that this was very serious. They immediately rushed her into an examination room, where the doctors started doing all sorts of tests. They diagnosed her with pneumonia and found that one of her lungs collapsed, and the other not doing well. She also was in renal failure. This was a very long agonizing day. They admitted her and we had to wait until the next morning for a bed in the ICU dept. She was in the emergency room for over 12 h. When we finally got a room, they had to put her on a ventilator and started constant dialysis. The meds they were giving her were not working and she was failing rapidly. We didn't leave her side and slept at the hospital; when we saw the lung doctor on Tuesday morning, he informed me that Deb was very serious and I should call my family because he didn't believe she was going to make it thru the day.

They said they could not do anything more for her at this hospital and we needed to get her to a hospital that deals with this type of illness. After hours of trying different hospitals, we were very, very fortunate to transfer her to a tertiary care academic medical center. When we arrived, the attending physician said she was very serious and may not survive. Deb remained on a ventilator in the center's ICU for over 14 days, with septic shock. The doctors never found what bacteria caused the pneumonia and treated her for Legionnaires. She was at the referral center for a total of another 21 days.

When Deb was in the ICU, it was a very emotional draining experience. For the first 10 days, I never left the hospital except to sleep in the adjoining hotel. When I knew she was stable, I would go home for a few hours, and when I did it was just to get a few things, take a shower, and make sure all was ok at home and head back. When I finally started going home daily, I would drive an hour and a half each way, leave the hospital around 9 PM, and be back at 7 AM to be sure I was there when the doctors did their rounds. I was very scared knowing that Deb may not make it through this. I wouldn't know what to do without her: What about our children? What about the house? Where would I begin? Your mind starts going in a thousand directions. What would she want as far as a service if she didn't make it? We never talked about that. Deb was also suffering from ICU delirium which made things very difficult.

Physically, this was very hard emotional experience that I never want to feel again. I didn't eat, sleep, or function properly for over a month while this was going on. Fortunately, I'm in my own business and my customers were very understanding. I did have a few that I no longer do business with and lost quite a bit of money, but, you know, it wasn't important; it's only money. There were many other expenses as I stayed at the hotel across the street as well as other hotels; when I did eat, it was out (and not healthy meals), and parking, gas, and tolls all added up. These of course are expenses that I don't have on a daily or in this case a monthly basis. We have very good health insurance, and our out of pocket was thousands but could have been hundreds of thousands of dollars.

The nurses were fantastic, very understanding of our needs, and were very good with Deb. They kept us informed of everything that was going on and answered all questions that I asked. They made me feel comfortable in the environment I was in. I only had one bad experience. Before leaving one evening, Deb was upset that the air tube was down her throat, I informed the nurse about it, and Deb did pull it out and had to be put back in. As far as the team of doctors, I could never thank them enough for the care they gave Deb, allowing me to be there when they made their rounds, and answering all my questions. They took the time to explain them to me in detail so I fully understood what they were saying and where we were with Deb's care. I truly believe if we had gone to another hospital Deb would not be here with us today. Deb is a ARDS survivor because of them. My family and I are forever grateful, and Deb continues to stay in contact with the attending 5 years later.

When Deb finally came home, it was very difficult. She didn't want a home health aid. If anything, I recommend make sure you get an aid to help you. Deb just wanted to be home alone after all the happenings at the hospitals. I did it with some help from my family. She couldn't walk, had to stay in bed, was on oxygen and medication, etc. I had to feed her, bathe her, medicate her, exercise her legs, as well as go over with her what happened; she had no memory of what happened. For the first 3 weeks, we had to order in three meals a day. I didn't have time to cook. I slept on the couch next to her, so if she needed me I would be right there, and she needed me quite often. We had convert our dining room into a bedroom because she couldn't walk. The schedules of doctor visits were overwhelming. This went on for months.

What I would say is when someone is ill like Deb, be sure to tell the family members in writing as to what to expect when they get home and are on their own. I felt very uncomfortable not knowing what to expect or what to do. I learned very quickly.

Chapter 3
Cognitive Barriers to Effective Surrogate Decision-Making

Joanna L. Hart and Scott D. Halpern

Introduction

Family members of critically ill patients are routinely asked to participate in medical decision-making. Commonly, they adopt the role of surrogate decision-maker or the individual advocating for and speaking on behalf of an incapacitated patient. In doing so, these surrogates are charged with sharing responsibility for complex medical decisions with uncertain risks, benefits, and outcomes. Participation in such shared decision-making is known to lead to later psychological distress among family members of both surviving patients and those who die from their illnesses [1–3]. Additionally, surrogates' difficulties in interpreting information provided to them and representing patients' wishes have been implicated in the undesirably high intensity of care many patients receive prior to death [4–7]. Understanding the cognitive processes involved in decision-making is crucial to identifying and responding to these known ways in which the realities of shared decision-making deviate from its ideals.

A "good" or "rational" decision may be defined as a complete consideration of possible courses of action, followed by the selection of a choice that will maximize potential benefits while minimizing possible risks [8]. However, within the intensive care unit (ICU) setting, as in most settings, there are a number of fundamental ways in which decision-making diverges from this rational model. For example, there is often insufficient time or personal resources available to fully consider all potential options. In the ICU, the full array of potential options and their attributes may not be presented or presented well to the decision-maker by clinicians assisting

---

J. L. Hart (✉) · S. D. Halpern
Department of Medicine, Palliative and Advanced Illness Research Center,
Philadelphia, PA, USA

Center for Health Incentives and Behavioral Economics at the Leonard Davis Institute
of Health Economics, University of Pennsylvania School of Medicine, Philadelphia, PA, USA
e-mail: joanna.hart@uphs.upenn.edu

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_3

with shared decision-making. The potential benefits and risks of the available treatment options are often undefined due to a lack of evidence and are always imbued with medical uncertainty. Finally, the known risks and benefits of each option must be integrated with the background of patients' values and preferences, which are frequently unknown.

Further, these complex decisions are made in the context of two key features of the choice environment that influence the process of decision-making. First, surrogates are themselves thinking human beings and, as such, are known to behave in predictably irrational ways when making decisions. Second, the family members acting as surrogates are also under extreme stress, as they are participating in the care of a loved one who is critically ill while making decisions on that individual's behalf. These two contexts in which surrogate decision-makers are operating contribute to foreseeable missteps in the decision-making process and may be centrally related to the known psychological burden carried by family members of critically ill patients [1]. In this chapter, we focus on the first of these contextual barriers: the cognitive barriers to effective decision-making and associated ways in which critical care decision-makers may predicatably deviate from rational decision-making. For this discussion, we define effective decision-making as choosing healthcare options that maximize the benefits to patients based on their own values and goals.

Heuristics and Biases

All decision-makers use heuristics or cognitive shortcuts [9]. We employ heuristics to reduce the cognitive load of decision-making and could hardly get through a day without them. Heuristics allow us to ignore or simplify certain pieces of information that we might otherwise need to process as we evaluate options. The result is a decreased burden of information integration as we make a decision, making decisions faster and less effortful (Fig. 3.1). Indeed, the burdens of decision fatigue are well documented [10, 11], highlighting the theological value of heuristics.

Consider choosing a new television. A quick search on Amazon.com yields nearly 2000 results. A purely rational decision might require a comparative evaluation of each of these options, weighing the trade-offs of price, size, picture quality, Internet connectivity, parental controls, anticipated malfunction, and other features. Realistically, you would narrow this "choice set" of televisions down using past experiences, brand recognition, reviews from people like you, or what size televisions are typical in your social network. In this way, you no longer have to consider all 2000 options and your decision becomes easier. Easing that cognitive load and effort required is the function of heuristics.

Two classical explanations exist for why we use heuristics. First, decision-makers may make a rational trade-off between the quality of the decision-making process and the effort involved in making the decision, electing to sacrifice a

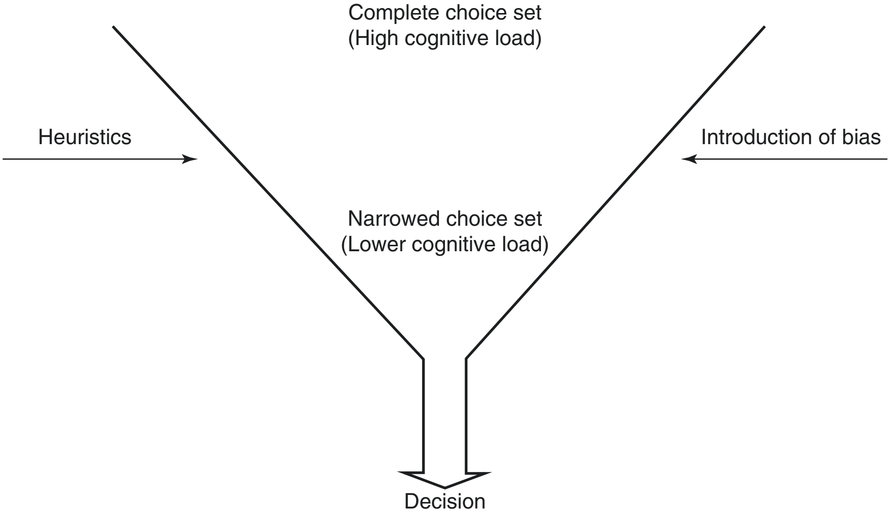


Fig. 3.1 Heuristics decrease cognitive load of decision-making and introduce bias

comprehensive process for speed and frugality. For our example, a rational actor may recognize that a *better* decision process would be to evaluate each television, but instead decide that's not worth her time or effort to do so. Using a shortcut may degrade decision process quality, but this is recognized and acceptable to the decision-maker. Alternatively, decision-makers may not have the cognitive capacity to engage in the lengthy process of ideal decision-making. Therefore, employing heuristics reflects the limitations in our judgment. We don't choose to use shortcuts; we are simply incapable of comparing all 2000 television options and so make suboptimal judgments.

Rejecting both of these theories, more recent views instead approach heuristics as a decision-maker's adaptive responses to a particular choice environment in order to meet his or her functional goals [9]. In other words, the use of heuristics represents neither an inherent loss of decision quality nor the necessary introduction of judgment errors but instead a useful tool that decision-makers may use to simplify decisions in precise ways based on the particular situation at hand [12]. In this way, using shortcuts as you select your television means that you have narrowed the field systematically based on values important to you and successfully selected a television with time leftover to eat dinner with your family, which you prefer to creating spreadsheets of television features.

While the use of heuristics should "confer no shame [13]," since we all use them, these tools may introduce error into the decision-making process or fail to appropriately correct for error once introduced. These errors are known as bias, or the systematic deviation away from making choices that promote one's own goals or interests. And in the context of surrogate decision-making in the ICU, such bias may lead to undesired outcomes for critically ill patients and their family members alike.

Biases in the ICU

Identifying when heuristics or resulting biases may be harmful in the context of critical care decision-making is a key first step in efforts to prevent them from causing actual harm to patients or surrogates. While evidence to date is limited in measuring the presence of these cognitive shortcuts in critical care decisions, clinicians guiding shared decision-making in the ICU would be helped by a working knowledge of how common heuristics and biases may influence decision-making [12]. We explore several well-described heuristics and biases that may be particularly relevant to the critical care setting (Table 3.1).

Optimism and Impact Biases

Medical decision-makers must develop expectations of potential health outcomes when considering the available options. These expectations are then used to compare and weigh the relative risks and benefits of each potential path. Patients and

Table 3.1 Selected biases relevant to critical care decision-making

Bias	Definition	Implications for critical care decision-making
Optimism bias	The tendency to overestimate the likelihood of desirable outcomes	May improve coping with unfavorable prognoses May prevent adaptation to negative outcomes and impair risk-benefit analysis of treatment decisions
Impact bias	The systematic overestimation of the impact an event will have on an individual's life	May lead to avoidance of potentially beneficial therapies or elect for treatments that leave decision-makers unsatisfied
Commission bias	The tendency to regard a harmful outcome from action to be *more desirable* than the same harmful outcome following inaction	May lead to decisions to act despite unfavorable risk-benefit ratios May lead to negative surrogate outcomes if they feel an increased personal responsibility for a negative outcome
Omission bias	The tendency to regard a harmful outcome from inaction to be *more desirable* than the same harmful outcome following action	May lead to avoidance of potentially beneficial treatments
Status quo bias	The tendency to maintain the current or previous choice rather than making a different choice	May cause a continuation of unwanted treatments because comfort-oriented goals of care in the ICU requires deviating from the status quo
Availability bias	The tendency to infer the likelihood of a future event by relying on whether they have any experience with such an event	May cause decision-makers to rely on their own prior experiences rather than objective data shared by clinicians

surrogates seek to make healthcare choices that maximize their well-being [14–19]. Yet, the difficulties of predicting future mortality, illness burden, and accompanying emotions may limit their abilities to accomplish this goal [20, 21]. These difficulties also make such prospection, or future thinking, cognitively burdensome. To offset this cognitive burden, patients and surrogates may rely on heuristics and emerge susceptible to their associated biases. Indeed, errors in prospection may arise through systematic errors, such as failing to assess or accurately interpret the risks and benefits of treatment options [22, 23].

One such systematic error is optimism bias, or the tendency to overestimate the likelihood of desirable outcomes [24]. Forming overly optimistic expectations may help some individuals cope with unfavorable prognoses or likely outcomes, such as death following critical illness. However, unrealistic optimism may also prevent these same individuals from adapting to future hardships [25–27] or from selecting treatments that mitigate such unfavorable outcomes. In this way, decision-makers may fail to be fiduciaries to their future selves or their loved ones.

Surrogates of critically ill patients are known to demonstrate high rates of optimism bias. In a demonstration of this, White and colleagues asked surrogates of ICU patients to interpret prognostic statements [7]. Although these statements were unrelated to their own loved one's condition, surrogates overwhelmingly demonstrated optimism bias in their interpretations. They reported that a physician statement of "90% chance of surviving" did not differ from the actual meaning while they interpreted a physician statement of "5% chance of surviving" as likely to result in a median of 15% survival with high variability in their responses (interquartile range, 5–40%) [7]. Wide ranges or deviation from the provided numerical estimate for both of these extremes would have suggested limited numeracy or mistrust of physician-provided estimates. However, the surrogates clearly responded differently to a poor prognosis when compared to a good one – the bias only emerged when a defense mechanism, such as optimism, was needed.

Impact bias is another well-recognized cause of prospective errors. When considering a health event or outcome, people systematically overestimate the impact that event will have on their life. Individuals may overestimate the beneficial effects that positive occurrences will have on their life or underestimate their ability to adapt to negative conditions [20]. For example, Smith and colleagues interviewed patients before and after kidney transplants [28]. Prior to transplant, the patients predicted how improved their quality of life would be after the transplant. Indeed, after transplant the patients did rate their quality of life as improved since pretransplant, but the magnitude of improvement was not nearly as dramatic as they had predicted.

In addition to overestimating the potential good to come from an event, human beings also underestimate their ability to adapt to negative situations. In a classic example, patients living with colostomies,[1] patients with reversed colostomies, and the general public indicated how many months of life they would give up in order to

---

[1] A colostomy is a surgical procedure that brings one end of the large intestine out through an opening made in the abdominal wall. Stool moves through the intestine and drains through the skin into a bag attached to the outside of the abdomen. This may be required due to blockage of or damage to the intestines and may be permanent or reversible. If reversed, the bowel is reconnected and stool no longer drains through the skin.

have normal bowel function rather than living with a colostomy. While all groups reported they would trade some months of life for normal bowel function, patients living with colostomies would give up 19 months of life on average while those without a colostomy would be willing to give up over 40 months of life. Therefore, although many patients who have not experienced colostomies rate bowel or bladder incontinence as states worse than death [29], those living with such conditions often find it more tolerable due to an unrecognized ability to adapt.

Unrealistic optimism and overestimates of impact may lead to systematic errors in medical decision-making. Optimism on the part of surrogate decision-makers may lead to preventable patient distress, excessive use of intensive measures near the end of life, and foreseeable, yet unforeseen, poor outcomes. In fact, critically ill patients are more likely to have longer ICU and hospital stays without any improvement in survival when their surrogates demonstrate optimism bias, even when adjusting for the patient's age and severity of illness [30]. Similarly, inaccurate expectations of impact may lead patients or surrogates to forgo potentially beneficial therapies or elect for treatments that leave them unsatisfied. Thus, these biases lead directly to care decisions that have been informed by inaccurate perceptions of future outcomes and are unlikely to maximize the benefit to patients.

Commission and Omission Biases

We often, somewhat cheekily, extoll our house officers to "don't just *do* something, *stand there*." In doing so, we intend to combat the tendencies of individuals – particularly those with less experience – to feel compelled to act, otherwise known as commission bias. This bias may contribute to the overuse of diagnostics and interventions that ultimately do not benefit the patient simply because to do so is to act rather than to be a passive observer and action may be favorable to some decision-makers. For example, Fagerlin and colleagues presented hypothetical scenarios to members of the public and asked them to consider treatment for a cancer diagnosis [31]. When faced with this hypothetical diagnosis, people were more likely to elect for cancer treatment that carried a *higher* risk of harm than living with the cancer itself! That is, they felt the need to act despite the fact that doing so carried an objectively unfavorable risk-benefit ratio. Similar situations undoubtedly play out in the critical care setting among patients and surrogates as well as clinicians. One possible explanation is that people feel the need to respond to a crisis rather than "standing by doing nothing," even if that response is more harmful than the crisis itself. Additionally, some may feel an increased personal responsibility for a negative outcome if the decision-maker makes no attempt to overcome the crisis.

However, omission bias may be even more common than commission bias. Individuals displaying omission bias regard a harmful outcome from *not* intervening (inaction) to be *more desirable* than the same harmful outcome following an active intervention. In an extreme but obvious form, allowing a person to die is viewed as preferable to actively killing. Evidence of this omission bias is apparent among physicians [32] and surrogates. For example, some parents choose not to vaccinate their children even though they recognize that the risks of vaccination are smaller than those associated with the disease the vaccine could prevent [14, 33, 34]. This omission bias may be due to decreased perceived personal responsibility for a poor outcome that follows from allowing the "natural progression" of disease.

While commission and omission biases oppose each other, together they provide the insight that medical decision-makers care not just about the outcomes of their decisions but also the *manner* in which those outcomes arise. The implications of omission and commission bias in the ICU have yet to be well described. In theory, a patient or surrogate's susceptibility to the biases of omission or commission would alter his or her treatment elections independent of the probabilities of predicted outcomes. For example, consider a surrogate choosing between electing for a life-supporting therapy or forgoing such a therapy. Rather than evaluating these options based on the patient's likely outcomes, the surrogate may instead base the decision on the perspective that electing for or against such a treatment alters his or her personal responsibility over poor outcomes that may follow. As such, the biases of omission and commission may not only influence the care a patient may receive but also the surrogate's well-being afterwards [2, 3].

Status Quo Bias

Distinct from these concepts but closely related is status quo bias or the tendency to maintain the current or previous choice rather than making a different choice [35]. Among several putative mechanisms underlying status quo bias is the possibility that people prefer to keep things the same lest they feel regret in the future over a choice they made that turned out poorly. Although decision-makers who maintain the status quo are also making a decision, they tend to experience less anticipated regret than those who choose against the status quo, as well as less actualized regret should a poor outcome result. This phenomenon suggests that decision-makers feel less personal responsibility for the outcome when they choose to remain with the existing status quo [36]. Therefore, decision-makers are again basing their choices on how large their personal role in outcomes would be rather than on the risks and benefits of each option.

In the critical care setting, nearly all individuals who enter the ICU do so with restorative goals [37]. Therefore, electing for comfort-oriented goals of care in the ICU requires deviating from the status quo. Interviews with surrogates of critically ill patients confirm their attention to regret management and desire to minimize personal responsibility for patients' death or poor outcomes [5], suggesting that status quo bias may have a large impact on patients' care.

The biases of commission, omission, and status quo together provide a framework for understanding how the process of decision-making may systematically introduce decision-making errors in the ICU. Patients and surrogates making decisions incorporate their own sense of personal responsibility into their choices, leading predictably to choices that seem to preserve future options and minimize regret, even when those choices differ from those that would be made in objective efforts to promote patients' goals.

Availability Bias

The availability bias is a heuristic that allows decision-makers to infer the likelihood of a future event by relying on whether they have any experience with such an event [38]. This is useful to decision-makers, as predicting future likelihoods requires considerable cognitive effort and, again, heuristics reduce the required cognitive load. One way to operationalize the availability bias is as *availability by recall.* This indicates that decision-makers rely on memory and experience to inform current decisions, often selecting the most available, or easily recalled, option [39].

Of particular interest within the context of critical care is the finding that the availability bias clearly influences risk perceptions. For example, when a person is asked whether death from leukemia or death from suicide is more common, the answer depends on his or her own experiences within his or her social network. That is, an individual with a family member who has died of leukemia will overestimate the risk of leukemia-associated deaths while an individual with a friend who has died from suicide will overestimate the risk of suicide-associated deaths [39]. Similar effects can be seen after exposure to media coverage of noteworthy but rare events, which leads people to overestimate the risk of such events [39].

These findings suggest that when patients or surrogates participate in high-stakes shared decision-making, they may rely on their own prior experiences rather than objective data shared by clinicians. Although this may reduce surrogates' cognitive load in an adaptive manner, the result may be predictable and systematic miscalculation of risk and subsequent errors in judgment.

We observed this phenomenon in interviewing individuals at high risk of adverse pulmonary conditions. When we asked patients and surrogates to consider the risks and benefits of management options for those conditions, some respondents relied on "available" but unrepresentative prior experiences [22]. As one respondent considered a bronchoscopy with transbronchial biopsies, he equated the risks with his prior experience undergoing a punch biopsy of the skin. Although they are both procedures with biopsies, the former is an invasive procedure requiring sedation and carrying the risk of a collapsed lung or hemorrhage while the latter is performed under local anesthetic and carries minimal risk. In this way, availability bias may lead that patient to bypass sufficient evaluation of the risks and benefits of the options. In that case, rather than helping the decision-maker, the heuristic has introduced error into the decision-making process.

Overcoming Biases

Strategies to overcome biases introduced by the use of well-recognized heuristics may improve decision quality. These strategies can generally be grouped as those that avoid bias by circumventing the heuristic shortcuts to decisions and those that directly harness the power of heuristics.

To date, much of the work in healthcare has focused on the avoidance of heuristics. By attempting to improve the quality and content of communication and information provided by clinicians to patients and their surrogates, these interventions have been based on the assumption that education would surmount the use of heuristics. In theory, strategies to improve decision-makers' knowledge may help overcome biases by slowing down the decision-making process or helping the decision-maker become aware of the decision, the available options, and the key features or considerations. Increasing such awareness, decreasing time pressures, and making the task of decision-making easier through facilitation of information acquisition are all meaningful ways of reducing the tendency to rely on heuristics [40]. Metacommunication, or drawing attention to the decision-making process and the heuristics employed, may have a similar impact. Thus, surrogates may be more likely to engage in rational decision-making, ultimately choosing options that would have the highest chance of a desirable outcome.

Unfortunately, this approach has largely failed in the realm of serious illness decision-making [41–43]. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) trial, a 2-year trial of clinician-focused and family-focused interventions to improve communication in the ICU, failed to improve patient care or outcomes [44]. More recently tested communication interventions have improved knowledge and awareness, but generally without changing treatment decisions or the care patients receive [45, 46].

By contrast, strategies that harness the use of heuristics recognize that it may be easier to redirect bias in constructive directions rather than to avoid bias altogether. Clinicians often act as *choice architects*, or the individuals responsible for designing choice environments for patients and surrogates. Clinicians therefore have both the opportunity and the great responsibility to influence choice environments in ways that maximize the likelihood that decision-makers choose options leading to good outcomes [47–49]. This approach uses insights from psychology, cognitive science, behavioral science, and economics, collectively termed *behavioral economics*. For example, simulation of treatments or outcomes and peer support may capitalize on the availability bias and the impact bias to allow the decision-maker to feel familiar with an otherwise unfamiliar choice or outcome. Scalable interventions that harness the default effect, or our tendency to opt for preselected choices, maintain autonomy while increasing the likelihood that a decision-maker will choose the option we have preselected for him or her [50–53]. Clinicians as choice architects have the opportunity to use these insights to help patients and surrogates overcome cognitive barriers to making choices that maximize benefit [47, 54].

Advance care planning is one area ripe for interventions that may influence the care patients receive and the burden of decision-making placed on their families during critical illness. Completing an advance directive (AD) is one form of advance care planning. These legal documents communicate the patient's wishes for treatments and goals of care to family members and clinicians in the event of serious illness when the patient cannot participate in decision-making. Yet, a minority of adults in the United States complete ADs [55]. One manner of decreasing the cognitive load required to complete an AD is to provide default selections rather than a blank form. Indeed, in a randomized trial of seriously ill patients completing ADs, the majority remained with a preselected set of choices that either favored comfort care or life extension [51]. This suggests that, even in high-stakes decisions, patients are employing heuristics to assist them in making choices. Therefore, designing interventions that account for and capitalize on such heuristics to bring about meaningful reductions in the burden of decision-making holds great potential.

However, the evidence base supporting use of these strategies in the ICU is still quite nascent. Used bluntly and without understanding, the potential impact of such strategies is likely to harm patients and surrogates [53]. Foundational work is therefore needed to identify the heuristics used most frequently by patients and surrogates and to quantify the varying degrees of impact each has on patient and family outcomes. Developing, testing, and implementing scalable interventions to overcome these frequent and highly influential heuristics would then follow.

Conclusion

Shared decision-making is one of the most important roles of family members in the ICU. As surrogates, they are asked to understand often unfamiliar treatment options, weigh complex risks and benefits, predict patients' and their own responses to future health status, and assume the voice of their loved ones. The difficulties they encounter while engaging in decision-making and the errors that they make when selecting the best option are not personal shortcomings, but rather predictable and systematic nuances of human behavior. If clinicians are able to guide patients and their surrogates past these cognitive barriers, the resulting healthcare choices would more accurately reflect and promote patients' true preferences and goals.

References

1. Wendler D, Rid A. Systematic review: the effect on surrogates of making treatment decisions for others. Ann Intern Med. 2011;154(5):336–46. https://doi.org/10.7326/0003-4819-154-5-201103010-00008. Epub 2011/03/02. PubMed PMID: 21357911
2. Gries CJ, Engelberg RA, Kross EK, Zatzick D, Nielsen EL, Downey L, et al. Predictors of symptoms of posttraumatic stress and depression in family members after patient death in

the ICU. Chest. 2010;137(2):280–7. https://doi.org/10.1378/chest.09-1291. PubMed PMID: 19762549; PubMed Central PMCID: PMCPMC2816640

3. Kose I, Zincircioglu C, Ozturk YK, Cakmak M, Guldogan EA, Demir HF, et al. Factors affecting anxiety and depression symptoms in relatives of intensive care unit patients. J Intensive Care Med. 2016;31(9):611–7. https://doi.org/10.1177/0885066615595791. PubMed PMID: 26168801
4. Nelson JE, Hanson LC, Keller KL, Carson SS, Cox CE, Tulsky JA, et al. The voice of surrogate decision makers: family responses to prognostic information in chronic critical illness. Am J Respir Crit Care Med. 2017;196:864. https://doi.org/10.1164/rccm.201701-0201OC. PubMed PMID: 28387538
5. Schenker Y, Crowley-Matoka M, Dohan D, Tiver GA, Arnold RM, White DB. I don't want to be the one saying 'we should just let him die': intrapersonal tensions experienced by surrogate decision makers in the ICU. J Gen Intern Med. 2012;27(12):1657–65. https://doi.org/10.1007/s11606-012-2129-y. Epub 2012/09/27. PubMed PMID: 23011253; PubMed Central PMCID: PMCPMC3509291
6. White DB, Ernecoff N, Buddadhumaruk P, Hong S, Weissfeld L, Curtis JR, et al. Prevalence of and factors related to discordance about prognosis between physicians and surrogate decision makers of critically ill patients. JAMA. 2016;315(19):2086–94. https://doi.org/10.1001/jama.2016.5351. Epub 2016/05/18. PubMed PMID: 27187301
7. Zier LS, Sottile PD, Hong SY, Weissfield LA, White DB. Surrogate decision makers' interpretation of prognostic information: a mixed-methods study. Ann Intern Med. 2012;156(5):360–6. https://doi.org/10.7326/0003-4819-156-5-201203060-00008. Epub 2012/03/07. PubMed PMID: 22393131; PubMed Central PMCID: PMCPMC3530840
8. Hamilton JG, Lillie SE, Alden DL, Scherer L, Oser M, Rini C, et al. What is a good medical decision? A research agenda guided by perspectives from multiple stakeholders. J Behav Med. 2017;40(1):52–68. https://doi.org/10.1007/s10865-016-9785-z. Epub 2016/08/28. PubMed PMID: 27566316; PubMed Central PMCID: PMCPMC5296255
9. Gigerenzer G, Gaissmaier W. Heuristic decision making. Annu Rev Psychol. 2011;62:451–82. https://doi.org/10.1146/annurev-psych-120709-145346. PubMed PMID: 21126183
10. Linder JA, Doctor JN, Friedberg MW, et al. Time of day and the decision to prescribe antibiotics. JAMA Intern Med. 2014;174(12):2029–31. https://doi.org/10.1001/jamainternmed.2014.5225.
11. Danziger S, Levav J, Avnaim-Pesso L. Extraneous factors in judicial decisions. Proc Natl Acad Sci. 2011;108(17):6889–92.
12. Blumenthal-Barby JS, Krieger H. Cognitive biases and heuristics in medical decision making: a critical review using a systematic search strategy. Med Decis Mak: Int J Soc Med Decision Making. 2015;35(4):539–57. https://doi.org/10.1177/0272989x14547740. Epub 2014/08/26. PubMed PMID: 25145577
13. McDonald CJ. Medical heuristics: the silent adjudicators of clinical practice. Ann Intern Med. 1996;124(1 Pt 1):56–62. Epub 1996/01/01. PubMed PMID: 7503478
14. Chapman GB, Coups EJ. Emotions and preventive health behavior: worry, regret, and influenza vaccination. Health psychology : official journal of the division of health psychology. Am Psychol Assoc. 2006;25(1):82–90. https://doi.org/10.1037/0278-6133.25.1.82. PubMed PMID: 16448301
15. Connolly T, Zeelenberg M. Regret in decision making. Curr Dir Psychol Sci. 2002;11(6):212–6.
16. Nea J-W. The importance and complexity of regret in the measurement of 'good' decisions: a systematic review and content analysis of existing assessment instruments. Health Expect. 2010;14:59–83.
17. Reb J. Regret aversion and decision process quality: effects of regret salience on decision process carefulness. Organ Behav Hum Decis Process. 2008;105(2):169–82. https://doi.org/10.1016/j.obhdp.2007.08.006.
18. Summerville A. Counterfactual seeking: the scenic overlook of the road not taken. Personal Soc Psychol Bull. 2011;37(11):1522–33. https://doi.org/10.1177/0146167211413295. PubMed PMID: 21734163

19. Zeelenberg M, Beattie JM, Van der Pligt J, de Vries NK. Consequences of regret aversion: effects of expected feedback on risky decision making. Organ Behav Hum Decis Process. 1996;65(2):148–58.
20. Ubel PA, Loewenstein G, Schwarz N, Smith D. Misimagining the unimaginable: the disability paradox and health care decision making. Health Psychol. 2005;24(4 Suppl):S57–62. https://doi.org/10.1037/0278-6133.24.4.S57. PubMed PMID: 16045420
21. Halpern J, Arnold RM. Affective forecasting: an unrecognized challenge in making serious health decisions. J Gen Intern Med. 2008;23(10):1708–12. https://doi.org/10.1007/s11606-008-0719-5. PubMed PMID: 18665428; PubMed Central PMCID: PMC2533375
22. Hart JL, Pflug E, Madden V, Halpern SD. Thinking forward: future-oriented thinking among patients with tobacco-associated thoracic diseases and their surrogates. Am J Respir Crit Care Med. 2016;193(3):321–9. https://doi.org/10.1164/rccm.201505-0882OC. Epub 2015/10/06. PubMed PMID: 26436758; PubMed Central PMCID: PMCPMC4803058
23. Weinstein ND. Unrealistic optimism about future life events. J Pers Soc Psychol. 1980;39(5):806–20. https://doi.org/10.1037/0022-3514.39.5.806.
24. Shepperd JA, Klein WM, Waters EA, Weinstein ND. Taking stock of unrealistic optimism. Perspect Psychol Sci: J Assoc Psychol Sci. 2013;8(4):395–411. https://doi.org/10.1177/1745691613485247. Epub 2013/07/01. PubMed PMID: 26045714; PubMed Central PMCID: PMCPMC4451212
25. Liberman N, Trope Y. Construal level theory of intertemporal judgment and decision. In: Loewenstein G, Read D, Baumeister RF, editors. Time and decision. New York: Russell Sage Foundation; 2003. p. 245–76.
26. Schacter DL, Addis DR, Buckner RL. Episodic simulation of future events: concepts, data, and applications. Ann N Y Acad Sci. 2008;1124:39–60. https://doi.org/10.1196/annals.1440.001. PubMed PMID: 18400923
27. Mischel W, Ayduk O, Mendoza-Denton R. Sustaining delay of gratification over time: a hot-cool systems perspective. In: Loewenstein G, Read D, Baumeister RF, editors. Time and decision. New York: Russell Sage Foundation; 2003. p. 175–200.
28. Smith D, Loewenstein G, Jepson C, Jankovich A, Feldman H, Ubel P. Mispredicting and misremembering: patients with renal failure overestimate improvements in quality of life after a kidney transplant. Health Psychol: Off J Div Health Psychol, Am Psychol Assoc. 2008;27(5):653–8. https://doi.org/10.1037/a0012647. Epub 2008/10/01. PubMed PMID: 18823192
29. Rubin EB, Buehler AE, Halpern SD. States worse than death among hospitalized patients with serious illnesses. JAMA Intern Med. 2016;176(10):1557–9. https://doi.org/10.1001/jamainternmed.2016.4362. Epub 2016/08/02. PubMed PMID: 27479808
30. White DB, Hough CL, Carson SS, Anderson W, Peterson MW, Steingrub J, et al. Is optimism bias about prognosis by surrogate decision makers associated with more health care utilization at the end of life? Am J Respir Crit Care Med. 2015;191:A3774.
31. Fagerlin A, Zikmund-Fisher BJ, Ubel PA. Cure me even if it kills me: preferences for invasive cancer treatment. Med Decis Mak: Int J Soc Med Decision Making. 2005;25(6):614–9. https://doi.org/10.1177/0272989x05282639. Epub 2005/11/12. PubMed PMID: 16282212
32. Aberegg SK, Haponik EF, Terry PB. Omission bias and decision making in pulmonary and critical care medicine. Chest. 2005;128(3):1497–505. https://doi.org/10.1378/chest.128.3.1497. Epub 2005/09/16. PubMed PMID: 16162749
33. Meszaros JR, Asch DA, Baron J, Hershey JC, Kunreuther H, Schwartz-Buzaglo J. Cognitive processes and the decisions of some parents to forego pertussis vaccination for their children. J Clin Epidemiol. 1996;49(6):697–703. Epub 1996/06/01. PubMed PMID: 8656233
34. Ritov I, Baron J. Reluctance to vaccinate: omission bias and ambiguity. J Behav Decis Mak. 1990;3:263–77.
35. Samuelson W, Zeckhauser R. Status quo Bias in decision making. J Risk Uncertain. 1988;1(1):7–59.

36. Nicolle A, Fleming SM, Bach DR, Driver J, Dolan RJ. A regret-induced status quo Bias. J Neurosci. 2011;31(9):3320.
37. Hart JL, Harhay MO, Gabler NB, Ratcliffe SJ, Quill CM, Halpern SD. Variability among US intensive care units in managing the Care of Patients Admitted with Preexisting Limits on life-sustaining therapies. JAMA Intern Med. 2015;175(6):1019–26. https://doi.org/10.1001/jamainternmed.2015.0372. Epub 2015/03/31. PubMed PMID: 25822402; PubMed Central PMCID: PMCPMC4451380
38. Tversky A, Kahneman D. Judgment under uncertainty: heuristics and biases. Science. 1974;185(4157):1124.
39. Pachur T, Hertwig R, Steinmann F. How do people judge risks: availability heuristic, affect heuristic, or both? J Exp Psychol Appl. 2012;18(3):314–30. https://doi.org/10.1037/a0028279.
40. Croskerry P. The importance of cognitive errors in diagnosis and strategies to minimize them. Acad Med. 2003;78(8):775–80. PubMed PMID: 00001888-200308000-00003
41. Curtis JR, Treece PD, Nielsen EL, Gold J, Ciechanowski PS, Shannon SE, et al. Randomized trial of communication facilitators to reduce family distress and intensity of end-of-life care. Am J Respir Crit Care Med. 2016;193(2):154–62. https://doi.org/10.1164/rccm.201505-0900OC. PubMed PMID: 26378963
42. Lautrette A, Darmon M, Megarbane B, Joly LM, Chevret S, Adrie C, et al. A communication strategy and brochure for relatives of patients dying in the ICU. N Engl J Med. 2007;356(5):469–78. https://doi.org/10.1056/NEJMoa063446. PubMed PMID: 17267907.
43. Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, et al. Guidelines for family-centered Care in the Neonatal, pediatric, and adult ICU. Crit Care Med. 2017;45(1):103–28. https://doi.org/10.1097/ccm.0000000000002169. Epub 2016/12/17. PubMed PMID: 27984278
44. Connors AF Jr, Dawson NV, Desbiens NA, et al. A controlled trial to improve care for seriously iii hospitalized patients: the study to understand prognoses and preferences for outcomes and risks of treatments (support). JAMA. 1995;274(20):1591–8. https://doi.org/10.1001/jama.1995.03530200027032.
45. Austin CA, Mohottige D, Sudore RL, Smith AK, Hanson LC. Tools to promote shared decision making in serious illness: a systematic review. JAMA Intern Med. 2015;175(7):1213–21. https://doi.org/10.1001/jamainternmed.2015.1679. PubMed PMID: PMC4794743
46. Oczkowski SJW, Chung H-O, Hanvey L, Mbuagbaw L, You JJ. Communication tools for end-of-life decision-making in the intensive care unit: a systematic review and meta-analysis. Crit Care. 2016;20(97):97. https://doi.org/10.1186/s13054-016-1264-y. PubMed PMID: PMC4826553
47. Milkman KL, Chugh D, Bazerman MH. How can decision making be improved? Perspect Psychol Sci. 2009;4(4):379–83. https://doi.org/10.1111/j.1745-6924.2009.01142.x.
48. Swindell JS, McGuire AL, Halpern SD. Shaping patients' decisions. Chest. 2011;139(2):424–9. https://doi.org/10.1378/chest.10-0605. Epub 2011/02/03. PubMed PMID: 21285056
49. Gorin M, Joffe S, Dickert N, Halpern S. Justifying clinical nudges. Hastings Cent Rep. 2017;47(2):32–8. https://doi.org/10.1002/hast.688. Epub 2017/03/17. PubMed PMID: 28301695
50. Halpern SD. Shaping end-of-life care: behavioral economics and advance directives. Semin Respir Crit Care Med. 2012;33(4):393–400. https://doi.org/10.1055/s-0032-1322403. PubMed PMID: 22875386
51. Halpern SD, Loewenstein G, Volpp KG, Cooney E, Vranas K, Quill CM, et al. Default options in advance directives influence how patients set goals for end-of-life care. Health Aff. 2013;32(2):408–17. https://doi.org/10.1377/hlthaff.2012.0895.
52. Halpern SD, Ubel PA, Asch DA. Harnessing the power of default options to improve health care. N Engl J Med. 2007;357(13):1340–4. https://doi.org/10.1056/NEJMsb071595. PubMed PMID: 17898105

53. Hart J, Halpern SD. Default options in the ICU: widely used but insufficiently understood. Curr Opin Crit Care. 2014;20(6):662–7. https://doi.org/10.1097/mcc.0000000000000146. Epub 2014/09/10. PubMed PMID: 25203352; PubMed Central PMCID: PMCPMC4445452
54. Anesi GL, Halpern SD. Choice architecture in code status discussions with terminally ill patients and their families. Intensive Care Med. 2016;42(6):1065–7. https://doi.org/10.1007/s00134-016-4294-7. Epub 2016/03/10. PubMed PMID: 26951425; PubMed Central PMCID: PMCPMC4846484
55. Yadav KN, Gabler NB, Cooney E, Kent S, Kim J, Herbst N, et al. Approximately one in three US adults completes any type of advance directive for end-of-life care. Health Aff. 2017;36(7):1244–51. https://doi.org/10.1377/hlthaff.2017.0175.

Chapter 4

Emotional Processing/Psychological Morbidity in the ICU

Ramona O. Hopkins

Introduction

Critical illness and its treatment in an intensive care unit (ICU) are stressful experiences for patients and their families. It is therefore unsurprising that what happens to the patient and family during the ICU is associated with significant life changes after the critical illness of their loved one. High rates of depression, anxiety, acute stress, and posttraumatic stress disorder (PTSD) are well described in survivors of critical illness and occur in rates that are substantially higher than rates reported in healthy individuals [1]. The 2010 Society of Critical Care Medicine conference on long-term adverse outcomes after critical illness not only identified new or worsening impairments in physical and mental health and cognitive impairment in patients called post-intensive care syndrome (PICS) but also identified similar sequelae in family members, termed post-intensive care syndrome-family (PICS-F) [2, 3]. These physical, cognitive, and psychological morbidities may persist months to years after intensive care unit discharge and in many patients are associated with functional impairments and reduced quality of life. The psychological disorders in survivors of critical illness have received significant clinical and research attention, whereas less is known regarding the impact of critical illness on families of critically ill patients. What the data clearly show is that the lives of the patient and their family change after the ICU and such changes are directly related to what they experienced during the critical illness and its treatment.

R. O. Hopkins
Pulmonary and Critical Care Medicine, Intermountain Medical Center, Murray, UT, USA

Center for Humanizing Critical Care, Intermountain Healthcare, Murray, UT, USA

Psychology Department and Neuroscience Center, Brigham Young University,
Provo, UT, USA
e-mail: mona_hopkins@byu.edu

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_4

Many ICU survivors require care from family members once they are discharged home. Family caregivers provide emotional and physical support, such as helping their loved one with activities of daily living (bathing, dressing, toileting, and feeding) and instrumental activities of daily living such as paying bills, managing medications, and following up medical care. Of critically ill patients who underwent mechanical ventilation for 7 or more days in the ICU, more than half of them require care from families once they are discharged home [4]. In the United States, family caregivers are estimated to provide $642 billion dollars of unpaid care [5]. Current data suggest that being a family caregiver is associated with significant personal costs. Over half of family caregivers of patients admitted to the ICU experience serious daytime sleepiness that impairs their ability to perform daily activities and decreased psychomotor reaction time [6]. Other studies suggest that sleepiness may play a role in development of the psychological disorders that are observed in many caregivers [7]. Many family caregivers of critically ill patients are at high risk to develop significant physical and psychological disorders that can persist months to years after hospital discharge.

Family caregivers in this chapter will refer to any person who belongs to intimate social groups or networks regardless whether they are biologically related to the patient or not. Families have long advocated to be included as part of the medical team, to be involved in the care of their loved one want increased access to ICU and improved communication with the clinical care team [8, 9]. The psychological disorders in family members occur regardless of whether the patient survives their critical illness or dies in the ICU. For bereaved family members, over a third will develop one or more adverse psychological outcomes including complicated grief, depression, anxiety, or PTSD [10]. When asked about the effect the critical illness of a loved one has on their daily lives, caregivers indicate their memories of the ICU and the new disability of the patient negatively affects their daily life, they experience a loss of the sense of self and a change in their relationships with the patient, and they report increased strain from the demands of caregiving [11]. Such caregiver concerns have received little study and interventions to improve the caregiving after critical illness are needed.

Psychological Morbidity and Caregiving

Being a caregiver for a family member who is critically ill and treated in the ICU is particularly stressful. Negative emotions including stress, fear, anger, and fatigue are extremely common during an ICU admission [12, 13]. Stress for family of critically ill patients occurs from a variety of sources including the emergent nature of the critical illness, uncertainly regarding patient prognosis, and making difficult and complex decisions regarding the care of their loved one [14]. Caregiving for a critically ill patient is associated with a variety of adverse outcomes ranging from acute stress, psychological disorders, and caregiver burden to increased caregiver mortality [15]. The impact of caregiving either during or after a critical illness is profound. In the early days of a patient's critical illness, caregivers may be overwhelmed with decision-making and, because of the complexity of the medical information, may struggle to come to terms with the illness, understand basic medical information [16], and adjust to their new responsibilities and roles as caregiver [17]. Caregiving and its associated burdens do not end at ICU discharge, and many patients continue to require significant assistance from family caregivers for ongoing care and support in the weeks to months after they leave the hospital. A study of 817 survivors of critical illness who underwent >48 h of mechanical ventilation found 75% of survivors of critical illness continued to require caregiver support at 2 months and 57% at 12 months [18]. The most common outcomes identified in a systematic review are caregiver burden, lifestyle interference, restriction in activities, and lower quality of life [19]. In fact, the lack of adequate rest and exercise and skipping meals were risk factors for increased caregiver burden [19]. Caregiver burden can worsen after hospital discharge due to the lack of support for caregivers and difficulties managing caregiving, work and child care [11]. The adverse sequelae that caregivers experience during and after caring for a critically ill family member as well as their prevalence, duration, and potential interventions are described below.

Acute Stress

As noted previously, patients and families consistently are exposed to stress when a family member is critically ill. A third of parents of children admitted to the pediatric ICU experienced acute stress disorder which was associated with an unexpected admission, worry that the child would die, and hospital readmission [20]. A variety of stressors including the sudden onset of the critical illness, treatments their loved ones undergo in the ICU, demands of work and family that conflict with the demands of caregiving for a loved one in the ICU, medical decision-making, and communication with the clinical care providers are common [21, 22]. Families of critically ill patients were asked to identify stressful factors; 92% reported worry about family members, 72% the unexpected ICU admission, and 68% lack of sleep, 50% did not like hospitals and experienced frustration in not being able to communicate with their family member, 48% reported missing a significant amount of work, and 38% reported difficulty in making medical decisions [23].

Contributing factors to families' stress were the inability of their loved one to communicate and the feeling that physician's support of their psychological needs was inadequate [24]. When families were asked to rate their stress level while their loved one was in the ICU; on a scale of 0–100 with the worst stress being 100, families' mean stress level was 63 (IQR 43–84), indicating moderate to severe stress [24]. A recent study that assessed 32 symptoms that are associated with acute stress found the mean number of symptoms reported by family members was nine (range

0–24 symptoms) [25]. Worry was the most frequently reported symptom occurring in 91% of patients. In addition to worry, the top four reported symptoms were sadness, difficulty concentrating, difficulty sleeping, and feeling nervous, all of which reflect psychological distress [25]. In other populations, the behavioral and psychological responses of the patient, such as irritability, lability, agitation, and aggression, increased caregiver stress [26].

A variety of stressors including physical, emotional, and intellectual stressors can result in changes in physiologic markers of stress, such as serum cortisol secretion. Both acute and chronic stresses can increase cortisol levels, and increased cortisol is associated with development of depression, anxiety, and PTSD [27–29]. A small study in six family caregivers of critically ill patients found higher cortisol levels were associated with depression, as was greater trauma avoidance [30]. Alternatively, factors such as a larger social network and coping using distraction were associated with lower cortisol levels [30]. A second study that assessed salivary cortisol responses in 92 family members of critically ill patients compared cortisol levels to symptoms of anxiety, depression, and PTSD at 3 months [31]. Of the 92 participants, 32% had significant symptoms of anxiety, 16% had depression, and 15% had PTSD at 3 months. The cortisol awakening response (reflects hypothalamic-pituitary activation) was associated with increased anxiety at 3-month follow-up suggesting that acute stress is associated with development or worsening of anxiety [31]. Thus, physiologic markers of acute stress have the potential to predict family members who are at risk to develop depression and anxiety both acutely and months after hospital discharge.

Fatigue and Sleep Deprivation

In addition to stress, family caregivers of critically ill patients often experience significant fatigue and sleepiness due to inadequate sleep, as the ICU environment is often disruptive to sleep [32]. A study in 47 family caregivers of critically ill patients found that clinically significant was fatigue, which was reported in almost 50% of caregivers, and that fatigue was associated with more severe symptoms of depression, reduced sleep quality, and increased caregiver burden [33]. A study that assessed subjective sleepiness using the Epworth Sleepiness Scale found half of caregivers reported excessive sleepiness [6]. Caregiver fatigue persisted 6–53 months after a loved one was discharged from the ICU [34]. Environmental factors that interfere with sleep included the light and sound levels in the ICU (noise from machines and their alarms) as well as nighttime activity by clinical caregivers [7, 35]. Stress can also contribute to sleep problems and lead to insomnia and daytime sleepiness [36]. Family caregivers often report daytime sleepiness and fatigue [32], and a study that measured sleep using actigraphy found reduced sleep duration and poor sleep quality were present in 64% of caregivers at ICU admission, 54% at

2 weeks, and 54% 2 months after the patient was discharged from the ICU [37]. Data in other populations shows that sleep deprivation negatively affects cognitive function resulting in impaired attention, memory, and decision-making [36]. In the ICU family caregiver sleepiness may affect their ability to understand the medical information and therefore impact their medical decision-making and ability to communicate with the clinical care providers [38]. Poor sleep quality has long-term effects and contributes to the development of psychological aspects of PICS-F, especially depression and PTSD.

Depression

During the acute phase of critical illness family caregivers frequently experience depression and anxiety. Prevalence rates of depression during ICU admission/discharge are quite variable. A review of caregiver burden found depression ranged from 16% to 90% of caregivers during the ICU but then declined to 12–26% at 3 months [14]. Few studies report the severity of the depression, but several studies suggest severe depression occurs in up to 60% of family caregivers [34, 39, 40]. A multicenter study in France found depression in 34% of family caregivers in the first 3–5 days after ICU admission [41]. A Canadian study that followed 280 caregivers found depression occurred in 67% of family caregivers at 7 days and decreased to 49% at 3 months [34]. While the rate of depression declined over time, almost half of caregivers' symptoms of clinical depression persisted for months with little change at 12 months. Importantly, in a subset of patients (14%), depression did not decline over time suggesting that there may be multiple outcome trajectories for depression. These caregivers reported similar patterns for psychological well-being [34]. Further, in more than 90% of depressed family caregivers who were caring for patient with more impairments in activities of daily living and instrumental activities of daily living, such caregiver burdens contributed to the caregiver engaging in health-risk behaviors [42].

Anxiety

A review of the literature found the prevalence of anxiety ranged from 42% to 80% of caregivers during the ICU and then declined to 24–63% at 3 months [14]. A multicenter study in France found depression in 69% of family caregivers in the first 3–5 days after ICU admission [41]. Anxiety symptoms may persist months to years after the patient is discharged from the ICU. Along with the high prevalence of psychological disorders in caregivers, psychological disorders often do not occur in isolation. Comorbid depression and anxiety are common, occurring in 10% of caregivers, while their loved one is in the ICU [43]. Among family caregivers, one study assessed physical and psychological symptoms ($n = 211$) and found seven or more symptoms were present in more than 50% of caregivers, with a median of nine symptoms [25]. These psychological symptoms included worry, sadness, problems in concentrating and sleeping, and nervousness; worry was the most frequently reported [25].

Posttraumatic Stress Disorder (PTSD)

Over half of family caregivers of critically ill patients will experience symptoms of PTSD during their loved one's ICU stay that can perist for months to years. Parents of children develop PTSD after PICU admission which persists long after hospital discharge [20]. PTSD occurred in 57% of caregivers during the ICU and declined somewhat to 30–42% at 3 months [14], although some data find PTSD to be stable over time (16% at 3 months and 22% at 6 months) [44]. In one prospective, multicenter study in France, more than two thirds of family members suffered symptoms of depression and anxiety while their loved ones were in the ICU, and these symptoms were associated with PTSD at 2- to 6-month follow-up [41]. Similar findings come from an Australian study, which found that 33% of family caregivers had PTSD symptoms during ICU admission of their loved one, which decreased by almost half in these affected families [45]. PTSD identified at hospital admission was a significant predictor of PTSD at 3 and 6 months in family caregivers [44]. Screening for psychological disorders at ICU admission may be a way to identify individuals who are at risk for long-term psychological disorders.

Change Over Time

While caregiver depression, anxiety, and PTSD rates are high in the ICU, once the patient is discharged, many studies show a decrease in the prevalence rates of psychological disorders over time [34, 41, 46, 47]. For example, a systematic review found that depression declined from 75% of caregivers during critical cares to 29% 1 year later, a prevalence comparable to caregivers of patients with dementia [19]. The reason for the decline in the rate of psychological disorders over time is unclear and merits further study. Alternatively, several studies reported no change in the rate of psychological disorders over time [41, 47], and studies also find increased depression [48] and anxiety [43] over time. The increase in psychological disorders over time may be attributable to increased caregiving demands once some patients leave the hospital and the entire burden falls on family caregivers.

Other Outcomes

In addition to substantial increases in caregiver's psychological disorders, nearly half of caregivers reduce the hours they are working or stop working altogether (i.e., quit their job or were fired) to care for their loved one [14]. Among caregivers, 50% stopped doing some of their own activities in order to care for their loved one. Up to 32% of caregivers require new medications including antidepressants, anxiolytics, hypnotics, and other psychotropic medications [14]. Almost half of family caregivers experience learned helplessness (feeling lack of control and helplessness to avoid an aversive situations) especially if they were involved in decision-making for their loved one in the ICU [49]. Learned helplessness is associated with development of depression.

Risk Factors of Psychological Disorders

Studies have identified a variety of risk factors for caregiver depression, anxiety, and PTSD. Table 4.1 shows the risk factors of psychological disorder. Risk factors for depression include caregiver's age [34, 50], female caregiver [40, 51], low educational attainment [52], and poor health [51]. Cameron et al. [34] found that depression was not associated with patient characteristics such as illness severity and/or functional outcomes, but rather with younger caregiver's age, less social support, low sense of control over their life, and lack of personal growth were associated with depression [34]. Similar findings come from a study in ICU survivors with at least 4 days of mechanical ventilation that report 90% of caregivers had depression while their loved one was in the ICU and 61% remained depressed at 2 months [53].

Table 4.1 Risk factors of the development of psychological disorders in family caregivers

Risk factor	Depression	Anxiety	PTSD
Younger caregiver's age	X		
Female caregiver	X	X	X
Low educational attainment	X	X	X
Caregiver's poor health	X		
Relationship to patient (spouse or parent)		X	
Older patient age	X		
Unpaid help	X		
Low social support	X		X
Baseline anxiety or PTSD			X
Weak relationship or bond	X		X
Low sense of control of life	X		X
Lack of coping skills (e.g., resilience, mindfulness)	X		X

Other risk factors for depression in caregivers include older patient age [54], higher patient requirements for caregiving [55], and use of paid help to care for their loved one [54].

While few studies have assessed risk factors for anxiety, female caregiver [40, 56] and being the patient's parent or spouse of the patient were risk factors [57]. PTSD has been associated with female caregivers [52, 53, 58, 59], low caregiver educational attainment [52, 60, 61], and relationship to the patient [59]. The likelihood of depression, anxiety, and PTSD in families of critically ill patients increases when they are involved in medical decision-making, perceive that communication with the medical team is insufficient or ineffective [56, 59], or have low social support [34]. Individuals with baseline anxiety, PTSD, weak bonds with the patient, and lower levels of mindfulness may be more likely to have PTSD 3 and 6 months after hospital discharge [44]. Prospective randomized clinical trials are needed to confirm these findings, and big data studies that use multivariate methods are needed to fully understand the risk factors of psychological disorders in family caregivers.

Limitations of Current Studies

There are a number of limitations regarding studies of psychological outcomes in family caregivers. The studies have used a variety of instruments to assess depression, anxiety, and PTSD. A variety of cut-off thresholds have been utilized to identify individuals with depression, anxiety, and PTSD, and such between-study differences are confusing at best. Research is needed to understand the best cut-off thresholds for family caregivers, and to determine the minimal clinically important differences for each measure. The use of self-report measures as findings is an additional concern, as these should be corroborated by structured clinical interviews to confirm psychiatric diagnoses in family caregivers. Loss to follow-up and/or withdrawal results in participation rates that are quite variable and range from 7% to 77% of caregivers [43, 51], raising the concern of potential bias.

Potential Targeted Approaches in the ICU

Targeted approaches to improving psychological outcomes in family caregivers are a growing field of research. Studies of interventions to improve psychological outcomes of family members are limited, showing limited or mixed results. While prevention and early treatment are important targets to prevent or improve long-term psychological outcomes in family caregivers, the ideal interventions and timing of such interventions are unclear given the limited data to date. Promising interventions are heterogeneous and include physical activity, music therapy, mindfulness training, ICU diaries, and peer support. Participation in physical activity (e.g., early mobilization/physical rehabilitation) is associated with reduced anxiety and depression symptoms in other populations and treatment settings [62, 63]. In critically ill patients, physical rehabilitation reduced depression [64], and another study found ICU survivors that participated in a combined physical rehabilitation and amino acid treatment had reduced depression [65]. Less is knowing about the effects of physical activity on morbidities of ICU caregivers.

Music therapy has the potential to improve psychological outcomes. Music reduces stress, [66], pain, and anxiety [67–69] and improves mood [70]. Caregiver burden and psychological symptoms improve with music therapy [71]. Another therapy used to improve outcomes are ICU diaries, which are used routinely in Europe and are becoming more common in the United States. ICU diaries have been shown to reduce the prevalence of PTSD among family caregivers of ICU survivors [72, 73], although not all studies find benefit. Additional research is needed to fully understand the benefits of ICU diaries on long-term outcomes of family caregivers.

Family caregivers of critically ill patients do not appear to effectively use coping skills such as relaxation [15, 16], though such interventions can be used to improve outcomes. In a preliminary evaluation, a telephone-based coping skills training intervention reduced depression, anxiety, and PTSD symptoms in family caregivers of survivors of acute lung injury [74]. Conversely, a more recent, randomized controlled trial comparing telephone- and web-based coping skills training to an education program found that training did not reduce depression, anxiety, or PTSD in family caregivers [75]. However, an improvement in depression, anxiety, and PTSD was observed in a subset of caregivers with high baseline levels of distress when given telephone-based coping skills [75]. Data are needed to better understand the timing of and types of coping skills training that may benefit patients and their family caregivers.

Trauma-focused psychological intervention to prevent or reduce the severity of PTSD [76], such as cognitive-behavioral therapy, is often recommended as a first-line treatment for PTSD symptoms in other populations. In populations outside of the ICU, exposure therapy or a combination of exposure with cognitive-behavioral therapy has been shown to be effective [77]. Psychological interventions for PTSD [76], such as cognitive-behavioral therapy, are widely used to treat not only PTSD but also other psychological disorders (e.g., depression and anxiety). A brief cognitive-behavioral psychoeducation program designed to manage stress and anxiety in family caregivers of ICU patients was compared to a control group without such an intervention [78]. The program was administered by nurses and included stress awareness, cognitive awareness (identifying thoughts and irrational beliefs), cognitive restricting, abdominal breathing, and muscle relaxation and feedback. The psychoeducation group had significant reductions in stress ($p < 0.05$), anxiety ($p < 0.01$), and depression ($p < 0.05$) and increased satisfaction ($p = 0.05$). This finding suggests that family caregivers likely need additional support and that training programs can provide the skills they need. Of note the biggest challenge in this study was participant recruitment as the ICU as families wanted to be with their loved one to provide support rather than participate in training [78].

Resilience and Posttraumatic Growth

While the focus of this chapter has been on adverse outcomes for family caregivers, some patients and family caregivers experience positive outcomes. Resilience and posttraumatic growth are examples of successful adaptation to stress [79], and social support also improves outcomes [80]. Resilience is the ability to adapt or respond to traumatic experiences in a positive way. A study of resilience in family caregivers of patients admitted to a neuroscience ICU found greater psychosocial resilience (mindfulness, coping, and self-efficacy) was associated with lower depression, anxiety, and anger and caregivers who had depression and anxiety reported lower coping and self-efficacy [80]. Greater ability to cope with stress (relaxation, assertiveness, and social social) was associated with reduced depression and anxiety in family caregivers. Targeted interventions that are designed to improve coping skills appear successful, but more work is needed.

Posttraumatic growth refers to positive psychological changes or growth that occurs following a traumatic or stressful experience, such as the critical illness of a family member. Posttraumatic growth can lead to positive reframing that improves their sense of self and life perspective and relationships with others and in their life perspective which may be achieved through adaptive responses in how a person responds to a stressful experience. This growth has been observed following a variety of traumatic events including medical illnesses (chronic illness, cancer, AIDS), military combat, man-made disasters (e.g., shootings) and natural disasters (e.g., tornados) [81, 82]. Individual characteristics such as openness, extraversion, agreeableness, and conscientiousness are associated with great posttraumatic growth; alternatively neuroticism is associated with less posttraumatic growth. Focused coping and cognitive processing of the traumatic event, involvement in religious activities, and high levels of perceived social support are associated with posttraumatic growth [82–84]. Overall, some degree of emotional processing of the traumatic event must take place for posttraumatic growth to occur [85], and such processing is most likely to result in posttraumatic growth in a particular personal and social contexts.

Further, increased posttraumatic growth is associated with reduced PTSD [86]. This interaction suggests that psychological outcomes among family caregivers are likely complex; but there is limited information in ICU populations as few positive outcomes have been studied to date. Almost 90% parents of children discharged from the pediatric ICU reported posttraumatic growth or due to positive change because of their pediatric ICU experiences, supporting the idea that psychological effects of critical illness may not be entirely negative [87]. A study in parents of children with severe illnesses found that two thirds of the parents reported moderate posttraumatic growth. A study in adults who had relative with a serious illness found posttraumatic growth was associated with the use of active program-focused coping strategies [88]. No studies to date have assessed posttraumatic growth in critically ill adults ICU patients and their family caregivers. Greater posttraumatic growth is reported with focused coping, better cognitive processing of the traumatic event, involvement in religious activities, and higher levels of perceived social support [82]. Although posttraumatic growth can occur naturally, deliberate interventions can increase its likelihood such as cognitive-behavioral therapy. Additional investigations are needed to fully understand posttraumatic growth in ICU populations, as are studies of interventions to promote posttraumatic growth.

Potential Future Research/Inquiry

Studies are needed to build on previous research to fully understand outcomes of family caregivers of ICU patients including studies in larger populations, effects of pre-illness on physical and mental health, trajectories of outcomes over time, and if there are distinct clusters of outcomes. A recent paper in ICU patients found four distinct subtypes of outcomes in survivors of acute respiratory distress syndrome (see Table 4.2) [89]. The outcome subtypes included mildly impaired physical and mental health, moderately impaired physical and mental health, severely impaired physical health with moderately impaired mental health, and severely impaired physical and mental health. Cognitive impairments were not associated with physical and mental health but rather were a separate outcome category. This finding suggests that there may be different causal mechanisms and risk factors for these outcome subtypes, and as such interventions may need to be targeted specifically to address the specific outcome subtype [89]. Such work needs to be carried out in family caregivers. We need to assess key characteristics of family caregivers to understanding how they may react to the critical illness of a loved one. A recent study that sought to identify individual differences in coping styles, information presentation preferences, and social relationships in individuals who reported previous ICU experience and were asked to make decisions in a simulated ICU experience [90]. Butler et al. identified three coping profiles (adaptive, maladaptive, and disengaged copers) which differed on personality, social relationships, coping styles, and history of psychological disorders and made different decisions in the simulated ICU [90]. This data suggests that individual factor affects how family caregivers respond to the critical illness of a loved one. Understanding differences in coping may lead using different interventions, but more work clearly is need. We also need to understand

Table 4.2 Outcome subtypes

Outcome subtypes	Frequency
Mild physical and mental health	Occurred in approximately 20% of patients
Moderate physical and mental health	Most common outcome subtype. Occurred in almost 40% of patients
Severe physical and moderate mental health	Occurred in 15% of patients
Severe physical and mental health	Occurred in approximately 20% of patients
Cognitive impairments	No association with physical and mental health

the associations between caregiver resiliency and psychological outcomes. Studies that seek to understand positive outcome such as resilience and posttraumatic growth are needed. Targeted interventions to prevent or ameliorated adverse outcomes in family caregivers should be a high priority of critical care research.

Mental health included measurements of depression, anxiety, and PTSD (Brown et al.). Physical health was measured by the Functional Performance Inventory, the SF-36 physical component score, and the EuroQol (EQ-5D). Cognitive function was measured using the Mini-Mental State Examination.

References

1. Myhren H, Ekeberg O, Toien K, Karlsson S, Stokland O. Posttraumatic stress, anxiety and depression symptoms in patients during the first year post intensive care unit discharge. Crit Care. 2010;14:R14.
2. Elliott D, Davidson JE, Harvey MA, Bemis-Dougherty A, Hopkins RO, Iwashyna TJ, Wagner J, Weinert C, Wunsch H, Bienvenu OJ, Black G, Brady S, Brodsky MB, Deutschman C, Doepp D, Flatley C, Fosnight S, Gittler M, Gomez BT, Hyzy R, Louis D, Mandel R, Maxwell C, Muldoon SR, Perme CS, Reilly C, Robinson MR, Rubin E, Schmidt DM, Schuller J, Scruth E, Siegal E, Spill GR, Sprenger S, Straumanis JP, Sutton P, Swoboda SM, Twaddle ML, Needham DM. Exploring the scope of post-intensive care syndrome therapy and care: engagement of non-critical care providers and survivors in a second stakeholders meeting. Crit Care Med. 2014;42:2518–26.
3. Needham DM, Davidson J, Cohen H, Hopkins RO, Weinert C, Wunsch H, Zawistowski C, Bemis-Dougherty A, Berney SC, Bienvenu OJ, Brady SL, Brodsky MB, Denehy L, Elliott D, Flatley C, Harabin AL, Jones C, Louis D, Meltzer W, Muldoon SR, Palmer JB, Perme C, Robinson M, Schmidt DM, Scruth E, Spill GR, Storey CP, Render M, Votto J, Harvey MA. Improving long-term outcomes after discharge from intensive care unit: report from a stakeholders' conference. Crit Care Med. 2012;40:502–9.
4. Chelluri L, Pinsky MR, Donahoe MP, Grenvik A. Long-term outcome of critically ill elderly patients requiring intensive care. JAMA. 1993;269:3119–23.
5. Chari AV, Engberg J, Ray KN, Mehrotra A. The opportunity costs of informal elder-care in the United States: new estimates from the American Time Use Survey. Health Serv Res. 2015;50:871–82.
6. Verceles AC, Corwin DS, Afshar M, Friedman EB, McCurdy MT, Shanholtz C, Oakjones K, Zubrow MT, Titus J, Netzer G. Half of the family members of critically ill patients experience excessive daytime sleepiness. Intensive Care Med. 2014;40:1124–31.
7. Day A, Haj-Bakri S, Lubchansky S, Mehta S. Sleep, anxiety and fatigue in family members of patients admitted to the intensive care unit: a questionnaire study. Crit Care. 2013;17:R91.
8. Barratt F, Wallis DN. Relatives in the resuscitation room: their point of view. J Accid Emerg Med. 1998;15:109–11.
9. Marfell JA, Garcia JS. Contracted visiting hours in the coronary care unit. A patient-centered quality improvement project. Nurs Clin North Am. 1995;30:87–96.
10. Siegel MD, Hayes E, Vanderwerker LC, Loseth DB, Prigerson HG. Psychiatric illness in the next of kin of patients who die in the intensive care unit. Crit Care Med. 2008;36:1722–8.
11. Cox CE, Docherty SL, Brandon DH, Whaley C, Attix DK, Clay AS, Dore DV, Hough CL, White DB, Tulsky JA. Surviving critical illness: acute respiratory distress syndrome as experienced by patients and their caregivers. Crit Care Med. 2009;37:2702–8.
12. Jamerson PA, Scheibmeir M, Bott MJ, Crighton F, Hinton RH, Cobb AK. The experiences of families with a relative in the intensive care unit. Heart Lung: J Crit Care. 1996;25:467–74.

13. Kleiber C, Halm M, Titler M, Montgomery LA, Johnson SK, Nicholson A, Craft M, Buckwalter K, Megivern K. Emotional responses of family members during a critical care hospitalization. Am J Crit: Off Publ Am Assoc Crit Care Nurses. 1994;3:70–6.
14. van Beusekom I, Bakhshi-Raiez F, de Keizer NF, Dongelmans DA, van der Schaaf M. Reported burden on informal caregivers of ICU survivors: a literature review. Crit Care. 2016;20:16.
15. Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. JAMA. 1999;282:2215–9.
16. Azoulay E, Chevret S, Leleu G, Pochard F, Barboteu M, Adrie C, Canoui P, Le Gall JR, Schlemmer B. Half the families of intensive care unit patients experience inadequate communication with physicians. Crit Care Med. 2000;28:3044–9.
17. Penley JA, Tomaka J, Wiebe JS. The association of coping to physical and psychological health outcomes: a meta-analytic review. J Behav Med. 2002;25:551–603.
18. Chelluri L, Im KA, Belle SH, Schulz R, Rotondi AJ, Donahoe MP, Sirio CA, Mendelsohn AB, Pinsky MR. Long-term mortality and quality of life after prolonged mechanical ventilation. Crit Care Med. 2004;32:61–9.
19. Haines KJ, Denehy L, Skinner EH, Warrillow S, Berney S. Psychosocial outcomes in informal caregivers of the critically ill: a systematic review. Crit Care Med. 2015;43:1112–20.
20. Balluffi A, Kassam-Adams N, Kazak A, Tucker M, Dominguez T, Helfaer M. Traumatic stress in parents of children admitted to the pediatric intensive care unit. Pediatr Crit Care Med: J Soc Crit Care Med World Federat Pediatr Intens Crit Care Soc. 2004;5:547–53.
21. Choi J, Donahoe MP, Hoffman LA. Psychological and physical health in family caregivers of intensive care unit survivors: current knowledge and future research strategies. J Korean Acad Nurs. 2016;46:159–67.
22. Pinquart M, Sorensen S. Associations of caregiver stressors and uplifts with subjective well-being and depressive mood: a meta-analytic comparison. Aging Ment Health. 2004;8:438–49.
23. Beesley SJ, Brown SM, Hopkins RO, Wilson E, Butler J, Kutler KG, Orme J, Hirshberg EL. Stress in family members of ICU patietns. Crit Care Med. 2015;43:141.
24. Dziadzko V, Dziadzko MA, Johnson MM, Gajic O, Karnatovskaia LV. Acute psychological trauma in the critically ill: patient and family perspectives. Gen Hosp Psychiatry. 2017;47:68–74.
25. Alfheim HB, Rosseland LA, Hofso K, Smastuen MC, Rustoen T. Multiple symptoms in family caregivers of intensive care unit patients. J Pain Symptom Manag. 2018;55(2):387–94.
26. Matsumoto N, Ikeda M, Fukuhara R, Shinagawa S, Ishikawa T, Mori T, Toyota Y, Matsumoto T, Adachi H, Hirono N, Tanabe H. Caregiver burden associated with behavioral and psychological symptoms of dementia in elderly people in the local community. Dement Geriatr Cogn Disord. 2007;23:219–24.
27. Grynderup MB, Kolstad HA, Mikkelsen S, Andersen JH, Bonde JP, Buttenschon HN, Kaergaard A, Kaerlev L, Rugulies R, Thomsen JF, Vammen MA, Mors O, Hansen AM. A two-year follow-up study of salivary cortisol concentration and the risk of depression. Psychoneuroendocrinology. 2013;38:2042–50.
28. Hsiao FH, Chang KJ, Kuo WH, Huang CS, Liu YF, Lai YM, Jow GM, Ho RT, Ng SM, Chan CLA. longitudinal study of cortisol responses, sleep problems, and psychological well-being as the predictors of changes in depressive symptoms among breast cancer survivors. Psychoneuroendocrinology. 2013;38:356–66.
29. Vasiliadis HM, Forget H, Preville M. The association between self-reported daily hassles and cortisol levels in depression and anxiety in community living older adults. Int J Geriatr Psychiatr. 2013;28:991–7.
30. Turner-Cobb JM, Smith PC, Ramchandani P, Begen FM, Padkin A. The acute psychobiological impact of the intensive care experience on relatives. Psychol Health Med. 2016;21:20–6.
31. Beesley SJ, Hopkins RO, Holt-Lunstad J, Wilson EL, Butler J, Kuttler KG, Orme J, Brown SM, Hirshberg EL. Acute physiologic stress and subsequent anxiety among family members of ICU patients. Crit Care Med. 2018;46:229–35.

32. Celik S, Genc G, Kinetli Y, Asiliogli M, Sari M, Madenoglu Kivanc M. Sleep problems, anxiety, depression and fatigue on family members of adult intensive care unit patients. Int J Nurs Pract. 2016;22:512–22.
33. Choi J, Tate JA, Hoffman LA, Schulz R, Ren D, Donahoe MP, Given BA, Sherwood PR. Fatigue in family caregivers of adult intensive care unit survivors. J Pain Symptom Manag. 2014;48:353–63.
34. Cameron JI, Chu LM, Matte A, Tomlinson G, Chan L, Thomas C, Friedrich JO, Mehta S, Lamontagne F, Levasseur M, Ferguson ND, Adhikari NKJ, Rudkowski JC, Meggison H, Skrobik Y, Flannery J, Bayley M, Batt J, dos Santos C, Abbey SE, Tan A, Lo V, Mathur S, Parotto M, Morris D, Flockhart L, Fan E, Lee CM, Wilcox ME, Ayas N, Choong K, Fowler R, Scales DC, Sinuff T, Cuthbertson BH, Rose L, Robles P, Burns S, Cypel M, Singer L, Chaparro C, Chow CW, Keshavjee S, Brochard L, Hébert P, Slutsky AS, Marshall JC, Cook D, Herridge MS. One-year outcomes in caregivers of critically ill patients. N Engl J Med. 2016;374:1831–41.
35. Stremler R, Adams S, Dryden-Palmer K. Nurses' views of factors affecting sleep for hospitalized children and their families: a focus group study. Res Nurs Health. 2015;38:311–22.
36. Owens RL, Huynh TG, Netzer G. Sleep in the intensive care unit in a model of family-centered care. AACN Adv Crit Care. 2017;28:171–8.
37. Choi J, Tate JA, Donahoe MP, Ren D, Hoffman LA, Chasens ER. Sleep in family caregivers of ICU survivors for two months post-ICU discharge. Intensive Crit Care Nurs. 2016;37:11–8.
38. Jones CB, Dorrian J, Jay SM, Lamond N, Ferguson S, Dawson D. Self-awareness of impairment and the decision to drive after an extended period of wakefulness. Chronobiol Int. 2006;23:1253–63.
39. Abou-Mrad F, Mourad C, Najem C. Depressive symptoms among surrogate decision makers in Lebanese ICUs. Funct Neurol. 2012;27:95–9.
40. Kao YY, Chen CI, Chen FJ, Lin YH, Perng SJ, Lin HY, Huang CY. Effects of resourcefulness on sleep disturbances, anxiety, and depressive symptoms in family members of intensive care unit patients. Arch Psychiatr Nurs. 2016;30:607–13.
41. Pochard F, Darmon M, Fassier T, Bollaert PE, Cheval C, Coloigner M, Merouani A, Moulront S, Pigne E, Pingat J, Zahar JR, Schlemmer B, Azoulay E, French Fsg. Symptoms of anxiety and depression in family members of intensive care unit patients before discharge or death. A prospective multicenter study. J Crit Care. 2005;20:90–6.
42. Choi J, Hoffman LA, Schulz R, Ren D, Donahoe MP, Given B, Sherwood PR. Health risk behaviors in family caregivers during patients' stay in intensive care units: a pilot analysis. Am J Crit Care. 2013;22:41–5.
43. Fumis RR, Ranzani OT, Martins PS, Schettino G. Emotional disorders in pairs of patients and their family members during and after ICU stay. PLoS One. 2015;10:e0115332.
44. Choi KW, Shaffer KM, Zale EL, Funes CJ, Koenen KC, Tehan T, Rosand J, Vranceanu AM. Early risk and resiliency factors predict chronic posttraumatic stress disorder in caregivers of patients admitted to a neuroscience ICU. Crit Care Med. 2018;55(2):387–94.
45. Schoeman T, Sundararajan K, Micik S, Sarada P, Edwards S, Poole A, Chapman M. The impact on new-onset stress and PTSD in relatives of critically ill patients explored by diaries study (The "INSPIRED" study). Aust Crit Care. 2018;55(2):387–94.
46. Anderson WG, Arnold RM, Angus DC, Bryce CL. Posttraumatic stress and complicated grief in family members of patients in the intensive care unit. J Gen Intern Med. 2008;23:1871–6.
47. Azoulay E, Pochard F, Chevret S, Arich C, Brivet F, Brun F, Charles PE, Desmettre T, Dubois D, Galliot R, Garrouste-Orgeas M, Goldgran-Toledano D, Herbecq P, Joly LM, Jourdain M, Kaidomar M, Lepape A, Letellier N, Marie O, Page B, Parrot A, Rodie-Talbere PA, Sermet A, Tenaillon A, Thuong M, Tulasne P, Le Gall JR, Schlemmer B, French Famirea G. Family participation in care to the critically ill: opinions of families and staff. Intensive Care Med. 2003;29:1498–504.
48. Douglas SL, Daly BJ. Caregivers of long-term ventilator patients: physical and psychological outcomes. Chest. 2003;123:1073–81.

49. Sullivan DR, Liu X, Corwin DS, Verceles AC, McCurdy MT, Pate DA, Davis JM, Netzer G. Learned helplessness among families and surrogate decision-makers of patients admitted to medical, surgical, and trauma ICUs. Chest. 2012;142:1440–6.
50. Cameron JI, Chu LM, Matte A, Tomlinson G, Chan L, Thomas C, Friedrich JO, Mehta S, Lamontagne F, Levasseur M, Ferguson ND, Adhikari NK, Rudkowski JC, Meggison H, Skrobik Y, Flannery J, Bayley M, Batt J, dos Santos C, Abbey SE, Tan A, Lo V, Mathur S, Parotto M, Morris D, Flockhart L, Fan E, Lee CM, Wilcox ME, Ayas N, Choong K, Fowler R, Scales DC, Sinuff T, Cuthbertson BH, Rose L, Robles P, Burns S, Cypel M, Singer L, Chaparro C, Chow CW, Keshavjee S, Brochard L, Hebert P, Slutsky AS, Marshall JC, Cook D, Herridge MS, Investigators RP, Canadian Critical Care Trials G. One-year outcomes in caregivers of critically Ill patients. N Engl J Med. 2016;374:1831–41.
51. Douglas SL, Daly BJ, O'Toole E, Hickman RL Jr. Depression among white and nonwhite caregivers of the chronically critically ill. J Crit Care. 2010;25:364 e311–69.
52. Paparrigopoulos T, Melissaki A, Efthymiou A, Tsekou H, Vadala C, Kribeni G, Pavlou E, Soldatos C. Short-term psychological impact on family members of intensive care unit patients. J Psychosom Res. 2006;61:719–22.
53. Choi J, Sherwood PR, Schulz R, Ren D, Donahoe MP, Given B, Hoffman LA. Patterns of depressive symptoms in caregivers of mechanically ventilated critically ill adults from intensive care unit admission to 2 months postintensive care unit discharge: a pilot study. Crit Care Med. 2012;40:1546–53.
54. Van Pelt DC, Milbrandt EB, Qin L, Weissfeld LA, Rotondi AJ, Schulz R, Chelluri L, Angus DC, Pinsky MR. Informal caregiver burden among survivors of prolonged mechanical ventilation. Am J Respir Crit Care Med. 2007;175:167–73.
55. Im K, Belle SH, Schulz R, Mendelsohn AB, Chelluri L. Prevalence and outcomes of caregiving after prolonged (> or = 48 hours) mechanical ventilation in the ICU. Chest. 2004;125:597–606.
56. Belayachi J, Himmich S, Madani N, Abidi K, Dendane T, Zeggwagh AA, Abouqal R. Psychological burden in inpatient relatives: the forgotten side of medical management. QJM: Monthly J Assoc Phys. 2014;107:115–22.
57. Garrouste-Orgeas M, Coquet I, Perier A, Timsit JF, Pochard F, Lancrin F, Philippart F, Vesin A, Bruel C, Blel Y, Angeli S, Cousin N, Carlet J, Misset B. Impact of an intensive care unit diary on psychological distress in patients and relatives. Crit Care Med. 2012;40:2033–40.
58. Andresen M, Guic E, Orellana A, Diaz MJ, Castro R. Posttraumatic stress disorder symptoms in close relatives of intensive care unit patients: prevalence data resemble that of earthquake survivors in Chile. J Crit Care. 2015;30:1152 e1157–11.
59. Azoulay E, Pochard F, Kentish-Barnes N, Chevret S, Aboab J, Adrie C, Annane D, Bleichner G, Bollaert PE, Darmon M, Fassier T, Galliot R, Garrouste-Orgeas M, Goulenok C, Goldgran-Toledano D, Hayon J, Jourdain M, Kaidomar M, Laplace C, Larche J, Liotier J, Papazian L, Poisson C, Reignier J, Saidi F, Schlemmer B. Risk of post-traumatic stress symptoms in family members of intensive care unit patients. Am J Respir Crit Care Med. 2005;171:987–94.
60. Chui WY, Chan SW. Stress and coping of Hong Kong Chinese family members during a critical illness. J Clin Nurs. 2007;16:372–81.
61. Pillai L, Aigalikar S, Vishwasrao SM, Husainy SM. Can we predict intensive care relatives at risk for posttraumatic stress disorder? Indian J Crit Care Med. 2010;14:83–7.
62. Emery CF, Leatherman NE, Burker EJ, MacIntyre NR. Psychological outcomes of a pulmonary rehabilitation program. Chest. 1991;100:613–7.
63. Emery CF, Schein RL, Hauck ER, MacIntyre NR. Psychological and cognitive outcomes of a randomized trial of exercise among patients with chronic obstructive pulmonary disease. Health Psychol. 1998;17:232–40.
64. McWilliams DJ, Atkinson D, Carter A, Foex BA, Benington S, Conway DH. Feasibility and impact of a structured, exercise-based rehabilitation programme for intensive care survivors. Physiother Theory Pract. 2009;25:566–71.

65. Jones C, Eddleston J, McCairn A, Dowling S, McWilliams D, Coughlan E, Griffiths RD. Improving rehabilitation after critical illness through outpatient physiotherapy classes and essential amino acid supplement: a randomized controlled trial. J Crit Care. 2015;30:901–7.
66. McCraty R, Barrios-Choplin B, Atkinson M, Tomasino D. The effects of different types of music on mood, tension, and mental clarity. Altern Ther Health Med. 1998;4:75–84.
67. Chlan LL, Weinert CR, Heiderscheit A, Tracy MF, Skaar DJ, Guttormson JL, Savik K. Effects of patient-directed music intervention on anxiety and sedative exposure in critically ill patients receiving mechanical ventilatory support: a randomized clinical trial. JAMA. 2013;309:2335–44.
68. Kemper KJ, Danhauer SC. Music as therapy. South Med J. 2005;98:282–8.
69. Wong HL, Lopez-Nahas V, Molassiotis A. Effects of music therapy on anxiety in ventilator-dependent patients. Heart Lung. 2001;30:376–87.
70. Bittman B, Bruhn KT, Stevens C, Westengard J, Umbach PO. Recreational music-making: a cost-effective group interdisciplinary strategy for reducing burnout and improving mood states in long-term care workers. Adv Mind Body Med. 2003;19:4–15.
71. Raglio A, Giovanazzi E, Pain D, Baiardi P, Imbriani C, Imbriani M, Mora G. Active music therapy approach in amyotrophic lateral sclerosis: a randomized-controlled trial. Int J Rehabil Res. 2016;39:365–7.
72. Jones C, Backman C, Capuzzo M, Egerod I, Flaatten H, Granja C, Rylander C, Griffiths RD. Intensive care diaries reduce new onset post traumatic stress disorder following critical illness: a randomised, controlled trial. Crit Care. 2010;14:R168.
73. Jones C, Backman C, Griffiths RD. Intensive care diaries and relatives' symptoms of post-traumatic stress disorder after critical illness: a pilot study. Am J Crit: Off Publ Am Assoc Crit Care Nurses. 2012;21:172–6.
74. Cox CE, Porter LS, Hough CL, White DB, Kahn JM, Carson SS, Tulsky JA, Keefe FJ. Development and preliminary evaluation of a telephone-based coping skills training intervention for survivors of acute lung injury and their informal caregivers. Intensive Care Med. 2012;38:1289–97.
75. Cox CE, Hough CL, Carson SS, White DB, Kahn JM, Olsen MK, Jones DM, Somers TJ, Kelleher SA, Porter LS. Effects of a telephone- and web-based coping skills training program compared with an education program for survivors of critical illness and their family members. A randomized clinical trial. Am J Respir Crit Care Med. 2018;197:66–78.
76. Forbes D, Creamer M, Bisson JI, Cohen JA, Crow BE, Foa EB, Friedman MJ, Keane TM, Kudler HS, Ursano RJ. A guide to guidelines for the treatment of PTSD and related conditions. J Trauma Stress. 2010;23:537–52.
77. Powers MB, Halpern JM, Ferenschak MP, Gillihan SJ, Foa EB. A meta-analytic review of prolonged exposure for posttraumatic stress disorder. Clin Psychol Rev. 2010;30:635–41.
78. Chiang VC, Chien WT, Wong HT, Lee RL, Ha J, Leung SS, Wong DFA. Brief cognitive-behavioral psycho-education (B-CBE) program for managing stress and anxiety of main family caregivers of patients in the intensive care unit. Int J Environ Res Public Health. 2016;13:962.
79. Brown KW, Ryan RM. The benefits of being present: mindfulness and its role in psychological well-being. J Pers Soc Psychol. 2003;84:822–48.
80. Shaffer KM, Riklin E, Jacobs JM, Rosand J, Vranceanu AM. Psychosocial resiliency is associated with lower emotional distress among dyads of patients and their informal caregivers in the neuroscience intensive care unit. J Crit Care. 2016;36:154–9.
81. Dekel S, Mandl C, Solomon Z. Shared and unique predictors of post-traumatic growth and distress. J Clin Psychol. 2011;67:241–52.
82. Linley PA, Joseph S. Positive change following trauma and adversity: a review. J Trauma Stress. 2004;17:11–21.
83. Ogińska-Bulik N. The role of social support in posttraumatic growth in people struggling with cancer. Health Psychol Rep. 2013;1:1–8.
84. Swickert R, Hittner J. Social support coping mediates the relationship between gender and posttraumatic growth. J Health Psychol. 2009;14:387–93.

85. Janoff-Bulman R. Shattered assumptions: towards a new psychology of trauma. New York: Free Press; 1992.
86. Morris BA, Shakespeare-Finch J, Rieck M, Newbery J. Multidimensional nature of posttraumatic growth in an Australian population. J Trauma Stress. 2005;18:575–85.
87. Colville G, Cream P. Post-traumatic growth in parents after a child's admission to intensive care: maybe Nietzsche was right? Intensive Care Med. 2009;35:919–23.
88. Loiselle KA, Devine KA, Reed-Knight B, Blount RL. Posttraumatic growth associated with a relative's serious illness. Fam Syst Health. 2011;29:64–72.
89. Brown SM, Wilson EL, Presson AP, Dinglas VD, Greene T, Hopkins RO, Needham DM, with the National Institutes of Health NAN. Understanding patient outcomes after acute respiratory distress syndrome: identifying subtypes of physical, cognitive and mental health outcomes. Thorax. 2017.
90. Butler JM, Hirshberg EL, Hopkins RO, Wilson EL, Orme JF, Beesley SJ, Kuttler K, Brown SM. Preliminary identification of coping profiles relevant to surrogate decision making in the ICU. PLoS One. 2016;11:e0166542.

Chapter 5
Family Psychological Morbidity After the Intensive Care Unit

Kristina Stepanovic, Julie Van, and James C. Jackson

This chapter addresses the array of psychological repercussions that may arise in family members of intensive care unit (ICU) survivors. In particular, it will address a range of issues known to exist under the rubric of a newly identified condition known as post-intensive care syndrome-family (PICS-F). The chapter will cover diverse topics such as risk factors and possible protective factors for psychological repercussions in family members, moderating factors, and dimensions of psychological morbidity, while providing a novel framework to help understand PICS-F. Additionally, proposed future research directions in the field are included.

Psychological Morbidity and Delineating the Syndrome of PICS-F

To date, medical care for ICU patients has centered largely on the individual, with concerns revolving around the acute needs of patients in the context of critical illness. Against this backdrop, the corresponding needs of families have often been overlooked. Recently, a paradigm shift has occurred, spurred on by research

---

K. Stepanovic · J. Van
Center for Critical Illness, Brain Dysfunction, and Survivorship (CIBS), Vanderbilt University Medical Center, Nashville, TN, USA

J. C. Jackson (✉)
Center for Critical Illness, Brain Dysfunction, and Survivorship (CIBS), Vanderbilt University Medical Center, Nashville, TN, USA

Department of Psychiatry, Vanderbilt University School of Medicine, Nashville, TN, USA

Research Service, Department of Veterans Affairs Medical Center, Tennessee Valley Healthcare System, Nashville, TN, USA
e-mail: james.c.jackson@vanderbilt.edu
http://www.icudelirium.org

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_5

findings leading to new awareness of the potential devastation wrought not only on patients but also on their loved ones. Indeed, Netzer and Sullivan [1] have poignantly suggested that “morbidity begins for many family members as they walk through the doors of the ICU.”

Far from being unaffected, family members of ICU patients may experience a wide variety of psychological concerns, including depression, anxiety, cognitive deficits, posttraumatic stress disorder (PTSD), fatigue, and insomnia, among others [1]. This cluster of mental complications from families’ exposure to intensive care is known as post-intensive care syndrome-family (PICS-F). These psychological effects of PICS-F may last for several years after discharge and are likely to affect family members’ later involvement in patient care. In addition, families and caregivers often experience many challenges after discharge related to proper care, continued treatment, and rehabilitation of patients [2]. Family members often play the role of informal caregivers, taking responsibility for patients’ care after discharge despite being inadequately prepared and, as a result, overwhelmed. Although these individuals are thought to buffer the physical and social limitations of ICU patients, the cost to their own wellbeing is unknown but is likely high [3].

Prevalence and Risk Factors for Psychological Morbidity

After the ICU, the risk of conditions including depression, anxiety, and PTSD, components of PICS-F, is extremely high. Pathologies observed in caregivers of ICU survivors are substantially higher than those observed in the general population, reflecting a current public health issue that is still largely unrecognized. In a general community of adults, 7% suffer from major depressive disorder, 2.9% suffer from generalized anxiety disorder, and 3.5% suffer from PTSD [4]. In contrast, studies included in this chapter report rates of clinically significant depressive symptoms as high as 55%, rates of anxiety symptoms as high as 69%, and rates of PTSD symptoms as high as 53%, suggesting that caregivers of ICU survivors are often profoundly impacted by their family members’ illnesses from a psychological standpoint [5]. Table 5.1 presents a range of reported psychological outcomes in families of ICU patients.

Risk factors for PICS-F have been widely understudied but have identified within several different domains [10]. Family members are at a greater risk for developing PICS-F if patients are younger in age, single, and female and have received less education [10]. A family history of mental disorders, such as mood disorders or

Table 5.1 Typical ranges of psychological outcomes in family members of ICU patients

Outcomes	Significant findings (%)
Anxiety	35–49
Depression	20–39
PTSD	16–35

References: Azoulay et al. [6], Hickman and Douglas [7], Young et al. [8], Wintermann et al. [9]

severe conditions, can also increase the risk of developing PICS-F. Family members with mental illnesses prior to having their loved ones admitted to the ICU are also at a greater risk. Additionally, elevated stress levels contribute to an increased risk for PICS-F [10].

Communication dynamics between the ICU staff and the patient's family have effects on the risk of developing PICS-F. Family members who did not find the patient's physician comforting have higher prevalence, while family members who attended proactive end-of-life conferences and received brochures on relevant topics have lower prevalence of PICS-F conditions [10]. Clinically relevant symptoms of depression and anxiety are most prevalent in family members who favor passive roles as opposed to active ones in decision-making [10]. In contrast, at least two protective factors exist. Mothers of critically ill children who shared their feelings during admission show lower symptoms of PTSD. Also, family members who receive social support exhibit lower anxiety levels [10]. Figure 5.1 presents an overview of general factors leading to a discord in communication among ICU patients and their family members. These two populations undergo a parallel process of dealing with conflicts specific to their roles, both eventually resulting in lack of effective communication.

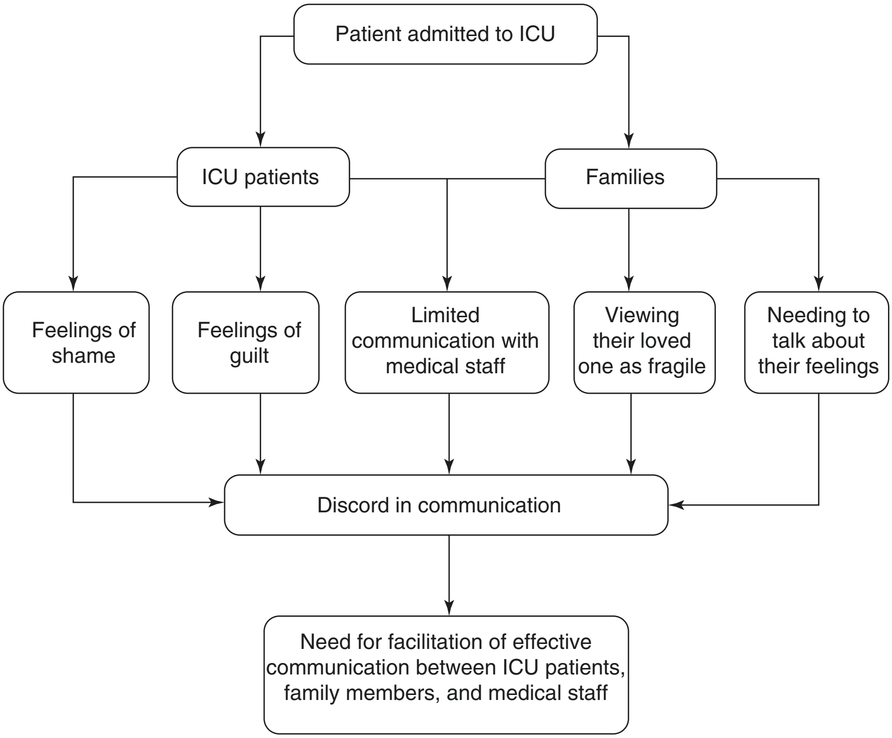


Fig. 5.1 Discord in communication between ICU patients and their families

Dimensions of Psychological Morbidity

The decrements experienced by family members – often, but not always including those in a caregiving role – are substantial, taking place primarily in areas including anxiety, depression, PTSD, cognitive deficits, and anticipatory grief. Figure 5.2 captures a common process experienced by family members of critically ill patients admitted to the ICU, often leading to psychological repercussion that influence abilities to properly care for their loved ones.

Anxiety and Depression

Numerous investigations have documented the extent to which clinically relevant symptoms of anxiety and depression are common in caregivers. Anxiety disorders, in which feelings of anxiety, apprehension, and fear exist to a clinically significant degree, are the most common family of disorders in the general population and highly prevalent in medical populations. Although they are often "uncovered"

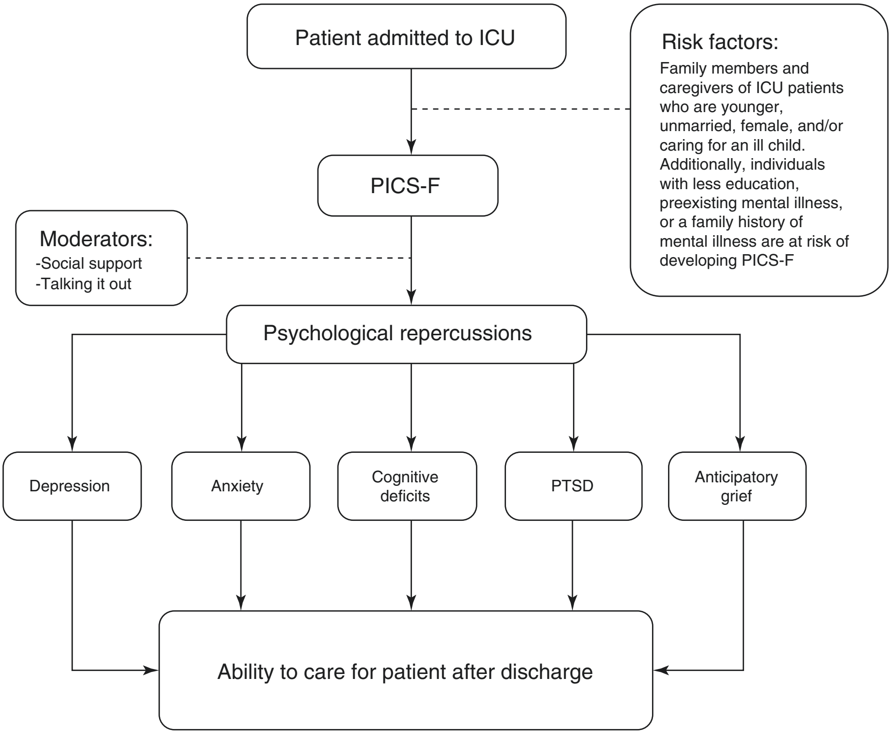


Fig. 5.2 Psychological morbidity in post-intensive care unit syndrome – family

during visits to primary care providers, specialists, and emergency room physicians, symptoms of anxiety have seldom been studied in close relatives of ICU survivors. When they have been assessed, studies almost uniformly suggest that anxiety symptoms are high and, indeed, evidence suggests that clinically significant anxiety may be present in up to 73% of family members and caregivers.

Depression is also common within the population. In a systematic review, symptoms of depression were the most frequently recorded psychiatric outcome in caregivers, with 22.8–31.9% of caregivers still experiencing symptoms after a year [3]. In patients with COPD, family caregivers reported psychological problems – typically depression – in 38% of relatives, with 32% of relatives taking medications for psychological problems that they did not have prior to their loved ones' time in the ICU [11].

PTSD

Posttraumatic stress disorder (PTSD) is a mental health condition born from the experience of being exposed to a trauma – typically a particularly intense one – in which an individual displays a characteristic set of symptoms involving intrusive memories, avoidance, hypervigilance, and an array of functionally disruptive behaviors. For years, trauma of the sort sufficient to cause PTSD was thought to almost exclusively involve such things as combat, sexual abuse, or assault. However, more recent evidence has emerged suggesting that medical events and illnesses can be profoundly traumatizing, both for those experiencing them and for those witnessing them (family members and caregivers). Indirect exposure may occur and affect these parties when trauma is either witnessed or learned about through secondary narrative accounts. The degree to which family members of ICU survivors experience trauma likely depends on a diversity of factors – still not widely explored.

Significant PTSD symptoms, which may or may not reflect a formal diagnosis of PTSD, occur in approximately 21% of family members with rates of approaching 60%, as reported in some studies. In families of critically ill patients, two-thirds of patients' spouses exhibit PTSD symptoms up to 55 months after their loved ones were discharged from critical care, highlighting the persistence and permanency of these symptoms [9]. A recent study showed that the median scores on an assessment of posttraumatic stress symptoms do not differ greatly between patients and their family members. Quality of life is also significantly lower in family members with PTSD when compared to controls [9].

Cognitive Deficits

Between 12% and 14% of family members or surrogates of critically ill patients report significant cognitive deficits, even without experiencing trauma that is characteristically associated with cognitive impairment [1]. For this reason, we speculate that new cognitive deficits in family members are likely and significantly overlooked. When a critically ill patient is hospitalized, family members must adapt to circumstances without having their needs fully met, all while lacking complete understanding of what is happening to their loved ones [12]. As a result, they are at risk for symptoms of anxiety, depression, PTSD, and sleep disorders [13].

The stress of caregiving, known to influence neuropsychological functioning, may play a seminal role in the development and maintenance of cognitive deficits. Post-intensive care syndrome in families, or PICS-F, includes common symptoms of limited mobility and mental processing issues [13]. Stress-related thoughts, often perceived as intrusive, impose a burden on cognitive resources that are already strained and disrupt already limited cognitive abilities [14, 15]. These difficulties are highly problematic and may prevent caregivers from successfully engaging in activities that are often crucial in the face of tending to impaired and frequently needy loved ones (e.g., making sure that bills are paid and finances are managed, ensuring that their loved ones are fully compliant with care, helping translate complex medical concepts to loved ones, etc.). Key questions remain about whether cognitive deficits experienced by caregivers reflect a “new normal” or diminish when the factors facilitating their development decrease in significance.

As an aside, a separate but important issue involving cognitive deficits among caregivers exists in the context of elderly spouses or relatives of ICU patients. There is an emerging priority in understanding the psychological burdens on families, caregivers, and surrogates of the critically ill. Anxiety and traumatic stress in family members may interfere with their ability to participate in patient care and treatment decisions [16].

Anticipatory Grief

One likely struggle experienced by individuals with PICS-F is anticipatory grief. Anticipatory grief refers to the natural stages of grief in the face of a loved ones feared impending death. As is well known, survivors of critical illness have very high mortality rates in the first 12 months, for example, after discharge; thus anticipatory grief is a realistic concern. Greater measures of anticipatory grief in caregivers for older adults with cognitive impairment have been found with a less positive orientation to problems, suggesting that higher levels of anticipatory grief deprecated problem-solving abilities [17]. Additionally, elevated levels of anticipatory grief correlate with elevated levels of post-loss avoidance, stress, complicated grief, and post-loss depression [18]. Exploratory study examining anticipatory grief in surrogate decision-makers illuminates the high levels of anticipatory grief experienced by surrogate decision-makers in the ICU.

Initial hypotheses of anticipatory grief suggest that “grief work” occurs prior to loss, and as a result, grief is mitigated after loss. However, studies have shown an absence of positive outcomes in grieving post-loss, which has also been identified as a risk factor for poor loss adjustment [18]. Caregivers experiencing anticipatory grief deal with emotional afflictions in many forms: ruminative anxiety, separation anxiety after loss, sadness, compassion fatigue, helplessness, and anger.

Some individuals avoid addressing death with their loved ones altogether and may continue discussing topics that involve future events [19]. Talking about an impending death may lead to feelings of hopelessness for families, causing them to avert additional emotional stress [19]. The nature of bereavement is based on the relationship between the caregiver and the deceased. How caregivers cope also affects the levels of grief they possess [18]. Overall, greater levels of anticipatory grief correlate with a decreased ability to solve problems [17].

Anticipatory grief requires further exploration to examine the mechanisms behind pre-loss grief and to assess the concept longitudinally [18]. It is possible that psychosocial intervention, namely, behavioral interventions and cognitive skills training, alleviates symptoms of grief after loss for a caregiver [20]. Caregivers require a narrative approach to transition from their caregiving role to a family member role to cope with the impending loss of loved ones [21]. There is a need for better understanding of anticipatory grief to develop effective methods for intervention in family caregivers with critical illness [20].

Fatigue and Insomnia Leading to Psychological Morbidity

Fatigue is almost inevitable among family members of ICU patients, and it is often a precursor to other health problems, illnesses, and mortality. For example, the length of stay for an ICU patient correlates with their family members' level of fatigue. Clinically relevant fatigue is present in roughly half of caregivers – greater than the general population and other caregivers for the chronically ill. Fatigue is associated with poorer sleep quality, burden, symptoms of depression, and health-risk behaviors. Further research is necessary to elucidate the effect of fatigue on family caregivers in the ICU and to develop effective interventions for families with loved ones in the ICU [22].

McPeake et al. [5] examined relationships between caregivers of critically ill patients after discharge and clinical and subclinical presentations of insomnia in this population. She reported that fully a quarter of caregivers had subclinical insomnia, 61% had trouble sleeping, and 33% had clinically relevant insomnia. Individuals experiencing high levels of insomnia also dealt with greater levels of anxiety [5]. Cognitive impairment is dependent on the severity of the insomnia. While it is common for sleep deprivation to occur in this population, a proportion of family members experience cognitive blunting, otherwise known as psychomotor slowing [23]. Guo et al. [24] found that patients with primary insomnia also have cognitive deficits, yielding lower scores for recall and immediate memory. Generally, the pathway to cognitive deficits in caregivers involves sleep deprivation, which has been linked to cognitive deficiencies in family members of survivors of critical illness [23].

Potential Positive Outcomes Among Family Members in the ICU

Often, traumatic events may lead to negative emotions. For many, these experiences result in positive changes in functioning, otherwise known as posttraumatic growth [2]. Some of these changes include greater appreciation of interpersonal relationships and increased levels of empathy. Research has supported many themes when facilitating posttraumatic growth in survivors of traumatic injury. Tedeschi and McNally [25] identified several different components when facilitating growth in a population of veterans: normalizing the experience of symptoms of trauma after combat, teaching emotion regulation skills, adding growth dimensions to the trauma narrative (referred to as "constructive self-disclosure"), and establishing healthy precepts about life. In a study on positive changes in parents of children in the ICU, Colville and Cream [26] noted that posttraumatic growth occurred more frequently in those experiencing moderate stress. Low levels of stress were not enough to catalyze parents into giving life "a new meaning." At the same time, high levels of stress left individuals with little opportunity for positive reactions [26].

Critically ill patients reported that family presence in the ICU was an important source of psychological support [27]. After surviving the ICU, survivors may harbor shame or guilt about the stress imposed upon their families during hospitalization. Family members are often afraid to share their feelings about these experiences because they feel that talking about their stress or experiences would be damaging to the survivor. As a result, this relationship may create discord in communication between the survivor and their family or partner. Facilitating communication between survivors and their families is essential to the relationship between both parties and plays a significant role in reducing negative psychological effects in family members [2].

While adjusting to the role of caregiver may be difficult, communicating with loved ones about their experiences may improve the dynamic between all those involved. Fifty-nine percent of families who communicated regularly with attending physicians reported confidence in patient recoveries, with 34% of families feeling "calmer" [27]. Figure 5.2, described above, captures a common process experienced by family members of critically ill patients admitted to the ICU, often leading to psychological repercussions that influence abilities to properly care for their loved ones.

Caregiver Burden

Providing care for a family member who is critically ill can have multifaceted, adverse impacts on the caregiver – physical, psychological, and emotional strain – as well as financial and social burden. Although over 40 million Americans provide care for adults older than 50, caregiver burden is frequently underestimated by physicians. Up to 90% of adult, long-term care is provided by informal caregivers (nonpaid family or friend). About 20% of caregivers spend over 40 h a week caring for their family member, and the estimated cost of such care, for dementia patients, is $56,290 a year.

Numerous risk factors have been identified that increase the magnitude of caregiver burden, including: living with the care recipient, less education, financial pressure, depression, lack of choice with respect to caregiving, and female sex. Clinical outcomes associated with caregiver burden are concerning and may include weight loss, lack of self-care, sleep deprivation, and increased mortality. Psychological morbidity also abounds, to include anxiety, depression, isolation, and – in extreme cases – suicide. The needs of caregivers are under recognized and should include education and information, physical and emotional support. Interventions have been suggested to improve the quality of life in caregivers as well as their family members.

Adelman suggests several practical interventions to lower caregiver strain. Patients and families should explore caregiving problems that may arise with their physician, who may have suggestions or solutions. Additionally, healthy behaviors for the caregiver should be encouraged. Providing the appropriate information and education for the caregiver is also essential – understanding the ICU survivor's needs and condition are imperative. Implementing goals and plans for long-term care should also be discussed with relevant experts, whether physicians, social workers, or case managers. Encouraging the caregiver to access assistance with care or respite care can also provide relief.

As has been observed, interventions in facilitated "sense making" may prepare caregivers in their role as a caretaker. Family members performing activities with their loved one may increase feelings of usefulness and greater correspondence with medical professionals [10]. This is important, as family members often feel quite helpless and, frequently, lack even a basic understanding of the medical illnesses and issues faced by their loved ones. Experiencing greater connection with medical professionals, against this backdrop, is likely very empowering.

Conclusions, Future Directions, and Recommendations

This chapter has highlighted the various psychological effects of PICS-F – moderating factors, risks for psychological repercussions in family members, dimensions of psychological repercussions, and a novel framework to feature the process in a digestible manner for those involved in healthcare. Family members of ICU patients may experience a variety of psychological concerns: depression, anxiety, cognitive deficits, insomnia, fatigue, PTSD, and anticipatory grief, among others. These concerns may be accelerated by diverse risk factors – some of them modifiable, some of them not. Presumably, they can be greatly improved, if not alleviated, by thoughtfully developed and skillfully implemented interventions, whether preventative or treatment focused.

With an “eye” toward improving outcomes of family members, a variety of future directions should be pursued. From a research standpoint, the difficulties experienced by family members of ICU survivors should be better characterized, and tailored interventions should be developed. It may be, for example, that there are specific methods for treating loved ones with PTSD that differ from conventional methods – only through investigation can this be determined. Other research questions of interest may include such things as the exploration of the psychobiological correlates of caregiver burden and the effects of having a loved one in the ICU on such outcomes as relational satisfaction and risk of divorce. From a clinical standpoint, focused efforts should be made to integrate family members of ICU survivors into psychotherapy, either individual therapy or family therapy, depending on their specific needs. Other clinically oriented goals should include the development of educational programming – both for medical providers and for patients and families – that highlight the nature and extent of the difficulties experienced by caregivers and family members. Such programming – reflected in either websites or brochures – could be developed with input from patients and families and could help normalize the experiences of depression, anxiety, and trauma.

While much remains to be known about PICS-F, available research, limitations and all, points to the existence of a serious and yet underappreciated public health problem. Through the combined efforts of researchers and clinicians, aided by the input of families, we remain hopeful that our understanding of PICS-F will increase substantially in years to come, resulting in less distress and better quality of life.

References

1. Netzer G, Sullivan D. Recognizing, naming, and measuring a family intensive care unit syndrome. Ann Am Thorac Soc. 2014;11(3):435–41. https://doi.org/10.1513/AnnalsATS.201309-308OT.
2. Jezierska N, Borkowski B, Gaszyński W. Psychological reactions in family members of patients hospitalised in intensive care unit. Anaesthesiol Intensive Ther. 2014;46:42–5. https://doi.org/10.5603/AIT.2014.0009.
3. Haines K, Denehy L, Skinner E, Warrillow S, Berney S. Psychosocial outcomes in informal caregivers of the critically ill: a systematic review. Crit Care Med. 2015;43(5):1112–20. https://doi.org/10.1097/CCM.0000000000000865.
4. American Psychiatric Association, editor. Diagnostic and statistical manual of mental disorders. 5th ed. Washington, DC: American Psychiatric Association; 2013.
5. McPeake J, Devine H, MacTavish P, Fleming L, Crawford R, Struthers R, et al. Caregiver strain following critical care discharge: an exploratory evaluation. J Crit Care. 2016;35:180–4. https://doi.org/10.1016/j.jcrc.2016.05.023.
6. Azoulay E, Pochard F, Kentish-Barnes N, Chevret S, Aboab J, Adrie C, et al. Risk of post-traumatic stress symptoms in family members of intensive care unit patients. Am J Respir Crit Care Med. 2005;171(9):987–94.
7. Hickman R, Douglas S. Impact of chronic critical illness on the psychological outcomes of family members. Am Assoc Crit–Care Nurs Adv Crit Care. 2010;21:80–90.
8. Young E, Eddleston J, Ingleby S, Streets S, McJanet L, Wang M, et al. Returning home after intensive care: a comparison of symptoms of anxiety and depression in ICU and elective cardiac surgery patients and their relatives. Intensive Care Med. 2005;31:86–91.

9. Wintermann G, Weidner K, Straub B, Rosendahl J. Predictors of posttraumatic stress and quality of life in family members of chronically critically ill patients after intensive care. Ann Intensive Care. 2016;6(69):1–11.
10. Davidson JE, Jones C, Bienvenu J. Family response to critical illness: postintensive care syndrome-family. Crit Care Med. 2011;40(2):1–7.
11. Miranda S, Pochard F, Chaize M, Megarbane B, Cuvelier A, Bele N, et al. Postintensive care unit psychological burden in patients with chronic obstructive pulmonary disease and informal caregivers: a multicenter study. Crit Care Med. 2011;39(1):112–8.
12. Herridge MS, Moss M, Hough CL, Hopkins RO, Rice TW, Bienvenu OJ, Azoulay E. Recovery and outcomes after the acute respiratory distress syndrome (ARDS) in patients and their family caregivers. Intensive Care Med. 2016;42(5):725–38.
13. Hoffman LA. Post intensive care syndrome: risk factors and prevention strategies. Crit Care Alert. 2015;22(12). Retrieved from http://login.proxy.library.vanderbilt.edu/login?url=https://search.proquest.com/docview/1987263825?accountid=14816.
14. Sliwinski MJ, Smyth JM, Hofer SM, Stawski RS. Intraindividual coupling of daily stress and cognition. Psychol Aging. 2006;21:545–57.
15. Stawski RS, Sliwinski MJ, Smyth JM. Stress-related cognitive interference predicts cognitive function in old age. Psychol Aging. 2006;21:535–44.
16. McAdam JL, Dracup KA, White DB, Fontaine DK, Puntillo KA. Symptom experiences of family members of intensive care unit patients at high risk for dying. Crit Care Med. 2010;38(4):1078–85. https://doi.org/10.1097/ccm.0b013e3181cf6d94.
17. Fowler NR, Hansen AS, Barnato AE, Garand L. Association between anticipatory grief and problem solving among family caregivers of persons with cognitive impairment. J Aging Health. 2013;25(3):493–509. https://doi.org/10.1177/0898264313477133.
18. Nielsen MK, Neergaard MA, Bonde Jensen A, Bro F, Guldin M. Do we need to change our understanding of anticipatory grief in caregivers? A systematic review of caregiver studies during end-of-life caregiving and bereavement. Clin Psychol Rev. 2016;44:75–93. https://doi.org/10.1016/j.cpr.2016.01.002.
19. Coelho A, Barbosa A. Family anticipatory grief: an integrative literature review. Am J Hosp Palliat Med. 2017;34(5):774–85. https://doi.org/10.1177/1049909116647960.
20. Wilson S, Toye C, Aoun A, Slatyer S, Moyle W, Beattie E. Effectiveness of psychosocial interventions in reducing grief experienced by family carers of people with dementia: a systematic review. JBI Database System Rev Implement Rep. 2017;15:809–39.
21. Toyama H, Honda A. Using narrative approach for anticipatory grief among family caregivers at home. Glob Qual Nurs Res. 2016;3:1–15. https://doi.org/10.1177/2333393616682549.
22. Choi J, Tate J, Hoffman L, Schulz R, Ren D, Donahoe M, et al. Fatigue in family caregivers of adult intensive care unit survivors. J Pain Symptom Manage. 2014;48(3):353–63.
23. Verceles AC, Corwin DS, Afshar M, et al. Half of the family members of critically ill patients experience excessive daytime sleepiness. Intensive Care Med. 2014;40:1124–31. https://doi.org/10.1007/s00134-014-3347-z.
24. Guo H, Wei M, Ding W. Changes in cognitive functioning in patients with primary insomnia. Shanghai Arch Psychiatry. 2017;29(3):137–45.
25. Tedeschi R, McNally R. Can we facilitate posttraumatic growth in combat veterans? Am Psychol. 2011;66(1):19–24. https://doi.org/10.1037/a0021896.
26. Colville GA, Cream P. Post-traumatic growth in parents after a child's admission to intensive care: maybe Nietzsche was right? Intensive Care Med. 2009;35:919–23.
27. Dziadzko V, Dziadzko MA, Johnson MM, Gajic O, Karnatovskaia LV. Acute psychological trauma in the critically ill: patient and family perspectives. Gen Hosp Psychiatry. 2017;47:68–74. https://doi.org/10.1016/j.genhosppsych.2017.04.009.

Chapter 6

Sleep and Sleep Deprivation Among Families in the ICU

Stuti J. Jaiswal and Robert L. Owens

Overview of Sleep: Background and Definitions

Sleep is the transient state in which all people spend 25–33% of their lifetimes. Its role in human health and disease is still poorly understood. However, it is increasingly recognized that sleep and sleep disorders have major impact on cardiovascular and neurocognitive health. For example, reported chronic short sleep duration – adjusted for all known covariates – is an independent risk factor for incident coronary artery disease [1], pneumonia [2], and weight gain [3]. Short sleep duration is associated with decreased antibody response to vaccination, suggesting immune modulation with short sleep [4, 5]. Recent epidemiological, basic, and animal research has begun to examine links between sleep duration and cancer [6]. Thus, sleep is likely to be important, but we have much to learn. Most society guidelines recommend 7–9 h of sleep per night [7, 8].

Sleep Stages

Sleep is typically divided into different sleep stages, based upon electroencephalographic (EEG), electrooculographic, and electromyographic patterns. The major division of sleep stages is between rapid eye movement (REM) and non-rapid eye movement (NREM) sleep. REM sleep shows characteristic conjugate eye

---

S. J. Jaiswal
The Scripps Research Institute, La Jolla, CA, USA
e-mail: Jaiswal.Stuti@scrippshealth.org

R. L. Owens (✉)
Pulmonary, Critical Care and Sleep Medicine Division, University of California San Diego, La Jolla, CA, USA
e-mail: rowens@ucsd.edu

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_6

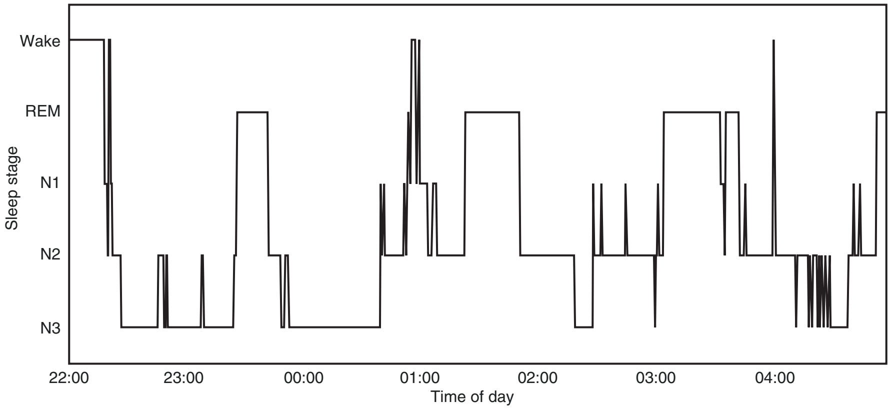


Fig. 6.1 An overnight hypnogram from a healthy subject that shows the pattern of the various sleep stages. The relative amounts of the sleep stages change with age, medications, and other factors

movements and is also referred to as "dreaming" sleep, as most recalled dreaming activity takes place during this phase of sleep. NREM sleep is further classified into phases called N1, N2, and N3 sleep, based upon the EEG appearance and rhythms (e.g., alpha, delta) that predominate. Because N3 is classified by delta wave activity (high amplitude, relatively slow frequency), it is sometimes referred to as slow wave sleep. In lay literature, either N3 or REM sleep is considered "deep" or "quality" sleep; however, the data to support these statements are incomplete. Although many studies consider the impact of sleep duration on a variety of outcomes (as above), the difficulty in reliably measuring the various sleep stages has limited the amount of studies that look at the various sleep stages and outcomes. Thus, most of the literature and this review will focus on overall sleep duration rather than specific sleep stages.

Typically, the sleep phases change throughout the night in a cyclical pattern of N1, N2, N3, then REM, and repeat (see normal hypnogram, Fig. 6.1, below) with a period of approximately 120 min. However, the timing and amounts of sleep can vary considerably according to multiple factors, including age, medication use, and genetics. For example, the amount of N3 sleep decreases with age. Alternatively, many commonly prescribed medications impact sleep stages, such as selective serotonin reuptake inhibitors (SSRIs) which suppress REM sleep, as well as most of the medications used in the ICU [9].

Circadian Rhythm

One of the most important factors affecting the timing of sleep in general and its various phases is the endogenous circadian rhythm. The circadian rhythm typically has a period of close to 24 h, with most rhythms also aligned for sleep during the

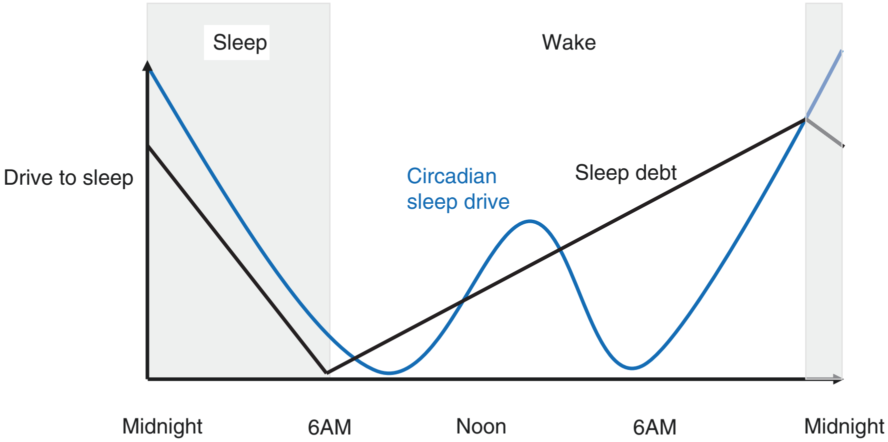


Fig. 6.2 The two stimuli for sleep are the endogenous circadian rhythm and sleep debt which accumulates during wake and recedes during sleep. Sleep during the night and with an early afternoon nap would mimic the endogenous circadian rhythm in most people

hours, 10 pm–6 am (and sometimes in the early afternoon; see Fig. 6.2). The endogenous circadian rhythm is affected by a variety of external cues, with light the most powerful. There is also variability in both the period and alignment. For example, some individuals show either an advanced or delayed sleep phase, with marked preference for either early morning (so-called morning larks) or late evening ("night owls"), respectively. However, when unable to accommodate to their preferred internal rhythm, symptoms of fatigue and sleepiness can result. The same mismatch between the internal circadian rhythm and the external environment commonly results in symptoms of "jet lag."

"I Can't Sleep": Lack of Opportunities for Sleep vs. Insomnia

Relevant to the ICU, family members of ICU patients often report difficulty sleeping. Broadly, this may be due either to lack of opportunities for sleep or insomnia, which have very different causes and treatments. Insomnia is defined as difficulty falling asleep, staying asleep, or non-restorative sleep *despite* an adequate opportunity for sleep. In the ICU, stress, anxiety, or other emotions could easily prevent sleep in a family member. However, the complaint of "I can't sleep" might more likely derive from the inability to find the right conditions for sleep in the ICU and could be due to light, sound, frequent interruptions, or lack of a bed/chair in which to sleep. These are both considered below.

Lack of Opportunities for Sleep: "I Don't Have Enough (Time, Space, Quiet) to Get Some Sleep"

Sleep is notoriously bad in the ICU, for both patients and their family members due to multiple reasons, with most pointing to environmental factors and frequent care interactions [10]. The primary rationale of the ICU is to group the sickest patients to allow for rapid responses as needed. This comes into direct conflict with efforts to promote sleep. Patients themselves will have unique barriers to sleep, such as pain, dyspnea, and ventilator dyssynchrony. However, loud alarms from multiple different types of equipment (e.g., telemetry, ventilator alarms), frequent interactions with clinicians, and procedures will interfere with sleep for both patients *and their loved ones*. Multiple studies have found the ICU to be a very poor environment for sleep, with very high sound levels, for example, frequently exceeding WHO-recommended guidelines [11, 12]. Thus, the Society of Critical Care Medicine recommends promotion of the sleep environment by clustering routines, optimizing the environment for sleep, and promoting uninterrupted sleep times [13].

Efforts to improve the sleep environment in the ICU have been difficult. Multiple interventions, which require substantial staff education and changes in practice, may be required [14]. Even in the landmark study by Kamdar and colleagues designed to improve sleep quality, which demonstrated an important reduction in ICU delirium, no improvement in patient subjective sleep quality was found. While multimodal interventions are unlikely to be implemented easily, even more targeted interventions must be carefully considered. For example, "just" focusing on noise reduction can result in statistically significant changes in noise level, but these are small and unlikely to have clinical benefit. Moreover, efforts to reduce noise levels may paradoxically increase difficulty sleeping since it is *changes* in sound level that actually lead to arousal from sleep [15, 16]. Consider the use of white noise machines to aid sleep, which work in part by increasing the average background noise level. Earplugs and eye masks have been shown to modestly improve sleep (increasing sleep time by about 16 min per night) for healthy patients exposed to a simulated ICU environment [17]; however, comfort and acceptance of earplugs in particular is low [18]. Finally, while efforts to reduce light during the circadian night are frequently recommended, light levels, when measured, have been low at night [19]. Instead, more light may be needed during the day to maintain a circadian rhythm, a finding seen in multiple studies [16, 19, 20].

Family members must encounter all of these problems and also frequently face additional challenges. First, some ICUs lack a physical space for family members to sleep or that space is a communal waiting room which is not designed for sleep or privacy. Second, family members may have multiple other interruptions not related to the ICU environment such as updating other family members, other work obligations, etc. Third, family members may also travel from distance and deal with the effects of jet lag as well. Finally, stress and anxiety may cause insomnia, preventing sleep even when the ICU environment allows it. Indeed, family members themselves report anxiety, tension, and fearfulness as the three most common causes of sleep disturbance, much more commonly than environmental factors such as unfamiliar bed or too much noise [21]. Stress may not only be about the medical condition of their loved one, but family members can also face financial stress in the form of substantial nonmedical out-of-pocket expenses such as meals, lodging, and parking or from missed days at work [22].

How Well Do Family Members Sleep in the Hospital?

Emerging literature suggest that family members of critically ill patients are sleep deprived and that they have symptoms as a result, although the symptoms vary between individuals [23]. There are few studies that have objectively measured sleep times of family members in the ICU. In this regard, the work by Choi and colleagues, while based on a limited sample, is an important first step. Using actigraphy, they found that family members of ICU patients at the time of ICU admission averaged 328 ± 71 min (i.e., <5.5 h) of sleep per night [24]. Family members of ICU patients often report fatigue and difficultly sleeping [25]. Family members report inadequate rest, and nearly half report an inability to slow down or rest when *they themselves* are sick [27]. This follows a general pattern where family members prioritize presence in the ICU rather than their own health, missing doctor's appointments of their own, missing scheduled medications, skipping meals, etc.

Why Do Family Members Put Themselves Through These Conditions?

Multiple studies have shown that family members want to stay with patients for a variety of reasons. Primarily, most report a desire to safeguard and support their loved ones [28, 29]. But open visitation is also associated with improved family satisfaction [30, 31] and reduced family anxiety [32] and has the practical benefit of improved communication with clinicians [33]. Recognizing these benefits, guidelines for family-centered care recommend open visitation and promote family presence [34]. However, increased family presence may worsen family and potentially patient sleep.

Could Family Presence Lead to Poor Patient Sleep?

Some families may visit loved ones according to their own schedule, such as late at night after work or during other designated rest times for patients. While no evidence exists that such visits should be discouraged, families should be educated on the importance of uninterrupted rest time [35]. Conversely, families should understand that periods of wake and mobilization are equally important and that sedation and sleep are not the same. For example, some family members may interpret the deeply sedated patient as sleeping comfortably and discourage efforts to lighten sedation or perform interruptions of sedation, despite evidence that such efforts are beneficial [36]. Families may also defer opportunities for mobilization since their loved one is "sleeping," even though early mobilization may confer benefit [37]. Finally, some families may ask for pharmacological interventions, i.e., sleeping pills, to aid in sleep although risks usually outweigh any benefit [38].

Impact of Sleep Deprivation

There are very few studies carried out among ICU family members specifically. Thus, we extrapolate from the literature of acute sleep deprivation. One interesting study is by van Dongen and colleagues [39]. They exposed young healthy subjects to various degrees of sleep restriction/deprivation for up to 14 days. Each day, subjects rated their subjective sleepiness and also completed the psychomotor vigilance test (PVT), a test of alertness. Subjects restricted to only 4 or 6 h per day felt tired, but their subjective sleepiness plateaued after a few days. In contrast, the objective PVT showed continued worsening every day. *Thus, one of the features of sleep deprivation is the inability for people to recognize how affected they are by sleep deprivation.* Relevant for families of ICU patients, families may not appreciate the degree of sleep deprivation they are experiencing or the impact of that sleep deprivation.

In general, the following domains impacted by acute sleep deprivation are likely to be important for family members and their interaction with the healthcare team. Sleep deprivation can cause increases in lapses in attention, increased risk taking [40], irritability, and decreased trust in others and increased aggressiveness [41].

One of the few studies to specifically test cognition in ICU family members found that most showed lapses in attention as measured by the psychomotor vigilance test [26]. Additionally, in this study, those subjects who were subjectively sleepy also experienced greater impairment in performing daily activities.

Taken together, lack of sleep may impact how families interact with clinicians, how they interpret information, and how they make decisions that affect their loved ones. Adequate sleep could be an important part of building a therapeutic bond between family and clinicians [42], and the atmosphere of the ICU is a factor identified as important in predicting family member dissatisfaction with intensive care [43]. For family members themselves, lack of sleep may impact decisions about their own care, such as ability to drive while drowsy [44].

Management of Sleep Deprivation

In general, the treatment for sleep deprivation is adequate sleep, which could occur during the night or as naps throughout the day. Caffeine is also frequently used (by both providers and family members) to mitigate the impact of sleep deprivation. An important corollary is the avoidance of sedatives such as alcohol or sleeping pills (e.g., benzodiazepines) which cause increased sedation but are unlikely to be effective at promoting sleep unless the sleep environment is also improved.

Suggestions for Improving Family Sleep in the ICU

There are few data to suggest how best to improve family sleep. Until such data become available, the suggestions below are based on common sense. We emphasize that consideration of *both* patient and family member sleep might be useful, as has been suggested when assessing mental wellbeing of patient-caregiver dyads [45]. Finally, other efforts that are not sleep specific – such as improved education and communication with families that generally reduces anxiety – have been advocated and may also be useful [46]:

1. *Improved physical space for sleeping*. This has been suggested as part of recent guidelines. Our own experience when physically relocating our ICU to new facilities (same type of patients, same providers, and same care policies in both ICUs) was an increase in nighttime visits by family members. While sleep and effects of sleep deprivation were not directly assessed, the average number of visitors in patient rooms at night increased from 50% of patients to 79% of patients [47]. In this regard, neonatal ICUs can lead the way, with sleeping areas for parents that allow closeness with their child and, at times, privacy [48].
2. *Education for families about the importance of wake and sleep.* As above, information to educate and engage family members will be important. Interestingly, some patients, and family members, feel secure with abundant nighttime activity and alarms [10]. What many clinicians and some patients/family members interpret as barriers to sleep are interpreted as active monitoring by others. Thus, any intervention will need some element of education for patient and families to provide reassurance. With appropriate education, family members may be the biggest advocates for uninterrupted rest time as well as periods of activity during the day. Furthermore, this information might also include education and resources about sleep after the ICU for both patients and family members. Sleeping pills should be discouraged for patients and family members.

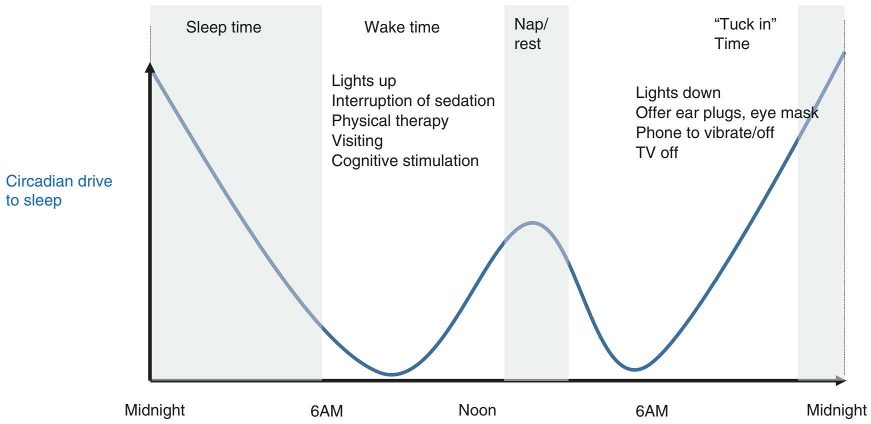


Fig. 6.3 Example protocol to optimize sleep in the hospital for both patients and family members. Activities during the day would ideally include family members. Bedtime tuck in would be aimed at patients and family members

3. *Active management of family member wake and sleep time.* Family member sleep could be encouraged both during the night and during rest ("nap") times during the day. Not only would such management improve family member sleep, but it may also improve patient sleep as well. For example, empowering family members to act as guardians of sleep time may also help reduce nighttime interruptions. During active periods during the day, family members might be encouraged to increase light levels in the room (which are frequently too low to entrain the circadian rhythm) [16, 19] and engage family members in conversations or simple cognitive activities (e.g., card playing) that might be useful in preventing or reducing delirium [49]. Similarly, if physically able and with appropriate guidance, they might participate in range-of-motion or other activities. This role for family members might provide a sense of usefulness for them and foster teamwork with the clinical team. See Fig. 6.3. We note that family engagement is now considered in the design of clinical trials [50]. Importantly, such physical activity during the day could improve family member's insomnia [51–53].
4. *Create protected sleep times at night and during the day for both patient and family.* We have previously advocated for a "tuck-in" time which would signal the start of the nighttime rest period for the patient [54]. For patients this might include management of pain and comfort, preparation of the room for sleep (lights down, TV off, setting of optimal desired temperature, etc.), and offering of earplugs and eye masks. Importantly, the "tuck in" could also be extended to family, as well, who could also be offered eye masks and earplugs. Family members could also be encouraged to disengage from their mobile phone and other electronic devices.

Insomnia: “I Just Can’t Seem to (Fall, Stay) Asleep”

A separate problem is insomnia – the inability to fall asleep despite an adequate opportunity to do so. Thus, lack of an opportunity for sleep may occur mostly when families attempt to sleep in the ICU, and insomnia might occur outside of the ICU. Insomnia is one of the most common medical conditions, and some studies suggest that almost all Americans will have an episode of acute insomnia at some point during their lifetime. Insomnia can include difficulty falling asleep, staying asleep, or waking up too early with inability to fall back asleep. This difficulty sleeping must also be paired with symptoms or distress from the poor sleep. Insomnia is endorsed frequently by ICU family members, and symptoms frequently correlate with stress or anxiety [21, 55, 56].

While insomnia may be a reflection of stress or anxiety, it may persist and become the dominant symptom even after the initial stress/anxiety has resolved. For example, stress over a loved one’s admission to the ICU may be the inciting event for prolonged insomnia even in family members of patients who recover well from critical illness. People with insomnia frequently have anxiety and frustration about their difficulty sleeping, and their responses to insomnia can further prolong or worsen sleep difficulties. People with difficulty falling asleep may perseverate on the problem by watching the clock or feel frustrated lying in bed awake. They may also compensate by staying in bed longer the next morning. All these behaviors will make it difficult to fall asleep the next night as well. Effective therapy focuses on eliminating the vicious cycle of these behaviors.

The cornerstone of therapy for insomnia is non-pharmacological. Education and cognitive behavioral therapy are the best initial treatment options. Education focuses on so-called sleep “hygiene” – the behaviors that help promote sleep, such as avoidance of naps (note that this is an effective strategy for sleep deprivation but will worsen insomnia) and maintenance of a consistent sleep schedule. Avoidance of behaviors that promote frustration with sleep, such as avoidance of clock watching or staying in bed awake, is recommended (i.e., stimulus control). For some, sleep restriction – the avoidance of too much time in bed – can also be very helpful. Medication would only be considered after an evaluation by a physician.

Sleep after the ICU

Both sleep deprivation and insomnia can occur after the ICU, depending on the course of illness for the patient. For those whose loved ones died in the ICU, the major post-ICU sleep abnormality may be insomnia in the setting of grief or subsequent depression. Conversely, those whose family members survive the ICU and return home may experience both insomnia and sleep deprivation as a result of the care they must provide to their loved ones. Multiple studies have shown that caregiver burden can be quite high and remain high after the ICU, particularly at the time of discharge home [57–62]. The course of caregiver burden is variable [63], and there are few data. As a starting point, in the study by Choi and colleagues, actigraphy was extended up to 2 months after the ICU [24]. We note that total sleep time at 2 months was highest in those whose family members died in the ICU, but their sleep tended to be more fragmented with more wake after sleep onset, a marker of insomnia. Conversely, those who family members returned home got less sleep, which was less fragmented. Thus, sleep is likely to be poor in caregivers after ICU discharge for a variety of reasons and will fluctuate over time. (See Fig. 6.4 conceptual examples.)

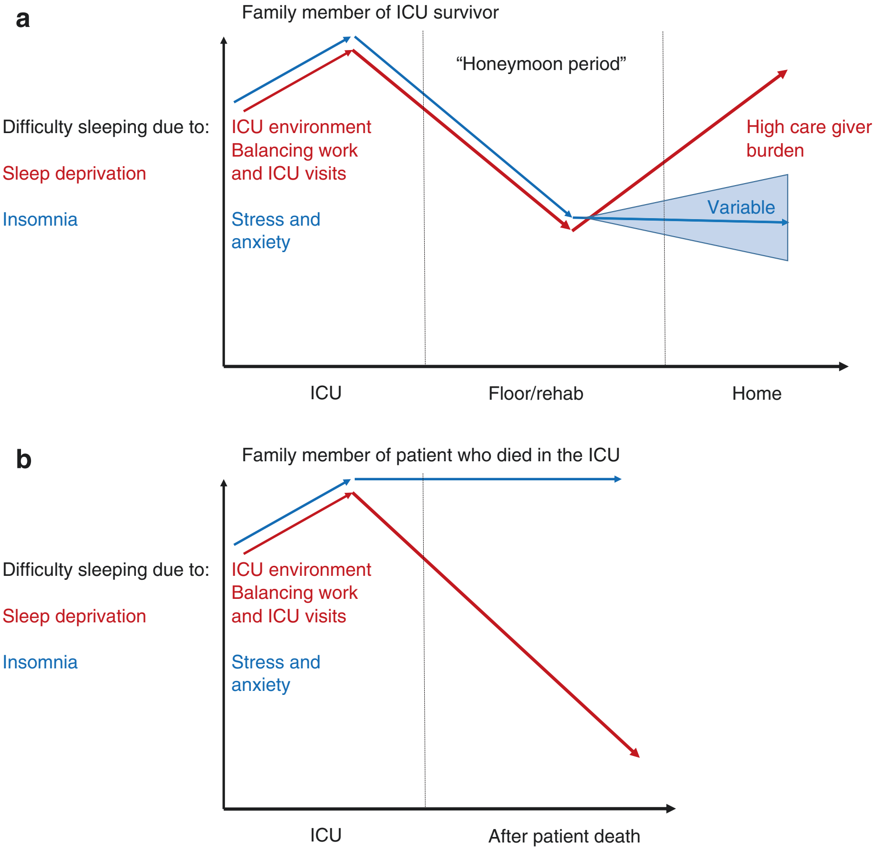


Fig. 6.4 Difficulty sleeping can be explained by lack of adequate sleep opportunity, insomnia, or both. The relative contribution of each may also fluctuate during the hospital stay and based on the outcome of the ICU patient. In panel (**a**), the patient survives to eventual home discharge. There may be a "honeymoon period" when caregivers sleep well, as patients improve yet remain cared for by others. This period may end when the patient returns home and caregiver burden increases or as anxiety builds over the slow pace of recovery. In panel (**b**), the patient does not survive to ICU discharge

In order to improve sleep after the ICU, it will be important first to obtain sufficient history to understand why the family member "can't sleep." Education to family members about the signs and symptoms of insomnia and basic sleep hygiene tips may be helpful. Persistent insomnia should prompt evaluation by a physician, and medication should be considered a last resort. If poor sleep is due to high caregiver burden, some caregiver relief will be needed.

Sleep and Relationship with PICS-F

Anxiety, depression, and posttraumatic stress disorder (PTSD) are now recognized complications for family members of ICU patients, and this constellation of symptoms has been termed post-ICU care syndrome-family (PICS-F) [64]. Poor sleep, then, may be a prominent symptom of PICS-F. Whether poor sleep in the hospital predisposes to PICS-F is not clear. Interestingly, some studies have shown that sleep deprivation after trauma reduces subsequent anxiety and development of PTSD [65–67]. It has been hypothesized that sleep deprivation slows or prevents new memory formation that could be used to reexperience the trauma.

Regardless of any possible causal role, an emphasis on improving sleep and reducing insomnia may improve symptoms of anxiety or depression [68]. Alternatively, sleep symptoms in PTSD are often particularly refractory and may need a focused approach [69]. Thus, a sleep history and a focus on sleep/difficulty sleeping will be important in family members after the ICU.

Summary

Difficulty in sleeping is a problem not only for patients in the ICU but also for their family members. Insufficient sleep causes symptoms in family members and may affect relationships with clinicians. An important first step is to differentiate between lack of opportunities for sleep vs. insomnia. Efforts to improve sleep for family members might also improve sleep for patients as well. Family members should be educated about symptoms of insomnia and first-step strategies to manage it.

References

1. Ayas NT, White DP, Manson JE, Stampfer MJ, Speizer FE, Malhotra A, et al. A prospective study of sleep duration and coronary heart disease in women. Arch Intern Med. 2003;163(2):205–9.
2. Patel SR, Malhotra A, Gao X, Hu FB, Neuman MI, Fawzi WW. A prospective study of sleep duration and pneumonia risk in women. Sleep. 2012;35(1):97–101.
3. Patel SR, Malhotra A, White DP, Gottlieb DJ, Hu FB. Association between reduced sleep and weight gain in women. Am J Epidemiol. 2006;164(10):947–54.

4. Spiegel K, Sheridan JF, Van Cauter E. Effect of sleep deprivation on response to immunization. JAMA. 2002;288(12):1471–2.
5. Prather AA, Hall M, Fury JM, Ross DC, Muldoon MF, Cohen S, et al. Sleep and antibody response to hepatitis B vaccination. Sleep. 2012;35(8):1063–9.
6. Owens RL, Gold KA, Gozal D, Peppard PE, Jun JC, Lippman SM, et al. Sleep and breathing … acd Cancer? Cancer Prev Res (Phila). 2016;9(11):821–7.
7. Mukherjee S, Patel SR, Kales SN, Ayas NT, Strohl KP, Gozal D, et al. An official American Thoracic Society statement: the importance of healthy sleep. Recommendations and future priorities. Am J Respir Crit Care Med. 2015;191(12):1450–8.
8. Watson NF, Badr MS, Belenky G, Bliwise DL, Buxton OM, Buysse D, et al. Recommended amount of sleep for a healthy adult: a joint consensus statement of the American Academy of sleep medicine and Sleep Research Society. Sleep. 2015;38(6):843–4.
9. Weinhouse GL. Pharmacology I: effects on sleep of commonly used ICU medications. Crit Care Clin. 2008;24(3):477–91. vi
10. Ding Q, Redeker NS, Pisani MA, Yaggi HK, Knauert MP. Factors influencing Patients' sleep in the intensive care unit: perceptions of patients and clinical staff. Am J Crit Care. 2017;26(4):278–86.
11. Tainter CR, Levine AR, Quraishi SA, Butterly AD, Stahl DL, Eikermann M, et al. Noise levels in surgical ICUs are consistently above recommended standards. Crit Care Med. 2016;44(1):147–52.
12. Knauert M, Jeon S, Murphy TE, Yaggi HK, Pisani MA, Redeker NS. Comparing average levels and peak occurrence of overnight sound in the medical intensive care unit on A-weighted and C-weighted decibel scales. J Crit Care. 2016;36:1–7.
13. Barr J, Fraser GL, Puntillo K, Ely EW, Gelinas C, Dasta JF, et al. Clinical practice guidelines for the management of pain, agitation, and delirium in adult patients in the intensive care unit. Crit Care Med. 2013;41(1):263–306.
14. Kamdar BB, King LM, Collop NA, Sakamuri S, Colantuoni E, Neufeld KJ, et al. The effect of a quality improvement intervention on perceived sleep quality and cognition in a medical ICU. Crit Care Med. 2013;41:800.
15. Stanchina ML, Abu-Hijleh M, Chaudhry BK, Carlisle CC, Millman RP. The influence of white noise on sleep in subjects exposed to ICU noise. Sleep Med. 2005;6(5):423–8.
16. Jaiswal SJ, Garcia S, Owens RL. Sound and light levels are similarly disruptive in ICU and non-ICU wards. J Hosp Med. 2017;12(10):798–804.
17. Huang HW, Zheng BL, Jiang L, Lin ZT, Zhang GB, Shen L, et al. Effect of oral melatonin and wearing earplugs and eye masks on nocturnal sleep in healthy subjects in a simulated intensive care unit environment: which might be a more promising strategy for ICU sleep deprivation? Crit Care. 2015;19:124.
18. Hu RF, Jiang XY, Hegadoren KM, Zhang YH. Effects of earplugs and eye masks combined with relaxing music on sleep, melatonin and cortisol levels in ICU patients: a randomized controlled trial. Crit Care. 2015;19:115.
19. Fan EP, Abbott SM, Reid KJ, Zee PC, Maas MB. Abnormal environmental light exposure in the intensive care environment. J Crit Care. 2017;40:11–4.
20. Verceles AC, Liu X, Terrin ML, Scharf SM, Shanholtz C, Harris A, et al. Ambient light levels and critical care outcomes. J Crit Care. 2013;28(1):110 e1–8.
21. Day A, Haj-Bakri S, Lubchansky S, Mehta S. Sleep, anxiety and fatigue in family members of patients admitted to the intensive care unit: a questionnaire study. Crit Care (London, England). 2013;17(3):R91.
22. Clark ME, Cummings BM, Kuhlthau K, Frassica N, Noviski N. Impact of pediatric intensive care unit admission on family financial status and productivity: a pilot study. J Intensive Care Med. 2017;885066617723278. [Epub ahead of print]
23. Halm MA, Titler MG, Kleiber C, Johnson SK, Montgomery LA, Craft MJ, et al. Behavioral responses of family members during critical illness. Clin Nurs Res. 1993;2(4):414–37.

24. Choi J, Tate JA, Donahoe MP, Ren D, Hoffman LA, Chasens ER. Sleep in family caregivers of ICU survivors for two months post-ICU discharge. Intensive Crit Care Nurs. 2016;37:11–8.
25. Celik S, Genc G, Kinetli Y, Asiliogli M, Sari M, Madenoglu Kivanc M. Sleep problems, anxiety, depression and fatigue on family members of adult intensive care unit patients. Int J Nurs Pract. 2016;22(5):512–22.
26. Verceles AC, Corwin DS, Afshar M, Friedman EB, McCurdy MT, Shanholtz C, et al. Half of the family members of critically ill patients experience excessive daytime sleepiness. Intensive Care Med. 2014;40(8):1124–31.
27. Choi J, Hoffman LA, Schulz R, Ren D, Donahoe MP, Given B, et al. Health risk behaviors in family caregivers during patients' stay in intensive care units: a pilot analysis. Am J Crit Care. 2013;22(1):41–5.
28. Burr G. The family and critical care nursing: a brief review of the literature. Aust Crit Care. 1997;10(4):124–7.
29. Elliott D, Davidson JE, Harvey MA, Bemis-Dougherty A, Hopkins RO, Iwashyna TJ, et al. Exploring the scope of post-intensive care syndrome therapy and care: engagement of non-critical care providers and survivors in a second stakeholders meeting. Crit Care Med. 2014;42(12):2518–26.
30. Roland P, Russell J, Richards KC, Sullivan SC. Visitation in critical care: processes and outcomes of a performance improvement initiative. J Nurs Care Qual. 2001;15(2):18–26.
31. Schnell D, Abadie S, Toullic P, Chaize M, Souppart V, Poncet MC, et al. Open visitation policies in the ICU: experience from relatives and clinicians. Intensive Care Med. 2013;39(10):1873–4.
32. Whitcomb JJ, Roy D, Blackman VS. Evidence-based practice in a military intensive care unit family visitation. Nurs Res. 2010;59(1 Suppl):S32–9.
33. Garrouste-Orgeas M, Philippart F, Timsit JF, Diaw F, Willems V, Tabah A, et al. Perceptions of a 24-hour visiting policy in the intensive care unit. Crit Care Med. 2008;36(1):30–5.
34. Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, et al. Guidelines for family-centered Care in the Neonatal, pediatric, and adult ICU. Crit Care Med. 2017;45(1):103–28.
35. Davidson JE, Savidan KA, Barker N, Ekno M, Warmuth D, Degen-De Cort A. Using evidence to overcome obstacles to family presence. Crit Care Nurs Q. 2014;37(4):407–21.
36. Kress JP, Pohlman AS, O'Connor MF, Hall JB. Daily interruption of sedative infusions in critically ill patients undergoing mechanical ventilation. N Engl J Med. 2000;342(20):1471–7.
37. Schweickert WD, Pohlman MC, Pohlman AS, Nigos C, Pawlik AJ, Esbrook CL, et al. Early physical and occupational therapy in mechanically ventilated, critically ill patients: a randomised controlled trial. Lancet. 2009;373(9678):1874–82.
38. Owens RL. Better sleep in the intensive care unit: blue pill or red pill... Or no pill? Anesthesiology. 2016;125(5):835–7.
39. Van Dongen HP, Maislin G, Mullington JM, Dinges DF. The cumulative cost of additional wakefulness: dose-response effects on neurobehavioral functions and sleep physiology from chronic sleep restriction and total sleep deprivation. Sleep. 2003;26(2):117–26.
40. Venkatraman V, Chuah YM, Huettel SA, Chee MW. Sleep deprivation elevates expectation of gains and attenuates response to losses following risky decisions. Sleep. 2007;30(5):603–9.
41. Anderson C, Dickinson DL. Bargaining and trust: the effects of 36-h total sleep deprivation on socially interactive decisions. J Sleep Res. 2010;19(1 Pt 1):54–63.
42. Huff NG, Nadig N, Ford DW, Cox CE. Therapeutic alliance between the caregivers of critical illness survivors and intensive care unit clinicians. Ann Am Thorac Soc. 2015;12(11):1646–53.
43. Hunziker S, McHugh W, Sarnoff-Lee B, Cannistraro S, Ngo L, Marcantonio E, et al. Predictors and correlates of dissatisfaction with intensive care. Crit Care Med. 2012;40(5):1554–61.
44. Jones CB, Dorrian J, Jay SM, Lamond N, Ferguson S, Dawson D. Self-awareness of impairment and the decision to drive after an extended period of wakefulness. Chronobiol Int. 2006;23(6):1253–63.

45. Shaffer KM, Riklin E, Jacobs JM, Rosand J, Vranceanu AM. Mindfulness and coping are inversely related to psychiatric symptoms in patients and informal caregivers in the neuroscience ICU: implications for clinical care. Crit Care Med. 2016;44(11):2028–36.
46. Schmidt M, Azoulay E. Sleepless nights in the ICU: the awaken family. Crit Care. 2013;17(5):1003.
47. Huynh TDJ, Owens RL. Overnight ICU family presence in a model of family-centered care. Soc Crit Care Med. 2018:2018.
48. Edell-Gustafsson U, Angelhoff C, Johnsson E, Karlsson J, Morelius E. Hindering and buffering factors for parental sleep in neonatal care. A phenomenographic study. J Clin Nurs. 2015;24(5–6):717–27.
49. Jackson JC, Ely EW, Morey MC, Anderson VM, Denne LB, Clune J, et al. Cognitive and physical rehabilitation of intensive care unit survivors: results of the RETURN randomized controlled pilot investigation. Crit Care Med. 2012;40(4):1088–97.
50. Burns KEA, Devlin JW, Patient HNS. Family engagement in designing and implementing a weaning trial: a novel research paradigm in critical care. Chest. 2017;152:707.
51. Alessi C, Vitiello MV. Insomnia (primary) in older people: non-drug treatments. BMJ Clin Evid. 2015;pii:2302.
52. Hartescu I, Morgan K, Stevinson CD. Increased physical activity improves sleep and mood outcomes in inactive people with insomnia: a randomized controlled trial. J Sleep Res. 2015;24(5):526–34.
53. Kredlow MA, Capozzoli MC, Hearon BA, Calkins AW, Otto MW. The effects of physical activity on sleep: a meta-analytic review. J Behav Med. 2015;38(3):427–49.
54. Owens RL, Huynh TG, Netzer G. Sleep in the intensive care unit in a model of family-centered care. AACN Adv Crit Care. 2017;28(2):171–8.
55. Busse M, Stromgren K, Thorngate L, Thomas KA. Parents' responses to stress in the neonatal intensive care unit. Crit Care Nurse. 2013;33(4):52–9. quiz 60
56. Lee SY, Kimble LP. Impaired sleep and Well-being in mothers with low-birth-weight infants. J Obstet Gynecol Neonatal Nurs. 2009;38(6):676–85.
57. Davydow DS, Hough CL, Langa KM, Iwashyna TJ. Depressive symptoms in spouses of older patients with severe sepsis. Crit Care Med. 2012;40(8):2335–41.
58. van den Born-van Zanten SA, Dongelmans DA, Dettling-Ihnenfeldt D, Vink R, van der Schaaf M. Caregiver strain and posttraumatic stress symptoms of informal caregivers of intensive care unit survivors. Rehabil Psychol. 2016;61(2):173–8.
59. Cameron JI, Chu LM, Matte A, Tomlinson G, Chan L, Thomas C, et al. One-year outcomes in caregivers of critically ill patients. N Engl J Med. 2016;374(19):1831–41.
60. Comini L, Rocchi S, Bruletti G, Paneroni M, Bertolotti G, Vitacca M. Impact of clinical and quality of life outcomes of long-stay ICU survivors recovering from rehabilitation on caregivers' burden. Respir Care. 2016;61(4):405–15.
61. Gallop KH, Kerr CE, Nixon A, Verdian L, Barney JB, Beale RJ. A qualitative investigation of patients' and caregivers' experiences of severe sepsis. Crit Care Med. 2015;43(2):296–307.
62. Cox CE, Docherty SL, Brandon DH, Whaley C, Attix DK, Clay AS, et al. Surviving critical illness: acute respiratory distress syndrome as experienced by patients and their caregivers. Crit Care Med. 2009;37(10):2702–8.
63. Van Pelt DC, Schulz R, Chelluri L, Pinsky MR. Patient-specific, time-varying predictors of post-ICU informal caregiver burden: the caregiver outcomes after ICU discharge project. Chest. 2010;137(1):88–94.
64. Needham DM, Davidson J, Cohen H, Hopkins RO, Weinert C, Wunsch H, et al. Improving long-term outcomes after discharge from intensive care unit: report from a stakeholders' conference. Crit Care Med. 2012;40(2):502–9.
65. Cohen S, Kaplan Z, Zohar J, Cohen H. Preventing sleep on the first resting phase following a traumatic event attenuates anxiety-related responses. Behav Brain Res. 2017;320:450–6.

66. Kuriyama K, Soshi T, Kim Y. Sleep deprivation facilitates extinction of implicit fear generalization and physiological response to fear. Biol Psychiatry. 2010;68(11):991–8.
67. Porcheret K, Holmes EA, Goodwin GM, Foster RG, Wulff K. Psychological effect of an analogue traumatic event reduced by sleep deprivation. Sleep. 2015;38(7):1017–25.
68. Buysse DJ. Insomnia, depression and aging. Assessing sleep and mood interactions in older adults. Geriatrics. 2004;59(2):47–51. quiz 2
69. Germain A, Buysse DJ, Nofzinger E. Sleep-specific mechanisms underlying posttraumatic stress disorder: integrative review and neurobiological hypotheses. Sleep Med Rev. 2008;12(3):185–95.

Chapter 7
Taking the Lead: Changing the Experience of Family ICU Syndrome by Changing the Organization of Care

Donald L. Zimmerman

The evidence is clear and compelling that the family of an ICU patient can experience increased rates of depression, anxiety, and stress disorders [1–3]. In response, it has been recommended that the concept of visiting hours be transitioned to a philosophy of family engagement [4, 5].

While open and patient-tailored guidelines have been recommended as the preferred family visitation model in critical care settings, many intensive care units continue to restrict visitation [6]. A number of reasons have been identified that help to explain this gap between recommendations and practice. For example, concerns with infection risk, violations of confidentiality, family interference with the provision of care, and the potential for additional work can all be found as "reasons" for caregivers and their organization to reject calls for an open visitation policy for the families of ICU patients [7].

One of the major developments in modern management theory and research has been its continued focus on better understanding how to introduce and manage organizational change [8]. A number of research traditions have contributed to this understanding, including those devoted to the diffusion of innovation, the processes of implementation, continuous quality improvement, communication theory, and organizational management and behavior studies.

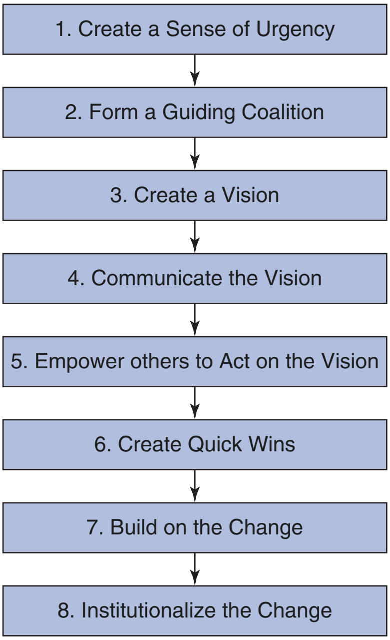
While management research within each of these traditions has yielded a number of important findings and insights, their direct and practical relevance to efforts at changing policy in the ICU is restricted by *two major limitations*:

The *first* limitation is that leading and managing a change effort within an ICU is not easy and not well suited to the simplistic and over-reductionist models that tend to dominate the popular business literature. For example, consider applying Kotter's [9] extremely widespread eight-step model for leading change to the day-to-day activities on an ICU (see Table 7.1).

D. L. Zimmerman
Healthcare Management, University of New Orleans, New Orleans, LA, USA
e-mail: dlzimmer@uno.edu

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_7

Table 7.1 Kotter's eight-step model for leading change



While each of these eight steps makes a certain amount of external sense (e.g., starting out by creating a sense of "urgency" seems quite self-evident), actually carrying out this task is quite another matter in practice. In other words, while each of the eight steps presents with a certain sense of obvious logic, how one really goes about the task of actualizing each of these steps in the context of one's real practice remains, if not mysterious, then highly problematic. In order to find any clarity about how one might actually go about the real processes of leading a change in ICU visitation policy, we then must dig deeper than the popular literature on change might suggest. One of the reasons making change is not easy is because it involves stepping into the actual "soup of reality" that holds the real, lived experience of clinicians, patients, and their families as they interact to create and animate their specific episode of care within a given ICU.

But as we take a step into the actual flow of experience that defines the ICU experience in everyday life, we run into a *second* major limitation about how to best proceed.

Despite the ongoing multidisciplinary scholarly interest in developing a more and more sophisticated understating of the processes of change, the unquestioned default approach for many in healthcare remains the model of continuous quality improvement (CQI). Emerging as part of the national conversation in the last part of the twentieth century, the model of CQI has served as a core strategy for addressing such issues as medical errors, excess wait and delay times, hospital-acquired infections, and other operational issues. In general, this approach argues that progressive improvements in clinical outcomes can be made by using a three-part strategy [10].

Sequentially, the strategy is as follows: (a) Specific operational variations in the processes producing a non-optimal outcome must be identified. (b) Specific interventions are made to standardize the aberrant variations in the processes of care. (c) Ongoing cycles of planning, doing, studying, and acting (PDSA) are implemented that use prior findings to continuously reduce variations in the processes of care to a diminishing point so that there are zero defects in producing a given outcome [11].

Several efforts have been attempted using a CQI approach to create changes in the everyday activities of the ICU. For example, Curtis et al. [12] outlined a "how-to" guide that advocated the use of scientifically sound performance measures, robust data collection, analysis, strong leadership, and the ability to learn from successes as well as failures, among others. Gershengorn, Kocher, and Factor [13] suggested strategies for creating a culture for change, improving cooperation and interaction between multidisciplinary teams of clinicians, and positioning the intensive care unit (ICU) optimally within the hospital environment.

While such work might be encouraging to potential change agents, considerable evidence exists that using a CQI approach does not necessarily result in success. For example, Rogness [14] reported that while their efforts to use a CQI approach to change to an open visitation policy resulted in a positive change for families, inconsistency of implementation was a barrier that undermined staff and physician appreciation for the benefits of this improvement project. Writing at a more general level, a recent review of the use of the CQI model in a variety of healthcare contexts found a number of reported failures of the "PDSA method to help frontline staff address the multiple improvement challenges they faced as the scale of investigation and range of issues they needed to address increased" [15].

Moreover, while the CQI model may provide value in many specific instances, a central contradiction in using this approach that is of particular relevance merits attention when looking at efforts to improve the personal experience of families and patients within the ICU. This contradiction is found in the origin of the CQI approach itself. As emphasized by such foundational thinkers as Berwick, Shewhart, Deming, and Juran, the CQI approach is fundamentally the application of methods, tools, and metaphors readily found in industry and business rather than in medicine [10].

While the practice of medicine may be viewed as a business, a fundamental error is made if the differences between providing care and treatment for a person in medical need are ever truly confused or conflated with the purpose, processes, and ethics of selling cars, shirts, insurance, or any other good or service in a purely economic marketplace. Clear and present evidence argues that modern medicine is deeply aligned with many of the core dimensions of business, e.g., accounting, finances, management, etc. [16]. But, at its heart and as a whole, providing healthcare services to those in need is foundationally different than any other type of commercial enterprise found in the general marketplace.

The concern about using industrial models for improving the ICU does not rest on a rejection of the idea that the everyday processes that produce goods and services within the context of a healthcare organization are not relevant. Such processes lay at the heart of what people actually do to produce and experience care.

Rather, the problem is when the CQI model is used to purposefully transform those processes from the field of real human interaction among real people into a reified and abstract "system" of standardized, industrial production. Simple application of industrial metaphors to understand and improve the provision of healthcare services, whether through the ICU or another unit, results in changing the way participants are viewed. When someone asserts that healthcare works like a production system, the processes of that system are then viewed in error precisely when they are most human and appear at greatest variation from the pre-set, rational, and determinist design of an ideal state of regulated industrial operation.

Efforts to reduce variations in the production processes are not limited to continuous quality improvement strategies taken from industry. At another level, they can also be viewed as an effort to transform and support efforts to improve the outcomes of care by embedding the following organizational characteristics into their overall management structures of healthcare organizations:

- Increased hierarchical administration
- Formal lines of authority (chain of command)
- A fixed area of activity
- Rigid division of labor
- Regular and continuous execution of assigned tasks
- All decisions and powers specified and restricted by regulations
- Officials with expert training in their fields
- Career advancement dependent on technical qualifications
- Qualifications evaluated by organizational rules, not individuals

Max Weber [17] first identified these organizational characteristics of what he called a "bureaucracy." More recently, Cockerham [18] applied these characteristics to hospitals.

Central to a bureaucratic organization and to the CQI model is the shared belief that positive change requires standardizing how things are produced. In this sense, the idea is that things must change so that the rules and procedures for doing a given task are replicable by anyone else so that the same outcome (results) are produced every time for every "patient." In this sense, one might speak of the power of the "medical bureaucracy" to reduce the naturally occurring variations among people – whether they be patients, families, or physicians and other caregivers – to zero as a primary methodology for standardizing the outcomes of its production systems.

The alternative to standardizing how healthcare is produced is not chaos in the hospital. There are many activities related to the provision of healthcare that are usefully viewed as identical to industrial processes, for example, sterilization, management of infection, evidence-based protocols, etc. But, the use of the industrial metaphor in defining the actual experience of the patient, family, and caregivers fundamentally transforms all participants into interlocking parts of an idealized and dehumanized bureaucratic system of care that is, by definition, not based on the individual experience of any of the people actually engaged in the care-producing activities delivered and received through that bureaucracy.

In using industrial models of quality improvement to standardize the process and structures of care into bureaucratic systems, there is a strong possibility that we may be helping to perpetuate and support a model of care that is in direct contradiction to the actual needs of a patient, family, and primary caregivers in the ICU. So, if popular models of change do not provide sufficient guidance to leading change and the dominant model of CQI suggests that the solution rests on creating a medical bureaucracy, what can we, in fact do to further encourage open visitation and other positive changes in the ICU?

What Does Person-Focused Change Look Like?

The importance of the person in healthcare might seem obvious to some, but in a system that relies on the clinical authority of medical care providers to deliver care through the institutional and bureaucratic power of organizations like hospitals, physician offices, and ICUs, the role of the patient – no matter how "centered" in that delivery system – can be lost or obscured in the routine institutional activities required for a highly complex healthcare system to function [19]. At its most basic, person-focused care is a perspective that expands and elevates the importance of the personal experience of the patient, family, and caregivers into key points of relevant coordination between clinical care delivery and the personal experience of care [20].

Person-centered care is not about simply giving patients whatever they want. It is about considering patients' preferences, values, family situations, social circumstances and lifestyles; seeing people as individuals and then working together to develop appropriate solutions [21]. In other words, person-centered care is about the coproduction of care among people rather than an industrial bureaucracy designed to meet needs of the "consumer" in a competitive business environment [22]. For healthcare professionals, this means that we must actively care about the patient, family, the physician, and other healthcare personnel by elevating the personal experience of patient care into an important and relevant part of clinical practice [23].

But while making the personal experience of care a priority may have an elective affinity with an open visitation policy for the ICU, it does not automatically open doors that are currently closed. What can be done, then, to further encourage open visitation and other positive changes in the in the ICU? To start an answer to this question, it is necessary to first focus on four key elements of a person-focused approach to ICU change. These are the patient, the family, key caregivers (e.g., physicians, nurse practitioners, physician assistants, etc.), and the ICU setting. Each is examined below.

The Patient

A person has roles. I am, for example, a husband, father, professor, volunteer, and citizen. I have also been a patient and many other things.

Sociologists have long pointed out that people live out their various roles by following the particular behavioral rules and expectations assigned to each. That is, I am a husband, father, etc., not in word alone, but because I know and follow the rules for how husbands, fathers, etc. are expected to behave.

Patients also have a role. Parsons [24] was the first to note that the primary expectations that helped transform a person into a patient to occupy what he called "the sick role." The sick role has its own set of norms of expected behavior. These include:

- The patient is released from the person's normal roles of their life.
- The patient should seek medical attention, do as the doctor says, and try to get well.
- The patient is not held accountable for her or his illness.

Given the ongoing evolution of healthcare, there may be need to update the specifics of Parsons' earlier formulation of the role, but the initial insight that sees the difference between the role and the actual person occupying that role remains sound and valid.

Recognizing the difference between treating a reified and abstracted patient role and caring for the actual experience of the real person living in that role is at the heart of a person-focused approach to ICU change.

The Family Has Many Forms

Rapid changes in the American family structure have altered the image of the definitions, roles, and behavioral expectations of the US family. In recognizing these changes, recent discussions of family visitation to the ICU have provided a very broad definition of a "family" that includes all the individuals whom the patient wants involved in his/her care, regardless of whether they are related biologically, legally, or otherwise [25].

But in recognizing such a broad array of existential possibilities qualifying as "family," a critical distinction remains between "the family" that is currently present in the ICU and the abstract concept of "a family" – however defined – that exists in discussions about family visitation policy. The distinction between the use of "the" and "a" is not trivial and is explicitly intended to highlight the gap between the individual specifics of a particular family and the general characteristics of a particular type of social unit called the "family." When we look at the gap between the specific and general sense of family, it is easy to find a host of typically unspoken but often assumed notions of what "family" means to a given individual.

A raft of cultural stereotypes provides ready-made cultural models and images concerning what and how families are supposed to act based on racial, ethnic, religious, socioeconomic class, and other broadly explicit expectations for "families like that." Overall, while some families celebrate and reinforce such cultural attributions, others actively fight against them as evidence of discrimination and other forms of restrictive categorization and prejudice [26].

On the other hand, behind the closed doors of any given family are the deeply held personal narratives of the individuals who are living through the actual experience of “being in that given family” – with all the good and bad times that can occur.

The tension between the external attributions about “a family” and the actual experience of being in “the family” is especially acute when current family structures and behaviors are compared against traditional models of two heterosexuals, engaging in consensual sexual relations, and having and raising children until maturity. For example:

- The share of Americans who have never married has been rising steadily in recent decades. At the same time, more adults are living with a partner instead of marrying and raising children outside of marriage [27].
- Fewer than half (46%) of US kids younger than 18 years of age are living in a home with two married heterosexual parents in their first marriage [28].
- An estimated three million (37% of) lesbian, gay, bisexual, and transgender adults have had a child at some point in their lives [29].
- Nearly half (44%) of young people ages 18–29 have a step sibling [30].
- The percentage of Americans living without a spouse or romantic partner increased from 39% to 42% over the past decade [31, 32].

Further, the National Coalition Against Domestic Violence has reported [33] that:

- One in three women and one in four men have been physically abused by an intimate partner.
- One in 15 children is exposed to intimate partner violence each year, and 90% of these children are eyewitnesses to this violence.
- Intimate partner victimization is correlated with a higher rate of depression and suicidal behavior.
- Only 34% of people who are injured by intimate partners receive medical care for their injuries – suggesting a significant undercount of violent episodes.
- An estimated one in four US children experiences some form of child maltreatment in their lifetimes.
- Four-fifths (80.3%) of perpetrators of child maltreatment were parents.

The personal experience of one’s family is often enough to keep the notion of “a family” grounded as a unique set of people with their own interconnected narratives and, if so, may serve as an important reference when working on building open visitation policies.

In sum, it is suggested here that the second part of our model of a person-focused approach to change would be to keep the distinction between “the family” and “a family” as clear as possible in future efforts at changing visitation policy in the ICU so that the full humanity of each person’s family is fully appreciated.

Clinical Care Givers

The role of key clinical caregivers in the ICU is multifaceted. Not only does it include highly specified requirements regarding training and practice, but clear behavioral expectations regarding professional demeanor, assumed norms regarding patient privacy, interaction, and intent of clinical and physical intervention [34]. Historically, the relationship between provider and patient has been a special one, with the trust of the receiver of care placed in the provider and in the institutions with which the provider is affiliated [35].

The trust between those providing needed care, e.g., physicians and advanced practitioners, and patient is not just about a patient's confidence in their caregivers, but it also serves as the basis for action. In order for "trust" to serve as a basis of action, the clinical caregiver must assume and the patient must not question the physician carrying out three basic types of activities. First, both parties must assume that the clinical caregiver and the ICU have the legal authority to provide care – and further, that the care being provided is rational and reflects best clinical knowledge. The second is based on the power of inertia created by the traditions, customs, habits, and social structures that are learned as part of the clinical caregiver's training and are presented as "given" to the patient as the way "things are done around here." And the third is the patient's presumption that clinical caregivers have special knowledge, skills, and powers that can rescue them from harm.

These three activities were first identified by Weber [17] as core forms of what he labeled "legitimate authority." While the use of such authority for providing care is not inherently bad (and perhaps necessary), in the hands of an individual provider, it has the potential to be so. Fundamental to the individual's development into a practicing clinician is the development of their own psychosocial identity of themselves as an expert practitioner. This development includes the individual clinical caregiver's own internal consciousness about who they are to themselves, how they are supposed to relate to others, and how they view, prioritize, and manage the choices of their personal and professional lives. When a clinician's authority is exercised over a patient without a sense of understanding and empathy about how the consequences of such an act will be actually experienced by the patient and the family, then the grounds of their authority shifts from trust to coercion. This shift replaces their reliance on their legitimate authority to determine the course of patient care with the brute power of providing or withholding care based on their own decision-making.

When the provider fails to maintain their relationship with a given patient on the grounds of trust, that caregiver may not fully recognize the personal suffering that routinely occurs through medical interventions within the ICU. The gap between the body being treated in the role of the patient and the personal experience of the patient living within that body was noted by Casel [36] in his distinction between suffering and physical distress. Bodies suffer medical distress but suffering is experienced by people. And further, as Casel emphasized, the failure to understand the nature of personal suffering can result in medical intervention that is technically correct but not only fails to relieve the source of suffering but becomes a source of suffering itself. Thus, the next step in our model of a person-focused approach to change would be to place a clinical caregiver who purposefully places the value of patient empathy and the patient's own experience of care at the center of any change effort aimed at changing visitation policy to the ICU.

The ICU Setting

The care provided in hospitals is structured into a set of organizational units defined by the primary type of care provided to patients. For example, the organizational components of many hospitals include the Emergency Department, various Medical-Surgical units, outpatient clinics, and Intensive Care Units. Each of these organizational components, while linked to the others through a set of common institutional ties, also stands alone in the way it actually produces patient care. That is, while the hospital reflects a single organizing framework in its given community, the provision of that care is provided through the particular organizational component with the principle responsible for meeting the particular needs of the given patient.

Every site of care within a hospital, whether it be in the ICU, clinic, emergency department, or in a medical-surgical unit, contains a defined and detailed set of behavioral opportunities and constrains for individual action. The given set of opportunities and constraints are defined to all involved as the norms of expected behavior for each individual participating in that site of care, whether they be clinicians, patients, or family members. The care provided in the ICU, like in any other organizational component of the hospital is carried out through established patterns of clinical, managerial, and operational behavior that defines the normal ICU experience experienced every day by for physicians, nurses, allied personnel, patients, and their families.

Supporting this sense of normal order are the deeply socialized taken-for-granted assumptions that infuse the sense of daily activity with a deep sense of self-evident expectations regarding the "way things are done" in a properly functioning ICU. One might think of an old-fashioned mechanical clock as a metaphor for all the various microstructures (routine patterns) and micro-processes (the routine personal interactions) that all have to work together in a coordinated whole to produce a total episode of ICU care. But just because a given ICU may operate like a fine watch does not mean that it is telling the proper time or that its current mechanical watchworks remain the most efficient in a world defined by the digital time of a smartphone and Fitbit.

While the social organization of an ICU may be intended to root each person and task into the grounds of sound clinical experience, knowledge, and science, its day-to-day operation must take into account a wide variety of situational and organizational circumstances that may or may not be consistent with the best interests of the patient. For example, a well-intended and properly designed ICU may still suffer from routine breakdowns in communication, poor personnel attitudes and lack of teamwork, use of obsolete tools and techniques, toxic relationships, temporary impairment, chronic burnout, gender-based harassment, failure to listen, and inadequate command and control systems of management, to name a few. All such issues can create the conditions for significant medical errors independently of the skill and knowledge of the individual clinical practitioner [37].

An ICU can easily be a constructed vision of reality that seems so naturalized that it appears to be the only vision of reality, the only fundamental, deeply logical, and taken as a self-evident universal way any ICU works. As such, the fourth part of a person-focused model of change is to ask: But must it really work that way?

Final Questions

Figuring out how to transform a given ICU to not only change its family visitation policy but to re-center its organizational principles around those of person-focused care requires much, much more than casual observation, speculative theory, or the generalization of personal experience. Rather, it requires a deep dive into the phenomenology of the ICU experience itself to, first, identify the operationally important social structures and processes that are embodied within the day-to-day behavior of the unit and then, second, to critically review the deeply internalized social and relational presuppositions [38] and taken-for-granted assumptions [39] that "go without saying" but are used to create the sense of "normalcy" of the daily functioning of an ICU and its host hospital.

The following three questions can help start this review and analysis process:

1. What would an ICU look like if an effort was made to look at how the current ICU experience is being created in order to fully re-center it on the people providing and receiving treatment?
2. What might we learn if the core ideas we think and tacitly believe everyone knows about how ICUs should behave were carefully and critically examined against the personal experience of patients, families, physicians, and other caregivers?
3. Is it possible to imagine a person-focused ICU that treats patients as real people, respects and engages with the diversity of families, and releases physicians and other caregivers from the constraints of existing medical bureaucracies?

Full and complete answers to each of these questions do not need to ever exist in practice. Rather, they can serve as initial guides for building a person-focused model of change that may fit the goals of medicine better than ones that are best suited for industry and commerce. Engaged, participatory, and directed efforts to integrate a more person-focused approach to care into open visitation policies for the ICU and other units is a critical opportunity for a large and significant discussion about how to answer each of these questions.

Table 7.2 Examples of skill sets and resources for leading changes in ICU visitation policy

Skill set	Follow-up resources
Case presentation followed by general discussion with the emphasis on the emotional content of the doctor-patient relationships	Salinsky J. (revised 2005, 2011, 2013). Balint groups and the Balint method. In: Burton J, Launer J (eds), Supervision and support in primary care. Radcliffe Medical Press, Oxford; 2003
Expanding understanding of how a caregiver's personal histories and current personal lives, values, attitudes, and biases affect the care of their patients	Novack D, Spstein R, Paulsen R. Toward creating physician-healers: fostering medical students' self-awareness, personal growth, and well-being. Acad Med. 1999;74(5)
Building core management competencies in role awareness, communication, and teamwork	Schmitt M, Blue A, Aschenbrener C, Viggiano T, Thomas R. Core competencies for interprofessional collaborative practice: reforming health care by transforming health professionals' education. Acad Med. 2011;86(11):1351
Developing greater awareness and skills in leadership competencies	Tubbs S, Schulz E. Exploring a taxonomy of global leadership competencies and meta-competencies. JAm Acad Business, Cambridge. 2005;8(2):29–34
Building empathy, reflection, and trust through narrative medicine	Charon R. Narrative medicine: a model for empathy, reflection, profession, and tust. JAMA. 2001;286(15):1897–1902
Building awareness of changes in family composition and dynamics	Water T, Carter B, Neville S, Dickinson A. Looking towards the horizon: changing landscapes and a shift to a more equitable future for children, young people and their families. Contemp Nurse. 2017;53(4):407–409
Opening up communication within the healthcare setting	Newton J, Henderson A, Jolly B, Greave J. A contemporary examination of workplace learning culture: an ethnomethodology study. Nurse Educ Today. 2014;35(1):91–96

The following table (Table 7.2) provides some examples of specific skills and background resources that can be used by caregivers to start these discussions with patients, families, and other caregivers.

References

1. Davidson J, Jones C, Bienvenu O. Family response to critical illness: post intensive care syndrome-family. Crit Care Med. 2012;40(2):618–24.
2. Sottile P, Lynch Y, Mealer M, Moss M. Association between resilience and family member psychologic symptoms in critical illness. Crit Care Med. 2016;44(8):e721.
3. Verhaeghe S, Defloor T, Van Zuuren F, Duijnstee M, Grypdonck M. The needs and experiences of family members of adult patients in an intensive care unit: a review of the literature. Clin Nurs. 2005;14(4):501–9.
4. Dokken D, Kaufman J, Johnson B, Perkins S, Benepal J, Roth A, Dutton K, Jones A. Changing hospital visiting policies: from families as "visitors" to families as partners. J Clin Outcomes Manage. 2015;22(1)

5. Netzer G, Davidson J. Creating patient- and family-focused care in the intensive care unit, Chapter 3. In: Zimmerman D, Osborn-Harrison D, editors. Person focused healthcare management. New York: Springer; 2017.
6. Chapman D, Collingridge D, Mitchell L, Wright E, Hopkins R, Butler J, Brown S. Satisfaction with elimination of all visitation restrictions in a mixed-profile intensive care unit. Am J Crit Care. 2016;25(1):46–50.
7. Astuto M, editor. Pediatric Anesthesia, Intensive Care and Pain: Standardization in Clinical Practice (Anesthesia, Intensive Care and Pain in Neonates and Children). Italiia: Springer; 2013. p. 62.
8. Cameron E, Green M. Making sense of change management: a complete guide to the models, tools and techniques of organizational change. 4th ed. Philadelphia: Logan Page Limited; 2015.
9. Kotter J. Leading change. Boston/Cambridge, MA: Harvard Business School Press; 1996.
10. Scoville R, Little K. Comparing lean and quality improvement. IHI white paper. Cambridge, MA: Institute for Healthcare Improvement; (Available at ihi.org); 2014.
11. Berwick D, Blanton G, Roessner J. Curing health care: new strategies for quality improvement. J Healthc Qual. 1991;13(5):65–6.
12. Curtis J. Intensive care unit quality improvement: a "how-to" guide for the interdisciplinary team. Crit Care Med. 2006;34:211–8.
13. Gershengorn H, Kocher R, Factor P. Management strategies to effect change in intensive care units: lessons from the world of business. Part III. Effectively effecting and sustaining change. Ann Am Thorac Soc. 2014;11(3):454–7.
14. Rogness B, et.al. Flexible ICU visitation hours improve family involvement in care, improvement stories, Institute for Healthcare Improvement. 2009. http://www.ihi.org/resources/Pages/ImprovementStories/FlexibleICUVisitationImproveFamilyInvolvement.aspx. Accessed Sept 2018.
15. Reed J, Card A. The problem with plan-do-study-act cycles. BMJ Qual Saf. 2016;25:147–52.
16. Moseley G. Managing Health Care Business Strategy. Burlington: Jones and Bartlett; 2018.
17. Weber M. Weber's rationalism and modern society, edited and translated by Tony Waters and Dagmar Waters. New York: Palgrave MacMillan; 1919; 2015. p. 73–127.
18. Cockerham W. Max Weber: bureaucracy, formal rationality and the Modern Hospital. In: Collyer F, editor. The Palgrave handbook of social theory in health, illness and medicine. London: Palgrave Macmillan; 2015.
19. Starfield B. Is patient-centered care the same as person-focused care? Perm J. 2011;15(2):63–9.
20. Zimmerman D. Overview and framework for person-focused healthcare management. In: Zimmerman D, Osborn-Harrison D, editors. Patient-focused healthcare management. New York City: Springer Publishing; 2017. p. 1–20.
21. de Silva D. Helping measure person-centred care: a review of evidence about commonly used approaches and tools used to help measure person-centred care, Health Foundation, 90 long acre. London; 2014.
22. Moumtzoglou A. M-Health innovations for patient-centered care. Hershey: IGI Global; 2016. p. 1.
23. Rickert J. Person-focused care and the physician: emphasizing the human condition, Chapter 2. In: Zimmerman D, Osborn-Harrison D, editors. Person focused healthcare management. New York: Springer; 2017.
24. Parsons T. The social system. Glencoe: The Free Press; 1951.
25. Brown S, Rozenblum R, Aboumatar H, Fagan M, Milic M. Defining patient and family engagement in the intensive care unit. Am J Respir Crit Care Med. 2015;191(3):358.
26. UNESCO World Report No. 2: investing in cultural diversity and intercultural dialogue. 2009. UNESCO Publishing.
27. Parker K, Stepler R. As U.S. marriage rate hovers at 50%, education gap in marital status widens, Fact Tank, Pew Research Center, September, 2017. http://www.pewresearch.org/fact-tank/2017/09/14/as-u-s-marriage-rate-hovers-at-50-education-gap-in-marital-status-widens/

28. Fact Tank. Pew Research Center. 2014. http://www.pewresearch.org/fact-tank/2014/12/22/less-than-half-of-u-s-kids-today-live-in-a-traditional-family/.
29. Gates G. LGBT parenting in the United States, Williams Institute, UCLA. 2013. http://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Parenting.pdf
30. Fact Tank. Pew Research Center. 2014. http://www.pewresearch.org/fact-tank/2014/04/30/5-facts-about-the-modern-american-family/.
31. Fact Tank. Pew Research Center. 2017. http://www.pewresearch.org/fact-tank/2017/10/11/the-share-of-americans-living-without-a-partner-has-increased-especially-among-young-adults/.
32. Fact Tank. Pew Research Center. 2017. http://www.pewresearch.org/fact-tank/2017/09/14/as-u-s-marriage-rate-hovers-at-50-education-gap-in-marital-status-widens/.
33. NCADV. 2015. Domestic violence national statistics. Retrieved from www.ncadv.org.
34. AMA Code of Medical Ethics. https://www.ama-assn.org/delivering-care/ama-code-medical-ethics.
35. Williams S, Nightingale E, Filner B. The physician's role in a changing health care system. Chapter 4. In: Medical education and societal needs: a planning report for the Health Professions, Institute of Medicine (US) Division of Health Sciences Policy. Washington (DC): National Academies Press (US); 1983.
36. Cassel E. The nature of suffering and the goals of medicine. N Engl J Med. 1982;306(11):639–45.
37. Winters B, Pronovost J, Miller M, Hunt E. Measuring safety. In: DeVita M, et al., editors. Textbook of rapid response systems. Cham: Springer; 2017.
38. Bourdieu, P., (1977). Outline of a Theory of Practice, (R. Nice Trans.). Cambridge University Press, New York, Available online: https://archive.org/stream/pierre-bourdieu-outline-of-a-theory-of-practice-1977/pierre-bourdieu-outline-of-a-theory-of-practice-1977_djvu.txt.
39. Schutz A. Some structures of the life-world. In: Schutz I, editor. Collected papers, vol. III: studies in phenomenological philosophy. The Hague: Nijhoff; 1957;1970. p. 116–32.

Chapter 8
Unique Challenges for Family Members of Patients with Acute and Chronic Critical Illness: The Older Caregiver

Nicole Roeder and Margaret A. Pisani

Demographics

Informal or unpaid caregivers are currently the primary source of long-term care in the United States, with an estimated one in five adults providing care to a relative or friend [1]. Increasing survival rates after an intensive care unit (ICU) admission has resulted in a population of chronically critically ill individuals who may experience prolonged, complicated recoveries outside of the hospital, with significant physical and psychological deficits [2]. These individuals commonly rely on family caregivers during this recovery process.

With the increase in average life expectancy, many ICU patients and survivors are themselves older adults [3–5]. The average age of patients receiving ICU-level care has increased, as well as the proportion of those who are over the age of 85 years [6]. As they are likely to have increased baseline comorbidities and functional dependence, studies have demonstrated that these older ICU survivors are at increased risk for poor outcomes (Table 8.1). Post-ICU disabilities may result in older ICU survivors being more likely to require formal or informal caregivers [7]. In many instances caregivers may be the patient's elderly spouse or partner. The unique deficits faced by older ICU survivors may result in new caregiver burden akin to what is seen in the geriatrics literature of caregivers for patients with dementia. Of the estimated 43 million informal caregivers of adults in the United States, 34% are over the age of 65 [8]. Due to increasing healthcare costs, decreasing ICU mortality, and the growing older adult population, the number of informal caregivers, and thus the number of older caregivers, is projected to rise [2].

Sixty percent of caregivers in the United States are female, providing an average of 24 h of care per week for an adult relative [8]. The typical older adult caregiver (Fig. 8.1) is a 79-year-old white female, who cares for a close relative, for 34 h per

---

N. Roeder (✉) · M. A. Pisani
Yale University, New Haven, CT, USA
e-mail: Nicole.Roeder@yale.edu; Margaret.Pisani@yale.edu

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_8

Table 8.1 Outcomes observed in older ICU survivors

Author, year	Design	Subjects	Primary outcome	Results
Barnato et al. (2011) [24]	Retrospective cohort $N = 54{,}771$	65+ year olds who did/did not undergo mechanical ventilation	Impact of a hospital stay that requires mechanical ventilation on functional status	Elderly survivors of mechanical ventilation may experience substantial functional declines
Iwashyna et al. (2012) [25]	Retrospective cohort $N = 637{,}867$	Sepsis survivors, 65+ years old	Burden of cognitive dysfunction and disability	71% of survivors had functional disability, and 16% had cognitive impairment 3 years after ICU admission
Ferrante et al. (2015) [26]	Prospective cohort $N = 754$	ICU survivors, 70+ years old	Functional trajectories before and 1 year after ICU admission	>50% of patients died within 1 month of ICU discharge or experiences significant functional decline over the following 1 year
Ferrante et al. (2016) [27]	Prospective cohort $N = 186$	ICU survivors, 70+ years old	Incidence and time to recovery of premorbid function within 6 months	Approximately half did not recover to pre-ICU level of function Pre-ICU hearing and vision impairments were associated with poor recovery
Villa et al. (2016) [28]	Observational $N = 176$	ICU survivors, 70+ years old	Functional status 1 year after ICU discharge	Survivors experienced significant deterioration in functional status that never returned to baseline at 1 year
Moitra et al. (2016) [29]	Retrospective cohort $N = 34{,}696$	ICU survivors, 65+ years old	Association between ICU length of stay and 1-year mortality	Mortality rates increase with increasing ICU length of stay

week. These older caregivers are more likely to be providing care without additional help, to be unemployed, and are more likely to be caring for their spouse [8].

In general, research on caregiving has primarily been focused on the care provided within biological families and heterosexual marriage, with little attention to informal care provided by friends, or “friend care.” This form of caregiving is common and plays an important role in the lesbian, gay, bisexual, and transgender (LGBT) community, as older LGBT adults may be less likely to have traditional supports in place [9]. While research on LGBT caregivers remains limited, friend caregivers have reported less social support and fewer available services, which was associated with higher perceived stress levels and depressive symptoms [9].

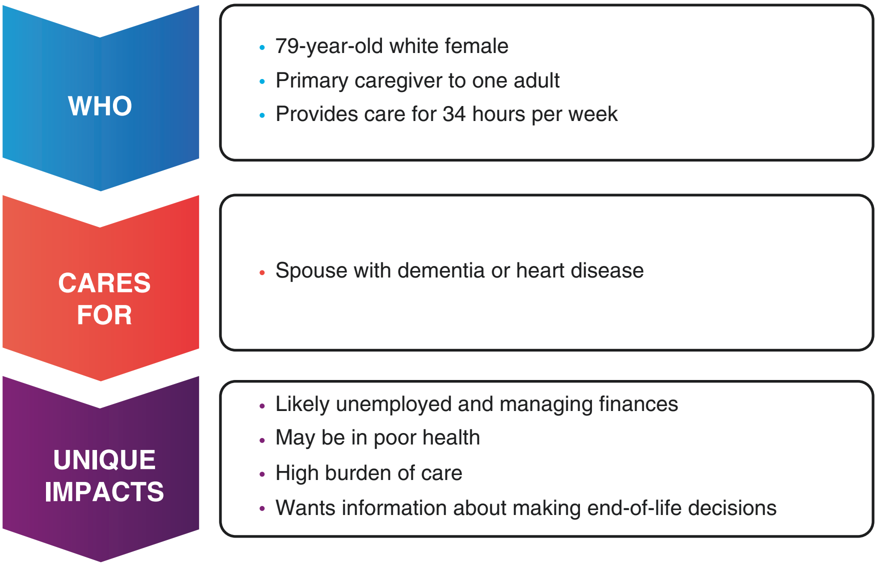


Fig. 8.1 The typical older caregiver

Adverse Consequences for Caregivers

Evidence continues to emerge that caregivers are at risk for physical and psychosocial morbidity because of their role. Caregivers who are younger, female, minorities, those caring for a spouse, and those who have pre-existing depression are all at higher risk for worse mental health outcomes [2, 10–12]. Primary caregivers and those who provide care for more hours are more likely to report worsening of their own personal health [8]. This is especially relevant for older caregivers, as they tend to have a higher care burden with more hours and are commonly the primary caregiver. More focused research is needed, as older caregivers have not been well-studied in terms of their risk profiles and adverse outcomes.

Caregiving generally requires a significant investment of time, energy, and finances and can involve tasks that are physically and psychologically demanding. Little is known about older caregivers' potentially unique needs and challenges in the acute ICU setting or as informal caregivers for chronically critically ill loved ones. Many ICU survivors have functional impairments and are dependent in activities of daily living requiring help with toileting, bathing, and ambulating. Much of what is known regarding the older caregiver population comes from studies of individuals caring for those with dementia, but we can extrapolate this to caring for a post-critical illness patient [10].

Family members or informal caregivers of ICU patients frequently play crucial roles in caregiving the and recovery process outside of the hospital. The World

Health Organization (WHO) International Classification of Functioning, Disability, and Health (ICF) provides a useful framework for studying disability, which can be applied to the experiences of our patients who survive critical illness and intensive care [13]. This framework can be viewed as a progression of disablement, starting with acute illness that results in bodily damage which can result in activity limitations, causing restrictions in social participation, and ultimately a reduction in quality of life. Throughout this progression our formal medical assessments may reveal concrete limitations in abilities; however the patient experiences impairments in routine daily functions. Patients with the same functional deficit will report varying levels of disability and reductions in quality of life, as these perceptions depend on their premorbid baseline social roles and function [13].

The progression through this framework of acute bodily injury and illness to disability is not absolute and depends on a multitude of factors including a patient's social environment, resources, psychological state, and social support network. This process is also impacted by critical care delivery. The recovery process should begin during the ICU stay, with attention to evidence-based care such as minimizing sedation, early mobilization, and physical and occupational therapy involvement. Caregivers play a vital role in this process, providing social support and home care, which has been shown to delay and prevent nursing home placement – an extreme form of social disability. While it has yet to be proven that caregivers themselves prevent the progression to disability, evidence suggests their roles are crucial and commonly carried out despite the well-described personal costs [13].

Caregivers During the Acute Critical Illness

A caregiver's role begins during the acute phase of critical illness, as they face competing demands between their presence in the ICU and personal responsibilities. Symptoms of depression and anxiety are common and have been reported in 70–80% of caregivers in this setting [2]. A higher burden of symptoms may be seen in family members who serve as surrogate decision makers, who are frequently involved in end-of-life decision-making [14]. These caregivers may face anticipatory grief, impaired cognition due to sleep deprivation, and personal and family conflicts, all of which impact decision-making abilities [15]. As a result, many experience decisional conflict and regret about decisions made in the ICU [16]. The constellation of psychiatric symptoms experienced by family members of critically ill patients has been well described and is referred to as post-intensive care syndrome family (PICS-F) [11]. However, this term may overlook the unique stressors and challenges that these individuals face during the acute ICU stay, where their role as caregivers begins. To acknowledge this, recognition of a family ICU syndrome (FICUS) has been proposed [15].

Despite the increasingly known psychiatric morbidity that caregivers face during a loved one's stay in the ICU, it remains unknown what supportive interventions provide meaningful improvements in outcomes and satisfaction [2]. Family members have ranked physical closeness to their loved one as the number one unmet need in the ICU, in terms of being able to visit the patient frequently [17]. How physicians communicate with families may also affect outcomes. Studies have shown that family members who perceive that they are receiving incomplete information, those who do not find their doctor comforting, and who are not allowed their preferred level of involvement in decision-making had a higher prevalence of PICS-F symptoms [11]. Communication between physicians and families in the ICU is an area ripe for further high-quality research.

Older family members and caregivers in the ICU setting may have additional unique challenges. Older caregivers in other settings cite limitations in transportation, their own poor health, and difficulty with hearing as factors that interfere with caregiving [18]. Transportation difficulties could limit elderly caregivers' ability to be physically present in the ICU, impeding their participation in decision-making, and in being physically close to their loved one. Physical and cognitive health issues and hearing loss may also contribute to the difficulties already faced in the frequently complex decision-making process [17, 18].

Long-Term Caregivers in Chronic Critical Illness

With the decreases in ICU mortality, more patients are surviving critical illness and subsequently face prolonged and complicated recoveries outside of the hospital. As a result, their loved ones may transition to long-term caregivers for a chronically critically ill patient. Caregivers have reported experiencing a lack of physical and emotional support at home after the patient has been discharged from the ICU [19]. Most existing studies focus on dementia caregivers, and research remains limited regarding what interventions may result in meaningful benefits for caregivers of ICU survivors upon the transition home. The possible benefit of developing post-ICU clinics for patients who survive a critical illness has started to be explored; however the focus has not included assessing the stressors of caregivers [20]. Given what is known about caregivers' increased risk, family clinics post ICU discharge should be explored as one method to improve health outcomes and adaptation to the outpatient caregiver role [11].

Informal caregivers in the outpatient setting are at risk for further adverse personal outcomes [2]. Regarding their psychological health, up to 29% of caregivers have reported significant depressive symptoms that persist for up to 1 year after the patients' discharge from the ICU. This number is comparable to rates of depression in the caregivers of dementia patients [19]. Caregivers providing more assistance with activities of daily living and higher levels of physical care tended to have increased depressive symptoms, which persisted over a longer period [12, 16, 19]. These impacts can persist for years, with evidence showing that 43% of critically ill patients' caregivers, with an average age of 53 years, have depressive symptoms at 1 year, and in another study 27% of caregivers continue to report psychological distress up to 5 years after their loved one's ICU discharge [2, 12].

Long-term caregivers may also be at increased risk for poor physical health outcomes. Many individuals report inadequate rest, skipping meals, difficulty managing their own health and medications, and delays in seeking personal medical care [2, 19]. Many also report that their own health has worsened since assuming the role of caregiver [8, 21]. Restriction in activities and lifestyle interference are also common, with 80% of caregivers describing themselves as lonely and socially isolated [19, 21]. Limitations in transportation faced by older caregivers may worsen this reported increase in loneliness and social isolation. Long-term informal caregivers may be at increased risk for serious illness due to the high physical demands and stress of caregiving and neglect of their own health [10].

Studies have suggested that among caregivers, younger age is a risk factor for increased depressive symptoms and worse mental health outcomes [12]. Given their higher likelihood for chronic medical comorbidities and poor personal health, older long-term caregivers may be at higher risk for adverse physical health outcomes [12]. They are more likely to be a primary caregiver, to provide care for more hours, and to be unemployed. This may place these individuals at higher risk of physical and negative impacts on their own health [8].

There are also opportunity costs and economic impacts of caregiving that cannot be overlooked. Many caregivers are forced to reduce their work hours, take a leave of absence, or quit a job to continue to provide informal care [8, 10, 20]. As a result, caregivers have reported financial limitations in paying for basic needs such as food and housing, having to delay educational plans, and being forced to file for bankruptcy [20]. Older caregivers are more likely to be unemployed and caring for their spouse, thus managing the household finances at a time of a fixed income, which may increase financial strains [8].

Support for Caregivers

Little is known about how to provide support for informal caregivers of individuals after critical illness and even less about older caregivers. Data on dementia caregivers has looked at interventions such as face-to-face self-help groups and telephone and Internet support groups [18]. Recent literature has examined telephone and web-based interventions to help family members cope after critical illness [2, 22]. Older caregivers have unique risk profiles and barriers that may impact them, and these should be taken into account when considering the design of supportive interventions (Table 8.2). Older individuals generally do not participate in self-help groups to the same degree as younger persons. For older caregivers, barriers cited to in-person groups included limited transportation, lack of respite from caregiving, and poor personal health [18]. Telephone interactions may be limited by hearing difficulties, and in one study only 15% of older caregivers reported having access to a computer to participate in online support groups [18].

Research into interventions to best support caregivers remains limited, with most studies lacking in meaningful clinical outcomes. This challenge may be in part due

Table 8.2 Unique barriers and risks of older caregivers and their impacts

Unique barriers and risks	Impact
Higher likelihood of poor personal health	Limited caregiving abilities More likely to neglect personal health/miss appointments Cognitive impairment impact on decision-making abilities
Hearing loss	Communication difficulties in the ICU Limits telephone-based outpatient support interventions
Likely to be primary caregiver	Lack of respite from caregiving Increased social isolation
More likely to be retired or unemployed	Increased financial strain Increased social isolation/loneliness
Transportation limitations	Limited ability to be present in the ICU/visit patient Limited access to outpatient resources/support Increased social isolation/loneliness
Lack of computer access	Lack of access to web-based support interventions Increased social isolation/loneliness

to the heterogeneity of caregivers, and interventions may need to be tailored to the needs of an individual or type of caregiver [23]. Research on caregivers of critically ill patients has progressed particularly slowly, in comparison to caregivers of individuals with other chronic conditions such as dementia, or malignancies. Unique challenges faced by these caregivers include more complex care demands given the likelihood for multiple comorbidities, high attrition rates due to the mortality of ICU survivors, and loss to follow-up due to transitions of care between multiple settings [2].

Defining practically important and clinically meaningful outcomes to target in the caregiver population, across different settings, remains challenging. Satisfaction is one of the most commonly studied outcomes in the ICU but has its limitations. When survey tools report high total satisfaction scores, details of individually low scoring queries may be lost [16]. Measuring satisfaction in the ICU also tells us very little about the impact the decision-making process may have on care [15]. Potentially novel outcomes to focus on include decisional conflict and regret, resilience, the therapeutic alliance between families and clinicians, and the quality of end-of-life care [16]. Additionally, objective clinical outcomes such as ICU length of stay generally do not consider the timing of family meetings, institution of limitations of care, or deaths that occur without consensus or care limitations in place [15].

Symptoms of anxiety and depression in the ICU and outpatient settings remain a valuable caregiver outcome to target, given the high prevalence, ease of measurement, and clinical meaningfulness [10, 16]. Health-related quality of life (HRQOL), which considers and assesses both mental and physical health in caregivers, is another potentially meaningful outcome for study [16]. From a societal perspective, time to institutionalization of patients being cared for in the home by informal caregivers is another important outcome [10].

Conclusions

Informal caregivers serve a crucial role in our healthcare system, and to their loved ones, frequently at a high personal cost to themselves. More research is needed, with an emphasis on high risk and understudied caregiver groups such as minorities, friends, and older caregivers. The significant number of caregivers over the age of 65 years enters their role with a higher likelihood of poor health, at a time of limited financial means, and additional limitations such as hearing difficulties and lack of computer access or reliable transportation. In a time when future supportive interventions are more likely to be telephone- or Internet-based, these unique constraints faced by older caregivers may cause them to be unintentionally excluded. As further strides are made in caregiver research and support, the unique needs and challenges faced by older caregivers should not be overlooked.

References

1. Chari AV, Engberg J, Ray KN, et al. The opportunity costs of informal elder-care in the United States: new estimates from the American Time Use Survey. Health Serv Res. 2015;50(3):871–82. https://doi.org/10.1111/1475-6773.12238.
2. Choi JY, Donahoe MP, Hoffman LA. Psychological and physical health in family caregivers of intensive care unit survivors: current knowledge and future research strategies. J Korean Acad Nurs. 2016;46(2):159–67. https://doi.org/10.4040/jkan.2016.46.2.159.
3. Yu W, Ash AS, Levinsky NG, et al. Intensive care unit use and mortality in the elderly. J Gen Intern Med. 2000;15(2):97–102. https://doi.org/10.1046//.1525-1497.2000.02349.x.
4. Yayan J. Trends in intensive care in patients over 90 years of age. Clin Interv Aging. 2012;7:339–47. https://doi.org/10.2147/CIA.S31780.
5. Garland A, Olafson K, Ramsey CD, et al. Epidemiology of critically ill patients in intensive care units: a population-based observational study. Crit Care. 2013;17:R212. https://doi.org/10.1186/cc13026.
6. Sjoding MW, Prescott HC, Wunsch H, et al. Longitudinal changes in ICU admissions among eldery patients in the United States. Crit Care Med. 2016;44(7):1353–60. https://doi.org/10.1097/CCM.0000000000001664.
7. Ferrante LE, Pisani MA, Terrence EM, et al. Factors associated with functional recovery among older intensive care unit survivors. Am J Respir Crit Carwe Med. 2016;194(3):299–307. https://doi.org/10.1164/rccm.201506-1256OC.
8. National Alliance for Caregiving and AARP Public Policy Institute. Caregiving in the U.S. 2015: Executive Summary. http://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-executive-summary-revised.pdf. 2015. Accessed 1 Sep 2017.
9. Shiu C, Muraco A, Fredriksen-Goldsen K. Invisible care: friend and partner care among older lesbian, gay, bisexual, and transgender (LGBT) adults. J Soc Social Work Res. 2016;7(3):527–46. https://doi.org/10.1086/687325.
10. Schulz R, Clinical Review MLM. Family caregiving of persons with dementia, prevalence, health effects, and support strategies. Am J Geriatr Psychiatry. 2004;12(3):240–9. https://doi.org/10.1097/00019442-200405000-00002.
11. Davidson JE, Jones C, Bienvenu OJ. Family response to critical illness: postintensive care syndrome-family. Crit Care Med. 2012;40(2):618–24. https://doi.org/10.1097/ccm.0b013e318236ebf9.

12. Cameron JI, Chu LM, Matte A, et al. One-year outcomes in caregivers of critically ill patients. NEJM. 2016;374:1831–41. https://doi.org/10.1056/NEJMoa1511160.
13. Iwashyna TJ, Netzer G. The burdens of survivorship: an approach to thinking about long-term outcomes after critical illness. Semin Respir Crit Care Med. 2012;33:327–38. https://doi.org/10.1055/s-0032-1321982.
14. Gries CJ, Curtis JR, Wall RJ, et al. Family member satisfaction with end-of-life decision-making in the intensive care unit. Chest. 2008;133(3):704–12. https://doi.org/10.1378/chest.07-1773.
15. Netzer G, Sullivan DR. Recognizing, naming, and measuring a family intensive care unit syndrome. Ann Am Thorac Soc. 2014;11(3):435–41. https://doi.org/10.1513/annalsats.201309-308ot.
16. Long AC, Kross EK, Curtis JR. Family-centered outcomes during and after critical illness: current outcomes and opportunities for future investigation. Curr Opin Crit Care. 2016;22:613–20. https://doi.org/10.1097/mcc.0000000000000360.
17. Khalaila R. Patients' family satisfaction with needs met at the medical intensive care unit. J Adv Nurs. 2012;69(5):1172–82. https://doi.org/10.1111/j.1365-2648.2012.06109.x.
18. Colantonio A. Support needs of elderly caregivers of persons with dementia. Can J Aging. 1998;17(3):330–45. https://doi.org/10.1017/s0714980800010230.
19. Haines KJ, Denehy L, Skinner EH, et al. Psychosocial outcomes in informal caregivers of the critically ill: a systematic review. Crit Care Med. 2015;43(5):1112–20. https://doi.org/10.1097/ccm.0000000000000865.
20. van Beusekom I, Bakhshi-Raiez F, de Keizer NF, et al. Reported burden on informal caregivers of ICU survivors: a literature review. Crit Care. 2016;20(16):1–8. https://doi.org/10.1186/s13054-016-1185-9.
21. 8 in 10 unpaid carers have experienced loneliness. In: Age UK. http://www.ageuk.org.uk/latest-news/-8-in-10-unpaid-carers-have-experienced-loneliness. Accessed 8 Sep 2017.
22. Cox CE, Hough CL, Carson SS, et al. Effects of a telephone and web-based coping skills training program compared to an education program rcfor survivors of critical illness and their family members: a randomized clinical trial. Am J Respir Crit Care Med. 2017;38:1289. https://doi.org/10.1007/s00134-012-2567-3.
23. Schulz R, Burgio L, Burns R, et al. Resources for enhancing Alzheimer's caregiver health (REACH): overview, site-specific outcomes, and future directions. Gerontologist. 2003;43(4):514–20. https://doi.org/10.1093/geront/43.4.514.
24. Barnato AE, Albert SM, Angus DC, et al. Disability among elderly survivors of mechanical ventilation. Am J Respir Crit Care Med. 2011;183(8):1037–42.
25. Iwashyna TJ, Cooke CR, Wunsch H, et al. The population burden of long-term survivorship after severe sepsis among older Americans. J Am Geriatr Soc. 2012;60(6):1070–7.
26. Ferrante LE, Pisani MA, Murphy TE, et al. Functional trajectories among older persons before and after critical illness. JAMA Intern Med. 2015;175(4):523–9.
27. Ferrante LE, Pisani MA, Murphy TE, et al. Factors associated with functional recovery among older ICU survivors. Am J Respir Crit Care Med. 2016;194(3):299–307.
28. Villa P, Pintado MC, Lujan J, et al. Functional status and quality of life in elderly ICU survivors. J Am Geriatr Soc. 2016;64(3):536–42.
29. Moitra VK, Guerra C, Linde-Zwirble WT, et al. Relationship between ICU length of stay and long-term mortality for elderly ICU survivors. Crit Care Med. 2016;44(4):655–62.

Chapter 9

Family Support and ICU Survivorship: Lessons Learned from the Pediatric Critical Care Experience

Bree Andrews, Nilu Rahman, and Neethi Pinto

Introduction

After the establishment of the first pediatric intensive care unit (PICU) in 1955, the field of pediatric critical care has achieved remarkable progress. Advances in pediatric medicine and technology have fueled tremendous growth of this subspecialty [1]. The centralization of care into PICUs with dedicated pediatric intensivists and the development of fellowship training programs was accompanied by a decreased likelihood of mortality [1–3]. Notably, PICU mortality decreased from 11% in the 1980s to 4.8% in the mid-2000s [4]. The mortality rate among critically ill children has continued to decrease to a historic low during the last decade [4, 5]. This progress remains one of the most significant accomplishments in contemporary pediatrics.

However, the risk of mortality in the PICU is not equivalent among all patients who experience critical illness. For example, adult patients between the ages of 20 and 29 years who are admitted to the PICU (typically, patients with complex medical problems who continue to be cared for primarily by pediatricians and/or pediatric subspecialists) exhibit increased baseline morbidity, greater severity of illness,

---

B. Andrews
Section of Neonatology, The University of Chicago Medicine Comer Children's Hospital, Chicago, IL, USA

Department of Pediatrics, The University of Chicago, Chicago, IL, USA

N. Rahman
Child Life Department, Johns Hopkins Children's Center, Baltimore, MA, USA

N. Pinto (✉)
Section of Pediatric Critical Care, The University of Chicago Medicine Comer Children's Hospital, Chicago, IL, USA

Department of Pediatrics, The University of Chicago, Chicago, IL, USA
e-mail: npinto@peds.bsd.uchicago.edu

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_9

and a twofold higher risk of mortality when compared with younger PICU patients between the ages of 15 and 18 years [6]. This difference in mortality by age group is consistent with overall trends in the adult intensive care unit (ICU) compared to the PICU, where overall mortality rates are 10–29% and 2–3%, respectively [7–9].

The landscape of pediatric critical care is changing, focusing on not only the PICU stay but what happens to children after they leave the PICU environment. As more children survive, attention to improving outcomes and function *after* discharge has become more relevant. Today, children survive with increased rates of moderate or severe disability compared to earlier rates of disability among PICU survivors [4]. In a study published in 2014 by the Collaborative Pediatric Critical Care Research Network, PICU morbidity was 4.8%, more than twice the PICU mortality rate of 2% [8]. Better survival brings with it the conundrum that these survivors face increasing medical burdens placing them at high risk for sequelae and even readmission to the PICU.

With these increases in morbidity, it is not surprising that the majority (72% of nearly 53,000 patients admitted in 2008) of PICU patients have chronic conditions and most (53%) of these are of complex. This trend is concerning because children with complex chronic conditions are at increased risk of mortality compared to all other children admitted to the PICU [10]. Even among children surviving critical illness, an ongoing risk of poor long-term outcomes exists, with twice as many children experiencing morbidity and mortality up to 3 years after hospital discharge [11]. Thus, although in-hospital ICU mortality may be markedly improved compared to historic data, survivors of contemporary pediatric critical illness increasingly experience ongoing morbidity, chronicity of disease, and increased risk of mortality paralleling the natural history of their adult counterparts after discharge [12].

Adults and children who experience critical illness may experience similar sequelae from their disease as well as from requisite invasive lifesaving therapies such as prolonged mechanical ventilation, central venous and arterial catheters, sedation, neuromuscular blockade, and use of vasoactive substances. Understanding the overlap of the pediatric and adult experiences during and after critical illness may be informative to both fields. Here, we focus on lessons from both the PICU and neonatal intensive care unit (NICU) that may have important implications for adult ICUs (Table 9.1).

At the Onset of Critical Illness: A Focus on Recovery

Studies indicate that clinicians in the NICU and the medical intensive care unit (MICU) are unable to reliably predict outcomes [13, 14]. Similarly, in the PICU, prognostication may be affected by level of confidence, experience, clinical skills, and patients' severity of illness or disease [15, 16]. With limited prognostic ability, it may be difficult to determine whether care is futile or to assess potential for recovery in certain clinical scenarios [13]. As a result, the typical initial approach to the

Table 9.1 Parallels between pediatric and adult experiences

Pediatric	Adult
Decreasing mortality	Decreasing mortality
Increased disease chronicity	Multiple comorbidities
Increased morbidity after critical illness	PICS[a]
Neuroplasticity and vulnerability	Resiliency
Parent/guardian as decision-maker	Patient, spouse, child as decision-maker
Loss of some parental control during illness	Power of attorney during and after illness
Readjusting with less support after illness	New caretaker/lack of independence after illness
School transition	Workplace transition
Impact on family	PICS-F[b]

[a] Post-intensive care syndrome
[b] Post-intensive care syndrome-family

critically ill pediatric patient is characteristically intense with an armamentarium of invasive measures undertaken. While this may raise concerns regarding resource utilization and ethics of provision of care unlikely to benefit the patient, the majority of care and resource consumption in the NICU and PICU settings is not futile [13, 17, 18]. This low percentage of care unlikely to benefit the patient may be secondary to the unique recovery potential associated with pediatric patients as well as advances in medicine and technology. In particular, children may be more resilient than adults with regard to physiologic recovery due to their typically fewer pre-existing comorbidities at the time of onset of critical illness, evidence of neuroplasticity and greater overall regenerative potential, and a dynamic developmental trajectory.

The Impact of Baseline Health

Although children typically have fewer comorbidities than adults, an increasing percentage of children admitted to the PICU are chronically ill and experience repeated PICU admissions. These include children with asthma, congenital heart disease, chronic lung disease, diabetes, cerebral palsy, and/or medical complexity, including technology dependence. Such children are at increased risk of readmission and longer lengths of stay with its attendant morbidity.

In contrast, children who were previously healthy, had less severe disease at the onset of critical illness, or with non-complex chronic conditions exhibit better long-term outcomes [10, 11]. With this knowledge, concerted strategies such as multidisciplinary inpatient rounds and/or conferences and follow-up clinics with a focus on preventive health, parent and caregiver education, and coordination of care to both reduce the short-term impact of comorbidities and improve long-term control of complex chronic conditions may have important, lasting implications for children who experience critical illness.

A similar focus on preservation and restoration of baseline health for adult survivors of critical illness warrants attention because adults are even more likely to have complex comorbidities both prior to and as an aftermath of critical illness.

Neuroplasticity and Resiliency

The concept of neuroplasticity, the ability of the central nervous system to adapt neural circuitry in response to environmental stimuli, may also explain the generally positive outcome trajectories of critically ill children [19]. For example, children who experience brain injury may exhibit near-complete recovery of function, faring better than their adult counterparts due to the effects of neuroplasticity [20]. Similarly, children with congenital heart disease who require prolonged hospitalization (and exposure to sedatives, neuromuscular blockade, etc.) do not necessarily exhibit increased neurocognitive delay when compared to healthy children [21]. However, there may be a spectrum of neural adaptability that ranges from neuroplasticity to early vulnerability predisposing some children to an increased risk of incomplete recovery. This "recovery continuum," the balance between early plasticity and early vulnerability, is subject to a multitude of influences including (1) the nature, extent, and site of insult, (2) age and developmental stage at the time of injury, (3) environmental influences, and (4) rehabilitative interventions [19].

Just as neuroplasticity and neurodevelopment may influence the trajectory of outcomes after pediatric critical illness, the related concept of resiliency may be an important factor in survivorship in adult critical care [22, 23]. *Resiliency refers to a psychological trait reflecting adjustment and adaptability to stress* [24]. *However, behavior that is adaptive to a stressful event may be unconventional, maladaptive, or self-detrimental. There may be a spectrum of adaptability, an "adaptability continuum," ranging from resiliency to maladaptation that parallels the recovery continuum for neuroplasticity and vulnerability. Similar to the aforementioned influences on the recovery continuum for children, adaptability may be influenced by (1) the nature and severity of critical illness; (2) age, baseline adaptability, and cognitive loss or dementia (in lieu of developmental stage); (3) environmental influences (supports, social networks,* etc.*); and (4) rehabilitative interventions* (including strategies for coping). *Understanding how to foster resiliency and adaptability may mitigate the overall impact of critical illness for adult survivors.*

During Critical Illness: Family-Centered Care as Normative

In 2001, the Institute of Medicine (IOM) issued recommendations for patient-centered care, defined as care that is "respectful of and responsive to individual patient preferences, needs, and values" [25]. Subsequently, in 2007, the American College of Critical Care Medicine (ACCM) issued guidelines for patient- and family-centered care in ICUs [26]. The 2012 American Academy of Pediatrics (AAP) policy statement on patient- and family-centered care and the pediatrician's role similarly delineates the core principles of patient- and family-centered care as care that is "based on the understanding that the family is the child's primary source of strength and support and that the child's and family's perspectives are important in clinical decision-making" [27]. The AAP recommendations for how all pediatricians (including pediatric intensivists and neonatologists) may integrate this patient- and family-centered care approach in hospitals include the development of collaborative relationships with patients and families; ensuring family presence during hospitalization, rounds, and procedures; facilitating family support and peer-to-peer support; attending to environmental issues that facilitate family presence; incorporating patients and families into decision-making; and ensuring appropriate transitions of care.

In 2013, the ACCM proposed new family-centered care recommendations [28]. The new recommendations called attention to:

1. Family presence in the ICU
2. Family support
3. Operational and environmental issues
4. Communication with family members
5. Use of specific consultations and ICU team members

PICUs and NICUs have embraced many of these recommendations from both the AAP and the ACCM with various components of family-centered care having been routinely adapted and becoming standard practice in the United States.

Family Presence in the ICU

Open Visitation

In alignment with the aforementioned AAP policy statement, family visitation has shifted from historically restrictive policies to open visiting policies 24 hours a day/7 days a week. In renovated or new PICUs, patient rooms often incorporate parent sleep spaces, fostering an environment conducive to unrestricted visitation, proximity of the child and family, and continual family presence [29]. Similarly, in prior decades, sibling visitation was either restricted or not permitted at all. Siblings likely experienced significant disruption of their routines due to absence of their parents and a lack of understanding of their affected sibling's illness. However, today, sibling visitation in the PICU is not only routinely expected, but commonly facilitated with the support of child life specialists who prepare siblings, facilitate questions, debrief after visits, anticipate the sibling's questions and reactions for the parent, educate healthcare providers regarding developmental stages, and utilize age-appropriate resources [30].

Family satisfaction and knowledge have been shown to improve with open visitation in the adult ICU setting [28]. *The model provided by child life specialists for* *critically ill children has important implications for critically ill adults; children may benefit from the opportunity to visit a critically ill parent or relative with appropriate assistance from child life specialists. Adults may benefit from active preparation by designated staff prior to and debriefing after visiting a critically ill relative or friend. (See* section "Use of Specific Consultations and ICU Team Members".)

Partnership in Rounds

Family presence on rounds allows for bidirectional education. Parents and guardians are able to relay information about and advocate for their child, while healthcare professionals are able to educate families about their child's condition, potentially reducing misunderstanding and miscommunication. Family-centered rounds also provide families and healthcare professionals with increased opportunities to interact, build trust, and develop relationships [30]. Overall, families report improved satisfaction when given the option to participate in rounds [28].

Family-centered rounds may also pose some challenges [31]. Families may not understand terminology or topics discussed on rounds and may experience increased anxiety as a result of this lack of understanding. Further explanation and discussion on rounds may not be practical given the need to attend to other critically patients. Family understanding and participation is dynamic; families may understand less, feel less comfortable asking questions, not want bad news shared during rounds, or need more information after rounds on the day of admission compared to subsequent days [32].

Additionally, parental presence may pose a challenge to open communication about sensitive topics such as non-compliance, medical abuse or neglect, and medical errors that warrant discussion among the healthcare team. Open visitation policies may also contribute to privacy concerns or interruption of rounds due to an unrestricted flow of visitors. Teaching on rounds may be negatively affected due to concerns for exposure of gaps in trainees' knowledge with resultant undermining of trainees' credibility with families [30].

Meert et al. note that an understanding of the true impact of family-centered rounds in the PICU is limited, as studies of family-centered rounds typically have selection bias since parents self-select whether or not to be present on rounds and partnership in rounds tends to occur predominantly in Western societies [30]. Keeping this selection bias in mind, parents report increased satisfaction, more contact with physicians, and better knowledge of test results. Nurses also report increased satisfaction with not being the intermediary between physicians and families. Physicians themselves report increased trust. However, there may be adverse consequences in a training environment; residents report decreased teaching and express preferences for being asked questions in a conference room [30].

Overall, the pediatric experience with family-centered rounds is generally favorable, and adaptation of family-centered rounds to the adult setting should take into account the potential for perceived barriers regarding increased duration of rounds, increased family anxiety, difficulty discussing sensitive topics, concerns for privacy, and impact on trainee learning environment.

Presence During Procedures

The option for family presence during invasive procedures, including cardiopulmonary resuscitation (CPR), was first recommended by the American Heart Association in 2000 [33]. Healthcare providers holding views supporting family presence suggest that family presence may facilitate understanding and grief due to direct observation of all measures taken. Opponents contend that family presence may exacerbate misunderstanding, generate interference, heighten anxiety and psychological trauma for the family, increase performance anxiety among healthcare providers, and result in medicolegal issues [28, 30]. Families themselves typically are supportive of family presence. In fact, parents believe their presence may directly help their child or help decrease their own anxiety about the procedure [30, 34, 35]. During an era where parental observation of invasive procedures was not a standard practice, Powers et al. demonstrated decreased parental procedure-related anxiety for their critically ill child when parents were allowed to be present for invasive procedures including endotracheal intubation, central line placement, and chest tube placement [34]. Now, family presence during invasive procedures in the PICU is more widely practiced; the spectrum of invasive procedures for which families may be present varies within and among individual institutions but may include endotracheal intubation, central line placement, arterial line placement, cardiopulmonary resuscitation, extracorporeal membrane oxygenation, and extracorporeal cardiopulmonary resuscitation. Similarly, variability exists with regard to families' preferences and decisions to remain present for any of these procedures.

In 2006, consensus recommendations regarding family presence during pediatric procedures recommended that specific definitions of family members and applicable procedures be identified [36]. Similarly, family preparation with presence of a facilitator, establishment of policies in the event of disagreements or obstruction to care, and attention to staff education and safety are key components of family presence during procedures that must be addressed at the institutional level to ensure that the needs of families and staff are met [28, 30]. Simulation training on how to support family during CPR has been shown to increase staff comfort with parental presence during procedures [37].

Adaptation of family presence during procedures in adult ICUs should be deliberately planned to ensure that clear definitions of family members and which procedures are appropriate for family presence exist. Attention to patient and staff safety must be paramount; policies and procedures including designation of a family facilitator who may help a grieving family or contend with disagreements or obstruction to care is essential prior to implementation of policies endorsing family presence during procedures.

Family Support

NICU care is fraught with concerns about parenting engagement and adjustment, as NICU care is often prolonged and in many cases prognosis is uncertain. Parents may not understand their exact role in the NICU as they observe an entire healthcare team attend to their child, and they may be uncertain of how to best engage with their new baby at the bedside [38]. Communication and education are key components for families to successfully navigate and make sense of the indeterminacies and chaotic circumstances created by a premature or complex birth and subsequent NICU hospitalization, which may extend over weeks to months for many neonates.

Conversely, the role of being a caregiver and assisting with care in the PICU is a natural extension of the expectations and responsibilities that parents and guardians hold prior to the child's critical illness. This is because children are inherently dependent on adult family members in order to meet their basic needs of food, clothing, shelter, health, and education (Fig. 9.1a). Thus, the challenge for families in the PICU is not in accepting the burden of the role, but in relinquishing some of

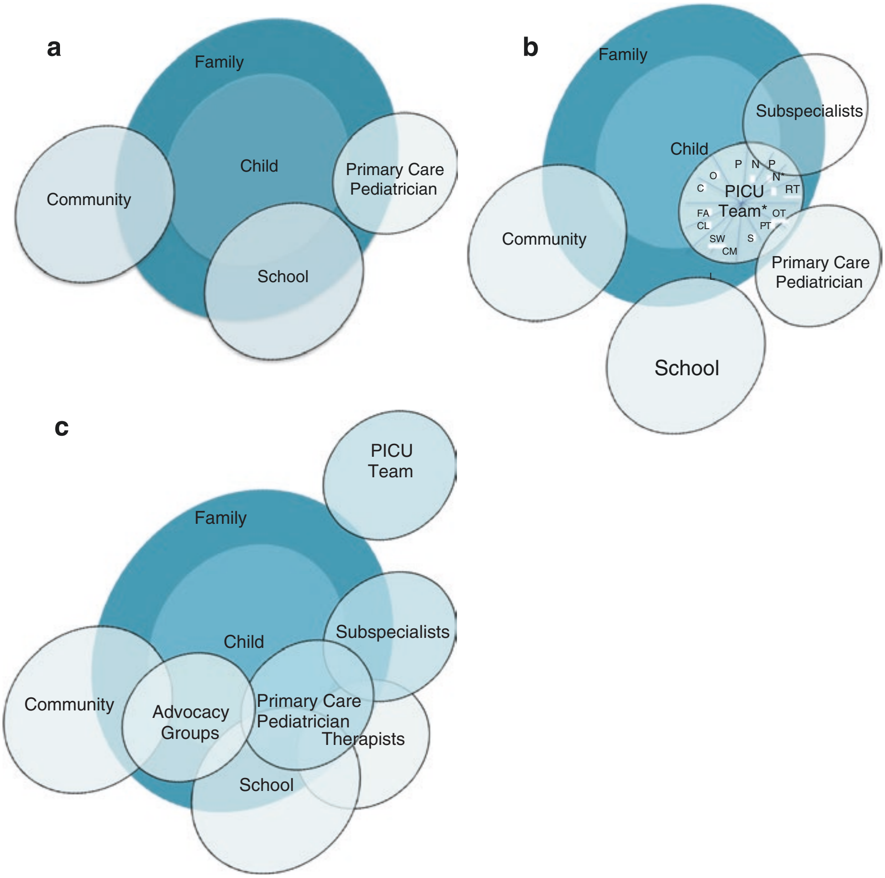


Fig. 9.1 (**a**) Prior to critical illness. (**b**) During critical illness. *PICU Team including: Physicians, Nurses, Pharmacists, Nutritionists, Respiratory Therapists, Occupational Therapists, Physical Therapists, Speech Therapists, Case Managers, Social Workers, Child Life Specialists, Family Advocates, Chaplain, Other. (**c**) After critical illness

this care to a myriad of new and relatively unknown healthcare providers who comprise the PICU team [39] (Fig. 9.1b). As the child recovers from acute illness, other challenges for family members include learning complex care for a child that may have been previously healthy but due to their condition is now technologically dependent (e.g., needing a tracheostomy or gastrostomy tube). Indeed, in this circumstance, parents face enormous difficulties reassuming increased responsibility for a child that may have achieved some independence prior to the critical illness (e.g., school-aged children or adolescents) but who no longer is functionally independent.

Teaching families how to assist with care of the critically ill neonate or child is pivotal to improving confidence, competence, and stress during and after the ICU stay [28]. Two randomized trials in the NICU population provide evidence for the improvement in satisfaction, enhanced active participation by parents, and possible reduction in readmissions with teaching families to participate in care while in the NICU [40, 41]. In addition to education, families also may benefit from professional, spiritual, and peer-to-peer support that is either organized or occurs informally in the context of shared, common spaces such as family lounges. In particular, evidence from observational studies in the NICU suggests that families report increased satisfaction and value peer-to-peer support [28]. Similarly, two randomized trials provide evidence for improved outcomes (including decreased anxiety, trauma, and depression) for mothers who received psychological interventions such as psychologist support, psychoeducation, cognitive behavioral therapy, and educational materials after the birth of a preterm infant [28].

In adult ICUs, there are direct parallels. The role of caregiving for an adult patient who is now dependent may be new for a friend or family member. Just as in the NICU and PICU, family presence on rounds and family support may facilitate an understanding of these transitions. Family education during hospitalization and gradual transition of bedside care from nurses to relatives may decrease stress after discharge by equipping family members with confidence and competence in their skills at providing care and managing levels of expectation regarding post-discharge outcomes. The importance of education and peer-to-peer support for both pediatric and adult ICU patients and their families is reflected by global resource development through organizations such as the Society of Critical Care Medicine's THRIVE initiative (www.myicucare.org/thrive) and ICUsteps (icusteps.org). Psychological support may also improve outcomes for adult patients with evidence of decreased post-traumatic stress disorder in adult patients who receive early psychological support [28].

Operational and Environmental Issues

Important to family presence and support is attention to the physical and social needs of parents during their child's PICU or NICU admission. For example, private rooms rather than open bays or curtained spaces, provision of parent bed or sleep spaces, self-care facilities, meal vouchers, and transportation have been reported to reduce parent stress and allow for increased family presence in the PICU and NICU [28–30].

Other environmental areas that require ongoing attention from healthcare providers include the need to recognize the importance of noise reduction, normalization of sleep-wake and day-night cycles with regard to lighting, and minimization of sleep interruptions while providing necessary care due to the impact on child and parent stress, delirium, and outcomes.

These same operational and environmental issues are likely to benefit the families of adult ICU patients. Increased family presence is more feasible when basic needs such as food, temporary lodging, parking, or transportation are addressed.

Communication with Family Members

Also central to the effectiveness of family presence and family support is the role of communication between the healthcare team and the family. Although family presence during rounds facilitates the opportunity for daily communication, bidirectional time constraints may present challenges in providing parents and the healthcare team adequate daily opportunities to interact in person. For example, due to other responsibilities such as care for siblings or other family members, work constraints, transportation issues, and lack of financial resources, parents may not be able to be routinely present in the ICU particularly if the ICU stay is prolonged. The healthcare team may need to attend to other critically ill patients, causing interruptions or limitations in the duration of a particular family discussion. Thus, in addition to daily face-to-face conversations about the child's status and plan, telephone conferences may be an important means of improving communication.

Effective communication beyond these relatively brief interactions is further facilitated by family conferences with discussion of a child's medical condition, prognosis, and treatment options. Clinicians' use of the VALUE mnemonic (Value family statements, Acknowledge family emotions, Listen to family, Understand the patient as a person, and Elicit family questions) may facilitate communication in these settings [42]. Mutual understanding between families and the healthcare team may benefit from these extended conversations. Moreover, family conferences that are multidisciplinary provide an opportunity to address family questions in a concerted, unified manner. In these conferences, consultative services may directly provide information to the family in the presence of the primary ICU team, harmonizing transfer of medical information. Considerations regarding the timing of the meeting (within the first 72 h of admission and/or on a weekly basis for prolonged stay patients) and the setting (private space separate from the child's room) are important as are acknowledgments of the families' concerns and need for empathy [30]. The family conference represents an opportunity for discussion of family preferences and values. With regard to end-of-life decision-making, clinicians and staff note that family conferences allow for improved communication among clinicians, information transfer between clinicians and family, and support of families [43]. Studies also suggest that families may benefit from family meetings after a child's death or discharge with decreased levels of depression and post-traumatic stress [44].

Parent functioning also may be affected by the consistency of communication and the availability of tools for enhanced education for families [45–48]. Empathetic support from the healthcare team toward parents is important for increasing parental engagement and satisfaction [27, 49–51]. Parents may utilize a diverse array of coping mechanisms and support options while in the ICU setting [52]. These alternative support options need to be considered when developing parental support resources. For example, parents in the NICU have shown preference for support programming that focuses on education about infant development [53].

The improved communication facilitated by family conferences has direct applicability to the adult ICU patient. In many MICUs these conferences occur but are typically at the discretion of the primary attending. Incorporation of family conferences as a routine element of patient care will likely benefit patients and multiple family members who would gain the opportunity to obtain information directly from healthcare providers. Additionally, educational information and the provision of resources such as ICU informational guides and diaries have been demonstrated to both improve patient and family understanding and satisfaction and reduce anxiety, depression, and stress [54, 55].

Use of Specific Consultations and ICU Team Members

The role of the multidisciplinary team is also pivotal for improving communication; the PICU team and rounds may incorporate nurses, physicians (intensivists, primary care pediatricians, and other medical and surgical subspecialists), pharmacists, nutritionists, respiratory therapists, physical/occupational therapists, social workers, case managers, chaplains or spiritual advisors, family advocates or navigators, and child life specialists. In particular circumstances, this team may also include consultations to palliative care, ethics, or psychology. When families are able to participate in rounds or multidisciplinary conferences, their ability to interact with this vast team of care providers and their understanding of the multiple aspects of their child's recovery have the potential to increase exponentially.

Child life specialists, in particular, are a fundamental part of this vast multidisciplinary team in the PICU. They actively use a multifaceted family-centered care approach to proactively identify the needs of a patient and family and collaborate with the medical team on how to best support those needs. They are able to address needs related to visitation, presence during invasive and noninvasive procedures, and operational and environmental issues while also directly focusing on reducing the stress and anxiety associated with the ICU setting. They normalize the hospital environment for the patient through play. Child life specialists in the PICU also serve an important role with legacy building and facilitating end-of-life conversations and interventions with the patient and family.

Operationalizing a model similar to that of the child life specialists in the adult ICU may be particularly helpful to families. Children may benefit from increased preparation and opportunity to visit a critically ill parent or relative with the assistance of child life specialists and provision of developmentally appropriate educational resources. Similarly, spouses, siblings, relatives, and friends of critically ill adults may also benefit from a designated family advocate or a team member *who is equipped to prepare them for visits, facilitate questions, debrief after visits, and anticipate questions and reactions. These advocates or team members ideally would be able to educate healthcare providers and provide appropriate resources.*

After Critical Illness: Embracing Multidisciplinary Follow-Up Care and Advocacy

After discharge, two modalities have been shown to improve patient outcomes as well as child and parental functioning. First, a multidisciplinary primary care clinic with pediatric or neonatal, nutrition, developmental, social work, and nursing expertise is an efficient and effective way to coordinate complex services in the first s and years after discharge. Second, systems of advocacy across the discipline of intensive care medicine with a focus on attainment of public and private benefits for patients can impact overall outcomes.

Multidisciplinary Follow-Up Clinics

The aforementioned concept of multidisciplinary rounding has been well embraced and includes a wide complement of professionals. However, follow-up care after admission to the PICU or NICU is not typically multidisciplinary and is often fragmented due to the complex logistics of coordinating various subspecialty and therapy providers. Ideally, a multidisciplinary follow-up clinic in which intensivists worked collaboratively with the other providers who (re)assume care in order to transition care for a patient would be implemented widely. The knowledge of the care the patient required and the new medical problems he/she may encounter is perhaps best understood by the ICU team. However, the provision of ongoing care is best undertaken by ambulatory providers. For example, collaboration between neonatologists and developmental and behavioral pediatricians may facilitate screening of former premature infants for developmental delays and appropriate institution of early therapy and resource implementation with resultant positive impact on the child's dynamic outcome trajectory [56].

Coordination of complex care and multiple (new) follow-up appointments and evaluations by subspecialists and therapists is often burdensome. For families, transportation, coordination of schedules, and missed school and work cause enormous challenges. Moreover, in the United States, transfer of relevant, summative health information after critical illness is often fragmented and incomplete. In neonatology, multidisciplinary clinics have been effective and efficient mechanisms to ensure appropriate medical care and support for parents traversing these difficulties after critical illness. Currently, in the United States and many other countries, if an institution offers high-level NICU services such as mechanical ventilation, extracorporal membrane oxygen, central lines, total parenteral nutrition, and pediatric surgical services, then the institution is expected to provide ongoing assessment and support for developmental delays and impairments until age 3 years in accordance with state and national public health guidelines for regional centers [57]. The extent to which hospitals offer these services varies, but this type of coordination of ongoing care has led to some of the most robust outcome evaluations for a subset of intensive care patients across the globe [58, 59].

This paradigm of follow-up clinics has gained widespread adaptation in neonatology; incorporating this model into pediatric and adult ICU post-discharge care as a standard of care would likely translate into improved outcomes for ICU survivors.

Advocacy

Transitions of care after NICU and PICU discharge to the primary care pediatrician and a multitude of specialists represent an important underdeveloped and understudied aspect of family support. In addition to providing ongoing medical care for survivors of critical illness, these primary and subspecialty healthcare providers often coordinate their patients' complex care and interface with important systems external to the healthcare setting to advocate for their patients (Fig. 9.1c). For example, pediatricians often undertake an advocacy role with regard to the development of individualized education plans (IEPs) for qualifying children in accordance with the requirements of the 1975 Individuals with Disabilities Education Act. Pediatricians also provide referrals to early intervention programs for children between the ages of 0 and 3 years who have disabilities and developmental delays. Pediatricians also advocate for "504 plans" for children with disabilities per Section 504 of the Rehabilitation Act of 1973 that requires provision of a free and appropriate public education in the least restrictive environment to children with disabilities (including children with medical conditions that result in functional limitations such as attention-deficit hyperactivity disorder, asthma, and diabetes) [60]. Pediatricians can advocate for special education, speech therapy, or occupational therapy under the purview of this legislation. Similar interactions are often required for governmental and private agency social services and concurrent therapies (physical therapy, mental health counseling, etc.). Either parents or pediatric healthcare providers may be more effective in advocating for such services by partnering with legal services or disability advocates such as the Council of Parent Attorneys and Advocates and the National Disability Rights Network [60].

Neonatology follow-up clinics demonstrate the importance of a such an advocacy role in order to improve child functioning for intensive care graduates. One key arena for child and family functioning is through legal advocacy especially around public health benefits. Medical legal partnerships (MLPs) provide one way for lawyers to partner with physicians in clinical care to improve the social determinants of health [61]. In a recent study of the impact of preventative legal advocacy to assist the medical team in providing an action plan for parents, physicians, and lawyers to help children, the use of a written document with action items and information about issues including early intervention, supplemental food and housing programs, special education, and social security was 80% effective in surmounting barriers to attainment of these services for families [62]. Additionally, only 24% of families required legal representation after 1 year. While direct legal service is a model well known within MLPs, widespread adaptation of such a preventative legal approach may lead to more care for patients.

Healthcare providers embracing the advocacy role and partnership with legal advocates has been an effective means of garnering resources for infants and children who survive critical illness with disabilities; adults who require additional assistance, therapies, nursing care, or assistance in the workplace may similarly benefit from such partnerships between their healthcare providers and advocacy organizations.

Summary

Patients who require intensive care across the age continuum may share similar challenges and opportunities at the onset, middle, and conclusions of their admission (Table 9.2). At the onset of critical illness, the neonatal and pediatric intensive care approach is grounded in an unwavering focus on recovery; attention to minimizing the impact of comorbidities and disease chronicity and anticipation of neuroplasticity rather than early vulnerability facilitates this recovery focus. During neonatal and pediatric critical illness, family-centered care has become widely accepted. Experiences with families of infants and children suggest that thoughtfully constructed policies that foster open visitation, family partnership in rounds, family presence during procedures, family support, and communication are

Table 9.2 Fundamentals of neonatal and pediatric intensive care unit management

	Onset of illness	During critical illness	After critical illness
Opportunities	Focus on recovery Minority of care is futile	Family-centered care shared decision-making	Advocacy (schools, services, etc.)
Challenges	Prognostication uncertainty	Privacy concerns Perceived work burden Impact on teaching Legal implications	Transition to primary care Multidisciplinary follow-up clinics

important and effective. In implementing such programs, one must consider carefully healthcare provider concerns and educational issues. Such measures may mitigate family stress, improve expectations, and smooth transitions after discharge from the ICU. After critical illness, experiences from both neonatology and pediatric critical care medicine suggest the need for post-ICU coordination of complex care in multidisciplinary follow-up clinics and a vital role for healthcare provider advocacy and partnership with legal and disability advocates to maximize resources and optimize long-term health for young survivors.

A focus on resiliency potential with an understanding that there may be potential limitations secondary to underlying disease and comorbidities and widespread adaptation of family-centered care practices will likely have similar positive effects for critically ill adults. Adult survivors would benefit from advocacy efforts to garner services that may affect their long-term health and ability to transition out of the hospital to home. Goals for both adults and children are a return to productive lives in the community. Thus, the parallels between the neonatal, pediatric, and adult intensive care unit experiences are strong; sharing our collective experiences and operationalizing effective components of family-centered care will facilitate important advances for all ICU survivors.

In conclusion, healthcare teams must focus on resiliency at the onset of illness, the provision of family-centered care during illness, and an ongoing responsibility to transition care and advocate for patients after ICU discharge in order to optimize outcomes for critically ill patients across the life span.

References

1. Epstein D, Brill JE. A history of pediatric critical care medicine. Pediatr Res. 2005;58(5):987–96.
2. Pollack MM, Cuerdon TT, Patel KM, Ruttimann UE, Getson PR, Levetown M. Impact of quality-of-care factors on pediatric intensive care unit mortality. JAMA. 1994;272(12):941–6.
3. Pollack MM, Patel KM, Ruttimann E. Pediatric critical care training programs have a positive effect on pediatric intensive care mortality. Crit Care Med. 1997;25(10):1637–42.
4. Namachivayam P, Shann F, Shekerdemian L, Taylor A, van Sloten I, Delzoppo C, et al. Three decades of pediatric intensive care: who was admitted, what happened in intensive care, and what happened afterward. Pediatr Crit Care Med. 2010;11(5):549–55.
5. Aspesberro F, Mangione-Smith R, Zimmerman JJ. Health-related quality of life following pediatric critical illness. Intensive Care Med. 2015;41(7):1235–46.
6. Edwards JD, Houtrow AJ, Vasilevskis EE, Dudley RA, Okumura MJ. Multi-institutional profile of adults admitted to pediatric intensive care units. JAMA Pediatr. 2013;167(5):436–43.
7. Namachivayam SP, Butt W. Outcomes after pediatric critical illness: important to be accurate. Pediatr Crit Care Med. 2016;17(6):576–7.
8. Pollack MM, Holubkov R, Funai T, Clark A, Berger JT, Meert K, et al. Pediatric intensive care outcomes: development of new morbidities during pediatric critical care. Pediatr Crit Care Med. 2014;15(9):821–7.
9. Critical Care Statistics. http://www.sccm.org/Communications/Pages/CriticalCareStats.aspx.
10. Edwards JD, Houtrow AJ, Vasilevskis EE, Rehm RS, Markovitz BP, Graham RJ, et al. 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. Crit Care Med. 2012;40(7):2196–203.

11. Pinto NP, Rhinesmith EW, Kim TY, Ladner PH, Pollack MM. Long-term function after pediatric critical illness: results from the survivor outcomes study. Pediatr Crit Care Med. 2017;18(3):e122–30.
12. Wunsch H, Guerra C, Barnato AE, Angus DC, Li G, Linde-Zwirble WT. Three-year outcomes for Medicare beneficiaries who survive intensive care. JAMA. 2010;303(9):849–56.
13. Meadow W, Cohen-Cutler S, Spelke B, Kim A, Plesac M, Weis K, et al. The prediction and cost of futility in the NICU. Acta Paediatr. 2012;101(4):397–402.
14. Meadow W, Pohlman A, Frain L, Ren Y, Kress JP, Teuteberg W, et al. Power and limitations of daily prognostications of death in the medical intensive care unit. Crit Care Med. 2011;39(3):474–9.
15. Marcin JP, Pretzlaff RK, Pollack MM, Patel KM, Ruttimann UE. Certainty and mortality prediction in critically ill children. J Med Ethics. 2004;30(3):304–7.
16. Marcin JP, Pollack MM, Patel KM, Sprague BM, Ruttimann UE. Prognostication and certainty in the pediatric intensive care unit. Pediatrics. 1999;104(4 Pt 1):868–73.
17. Sachdeva RC, Jefferson LS, Coss-Bu J, Brody BA. Resource consumption and the extent of futile care among patients in a pediatric intensive care unit setting. J Pediatr. 1996;128(6):742–7.
18. Goh AY, Mok Q. Identifying futility in a paediatric critical care setting: a prospective observational study. Arch Dis Child. 2001;84(3):265–8.
19. Anderson V, Spencer-Smith M, Wood A. Do children really recover better? Neurobehavioural plasticity after early brain insult. Brain. 2011;134.(Pt 8:2197–221.
20. Mundkur N. Neuroplasticity in children. Indian J Pediatr. 2005;72(10):855–7.
21. Sterken C, Lemiere J, Van den Berghe G, Mesotten D. Neurocognitive development after pediatric heart surgery. Pediatrics. 2016;137(6):e20154675.
22. Maley JH, Brewster I, Mayoral I, Siruckova R, Adams S, McGraw KA, et al. Resilience in survivors of critical illness in the context of the survivors' experience and recovery. Ann Am Thorac Soc. 2016;13(8):1351–60.
23. Charney DS. Psychobiological mechanisms of resilience and vulnerability: implications for successful adaptation to extreme stress. Am J Psychiatry. 2004;161(2):195–216.
24. Connor KM. Assessment of resilience in the aftermath of trauma. J Clin Psychiatry. 2006;67(Suppl 2):46–9.
25. Crossing the quality chasm: a new health system for the 21st century. Washington (DC); 2001.
26. Davidson JE, Powers K, Hedayat KM, Tieszen M, Kon AA, Shepard E, et al. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004-2005. Crit Care Med. 2007;35(2):605–22.
27. Committee On Hospital C, Institute for P, Family-Centered C. Patient- and family-centered care and the pediatrician's role. Pediatrics. 2012;129(2):394–404.
28. Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, et al. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. Crit Care Med. 2017;45(1):103–28.
29. Smith AB, Hefley GC, Anand KJ. Parent bed spaces in the PICU: effect on parental stressPediatr Nurs. 2007;33(3):215–21.
30. Meert KL, Clark J, Eggly S. Family-centered care in the pediatric intensive care unit. Pediatr Clin N Am. 2013;60(3):761–72.
31. Stickney CA, Ziniel SI, Brett MS, Truog RD. Family participation during intensive care unit rounds: goals and expectations of parents and health care providers in a tertiary pediatric intensive care unit. J Pediatr. 2014;165(6):1245–51. e1241
32. Aronson PL, Yau J, Helfaer MA, Morrison W. Impact of family presence during pediatric intensive care unit rounds on the family and medical team. Pediatrics. 2009;124(4):1119–25.
33. Guidelines 2000 for cardiopulmonary resuscitation and emergency cardiovascular care. Part 2: ethical aspects of CPR and ECC. Circulation. 2000;102(8 Suppl):I12–21.
34. Powers KS, Rubenstein JS. Family presence during invasive procedures in the pediatric intensive care unit: a prospective study. Arch Pediatr Adolesc Med. 1999;153(9):955–8.
35. Robinson SM, Mackenzie-Ross S, Campbell Hewson GL, Egleston CV, Prevost AT. Psychological effect of witnessed resuscitation on bereaved relatives. Lancet. 1998;352(9128):614–7.

36. Henderson DP, Knapp JF. Report of the National Consensus Conference on family presence during pediatric cardiopulmonary resuscitation and procedures. J Emerg Nurs. 2006;32(1):23–9.
37. Pye S, Kane J, Jones A. Parental presence during pediatric resuscitation: the use of simulation training for cardiac intensive care nurses. J Spec Pediatr Nurs. 2010;15(2):172–5.
38. Fegran L, Helseth S, Fagermoen MS. A comparison of mothers' and fathers' experiences of the attachment process in a neonatal intensive care unit. J Clin Nurs. 2008;17(6):810–6.
39. Board R, Ryan-Wenger N. Long-term effects of pediatric intensive care unit hospitalization on families with young children. Heart Lung. 2002;31(1):53–66.
40. Franck LS, Oulton K, Nderitu S, Lim M, Fang S, Kaiser A. Parent involvement in pain management for NICU infants: a randomized controlled trial. Pediatrics. 2011;128(3):510–8.
41. Bastani F, Abadi TA, Haghani H. Effect of family-centered care on improving parental satisfaction and reducing readmission among premature infants: a randomized controlled trial. J Clin Diagn Res. 2015;9(1):SC04–8.
42. Curtis JR, White DB. Practical guidance for evidence-based ICU family conferences. Chest. 2008;134(4):835–43.
43. Michelson KN, Emanuel L, Carter A, Brinkman P, Clayman ML, Frader J. Pediatric intensive care unit family conferences: one mode of communication for discussing end-of-life care decisions. Pediatr Crit Care Med. 2011;12(6):e336–43.
44. Colville GA, Cream PR, Kerry SM. Do parents benefit from the offer of a follow-up appointment after their child's admission to intensive care?: an exploratory randomised controlled trial. Intensive Crit Care Nurs. 2010;26(3):146–53.
45. Jackson K, Ternestedt BM, Schollin J. From alienation to familiarity: experiences of mothers and fathers of preterm infants. J Adv Nurs. 2003;43(2):120–9.
46. Garfield CF, Lee Y, Kim HN. Paternal and maternal concerns for their very low-birth-weight infants transitioning from the NICU to home. J Perinat Neonatal Nurs. 2014;28(4):305–12.
47. Horwitz SM, Storfer-Isser A, Kerker BD, Lilo E, Leibovitz A, St John N, et al. A model for the development of mothers' perceived vulnerability of preterm infants. J Dev Behav Pediatr. 2015;36(5):371–80.
48. Stefana A, Lavelli M. Parental engagement and early interactions with preterm infants during the stay in the neonatal intensive care unit: protocol of a mixed-method and longitudinal study. BMJ Open. 2017;7(2):e013824.
49. Enke C, Oliva YHA, Miedaner F, Roth B, Woopen C. Communicating with parents in neonatal intensive care units: the impact on parental stress. Patient Educ Couns. 2017;100(4):710–9.
50. Boss RD, Donohue PK, Larson SM, Arnold RM, Roter DL. Family conferences in the neonatal ICU: observation of communication dynamics and contributions. Pediatr Crit Care Med. 2016;17(3):223–30.
51. Rossman B, Greene MM, Meier PP. The role of peer support in the development of maternal identity for "NICU Moms". J Obstet Gynecol Neonatal Nurs. 2015;44(1):3–16.
52. Huenink E, Porterfield S. Parent support programs and coping mechanisms in NICU parents. Adv Neonatal Care. 2017;17(2):E10–8.
53. Varni JW, Seid M, Rode CA. The PedsQL: measurement model for the pediatric quality of life inventory. Med Care. 1999;37(2):126–39.
54. Azoulay E, Pochard F, Chevret S, Jourdain M, Bornstain C, Wernet A, et al. Impact of a family information leaflet on effectiveness of information provided to family members of intensive care unit patients: a multicenter, prospective, randomized, controlled trial. Am J Respir Crit Care Med. 2002;165(4):438–42.
55. Jones C, Backman C, Capuzzo M, Egerod I, Flaatten H, Granja C, et al. Intensive care diaries reduce new onset post traumatic stress disorder following critical illness: a randomised, controlled trial. Crit Care. 2010;14(5):R168.
56. Andrews B, Myers P, Osterhout P, Pellerite M, Zimmerman A, Msall M. NICU follow-up care: the development and advocacy perspectives. NeoReviews. 2014;15(8):e336–43.
57. Bockli K, Andrews B, Pellerite M, Meadow W. Trends and challenges in United States neonatal intensive care units follow-up clinics. J Perinatol. 2014;34(1):71–4.

58. Marlow N, Wolke D, Bracewell MA, Samara M, Group EPS. Neurologic and developmental disability at six years of age after extremely preterm birth. N Engl J Med. 2005;352(1):9–19.
59. Doyle LW, Anderson PJ, Battin M, Bowen JR, Brown N, Callanan C, et al. Long term follow up of high risk children: who, why and how? BMC Pediatr. 2014;14:279.
60. Lipkin PH, Okamoto J, Council on Children with D, Council on School H. The individuals with disabilities education act (IDEA) for children with special educational needs. Pediatrics. 2015;136(6):e1650–62.
61. Raju TN, Pemberton VL, Saigal S, Blaisdell CJ, Moxey-Mims M, Buist S, et al. Discussants: long-term healthcare outcomes of preterm birth: an executive summary of a conference sponsored by the National Institutes of Health. J Pediatr. 2017;181:309–18. e301
62. Redd L, Belcher R, Dotts B, Andrews B. A silver lining for neonatal intensive care (NICU) graduates: coordinated services from 0-6 years. Int Public Health J. 2018;10(3).

Chapter 10

Life After the ICU: Post-intensive Care Syndrome in Family Members

Jason H. Maley, Julie Rogan, and Mark E. Mikkelsen

Introduction

Family members of critically ill patients experience significant stress and trauma during an ICU stay. The acute effects of this experience are profound, and lasting psychological distress, regardless of the loved one's outcome, is common [1]. Post-intensive care syndrome-family (PICS-F) describes the psychological morbidity experienced by family members of critically ill patients following their care within an ICU [2]. These impairments occur in approximately 25–50% of family members of ICU patients and are often severe and enduring. Some family members report symptoms months to years following the episode of critical illness. In addition to causing distress to family members and impacting their quality of life, these symptoms also hinder family members' abilities to care for ICU survivors as they recover after critical illness. In 2010, a Society of Critical Care Medicine conference was convened, which aimed to bring experts in critical illness survivorship together to improve the long-term outcomes after critical illness for patients and their families. The PICS construct emerged from this discussion and subsequently fueled a growing body of work in the long-term post-ICU outcomes of both patients and family members [3].

J. H. Maley (✉)
Massachusetts General Hospital, Harvard Medical School, Boston, MA, USA
e-mail: jason.maley@mgh.harvard.edu

J. Rogan
Medical Intensive Care Unit, Penn Presbyterian Medical Center, Philadelphia, PA, USA

M. E. Mikkelsen
Medical Intensive Care Unit, Penn Presbyterian Medical Center, Philadelphia, PA, USA

Critical Care Section, Perelman School of Medicine at the University of Pennsylvania, Philadelphia, PA, USA

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_10

Psychological morbidity in PICS-F may manifest as anxiety, post-traumatic stress disorder (PTSD), depression, sleep disturbance, and complicated grief. These effects may be mitigated through measures taken during, and after, the ICU stay. In this chapter, we discuss the epidemiology and risk factors of PICS-F, along with its clinical manifestations. We then segue to a review of interventions to prevent or improve these symptoms among family members and emerging work in this area of critical care medicine [1, 4].

Background

PICS-F is common, though estimates of its prevalence vary. In family members of adult patients, estimates of the prevalence of PTSD range from 13% to 56% across studies [2, 4, 5]. Symptoms of anxiety, also commonly experienced by family members, range from 21% to 56% in frequency [1, 5–7]. Similarly, depressive symptoms occur in as few as 8% of family members or as many as 42% depending on risk factors such as age of patient, age of family member, relationship to patient, and death or near death of patient [1, 4–7]. These symptoms impact quality of life in ways that are less well described and that are likely exacerbated by financial stressors – leading to emotional distresses and impairments in sleep, fractured relationships, stunted personal growth, and challenging family dynamics.

Clinical Manifestations of PICS-F

Psychological morbidity in family members of ICU patients may have a variety of manifestations. Anxiety, depression, and post-traumatic stress symptoms are the most frequently documented and studied conditions associated with PICS-F. Other symptoms may include acute stress disorder, sleep disturbance, complicated grief, and milder mood disturbances that do not meet the clinical thresholds of screening tests. Learned helplessness, frequently acquired during a loved one's critical illness, may serve as a catalyst to enduring symptoms [2].

Anxiety occurs in upward of half of family members of ICU patients. Often beginning during the ICU stay, this anxiety may endure for months to years afterward [8, 9]. Likewise, depressive symptoms occur in approximately half of family members [10, 11]. In one longitudinal study by Cameron and colleagues, 67% of caregivers experienced depression 7 days after ICU discharge, while 43% had symptoms at 1 year [10]. Family members may feel withdrawn and experience lack of interest in daily activities, particularly regarding their role as a caregiver.

Families may begin to experience symptoms of acute stress disorder during a loved one's ICU stay [12]. When persistent after discharge, these symptoms may progress to post-traumatic stress disorder. PTSD may manifest as sleep disturbance, nightmares, intrusive thoughts, and affected mood. Episodes of reexperiencing life-threatening events faced by a loved one may continue for months to years afterward. While these symptoms decline in prevalence over time, at 6-months post-discharge, up to one third of family members may still manifest symptoms of PICS-F [9, 12–15]. Although not formally examined, given the rate of hospital readmission after critical illness, psychological distress is likely a consequence of ongoing stressors resulting from a combination of acute and chronic illnesses that lead to rehospitalizations [16].

Risk Factors

Numerous factors may place families at increased risk for the development of PICS-F. Broadly, these can be categorized as patient-specific, family member-specific, and relational (relations with providers and patient-family dyad relationships) (Table 10.1). At the patient level, younger age and outcome (death or near death) increase the risk of PICS-F. At the family-member level, younger age and lower education level, as well as preparation to serve in a decision-making role, likely related to the aforementioned factors, have been identified as risk factors for PICS-F [12, 17, 18].

At the relational level, proximity of relationship to patient (e.g., being a spouse of the patient[8]*)* and the gamut of emotions, ranging from fear, anger, and sadness to hope and optimism, that family members experience during their loved one's critical illness event appear to influence the likelihood of developing enduring symptoms of PICS-F [19].

The behavior of the ICU medical staff may be a modifiable driver of the development of PICS-F. Poor communication between the medical staff and family, paucity of family meetings regarding end-of-life care, lack of emotional support, and family perception of physician compassion may all contribute to PICS-F [20]. Further, as issues of survivorship are rarely addressed during critical illness, lack of preparation and support regarding the challenges that exist after discharge for survivors of critical illness likely contributes to enduring psychological distress among family members [21].

Table 10.1 Risk factors associated with the development of post-intensive care syndrome-family, categorized as patient-specific, family member-specific, and relational, defined as relations with providers and patient-family dyad relationships

Patient-specific	Family member-specific	Relational
Younger age	Younger age	Spouse or primary caregiver
Patient death	Lower educational level	Poor communication (provider and patient/family)
	Lack of preparation to serve in decision-making role	Infrequent family meetings
	Avoidant coping strategies	Inadequate preparation of post-discharge challenges

In the setting of prolonged illness, spouses or the primary caregivers of patients experience increased symptoms of PICS-F compared to other family members, as they carry this additional burden [22, 23]. In circumstances where the patient survives, relationship stress and strain, common among survivors and their loved ones, may be exacerbated if the younger family member needs to serve as caregiver [24]. The burden of caregiving can impact significantly upon mental health outcomes in family members, especially if the role comes at the expense of a change in employment status (e.g., reduced work hours) that results in financial loss [25]. Factors associated with worsened outcomes include greater effect of patient care on caregivers' daily activities, less social support for caregiver, less sense of control over life, and less personal growth as a result of caregiving [10].

Involvement in medical decision-making, particularly end-of-life decisions, may increase the family members' risk of developing anxiety, depression, and post-traumatic stress symptoms [13]. Similarly, family members of patients who experience death or near death during the ICU stay are at increased risk of developing both acute stress and post-traumatic stress symptoms, compared with family members of ICU survivors with less severe critical illness [26]. Coping strategies used by family members predict symptoms of PTSD, with persistent, avoidant coping strategies explaining, in part, the relationship between a loved one's death and symptoms of PTSD [18].

Potential PICS-F Preventative Measures in the ICU

As presented in Table 10.2, there are a number of preventative measures that could reduce PICS-F risk. The evidence and rationale for each of these measures are presented below.

Table 10.2 Strategies in the ICU and post-discharge that may prevent post-intensive care syndrome-family

ICU strategies	Post-discharge strategies
Education (informational brochure and patient- and family-centered website)	Care coordination at hospital discharge
Palliative care-based interventions	Assessment for post-acute care placement for survivor (e.g., acute rehabilitation)
Family meetings and team communication	Communication to prepare survivors and caregivers for what to expect post-discharge (e.g., post-intensive care syndrome, timeline for recovery)
Patient- and family-centered multidisciplinary rounds	ICU follow-up clinic
ICU diary	Timely hospice referral
Empowering family members as caregivers	
Family presence during resuscitation and procedures	
Spiritual support	

Education

Educational resources may help to guide family members during a loved one's ICU stay, in an effort to prevent the development of PICS-F. Mistraletti and colleagues examined the impact of an informational brochure and website designed to educate families about their loved one's condition, conveying what to expect during and after an ICU stay. The brochure was intended to legitimize the emotional aspects of both coping with illness and serving as a caregiver during recovery. Through a randomized trial conducted in nine Italian ICUs, investigators enrolled relatives of patients estimated to require at least 96 h of mechanical ventilation at the time of ICU admission. Prior to their first family meeting with the medical team relatives were given an informational brochure, and following the family meeting they were informed of the informational website. Following family meetings, family members completed validated questionnaires to assess medical understanding, satisfaction with care, anxiety, PTSD, and depression. Families who participated in this educational intervention experienced a significantly lower rate of symptoms of post-traumatic stress and increased understanding of prognosis and planned therapeutic procedures, without a reduction in symptoms of depression or anxiety [27].

Palliative Care-Based Interventions

In a large randomized trial of palliative care in the ICU, Carson and colleagues tested whether educational and emotional support-focused meetings led by palliative care providers could improve symptoms of PICS-F, compared to routine ICU team-led meetings. The intervention targeted family members of adult patients requiring 7 days of mechanical ventilation and assessed symptoms of anxiety and depression using the validated Hospital Anxiety and Depression Scale (HADS). Among the 312 family surrogate decision-makers who completed the study, a significant reduction in anxiety or depressive symptoms was not observed. Paradoxically, the palliative care-based intervention may have increased post-traumatic stress disorder symptoms. Limitations of this study include relatively few meetings per family and limited physician presence at family meetings. These findings do not support the use of routine or mandatory palliative care-led discussions to mitigate PICS-F [28].

Family Meetings and Team Communication

Effective communication between providers and relatives is essential to supporting family needs and reducing the risk of PICS-F. Multiple studies have examined communication surrounding families' understanding of ICU-level care, prognosis, and end-of-life care.

In a randomized, multicenter trial, investigators examined the impact of a designated communication facilitator on reducing family distress and the intensity of end-of-life care. The communication facilitators were nurses or social workers, trained to gain an understanding of family concerns, needs, and communication characteristics, and use that understanding to act as a liaison between the medical team and family. Additionally, communication facilitators provided emotional support to the family. The investigators found that communication facilitators, used in this capacity, reduced cost of care and length of stay, especially for patients who ultimately died during their ICU stay. Additionally, families randomized to interact with communication facilitators experienced fewer depressive symptoms at 6 months [29]. The differences in provider disciplines and timing of the interventions between the Carson et al. palliative care-focused intervention and communication facilitator intervention may explain the contrasting results between these two studies.

Multiple communication tools have been developed to guide or supplement healthcare providers' discussions with family members. A study of end-of-life communication with family members examined the effect of a structured end-of-life meeting between clinicians and family, along with an educational brochure, on the development of PICS-F. The structured end-of-life meeting in the intervention group focused on five key objectives, summarized by the mnemonic VALUE: "to *value* and appreciate what the family members said, to *acknowledge* the family members' emotions, to *listen*, to ask questions that would allow the caregiver to *understand* who the patient was as a person, and to *elicit* questions from the family members." Investigators demonstrated that these structured meetings, along with the brochure, allowed longer meeting time length and more time for family members to speak as compared to standard end-of-life discussions. This resulted in a significant decrease in symptoms of PTSD, anxiety, and depression in family members [30].

The ICU Diary

The ICU diary is a promising tool for reducing symptoms of PICS and PICS-F. The diary consists of a notebook composed of recorded events from a patient's ICU stay, written in simple, understandable language. Family members or nurses most commonly populate the contents of the ICU diary, with the intention of reviewing the events of an ICU stay with the patient following their discharge and allowing the patient to realign periods of confusion or inaccurate memories of their ICU stay with the reality of these events. The diary may be reviewed with the patient after discharge in the presence of a primary care provider, a family member educated in the use of the diary, or an ICU follow-up clinic provider.

The use of an ICU diary may lead to reduction in post-traumatic stress symptoms for both ICU survivors and their families [31]. Garrouste-Orgeas and colleagues conducted a prospective study of ICU diaries, examining the effects of the diary on psychological distress in patients and relatives. After implementing the ICU diary, patients and families were surveyed in the domains of depression, anxiety, and PTSD up to 12 months after discharge from the ICU. The intervention period was preceded and followed by control periods in an attempt to account for confounding changes to ICU practices after the intervention was stopped. Eighty percent of family members in the pre-study control period and 67.6% of family members in the post-study control period reported post-traumatic stress symptoms. During the intervention phase, with ICU diary implementation, 31.7% of family members reported post-traumatic stress symptoms, a significant decrease compared to control periods [32].

Based on evidence and experience in European countries, the ICU diary was recommended in the recent guidelines for family-centered critical care [1]. While adoption in the United States has been slow, in part due to concerns regarding risk management, interest is growing, and several US centers have successfully implemented the ICU diary (e.g., University of California, San Diego, Madigan Army Medical Center, Mission Hospital, Mission Viejo, California).

Engaging and Empowering Families as Caregivers

Historically, adult ICUs have lagged behind pediatric ICU practice with regard to family presence during procedures and other clinical events. Some providers have raised concerns in opposition to family presence, including family distress, provider stress, trainee education, medicolegal consequences, and quality of care. However, a growing body of literature supports family presence and speaks to the contrary regarding these concerns. Family presence during procedures and cardiopulmonary resuscitation (CPR) may, in fact, decrease the impact of PICS-F.

Jabre and colleagues randomized families of patients who experienced cardiac arrest to be offered the opportunity to witness CPR versus usual institutional practice. In the intervention arm, 211 of 266 relatives (79%) witnessed CPR, as compared with 131 of 304 relatives (43%) in the control group. Families in the control group reported significantly more post-traumatic stress symptoms than those who were given the opportunity to witness CPR. Families who did not witness CPR had symptoms of anxiety and depression more frequently than those who did witness CPR. Family-witnessed CPR did not affect resuscitation characteristics, patient survival, or the level of emotional stress in the medical team and did not result in legal action. At 1 year after the event, psychological benefits persisted for family members offered the opportunity to witness the CPR of a relative in cardiac arrest [33, 34].

Within the pediatric intensive care community, family engagement in CPR and invasive procedures is endorsed by the American Academy of Pediatrics, Society of Critical Care Medicine, and American Heart Association, and a growing body of literature over the past 10 years supports its adoption. In a 2014 systematic review, McAlvin and colleague noted that this engagement increases parents' satisfaction and coping when their children undergo invasive procedures or CPR [35].

Engaging patients and families in conversations about improving ICU care may be a powerful means to identify potential targets for intervention. Gill and colleagues conducted a study in which former ICU patients and family members were trained to facilitate focus groups and interviews of ICU survivors and family members [36]. They sought to describe the ICU experience and identify areas of focus for patient- and family-oriented interventions in the ICU. Participating family members and patients characterized admission to ICU as defined by "family *shock and* disorientation" requiring the "presence and support of a provider." Participants described five important elements of daily care: honoring the patient's voice, the need to know, decision-making, medical care, and culture in ICU. After discharge from the ICU, participants noted the challenges of the transition from ICU to a hospital ward and long-term effects of critical illness. Participating families and patients provided suggestions for improvement, including dedicated family navigators, increased provider awareness of the fragility of family trust, improved provider communication skills, improved transition from ICU to hospital ward, and information for patients regarding the long-term effects of critical illness [36].

Spiritual Support

Spiritual care from a hospital chaplain, palliative care service, or other spiritual leader from one's own community can be meaningful to patients and impactful on family outcomes. One retrospective investigation of the facilitators of ICU recovery found that spiritual support was the most commonly reported facilitator of recovery among ICU survivors [37]. In a prospective study of spiritual care provider activity within an ICU, investigators surveyed spiritual care providers to determine their activities within a single center and surveyed families to determine satisfaction with ICU care. Discussions about the patient's wishes for end-of-life care and a greater number of spiritual care activities performed were both associated with significantly increased overall family satisfaction with ICU care. Discussions about a patient's end-of-life wishes, preparation for a family conference, and total number of activities performed by spiritual leaders were also associated with significantly improved family satisfaction with decision-making in the ICU [38].

Ongoing Work and Future Directions

Resilience and Post-traumatic Growth

Resilience is a psychological trait that describes one's ability to adapt and overcome challenges when faced with adversity. Interest in the concept of resilience in survivors of critical illness and their families has grown recently. As a modifiable trait related to coping, resilience serves as a potential target for interventions to reduce the impact of PICS-F. A study of 178 family members of ICU patients measured resilience and symptoms of anxiety, depression, and acute stress prior to patient discharge from the ICU. A validated tool for measuring resilience, the Connor-Davidson Resilience Scale, was used to stratify family members as resilient or not resilient. Resilient family members reported significantly fewer symptoms of anxiety, depression, and acute stress as compared to those defined as "not resilient" [39]. Resilience, as well as optimism and social support, was found to be associated with fewer symptoms of psychological distress among family members of survivors of mechanical ventilation. Notably, as a scale measuring one's ability to cope with stress, spiritual influences play a central role in assessments of resilience [40]. Interventions such as training in coping strategies and mindfulness may facilitate the development of resilience in family members of survivors of critical illness. Support networks, including those discussed in the following section, may also provide essential resources and assistance to caregivers, including an opportunity to build resilience through a shared experience with fellow caregivers of ICU survivors. Collectively, these potentially beneficial interventions reflect the potential impact of design thinking, an approach to healthcare innovation that engages healthcare providers, patients, and families to identify healthcare solutions [41].

A related yet unexplored concept within the critical care survivorship literature is that of post-traumatic growth. The majority of PICS-F studies have examined the experience of family members over a relatively short time horizon (e.g., months) and have focused on negative consequences, such as symptoms of anxiety, depression, and PTSD. Whether post-traumatic growth, a concept realized after a traumatic (noncritical illness) event, is possible among family members of critically ill patients remains unknown [42]. As resilience is "ordinary, not extraordinary," so too, we may find, is post-traumatic growth [43].

Preparing and Supporting Family Members After ICU Discharge

To address the informational needs of survivors and their family members, several national initiatives have emerged. Dedicated to increasing the awareness of sepsis, the Sepsis Alliance is a nonprofit that was born from the tragedy of the founder's daughter, who succumbed to sepsis. The Sepsis Alliance website is designed to inform the public, including survivors and their loved ones, about sepsis and its long-term consequences. The ARDS Foundation, led by an ARDS survivor, provides information about ARDS and the impairments that ARDS survivors endure.

More generally, ICUsteps and the Society of Critical Care Medicine's Thrive initiative were founded on the principles that survivors of critical illness, and their loved ones, require more preparation and support than is presently provided in our fragmented healthcare system. Launched in 2015, the Thrive initiative was designed to improve patient and family support, encourage innovation in survivorship care, accelerate recovery, and mitigate the effects of PICS and PICS-F. The international Peer Support Collaborative, which engages survivors and family members of survivors, has established a support network for ICU survivors and their families at health systems in the United States, the United Kingdom, Scotland, and Australia. The early experience confirms that family members, like survivors, have a great deal to offer others in sharing their experience [44]. Whether shared stories, empathy, and practical advice afforded through such programs can reduce symptoms of PICS-F remains unknown and requires rigorous evaluation.

ICU Follow-up Clinics

The benefits of an ICU follow-up clinic have yet to be demonstrated in terms of patient and family outcomes. Conceptually, ICU follow-up clinics are staffed by pulmonary and critical care specialists and employ a multidisciplinary approach with extensive care coordination between physical and occupational therapists, physical medicine and rehabilitation physicians, neurologists, and neuropsychologists [45].

With regard to PICS-F, these clinics offer the potential to rehabilitate PICS, further reduce the burden of caregiving by providing optimal support for families, explore the family experience of an ICU stay, and potentially provide education and resources to families experiencing PICS-F. Admittedly, the potential of post-ICU clinics has not been realized. For example, a pragmatic trial of a nurse-led follow-up program designed to improve health-related quality of life and mitigate psychological distress in survivors was neither effective nor cost-effective [46]. However, comprehensive discharge planning and home follow-up after an acute care hospitalization reduced hospital readmissions and healthcare costs among the elderly [47].

It is conceivable that ICU follow-up clinics, designed and coordinated with optimal discharge planning for the survivor and caregivers, could improve patient-centered outcomes such as time spent at home and ease the psychological distress of caregivers. Given the functional impairments of survivors, which can negatively impact caregivers, timely assessment of post-acute care services and/or placement (e.g., acute rehabilitation) at the time of hospital discharge is a potential strategy to improve outcomes for the survivor-caregiver dyad. Last, by openly eliciting the preferences and goals of survivors, timely consideration of hospice may result in improved outcomes for some survivors and their caregivers.

Conclusion

Family members of ICU patients commonly experience anxiety, depression, and post-traumatic stress symptoms following a loved one’s critical illness. While these symptoms may be severe and enduring, opportunities exist for providers to intervene in the ICU setting and thereafter, potentially reducing the risk of PICS-F. Family members have consistently taught us that they want a partnership and presence from care providers and they seek engagement in the care of their loved ones. They want to know what to expect when they leave the ICU – both in terms of long-term effects for their loved ones and for themselves. By embracing the interventions discussed throughout this chapter, in addition to preparing and supporting family members across the continuum of care, providers may reduce the risk of psychological morbidity among the families of ICU patients.

References

1. Davidson JE, Aslakson RA, Long AC, et al. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. Crit Care Med. 2017;45(1):103–28.
2. Netzer G, Sullivan DR. Recognizing, naming, and measuring a family intensive care unit syndrome. Ann Am Thorac Soc. 2014;11(3):435–41.
3. Needham DM, et al. Improving long-term outcomes after discharge from intensive care unit: report from a stakeholders' conference. Crit Care Med. 2012;40:502–9.
4. Davidson JE, Jones C, Bienvenu OJ. Family response to critical illness: postintensive care syndrome-family. Crit Care Med. 2012;40(2):618–24.
5. Desai SV, Law TJ, Needham DM. Long-term complications of critical care. Crit Care Med. 2011;39(2):371–9.
6. Prendergast TJ. Resolving conflicts surrounding end-of-life care. New Horiz. 1997;5(1):62–71.
7. Hopkins RO, Suchyta MR, Farrer TJ, Needham D. Improving post-intensive care unit neuropsychiatric outcomes: understanding cognitive effects of physical activity. Am J Respir Crit Care Med. 2012;186(12):1220–8.
8. Pochard F, Darmon M, Fassier T, et al. Symptoms of anxiety and depression in family members of intensive care unit patients before discharge or death. A prospective multicenter study. J Crit Care. 2005;20(1):90–6.
9. Anderson WG, Arnold RM, Angus DC, Bryce CL. Passive decision-making preference is associated with anxiety and depression in relatives of patients in the intensive care unit. J Crit Care. 2009;24(2):249–54.
10. Cameron JI, Chu LM, Matte A, et al. One-year outcomes in caregivers of critically ill patients. N Engl J Med. 2016;374(19):1831–41.
11. Rodríguez AM, Gregorio MA, Rodríguez AG. Psychological repercussions in family members of hospitalised critical condition patients. J Psychosom Res. 2005;58(5):447–51.
12. Anderson WG, Arnold RM, Angus DC, Bryce CL. Posttraumatic stress and complicated grief in family members of patients in the intensive care unit. J Gen Intern Med. 2008;23(11):1871–6.
13. Gries CJ, Engelberg RA, Kross EK, et al. Predictors of symptoms of posttraumatic stress and depression in family members after patient death in the ICU. Chest. 2010;137(2):280–7.
14. Jones C, Skirrow P, Griffiths RD, et al. Post-traumatic stress disorder-related symptoms in relatives of patients following intensive care. Intensive Care Med. 2004;30(3):456–60.
15. Azoulay E, Pochard F, Kentish-Barnes N, et al. Risk of post-traumatic stress symptoms in family members of intensive care unit patients. Am J Respir Crit Care Med. 2005;171(9):987–94.
16. Hua M, Gong MN, Brady J, Wunsch H. Early and late unplanned rehospitalizations for survivors of critical illness*. Crit Care Med. 2015;43(2):430–8.
17. Kross EK, Engelberg RA, Gries CJ, Nielsen EL, Zatzick D, Curtis JR. ICU care associated with symptoms of depression and posttraumatic stress disorder among family members of patients who die in the ICU. Chest. 2011;139(4):795–801.
18. Petrinec AB, Mazanec PM, Burant CJ, Hoffer A, Daly BJ. Coping strategies and posttraumatic stress symptoms in post-ICU family decision makers. Crit Care Med. 2015;43(6):1205–12.

19. Nelson JE, Hanson LC, Keller KL, et al. The voice of surrogate decision makers: family responses to prognostic information in chronic critical illness. Am J Respir Crit Care Med. 2017;196:864.
20. Wall RJ, Curtis JR, Cooke CR, Engelberg RA. Family satisfaction in the ICU: differences between families of survivors and nonsurvivors. Chest. 2007;132(5):1425–33.
21. Govindan S, Iwashyna TJ, Watson SR, Hyzy RC, Miller MA. Issues of survivorship are rarely addressed during intensive care unit stays. Baseline results from a statewide quality improvement collaborative. Ann Am Thorac Soc. 2014;11(4):587–91.
22. Lynn J. Strategies to ease the burden of family caregivers. JAMA. 2014;311(10):1021–2.
23. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: a clinical review. JAMA. 2014;311(10):1052–60.
24. Cox CE, Docherty SL, Brandon DH, et al. Surviving critical illness: acute respiratory distress syndrome as experienced by patients and their caregivers. Crit Care Med. 2009;37(10):2702–8.
25. Griffiths J, Hatch RA, Bishop J, et al. An exploration of social and economic outcome and associated health-related quality of life after critical illness in general intensive care unit survivors: a 12-month follow-up study. Crit Care. 2013;17(3):R100.
26. McAdam JL, Dracup KA, White DB, Fontaine DK, Puntillo KA. Symptom experiences of family members of intensive care unit patients at high risk for dying. Crit Care Med. 2010;38(4):1078–85.
27. Mistraletti G, Umbrello M, Mantovani ES, et al. A family information brochure and dedicated website to improve the ICU experience for patients' relatives: an Italian multicenter before-and-after study. Intensive Care Med. 2017;43(1):69–79.
28. Carson SS, Cox CE, Wallenstein S, et al. Effect of palliative care-led meetings for families of patients with chronic critical illness: a randomized clinical trial. JAMA. 2016;316(1):51–62.
29. Curtis JR, Treece PD, Nielsen EL, et al. Randomized trial of communication facilitators to reduce family distress and intensity of end-of-life care. Am J Respir Crit Care Med. 2016;193(2):154–62.
30. Lautrette A, Darmon M, Megarbane B, et al. A communication strategy and brochure for relatives of patients dying in the ICU. N Engl J Med. 2007;356(5):469–78.
31. Mehlhorn J, Freytag A, Schmidt K, et al. Rehabilitation interventions for postintensive care syndrome: a systematic review. Crit Care Med. 2014;42(5):1263–71.
32. Garrouste-Orgeas M, Coquet I, Périer A, et al. Impact of an intensive care unit diary on psychological distress in patients and relatives*. Crit Care Med. 2012;40(7):2033–40.
33. Jabre P, Belpomme V, Azoulay E, et al. Family presence during cardiopulmonary resuscitation. N Engl J Med. 2013;368(11):1008–18.
34. Jabre P, Tazarourte K, Azoulay E, et al. Offering the opportunity for family to be present during cardiopulmonary resuscitation: 1-year assessment. Intensive Care Med. 2014;40(7):981–7.
35. McAlvin SS, Carew-Lyons A. Family presence during resuscitation and invasive procedures in pediatric critical care: a systematic review. Am J Crit Care. 2014;23:477–84.
36. Gill M, Bagshaw SM, McKenzie E, et al. Patient and family member-led research in the intensive care unit: a novel approach to patient-centered research. PLoS One. 2016;11(8):e0160947.
37. Maley JH, Brewster I, Mayoral I, et al. Resilience in survivors of critical illness in the context of the Survivors' experience and recovery. Ann Am Thorac Soc. 2016;13(8):1351–60.
38. Johnson JR, Engelberg RA, Nielsen EL, et al. The association of spiritual care providers' activities with family members' satisfaction with care after a death in the ICU*. Crit Care Med. 2014;42(9):1991–2000.
39. Sottile PD, Lynch Y, Mealer M, Moss M. Association between resilience and family member psychologic symptoms in critical illness. Crit Care Med. 2016;44(8):e721–7.
40. Nadig N, Huff NG, Cox CE, Ford DW. Coping as a multifaceted construct: associations with psychological outcomes among family members of mechanical ventilation survivors. Crit Care Med. 2016;44(9):1710–7.
41. Kalaichandran A. Design thinking for doctors and nurses. New York Times, August 3, 2017.
42. Rendon J. Upside: the new science of post-traumatic growth. New York: Touchstone; 2015.

43. Newman R. The road to resilience. Monitor on psychology. 2002; http://www.apa.org/monitor/oct02/pp.aspx. Accessed April 11, 2017.
44. Mikkelsen ME, Jackson JC, Hopkins RO, et al. Peer support as a novel strategy to mitigate post-intensive care syndrome. AACN Adv Crit Care. 2016;27(2):221–9.
45. Jackson JC, Jutte JE. Rehabilitating a missed opportunity: integration of rehabilitation psychology into the care of critically ill patients, survivors, and caregivers. Rehab Psych. 2016;61(2):115–9.
46. Cuthbertson BH, Rattray J, Campbell MK, et al. The PRaCTICaL study of nurse led, intensive care follow-up programmes for improving long term outcomes from critical illness: a pragmatic randomized controlled trial. BMJ. 2009;339:b3723.
47. Jacobsen BS, Campbell R, Brooten D, et al. Comprehensive discharge planning and home follow-up of hospitalized elders: a randomized clinical trial. JAMA. 1999;281(7):613–20.

Chapter 11
Humanizing Intensive Care: Questions, Balance, and Tragic Trade-Offs

Samuel M. Brown, Michael E. Wilson, Chris Benda, Negin Hajizadeh, and Ramona O. Hopkins

Introduction

Intensive Care Units (ICUs) are astonishing spectacles of modern medical technology. They are highly effective at improving survival for many once-fatal diseases [1]. These astounding successes are deservedly much lauded and supported. Despite these medical successes, death can only ever be postponed—human beings remain mortal. This fact sometimes feels forgotten in the dramatic, technological battles with critical illness. For this and other reasons, intensive care clinicians and ICUs

---

S. M. Brown (✉)
Pulmonary and Critical Care Medicine, Intermountain Medical Center, Murray, UT, USA

Center for Humanizing Critical Care, Intermountain Healthcare, Murray, UT, USA

Pulmonary and Critical Care Medicine, University of Utah School of Medicine, Salt Lake City, UT, USA

Intermountain Medical Center, Shock Trauma Intensive Care Unit, Murray, UT, USA
e-mail: samuel.brown@imail.org

M. E. Wilson
Pulmonary and Critical Care Medicine, Mayo Clinic, Rochester, MN, USA

C. Benda
Intensive Care Unit Patient-Family Advisory Council, Intermountain Medical Center, Murray, UT, USA

N. Hajizadeh
Center for Health Innovations and Outcomes Research (CHIOR), Hofstra Northwell School of Medicine and Northwell Health, Manhasset, NY, USA

R. O. Hopkins
Pulmonary and Critical Care Medicine, Intermountain Medical Center, Murray, UT, USA

Center for Humanizing Critical Care, Intermountain Healthcare, Murray, UT, USA

Psychology Department and Neuroscience Center, Brigham Young University, Provo, UT, USA

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_11

commonly figure in the last weeks or months of individuals who die, whether the death is the end of a long illness or occurs unexpectedly.

Unfortunately, the severity of illness, the invasiveness of intensive therapies, and a sometimes extreme focus on reversal of critical illness can make ICUs brutal places to practice medicine and to receive medical care [2, 3]. Similarly, uncertainty about whether recovery from an acute illness is possible or likely makes it difficult to know whether one is treating a patient who will survive or whether the patient will die despite support. Western biomedical culture of the last 50 years has also had a tendency to isolate patients from their families, failing to acknowledge the extent to which human beings are most human, most themselves, when their intimate relationships are honored and sustained. A broad array of factors related to the structure and function of ICUs contribute to dehumanization.

We have considered theoretical considerations relevant to the humanization of ICUs elsewhere [4]. In this chapter, we will focus on other important topics in the humanization of critical care. Specifically, we emphasize (1) the forms of and reasons for dehumanization, (2) negative consequences of dehumanization, (3) practical approaches to (re)humanization, (4) tragic trade-offs and research considerations, and (5) dehumanization of clinicians.

We begin, for purposes of orientation, with a definition of dehumanization. Extensive philosophical writing (especially in France after World War II) has emphasized the impossibility of understanding ourselves, let alone others. Rather than attempting to map humanization on problems of mutual unintelligibility, we employ the practical definition proposed by social psychologists. Dehumanization is seeing and/or treating another person as if they lacked the mental capacities (whether realized or not) that we enjoy as human beings [5–7]. Dehumanization can be prolonged or momentary and can be mild or severe. While both thoughts and deeds may dehumanize, we emphasize the practical aspects of dehumanization—the acts clinicians perform—given their likely relevance in the ICU [8].

Dehumanization is rampant in human society. Almost every person has engaged in at least a mild act of dehumanization at some point. In one of the odd twists of language and culture, the tendency to dehumanize may be an attribute of humanity itself. The best-known examples of dehumanization, however, are genocides, whether the infamous systematic murders of National Socialist Germany or Stalinist Russia or the more recent miseries practiced in Rwanda, Sudan, or Syria. The dehumanization attendant on genocide is the most extreme version of ubiquitous phenomena. Multiple observational and psychology laboratory experiments have strongly suggested that in order for genocide to occur, the aggressor must first fail to acknowledge the humanity of the victim [7].

The social psychologist Nick Haslam has identified two main modes of dehumanization: animal and mechanical [7]. The animal form of dehumanization sees the individual as lacking intellectual sophistication. Such individuals are seen as too passionate, subrational, like a wild animal rather than a human being. Closer to the ICU (admitting that the “animalistic” categorization is inexact), an agitated patient may be seen as a “wild animal,” while a neurologically disabled patient may be characterized as a “vegetable” (a misunderstanding of ancient Greek ideas about the essential forces animating living beings). Mechanical dehumanization, on the other hand, maintains that the victim of the dehumanization is robotic, entirely lacking in human emotion. Clinicians may view patients as mere objects lying in a hospital bed, a perception perhaps compounded by the effects of sedative medications. Mechanical dehumanization may also be aimed at clinicians by frightened or resentful patients and families. Administrators may also dehumanize clinicians by treating them as cogs in an industrial machine. The different forms of dehumanization may induce each other in a kind of positive feedback loop.

Rhetoric around the US Presidential election of 2016 exemplified this pattern quite well: the Republican candidate was often dehumanized as animalistic, while the Democratic candidate was often dehumanized as robotic or mechanistic. The dehumanization of the opponent was an important aspect of the dueling strategies aimed at assuring the election of one's favored candidate.

While genocide is fortunately quite rare in the modern West, lesser forms of dehumanization are ubiquitous, including racist stereotyping or stigmatization of political opponents as subhuman. Dehumanizing practices may at times persist because they have been useful in the past. Dehumanization can help to maintain social boundaries; in one of the paradoxes of human society, people may be prone to sacrifice a larger community for a smaller one, recognizing that communities are often defined in opposition to other communities. Dehumanization may also be protective (or be perceived to be protective) against certain forms of stress by allowing clinicians to distance themselves from the direct experience of patients' or families' emotional distress.

Concerns about dehumanization apply prominently in the ICU. In this chapter, we consider current problems and potential early solutions with an eye toward clarifying the cognitive errors and blind spots that often interfere with humanization in the ICU.

The Persistence of Dehumanization in the ICU

Dehumanization in the ICU is a frequent occurrence. Although data are limited, single-center surveys ($N > 1500$ respondents) suggest that disrespect (behaviors that overlap substantially with dehumanization) is experienced in 20–30% of patients/families in the ICU [9]. Dehumanization in the ICU can be divided into casual, physiologic, and substantial forms. *Casual* dehumanization refers to the apparently incidental attributes of medical environments that tend to strip people of their identity. *Physiological* dehumanization refers to the attributes of illness and treatment that sap individuals of their inner mental life and capacity to express agency. *Substantial* dehumanization refers to avoidable dehumanizing acts that are neither intrinsic to medicine nor justifiable.

All forms of dehumanization have special implications in the setting of a hospitalization for critical illness. Part of what's frightening about hospitalization for patients and families, especially in the ICU, is the threat of extinction of the individual self. This is, existentially, a key reason why dehumanization is an important concern. All forms of dehumanization may contribute to this risk of personal extinction and the violation of the integrity of the self.

Casual dehumanization The attributes of the medical environment that contribute to the loss of identity and treatment of individuals as if they were not fully human. The emblem of casual dehumanization is the uniform of the hospital "Johnny" gown. This piece of industrial clothing is obviously designed to provide strangers casual access to the private parts of the wearer's body. In exchange for the hospital gown, patients are asked to remove all personal items including clothing, underwear, shoes, socks, wallets, keys, cellphones, and sometimes even deeply intimate objects such as wedding rings, eyeglasses, and dentures. Patients' hairstyles transform from their preferred, often highly identifiable hairstyles to various levels of dishevelment. Stickers, wristbands, and wires are routinely attached to each patient's body. Such labels openly reveal personal information such as the patient's name, date of birth, whether they have been deemed a "fall risk," or whether they are not to receive cardiopulmonary resuscitation. Tubes attached to poles, bags, and machines may be inserted into every orifice. The totality of these effects incrementally but dramatically changes the appearance of each hospitalized ICU patient, often replacing individual identity. Physicians, nurses, and other medical staff may refer to patients by their assigned room number instead of the patients' names. Instead of being known as "Mr. Gregory Jones, a retired history professor and father of 6, whose wife just passed away 3 months ago," a patient may be casually referred to as "Room 512 on the vent for a COPD exacerbation."

Along with loss of identity comes a loss of control. Patients often cannot control whether or not they eat, what they eat, when they sleep or awaken, when the doctors will visit, or when procedures will be performed. Patients may be forced to rely on assistance to perform activities such as eating, bathing, walking, toileting, and sleeping. Bed and chair alarms are reminders that patients are sometimes not even allowed to stand up on their own. These attributes of the hospital environment may make patients seem less than human to hospital staff. By way of orientation and contextualization, the penal system is another modern institution where people are stripped of identity, assigned a number, placed in a uniform designed for the convenience of others, and experience a profound loss of control.

Physiological dehumanization Biological threats to the expression of one's capacity for a rich mental life. Many aspects of critical illness and its treatments may result in the loss of mental awareness for a patient. This loss of mental awareness leads to what we call physiologic dehumanization. We draw attention here to a limitation of the social psychologists' definition of dehumanization for the ICU. Critically ill patients may manifestly lack the attributes—a rich inner mental life—the presence of which defines humanization. It's this limitation that drives us to describe the capacity (whether realized at the moment or not) for such a life. Such changes may range from mild (e.g., a patient unable to recall several days of medical illness) to severe (e.g., coma). The causes of such loss of awareness include the underlying disease processes and sedatives administered to improve the tolerance of mechanical ventilation or modulate an agitated delirium. The restraints used to prevent inadvertent dislodgment of medical equipment as well as the disrupted sleep-wake cycles may also threaten autonomy and awareness.

Clinicians, often unintentionally or even unknowingly, may have dramatically different (even dehumanizing) interactions with patients with altered mental status compared to patients without such altered mental status. For example, when approaching the rooms of patients whose eyes are closed or who may be in a moderately sedated state, ICU physicians may not knock or introduce themselves to the patient, as would otherwise be customary. ICU clinicians may not explain that they are about to perform an examination of sensitive areas of the body. Instead, clinicians may assume, sometimes mistakenly, that such patients cannot perceive their environment. In addition, for patients without altered mentation, the critical nature of their illness may cause clinicians to overlook or deprioritize basic introductions and patient-centered communication. Often—perhaps even usually—physicians arrive at the bedside of an acutely deteriorating patient and think of the patient strictly in terms of his/her medical illnesses. The humanness of the patient lying in bed easily gets lost in the commotion of diagnosis and treatment.

Substantial dehumanization Can run the gamut from horrifying lapses such as intentional provision of substandard care to more complex questions of the optimal personalization of humanizing care. The extreme of medical dehumanization is exemplified by the Tuskegee experiments, in which poor African American men were observed as they developed serious complications of untreated syphilis despite the availability of antibiotic treatment. The current regulatory system for research exists, in large part, in response to substantial dehumanization by researchers in prior generations. Fortunately, such extreme dehumanization is much less common in the contemporary world. The dehumanization we encounter in contemporary environments is more likely to be related to behaviors of well-intentioned clinicians.

The ideal of full humanization implies an approach to understanding other persons in their full humanity, which means seeing them as equal members of a community. Deviations from such complete humanization are unfortunately common and exist across a spectrum. Some portions of that spectrum may be more or less difficult to address. While we acknowledge that the ideal of perfect humanization may not be achieved in practice (and draw attention to occasional tragic trade-offs below), we nevertheless feel that movement toward that ideal is important.

Reasons for dehumanization While most forms of dehumanization of ICU patients are unintentional, dehumanization persists in the modern ICU [9]. Several factors may contribute to the loss of identity, lack of personalization, and sense of disrespect experienced by patients and their family members.

First is poor clinician well-being. Common issues that may impact clinician well-being include physical illness, mental illness, substance abuse, stress, and burnout. Each of these difficulties may contribute to an individual clinician's inability to tend to the well-being of patients and their family members. Clinician burnout is particularly worrisome and is characterized by emotional exhaustion, depersonalization and detachment, and a decreased sense of personal fulfillment [10]. The rate of burnout experienced by ICU physicians and nurses ranges from 30% to 80% [11]. Factors that contribute to burnout in ICU clinicians include high patient acuity, morally distressing situations, caring for dying patients, conflicts with family members or healthcare colleagues, excessive work hours, lack of control of workplace events such as scheduling, and dissatisfaction with salary among others. Physicians and nurses who experience burnout are at risk of perceiving patients as objects rather than human beings [12]. In addition, ICU clinicians (especially nurses) are caregivers for both patients and their family members. When team members significantly identify with a patient or family member on a personal level, trying to absorb their pain and suffering may result in compassion fatigue [13, 14]. To put the matter starkly—if we clinicians experience the death of every patient as if it were the death of a close friend, we would be insane with grief very quickly. Such emotional exhaustion may contribute to low personal well-being and inability or unwillingness to identify with future patients on a human level.

Second, cognitive errors by clinicians may contribute to dehumanization. These cognitive errors are understandable, even predictable. The ICU is stressful and disorienting enough that all participants—clinicians, patients, and families—are prone to misperceive ways that may contribute to dehumanization. Clinicians may, for example, not realize that they are experiencing pseudo-empathy (believing that one is seeing the world from the perspective of another when in fact one has imputed one's own views to the other person) when they are considering risks and benefits of continued treatment. From the other side, family members may fail to imagine the world from the perspective of the clinician, blaming clinicians for factors that are outside their control. Such failures of mutual understanding may figure prominently in disputes about "potentially inappropriate care," in which clinicians may worry that family members do not understand how best to represent the patient's sensibilities about high-risk treatments that may not work, while family members may worry that clinicians are callously "giving up" on the patient.

While clinician diagnostic errors have been well described by cognitive psychologists in recent decades [15], the risks of misapprehension and cognitive errors related to human aspects of the ICU experience are also endemic and merit consideration. Increasingly sophisticated work on judgment and decision-making may shed considerable light on the problems of dehumanization in the ICU.

Third, ICU policies and practices, sometimes deeply entrenched, may contribute to persistent dehumanization. For example, too many ICUs in the United States continue to have restrictive visiting policies, a tradition that started in the 1800s to restore "order" in hospital wards with non-paying patients [16, 17]. Once thought to be necessary to protect the patient from exhaustion or overstimulation, restricted visiting hours have now been shown to be associated with poorer patient and family well-being [16]. Another hospital tradition (and sometimes policy) is that family members must leave the room for ICU procedures such as central line placement, intubation, or thoracentesis. While the evidence base supporting restricted family presence in the ICU is essentially nonexistent, such policies and practices continue to be implemented, regardless of the toll on patients and families.

Similarly, policies favoring the overuse of deep sedation for mechanically ventilated patients may inadvertently contribute to physiological dehumanization. Once thought to be necessary for the patient, deep sedation (especially with medications such as benzodiazepines [18]) are now largely felt to be harmful to mechanically ventilated patients (contributing significantly to delirium and weakness) [19]. Strategies to reduce the amount and type of sedating medications are in place in many ICUs [20]. Some types of dehumanization are necessary parts of critical illness and ICU treatment, as we describe below, while others can and should be eliminated. Rethinking systems and our parts within those systems is important work. We'll all need to see patients and family more clearly than we do. More careful research is necessary.

Intrinsic and Secondary Implications of Dehumanization

Dehumanization affects clinicians, patients, and families in a variety of ways. Before reviewing the negative consequences in specific detail, we draw attention to an important ethical point. Are the secondary consequences necessary to reject dehumanization? Is humanization intrinsically important, independent of any secondary effects? Or should humanization be weighed on the basis of its secondary effects? At the extremes of dehumanization, it seems clear that dehumanization is intrinsically wrong and must be avoided at all costs. Admittedly in those circumstances, secondary effects are extremely likely. What's less clear is whether milder forms of dehumanization—neglecting to use a patient's preferred name, or introducing oneself to a sedated patient, for example—are intrinsically severe enough to require substantial resources in the absence of demonstrated secondary effects. We are mindful of the risks of extremism. We acknowledge that some mild forms of dehumanization, while intrinsically undesirable, may need to be weighed against the risks and benefits associated with large-scale efforts to address them. Finding the optimal balance in such settings will require ongoing, careful work that incorporates the perspectives of patients and families alongside those of clinicians.

Dehumanization and the patient Feeling that one has been dehumanized is dispiriting and discomfiting. Dehumanization is associated with decrease in self-efficacy and increased depression and anxiety. It also increases the risk that the person will in turn dehumanize other individuals. In addition, dehumanization may interrupt the natural processes by which people establish and maintain communities, contributing to further isolation, in a positive feedback loop [5, 7]. The remarkable prevalence of PTSD among ICU patients and families may further complicate attempts to meaningfully humanize [21, 22]. A classic pragmatic experiment (using historical controls) in a nursing facility suggested that dehumanization (especially through the restriction of patient agency)—can be reduced by allowing nursing home residents to manage a plant or a pet. This intervention was associated with substantial improvements in satisfaction and self-efficacy—markers of increased humanization [23].

Dehumanization and the family Feeling that one's close family member has been dehumanized may be as disorienting as being dehumanized oneself. Dehumanization may also increase the risk that the person will in turn dehumanize other individuals, while disrupting the establishment and/or maintenance of community [5, 7]. Critical illness causes ICU patients to find themselves in precarious and vulnerable states. When patients and family members sense that the behaviors of the healthcare team members are causing additional, potentially unnecessary, disrespect or dehumanization, there is likely a loss of trust in the healthcare team and a degradation of the therapeutic patient/physician relationship. Such loss of trust has the potential to lead to impaired communication, conflict, poor-quality shared decision-making, and potentially adverse patient outcomes.

Dehumanization and the clinician Clinicians—many of whom may already be experiencing burnout—may be at risk of further burnout when dehumanizing practices occur. The literature on ICU clinician burnout is modest, but it accords with the intuition of many practitioners. Traditionally, medical training has not included tools for clinicians to recognize and process the intense emotions that arise from interaction with pain, suffering, uncertainty, and grief inherent in the management of disease. Rather, medical education has informally addressed emotions through distance from emotions [24]. Teaching better approaches to emotion may lead to increased empathy, which in turn could decrease dehumanizing practices and might help ease the burden of PTSD noted among ICU clinicians [25].

In addition, evidence from the psychology literature suggests that dehumanization (especially through employment of racial heuristics) may be associated with provision of substandard clinical care [26, 27]. Similarly, an early study from the theorists of "heuristics and biases" suggested that clinicians perform distinct workups when they are primed to think of groups of people rather than distinct individuals. In other words, the medical workup may vary as a result of differential humanization [28]. (We should be mindful of the possibility that the psychology literature may be overstating the evidence, however [29].)

Given the prevalence and important negative consequences of dehumanization, reasonable tactics to prevent dehumanization are important to identify and implement. In the following section, we consider a schema for considering such tactics as well as introduce representative examples of problems and solutions.

Tactics and Strategies

The state of Utah boasts marvelous powder snow year after year, making the experience of skiing a prized component of life in that section of the Rocky Mountains. At the ski resorts, a system exists to distinguish grades of difficulty for the various runs. Green circles indicate easy slopes appropriate to beginners, blue squares indicate intermediate slopes that may challenge beginners and bore experts, and black diamonds indicate runs that may present substantial dangers for inexperienced skiers but promise great satisfaction to the experienced athlete. We use that framing to describe tactics and strategies that could be easily applied to prevent dehumanization without much additional personal work or further research (green circles) all the way to techniques that will likely require substantial additional research and experience (black diamonds). We display a relevant taxonomy, with examples, in Table 11.1.

We will need to remember that the proposed behaviors and their contexts represent complex human encounters, many of which cannot be experimentally interrogated. We should be humble about claims made, scientific or otherwise. We also should acknowledge that the regulatory environment and its associated incentives have changed substantially in recent years and rely increasingly on quantitative measures which may bear unpredictable relationships to actual humanization. Efforts to improve humanization in the ICU will have to acknowledge the risks and constraints imposed by regulatory schemes, which may not be based on reliable evidence or may impose metrics that do not measure what is intended.

Green Circles

The "dinner party" rule for basic humanizing behaviors in the ICU is a simple thought experiment: how would we behave toward the respected host of a dinner party to which we have been invited? This thought experiment tends toward simple acts of respect. We prefer not to think of the host at the dinner party as a "customer" to be "serviced" because we find such consumer-based metaphors distracting and misleading, especially in the intensive care unit. Individuals with critical illness and their families are not people in a shop that we hope to upsell into an extended warranty. We do not grapple with these important issues of care in hopes of persuading a customer to spend more money. The point, in our estimation, is to see the person rather than an object for manipulation. We display core components of treating our patients as we would the host of a dinner party in Table 11.2.

Get-to-know-me boards and modifications to the electronic medical record to facilitate the preferred name of a patient also seem to us to fit comfortably in the green circles.

We think of family members as part of the team caring for the patient. Among the clinicians, each has a specific role and expertise. When special problems are

Table 11.1 Interventions to humanize the ICU and show respect to all patients, ranked by degree of difficulty and/or need for new research

	The healthcare team:
First steps (green circles) “Basic common courtesy” or the “dinner party” rule 🟢	Allows unrestricted visiting hours by family members Shows common courtesy to patient (even if sedated or delirious or not fully conscious) Knocks before entering room and asks the patient permission to enter room Addresses the patient by their preferred name and introduces themselves Asks permission before touching patient and explains what they are about to do so (e.g., draw blood or perform physical examination) Gets to know the patient (e.g., helps patient/family fill out a “get-to-know-me” board including photographs from home as applicable) Communicates with patient in an understandable manner Uses adaptive communication strategies if needed (including language interpreters) Explains basic concepts of illness and treatments Locates and allows patient to wear eyeglasses, hearing aids, or other relevant assistive devices
Second steps (blue squares) 🟦	Offers physical therapy and mobilizes the patient in bed and out of bed as possible Invites and allows family members to be present during sensitive moments such as: Procedures (e.g., central lines, intubation, thoracentesis, chest tube, etc.) Toileting and bathing (as desired by patient and family) Initial stabilization in ICU Cardiopulmonary resuscitation Writes condolence letters Engages in a “going off to war” talk prior to intubation (by hoping for good outcome but preparing for the worst, this may prevent stealing the last words of patient from them and their family)
Advanced steps (black diamonds) ◆	Utilizes additional team members to deliver humane care (doulas, communication facilitators, navigators) Completes personal and systemic diagnostic testing for conscious and unconscious biases and tries to improve biases with de-biasing techniques

encountered beyond the expertise of the current team, a consultation is performed with a subspecialist. Such consultation-seeking is routine in diagnosis and treatment of complex conditions. We consider the family to be the world experts in the humanity of the patient. It makes about as much sense to restrict them from the bedside as to refuse to allow a cardiac surgeon to see a patient with critical, life-threatening valve disease.

Table 11.2 Core elements of the dinner party rule

Behavior	Explanation
Knock before entering a room	Patients may experience the ICU room as their own bedroom. Knocking communicates respect for the integrity of the person as it includes the lived environment
Ascertain and use a patient's preferred name	The birth certificate name may have been rejected long since. Our names, as our faces/appearance, are our calling cards as human beings
Do not touch without permission or acknowledgment	Access to one's own body is central to personhood. Violations of that integrity are marks of grave disrespect. Even comatose individuals deserve to be warned before being touched
Speak to comatose individuals	Anesthesia recall is rare but concerning; some comatose individuals may in fact be able to hear; clinicians rarely know when memories begin to be formed; families often acknowledge that conversation as a mark of human respect

Straddling Green and Blue

Morally, fully open access for family members to the bedside is part of the green circle. There is no good reason to exclude family members from the bedside. Those old days should be well over. When it comes to visiting hours, the data and consensus are clear [16, 30–34]. Even if the benefits of open visitation weren't clear, in our view, a randomized controlled trial would need to show benefit from restricting visitation before it would be justified. There also may be a matter of justice, given the likelihood of selective enforcement of visiting hour restrictions (some family allowed to visit where other families are not) [35].

The reason we rate fully open access as spanning green circles to blue squares is the possible effect on clinician burnout. Some families may lack interpersonal skills necessary for easy communication. Some clinicians may feel that their authority is being second-guessed, that they are being treated as waitstaff (when, e.g., a family member wants a coffee), and that they have no time to be quietly reflective during the day when family members are always present. Furthermore, clinicians may not have space to express emotions frankly with colleagues about difficult interpersonal dynamics or vexing clinical scenarios. When we opened visitation fully at one ICU (i.e., no specific restrictions by time of day), three nurses resigned in protest. In our experience, this happens when clinicians are already struggling with symptoms of burnout. We strongly advocate opening ICUs and believe it's a moral imperative. We find the experience of pediatric ICUs reassuring in this respect: most pediatric ICUs have had open family presence for decades. We acknowledge that the process in any given ICU may take some time, as management develops in collaboration with frontline staff to determine the best mechanisms to help clinicians thrive in the new system. We recommend involving both patients and families in the process of designing methods of collaboration in a regime of fully open visitation and collaboration.

Blue Squares

As for family presence during procedures, our experience has been quite positive [36]. In general patients and families are glad not to be separated against their will at a time of great stress. This intervention is probably a blue square (intermediate difficulty) as it may take a clinician a few procedures to become accustomed to the family presence. In our experience, though, it is less cognitively challenging than learning to teach trainee physicians how to perform procedures. (A case series and orientation scripts for family procedural presence have been published [36].) Similarly, some early evidence suggests that formal participation of family members in bedside nursing care might improve patient and family outcomes [37]. Early evidence may even support family integration into the care team directly [37].

We also place an informal practice we developed over the years into the blue square category: what we call the "going off to war" speech. Intubation and mechanical ventilation often deprive the patient of speech. For patients who do not survive mechanical ventilation, therefore, the moments before intubation may represent the patient's last opportunity to speak before death. Given the high importance that people place on last words and being able to say goodbye, failing to signal the possibility that these are the last words may steal from people the opportunity to have final words with a loved one. Using the "hope for the best but prepare for the worst" framing, we encourage family members, if they so desire, to share special words with the loved one before intubation. (We often use noninvasive ventilation to preoxygenate while preparing for the procedure, so the family time does not substantially postpone intubation.) We call it the "going off to war" talk because bidding farewell to a military service member is a nonmedical situation in which one earnestly hopes for the return of the beloved unscathed but simultaneously acknowledges the possibility that the beloved may not return. While this technique has not been studied formally, in our experience (with scores, if not hundreds, of patients and families), people understand it and are grateful for the opportunity to speak with their loved one. In our experience, when families have the opportunity to say goodbye or share their feelings with their conscious loved one, feel better able to allow a transition to exclusively comfort-focused care when further mechanical ventilation has not seemed true to the patient desires (generally, a very low probability of recovery from ventilator dependence and ongoing evidence of pain and discomfort) [2].

Another way to humanize critical care for families has historically been a condolence letter after the death of their family member. An esteemed traditional practice in the United States, the condolence letter, was deployed in a randomized, controlled trial ($N = 242$) by experienced French investigators [38]. The letters were written by team members who had cared for the patient before death. The letters were mailed shortly after the death, with an early measurement (1 month) of depression, anxiety, and PTSD. While the 1-month outcomes did not differ, depression and PTSD were significantly worse at 6 months among individuals who received a condolence letter. For those of us who have written such letters routinely for years, this was a sobering result. What should those of us who have written these notes for years do? Is this effect specific to France? Were the letters too impersonal or formulaic? Did they exceed the scope of the relationship established in the ICU? Were the investigators measuring the correct endpoints? Or is this a methodological problem, in which the condolence letter was a good thing overall but primed people to respond to the PTSD instrument differently? Could it be similar to the paradoxical effect of a debrief performed too early in the course of a traumatic stress [39–41] or forcing families to "re-experience the death," causing increased grief and distress without associated support to cope cognitively with the re-experiencing? Secondary qualitative analyses from the trial suggested that the problem may have been that the condolence letters raised expectations for ongoing bereavement support, which the healthcare system failed to deliver [42]. Still, the results of that trial likely remove condolence letters from the green circle category (where we had previously thought they belonged, as a basic expression of courtesy) and moved them into the blue square category.

Black Diamonds

Some approaches span the blue square and black diamond, especially perhaps what we have called sickbed doulas (a somewhat similar role has been termed a "communication facilitator" [43]) and/or active peer support while in the ICU [2]. We find the idea intuitively attractive and would like to build the capacity to support such individuals. Given the additional expense (although in some circumstances similar individuals may save resources [44]) and the need to understand how such mediators/navigators would fit into the current teamwork dynamics, we recommend careful research preceding or as part of deployment of such individuals into the ICU milieu. Similarly, we worry that routine emphasis on more frequent end of life conversations without considerable attention to how those conversations occur and how patients and families experience them may lead to undesired consequences, a point made clear in an RCT of simulation training for end of life communication among physician trainees, which led to greater depression among ICU family members [45]. We note the expertise required not to discourage enthusiasm but to advocate that it be methodologically rigorous.

If we might draw a link between clinician burnout and ICU dehumanization, it may be that teaching clinicians and (perhaps) patients and family members to recognize and engage emotion may be an effective approach to limiting dehumanization. This will require research, but given the potential association between mindfulness-based practice and increased empathy [46], attention to healthful engagement of emotion may have a role to play in improving humanization in the ICU.

Tragic Trade-Offs

There's a tendency to think in exclusivist terms, what the philosophers term deontological rather than consequentialist/utilitarian terms. In such reasoning, certain actions or beliefs are simply right or wrong, independent of what effects they may have. We are not averse to such approaches to certain questions—some behaviors do appear to be intrinsically wrong, while other seem intrinsically right, no matter the consequences.

What this deontological approach risks missing, though, is consideration of relevant context and the acknowledgment of tragic trade-offs. There is, as the saying goes, no free lunch. Dehumanization is intrinsically bad. In general, when the choice is between dehumanization and (re)humanization, we should choose (re)humanization. In specific circumstances, though, we may need to strike an appropriate balance attuned to competing priorities in the support of patients and their families. At the most basic level, if certain forms of humanization led to lower-quality technical medical care, most people would not want to exchange survival for humanization.

Some evidence suggests the possibility that there may be tragic trade-offs of just that sort. Admitting the crisis of reproducibility in experimental psychology in recent decades, we are intrigued by evidence suggesting that moral concern (e.g., considering the suffering of another person or making ethical assessments of competing needs of individuals) may impair a study subject's ability to perform certain analytical tasks like math problems or logical puzzles [47]. Admitting that the evidence is not yet based in clinical settings, the findings of cognitive science—that moral regard may compete cognitively with analytical thinking—are of concern.

One mark of the difficulty in interpreting the relevant literature comes in a psychology experiment reported in 2011, in which participants were asked to think of themselves as either the supervising physician or the trainee physician in deciding about a painful but important surgery. Although the authors maintained that they had shown that "power increases dehumanization," the story is more complex. Not only was thinking of oneself as the supervising physician associated with modestly more dehumanization, it was also associated with greater ability to make the good but difficult decision on behalf of the patient [48].

Some tragic trade-offs are urgently evoked in a quotation from qualitative work by Dickert and colleagues. One patient's response indicated, sympathetically, "There's a certain amount of detachment I know [doctors] have to have to function. But if you're gonna treat patients, you gotta care about them and you've got to let them know you care about them because if you don't, they feel like a slab of meat" [49]. That sense of being reduced to their mere physicality—being deprived of their personhood—is precisely the resistance to frank dehumanization, even as the respondent acknowledged that a modest amount of separation may in fact be required. Something like balance is important to achieve in order to allow for a clinician to complete a task which may seem barbaric and painful (such as insertion of central venous catheters) as respectfully as possible (e.g., local anesthetic, covering unnecessarily exposed body parts, limiting claustrophobia, assuring that someone is talking quietly with the patient, etc.) without compromising the technical integrity of the procedure.

Clinician Dehumanization and the Nature of Teamwork

Early efforts to improve the humanization of patients and families at one of our ICUs led to protests from certain nurses that the efforts were dehumanizing the nurses. While the word can be overused to describe any situation in which an individual feels uncomfortable (i.e., making someone's job a little more demanding is not in itself a mark of dehumanization), this feedback did cause us to reflect on the risks to clinicians.

In our clinical experience, we have occasionally found that families may actively dehumanize clinicians—especially nurses—although this memorable phenomenon is uncommon. What's more common is that teamwork dynamics can be difficult, a phenomenon further complicated by formal incorporation of family members into the treatment team. In fairness to the nurses, we're creating ad hoc treatment teams around the care of a patient with an acute illness, and some members of the team are in the midst of the most stressful situation of their lives, drowning in frightening and unfamiliar information. In cases such as trauma related to alcohol or drug-associated violence, drug overdose, or other complications of substance use disorders, family members may already be stretched thin by ambivalent relationships with the patient related to the psychiatric illness or substance abuse. These are not ideal settings for smooth and effective teamwork. As a result, focusing on the humanity of patients and families—even the "difficult" ones—may result in heightened clinician stress, distress, and burnout. Nursing shifts and overwork may contribute to even greater difficulty with teamwork. Careful research is indicated to improve the health and quality of these evanescent teams. What is clear is that attempts to rehumanize the ICU must attend to the needs of patients, family members, and clinicians, with careful consideration of potential trade-offs.

We draw attention here to the responsibility that managers and administrators have in the dynamics related to dehumanization and treatment teams in the ICU. They may be prone to see the people who report to them as somehow lacking in the rich inner mental life of a manager. Especially when bureaucratic cost-cutting is an operative concern, the work contexts of clinicians may dehumanize the clinicians, increase their burnout, and lead to worsening dehumanization of patients and families. Attention to burnout symptoms and to providing meaningful support for all clinicians will be central to attempts to better humanize the experience of patients and families in the ICU.

Humanization in medicine is vitally important. But it's not easy. We need more research and commitment to improve humanization for patients, families, and clinicians. A rich and stimulating field of scientific, intellectual, and moral investigation beckons.

References

1. Zimmerman JE, Kramer AA, Knaus WA. Changes in hospital mortality for United States intensive care unit admissions from 1988 to 2012. Crit Care. 2013;17:R81.
2. Brown SM. Through the valley of shadows: living wills, intensive care, and making medicine human. New York: Oxford University Press; 2016.
3. Alonso-Ovies A. Heras La Calle G. ICU: a branch of hell? Intensive Care Med. 2016;42(4):591–2.
4. Brown SM, Beesley SJ, Hopkins RO. Humanizing intensive care: theory, evidence, and possibilities. In: Vincent JL, editor. Annual update in intensive care and emergency medicine 2016. Cham: Springer; 2016. p. 405–20.
5. Haslam N, Loughnan S. Dehumanization and infrahumanization. Annu Rev Psychol. 2014;65:399–423.
6. Haslam N. Humanizing medical practice: the role of empathy. Med J Aust. 2007;187:381–2.
7. Haslam N. Dehumanization: an integrative review. Personal Soc Psychol Rev. 2006;10:252–64.
8. Sokol-Hessner L, Folcarelli PH, Sands KE. Emotional harm from disrespect: the neglected preventable harm. BMJ Qual Saf. 2015;24:550–3.
9. Brown SM, Azoulay E, Benoit D, et al. The practice of respect in the intensive care unit. Am J Respir Crit Care Med. 2018;197:1389.
10. Moss M, Good VS, Gozal D, Kleinpell R, Sessler CN. A critical care societies collaborative statement: burnout syndrome in critical care health-care professionals. A call for action. Am J Respir Crit Care Med. 2016;194:106–13.
11. Embriaco N, Papazian L, Kentish-Barnes N, Pochard F, Azoulay E. Burnout syndrome among critical care healthcare workers. Curr Opin Crit Care. 2007;13:482–8.
12. van Mol MM, Kompanje EJ, Benoit DD, Bakker J, Nijkamp MD. The prevalence of compassion fatigue and burnout among healthcare professionals in intensive care units: a systematic review. PLoS One. 2015;10:e0136955.
13. Vaes J, Muratore M. Defensive dehumanization in the medical practice: a cross-sectional study from a health care worker's perspective. Br J Soc Psychol. 2013;52:180–90.
14. Schulman-Green D. Coping mechanisms of physicians who routinely work with dying patients. OMEGA-J Death Dying. 2003;47:253–64.
15. Singh H, Petersen LA, Thomas EJ. Understanding diagnostic errors in medicine: a lesson from aviation. Qual Saf Health Care. 2006;15:159–64.
16. Berwick DM, Kotagal M. Restricted visiting hours in ICUs: time to change. JAMA. 2004;292:736–7.
17. Lee MD, Friedenberg AS, Mukpo DH, Conray K, Palmisciano A, Levy MM. Visiting hours policies in New England intensive care units: strategies for improvement. Crit Care Med. 2007;35:497–501.
18. Lonergan E, Luxenberg J, Areosa Sastre A. Benzodiazepines for delirium. Cochrane Database Syst Rev. 2009;(1):CD006379.
19. Zaal IJ, Devlin JW, Peelen LM, Slooter AJ. A systematic review of risk factors for delirium in the ICU. Crit Care Med. 2015;43:40–7.
20. Pandharipande P, Banerjee A, McGrane S, Ely EW. Liberation and animation for ventilated ICU patients: the ABCDE bundle for the back-end of critical care. Crit Care. 2010;14:157.
21. Patel MB, Jackson JC, Morandi A, et al. Incidence and risk factors for intensive care unit-related post-traumatic stress disorder in veterans and civilians. Am J Respir Crit Care Med. 2016;193:1373–81.
22. Davydow DS, Gifford JM, Desai SV, Needham DM, Bienvenu OJ. Posttraumatic stress disorder in general intensive care unit survivors: a systematic review. Gen Hosp Psychiatry. 2008;30:421–34.
23. Langer EJ, Rodin J. The effects of choice and enhanced personal responsibility for the aged: a field experiment in an institutional setting. J Pers Soc Psychol. 1976;34:191–8.

24. Shapiro J. Perspective: Does medical education promote professional alexithymia? A call for attending to the emotions of patients and self in medical training. Acad Med. 2011;86:326–32.
25. Mealer ML, Shelton A, Berg B, Rothbaum B, Moss M. Increased prevalence of post-traumatic stress disorder symptoms in critical care nurses. Am J Respir Crit Care Med. 2007;175:693–7.
26. Chapman EN, Kaatz A, Carnes M. Physicians and implicit bias: how doctors may unwittingly perpetuate health care disparities. J Gen Intern Med. 2013;28:1504–10.
27. Green AR, Carney DR, Pallin DJ, et al. Implicit bias among physicians and its prediction of thrombolysis decisions for black and white patients. J Gen Intern Med. 2007;22:1231–8.
28. Redelmeier DA, Tversky A. Discrepancy between medical decisions for individual patients and for groups. N Engl J Med. 1990;322:1162–4.
29. Dehon E, Weiss N, Jones J, Faulconer W, Hinton E, Sterling S. A systematic review of the impact of physician implicit racial bias on clinical decision making. Acad Emerg Med. 2017;24:895–904.
30. Brown SM. We still lack patient centered visitation in intensive care units. BMJ. 2015;350:h792.
31. Chapman DK, Collingridge DS, Mitchell LA, et al. Satisfaction with elimination of all visitation restrictions in a mixed-profile intensive care unit. Am J Crit Care. 2016;25:46–50.
32. Ciufo D, Hader R, Holly C. A comprehensive systematic review of visitation models in adult critical care units within the context of patient- and family-centred care. Int J Evid Based Healthc. 2011;9:362–87.
33. Fumagalli S, Boncinelli L, Lo Nostro A, et al. Reduced cardiocirculatory complications with unrestrictive visiting policy in an intensive care unit: results from a pilot, randomized trial. Circulation. 2006;113:946–52.
34. See KC, Song XY, Aung HT. Effect of extended visiting hours on physician distractions in the ICU: a before-and-after study. Crit Care. 2017;21:243.
35. Netzer G, Iwashyna TJ. Fair is fair: preventing the misuse of visiting hours to reduce inequities. Ann Am Thorac Soc. 2017;14:1744.
36. Beesley SJ, Hopkins RO, Francis L, et al. Let them in: family presence during intensive care unit procedures. Ann Am Thorac Soc. 2016;13:1155–9.
37. van de Graaff M, Beesley SJ, Butler JM, et al. Partners in healing: postsurgical outcomes after family involvement in nursing care. Chest. 2018;153(2):572–4.
38. Kentish-Barnes N, Chevret S, Champigneulle B, et al. Effect of a condolence letter on grief symptoms among relatives of patients who died in the ICU: a randomized clinical trial. Intensive Care Med. 2017;43:473–84.
39. Rose S, Bisson J, Churchill R, Wessely S. Psychological debriefing for preventing post traumatic stress disorder (PTSD). Cochrane Database Syst Rev. 2002;(2):CD000560.
40. Bisson JI, Jenkins PL, Alexander J, Bannister C. Randomised controlled trial of psychological debriefing for victims of acute burn trauma. Br J Psychiatry. 1997;171:78–81.
41. Shalev AY. Posttraumatic stress disorder (PTSD) and stress related disorders. Psychiatr Clin North Am. 2009;32:687–704.
42. Kentish-Barnes N, Cohen-Solal Z, Souppart V, et al. “It Was the Only Thing I Could Hold Onto, But...”: receiving a letter of condolence after loss of a loved one in the ICU: a qualitative study of bereaved relatives’ experience. Crit Care Med. 2017;45:1965–71.
43. Curtis JR, Treece PD, Nielsen EL, et al. Randomized trial of communication facilitators to reduce family distress and intensity of end-of-life care. Am J Respir Crit Care Med. 2016;193:154–62.
44. Khandelwal N, Benkeser D, Coe NB, Engelberg RA, Curtis JR. Economic feasibility of staffing the intensive care unit with a communication facilitator. Ann Am Thorac Soc. 2016;13:2190–6.
45. Curtis JR, Back AL, Ford DW, et al. Effect of communication skills training for residents and nurse practitioners on quality of communication with patients with serious illness: a randomized trial. JAMA. 2013;310:2271–81.
46. Birnie K, Speca M, Carlson LE. Exploring self-compassion and empathy in the context of mindfulness-based stress reduction (MBSR). Stress Health. 2010;26:359–71.

47. Jack AI, Friedman JP, Boyatzis RE, Taylor SN. Why do you believe in god? Relationships between religious belief, analytic thinking. Mentalizing and moral concern. PLoS One. 2016;11:e0149989.
48. Lammers J, Stapel DA. Power increases dehumanization. Group Process Intergroup Relat. 2011;14:113–26.
49. Dickert NW, Kass NE. Understanding respect: learning from patients. J Med Ethics. 2009;35:419–23.

Chapter 12
Intensive Care Unit Conflicts and the Family

O. Joseph Bienvenu

Conflicts are common in the intensive care unit (ICU) setting: between clinicians, between clinicians and families, and within families [1, 2]. This should not be surprising, as numerous factors contribute to a relatively stressful environment, including very vulnerable patients and the need for rapid and frequent patient-related decisions and activities, often incorporating input from consultants, in an evolving ethical and legal landscape [3]. The focus of this chapter is the nature and effects of conflicts on families of adult patients in intensive care, as well as how clinicians might mitigate or resolve these conflicts.

Figure 12.1 illustrates, in a simplified form, some of the kinds of conflicts that can occur in ICU settings. For the purposes of the illustration, we assume that the patient's illness and/or medications incapacitate him or her cognitively (i.e., the

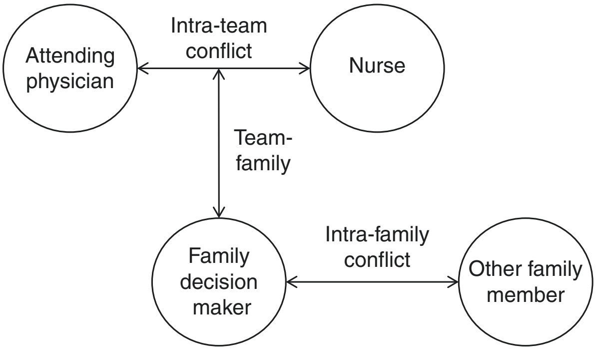


Fig. 12.1 Simplified diagram of the kinds of conflicts that can occur in ICUs

---

O. J. Bienvenu
Psychiatry and Behavioral Sciences, Johns Hopkins University School of Medicine,
Baltimore, MD, USA
e-mail: obienve1@jhmi.edu

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_12

patient is not shown). Second, we assume a simple team structure (ignoring the possibility of multiple physicians working together as a team, as well as consulting physicians, rotating nurses, social workers, rehabilitation specialists, respiratory therapists, chaplains, palliative care clinicians, and others who may meet with the patient and family). Third, we ignore the fact that families often include multiple persons, who may not be able to be present, and many patients have loved ones besides family members. One would hope that all parties represented in this simplified diagram are communicating, in some fashion, and that shared understanding is possible, though this may be naïve. However, even if these are the case, conflicts can occur.

Conflict Between Groups

It may be useful to consider ways in which theories from social psychology may inform intergroup conflicts in the ICU. Such theories might illuminate conflicts between families and clinical teams, as well as conflicts between discipline groups (e.g., physicians vs. nurses).

Intergroup conflict can occur when groups perceive they are competing for limited resources, as opposed to working together toward a goal [4, 5]. An imperfect example would be competition for scarce ICU beds; this example is imperfect because conflict would typically occur between families and ICU clinicians, as opposed to directly between families. Nevertheless, families may perceive that ICU teams are discriminating against them and their loved ones because of race, socioeconomic status, etc., favoring patients and families like the ICU clinicians themselves [6]. Clinicians working together with families to help the patient recover or be comfortable with preserved dignity is the obvious preferred goal.

Conflicts in the ICU

In 2010, Fassier and Azoulay reviewed the literature on conflicts in adult ICUs [1]. They noted wide variability in the literature, in the definition of conflict, in its measurement, in patient settings, in respondents, etc. [7–12] (Table 12.1). From the perspective of ICU clinicians [9, 10, 12], intra-team conflict was common, and end-of-life decision-making and communication were a common source of conflict. The authors noted that in-ICU conflict negatively affects patient safety and patient- and family-centered care. In addition, the authors noted that in-ICU conflict negatively affects treatment team cohesion and morale, leading to staff burnout [13–15]. All treatment team members and family members deserve to have a voice in a patient's care, not just a passive role. Team and family members need clear explanations and an opportunity to ask questions, as well as make suggestions, to facilitate a sense of mastery in what can be a stressful situation. The authors also noted that in-ICU

Table 12.1 Brief summary of studies reviewed by Fassier and Azoulay [1], in chronological order

Burns and colleagues [7] prospectively identified patients with conflicts or at risk for decision-making conflicts as reported by clinical teams in seven Boston ICUs. Definition of positive screen for risk for decision-making conflicts: (a) the patient lacked decision-making capacity and a clearly identified surrogate; (b) the team perceived intra-team, team-family, or intra-family conflict; (c) the patient exceeded the 85th percentile of length of stay in that ICU; or (d) the patient was admitted to the ICU because of an iatrogenic event. In phase I, 21% of patients screened positive, and in phase II, 18% of patients screened positive. In phase II, social workers met with family members of patients who screened positive and provided feedback to the clinical team, and the team decided whether to take further action (e.g., a family meeting, regular family meetings, a social services consult, pastoral services, an ethics consult, a pain service consult, etc.). The intervention increased the likelihood of deliberative decision-making (deciding to forego resuscitation, to choose comfort care only, or to pursue an aggressive-care treatment plan), though it was not associated with a change in patient or surrogate satisfaction with care
Abbott and colleagues [8] performed semi-structured interviews with next-of-kin family members of patients in Durham, NC, ICUs who had faced decisions to forego life-sustaining treatment (>1 year afterward). Family members recalled conflicts in 46% of cases: Intra-team 4%, team-family 40%, and intra-family 4%. Family members recalled conflicts with the team mainly about communication and perceived unprofessional behavior (e.g., not involving next-of-kin sufficiently in treatment discussions). Family members who had spoken with patients in advance about end-of-life decisions (63%) reported that treatment decisions were less burdensome, 48% of family members found the presence of chaplains reassuring, and 48% of family members preferred the attending physician (“doctor in charge”) as their source of information. 27% of family members mentioned a need for physical space to have conferences with physicians and family discussions
Breen and colleagues [9] performed semi-structured interviews with Durham, NC, ICU physicians and nurses involved in the care of patients for whom decisions to forego life-sustaining therapy were considered. At least one team member perceived a conflict in 78% of patient cases: Intra-team 48%, team-family 48%, intra-family 24%. Clinicians attributed conflict to decisions regarding life-sustaining treatment, communication, pain control, and social issues
Studdert and colleagues [10] performed semi-structured interviews with Boston ICU physicians and nurses to learn about conflict regarding patients whose length of stay exceeded the 85th percentile for their unit. The clinicians reported conflicts in 32% of cases: Intra-team 31%, team-family 57%, intra-family 12%. The main perceived sources of conflict between teams and families included decisions regarding life-sustaining treatment, difficulties communicating effectively, inability or unavailability of surrogate decision-makers, and overwhelming emotions due to the patient’s state. The main perceived source of intra-team conflict was disagreement about particulars of the care plan. The main perceived sources of intra-family conflict were decisions regarding life-sustaining treatment and other care. Nurses detected all conflicts more frequently, especially intra-team conflicts. Spousal presence was associated with less team-family conflict, especially disputes over life-sustaining treatment
Danjoux Meth and colleagues [11] performed semi-structured interviews with Ontario ICU clinicians, administrators, and bioethicists regarding in-ICU conflicts. Qualitative results focused on inter-team, intra-team, and team-family conflicts. Respondents perceived lack of communication, personnel (nursing shortage), experience, and goals of care as contributing to conflict
Azoulay and colleagues [12] conducted an international multicenter survey to measure the prevalence and correlates of conflict perceived by ICU physicians and nurses in the last week. 72% of clinicians perceived at least one conflict: Intra-team 85%, team-family 27%. Clinicians attributed conflict to personal behaviors and end-of-life decisions and noted that conflicts contributed to job strain

Table 12.2 Common perceived sources of conflict for family members of patients in the ICU

Decisions to withdraw or withhold treatments
Adequacy of communication
Staff behavior (perceived lack of professionalism, disrespect, experimentation on loved ones)
Family members' strong emotional reactions, mistrust of staff, unavailability, and indecisiveness
Pain management

conflict could increase healthcare costs, through delays in decision-making and even lawsuits. Fassier and Azoulay had several recommendations for the field [1]. First, the field could benefit from a more in-depth social science perspective on conflict, to address the ICU system of care as a whole. Second, the field could benefit from further studies of multimodal interventions to prevent and mitigate or resolve conflict. As shown in Table 12.1, only one study tested such an intervention [7], which relied heavily on the communication and psychosocial assessment skills of ICU social workers [16]. Third, the field could benefit from guidelines to address conflict. Finally, the authors opined that conflict prevention strategies should better incorporate family concerns and team communication [1]. As noted in Table 12.1, only one study sought family members' perspectives directly [8]. Table 12.2 lists common perceived sources of conflict for family members of patients in the ICU.

More recently, clinical investigators have addressed some of the issues raised by Fassier and Azoulay [1], particularly the perspective of family members:

- Schuster and colleagues assessed physician-surrogate conflict in San Francisco ICUs simultaneously in physicians (attendings or fellows) and surrogates (all patients were incapacitated) [17]. The authors reported that either the physician or a surrogate identified conflict in 63% of cases, though physicians were less likely to perceive conflict than surrogates were (28% vs 43%). In addition, with some exceptions, physician and surrogate perceptions regarding the presence of any conflict were quite different (60% agreement, kappa = 0.14). Surrogates and physicians were less likely to perceive conflict if surrogates rated the physicians' bedside manner highly. Additionally, physicians perceived any conflict more frequently when surrogates reported discrimination in a healthcare setting in the last year.
- Huff and colleagues interviewed non-clinician caregivers at Duke and the Medical University of South Carolina to determine how relationships between caregivers and ICU clinicians affected a number of patient- and caregiver-centered outcomes [18]. Non-clinician caregivers who described a greater therapeutic alliance with the attending physician reported greater communication quality, trust, and patient-centeredness of care, as well as less decisional conflict. One might expect that therapeutic alliance, as measured in this study [18], might be related to bedside manner in Shuster and colleagues' study [17].
- Charchiaro and colleagues surveyed surrogate decision-makers of patients with acute respiratory distress syndrome in the context of a multicenter prospective cohort study involving five American academic medical centers [19]. Nearly half of surrogates reported moderate to high levels of decisional conflict regarding

foregoing life-sustaining treatments. Surrogate decision-makers who reported prior conversations with their ill loved ones regarding care preferences if incapacitated reported lower decisional conflict about whether to continue life support. These findings are reminiscent of those of Abbott and colleagues [8] (Table 12.1). The authors noted that, in addition to helping ensure that clinicians honor incapacitated patients' choices, advance care planning can reduce the burden on loved ones who must act as surrogates [19]. Such a burden can be substantial [20].

- Miller and colleagues assessed decision conflict in surrogate decision-makers of incapacitated patients on mechanical ventilation >96 h in the medical ICU at Wake Forest Baptist Medical Center [21]. Consistent with one of the authors' hypotheses, surrogates reported more decisional conflict with end-of-life decisions than other treatment decisions. Interestingly, surrogates expressed little decisional regret a month later.
- Olding and colleagues conducted a scoping review of patient and family involvement in adult critical care settings [22]. They noted two research gaps relevant to this chapter: (1) the broader sociocultural processes that shape patient and family involvement and (2) potential bidirectional relationships between family involvement and ICU clinician teamwork.

End-of-Life Decision-Making Conflict

End-of-life decision-making is a prominent source of conflict in the ICU setting, recognized universally in the studies cited previously. It is perhaps worth noting in what ways ethical and legal principles in end-of-life ICU care have developed over the years. In 2010, Luce provided a cogent account of this, from an American perspective [3]. He began by noting that, in the early days of ICU care in the 1950s and 1960s, beneficence and non-maleficence guided medical care in the ICU and elsewhere. Clinicians generally behaved more paternalistically than now, and "do not resuscitate" and "do not intubate" orders did not exist. In fact, clinicians considered withholding cardiopulmonary resuscitation (CPR) immoral (even homicide or, at least, euthanasia), and doing so was against hospitals' policies, though clinicians gradually realized the limits of CPR [23]. In the 1970s, family members began challenging these ideas, arguing in effect for increasing patient autonomy to refuse life-sustaining treatments, though the legal cases actually involved family members of unconscious patients. Over the years, shared decision-making became common practice, as did withholding and withdrawing life support in ICUs [24–26]. With the rise of patient and family autonomy, clinicians became increasingly uncomfortable with providing treatments that they did not see as beneficial [27]. Luce described the rise and fall of the "futility" movement, which ebbed with increasing recognition of substantial variability in physicians' and families' values regarding life in particular circumstances. However, Luce made the important point that, despite conflicts and sometimes-intense emotions, most families and physicians eventually agree on treatment plans [3].

What Should We Do to Mitigate Team-Family Conflicts Regarding Potentially Inappropriate Treatments?

In 2015, the American Thoracic Society, the American Association of Critical-Care Nurses, the American College of Chest Physicians, the European Society of Intensive Care Medicine, and the Society of Critical Care Medicine issued a joint statement regarding how clinicians should respond to requests for potentially inappropriate treatments in ICUs [28]. First, the committee recommended that hospitals employ strategies to prevent intractable treatment conflicts, including proactive communication and early involvement of ethics or palliative care consultants if needed. Second, the committee recommended using the term "potentially inappropriate," rather than "futile," when discussing treatments that might accomplish the effect sought by the patient/family, but about which clinicians have conflicting ethical concerns. In that case, ICU clinicians should explain and advocate for the treatment plan they believe appropriate. If conflicts remain intractable after thorough communication and negotiation, the committee recommends hospital review, attempts to find a willing provider at another institution, and an opportunity for external review. In cases in which there is insufficient time to follow these steps, and clinicians have a high degree of certainty that the requested treatment is outside the realm of accepted practice, the committee recommended that clinicians seek procedural oversight if possible but opined that clinicians need not provide the requested treatment. Third, the committee recommended against clinicians providing treatments that cannot accomplish a given physiologic goal, as well as legally proscribed (or discretionary) treatments. Fourth, the committee recommended that the medical profession engage the public and advocate for policies and laws regarding when life-prolonging treatments are appropriate.

Palliative Care Interventions in the ICU: Potential Role in Reducing In-ICU Conflict?

Aslakson and colleagues recently systematically reviewed studies of palliative care interventions in ICUs [29]. The authors defined palliative care relatively broadly, drawing on Robert Wood Johnson consensus group-identified domains for quality end-of-life care in the ICU [30]:

(a) Patient- and family-centered decision-making.
(b) Communication.
(c) Continuity of care.
(d) Emotional and practical support.
(e) Symptom management and comfort care.
(f) Spiritual support.
(g) Emotional and organizational support for ICU clinicians.

Notably, many of the above domains are relevant to any medical care, not just end-of-life care, and many of these interventions could reduce team-family conflict. The interventions included, e.g., intensive communication efforts (e.g., early multidisciplinary family meetings, informational brochures, etc.) [31, 32], ethics team consults [33], palliative care consults [34], and referral to a comprehensive supportive care team for hopelessly ill patients and their family members [35]. Perhaps not surprisingly, the authors found that most of the interventions decreased ICU and hospital length of stay. Importantly, though, most of the interventions were associated with, if anything, decreased mortality [29].

One of the studies reviewed by Aslakson and colleagues [29] deserves further mention, in that it addressed in-ICU conflict more directly. In addition, though not included in the review of Fassier and Azoulay [1], it is a multimodal intervention that seems to prevent and mitigate or resolve conflict by promoting its obverse – consensus:

Lilly and colleagues performed a before-and-after study of proactive multidisciplinary meetings within 72 h of critical care admission for patients who had a predicted ICU length of stay longer than 5 days, a predicted mortality of >25%, or a change in functional status that was potentially irreversible and sufficient to preclude eventual return home [31]. Meetings were led by attending physicians and included a nurse, house officer, the patient's family (including the health care proxy), and, whenever possible, the patient. Meetings had four objectives:

1. To review the medical facts and options for treatment
2. To discuss the patient's perspectives on death and dying, chronic dependence, loss of function, and the acceptability of the risks and discomforts of critical care
3. To agree on a care plan
4. To agree on criteria by which success or failure of the care plan would be judged (clinical milestones, with expected time frames)

The clinicians used the agreed-upon time frames to set up subsequent formal family meetings, or varied if patients and/or families needed more time to process difficult medical facts. The clinical teams educated and prepared patients and families for home care, rehabilitation, or chronic care, as appropriate. If clinical milestones were not achievable, patients and families learned the limits of advanced supportive technology, and the teams and families explored other alternatives, including palliative care. Attending physicians also held weekly multidisciplinary meetings with nurses, social workers, chaplains, and rehabilitation specialists to ensure a uniform understanding of the patient's wishes and care plan. Thus, clinical teams could provide consistent information to the patient and family and identify barriers to the care plan.

Attending physicians recorded disagreements within the team and between the team and family on a daily basis. During the intervention period, the average time of within-team non-consensus decreased from 0.56 to 0.02 days per patient, and the average time of team-family non-consensus decreased from 1.7 to 0.09 days per patient. The median length of stay decreased from 4 to 3 days, and mortality did not change.

Conclusions

In-ICU conflicts are common and tend to be less apparent to physicians than to nurses, who spend more time with patients and family members. Timely and clear communication, involving multiple voices, is necessary to prevent or mitigate conflict regarding patients with poor prognoses. Ethics and palliative care consults can facilitate conflict resolution without increasing patient mortality.

References

1. Fassier T, Azoulay E. Conflicts and communication gaps in the intensive care unit. Curr Opin Crit Care. 2010;16(6):654–65.
2. Wujtewicz M, Wujtewicz MA, Owczuk R. Conflicts in the intensive care unit. Anaesthesiol Intensive Ther. 2015;47(4):360–2.
3. Luce JM. A history of resolving conflicts over end-of-life care in intensive care units in the United States. Crit Care Med. 2010;38(8):1623–9.
4. Sherif M, Harvey OJ, White BJ, Hood WR, Sherif CW. Intergroup cooperation and competition: the Robbers Cave experiment. Norman: University Book Exchange; 1961.
5. Jackson JW. Realistic group conflict theory: a review and evaluation of the theoretical and empirical literature. Psychol Rec. 1993;43(3):395–413.
6. Tajfel H, Turner JC. An integrative theory of intergroup conflict. In: Austin WG, Worchel S, editors. The social psychology of intergroup relations. Monterey: Brooks/Cole; 1979. p. 33–47.
7. Burns JP, Mello MM, Studdert DM, Puopolo AL, Truog RD, Brennan TA. Results of a clinical trial on care improvement for the critically ill. Crit Care Med. 2003;31(8):2107–17.
8. Abbott KH, Sago JG, Breen CM, Abernethy AP, Tulsky JA. Families looking back: one year after discussion of withdrawal or withholding of life-sustaining support. Crit Care Med. 2001;29(1):197–201.
9. Breen CM, Abernethy AP, Abbott KH, Tulsky JA. Conflict associated with decisions to limit life-sustaining treatment in intensive care units. J Gen Intern Med. 2001;16(5):283–9.
10. Studdert DM, Mello MM, Burns JP, Puopolo AL, Galper BZ, Truog RD, et al. Conflict in the care of patients with prolonged stay in the ICU: types, sources, and predictors. Intensive Care Med. 2003;29(9):1489–97.
11. Danjoux Meth N, Lawless B, Hawryluck L. Conflicts in the ICU: perspectives of administrators and clinicians. Intensive Care Med. 2009;35(12):2068–77.
12. Azoulay E, Timsit JF, Sprung CL, Soares M, Rusinová K, Lafabrie A, et al. Prevalence and factors of intensive care unit conflicts: the Conflicus study. Am J Respir Crit Care Med. 2009;180(9):853–60.
13. Embriaco N, Azoulay E, Barrau K, Kentish N, Pochard F, Loundou A, et al. High level of burnout in intensivists: prevalence and associated factors. Am J Respir Crit Care Med. 2007;175(7):686–92.
14. Burghi G, Lambert J, Chaize M, Goinheix K, Quiroga C, Fariña G, et al. Prevalence, risk factors and consequences of severe burnout syndrome in ICU. Intensive Care Med. 2014;40(11):1785–6.
15. Bienvenu OJ. Is this critical care clinician burned out? Intensive Care Med. 2016;42(11):1794–6.
16. Hartman-Shea K, Hahn AP, Fritz Kraus J, Cordts G, Sevransky J. The role of the social worker in the adult critical care unit: a systematic review of the literature. Soc Work Health Care. 2011;50(2):143–57.
17. Schuster RA, Hong SY, Arnold RM, White DB. Investigating conflict in ICUs-is the clinicians' perspective enough? Crit Care Med. 2014;42(2):328–35.

18. Huff NG, Nadig N, Ford DW, Cox CE. Therapeutic alliance between the caregivers of critical illness survivors and intensive care unit clinicians. Ann Am Thorac Soc. 2015;12(11):1646–53.
19. Chiarchiaro J, Buddadhumaruk P, Arnold RM, White DB. Prior advance care planning is associated with less decisional conflict among surrogates for critically ill patients. Ann Am Thorac Soc. 2015;12(10):1528–33.
20. Wendler D, Rid A. Systematic review: the effect on surrogates of making treatment decisions for others. Ann Intern Med. 2011;154(5):336–46.
21. Miller JJ, Morris P, Files DC, Gower E, Young M. Decision conflict and regret among surrogate decision makers in the medical intensive care unit. J Crit Care. 2016;32:79–84.
22. Olding M, McMillan SE, Reeves S, Schmitt MH, Puntillo K, Kitto S. Patient and family involvement in adult critical and intensive care settings: a scoping review. Health Expect. 2016;19(6):1183–202.
23. Bedell SE, Delbanco TL, Cook EF, Epstein FH. Survival after cardiopulmonary resuscitation in the hospital. N Engl J Med. 1983;309(10):569–76.
24. Smedira NG, Evans BH, Grais LS, Cohen NH, Lo B, Cooke M, et al. Withholding and withdrawal of life support from the critically ill. N Engl J Med. 1990;322(5):309–15.
25. Prendergast TJ, Luce JM. Increasing incidence of withholding and withdrawal of life support from the critically ill. Am J Respir Crit Care Med. 1997;155(1):15–20.
26. Prendergast TJ, Claessens MT, Luce JM. A national survey of end-of-life care for critically ill patients. Am J Respir Crit Care Med. 1998;158(4):1163–7.
27. Schneiderman LJ, Jecker NS, Jonsen AR. Medical futility: its meaning and ethical implications. Ann Intern Med. 1990;112(12):949–54.
28. Bosslet GT, Pope TMR, D G, Lo B, Truog RD, Rushton CH, Curtis JR, et al. An official ATS/AACN/ACCP/ESICM/SCCM policy statement: responding to requests for potentially inappropriate treatments in intensive care units. Am J Respir Crit Care Med. 2015;191(11):1318–30.
29. Aslakson R, Cheng J, Vollenweider D, Galusca D, Smith TJ, Pronovost PJ. Evidence-based palliative care in the intensive care unit: a systematic review of interventions. J Palliat Med. 2014;17(2):219–35.
30. Clarke EB, Luce JM, Curtis JR, Danis M, Levy M, Nelson J, et al. Quality indicators for end-of-life care in the intensive care unit. Crit Care Med. 2003;31(9):2255–62.
31. Lilly CM, De Meo DL, Sonna LA, Haley KJ, Massaro AF, Wallace RF, et al. An intensive communication intervention for the critically ill. Am J Med. 2000;109(6):469–75.
32. Azoulay E, Pochard F, Chevret S, Jourdain M, Bornstain C, Wernet A, et al. Impact of a family information leaflet on effectiveness of information provided to family members of intensive care unit patients: a multicenter, prospective, randomized, controlled trial. Am J Respir Crit Care Med. 2002;165(4):438–42.
33. Dowdy MD, Robertson C, Bander JA. A study of proactive ethics consultation for critically and terminally ill patients with extended lengths of stay. Crit Care Med. 1998;26(2):252–9.
34. Campbell ML, Guzman JA. Impact of a proactive approach to improve end-of-life care in a medical ICU. Chest. 2003;123(1):266–71.
35. Carlson RW, Devich L, Frank RR. Development of a comprehensive supportive care team for the hopelessly ill on a university hospital medical service. JAMA. 1988;259(3):378–83.

Chapter 13
Identifying, Analyzing, and Combating Family Intensive Care Unit Syndrome in Long-Term Acute Care Hospitals

Arunmozhi Aravagiri, Waqas Bhatti, Jetina Okereke, and Avelino C. Verceles

Introduction: What Is an LTACH?

Long-term acute care hospitals (LTACHs) provide care for patients who require prolonged mechanical ventilation (PMV) for respiratory failure as well as other complex medical needs [1]. During the 1980s, LTACHs, also referred to as long-term care hospitals by Medicare, were created in order to facilitate timely discharge of patients with complex medical disorders in order to save increasing costs for Medicare [2]. In recent years, LTACHs have become the mainstay care model for patients recovering from severe acute illness [3]. Defined by the Centers for Medicare and Medicaid Services as acute care hospitals with an average length of stay of 25 days or greater, these are among the fastest-growing sectors of the health-care system [4]. The number of long-term acute care hospitals in the USA has been growing over the last 20 years, with over 400 facilities operating nationwide [5]. Additionally, this growth in LTACH hospitals has resulted in an increased number of admissions with corresponding annual costs, from $484 million to $1.325 billion.

LTACHs are institutions that comply with all accreditations that apply to acute care hospitals [2], yet care for specifically “medically complex” patients, who have endured a prolonged hospital, more commonly ICU, stay. There are two types of LTACHS: hospital-within-the-hospital and free-standing LTACHs. The hospital-within-the hospital model is technically considered to be a separate entity of the hospital, even if the unit or floor is located in the larger acute care hospital. Also, formal paperwork is necessary for admission, discharge, or transfers from the hospital to the LTACH and vice versa. Patients requiring continuous care after their treatment in an acute care hospital can receive assistance in free-standing LTACHs,

---

A. Aravagiri · W. Bhatti · J. Okereke · A. C. Verceles (✉)
Division of Pulmonary and Critical Care Medicine,
University of Maryland School of Medicine, Baltimore, MD, USA
e-mail: avercele@som.umaryland.edu

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_13

which are separate buildings unlike the hospital-within-the hospital model [2]. While in the LTACH, the medical team caring for the patients includes nursing staff, comprised of either registered nurses or licensed practical nurses, determined by each state's authority for health care. The ratio of patients to nurses in this setting depends on the level of acuity and the state's regulations. In certain cases, the ratio can be as low 1:1 or around 5 to 6:1 in the LTACH, with the ratio being determined case by case [4].

Patients requiring long-term care tend to present with multiple comorbidities and complicated medical illnesses, which are not always resolved after leaving an acute care setting [6]. Clinical manifestations commonly seen in LTACH patients such as renal failure, septicemia, pulmonary dysfunctions, and neurologic/spinal injuries require extensive long-term assistance in nursing or various therapies [6]. Around 10% of patients eventually admitted to a LTACH transfer from the medical or surgical ICU after averaging a length of stay of 30 days and usually need PMV [7].

Chronic Critical Illness and Its Effect on Family

In recent years, the term chronic critical illness (CCI) has been developed to define a group of patients who have survived an ICU stay, suffer from residual organ dysfunctions – including the need for prolonged mechanical ventilation – and require ongoing advanced care [6]. Furthermore, these multiple organ dysfunctions as well as the patients' comorbidities further hamper the ventilator weaning process and contribute to PMV [7]. With advances in medicine, especially in critical care, and the aging population, the number of patients suffering chronic critical illness will undoubtedly increase in the future [8]. Chronic critically ill patients have a poor prognosis, with the majority dying within 6 months. Many of these survivors suffer extreme functional dependence and severe cognitive impairment and are institutionalized to nursing facilities [9]. Families of those stricken with chronic critical illness experience high rates of depression and financial hardships [10].

Although LTACH usage among the critically ill is increasing, little is understood regarding how this long-term care impacts patients' families [11]. Family members may witness invasive medical procedures, as well as be exposed to a complex medical plan that uses medical terminology that may not be explained to them in great detail [12]. The original admission to the intensive care unit (ICU), the patient's uncertain length of stay and course, and acuity of the patient's illness during chronic critical illness can precipitate psychological sequelae in family members that can last several years after their loved ones' ICU stay. Many patients in the ICU lack the capacity to make decisions; therefore, family members are asked to assume the role of surrogate decision-maker [13]. This can be a heavy responsibility, and thus family members of ICU patients can possibly develop anxiety, depression, and even post-traumatic stress syndrome as a result of the stressful situation [12].

These psychological symptoms experienced by the family can obscure the decision-makers' judgment when making crucial decisions for their loved one –

characterizing a condition known as family intensive care unit syndrome (FICUS) [14]. A majority of family members of ICU patients experience anxiety or depression [15], possibly attributable to FICUS. Although FICUS develops as a response to acute ICU stay, this syndrome can persist and perpetuate in long-term acute care hospitals (LTACHs). Symptoms of anxiety, depression, and post-traumatic stress may develop or persist following ICU discharge [16]. According to a study by Petrinec, 27% of family decision-makers experienced moderate to severe anxiety when their family members were admitted to a LTACH [11]. Other studies have determined that the risk of depression persists for at least 6–12 months during recovery from critical illness, demonstrating a persistent depressive component which can persist in the LTACH, causing both mental and psychiatric symptoms in this setting [11].

Upon discharge from the ICU setting, many of these patients require long-term care. The impression that a family member may be receiving continued, high-intensity medical assistance at these long-term care facilities may assuage anxiety for some family members, relieving the possibility of the need for continued care at home. However, caregiver burdens of families can also exist in settings outside the home, such as an LTACH. The depression, feelings of being overwhelmed, and even physical stress can be more severe in family members with patients in other healthcare institutions compared to those whose family members are home [10]. Even though patients in the LTACH have more medical care than if discharged home, and their medical acuity is decreased, the emotional and mental burden of the patient's illness may persist during their LTACH stay resulting in increased family anxiety, depression, and other psychiatric disorders.

Given that the majority of patients in the LTACH were previously in an intensive care unit, their family members have likely been exposed to an extended duration of duress as the surrogate decision-maker. Often, major medical decisions in the ICU setting, such as end-of-life care and invasive procedures, were made in time periods less than14 days, whereas similar decisions were made in the LTACH after 200 days [17]. These data demonstrate how the drawn-out decisions in the LTACH can prolong the anxieties plaguing the families during their time in these facilities.

Family Decision-Making in the LTACH

A number of situations are experienced by families in the LTACH differently from the ICU setting. Since the patients are relatively stable, surrogates and family members have more time to make decisions about their family member's long-term care. Decisions regarding life-sustaining treatments and the consequences of such treatments require close interaction between the medical team, the patient, and the family members [6]. Patients who require mechanical ventilation often times cannot convey their true wishes, and thus this responsibility now falls on the family to make the medical decisions for the patient.

Cahmhi et al. conducted a large prospective study conducted in the respiratory care unit of a large tertiary, university-affiliated medical center in New York City [18]. This study reviewed patients' records to determine if the respiratory care unit team identified durable power of attorney for health care, written "living will" or an advanced directive, and instructions regarding resuscitation wishes. The study evaluated patients who were mechanically ventilated or on renal replacement therapy, artificial nutrition, intravenous hydration, and vasopressor treatment. Among the 203 patients being treated for chronic critical illness in the respiratory care unit, approximately half (53%) failed to designate a surrogate decision-maker, failed to express any preference to life-sustaining treatments, or failed to express what their wishes were for end-of-life care before their admission. Limitations on life-sustaining treatments were continued until the last days of a prolonged and complicated hospital course, when death was imminent. Thus, chronically ill patients incur extended hospital stays, impose heavy burdens on the patients and their families, and often benefit little from their treatment. The importance of communicating the outcomes of treatments for chronic critical illness and the future potential complications of such treatments is essential in this specific patient population in order to facilitate informed decision-making and earlier establishment of realistic care goals. Similarly, identifying an authorized medical surrogate earlier in the treatment course with specific knowledge of the patient's values and preferences would further aid in this process [18]. The above findings highlight the importance of encouraging able patients to designate their care preferences at the time of hospital admission granted they possess capacity.

Involvement of specialists such as palliative medicine can also help clarify goals of treatment and preferences of the patient and provide increased needed support to the family during this trying time. Surrogates described anxiety about certain aspects about their experience in the LTACH [4]: what would be their loved one's quality of life if they survived, would their loved one resent the decisions surrogates had made, and would there be sufficient finances once they were discharged from the hospital? Among both patients and their surrogates, the goals ranked as most important were "to be at home" and "to be physically comfortable." The least important were "to be mentally aware" and "to live as long as possible, no matter what." [4]. Surrogates expressed concern over the transition between acute and LTACHs, specifically disruption in provider continuity and difficulty adapting to differences between acute care hospital and LTACH. Additionally, patients as well as surrogates may be confused as to the role of each medical care provider. Some surrogates and patients could not clearly identify who their primary doctor was - often confusing them with consultant subspecialists - and therefore were more apprehensive to consult the physician about pressing issues. Surrogate decision-makers reported receiving different messages from clinicians across institutions, making them feel lied to, or clinicians were inattentive to their loved one. Family members then felt disconnected from the medical treatment of their loved one, and felt as though they could not trust the medical team [4]. Thus, a thorough evaluation of the surrogate decision-making process is crucial in understanding these anxieties and what perpetuates the psychiatric conditions faced by family members after the patient's LTACH stay.

Lesbian, Gay, Bisexual, Transvestite, and Queer Community in the LTACH

Although data are sparse concerning the LGBTQ community in the LTACH, some studies demonstrate that LGBTQ patients face harsher treatment and different hardships when placed in long-term care facilities. Older LGB adults may have different family structures than older heterosexual adults; they are less likely to be married, less likely to have children, and more likely to experience conflict with their nuclear family [19]. Few studies have examined long-term care expectation in older LGB populations. These studies indicate that these individuals may use nursing homes sooner than general population due to the lack of caregivers at home [20, 21].

Many of these institutional facilities have limited knowledge about the LGBTQ community and do not provide adequate training among providers, and this puts the older adults at heightened risk of neglect and abuse and sometimes blatant discrimination on the part of staff and fellow residents [22]. In one survey, 328 respondents reported 853 instances of mistreatment among LBGTQ older adults in the long-term care setting [22]. Another study demonstrated how staff and fellow residents experienced poor treatment, segregation, hostility, and even denial of family visits toward older LGBTQ adults [23]. Therefore, some older LBTQ members will avoid long-term facilities due to fear of discrimination and abuse and concerns about going “back into the closet” and being separated from their partners [19].

According to the US Department of Health and Human Services, under the Defense of Marriage Act (DOMA), while some states allow same-sex marriages, the majority do not recognize the union of same-sex partners [23]. Thus, partners engaged in these marriages are not entitled to many federal benefits, including tax benefits, Social Security survivor benefits, and retirement benefits. The discrepancies in what is covered by benefits and what is not depending on the state cause further financial burden to the loved one’s family and partner. Also, the legalities of same-sex spouses being able to make decisions on the behalf of the patient vary from state to state and thus can undermine the next of kin ethics in certain situations. Thus, it is difficult for older member of the LGBTQ community to assign a surrogate to make their medical decisions, which are vital for patient care in the LTACH. In one study, LGBTQ adults were significantly less likely than heterosexual adults to expect to rely on family members, perhaps because they were less likely to have children or kin caregivers whom they could rely on due to their sexual orientation [24, 25]. This situation may place LGBTQ older adults at increased risk for using more expensive, formal systems of care and therefore may not receive standard long-term care vital to their acute disease processes [26].

FICUS: Risk Factors and Assessment

Although little research exists regarding the development of FICUS in the LTACH, many of the risk factors that lead to FICUS in the ICU can be extrapolated to the LTACH environment. Demographic risk factors include female gender, patient age, lower education level, having a critically ill spouse, being an unmarried parent of a critically ill child, and having a younger relative with FICUS [27]. Other factors include distance from the hospital, adequate support including financial stability, preference for decision-making, comprehension of the disease process, satisfaction with care, quality of life, sleep status, as well as preexisting anxiety, depression, or acute stress disorder. While tools for risk assessment already exist, further work is needed to streamline these tools and develop more instruments to identify family members at increased risk [28, 29] in the LTACH setting. The following sections will discuss each individual risk factor as well as the tools for risk assessment.

Demographic Risk Factors Leading to Family Morbidity in the LTACH

Acute stress is experienced by up to 57% of family members within 3–5 days after their loved ones' admission to the ICU and is a common risk factor for the development of FICUS [12, 30]. Evidence suggests that family members with acute stress disorder (ASD) may progress to chronic post-traumatic stress disorder (PTSD) – another prominent characteristic of FICUS – in up to over three fourths of cases [31]. The most common symptoms of PTSD include hyperarousal, flashbacks, or nightmares [12, 32]. These are associated with female gender, for unknown reasons [33], thus putting women at increased risk of developing FICUS in the LTACH environment. Women who knew the patient for a shorter time, and those whose preference for decision-making was discordant with their actual decision-making role, had higher prevalence of PTSD and depression [27, 34, 35].

Patient age is a risk factor for the development of FICUS within the LTACH, as younger patients may be more likely to receive aggressive care than elderly patients in the LTACH setting. This may predispose younger patients to more invasive procedures, a greater number of diagnostic tests, and more frequent interventions with consultants which may impose increased stress on family members, thus increasing the likelihood of FICUS [36]. This may need to be considered by the family of older patients considering LTACH care.

As a means of providing support for family makers when making decisions for their ill loved ones, critical care societies have strongly supported shared decision-making [37, 38]. In shared decision-making, the patient (or their legally authorized representative) and physicians work together to make appropriate decisions to determine which treatment modality or modalities are best for the patient while incorporating the patient's values and preferences as well as the physician's knowledge of the benefits and risks of a treatment. One way to build partnerships is through formal family meetings. The Academy of Certified Case Managers recommends that family meetings with the multi-professional ICU team begin within 24–48 h of ICU admission and should be scheduled at regular intervals and as needed [39]. If the patient is young (aged 18–45), family members are more likely to have increased anxiety and stress due to the emotional turmoil of seeing a young family member in the LTACH. For example, a mother of a 20-year-old quadriplegic man will want to pursue all possible avenues and resources to treat her son. Caregivers may recommend to admit her son to the LTACH. The mother will experience a multitude of emotions during this time period witnessing her son experience a long-protracted stay. The daughter of a 98-year-old man with end-stage renal disease requiring renal transplant would have a very different decision to make regarding her father. Although in unadjusted analyses age has been shown to be strongly associated with mortality, after adjusting for other factors like severity of illness, preexisting comorbidities, and functional mobility, the effect of age on mortality is largely reduced [37, 40]. When considering this, a family member would experience high levels of stress when having to make decisions about even sending a loved one to the LTACH or making end-of-life care decisions. With a recent focus on transitioning care outside of the acute care facility to the greatest extent possible, the frequency of FICUS outside the ICU will only increase [41].

Another risk factor is having a chronically critically ill spouse admitted to the LTACH. Chronically critically ill patients may be at higher risk for readmission to acute care facilities and mortality than other populations of patients due to the severe nature their illnesses [42]. Bearing witness to their loved ones experiencing continuous medical struggles within this facility as well as repeated transfers back and forth from acute care ICUs to long-term acute care facilities can be physically exhausting and psychologically taxing. In a healthy relationship, couples confide in each other to make day-to-day decisions. In relationships where one's spouse is chronically critically ill, one's greatest emotional and psychological support system is lost. When a loved one must make medical decisions for a spouse without having the spouse to confide in, a great deal of emotional turmoil may be experienced which may lead to the development of FICUS. Frequently, the spouse may lack capacity to make decisions, or may be unable to communicate, again leaving the caregiver with the burden of sole decision-maker.

Financial Hardship Endured by LTACH Families

Another, often overlooked risk factor for the development of FICUS is insufficient financial resources. Up to 50% of ICU survivors require long-term care or inpatient rehabilitation that may not be covered by insurance [41, 43]. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) demonstrated that 31% of ICU survivor patients depleted their savings accounts, 29% became financially crippled because they were unable to return to work, and 20% reported that their family members had to leave gainful employment in order to care for them [41, 44]. Inadequate financial support of family members in the LTACH can result in a family's experiencing severe stress from being pressured from debtors or collectors, facing foreclosure or wage garnishment. Long-term care costs can vary widely by geography, level of care, duration of care, service packages, occupancy, payer source, and a variety of other factors [45]. The stress of having to address these issues can result in psychological strain, contributing to the development of FICUS in family members of LTACH patients.

Emotional Burden as a Risk Factor for FICUS

Family members who are suddenly thrust into a stressful caregiver or surrogate role may result in the individual being unable to distinguish their current emotions or preferences from those that they would have in more mundane, day-to-day situations [17]. Such a condition may result in more abrupt, haphazard responses to usually stress-free situations. Reactions and responses to certain events are often normally discussed among individuals and their families, and when not under duress, decision-making ability may be intact. However, in the LTACH, decisions regarding a loved one's course of management and continued care are made by a family member under stress or anxiety-provoking circumstances. Anger or fear can affect decision-making capability which, in turn, leads to uninformed decisions and systematic bias [17, 57, 58].

Furthermore, in some circumstances, family members or individuals who are not the designated decision-maker may have to assume such role due to the ill-timing of a critical illness. If this happens, insightful decision-making may be negatively impacted due to the situation of suddenly being thrust into the role of surrogate, potentially leading to passivity in decision-making by some families [17, 51]. Discordance between physician and family expectations of patients being treated in LTACHs may possibly occur due to an alteration in affect, which may influence the families' perception of the likelihood of positive and negative outcomes for the patient. Implementing proper support systems within patient care facilities may help family members make more informed and deliberate decisions.

Lack of Bidirectional Communication Leading to FICUS

Comprehension of the disease process [46], satisfaction with care [47], and the patients' quality of life can all affect the progression of FICUS within the LTACH. Many family members lack the knowledge or have misunderstandings of what is occurring with their loved one, especially in an LTACH environment where unplanned transfers back to an acute care facility can occur unexpectedly [48].One study determined the median length of stay in an LTACH was 45 days, with a mortality of 32% in 7 days of those transferred back to an acute facility [48]. By improving communication between caregiver and family, a better understanding of the disease process can be communicated to the family [16, 34, 49–51]. Better assessment of psychological disorders occurs when caregivers recognize the importance of psychological issues. When family members truly understand the medical management plan as well as the prognosis of their loved one, it becomes easier to understand the rationale driving the patients' care. By understanding the disease process and having satisfaction with care, the family member will gain greater insight into the patient's condition and resultant quality of life, a process known as intellectualization. Using intellectualization as a defense mechanism counteracts the progression of FICUS in the LTACH.

Morbidity of FICUS in the LTACH

Up to 50% of patients transferred to LTACHs for ventilator weaning fail liberation from mechanical ventilation and either remain fully ventilator dependent or die in the LTACH setting [7]. One-year mortality of patients admitted to LTACHs is approximately 50% and is worse than those of who survive critical illness after receiving mechanical ventilation and are discharged to a skilled nursing facility (33% mortality) [5, 52]. Patients receiving prolonged mechanical ventilation boast a slightly higher 1-year survival, ranging from 49% to 77% [53–58]. Evidence suggests that families and other surrogates, as well as physicians and patients themselves, may not fully comprehend the poor outcomes and prognoses of this population [59]. Thus, efforts are needed to temper overly optimistic outcome expectations of family members when their loved ones are admitted to long-term care facilities. When loved ones are informed of these statistics, realistic expectations can be formulated, ensuring that they have a clear understanding of the prognosis of their loved ones.

Prevention of FICUS

Prevention of psychological morbidity among families of patients with chronic critical illness requiring long-term acute care is a topic that has not been studied in depth. The notion that family members of these patients do not experience as much psychological, emotional, or physiologic issues because their loved one has been discharged from the ICU is incorrect [60]. These effects tend to be amplified in family members with a history of anxiety or depression. In addition, the long-term care of their loved one can cause financial strife further increasing odds of developing or worsening the depression or anxiety [10, 61] (Fig. 13.1). Different types of nonpharmacological therapies, such as art, music, and journaling or writing, are modalities that have improved patients' emotional and mental well-being in acute care setting and thus may have the potential to alleviate some of the psychological, emotional, or physiologic issues experienced by family members [62]. Since these therapies have demonstrated efficacy in reducing symptoms of FICUS in the ICU population, it is possible they could be utilized to prevent FICUS in the LTACH setting [63–65].

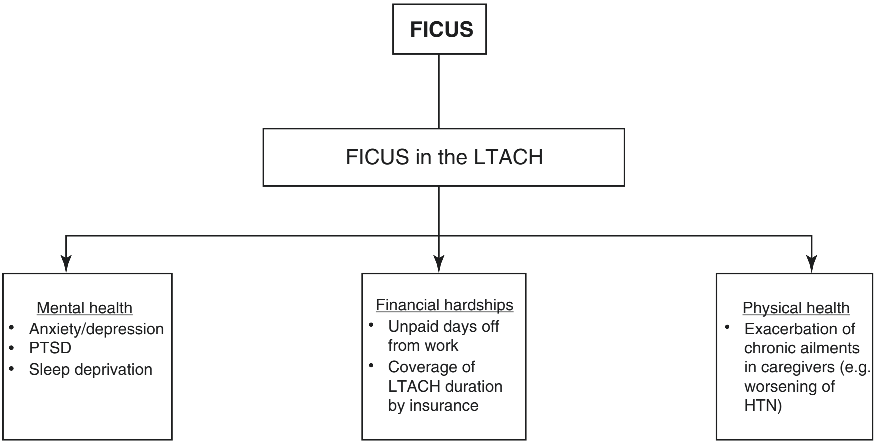


Fig. 13.1 Flow chart of FICUS manifestations family members may experience

Music Therapy as Prevention

Music therapy is one of most well-researched non-pharmacological interventions available to patients [63]. One study evaluating patients receiving mechanical ventilation in the ICU showed it lowered levels of anxiety more than having uninterrupted rest time [66]. Music may be associated with a decrease in heart rate, blood pressure, and serum cortisol in patients receiving this therapy [63]. Therefore, it is possible these same benefits could occur in family members of chronically critically ill patients. Playing music in the waiting room, and also allowing the patient to select the music for his or her room, has been shown to facilitate a calmer atmosphere reducing family members' anxiety, thus allowing them to think more clearly about decisions for their loved one. This has been demonstrated most recently in the palliative care setting [67].

Music therapy can allow family members of patients requiring palliative care to connect and express feelings and thoughts normally very difficult to convey. One palliative music therapy program included sessions where patients were able to write songs, which discuss their feelings in terms of gratitude toward their family, fear of the unknown, and coming to terms with their prognosis [63]. Despite discussing topics that normally evoke deep sadness and despair, this study realized that family members and patients felt less anxious and closer to their loved one [63]. In addition, patients receiving end-of-life care also experienced improvements in their mood and felt more relaxed after having music therapy sessions [67]. In the LTACH, incorporating music therapy may be helpful as it may alleviate some of the feeling of anxiety and confinement experienced by both the patient and their family. Due to the success of this approach, it may be advantageous to allow family members to create their own song or poem. This may prove to be a cathartic release for family members and give them the opportunity to clearly articulate any concerns or feelings that may be present. Music therapy, although most commonly used as an adjunctive therapy for patients, should also be considered for family members, despite their history of anxiety or depression. Furthermore, it should not be limited to patients and families in the hospice setting; by implementing this type of therapy in LTACHs, caregivers and patients may be able to express their emotions in a more comfortable environment.

Art Therapy to Prevent FICUS in the LTACH

Another intervention studied and similar to music is art therapy, i.e., painting and drawing. This approach has not been extensively studied, but data exist that demonstrate its efficacy in preventing psychological stress and improving health, quality of life, and well-being [68]. Studies evaluating residents of long-term care facilities and their quality of life demonstrated that art therapy plays a role in improving their overall health and quality of life [69, 70]. By incorporating family members in art therapy with patients, it may also allow them to better connect and potentially develop an outlet for dealing with any anxiety or stress. One study concluded that patients who participated in art therapy, along with the known benefits of it, also learned and came to truly appreciate their newfound interest [70]. They realized patients became more social and felt a more at ease. It would be beneficial for LTACH patients and family members to try this same approach as it may serve as an outlet that cannot only relieve stress and anxiety but also serve as a means of expression, allowing a patient and family members to share feelings and emotions. Thus, a patient's participation in art therapy with their family may allow the patient to better express their thoughts, while allowing the family to empathize and understand situations from the patient's perspective, while also reducing anxiety and stress [71]. However, it is important to take into account the stage in the patient's illness and decide whether any form of art will prove to be therapeutic to the patient and their family as one study found that patients during the acute stage of their illnesses found art therapy to be less useful [70]. Such a problem should not be an issue in the LTACH as all patients have usually endured a prolonged acute ICU stay and are supposedly en route to clinical recovery. In contrast, patients who were in the recovery stage expressed more success with art therapy [70]. Therefore, chronically critically ill patients and their family members could potentially psychologically benefit from participating in art therapy, since patients in the LTACH are receiving medical care for a prolonged period of time.

Writing or Journaling as a Prevention Tool

Journaling or writing is a therapy that helps ameliorate some of the concerns and stressors family members may have regarding the care of the patient. Also, they allow for a family to organize their thoughts in the midst of a stressful situation.

Because of the volume of information family members or surrogates receive during an extremely tense time, they may forget to ask questions or express any issues pertaining to the treatment plan of their loved one. Therefore, having a notebook or a journal to write down their thoughts could prove to ease their anxieties but also provide some therapeutic relief. One multinational study conducted in Europe and the USA involved the use of diaries during an ICU admission [72]. The overall purpose of the diary was for patients and their family members to write down facts about the patient that are not normally asked during the medical interview, thereby allowing the nursing staff to understand the patient in greater depth. It also allowed the patient to remember parts of their hospital course that may have been forgotten after discharge [72]. Families were able to keep track of messages or thoughts from distant family members and convey them to the patients. In addition, some of the nurses would write messages concerning the clinical aspect of their stay [73]. Given the simplicity of such an intervention, providing notebooks or journals for family members may prove to be a useful tool that will allow them to better cope with the situation presented by a family member admitted to an LTACH.

Communication as a Prevention Tool

One of the most effective ways to prevent FICUS in LTACHs is ensuring proper and clear communication between the medical staff and the family or surrogates. Between 80% and 93% of family members or decision-makers were not given information concerning the functional status or the prognosis of chronically critically ill patients [62]. This could be mitigated by having a designated person on the medical team that acts as a liaison between the family and rest of the medical staff. One study conducted analyzed the needs of family members and how to improve the overall satisfaction care, and they determined the need for a member of the medical team to act as a family care specialist [74]. Having someone from the medical team who fulfills this role would allow family members to feel more connected and assured they are receiving information about their loved one and can be explained to them in a way they best understand [74]. A similar trial trained nurses and social workers how to act as the communicator or facilitator for patients and their families in the ICU setting and demonstrated a decrease in depression-like symptoms in patients and family members with no change in anxiety and PTSD symptoms [75]. Despite the lack of change in feeling anxious or having PTSD episodes, having someone in the medical field help assist in making difficult decisions concerning end-of-life care proved to be beneficial in reducing some psychiatric manifestations of FICUS [75]. Another study provided family members with pamphlets discussing the patient's diagnosis and all the medical information regarding their disease [76]. Although the pamphlet was useful, researchers determined that some family members preferred having the information more specific to their situation instead of something more generic.

Communication is one of the most important aspects to medical care, and it is imperative the medical team and family members continue to maintain constant dialogue. In addition, providing and executing effective communication strategies, i.e., pamphlet or brochures, can further ensure family decision-makers or caregivers feel more capable of deciding certain treatment options for their loved ones despite the severity of the disease [64].

Support in the LTACH

Offering different avenues for support is vital for caregivers or family decision-makers especially when the medical team suggests end-of-life or palliative care for the patient, which is an important topic in the LTACH. The discussion concerning the wishes of the patient can prove to be very emotionally or mentally taxing due to fears about making the right the decision for their loved one [77]. In addition, it can cause or exacerbate mental health issues such as anxiety, depression, or PTSD in these family members [61, 78]. In theory, providing information about the patient's prognosis and the best treatment options in terms of end-of-life care should ameliorate the worries of the decision-makers, but one article realized this assumption is not necessarily true. One study conducted meetings with the palliative care team and provided support in terms of information about the disease and emotional assistance, and they discovered that these meetings did not help family caregivers who were suffering from anxiety or depression [78]. This result may have occurred if the information was given to the families later in the patient's prognosis or involving families later in the discussion concerning their loved one's treatment plans, thereby further exacerbating any mental health issues. Another study conducted in France provided family decision-makers or caregivers with information about end-of-life care for the patient when it was time to withdrawal therapy, and ironically researchers noticed a decrease in severity of anxiety, depression, and PTSD [64]. This positive result was attributed to the involvement of families early in discussion regarding the prognosis and treatment options for the patient [64]. This seemed truer with families with loved ones in long-term facilities in comparison to families of patients in acute care settings [79]. Implementing these strategies in the LTACH will allow families to make informed decisions about their loved one while also reducing symptoms of depression, anxiety, and PTSD.

Non-pharmacological options are available to help prevent or decrease the stress, anxiety, and fears commonly seen in family members or decision-makers of patients that have chronic critical illness. It is important for the medical team to remember the families of these patients and address their concerns or worries regarding any aspect of the patient's care. By doing so, families will feel more comfortable with the medical team and possibly share information regarding the patient that could prove to be useful. Providing simple things such as a notebook for writing or drawing or spiritual care may seem trivial to some but may have a profound impact on the family and give them the strength and knowledge to make difficult decisions regarding the care of someone they love dearly. This process allows families to alleviate some of the excruciating anxiety and stress faced while making these difficult medical decisions and thus can ameliorate some of the FICUS symptoms in the future.

Conclusion

Although family intensive care unit syndrome (FICUS) is a multifaceted syndrome that manifests as impairments in mental health, social/financial hardships, and physical health in family members of ICU patients, the syndrome can be seen in family members of patients who have survived a long, protracted ICU stay who are being treated in the LTACH setting. It is imperative for health-care professionals to be cognizant of FICUS effecting family members regardless of care setting – as most of the focus remains on the critically ill patient – in order to avoid future strain on the surrogate decision-makers.

References

1. Hotes LS, Kalman E. The evolution of care for the chronically critically ill patient. Clin Chest Med. 2001;22(1):1–11.
2. Munoz-Price LS. Long-term acute care hospitals. Clin Infect Dis. 2009;49(3):438–43.
3. Kahn JM. The evolving role of dedicated weaning facilities in critical care. Intensive Care Med. 2010;36(1):8–10.
4. Lamas DJ, et al. Opening the door: the experience of chronic critical illness in a long-term acute care hospital. Crit Care Med. 2017;45(4):e357–62.
5. Kahn JM, et al. Long-term acute care hospital utilization after critical illness. JAMA. 2010;303(22):2253–9.
6. Sviri S, et al. Contradictions in end-of-life decisions for self and other, expressed by relatives of chronically ventilated patients. J Crit Care. 2009;24(2):293–301.
7. Scheinhorn DJ, et al. Post-ICU mechanical ventilation at 23 long-term care hospitals: a multicenter outcomes study. Chest. 2007;131(1):85–93.
8. Kahn JM, Angus DC. Health policy and future planning for survivors of critical illness. Curr Opin Crit Care. 2007;13(5):514–8.
9. Nelson JE, et al. Communication about chronic critical illness. Arch Intern Med. 2007;167(22):2509–15.
10. Nelson JE, et al. Chronic critical illness. Am J Respir Crit Care Med. 2010;182(4):446–54.
11. Petrinec A. Post-intensive care syndrome in family decision makers of long-term acute care hospital patients. Am J Crit Care. 2017;26(5):416–22.
12. Schmidt M, Azoulay E. Having a loved one in the ICU: the forgotten family. Curr Opin Crit Care. 2012;18(5):540–7.
13. White DB, et al. Expanding the paradigm of the physician's role in surrogate decision-making: an empirically derived framework. Crit Care Med. 2010;38(3):743–50.
14. Netzer G, Sullivan DR. Recognizing, naming, and measuring a family intensive care unit syndrome. Ann Am Thorac Soc. 2014;11(3):435–41.

15. Pochard F, et al. Symptoms of anxiety and depression in family members of intensive care unit patients: ethical hypothesis regarding decision-making capacity. Crit Care Med. 2001;29(10):1893–7.
16. Siegel MD, et al. Psychiatric illness in the next of kin of patients who die in the intensive care unit. Crit Care Med. 2008;36(6):1722–8.
17. White AC, et al. Terminal withdrawal of mechanical ventilation at a long-term acute care hospital: comparison with a medical ICU. Chest. 2009;136(2):465–70.
18. Camhi SL, et al. Deciding in the dark: advance directives and continuation of treatment in chronic critical illness. Crit Care Med. 2009;37(3):919–25.
19. Henning-Smith C, Gonzales G, Shippee TP. Differences by sexual orientation in expectations about future long-term care needs among adults 40 to 65 years old. Am J Public Health. 2015;105(11):2359–65.
20. http://www.lgbtmap.org/file/improving-the-lives-of-lgbt-older-adults.pdf. LGBT movement advancement project. Improving the lives of LGBT older adults.
21. Inouye SK. Delirium in older persons. N Engl J Med. 2006;354(11):1157–65.
22. Smith PW. Nosocomial infections in the elderly. Infect Dis Clin N Am. 1989;3(4):763–77.
23. Pohlman MC, et al. Feasibility of physical and occupational therapy beginning from initiation of mechanical ventilation. Crit Care Med. 2010;38(11):2089–94.
24. Bailey P, et al. Early activity is feasible and safe in respiratory failure patients. Crit Care Med. 2007;35(1):139–45.
25. de Vries B, Carr D, Crosnoe R, Hughes ME, Pienta AM. Gays and lesbians, later life. In: Encyclopedia of the life course and human development: Macmillan Reference. p. 161–5.
26. Feder J, Komisar HL, Niefeld M. Long-term care in the United States: an overview. Health Aff (Millwood). 2000;19(3):40–56.
27. Davidson JE, Jones C, Bienvenu OJ. Family response to critical illness: postintensive care syndrome-family. Crit Care Med. 2012;40(2):618–24.
28. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatr Scand. 1983;67(6):361–70.
29. Horowitz M, Wilner N, Alvarez W. Impact of event scale: a measure of subjective stress. Psychosom Med. 1979;41(3):209–18.
30. McAdam JL, et al. Symptom experiences of family members of intensive care unit patients at high risk for dying. Crit Care Med. 2010;38(4):1078–85.
31. Shalev AY. Posttraumatic stress disorder and stress-related disorders. Psychiatr Clin North Am. 2009;32(3):687–704.
32. Auerbach SM, et al. Optimism, satisfaction with needs met, interpersonal perceptions of the healthcare team, and emotional distress in patients' family members during critical care hospitalization. Am J Crit Care. 2005;14(3):202–10.
33. Arabi YM, et al. Permissive underfeeding and intensive insulin therapy in critically ill patients: a randomized controlled trial. Am J Clin Nutr. 2011;93(3):569–77.
34. Gries CJ, et al. Predictors of symptoms of posttraumatic stress and depression in family members after patient death in the ICU. Chest. 2010;137(2):280–7.
35. Kross EK, et al. ICU care associated with symptoms of depression and posttraumatic stress disorder among family members of patients who die in the ICU. Chest. 2011;139(4):795–801.
36. Chen RC, Fang Tian ADF, Basak R, Hanson L, Selvam N, Dusetzina S; The University of North Carolina at Chapel Hill, Chapel Hill, NC; NC Cancer Hospital, Chapel Hill, NC; HealthCore Inc., Wilmington, DE. Aggressive care at the end-of-life for younger patients with cancer: impact of ASCO's choosing Wisely campaign. [Abstract/Poster] 2016 [cited 2017 11/13/17]; Available from: https://meetinglibrary.asco.org/record/125040/abstract.
37. Ehlenbach WJ. Considering age when making treatment decisions in the ICU: too little, too much, or just right? Crit Care. 2014;18(5):483.
38. Kon AA, et al. Shared decision making in ICUs: an American College of Critical Care Medicine and American Thoracic Society Policy Statement. Crit Care Med. 2016;44(1):188–201.

39. Davidson JE, et al. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004-2005. Crit Care Med. 2007;35(2):605–22.
40. Bo M, et al. Predictive factors of in-hospital mortality in older patients admitted to a medical intensive care unit. J Am Geriatr Soc. 2003;51(4):529–33.
41. Myers EA, et al. Post-ICU syndrome: rescuing the undiagnosed. JAAPA. 2016;29(4):34–7.
42. Coomer NM, et al. A preliminary look at readmission and mortality among chronically critically ill and other medically complex medicare patients. Appl Econ Lett. 2017;24(2):1435–8.
43. Harvey MA. The truth about consequences-post-intensive care syndrome in intensive care unit survivors and their families I'm sorry to say but sadly it’s true that bang-ups and hang-ups can happen to you.-Dr. Seuss. Crit Care Med. 2012;40(8):2506–7.
44. Hopkins RO, Girard TD. Medical and economic implications of cognitive and psychiatric disability of survivorship. Semin Respir Crit Care Med. 2012;33(4):348–56.
45. Migliaccio JN. Long-term care insurance for the caregivers: a financial gerontology proposal. J Financ Serv Professionals. 2017;71(4):33–9.
46. Azoulay E, et al. Impact of a family information leaflet on effectiveness of information provided to family members of intensive care unit patients: a multicenter, prospective, randomized, controlled trial. Am J Respir Crit Care Med. 2002;165(4):438–42.
47. Plost G, Nelson D. Family care in the intensive care unit: the golden rule, evidence, and resources. Crit Care Med. 2007;35(2):669–70.
48. White AC, et al. Unplanned transfers following admission to a long-term acute care hospital: a quality issue. Chron Respir Dis. 2011;8(4):245–52.
49. Azoulay E, et al. Risk of post-traumatic stress symptoms in family members of intensive care unit patients. Am J Respir Crit Care Med. 2005;171(9):987–94.
50. Abbott KH, et al. Families looking back: one year after discussion of withdrawal or withholding of life-sustaining support. Crit Care Med. 2001;29(1):197–201.
51. Curtis JR, White DB. Practical guidance for evidence-based ICU family conferences. Chest. 2008;134(4):835–43.
52. Wunsch H, et al. Three-year outcomes for Medicare beneficiaries who survive intensive care. JAMA. 2010;303(9):849–56.
53. Carson SS, et al. Outcomes after long-term acute care. An analysis of 133 mechanically ventilated patients. Am J Respir Crit Care Med. 1999;159(5 Pt 1):1568–73.
54. Schonhofer B, et al. Survival of mechanically ventilated patients admitted to a specialised weaning Centre. Intensive Care Med. 2002;28(7):908–16.
55. Combes A, et al. Morbidity, mortality, and quality-of-life outcomes of patients requiring >or=14 days of mechanical ventilation. Crit Care Med. 2003;31(5):1373–81.
56. Engoren M, Arslanian-Engoren C, Fenn-Buderer N. Hospital and long-term outcome after tracheostomy for respiratory failure. Chest. 2004;125(1):220–7.
57. Pilcher DV, et al. Outcomes, cost and long term survival of patients referred to a regional weaning centre. Thorax. 2005;60(3):187–92.
58. Carson SS, et al. A prognostic model for one-year mortality in patients requiring prolonged mechanical ventilation. Crit Care Med. 2008;36(7):2061–9.
59. Cox CE, et al. Expectations and outcomes of prolonged mechanical ventilation. Crit Care Med. 2009;37(11):2888–94. quiz 2904
60. Van Pelt DC, et al. Informal caregiver burden among survivors of prolonged mechanical ventilation. Am J Respir Crit Care Med. 2007;175(2):167–73.
61. Douglas SL, Daly BJ. Caregivers of long-term ventilator patients: physical and psychological outcomes. Chest. 2003;123(4):1073–81.
62. Lee D, Higgins PA. Adjunctive therapies for the chronically critically ill. AACN Adv Crit Care. 2010;21(1):92–106.
63. Kemper KJ, Danhauer SC. Music as therapy. South Med J. 2005;98(3):282–8.
64. Lautrette A, et al. A communication strategy and brochure for relatives of patients dying in the ICU. N Engl J Med. 2007;356(5):469–78.

65. Nelson JE, et al. The voice of surrogate decision-makers. Family responses to prognostic information in chronic critical illness. Am J Respir Crit Care Med. 2017;196(7):864–72.
66. Wong HL, Lopez-Nahas V, Molassiotis A. Effects of music therapy on anxiety in ventilator-dependent patients. Heart Lung. 2001;30(5):376–87.
67. Warth M, et al. Music therapy in palliative care. Dtsch Arztebl Int. 2015;112(46):788–94.
68. Roe B. Arts for health initiatives: an emerging international agenda and evidence base for older populations. J Adv Nurs. 2014;70(1):1–3.
69. Stuckey HL, Nobel J. The connection between art, healing, and public health: a review of current literature. Am J Public Health. 2010;100(2):254–63.
70. Moss H, O'Neill D. The aesthetic and cultural interests of patients attending an acute hospital – a phenomenological study. J Adv Nurs. 2014;70(1):121–9.
71. Staricoff RL. Arts in health: the value of evaluation. J R Soc Promot Heal. 2006;126(3):116–20.
72. Aitken LM, et al. The use of diaries in psychological recovery from intensive care. Crit Care. 2013;17(6):253.
73. Blair KTA, et al. Improving the patient experience by implementing an ICU diary for those at risk of post-intensive care syndrome. J Patient Exp. 2017;4(1):4–9.
74. Nelson DP, Plost G. Registered nurses as family care specialists in the intensive care unit. Crit Care Nurse. 2009;29(3):46–52. quiz 53
75. Curtis JR, et al. Randomized trial of communication facilitators to reduce family distress and intensity of end-of-life care. Am J Respir Crit Care Med. 2016;193(2):154–62.
76. Davidson JE. Family-centered care: meeting the needs of patients' families and helping families adapt to critical illness. Crit Care Nurse. 2009;29(3):28–34. quiz 35
77. Chen YC, et al. Determinants of receiving palliative care and ventilator withdrawal among patients with prolonged mechanical ventilation. Crit Care Med. 2017;45(10):1625–34.
78. Carson SS, et al. Effect of palliative care-led meetings for families of patients with chronic critical illness: a randomized clinical trial. JAMA. 2016;316(1):51–62.
79. Azoulay E, et al. Family participation in care to the critically ill: opinions of families and staff. Intensive Care Med. 2003;29(9):1498–504.

Chapter 14
Personalized Interventions to Support Families in the Intensive Care Unit

Christopher E. Cox

Background

Clinical interventions in the field of critical care are increasingly focused on building the evidence base for individualizing management. Ideal positive end-expiratory pressure (PEEP) targeting, echocardiography-targeted volume resuscitation, and biomarker-guided antibiotics reflect our desire to better personalize and possibly amplify the effects initially observed with interventions applied relatively rigidly. It seems that the tension entailed between one clinician's concern about "cookbook medicine" and a manager's concern about high inter-clinician variability is in no danger of receding anytime soon.

In this spirit, it is worth considering ways in which one could conduct replicable family-focused interventions that permit at least a moderate amount of individualization—all within the limitations of the clinical setting itself. The rationale for this approach is strong:

1. The gold standard of medical care is to center it on the patient and their family.
2. Families often feel as though their role is ill-defined in the clinical encounter, which limits engagement.
3. Families commonly have information and comprehension deficits that prevent full participation in care and may limit their own well-being.

C. E. Cox
Department of Medicine, Division of Pulmonary & Critical Care Medicine,
Duke University, Durham, NC, USA

Program to Support People and Enhance Recovery, Duke University, Durham, NC, USA
e-mail: christopher.cox@duke.edu

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_14

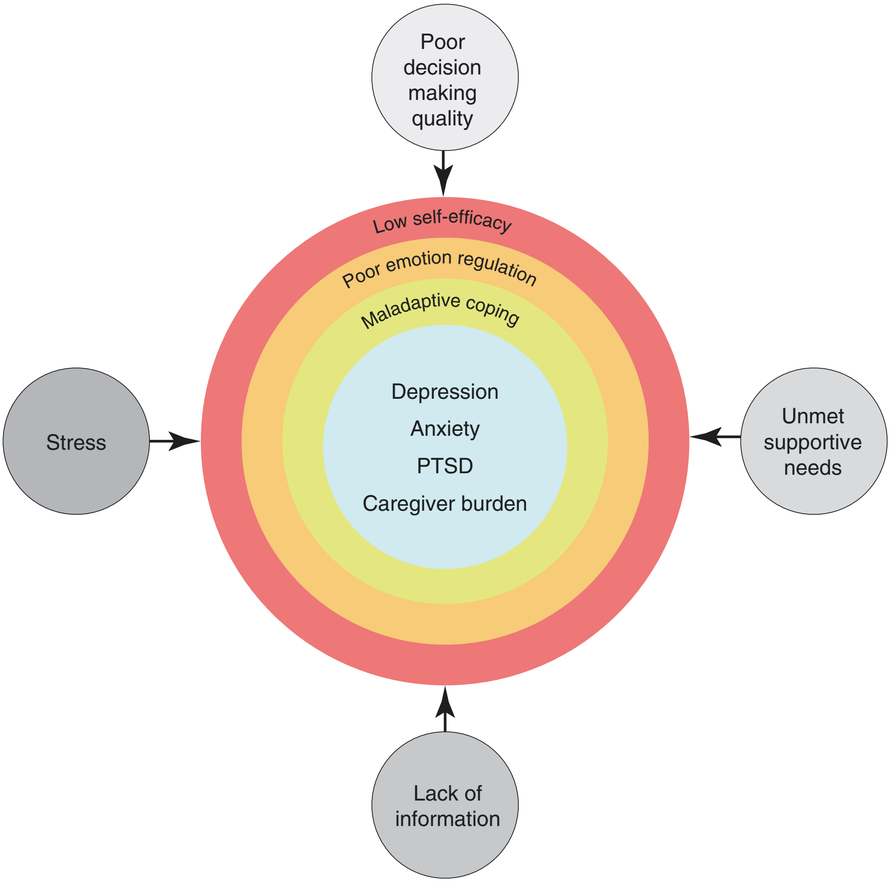


Fig. 14.1 Conceptual model

4. Few systems can actually assist clinicians in understanding if family members have specific needs—and if so, what types or severity exist.
5. Few interventions are able to be adapted to the specific needs of families which could vary tremendously based on age, health literacy level, language skills, and cultural background.

As shown in the conceptual model in Fig. 14.1, the end result of these factors may be a set of serious missed opportunities that define the family intensive care unit syndrome [1].

In this chapter, we offer three examples of how these different missed opportunities could be transformed into "wins." These examples include lessons learned from our own mistakes, unlucky decisions, and difficult-to-swallow outcomes—but successes as well. We focus on our own interventions not because we think they are comparatively exceptional to the work of others, but because we can be intensely critical of their conception and conduct. It is our hope that these lessons can help others to move the field forward just a little bit quicker.

Example 1: Providing Personalized Information to Assist in Decision-Making

Decision-making is central to the practice of medicine. Observational studies have shown that ICU clinicians make over 100 decisions a day, nearly 10 per patient [2]. Yet some of the most crucial decisions involve patients' surrogates, that is, their family caregivers. There is reason to believe that the quality of this decision-making process is suboptimal. In fact, one observational study found that half of family members did not adequately understand the diagnosis, treatments, or prognosis of their critically ill loved one [3].

It can be easy for clinicians to lose sight of just how overwhelming it can be for surrogate decision makers to navigate a loved one's critical illness and the high-stakes decisions involved. Although we often focus interventions and attention on the decision itself, it is important to emphasize that the process of decision-making includes information gathering, decision-making, operationalizing the decision, and understanding the impact of the decision [4]. The evidence suggests that ICU clinicians may conduct the process of shared decision-making with family caregivers incompletely [5, 6]. Another barrier to high-quality decision-making is poor numeracy among family caregivers [7].

With this in mind, we developed a written decision aid for family caregivers of patients with prolonged mechanical ventilation that included individualized 1-year estimates of prognosis [8]. The aim of this intervention was to provide a template for shared decision-making, including stages from information gathering to value elicitation to the decision itself. When administered to family members and their ICU clinicians on day 10 of ventilation, we observed that there were sizable differences in key outcomes in comparison to a usual care control condition. The level of prognostic discordance was reduced from 47% to 7% with the decision aid, while it changed little in control. Similarly, the quality of communication reported by family members, their comprehension of relevant medical factors related to the decision about life support prolongation, and the amount of decisional conflict improved. Equally important were the impact on the likelihood that ICU teams discussed what to expect long term for survival and functional status.

Since this study, other investigators have described the clinician-family member interaction and the informational challenges faced by both groups [9, 10]. Currently, a multicenter trial of a digital version of the prolonged mechanical ventilation decision aid is ongoing.

Example 2: Providing Personalized Support to Reduce Psychological Distress

Many researchers have described the psychological sequelae of critical illness among both patients and family caregivers [11–14]. Although this distress is common and persistent, few interventions have reliably improved these symptoms. We recently tested two novel interventions designed to reduce patient and family member distress that are worth discussing as touchpoints for future research.

Because psychological distress can persist for months to years, we aimed to target the post-discharge timeframe. After a development and testing pilot study [15], we evaluated a telephone- and web-based coping skills training program among ICU survivors and their family members [16]. The six-session coping skills intervention did not reduce symptoms of depression, anxiety, or post-traumatic stress disorder (PTSD) at 3 months. However, among patients with elevated levels of baseline distress, the intervention reduced depression at a statistically and clinically significant difference at 6 months.

A number of somewhat painful lessons were learned from the coping skills trial that are important for future researchers to consider. First, focusing interventions on those with clinically important symptoms at baseline is critical. We greatly overestimated incident distress occurring throughout follow up. Second, starting the intervention quickly after discharge can reduce attrition. Unfortunately, waiting weeks to months for those transferred to nursing homes or rehabilitation facilities does not translate into good policy. Third, we need better metrics to identify those who are neither too well to benefit nor too ill to adhere to post-discharge interventions. A sad postscript of the study was that the most vulnerable participants with low education and great financial distress were the most likely to drop out from the study.

We recently conducted a multicenter pilot trial of a self-directed mobile app-based mindfulness intervention, comparing it to a standard telephone intervention and an education program control [17]. Based on a moderately successful pilot [18], we aimed to try a different approach to distress that focused less on didactics and more on mastering just a couple key techniques. Though this trial was unable to include lessons learned from the coping trial such as excluding those without elevated baseline distress, we were able to relax inclusion criteria beyond just those who received mechanical ventilation. Also, we used patient and family feedback from the coping skills trial to build an intervention that was self-directed and shorter (4 weekly sessions). Interestingly, we found that the mobile app group experienced the greatest reduction in 3-month symptoms of depression, anxiety, and physical symptoms. The differences were even more pronounced when analyses were restricted to those with elevated baseline distress. Importantly, adherence and retention were substantially better than that observed in the coping skills trial.

The mindfulness study shows the promise of a new direction in addressing distress that is convenient, inexpensive, and flexible. However, it is unclear to what extent the different component pieces of the intervention may be important in modulating distress. Also, because adherence and retention were slightly better in the telephone group, it seems too early to say that the complete exclusion of the interventionist expert is wise. Last, building an automated digital system wherein distress screening can be feasibly performed after discharge will be key to the broader application of interventions such as this.

Example 3: Using Family Caregiver-Reported Information to Power Smart Systems of Care

Palliative care aims to address the needs of patients and their family members and, by so doing, improve quality of life. In different populations and care settings, palliative care has reduced suffering, aligned treatment with values, and enhanced physical, spiritual, and emotional well-being [19]. Yet, in the ICU setting, there is evidence that the quality of palliative care is highly variable across the spectrum of care from hospital systems to the level of the individual patient or family member [20].

There are two types of barriers to efficiently, reliably, and effectively delivering ICU-based palliative care. First, there are structural barriers to effective care delivery related to the small palliative care specialist workforce and the common deficiencies among intensivists in communication, shared decision-making, and recognition of symptoms. Clearly structural barriers are difficult to change. Second, there are process barriers related to issues such as identifying which patients and families need help, engaging family members in palliative care, and promoting efficient collaboration between palliative care specialists and ICU clinicians. Because process barriers are a more feasible intervention target, we have focused on these as a way to improve care quality.

Recently we conducted a pilot trial to evaluate the clinical impact of a novel intervention that targets all three process barriers described above [21]. Guided by our previously published conceptual model and extensive pilot work [22, 23], the intervention is an electronic health record (EHR) system-integrated app platform that identifies high-risk patient phenotypes, assesses family-reported needs, and promotes collaborative care delivered by palliative care specialists and ICU clinicians. These elements are described in greater detail below.

First, although studies suggest that at least a quarter of patients and families likely have notable unmet palliative care needs [24], it is difficult to identify them—and even more challenging to do so in an efficient, automated manner. On average intensivists order palliative care consults for 5–9% of patients, suggesting that they may either fail to recognize needs or feel that they are adequately addressing them. However, while hospitals that use specific diseases or conditions to “trigger” consultation can reliably increase specialist utilization, this may either overwhelm the specialist service or direct care away from others who may need it more. Importantly, there is no strong evidence that the presence of a trigger correctly reflects a greater burden of unmet need than its absence [25]. Our intervention harnesses an automated process in which its direct integration with EHR data identifies patients with phenotypes that are associated with poor short- and long-term survival, limited functional recovery, and high caregiver burden and displays it in a single user interface for clinicians. Second, the app platform allows families to report their needs directly, displaying them by domain for rapid review by clinicians (see Fig. 14.2). Third, the app system provides a centralized structure for the delivery of palliative care for both specialists and ICU clinicians that is largely automated, easily visible, and acceptable.

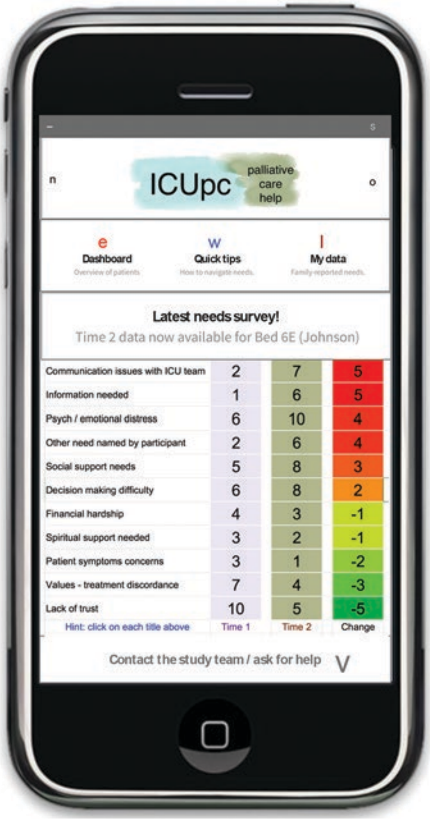


Fig. 14.2 Screenshot from palliative care prototype app

Latest needs survey!

Time 2 data now available for Bed 6E (Johnson)

Communication issues with ICU team	2	7	5
Information needed	1	6	5
Psych / emotional distress	6	10	4
Other need named by participant	2	6	4
Social support needs	5	8	3
Decision making difficulty	6	8	2
Financial hardship	4	3	-1
Spiritual support needed	3	2	-1
Patient symptoms concerns	3	1	-2
Values - treatment discordance	7	4	-3
Lack of trust	10	5	-5
Hint: click on each title above	Time 1	Time 2	Change

In our pilot, we found that the EHR-integrated app platform reduced unmet needs substantially among family members, improved the patient-centeredness of care, expedited the delivery of palliative care, reduced hospital length of stay, and increased the receipt of hospice care—in comparison to standard palliative care specialist controls. While these findings are compelling, the system's limitations are worth discussing. First, while some patient populations may have specific interest for administrators (e.g., chronic critical illness), it is likely that this distinction may be unimportant at the ground level for clinicians and family members alike. Second, a focus on unmet need is more practical, though it is unclear how to define what constitutes an elevated level of need that is actionable—and whether there is a certain needs score cutoff that should prompt the involvement of a specialist. Third, knowledge of various domains of need could allow non-physicians (e.g., chaplains, social workers, nurses) to address needs, though the impact of multiple new providers is unknown. Last, adjuncts to needs' measurement could also include the patient's review of her own medical records to ensure harmonization of the health care focus as advocated by the OpenNotes movement.

Summary

This chapter provides practical examples of how we can empower ICU family members with information, therapeutic resources, and systems through which to directly report their needs. Though these examples represent different approaches and areas of impact, they are united by a goal of giving family members greater leverage and purpose within the dyadic clinician-family relationship. Focusing on approaches through which to better level this interaction may not only help to simplify interventions but possibly increase their efficacy.

Conflicts of Interest Dr. Cox has neither competing financial or non-financial interests in this research.

References

1. Netzer G, Sullivan DR. Recognizing, naming, and measuring a family intensive care unit syndrome. Ann Am Thorac Soc. 2014;11(3):435–41.
2. McKenzie MS, Auriemma CL, Olenik J, Cooney E, Gabler NB, Halpern SD. An observational study of decision making by medical intensivists. Crit Care Med. 2015;43(8):1660–8.
3. Azoulay E, Chevret S, Leleu G, et al. Half the families of intensive care unit patients experience inadequate communication with physicians. Crit Care Med. 2000;28(8):3044–9.
4. Longo DR, Woolf SH. Rethinking the information priorities of patients. JAMA. 2014;311(18):1857–8.
5. White DB, Braddock CH 3rd, Bereknyei S, Curtis JR. Toward shared decision making at the end of life in intensive care units: opportunities for improvement. Arch Intern Med. 2007;167(5):461–7.
6. Cox CE, Martinu T, Sathy SJ, et al. Expectations and outcomes of prolonged mechanical ventilation. Crit Care Med. 2009;37(11):2888–94; quiz 2904
7. Leiter N, Motta M, Reed RM, et al. Numeracy and interpretation of prognostic estimates in intracerebral hemorrhage among surrogate decision makers in the neurologic ICU. Crit Care Med. 2018;46(2):264–71.
8. Cox CE, Lewis CL, Hanson LC, et al. Development and pilot testing of a decision aid for surrogates of patients with prolonged mechanical ventilation. Crit Care Med. 2012;40(8):2327–34.
9. White DB, Ernecoff N, Buddadhumaruk P, et al. Prevalence of and factors related to discordance about prognosis between physicians and surrogate decision makers of critically ill patients. JAMA. 2016;315(19):2086–94.
10. Detsky ME, Harhay MO, Bayard DF, et al. Discriminative accuracy of physician and nurse predictions for survival and functional outcomes 6 months after an ICU admission. JAMA. 2017;317(21):2187–95.
11. Huang M, Parker AM, Bienvenu OJ, et al. Psychiatric symptoms in acute respiratory distress syndrome survivors: a 1-year National Multicenter Study. Crit Care Med. 2016;44(5):954–65.
12. Bienvenu OJ, Colantuoni E, Mendez-Tellez PA, et al. Cooccurrence of and remission from general anxiety, depression, and posttraumatic stress disorder symptoms after acute lung injury: a 2-year longitudinal study. Crit Care Med. 2015;43(3):642–53.
13. Rabiee A, Nikayin S, Hashem MD, et al. Depressive symptoms after critical illness: a systematic review and meta-analysis. Crit Care Med. 2016;44(9):1744–53.

14. Jackson JC, Pandharipande PP, Girard TD, et al. Depression, post-traumatic stress disorder, and functional disability in survivors of critical illness in the BRAIN-ICU study: a longitudinal cohort study. Lancet Respir Med. 2014;2(5):369–79.
15. Cox CE, Porter LS, Hough CL, et al. Development and preliminary evaluation of a telephone-based coping skills training intervention for survivors of acute lung injury and their informal caregivers. Intensive Care Med. 2012;38(8):1289–97.
16. Cox CE, Hough CL, Carson SS, et al. Effects of a telephone- and web-based coping skills training program compared to an education program or survivors of critical illness and their family members: a randomized clinical trial. Am J Resp Crit Care Med. 2018;197:66–78.
17. Cox CE, Hough CL, Jones DM, et al. Effects of mindfulness training programs delivered by a self-directed mobile app and by telephone compared to an education program for survivors of critical illness: a pilot randomized clinical trial. Published Online First: 23 May 2018. doi: 10.1136/thoraxjnl-2017-211264.
18. Cox CE, Porter LS, Buck PJ, et al. Development and preliminary evaluation of a telephone-based mindfulness training intervention for survivors of critical illness. Ann Am Thorac Soc. 2014;11(2):173–81.
19. Kelley AS, Morrison RS. Palliative care for the seriously ill. N Engl J Med. 2015;373(8):747–55.
20. Aslakson RA, Reinke LF, Cox CE, Kross EK, Benzo RP, Curtis JR. Developing a research agenda for integrating palliative care into critical care and pulmonary practice to improve patient and family outcomes. J Palliat Med. 2017;20(4):329–43.
21. Cox CE, Jones DM, Reagan W, et al. Palliative care planner (PCplanner): a pilot study to evaluate acceptability and usability of an electronic health records system-integrated, needs-targeted app platform. Ann Am Thor Soc. 2018;15:59–68.
22. Carson SS, Cox CE, Wallenstein S, et al. Effect of palliative care-led meetings for families of patients with chronic critical illness: a randomized clinical trial. JAMA. 2016;316(1):51–62.
23. Wysham NG, Hua M, Hough CL, et al. Improving ICU-based palliative care delivery: a multicenter, multidisciplinary survey of critical care clinician attitudes and beliefs. Crit Care Med. 2017;45(4):e372–8.
24. Hua MS, Li G, Blinderman CD, Wunsch H. Estimates of the need for palliative care consultation across United States intensive care units using a trigger-based model. Am J Respir Crit Care Med. 2014;189(4):428–36.
25. Creutzfeldt CJ, Engelberg RA, Healey L, et al. Palliative care needs in the neuro-ICU. Crit Care Med. 2015;43(8):1677–84.

Chapter 15
Family-Centered Care Interventions to Minimize Family Intensive Care Unit Syndrome and Post-intensive Care Syndrome-Family

Judy Elisa Davidson, Janet Marty Mendis, Truong-Giang Huynh, Samantha Gambles Farr, Suzette Jernigan, Steffanie A. Strathdee, and Thomas Patterson

---

Note: Standardized to use of term *clinician*, nurse used only when the intervention is specific to nursing. *Facilitated Sensemaking* (capitalized) is used in the sentence to reflect the name of the theoretical model. It is spelled in lower case when reflecting the process.

J. E. Davidson (✉)
University of California, San Diego Health, San Diego, CA, USA
e-mail: jdavidson@ucsd.edu

J. M. Mendis
NICU, University of California, San Diego Health, San Diego, CA, USA
e-mail: jmendis@ucsd.edu

T.-G. Huynh
Medical-Surgical ICU, University of California, San Diego Health, San Diego, CA, USA
e-mail: th013@ucsd.edu

S. G. Farr
Surgical Intensive Care, University of California, San Diego Health, San Diego, CA, USA
e-mail: sgambles@ucsd.edu

S. Jernigan
Burn ICU, Burn Special Care, University of California, San Diego Health,
San Diego, CA, USA
e-mail: sjernigan@ucsd.edu

S. A. Strathdee
University of California, San Diego Department of Medicine, San Diego, CA, USA
e-mail: sstrathdee@ucsd.edu

T. Patterson
University of California, San Diego Department of Psychiatry, San Diego, CA, USA
e-mail: tpatterson@ucsd.edu

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_15

Introduction

Approximately 11 million people experience critical illness in the United States (USA) each year, with up to half of survivors requiring caregiving following discharge. This caregiving is often provided by direct family members. Family, in the modern context, includes anyone the patient may have designated as family if they were able to do so and not restricted to direct lineage. From a review of the collective literature on family response to critical illness, it is estimated that 1/3 of families will suffer from anxiety, depression, and posttraumatic stress as a result of their exposure to the crisis of critical illness [1]. Stress disorders start in the ICU (family ICU syndrome) [2] but may last months to years following discharge or death of the patient (post-intensive care syndrome-family) [3]. This means that, conservatively, 4 million family members a year, in the United States alone, will develop stress disorders or depression as a result of exposure to an ICU stay. It is incumbent upon ICU clinicians to proactively provide family care in a manner that will minimize the risk of this trauma.

Without careful attention, the results may also adversely affect social and physical endpoints such as the intensity of caregiver burden, quality of life, ability to work, financial strain, marital strain, decompensation of pre-existing health conditions, and the development of sleep disorders [4, 5]. Impaired or inadequate sleep may result in the inability to participate effectively in decision-making during the ICU stay [6]. In the event of patient death, families may also suffer complicated grief [3]. Although more research is definitely needed, the prevailing wisdom is that the manner in which we (a) communicate and (b) involve families in care may affect these outcomes. Through an organized approach to family-centered care, communication and family engagement can be enhanced. Key published definitions are found in Table 15.1.

Table 15.1 Definitions

Construct	Definition	Source
Family	Family is defined by the patient or, in the case of minors or those without decision-making capacity, by their surrogates. In this context, the family may be related or unrelated to the patient. They are individuals who provide support and with whom the patient has a significant relationship	Davidson et al. [7]
Family-centered care	Family-centered care is an approach to healthcare that is respectful of and responsive to individual families' needs and values	Davidson et al. [7]
Family ICU syndrome	Morbidity and associated decision-making impairment experienced by many family members of patients with acute critical illness (in the ICU) and chronic critical illness (in the long-term acute care hospital)	Netzer and Sullivan [2]
Post-intensive care syndrome-family	New or worsening problems with physical, cognitive, or mental health status arising after family exposure to critical illness and persisting past acute care hospitalization	Needham et al. [3]
Facilitated Sensemaking	Facilitated Sensemaking is a midrange theory of family engagement with the goal of helping the family make sense of the situation their new role as caregivers in a structured manner ultimately decreasing negative outcomes resulting from exposure to critical illness	Davidson [10]

The purpose of this chapter is to outline family-centered care interventions to be deployed within the intensive care unit stay to optimize family health as recommended within guidelines published by the Society of Critical Care Medicine (SCCM) and endorsed by nine professional agencies worldwide [7]. Facilitated Sensemaking, a midrange theory recommended by the SCCM as one framework from which to apply principles of family-centered care, will be presented [8–11]. Special situations such as provision of family care that is gender-sensitive and specific to needs of infants and children and needs of non-English-speaking families will be addressed. Needs of the unbefriended patient will also be explored. Case studies and personal testimony will be presented to translate abstract concepts into perspective further emphasizing the importance of strategically deploying family interventions. Methods to optimize clinician resiliency to increase capacity for family-centered care are described.

Facilitated Sensemaking as a Framework for Family-Centered Care

Family members of intensive care patients are at high risk for anxiety, depression, and psychological distress that may extend well beyond their family members' ICU stay [2]. Often, the words spoken by family members seem rhetorical: "I don't understand," "I can't deal with this," and "What am I going to do?" These seemingly rhetorical statements provide valuable insight into how we can help them through their crisis.

Facilitated Sensemaking [12] is a midrange theory of family engagement derived from two sources: Roy's adaptation model [13] and Wieck's business leadership organizational sensemaking model [14]. Roy's adaptation model states that in order to respond positively to change, an individual must adapt through two subsystems. The first system, which involves learning, emotion, perception, and judgment, is named the cognator system. The second, or regulator system, involves neural, endocrine, and chemical channels. When people experience critical illness, they need to adapt to the situation, and the consequences of this exposure to crisis may result in a range of consequences, positive or negative, depending upon the nature of that process of adaptation [13]. Wieck's model emphasizes the role that leaders play in employee's perception of their roles and events occurring within the organization by providing feedback on employees' performance, expectations of roles, and an understanding or sensemaking of events which may otherwise be misinterpreted. Leaders interpret the status of the organization, e.g., financial viability or successes in attaining targets, and "message" this interpretation to staff to promote a positive image of the organization [14].

In Facilitated Sensemaking these same principles are applied to decoding the situation of critical illness for family members. Instead of leaving it up to themselves to form an impression of what is happening from the cues in the environment, clinicians are encouraged to interpret the cues for them to construct a reality-based narrative. Proactive communication is essential. We cannot assume that families will interpret what is happening around them accurately without interpretation from the healthcare team. For instance, simple things – such as the fact that family members are welcome to attend round – need to be articulated verbally.

Nursing interventions derived from the Facilitated Sensemaking theory initially help the family adapt to their loved one's illness or injury by assisting them to make sense of the immediate situation and helping them to do what is needed in the moment. The process is continuous and iterative. As the patient's condition changes, family interventions evolve. Family members' comfort with their new caregiving role and the ICU environment improves with communication and engagement in care. The questions "What am I going to do?" and "How am I ever going to deal with this?" are answered as family members eventually accept the new turn their life has taken and the new roles which are theirs to assume. Fear and helplessness (antecedents to post-traumatic stress disorder (PTSD)) are replaced with knowledge, understanding, and purpose when family members are provided with the tools and knowledge to assist in the care of their loved one. When this process is used, it is welcomed by family members [11] and has been shown to decrease state anxiety [15].

How It Works

Ninety percent of Americans will experience a traumatic event in their lifetime. A 2009 survey indicated that the rate of individuals with PTSD in primary care ranged from 8% to 30%. A traumatic event may be experienced, witnessed, or learned of. Initial reactions most commonly include fear, horror, and helplessness. As described above, these reactions are reflective of the components of Roy's cognator system. Further, Roy's regulator system is evidenced in the physiologic response to stress through neuroendocrine, neurochemical, and anatomic pathways [16].

Several systems cascade in this physiologic response. The immediate neuroendocrine reaction to stress is the secretion of corticotropin-releasing hormone (CRH) from nerve terminals of neurons in the hypothalamic paraventricular nucleus, a group of stress-responsive neurons contained in the hypothalamus. Dopamine release results in hypervigilance, while norepinephrine is responsible for the classic fight or flight response initiated by the sympathetic portion of the autonomic nervous system. The inability to downregulate the stress response is responsible for increased arousal states and elevated pulse, respirations, and blood pressure in response to environmental triggers and recall of the traumatic event [17].

The anatomic structures in the brain affected by traumatic events include the hippocampus, prefrontal cortex, and the amygdala. During stress, the hippocampus produces an inhibitory effect of CRH, decreasing the subsequent production and release of ACTH and release of glucocorticoids from the adrenal cortex. Prolonged exposure to elevated glucocorticoids in laboratory animals result in damage to dendrites of the animals' hippocampus. Stress responses, relegation of fear to appropriate contexts, learning, and explicit memory are all functions of the hippocampus [17].

Unlike the hippocampus and the prefrontal cortex, the amygdala stimulates CRH neurons in the paraventricular nucleus during extreme stress, cementing the fear response to the stressful situation. The amygdala is enlarged during the stress response which may result in long-term inability to distinguish between a threatening and a non-threatening event [16, 17].

When these stress responses are activated, family members will have difficulty learning, making decisions, and sleeping. Considering the fight vs. flight response, families may project as angry, irritable, blaming, or suspicious when the "fight" response is activated and disengaged when in flight. Sleep disturbances will further erode the ability to problem-solve and perform in the surrogate decision-maker role. Fear, horror, and helpless are the antecedents to stress disorders (Fig. 15.1). Preventing escalation of these emotions may be brain protective.

Conversely, the prefrontal cortex inhibits the stress response, exerting control over emotional reactivity and acquisition of conditioned fear responses. The prefrontal cortex is reduced in size in the presence of trauma or severe stress. Individuals presenting with a reduction in the volume of the prefrontal cortex may exhibit problems with cognitive processes such as behavioral control, attention, memory, flexible thinking, planning, and goal attainment [16, 17]. The goal, then, is to preserve

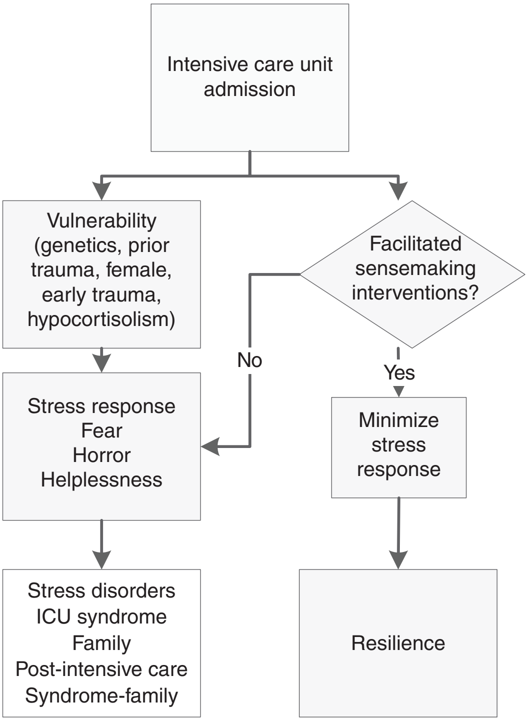


Fig. 15.1 Facilitated sensemaking

or enhance activity in the prefrontal cortex to inhibit the stress response. Through the process of facilitated sensemaking, families are provided with purpose in crisis by teaching them how to engage at the bedside. Engagement moves attention away from the primal fight vs. flight response and the midlevel instinct to safeguard and protect. Engaging in care requires activation of the prefrontal cortex and higher-level brain functions modulating down the cycle of stress activation. Information decreases fear of the unknown and the horror associated with unpleasant sights and sounds. Knowing what to do next decreases helplessness. Participating in rounds, being assigned a specific role, such as mobility coach, raises engagement to the highest levels and maintains activation of the prefrontal cortex with the goal of minimizing the stress response.

Reactivity to a traumatic situation is acute, transient, and self-limited for the majority of the population. Specific vulnerabilities, such as genetics, prior trauma, female sex, trauma at developmental stages, injury, and hypocortisolism, create a greater vulnerability for the development of PTSD [18]. Facilitated Sensemaking provides the means to assuage the fear, horror, and helplessness experienced by loved ones of intensive care patients, potentially limiting the family's submersion into a vortex of nightmares, agitation, impulsivity, avoidance, and anger [10, 19].

Facilitated Sensemaking quells the fear, horror, and helplessness which may be experienced by those whose loved ones are experiencing life-threatening critical illness. A situation which may, at first, seem unsurmountable is broken down for the family into a scenario which makes sense and in which they can engage in care to make a positive impact 1 day at a time.

Basic Bedside Strategies

Guidelines on family-centered care were recently released by the Society of Critical Care Medicine (SCCM) were written from an evidence-based systematic review of the literature and not consensus statements. The guidelines recommended many different clinical strategies to improve family-centered care with the goal of decreasing PICS/PICS-F that can be used in the Facilitated Sensemaking process (Table 15.2). Both the guidelines and the theoretical model were developed from the same literature base, so the recommendations are aligned to the Facilitated Sensemaking interventions described below and do not conflict. Here several strategies to translate recommendations into practice using Facilitated Sensemaking are described. There are four broad categories of interventions to be deployed within the Facilitated Sensemaking model intended to develop caring relationships, enhance communication, encourage family presence and engagement, and support families in decision-making [8].

Table 15.2 Recommendations from Society of Critical Care Medicine Guidelines

Presence
Open flexible family presence
Family presence on rounds
Family presence at resuscitation
Communication
Diaries
Whiteboard where family can write questions/suggestions
Family education/leaflets
Shared decision-making/nurse involved in decision-making
Use validated decision-support tools for surrogate decision-making
Family conferences with structured approach to communication:
Value input
Acknowledge emotions
Listen
Understand patient as person
Elicit questions
Messages of hope and non-abandonment
Consults as indicated
Spiritual support
Palliative care referrals
Ethics when value-laden conflict arises
Social workers to support family conference
Navigators (specially trained family liaisons)
Environmental/organizational considerations
Leaflet with helpful tips (e.g., visitation rules, time rounds usually occur)
Noise reduction/environmental hygiene/private rooms
Teach family sleep hygiene, provide family sleep surface
Develop policy for family-centered care
Staff education and training
Neonatal specific
Peer-to-peer support
Teach parents role and engage in care
Consider psychologist referral for cognitive behavioral therapy in mothers of preterm infants

Caring Relationships

In order to build caring relationships, trust must first be established. Trust comes with demonstrating care through gentle touch, use of a caring voice, empathetic and active-listening, and inquiring about the patient and family as people. Families may exhibit a hypervigilant need to safeguard the patient until trust is formed. Though not studied scientifically, we posit that trust will develop sooner if the family witnesses care through presence, feels cared for, and is engaged as a team member. This could include the simple act of bringing a caregiver a cup of coffee or allowing the caregiver to provide observations or ask questions at the end of rounds. Following through on promises, such as answering questions or requests for pain medications in a timely manner, enhances trust. Many of the strategies listed below that enhance communication and engagement also help in forming the caring relationship.

Communication

Optimizing communication through actively promoting family presence and engagement coupled with structured frequent communication is recommended [7]. Effective communication between patients and family and physician correlates with health outcomes of both the patient and family, including decreased anxiety, depression, and symptoms of posttraumatic stress. One approach to improving communication is to practice family inclusion and engagement during interdisciplinary rounds. Members attending interdisciplinary rounds may include but are not limited to the intensivist, respiratory therapist, nurse, pharmacist, case manager, and family/surrogate decision-maker. In a concise definitive review of the literature on family inclusion in rounds, it was found that families were more satisfied when included in rounds as compared to not being included and when questioned over 95% would want to be included [23]. Family presence on rounds could serve to improve trust and relationship with the healthcare team. Further, when included, families have the opportunity to provide clinicians with important information regarding baseline status and previously failed or intolerated treatments and medications [23]. Several observational studies specific to the ICU reported that family presence during rounds increased family knowledge, involvement in asking questions, and decision-making [7].

Once a trusting relationship has been established, communication on decoding the environment and reflective inquiry are important to reduce family stress. Families are generally unfamiliar with the ICU environment; one filled with lights, sounds, alarms, and different providers representing various disciplines coming in and out constantly. Decoding the environment includes explaining what the ICU monitors are, what the different numbers and alarms mean, and a basic explanation of each piece of equipment and how it relates to the treatment plan. The roles each person on the care team play are explained to family members because it is often not obvious, even from our titles. Families also need to be cued in to their new role as caregiver. The act of decoding the environment may need to be performed iteratively because stress may block learning and memory formation during the acute exposure to critical illness [8].

Families need to be assured that not all alarms require immediate attention. This can decrease anxiety as well as mitigate forming an inappropriate impression of clinician inattention. In addition to decoding the environment, practicing reflective inquiry daily helps to identify false perceptions or myths regarding the situation. Reflective inquiry is another strategy of Facilitated Sensemaking in which clinicians can ask the family members open-ended questions such as “if you were going to tell the rest of your family the most important thing that happened in your (husband’s, brother’s, mother’s, daughter’s) care today, what would it be?” [8]. In the case of the family labelled as difficult, were they upset because of the perception that the alarms were not tended to. In the reflective practice, the “mythical realities” could be redirected toward a constructive truthful narrative.

Monitoring bedside conversations is important to assure the choice of words is healing not only to the patient but to the listening family as well. Words can harm or heal. It has been demonstrated that the incidence of PICS-F is greater when clinicians are not perceived as caring [24]. Interteam conflict can erode family coping ability [25]. Even when patients appear not to be conscious enough to listen and retain information, many survivors report details of conversations that both helped them in the healing process and also those that scared them resulting in nightmares, hallucinations, or flashbacks of a horrifying ICU experience [26]. Imagine the last time a colleague described a “difficult” family member. Think back to the event and reflect upon whether the difficulty could have been iatrogenic. Did they overhear something that was said inappropriately? Did they distort information because of a lack of communication or insufficient information? Increased or improved communication may prevent or solve the tension between the family and the healthcare team and decrease the likelihood of a family member being labelled as “difficult.” Clinicians need to be aware that in addition to decreased satisfaction, the likelihood of posttraumatic stress after they leave the ICU rises. According to the most recent *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), the threat or even perceived threat of actual or potential death to their family member may result in posttraumatic stress [27].

Engagement

Utilizing a tool designed to facilitate conversations during rounds such as the ABCDEF (*A*ssess, prevent and manage pain, *B*oth spontaneous awakening and breathing trials, *C*hoice of analgesia and sedation, *D*elirium assessment, *E*arly mobilization and exercise, and *F*amily engagement and empowerment) bundle can also improve patient and family outcomes [28]. This evidence-based bundle has been demonstrated to reduce pain, delirium, agitation, and long-term consequences of critical illness. The F portion of the bundle implies that families support clinicians with attaining the ABCDE goals. They can be encouraged to report pain, report changes in mentation and cognition, coach the patient through breathing trials and attempts at mobilization, and keep the patient cognitively active to prevent delirium [29].

Family engagement in the rounds utilizing this bundle empowers family members to help navigate decision-making and understand the severity of illness. It also influences clinicians’ understanding of the family or patients’ concept of illness to further individualize care [30]. Involving families in rounds may address questions families have at the moment, facilitate communication, and clarify family role during the ICU stay. This intervention also demonstrates respect for persons increasing the speed and quality with which a trusting relationship is formed. Structuring time out of each day to have open conversation between physician-patient and nurse-patient is also indicated. The time spent in proactive communication may decrease the need for after-hours phone calls later in the day.

A simple beside poster or whiteboard organization that is tailored toward "persons" rather than "patients" and their families also conveys messages of care. Some refer to these as "All About Me" posters, in which clinicians and the family members can fill in information about what the patient likes or dislikes, their preferred name, spiritual beliefs, hobbies, what gives them meaning, favorite foods, music, etc. Family pictures and a picture of the patient at baseline health can be posted. Each clinician that enters the room can use the information to develop a better image of who the person is behind the patient, which in turn can be used to form a trusting and caring relationship. Care, stemming from the information provided, can be tailored to the individual in order to create a healing environment such as playing their favorite music in the background, or sharing a prayer, and not feeding them their most disliked foods. This simple yet effective strategy involves families as partners in designing the ideal environment and care for their loved one.

The SCCM guidelines recommend that family presence in the ICU should be open and flexible with the intent to accommodate patient and family presence 24 h a day [7]. Family members now move past the concept of being visitors or visiting to being present and engaged in the caring process. Family presence paired with empowerment can improve outcomes for both the patient and family [31, 32]. In a randomized controlled trial of mothers whose child was in a pediatric ICU, the mothers who were encouraged to visit and engage in care activities taught to them by the nurse reported significantly less stress and PTSD symptoms than those who were not [31, 32].

Encouraging family presence is necessary to facilitate sensemaking. How can families understand what is happening or what their role is if they are not present? In the process of Facilitated Sensemaking, family members are encouraged to be present, are welcomed by clinicians, and provided opportunities to perform simple bedside care, if desired [8]. An assessment is necessary to identify the family's preference for inclusion in care and determine which care activities would be most appropriate in this situation. Providing a comforting presence, assisting with care, participation in rounds, and goal setting are some of the means by which the family member's with which to serve as a surrogate decision-maker may be strengthened [21]. Following the assessment, family members are offered tailored interventions. Perhaps the family members are very stressed, anxious, and pacing around the room. The nurse can provide them with an invitation to perform a very basic task, such as holding or massaging the patient's hand or providing a hand massage with lotion. Activities can further progress to applying lip balm, reading, playing cards, letter recognition from word puzzles, passive range of motion, or simply praying together.

Once the patient is more awake and interactive, families can be encouraged to be their individualized coach [8]. The role of the coach is to motivate the patient to recovery. Encouraging the ICU patient to practice active range of motion exercises or mobilizing while intubated or on dialysis can be best accomplished by the familiar voice and encouragement of the family. Explain why mobilizing or exercising is good for the patient to the family, who can then in turn convey the message to their loved one in a manner they would best understand. Knowing that mobility can prevent delirium and that they played a role in this important preventive health strategy is empowering for the family, giving them purpose in crisis which can be protective to their mental health.

Other coachable opportunities can include encouraging the patient to brush their own teeth or hair, help bathe themselves, help them use a phone or laptop, or be as independent as possible. In addition to encouraging activities, the family member can also encourage the patient to sleep and rest. Sleep is vital to the patient's outcome as evidence demonstrates patient sleep in the ICU is very poor [33]. If present at night, families are in a great position to facilitate nighttime hours and a nighttime routine, turning the lights out at 10 p.m. and ensuring quiet hours [34]. In turn, family members can also sleep during those hours to promote their own health, so they can better take care of their loved one during daytime hours [34].

Decision-Making

The role of surrogate decision-maker needs to be taught to the person within the family assuming this role and explained to the entire family unit to prevent role and family conflict. It is important for them to know that requesting whether or not the patient has an advanced directive, living will, durable power of attorney, or other advanced planning document is routine part of practice and not because death is imminent. Usually these explanations are done by the physician and reinforced by the nurse. The physician also assesses the preference for inclusion in decision-making. Due to the volume of time nurses spend with family members, they may advocate by providing the physician with their assessment of the family's desire for participation in decision-making as well as quantity of information desired. Decision regret among family members can be avoided by reminding surrogates that their role is to inform the clinical team of what the patient would have wanted if they had been able to voice their own opinion. Therefore, the decisions are really that of the patient and not what the surrogate would do for themselves in a similar situation. Care is taken to help the family through disparate views on next steps to prevent family fragmentation. Detailed policy statements regarding how to engage families in decision-making are published elsewhere [35, 36].

Staff Need Practice and Training

Staff may need assistance to incorporate the interventions which solidify each of the four components of Facilitated Sensemaking into a whole. Whereas technical skills are often taught and tested, teaching and evaluating competency in family care, though recommended, is generally not, resulting in a wide range of skill in working with families. All components of Facilitated Sensemaking require interpersonal skills to deploy: development of caring relationships, encouraging family presence and engagement; encouraging participation in decision-making; and facilitating communication.

It is no longer acceptable to care for the patient without tending to the family [7]. Care of the patient encompasses not only the singular patient but the family as well. In an environment which dictates proficiency, efficiency, and critical thought, it is easy for the clinician to become so entrenched in the tasks of the moment that they allow little room for the caring self to shine through. It is important that the family know that their clinician is not only competent but also that they care. Further, feeling cared for is an important factor that can affect family health and well-being as well as their capacity to optimally engage in health-promoting self-care [20]. Clinicians need to take the time for empathic listening in order to be open to the family's suffering, hear their fears, and recognize their needs, preferences, and desires [21].

The clinician must also be aware of available resources which can be utilized in the event that the medical goals of care are in conflict with the family's desires. A family conference can provide the setting for information exchange, role clarification, resolution of conflict, an opportunity for the family to express their wishes in a supportive environment, and if appropriate, revision of goals. When this is not effective, or when conflict exists despite standard communication efforts, an ethics consult is indicated [7]. It has been recommended that at a minimum family conferences are organized when death is determined to be a potential outcome, there are significant changes in prognosis or multiple consults on the case with conflicting messages, and every 7 days [22].

The hurried pace of the ICU, frequent shift changes cramped quarters may interfere with the type of communication needed to provide the greatest family support. Though the clinician is knowledgeable of and familiar with the ICU environment, the family, most likely, is not. Part of clinician training may include developing lay language scripts to explain treatments, equipment, alarms, and/or manifestations of illness. The use of medical jargon should be avoided. Verbal explanations should supplement any visual aide provided. A combined approach of verbal, written, and video educational materials is recommended. Inquiring as to the family's understanding of the day's events or of what was said to them by other clinicians may provide clarification and avoid false impressions. Lastly, a review of how the family felt that the patient's or their needs were met or not met is an important factor in communication which clinicians should include in daily conversation [21].

With practice, clinicians will not only learn to incorporate the family into a collaborative approach to patient care, recognizing and valuing the family as their partner in care, and look forward to family presence.

Vulnerable Populations

Neonates

The patients of the Neonatal Intensive Care Unit (NICU) are infants whose births, and quite possibly, whose futures have been complicated through problematic pregnancies, intrauterine accidents, premature births, syndromes, malformations, and the inability to adapt to life outside of their mothers' uteruses. Having hoped for, envisioned, or planned for a different beginning, parents are forced into the painful realization that the plans which they had for their children's births have been rewritten [37].

Parents whose children begin their lives in an NICU must deal with an enormity of feelings and emotions. Tubes, machines, monitors, alarms, their infant's physical appearance, a new language, and not knowing what to expect may shock and overwhelm them [38, 39]. Fathers are uneasy, as they accompany the infant from the delivery room to the NICU, where mom is left behind. Both may feel that they are incapable of keeping their family together. They experience a strong desire to be close to and touch their newborn so that the infant knows that they are, but at the same time, fear that their infant would not like being touched or that they would cause harm [40]. Parents may feel that they may be judged that they decided to sustain the life of the baby whose termination was advised [41]. Some may feel that their faith is being tested, while others may feel that they are being abandoned and punished by God [42]. Some families, upon giving up hope, allow a sense of powerlessness to consume them [43]. Many wrestle between fear of their infants' death and concern over the long-term effects should the infant survive, knowing that it may be years until the full extent of neurological and sensory injuries are known [38, 44]. Thoughts of how it should have been, the planned-upon child, will continue to haunt them [39].

The vast extent of feelings and emotions experienced by the parents of infants in the NICU can result in long-term emotional struggles and far-reaching effects. Coping with grief, anxiety, helplessness, depression, and unmatched healthcare needs of their children, families may be left vulnerable to isolation and impaired relationships [42]. PTSD is an outcome for some parents, which is associated with severity of illness in the infant [39, 44, 45]. Severe PTSD in mothers has been associated with impaired maternal-infant relationships based on a pattern of control, inconsistency, and insensitivity in interactions with their infants. While patterns of control in maternal-infant relationships are associated with later behavioral problems, mothers' inconsistencies and insensitivities in interactions with their infants may also affect their infants' cognitive and social development [44]. The impact of how care is delivered in the early days of the infant's life can have a significant effect on the early- and long-term experiences of parents and their infants [46].

Early interventions to support the formation of healthy maternal-infant dyads may help to reduce psychological distress in parents and developmental and behavioral problems in their infants [44].

Traditionally, parents have been left on the periphery, while care is focused on the infant. Powerless, intimidated, and left to observe while others take care of the child that they long to hold, parents struggle to see themselves as parents and define their role [46–48]. Some even feel fraudulent [37].

Family-centered care recognizes that parents are not visitors. Moved from the sidelines to the bedside, parents are introduced to the NICU environment and learn about the complexities of their infants' problems [37]. Parents express an increased connection to their infants and increased satisfaction with their parenting role when holding their infants skin to skin. Mothers' milk production increases, as does their bonding experience, sensitivity, and expression of affectionate behaviors toward their infants [37]. Benefits of skin-to-skin care for the infants include less episodes of apnea, better sleep regulation, regularity of heart rates, reduced bouts of infection, less advanced retinopathy, and less chronic lung disease [37, 49]. Exposure to mothers' voices and odors was also shown to have a positive influence on feeding progression as well as to contribute to their infants' cardiorespiratory stability and state regulation [46].

As they become increasingly comfortable with their infants, parents are instructed on feeding, bathing, dressing, diaper changes, and administering oral medications under the supervision of the clinician [46, 50]. Parents' increasing participation in their infants' care has demonstrated reduced lengths of stay, increased rates of weight gain, increased rates of breast feeding at discharge, decreased hospital-acquired infections, less maternal anxiety and depression, and more positive interactions with their infants. Fathers who participate in their infants' care state that they were able to communicate with their infants and that eye contact and their infants' reaction to their voices were especially important [40, 51].

Involvement in infant care is vital for both parents and infant. Protecting mothers from overwhelming stress improves the maternal-infant relationship. Lasting behavioral outcomes are associated with daily interactions between mothers and their NICU infants and the mother's ability to interact successfully with her infant. Positive parenting provides premature infants with the gift of resilience [39]. Family-centered care reconnects parent and child. Therefore, care of the family is essential for the well-being of the child and is an essential part of the scope of ICU clinicians, not an afterthought.

Pediatrics

> I can still recall the night which changed our lives forever. I was coming back with a friend in the car when I received an urgent call from one of my neighbors asking me where I am at the moment- she said that she saw smoke and my house was on fire. I started to panicked and tried calling everyone's phone number to find out more about the situation. I finally got

> hold of my ex –husband to check on the kids who were left in the care of their aunt and boyfriend. I drove home without ever realizing how fast I was driving. I had 3 children – Fernando, 11 years old, Junior, 5 year old, and Ezmi, 3 year old who were being watched over by their aunt and her boyfriend. The children were asleep at the back room of the house when the fire from the space heater slowly engulfed the house. Their aunt's boyfriend tried to get the children but he was only able to get Junior out who was passed out due to smoke inhalation. Ezmi was also unconscious but Fernando died on the scene. When I got to UCSD Burn Unit, I was unsure what I was going to see. I wanted to be with my children but I know that they need to be taken cared of because they were severely burned. I try to be strong for my children. Everyone was helping us - doctors, nurses, social worker, case manager and other staff to get through this challenging times. I stayed in the room on Ezmi more because she was awake but I also go to see Junior when he was intubated. Physically and emotionally I am drained throughout the hospitalization but I do know that my faith help me move forward instead of putting blame on others for the accident. Junior and Ezmi are now at home playing like normal kids. We still do regular doctor's follow- up for Junior because of his trach. They cannot sleep without each other or someone else in the room at night. Both are in school doing well. – paraphrased from testimony with permission by Juanna Vasquez Nunez (Mother)

As is seen in other pediatric critical care admissions, anxiety, depression, and posttraumatic stress disorder for both parents and burn-injured children are significantly elevated and may remain abnormal for many years after discharge. Parents also suffer from guilt [52]. The burn event is always unexpected, and coping with the trauma can be further complicated by the patient's pain, elevated anxiety, fear, uncertainty of outcome, need for multiple surgeries, the sight of wound care sessions, grueling rehabilitation therapy, disfigurement, and the extended period of time away from home.

In this case the immediate need was to provide burn care to the injured live children, but the staff were conflicted with how and when to approach the mother with news that her third child had not survived. All clinicians support the parents with understanding the sights, sounds, and expectations of the ICU environment. However, clinicians also expect to fill in the social-emotional gap when parents are not present for their children or need to trade off time between children. Targeted support for these needs may be provided by a variety of resources.

Certified Child Life Specialists support the healthcare team with developmental, social, and emotional needs of hospitalized children and their families. It is the goal of the child life program to minimize the fear and anxiety often experienced in the healthcare setting by providing knowledgeable, compassionate, and developmentally appropriate support services (Personal communication: Kathryn Hamelin, Certified Child Life Specialist Manager, July, 2017). In this particular case, the situation was further complicated by the death of the oldest child and competing priorities providing support for the two burn surviving children. Early activation of a child life specialist, family navigator [7], or family ombudsman is essential for prompt attention to emotional and psychological of the parent/child needs during the critical care admission, while clinicians are stabilizing the patient and providing direct care.

As ever greater number of children and youth survive serious burn injuries, more focus will be placed on preparing parents and siblings of survivors for caregiving after discharge. Providing care is the normal expectation of parents. However, the role of pediatric burn patient's parent/caregiver, and at times siblings, is often expanded to include unfamiliar nursing and physical and occupational therapy duties. Once discharged, parents provide wound care, change dressings, perform scar massage/hydration, and ensure that their child engages in a home exercise program: all responsibilities outside the normal and expected realm of parenting. Allowing them presence so that they can gradually learn the skills necessary for these tasks is indicated.

After initial stabilization, role modeling bedside behaviors and care will help parents to find their desired level of involvement. Because anxiety can be shared between humans [53], it is important for clinicians to remain calm at the bedside and provide parent's permission to take a break from the bedside when needed. A psychologist may also be necessary, though only tested in parents of neonates [7]. Given the high prevalence of persistent mental health issues, it is prudent upon transfer, discharge or death, to include the possible necessity of a psychologist or psychiatrist referral with handoff communication and parent education. Early spiritual assessment is necessary to identify the value structure of the family and activate the faith community to provide support when indicated by the assessment [22]. Emerging evidence suggests that specially trained care coordinators or communication specialists call navigators may improve family satisfaction with physician communication, reduce cost of care, length of ICU and hospital stay, and decrease family psychological symptoms. The use of a family navigator is recommended [7], yet the cost of adding a member to the team may be prohibitive.

In addition, clinicians can predict that hospitalized children will need parental presence, and parents will want to be present but will require help in learning how to participate in care and support their child. In the special case of burns, parents will need to overcome the dramatic change in appearance of their child as well as receive help to cope with witnessing their pain. With enough support, the parents, in turn, can be taught to provide the role of coach, encouraging their child to adhere to the treatment plan and endure the difficult treatments. Presence may include presence during rounds as recommended by the Society of Critical Care Medicine (SCCM) and endorsed by many other professional societies [7]. Though concerns have been raised by clinicians over the quality of teaching, the quantity of time parents may take during rounds with questions, and issues of privacy, in a concise definitive review, it was found that families find information a higher priority than privacy and a full 95% would want to be present during rounds [23].

A 2013 study conducted in a burn unit among parents of 58 children with burns, aged 8 months to 16 years, found that the parents in the burn group experienced a lack of resilience, and more symptoms of PTSD than parents in a comparative community. Parents with children in the burn unit suffered significant psychological distress within the first week of their child's burn [54]. Five years following a burn, 14–52% of parents still exhibit signs of PTSD [55]. An understanding of the effects of the injury on the body and expectations from treatment plan are necessary to minimize this stress [10].

In this and similar situations, families may benefit from a navigator; a clinician whose role it is to step aside from patient care activities in order to support family members with the information that they need in order to make sense of the immediate situation, provide emotional support, and support adaptive coping skills [7, 56]. Navigators may bridge the gap between the medical team and the family throughout the hospitalization, provide ongoing support, help parents understand the present and developing needs of their child, and provide anticipatory guidance throughout the hospitalization [12].

Once discharged, children are dependent upon their parents for care far beyond the care that their childhood once entailed. It is hoped that the support provided to parents in the acute care setting will diminish distress and caregiving burden.

Non-English Speaking

Communication is likely the single most important aspect of family-centered care. It is well known that the timeliness, quality, and quantity of communication drive both satisfaction and psychological outcomes [57]. Quality includes provision of information in the surrogate's preferred language. Accreditation standards in the United States require interpretation for patients and their surrogates so that they can understand the plan of care and thoughtfully consent to tests and treatments (the Joint Commission, RI.01.01.03, RC.02.01.01, EP 1, PC.02.01.21.01) [58]. Nonetheless, communicating with non-English-speaking families remains a problem. Even though the technology exists to provide translation of the written word and interpretation of oral conversation through video and phone interpreters, time pressures promote the inappropriate tendency to take shortcuts and use of family members, use of native speakers not tested for medical fluency, or not to communicate at all. Use of family members as the interpreter is not acceptable for several reasons. First, the family may filter the discussion to the patient or surrogate so that only issues they feel should be discussed are relayed. Secondly, the privacy of the patient is compromised when a family member who is not the surrogate is used to convey sensitive information like prognosis, tests, or diagnoses of sexually transmitted communicable diseases. And finally, culturally based gender issues might make it inappropriate for a man to discuss issues such as women's health concerns with a female family member who is not their wife. Minors should never be used for any reason as interpreters [7, 23].

Consider additionally that it is legally acceptable for an institutional (ethics) review board to approve "abridged short forms" of research consent for non-English-speaking subjects in the United Sates [59]. The practice of short-form consents seriously limits the amount of information surrogates receive in their own language prior to making the decision whether or not to participate in research. Though legally accepted one could question whether or not the consent truly reflects operating within a framework of family-centered care.

Appropriate, timely, transparent, high-quality communication builds trust, decreasing risk of litigation even amidst negative patient outcomes [23, 60]. Despite standards to encourage compliance with interpretation and keen focus on interpretation during regulatory and accreditation on-site audits, wide variation occurs from organization to organization in available resources and the practice of holding clinicians accountable for appropriate use of interpreters. Leaders in the clinical environment can work to assure that the interpretation phone/video system is available in all conference rooms used for family conferences. Having a nurse or social worker present during family meetings to set up equipment and advocate for interpretation may increase compliance. Prescheduling daily interpretation sessions with non-English-speaking surrogates, to provide updates for the plan of care and obtain consent for planned tests and procedures, is warranted.

Lesbian Gay Bisexual Transgender Queer or Questioning Intersex, Asexual (LGBTQIA) Population

The US Department of Health and Human Services (HHS) Lesbian, Gay, Bisexual, and Transgender (LGBT) Policy Coordination Committee has worked diligently to improve the health and well-being of LGBT communities. Note that while recognizing that the initial “Q” for queer or questioning, I for intersex, and A for asexual are now commonly added to the acronym LGBT, the titles of the regulatory standards at the time they were written referred to only LGBT without intention of negating the rights of the queer or questioning, intersex, or asexual patients and family members. With the signing of the Patient Protection and Affordable Care Act (PPACA) on March 23,2010, under 42 CFR 482.608(a), this legislature guaranteed that all people, including LGBT people, have the right to be visited by their loved ones while in the hospital [61]. This provision also addressed who can make medical decisions on their behalf through advance directives. Under previous legislation, LGBT patients and their families suffered prejudiced practices regarding family involvement. Historically, the definition of family consisted of only blood-related relatives.

The definition of “family” used for this legislation was taken from the Institute for Patient- and Family-Centered Care [62] and is consistent with the definition published by the Society of Critical Care Medicine which was specifically vetted by members of the LBGTQIA population prior to adopting into practice (Table 15.1) [7]. In both definitions, family refers to two or more persons who are related in any way, biologically, legally, or emotionally. Family is defined by the patient. The patient designates who should be considered family members, as able, for the purpose of visitation [63]. Family members and surrogates of the LGBTQIA patient are awarded the same rights as those of any other patients.

Of the LGBTQIA population, possibly the most vulnerable for medical and communication errors are individuals whose gender identity is different from the sex assigned to that person at birth (e.g., transgender, queer, or questioning), also protected by PPACA legislation. Gender identity is an individual’s internal sense of gender. Individuals may identify as male, female, neither, or some combination of male and female. This identity may be expressed through dress, grooming, mannerisms, speech patterns, or social interactions. The patient's pronouns should be reflected in the medical records. Instead of assuming pronouns based on physical appearance, it is always best to ask the patient for the pronoun to use and document. At one time it was common to ask "preferred pronoun," but this has fallen out of favor because to some their pronoun is not preferred; it is just the way it is. Special attention is needed so that once assessed, clinicians accurately record gender in the medical record along with legal name change as indicated. Because some people have both a legal name and a different changed (but not legal) name, it is important to assess patients for both. For family members, there is only a need to know the legal name when it is related to matching the person to the name on legal papers such as a medical directive or power of attorney. It is a matter of respect to ask family about the use of pronoun when unsure, so that the proper pronoun can be used during conversation. It is more offensive not to ask or guess wrong than to ask the question.

Clinically it is important that providers are cognizant of the birth gender of the patient, current gender identity, and the pronoun and name by which the patient wishes to be addressed. Solutions can be provided by vendors of the electronic health record software to assure this information is available in a readily retrievable manner once the social situation is assessed and recorded. The risk of making errors in documentation or communication is high if the patient transitioned to a new gender and name after becoming a patient to that particular healthcare organization. A full description of clinical considerations is beyond the scope of this chapter but includes the need to treat the patient according to birth gender when gender-specific laboratory normals exist. Most important to the discussion of patient- and family-centered care is that it can be psychologically damaging to repeatedly use the wrong pronoun or name when referring to a person, either to the patient themselves or when communicating with family. According to the general principal of respect for humans, it is important to use the gender pronoun and name as directed by the patient or, when unable, their surrogate.

> "Every single American -- gay, straight, lesbian, bisexual, transgender – every single American deserves to be treated equally in the eyes of the law and in the eyes of our society. It's a pretty simple proposition." – President Barack Obama, October 1, 2011 [64]

The Unbefriended Patient

This unbefriended patient is one who does not have a surrogate to act on their behalf as a healthcare proxy. Legislation from state to state varies regarding patients who are decisionally incapacitated and lack an identified healthcare surrogates. Historically, the largest proportion of unbefriended patients have been those suffering from mental illness, homeless, or baby boomers [65]. As the numbers of elderly people and therefore people with dementia rise, the number of unbefriended patients also rises [66].

Providers caring for critically ill patients often perform emergent, life-shaving procedures as surrogate decision-makers until surrogates can be identified. However, if the patient remains unbefriended, a surrogate decision-maker may be appointed by court order [65]. In 2016, the American Geriatric Society (AGS) issued a policy statement issuing a call for action to create national (vs. state) standards regarding the unbefriended patient. At this writing, however, the issue is still handled at the state level, and readers are encouraged to research the laws in the state in which they practice. The AGS policy statement also stated that healthcare teams, and not individual clinicians, should make the decisions for these patients according to best interest standards. Hospital ethics consultation is advised prior to court ordered surrogate placement. Early medical social worker (MSW) consultation is indicated to deploy due diligence to attempt to locate family [66]. It is incumbent upon providers of patients on a trajectory toward dementia or cognitive incapacitation to prevent them from becoming unbefriended by encouraging the appointment of a surrogate while still able to make medical decisions [66].

This unbefriended population of patients within the ICU require special care considerations while hospitalized. In addition to legal issues, the healthcare team may fulfill the social role of family, while the patient is hospitalized. Recognize that without visitors the only human voices or touch this patient will receive will come from those providing bedside care. The importance of acts of caring is heightened because without conscious recognition and attention to the human need for affiliation [20], the patient will not benefit from the healing power of presence and caring human touch.

Novel Intervention: The Diary

Diaries

European hospitals have been implementing ICU diaries since the 1980s for their patients and families as a means to optimize mental health and improve quality of life after critical illness [67]. ICU diary programs vary throughout the world. A review of recent United States literature shows that diaries are typically comprised of a collaboration of authors including physicians, nurses, family, and visitors [68]. Entries are written to the patient rather than about the patient in patient language, offering messages of hope and caring. Some diaries include pictures of common ICU equipment and/or the view of the room as the patient might see it [69]. Clinical staff may provide more clinically focused entries in lay terms and are encouraged to write about issues that often stimulate nightmares or hallucinations such as restraint, endotracheal tubes, the magnetic resonance imaging machine, and urinary catheters, in addition to messages of hope and caring. Family and visitors offer more emotional messages [69]. Studies have shown that when patients survive the critical illness and are able to read their illness narrative, the diary helps fill in memory gaps or reconstruct delusional memories toward reality [70].

In addition to improving patient and family outcomes [71, 72], ICU diaries can influence family members and nurses. Families have reported that reading messages of care, empathy, and support humanized the clinical staff [73]. ICU diaries with multiple family member are more cohesiveness if all members share the same inner narrative. Opposing or family members in disagreement might not benefit from the jointly authored diary. When multiple family members contribute to a diary, a leader emerges in influencing the illness narrative which can shape the future perception of the ICU experience for the patient [74].

The use of diaries can be utilized as a starting point for conversations between family members and family to staff [74, 75]. The use of diaries allows staff to discern family frustrations and identify areas requiring additional education or resources [69]. Diaries provide an opportunity for clinicians to monitor the illness narrative for myths, distortions, and concerns so that communication can be course-corrected in real time.

Nurses and physicians report that writing in the ICU diary allowed them to connect to the person behind the patient and therefore strengthen the relationship between clinician and patient. Writing messages to preserve hope when a patient deteriorated is difficult, but learning these skills foster professional development and exposure to written reflection, a skill that may need to be cultivated [62].

Joint ICU diary entries between staff and families have a potential to improve family communication and satisfaction [69]. Though families anecdotally and through qualitative research consistently report that diaries are helpful, family satisfaction scores may be slow to improve after starting a diary program or may not be the best measure of success [76].

Though ICU diary implementation practices vary throughout organizations, the underlying goal of improving patient and family outcomes related to PICS and PICS-F remains constant. Diaries may also be useful as a screening tool to refer patients to a post-ICU recovery clinic, where a trained professional can debrief the patient and family on their experience and screen for symptoms of PICS or PICS-F [76]. It has been suggested that use of a trained professional in ICU stay debriefing adds a deeper level of caring and empathy ultimately decreasing the likelihood of posttraumatic stress [77].

The SCCM family-centered care guidelines recommends the use of ICU diaries to improve psychological effects from critical illness exposure. The guidelines based their recommendation upon on the evidence supporting decreased patient and family stress disorders and improved communication with no evidence of harm [7]. Literature supports the use of ICU diaries in decreasing PICS and PICS-F however continued studies on the mechanism in which diaries have this effect needs to be addressed [75].

Staff Resilience

Self-care is an essential part of the scope and practice of nursing [78–80]. There is an increasing emphasis on the psychological health for staff providing direct clinical care [81]. Cumulative stress may lead to second victim syndrome, being a victim of one's own work environment. This stress can result in burnout and/or compassion fatigue [82]. Clinicians have a moral and professional obligation to care for critically ill patients and their families in often challenging situations [79]. They provide emotional and psychological support to the family who have come to trust them, experiencing directly the raw emotions of agony, despair, grief, and suffering on a regular basis. This caregiving may take a toll on clinicians, especially when conflicts arise between their moral values about how the medical treatment of the patient is being managed, or when exposed to repeated traumatic events such as death or disfigurement. Family trust and ability to cope can be negatively affected when they sense or witness conflict within the team [25].

Stress debriefing has been shown to be an effective technique for stress management and helps in improving overall staff psychological well-being [83]. Through debriefings clinicians may be able to learn through the experience which may lead to posttraumatic growth rather than stress disorders [84]. Debriefings may be led by a chaplain, social worker, specially trained nurse, counselor, ethics consultant, or palliative care expert and offered to all disciplines involved in the care of a critical ill patient whose case triggers an emotional response. During a debriefing, clinicians are welcome to share their thoughts about how it felt to be involved in patient's hospitalization, what went well, and what went wrong. This form of psychological assistance helps staff to express emotions which they are unable to show, or kept to themselves, while taking care of critically ill patients and the family who rely on them for support.

Emotional grand rounds can also be conducted to focus on the emotional toll of providing care in challenging cases. These interprofessional forums help clinicians to process their feelings and build recognition that they are not alone in their thoughts or feelings. Debriefings also promote the concept and culture that it is an acceptable practice to tend to self-care in the work environment [85]. Lastly, in the moment when the team experiences a patient death, one helpful practice is to perform a "pause" for 45 seconds after the death for everyone involved to honor the person that has passed and reflect upon the efforts made to save that person's life or provide a peaceful death [86]. These forms of self-care are an essential component of family-centered care because it is only when we are emotionally healthy that we can provide the optimal care to those we serve [20].

Our Experience: Steffanie Strathdee and Thomas Patterson

In November 2015, Tom and Steffanie were on vacation in Egypt when Tom fell seriously ill with gallstone pancreatitis. After being treated briefly at a clinic in Luxor, he was medevacked first to an ICU in Germany and then to an ICU at home in San Diego, CA. He was further diagnosed with a large abdominal abscess infected with MDR Acinetobacter baumannii, which quickly became resistant to every antibiotic he could tolerate. His care team debated how to treat him, but ultimately decided he was too weak for surgery and attempted to drain his abscesses with abdominal catheters. One day before discharge to an LTAC, an internal drain slipped inside Tom's abdominal cavity, spilling the infected fluid into his bloodstream and sending him into septic shock. He was placed on a ventilator and multiple pressors and slipped in and out of a coma. Two months later, he was on the verge of multisystem organ failure. He was ultimately saved with intravenous phage therapy [87]. Despite experiencing seven episodes of septic shock and 9 months of hospitalization, he was discharged home in August, 2016, and has made a full recovery.

Our experience with an acute care facility in Egypt followed by two ICUs, one in Europe and one in the United States, offers insights that illustrate several key messages referred to earlier in this chapter. In general, the care Tom received in all three facilities was excellent. However, in retrospect, several aspects of family-centered care could have reduced the stress and anxiety Tom, myself, and our family experienced.

One cannot overstate the importance of language and culture in the context of the ICU environment. For example, in Egypt, the Muslim faith of the female nurses did not permit them to bathe or assist male patients with toileting. This was not communicated, so I felt obligated to stay with Tom 24/7 to attend to his needs. On the other hand, the care team in this under-resourced clinic was very attentive to my needs. I will never forget the doctor who furnished me with a blanket and a pillow so I could sleep beside Tom at night and the nurse who brought me a Turkish coffee in the morning.

Upon admission to the ICU in Germany, language barriers and the hectic pace of the ICU meant that the care team did not explain that Tom was to be kept in isolation under strict infection control measures because he was arriving from Egypt. This practice was clearly critical, as he was soon diagnosed with MDR *A. baumannii*, a bacteria which had caused outbreaks that led several ICUs to be closed across Europe. However, the lack of communication about the need for Tom to be kept in a locked ward only served to exacerbate Tom's delirium and paranoia. In his mind, he was being locked in an asylum and I was complicit in allowing the care team to do so. Other logistical aspects were important as well. The ICU in Germany was staffed by a relatively small number of doctors and nurses and were in close communication with one another, which made them extremely efficient. However, the ICU only offered visiting hours from 4 to 6 p.m., and since the care team rounded early in the morning, there was no opportunity for family members to participate in rounds. At the time, Tom was conscious but often delirious. One morning he called me at the hotel and said that at rounds that morning he was informed that he had a brain tumor. "Or at least I think that's what they said," Tom admitted, "because I could have imagined it." But Tom hadn't imagined the conversation. The tumor ended up being a pituitary adenoma that was an incidental finding unrelated to his illness and was treated at a later date. However, at the time, the way this information was conveyed caused considerable stress for both of us.

The ICU back home in the United States was run very differently. The hospital was large, and the ICU was overflowing with patients. Although my husband and I are both in allied health professions field, we were overwhelmed by the never-ending number of doctors, nurses, and other health professionals who were following his case. I joked that someone should write a book called "ICU for Dummies" that would help explain simple things like the protocol for entering the

ICU, determining which nurse and doctor was assigned to his care that day, and what various acronyms and slang terms meant like NMU, desat, or pressors. Our confusion was complicated by frequent shift changes, which meant we never seemed to know who the point person was that could address our questions or concerns. We also had some irrational expectations. For example, when Tom was placed on a ventilator and later received a tracheotomy, his daughters and I assumed he would be able to speak. It was not explained to us until later what a speech valve was and how Tom would need to successfully breathe off the ventilator for some time and to relearn how to swallow before we could hear his voice again.

Once we learned that family members could participate in rounds, the anxiety level eased among our family. Rounds was one of the few times I felt like I had control over the terrible situation that was suddenly facing us, and where I could learn about Tom's conditions and potential avenues for treatment. This empowered me. It also allowed me to reassure Tom during the moments when he was conscious and communicate with other family and friends about his status and prognosis. This reduced the number of times other family members called the care team with questions. In the end, I believe this changed their opinion about our role from a "difficult" family to one that was actively engaged as a valued member of the care team. On several occasions, my role in rounds allowed me to play an important role in clinical decision-making, such as deciding whether Tom should be switched from an NJ feeding tube to a GJ feeding tube. Once I averted a potentially dangerous situation by alerting the PT that Tom had just been diagnosed with a DVT, which she was unaware of since this had not yet been entered into his electronic medical record. Most importantly, feeling valued as a member of the care team gave me the confidence to propose an alternative treatment – bacteriophage therapy – to the care team when it was clear that Tom was dying. The entire hospital system supported this unproven, untested treatment that was ultimately provided on a compassionate basis after obtaining an emergency investigational new drug approval from the Food and Drug Administration. The successful outcome (Tom's survival) is one that is being viewed as a potential "game-changer" in the treatment of MDR bacterial infections.

Another advantage of this ICU was that visiting hours were 24/7. We appreciated this immensely, especially when Tom's condition was grave because we could schedule friends and family to spend time with him around the clock. Online apps such as Caring Bridge and Facebook also proved to be helpful for sharing updates and photos with family and friends who provided support. The use of a "guest book" which served as a diary was important during this period because visitors could write to Tom and our family and share their reflections when they visited even when Tom was comatose. Later, during his recovery, the diary later served as a means of reacquainting Tom with what he had missed and showed him how much he was cared for. We have turned to it several times since his discharge.

One of the most difficult aspects of Tom's ICU experience was his chronic delirium. Tom's experience was framed by his training as a psychologist who has published numerous papers on patients with schizophrenia. Unlike drug-induced hallucinations, Tom's hallucinations were his reality, replacing all "real-world" experiences. This new “reality” was terrifying in part because these hallucinations lasted for long periods of time. During his occasional moments of lucidity, he understood that that he was unable to distinguish between these hallucinations and the real world around him. The care teams we worked with were sensitive to this and offered various suggestions, such as melatonin and sunlight to regulate his internal clock and, later when he was recovering, visits outside in a wheelchair. However, the most helpful intervention was a note the charge nurse pasted above Tom’s bed one day, when it was clear that turning him every 2 h was no longer needed because he was more mobile now, turning himself during sleep, and had no pressure wounds. “GOAL: A GOOD NIGHT SLEEP! TURN ONLY EVERY 4 HRS.”

As Tom recovered, some members of his care team who had treated him when he was comatose had trouble adjusting. After his usual nurse on night shift complained that Tom was being argumentative and had refused his bed bath, Tom explained that he refused because the nurse wanted to give him the bed bath at 1 AM, with cold water. “He never complained before,” the nurse replied to me. Another time, a GI resident entered Tom’s cubicle and placed his hands on his abdomen without introducing himself. “Hey!” Tom cried out. “I’m not a loaf of bread!”

Due to his prolonged illness and its severity, Tom, myself, and other members of our family experienced symptoms of PTSD. I think the moment we realized this was a few months after Tom was discharged, when he tripped and fell one day and skinned his knee; we both burst into tears. I expected Tom to experience PTSD, but no one ever told me that I might too. We first sought out a psychologist which allowed us to work through our trauma and to share them with each other. We realized that we had shared the same ordeal, but we had very different experiences and perspectives. Our daughter sought Eye Movement Desensitization and Reprocessing (EMDR) therapy which she found extremely helpful. Although Tom and I were both skeptical and knew there was no evidence that it would work in this specific situation, we both underwent several sessions and found that it eased our symptoms of stress, anxiety, and hyperreactivity. It has also helped to revisit the ICU on several occasions, which no longer feels like a terrifying place, but a place where people are cared for and, sometimes, are healed.

Conclusion

In conclusion, family-centered care is a matter of public health with the potential to optimize the mental health and quality of life of millions of ICU family members in the United States every year. A well-rounded program of family-centered care may reduce PICS-F but requires forethought, practice, education, and organizational support. Communication, caring, and engagement are key elements of any program of family-centered care. Facilitated Sensemaking is one tested method to organize care to deploy the evidence-based recommendations published by the Society of Critical Care Medicine.

References

1. Davidson JE, Jones C, Bienvenu OJ. Family response to critical illness: postintensive care syndrome-family. Crit Care Med. 2012;40(2):618–24.
2. Netzer G, Sullivan DR. Recognizing, naming, and measuring a family intensive care unit syndrome. Ann Am Thorac Soc. 2014;11(3):435–41.
3. Needham DM, Davidson J, Cohen H, Hopkins RO, Weinert C, Wunsch H, et al. Improving long-term outcomes after discharge from intensive care unit: Report from a stakeholders' conference. Crit Care Med. 2012;40(2):502–9.
4. Critical care ethics: a practice guide. 2nd ed. Mount Prospect: Society of Critical Care Medicine; 2009. 229 p.
5. Davidson JE, Netzer G. Family response to critical illness. In: Bienvenu OJ, Jones C, Hopkins RO, editors. Psychological and cognitive impact of critical illness. New York: Oxford University Press; 2017. p. 191–209.
6. Benner P. From novice to expert. Am J Nurs. 1982;82(3):402–7.
7. Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, et al. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. Crit Care Med. 2017;45(1):103–28.
8. Davidson JE, Zisook S. Implementing family-centered care through facilitated sensemaking. AACN Adv Crit Care. 2017;28(2):200–9.
9. Hwang D, Davidson JE, Kraus S, Bullard HM, Christie L, Franck LS, et al. SCCM family-centered care guidelines supplement: work tools for guideline implementation Chicago: society of. Crit Care Med. 2017.; [updated 7/16/2016. Available from: http://www.learnicu.org/SiteCollectionDocuments/Family-Centered-Care-Guidelines-Implementation-Tools.pdf.
10. Davidson JE. Facilitated sensemaking a strategy and new middle-range theory to support families of intensive care unit patients. Crit Care Nurse. 2010;30(6):28–39.
11. Davidson JE, Daly BJ, Agan D, Brady NR, Higgins PA. Facilitated sensemaking: a feasibility study for the provision of a family support program in the intensive care unit. Crit Care Nurs Q. 2010;33(2):177–89.
12. Jacobs C, Dobbins C. From rough waters to smooth sailing: NICU population management model. Newborn Infant Nurs Rev. 2016;16:164–7.
13. Roy C, Andrews HA. The Roy adaptation model: Prentice Hall, New Jersey; 1999.
14. Davidson J, Daly B, Agan D, Brady N, Higgings P. Facilitated sensemaking: a feasibility study for the provision of a family support program in the intensive. Care Unit Critical Care Nursing. 2010;33:177–89.
15. Skoog M, Milner KA, Gatti-Petito J, Dintyala K. The impact of family engagement on anxiety levels in a cardiothoracic intensive care unit. Crit Care Nurse. 2016;36(2):84–9.
16. Bartzak P. The physiological antecedents of psychological manifestations occurring in patients with PTSD. Medsurg Nurs. 2016:S14–5.
17. Sherin J, Nemeroff C. Post-traumatic stress disorder: the neurobiological impact of psychological trauma. Dialogues Clin Neurosci. 2011;13:263–78.
18. Gill J, Saligan L, Henderson W, Szanton SPTSD. Know the warning signs. Nurse Pract. 2009;34:30–6.
19. Netzer G, Davidson J. Creating patient and family-focused care in the intensive care unit. Person-focused health care. Springer Publishing Company, New Jersey; 2016. p. 39–62.
20. Duffy JR. Quality caring in nursing and health systems: implications for clinicians, educators, and leaders. 2nd ed. New York: Springer Pub; 2013. 312 p.
21. Davidson J, Zisook S. Implementing family-centered care through facilitated sensemaking. Adv Crit Care. 2017;28:1–10.
22. Davidson JE, Powers K, Hedayat KM, Tieszen M, Kon AA, Shepard E, et al. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004-2005. Crit Care Med. 2007;35(2):605–22.
23. Davidson JE. Family presence on rounds in neonatal, pediatric, and adult intensive care units. Ann Am Thorac Soc. 2013;10(2):152–6.

24. Siegel MD, Hayes E, Vanderwerker LC, Loseth DB, Prigerson HG. Psychiatric illness in the next of kin of patients who die in the intensive care unit. Crit Care Med. 2008;36(6):1722–8.
25. Fassier T, Azoulay E. Conflicts and communication gaps in the intensive care unit. Curr Opin Crit Care. 2010;16(6):654–65.
26. Davidson JE, Harvey M, Schuller J, Black G. Post-intensive care syndrome: what it is and how to help prevent it. Am Nurse Today. 2013;8(5):32–7.
27. American Psychiatric Association. Diagnostic and statistical manual of mental disorders (DSM-5®): American Psychiatric Pub, New Jersey; 2013.
28. Maley JH, Mikkelsen ME. Short-term gains with long-term consequences. Clin Chest Med. 2016;37(2):367–80.
29. Ely EW. The ABCDEF bundle: science and philosophy of how ICU liberation serves patients and families. Crit Care Med. 2017;45(2):321–30.
30. ICU liberation Mount Prospect, Illinois: Society of critical care medicine; 2015. Available from: http://www.sccm.org/Research/Quality/Pages/ICU-Liberation.aspx.
31. Melnyk BM, Small L, Carno MA. The effectiveness of parent-focused interventions in improving coping/mental health outcomes of critically ill children and their parents: an evidence base to guide clinical practice. Pediatr Nurs. 2004;30(2):143–8.
32. Melnyk BM, Alpert-Gillis L, Feinstein NF, Crean HF, Johnson J, Fairbanks E, et al. Creating opportunities for parent empowerment: program effects on the mental health/coping outcomes of critically ill young children and their mothers. Pediatrics. 2004;113(6):e597–607.
33. Elliott R, McKinley S, Cistulli P. The quality and duration of sleep in the intensive care setting: an integrative review. Int J Nurs Stud. 2011;48(3):384–400.
34. Owens RL, Huynh T-G, Netzer G. Sleep in the intensive care unit in a model of family-centered care. AACN Adv Crit Care. 2017;28(2):171–8.
35. Kon AA, Shepard EK, Sederstrom NO, Swoboda SM, Marshall MF, Birriel B, et al. Defining futile and potentially inappropriate interventions: a policy statement from the Society of Critical Care Medicine Ethics Committee. Crit Care Med. 2016;44(9):1769–74.
36. Kon AA, Davidson JE, Morrison W, Danis M, White DB. Shared decision-making in intensive care units. Executive summary of the American College of Critical Care Medicine and American Thoracic Society Policy Statement. Am J Respir Crit Care Med. 2016;193(12):1334–6.
37. Gooding J, Cooper L, Blaine A, Franck L, Howse J, Berns S. Family support and family centered care in the neonatal intensive care unit: origins, advances, impact. Semin Perinatol. 2011;35:20–8.
38. Pepper D, Rempel G, Austin W, Ceci C, Hendson L. More than information a qualitative study of Parents' perspectives on neonatal intensive care at the extremes of prematurity. Adv Neonatal Care. 2012;12:303–9.
39. Zimmerman K, Bauersachs C. Empowering NICU parents. Int J Childbirth Educ. 2012;27:50–3.
40. Martel M, Milette I, Bell L, St-Cyr Tribble D, Payot A. Establishment of the relationship between fathers and premature infants in neonatal units. Adv Neonatal Care. 2016;16:390–8.
41. Stafford C. A case study of trisomy 13: balancing hope and reality. Adv Neonatal Care. 2015;15:285–9.
42. Brelsford G, Ramirez J, Veneman K, Doheny K. Sacred space religious and secular coping and family relationships in the neonatal intensive care unit. Adv Neonatal Care. 2016;16:315–22.
43. Amendolia B. Hope and parents of the critically ill newborn. Adv Neonatal Care. 2010;10:140–4.
44. Borghini A, Habersaat S, Forcada-Guex M, Nessi J, Pierrehumbert B, Ansermet F, et al. Effects of an early intervention on maternal post-traumatic stress symptoms and the quality of mother-infant interaction: the case of preterm birth. Infant Behav Dev. 2014;37:624–31.
45. Feeley N, Zelkowitz P, Cormier C, Charbonneau L, Lacroix A, Papageorgiou A. Posttraumatic stress among mothers of very low birthweight infants at 6 months after discharge from the neonatal intensive care unit. Appl Nurs Res. 2011;24:114–7.
46. Jiang S, Warre R, Qiu X, O'brien K, lee S. Parents as practitioners in preterm care. Early Hum Dev. 2014;90:781–5.

47. Bracht M, O'Leary L, Lee S, O'Brien K. Implementing family integrated care in the NICU: a parent education and support program. Adv Neonatal Care. 2013;13:115–26.
48. Galarza-Winton M, Dicky T, O'Leary L, Lee S, O'Brien K. Implementing family-integrated care in the NICU: educating nurses. Adv Neonatal Care. 2013;13:335–40.
49. O'Brien K, Bracht M, MacDonell K, McBride T, Robson K, O'LKeary L, et al. A pilot cohort analytic study of family integrated care in a Canadian neonatal intensive care unit. BMC Pregnancy Childbirth. 2013;31:1–8.
50. Lee S, O'Brien K. Parents as primary caregivers in the neonatal intensive care unit. Can Med Assoc J. 2014;186:845–7.
51. O'Brien K, Robson K, Bracht M, Cruz M, Lui K, Alvaro R, et al. Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial. Lancet Child Adolesc Health. 2018;2:245.
52. Bakker A, Maertens KJ, Van Son MJ, Van Loey NE. Psychological consequences of pediatric burns from a child and family perspective: a review of the empirical literature. Clin Psychol Rev. 2013;33(3):361–71.
53. Eley TC, McAdams TA, Rijsdijk FV, Lichtenstein P, Narusyte J, Reiss D, et al. The intergenerational transmission of anxiety: a children-of-twins study. Am J Psychiatry. 2015;172(7):630–7.
54. McGarry S, Girdler S, McDonald A, Valentine J, Wood F, Elliott C. Paediatric medical trauma: the impact on parents of burn survivors. Burns. 2013;39(6):1114–21.
55. Willebrand M, Sveen J. Perceived support in parents of children with burns. Gen Hosp Psychiatry. 2016;38:105–8.
56. Torke A, Worial L, Johns S, Sachs G, Callahan C, Bosslet G, et al. The family navigator: a pilot intervention to support intensive care unit family surrogates. Am Assoc Crit Care Nurses. 2016;25:498–506.
57. Shaw DJ, Davidson JE, Smilde RI, Sondoozi T, Agan D. Multidisciplinary team training to enhance family communication in the ICU. Crit Care Med. 2013;42(2):265–71.
58. The joint commission on Accreditation of Healthcare Organizations. Comprehensive accreditation manual for hospitals: the official handbook (CAMH), Joint Commission Resources. Oakbrook Terrace. 2007;5(1):14–5.
59. Informed consent of subjects who do not speak English (1995) Rockville: Office for Human Research Protections; 1995. Available from: https://www.hhs.gov/ohrp/regulations-and-policy/guidance/obtaining-and-documenting-infomed-consent-non-english-speakers/index.html.
60. Lambert BL, Centomani NM, Smith KM, Helmchen LA, Bhaumik DK, Jalundhwala YJ, et al. The "seven pillars" response to patient safety incidents: effects on medical liability processes and outcomes. Health Serv Res. 2016;51(S3):2491–515.
61. Public law 111–148—MAR. 23, 2010 124 STAT. 119 Washington: Government Printing Office; 2010. Available from: https://www.gpo.gov/fdsys/pkg/PLAW-111publ148/pdf/PLAW-111publ148.pdf.
62. Ednell A-K, Siljegren S, Engström Å. The ICU patient diary–a nursing intervention that is complicated in its simplicity: a qualitative study. Intensive Crit Care Nurs. 2017;40:70–6.
63. Burwell S. Advancing LGBT health and well-being: 2016 cover letter announcing report of the HHS LGBT policy coordinating committee Washington: HHS.gov; 2016 [Available from: https://www.hhs.gov/programs/topic-sites/lgbt/reports/2016-cover-letter.html.
64. Remarks by the President at the Human Rights Campaign's Annual National Dinner Washington: The White House; 2011. Available from: https://obamawhitehouse.archives.gov/the-press-office/2011/10/01/remarks-president-human-rights-campaigns-annual-national-dinner.
65. Pope TM. Legal briefing: adult orphans and the Unbefriended: making medical decisions for unrepresented patients without surrogates. J Clin Ethics. 2015;26(2):180–8.
66. Farrell TW, Widera E, Rosenberg L, Rubin CD, Naik AD, Braun U, et al. AGS position statement: making medical treatment decisions for unbefriended older adults. J Am Geriatr Soc. 2016; 65(1):14–5.
67. Egerod I, Christensen D, Schwartz-Nielsen KH, Ågård AS. Constructing the illness narrative: a grounded theory exploring patients' and relatives' use of intensive care diaries. Crit Care Med. 2011;39(8):1922–8.

68. Hester M, Ingalls NK, Hatzfeld JJ. Perceptions of ICU diary utility and feasibility in a combat ICU. Mil Med. 2016;181(8):895–9.
69. Blair KTA, Eccleston SD, Binder HM, McCarthy MS. Improving the patient experience by implementing an ICU diary for those at risk of post-intensive care syndrome. J Patient Exp. 2017;4(1):4–9.
70. Aitken LM, Rattray J, Hull A, Kenardy JA, Le Brocque R, Ullman AJ. The use of diaries in psychological recovery from intensive care. Crit Care. 2013;17(6):253.
71. Garrouste-Orgeas M, Coquet I, Perier A, Timsit JF, Pochard F, Lancrin F, et al. Impact of an intensive care unit diary on psychological distress in patients and relatives. Crit Care Med. 2012;40(7):2033–40.
72. Jones C, Backman C, Griffiths RD. Intensive care diaries and relatives' symptoms of posttraumatic stress disorder after critical illness: a pilot study. Am J Crit Care Off Publ Am Assoc Crit Care Nurses. 2012;21(3):172–6.
73. Garrouste-Orgeas M, Perier A, Mouricou P, Gregoire C, Bruel C, Brochon S, et al. Writing in and reading ICU diaries: qualitative study of families' experience in the ICU. PLoS One. 2014;9(10):e110146.
74. Nielsen AH, Angel S. Relatives perception of writing diaries for critically ill. A phenomenological hermeneutical study. Nurs Crit Care. 2016;21(6):351–7.
75. Beg M, Scruth E, Liu V. Developing a framework for implementing intensive care unit diaries: a focused review of the literature. Aust Crit Care. 2016;29(4):224–34.
76. Huynh TG, Covalesky M, Sinclair S, Gunter H, Norton T, Chen A, et al. Measuring outcomes of an intensive care unit family diary program. AACN Adv Crit Care. 2017;28(2):179–90.
77. Knowles RE, Tarrier N. Evaluation of the effect of prospective patient diaries on emotional well-being in intensive care unit survivors: a randomized controlled trial. Crit Care Med. 2009;37(1):184–91.
78. AACN's healthy work environment's initiative. Aliso Viejo: American Association of Critical Care Nurses; 2005. updated 2015. Available from: http://www.aacn.org/wd/hwe/content/hwe-home.pcms?menu=hwe.
79. American Nurse's Association. Code of ethics for nurses with interpretive statements. Silver Springs: Nursebooks.org; 2015.
80. Nursing scope and standards of practice, Silver Springs: American Nurses Association; 2015.
81. Moss M, Good VS, Gozal D, Kleinpell R, Sessler CN. A Critical Care Societies collaborative statement: burnout syndrome in critical care health-care professionals. A call for action. Am J Respir Crit Care Med. 2016;194(1):106–13.
82. Sabo BM. Compassion fatigue and nursing work: can we accurately capture the consequences of caring work? Int J Nurs Pract. 2006;12(3):136–42.
83. Hanna DR, Romana M. Debriefing after a crisis. Nurs Manag. 2007;38(8):38–42.
84. Mealer M, Jones J, Moss M. A qualitative study of resilience and posttraumatic stress disorder in United States ICU nurses. Intensive Care Med. 2012;38(9):1445–51.
85. Thompson A. How Schwartz rounds can be used to combat compassion fatigue: Alison Thompson reflects on an initiative that helps to maintain staff wellbeing and quality of patient care. Nurs Manag. 2013;20(4):16–20.
86. Bartels JB. The pause. Crit Care Nurse. 2014;34(1):74–5.
87. Schooley RT, Biswas B, Gill JJ, Hernandez-Morales A, Lancaster J, Lessor L, et al. Development and use of personalized bacteriophage-based therapeutic cocktails to treat a patient with a disseminated resistant Acinetobacter baumannii infection. Antimicrob Agents Chemother. 2017;61:e00954.

Chapter 16
Strategies to Facilitate Communication with Families in the ICU

Andre Carlos Kajdacsy-Balla Amaral

A Framework for Communication

Communication lies in the center of all sociocultural interactions [1]. Actions are a product of social interactions and are preceded by some sort of communication. Therefore, it follows that communication is a *necessary* component of systems composed of more than one subject, to initiate and guide actions toward achieving a goal.

To better understand strategies to improve communication, it is helpful to consider a framework, such as the one based on the seminal work of Shannon [2], which describes communication as the flow of information between two points. This framework considers communication as a rational process, not taking into account social characteristics of the participants, limitations in memory, and how cognition influences communication [3]. These three elements modulate the flow of information and underline why the same type of information sharing leads to different actions and outcomes in encounters with different parties.

For this chapter we define communication as the exchange of *information* and *meaning* between subjects, which is modulated by cognition, social aspects of the interaction, and memory constraints [4] (Fig. 16.1).

A. C. K.-B. Amaral
Department of Critical Care Medicine, Sunnybrook Health Sciences Centre,
Toronto, ON, Canada

Interdepartmental Division of Critical Care Medicine, University of Toronto,
Toronto, ON, Canada
e-mail: andrecarlos.amaral@sunnybrook.ca

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_16

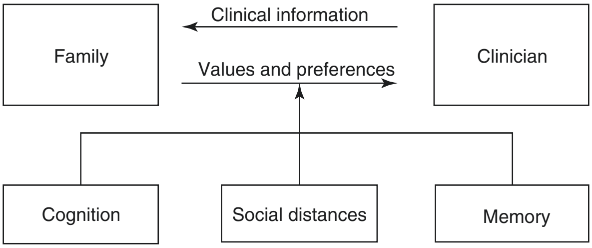


Fig. 16.1 Communication framework

Cognitive Influences on Communication

Because individuals have different *cognitive processes*, people understand the same information and meaning in different ways. Clinicians interpret a statement of "do not resuscitate" (DNR) differently, depending on their cognitive background. In a recent survey, patients with a DNR orders would not be offered antibiotics or oxygen therapy by of 6% hospital physicians, 27% of nurses, and 30% of primary practice doctors ($p < 0.001$) [5]. Therefore, it is no surprise that discussion of a "no resuscitation" order with families is likely to lead to confusion. Many families will instinctively (and rightly so) believe it means "no more treatments."

Environmental factors influence cognition and understanding information. The same information is associated with different responses if received under [1] strenuous conditions (such as the family that was awake all night or struggling to visit their loved one while working and taking care of their immediate family), [2] emotional distress (such as a family members being angry due to perceptions of unfairness, which leads to non-rational decisions [6]), or [3] time constraints.

For example, if a family member comes to visit their loved one after an entire day of work and family obligations, their cognitive and emotional capacities will be exhausted, and they won't be able to fully engage and understand complex problems, increasing the likelihood of default decisions, such as no change in goals of care. This phenomenon of cognitive exhaustion is well described in other situations. For example, primary care clinicians prescribe more antibiotics for upper respiratory tract infections during late morning or late afternoon appointments [7].

Another important cognitive bias is the rules and norms of an institution. Local norms related to end-of-life practices are as influential on decision-making as patient characteristics. In the United States, the median risk-standardized hospital rate of DNR orders is 9% (IQR 5–14%); interestingly the adjusted odds of having a DNR order is the same for metastatic cancer or admission to hospitals with higher rates of DNR orders [8]. The explanation for this phenomenon was elegantly demonstrated in a high-fidelity simulation study. Researchers enrolled clinicians from two organizations within the same state, but on opposite ends of the spectrum of treatment intensity at end of life. When exposed to the same simulated patient with a known preference for no intubation or ICU admission, clinicians from the hospital that usually provided higher intensity end-of-life care felt more conflict and difficult in decision-making about not providing life-supporting therapies [9].

The Role of Clinician's Emotional Response on Communication and Treatment Options

It's important to also consider that clinicians are human and also affected by their own emotional responses and how they may influence the quality of communication and patient's assessments and how treatment options are explored with families and patients.

In a qualitative study of primary care clinicians, the emotional response to a patient's request for antidepressants, frequently characterized by annoyance, influenced their assessment and led to changes in decision-making. More interestingly, while clinicians were unaware of this bias [10], in a follow-up randomized trial, the same group demonstrated that not only asking for an antidepressant led to more prescriptions for patient with (53% vs 31%) or without depression (55% vs 10%) but also a difference in prescription rates when the request was for a brand-specific or generic antidepressant (53% vs 76%) [11].

Unrecognized emotions are frequent in physicians [12] and may impede the use of patient-centered skills and may be associated with harmful behaviors, such as inappropriately interrupting the patient, changing the subject, avoiding patients' psychological issues, avoiding bonding with patients to prevent suffering, avoiding conducting certain medical procedures again, or avoiding patients altogether [13].

An interesting insight into how emotions can influence decision-making and potentially outcomes is demonstrated in a simulation study of "rude" parents in pediatrics. The authors randomized teams to meet with simulated parents that would either provide rude comments unrelated to the team's performance or to a control group with neutral comments. Simulation scores for both treatment and team communication were lower in those teams exposed to rudeness. This effect was mitigated by a strategy to modify cognitive biases before the encounters [14].

Social Influences on Communication

Social characteristics of the participants – such as hierarchical position, professional background, age, and gender – will influence the amount, type, and quality of information sharing and understanding. These social determinants of communication can be divided into three social dimensions: affinity, rank, and knowledge [4]. Greater perceived distances in social dimensions limit shared understanding of problems and impair communication (Table 16.1).

Affinity between subjects is how similar they see each other. These similarities include gender, age, ethnicity, language, citizenship, and other characteristics. We use the term *affinity distance* to describe differences in these characteristics between parties involved in a conversation. For example, a conversation between two surgeons is different than a conversation between a family doctor and surgeon. Affinity distances influence communication, for example, in a study of perceived

Table 16.1 Social dimensions that influence communication

Social dimension	Definition	Example
Affinity	The degree to which participants perceive similarities between them	Race, gender, and cultural background influence decision-making [15–17]
Ranking	The degree to which participants perceive hierarchical differences between them	Information sharing and acceptance of palliation at end of life are influenced by socioeconomic status [18, 19]
Specific knowledge	The degree to which participants have differences in knowledge in a specific domain (such as medicine)	Physicians overestimate medical literacy and tend to be more empathetic toward patients with higher educational background [20, 21]

differences about health beliefs, patients cared by clinicians of the same race were more likely to have similar health beliefs than patients cared by clinicians of a different race [22]. Patient's race also influenced opioid prescribing patterns in a vignette study of patients with chronic low back pain [15], and matching patient to physician's gender impacts the quality of patient-centered communication [16]. An interesting manifestation of the affinity distance is exemplified in a study about recent immigrants to Canada, suggesting that cultural background had an important influence on decisions at the end of life. Compared to long-term residents, immigrants to Canada had a higher relative risk of receiving ICU admission (RR 1.16), mechanical ventilation (RR 1.28), or tracheostomy (RR 1.61) at the end of life [17]. Interestingly, this effect was no longer observed for immigrants that had lived in Canada for longer than 10 years, suggesting an adaptation to the social values and norms.

Ranking is how individuals see themselves as "higher," "lower," or in the "same" rank as the other subject. For example, a soldier will recognize the higher rank of a lieutenant while in the army but may (or may not!) assign the same rank when they meet in a nonmilitary party. Greater rank distances impair communication. For example, socioeconomic status shapes communication encounters between patients and physicians. Patients from lower socioeconomic status experience a more directive and less participatory consultation, while those from higher classes receive more information from physicians [18]. In a study of the effects of income on decision-making in critical care, decision-makers' willingness to accept palliation for patients on prolonged mechanical ventilation was associated with higher income [19].

Specific knowledge is the amount of task-related knowledge that a subject has. More knowledgeable subjects will assume a more active role in communications, while less knowledgeable subjects will assume a more passive role. Greater knowledge distances impair communication. This is an important subconscious bias, demonstrated by physicians more frequently "mirroring" body language from patients with higher educational backgrounds [20]. Information should be discussed at the proper literacy level, but unfortunately physicians overestimate medical literacy in as many as 54% of patients [21].

The Effects of Memory on Communication

Memory capacity influences communication. In communications with families about diagnosis, treatments and prognosis, most, if not all, the information is novel. Because we are able to deal with 7 (±2) items at a time [23], the amount of information that can be processed by families is limited, and excess information will be forgotten or misunderstood. The implications for communication are clear, in complex cases multiple meetings are required to allow families to understand all relevant information, and in simpler cases, the amount of information should be limited to allow for better understanding and decision-making.

Communication Moments in the Critical Care Environment

We meet family members both in formal and informal moments. The most recognized moments of communication with families are interprofessional rounds (IPR) and family meetings.

IPR are key moments of patient-centered interprofessional communication, collaboration, and education. These moments can be used to engage patients and families in information sharing and decision-making, effectively creating family- and patient-centered rounds (FCR) [24, 25]. Family presence at bedside rounds is advocated by various professional organizations in health care, but nowhere is the need for family-centered rounds greater than in intensive care units (ICU), where many patients lack the capacity for medical decision-making [25]. Family inclusion into rounds is the least studied area within family-centered care, especially in adult ICUs. Data from two systematic reviews of family presence on rounds in neonatal, pediatric, and adult ICUs and medical wards reveal that FCRs can lead to increased satisfaction among patients, families, and health-care staff, enhance communication among them, and decrease family stress and anxiety while improving patient outcomes [24, 25]. If family-centered principles are not translated into practice, FCRs may not have their intended results [26]. In a survey of Canadian ICUs, only 66 percent units surveyed allowed families to participate on rounds [27].

Barriers to include families on rounds include concerns about duration of discussions, appropriate teaching, and difficulties in discussing goals of care during rounds [28]. These concerns are not backed up by empirical data. Post-implementation data of family inclusion on rounds in a trauma center suggests that their presence may actually favor more discussions about goals of care and reduces the need for family meetings (from 5 meeting/week to less than 1 meeting/week, $p < 0.01$) [29]. In a single-center observational study of rounding time and ICU strain, the presence of families on rounds did not influence the duration of individual patient's rounding time [30]. These results should be seen in the light of the potential unintended consequence of not providing families with enough time for questions and decision-making. In another study of family inclusion during rounds, the family member's perception of having adequate time for questions decreased from 40% to 23% ($p < 0.02$) post-implementation [31].

On the other end of the spectrum, scheduled family meetings cover a large spectrum of the current literature on communication with families of critically ill patients. Having a formal family meeting within a prespecified time frame is even considered by some to be an important marker of quality of care. However, it is important to recognize that the literature on family meetings for critically ill patients heavily emphasizes end-of-life care and relatively little effort is devoted to understanding the communication practices and gaps with family members of patients where a decision about end of life is not being sought. Therefore, the discussion around strategies to improve communication will also rely on data from other clinical settings. The integration of formal (family meetings and bedside rounds) and informal communication moments (bedside updates) is probably necessary to fully support the different communication and information needs of all patients and family members in an ICU [32].

Strategies to Improve Communication in the Critical Care Environment

Guidelines and Good Communication Practices

Several examples of good communication practices exist in the literature [25]. They are presented here for completeness, but the more in-depth discussion is limited to other strategies (Table 16.2) where relevant gaps exist and clinicians may not be aware of them.

Table 16.2 Strategies to improve communication with families

Strategy	Mechanisms	Example
Increase medical literacy	Decreases knowledge distances	Video-assisted education on goals of care [33–36]
Default options and clear recommendations	Decreases cognitive exhaustion of family members	Default option for "comfort care," when appropriate [37]
Explore and validate concerns	Decreases clinicians' cognitive fatigue and subconscious social distances Decreases affinity distance Improves family recall of conversation	Clinician training [38] VALUE mnemonic [39] Use tools to help families express their concerns [40]
Train emotional self-awareness	Decreases clinicians' subconscious social distances	Reframe problems to consider alternative approaches [41]
Avoid conflicting information	Decreases knowledge distance Increases cognitive load	Nighttime communication bundle [42]

Good communication practices in critical care include:

1. Establish early (less than 48 h) meetings with families/patients.
2. Use a “shared decision-making” model.
3. Have consistent staff for each patient.
4. Interprofessional team participates in communication.
5. Open visitation, including participation on rounds.

Increase Medical Literacy of Patients and Families

Tools and behaviors aimed at increasing medical literacy should improve communication by decreasing social distances and helping patients and families better understand treatment options. Better understanding leads to better decision-making. For example, in a study about surrogate decision-makers willingness to accept palliation for patients on prolonged mechanical ventilation, better knowledge of palliative care was associated with increases in acceptance of palliation [19].

However, families understand very little about critical illness. Only 50% of families can describe whether the patient is at risk of dying, and don’t know which organs are failing or which treatments are being provided in the ICU [43]. Families’ limited understanding of these issues makes it “almost impossible” to make informed decisions [44].

The systematic use of tools that cover knowledge gaps leads to changes in decision-making. In a randomized trial of 119 hospitalized patients, preference for a DNR order was 56% for those who watched a video about code status and cardiopulmonary resuscitation (CPR), versus 17% in a control group ($p < 0.01$) [33]. Similar effects of video-assisted education were seen for intubation preferences in hospitalized patients [34] and for prioritizing comfort care in outpatients with advanced heart failure [35] and elderly patients [36].

It is possible that these effects are mediated not solely by the improved knowledge (in this case about goals of care) but also by providing information in a standardized way and without emotional attachments (positive or negative) that may exist if the same information was provided by clinicians caring for the patient.

Consider the Use Default Options and Make Recommendations When Medically Appropriate

When presenting therapeutic options, the format of presentation influences decision-making. For example, in a randomized controlled trial of advance directives, patients were randomized to three groups and received the same advance directive document. However, one group received the document with “comfort care” as the default, a second received a “life extension” default, and a third received it without a default.

Patients were allowed to choose their option, and if it differed from the default, they would cross it and choose their preference. Patients with a default of "comfort care" chose comfort care more frequently than those randomized to "life extension" (77% vs 41%, $p < 0.01$) [37].

These results strongly suggest that framing decisions influences choice. Therefore, when clinicians communicate and propose plans of care, if one exists that is medically preferred, it can (and should) be suggested. While patient's autonomy for decision-making is pivotal in communication, it should not be used as an excuse to avoid making medical recommendations when a preferred approach exists.

In a study of four US hospitals with distinct approaches and cultures toward autonomy and best interests, the training environment influenced trainees' attitudes regarding decision-making and on their willingness to discuss and suggest limitations in goals of care [45]. Those trained in hospitals with a strong patient autonomy culture had an unreflective attitude about autonomy and would offer treatments at the end of life even when their medical expertise would suggest otherwise. Professional guidance is relevant for medical decision-making and should be used to help families. This is not to say that families may not disagree with the recommendations and ask for a different plan of care. Default options help in solving this problem as they institutionalize the suggested "norm" for certain conditions while empowering patients and families to make different decisions.

Explore and Validate Concerns

Exploring and validating patient's concerns lead to in-depth understanding of patient's symptoms, feelings, expectations, and ideas. When patients/families ask questions or make assertive statements/requests in a meeting, exploring these concerns can influence outcomes of the discussion. In an ideal situation, these concerns would prompt clinicians to further investigate the subject and come to better informed decisions; on the other hand, said concerns may also lead to premature closure when taken at face value, leading to poorly informed decisions.

Clinicians frequently don't respond to important emotional cues during an assessment [46], which is important as responding to those increases patient's recall of information [47]. Moreover, clinicians react to these emotional cues by reducing communication space (e.g., topic changing) instead of acknowledging the information. For example, neurologists reacted to patient emotions by reducing space (changing subject, taking no notice, giving medical advice) for 58% of cues and 76% of concerns [48].

Exploring concerns positively changes decision-making. In a study of patients with and without depression, a patient's request for antidepressants influenced prescribing behavior ten times more when concerns were not explored (OR 43 vs 4) [49].

Clinicians can be effectively trained to recognize and respond to these emotional cues [38], and patients can use tools, such as the interactive tailored patient assessment (ITPA), to increase their expression of cues and concerns [40]. Interestingly, the

Table 16.3 VALUE mnemonic to approach family meetings [39]

Item	Description
V	Value and appreciate what family members say
A	Acknowledge family members' emotions
L	Listen
U	Understand the patient as a person by asking questions
E	Elicit questions from family members

most common type of emotional cue is a verbal hint to a hidden concern (such as "I hope it won't be worse than the last treatment" or "Is this normal?") [40].

Responding to these cues in an empathetic way is also important. In a study of empathy during family meetings of critically ill patients, clinicians commented on the difficulties of the SDM role, about having a loved one critically ill, and on anticipation of death [50]. The number of empathetic statements was associated with family satisfaction with the meeting. The authors suggested the following recommendations for empathetic behaviors:

1. Take a moment at the beginning of a family conference to inquire into the families' emotional state.
2. Acknowledge both verbal and non-verbal expressions of emotion. Use these expressions of emotion as opportunities to support family members.
3. Create empathic opportunities by acknowledging that most families face a significant emotional burden when a loved one is critically ill or dying.

In another study of the emotional content of family meetings in the ICU, three types of statements were associated with increased family satisfaction: [1] assurance that the patient will not be abandoned, [2] assurance that the patient will be comfortable and won't suffer, and [3] support for decisions about end of life, whether to withdrawal or not [51].

Exploring concerns may also improve outcomes for family members. In a multicentric randomized trial in France, the use of a structured approach to family meetings at the end of life, which included several strategies directed to exploring and validating concerns (VALUE [39], Table 16.3) and family member's symptoms of anxiety (67% vs 45%, $p = 0.02$) and depression (56% vs 29%, $p = 0.003$), decreased significantly in the intervention group [52].

Train Emotional Self-Awareness

Because emotions interfere with clinician's responses to patients' and families' requests, increased self-awareness may lead to less biased assessments and treatments. Most aspects of social distances should be removed once the clinician practices self-awareness or consider the use of decision-rules that are clearly outlined. The act of removing these biases has also been termed *cognitive debiasing*, and others have suggested several strategies to mitigate it [14, 53].

Consider self-reflection when in meetings with families. Self-reflection may help reframe problems and diagnosis to identify missing or incorrect information [41]. After, or ideally during an encounter, clinicians can ask themselves questions that may point toward biases and use these to reorient the discussion. Common questions that can help include:

1. Were there any points at which I wanted to end the visit prematurely?
2. If there were relevant data that I ignored, what might they be?
3. What would a trusted peer say about the way I managed this situation?
4. Were there any points at which I felt judgmental about the patient – in a positive or negative way?

Avoid Conflicting Information

Parents of hospitalized children most often attribute miscommunication to conflicting information from health-care providers [54]. Families of critically ill patients are exposed to a large number of different providers, increasing the chances of conflicting information, and decreasing trust in the team and satisfaction with care. As many of these encounters occur at night, strategies to improve nighttime communication may prove useful to increase family's experiences.

In a single-center pediatric study, a nighttime communication bundle led to improvements in parent-reported quality of communication [42]. The bundle included [1] an early nighttime interprofessional brief to discuss active patients and family concerns, [2] bedside team huddle on the two most active patients, and [3] a written family update sheet for the two most active patients written by the daytime team. A strategy commonly used by experienced clinicians to avoid the traps of conflicting information involves asking families to explain their understanding of the current situation, their expectations, and what they have been told in previous encounters.

Conclusions

A framework for understanding communication beyond the simple concept of information sharing is helpful in understanding communication problems and potential solution. The role of emotions, cognition, social aspects, and memory in communication cannot be overseen and may actually represent important variables that can help clinicians improve communication in difficult situations.

Based on this framework, this chapter discussed five generic and practical strategies that can help clinicians assess and reshape their communication practices.

References

1. Eco U. A theory of semiotics: Indiana University press. Bloomington; 1978. 354 p
2. Shannon CE. A mathematical theory of communication. Bell System Tech J. 1948;27:379–423.
3. Kajdacsy-Balla Amaral AC. Facilitating interactions between healthcare providers in the ICU. In: Scales D, Rubenfeld G, editors. The organization of critical care. Respiratory medicine. New York: Humana Press; 2014. p. 109–25.
4. Kluver JK. On communication : an interdisciplinary and mathematical approach. Dordrecht: Springer; 2007. p. 240.
5. O'Brien H, Scarlett S, Brady A, Harkin K, Kenny RA, Moriarty J. Do-not-attempt-resuscitation (DNAR) orders: understanding and interpretation of their use in the hospitalised patient in Ireland. A brief report. J Med Ethics. 2017:44–201.
6. van't Wout M, Chang LJ, Sanfey AG. The influence of emotion regulation on social interactive decision-making. Emotion (Washington, DC). 2010;10(6):815–21.
7. Linder JA, Doctor JN, Friedberg MW, Reyes Nieva H, Birks C, Meeker D, et al. Time of day and the decision to prescribe antibiotics. JAMA Intern Med. 2014;174(12):2029–31.
8. Walkey AJ, Barnato AE, Rinne ST, Cooke CR, Shieh MS, Pekow PS, et al. Hospital variation in do-not-resuscitate orders and end-of-life healthcare use in the United States. Ann Am Thorac Soc. 2017;14(9):1485–9.
9. Barnato AE, Mohan D, Lane RK, Huang YM, Angus DC, Farris C, et al. Advance care planning norms may contribute to hospital variation in end-of-life ICU use: a simulation study. Med Decision Making: Int J Soc Med Decision Making. 2014;34(4):473–84.
10. Tentler A, Silberman J, Paterniti DA, Kravitz RL, Epstein RM. Factors affecting physicians' responses to patients' requests for antidepressants: focus group study. J Gen Intern Med. 2008;23(1):51–7.
11. Kravitz RL, Epstein RM, Feldman MD, Franz CE, Azari R, Wilkes MS, et al. Influence of patients' requests for direct-to-consumer advertised antidepressants: a randomized controlled trial. JAMA. 2005;293(16):1995–2002.
12. Silva JV, Carvalho I. Physicians experiencing intense emotions while seeing their patients: what happens? Permanente J. 2016;20(3):31–7.
13. Ely JW, Levinson W, Elder NC, Mainous AG 3rd, Vinson DC. Perceived causes of family physicians' errors. J Fam Pract. 1995;40(4):337–44.
14. Riskin A, Erez A, Foulk TA, Riskin-Geuz KS, Ziv A, Sela R, et al. Rudeness and medical team performance. Pediatrics. 2017;139(2):e20162305.
15. Burgess DJ, Crowley-Matoka M, Phelan S, Dovidio JF, Kerns R, Roth C, et al. Patient race and physicians' decisions to prescribe opioids for chronic low back pain. Soc Sci Med. 2008;67(11):1852–60.
16. Sandhu H, Adams A, Singleton L, Clark-Carter D, Kidd J. The impact of gender dyads on doctor–patient communication: a systematic review. Patient Educ Couns. 2009;76(3):348–55.
17. Yarnell CJ, Fu L, Manuel D, Tanuseputro P, Stukel T, Pinto R, et al. Association between immigrant status and end-of-life care in Ontario, Canada. JAMA. 2017;318(15):1479–88.
18. Willems S, De Maesschalck S, Deveugele M, Derese A, De Maeseneer J. Socio-economic status of the patient and doctor-patient communication: does it make a difference? Patient Educ Couns. 2005;56(2):139–46.
19. Chen YC, Fan HY, Curtis JR, Lee OK, Liu CK, Huang SJ. Determinants of receiving palliative care and ventilator withdrawal among patients with prolonged mechanical ventilation. Crit Care Med. 2017;45(10):1625–34.
20. Street R, Buller D. Patients characteristics affecting physician–patient nonverbal communication. Hum Commun Res. 1988;15:60–90.
21. Kelly PA, Haidet P. Physician overestimation of patient literacy: a potential source of health care disparities. Patient Educ Couns. 2007;66(1):119–22.

22. Kennedy BM, Rehman M, Johnson WD, Magee MB, Leonard R, Katzmarzyk PT. Healthcare providers versus patients' understanding of health beliefs and values. Patient experience. Journal. 2017;4(3):29–37.
23. Miller GA. The magical number seven plus or minus two: some limits on our capacity for processing information. Psychol Rev. 1956;63:81–97.
24. Cypress BS. Family presence on rounds: a systematic review of literature. Dimens Crit Care Nursing: DCCN. 2012;31(1):53–64.
25. Davidson JE, Powers K, Hedayat KM, Tieszen M, Kon AA, Shepard E, et al. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004-2005. Crit Care Med. 2007;35(2):605–22.
26. Subramony A, Hametz PA, Balmer D. Family-centered rounds in theory and practice: an ethnographic case study. Acad Pediatr. 2014;14(2):200–6.
27. Holodinsky JK, Hebert MA, Zygun DA, Rigal R, Berthelot S, Cook DJ, et al. A survey of rounding practices in Canadian adult intensive care units. PLoS One. 2015;10(12):e0145408.
28. Santiago C, Lazar L, Jiang D, Burns KE. A survey of the attitudes and perceptions of multidisciplinary team members towards family presence at bedside rounds in the intensive care unit. Intens Crit Care Nursing: Off J Brit Assoc Crit Care Nurses. 2014;30(1):13–21.
29. Allen SR, Pascual J, Martin N, Reilly P, Luckianow G, Datner E, et al. A novel method of optimizing patient- and family-centered care in the ICU. J Trauma Acute Care Surg. 2017;82(3):582–6.
30. Brown SE, Rey MM, Pardo D, Weinreb S, Ratcliffe SJ, Gabler NB, et al. The allocation of intensivists' rounding time under conditions of intensive care unit capacity strain. Am J Respir Crit Care Med. 2014;190(7):831–4.
31. Jacobowski NL, Girard TD, Mulder JA, Ely EW. Communication in critical care: family rounds in the intensive care unit. Am J Crit Care: Off Publ, Am Assoc Crit-Care Nurses. 2010;19(5):421–30.
32. Seaman JB, Arnold RM, Scheunemann LP, White DB. An integrated framework for effective and efficient communication with families in the adult intensive care unit. Ann Am Thorac Soc. 2017;14(6):1015–20.
33. Merino AM, Greiner R, Hartwig KA. Randomized controlled trial of a CPR decision support video for patients admitted to the general medicine service. J Hosp Med: Off Publ Soc Hosp Med. 2017;12(9):700–4.
34. El-Jawahri A, Mitchell SL, Paasche-Orlow MK, Temel JS, Jackson VA, Rutledge RR, et al. A randomized controlled trial of a CPR and intubation video decision support tool for hospitalized patients. J Gen Intern Med. 2015;30(8):1071–80.
35. El-Jawahri A, Paasche-Orlow MK, Matlock D, Stevenson LW, Lewis EF, Stewart G, et al. Randomized, controlled trial of an advance care planning video decision support tool for patients with advanced heart failure. Circulation. 2016;134(1):52–60.
36. Volandes AE, Paasche-Orlow MK, Barry MJ, Gillick MR, Minaker KL, Chang Y, et al. Video decision support tool for advance care planning in dementia: randomised controlled trial. BMJ. 2009;338:b2159.
37. Halpern SD, Loewenstein G, Volpp KG, Cooney E, Vranas K, Quill CM, et al. Default options in advance directives influence how patients set goals for end-of-life care. Health Affairs (Project Hope). 2013;32(2):408–17.
38. Blanch-Hartigan D. An effective training to increase accurate recognition of patient emotion cues. Patient Educ Couns. 2012;89(2):274–80.
39. Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, et al. Guidelines for family-centered Care in the Neonatal, pediatric, and adult ICU. Crit Care Med. 2017;45:103–28.
40. Heyn L, Ruland CM, Finset A. Effects of an interactive tailored patient assessment tool on eliciting and responding to cancer patients' cues and concerns in clinical consultations with physicians and nurses. Patient Educ Couns. 2012;86(2):158–65.
41. Borrell-Carrio F, Epstein RM. Preventing errors in clinical practice: a call for self-awareness. Ann Fam Med. 2004;2(4):310–6.

42. Khan A, Baird J, Rogers JE, Furtak SL, Williams KA, Allair B, et al. Parent and provider experience and shared understanding after a family-centered nighttime communication intervention. Acad Pediatr. 2017;17(4):389–402.
43. Azoulay E, Chevret S, Leleu G, Pochard F, Barboteu M, Adrie C, et al. Half the families of intensive care unit patients experience inadequate communication with physicians. Crit Care Med. 2000;28(8):3044–9.
44. Nelson JEMDJD, Puntillo KAR, Pronovost PJM, Walker ASMA, McAdam JLR, Ilaoa DRN, et al. In their own words: patients and families define high-quality palliative care in the intensive care unit. [Article]. Crit Care Med. 2010;38(3):808–18.
45. Dzeng E, Colaianni A, Roland M, Chander G, Smith TJ, Kelly MP, et al. Influence of institutional culture and policies on do-not-resuscitate decision making at the end of life. JAMA Intern Med. 2015;175(5):812–9.
46. Butow PN, Brown RF, Cogar S, Tattersall MH, Dunn SM. Oncologists' reactions to cancer patients' verbal cues. Psychooncology. 2002;11(1):47–58.
47. Jansen J, van Weert JC, de Groot J, van Dulmen S, Heeren TJ, Bensing JM. Emotional and informational patient cues: the impact of nurses' responses on recall. Patient Educ Couns. 2010;79(2):218–24.
48. Del Piccolo L, Pietrolongo E, Radice D, Tortorella C, Confalonieri P, Pugliatti M, et al. Patient expression of emotions and neurologist responses in first multiple sclerosis consultations. PLoS One. 2015;10(6):e0127734.
49. Epstein RM, Shields CG, Franks P, Meldrum SC, Feldman M, Kravitz RL. Exploring and validating patient concerns: relation to prescribing for depression. Ann Fam Med. 2007;5(1):21–8.
50. Selph RB, Shiang J, Engelberg R, Curtis JR, White DB. Empathy and life support decisions in intensive care units. J Gen Intern Med. 2008;23(9):1311–7.
51. Stapleton RD, Engelberg RA, Wenrich MD, Goss CH, Curtis JR. Clinician statements and family satisfaction with family conferences in the intensive care unit. Crit Care Med. 2006;34(6):1679–85.
52. Lautrette A, Darmon M, Megarbane B, Joly LM, Chevret S, Adrie C, et al. A communication strategy and brochure for relatives of patients dying in the ICU. N Engl J Med. 2007;356(5):469–78.
53. Croskerry P, Singhal G, Mamede S. Cognitive debiasing 2: impediments to and strategies for change. BMJ Qual Saf. 2013;22(Suppl 2):ii65–72.
54. Khan A, Furtak SL, Melvin P, Rogers JE, Schuster MA, Landrigan CP. Parent-provider miscommunications in hospitalized children. Hosp Pediatr. 2017;7(9):505–15.

Chapter 17
End-of-Life Care

Jennifer L. McAdam

End-of-Life Care

Intensive care units (ICUs) offer aggressive treatments with the goal of helping patients recover from life-threatening conditions. When these efforts are unsuccessful, the next measures rely on end-of-life care [1]. Mortality rates in ICUs remain high, where on average one in five patients will die either in the unit or shortly thereafter [2]. In many of these cases, patients die after the decision is made to withdraw or withhold life-sustaining therapies [3–5]. During this process, ICU families who participate in making these difficult decisions may suffer both physically and psychologically [6–8]. They often face challenges they are not equipped to understand [9]. Families may experience confusion, frustrations, anger, or shock [10, 11]. They are preparing for the loss of their loved one, often not knowing what to expect during this time [10, 12, 13]. This burden impacts families in many ways and may lead to negative sequelae [14–16]. An ICU patient's wife demonstrates this suffering, "*Brutal hell. The whole process has just ripped the life out of me. My husband suffered greatly for all of this. This is just something that you don't ever wanna see a loved one go through...*" [17].

Providing family-centered care in the ICU is a recommended practice [18]. Optimizing the support given to families using evidence-based strategies may help improve family and patient outcomes. These approaches should be a high priority for the healthcare team. This chapter will cover the care of families of dying ICU patients. It will focus on the symptom burden experienced by families as they transition from intervention to end-of-life care and will offer practical interventions to help alleviate families' symptom burden. This chapter will also provide suggestions on how best to support families that are in conflict during

---

J. L. McAdam
School of Nursing, Samuel Merritt University, Oakland, CA, USA
e-mail: jmcadam@samuelmerritt.edu

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_17

end-of-life decision-making. In addition, it will discuss strategies that help families prepare for and cope during the transition where the patient is actively dying. Finally, issues affecting end-of-life care of families of underrepresented and LGBTQ populations will be discussed.

Family Symptom Burden

ICUs can be an extremely stressful environment for families. In one study, researchers found that ICU families whose loved ones were at high risk of dying had a high prevalence of traumatic stress, along with high levels of intrusion symptoms (unwelcome thoughts about the ICU) and hyperarousal symptoms (heightened startle response and nightmares) [19]. In addition, 60% of these families were at risk for anxiety, 43% were at risk for depression, and 90% had other distressing symptoms such as fatigue, sadness, frightened, poor appetite, and poor well-being [19]. Three months after the ICU experience, these same families still had high levels of traumatic stress, anxiety, and depression [20]. Others have also found high levels of PTSD [6], anxiety [21], and depression [21] in families during the ICU stay. Research supports that ICU families carry a high symptom burden.

These sets of conditions during and after the ICU visit affect families in multiple ways. First, these symptoms have been associated with long-term negative consequences such as PTSD [14, 22], anxiety [6, 20], prolonged grief [15, 22, 23], and major depression [14, 24]. Occurring well past the ICU stay, this constellation of symptoms has been termed post-intensive care syndrome-family [25, 26]. Second, a high symptom burden may impact the way families' process information and deal with situations in the ICU. For example, high levels of stress and anxiety may affect the families' ability to participate in decision-making [27]. When they are stressed or anxious, they may over- or underestimate the effectiveness of treatment options [28]. Or, they may have trouble concentrating and understanding information presented to them [29]. As a nurse noted in one study, "…[we know] when communication is not working such as when [the family's] eyes glaze over" [30]. The consequences of a high symptom burden affect the well-being of the family, affects patient care, and may lead to frustration for the healthcare team.

Interventions to Help Alleviate Families' Symptom Burden (See Table 17.1)

The high symptom burden of ICU families is typically influenced by several components including the information needs of the family, decision-making stressors, and pre-existing risk factors [27]. In order to better support ICU families, interventions targeting the multifactorial nature of their symptom burden are needed. The first

Table 17.1 Multifactorial approach to help alleviate ICU family symptom burden

Informational needs	Decision-making	Pre-existing family symptoms
Provide only the most critical information [34] Repeat critical information several times if needed [34]	Tailor the decision-making approach to the individual family case, but active and shared decision-making is recommended [41]	Routinely assess families for risk factors (i.e., female family members, spouses, poor coping skills, etc.) [45]
Use multiple formats to deliver information (e.g. electronic tablets, written brochures) [18, 29, 35]	Remain unbiased [42, 43]	Routinely assess families for symptom burden [45]
Provide daily updates [36]	Avoid personal opinions [42, 43]	Use validated tools such as the Hospital Anxiety and Depression Scale [46] and the Impact of Event Scale-Revised [47, 48] to assess common symptoms such as anxiety, depression, and traumatic stress
Allow time to process information [37]	Accept the families' decision [42, 43]	
Provide consistent information [36]		

Sources: Davidson et al. (2017) [18], Stephenson (2006) [29], Price (2017) [34], Chiang et al. (2017) [35], Seaman et al. (2017) [36], Fawole et al. (2013) [37], Kon et al. (2016) [41], Adams et al. (2014) [42], Stapleton et al. (2006) [43], Kentish-Barnes et al. (2009) [45], Zigmond et al. (1983) [46], Creamer et al. (2003) [47], Weiss (2004) [48]

component, information, has consistently been reported in the literature as one of the most important needs of ICU families [31–33]. Although formal education and structured family care conferences are recommended to provide information [18], other techniques can be effective. Families who are stressed and anxious may better process only the most critical information, requiring this information multiple times [34]. This will assist the family in focusing on the main issues and help to mitigate overload. In addition, they may need the information given in multiple formats such as verbal, written, or electronic [18, 29, 35]. One group of researchers found that providing education and information via an electronic tablet significantly reduced depression and anxiety in ICU families [35]. Another routine for delivering information includes providing families daily updates [36]. This permits more time to process information, [37] the goal being to prevent confusion and frustration [38]. In one study, the majority of families wanted to receive information about the patient's progress on a daily basis. As one family member stated, "…Just inform us from day one that today he is this and that. Maybe at least twice a day or even once a day" [10], p. 61.

The second component in reducing families' symptom burden is related to decision-making stressors. Surrogate decision-makers often face uncertainty, experience empathetic suffering and tension, and have conflicting emotional needs [17, 39]. The negative outcomes associated with this state are that families may focus on small details rather than the big picture. They may seek more positive prognostic information. However, they may disbelieve this information and demand inappropriate treatments [40]. As one family member in a recent study stated, "…if I didn't like my options, I would search out other options" [40], p. 245.

By recognizing in advance the strain this role may place on families, interventions can be initiated to help support them. The current recommendation to best support surrogate decision-makers includes tailoring the decision-making process (i.e., shared, active, or passive) to each individual case [41]. In one study, researchers reported that 65% of surrogate decision-makers preferred an active decision-making role, 35% preferred to share the responsibility, and none of the families preferred a passive role. They also found that when families used the decision-making approach of their choice, it helped surrogates to better cope with the experience [17]. Other supportive interventions cited by family decision-makers include that the healthcare team remain unbiased, avoid personal opinions, and accept the decision of the family [42, 43]. This improves families' trust with the healthcare team and reduces families' decisional regret and psychological burden [44].

Finally, the third component to consider is pre-existing family risk factors. Researchers have reported female family members [8, 19, 23], spouses [8, 19], families of patients of a younger age [8, 19], families of a race other than white [19], and poor family coping [27] tend to have a higher symptom burden. Although most of these are non-modifiable, it is recommended that families are routinely assessed for their risk factors and symptom burden while in the ICU [45]. Using validated tools such as the Hospital Anxiety and Depression Scale [46] and the Impact of Event Scale-Revised [47, 48] to recognize these high-risk families, interventions can begin early in the ICU stay. Appropriate referrals such as counseling, palliative care, spiritual care, and ethics consultations can be given to help reduce potential negative consequences [45].

Supporting Families During Transitions in Care
(See Table 17.2)

Transition from active treatment to end-of-life care in the ICU is complex for multiple reasons. Identification of patients who will not survive the ICU stay is difficult [49]. A lack of agreement often exists between different disciplines regarding the goals of end-of-life care [50–53]. The families may be in denial and not ready to accept the outcome [10]. Having an understanding of the key transitional stages describing the end-of-life trajectory in the ICU is helpful in overcoming some of these challenges. These transitions as described by Coombs and colleagues [54] include the following:

- Admission to the ICU where there is still hope of recovery.
- Transition from aggressive treatment to end-of-life care.
- The actively dying patient.

Table 17.2 Interventions to support families in each transition phase

Hope of recovery	Intervention to EOL	Actively dying patient
Prepare families for what they may see, hear, experience [12]	Consider the length of the transition that patient is in the ICU (acute condition vs chronic condition) [61]	Use end-of-life protocols to help guide withdrawing and/or withholding of life-sustaining measures [78]
Hold a family meeting early in the ICU stay (within 3–5 days) [12, 55]	Give families time to adjust to this phase [38]	Avoid the use of the term “withdrawal of care” [89]
Use a family coordinator of care [56]	Deal with family conflicts by using relationship building communication skills [66]	When a decision is made to withhold or withdraw life-sustaining measures, there should be no delays; it should occur as soon as possible [61]
	Use a family coordinator of care [56]	Keep the patient in the ICU [78]
	Incorporate palliative care principles early in the ICU stay [71]	Maintain consistent staff caring for the patient and family [57]
	Clarify information and help assist families recognize the deteriorating status of their loved one [38]	Do not abandon the patient and family [91]
	Assess nonverbal cues and utilize these as indicators of family readiness [30]	Display caring behaviors [57]
		Prepare families for the dying process (what they may see, hear, the timeframe) [57]
		Allow families to be present and participate in patient care [78]
		Prepare the room for the dying process by creating a sacred space [57]

Sources: Coombs (2010) [12], Bloomer et al. (2017) [30], Peden-McAlpine et al. [38], Torke et al. (2016) [56], Wiegand (2016) [58], Wiegand et al. (2010) [62], Chiarchiaro et al. (2016) [67], Noreika et al. (2015) [72], Downar et al. (2016) [79], Connolly et al. (2016) [90], Hinkle et al. (2015) [92]

Supporting Families During the Transition Stage: Admission with Hope of Recovery

In the first transition, the use of full and intensive interventions predominates patient care. This is also the stage where families begin their adjustment to the ICU. In this stage, the healthcare team should prepare families on what they may see, hear, or experience while visiting their loved one in the ICU [12]. It is important to hold family meetings early in the ICU stay, within 3–5 days if possible [12, 55]. Additionally, ICUs should consider having a coordinator of care for the family. One group of researchers reported that the use of a family navigator who provided informational and emotional communication needs was feasible and well received by both families and staff [56]. Another group of investigators assessing the use of a communication facilitator found this intervention was associated with a decrease in families' depressive symptoms 6 months post-ICU death with a reduction in ICU costs and length of stay at the end of life [57]. As care can seem fragmented to families [58], the use of this type of family support person has shown to reduce the intensity of end-of-life care [57] and improve communication, satisfaction, and patient-centered care [59, 60].

Supporting Families During the Transition Stage: Intervention to End of Life

The second transition is typically initiated when the healthcare team notes a continued deterioration in the condition of the patient. This stage is usually the most problematic and challenging to navigate for both the healthcare team and families [54, 61]. This transition, from intervention to end of life, occurs when the patient's condition is not improving and decisions need to be made on how to proceed [54]. The duration of this transition period can affect how families perceive the dying process in the ICU. For example, in one study, when the patient had an acute illness and died suddenly, families reported that although the suddenness was difficult for them, they still thought it was a "good death" because the patient didn't suffer [62]. Conversely, families viewed the death of patient with a prolonged hospital course as a "bad death," as they questioned the rationale behind treatments and why their loved one had to suffer [62]. It is important to realize that families' experiences will differ depending on the time it takes to process the information [38]. As one group of researchers noted, "time is a valuable commodity where we give families the opportunity to move from a position of hope for recovery to understanding the discussions and impact of end-of-life care" [54], p. 524.

During this transition from intervention to end of life, families often have interpersonal conflicts that need to be addressed and managed. Families struggle with not wanting to feel responsible for their loved ones death, the desire to continue to pursue recovery, and the need to preserve the family well-being [39]. This can lead to confusion, anxiety, depression, and stress in families [19, 63, 64]. This in turn can lead to poor coping strategies within families [39] and misunderstandings and miscommunication with the healthcare team [10, 65, 66].

Several strategies can help families in conflict. One approach, discussed earlier, is the use of a family support coordinator; it has been shown to help conflicted families by improving their satisfaction with ICU communication and care [60]. In addition, updating families daily with factual information and gradually helping them face bad news assisted families in making difficult decisions [40, 44]. Nurses can be key in this area, by interpreting and clarifying the medical information for the family and by helping the family recognize the deteriorating status of the patient [38]. As one nurse observed, "…they've just had really bad news, so there's got to be a bit of [emotional processing] with what they do, and I try and give it to them in small increments so they don't get a big waft of information all at once" [30], p. 694. In addition, the healthcare team can assess the nonverbal cues (e.g., body positioning such as crossed arms, avoidance actions such as leaving the room) of families and use these indicators to balance when the most appropriate time should be for delivering information which may reduce conflict [30].

Another effective intervention for dealing with family conflict involves the development of communication skills that are relationship-building rather than task-related. Relationship-building communication skills consist of respecting families, supporting them emotionally, and expressing empathy. For comparison, task-oriented communication skills ensure families understand medical facts and their role as a decision-maker. In managing conflicts, the use of relationship-building communication has been found to be more effective in helping deal with family disagreements [67, 68]. Other relationship building techniques such as the VALUE tool and NURSE mnemonic have been reported in the literature to be helpful in dealing with conflicted families making end-of-life decisions [12, 69, 70].

Another strategy to support families during the transition from intervention to end of life is to incorporate palliative care principles early in the patient's ICU stay. This approach improves the quality of life of both patients and families who are experiencing a life-threatening illness. Palliative care includes such tenets as communication, symptom management, and early goal setting that is in line with the patients' wishes [71]. Incorporating palliative care into the ICU can occur by the use of a consultative model, or an integrative model – or a combination of both models. The consultant model focuses on increasing the involvement of individuals, outside of the ICU who have specialty training in palliative care [72]. The integrative model focuses on embedding palliative care principles and interventions (e.g., communication and symptom management) into the daily practice of the ICU team [72]. There are trade-offs to each model (see Table 17.3) [73], but the use of the consultative model appears to be used much more frequently in the acute care setting [74].

When incorporating palliative care into the ICU, especially using the consultative model, it should be done early and it should be ongoing. This allows families the opportunity to develop relationships and build trust with palliative care consultants. A current study assessing the effectiveness of palliative care-led meetings for families of chronically critically ill patients highlights this point. The investigators found that this intervention did not decrease anxiety or depression in families and, in fact, may have increased their PTSD symptoms. This lack of benefit may have been due to the structure of the intervention: families only had one or two meetings with the palliative care team, and relationship building and trust were likely difficult to achieve. Their recommendation and a reasonable conclusion are that palliative care consults with families should be ongoing, and this should assist with identifying families at high risk for poor emotional outcomes that would benefit most from palliative care interventions [75].

Table 17.3 Pros and cons of the main models for integrating palliative care in the intensive care unit

Model	Consultation by palliative care service	Integration by critical care team in daily ICU practice
Advantages	Expert input from interdisciplinary team of specialists Expertise already exists, additional training unnecessary Empirical evidence of benefit Continuity of care before, during and after ICU Facilitation of transfer out of ICU for end-of-life care, if appropriate	Availability of palliative care for all ICU patients and families Palliative care service not required Clearly acknowledges importance of palliative care as core element of intensive care Systematization of ICU work processes promotes reliable performances of palliative care
Disadvantages	Requires palliative care service with adequate staffing and other resources Palliative care clinicians may be seen as "outsiders" in ICU Consultants may lack familiarity with biomedical and nursing aspects of critical care Activities of palliative care and ICU teams may overlap and/or conflict Consultants must rapidly establish effective relationship with patients/families Fragmentation of care may be compounded ICU team may have less incentive to improve palliative care knowledge and skills	Requires education of ICU clinicians in palliative care knowledge and skills Depends on commitment of critical care clinicians and supportive ICU culture Requires dedication of staff and other resources that may be lacking in ICU Requires handoff to new team for post-ICU palliative care for patients who cannot benefit from or no longer need the ICU

© Used with Permission from Wolters Kluwer, Nelson et al. [73]. https://www.ncbi.nlm.nih.gov/pubmed/20562699
ICU intensive care unit

Supporting Families During the Transition Stage: The Actively Dying Patient

In the final stage, when the patient is actively dying, making the patient comfortable and ensuring that families are adequately supported become the goal [54]. Interventions during this transition focus mainly on palliation for the patient and grief and bereavement support for families. These interventions will be discussed in terms of end-of-life protocols, healthcare team factors, educational needs, and environmental elements.

End-of-Life Protocols

Protocols or guidelines surrounding both end-of-life care and treatment withdrawal are complex, used inconsistently, or may be lacking in many ICUs [76–78]. However, it is clear that having standardized protocols of these practices is helpful for all involved [79–81]. For example, Epker and colleagues, using a standardized protocol for end-of-life care, found that patients' achieved adequate comfort, were well sedated, and showed few signs of distress such as terminal restlessness, death rattle, or stridor [82]. Others have found similar benefits when using a standardized protocol on withdrawing mechanical ventilation [83] and providing end-of-life care [30].

In general, removal of life-sustaining measures and ventilator support should include the following:

- Ensure a do-not-resuscitate (DNR) order has been documented [84, 85].
- Ensure that analgesics and sedatives are at the bedside, with the recommendation for both infusions and bolus doses as needed [79].
- Discontinue any treatments that do not provide comfort (i.e., lab draws, antibiotics, vasopressors, dialysis, IV fluids, neuromuscular blockade agents) [79, 80, 86].
- The typical order of withdrawal of life-sustaining measures is vasopressors and inotropes followed by mechanical ventilation [79].
- Consider two approaches for ventilator removal: terminal weaning or immediate extubation. The suggested method is immediate extubation; however, the strategy chosen should be individualized to reflect the patient situation and their values and preferences [79]. See Table 17.4 for description of both methods of ventilator removal along with the positives and negatives of both approaches [80, 87–89].

Table 17.4 Two primary methods of mechanical ventilation removal

Immediate extubation	Terminal weaning
Description: Abruptly removing the patient from the ventilator by extubation Provide suctioning (if necessary) Provide humidified air or oxygen to prevent airway drying	Description: Gradual withdrawal of ventilator assistance by decreasing the amount of inspired oxygen, decreasing the ventilator rate and mode, and/or removal of positive end-expiratory pressure (PEEP) Usual time for extubation can range from 30–60 min but in some cases may be over days
Positives: Patient free of tubes Dying process less likely to be prolonged	Positives: Allows titration of medications for better symptom management Maintains airway for suctioning (if necessary) Patient has less potential to develop upper airway obstruction Moral burden on family may decrease because method appears less active
Negatives: Dyspnea Potential for airway obstruction and gasps Potential to be more stressful to patient/family Time course to death is unpredictable but is typically shorter than terminal weaning	Negatives: May prolong dying Patient unable to communicate Barrier of technology/machine between patient and family Time course to death is unpredictable

Sources: Downar et al. (2016) [79], Truog et al. (2008) [80], Billings (2012) [87], Campbell (2007) [88], Szalados et al. (2007) [89]

Finally, when the decision to withdraw life-sustaining measures is made, two key principles may be kept in mind. The first is avoiding the phrase "withdrawal of care" as it is factually inaccurate and can make families and patients feel abandoned [90]. It is essential to emphasize that care continues even if the goals of care change from intervention to comfort. The second is that once the decision to remove life-sustaining measures is made, the plan of care should be implemented promptly, ensuring that delays are avoided at all possible. In one study, delays in withdrawing treatment was labeled "a bad death" by families [62]. In another, families became distressed with delays in withdrawing treatment [91].

Healthcare Team Factors

When patients are actively dying, one important consideration for the healthcare team is ensuring that consistent staff are caring for the patient and their family [58]. In addition, the healthcare team needs to be present with the dying patient and their family. Do not abandon them during this stage [92]. Families have reported feelings of anger and disappointment when the healthcare team disappears [91]. Equally important to families is that physician(s) visit with them, even if they are no longer treating the patient, to assess how they are doing. Families have reported that these visits helped them answer questions, provided them with recommendations, and provided them with clarification of information [91]. Other benefits of this to families include a feeling of confidence, the opportunity to have all of their questions answered, the ability to build trust in the healthcare team, and a significant reduction in PTSD, prolonged grief, depression, and guilt [57, 69, 93]. Finally, it is imperative that the healthcare team display caring behaviors. While this point may seem obvious, many ICU families still feel that the team is not always respectful and caring [10, 42]. Families report small acts such as combing the patient's hair, calling them by their name, and making sure the patient is clean are very meaningful to them during the dying transition [58].

Educational Needs

An important educational need for families of actively dying patients is for them to know what to expect during the dying process and withdrawal of life-sustaining measures [58]. Education should include the expected duration, which can be anywhere from minutes to days. An important point to highlight to families is if the team feels death may be delayed or prolonged. Most families believe that once life-sustaining measures are discontinued, the dying process will be quick. When it is not, families may become distraught and frustrated [58]. As stated by a family member in one study, "It isn't what I expected. I expected this to happen quickly. When you think of removing life-support you think it's going to happen quickly" [91]. Education should also include what to expect, such as the sounds the patient may make and changes in breathing patterns [79]. Assuring families that the patient will be comfortable is vital. Another helpful tool for families is a diary [94]. One group of researchers found that families who kept a diary had a better rational and emotional understanding of the patient's death [95]. Finally, when providing family education, it should take several forms (i.e., verbal, brochures, videos) depending on family needs, background, characteristics, and emotional state. Effective education occurs when it is delivered in a sensitive, empathetic, respectful, and patient-specific manner [96].

Environmental Elements

Several environmental and organizational elements should be considered during this transition. First, keep the dying patient in the ICU and only transfer them if it is absolutely necessary or requested by the family [79]. Second, allow families to have patient access at all times and allow them to be present when the patient is actively dying if they wish [79]. Third, prepare the ICU room for the dying process [58]. This is achieved by giving families privacy, providing comfortable chairs, providing beverages and snacks, and removing all unnecessary equipment [58]. In one study, this was termed creating a "sacred space." [38] It is important to create this space to both encourage and allow families to say goodbye. Finally, ICUs should consider allowing families to participate in care, if they desire, by providing a bed bath, massage, oral care, and even postmortem care [79].

The End-of-Life Care Needs of Underrepresented Populations

End of life in the ICU is challenging but can be more so for underrepresented populations. Families from an ethnic minority group are at higher risk of conflict and stress due to differences in their cultural background [97, 98]. In these populations, common issues that occur revolve around communication and information sharing, religious beliefs, cultural norms and values, care practices, and attitudes toward illness and treatments as well as attitudes toward death and dying [99]. The potential for miscommunication increases when there are multiple cultures and languages involved [100]. When this happens, the use of specific religious leaders, community leaders, or professional interpreters has been shown to be helpful [100]. When language is an issue, beneficial interventions include speaking slowly, reducing background noise, and using pictures or drawings as needed [101]. Attitudes and beliefs toward illness, treatments, death and dying, and decisions to withdraw or withhold life-sustaining treatments vary depending on the patient and families' cultural backgrounds and religious preferences [102, 103, 104]. Conflict can be reduced by treating these as clinical procedures that deserve the same preparation and expectation of quality as other procedures [104].

Differences in cultural norms and values as well as care practices between the ethnic minority and ethnic majority are daily challenges in the ICU. In one focus group study, ICU nurses from Norway discussed challenges of caring for immigrants from sub-Saharan Africa and from Middle Eastern countries. One challenge presented included protecting other patients and families from ethno-culturally based expressive behaviors such as crying uncontrollably and shouting loudly. The nurses also discussed the need to balance control of the clinical environment versus the families' need of self-determination. This was exemplified in the number of visitors of some of the families (up to 50 at a time) to the time spent holding a family vigil [98]. In another ethnographic study, Van Keer and colleagues discussed conflicts that professionals in a Belgium ICU experienced when caring for immigrants from North Africa, Turkey, Central Africa, and Southern Europe. In this study, most conflicts involved the appropriateness of bedside care activities, the high emotional involvement of the family contrasted with the low emotional involvement of the ICU professionals, and end-of-life decision-making. In the latter case, many of the minority families considered the decision to withdraw treatment as an act of "killing" the patient, and they held onto a strong belief in infinite cure expectations as well as the idea that God/Allah would decide the fate of the patient [99]. Steps that may help prevent conflict in these areas include acknowledging these differences occur, avoid stereotyping individuals, being sensitive to cultural customs, and negotiating compromises [98, 99, 105]. In one study, nurses demonstrated cultural sensitivity by showing respect for rituals (e.g., playing Buddhist music for a dying patient) and religious symbols (e.g., placing a statue of an Indian god near the patient). Minority families reported that these gestures helped them preserve their cultural traditions and helped them feel supported by the healthcare team [105]. Finally, incorporating training on the variety of attitudes in our multicultural society and by maintaining an open dialogue on end-of-life issues can improve care given to minority patients and families [99].

The End-of-Life Care Needs of the LGBTQ Community

There is documentation that socially excluded populations such as lesbian, gay, bisexual, transgender, and queer (LGBTQ) communities may receive poorer access to end-of-life care than their heterosexual counterparts [106]. Members of this population often hide their identities due to fear of stigmatization [107]. This can lead to feelings of isolation and may prevent or delay them from seeking appropriate healthcare resources [108]. Members of this population have stated that although healthcare providers' attitudes toward them were vital to their care [109], discrimination is still common in healthcare settings [110, 111]. In one survey, lesbian, gay, or bisexual individuals reported that 34% had concerns about arranging end-of-life care and 24% expected to face barriers relating to their sexual identity when planning a funeral [112]. Here are key issues that LGBTQ partners often face at the end of life, along with strategies that may better support this population.

When facing the patient's end of life, LGBTQ partners may struggle with living openly for fear of discrimination [113]. This fear could prevent them from accessing supportive end-of-life resources such as palliative care or hospice care because of stigmatization [114, 115]. This anticipated discrimination leads to feelings of caregiver burden, isolation, and vulnerability [116]. One strategy that may promote inclusion is representing LGBTQ language and imagery in promotional materials for these services. This may decrease the invisibility felt by this population and may improve perception that these resources are inclusive [117]. Other concerns for LGBTQ partners are being excluded from participating in decision-making or being denied access to the patient at the time of death [116]. A strategy that may alleviate this concern is to encourage advanced care planning [113]. This will provide a legal framework for the partner to be involved with the patient's care and will prevent any confusion on the patient's choice of surrogate [113]. As one healthcare worker stated, "If you have the paperwork done, it alleviates the chaos, and makes the roles really clear … the partner could just get on with giving care. Then everything around the death went smoothly as there were defined roles and responsibilities" [118], p. 544.

Other issues cited by LGBTQ partners are feelings of social isolation and the need to silently mourn their loved one [113]. Strategies that may help mitigate these emotions can be as simple as asking them about their needs, their well-being, and whether they feel they have enough support [116]. In addition, offering support groups that are specific for the needs of LGBTQ people could be beneficial [119]. Another area of concern for LGBTQ partners is around religion and spirituality. This is an area often ignored even though many in this population can be deeply rooted in faith [114, 116]. Healthcare workers need to consider the role of religion and spirituality in this population to better deliver holistic end-of-life care [117]. Finally, heterosexual assumptions about identity and family structure are also commonplace [114, 116]. A key way to improve this is to promote inclusive language. Asking the patient who they would like to be involved with their care or using straightforward questions such as "who are the most important people in your life?" or "what is your preferred name?" can help start conversations between patients, families, and providers and create an open, nonjudgmental environment [117].

Conclusion

Supporting the ICU family is important for healthcare professionals in providing family-centered care. Recognizing and alleviating the symptom burden in families both during and after the ICU stay can help reduce negative outcomes. Supporting families through ICU transitions from the hope of recovery, to patient decline, to the actively dying patient is essential. Finally, it is necessary to understand the barriers of providing quality end-of-life care and the importance of overcoming those barriers in providing effective care to all ICU families.

References

1. Makino J, Fujitani S, Twohig B, Krasnica S, Oropello J. End-of-life considerations in the ICU in Japan: ethical and legal perspectives. J Intensive Care. 2014;2(1):9.
2. Angus DC, Barnato AE, Linde-Zwirble WT, et al. Use of intensive care at the end of life in the United States: an epidemiologic study. Crit Care Med. 2004;32(3):638–43.
3. Verkade MA, Epker JL, Nieuwenhoff MD, Bakker J, Kompanje EJ. Withdrawal of life-sustaining treatment in a mixed intensive care unit: most common in patients with catastropic brain injury. Neurocrit Care. 2012;16(1):130–5.
4. Wunsch H, Harrison DA, Harvey S, Rowan K. End-of-life decisions: a cohort study of the withdrawal of all active treatment in intensive care units in the United Kingdom. Intensive Care Med. 2005;31(6):823–31.
5. Azoulay E, Metnitz B, Sprung CL, et al. End-of-life practices in 282 intensive care units: data from the SAPS 3 database. Intensive Care Med. 2009;35(4):623–30.
6. Azoulay E, Pochard F, Kentish-Barnes N, et al. Risk of post-traumatic stress symptoms in family members of intensive care unit patients. Am J Respir Crit Care Med. 2005;171(9):987–94.
7. Kross EK, Engelberg RA, Gries CJ, Nielsen EL, Zatzick D, Curtis JR. ICU care associated with symptoms of depression and posttraumatic stress disorder among family members of patients who die in the ICU. Chest. 2011;139(4):795–801.
8. Pochard F, Azoulay E, Chevret S, et al. Symptoms of anxiety and depression in family members of intensive care unit patients: ethical hypothesis regarding decision-making capacity. Crit Care Med. 2001;29(10):1893–7.
9. Fridh I, Forsberg A, Bergbom I. Close relatives' experiences of caring and of the physical environment when a loved one dies in an ICU. Intensive Crit Care Nurs. 2009;25(3):111–9.
10. Kisorio LC, Langley GC. End-of-life care in intensive care unit: family experiences. Intensive Crit Care Nurs. 2016;35:57–65.
11. Verhaeghe S, Defloor T, Van Zuuren F, Duijnstee M, Grypdonck M. The needs and experiences of family members of adult patients in an intensive care unit: a review of the literature. J Clin Nurs. 2005;14(4):501–9.
12. Coombs MA. The mourning before: can anticipatory grief theory inform family care in adult intensive care? Int J Palliat Nurs. 2010;16(12):580–4.
13. Fridh I, Forsberg A. A new tool to assess relatives' experience of dying and death in the intensive care unit. J Thorac Dis. 2016;8(8):E781–3.
14. Siegel MD, Hayes E, Vanderwerker LC, Loseth DB, Prigerson HG. Psychiatric illness in the next of kin of patients who die in the intensive care unit. Crit Care Med. 2008;36(6):1722–8.
15. Wright AA, Keating NL, Balboni TA, Matulonis UA, Block SD, Prigerson HG. Place of death: correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health. J Clin Oncol. 2010;28(29):4457–64.
16. Davidson JE. Family-centered care: meeting the needs of patients' families and helping families adapt to critical illness. Crit Care Nurse. 2009;29(3):28–34. quiz 35
17. Nunez ER, Schenker Y, Joel ID, et al. Acutely bereaved surrogates' stories about the decision to limit life support in the ICU. Crit Care Med. 2015;43(11):2387–93.
18. Davidson JE, Aslakson RA, Long AC, et al. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. Crit Care Med. 2017;45(1):103–28.
19. McAdam JL, Dracup KA, White DB, Fontaine DK, Puntillo KA. Symptom experiences of family members of intensive care unit patients at high risk for dying. Crit Care Med. 2010;38(4):1078–85.
20. McAdam JL, Fontaine DK, White DB, Dracup KA, Puntillo KA. Psychological symptoms of family members of high-risk intensive care unit patients. Am J Crit Care. 2012;21(6):386–393; quiz 394.
21. Pochard F, Darmon M, Fassier T, et al. Symptoms of anxiety and depression in family members of intensive care unit patients before discharge or death. A prospective multicenter study. J Crit Care. 2005;20(1):90–6.

22. Anderson WG, Arnold RM, Angus DC, Bryce CL. Posttraumatic stress and complicated grief in family members of patients in the intensive care unit. J Gen Intern Med. 2008;23(11):1871–6.
23. Kentish-Barnes N, Chaize M, Seegers V, et al. Complicated grief after death of a relative in the intensive care unit. Eur Respir J. 2015;45(5):1341–52.
24. Gries CJ, Engelberg RA, Kross EK, et al. Predictors of symptoms of posttraumatic stress and depression in family members after patient death in the ICU. Chest. 2010;137(2):280–7.
25. Netzer G, Sullivan DR. Recognizing, naming, and measuring a family intensive care unit syndrome. Ann Am Thorac Soc. 2014;11(3):435–41.
26. Davidson JE, Jones C, Bienvenu OJ. Family response to critical illness: postintensive care syndrome-family. Crit Care Med. 2012;40(2):618–24.
27. Butler JM, Hirshberg EL, Hopkins RO, et al. Preliminary identification of coping profiles relevant to surrogate decision making in the ICU. PLoS One. 2016;11(11):e0166542.
28. Ganzini L, Lee MA, Heintz RT, Bloom JD, Fenn DS. The effect of depression treatment on elderly patients' preferences for life-sustaining medical therapy. Am J Psychiatry. 1994;151(11):1631–6.
29. Stephenson PL. Before the teaching begins: managing patient anxiety prior to providing education. Clin J Oncol Nurs. 2006;10(2):241–5.
30. Bloomer MJ, Endacott R, Ranse K, Coombs MA. Navigating communication with families during withdrawal of life-sustaining treatment in intensive care: a qualitative descriptive study in Australia and New Zealand. J Clin Nurs. 2017;26(5–6):690–7.
31. Coombs MA, Parker R, Ranse K, Endacott R, Bloomer MJ. An integrative review of how families are prepared for, and supported during withdrawal of life-sustaining treatment in intensive care. J Adv Nurs. 2017;73(1):39–55.
32. Scheunemann LP, McDevitt M, Carson SS, Hanson LC. Randomized, controlled trials of interventions to improve communication in intensive care: a systematic review. Chest. 2011;139(3):543–54.
33. Jacob M, Horton C, Rance-Ashley S, et al. Needs of patients' family members in an intensive care unit with continuous visitation. Am J Crit Care. 2016;25(2):118–25.
34. Price B. Managing patients' anxiety about planned medical interventions. Nurs Stand. 2017;31(47):53–63.
35. Chiang VCL, Lee RLP, Ho FM, et al. Fulfilling the psychological and information need of the family members of critically ill patients using interactive mobile technology: a randomised controlled trial. Intensive Crit Care Nurs. 2017;41:77–83.
36. Seaman JB, Arnold RM, Scheunemann LP, White DB. An integrated framework for effective and efficient communication with families in the adult intensive care unit. Ann Am Thorac Soc. 2017;14(6):1015–20.
37. Fawole OA, Dy SM, Wilson RF, et al. A systematic review of communication quality improvement interventions for patients with advanced and serious illness. J Gen Intern Med. 2013;28(4):570–7.
38. Peden-McAlpine C, Liaschenko J, Traudt T, Gilmore-Szott E. Constructing the story: how nurses work with families regarding withdrawal of aggressive treatment in ICU – a narrative study. Int J Nurs Stud. 2015;52(7):1146–56.
39. Schenker Y, Crowley-Matoka M, Dohan D, Tiver GA, Arnold RM, White DB. I don't want to be the one saying 'we should just let him die': intrapersonal tensions experienced by surrogate decision makers in the ICU. J Gen Intern Med. 2012;27(12):1657–65.
40. Schenker Y, White DB, Crowley-Matoka M, Dohan D, Tiver GA, Arnold RM. "It hurts to know... and it helps": exploring how surrogates in the ICU cope with prognostic information. J Palliat Med. 2013;16(3):243–9.
41. Kon AA, Davidson JE, Morrison W, et al. Shared decision making in ICUs: an American College of Critical Care Medicine and American Thoracic Society Policy Statement. Crit Care Med. 2016;44(1):188–201.
42. Adams JA, Anderson RA, Docherty SL, Tulsky JA, Steinhauser KE, Bailey DE Jr. Nursing strategies to support family members of ICU patients at high risk of dying. Heart Lung. 2014;43(5):406–15.

43. Stapleton RD, Engelberg RA, Wenrich MD, Goss CH, Curtis JR. Clinician statements and family satisfaction with family conferences in the intensive care unit. Crit Care Med. 2006;34(6):1679–85.
44. Hutchison PJ, McLaughlin K, Corbridge T, et al. Dimensions and role-specific mediators of surrogate trust in the ICU. Crit Care Med. 2016;44(12):2208–14.
45. Kentish-Barnes N, Lemiale V, Chaize M, Pochard F, Azoulay E. Assessing burden in families of critical care patients. Crit Care Med. 2009;37(10 Suppl):S448–56.
46. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatr Scand. 1983;67(6):361–70.
47. Creamer M, Bell R, Failla S. Psychometric properties of the impact of event scale – revised. Behav Res Ther. 2003;41(12):1489–96.
48. Weiss D. Assessing psychological trauma and PTSD. 2nd ed. New York: The Guilford Press; 2004.
49. Toua RE, de Kock JE, Welzel T. Predicting mortality rates: comparison of an administrative predictive model (hospital standardized mortality ratio) with a physiological predictive model (acute physiology and chronic health evaluation IV)--a cross-sectional study. J Crit Care. 2016;31(1):7–12.
50. Festic E, Wilson ME, Gajic O, Divertie GD, Rabatin JT. Perspectives of physicians and nurses regarding end-of-life care in the intensive care unit. J Intensive Care Med. 2012;27(1):45–54.
51. Long-Sutehall T, Willis H, Palmer R, Ugboma D, Addington-Hall J, Coombs M. Negotiated dying: a grounded theory of how nurses shape withdrawal of treatment in hospital critical care units. Int J Nurs Stud. 2011;48(12):1466–74.
52. Pattison N, O'Gara G, Wigmore T. Negotiating transitions: involvement of critical care outreach teams in end-of-life decision making. Am J Crit Care. 2015;24(3):232–40.
53. McCallum A, McConigley R. Nurses' perceptions of caring for dying patients in an open critical care unit: a descriptive exploratory study. Int J Palliat Nurs. 2013;19(1):25–30.
54. Coombs MA, Addington-Hall J, Long-Sutehall T. Challenges in transition from intervention to end of life care in intensive care: a qualitative study. Int J Nurs Stud. 2012;49(5):519–27.
55. Nelson JE, Walker AS, Luhrs CA, Cortez TB, Pronovost PJ. Family meetings made simpler: a toolkit for the intensive care unit. J Crit Care. 2009;24(4):626 e627–14.
56. Torke AM, Wocial LD, Johns SA, et al. The family navigator: a pilot intervention to support intensive care unit family surrogates. Am J Crit Care. 2016;25(6):498–507.
57. Curtis JR, Treece PD, Nielsen EL, et al. Randomized trial of communication facilitators to reduce family distress and intensity of end-of-life care. Am J Respir Crit Care Med. 2016;193(2):154–62.
58. Wiegand DL. Family experiences during the dying process after withdrawal of life-sustaining therapy. Dimens Crit Care Nurs. 2016;35(3):160–6.
59. White DB, Cua SM, Walk R, et al. Nurse-led intervention to improve surrogate decision making for patients with advanced critical illness. Am J Crit Care. 2012;21(6):396–409.
60. Moore CD, Bernardini GL, Hinerman R, et al. The effect of a family support intervention on physician, nurse, and family perceptions of care in the surgical, neurological, and medical intensive care units. Crit Care Nurs Q. 2012;35(4):378–87.
61. McAndrew NS, Leske JS. A balancing act: experiences of nurses and physicians when making end-of-life decisions in intensive care units. Clin Nurs Res. 2015;24(4):357–74.
62. Wiegand DL, Petri L. Is a good death possible after withdrawal of life-sustaining therapy? Nurs Clin North Am. 2010;45(3):427–40.
63. Wujtewicz M, Wujtewicz MA, Owczuk R. Conflicts in the intensive care unit. Anaesthesiol Intensive Ther. 2015;47(4):360–2.
64. Jezierska N. Psychological reactions in family members of patients hospitalised in intensive care units. Anaesthesiol Intensive Ther. 2014;46(1):42–5.
65. Adams A, Mannix T, Harrington A. Nurses' communication with families in the intensive care unit – a literature review. Nurs Crit Care. 2017;22(2):70–80.
66. Schuster RA, Hong SY, Arnold RM, White DB. Investigating conflict in ICUs-is the clinicians' perspective enough? Crit Care Med. 2014;42(2):328–35.

67. Chiarchiaro J, White DB, Ernecoff NC, Buddadhumaruk P, Schuster RA, Arnold RM. Conflict management strategies in the ICU differ between palliative care specialists and intensivists. Crit Care Med. 2016;44(5):934–42.
68. Bruce CR, Newell AD, Brewer JH, et al. Developing and testing a comprehensive tool to assess family meetings: empirical distinctions between high- and low-quality meetings. J Crit Care. 2017;42:223–30.
69. Lautrette A, Darmon M, Megarbane B, et al. A communication strategy and brochure for relatives of patients dying in the ICU. N Engl J Med. 2007;356(5):469–78.
70. Pollak KI, Arnold RM, Jeffreys AS, et al. Oncologist communication about emotion during visits with patients with advanced cancer. J Clin Oncol. 2007;25(36):5748–52.
71. Mirel M, Hartjes T. Bringing palliative care to the surgical intensive care unit. Crit Care Nurse. 2013;33(1):71–4.
72. Noreika DM, Coyne PJ. Implementing palliative care interdisciplinary teams: consultative versus integrative models. Crit Care Nurs Clin North Am. 2015;27(3):297–306.
73. Nelson JE, Bassett R, Boss RD, et al. Models for structuring a clinical initiative to enhance palliative care in the intensive care unit: a report from the IPAL-ICU project (improving palliative care in the ICU). Crit Care Med. 2010;38(9):1765–72.
74. Mun E, Nakatsuka C, Umbarger L, et al. Use of improving palliative care in the ICU (intensive care unit) guidelines for a palliative care initiative in an ICU. Perm J. 2017;21.
75. Carson SS, Cox CE, Wallenstein S, et al. Effect of palliative care-led meetings for families of patients with chronic critical illness: a randomized clinical trial. JAMA. 2016;316(1):51–62.
76. Efstathiou N, Walker W. Intensive care nurses' experiences of providing end-of-life care after treatment withdrawal: a qualitative study. J Clin Nurs. 2014;23(21–22):3188–96.
77. Mark NM, Rayner SG, Lee NJ, Curtis JR. Global variability in withholding and withdrawal of life-sustaining treatment in the intensive care unit: a systematic review. Intensive Care Med. 2015;41(9):1572–85.
78. van Beinum A, Hornby L, Ramsay T, Ward R, Shemie SD, Dhanani S. Exploration of withdrawal of life-sustaining therapy in Canadian intensive care units. J Intensive Care Med. 2016;31(4):243–51.
79. Downar J, Delaney JW, Hawryluck L, Kenny L. Guidelines for the withdrawal of life-sustaining measures. Intensive Care Med. 2016;42(6):1003–17.
80. Truog RD, Campbell ML, Curtis JR, et al. Recommendations for end-of-life care in the intensive care unit: a consensus statement by the American College [corrected] of Critical Care Medicine. Crit Care Med. 2008;36(3):953–63.
81. Sprung CL, Truog RD, Curtis JR, et al. Seeking worldwide professional consensus on the principles of end-of-life care for the critically ill. The Consensus for Worldwide End-of-Life Practice for Patients in Intensive Care Units (WELPICUS) study. Am J Respir Crit Care Med. 2014;190(8):855–66.
82. Epker JL, Bakker J, Lingsma HF, Kompanje EJ. An observational study on a protocol for withdrawal of life-sustaining measures on two non-academic intensive care units in the Netherlands: few signs of distress, no suffering? J Pain Symptom Manag. 2015;50(5):676–84.
83. Campbell ML, Yarandi HN, Mendez M. A two-group trial of a terminal ventilator withdrawal algorithm: pilot testing. J Palliat Med. 2015;18(9):781–5.
84. Valentin A, Druml W, Steltzer H, Wiedermann CJ. Recommendations on therapy limitation and therapy discontinuation in intensive care units: consensus paper of the Austrian associations of intensive care medicine. Intensive Care Med. 2008;34(4):771–6.
85. Vincent JL, Schetz M, De Waele JJ, et al. "Piece" of mind: end of life in the intensive care unit statement of the Belgian Society of Intensive Care Medicine. J Crit Care. 2014;29(1):174–5.
86. Delaney JW, Downar J. How is life support withdrawn in intensive care units: a narrative review. J Crit Care. 2016;35:12–8.
87. Billings JA. Humane terminal extubation reconsidered: the role for preemptive analgesia and sedation. Crit Care Med. 2012;40(2):625–30.
88. Campbell ML. How to withdraw mechanical ventilation: a systematic review of the literature. AACN Adv Crit Care. 2007;18(4):397–403. quiz 344–395

89. Szalados JE. Discontinuation of mechanical ventilation at end-of-life: the ethical and legal boundaries of physician conduct in termination of life support. Crit Care Clin. 2007;23(2):317–37. xi
90. Connolly C, Miskolci O, Phelan D, Buggy DJ. End-of-life in the ICU: moving from 'withdrawal of care' to a palliative care, patient-centred approach. Br J Anaesth. 2016;117(2):143–5.
91. Wiegand DL. Withdrawal of life-sustaining therapy after sudden, unexpected life-threatening illness or injury: interactions between patients' families, healthcare providers, and the healthcare system. Am J Crit Care. 2006;15(2):178–87.
92. Hinkle LJ, Bosslet GT, Torke AM. Factors associated with family satisfaction with end-of-life care in the ICU: a systematic review. Chest. 2015;147(1):82–93.
93. Downar J, Barua R, Sinuff T. The desirability of an Intensive Care Unit (ICU) clinician-led bereavement screening and support program for family members of ICU Decedents (ICU Bereave). J Crit Care. 2014;29(2):311 e319–6.
94. Garrouste-Orgeas M, Perier A, Mouricou P, et al. Writing in and reading ICU diaries: qualitative study of families' experience in the ICU. PLoS One. 2014;9(10):e110146.
95. Johansson M, Wahlin I, Magnusson L, Runeson I, Hanson E. Family members' experiences with intensive care unit diaries when the patient does not survive. Scand J Caring Sci. 2018;32(1):233–40.
96. Arbour RB, Wiegand DL. Self-described nursing roles experienced during care of dying patients and their families: a phenomenological study. Intensive Crit Care Nurs. 2014;30(4):211–8.
97. Hoye S, Severinsson E. Intensive care nurses' encounters with multicultural families in Norway: an exploratory study. Intensive Crit Care Nurs. 2008;24(6):338–48.
98. Hoye S, Severinsson E. Professional and cultural conflicts for intensive care nurses. J Adv Nurs. 2010;66(4):858–67.
99. Van Keer RL, Deschepper R, Francke AL, Huyghens L, Bilsen J. Conflicts between healthcare professionals and families of a multi-ethnic patient population during critical care: an ethnographic study. Crit Care. 2015;19:441.
100. Kagawa-Singer M, Blackhall LJ. Negotiating cross-cultural issues at the end of life: "you got to go where he lives". JAMA. 2001;286(23):2993–3001.
101. Norris WM, Wenrich MD, Nielsen EL, Treece PD, Jackson JC, Curtis JR. Communication about end-of-life care between language-discordant patients and clinicians: insights from medical interpreters. J Palliat Med. 2005;8(5):1016–24.
102. Bulow HH, Sprung CL, Reinhart K, et al. The world's major religions' points of view on end-of-life decisions in the intensive care unit. Intensive Care Med. 2008;34(3):423–30.
103. Sprung CL, Maia P, Bulow HH, et al. The importance of religious affiliation and culture on end-of-life decisions in European intensive care units. Intensive Care Med. 2007;33(10):1732–9.
104. Curtis JR, Vincent JL. Ethics and end-of-life care for adults in the intensive care unit. Lancet. 2010;376(9749):1347–53.
105. Hoye S, Severinsson E. Multicultural family members' experiences with nurses and the intensive care context: a hermeneutic study. Intensive Crit Care Nurs. 2010;26(1):24–32.
106. Koffman J, M C. No way in: Including disadvantaged population and patient groups at the end of life. Berkshire: Open University Press; 2008.
107. Eliason MJ, Schope R. Does "don't ask don't tell" apply to health cate? Lesbian, gay, and bisexual people's disclosure to health care providers. J Gay Lesbian Med Assoc. 2001;5(4):125–34.
108. Clark ME, Landers S, Linde R, Sperber J. The GLBT health access project: a state-funded effort to improve access to care. Am J Public Health. 2001;91(6):895–6.
109. Neville S, Henrickson M. Perceptions of lesbian, gay and bisexual people of primary healthcare services. J Adv Nurs. 2006;55(4):407–15.
110. Sinding C, Barnoff L, Grassau P. Homophobia and heterosexism in cancer care: the experiences of lesbians. Can J Nurs Res. 2004;36(4):170–88.

111. Grant J, Mottet L, Tanis J. National transgender discrimination survey report on health and healthcare. Washington D.C.: National Center for Transgender Equality and the National Gay and Lesbian Task Force; 2010.
112. Stonewall. Planning for later life: a guide for lesbian, gay and bisexual people. Manchester: Stonewall and the Cooperative Funeral Care; 2014.
113. Rawlings D. End-of-life care considerations for gay, lesbian, bisexual, and transgender individuals. Int J Palliat Nurs. 2012;18(1):29–34.
114. Harding R, Epiphaniou E, Chidgey-Clark J. Needs, experiences, and preferences of sexual minorities for end-of-life care and palliative care: a systematic review. J Palliat Med. 2012;15(5):602–11.
115. Moss V. Caring for persons with AIDS: initiatives. The Mildmay approach. J Palliat Care. 1988;4(4):102–6.
116. Bristowe K, Marshall S, Harding R. The bereavement experiences of lesbian, gay, bisexual and/or trans* people who have lost a partner: a systematic review, thematic synthesis and modelling of the literature. Palliat Med. 2016;30(8):730–44.
117. Marie C. Hiding who I am: the reality of end of life care for LGBT people. 2016. https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2016/reality-end-of-life-care-lgbt-people.pdf.
118. Cartwright C, Hughes M, Lienert T. End-of-life care for gay, lesbian, bisexual and transgender people. Cult Health Sex. 2012;14(5):537–48.
119. Matthews AK, Peterman AH, Delaney P, Menard L, Brandenburg D. A qualitative exploration of the experiences of lesbian and heterosexual patients with breast cancer. Oncol Nurs Forum. 2002;29(10):1455–62.

Chapter 18
The Integrative Approach to Supporting Families in the ICU

Delia Chiaramonte

Introduction

Integrative Medicine Defined

Integrative medicine emphasizes the care of the whole person and uses multiple therapeutic approaches to support optimal health and healing. It is provided alongside conventional medicine and includes aspects of lifestyle management. Defining principles of integrative medicine include [1, 2]:

- Patient and practitioner are partners in the healing process.
- Integrates conventional and complementary methods for treatment and prevention.
- Engages mind, body, spirit, and community to facilitate healing.
- Supports the body's innate healing response.
- Maintains that healing is always possible even when curing is not.
- Practitioners of integrative medicine should actively practice self-care.

The label "alternative medicine" is generally avoided as it suggests using complementary modalities, such as acupuncture or massage, in lieu of conventional approaches rather than alongside them. Conditions for which integrative medicine is commonly used outside of the intensive care unit (ICU) include pain, anxiety, headache, sleep dysfunction, and stress [3].

D. Chiaramonte
University of Maryland School of Medicine, Center for Integrative Medicine, Baltimore, MD, USA
e-mail: dchiaramonte@som.umaryland.edu

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_18

The Healing Encounter

Creating an optimal healing encounter, for patients and families, requires more than simply the accurate implementation of pharmaceuticals or procedures. It includes a focus on collaborative and relationship-centered care, attention to the treatment environment, a healing intention, and clinicians who attend to their own wellness [4]. Establishing a therapeutic relationship with the patient and family is crucial. Psychiatrists with strong patient relationships using placebo medication for depression have better outcomes than psychiatrists rated lower on relationship skills administering active drugs [5]. Thus, the clinician his or herself contributes directly to the healing encounter.

The Need for Physician as Mentor for Health

Practitioner self-care is a tenet of the integrative approach to the care of patients and families. Yet the culture of medical and nursing training may encourage physicians and nurses to ignore their hunger, fatigue, elimination needs, and psychological stress. Thus, ironically, healthcare providers who are tasked with shepherding people to health often fail to attend to their own health and wellness.

Prolonged psychological stress can lead to burnout, which is significantly more common in physicians than in the general population [6]. Intensive care unit clinicians, both physicians and nonphysicians, are at particularly high risk with over 50% experiencing burnout [7]. Burnout syndrome is characterized by depersonalization, emotional exhaustion, and a reduced sense of personal accomplishment and can be associated with anxiety, hopelessness, lack of professionalism, physical symptoms, and decreased empathy [8]. Alcohol abuse is associated with burnout in medical students [9], yet many burned out clinicians do not seek help because of perceived stigma of admitting to burnout [10]. Burned out physicians may provide less than ideal patient and family care, and physician burnout is associated with decreased patient and, presumably family, satisfaction [11]. ICU clinicians who practice wellness behaviors, such as exercise, mindfulness, self-reflection, and group support, may decrease their risk of burnout [12, 13].

Integrative Medicine in the Intensive Care Unit

The integrative approach prioritizes wellness of the mind, body, and spirit and is appropriate for patients, families, and clinicians. A patient might use acupuncture to address neuropathic pain, a family member might be taught diaphragmatic breathing to help initiate sleep, and an ICU clinician might use yoga as part of a burnout prevention plan. Adding integrative medicine services into intensive care units can benefit patients, families, clinicians, and ICU staff. Over three quarters of family caregivers of seriously ill patients are interested in learning about stress reduction techniques [14].

Integrative Approaches to Enhance Family Wellness in the ICU

Mind-Body Medicine

Family members of patients in the ICU experience tremendous stress, with resulting negative physical and emotional outcomes [15]. Mind-body techniques have been shown to decrease perceived stress and improve symptoms of anxiety, depression [16], and PTSD [17]. They are easy to learn, safe [18], accessible, and often without cost. Even telephone-based [19] and online mind-body skill programs have shown benefit in improving psychological distress, decreasing perceived stress, and increasing mindfulness, empathy, and resilience [20].

Breathing for Relaxation

Breathing can be used therapeutically to decrease the stress response and elicit the relaxation response. Therapeutic breathing may involve altering the speed of breathing or the muscles associated with breathing, and it may be linked with relaxing imagery. The relaxation response is essentially the opposite of the fight-or-flight stress response, and it is characterized by decreased blood pressure, respiratory rate, heart rate, and metabolic rate [21]. It has been described as a "hypometabolic state of parasympathetic activation." [22] Breathing that focuses the inhalation into the lower abdomen, commonly called diaphragmatic breathing, can stimulate the relaxation response as evidenced by decreased anxiety, heart rate, and respiratory rate [23]. In addition, it has been shown to decrease negative affect and levels of cortisol [24]. Shallow breathing into the chest may be associated with feelings of anxiety [25]. Family members can be instructed to use breath to stimulate the relaxation response. Instruction usually includes direction to "breathe deeply into the belly" and to slow down the rate of breathing, perhaps slightly prolonging the exhalation. One simple breathing exercise that can easily be taught to family members is called "counting breaths" (Table 18.1). Some experts suggest that a breath rate of six breaths per minute or a 1:2 inhalation to exhalation rate is particularly beneficial [26].

Meditation/Mindfulness

Meditation is the intentional and nonjudgmental focus of attention on something in the present moment. It does not require belief in any religious or spiritual system. The attentional focus can be almost anything, including a sound, a word or phrase, a picture, a behavior (such as breathing or walking), a candle flame, or simply the experience of being in the present moment. When the mind wanders, the meditator simply brings attention, without judgment, back to the meditative focus. This refocusing of attention will likely occur repeatedly, which is to be expected. Some people believe that they "can't meditate" because their attention

Table 18.1 Counting breaths

As you breathe in, think to yourself “one”
As you breathe out, think to yourself “calm”
As you breathe in, think to yourself “two”
As you breathe out, think to yourself “calm”
As you breathe in, think to yourself “three”
As you breathe out, think to yourself “calm”
Continue this pattern until you reach “ten”
When to count breaths:
First thing in the morning
Before a meal
When you’re feeling agitated or frustrated
Every hour on the hour while you’re in the hospital room
After anyone enters/leaves the hospital room
As you lie in bed at night

frequently wanders. This is a misconception as it is the repeated refocusing of attention that trains the mind in a way that may explain some of the benefits of meditation. Just as repeatedly lifting weights creates stronger muscles, repeatedly noticing one’s thoughts and choosing not to get carried away by them train mindfulness, which results in multiple health improvements including decreased anxiety and depression [27].

“Mindfulness” is the ability to retain one’s focus on the present moment without judgment. It involves intentional awareness of one’s moment-by-moment thoughts, feelings, environment, and bodily sensations. Mindfulness can be achieved through a formal meditation practice and/or via an informal cognitive practice of refocusing attention to the present moment when attention wanders either to the past or the future. Anxious thinking requires that attention be focused in the future – imagining the many terrible things that might happen. Depressive thinking tends to be focused in the past, ruminating on negative experiences or slights. Thus, intentionally focusing on the present moment can counteract a tendency toward anxious or depressive thinking. The greater one’s ability to remain focused on the present moment, the higher one’s mindfulness. There are validated metrics to assess level of mindfulness, such as the Five Facet Mindfulness Questionnaire (FFMQ) [28]. The practice of meditation, with its repeated focus on attending to something in the present moment, trains the skill of mindfulness. However, it is not necessary to practice meditation in order to achieve a mindful perspective. One can use cognitive skills to notice when attention has wandered to the future or the past and intentionally bring it back to the present. It can be helpful to use an anchor such as taking a deep breath, rubbing the hands together, or pressing the thumb and forefinger firmly together. Mindfulness interventions have been shown to improve data-driven information processing [29] which could be helpful for family members facing difficult medical decisions. They are acceptable to multiple populations including African American women with PTSD [30].

The Western, secular practice of mindfulness was introduced and championed by Jon Kabat-Zinn at the University of Massachusetts Medical School in 1979, where he created a highly successful program called mindfulness-based stress reduction (MBSR). MBSR is a well-researched mindfulness and meditation training program that is widely available in the USA. [31] It is a standardized 8-week mind-body training program that includes eight 2.5 hour classes, a full day retreat, and at least 45 min per day of home meditation practice. It is offered in many communities and can be recommended to family members who are interested in intensive mind-body training. Practicing MBSR has been shown to increase well-being and mindfulness and decrease rumination and symptoms of depression [32]. In one study of 141 family caregivers randomly assigned to MBSR or a self-help control group, the intervention resulted in decreased anxiety and depressive symptoms as well as increased self-efficacy and mindfulness [33]. In another study of caregivers of patients with cirrhosis, participation in an MBSR program decreased perceived caregiver burden and improved sleep [34].

Guided Imagery

Guided imagery is the intentional use of imagination to facilitate positive health and wellness outcomes. The term is used to describe a variety of techniques including visualization and imagery-based suggestions. It can be used to support physical and psychological relaxation, facilitate symptom relief, and improve quality of life [35]. In family-centered ICU care, guided imagery can be used for patients and family members simultaneously. Guided imagery can be delivered live or from a recording, and once a particular script is listened to repeatedly, patients or family members can replicate the images in their mind without outside assistance. Potential images are unlimited and may include progressive relaxation of the muscles, being in a relaxing location, wrapping painful body parts in bubble wrap or white light or stimulating an activated immune system to attack cancer cells. Patients with pain may benefit from an imagery involving an “inner sanctuary,” while families facing difficult medical decisions might be offered an imagery of a wise “inner advisor.”

Creative Arts

Creative arts such as therapeutic music, visual arts, and writing for wellness can be used in the ICU setting to help support family members who are struggling with anxiety, anticipatory grief, and difficulty coping with a seriously ill loved one. These techniques can facilitate mindfulness, stimulate the relaxation response, enhance self-awareness, and help the family member to find meaning in a difficult experience.

Therapeutic Music

Therapeutic music and music therapy are distinct interventions. Music therapy is a designated health profession that engages patients in creating, singing, moving to, and/or listening to music with the goal of strengthening the client's abilities and applying these abilities to other areas of life [36]. The approach to therapeutic music may be considered in three categories:

1. Music therapy certification requires a 4-year college degree and over 1000 hours of clinical training. This therapy attempts to accomplish a specific long-term goal or outcome [37]. Music therapy is generally impractical as a family intervention in the ICU setting.
2. Therapeutic music is offered by Certified Music Practitioners (CMPs), or similarly trained musicians, and focuses on meeting patients' immediate needs for relaxation, support, or a healing environment. Live therapeutic music is performed by musicians who have special training in providing care to patients with serious illness and their families. CMPs are trained to choose the music played based on the current needs of the patient or family member and to modify the music as needed. Training programs include the Music for Healing and Transition Program [37] and the International Harp Therapy Program [38]. Exposure to live therapeutic music has been shown to improve patients' mood and overall satisfaction with their hospital care [39], and this is likely to benefit their family caregivers as well.
3. Recorded music has also been used in ICU settings. Structured music listening time has been shown to decrease cortisol in ICU patients [40] as well as blood pressure and pulse during weaning from mechanical ventilation [41]; family members could be expected to benefit as well if the music is played aloud in the hospital room. The vibrational quality of live music coupled with the healing presence of the therapeutic musician may offer some advantage over recorded music.

Therapeutic sound is another low-cost option that can be provided to both patients and family members in the ICU setting. Playing live Tibetan singing bowls resulted in decreased tension, anger, fatigue, and depressed mood and enhanced feelings of spiritual well-being [42].

Visual Arts

Formal art therapy is not practical for family members in the ICU setting, but therapeutic art can be used to enhance coping skills and facilitate coping. Art-based activities have been shown to decrease anxiety in parents of hospitalized infants [43] and help hospitalized children improve communication with healthcare providers and develop more effective coping skills [44]. Mindfulness-based art therapy decreased anxiety and depression in breast cancer patients [45]. Simple techniques such as coloring and mandalas are inexpensive, portable, and easy to provide to family members. Mandalas, geometric drawings that may be seen to represent universal concepts, can be used to focus attention and to facilitate relaxation and meditation. Therapeutic visual art interventions can also be used to identify coping strategies and personal strengths. One sample exercise involves having the participant draw a "hole" that represents a difficulty with which they are coping and then drawing how they would traverse this hole. The therapeutic artist reviews the drawing with the participant, using the discussion to identify the strategies chosen to overcome the difficulty. Examples might include recruiting the help of others, using animals for support, using personal creative skills to build a bridge, etc. Thus, the art exercise can be used to facilitate a discussion about personal strengths and resources.

Writing for Wellness

Journaling may help manage stress-related physical symptoms [46], manage negative thoughts, and assist with problem-solving. Journaling techniques are varied and can be targeted to the wishes of the family member and the situation. Examples of patient journaling techniques include:

- *Dumping journal*

  In this form of journaling, the writer's goal is simply to release thoughts and concerns about which they are ruminating. The technique involves writing quickly, without stopping or censoring and without attention to punctuation or spelling. It may be particularly helpful for family members with sleep dysfunction caused by rumination about stressful events. The journal may be kept at the side of the bed and used as a repository for thoughts that are contributing to insomnia.
- *Writing to a symptom*
  In this form of journaling, family members would choose a symptom that is bothering them such as headaches, sleeplessness, back pain, or anxiety. The writer writes first as themselves and then as their symptom, continuing this written dialogue back and forth for approximately 10 min. They then review what they have written looking for insights that have emerged. For example, in response to the question "anxiety, why won't you leave me alone?" the response might be "I'm just trying to keep you safe."
- *Responding to prompts*
  Family members can be offered writing prompts to facilitate self-discovery and identification of personal resources. Examples of writing prompts include:

  - Words I like to live by are…
  - Things I can do to be kind to myself include…
  - Things that inspire me and give me hope include…
  - Ways that I cope effectively with difficult things are…

- *Gratitude journaling*

> Developing a regular gratitude practice has been shown to improve well-being and positive affect [47]. Gratitude journaling can be both a daily practice and an intervention to facilitate coping with a difficult experience. For daily gratitude journaling, the participant writes 3–5 things every day for which they are grateful in a dedicated gratitude journal. The most important instruction is that each day the list must be different from what was written the day before. This trains the cognitive skill of identifying things for which one is grateful even on difficult days. It is important to emphasize that listing things for which the family member is grateful does not in any way minimize the sadness, worry, or grief that they feel for their loved one in the ICU. Another method of gratitude journaling involves listing, in one sitting, a full page of things for which a person is grateful. The list should include large things ("my family"), small things ("a seat heater in my car"), conveniences ("air conditioning"), and personal traits ("my sense of humor").

Intensive care diaries, in which healthcare staff (and sometimes family members) document daily notes and pictures in a document presented to the patient after discharge, have been shown to reduce incidence of post-traumatic stress disorder [48].

Biofield Therapy

Biofield therapy, sometimes referred to as energy medicine, has been defined as "noninvasive, practitioner-mediated therapies that explicitly work with the biofield of both the practitioner and client to stimulate a healing response in the client." [49] These therapies are controversial, with many passionate advocates and equally passionate critics. Many cultures use the concept of "energy" in discussions of health and wellness, using terms such as life energy, chi, prana, and others. There are varied approaches to energy medicine, including healing touch, Reiki, zero balancing, and many others. The evidence base for biofield therapies is small but growing. A review of studies published between 2008 and 2013 concluded that biofield therapies may be effective in improving quality of life, pain, well-being, and stress in palliative care patients [50], although not all reviews have found benefit [51].

Seated Massage and Touch Therapy

Seated massage therapy has shown benefit in family caregivers, including relaxation, comfort, distraction, relief from anxiety, and an increase in well-being [52]. Full body massage is not practical for family members in the ICU, but seated massage or structured touch techniques, such as M technique, may be both beneficial and feasible. Seated massage requires a massage chair, as well as the services of a licensed massage therapist; thus there may be barriers to implementation. In contrast, the M technique can be offered to family members in the patient's room. M technique is a method of structured light touch, provided in a set pattern, sometimes just to the hands and feet. It can be easily learned by licensed healthcare providers and even family caregivers. Family members can offer the M technique to each other and to the patient. M technique is often used in hospital and hospice settings, although it cannot be provided on abraded skin or open wounds. A study of hand and foot massage provided to family caregivers showed positive outcomes, including feeling “cared for” and experiencing “body vitality” and “peace of mind.” Participants were able to temporarily put aside their worries and experience simply “being.” [53]

Emotional Freedom Technique (EFT)

Emotional freedom technique, also called “tapping,” can be thought of as a combination of acupressure, exposure therapy, and cognitive therapy. It involves the participant tapping on predetermined acupressure points while verbally acknowledging negative emotions. Proponents believe that this allows for acceptance and resolution of these negative emotions. Evidence supports the benefit of EFT in adolescents with anxiety [54], stress and anxiety in nursing students [55], stress-related headaches [56], and reducing depressive symptoms [57, 58]. One study of cancer patients and caregivers showed that EFT led to improved marital functioning and improved patients’ experience of caregiver empathic care.[59]

The process involves identifying a specific issue to work on, for example, a disagreement the previous week with a sister over treatment decisions for their mother. Then as a predetermined acupressure point is stimulated, the participant says an “even though” statement to the effect of “even though my sister and I don’t agree on what to do with mom…I am open to us finding a resolution.” The participant then taps approximately 5–7 times on a series of nine predetermined acupressure points, including the top of the head, side of the eyes, under the nose, chin crease, under the clavicle, and more while restating and expanding upon the problem: “my sister and I don’t agree,” “I hate that we’re fighting,” “she’s so unreasonable,” “I just want to do the right thing,” and “I just want to help mom.” After going through two cycles of tapping, the participant takes a deep breath and assesses if their level of distress has decreased. If not they might repeat the cycle.

EFT is easy to learn, requires no equipment, and can be done anywhere. It can either be guided by a therapist or it can be used as a self-care tool by patients and family members without the assistance of a practitioner. Licensed healthcare providers can easily learn EFT and teach it to patients, or they can refer patients to online education resources.

Summary

Complementary and integrative approaches can effectively help family members of ICU patients manage their stress and distress. A sample stress reduction plan is presented in Table 18.2. Teaching mindfulness, providing stress management skills,

Table 18.2 A sample stress reduction plan

Elicit the relaxation response
Meditation, guided imagery, diaphragmatic breathing
Choose a movement plan
Walking, yoga, tai chi, aerobics, dancing
Sleep enough
Try to get 7–8 h of sleep most nights
Start a gratitude practice
At the end of the day, call to mind 3–5 things that you are grateful for from the day. Make them different each day
Spend time doing things that enrich you
Nature, animals, friends/family, learning, music, reading, volunteering, etc.
Become an observer of your thoughts
“That was an anxious thought.” “that was a negative thought”
Ask positive questions
“What will help me find strength?” “what can I learn from this experience?“”how can I use this experience to help someone else?”

and offering techniques to support self-reflection can facilitate coping and resilience. ICUs may choose to hire dedicated practitioners to provide modalities such as massage and Reiki if funding is available. If funding is not available, nurses, physicians, nurse practitioners, physician assistants, social workers, and chaplains can pursue training in complementary modalities and provide these services as part of their standard interactions with family members. Facilities that offer integrative medicine patient consultation in the ICU can include care of the family members as part of the consultation.

References

1. https://integrativemedicine.arizona.edu/about/definition.html. Accessed 2nd Dec 2017.
2. Rakel D. Integrative medicine. 3rd ed: Elsevier; 2012. p. 7.
3. Barnes PM, Bloom B, Nahin RL. Complementary and alternative medicine use among adults and children: United States, 2007. Natl Health Stat Report. 2008;12:1–23.
4. Rakel D. Integrative medicine. 3rd ed: Elsevier; 2012. p. 15.
5. McKay KM, Imel ZE, Wampold BE. Psychiatrist effects in the psychopharmacological treatment of depression. J Affect Disord. 2006;92(2–3):287–90.
6. Shanafelt TD, Boone S, Tan L, Dyrbye LN, Sotile W, Satele D, West CP, Sloan J, Oreskovich MR. Burnout and satisfaction with work-life balance among US physicians relative to the general US population. Arch Intern Med. 2012;172(18):1377–85. Malaquin S, Mahjoub Y, Musi A, Zogheib E, Salomon A, Guilbart M, Dupont H. Burnout syndrome in critical care team members: a monocentric cross sectional survey. Anaesth Crit Care Pain Med. 2017;36(4):223–8. doi: https://doi.org/10.1016/j.accpm.2016.06.011. Epub 2016 Sep 23.
7. Moss M, Good VS, Gozal D, Kleinpell R, Sessler CN. An official critical care societies collaborative statement: burnout syndrome in critical care healthcare professionals: a call for action. Crit Care Med. 2016;44:1414–21.

8. Jackson ER, Shanafelt TD, Hasan O, Satele DV, Dyrbye LN. Burnout and alcohol abuse/dependence among U.S. medical students. Acad Med. 2016;91(9):1251–6. https://doi.org/10.1097/ACM.0000000000001138.
9. Dyrbye LN, Eacker A, Durning SJ, Brazeau C, Moutier C, Massie FS, et al. The impact of stigma and personal experiences on the help-seeking behaviors of medical students with burnout. Acad Med. 2015;90(7):961–9. https://doi.org/10.1097/ACM.0000000000000655.
10. Anagnostopoulos F, Liolios E, Persefonis G, Slater J, Kafetsios K, Niakas D. Physician burnout and patient satisfaction with consultation in primary health care settings: evidence of relationships from a one-with-many design. J Clin Psychol Med Settings. 2012;19(4):401–10. https://doi.org/10.1007/s10880-011-9278-8.
11. Dyrbye LN, Satele D, Shanafelt TD. Healthy exercise habits are associated with lower risk of burnout and higher quality of life among U.S. medical students. Acad Med. 2017;92(7):1006–11. https://doi.org/10.1097/ACM.0000000000001540.
12. West CP, Dyrbye LN, Rabatin JT, Call TG, Davidson JH, Multari A, et al. Intervention to promote physician Well-being, job satisfaction, and professionalism: a randomized clinical trial. JAMA Intern Med. 2014;174(4):527–33. https://doi.org/10.1001/jamainternmed.2013.14387.
13. Keir ST. Levels of stress and intervention preferences of caregivers of brain tumor patients. Cancer Nurs. 2007;30(6):E33–9.
14. Netzer G, Sullivan DR. Recognizing, naming, and measuring a family intensive care unit syndrome. Ann Am Thorac Soc. 2014;11(3):435–41. https://doi.org/10.1513/AnnalsATS.201309-308OT.
15. Gotink RA, Chu P, Busschbach JJ, Benson H, Fricchione GL, Hunink MG. Standardised mindfulness-based interventions in healthcare: an overview of systematic reviews and meta-analyses of RCTs. PLoS One. 2015;10(4):e0124344. https://doi.org/10.1371/journal.pone.0124344.eCollection2015.
16. Polusny MA, Erbes CR, Thuras P, Moran A, Lamberty GJ, Collins RC, et al. Mindfulness-based stress reduction for posttraumatic stress disorder among veterans: a randomized clinical trial. JAMA. 2015;314(5):456–65. https://doi.org/10.1001/jama.2015.8361.
17. https://nccih.nih.gov/health/meditation/overview.htm#hed5. Accessed 12/22/17.
18. Cox CE, Porter LS, Buck PJ, Hoffa M, Jones D, Walton B, et al. Development and preliminary evaluation of a telephone-based mindfulness training intervention for survivors of critical illness. Ann Am Thorac Soc. 2014;11(2):173–81. https://doi.org/10.1513/AnnalsATS.201308-283OC.
19. Kemper KJ, Khirallah M. Acute effects of online mind-body skills training on resilience, mindfulness, and empathy. J Evid Based Complementary Altern Med. 2015;20(4):247–53. https://doi.org/10.1177/2156587215575816. Epub 2015 Mar 17
20. Benson H. The relaxation response. New York: Morrow; 1975.
21. Benson JBK, Crassweller KD. The relaxation response: a bridge between psychiatry and medicine. Med Clin North Am. 1977;61:929–38.
22. Chen YF, Huang XY, Chien CH, Cheng JF. The effectiveness of diaphragmatic breathing relaxation training for reducing anxiety. Perspect Psychiatr Care. 2017;53(4):329–36. https://doi.org/10.1111/ppc.12184. Epub 2016 Aug 23
23. Ma X, Yue ZQ, Gong ZQ, Zhang H, Duan NY, Shi YT, et al. The effect of diaphragmatic breathing on attention, negative affect and stress in healthy adults. Front Psychol. 2017;8:874. https://doi.org/10.3389/fpsyg.2017.00874.eCollection2017.
24. Conrad A, Müller A, Doberenz S, Kim S, Meuret AE, Wollburg E, et al. Psychophysiological effects of breathing instructions for stress management. Appl Psychophysiol Biofeedback. 2007;32(2):89–98. Epub 2007 May 23
25. Rakel D. Integrative medicine. 3rd edn. Elsevier; 2012. p. 896.
26. Goyal M, Singh S, Sibinga EM, Gould NF, Rowland-Seymour A, Sharma R, et al. Meditation programs for psychological stress and well-being: a systematic review and meta-analysis. JAMA Intern Med. 2014;174(3):357–68. https://doi.org/10.1001/jamainternmed.2013.13018.
27. Baer RA, Smith GT, Hopkins J, et al. Using self-report assessment methods to explore facets of mindfulness. Assessment. 2006;13(1):27–45.

28. Wimmer L, Bellingrath S, von Stockhausen L. Cognitive effects of mindfulness training: results of a pilot study based on a theory driven approach. Front Psychol. 2016;7:1037. https://doi.org/10.3389/fpsyg.2016.01037.eCollection2016.
29. Dutton MA, Bermudez D, Matas A, Majid H, Myers NL. Mindfulness-based stress reduction for low-income, predominantly African American women with PTSD and a history of intimate partner violence. Cogn Behav Pract. 2013;20(1):23–32.
30. Kabat-Zinn J. Full catastrophe living: using the wisdom of your body and mind to face stress, pain and illness, vol. 1990. New York: Bantam Books; 2013.
31. Deyo M, Wilson KA, Ong J, Koopman C. Mindfulness and rumination: does mindfulness training lead to reductions in the ruminative thinking associated with depression? Explore (NY). 2009;5(5):265–71. https://doi.org/10.1016/j.explore.2009.06.005.
32. Hou RJ, Wong SY, Yip BH, Hung AT, Lo HH, Chan PH, et al. The effects of mindfulness-based stress reduction program on the mental health of family caregivers: a randomized controlled trial. Psychother Psychosom. 2014;83(1):45–53. https://doi.org/10.1159/000353278. Epub 2013 Nov 19
33. Bajaj JS, Ellwood M, Ainger T, Burroughs T, Fagan A, Gavis EA, et al. Mindfulness-based stress reduction therapy improves patient and caregiver-reported outcomes in cirrhosis. Clin Transl Gastroenterol. 2017;8(7):e108. https://doi.org/10.1038/ctg.2017.38.
34. Giacobbi PR Jr, Stabler ME, Stewart J, Jaeschke AM, Siebert JL, Kelley GA. Guided imagery for arthritis and other rheumatic diseases: a systematic review of randomized controlled trials. Pain Manag Nurs. 2015;16(5):792–803. https://doi.org/10.1016/j.pmn.2015.01.003. Epub 2015 Jul 11
35. https://www.musictherapy.org/about/quotes/. Accessed 12/22/17.
36. http://www.mhtp.org. Accessed 12/22/17.
37. www.harptherapyinternational.com. Accessed 12/22/17.
38. Mogos MF, Angard N, Goldstein L, Beckstead JW. The effects of live therapeutic music on patient's affect and perceptions of care: a randomized field study. Complement Ther Clin Pract. 2013;19(4):188–92. https://doi.org/10.1016/j.ctcp.2013.07.003. Epub 2013 Sep 5
39. Beaulieu-Boire G, Bourque S, Chagnon F, Chouinard L, Gallo-Payet N, Lesur O. Music and biological stress dampening in mechanically-ventilated patients at the intensive care unit ward-a prospective interventional randomized crossover trial. J Crit Care. 2013;28(4):442–50. https://doi.org/10.1016/j.jcrc.2013.01.007. Epub 2013 Mar 15
40. Jaber S, Bahloul H, Guétin S, Chanques G, Sebbane M, Eledjam JJ. Effects of music therapy in intensive care unit without sedation in weaning patients versus non-ventilated patients [Article in French]. Ann Fr Anesth Reanim. 2007;26(1):30–8. Epub 2006 Nov 3
41. Goldsby TL, Goldsby ME, McWalters M, Mills PJ. Effects of singing bowl sound meditation on mood, tension, and Well-being: an observational study. J Evid Based Complementary Altern Med. 2016.; pii: 2156587216668109. [Epub ahead of print]
42. Mouradian LE, DeGrace BW, Thompson DM. Art-based occupation group reduces parent anxiety in the neonatal intensive care unit: a mixed-methods study. Am J Occup Ther. 2013;67(6):692–700. https://doi.org/10.5014/ajot.2013.007682.
43. Aguilar BA. The efficacy of art therapy in pediatric oncology patients: an integrative literature review. J Pediatr Nurs. 2017;36:173–8. https://doi.org/10.1016/j.pedn.2017.06.015. Epub 2017 Jun 30
44. Jang SH, Kang SY, Lee HJ, Lee SY. Beneficial effect of mindfulness-based art therapy in patients with breast Cancer-a randomized controlled trial. Explore (NY). 2016;12(5):333–40. https://doi.org/10.1016/j.explore.2016.06.003. Epub 2016 Jun 21
45. Smyth M, Stone AA, Hurewitz A, Kaell A. Effects of writing about stressful experiences on symptom reduction in patients with asthma or rheumatoid arthritis. JAMA. 1999;281:1304–9.
46. Emmons, R. A., & McCullough, M. E. Counting blessings versus burdens: an experimental investigation of gratitude and subjective Well-being in daily life. J Pers Soc Psychol, 84, 377–389. 2003. https://doi.org/10.1037/0022-3514.84.2.377
47. Jones C, Bäckman C, Capuzzo M, Egerod I, Flaatten H, Granja C, et al. RACHEL group. Intensive care diaries reduce new onset post traumatic stress disorder following critical illness:

a randomised, controlled trial. Crit Care. 2010;14(5):R168. https://doi.org/10.1186/cc9260. Epub 2010 Sep 15
48. Jain R, Hammerschlag PM, et al. Clinical studies of biofield therapies: summary, methodological challenges, and recommendations. Global Adv Health Med. 2015;4(Suppl):58–66. S
49. Hennaghan AM, Schnyer RN. Biofield therapies for symptomatic management in palliative care and end-of-life. Am J of Hosp Palliat Med. 2015;32(1):90–100.
50. Gonella SG, Garrina L, Dimonte V. Biofield therapies and cancer related symptoms: a review. Clin J Oncol Nurs. 2014;18(5):568–76.
51. Mackereth P, Campbell G, Maycock P, Hennings J, Breckons M. Chair massage for patients and carers: a pilot service in an outpatient setting of a cancer care hospital. Complement Ther Clin Pract. 2008;14(2):136–42. https://doi.org/10.1016/j.ctcp.2007.11.003. Epub 2007 Dec 31
52. Cronfalk BS, Strang P, Ternestedt BM. Inner power, physical strength and existential Well-being in daily life: relatives' experiences of receiving soft tissue massage in palliative home care. J Clin Nurs. 2009;18(15):2225–33. https://doi.org/10.1111/j.1365-2702.2008.02517.x.
53. Gaesser AH, Karan OC. A Randomized controlled comparison of emotional freedom technique and cognitive-behavioral therapy to reduce adolescent anxiety: a pilot study. J Altern Complement Med. 2017;23(2):102–8. https://doi.org/10.1089/acm.2015.0316. Epub 2016 Sep 19
54. Chatwin H, Stapleton P, Porter B, Devine S, Sheldon T. The effectiveness of cognitive behavioral therapy and emotional freedom techniques in reducing depression and anxiety among adults: a pilot study. Integr Med (Encinitas). 2016;15(2):27–34.
55. Bougea AM, Spandideas N, Alexopoulos EC, Thomaides T, Chrousos GP, Darviri C. Effect of the emotional freedom technique on perceived stress, quality of life, and cortisol salivary levels in tension-type headache sufferers: a randomized controlled trial. Explore (NY). 2013;9(2):91–9. https://doi.org/10.1016/j.explore.2012.12.005.
56. Nelms JA, Castel L. A systematic review and meta-analysis of randomized and nonrandomized trials of clinical emotional freedom techniques (EFT) for the treatment of depression. Explore (NY). 2016;12(6):416–26. https://doi.org/10.1016/j.explore.2016.08.001. Epub 2016 Aug 18
57. Church D, De Asis MA, Brooks AJ. Brief group intervention using emotional freedom techniques for depression in college students: a randomized controlled trial. Depress Res Treat. 2012;2012:257172. https://doi.org/10.1155/2012/257172. Epub 2012 Jul 17
58. McLean LM, Walton T, Rodin G, Esplen MJ, Jones JM. A couple-based intervention for patients and caregivers facing end-stage cancer: outcomes of a randomized controlled trial. Psychooncology. 2013;22(1):28–38. https://doi.org/10.1002/pon.2046. Epub 2011 Sep 15

Chapter 19
The Role of Ethics Consultation in Enhancing Family-Centered Care

Henry J. Silverman

The Role and Contribution of Ethics Consultation to Family–Centered Care

Most critically ill patients lack the capacity to make decisions, and hence, family often acts as the surrogate decision-maker for treatment as well as for end-of-life decisions, the latter resulting in tremendous emotional burdens for them. To be sure, families report wanting a greater role in decision-making in order to communicate and put into effect their loved one's unique values and preferences [1, 2]. As a result, family-clinician communication becomes a central component of medical decision-making in the intensive care unit (ICU).

However, the evidence is mixed regarding the effect of communication interventions on patient- and family-centered outcomes that include "satisfaction" and decreased "emotional distress" [3, 4]. Furthermore, despite interventions that strive to enhance communications, end-of-life decision-making frequently depends on moral, religious, and cultural viewpoints that may differ broadly in our pluralistic society and hence, may differ between the perspectives of families and healthcare providers. Accordingly, potentially disparate moral perspectives between families and healthcare providers can result in intractable *conflicts*, which can have profound adverse effects on families and on clinicians. Consequences for families include depression, complicated grief, anxiety, and posttraumatic stress disorder [5–7]. For healthcare providers, conflicts can cause moral distress, disengagement, cynicism, and burnout [8].

Several studies have shown a high prevalence of clinician-surrogate conflicts, ranging between 22% and 48% [9–11]. A recent study demonstrated that either physicians or surrogates reported conflict in 63% of the cases and that physicians

---

H. J. Silverman
University of Maryland Baltimore, Baltimore, MD, USA
e-mail: hsilverm@som.umaryland.edu

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_19

reported conflict less frequently than family members (27.8% vs. 42.3%, respectively); concordance between physicians and family reports of conflicts was extremely poor [12]. Clinicians and surrogates agreed to the existence of a conflict in only approximately 26% of the cases.

Conflicts regarding end-of-life decisions may also occur between members of the healthcare team caring for the patient and within the family unit itself, which can lead to ethical *uncertainty* regarding the "correct" decision to make. Due to the presence of moral, religious, and culturally disparate factors that influence decision-making at the end of life and the uncertain nature of proactive communication strategies in preventing conflict, the use of "experts" to help resolve conflicts, specifically an ethics or a palliative care consult, can be recommended. One study showed that the presence of conflicts triggered ethics consultation requests more commonly than other ethical concerns [13].

In this chapter, I will review the role of ethics consultants in addressing moral uncertainty and resolving conflicts between families and clinicians, the evidence demonstrating the effectiveness of ethics consults at the end of life, how best to incorporate ethics expertise in end-of-life decision-making, and what areas warrant further investigation to optimize the role of ethics consultants.

Role of Ethics Consults

Ethics consultation represents a set of services provided by an individual or a group in response to questions from patients, families, surrogates, and healthcare professionals who seek to resolve moral *uncertainty* or *conflict* regarding value-laden concerns that emerge in healthcare, especially at the end of life [14]. Although all healthcare professionals engage in ethical decision-making as part of their everyday practice, ethics consultants respond to specific ethical concerns and questions that arise in healthcare. Advances in medical science and innovations in healthcare have expanded the scope of medical options across the lifespan. While many options might be appropriate for any given situation, the job of the ethicist is to help facilitate which option might be most appropriate based on the value systems of the involved stakeholders and which options are inappropriate to consider. As such, ethics consultants require a distinctive set of competencies to perform their role effectively. Such competencies fall into the following domains: (1) knowledge of common bioethical issues and concepts, (2) moral reasoning skills, (3) process skills that enable one to communicate and collaborate with different individuals and interpersonal skills, (4) facilitation of meetings, and (5) ethical assessment and analytic skills [14].

Such competencies enable ethics consultants to identify, analyze, and resolve ethical questions or concerns. Also, consultants' knowledge of ethical arguments may help them clarify unrecognized implications of the parties' view, allowing the primary decision-makers to come to more firmly grounded conclusions. Additionally, ethics consultants help promote practices consistent with ethical norms and standards, inform policy development to ensure the institutionalization of such practices, and assist individuals to address future ethical problems by providing education in healthcare ethics.

Ethics issues in healthcare typically arise in one or more of several broad domains:

- Ethical practices in end-of-life care and beginning of life
- Issues regarding privacy and confidentiality
- Selection of the appropriate surrogate
- Weighing between the extent of autonomous choices and patient beneficence
- Weighing between family's values that ground requests for continued treatment vs. professional integrity
- Determining when treatment might be futile or ethically inappropriate
- Appropriateness of a feeding tube in elderly patients with multiple comorbidities and an unfavorable prognosis
- The determination of what constitutes a "safe" discharge

Examples of specific ethical questions include the following:

- At what point would it be ethically appropriate not to insert a feeding tube in a patient with dementia who keeps pulling out the tube and has a poor prognosis?
- When can a patient with an aspiration syndrome still be fed orally at the patient's request?
- How does one resolve differences between siblings regarding continuation of ventilator treatment?
- When is it ethically appropriate to stop blood products in a patient with continued bleeding in the presence of end-stage liver disease?
- How to resolve differences between the healthcare team who thinks an intervention is required (e.g., leg amputation in a patient with gangrene or ventilator treatment in a patient with respiratory failure), but the patient/surrogate refuses?
- When is a family's request for a tracheostomy inappropriate in a patient with advanced lung cancer and respiratory failure?
- When is continued treatment still appropriate in a patient with an irreparable small bower leak who is still awake and wants to continue "fighting"?
- When is it inappropriate to allow surrogates to withdraw life-prolonging treatments in a patient with a spinal cord injury who has not had a head injury and remains sedated, but can regain his autonomy?
- How long is it appropriate to maintain interventions that preserve cardiopulmonary function in a patient who has been declared brain dead and the family is finding it difficult to accept the concept of death by neurologic criteria?

Common examples that highlight cultural and religious perspectives regarding routine intensive care that might lead to conflict include:

- The patient with a low hemoglobin level who could be treated with a transfusion, but the family of the Jehovah Witness faith refuses.
- The family who requests that their father not be told that he has a terminal condition, as it is not in their culture to tell the elders of their cancer diagnosis.

- The family of the orthodox Jewish faith who refuses to have the ventilator withdrawn from their mother who has been declared brain dead.
- The family who refuses to forgo life-sustaining treatments as they expect that God will perform a miracle and that only God can decide when a patient will die.

Requests that do not involve ethical concerns should be handled by other mechanisms in the institution (e.g., general complaints or allegations of misconduct or unprofessionalism) or referred to other departments (e.g., chaplain's department, risk management, patient advocate, or office of general council).

What Do the Data Show Regarding the Value of Ethics Consultations?

Members of the healthcare team may call on ethics consultants to help resolve uncertainty within the family unit or when conflicts arise between stakeholders the ICU. Studies are limited regarding the value of ethics consultation. Such studies have assessed the effects of ethics consults on quality of care measured by the length of stay (LOS), the avoidance of nonbeneficial treatments, and family satisfaction.

Four studies of diverse methodological quality and performed in different populations have assessed the effects of ethics consults on LOS [15–18]. In a study involving 99 patients, Dowdy showed that proactive ethics consultation for critically and terminally ill patients who were receiving mechanical ventilation for >96 h had more frequent decisions to forgo life-sustaining treatments and reduced ICU LOS [15]. Schneiderman and colleagues performed a randomized trial involving 74 patients and evaluated routine ethics consultation for patients "in whom value related treatment conflicts arose" [16]. By focusing on improving communications and addressing ethical dilemmas, these investigators showed that ethics consultations reduced the number of days patients spent in the ICU before death and led to reductions in life-sustaining treatments. These investigators conducted a follow-up study involving several centers that randomized 551 patients; ethics consultations were associated with reductions in hospital and ICU days and life-sustaining treatments [17]. Andereck and colleagues performed a single-center randomized control study that measured the effects of using an ethics consultative model preventively (i.e., before an ethics issue or conflict arose) and showed no effect on LOS between the two study groups [18].

Two of the previous trials examined the effects of ethics consultation on family satisfaction in the intervention arm but not in the control arm; family satisfaction was high in both these studies. Specifically, in Schneiderman and colleagues' single-center study involving 74 patients that studied the effect of ethics consultation in response to disputes that arose between family members and the healthcare team or within the healthcare team, of the 8 families they interviewed, 6 of 8 agreed that the consult helped resolve differences, and 7 of 8 agreed that it was responsive to their personal values.

In their follow-up multicenter randomized study involving more than 540 patients randomized to an intervention (ethics consultation offered) or to usual care in response to conflicts either within the healthcare team, within the family, or between families and the healthcare team, Schneiderman and colleagues showed in follow-up interviews that 87% of both the nurses and physicians and the patients/surrogates agreed or strongly agreed that ethics consultation was helpful.

In the study performed by Andereck and colleagues that involved a randomized control study examining a preventative ethics intervention for patients in an ICU prior to any recognized ethical conflict, patients' and providers' perceptions of quality of care were not different between the two groups [18].

Based on these studies, a recent guideline concluded that the overall quality of evidence for ethics consultation is low and recommended that ethics consultation should be provided to decrease ICU and hospital LOS among critically ill patients for whom there is a value-related conflict between clinicians and family. Due to the limited data regarding family satisfaction showed in the abovementioned studies, the guideline did not recommend using ethics consultation with the goal of increasing family satisfaction [19].

Regarding process, several studies investigated the effects of a "consultative" model in which specialists (e.g., palliative care and ethics consultants) work with the usual ICU personnel to implement communication interventions, whereas other studies examined effects of an "integrative model" in which palliative care and ethics principles are embedded into the daily practice of the usual care team. In a paper that performed a systemic review of communication quality improvement interventions, a higher percentage of studies that were consultative in nature as opposed to those that were integrative led to significant improvement in outcomes regarding healthcare utilization [4]. The authors of this study hypothesized that the benefit associated with a consultative model could be due to multiple potential reasons, e.g., consultative teams may focus specifically on communication-related issues as opposed to balancing them with other clinical responsibilities, which must occur with integrative interventions. Additionally, optimization of healthcare utilization represents a culture change in the workplace in which consults who represent "outside agents of such change" might be able to effect change more reliably and/or rapidly effective [4].

Considerations for Implementing the Ethics Consult Team in Clinical Decision–Making

Several aspects of ethics consults should be considered when used to enhance end-of-life decision making. One involves the timing of an ethics consult. Since many disagreements in ICUs arise not from conflicts in values, but from breakdowns in communication, it is reasonable to resolve such disagreements through routine communication interventions, e.g., family conferences. However, for disputes that are based on value conflicts, once they become intractable, resolution strategies are likely to be protracted and burdensome. Hence, while commentators recommend the use of ethics consultants when there are value conflicts causing disputes, the question is when should ethics consultants become involved. On the one hand, there is a concern that such consults are employed in a reactive fashion, whereby ethics consults are requested only after an ethics issue has already caused doubts, confusion, and mistrust. On the other hand, one study showed that when used preventively, i.e., when an ethics concern does not yet exist, there was no difference in quality of care or family satisfaction. Such a "broad application" may be too early, as implied in Andereck's study [18], but waiting for a problem to develop could lead to intractable conflicts. A more helpful process would involve the identification of a specific set of early triggers that foreshadow a value-laden conflict in its early stages. Table 19.1 shows one set of "early triggers" to request involvement of an ethics consult that is used at the University of Maryland Medical System.

Table 19.1 Triggers for an ethics screen

Trigger	Select if applicable
Length of stay is ≥ 30 days and any one of the following is present:	
• End organ failure is present in ≥ 3 systems OR the patient has experienced a cardiopulmonary arrest more than once this admission.	☐
• Ventilator OR vasopressor requirements are increasing.	☐
• Patient is receiving interventions that some might consider to be 'futile'.	☐
• Discussions with the patient or the family regarding code status have not occurred.	☐
• Communications with family members have diminished during the past week.	☐
• Conflicts are present between family members, between the family and the health care team, or within the health care team.	☐
• Plan of care is not congruent with what is stated in the advance directive.	☐
• Patient is a guardian of the State and is receiving life-sustaining treatments that might be considered ethically inappropriate.	☐
Patient resides in any chronic care facility and has been admitted 4 or more times to any ICU in the last 6 months; any length of stay.	☐

An issue regarding requests for ethics consultation involves access to ethics services including: who can requests an ethics consults? is physician permission required for such requests? are patients and families aware of the process of requesting an ethics consults? and, how can patients and families be empowered to make such requests within the strict hierarchy of the medical institution? Related to the issue of access is whether requests for ethics consults are associated with racial, ethnic, and gender characteristics of patients. One retrospective study showed that consultation requests for females were made significantly earlier in their hospital stays (6.57 days) compared with that for males (16.07 days). For African-American patients, the differences in admission-to-request intervals for female patients (5.93 days) and male patients (18.64 days) were greater than for Caucasian male and female patients [20]. Future investigations are warranted to determine whether there are racial and gender disparities in the extent of requests as well as the timing of ethics consultations.

Another aspect of ethics consultations regards the approach taken by ethics consultants. One commentator opined that "on balance, ethics consults may be an inappropriate mechanism to resolve conflict" [21]. The concern is that the extent to which ethics consultants engage the patient or family when addressing concerns is unclear and that "decisions by the ethics service may be rendered in a hierarchical manner with a vote either 'for' or 'against' one of the disputants," e.g., voting for the withholding of dialysis or cardiopulmonary resuscitation, resulting in a "win-lose" scenario [19]. Rather than the authoritative or the consensus approach, the ASBH recommends a facilitated approach to ethics consultation [14]. With this approach, the ethics consultant engages all stakeholders respectfully and simultaneously in an effort to create a "win-win" solution. The goal is for all stakeholders to leave a meeting feeling their concerns have been recognized and equally considered leading to an actionable resolution. However, not all ethics consultants are trained in principles of negotiation.

A related issue involves whether ethics consultations should be performed by a single-trained ethicist, by a small consultative team, or by all of the members of the ethics committee. No one model fits all type of cases, and an ethics consult service should try to match a particular model to the contextual features of each case, balancing responsiveness and representativeness of the committee [22]. Additionally, when considering the type of ethics consult model to use in any one case, one should consider the potential adverse psychological effects on a family that occurs from an inquiry into patients' preferences and values, which has been recently shown [23]. For example, a team or committee approach might be threatening to a family as opposed to a single ethicist, especially if families believe that their "ethics" are being questioned by the involvement of an ethics consult. That said, it might not be possible to have families explore the preferences and values of their family member who is critically ill and also reduce the emotional burden that occurs with such conversations [24]. However, trade-offs may need to be made between effectiveness of ethics consults and the emotional burden that might occur for families with such consults. For example, in the two studies that explored the "effects" of ethics consults, both showed that while many surrogates found the ethics process to be "stressful," a greater number of surrogates agreed that the ethics process was more "helpful" and would "seek" it again and "recommend" it to others [16, 17]. Similarly, a recent study compared family meetings led by palliative care specialists and provision of an informational brochure (intervention) compared with provision of an informational brochure and routine family meetings conducted by ICU teams (control) [23]. The results showed no significant difference in anxiety and depression symptoms between surrogate decision-makers in the intervention group and the control group and showed that posttraumatic stress disorder symptoms were higher in the intervention group at 3 months. Hence, somewhat counterintuitive, in attempts to help families/surrogates understand their values and those of the patients when making end-of-life decision, such communications might enhance unwanted emotional and psychological reactions. However, the above palliative care study was not representativeness of a representative palliative care consult, and hence, intensive and broad support is necessary to improve surrogates' psychological outcomes and decision-making for patients with chronic critical illnesses [25]. Accordingly, when either ethics or palliative care consultants help families resolve difficult end-of-life decisions, there should be active management of patients'/families' emotional and psychological symptoms by enlisting the help of social workers and chaplains.

A final issue regards the role of ethics consultants in "futility disputes" between families and healthcare providers. Such disputes can often be intractable. Surrogates opposed to the withdrawal of life support often appeal to the ethical principle of autonomy or embrace the concept of miracles. Healthcare providers express concern with potential harms that can occur to patients from resuscitative attempts as well as the moral distress that healthcare providers experience with providing CPR that is deemed to be futile [26].

Attempts at reaching consensus on a definition of medical futility have failed, as it became obvious that the concept of futility is very value-laden [27]. As such, commentators have recommended a procedural approach to address futility disputes, rather than giving all decision-making authority to either surrogates or individual clinicians [28]. Although it is generally accepted that surrogates should be allowed to request available treatment options, giving sole authority to surrogates is problematic, as there is no positive right to interventions that are outside the boundaries of accepted practice and surrogates sometimes experience strong emotional and psychological reactions that interfere with accepting decisions to forego life support, even when those decisions are clearly consistent with the patient's values and preferences [28]. Giving sole authority to clinicians is problematic because there is well-documented undue variability between clinicians in their judgments about when it is appropriate to write DNR orders for patients. Additionally, giving all authority to clinicians may also create a disincentive for them to "fully engage in the time-consuming, challenging conversations often required to support surrogates and achieve mutually agreeable decisions" [28].

Instead, a procedural approach will incorporate multiple perspectives to minimize the risk that the values of any one individual or party dominates the discussion and is better with fulfilling transparency, legitimacy, accountability, and opportunity for appeal. Finally, a procedural approach allows mutually agreeable solutions to emerge as the conflict-resolution process occurs over time. Ethics consultants can play an important role as facilitators with such a process-oriented approach. Recently, the American Thoracic Society proposed a seven-step process for addressing requests for inappropriate treatment that remain intractable [28]. Also, the Massachusetts General Hospital developed a “Do No Harm” policy that involved the intervention of the ethics committee in their procedural approach [29]. Reviewing their data collected during the past few years showed that about a third of the surrogates reversed their initial request for CPR and consented to a DNR order (45/134) after a procedural approach. For the remaining surrogates, the ethics committee determined that a CPR order should persist, but recommended a DNR order in the remaining 67 cases. The healthcare providers subsequently entered a DNR order in 61 of these patients, and most surrogates of these patients agreed, but 19 persisted to request CPR that was denied by the healthcare team. Although not assessed, it would not be difficult to assume that the surrogates of these patients suffered a range of negative emotions, which begs the question as to how to manage trade-offs between giving priority to surrogates’ preferences for CPR and writing DNR orders to support professional integrity and lessen health caregivers’ moral distress albeit with potential greater anxiety, depression, and posttraumatic distress syndrome for surrogates.

Future Themes to Explore Regarding Ethics Consultation at the End of Life

Further research is needed to better understand the effective components of ethics consultations, which consultative model is successful in terms of achieving consensus while reducing or limiting the emotional burden surrogates experience with a process of inquiry, and to identify the patients for whom ethics consultation is most beneficial.

Furthermore, the timing of an ethics consults might prove to be important, as its use after conflicts have become intractable might thwart its effectiveness. As such, determining what early triggers for ethics consults would be useful to prevent intractable disputes without decreasing the cost-effectiveness of such consults.

Conclusion

Ethics consults are used as a communication quality improvement intervention to enhance discussions between providers, patients, and families about value-laden ethical issues and address conflicts. Effective hospital ethics consultation plays an important role in clarifying values and obligations, defusing tensions, and refocusing attention on appropriate goals.

References

1. Johnson SK, Bautista CA, Hong SY, Weissfeld L, White DB. An empirical study of surrogates' preferred level of control over value-laden life support decisions in intensive care units. Am J Respir Crit Care Med. 2011;183(7):915–21. https://doi.org/10.1164/rccm.201008-1214OC.
2. Anderson WG, Arnold RM, Angus DC, Bryce CL. Passive decision-making preference is associated with anxiety and depression in relatives of patients in the intensive care unit. J Crit Care. 2009;24(2):249–54. https://doi.org/10.1016/j.jcrc.2007.12.010.
3. Scheunemann LP, McDevitt M, Carson SS, Hanson LC. Randomized, controlled trials of interventions to improve communication in intensive care: a systematic review. Chest. 2011;139(3):543–54. https://doi.org/10.1378/chest.10-0595.
4. Fawole OA, Dy SM, Wilson RF, Lau BD, Martinez KA, Apostol CC, et al. A systematic review of communication quality improvement interventions for patients with advanced and serious illness. J Gen Intern Med. 2013;28(4):570–7. https://doi.org/10.1007/s11606-012-2204-4.
5. Wright AA, Zhang B, Ray A, Mack JW, Trice E, Balboni T, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. JAMA. 2008;300(14):1665–73. https://doi.org/10.1001/jama.300.14.1665.
6. Gries CJ, Engelberg RA, Kross EK, Zatzick D, Nielsen EL, Downey L, et al. Predictors of symptoms of posttraumatic stress and depression in family members after patient death in the ICU. Chest. 2010;137(2):280–7. https://doi.org/10.1378/chest.09-1291.
7. Pochard F, Azoulay E, Chevret S, Lemaire F, Hubert P, Canoui P, et al. Symptoms of anxiety and depression in family members of intensive care unit patients: ethical hypothesis regarding decision-making capacity. Crit Care Med. 2001;29(10):1893–7.
8. Azoulay E, Timsit JF, Sprung CL, Soares M, Rusinova K, Lafabrie A, et al. Prevalence and factors of intensive care unit conflicts: the conflicus study. Am J Respir Crit Care Med. 2009;180(9):853–60. https://doi.org/10.1164/rccm.200810-1614OC.
9. Abbott KH, Sago JG, Breen CM, Abernethy AP, Tulsky JA. Families looking back: one year after discussion of withdrawal or withholding of life-sustaining support. Crit Care Med. 2001;29(1):197–201.
10. Breen CM, Abernethy AP, Abbott KH, Tulsky JA. Conflict associated with decisions to limit life-sustaining treatment in intensive care units. J Gen Intern Med. 2001;16(5):283–9.
11. Studdert DM, Mello MM, Burns JP, Puopolo AL, Galper BZ, Truog RD, et al. Conflict in the care of patients with prolonged stay in the ICU: types, sources, and predictors. Intensive Care Med. 2003;29(9):1489–97. https://doi.org/10.1007/s00134-003-1853-5.
12. Schuster RA, Hong SY, Arnold RM, White DB. Investigating conflict in ICUs-is the clinicians' perspective enough? Crit Care Med. 2014;42(2):328–35. https://doi.org/10.1097/CCM.0b013e3182a27598.
13. DuVal G, Sartorius L, Clarridge B, Gensler G, Danis M. What triggers requests for ethics consultations? J Med Ethics. 2001;27(Suppl 1):i24–9.
14. American Society for Bioethics and Humanities. Core competencies for healthcare ethics consultation. 2nd ed. Glenview: ASBH; 2011.
15. Dowdy MD, Robertson C, Bander JA. A study of proactive ethics consultation for critically and terminally ill patients with extended lengths of stay. Crit Care Med. 1998;26(2):252–9.
16. Schneiderman LJ, Gilmer T, Teetzel HD. Impact of ethics consultations in the intensive care setting: a randomized, controlled trial. Crit Care Med. 2000;28(12):3920–4.
17. Schneiderman LJ, Gilmer T, Teetzel HD, Dugan DO, Blustein J, Cranford R, et al. Effect of ethics consultations on nonbeneficial life-sustaining treatments in the intensive care setting: a randomized controlled trial. JAMA. 2003;290(9):1166–72. https://doi.org/10.1001/jama.290.9.1166.
18. Andereck JW, Kipp AM, Ondiek M, Vermund SH. Helminth prevalence among adults in rural Kenya: a stool survey for soil-transmitted helminths and schistosomiasis in Nyanza province. Trans R Soc Trop Med Hyg. 2014;108(12):804–9. https://doi.org/10.1093/trstmh/tru164.

19. Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, et al. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. Crit Care Med. 2017;45(1):103–28. https://doi.org/10.1097/CCM.0000000000002169.
20. Spielman B, Gorka C, Miller K, Pointer CA, Hinze B. Gender and race in the timing of requests for ethics consultations: a single-center study. J Clin Ethics. 2016;27(2):154–62.
21. Kayser JB. Ethics, communication and the ICU: charting a course for resolving conflict. Society of Critical Care Medicine. 2014. Retrieved at: http://www.sccm.org/Communications/Critical-Connections/Archives/Pages/Ethics,-Communication-and-the-ICU-Charting-a-Course-for-Resolving-Conflict.aspx.
22. Cohen CB. Avoiding "Cloudcuckooland" in ethics committee case review: matching models to issues and concerns. Law Med Health Care. 1992;20(4):294–9.
23. Carson SS, Cox CE, Wallenstein S, Hanson LC, Danis M, Tulsky JA, et al. Effect of palliative care-led meetings for families of patients with chronic critical illness: a randomized clinical trial. JAMA. 2016;316(1):51–62. https://doi.org/10.1001/jama.2016.8474.
24. Wendler D. The theory and practice of surrogate decision-making. Hast Cent Rep. 2017;47(1):29–31. https://doi.org/10.1002/hast.671.
25. White DB. Strategies to support surrogate decision makers of patients with chronic critical illness: the search continues. JAMA. 2016;316(1):35–7. https://doi.org/10.1001/jama.2016.8691.
26. McCoy KM. Nurses' perceptions of moral distress when initiating cardiopulmonary resuscitation. 2012. MSU Graduate Theses. https://bearworks.missouristate.edu/theses/1702.
27. Olmstead JA, Dahnke MD. The need for an effective process to resolve conflicts over medical futility: a case study and analysis. Crit Care Nurse. 2016;36(6):13–23. https://doi.org/10.4037/ccn2016472.
28. Bosslet GT, Pope TM, Rubenfeld GD, Lo B, Truog RD, Rushton CH, et al. An official ATS/AACN/ACCP/ESICM/SCCM policy statement: responding to requests for potentially inappropriate treatments in intensive care units. Am J Respir Crit Care Med. 2015;191(11):1318–30. https://doi.org/10.1164/rccm.201505-0924ST.
29. Robinson EM, Cadge W, Zollfrank AA, Cremens MC, Courtwright AM. After the DNR: surrogates who persist in requesting cardiopulmonary resuscitation. Hast Cent Rep. 2017;47(1):10–9. https://doi.org/10.1002/hast.664.

Chapter 20
Family Role in Patient Safety in the Intensive Care Unit

A. Doran Bostwick and Sarah J. Beesley

Introduction

Family members feel a natural inclination to protect and serve their loved ones. Unsurprisingly, this is only accentuated when their loved one is sick, yet it is at this critical time a family member may feel most helpless to provide aid [1]. As in prior chapters, the definition of family is broad and includes "spouses, blood relatives, in-laws, step-relatives, fiancés, significant others, friends, caring neighbors, colleagues, fellow congregants, and other people with a personal attachment to the person with advanced serious illness—in other words, the people 'for whom it matters'." [2]. Despite this, heteronormative biases and the gender binary paradigm permeate the US medical system and have often led to exclusion of important family members from the bedside of their loved ones. To best involve families, providers must avoid assumptions and seek to treat each patient and family member with respect and dignity. The patient's values will be best represented by involving the patient-designated family members into their care. Because of varied legislation in the United States, it's also important to be sure that the patient's designated healthcare representative is formally established through an advance directive [3, 4].

A. Doran Bostwick
Division of Pulmonary and Critical Care, Department of Medicine, University of Utah School of Medicine, Salt Lake City, UT, USA
e-mail: Anne.Bostwick@hsc.utah.edu

S. J. Beesley (✉)
Division of Pulmonary and Critical Care, Department of Medicine, University of Utah School of Medicine, Salt Lake City, UT, USA

Pulmonary Division, Department of Medicine, Intermountain Medical Center, Shock Trauma Intensive Care Unit, Murray, UT, USA
e-mail: sarah.beesley@imail.org

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_20

Table 20.1 Family Involvement in ICU Patient Safety

Family member role	Potential safety benefits
Assist in bedside care	Better preparation for discharge needs
Visit patient	Reduce emotional harms to both patient and family
Be present during procedures	Patient calmer and more cooperative, more vigilance by provider
Alert staff to changes in condition	More rapid response to clinical change
Represent patient values and wishes to team	Patient treated in the manner that best respects them

As the personal representative of the patient, a family member can play a critical role in patient safety in the intensive care unit (ICU) [5]. However, family members have often been excluded from this role by policies that keep them away from the bedside (such as restricted visitation) and have not been included in safety process design. In order to include families in a way that can maximize patient safety, healthcare providers must encourage the following: (1) family members must be included as part of the team during rounds, procedures, and bedside care; (2) family members need to be empowered to speak up if something is not going well with their loved one or if they are concerned about a potential error; and (3) family members need to be given a role to play in development of hospital safety policy and plans that would encourage these actions, such as through Patient-Family Advisory Councils (PFACs). A sample of the roles a family member can play and the impact on safety is found in Table 20.1.

Emotional Safety

Over the past several years, emotional harms have been increasingly recognized as a preventable medical error [6]. To many patients, these emotional harms are more distressing than other more traditional physical adverse events [7]. Emotional injury can include insults to a person's dignity or self-respect, including racism and other forms of discrimination [6, 8]. ICU patients are particularly susceptible to dehumanization due to their frequently impaired consciousness, limited agency, and the deindividuation and mechanization that are frequent in the ICU [9]. The psychological demands of ICU clinical practice may drive clinicians to dehumanize patients inadvertently through empathy reduction and moral disengagement [9]. At its root, family engagement works to maintain or reinstate the humanity of the patient by recognizing family members as full partners in care [10]. While much work needs to be done to further characterize the best way to engage with patients and families, inclusion of families as part of the team should not wait [11, 12]. Families can provide independent knowledge of the patient's full identity, and empowering family members to be part of the team both combats dehumanization and encourages safety [13].

Necessity of Family Presence

Family members cannot participate in or contribute to safety in the ICU if they are not present. As recently as 2013, 90% of ICUs in the United States still reported some restrictions on visiting [14]. Family members want to be able to visit their loved ones on their own schedule and as much as they and the patient would like [15–18]. When family members are allowed unrestricted access, communication with staff and satisfaction with care are improved [15, 19–23]. Frequently exceptions are made to visiting hours by ICU staff; unfortunately, having informal and unregulated exceptions by ICU staff can lead to discrimination as the decision to restrict or liberalize visiting hours may be based on physical appearance, language, culture, race, or religion [24]. This perpetuates clinician-centered, paternalistic approaches to medical care [25]. The presence of family members at the bedside can also directly benefit patients by reducing the incidence and duration of delirium [26]. The first step to allowing family members to participate in and improve patient safety is to allow them to be present in the ICU.

Family Involvement in Daily Rounds

Beyond simple visitation, family members are increasingly joining daily ICU rounds [27]. This appears to improve family member satisfaction with communication without prolonging rounding time for the ICU team [28, 29]. Family presence during rounds may add to the discussion in ways that improves safety—providing important history or insights impacting the plan of care.

Family Involvement in Bedside Care

Family members may also want to be part of routine bedside care in the ICU, participating in activities such as bathing, feeding, and suctioning [30, 31]. Having family participate in care during the hospital stay may improve safety during the ICU stay and after discharge. While their loved one is in the hospital, family members can facilitate bedside care—examples include holding an emesis bag up when the patient vomits or reorienting them when confused. These are tasks that a healthcare provider often does, but as they may not be constantly at the bedside, family members can step in. Additionally, family members who are involved during an inpatient stay often become attuned to activities such as wound care, physical therapy, and keeping track of inputs and outputs. A program designed by nurses in a cardiothoracic acute care floor formally invited family members to help care for patients as they recovered from cardiothoracic surgical procedures. Participation in this program was associated with a reduction in 30-day hospital readmission among these selected patients, possibly indicating that safety after discharge was improved by involving the family members early in care [32].

Family involvement in care may also reduce emotional harms. In two randomized trials where families were educated and invited to participate in care in the newborn intensive care unit (NICU) [33, 34], family involvement led to improved satisfaction. Part of that satisfaction came from the increased amount of time mothers spent in the ICU [34].

Family Presence During ICU Procedures

Families in adult ICUs are still frequently asked to leave the patient's room during procedures, including central line placement and intubation as well as cardiopulmonary resuscitation (CPR), regardless of whether the patient would prefer family to be present [35, 36]. Family presence in ICU during procedures provides an additional layer of supervision encouraging professionalism and best practices [37, 38]. As a physician prepares for a procedure, if she knows that a family member may be scrutinizing her sterile technique, she is more careful as she dons her gown. While some physicians may feel that this attention could increase clinician stress, having a family member present has not increased self-reported stress in staff who participated in witnessed resuscitation efforts [39, 40].

Additionally, having a family member present may comfort the patient, making an adverse event due to patient agitation or misunderstanding less likely. When family members are at the bedside to hold a hand or talk to their loved one, an agitated patient (from pain, delirium, fear, language barriers) can be calmed and safely taken through a procedure without sedating medications (Fig. 20.1).

Many clinicians express a concern that family member presence may increase the risk of malpractice litigation should a bad outcome occur during a procedure. The limited available data do not demonstrate a significant increase in risk of mal-

Fig. 20.1. Family present during ICU procedure

practice litigation when family members are present during procedures. As some lawsuits are filed in order to find out why and how a loved one was injured, having family members present could reduce litigation. Communication and transparency improve when family members are part of all aspects of care, including procedures [21]. This open relationship and transparent communication is associated with better family-team dynamics [41–43].

Of note, there have been reports of family members who were injured while witnessing a medical procedure of a loved one, usually due to passing out [44]. In one tragic case in California, a family member fainted as he watched his wife get an epidural; he hit his head and died of an intracranial hemorrhage [45]. Partners are still routinely allowed to be present during these kinds of obstetrics procedures, and this rare, terrible outcome should not keep family members from the bedside in general. Fainting may be avoided by having family members sit during procedures.

Medical Error and Adverse Events

Several years ago, the Institute of Medicine concluded that preventable adverse events could cause tens of thousands of injuries and deaths per year [46]. Family members are invested in preventing errors that could harm their loved one and can be recruited and encouraged to act as another gatekeeper at the bedside. For example, if family members are aware of the medication plan and their loved one's allergies, they can help prevent the administration of the wrong drug. This provides another slice in the "Swiss cheese model" to keep a mistake from leading to harm [47]. A recent case in a tertiary care hospital intensive care unit illustrated this. A patient had a complicated abdominal surgery, resulting in a partial gastrectomy and discontinuity of the alimentary track. Despite an order to only use a jejunal tube for feeds, the feeds were connected to a nasogastric tube and started. The patient's spouse arrived soon after and noticed the error, notifying the medical team immediately. The feeds were switched to the jejunal tube, and a serious adverse event was prevented. While the medical team cannot count on family members to prevent errors and should be as vigilant as possible, the reality is that medical errors are terrifyingly common. In a recent study in the United States, family members participated in semi-structured interviews to identify errors that occurred during the admission. The family member reporting yielded 16% more errors and 10% more adverse events than hospital incident reports completed solely by staff. By including families in safety surveillance, the group identified otherwise unrecognized errors and adverse events [48].

Additionally, despite the best efforts of medical facilities, ICU's and medical ward nurses are at times understaffed; in this situation, risk to patients can increase as the nurse is stretched between many demands. Nurses have mentioned to the authors the appreciation they have for the family members who help keep a delirious patient from falling.

Medical teams should encourage family members to know what is happening with their loved one's treatment, to be involved in care, and, when they see something, to say something.

Family Role in Hand Hygiene

Another major safety issue in hospitals is healthcare-associated infections. A concerning contributor to the spread of infections in the hospital remains hand hygiene noncompliance among healthcare workers. The World Health Organization has developed a five-step strategy to improve hand hygiene in healthcare. One of the steps includes instituting a "safety climate, with active and visible participation form healthcare workers, managers and, when feasible, patients." [49] One model for improvement educated patients on the importance of asking their healthcare workers to wash their hands. This patient education model increased hand hygiene by healthcare workers an average of 34%. While some patients feel less comfortable with verbally prompting healthcare workers, wristbands with reminders can also play a role. Confused patients or those in the intensive care unit cannot be successfully educated on the importance of hand hygiene and their role in prompting healthcare workers. However, family members and visitors were willing to assume the role when the patient was unable [50]. The main limitation to this practice is patients' comfort level in asking nurses and physician to wash their hands. In another study patients cited that their hesitation in asking was associated with feeling as though caregivers already know when to perform hand hygiene and the belief it was not their role to remind them to do so. Additionally, family members felt a feeling of embarrassment and a fear of reprisal. An explicit invitation from a healthcare worker to ask about hand hygiene increased the probability they would do so [51]. While difficult cultural barriers exist and relationship dynamics between patient and healthcare workers can be complex, it is clear that if healthcare workers encourage patient involvement in safety practices, an improvement in hand hygiene can be made. Additionally, the patient and family education model is a cost-effective means to decrease the spread of infection [50].

Family-Activated Rapid Response Teams

A primary benefit of hospitalization for an ill patient is to allow for close monitoring of clinical status, but despite this, there are frequently unanticipated events, and it is infeasible for staff to be present with a patient at all times. In some cases, patients may worsen prior to hospital staff recognition. To help decrease the delay in recognition and treatment, early warning scores and rapid response teams have been developed to alert care providers to early signs of clinical deterioration. To further optimize the recognition of clinical deterioration, families are now being integrated into the rapid response team. Family members, who are often present and intently aware of their family member's mental state, can alert key staff if there is a change in the status of the patient. In 2007, a rapid response team (RRT) activated by hospital staff was implemented at Shands Jacksonville Medical Center. Later that year an addition to the program was made where families and patients could activate the RRT. Families were educated on the program at admission and given the number for the dedicated phone line. They were told that calling an RRT is like calling 911 for help from home. There was particular concern prior to the study that an overload of false-positive calls could overwhelm the service and this was not seen. On observational analysis, with implementation of the RRT team, there was a significant decrease in non-ICU codes which continued to trend down (though not significantly) when patients and families were integrated into the activation system [52]. Family members can be an important ally for patients and for the medical team through early recognition of changes in a loved one.

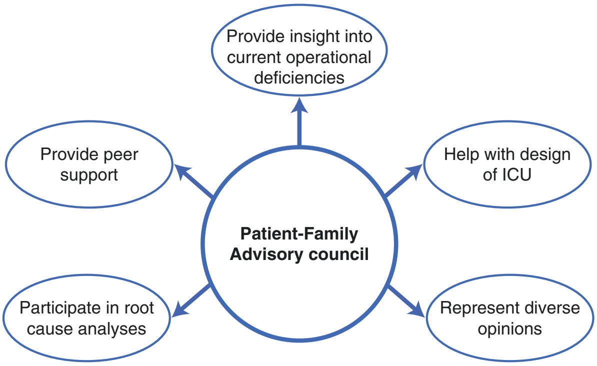
Speaking Up

If family members are present and have a concern regarding patient care or safety, there is no benefit if the family member doesn't inform the team. However, family members must feel that the team will be receptive to feedback and concerns from a layperson. Concerns about fear of abandonment or reprisal from the medical team have been expressed by family members as reasons for not wanting to speak up if they see something concerning [53]. In particular, for family members marginalized by education, cultural or language barriers, this can be particularly challenging [54]. Additionally, when concerns are raised by family members, they often do not feel that they are being adequately understood and addressed [55]. Family members must be respected when they bring concerns to the table, and some institutions have begun including the patient and family perspective in analysis of adverse events [56]. When asked about medical error, family members are able to identify factors contributing to the error and possible recommendations for addressing these [57]. While the structure of family and patient involvement in medical error discussions continues to evolve, including patient and family members when able could help improve safety for future patients.

Patient-Family Advisory Councils

Another way for family members to have a venue to speak up and influence care for future patients is in the form of Patient-Family Advisory Councils (PFACs) (see Fig. 20.2). The first PFAC was started in 1998 at Dana-Farber Cancer Center, and these councils have become increasingly common over the past decade [58]; in Massachusetts, there is now a law mandating hospitals must have a PFAC and report on its work [5].

Fig. 20.2. Roles of Patient-Family Advisory Councils



PFACs are usually formed from prior patients or family members who are interested in more engagement, sometimes following invitation from the medical team who has interacted with them. These groups have varied formats but in general meet together periodically with ICU or hospital leadership to provide patient and family perspective to ICU operations, design, and safety procedures. The PFAC can also identify issues that were not apparent to the ICU staff, such as the way certain care transitions are stressful and how signage appears to family to be unwelcoming or confusing. Family involvement in designing ICU layout provides a unique perspective that can improve the environment, making it more patient and family centered [59].

PFAC members may be motivated to reach out to other family members and provide peer support. In a pediatric ICU in Utah, PFAC members spend time with family members of current ICU patients to answer questions as well as help with expectations for life beyond the ICU. Formal peer support groups are also being studied for the impact on PICS-F more broadly.

Beyond having family members represented on PFACs, some institutions have included them on safety or quality committees where direct input on hospital policy and procedure is sought [5]. Family member involvement in hospital or ICU policy is critical as they can represent diverse viewpoints to change clinical practice, making care more patient- and family-friendly, as well as safer. However, for a PFAC to be an effective voice in an institution, the PFAC must be included in decision-making processes, and the institution must be open to change based on PFAC feedback [60]. Advice for forming and utilizing a PFAC can be found from multiple sources online, including a helpful handbook from the Agency for Healthcare Research and Quality [61].

Conclusion

Family members want to be a part of loved one's care and can help to protect their loved one from both emotional and physical harms [15, 21, 23, 62]. Including those who have the most invested in good outcomes for a patient can improve vigilance at the bedside and may lead to reduced errors and better overall safety for patients in these critical and tenuous situations. Family members should be involved in patient safety design and implementation, including PFACs.

Acknowledgments We appreciate the insights and advice on this chapter from the following: Intermountain Medical Center, Patient-Family Advisory Council members, nursing staff of the Shock Trauma Intensive Care Unit at Intermountain Medical Center, and the Center for Humanizing Critical Care led by Samuel Brown, MD, and Elliotte Hirshberg, MD.

Financial Support and Conflicts of Interest No disclosures

References

1. Davidson JE. Family-centered care: meeting the needs of patients' families and helping families adapt to critical illness. Crit Care Nurse. 2009;29(3):28–34; quiz 35.
2. Pizzo P, Walker D, Bomba P. Dying in America: improving quality and honoring individual preferences near the end of life. Washington, DC: Institute of Medicine; 2015.
3. Lawton A, White J, Fromme EK. End-of-life and advance care planning considerations for lesbian, gay, bisexual, and transgender patients# 275. J Palliat Med. 2014;17(1):106–8.
4. DeMartino ES, Dudzinski DM, Doyle CK, et al. Who decides when a patient can't? Statutes on alternate decision makers. N Engl J Med. 2017;376(15):1478–82.
5. Institute NPSFsLL. Safety is personal: partnering with patients and families for the safest care. Boston: Foundation NPS; 2014.
6. Sokol-Hessner L, Folcarelli PH, Sands KE. Emotional harm from disrespect: the neglected preventable harm. BMJ Qual Saf. 2015;24(9):550–3.
7. Masso Guijarro P, Aranaz Andres JM, Mira JJ, Perdiguero E, Aibar C. Adverse events in hospitals: the patient's point of view. Qual Saf Health Care. 2010;19(2):144–7.
8. Johnstone MJ, Kanitsaki O. The neglect of racism as an ethical issue in health care. J Immigr Minor Health. 2010;12(4):489–95.
9. Haque OS, Waytz A. Dehumanization in medicine: causes, solutions, and functions. Perspect Psychol Sci J Assoc Psychol Sci. 2012;7(2):176–86.
10. Brown SM, Rozenblum R, Aboumatar H, et al. Defining patient and family engagement in the intensive care unit. Am J Respir Crit Care Med. 2015;191(3):358–60.
11. Haines KJ, Kelly P, Fitzgerald P, Skinner EH, Iwashyna TJ. The untapped potential of patient and family engagement in the organization of critical care. Crit Care Med. 2017;45(5):899–906.
12. Olding M, McMillan SE, Reeves S, Schmitt MH, Puntillo K, Kitto S. Patient and family involvement in adult critical and intensive care settings: a scoping review. Health Expect Int J Public Particip Health Care Health Policy. Dec 2016;19(6):1183–202.
13. Spruce L. Back to basics: patient and family engagement. AORN J. 2015;102(1):34–7; quiz 38-39.
14. Liu V, Read JL, Scruth E, Cheng E. Visitation policies and practices in US ICUs. Crit Care. 2013;17(2):R71.
15. Davidson JE, Powers K, Hedayat KM, et al. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004-2005. Crit Care Med. 2007;35(2):605–22.
16. American Association of Critical-Care Nurses. Practice alert: Family presence during resuscitation and invasive procedures (position statement). 2010. http://www.aacn.org/wd/practice/docs/practicealerts/familypresence-during-resuscitation-invasive-procedures.pdf. Accessed March 12, 2015.

17. Fulbrooke P, Latour J, Albarran J, et al. The presence of family members during cardiopulmonary resuscitation: European federation of Critical Care Nursing associations, European Society of Paediatric and Neonatal Intensive Care and European Society of Cardiology Council on Cardiovascular Nursing and Allied Profressions Joint Position Statement. Connect World Crit Care Nurs. 2007;5(4):86–8.
18. Jacob M, Horton C, Rance-Ashley S, et al. Needs of patients' family members in an intensive care unit with continuous visitation. Am J Crit Care Off Publ Am Assoc Crit-Care Nurs. 2016;25(2):118–25.
19. Barratt F, Wallis DN. Relatives in the resuscitation room: their point of view. J Accid Emerg Med. 1998;15(2):109–11.
20. Brown SM. We still lack patient centered visitation in intensive care units. BMJ : Br Med J (Online). 2015;250:h792.
21. Carman KL, Dardess P, Maurer M, Workman T, Ganachari D, Pathak-Sen E. A roadmap for patient and family engagement in healthcare practice and research. Prepared by the American Institutes for Research under a grant from the Gordon and Betty Moore Foundation, Dominick Frosch, Project Officer and Fellow; Susan Baade, Program Officer. 2014.
22. Chapman DK, Collingridge DS, Mitchell LA, et al. Satisfaction with elimination of all visitation restrictions in a mixed-profile intensive care unit. Am J Crit Care. 2016;25(1):46–50.
23. Chapman DK, Collingridge DS, Mitchell LA, et al. Satisfaction with elimination of all visitation restrictions in a mixed-profile intensive care unit. Am J Crit Care. 2016;25(1):46–50.
24. Netzer G, Iwashyna TJ. Fair is fair: preventing the misuse of visiting hours to reduce inequities. Ann Am Thorac Soc. 2017;14(12):1744–6.
25. Simon SK, Phillips K, Badalamenti S, Ohlert J, Krumberger J. Current practices regarding visitation policies in critical care units. Am J Crit Care Off Publ Am Assoc Crit-Care Nurs. 1997;6(3):210–7.
26. Rosa RG, Tonietto TF, da Silva DB, et al. Effectiveness and safety of an extended ICU visitation model for delirium prevention: a before and after study. Crit Care Med. 2017;45(10):1660–7.
27. Stickney CA, Ziniel SI, Brett MS, Truog RD. Family participation during intensive care unit rounds: attitudes and experiences of parents and healthcare providers in a tertiary pediatric intensive care unit. J Pediatr. 2014;164(2):402–6. e401–404.
28. Jacobowski NL, Girard TD, Mulder JA, Ely EW. Communication in critical care: family rounds in the intensive care unit. Am J Crit Care Off Publ Am Assoc Crit-Care Nurs. 2010;19(5):421–30.
29. Davidson JE. Family presence on rounds in neonatal, pediatric, and adult intensive care units. Ann Am Thorac Soc. 2013;10(2):152–6.
30. Azoulay E, Pochard F, Chevret S, et al. Opinions about surrogate designation: a population survey in France. Crit Care Med. 2003;31(6):1711–4.
31. Wyskiel RM, Weeks K, Marsteller JA. Inviting families to participate in care: a family involvement menu. Jt Comm J Qual Patient Saf. 2015;41(1):43–6.
32. Van De Graaff M, Beesley SJ, Butler J, et al. Partners in healing: postsurgical outcomes after family involvement in nursing care. Chest. 2018;153(2):572–4.
33. Franck LS, Oulton K, Nderitu S, Lim M, Fang S, Kaiser A. Parent involvement in pain management for NICU infants: a randomized controlled trial. Pediatrics. 2011;128(3):510–8.
34. Bastani F, Abadi TA, Haghani H. Effect of family-centered care on improving parental satisfaction and reducing readmission among premature infants: a randomized controlled trial. J Clin Diagn Res. 2015;9(1):SC04–8.
35. Mortelmans LJ, Cas WM, Van Hellemond PL, De Cauwer HG. Should relatives witness resuscitation in the emergency department? The point of view of the Belgian Emergency Department staff. Eur J Emerg Med Off J Eur Soc Emerg Med. 2009;16(2):87–91.
36. McClenathan BM, Torrington KG, Uyehara CF. Family member presence during cardiopulmonary resuscitation: a survey of US and international critical care professionals. Chest. 2002;122(6):2204–11.
37. Haley KJ, Fessler DMT. Nobody's watching: subtle cues affect generosity in an anonymous economic game. Evol Hum Behav. 2005;26(3):245–56.

38. Sevransky JE, Nicholl B, Nicholl JB, Buchman TG. Patient- and family-centered care: first steps on a long journey. Crit Care Med. 2017;45(5):757–8.
39. Boyd R, White S. Does witnessed cardiopulmonary resuscitation alter perceived stress in accident and emergency staff? Eur J Emerg Med Off J Eur Soc Emerg Med. 2000;7(1):51–3.
40. Jabre P, Belpomme V, Azoulay E, et al. Family presence during cardiopulmonary resuscitation. N Engl J Med. 2013;368(11):1008–18.
41. Teutsch C. Patient-doctor communication. Med Clin North Am. 2003;87(5):1115–45.
42. Mello MM, Studdert DM, Kachalia A. The medical liability climate and prospects for reform. JAMA. 2014;312(20):2146–55.
43. Boothman RC, Imhoff SJ, Campbell DA Jr. Nurturing a culture of patient safety and achieving lower malpractice risk through disclosure: lessons learned and future directions. Front Health Serv Manage. 2012;28(3):13–28.
44. Axelsen P. Correspondence: should family members be present during cardiopulmonary resuscitation. N Engl J Med. 2002;347:450–2.
45. Reuters. Hospital sued over deadly faint. The Boston Globe. July 8, 2005.
46. Committee on Quality of Health Care in America IoM. To err is human: building a safer health system. Washington, DC: National Academics Press; 2000.
47. Reason J. Human error: models and management. BMJ. 2000;320(7237):768–70.
48. Khan A, Coffey M, Litterer KP, et al. Families as partners in hospital error and adverse event surveillance. JAMA Pediatr. 2017;171(4):372–81.
49. McGuckin M, Govednik J. Patient empowerment and hand hygiene, 1997-2012. J Hosp Infect. 2013;84(3):191–9.
50. McGuckin M, Waterman R, Porten L, et al. Patient education model for increasing handwashing compliance. Am J Infect Control. 1999;27(4):309–14.
51. Longtin Y, Sax H, Allegranzi B, Hugonnet S, Pittet D. Patients' beliefs and perceptions of their participation to increase healthcare worker compliance with hand hygiene. Infect Control Hosp Epidemiol. 2009;30(9):830–9.
52. Gerdik C, Vallish RO, Miles K, Godwin SA, Wludyka PS, Panni MK. Successful implementation of a family and patient activated rapid response team in an adult level 1 trauma center. Resuscitation. 2010;81(12):1676–81.
53. Mazor KM, Roblin DW, Greene SM, et al. Toward patient-centered cancer care: patient perceptions of problematic events, impact, and response. J Clin Oncol Off J Am Soc Clin Oncol. 2012;30(15):1784–90.
54. Delbanco T, Bell SK. Guilty, afraid, and alone – struggling with medical error. N Engl J Med. 2007;357(17):1682–3.
55. Fisher KA, Ahmad S, Jackson M, Mazor KM. Surrogate decision makers' perspectives on preventable breakdowns in care among critically ill patients: a qualitative study. Patient Educ Couns. 2016;99(10):1685–93.
56. Etchegaray JM, Ottosen MJ, Burress L, et al. Structuring patient and family involvement in medical error event disclosure and analysis. Health Aff. 2014;33(1):46–52.
57. Etchegaray JM, Ottosen MJ, Aigbe A, et al. Patients as partners in learning from unexpected events. Health Serv Res. 2016;51(Suppl 3):2600–14.
58. Niehaus K. Using a patient and family advisory council as a mechanism to hear the patient's voice. J Oncol Pract. 2017;13(8):509–11.
59. Bazuin D, Cardon K. Creating healing intensive care unit environments: physical and psychological considerations in designing critical care areas. Crit Care Nurs Q. 2011;34(4):259–67.
60. Niehaus K. A patient and family advisory council for quality; making its voice heard at Memorial Sloan Kettering Cancer Center. NEJM Catalyst. Strategy 1: Working with patients and families as advisors. Content last reviewed. Rockville: Agency for Healthcare Research and Quality. 2017. http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/strategy1/index.html. Accessed Sep 29, 2017.
61. Strategy 1: working with patients and families as advisors. http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/strategy1/index.html. Accessed 29 Sept 2017.
62. Azoulay E, Pochard F, Chevret S, et al. Meeting the needs of intensive care unit patient families: a multicenter study. Am J Respir Crit Care Med. 2001;163(1):135–9.

Chapter 21

Family and Patient Spiritual Narratives in the ICU: Bridging Disclosures through Compassion

Simon Lasair and Shane Sinclair

Introduction

Over the last half century, medical care has become increasingly driven by technology [1, 2]. This is especially true in intensive care units (ICUs) [3, 4]. Typically, patients' and their family members' experiences in the ICU occur after a critical incident necessitating the most intensive, expensive, and invasive healthcare interventions. Despite these life-preserving measures and the advanced expertise of interdisciplinary healthcare teams to extend patients' lives and to support their family members, ICUs have often been described as dehumanizing and alienating [3, 4]. This seems due to a number of factors: the highly intensive and technical nature of the clinical setting, patients' conditions and needs, and healthcare providers' challenges in addressing psychosocial and spiritual issues ([3]; cf. also [5]). The purpose of this chapter is to provide a framework for interdisciplinary healthcare providers to understand spirituality as an inherent part of patient and family narratives. Furthermore, it is intended to provide guidance on how ICU healthcare providers can engage spiritual concerns by becoming aware of patient and family narratives, in addition to the various components of compassionate care.

Over the past decade, there has been a considerable increase in healthcare research investigating associations between medical outcomes and patients' and family members' spiritual well-being ([6, 7]; cf. also [8]). Many of these studies have concluded that engaging in the spiritual domain of health is an integral aspect of comprehensive care that falls within the scope of practice of physicians, nurses, and other members of the healthcare team [7, 8]. Furthermore, clinicians and researchers, particularly within the disciplines of nursing, medicine, and spiritual care, have thus begun to investigate and produce early evidence demonstrating that

---

S. Lasair · S. Sinclair (✉)
Compassion Research Lab, Faculty of Nursing, University of Calgary, Calgary, AB, Canada
e-mail: sinclair@ucalgary.ca

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_21

care for patients' spiritual needs is an important, if not crucial, component of healthcare delivery [9].

Attending to patients' spiritual concerns has been a long-standing feature of nursing theory and practice. Nursing researchers, in particular, have begun to apply an empirical lens to investigate the importance of spirituality within an ICU setting (cf., e.g., [3, 4]). As a result, a number of inherent challenges associated with providing spiritual care in the ICU have been identified, including a general lack of familiarity with spiritual care services in healthcare facilities, patients being incapacitated, and a lack of integration of spiritual care specialists within these settings [3]. Coupled with these clinical and operational challenges are widespread misunderstandings about spirituality and what actually constitutes spiritual care by patients, family members, and healthcare providers alike [3, 9–12].

While patients and family members increasingly desire to have their spiritual concerns addressed, providers face a number of barriers in meeting these needs, including professional discomfort, sense of inadequacy, lack of training, and time constraints [5, 13, 14]. When these barriers are overcome and professional spiritual care is provided, especially when death is imminent, families perceive these interventions as helpful [15], have greater satisfaction at the time of death [16], and experience the ICU more positively than when professional spiritual care was absent [17]. Furthermore, when professional spiritual care is provided by the interdisciplinary team, requests for expensive and invasive interventions at the end of life have been shown to decrease in favor of palliation or hospice care [18]. Because the provision of spiritual care is a requirement of healthcare accreditation bodies like the Joint Commissions, ICU researchers recommend referring patients' families to professional spiritual care workers if the families are open to receiving this form of care [19]. Nevertheless, more research is needed to reveal the concrete outcomes associated with receiving spiritual care in the ICU and elsewhere [19].

In light of these issues, there have been increasing calls for all members of the healthcare team to become more familiar with the spiritual concerns and resources of their patients and families. Concurrently, the need for spiritual care professionals to better articulate the services they offer and their specific roles and expertise within the broader healthcare team grows [9–11, 20]. This twofold need to integrate the specialized role of spiritual care professionals into healthcare teams and extend the scope of practice of other healthcare providers in addressing basic spiritual needs has resulted in a number of spiritual screening and assessment tools being proposed and embedded within patients' medical records [21–23]. Clinical pastoral education (CPE), the gold standard spiritual care training program in the USA and Canada, has also been adapted and delivered to various members of the interdisciplinary team [24]. While these initiatives have resulted in participants reporting increased comfort in addressing and engaging religious and/or spiritual concerns presented by patients [24], the extent to which these assessment tools and training programs are actually utilized has not been established. To compassionately engage patients' and their families' spiritual concerns is thus emerging as a significant yet somewhat under-addressed component of the current healthcare mandate.

Accordingly, the virtue of compassion itself has been identified as the ultimate outcome of the major world spiritual traditions and a salient medium for addressing the spiritual needs of patients from diverse spiritual backgrounds, whether for patients who identify with formal faith traditions or for those who express their spirituality in a secular manner [25]. While patients and family members are clear about the importance of and their desire to have their spiritual needs addressed by members of their healthcare team, recent research demonstrates that often these needs are unmet [6, 7]. Similarly, while compassion is the quintessential indicator and a universal medium for addressing patient and family members' spiritual needs—and an expectation patients have increasingly across their healthcare experiences—many patients and their families are likewise challenged in receiving it [25, 26]. This chapter will thus proceed in three parts: (1) we will discuss concepts of spirituality currently utilized in healthcare literature, distinguishing spirituality from religion; (2) we will show spirituality as an inherent part of any patient or family member's personal narrative; and (3) we will articulate a model demonstrating how practitioners can sensitively and compassionately engage patients' and family members' spiritual concerns as manifest in their personal narratives. All these sections will strive to demonstrate how concrete manifestations of compassionate care in the ICU can work to counterbalance the dehumanization and alienation often experienced in this clinical environment.

Distinguishing Spirituality from Religion

One significant challenge in addressing spiritual concerns is that no broad consensus exists as to how to define spirituality conceptually, even among spiritual care professionals [10, 11, 20, 27]. Within medicine and nursing, attempts have been made at undertaking concept analyses of spirituality and spiritual care, respectively [6, 28–31]. Within each of these studies and reviews, there is some empirical consideration of the concepts under investigation, yet more work is needed to construct an empirically valid concept of spirituality that will inform evidence-based practice, research, education, and policy.

While a plethora of conceptualizations of spiritualty exist, what is consistent in the literature is the distinction between spirituality and religion (cf., e.g., [27, 32]). For some, a person's religion and spirituality are closely related phenomena sometimes expressed as the specific beliefs or practices enabling that person to connect with "the sacred" or "the transcendent," often drawing upon concepts originating in specific groups that are understood as "religious" (cf. [32]). However, there is an emerging understanding that "the sacred" can become manifest in many different settings—in nature, in relationships, or even in sporting events, in addition to in religious rituals and practices [32]. Similarly, it is also becoming evident that the sacred is an inherent part of society and culture, often manifesting around such secular topics such as national identity, human rights, and social justice (cf. [33]). To state that "the sacred" or transcendent is the sole province of groups and experiences stereotypically understood as religious, then, does not reflect the empirical data concerning these phenomena [32, 33] nor the growing numbers in western societies who increasingly consider themselves spiritual but not religious (cf. [34, 35]).

As a result, the terms spirituality and religion are typically defined in generalized terms in healthcare literature, regardless of whether concepts of "the sacred" are used or not. Spirituality can therefore be defined as "an individual's beliefs, values, behaviors and experiences related to ultimate meaning," whereas religion is correspondingly defined as "an individual's beliefs, values, behaviors and experiences related to ultimate meaning*, often involving deities and dogma, formulated by faith groups and institutions, over time*" ([36]: 73). As McBrien summarized in his concept analysis of spirituality, "Spirituality is … considered an individual's search for meaning and purpose in life. In contrast, religion is described as a formalized set of beliefs, customs, and practices" (2006: 43). Although these definitions have limitations (cf., e.g., [37]), we assume herein that patients and their families can express their spirituality through the beliefs and practices of specific religions or through no religion, thus rendering "religion" a smaller and more specific phenomenon of the more global construct: spirituality (cf. [27, 36]).[1]

Healthcare Narratives

Narrative is one significant way people make sense of their lives and experiences, serving as a framework to understand and address the ephemeral spiritual domain [2, 38, 39]. Because spirituality is so closely associated with questions of meaning (cf. [28, 36, 38]), spiritual care researchers agree that quality spiritual care empowers patients to narrate, on their own terms, the stories of their lives and of their experiences in healthcare [1, 2]. Narrative in this framework is thus understood explicitly as a hermeneutic phenomenon that by telling the stories of their lives and experiences, patients and families interpret the events of their lives, making meaning for themselves and others [2, 38, 39]. Furthermore, this drive toward narrative empowerment comes with the understanding that people experience themselves through a number of different pathways, including personal traits such as gender, ethnicity, nationality, sexual orientation, religion, political allegiances, and family dynamics, among others (cf. [40]). Compassionate engagement with patient and family narratives thus begins by seeing patients and their family members in the uniqueness of their own experiences, regardless of the typicality or atypicality of their medical concerns [2, 25].

---

[1] Note that Swinton argues for the opposite position that religion is the larger phenomenon containing spirituality. While there is merit in this position as well, for our purposes, we will assume the perspective we have articulated, just given some of the problems bound up with concepts of "religion" (cf., [37]).

Narrative awareness additionally involves the knowledge that healthcare systems also have their own narratives concerning patients and their families. These manifest simultaneously in explicit practices and the implicit thought structures behind these practices (cf. [40–42]). Healthcare narratives are particularly apparent in the diagnostic language that is utilized when referring to patients (e.g., "the MVA in Bed 2"), the medical interventions to treat them (e.g., "Bed 2 needs to be intubated"), and how we describe patients' responses to these interventions (e.g., "failure to thrive/noncompliant/crashing") [2, 40, 42]. What is often not understood is how these healthcare narratives can introduce dehumanizing and alienating dynamics into the care received by patients and their families [1, 2]. This is especially the case in ICUs, where the interventions are the most intensive and invasive offered by healthcare [3, 4, 43].

When providers speak of and engage patients solely in terms of their illness, treatment, and prognosis, then these dynamics are seen as significant contributors to the depersonalization of medical care that produces patient experiences of dehumanization and alienation [25, 42]. Compassionate engagement with patients' and their families' emotional and spiritual concerns therefore involves the active mitigation of (a) the alienating, dehumanizing, and depersonalizing dynamics created by healthcare systems and (b) the narratives they might tell about patients and their families through their clinical practices ([25]; cf. [2, 40]). Accordingly, research on compassion in healthcare reveals several ways patients and their families experience compassion from healthcare professionals, thus counterbalancing the alienating and dehumanizing narratives bound up in encounters with healthcare systems [25, 26, 44].

The Role of Compassion in Engaging Patients' and Family Members' Spiritual Narratives: Five Fundamentals

According to patients, compassion is a multidimensional care construct, distinguishable and preferred from empathy and sympathy [44]. This can be defined as a "virtuous response that seeks to address the suffering and needs of a person through relational understanding and action" ([25]: 195; Fig. 1; cf. [45]). Because expressing compassion is dependent on and engendered within relationships [25, 26, 45–47], compassionate care of patients' and families' spiritual concerns can occur within routine medical care and by healthcare providers going beyond routine care, by taking an active interest in patients as people. This incorporates the patient's and family's narrative into the overall delivery of medical care ([25, 46, 47]; cf. also [2]). Here are five evidence-based clinical skills, distilled from the Patient Compassion Model [25], along with a clinical mnemonic that is presented to help ICU healthcare professionals engage patients' and family members' emotional and spiritual needs in a compassionate manner.

Attend to HCP Narratives to Cultivate a Virtuous Response

Patients identify compassionate healthcare providers as individuals who care not simply out of professional duty but as a person, through the personal virtues they bring into the clinical encounter ([25]; cf. also [48]). In a qualitative study of 53 patients facing the end of life, virtues were defined simply as "good or noble qualities embodied in the character of the health care provider" ([25]: 195). Healthcare providers wishing to cultivate compassion in their clinical practice need to spend time examining their own personal and professional narratives to determine how these affect their ability to express virtues of love, kindness, understanding, acceptance, and authenticity ([13, 48]; cf. [11]). This may involve asking reflective questions like: Why did I choose to be a healthcare professional? What are the personal and professional experiences that have shaped me as a physician/nurse in both positive and negative ways? What personal qualities can help bring healing for this family? What parts of my narrative can cause harm? By exploring these questions for themselves, HCPs will grow in self-awareness and will also be able to resonate with the narratives of their patients and family members on an emotional level [11, 25].

Engender a Relational Space

Because compassion is dependent on and engendered through human relationships between HCPs and patients and their families [25, 26, 47, 48], space must be made in provider–patient interactions for a relationship to develop. In part, this means that after attending to their own narratives and the impact they may have in the clinical encounter, HCPs need to set these aside to engage the narratives of patients and their families in an open and sensitive manner [1, 2, 11, 25, 48]. Creating the space to engage patient and family narratives invites patients and their families to make meaning of their experiences and thus engages their spirituality and their spiritual concerns [2, 36, 38]. While relationships primarily occur between providers and individuals in their care, creating a relational space is not the sole responsibility of providers but also of the organizations and practice cultures in which they work [45, 47, 49]. While individual providers are often reprimanded in incidences where compassion is lacking, compassion flourishes or fails at a systems level through the leadership, organizational values, and the hidden curricula in which providers practice ([45–47, 49]; cf. also www.schwartzcenter.org).

Develop and Incorporate Relational Communication into Clinical Encounters

Creating a relational space wherein patients and their families can tell their narratives in their own terms allows the core components of compassion within the Patient Compassion Model to be optimized (Fig. 21.1). The first core component,

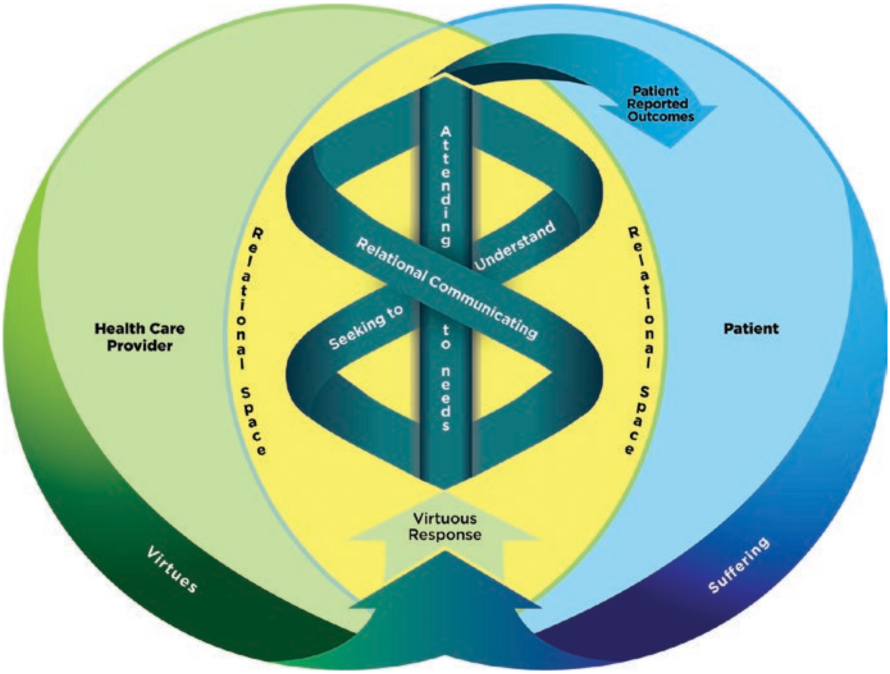


Fig. 21.1 A graphic rendering of the Patient Compassion Model [25]

relational communication, includes and extends strictly clinical communication between HCPs and patients to communication that occurs at a more human-to-human level. According to patients' perceptions, compassionate providers connect to their patients from a place of shared humanity through "verbal and nonverbal displays of compassion conveyed through healthcare provider demeanor, affect, behavior and engagement" ([25]: 199) [25, 26, 36, 47, 48]. In clinical terms, this involves providers not only enacting compassion but also evoking patient and family narratives through engaged listening, emotional resonance, and acts of kindness that attend to the totality of patients' and family members' experiences, not just "the clinical facts" [2, 25, 38, 46, 47]. This may involve providers reflecting on the following questions as they interact with those in their care: What does the information conveyed by this person tell me about how they derive meaning in his or her life? What beliefs, values, fears, and hopes are embedded in this person's personal narrative? How can I honor the emotional and spiritual experiences being narrated by this person through my demeanor, affect, behavior, and engagement?

Seek to Understand the Person and Their Individualized Needs

By creating a relational space and incorporating relational communication into their practice, providers will develop an understanding of individuals as persons, and not simply patients or kin [25, 46, 50]. This understanding can consequently guide

HCPs in tailoring their caregiving interactions and interventions to best suit the personal needs of those receiving their care ([25, 46]; cf. [2, 21, 23, 38]). In this regard, patients are clear that compassion is manifested when providers take time to recognize, accept, and appreciate their individuality [25, 46, 50]. Seeking to understand the person, according to patients, involves understanding how their personal narratives, and those of their family members, affect their experiences of healthcare [25, 26].

Developing a personal understanding also renders insights as to how patients' and their families' lives will be impacted by their experiences in the healthcare system [25, 46, 50]. This may cause providers to consider the following questions: How is this person's narrative affecting their healthcare experience? Based on my understanding of this person, how can I personalize their care so they can maintain some autonomy and therefore create meaning for themselves in their healthcare experience? It may also require providers to ask further questions aimed at developing a deeper understanding of the patient and their family members such as, "What do I need to know about you as a person in order to give you the best care possible?" (cf. [51]). In doing so, providers convey compassion to their patients and family members, thus mitigating institutional tendencies to treat them solely as a medical diagnosis, a number, or simply as a "medical case" ([25, 48, 50]; cf. [2]).

Engage with Action: Actively Participate in Patient's and Family Members' Healthcare Narratives Through Tangible Acts Aimed at Alleviating Suffering

After communicating relationally and seeking to understand patients and their families, compassionate care is brought to its climax through action—by providers acting upon the care receivers' personal narratives [25, 26, 46, 48, 50]. Healthcare practitioner actions can be as simple as giving patients options as to how they would like to receive personal care, making a referral to a spiritual care professional, providing comfort care, or facilitating a family meeting to develop a care plan [46, 50]. It can also mean taking into account patients' or families' emotional well-being when conveying diagnoses, treatment options, and prognostic information by providing emotional support [25, 45, 47, 50]. By implementing simple practices like these, patients report feeling like providers treated them as people [46].

In this way, healthcare narratives about patients and their families become narratives constructed in collaboration with those receiving care, thus personalizing their care and mitigating alienation and dehumanization they might otherwise experience [2, 25, 47, 50]. These examples might involve HCPs considering the following questions: How can I be sensitive to the patient's and their family's personal narratives as I engage them within the scope of my professional practice? How can I adjust my caregiving practices in light of the patient's and their family's narratives while still providing quality care? What small act can do that will positively impact their personal narrative?

In light of these five fundamentals for engaging patients' and families' spiritual narratives in a compassionate manner, we propose the following mnemonic and associated key questions for compassionate care in an ICU setting. This provides a clinical framework that healthcare providers can reflect on when engaging patient and family members in this clinical context:

V	Virtuous response	What are the personal and professional experiences that have shaped me as a physician/nurse in both positive and negative ways? Why did I choose to be a healthcare professional? Am I being true to these professional motivators? What personal qualities can help bring healing for this family? What parts of my narrative can cause harm?
E	Engage with action	What is a small act that I can do that will positively impact this patient or families narrative? How can I be sensitive to the patient's and their family's personal narratives as I engage them within the scope of my professional practice? How can I adjust my caregiving practices in light of the patient's and their family's narratives while still providing quality care?
R	Relational communication	What does the information conveyed by this person tell me about how they derive meaning in his or her life? What beliefs, values, fears, and hopes are embedded in this person's personal narrative? How can I honor the spiritual experiences being narrated by this person through my demeanor, affect, behavior, and engagement?
S	Seek to understand	What do I need to know about you as a person in order to give you the best care possible? How is this person's narrative affecting their healthcare experience? Based on my understanding of this person, how can I personalize their care in order to help them maintain meaning within their healthcare experience?
E	Engender a relational space	How can I work to create a relational space within my specific clinical practices? Are there any organizational or systemic challenges to creating a relational space in my practice? How can I bring who I am as a person into my clinical interactions in order to promote healing?

Conclusion

Despite ICUs being described as dehumanizing and alienating, research on compassion and narratives reveals concrete ways that the emotional and spiritual concerns of patients and their families can be sensitively engaged by ICU providers. Although this chapter calls for a broader scope of practice on the part of medical, nursing, and other healthcare practitioners, this by no means undermines or undervalues the role of professional spiritual care professionals (cf. [2, 11, 38]). When a patient's or family's emotional, spiritual, and/or religious concerns exceed what any given provider can provide within the bounds of his or her professional competence, a referral to an appropriate professional spiritual care provider is necessary and often beneficial.

However, this chapter is also predicated on the awareness that most, if not all, providers are capable and increasingly expected to provide compassionate care that is sensitive to patients' and families' emotional and spiritual needs. In ICUs where the intensity and invasiveness of the medical interventions are experienced as alienating and dehumanizing, such care is exceedingly important and can no longer be overlooked.

References

1. Cadge W. Paging god: religion in the halls of medicine. Chicago: University of Chicago Press; 2012.
2. Lasair S. Reconciliation through narrative: toward a theology of spiritual care in public health care. Pract Theol. 2017;10(2):160–73. https://doi.org/10.1080/1756073X.2016.1256713.
3. Ho JQ, et al. Spiritual care in the intensive care unit: a narrative review. J Intens Care Med [online pre-publication]. 2017; https://doi.org/10.1177/0885066617712677.
4. Timmins F, Naughton MT, Plakas S, Pesut B. Supporting patients' and families' religious and spiritual needs in ICU—can we do more? Br Assoc Crit Care Nurs. 2015;20(3):115–7.
5. Wittenberg E, Ragan SL. Exploring nurse communication about spirituality. Am J Hospice Palliat Med. 2016;34(6):566–71. https://doi.org/10.1177/1049909116641630.
6. Balboni TA, et al. State of the science of spirituality and palliative care research Part II: screening, assessment, and interventions. J Pain Symptom Manag. 2017;54(3):441–53. https://doi.org/10.1016/j/jpainsymman.2017.07.029.
7. Steinhauser KE, et al. State of the science of spirituality and palliative care research Part I: definitions and taxonomy, measurement, and outcomes. J Pain Symptom Manag. 2017;54(3):428–40. https://doi.org/10.1016/j.jpainsymman.2017.07.028.
8. Hummel L, Galek K, Murphy KM, Tannenbaum HP, Flannelly LT. Defining spiritual care: an exploratory study. J Health Care Chaplain. 2008;15:40–51. https://doi.org/10.1080/08854720802698509.
9. Timmins F, et al. The role of the healthcare chaplain: a literature review. J Health Care Chaplai [online pre-publication]. 2017; https://doi.org/10.1080/08854726.2017.1338048.
10. Handzo GF, Cobb M, Holmes C, Kelly E, Sinclair S. Outcomes for professional health care chaplaincy: an international call to action. J Health Care Chaplain. 2014;20(2):43–53.
11. Lasair S. Ethics, politics, and religion in public health care: a manifesto for health care chaplains in Canada. J Pastoral Care Counsel. 2016;70(1):63–9. https://doi.org/10.1177/1542305015619888.
12. Sinclair S, Pereira J, Raffin S. A thematic review of the spirituality literature in palliative care. J Palliat Med. 2006;9(2):464–79.
13. Sinclair S. Spiritual communication. In: Wittenburg E, et al., editors. Textbook of palliative care communication. Oxford, UK: Oxford University Press; 2016. p. 301–10.
14. Tornøe KA, Danbold LJ, Kvigne K, Sørlie V. The challenge of consolation: nurses' experiences with spiritual and existential care for the dying-a phenomenological hermeneutical study. BMC Nurs. 2015;14(62) https://doi.org/10.1186/s12912-015-0114-6.

15. Halm MA, Myers RN, Bennetts P. Providing spiritual care to cardiac patients: assessment and implications for practice. Crit Care Nurse. 2000;20:54–6, 58–64, 66–72.
16. Wall RJ, Engelberg RA, Gries CJ, et al. Spiritual care of families in the intensive care unit. Crit Care Med. 2007;35:1084–90.
17. Johnson JR, et al. The association of spiritual care providers' activities with family members' satisfaction with care after a death in the ICU. Crit Care Med. 2014;42(9):1991–2000. https://doi.org/10.1097/CCM.0000000000000412.
18. Balboni TA, et al. Provision of spiritual support to patients with advanced cancer by religious communities and associations with medical care at the end of life. JAMA Intern Med. 2013;173 https://doi.org/10.1001/jamainternmed.2013.903.
19. Davidson JE, et al. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. Crit Med. 2017;45 https://doi.org/10.1097/CCM.0000000000002169.
20. Pesut B, et al. Health care chaplaincy: a scoping review of the evidence 2009-2014. J Health Care Chaplain. 2016;22:67–84.
21. Fitchett G. Assessing spiritual needs: a guide for caregivers. Lima: Academic Renewal Press; 2002.
22. Puchalski C, Romer AL. Taking a spiritual history allows clinicians to understand patients more fully. J Palliat Med. 2000;3(1):129–37.
23. Swinton J. Spirituality and mental health care: rediscovering a 'forgotten' dimension. London: Jessica Kingsley; 2001.
24. Zollfrank AA, et al. Teaching health care providers to provide spiritual care: a pilot study. J Palliat Med. 2015;18(5):408–14.
25. Sinclair S, et al. Compassion in health care: an empirical model. J Pain Symptom Manag. 2016;51(2):193–203.
26. Sinclair S, et al. Compassion: a scoping review of the healthcare literature. BMC Palliat Care. 2016;15(6) https://doi.org/10.1186/s12904-016-0080-0.
27. Swinton J. Healthcare spirituality: a question of knowledge. In: Cobb M, Puchalski CM, Rumbold B, editors. Oxford textbook of spirituality in healthcare. Oxford, UK: Oxford University Press; 2012. p. 99–104.
28. McBrien B. A concept analysis of spirituality. Br J Nurs. 2006;15(1):42–5.
29. Puchalski C, et al. Improving the quality of spiritual care as a diminsion of palliative care: the report of the consensus conference. J Palliat Med. 2009;12(10):885–904.
30. Puchalski C, Vitillo R, Hull SK, Reller N. Improving the spiritual dimension of whole person care: reaching national and international consensus. J Palliat Med. 2014;17(6):642–56.
31. Ramezani M, Ahmadi F, Mohammadi E, Kazemnejad A. Spiritual care in nursing: a concept analysis. Int Nurs Rev. 2014;61(2):211–9.
32. Pargament KI. Spiritually integrated psychotherapy: understanding and addressing the sacred. New York: Guilford Press; 2007.
33. Lynch G. The sacred in the modern world: a cultural sociological approach. Oxford, UK: Oxford University Press; 2012.
34. Bibby RW. Beyond the gods and back: religion's demise and rise and why it matters. Lethbridge: Project Canada Books; 2011.
35. Pattison S. Situating chaplaincy in the United Kingdom: the acceptable face of 'religion'? In: Smith C, Cobb M, Todd A, editors. A handbook of chaplaincy studies: understanding spiritual care in public places. Farnham: Ashgate; 2015. p. 13–30.
36. Sinclair S, Chochinov HM. Communicating with patients about existential and spiritual issues: SACR-D work. Prog Palliat Care. 2012;20(2):72–8. https://doi.org/10.1179/1743291X12Y.0000000015.
37. Nongbri B. Before religion: the history of a modern concept. New Haven: Yale University Press; 2012. Kindle ebook.
38. Lasair S. Spiritual care as a secular profession: politics, theory, practice. J Stud Spiritual. 2018;8(1):5–18. https://doi.org/10.1080/20440243.2018.1431022.
39. Ricoeur P. Life: a story in search of a narrator. In: Valdés MJ, editor. Paul Ricoeur: reflection and imagination. Toronto: University of Toronto Press; 1991. p. 425–37.

40. Madigan S. Narrative therapy, Theories of psychotherapy series. Washington, DC: American Psychological Association; 2011.
41. Frank AW. The wounded storyteller: body, illness, and ethics. 2nd ed. Chicago: University of Chicago Press; 2013/[1995].
42. Foucault M. The birth of the clinic: an archaeology of medical perception. Translated by A.M. Sheridan Smith. New York: Vintage; 1994/[1974].
43. Swinton M, et al. Experiences and expressions of spirituality at the end of life in the intensive care unit. Am J Respir Crit Care Med. 2017;195(2):198–204.
44. Sinclair S, et al. Sympathy, empathy, and compassion: a grounded theory study of palliative care patients' understandings, experiences, and preferences. Palliat Med. 2017;31(5):437–47. https://doi.org/10.1177/0269216316663499.
45. Schantz ML. Compassion: a concept analysis. Nurs Forum. 2007;42(2):48–55.
46. Badger K, Royse D. Describing compassionate care: the burn survivor's perspective. J Burn Care Res. 2012;33(6):772–80. https://doi.org/10.1097/BCR.0b013e318254d30b.
47. Fogarty LA, et al. Can 40 seconds of compassion reduce patient anxiety? J Clin Oncol. 1999;17(1):371–9.
48. Cameron RA, et al. In search of compassion: a new taxonomy of compassionate physician behaviours. Health Expect. 2013;18:1672–85.
49. Francis R. Report of the mid Staffordshire NHS foundation trust public inquiry. London: The Stationary Office; 2013.
50. Riggs JS, et al. "Don't get weak in your compassion": bereaved next of kin's suggestions for improving end-of-live care in Veterans Affairs Medical Centers. J Am Geriatr Soc. 2014;62:642–8. https://doi.org/10.1111/jgs.12764.
51. Chochinov HM. Dignity therapy: final words for final days. Oxford, UK: Oxford University Press; 2012.

Chapter 22
The Role of the Pharmacist in Family Engagement in the Intensive Care Unit and During Transitions of Care

Joanna L. Stollings

Introduction

The ABCDEF bundle is an interdisciplinary, intensive care unit (ICU) bundle (*A*ssess, prevent, and manage pain; *B*oth spontaneous awakening trials (SATs) and spontaneous breathing trials (SBTs); *C*hoice of analgesia and sedation; *D*elirium – assess, prevent, and mange; *E*arly mobility and exercise; and *F*amily engagement and empowerment). It integrates the prevention and treatment of pain, agitation, and delirium, resulting in a reduction in duration of mechanical ventilation, a decrease in ICU-acquired delirium and weakness, and optimization of family engagement and empowerment [1]. Utilization of the ABCDEF bundle promotes interprofessional care [2–7] and improves patient outcomes [2, 3]. A reduction in ICU mortality has been demonstrated with the degree of bundle compliance [8].

Post-intensive care syndrome (PICS) is a term that refers to new or worsening impairment in mental health, physical function, and cognition following critical illness. The development of physiological conditions including posttraumatic stress, depression, complicated grief, and anxiety in family members of critically ill patients has been termed post-intensive care syndrome-family (PICS-F) [9].

The 2017 Society of Critical Care Medicine (SCCM) Guidelines for Family-Centered Care outlines the best evidence available for providing support for family members of critically ill patients in the ICU [10]. The guidelines suggest that routine interprofessional care be used to improve family satisfaction and to reduce conflict between the clinicians and the family [10]. Although numerous studies have demonstrated the role of the pharmacist in enhancing compliance with the different letters of the ABCDEF bundle [11–18] and the utilization of a pharmacist in a PICS

J. L. Stollings
Department of Pharmaceutical Services, Vanderbilt University Medical Center, Nashville, TN, USA
e-mail: joanna.stollings@vumc.org

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_22

clinic has been described [19–21], the role of the pharmacist with family engagement and empowerment or PICS-F has not been defined.

The ABCDEF Bundle

The pharmacist has a unique role engaging the family and assisting with implementation of the ABCDEF bundle.

A: *A*ssess, prevent, and manage pain is the first place that the pharmacist can interact with the family to aid in the recognition and treatment of the patient's pain. Numerous complications including nosocomial infections, increased duration of mechanical ventilation, and delirium have been associated with inadequate pain management [22]. Utilization of opiates for treatment of pain in critically ill patients has been associated with a heightened risk of delirium in some studies [23–27] and a lower risk of delirium in others [23, 28]. Pain assessment in critically ill patients is imperative due to the risk for the development of delirium secondary to untreated pain. The pain, agitation, and delirium (PAD) guidelines [29] state that all adult critically ill patients be routinely assessed for pain. The reference standard for pain assessment is self-reporting of pain [30]. Additionally, some patients do not wish to have pain treated with opiates due to the fear of development of addiction. Through incorporation of the family into discussions about the importance of accurate pain assessment and treatment when indicated, the pharmacist and family can act together to aid in the patient receiving appropriate pain treatment.

B, C: *B*oth SATs and SBTs and *C*hoice of analgesia and sedation are another place where the pharmacist can empower the family in assisting with patient. When turning off the patient's sedation and analgesia, the patient can become agitated. The pharmacist can educate the family to calm the patient first, potentially preventing the use of analgesia/sedation. Additionally, a survey of ICU healthcare practitioners found that only 44% of respondents practice spontaneous awakening trials on greater than half of ICU days [31].

D: Pharmacists can provide family education on the letter D, *D*elirium – assess, prevent, and mange – including utilization of both nonpharmacologic, e.g., noise reduction strategies [10], and pharmacologic therapies.

E:The letter E, *E*arly mobility and exercise, can be performed by nurses, physical therapists, occupational therapists, and physicians. With many institutions experiencing a shortage of physical and occupational therapists and the busy schedules of nurses, physicians, and mid-level providers, early mobility is sometimes overlooked as a means to involve the family in patient care. Pharmacists can recommend consulting with physical/occupational therapy during interprofessional rounds.

F: By doing all of the above listed letters and aiding the interprofessional team in inviting the family to participate in interprofessional rounds [10], the pharmacist can promote the letter F, *F*amily engagement and empowerment. By allowing a family member to assist with the patient's care, it improves confidence and competence in the caregiving role in addition to improving psychological health during and after the ICU stay [10].

Medication Reconciliation at Transitions of Care

The Centers for Medicare and Medicaid Services started the Readmissions Reduction Program, which decreased payments to hospitals with excess 30-day readmissions in 2012 [32]. A transition of care is defined as when a patient leaves a particular unit or healthcare facility and moves to a different location (e.g., a different area of a hospital, a different facility, or home) [33]. Over the last decade, transitions of care have been deemed as a significant risk for adverse drug events (ADEs) [34, 35]. ADEs have been shown to increase hospital length of stay, healthcare costs, and mortality [36, 37]. Medication reconciliation is defined as verifying medication indication and discrepancies and resolving all medication-related issues at all transitions of care [38]. Pharmacist-conducted medication histories when compared to other healthcare practitioners have been shown to have a lower rate of errors [39, 40]. The Joint Commission on Accreditation of Healthcare Organizations declared "sustaining and properly communicating correct medication information" to be a National Patient Safety Goal in 2011 in response to the growing amount of data demonstrating medication errors at transitions of care.

The goal of pharmacists when performing medication reconciliation during each transition of care is to gauge understanding of the medications, ensure adherence, determine any barriers to medication management, and evaluate for support systems. Having the family in addition to the patient present during medication reconciliation is key. When the pharmacist is communicating with the patient and family, the pharmacist should use a structured communication approach such as the VALUE pneumonic: *V*alue comments made by the family, *A*cknowledge family emotions, *L*isten, *U*nderstand the patient as a person, and *E*licit family questions [10]. The family member can help recall which medications that patient takes, potentially provide a medication list, or direct the pharmacist to which pharmacy to call to obtain a medication list. The additional benefits of having a family member or members present during medication reconciliation at transitions of care are provided in Table 22.1.

A survey of pharmacists that had participated in admission medication reconciliation recommendations for improving care transitions found that sometimes patients were out of the room or undergoing a procedure and could not have counseling. Additionally, the patient was often too delirious or sleepy to receive counseling

Table 22.1 Benefits of family presence during pharmacist discharge counseling

Benefits
Ensure patient and family understanding of what medications that he or she will be taking post discharge
Verify that the patient and family know how to take all of their medications (e.g., what time of day, with food, without food, etc.)
Clarify what side effects to watch out for
Explain what other medications to avoid
Determine what pharmacy will be utilized to obtain medications
Provide any other needed counseling

[41]. Given that the incidence of delirium has been reported to be between 20% and 50% among non-ventilated ICU patients and 60–80% of ventilated patients, this is not surprising. Given the degree of delirium and sedation in ICU patients, involvement of the family in medication reconciliation at all transitions of care is imperative. Additionally, the pharmacists encouraged the family members during the admission medication reconciliation to be present at the discharge medication reconciliation to better aid the patient in handling their medication regiment upon transfer to home [41].

Deprescribing

Elderly patients with cognitive impairment or low health literacy [42] or those with polypharmacy (taking five to nine concomitant medications) are three examples of patient populations at higher risk for ADEs during transitions of care [35]. Additionally, the number of medications a patient is receiving has been shown to be a risk factor for drug-drug interactions [43], increased mortality in the elderly [44], and delirium [45]. "Deprescribing" is defined as tapering or stopping medications to reduce polypharmacy and improve patient outcomes. The following five-step protocol for deprescribing has been recommended:

1. Determine that each medication has an appropriate indication.
2. When determining the number of medications that should be discontinued, the overall potential harm of the medications should be considered.
3. Determine if each individual drug should be discontinued.
4. Prioritize which medications should be discontinued first.
5. Start and monitor a drug discontinuation plan.

In the ICU, deprescribing can be further enhanced by determining if medication has a current indication [46]. For example, a patient using nasal steroids for allergies does not need this restarted while in the ICU.

The 2013 PAD guidelines conclude that no evidence supports the use of haloperidol for the treatment of delirium and low-quality evidence supports the use of atypical antipsychotics. Despite this, numerous surveys have shown that prescribers utilize haloperidol or atypical antipsychotics for the treatment of delirium in the ICU. A single-center, prospective cohort study of 172 ICU survivors found that 42 (24%) of these were prescribed an antipsychotic at discharge [47]. Multiple other studies have demonstrated the continuation of antipsychotics at hospital discharge following ICU admission [48–51]. Risk factors associated with the utilization of antipsychotics include ventricular arrhythmias, excess sedation, akathisia, and hypotension [52]. Additionally, a population-based, retrospective cohort study found that new use of atypical antipsychotics was associated with an increased risk of death compared with nonuse in elderly patients with dementia [53]. These studies demonstrate the importance of discontinuing these medications following ICU admission especially given that clinicians may be reluctant to stop medications that were started in the ICU. The family can serve as resource to clarify home medications and allow clinicians to feel more comfortable with deprescribing medications utilized temporarily.

Stress ulcer prophylaxis with acid-suppressive therapy is commonly continued in patients following an ICU admission. Quality improvement initiatives have been developed to decrease this practice. In one study, in the pre-intervention group, 7% of patients were discharged inappropriately compared to none of the patients in the post-intervention group ($p = 0.22$) [54]. The inappropriate continuation of acid-suppressive therapy at hospital discharge following ICU stay has been documented in other studies [54–57]. Numerous complications have been associated with proton pump inhibitor use including hospital-acquired *Clostridium difficile* infection, pneumonia, hip fracture, and dementia [58–62]. If a current indication such as mechanical ventilation or gastrointestinal bleed does not exist, the family can be a valuable resource to verify if the patient has gastroesophageal reflux disease or another indication that merits continuation.

A qualitative study of focus groups including pharmacists, general practitioners, and specialist physicians was conducted to investigate perspectives of healthcare providers on deprescribing of anticholinergic and sedative medications. Lack of accountability was the most common reason that anticholinergics and sedatives were not discontinued. Pharmacists were frustrated with general practitioners for not stopping anticholinergic and sedative medications. Irritation was expressed by the general practitioners that the specialist physicians did not take ownership of deprescribing and vice versa [63]. Since family members are quite often present at all physician visits and hospital admissions, they are the logical members to assist with deprescribing. Family can serve as a means of communication between multiple physicians.

The frequency of prescribed potentially inappropriate medications, medications potentially harmful to the elderly based on prior research and knowledge of pharmaceutical effect, and actually inappropriate medications, the benefit of the drug was outweighed by the harm after considering clinical circumstances, was described in a single-center study of 120 elderly adult ICU survivors [64]. Using the 2003 Beers criteria and additional medication safety data published after 2003, charts were reviewed, and medications were identified as potentially inappropriate medications. At five specific points within the hospital stay, admission, medical/surgical unit admission, ICU admission, ICU discharge, and hospital discharge, medications were evaluated to determine if actually inappropriate medications were started. The following were the most common categories of potentially inappropriate medications identified at hospital discharge: opioids, anticholinergic medications, antidepressants, and drugs causing orthostasis. Of these potentially inappropriate medications, 36% were considered to be actually inappropriate medications by a team consisting of a hospitalist, a geriatrician, and a clinical pharmacist. The potentially inappropriate medication categories at hospital discharge with the highest positive predictive values for being actually inappropriate medications were anticholinergics (55%), nonbenzodiazepine hypnotics (67%), benzodiazepines (67%), atypical antipsychotics (71%), and muscle relaxants (100%). In multivariate analysis, the number of discharge potentially inappropriate medications was independently predicted by the number of preadmission potentially inappropriate medications ($p < 0.001$), discharge to somewhere other than home ($p = 0.03$), and

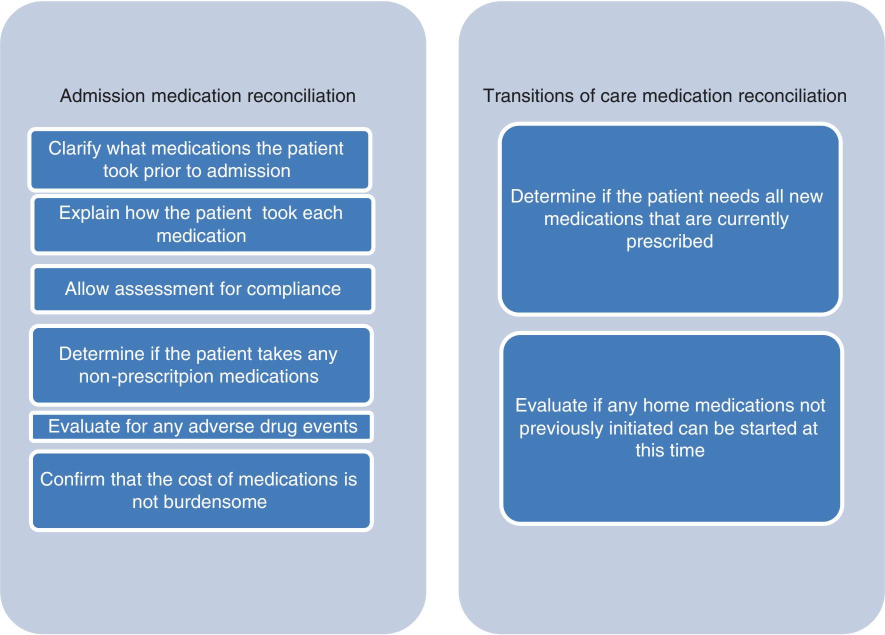


Fig. 22.1 Benefits of family presence during pharmacist admission medication reconciliation and at transitions of care

discharge from a surgical service ($p < 0.001$). Nearly 2/3 of actually inappropriate medications were initiated in the ICU.

Many of these medications initiated in the ICU or at any other time within the hospitalization may have been appropriately initiated for the patient's current clinical situation. However, failure to discontinue these medications once no longer indicated can lead to inappropriate and prolonged use increasing the potential for adverse drug events and drug-drug interactions. The importance of reviewing patients' medication lists daily and during transitions of care is emphasized by this study. Involvement of the family in this process is imperative in determining exactly what medications the patient takes at home to facilitate the deprescribing process. Benefits of inclusion of the family in the transition of care medication reconciliation are found in Fig. 22.1.

Reinitiation of Home Medications

In contrast to the inappropriate continuation medications after hospital discharge, another problem is failure to initiate patients' home maintenance medications upon hospital admission. A large Canadian cohort study of 396,380 elderly patients evaluated records of hospital and outpatient medications prescribed from at least one of the five following groups: (1) statins, (2) antiplatelet/anticoagulant agents, (3) levothyroxine, (4) respiratory inhalers, and (5) gastric acid-suppressing drugs [65]. Patients were classified into the following three groups: hospitalization with an ICU admission, hospitalization without ICU admission, and nonhospitalized patients (controls). Compared to the control group, patients admitted to a hospital without an ICU stay were significantly more likely to have medications discontinued within all five of the medication groups. Likewise, control group patients were less likely to have medications discontinued among all five of the medication groups compared to patients admitted to a hospital with an ICU stay. Compared to patients that were hospitalized without an ICU stay, there was a higher risk of medication discontinuation in all medication groups with the exception of respiratory inhalers in patients hospitalized with an ICU admission. In all study patients, the composite risk of death, hospitalization, and emergency department visits up to 1 year after hospital discharge was found to be significantly higher in patients in which a statin or antiplatelet or anticoagulant was discontinued. To prevent errors of omission in the patient's discharge medication list, this study once again emphasizes the importance of medication reconciliation at all transitions of care. Inclusion of the family in this process is logical in that they often may serve as the best source of information in obtaining the most accurate medication list. Benefits of inclusion of the family in the transition of care medication reconciliation are found in Fig. 22.1.

Discharge Counseling

Following hospital discharge, up to 20% of patients experience an adverse drug event, with approximately 60% being associated with a medication and being deemed preventable [66–68]. These adverse events have been associated with emergency department visits, hospital admissions, and costly healthcare utilization [69–72].

Readmissions occurred in 20% of Medicare recipients within 30 days of discharge and in 34% within 90 days of discharge in one study [70]. Physicians in the hospital may start new medications and stop the use of other medications, while the patient still has the other medications at home [73]. Once the patient is discharged, it is unclear what medications that the patient should be taking. A survey showed that less than 60% of patients understood the indications for their new medication at discharge and only 12% conveyed awareness of a known side effect [74].

Discharge counseling is an important patient safety initiative. Pharmacists are the logical individuals to provide discharge counseling given their medication expertise. A survey of pharmacists found that uniformly, all pharmacists found counseling on medications at discharge facilitated understanding among patients about their medication regimens [41]. Pharmacist counseling on medications at discharge is cost-effective [75], improves patient satisfaction, and increases medication adherence [76]. However, the impact of pharmacists on readmission has not been consistently demonstrated [69, 77–80].

Discharge medication counseling should include the plan for filling medications, troubleshooting anticipated and potential barriers to adherence, utilization of adherence aids such as a pill box, and a teach-back approach to verify understanding. Having the family in addition to the patient present during discharge counseling is imperative and has been reported to be helpful by pharmacists [41]. The additional benefits of having a family member or members present during pharmacist discharge counseling are provided in Table 22.1.

As part of a randomized controlled trial, the frequency and predictors of nonadherence with medications post discharge in patients that had received discharge medication counseling by a pharmacist were evaluated. Patients who lived alone were less likely to fill their prescriptions than patients that were married or that did not live alone (odds ratio 2.2, 95% confidence interval, 1.01–4.8, $p = 0.047$). Nonadherence was more likely to be demonstrated in patients that were discharged on greater than ten medications (odds ratio 2.3, 95% confidence interval, 1.05–4.98, $p = 0.036$). Patients that had lower incomes were less likely to have prescriptions filled univariate analysis ($p = 0.04$). However, this was not demonstrated in multivariate analysis [81].

Given the known predictors of nonadherence with medications post discharge, the pharmacist can engage the family of patients that meet these criteria to enhance compliance. For a patient that lives alone, family can be counseled regarding this known risk factor and given the suggestion of calling or visiting the patient, getting a neighbor to remind the patient about medications, or potentially getting a caregiver involved if needed. For patients that are discharged on greater than ten medications, the pharmacist could provide a pill box or an adherence aid to assist the patient and family with adherence. Additionally, the pharmacist could provide counseling to the patient and family about incorporating medication administration into activities of daily life such as eating and setting medication timers. For patients with lower incomes, the pharmacist can discuss with the patient and family about medication coupons and programs to assist with obtaining medications in indigent patients.

Several barriers have been identified to medication discharge counseling. Patients who were in a hurry to leave the hospital were less receptive to being counseled. Involvement of the family in the discharge counseling process may give the pharmacist a second advocate to the importance of this activity. Due to the need for quick turn over of patient beds for the next patient, pharmacists felt hurried to go through the discharge medication process. Pharmacists also were suspicious that patients did not ask as many questions as needed [41]. By including the family in the discharge medication reconciliation process, the pharmacist can ask questions to gauge both the patients' and family members' understanding. Even with these identified barriers, pharmacists still considered discharge counseling an essential part of the patient's healthcare stay.

Post-ICU Clinics

A post-ICU clinic is one means of aiding the transition back to a primary care provider following an ICU stay. Many specific issues are seen in patients following an ICU stay that primary care providers may not be familiar with. Additionally, primary care providers may not be familiar with the tools to diagnose and manage these complications. An interprofessional team of providers that staff a post-ICU clinic can assist in the diagnosis and treatment of PICS by using their expertise about specific complications related to critical care. Given that 50% of patients who are readmitted within 30 days of discharge did not visit a primary care provider post-hospitalization, it is not surprising that lack of understanding of medications contributed to readmissions [35]. Review of medications, reconciliation, and counseling should all be considered essential parts of a patient's visit to a post-ICU clinic. A pharmacist is the ideal person to perform these tasks [19–21]. Although information highlighting a pharmacist's interaction with the family in an outpatient setting is limited [82, 83], it is imperative that the pharmacist involve the family in the complete medication use process [41]. The steps of the complete medication use process are listed in Table 22.2. These steps include not only asking the patient

Table 22.2 Medication-related questions asked at a post-intensive care syndrome clinic

Questions for the patient	Questions for the family member
1. Why do you take each of these medications?	1. Do you know what reason the patient takes each of these medications?.
2. What dose and how often do you take each of these medications?	2. Do you know what dose and how often the patient takes each of these medications?
3. How do you take each medication (i.e., what time of day, with meals, etc.)?	3. How does the patient take each of these medications?
4. How often do you miss a dose? What do you do if you miss a dose?	4. How often does the patient miss a dose? What does he or she do if he or she misses a dose?
5. Do you use a pill box?	5. Does the patient use a pill box?
6. What side effects have you experienced with these medications?	6. What side effects has the patient experienced from these medications?
7. How much and how often do you use your prn medications?	7. How much and often does the patient use their prn medications?
8. Do you use any over-the-counter medications?	8. Does the patient use any over-the-counter medications?
9. Do you take any herbal medications?	9. Does the patient take any herbal medications
10. Do you visit one pharmacy?	10. Does the patient visit one pharmacy?
11. Do you ask your physician or pharmacist prior to taking any over-the-counter or herbal medications?	11. Does the patient ask their physician or pharmacist prior to taking any over-the-counter or herbal medications?
12. Is the cost of medications problematic?	12. Is the cost of the patient's medications problematic?
13. Do you smoke?	13. Does the patient smoke?
14. Do you drink alcohol?	14. Does the patient drink alcohol?
15. Do you use illicit drugs?	15. Does the patient use illicit drugs?
16. Do you take your blood pressure at home?	16. Does the patient take their blood pressure at home?
17. Do you have regular bowel movements?	17. Does the patient have regular bowel movements?
18. Have you had an influenza vaccine?	18. Has the patient had an influenza vaccine?
19. Have you had a pneumococcal vaccine?	19. Has the patient had a pneumococcal vaccine?
20. Do you need refills of any medications?	20. Does the patient need any refills of any medications?

questions but allowing the family to participate as well to obtain the most complete medication information. This process also should alleviate symptoms of PICS-F as the medication review, reconciliation, and counseling from a medication expert can instate confidence in the family member about the patient's quite often complicated medication regimen.

Conclusion

A pharmacist is a key member in family engagement both in the ICU and during transitions of care. Empowering the family to assist with conduction of the ABCDEF bundle, performing medication reconciliation at all transitions of care, promoting deprescribing, performing discharge counseling, and serving as an integral member of an interprofessional post-ICU clinic team are all roles of the pharmacist in facilitating family engagement and empowerment.

Financial Support None

Conflicts of Interest and Sources of Funding Joanna L. Stollings has no conflicts of interest to disclose.

References

1. Marra A, Ely EW, Pandharipande PP, Patel MB. The ABCDEF bundle in critical care. Crit Care Clin. 2017;33(2):225–43.
2. Balas MC, Vasilevskis EE, Olsen KM, Schmid KK, Shostrom V, Cohen MZ, Peitz G, Gannon DE, Sisson J, Sullivan J, et al. Effectiveness and safety of the awakening and breathing coordination, delirium monitoring/management, and early exercise/mobility bundle. Crit Care Med. 2014;42:1024.
3. Pandharipande P, Banerjee A, McGrane S, Ely EW. Liberation and animation for ventilated ICU patients: the ABCDE bundle for the back-end of critical care. Crit Care. 2010;14(3):157.
4. Carrothers KM, Barr J, Spurlock B, Ridgely MS, Damberg CL, Ely EW. Contextual issues influencing implementation and outcomes associated with an integrated approach to managing pain, agitation, and delirium in adult ICUs. Crit Care Med. 2013;41(9 Suppl 1):S128–35.
5. Balas MC, Vasilevskis EE, Burke WJ, Boehm L, Pun BT, Olsen KM, Peitz GJ, Ely EW. Critical care nurses' role in implementing the "ABCDE bundle" into practice. Crit Care Nurse. 2012;32(2):35–47.
6. Morandi A, Brummel NE, Ely EW. Sedation, delirium and mechanical ventilation: the 'ABCDE' approach. Curr Opin Crit Care. 2011;17(1):43–9.
7. Vasilevskis EE, Ely EW, Speroff T, Pun BT, Boehm L, Dittus RS. Reducing iatrogenic risks: ICU-acquired delirium and weakness – crossing the quality chasm. Chest. 2010;138(5):1224–33.
8. Barnes-Daly MA, Phillips G, Ely EW. Improving hospital survival and reducing brain dysfunction at seven California community hospitals: implementing PAD guidelines via the ABCDEF bundle in 6,064 patients. Crit Care Med. 2017;45(2):171–8.
9. Needham DM, Davidson J, Cohen H, Hopkins RO, Weinert C, Wunsch H, Zawistowski C, Bemis-Dougherty A, Berney SC, Bienvenu OJ, et al. Improving long-term outcomes after

discharge from intensive care unit: report from a stakeholders' conference. Crit Care Med. 2012;40(2):502–9.

10. Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, Cox CE, Wunsch H, Wickline MA, Nunnally ME, et al. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. Crit Care Med. 2017;45(1):103–28.
11. Marshall J, Finn CA, Theodore AC. Impact of a clinical pharmacist-enforced intensive care unit sedation protocol on duration of mechanical ventilation and hospital stay. Crit Care Med. 2008;36(2):427–33.
12. Stollings JL, Foss JJ, Ely EW, Ambrose AM, Rice TW, Girard TD, Wheeler AP. Pharmacist leadership in ICU quality improvement: coordinating spontaneous awakening and breathing trials. Ann Pharmacother. 2015;49(8):883–91.
13. MacLaren R, Plamondon JM, Ramsay KB, Rocker GM, Patrick WD, Hall RI. A prospective evaluation of empiric versus protocol-based sedation and analgesia. Pharmacotherapy. 2000;20(6):662–72.
14. Devlin JW, Marquis F, Riker RR, Robbins T, Garpestad E, Fong JJ, Didomenico D, Skrobik Y. Combined didactic and scenario-based education improves the ability of intensive care unit staff to recognize delirium at the bedside. Crit Care. 2008;12(1):R19.
15. Gesin G, Russell BB, Lin AP, Norton HJ, Evans SL, Devlin JW. Impact of a delirium screening tool and multifaceted education on nurses' knowledge of delirium and ability to evaluate it correctly. Am J Crit Care. 2012;21(1):e1–11.
16. Swan JT. Decreasing inappropriate unable-to-assess ratings for the confusion assessment method for the intensive care unit. Am J Crit Care. 2014;23(1):60–9.
17. Louzon P, Jennings H, Ali M, Kraisinger M. Impact of pharmacist management of pain, agitation, and delirium in the intensive care unit through participation in multidisciplinary bundle rounds. Am J Health-Syst Pharm Off J Am Soc Health-Syst Pharm. 2017;74(4):253–62.
18. Marino J, Bucher D, Beach M, Yegneswaran B, Cooper B. Implementation of an intensive care unit delirium protocol: an interdisciplinary quality improvement project. Dimens Crit Care Nurs. 2015;34(5):273–84.
19. Stollings JL, Bloom SL, Huggins EL, Grayson SL, Jackson JC, Sevin CM. Medication management to ameliorate post-intensive care syndrome. AACN Adv Crit Care. 2016;27(2):133–40.
20. Stollings JL, Caylor MM. Postintensive care syndrome and the role of a follow-up clinic. Am J Health-Syst Pharm Off J Am Soc Health-Syst Pharm. 2015;72(15):1315–23.
21. Huggins EL, Bloom SL, Stollings JL, Camp M, Sevin CM, Jackson JC. A clinic model: post-intensive care syndrome and post-intensive care syndrome-family. AACN Adv Crit Care. 2016;27(2):204–11.
22. Chanques G, Jaber S, Barbotte E, Violet S, Sebbane M, Perrigault PF, Mann C, Lefrant JY, Eledjam JJ. Impact of systematic evaluation of pain and agitation in an intensive care unit. Crit Care Med. 2006;34(6):1691–9.
23. Pandharipande P, Cotton BA, Shintani A, Thompson J, Pun BT, Morris JA Jr, Dittus R, Ely EW. Prevalence and risk factors for development of delirium in surgical and trauma intensive care unit patients. J Trauma. 2008;65(1):34–41.
24. Dubois MJ, Bergeron N, Dumont M, Dial S, Skrobik Y. Delirium in an intensive care unit: a study of risk factors. Intensive Care Med. 2001;27(8):1297–304.
25. Ouimet S, Kavanagh BP, Gottfried SB, Skrobik Y. Incidence, risk factors and consequences of ICU delirium. Intensive Care Med. 2007;33(1):66–73.
26. Van Rompaey B, Elseviers MM, Schuurmans MJ, Shortridge-Baggett LM, Truijen S, Bossaert L. Risk factors for delirium in intensive care patients: a prospective cohort study. Crit Care. 2009;13(3):R77.
27. Pisani MA, Murphy TE, Araujo KL, Slattum P, Van Ness PH, Inouye SK. Benzodiazepine and opioid use and the duration of intensive care unit delirium in an older population. Crit Care Med. 2009;37(1):177–83.
28. Agarwal V, O'Neill PJ, Cotton BA, Pun BT, Haney S, Thompson J, Kassebaum N, Shintani A, Guy J, Ely EW, et al. Prevalence and risk factors for development of delirium in burn intensive care unit patients. J Burn Care Res. 2010;31(5):706–15.

29. Barr J, Fraser GL, Puntillo K, Ely EW, Gelinas C, Dasta JF, Davidson JE, Devlin JW, Kress JP, Joffe AM, et al. Clinical practice guidelines for the management of pain, agitation, and delirium in adult patients in the intensive care unit. Crit Care Med. 2013;41(1):263–306.
30. Peacock S, Patel S. Cultural influences on pain. Rev Pain. 2008;1(2):6–9.
31. Patel RP, Gambrell M, Speroff T, Scott TA, Pun BT, Okahashi J, Strength C, Pandharipande P, Girard TD, Burgess H, et al. Delirium and sedation in the intensive care unit: survey of behaviors and attitudes of 1384 healthcare professionals. Crit Care Med. 2009;37(3):825–32.
32. Rodrigues CR, Harrington AR, Murdock N, Holmes JT, Borzadek EZ, Calabro K, Martin J, Slack MK. Effect of pharmacy-supported transition-of-care interventions on 30-day readmissions: a systematic review and meta-analysis. Ann Pharmacother. 2017;51(10):866–89.
33. American College of Clinical P, Kirwin J, Canales AE, Bentley ML, Bungay K, Chan T, Dobson E, Holder RM, Johnson D, Lilliston A, et al. Process indicators of quality clinical pharmacy services during transitions of care. Pharmacotherapy. 2012;32(11):e338–47.
34. Leendertse AJ, Egberts AC, Stoker LJ, van den Bemt PM, Group HS. Frequency of and risk factors for preventable medication-related hospital admissions in the Netherlands. Arch Intern Med. 2008;168(17):1890–6.
35. American College of Clinical P, Hume AL, Kirwin J, Bieber HL, Couchenour RL, Hall DL, Kennedy AK, NM LP, Burkhardt CD, Schilli K, et al. Improving care transitions: current practice and future opportunities for pharmacists. Pharmacotherapy. 2012;32(11):e326–37.
36. Bates DW, Spell N, Cullen DJ, Burdick E, Laird N, Petersen LA, Small SD, Sweitzer BJ, Leape LL. The costs of adverse drug events in hospitalized patients. Adverse Drug Events Prevention Study Group. JAMA. 1997;277(4):307–11.
37. Hug BL, Keohane C, Seger DL, Yoon C, Bates DW. The costs of adverse drug events in community hospitals. Jt Comm J Qual Patient Saf/Jt Comm Resour. 2012;38(3):120–6.
38. Agrawal A, Wu WY. Reducing medication errors and improving systems reliability using an electronic medication reconciliation system. Jt Comm J Qual Patient Saf/Jt Comm Resour. 2009;35(2):106–14.
39. Reeder TA, Mutnick A. Pharmacist- versus physician-obtained medication histories. Am J Health-Syst Pharm Off J Am Soc Health-Syst Pharm. 2008;65(9):857–60.
40. Pippins JR, Gandhi TK, Hamann C, Ndumele CD, Labonville SA, Diedrichsen EK, Carty MG, Karson AS, Bhan I, Coley CM, et al. Classifying and predicting errors of inpatient medication reconciliation. J Gen Intern Med. 2008;23(9):1414–22.
41. Haynes KT, Oberne A, Cawthon C, Kripalani S. Pharmacists' recommendations to improve care transitions. Ann Pharmacother. 2012;46(9):1152–9.
42. Davis TC, Wolf MS, Bass PF 3rd, Thompson JA, Tilson HH, Neuberger M, Parker RM. Literacy and misunderstanding prescription drug labels. Ann Intern Med. 2006;145(12):887–94.
43. Qato DM, Alexander GC, Conti RM, Johnson M, Schumm P, Lindau ST. Use of prescription and over-the-counter medications and dietary supplements among older adults in the United States. JAMA. 2008;300(24):2867–78.
44. Jyrkka J, Enlund H, Korhonen MJ, Sulkava R, Hartikainen S. Polypharmacy status as an indicator of mortality in an elderly population. Drugs Aging. 2009;26(12):1039–48.
45. Inouye SK, Charpentier PA. Precipitating factors for delirium in hospitalized elderly persons. Predictive model and interrelationship with baseline vulnerability. JAMA. 1996;275(11):852–7.
46. Scott IA, Hilmer SN, Reeve E, Potter K, Le Couteur D, Rigby D, Gnjidic D, Del Mar CB, Roughead EE, Page A, et al. Reducing inappropriate polypharmacy: the process of deprescribing. JAMA Intern Med. 2015;175(5):827–34.
47. Tomichek JE, Stollings JL, Pandharipande PP, Chandrasekhar R, Ely EW, Girard TD. Antipsychotic prescribing patterns during and after critical illness: a prospective cohort study. Crit Care. 2016;20(1):378.
48. Kram BL, Kram SJ, Brooks KR. Implications of atypical antipsychotic prescribing in the intensive care unit. J Crit Care. 2015;30(4):814–8.
49. Jasiak KD, Middleton EA, Camamo JM, Erstad BL, Snyder LS, Huckleberry YC. Evaluation of discontinuation of atypical antipsychotics prescribed for ICU delirium. J Pharm Pract. 2013;26(3):253–6.

50. Flurie RW, Gonzales JP, Tata AL, Millstein LS, Gulati M. Hospital delirium treatment: continuation of antipsychotic therapy from the intensive care unit to discharge. Am J Health-Syst Pharm Off J Am Soc Health-Syst Pharm. 2015;72(23 Suppl 3):S133–9.
51. Rowe AS, Hamilton LA, Curtis RA, Davis CR, Smith LN, Peek GK, Reynolds VW. Risk factors for discharge on a new antipsychotic medication after admission to an intensive care unit. J Crit Care. 2015;30(6):1283–6.
52. Glassman AH, Bigger JT. Antipsychotic drugs: prolonged QTc interval, torsade de pointes, and sudden death. Am J Psychiatry. 2001;158:1774–84.
53. Gill SS, Bronskill SE, Normand SLT, Anderson GM, Sykora K, Lam K, Bell CM, Lee PE, Fischer HD, Herrmann N, et al. Antipsychotic drug use and mortality in older adults with dementia. Ann Intern Med. 2007;146(11):775–86.
54. Tasaka CL, Burg C, VanOsdol SJ, Bekeart L, Anglemyer A, Tsourounis C, Rennke S. An interprofessional approach to reducing the overutilization of stress ulcer prophylaxis in adult medical and surgical intensive care units. Ann Pharmacother. 2014;48(4):462–9.
55. Murphy CE, Stevens AM, Ferrentino N, Crookes BA, Hebert JC, Freiburg CB, Rebuck JA. Frequency of inappropriate continuation of acid suppressive therapy after discharge in patients who began therapy in the surgical intensive care unit. Pharmacotherapy. 2008;28(8):968–76.
56. Pavlov A, Muravyev R, Amoateng-Adjepong Y, Manthous CA. Inappropriate discharge on bronchodilators and acid-blocking medications after ICU admission: importance of medication reconciliation. Respir Care. 2014;59(10):1524–9.
57. Shin S. Evaluation of costs accrued through inadvertent continuation of hospital-initiated proton pump inhibitor therapy for stress ulcer prophylaxis beyond hospital discharge: a retrospective chart review. Ther Clin Risk Manag. 2015;11:649–57.
58. Gomm W, von Holt K, Thome F, Broich K, Maier W, Fink A, Doblhammer G, Haenisch B. Association of proton pump inhibitors with risk of dementia: a pharmacoepidemiological claims data analysis. JAMA Neurol. 2016;73(4):410–6.
59. Lazarus B, Chen Y, Wilson FP, Sang Y, Chang AR, Coresh J, Grams ME. Proton pump inhibitor use and the risk of chronic kidney disease. JAMA Intern Med. 2016;176(2):238–46.
60. Miano TA, Reichert MG, Houle TT, MacGregor DA, Kincaid EH, Bowton DL. Nosocomial pneumonia risk and stress ulcer prophylaxis: a comparison of pantoprazole vs ranitidine in cardiothoracic surgery patients. Chest. 2009;136(2):440–7.
61. Khalili H, Huang ES, Jacobson BC, Camargo CA Jr, Feskanich D, Chan AT. Use of proton pump inhibitors and risk of hip fracture in relation to dietary and lifestyle factors: a prospective cohort study. BMJ. 2012;344:e372.
62. Barletta JF, Sclar DA. Proton pump inhibitors increase the risk for hospital-acquired Clostridium difficile infection in critically ill patients. Crit Care. 2014;18(6):714.
63. Kouladjian L, Gnjidic D, Reeve E, Chen TF, Hilmer SN. Health care practitioners' perspectives on deprescribing anticholinergic and sedative medications in older adults. Ann Pharmacother. 2016;50(8):625–36.
64. Morandi A, Vasilevskis EE, Pandharipand PP, Girard TD, Solberg LM, Neal EB, Koestner T, Torres RE, Thompson JL, Shintani AK, et al. Inappropriate medications in elderly ICU survivors: where to intervene? Arch Intern Med. 2011;**171**:**1032**–4.
65. Bell CM, Brener SS, Gunraj N, Huo C, Bierman AS, Scales DC, Bajcar J, Zwarenstein M, Urbach DR. Association of ICU or hospital admission with unintentional discontinuation of medications for chronic diseases. JAMA. 2011;306(8):840–7.
66. Forster AJ, Clark HD, Menard A, Dupuis N, Chernish R, Chandok N. Adverse events among medical patients after discharge from hospital (vol 170, pg 345, 2004). Can Med Assoc J. 2004;170(3):345–9.
67. Forster AJ, Murff HJ, Peterson JF, Gandhi TK, Bates DW. The incidence and severity of adverse events affecting patients after discharge from the hospital. Ann Intern Med. 2003;138(3):161–7.
68. Pirmohamed M, James S, Meakin S, Green C. Adverse drug reactions as cause of admission to hospital – admissions to ear, nose, and throat departments were not mentioned – reply. Br Med J. 2004;329(7463):460–460.

69. Jack BW, Chetty VK, Anthony D, Greenwald JL, Sanchez GM, Johnson AE, Forsythe SR, O'Donnell JK, Paasche-Orlow MK, Manasseh C, et al. A reengineered hospital discharge program to decrease rehospitalization: a randomized trial. Ann Intern Med. 2009;150(3):178–87.
70. Jencks SF, Williams MV, Coleman EA. Rehospitalizations among patients in the medicare fee-for-service program REPLY. N Engl J Med. 2009;361(3):312.
71. Friedman B, Basu J. The rate and cost of hospital readmissions for preventable conditions. Med Care Res Rev. 2004;61(2):225–40.
72. Raschetti R, Morgutti M, Menniti-Ippolito F, Belisari A, Rossignoli A, Longhini P, La Guidara C. Suspected adverse drug events requiring emergency department visits or hospital admissions. Eur J Clin Pharmacol. 1999;54(12):959–63.
73. Kripalani S, Jackson AT, Schnipper JL, Coleman EA. Promoting effective transitions of care at hospital discharge: a review of key issues for hospitalists. J Hosp Med. 2007;2(5):314–23.
74. Kerzman H, Baron-Epel O, Toren O. What do discharged patients know about their medication? Patient Educ Couns. 2005;56(3):276–82.
75. Chinthammit C, Armstrong EP, Warholak TL. A cost-effectiveness evaluation of hospital discharge counseling by pharmacists. J Pharm Pract. 2012;25(2):201–8.
76. Sarangarm P, London MS, Snowden SS, Dilworth TJ, Koselke LR, Sanchez CO, D'Angio R, Ray G. Impact of pharmacist discharge medication therapy counseling and disease state education: pharmacist assisting at routine medical discharge (project PhARMD). Am J Med Qual. 2013;28(4):292–300.
77. Al-Rashed SA, Wright DJ, Roebuck N, Sunter W, Chrystyn H. The value of inpatient pharmaceutical counselling to elderly patients prior to discharge. Br J Clin Pharmacol. 2002;54(6):657–64.
78. Kilcup M, Schultz D, Carlson J, Wilson B. Postdischarge pharmacist medication reconciliation: impact on readmission rates and financial savings. J Am Pharm Assoc. 2013;53(1):78–84.
79. Walker PC, Bernstein SJ, Jones JN, Piersma J, Kim HW, Regal RE, Kuhn L, Flanders SA. Impact of a pharmacist-facilitated hospital discharge program: a quasi-experimental study. Arch Intern Med. 2009;169(21):2003–10.
80. Holland R, Desborough J, Goodyer L, Hall S, Wright D, Loke YK. Does pharmacist-led medication review help to reduce hospital admissions and deaths in older people? A systematic review and meta-analysis. Br J Clin Pharmacol. 2008;65(3):303–16.
81. Wooldridge K, Schnipper JL, Goggins K, Dittus RS, Kripalani S. Refractory primary medication nonadherence: prevalence and predictors after pharmacist counseling at hospital discharge. J Hosp Med. 2016;11(1):48–51.
82. El-Rachidi S, LaRochelle JM, Morgan JA. Pharmacists and pediatric medication adherence: bridging the gap. Hosp Pharm. 2017;52(2):124–31.
83. Bailey AM, Wermeling DP. Naloxone for opioid overdose prevention: pharmacists' role in community-based practice settings. Ann Pharmacother. 2014;48(5):601–6.

Chapter 23
Respiratory Therapy and Family Engagement in the Intensive Care Unit

Deborah Linehan and Giora Netzer

Respiratory therapists (RTs) are an integral part of the modern intensive care unit (ICU) team. In the ICU, patients and families may meet a respiratory therapist due to an extreme situation, such as respiratory failure and/or code blue. The RT is part of the team that rushes in to establish an airway, while the family may watch in shock as we sedate, intubate, and ventilate their loved one. In the aftermath, their loved one may have their hands tied down, a tube taped to their face, and a strange machine making all kinds of unknown noises helping them breathe. Through the days that follow, families must deal with understanding new terms, make complex decisions, and deal with the emotional roller coaster that accompanies this situation.

While the reasons for intubation differ for each patient, recurrent themes emerge across the population of patients with respiratory failure. They are (1) respiratory distress/failure, (2) intubation, (3) management of crisis on ventilator, (4) ventilator liberation, (5) tracheostomy, (6) extubation, (7) transitioning out of the ICU, and (8) end of life. Each of these represents an opportunity for respiratory therapists to engage the family. In this chapter, we will examine each of these possible intervention points to identify current practice. We will then identify practical ways bedside respiratory therapists can incorporate facilitated sensemaking interventions that "help families make sense of the situation and help give meaning to the caregiver role" [1]. Finally, we will discuss barriers to practice change.

In Table 23.1, we present an overview of possible respiratory intervention points and the emotions families may experience at those times. In many instances, the respiratory therapist encounters the patient when respiratory failure occurs and the

---

D. Linehan (✉)
University of Maryland Medical Center, Department of Respiratory Care,
Baltimore, MD, USA
e-mail: deborahlinehan@umm.edu

G. Netzer
Division of Pulmonary and Critical Care Medicine, University of Maryland
School of Medicine, Baltimore, MD, USA

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_23

Table 23.1 Possible points of intervention

Patient event	Family response
Respiratory distress/failure	Shock Disbelief Helpless
Intubation/ventilation	Fear Confusion Helpless
Crisis ventilator management	Fear to touch patient or be in the way Fear of vent alarms Confusion
Weaning	Hopeful Frustration when failing
Extubation	Excitement/fear Frustration and despair when failed
Tracheostomy	Fear
Transitioning out of the ICU	Excitement/fear Frustration due to level of care change
End of life	Overwhelmed Guilt Conflict

patient needs to be intubated. Due to the urgent nature to treat the patient, the RT does not get a chance to introduce themselves to the family until afterward. We must recognize that watching their loved one in respiratory failure, and seeing them intubated, is a traumatic event for the family. How RTs approach the family can affect their response.

Crisis Management

Let us begin our discussion with how to implement facilitated sensemaking during crisis management of the disease process on the ventilator. Most commonly, a typical first interaction with the patient's family may sound like the following: "Hi, I'm (insert name), your respiratory therapist. I am going to check the ventilator, suction, and listen to the patient," and then we proceed to do our job. We may even ask the family if they have any questions, but often, they offer none. We leave the room having done our job, but we have done nothing to help the family make sense of what is happening.

We must remember that everything in the ICU that is routine to us is unknown to most family members. To gain insight into how we can help these families, let's take a step back and evaluate this interaction from the family's perspective. The family walked into the room to see their loved one strapped to the bed with a plastic tube sticking out of their mouth and a strange machine making all kinds of scary noises. A stranger then walks in, saying he or she is a respiratory therapist—whatever that

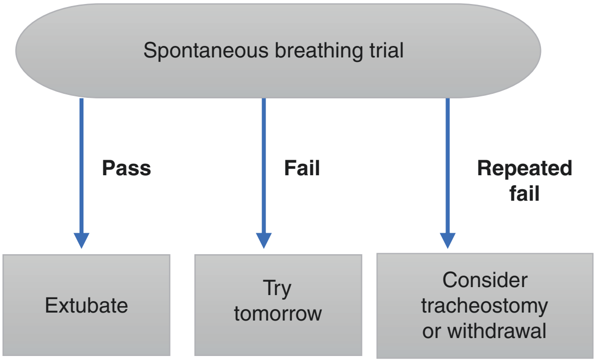


Fig. 23.1 Ventilator liberation decision tree

is—then messes with the breathing machine, and shoves something down the plastic tube and makes their loved one choke violently. It should be no wonder that they have no questions. They are overwhelmed trying to process the strange reality they are in.

Literature shows that it does not take long for families to adapt to this reality. In a 2009 qualitative study that surveyed family members of critically ill ICU patients, a theme that authors noted was that the "initial shock" about the ventilator "evolved into adaptation" over the course of several days [2]. Roy's adaptation model describes that people "adapt to the (health) situation using coping mechanisms that result in either adaptive or maladaptive coping" and how they adapt affects future "positive or negative outcomes and consequences" [3]. This means that the family interactions we have in the first 24 h are vital in setting the tone for our families as they adjust to their new reality. If we can discover ways to help the family adapt in a positive way, we may be able to affect positive outcomes.

So how can RTs change the way they approach the family in order to help them through their loved one's crisis? We can do this by examining each of the possible intervention points previously discussed and strategically changing what these interactions look like. Figure 23.1 provides a summary of these points and the possible changes to RT practice that we will discuss in the remainder of this chapter.

During crisis management, one essential concept of mechanical ventilation that should be made clear from the beginning is that mechanical ventilation constitutes life support. This should be reinforced by the entire team to ensure consistency of message. Unfortunately, many families do not consider the ventilator life support, even though the machine is providing essential support [2]. If families begin the journey with this misconception, potential discussions regarding discontinuing the ventilator during end of life may be more difficult.

One approach by which RTs can help families make sense of their new reality is by providing basic education about the respiratory interventions they are seeing. This can be a purposeful conversation with the family in which we introduce ourselves, describe the RT role, and provide them with educational materials to help the family understand "the environmental cues" [3] that pertain to the ventilator and other interventions. For the past two decades, pediatric practice has led in this approach. In pediatrics, many facilities offer standardized training to families of ventilator- and tracheostomy-dependent patients. This training is in the form of handouts, videos, simulations, and skills demonstrations [4, 5] that follow a sequential path that allows a patient to be discharged home with family caregivers. Studies have demonstrated that standardization helps decrease length of stay and increase the family's comfort level caring for their child [4, 5].

To bring this practice to our adult patients, we will need easy-to-read educational materials, to both guide our discussions and provide as a resource for later review. When developing written information, consultation with the interdisciplinary ICU team will ensure a consistent message and consistent training from all parties. Consistency in messages is important to families [6] and is necessary for trust to occur between the team and the family. To achieve this, Yale New Haven Children's Hospital created a committee consisting of multidiscipline practitioners and previous family members to evaluate and revise the training program they had in their pediatric respiratory unit. Working together, they standardized educational materials and teaching, created checklists and critical thinking scenarios, and developed a timeline for training. The result was a decrease in hospital stay and greater patient/family satisfaction [7].

Initial educational materials should include information about the endotracheal (ET) tube. This information should include a simple diagram of the anatomy which we can use as a visual aid to help us clearly explain the suctioning procedure. The RT can demonstrate that with the tube in place, secretions are unable to be expectorated, necessitating the use of a suction catheter to get them out. Suctioning is very upsetting to families. Some families are so upset by the cough reaction that they must leave the room when their loved one is suctioned. Explaining the procedure and the patient response beforehand allows the family to understand and accept it.

Another issue that is upsetting to both patients and their families is the loss of communication due to an artificial airway. Using a diagram showing the ET tube and its relationship to anatomy may also be useful in explaining why that their loved one will not be able to talk. Families should be made aware of this, as this is upsetting and may cause anxiety for the patient when he/she awakens from sedation. This presents an opportunity for the RT to give the family a purpose in their new role. From the outset of mechanical ventilation, RTs can help the family understand how they can help with communication in several ways. First, it is important to help the family understand that they can talk to and touch their loved ones. We must specifically address this issue because families have reported being afraid to touch the patient due to the ventilator [8]. RTs can also familiarize the family with the communication resources that are available in the ICU. These resources include low-technology interventios such as clipboards and patient boards and high technology interventions that use software and computerized apps [9, 10]. A 2017 review of the effectiveness of these communication strategies found that their use corresponds to patient satisfaction with communication in the ICU [9].

RTs should partner with nursing and speech therapy to learn about the different types of communication strategies that are available. This collaboration is important because each discipline has different skills and knowledge pertaining to the communication aids that are available. Another benefit of working together is that the understanding of different roles encourages earlier referrals to the qualified practitioner. Multidisciplinary teamwork is important when developing training materials about communication aids. One facility's multidisciplinary team developed training resources and a "communication assessment tool for nonverbal patients" [10] that is filled out and displayed at bedside to ensure effective and consistent provider communication. Families will work with the team to individualize the information in this bedside tool.

If mechanical ventilation becomes prolonged and the patient progresses to a tracheostomy, we can partner with speech therapy to evaluate if the patient is a candidate for a speaking valve. Speaking valves are commonly used for tracheostomy patients who are not on the ventilator, but speaking valve use during mechanical ventilation has been shown to be a safe way to provide early voice return in several studies [11–13]. Other options we can use for speech on the ventilator are PEEP speech and special "talking" tracheostomy tubes [14–16].

RTs should also provide education to the family about ventilator basics. A simple explanation of how the ventilator "breathes" helps the family adapt to this new normal. We must be careful to explain that there are alarms on the vent that notify us of a change in the patient and that many of these alarms correct themselves, but we will be available for any issues that arise. Educational handouts may include information about ventilator modes and alarms and a list with definitions of common words that they may hear regarding the ventilator. Many hospitals have created educational documents about ventilators [17, 18] for their patients. RTs and families can work together as part of the team that develops these materials.

Family Engagement in Research

In our discussion thus far, we have discussed the standardization of messages and educational materials for the family. One way that RTs can give the family a sense of purpose in respiratory issues is to engage families of former ICU patients in the process of creating educational materials and engagement strategies. Recent studies have demonstrated that former patients and families want to provide input into how to make the experience better. Their participation has been shown to provide valuable insight into providing meaningful care [19, 20]. In fact, many of the interventions they suggest are described in this chapter [20].

Ventilator Liberation

Another opportunity for RTs to examine their practice is when spontaneous breathing trials begin. At this point in the process, families have adjusted to the reality of their loved one being on a ventilator and now need to understand that a spontaneous breathing trial is an important step in ventilator liberation. This is another opportunity in which written educational materials would be useful to help the family make sense of the situation and ensure consistency of the message between the providers. The RT should make every effort to meet with the family to discuss these educational materials before the first spontaneous breathing trial. Written education at this point should include a clear definition of what a spontaneous breathing trial is, how ventilator support is changed during the trial, and what we are looking at to decide if the test is passed or failed. Again this material must be in layman's terms.

Spontaneous breathing trials are an ideal opportunity to engage the family members. It has been observed that families in the ICU environment often engage in surveillance activities such as "observation and interpretation of the patient's physiological or psychological status or numerical displays" [21]. To give the family meaning in the caregiver role, we can use that tendency to help the patient's response to weaning. We can encourage the family member to hold their loved one's hand and talk to them if they look upset or anxious. This could be helpful, as if the patient gets anxious and the family members know how to distract them, he or she may be more likely to have a successful weaning trial.

Teaching families what to do if the patient is anxious during a breathing trial is an example of how the family member can be a coach. Happ et al. observed family/patient/clinician interactions in a 20-bed MICU. Clinicians stated that "family presence was either: calming and helpful, or a hinderance" [21]. What made the difference was how effective the family was at remaining calm, coaching the patient through anxiety, and gently being there for the patient. One major barrier for the RT to enlist the family to help with anxiety is the observation that some families hinder breathing trials when they are overly anxious, hovering, or their overall demeanor upsets the patient and makes them more anxious [21]. We must consider that perhaps this anxiety on the part of the family is a manifestation of the maladaptive coping strategies that they have developed to help them deal with the patient being on the ventilator. If that concept is true, then it is possible that through the process of facilitated sensemaking, we can help to modify the family's response in the beginning so that they positively adapt and perhaps in turn these families would be more effective at helping their loved one come off the ventilator.

Another simple intervention we can use to engage the family is by asking questions about the patient so we can use the family's knowledge to help the patient through the spontaneous breathing trial. A questionnaire could include the following: Is the patient an anxious person normally? If so we may need to use distraction techniques. Does the patient like to set and reach goals? Do they enjoy music and what kind? Using this survey and what we learn about the patient can help us to partner with the family to come up with a plan of how best to use talk, touch, and maybe music to support the patient.

Music therapy is easy to implement and has shown promise for dealing with anxiety during attempts at ventilator liberation. Hunter et al. used music therapy three times a week with 61 mechanical ventilator patients during spontaneous breathing trials. Patients declared they were less anxious and physiologic signs of anxiety and heart and respiratory rate were lower when the therapy was finished. Forty-one patients were able to be weaned with the help of music [22]. Music is a

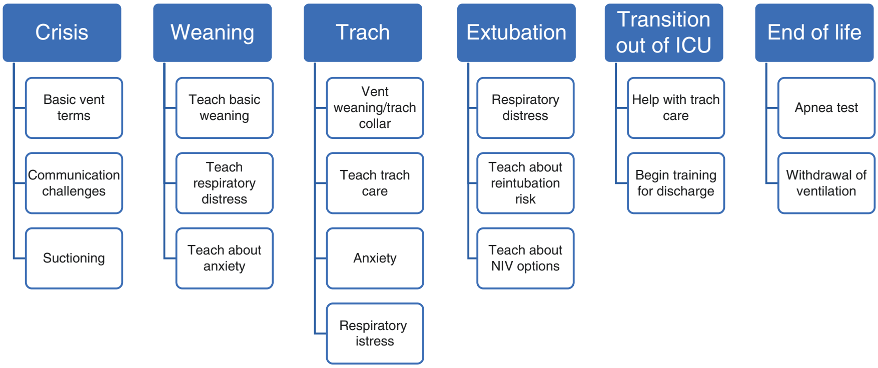


Fig. 23.2 Respiratory interventions at different stages

strategy that RTs can use at the bedside. RTs can encourage the family members to play favorite music for their loved ones during breathing trials, or RTs can advocate for music therapy to be ordered for the patient during weaning trials.

Before beginning spontaneous breathing trials, it is important to educate the family about the overall plan we will follow to help the patient come off the ventilator and what the plan is if they cannot. A simple diagram such as in Fig. 23.2 could be used to represent the plan whether the patient passes or fails the spontaneous breathing trial. Discussing the possibilities of failure, especially repeated failure that requires tracheostomy, is important. Mentioning tracheostomy or withdrawal of life support at this point allows for the family to acknowledge these possibilities, presaging future discussions regarding the patient preferences regarding these procedures. This diagram could be developed into a decision aid. A decision aid is "a means of helping people make informed choices about healthcare that takes into account their personal values and preferences" [23]. This decision aid would be introduced at the provider level and would give the family a resource to look at the options and evaluate them in light of their overall goals of care. The use of a decision aid has been shown to "improve decision making quality and less resource utilization" [24] in the setting of prolonged mechanical ventilation. As RTs we can be involved in the creation of this decision aid.

Extubation

Extubation is a time of great emotion for the family. They are hopeful that their family member is coming off the ventilator, and it can be very scary and disheartening to them when the patient must be reintubated. In current practice, I am sure that the patient's family is briefed on the possible outcomes of extubation, but because they have no training, they are more like passive observers and feel helpless in the process.

RTs can explain the extubation procedure to the families and let them know that the patient’s throat may be sore. We can also let them know that we will be encouraging the patient to cough, take deep breaths, and get on the chair, because it is important to keep their lungs open, and employ the family member in their role as coach to encourage the same behavior. Care should be taken to help the family understand the types of noninvasive support options that may be used post-extubation, what they are, how they work, and when each would be implemented. This information should be given in both verbal and written formats.

Taking time to coach the family before extubation helps them achieve a sense of control about what happens post-extubation. If things go well, the family knows what to do. If things do not, the family—now grasping what they were taught previously—may be better able to understand both the respiratory distress and the potential need to reintubate. If the patient does need reintubation, respiratory therapist can sit down with the family to discuss the next step in the plan, including whether factors exist that are more quickly remediable, like stridor, and the ability to try again. The family’s input about possible prior liberation attempts can be elicited, and whether they want to redirect care or if it is time to discuss tracheostomy.

Tracheostomy

As discussed above, RTs can anticipate future conversations regarding tracheostomy. During this time the RT’s main strategy would again be education. Before a tracheostomy is performed, the goal of education would be to help the family understand how care will differ with a tracheostomy tube. A diagram of tracheostomy anatomy can be presented and compared to the diagram of the endotracheal tube so that the family can see the differences. It is important to educate the family about how the ventilator liberation process is different when the patient has a tracheostomy. They will need to understand trach collar trials and how the tracheostomy makes it easier to remove and replace ventilator support when needed. We must ensure we teach the family that the trach is not permanent and can be removed if their loved one recovers.

Once the patient has undergone tracheostomy, RTs can give the family a sense of purpose in their new role by teaching them how to do basic tracheostomy care. In the pediatric world, families are encouraged to help from the beginning. In addition to hands-on at the bedside, many facilities also have a training program that targets tracheostomy education using a combination of handouts, simulators, manikins, and videos [4, 5, 7, 25]. Working alongside the RT and nurses, families can become adept at changing trach ties, cleaning around the stoma, and performing tracheostomy changes. They can also be taught emergency management and suctioning. This teaching may allow families to transition from fear to confidence.

This lesson applies to the adult patient population as well. One head and neck cancer center in Florida noticed increased hospitalization of their neck cancer patients and implemented a pilot study called T-CARES (Tracheostomy Care

Anxiety Relief Through Education and Support) to complement bedside teaching. T-CARES consisted of a standardized 1-h class for family that combines video, hands-on with a manikin, and RT and RN instruction. Training covered the basics of tracheostomy care, suctioning, and emergency response. The 11 participants reported decreased anxiety and increased proficiency in the tasks taught [26]. Standardized training such as this is an opportunity for the RT. The benefit of teaching the family gives them time to get comfortable with the process and gives them a sense of control. Beginning to teach care for a tracheostomy during ICU stay gives us time to correct technique and helps the patient as they transition to the next level of care.

Transitioning Out of the ICU

When the patient is stable, either on or off the ventilator, he or she will be moved to a lower level of care. This may be in the form of a hospital step-down unit, a skilled nursing facility, a long-term acute care hospital (LTACH), or home. Major challenges will be faced by the family of adult patients with chronic respiratory failure as they transition to the next level of care. One of these is that the patient will have a noticeable lower level of monitoring and care. This may be stressful for families as they worry about their loved one receiving proper care. If RTs initiate tracheostomy care teaching during the ICU stay, this may help the family through the transition.

Another challenge for the family is finding an appropriate and available rehabilitation setting that will accept the patient's healthcare payor. This may be a real shock to families. Unlike in pediatric practice, where tracheostomy is understood to be a long-term commitment necessitating planning toward home care complete with guidelines [27, 28] and training targeting their needs [4, 7, 25, 29], adult care lacks this focus. The families of adult patients may be unprepared to bring their loved one home if insurance denies coverage, further limiting their options. Denial of coverage was noted by practitioners in Houston in 2010. They noticed difficulty in discharge planning when the "chance for weaning from the ventilator became smaller or financial constraints prevented the patient from progressing to a LTAC" [30]. To better support the patients and their families, this facility created a multidisciplinary team to identify barriers to the patient going home and developed a home trach/vent discharge planning algorithm [30] to guide the care of these patients. RTs were a part of the planning committee and provided standardized education to patients and their families.

End of Life

While the end of life is difficult regardless, for families of mechanically ventilated patients, additional burdens are created. The decision to remove life support often makes the family feel like they are, in essence, killing their loved one: bringing anguish and guilt that can persist long after the ICU experience [31]. RTs can help the families through this time in several ways. The first thing is to reinforce the message that the ventilator is life support that remains consistent throughout the disease process and that the removal of ventilator support is the removal of an artificial measure, allowing natural death.

In the case of suspected brain death, education by RTs during this time can also include information about apnea testing. Apnea testing is a test that includes removing the patient from the ventilator and watching for evidence of spontaneous breathing. The apnea test tests the neurological reflex to breathe and is considered a brain death test [32]. Encouraging the family to be present for the apnea test may help the family to accept the often-confusing concept of brain death more easily. Evidence of breathing, even if only the set rate of the ventilator, can be interpreted by the family as life. One family struggling with this issue found that when they saw for themselves their loved one is not breathing, it helped them realize it was time to say goodbye [33].

At the end of life, the most important thing a RT can do is care. Traditionally, nurses are considered the key providers for support of families at the bedside during the end of life. However, due to their presence at the bedside of dying patients, RTs find themselves in this role as well. For example, RTs are often drawn into end-of-life conversations with the family. These conversations happen when the patient and/or family is ready and finds they trust the person they are with [34]. These conversations can be incidental or deliberate. Incidental conversations occur when the patient/family begins to share personal thoughts. This could be "listening to patients [families] share past regrets so they can move on" [35] or asking the family to share a good memory about a loved one. Though these moments seem small, these interactions are meaningful to families and can help them through the acknowledgment process of the impending death.

RTs can also initiate deliberate end-of-life conversations. Using open-ended questions such as "What do you understand about the status of the illness?" [36] has been shown to be an effective conversation starter. Listening to how the family answers gives clues as to where the family is in the acknowledgment process and helps identify if they have any misunderstandings. The insight gained from these types of conversations can be shared with the rest of the healthcare team, to clear any misconceptions and communicate more effectively with the family.

Another mechanism by which RTs can help support families is to be present at family meetings. Currently, RTs are not usually included, though they desire to be [37–39], especially when discussing the removal of life support. The RT's presence would be beneficial for the family because often the RT has developed a supportive relationship to the family and the RT's presence at the meeting helps them. Also, because the RT is the team member that removes ventilatory support, being at the meeting allows him or her to use both technical knowledge and knowledge of the patient to contribute to the plan for withdrawal of support.

Conclusion

As bedside clinicians in the ICU, respiratory therapists often build relationships with the families of their mechanically ventilated patients, and this places them in a prime position to help the family find meaning and make sense of their complicated new role. RTs develop their practice to better meet the family's needs. This may include collaborating with families and other disciplines to develop educational materials, training programs, and decision aids. Therapists can also coach the family to touch and talk to the patient and teach them to be a coach during breathing trials. The RT plays a key role in helping families adapt to both the physical and emotional challenges of mechanical ventilation, and we should work alongside both the families and ICU team to provide the best engagement with the family.

Acknowledgment (DL) Dedicated in loving memory to my little brother Tim LaBarge. Your giving and caring nature inspired many. I miss you dearly.

References

1. Davidson JE. Facilitated sensemaking: a strategy and new middle-range theory to support families of intensive care unit patients. Crit Care Nurse. 2010;30(6):28.
2. Sinuff TMDP, et al. "Living with dying": the evolution of family members' experience of mechanical ventilation. Crit Care Med. 2009;37(1):154–8.
3. Davidson JE, Zisook S. Implementing family-centered care through facilitated sensemaking. AACN Adv Crit Care. 2017;28(2):200.
4. Tofil NM, et al. Ventilator caregiver education through the use of high-fidelity pediatric simulators. Clin Pediatr. 2013;52(11):1038–43.
5. Thrasher J, et al. Hospital to home: a quality improvement initiative to implement high-fidelity simulation training for caregivers of children requiring long-term mechanical ventilation. J Pediatr Nurs. 2018;38:114–21.
6. Wetzig K, Mitchell M. The needs of families of ICU trauma patients: an integrative review. Intensive Crit Care Nurs. 2017;41:63–70.
7. Szondy MV, et al. Standardizing family education in a pediatric respiratory care unit. J Pediatr Nurs. 2014;29(3):272–8.
8. Skoog M, In Our Unit. The impact of family engagement on anxiety levels in a cardiothoracic intensive care unit. Crit Care Nurse. 2016;36(2):84–9.
9. Carruthers H, Astin F, Munro W. Which alternative communication methods are effective for voiceless patients in intensive care units? A systematic review. Intensive Crit Care Nurs. 2017;42:88–96.
10. Grossbach I, Stranberg S, Chlan L. Promoting effective communication for patients receiving mechanical ventilation. Crit Care Nurse. 2011;31(3):46–61.
11. Freeman-Sanderson AL, et al. Return of voice for ventilated tracheostomy patients in ICU: a randomized controlled trial of early-targeted intervention. Crit Care Med. 2016;44(6):1075–81.
12. Sutt A-L, et al. The use of tracheostomy speaking valves in mechanically ventilated patients results in improved communication and does not prolong ventilation time in cardiothoracic intensive care unit patients. J Crit Care. 2015;30(3):491–4.
13. Sutt A-L, Fraser JF. Speaking valves as part of standard care with tracheostomized mechanically ventilated patients in intensive care unit. J Crit Care. 2015;30(5):1119–20.

14. McGrath B, et al. Above cuff vocalisation: a novel technique for communication in the ventilator-dependent tracheostomy patient. J Intensive Care Soc. 2016;17(1):19–26.
15. ten Hoorn S, et al. Communicating with conscious and mechanically ventilated critically ill patients: a systematic review. (Report). Crit Care. 2016;20(1):333.
16. Prigent H, et al. Speech effects of a speaking valve versus external PEEP in tracheostomized ventilator-dependent neuromuscular patients. Intensive Care Med. 2010;36(10):1681–7.
17. Colorado, C.h.o. Ventilator care program: caregiver education. Children's Hospital of Colorado; 2016.
18. UPMC. When someone you love is on a ventilator. University of Pittsburgh Medical Center; 2011.
19. Burns KEA, Devlin JW, Hill NS. Patient and family engagement in designing and implementing a weaning trial: a novel research paradigm in critical care. Chest. 2017;152(4):707–11.
20. Gill M, et al. Patient and family member-led research in the intensive care unit: a novel approach to patient-centered research. PLoS One. 2016;11(8):e0160947.
21. Happ MB, et al. Family presence and surveillance during weaning from prolonged mechanical ventilation. Heart Lung J Acute Crit Care. 2007;36(1):47–57.
22. Hunter BC, et al. Music therapy as an adjunctive treatment in the management of stress for patients being weaned from mechanical ventilation. J Music Ther. 2010;47(3):198–219.
23. From Drug and Therapeutics Bulletin. An introduction to patient decision aids. BMJ Br Med J. 2013;347(7918):27–9.
24. Cox CE, et al. Development and pilot testing of a decision aid for surrogates of patients with prolonged mechanical ventilation. Crit Care Med. 2012;40(8):2327.
25. Tearl DK, Hertzog JH. Home discharge of technology-dependent children: evaluation of a respiratory-therapist driven family education program. (Clinical report). Respir Care. 2007;52(2):171.
26. Loerzel VW, et al. Developing the tracheostomy care anxiety relief through education and support (T-CARES) program. Clin J Oncol Nurs. 2014;18(5):522–7.
27. Amin R, et al. Caregiver knowledge and skills to safely care for pediatric tracheostomy ventilation at home. Pediatr Pulmonol. 2017;52(12):1610–5.
28. Sterni LM, et al. An official American Thoracic Society clinical practice guideline: pediatric chronic home invasive ventilation. Am J Respir Crit Care Med. 2016;193(8):e16–35.
29. Fiske E. Effective strategies to prepare infants and families for home tracheostomy care. Adv Neonatal Care. 2004;4(1):42–53.
30. Warren ML, et al. An interdisciplinary approach to transitioning ventilator-dependent patients to home. J Nurs Care Qual. 2004;19(1):67–73.
31. Russ A, Kaufman S. Family perceptions of prognosis, silence, and the "suddenness" of death. Int J Compar Cross-Cult Res. 2005;29(1):103–23.
32. Scott JB, et al. Apnea testing during brain death assessment: a review of clinical practice and published literature. Respir Care. 2013;58(3):532.
33. Freeman TB. Death perception: how temporary ventilator disconnection helped my family accept brain death and donate organs. Narrat Inq Bioeth. 2015;5(1):9–12.
34. Walczak A, et al. Patient perspectives regarding communication about prognosis and end-of-life issues: how can it be optimised? Patient Educ Couns. 2013;90(3):307–14.
35. Newson P. The elephant in the room: communication at end of life. Nurs Resident Care. 2012;14(2):96–8.
36. Anderson WG, Kools S, Lyndon A. Dancing around death:hospitalist–patient communication about serious illness. Qual Health Res. 2013;23(1):3–13.
37. Grandhige AP, et al. Respiratory therapists' experiences and attitudes regarding terminal extubations and end-of-life care. Respir Care. 2016;61(7):891–6.
38. Willms DC, Brewer JA. Survey of respiratory therapists' attitudes and concerns regarding terminal extubation. Respir Care. 2005;50(8):1046.
39. Rocker GM, et al. Canadian nurses' and respiratory therapists' perspectives on withdrawal of life support in the intensive care unit. J Crit Care. 2005;20(1):59–65.

Chapter 24
The Role of the ICU Social Worker in Supporting Families

John G. Cagle and Morgan Bunting

Introduction

When an intensive care unit (ICU) patient is incapacitated or otherwise lacks capacity to communicate their choices, the responsibility to make health-care decisions often falls on the shoulders of close family members. These natural surrogates, however, are often dealing with intense emotions, unrealistic expectations, and a compromised ability to process complex information. This commonly observed constellation of symptoms is known as the family ICU syndrome (FICUS). As Netzer and Sullivan [27] describe it, FICUS is characterized by maladaptive reasoning, high-intensity emotions, interpersonal conflict, persistent insomnia, cognitive bias, and anticipatory grief. The syndrome is dynamic and multifaceted and typically requires an interdisciplinary approach to combat the duress families experience after critical illness. The ICU social worker, as an instrumental member of the interdisciplinary team, utilizes a biopsychosocial perspective to assess individuals within their environment and to develop effective strategies to optimize family support, coping, and decision-making. Social workers are uniquely positioned to intervene and support families during this critical period.

Within the context of FICUS, in this chapter, we (1) provide an overview of the dynamic needs of patients and families who encounter the ICU; (2) define the role of social work in the ICU within the context of an interdisciplinary team approach; and (3) discuss evidence-supported interventions that social workers can employ to address the needs of patients, family members, and team members. We also present a conceptual model emphasizing the role of social work within an interdisciplinary

---

J. G. Cagle (✉)
University of Maryland, Baltimore, School of Social Work, Baltimore, MD, USA
e-mail: jcagle@ssw.umaryland.edu

M. Bunting
School of Medicine, Division of Gerontology,
University of Maryland-Baltimore, Baltimore, MD, USA

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_24

framework to best serve families and patients in the ICU. We further discuss evidence-supported communication approaches that support families and their ability to weigh and make decisions. Special attention is given to minority populations who encounter the ICU because racial and ethnic disparities are prominent in this setting and often lead to poor patient and family outcomes. Case examples are also provided to foster critical thinking about complex encounters with families in the ICU. First, we consider the precipitating factors that bring families into the ICU setting.

Background

Annually, more than five million patients are admitted to intensive care units [35]. An admission to the ICU typically comes from one of three primary sources: acute care, emergency department, or an ICU in another hospital. The majority of patients (58%) are admitted to the ICU directly from the emergency department [35]. The source of admission has been found to be associated with patient outcomes. Patients transferred from an ICU in another hospital tend to have poorer outcomes in terms of mortality, duration of mechanical ventilation, length of stay, and ICU complications [11]. The five leading diagnoses of adult patients admitted to ICU are respiratory disease or distress, acute myocardial infarction, intracranial hemorrhage, cardiovascular accident, and severe sepsis [14, 35].

Overview of Patient and Family Needs in the ICU

Being thrust into a stressful environment can be physically, emotionally, and socially challenging for patients and families in the ICU. Patients in the ICU have a wide variety of medical, social, financial, spiritual, and cognitive needs. Contextual issues may hamper communication and create distress for both patients and families. For some patients, infection control protocols – such as isolation and the use of masks, gowns, and gloves – can make patients feel stigmatized and socially quarantined. Fictionalized portrayals of critical care interventions in popular media distort understanding about prognosis and interventions. For example, one study of fictionalized accounts of so-called heroic measures in television and film found that television programs give a misleading impression about success rate of CPR compared to the medical literature [13]. Because of exposure to the media, many patients and families may overestimate the likelihood of treatment success and underestimate the risks/costs [16]. Thus, it is imperative that patients and families are provided with an accurate understanding of risks and benefits involved. When a patient is incapacitated, decisions are often made by family or other surrogate. As such, high-intensity emotions and compromised ability to process complex information may cause duress for the family. Offering families ample visitation and space for reflection and relaxation is imperative for creating an environment conducive for discussion, emotional expressions, and informed decision-making.

Critical care is a dynamic medical environment in which families often feel emotionally exhausted, anxious, and confused about highly technical interventions and medical jargon [1]. Intervention options, including risks and benefits, are often communicated with an inaccessible medical parlance. Physician-to-family communication is regularly peppered with Latin-based terms, unfamiliar acronyms, and statistical probabilities. Terms like “intubation,” “chemical code,” or “MRSA” will likely be unfamiliar to nonmedical audiences. The use of such terms in clinical conversations with families may unnecessarily foster confusion and misunderstanding. Inaccessible communication such as this can further complicate FICUS. FICUS is complex and multifaceted and often requires an interdisciplinary approach to address duress. Within the interdisciplinary ICU team, social workers are uniquely trained to identify and address FICUS.

Determining Decision–Making Capacity

In order to maximize patient autonomy, critical care providers should be attuned to fluctuations in a patient’s ability to make informed decisions. Informed decision-making requires an ability to (1) understand burdens, risks, and benefits of a proposed treatment; (2) rationally evaluate the burdens, risks, and benefits of the proposed treatment; and (3) communicate a decision. If a person lacks any one of these three requirements, then the person does not have the capacity to make health-care decisions. A diagnosis alone does not imply incapacity; and capacity can fluctuate. Patients with mild/moderate dementia, for example, may be capable of making their own decisions until the latter stages of the disease.

Social workers assigned to critical care units should be knowledgeable about advance directives (e.g., health-care power of attorney, living will documents) and pertinent state laws for identifying the appropriate proxy decision-maker when a patient lacks capacity to make health-care decisions for themselves. Some states assign equal decision-making authority to certain categories of family relative, which can prolong and complicate pressing decisions if multiple family members of a certain category disagree about the appropriate course of treatment. For example, Maryland ranks adult children with equivalent decision-making authority. Holding advance care planning conversations and completing advance directives early on – prior to the onset of a medical crisis – can help prevent or minimize family conflicts because identifying a primary surrogate decision-maker can sidestep the problems associated with giving multiple individuals equal decision-making authority. Plus, by holding advance care planning conversations and documenting patient preferences prior to a potential ICU encounter, patient preferences are more likely to be considered and honored. Social workers are known to play a prominent role in leading and facilitating advance care planning conversations [30].

The Interdisciplinary Team Approach in the ICU

Contemporary critical care is based on the premise that optimal care involves active support from an interdisciplinary health-care team. Team members regularly include physicians, nurses, advanced practice providers, respiratory therapists, pharmacists, dieticians, chaplains, rehabilitation specialists, and social workers. As previously described, critical care providers routinely encounter patients and families with a variety of multifaceted needs, including medical, informational, emotional, spiritual, as well as pragmatic resource needs (e.g., financial and/or benefit assistance). Coordinated involvement of representatives from medicine, nursing, social work, and chaplaincy can help to efficiently and effectively identify and address these complex multidimensional needs. As Fig. 24.1 illustrates, the interdisciplinary team works together to meet the various needs of the ICU patient and his or her family. Although a strength of the interdisciplinary approach is that different disciplines contribute differing clinical perspectives and expertise to inform the management of complex illness, inconsistent messages from team members can muddle the clarity of information that families need to facilitate informed decision-making. Thus, it is vital that team members communicate frequently and openly with one another and complement each other when possible.

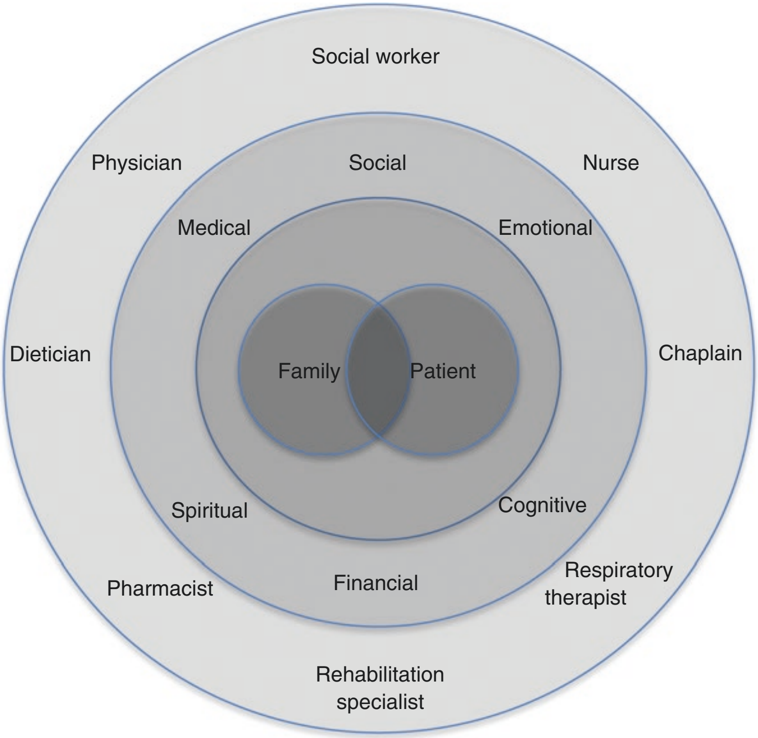


Fig. 24.1 Illustration of the interdisciplinary team working together to meet the various needs of the ICU patients and his or her family. (Adapted from Cagle and Widera [8])

The Role of the ICU Social Worker

Understanding family dynamics, psychosocial risk factors, empathetic communication approaches, and crisis response are integral components of social work education at both the master's and bachelor's level. Social workers are often equipped to evaluate, monitor, and treat complex psychosocial needs of patients and families. Social workers, for example, are the largest direct provider of mental health services in the USA. They may also have specialized training in conflict management, trauma counseling, geriatric care, or practice in medical settings. Many social workers pursue licensure after obtaining their master's degree. Although licensing standards differ greatly depending on the issuing state or country, the process typically involves an extensive period of clinical supervision and a formal clinical competency exam. Licensed clinical social workers can provide mental health counseling services, bill insurance companies directly, and – in some cases – make mental health diagnoses.

According to Hartman-Shea et al. [17], social workers in the critical care setting are recognized for their expertise as professional counselors, facilitators of communication, and resource agents (Table 24.1). However, the role of the ICU social worker can be vast and varied and will depend on the clinical setting, patient population, and team dynamics. While roles overlap substantially among ICU team members, social workers are often charged with facilitating decision-making, fostering coping skills, mediating family conflict, assisting with advance directive completion, helping families navigate the complexities of the health-care system, serving as a "translator" for medical jargon, strengthening team dynamics, and helping families process poor prognoses and end-of-life issues. In reference to this latter point, the physician is typically recognized as the initial provider of a patient's diagnosis and prognosis. Some evidence suggests that psychosocial support provided by social workers contribute to family satisfaction and reduced anxiety [24]. Chik et al. [10] found that early social work involvement and palliative care consults reduced the risk of critical care and burdensome interventions. Furthermore, conducting a thorough psychosocial assessment upon admission to the hospital provides relevant information for the ICU clinical team about how the family prefers to communicate, their current understanding of the patient's resource needs, as well as indications for ongoing social work counseling or other follow-up [26, 31].

Promoting Family Self-Care

For families exhibiting FICUS, encouraging vigilant self-care can mitigate anxiety and promote healthy coping. Self-care includes activities that facilitate physical health, direct attention to the present or future, and reinforce healthy coping strategies. While optimal self-care behaviors are unique to the person, ICU social workers can ally with families to reinforce and identify key health-promoting habits or other restorative behaviors. In stressful situations, such as a family medical crisis, it can be easy to abandon restorative routines and to slip into maladaptive patterns. When

Table 24.1 Common needs experienced by ICU patients and families and research-supported assessment instruments

Elements of the family ICU syndrome	Social work interventions	Examples
Maladaptive reasoning	Psychoeducational cognitive restructuring Future-oriented planning	Creating awareness about links between thoughts, emotions, and behaviors
Learned helplessness		
Disengagement from decision-making		
High-intensity emotions	Systematic desensitization Strength inventory Coordinate and facilitate family conferences	The process of replacing maladaptive thinking patterns with positive, reality-based beliefs Reducing psychological distress by pairing physical relaxation with progressive exposure to a stress-producing stimulus Guided review of personal resources and successful coping techniques Step-by-step processes to reduce stress and anxiety by regulating breathing or tensing and relaxing of select muscle groups
Overwhelmed cognitive processing		
Decisions inconsistent with patient values		
Sleep deprivation	Promotion of self-care behaviors Distraction/behavioral activation Fostering sense of self-efficacy and control Guided imagery	Encouraging rejuvenating activities such as walks, progressive muscle relaxation, deep breathing exercises, prayer, or meditation
Cognitive blunting		
Reduced quality of life		
Bias (cognitive, optimism, base rate, encoding)	Identification of proxy decision-maker Family education	Active diversion of one's attention away from distressing thoughts or activities
Personal and family conflict	Facilitating advanced care planning Completion of advance directives Facilitating support groups	Find, or establish, surrogate decision-maker(s) and living will Active diversion of one's attention away from distressing thoughts or activities Foster self-efficacy while tactfully confronting self-devaluation
Avoidance of decisions/conflict		
Guilt, anger		
Feeling responsible for negative outcomes		
Anticipatory grief	Crisis intervention Psychosocial assessment and counseling	Work to ensure that expectations match likely outcomes Educate family on opportunities to actively participate in care Supportive presence; encourage self-care Assist with concerns related to employment, finances, and insurance
Depression		

coping resources are exhausted, family members may resort to poor eating and/or sleeping habits and excessive substance use. Such maladaptive coping responses can be useful for managing short-term crises [36]. However, if these behaviors persist, neglecting one's own self-care needs may contribute to negative outcomes and eclipse any short-term benefits. Encouraging restorative activities such as exercise (even short walks), meditation, healthy eating, or a full night's sleep can give families a much-needed sense of routine and normalcy.

Referrals to Hospice and Palliative Care

Hospice is an interdisciplinary form of end-of-life care that focuses on patient quality of life, the management of pain and symptoms, and family support. According to the Medicare Hospice Benefit, patients are eligible if they (1) have a prognosis of 6 months or less and (2) forego disease-modifying treatments (e.g., surgery, chemotherapy, or radiation intended to cure). Hospice services can be provided in a variety of settings including at home. Hospice is associated with better outcomes than alternate forms of end-of-life care, such as dying in the ICU [6, 18]. Palliative care service is similar to hospice although a life-limiting prognosis is not required and cure-oriented interventions are typically allowed.

ICU social workers should be knowledgeable about the eligibility criteria for hospice. When potentially eligible patients are identified, team members should be informed, and, if eligibility is confirmed, then family members should be informed about hospice services and referred if appropriate. While many people are familiar with the term "hospice," few have an accurate understanding of the scope of services and philosophy of care [7]. While most Americans have heard of hospice, misunderstandings regarding its goals and patient eligibility are common. Thus, it is important that potential misperceptions about hospice are addressed and that accurate information is conveyed. Given that social workers are trained in negotiating family dynamics, empathetic communication approaches, and facilitating difficult discussions, their involvement in conversations about care transitions at the end of life may be beneficial. Critical care team members may also set up a family meeting with hospice or palliative care professionals to discuss whether a shift in care is appropriate or desired.

When intensive care becomes unlikely to benefit the patient, the shift from restorative care or stabilization to less invasive forms of end-of-life care, such as hospice or palliative care, is often rife with clinical uncertainty and conflicting opinions about the optimal course of care among family members and team members. Prognostic ambiguity, lack of a meaningful recovery, or mixed response to treatment can create distress for families and discomfort for critical care clinicians. The presence of documented preferences for care, or an identified health-care proxy, can provide some clarity for when and whether discontinuation of critical care treatment is warranted [9]. However, family conflict or fear of litigation may prompt care decisions that are inconsistent with patient preferences.

Acknowledging and Addressing Disparities in the ICU

A substantial body of literature has consistently demonstrated racial and ethnic disparities in the ICU. Disproportionately higher numbers of African-American and Hispanic patients receive aggressive critical care interventions, such as intubation and mechanical respiration, prior to death [22]. Additionally, a greater proportion of minority patients die while in the ICU [20]. These experiences are linked to lower levels of family satisfaction and greater financial burden. Thompson [32] argues that racial and ethnic disparities in health care clearly exist, and, because they are more often associated with poor outcomes, the perpetuation of such disparities is unacceptable. Some have hypothesized that such differences are the result of a cultural mistrust of the health-care system or a desire that the patient receives the full gamut of medical interventions available to them [3, 4, 19, 29]. Furthermore, minority populations and younger patients are overrepresented in the ICU. Admission to the ICU may further contribute to poor outcomes and greater costs – including out-of-pocket costs for the patient and family. Social workers can, and should, work to address these disparities. Such efforts may include comprehensive advance care planning (ideally prior to an ICU admission), educating families about the risks (including costs) and benefits of aggressive care options, informing families about hospice or other forms of palliative care if appropriate, and advocating for systemic change to improve obstacles to high-quality care. Given that the profession strongly values social justice and advocacy on behalf of vulnerable populations, social workers may be uniquely prepared to address these inequities.

Facilitating Goals of Care Discussions

ICU social workers are often charged with facilitating family conversations about treatment, relevant values, and goals of care. Widespread use of documented treatment instructions such as the Physician Orders for Life-Sustaining Treatment (POLST), for example, requires conversations about the patient's preferences and priorities. A popular clinical framework is the shared decision-making model: (1) reviewing the various decisions that need to be made; (2) exchanging information about patient values, current medical status, and treatment options; (3) working to ensure that all stakeholders comprehend the information being provided; (4) conducting a dialog about decision-making roles and responsibilities; and (5) establishing a care plan consistent with patient/family values. Shared decision-making also ensures that all relevant care preferences and decisions are documented in advance directives and honored by health-care providers. When initiating advance care planning conversations, it may be helpful for social workers to begin by inquiring about specific priorities in terms of a desire for care to preserve comfort, longevity, or functionality. Because goals and preferences change over time, such discussions should be considered part of an ongoing conversation, revisiting and revising medical directives as needed.

Conducting and Facilitating Family Meetings

Family meetings can improve communication and family satisfaction in critical care settings, and interdisciplinary involvement is typically considered best practice [12]. In such meetings, family members can learn about the medical status and treatment options, ask pressing questions, communicate concerns, and provide important contextual information, including patient values or pertinent details about the patient's history. Family meetings can produce consensus and cohesion agreement among members, powerful emotions, or heated arguments. When conflicts surface, family meetings may require diplomatic mediation (i.e., the application of basic conflict resolution skills) to ensure that all stakeholders have been heard, the various perspectives are shared and understood, and all persons feel that their opinions are respected. This would likely involve basic clinical skills including validation, reflection, rephrasing and clarifying key ideas, empathy, and face-saving strategies [23]. Ideally family meetings should be offered *prior* to admission to the ICU or at the earliest feasible time in the clinical encounter. Meetings should be proactive, avoiding crisis-driven decisions. A family meeting is a prime opportunity for social workers to take the initiative by setting up the meeting, developing an agenda, leading or moderating discussions, taking notes, advocating for patients and caregivers, documenting decisions, and ensuring adequate follow-up. Facilitating interdisciplinary family meetings is critical to improving communication between the ICU team and the family. These meetings may also help to reduce the burden of FICUS [15].

Strategies for Communicating Difficult Information

Because ICU patients are often coping with critical, and potentially life-threatening, conditions, it is imperative that social workers are equipped to hold difficult conversations and broach difficult subjects. Disclosing unwelcome news of a terminal prognosis, unresponsiveness to treatments, or the futility of medical interventions can be challenging for even the most seasoned of practitioners. When communicating difficult news, it may be useful to follow a clinically validated communication template to guide the conversation and provide structure to interactions. Table 24.2 shows selected models for breaking bad news to families. While each model is unique, they share a number of common components, including (1) preparing the environment, team members, self, and family; (2) establishing clinical rapport and avoiding distractions; (3) exploring what is already known and what information is wanted; (4) educating the patient/family in clear easy-to-understand terms; (5) allowing time for affective responses; (6) being supportive and expressing empathy; and (7) summarizing key points and reviewing next steps. Difficult discussions involving the disclosure of a life-limiting condition or prognosis demand patience, flexibility, revisiting advance directives, and, if appropriate, a referral to hospice or palliative care services. Ultimately, communication from the social worker and interdisciplinary team should be responsive to the multifaceted needs and responses of the family.

Table 24.2 Selected models of communicating difficult news to families in the ICU

Model *reference*	Brief description	Patient populations and settings	Evidence of use by social work
COMFORT *Wittenberg-Lyles et al. [34]*	C – Communication O – Orientation and opportunity M – Mindful presence F – Family caregiver communication O – Openings R – Relating T – Team	Setting(s): Home, nursing home, hospital, palliative care	Yes
BREAKS *Narayanan et al. [25]*	B – Background R – Rapport E – Explore patient's knowledge A – Announce a warning K – Kindling (i.e., space for emotions) S – Summarize	Not specified	No evidence identified
SPIKES *Baile et al. [2]*	S – Setup P – Perception I – Invitation K – Knowledge E – Empathize S – Summarize and strategize	Population(s): Oncology patients Setting(s): Hospital, clinical settings	Yes
ABCDE *Rabow and McPhee [28]*	A – Advance preparations B – Build therapeutic environment C – Communicate well D – Deal with patient/family reactions E – Encourage and validate emotions	Not specified	Yes
The Kaye 10-step approach [37]	1. Preparation 2. What does the patient know? 3. Is more information wanted? 4. Give a "warning shot" 5. Allow denial 6. Explain (if requested) 7. Listen to concerns 8. Encourage ventilation 9. Summary and plan 10. Offer availability	Not specified	No evidence identified

ICU outcomes are often fraught with clinical uncertainty. Thus, when holding discussion with patients and families, the critical care team, including ICU social workers, should acknowledge the many unknowns and, when appropriate, should feel comfortable telling families “I don’t know.” Given the challenges of FICUS, it is important to know that family preferences may change over time. Changing preferences may be due to treatment side effects, being unresponsive to interventions, disease progression, symptom burden, and fluctuations in emotional capacity (e.g., moving from denial of impending death to acceptance). Regular check-ins with families about the appropriateness of current care plans, the success of treatment, and the changes in patient status are essential to ensure that preferences are honored and to avoid unnecessary and prolonged suffering. In addition to communicating difficult information such as a poor outlooks, treatment failures, or the prospects of death, ICU social workers must also be willing to discuss potentially uncomfortable or off-putting subjects such as personal finances and medical bills/debt, mental illness, substance use or addiction, or spiritual issues.

A large part of supporting families during an ICU stay is managing expectations. Social workers can help to understand and address misaligned expectations by asking family members “Given what you know about the circumstances, can you tell me your expectations?” ICU team members can then provide basic information: “Based on what we know about the condition, here are some things you can expect….” This would be followed by specific information based on the patient’s status and clinical circumstances. Such conversations might cover expected physical changes, cognitive and emotional reactions, care needs, and available resources.

When discussing patient prognosis and expected outcomes, team members can present a balanced, evidence-informed approach that is candid and realistic but also allows families to maintain a sense of hope. This can be done by communicating three types of information to families: (1) expected trajectories in terms of odds, likelihoods, or probabilities; (2) the worst-case scenario; and (3) the best-case scenario. Prior to beginning a new treatment, especially one that is high risk or high burden, social workers should confirm with families and team members how success will be determined and when the treatment will be discontinued if success is not achieved. It is also important to preserve patient dignity and person-centeredness. This can be facilitated by asking families the “dignity question”: “What do we need to know about [the patient] as a person to give him/her the best care possible?”

Given the emotional burden and stress of a medical crisis, it is often difficult for patients and family members to retain information. The multiple stressors associated with FICUS are known to negatively impact one’s concentration and the ability to process information. Thus, it is important that social workers and other team members summarize key points of a conversation in writing and to provide patients/families with a reliable way to contact providers if they have additional questions or concerns.

The Navigator Role

Navigating resources and processing information in the ICU can be challenging for families. The complexities of the ICU are further elevated when FICUS is experienced. Social workers can help negotiate these complexities, and mitigate FICUS, by serving as ICU navigators. Within the navigation role, social workers are equipped to provide unique functions such as identifying community resources, patient/family empowerment, facilitating communication, educating the family, managing and maintaining ethical conduct, care coordination, and patient advocacy [33]. One well-known clinical trial used social work navigators to proactively address family decisional conflict and manage ICU communication, finding that families receiving the intervention were more likely to make informed decisions and achieve outcomes desired by the patient, family, and clinicians compared to families receiving no navigational support [5]. Utilizing the developed skills of ICU social workers to serve as navigators to families in the ICU may help to prevent, or at least minimize, FICUS.

Supporting Families in Pediatric ICUs

Although this chapter primarily focuses on supporting families of adult ICU patients, social workers are also a prominent fixture in pediatric critical care. When infants or children are critically ill and require a stay in a neonatal ICU (NICU) or pediatric ICU (PICU), their families tend to have very unique and challenging psychosocial needs. Working parents, for example, often have to quit their job or take extensive leave to care for their child. Meanwhile, out-of-pocket costs and mounting bills may be contributing additional distress to an already stressful situation. Parents may exhibit profound guilt, interpersonal anger/conflict, anxiety, depression, or spiritual conflicts. Young siblings may have a difficult time comprehending the reality or possible permanence of the situation. Social workers in NICUs and PICUs often hold overlapping roles in providing psychoeducational, communication, and logistical support to families [21]. Social workers providing support in PICUs should have a strong background in developmental growth, both physical and cognitive, family dynamics, and safety net resources.

Case Scenarios

The following case scenarios can be used by social workers and other disciplines to generate critical thinking and clinical debate about the best approach to patient care and family support. Critical questions are also provided to prompt responses relevant to FICUS and family support.

Case Scenario 1. Harold

Harold is a 45-year-old Hispanic male with liver disease, HEP C, who was admitted to the ICU from the state penitentiary with altered mental status. He is morbidly obese, weighing over 400 pounds, with a history of IV substance use. He is currently sedated, intubated, and handcuffed to the bedside rails with 24–7 security personnel posted outside the room. He is agitated with extensive bouts of delirium and hallucinations. His orientation is compromised, and he is unable to respond to assessment questions from the clinical team. Harold is serving a life sentence for having committed a violent crime when he was 19. The patient's family – which includes his mother, two brothers, and a sister – has been praying and holding vigil at the hospital for 48 h with minimal sleep. They are adamant, based on a deep spiritual faith, that Harold will miraculously recover. They are simultaneously inquiring about his prognosis and requesting a compassionate release home.

Critical questions: What additional assessment information is needed? What decisions need to be made or considered? How might the ICU social worker and other health-care providers support these family members? What are the appropriate next steps?

Case Scenario 2. Maria

Maria is a 37-year-old Caucasian female who was admitted to the ICU post-CVA for stabilization and medical monitoring. The stroke resulted in major changes in cognition, affect, and function including severe right-side paralysis. Her condition has begun to stabilize; and she is expected to be discharged from the unit within the next 24 h. Her frail, elderly mother and two sons, ages 7 and 12, will be sitting down with to discuss Maria's current condition and discharge arrangements. The mother has been caring for the boys since her mother was admitted to the hospital 5 days ago. The mother has suspected early dementia and has loudly displayed verbal hostility toward the medical staff about their "cold-blooded bedside manner," "gross incompetence," and "substandard care." Maria is estranged and separated from her sons' father, but they technically remain married and are not legally divorced.

Critical questions: What additional assessment information is needed? What decisions need to be made or considered? How might the ICU social worker and other health-care providers support these family members? What are the appropriate next steps?

Case Scenario 3. Esther

Esther is an 87-year-old African-American female with end-stage COPD, HTN, edema, and cor pulmonale with an ejection fraction < 20%. She was recently admitted to the ICU at the behest of her family for intubation and mechanical ventilation due to acute respiratory distress. Esther is recently widowed. Her family, made up of a brother, adult son, grandson, and family minister, has declined past referrals to palliative care. Esther does not have an advance directive, and the critical care team is beginning to express concerns about the futility of the current course of treatment.

Critical questions: What additional assessment information is needed? What decisions need to be made or considered? How might the ICU social worker and other health-care providers support these family members? What are the appropriate next steps?

Conclusion

Social workers are a key member of the critical care medical team. Drawing upon their counseling skills, knowledge of family dynamics, and ability to connect families with needed resources, social workers can work with the interdisciplinary team to identify and address family needs in the ICU.

References

1. Ahrens T, Yancey V, Kollef M. Improving family communications at the end of life: implications for length of stay in the intensive care unit and resource use. Am J Crit Care. 2003;12(4):317–23.
2. Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES – a six-step protocol for delivering bad news: application to the patient with cancer. Oncologist. 2000;5(4):302–11. https://doi.org/10.1634/theoncologist.5-4-302.
3. Boulware LE, Cooper LA, Ratner LE, LaVeist TA, Powe NR. Race and trust in the health care system. Public Health Rep. 2003;118(4):358–65. https://doi.org/10.1016/S0033-3549(04)50262-5.
4. Brooks RT, Hopkins R. Cultural mistrust and health care utilization: the effects of a culturally responsive cognitive intervention. J Black Stud. 2017;48(8):816. https://doi.org/10.1177/0021934717728454.
5. Burns JP, Mello MM, Studdert DM, Puopolo AL, Truog RD, Brennan TA. Results of a clinical trial on care improvement for the critically ill. Crit Care Med. 2003;31(8):2107–17. https://doi.org/10.1097/01.CCM.0000069732.65524.72.
6. Cagle JG, Pek J, Clifford M, Guralnik J, Zimmerman S. Correlates of a good death and the impact of hospice involvement: findings from the National Survey of households affected by cancer. Support Care Cancer. 2015;23:809–18. https://doi.org/10.1007/s00520-014-2404-z.
7. Cagle JG, Van Dussen DJ, Culler KL, Carrion IV, Hong S, Guralnik J, Zimmerman S. Knowledge about hospice: exploring misconceptions, attitudes, and preferences for care. Am J Hospice Palliat Med. 2016;33:27–33. https://doi.org/10.1177/1049909114546885.
8. Cagle JG, Widera EW. Geriatrics and palliative care. In: Williams B, Chang A, Ahalt C, Chen R, Conant R, Landefeld S, et al., editors. Current diagnosis and treatment: geriatrics. 2nd ed. New York: McGraw Hill; 2014.
9. Cagle JG, Williams K. Communication education for social workers. In: Wittenberg-Lyles E, Ferrell J, Goldsmith J, Smith T, Ragan S, Glajchen M, Handzo G, editors. Textbook of palliative care communication. New York: Oxford University Press; 2016.
10. Chik I, Fischberg D, Bernstein I. The impact of social work encounters on risk of ICU admission, ICU death, and CPR among hospitalized patients with cancer at end of life. J Pain Symptom Manag. 2017;53(2):325. https://doi.org/10.1016/j.jpainsymman.2016.12.047.
11. Choudhuri AH, Chakravarty M, Uppal R. Influence of admission source on the outcome of patients in an intensive care unit. Indian J Crit Care Med. 2017;21(4):213–7. https://doi.org/10.4103/ijccm.IJCCM_7_17.

12. Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, et al. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. Crit Care Med. 2017;45(1):103–28. https://doi.org/10.1097/CCM.0000000000002169.
13. Diem SJ, Lantos JD, Tulsky JA. Cardiopulmonary resuscitation on television: miracles and misinformation. N Engl J Med. 1996;334(24):1578–82. https://doi.org/10.1056/NEJM199606133342406.
14. Dombrovskiy VY, Martin AA, Sunderram J, Paz HL. Rapid increase in hospitalization and mortality rates for severe sepsis in the United States: a trend analysis from 1993 to 2003. Crit Care Med. 2007;35(5):1244–50. https://doi.org/10.1097/01.CCM.0000261890.41311.E9.
15. Gay EB, Pronovost PJ, Bassett RD, Nelson JE. The intensive care unit family meeting: making it happen. J Crit Care. 2009;24(4):629. https://doi.org/10.1016/j.jcrc.2008.10.003.
16. Harris D, Willoughby H. Resuscitation on television: realistic or ridiculous? A quantitative observational analysis of the portrayal of cardiopulmonary resuscitation in television medical drama. Resuscitation. 2009;80:1275–9. https://doi.org/10.1016/j.resuscitation.2009.07.008.
17. Hartman-Shea K, Hahn AP, Kraus JF, Cordts G, Sevransky J. The role of the social worker in the adult critical care unit: a systematic review of the literature. Soc Work Health Care. 2011;50(2):143–57. https://doi.org/10.1080/00981389.2010.506411.
18. Hong S, Cagle JG, Plant AJ, Culler KL, Carrion IV, Van Dussen DJ. Quality of death among hospice decedents: proxy observations from a survey of community dwelling adults in the contiguous United States. Death Stud. 2016;40:529–37. https://doi.org/10.1080/07481187.2016.1188867.
19. King WD. Examining African Americans' mistrust of the health care system: expanding the research question. Public Health Rep. 2003;118(4):366–7.
20. Lee JJ, Long AC, Curtis JR, Engelberg RA. The influence of race/ethnicity and education on family ratings of the quality of dying in the ICU. J Pain Symptom Manag. 2016;51(1):9–16. https://doi.org/10.1016/j.jpainsymman.2015.08.008.
21. Lentini N, Martinez E, Michelson K. Characterizing social worker and chaplain interactions with parents of critically ill children with cancer. J Clin Oncol. 2017:e22024. https://doi.org/10.1200/JCO.2017.35.15_suppl.e22024.
22. Loggers ET, Maciejewski PK, Paulk E, DeSanto-Madeya S, Nilsson M, Viswanath K, et al. Racial differences in predictors of intensive end-of-life care in patients with advanced cancer. J Clin Oncol. 2009;27(33):5559–64. https://doi.org/10.1200/JCO.2009.22.4733.
23. McCormick AJ, Curtis JR, Stowell-Weiss P, Toms C, Engelberg R. Improving social work in intensive care unit palliative care: results for a quality improvement intervention. J Palliat Med. 2010;13(3):297–304. https://doi.org/10.1089/jpm.2009.0204.
24. McCormick AJ, Engelberg R, Curtis JR. Social workers in palliative care: assessing activities and barriers in the intensive care unit. J Palliat Med. 2007;10(4):929–37. https://doi.org/10.1089/jpm.2006.0235.
25. Narayanan V, Bista B, Koshy C. "BREAKS" protocol for breaking bad news. Indian J Palliat Care. 2010;16(2):61–5. https://doi.org/10.4103/0973-1075.68401.
26. Nelson JE, Mulkerin CM, Adams LL, Pronovost PJ. Improving comfort and communication in the ICU: a practical new tool for palliative care performance measurement and feedback. Qual Saf Health Care. 2006;15(4):264–71. https://doi.org/10.1136/qshc.2005.017707.
27. Netzer G, Sullivan DR. Recognizing, naming, and measuring a family intensive care unit syndrome. Ann Am Thorac Soc. 2014;11(3):435–41. https://doi.org/10.1513/AnnalsATS.201309-308OT.
28. Rabow MW, McPhee SJ. Beyond breaking bad news: how to help patients who suffer. West J Med. 1999;171(4):260–3.
29. Schwei RJ, Kadunc K, Nguyen AL, Jacobs EA. Impact of sociodemographic factors and previous interactions with the health care system on institutional trust in three racial/ethnic groups. Patient Educ Couns. 2014;96:333–8. https://doi.org/10.1016/j.pec.2014.06.003.
30. Stein G, Cagle JG, Christ GH. Social work involvement in advance care planning: findings from a large survey of social workers in hospice a palliative care settings. J Palliat Med. 2016;53:198–207. https://doi.org/10.1089/jpm.2016.0352.

31. Sundararajan K, Sullivan TS, Chapman M. Determinants of family satisfaction in the intensive care unit. Anaesth Intensive Care. 2012;40(1):159–65.
32. Thompson EC. Race and the ICU. In: Crippon D, editor. The interventionist's challenge: Springer; 2016. p. 75–9. https://doi.org/10.1007/978-3-319-30454-0.
33. Willis A, Reed E, Pratt-Chapman M, Kapp H, Hatcher E, Vaitones V, et al. Development of a framework for patient navigation: delineating roles across navigator types. J Oncol Navig Survivorship. 2013;4(6):20–6.
34. Wittenberg-Lyles E, Goldsmith J, Ferrell B, Burchett M. Assessment of an interprofessional online curriculum for palliative care communication training. J Palliat Care. 2014;17(4):400–6. https://doi.org/10.1089/jpm.2013.0270.
35. Wunsch H, Angus DC, Harrison DA, Linde-Zwirble WT, Rowan KM. Comparison of medical admissions to intensive care units in the United States and United Kingdom. Am J Respir Crit Care Med. 2011;183(12):1666–73. https://doi.org/10.1164/rccm.201012-1961OC.
36. Zuckerman M, Gagne M. The COPE revised: proposing a 5-factor model of coping strategies. J Res Pers. 2003;37:169–2014. https://doi.org/10.1016/S0092-6566(02)00563-9.
37. Kaye P. Breaking bad news: A 10 step approach. ELP: Northampton, UK; 1996.

Chapter 25
Rehabilitation

Kimberley Haines

Engaging Families in Rehabilitation for the Critically Ill

Introduction: Toward More Compassionate Care

Family members are increasingly recognized as valued members of the healthcare team [1–4]. This principle of engaging families can be applied to rehabilitation across transitions of care from the intensive care unit (ICU) to home, under the premise of "invite, educate and support" [5]. Approaches to engaging families in rehabilitation of the critically ill can be informed by a conceptual framework describing the tenets of family-centered care [6]: "Families are considered experts in what helps and hurts them, are indispensable, invaluable partners for policy-makers, professionals and advocates, are not called or treated as dependent but should be considered as equals with whom to collaborate and empower. Family-centred policies and practices promote peer and community-based systems of care and mutual support, democratization and gender equity."

Previously, critical care rehabilitation trials were designed from the perspective of health professionals; interventions were applied *to* the patient [7–9]. Families were overlooked in design and implementation; however, families are an underutilized resource. Increasingly, we recognize the need to design interventions *with* ICU patients and their families – at much higher levels of engagement than before [10]. Our hypothesis is that greater partnership will result in improved outcomes for both patients and families, although this requires testing. As we begin this process, research is needed to better understand and refine the following concepts of family engagement in rehabilitation, specifically in the following areas:

K. Haines
Western Health, Australia and New Zealand Intensive Care Society Research Center,
Monash University, Melbourne, VIC, Australia
e-mail: kimberley.haines@wh.org.au

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_25

1. What types of rehabilitative activities do families want to engage in within the acute and subacute settings, and how can we best support them?
2. Are family and patient outcomes improved following critical illness, with the benefit of family engagement in rehabilitation?
3. What are the potential barriers and facilitators to implementing family involvement in rehabilitation at the clinical interface?

Implementing engagement strategies via a blanket approach should not be the goal but, rather, creating a culture where patients and families can have control and decisional input to individualize their own care [2]. Orchestrating opportunities where families are, with patient consent, invited to be involved in an active role may address shared emotional needs between family and patient and invests in the long-term outcomes and recovery trajectories for both. These complexities and challenges may be made worse during times of illness and stress (and the converse may be true). As in all clinical care, suggestions made within this chapter should be considered in the context of whether they are likely to benefit any specific patient's recovery.

Few studies engaging families in rehabilitation for survivors exist within and/or beyond the ICU to describe the "what, why, when and how" this could be effective. As a result, this chapter will draw on existing research and theories describing family participation and how this might be applied and integrated within rehabilitation of the critically ill.

Transitions of Care and Rehabilitation

The ICU is only one point on the patient and family journey, in which the burden of critical illness extends from pre-ICU to the post-hospital phase [11]. Across this spectrum of care, the question has been rightly posed – *"who is visiting whom?"* – recognizing that we as healthcare providers may simply be visitors in the lives of patients and families and not the other way around [2]. Given that families are often the primary caregivers to the patient prior to and following hospitalization, this role should not be made redundant within the ICU setting, and families should be empowered to maintain this role across the transitions of care (Fig. 25.1). While the nature of the tasks in which families can engage families will change as the patient acuity changes (Fig. 25.1), regular opportunities should be given to facilitate participation as the patient and family wish.

Rehabilitation has been defined by the World Health Organization as an enablement process to attain "optimal physical, sensory, intellectual, psychological and social functional levels" [12]. The fundamental goal of rehabilitation is to achieve participation meaningful to the individual. Family is integral in this process. These concepts are captured within the International Classification of Functioning, Disability and Health (ICF) [13, 14]. Used extensively in rehabilitation settings, this model of disability categorizes the disability of acute illness into categories: damage to body structures, limitations in activity, restriction in social roles, and health-related quality of life [13]. The ICF illustrates interrelating steps culminating in varying

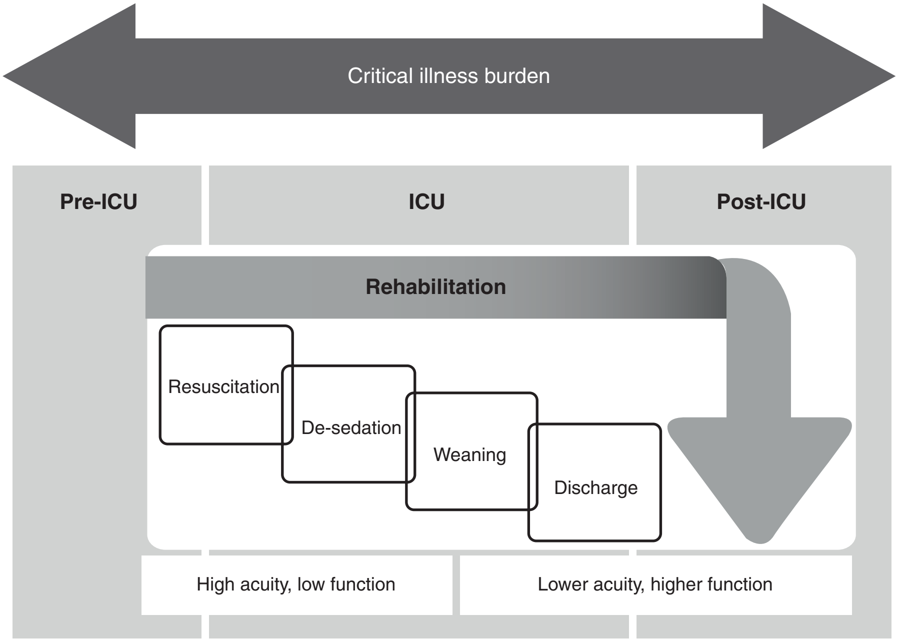


Fig. 25.1 Transitions of care and rehabilitation in ICU

levels of disablement and considers the effect other modifiers may have on patient recovery such as social environment and caregiver support [15]. The functional limitations patients experience following critical illness can become restrictions dependent on their social infrastructure [13]. It is therefore crucial that families are integrated early within the rehabilitation process. There are three overarching concepts for doing this:

1. Benefit to the family – channeling psychological distress into a purposeful active role.
2. Benefit to the patient – humanizing the illness and recovery experience through provision of emotional support and maintenance of patient identity, social structures, and connectedness to the outside world.
3. Benefit to staff and health system – utilizing families as a supporting resource to deliver therapeutic interventions outside of constrained therapy time.

The provision of rehabilitation within and beyond the ICU is often led and largely underpinned by the allied health professions. Allied health represents the third pillar of healthcare that complements medicine and nursing [16]. Allied health professionals have diagnostic and therapeutic skills with a particular focus on provision of therapy to restore function, participation, and community reintegration. Table 25.1 depicts various allied health therapeutic roles and potential for engagement of families in rehabilitative activities particular to their profession.

Table 25.1 Allied health professions, therapeutic roles, and rehabilitation

Allied health profession	Therapeutic role	Types of acute rehabilitative activities families could be engaged in related to each professional group
Physical therapy[a]	Multi-system assessment of respiratory, cardiovascular, neurological, and musculoskeletal systems to formulate individualized treatment plans and the use of functional activities to rehabilitate and restore physical condition [17, 18]	Assistance with activities of daily living, in bed exercises/activities (e.g., bridging, rolling), out-of-bed exercises (e.g., sit to stand, walking), other physically therapeutic activities such as stretching and massaging
Occupational therapy	Facilitation of task performance by improving relevant performing skills or developing and teaching compensatory strategies to overcome lost performance skills [19]	Assisting with activities of daily living, cognitive stimulation, and the use of adaptive devices (e.g., helping patients with activities of daily living, helping the patient to use adaptive utensils at meal times, helping patients using wheelchairs, assisting with appropriate levels of cognitive stimulation and engagement such as reading newspaper, playing cards)
Speech language therapy	Assessment and management of communication and swallowing difficulties [20] through rehabilitation, goals, programs, equipment, and advice to optimize and maintain function [21, 22]	Assistance with communication devices to facilitate/augment communication [22] (e.g., helping patient to use a communication board or app). Being aware of swallowing difficulties and preparation of suitable food and fluid consistencies following discharge from hospital
Dietetics	Assessment of nutritional status and provision of nutrition support and counselling to optimize nutrition and support health-promoting behaviors [23]	Physically assisting the patient at meal times to help them eat and encouraging them to consume oral nutrition supplements to meet their nutritional requirements [24] or bringing preferred food from home to do this
Psychology	Diagnosis and treatment of mental and behavioral health problems to enhance health-promoting behaviors, treatment adherence, and functional ability [25]	Assisting patient to use a mindfulness app or helping them practice other psychological support techniques such as resilience and coping. Advocating for patients to be able to participate in activities that support their psychological well-being such as going outside, listening to music, bringing their pet in to visit, or engaging in animal-assisted therapy [26]
Social work	Psychosocial support and counseling as well as crisis intervention, psychosocial assessment, facilitation of communication, end-of-life care, and practical assistance [27]	Assisting and maintaining patient engagement with outside world and their social networks (e.g., bringing in photos and news or correspondences from family and friends)

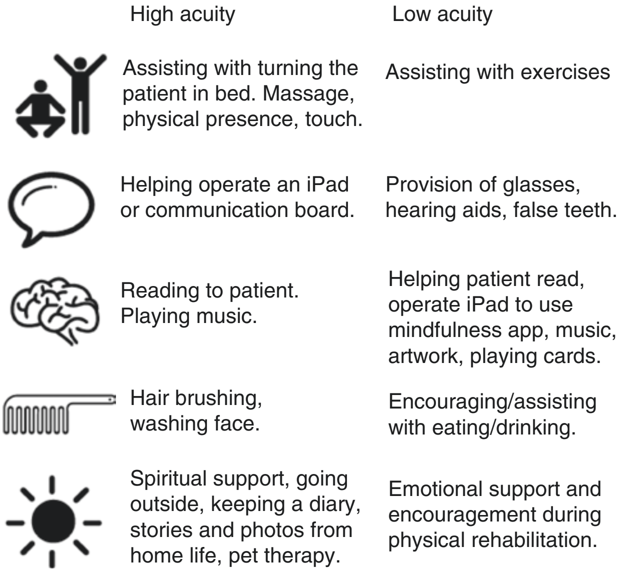
[a] Also known as physiotherapy in Australia, the UK, South Africa, Europe, New Zealand, and other countries [28]

Engaging Families at the Bedside

As critical care clinicians, we must recognize that families are potentially in crisis. We have a significant opportunity to lessen that distress. We need to focus our efforts of care not only on the patient on the bed but those keeping the bedside vigil as the two are inextricably linked. To treat one without consideration of the other may be ineffective and in some cases detrimental.

The theoretical context underpinning the engagement of families in rehabilitation in the ICU is supported by the theory of facilitated sense-making. This theory recognizes the value of an active role for family members where clinicians help them make sense of what they are experiencing through an iterative process as the patient condition changes [29]. This process of practically engaging families in care can help them make sense of what is happening and gives meaning to their new and changing role [29].

With this in mind, there may be many practical low-cost, high-value rehabilitative activities in which families engage to. If a patient is acutely unwell, this should not preclude family engagement in rehabilitative activities, but, rather, an adaptive approach can be taken. Some examples of rehabilitative activities families may want to participate are provided in Fig. 25.2, focused on assisting patients with activities of daily living. By encouraging and supporting families to help the patient carry out these tasks, they are engaging in rehabilitation and restoration of function and participation. For example, physical therapists might be responsible for supporting families to do exercises, speech language therapists might set up a communication board, and occupational therapists might devise cognitive engagement exercises and teach families how to engage the patient to use these strategies (Fig. 25.2). However these activities are not exclusive to a particular professional group and should be shared among the team.



High acuity	Low acuity
Assisting with turning the patient in bed. Massage, physical presence, touch.	Assisting with exercises
Helping operate an iPad or communication board.	Provision of glasses, hearing aids, false teeth.
Reading to patient. Playing music.	Helping patient read, operate iPad to use mindfulness app, music, artwork, playing cards.
Hair brushing, washing face.	Encouraging/assisting with eating/drinking.
Spiritual support, going outside, keeping a diary, stories and photos from home life, pet therapy.	Emotional support and encouragement during physical rehabilitation.

Fig. 25.2 Types of rehabilitative activities to invite family participation

A Spectrum of Participation

A spectrum of engagement by families in rehabilitation and care tasks may be influenced by gender, social, cultural, and religious factors. At one end of the spectrum, families may feel more comfortable to simply maintain their role as a family member where participation at the bedside may be defined by companionship, emotional support, and reassurance, with therapeutic benefit to both. At the other end of the spectrum, some families may wish to be consistently and very involved in care and rehabilitation. This spectrum of participation should be tempered by the patients' preferences and ability of staff to provide the necessary support to the family, as well as consideration of pre-existing relationships of the patient with different family members.

This spectrum is particularly important to consider within the context of diversity within families, for example, differences in caregiver roles (partner, sibling, parent); trans-generational, single-parent, and "blend" families [30]; "families of origin" and "families of choice" which may be relevant to people who identify as LGBTQI [31]; cultural differences where the entire family unit expect to be involved in care; and those from migrant or asylum family roles where they may be under additional duress external to ICU. It is essential to consider the healthcare needs of caregivers from minority groups. To achieve equity and not just equality, we must treat these groups differently and better understand their needs in order to achieve the same outcomes as a result of our care. Some suggested strategies are listed in Box 25.1.

Box 25.1 Strategies for Supporting and Engaging Families from Minority Groups

1. Spend time getting to know the caregiver to establish their needs and preferences. Some potential questions to do this might include:
   What's important to you as a caregiver?
   Who's important to you as a caregiver?
   What are your preferences for how we communicate with you?
   What aspects of care do you expect to be involved in or would like to be involved in?
   What do you need from us to help you during this time? Is there anything you would like us to do differently?
2. With consent of the caregiver, communicate a summary of these preferences to the rest of the team (via medical records or whiteboard in bed space) to avoid duplication so knowledge can be built upon.
3. Be aware of own subconscious biases.
4. Avoid assumptions based on appearance.
5. Educate self about minority groups.

Importantly, wherever families (and patients) are on this participation spectrum, their involvement should be supported by an environment and systems, which allows the individuals, in partnership with staff, to tailor their participation and integration with patient care.

What Is the Evidence?

There are very few studies currently describing family engagement in rehabilitation of the critically ill, and much of the literature describes involvement in bedside care (which may incorporate aspects of rehabilitation). Table 25.2 outlines key findings where families have been engaged or participated in rehabilitation or other aspects of care. These are presented from the perspective of clinicians, families, and patients.

Overall, Table 25.2 shows the majority of staff, families, and patients were supportive of family participation in a range of care activities, many of which could be classified as rehabilitative. However, in practice, very few families actually participated in the care of the patient. This suggests that while beliefs and attitudes may be positive toward participation, implementation strategies may be required to facilitate engagement of families in care and rehabilitative activities.

Table 25.2 Engagement of families in bedside care

Study	*n*	Design	Key findings
Intensive care settings			
Blom et al. [32]	7 family members	Qualitative	*Families*: Being allowed to participate in patient care was important with four components: 1. Participation in care and being close to the patient – "Being there" as well as "doing" 2. Confidence in the care the patient receives 3. Support needed for involvement in caregiving 4. Vulnerability An atmosphere needs to be created that supports and invites families to participate
Rukstele et al. [5]	N/A	Review	Adoption of a philosophical approach and establishing a foundation for patient- and family-centered care (steering committee created, staff education, open visiting, addressing myths/fears). Engaging families in mobilization through *invite* (welcome pack), *education* (brochure on implications of immobility, task demonstration, provision of written instructions, determination of what role meets patient and family needs), *support* (encourage families to bring items from home, engage patient in the outside world)

(continued)

Table 25.2 (continued)

Study	*n*	Design	Key findings
McQueen et al. [33]	10 family caregivers of preterm infants	Pilot, feasibility	Family caregivers were willing and able to do learnt exercises correctly *Families*: Described the exercises as beneficial for their infants and facilitated bonding. Caregivers initially were fearful of hurting their babies although this reduced with practice
Garrouste-Orgeas et al. [34]	101 patient-family pairs	Observational	*Staff*: The majority of physicians and nurses were favorable to family participation in a range of care tasks (washing/cleaning, transfers, massage to prevent pressure injuries)
			Families: 97% were willing to participate and were favorable to a range of 13 care tasks. Only 14% participated in care spontaneously. 58% and 26% had symptoms of anxiety and depression, respectively. There was a nonsignificant relationship between symptoms and willingness to participate
			Patients: Of the 44/101 who were able to complete the retrospective phone interview, 77% were favorable to their families participating in care. Of the remaining proportion who did not want care from their families, reasons included desire to preserve image, unwillingness to be assisted, embarrassment, nurses being better-skilled, and physical modesty
Azoulay et al. [35]	2754 staff	Observational	*Staff*: 88% felt participation in care (e.g., feeding, bathing, tracheal suctioning) should be offered to families. Only 60% of these had involved family in care. Of the staff who felt families should not participate, 66% believed that it might contribute to family suffering
	544 families		*Families*: 33% wanted to participate. Predictors of desire were related to patient severity of illness on admission, ICU LOS, and family factors (age, not of European descent, previous experience of ICU in the family, emotional burden and effectiveness of information, more time wanted for information). Most common reason for not wanting to participate was staff did their job perfectly (85%). Families may not have understood what participation in care meant and potential benefits
Hammond et al. [36]	27 nurses 20 families	Mixed methods	*Staff*: 96% agreed with concept of involving families in physical care. Major theme: there were problems of role adaptation for nurses and families involved and building relationships *Families*: 85% wanted to be involved in physical care of the patient, and 15% did not. Major theme: adapting to the demanding ICU environment and identifying boundaries of their new role as caregiver

How Might We Practically Do This?

Adopting an approach to family engagement in rehabilitation requires a philosophical approach and paradigm shift toward the adoption of true family-centered care that is facilitated by leadership, teamwork, patience, and compassion. In ICU, we need to borrow more from models of rehabilitative care where families are viewed as integral to the recovery process. In stroke rehabilitation, for example, families would be regularly involved in interprofessional team meetings to set goals, understand more about patient needs/preferences, and plan for return home. The concept of a 24-h model of rehabilitation in subacute settings is one idea to actively promote rehabilitation around the clock to engage all members of the team to approach care in this way and reduce inactivity common on hospital wards. Families are viewed as an essential part of this philosophy of care where they may be able to continue the patient's exercises with them, helping them with eating or cognitive tasks outside of the relatively short periods of therapy time.

To adopt such an approach in ICU may require a cultural shift in practice away from what is easiest for the clinicians, to what is best for the patient, and how we can create opportunities throughout the 24-h period that are based on patient goals. (The difficulty of this cultural shift should neither be understated nor overstated, as it is already underway in many ICUs.) For example, it may be easiest and take less time to turn a patient in bed where staff do most of the activity compared to setting up the environment, using verbal and physical prompts to facilitate the patient to complete the task. Prompting and supporting the patient may take more time but is likely to have greater rehabilitative benefit. To then go a step further to engage the families in this sort of care, may require even more time and patience from the staff, but again may have rehabilitative benefit to the family. Over time, attitudes from staff toward families may change from that of hindrance to help.

Other strategies might include the early adoption of joint goal setting between the patient, family, and interprofessional team. This might take the form of an interprofessional team ward round (medical, nursing, and allied health) for complex, long-stay ICU patients, where families are welcomed in this process. Allied health professionals often receiving training in how to set rehabilitative goals with patients and families can serve as an important resource in the healthcare team by actively leading these discussions. A key question often asked by allied health professionals when establishing therapeutic alliance is "what matters to you?"[37]. These can help define short-, medium-, and long-term rehabilitation goals which can be captured as a daily care plan and made visible on whiteboards at the bedside to help remind all those caring for the patient and avoid daily reinvention when staff members change. Example headings that could be used on a whiteboard at a patient's bedside to display their care plan might include:

1. My goals are…
2. People important to me are…
3. I communicate by…
4. I would like to know…

Table 25.3 Practical strategies and considerations to support family engagement

Target group	Strategy
Staff	A system-based approach may help support the partnership between staff and families. Strategies might include prompts in electronic medical records or bedside charts reminding staff to invite families to participate, structuring of ward rounds to engage with families, operationalizing family-centered care in guidelines and policies, educating staff about how to engage and coach families as partners, and better understanding regarding the role of family as advocate [39]
Patient	Preferences and goals are clear and accessible to the patient and care plan is documented and goal-driven. Being aware of those patients who are more likely to be alone without family support and considering other ways their rehabilitation could be supported such as engaging therapy assistants and volunteers
Family	Written or verbal information provided in the waiting room and at the bedside about participating in patient care that gives direction about the types of tasks families can do to help the patient's recovery, education about standard steps and milestones of recovery, how to participate as well as facilitate (e.g., some tasks may appear difficult for the patient to undertake, but there may be therapeutic benefit to them completing rather than family doing it for them), understanding the partnership with staff, facilitating accessibility to the patient (e.g., open visiting hours)

5. From home I need…
6. My expected date of discharge is…
7. My planned discharge destination is…

Families can also be easily involved in clinician handover at the bedside as they can provide the nuances of care that may not otherwise be handed over about the patients' preferences. Families remain the constant advocate for the patient, and if we engage them in this way, we recognize them as expert members of the team, which may help us be more effective and efficient as clinicians through the creation of therapeutic alliance [38]. Table 25.3 displays some practical strategies to support implementation of family engagement. In addition, many useful "work tools" to support the implementation of the Society of Critical Care Medicine's Family-Centered Care guidelines are available [40].

Thinking Beyond ICU

It is important we consider how to prepare families in their ongoing journey beyond ICU. Many families and patients report challenges when transitioning from the high-monitored environment of the ICU to the general wards [41] and from the wards to home. Strategies to improve these transitions of care could be achieved through:

- Meeting informational needs – written or verbal communication about what to expect when leaving ICU or hospital that addresses patient factors, family factors, and health system factors and how to access ongoing support.

- In some cases, introducing the patient and family to the ward environment and staff prior to discharge from ICU (e.g., long ICU stay, highly complex) may be beneficial to relieve anxiety. While this may not always be practical (even though we can transport the sickest of ICU patients for procedures), it requires a shift in thinking about what is important and when and rearranging resources to be more patient- and family-centered wherever possible.

Beyond hospital discharge, families often go on to support patients in their struggle to achieve functional independence by assisting them physically, psychologically, and socially [42]. This can impact the psychosocial outcomes of families [43]. This role shift for spouses has been described as a “dynamic process initially triggered by the critical illness incident and later influenced by the patient’s gradual recovery,” involving four elements [42]: committing to caregiving, acquiring caregiving skills, negotiating level of caregiver, and gradually leaving the caregiving role. This study is particularly useful as it provides insights to the challenges faced by families in the post-ICU phase of recovery. The authors suggest the findings can inform clinicians’ efforts in preparing families of what to expect following hospitalization and the development of targeted supportive interventions delivered by either the primary or secondary healthcare sector.

Allied health professionals and other rehabilitation specialists play an important role in facilitating this transition from hospital to home. To empower families and support the transition out of hospital, common strategies include:

- Regular involvement of families in patient goal setting on admission and throughout the subacute stay.
- Regular family meetings with the healthcare team to discuss questions or concerns. Families are provided with updates on patient progress from the various professionals, and discussion of the estimated discharge date and destination occurs.
- Involvement in caregiver training sessions and education with allied health professionals about how to use specialist equipment, how to assist the patient with activities of daily living or ongoing physical rehabilitation tasks, and how to meet dietary and communication or swallowing requirements. This ensures families are safely and confidently able to meet the patient care needs post-discharge.
- Involvement in trial of care sessions for more complex discharges. Families are invited and encouraged to stay with the patient for a 24-h period on the ward to receive additional education and exposure to the patient’s care requirements while remaining in a supported and safe environment. This often serves the purpose of informing the team and ongoing decision-making about whether the patient and family are likely to cope post-discharge.
- Meeting informational needs about post-intensive care syndrome (showing them SCCM’s thrive resources), what to expect following discharge, and where to go for support and help such as in-person or online peer support groups [44].
- Ensuring appropriate referrals to community providers is made so that the patient and family are linked in with ongoing supports.

Conclusion

There is little evidence to guide our practice in engaging families in rehabilitation of the critically ill. These data are important to generate to help us better understand how families might modify patient disability and whether families benefit from engagement. In the absence of data, we need to consider how we, as ICU clinicians, can promote a more family-centered environment in the ICU, extending to inclusion of family in rehabilitative activities where appropriate. To empower families in the rehabilitation arc, we need to be open and willing to learn *from* and *with* patients and their families, which may lead to better outcomes.

Acknowledgments I would like to thank Mel Gregory for sharing and discussing her insights as a rehabilitation physiotherapist at Austin Health and my allied health colleagues at Western Health. I would also like to thank Jack Iwashyna for his critical review. The content of this chapter is re-used with permission of Oxford University Press, following publication in *Physical Therapy*, the Journal of the American Physical Therapy Association.

References

1. Beesley SJ, Hopkins RO, Francis L, Chapman D, Johnson J, Johnson N, Brown SM. Let them in: family presence during intensive care unit procedures. Ann Am Thorac Soc. 2016;13(7):1155–9. https://doi.org/10.1513/AnnalsATS.201511-754OI.
2. Berwick DM, Kotagal M. Restricted visiting hours in ICUs: time to change. JAMA. 2004;292(6):736–7. https://doi.org/10.1001/jama.292.6.736.
3. Cypress BS. Family presence on rounds: a systematic review of literature. Dimens Crit Care Nurs. 2012;31(1):53–64. https://doi.org/10.1097/DCC.0b013e31824246dd.
4. Davidson JE, Powers K, Hedayat KM, Tieszen M, Kon AA, Shepard E, Spuhler V, Todres ID, Levy M, Barr J, Ghandi R, Hirsch G, Armstrong D, American College of Critical Care Medicine Task Force SoCCM. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004-2005. Crit Care Med. 2007;35(2):605–22. https://doi.org/10.1097/01.CCM.0000254067.14607.EB.
5. Rukstele CD, Gagnon MM. Making strides in preventing ICU-acquired weakness: involving family in early progressive mobility. Crit Care Nurs Q. 2013;36(1):141–7. https://doi.org/10.1097/CNQ.0b013e31827539cc.
6. Briar Lawson K, Lawson H, Hennon C, Jones A. Family-centered policies and practices: international implications. New York: Columbia University Press; 2001.
7. Denehy L, Skinner EH, Edbrooke L, Haines K, Warrillow S, Hawthorne G, Gough K, Hoorn SV, Morris ME, Berney S. Exercise rehabilitation for patients with critical illness: a randomized controlled trial with 12 months of follow-up. Crit Care. 2013;17(4):R156. https://doi.org/10.1186/cc12835.
8. Morris PE, Berry MJ, Files DC, Thompson JC, Hauser J, Flores L, Dhar S, Chmelo E, Lovato J, Case LD, Bakhru RN, Sarwal A, Parry SM, Campbell P, Mote A, Winkelman C, Hite RD, Nicklas B, Chatterjee A, Young MP. Standardized rehabilitation and hospital length of stay among patients with acute respiratory failure: a randomized clinical trial. JAMA. 2016;315(24):2694–702. https://doi.org/10.1001/jama.2016.7201.
9. Schweickert WD, Pohlman MC, Pohlman AS, Nigos C, Pawlik AJ, Esbrook CL, Spears L, Miller M, Franczyk M, Deprizio D, Schmidt GA, Bowman A, Barr R, McCallister KE, Hall JB, Kress JP. Early physical and occupational therapy in mechanically ventilated, critically ill patients: a randomised controlled trial. Lancet. 2009;373(9678):1874–82. https://doi.org/10.1016/S0140-6736(09)60658-9.

10. Haines KJ, Kelly P, Fitzgerald P, Skinner EH, Iwashyna TJ. The untapped potential of patient and family engagement in the organization of critical care. Crit Care Med. 2017;45(5):899–906. https://doi.org/10.1097/CCM.0000000000002282.
11. Angus DC, Carlet J, Brussels Roundtable P. Surviving intensive care: a report from the 2002 Brussels roundtable. Intensive Care Med. 2003;29(3):368–77. https://doi.org/10.1007/s00134-002-1624-8.
12. World Health Organization. Rehabilitation. World Health Organization; 2017. http://www.who.int/topics/rehabilitation/en/. Accessed 11 May 2017.
13. Iwashyna TJ, Netzer G. The burdens of survivorship: an approach to thinking about long-term outcomes after critical illness. Semin Respir Crit Care Med. 2012;33(4):327–38. https://doi.org/10.1055/s-0032-1321982.
14. World Health Organization. International classification of functioning, disability and health. Geneva: World Health Organization; 2001.
15. Herridge MS, Cameron J. Models of rehabilitative care after critical illness. In: Stevens RD, Hart N, Herridge MS, editors. Textbook of post-ICU medicine. Oxford: Oxford University Press; 2014.
16. Philip K. Allied health: untapped potential in the Australian health system. Aust Health Rev Publ Aust Hosp Assoc. 2015;39(3):244–7.
17. Berney S, Haines K, Denehy L. Physiotherapy in critical care in Australia. Cardiopulm Phys Ther J. 2012;23(1):19–25.
18. Skinner EH, Thomas P, Reeve JC, Patman S. Minimum standards of clinical practice for physiotherapists working in critical care settings in Australia and New Zealand: a modified Delphi technique. Physiother Theory Pract. 2016;32(6):468–82. https://doi.org/10.3109/09593985.2016.1145311.
19. Steultjens EM, Dekker J, Bouter LM, van de Nes JC, Cup EH, van den Ende CH. Occupational therapy for stroke patients: a systematic review. Stroke. 2003;34(3):676–87. https://doi.org/10.1161/01.STR.0000057576.77308.30.
20. Brodsky MB, Huang M, Shanholtz C, Mendez-Tellez PA, Palmer JB, Colantuoni E, Needham DM. Recovery from dysphagia symptoms after oral endotracheal intubation in acute respiratory distress syndrome survivors. A 5-year longitudinal study. Ann Am Thorac Soc. 2017;14(3):376–83. https://doi.org/10.1513/AnnalsATS.201606-455OC.
21. Baumgartner CA, Bewyer E, Bruner D. Management of communication and swallowing in intensive care: the role of the speech pathologist. AACN Adv Crit Care. 2008;19(4):433–43. https://doi.org/10.1097/01.AACN.0000340724.80280.31.
22. Therapists TRCoSaL. Position paper: speech and language therapy in adult critical care. London: The Royal College of Speech and Language Therapists; 2014.
23. Hampl JS, Anderson JV, Mullis R, American Dietetic A. Position of the American Dietetic Association: the role of dietetics professionals in health promotion and disease prevention. J Am Diet Assoc. 2002;102(11):1680–7.
24. Wischmeyer P. Optimising nutrition for recovery after ICU. ICU Manage Pract. 2017;17(3):156–8.
25. Association AP. Briefing series on the role of psychology in health care: integrated health care: American Psychological Association; 2017. http://www.apa.org/health/briefs/integrated-healthcare.pdf. Accessed 22 Sept 2017.
26. Hosey MJ, Mantheiy E, Kudchadkar S, Needham D. Animal-assisted activity in the intensive care unit. ICU Manage Pract. 2017;17(3):193–5.
27. Hartman-Shea K, Hahn AP, Fritz Kraus J, Cordts G, Sevransky J. The role of the social worker in the adult critical care unit: a systematic review of the literature. Soc Work Health Care. 2011;50(2):143–57. https://doi.org/10.1080/00981389.2010.506411.
28. Skinner EH, Warrillow S, Denehy L. Organisation and resource management in the intensive care unit: a critical review. Int J Ther Rehabil. 2015;22(4):187.
29. Davidson JE. Facilitated sensemaking: a strategy and new middle-range theory to support families of intensive care unit patients. Crit Care Nurse. 2010;30(6):28–39. https://doi.org/10.4037/ccn2010410.

30. Shudy M, de Almeida ML, Ly S, Landon C, Groft S, Jenkins TL, Nicholson CE. Impact of pediatric critical illness and injury on families: a systematic literature review. Pediatrics. 2006;118(Suppl 3):S203–18. https://doi.org/10.1542/peds.2006-0951B.
31. Hash KaMM. Caregiving in the LGBT community. In: Annual review of gerontology and geriatrics. Springer; 2017.
32. Blom H, Gustavsson C, Sundler AJ. Participation and support in intensive care as experienced by close relatives of patients: a phenomenological study. Intensive Crit Care Nurs. 2013;29(1):1–8. https://doi.org/10.1016/j.iccn.2012.04.002.
33. McQueen D, Lakes K, Rich J, Vaughan J, Hayes G, Cooper D, Olshansky E. Feasibility of a caregiver-assisted exercise program for preterm infants. J Perinat Neonatal Nurs. 2013;27(2):184–92. https://doi.org/10.1097/JPN.0b013e31828b244a.
34. Garrouste-Orgeas M, Willems V, Timsit JF, Diaw F, Brochon S, Vesin A, Philippart F, Tabah A, Coquet I, Bruel C, Moulard ML, Carlet J, Misset B. Opinions of families, staff, and patients about family participation in care in intensive care units. J Crit Care. 2010;25(4):634–40. https://doi.org/10.1016/j.jcrc.2010.03.001.
35. Azoulay E, Pochard F, Chevret S, Arich C, Brivet F, Brun F, Charles PE, Desmettre T, Dubois D, Galliot R, Garrouste-Orgeas M, Goldgran-Toledano D, Herbecq P, Joly LM, Jourdain M, Kaidomar M, Lepape A, Letellier N, Marie O, Page B, Parrot A, Rodie-Talbere PA, Sermet A, Tenaillon A, Thuong M, Tulasne P, Le Gall JR, Schlemmer B, French Famirea G. Family participation in care to the critically ill: opinions of families and staff. Intensive Care Med. 2003;29(9):1498–504. https://doi.org/10.1007/s00134-003-1904-y.
36. Hammond F. Involving families in care within the intensive care environment: a descriptive survey. Intensive Crit Care Nurs. 1995;11(5):256–64.
37. Barry MJ, Edgman-Levitan S. Shared decision making – pinnacle of patient-centered care. The. N Engl J Med. 2012;366(9):780–1. https://doi.org/10.1056/NEJMp1109283.
38. Huff NG, Nadig N, Ford DW, Cox CE. Therapeutic Alliance between the Caregivers of Critical Illness Survivors and Intensive Care Unit Clinicians. Ann Am Thorac Soc. 2015;12:1646-1653.
39. Bamm EL, Rosenbaum P. Family-centered theory: origins, development, barriers, and supports to implementation in rehabilitation medicine. Arch Phys Med Rehabil. 2008;89(8):1618–24. https://doi.org/10.1016/j.apmr.2007.12.034.
40. Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, Cox CE, Wunsch H, Wickline MA, Nunnally ME, Netzer G, Kentish-Barnes N, Sprung CL, Hartog CS, Coombs M, Gerritsen RT, Hopkins RO, Franck LS, Skrobik Y, Kon AA, Scruth EA, Harvey MA, Lewis-Newby M, White DB, Swoboda SM, Cooke CR, Levy MM, Azoulay E, Curtis JR. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. Crit Care Med. 2017;45(1):103–28. https://doi.org/10.1097/CCM.0000000000002169.
41. Bench SD, Day T, Griffiths P. Involving users in the development of effective critical care discharge information: a focus group study. American journal of critical care : an official publication. Am Assoc Crit-Care Nurs. 2011;20(6):443–52. https://doi.org/10.4037/ajcc2011829.
42. Agard AS, Egerod I, Tonnesen E, Lomborg K. From spouse to caregiver and back: a grounded theory study of post-intensive care unit spousal caregiving. J Adv Nurs. 2015;71(8):1892–903. https://doi.org/10.1111/jan.12657.
43. Haines KJ, Denehy L, Skinner EH, Warrillow S, Berney S. Psychosocial outcomes in informal caregivers of the critically ill: a systematic review. Crit Care Med. 2015;43:1112. https://doi.org/10.1097/CCM.0000000000000865.
44. Mikkelsen ME, Jackson JC, Hopkins RO, Thompson C, Andrews A, Netzer G, Bates DM, Bunnell AE, Christie LM, Greenberg SB, Lamas DJ, Sevin CM, Weinhouse G, Iwashyna TJ. Peer support as a novel strategy to mitigate post-intensive care syndrome. AACN Adv Crit Care. 2016;27(2):221–9. https://doi.org/10.4037/aacnacc2016667.

Chapter 26
Training Providers in Family-Centered Care

Erin K. Kross and Catherine L. Hough

Introduction

Each year, over 30,000 resident physicians begin their journey as medical providers, learning their trade by actively providing care to millions of patients each year in the United States alone [1]. Training resident physicians (and other clinicians in training) to provide family-centered care is essential both in the present—given the large footprint of resident care provision—and in the future of medical practice. In this chapter, we will discuss key aspects of training providers in family-centered care, with a focus on resident physicians. We will begin with a review of studies of directed educational programs intended to promote family-centered care. Next, we will consider the impact of the care environments in which we practice and train providers. Third, we will explore the importance of self-care and programs that incorporate provider wellness into training. We will present recent guidelines relevant to training. And finally, we will discuss opportunities to improve the evidence base regarding training providers in family-centered care.

Directed Educational Activities

Effective training of providers can be achieved through direct training and educational activities to teach house officers how to respond to family needs and provide family-centered care. Given the importance of high-quality family communication to family-centered care and family-centered outcomes, communication training

---

E. K. Kross (✉) · C. L. Hough
Division of Pulmonary, Critical Care and Sleep Medicine, Harborview Medical Center, University of Washington, Seattle, WA, USA
e-mail: ekross@uw.edu

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_26

programs are an appealing intervention to improve the quality of communication in the ICU. In the ICU setting, a family conference is a key event which often defines the goals of care for the patient, facilitates shared decision-making between the ICU team and surrogate decision-makers, and shapes the experience of the family involved in a patient's care [2, 3]. Several approaches to teaching the ICU family conference have been described, including the use of simulation or structured feedback from faculty [4, 5]. Options for teaching the ICU conference include dedicated communication skills training programs or workshops that occur outside of clinical training or a more integrative approach which incorporates didactics and simulation training into critical care rotations. Advantages to the integrative approach include the ability to use internal resources with less interruption to the clinical schedule. There are several key features that should be ensured when developing a training program in order to provide a safe environment for training (Table 26.1). Some of these include having faculty champions and buy-in from program directors and other leaders in the training program, creating space and time for learner reflection, and creating ground rules for learner-centered expectations and faculty evaluator feedback.

Several different types of training programs have been described in the literature. The critical care training program at the Montefiore Medical Center at Albert Einstein College of Medicine used family meeting simulation training along with a didactic lecture and case series of discussions and showed that their training program increased trainee level of comfort and performance of specific communication tasks including agenda setting, provision of meeting summary, and creation of follow-up plans [5]. A different type of training program has been described by a multidisciplinary group at Scripps Mercy Hospital where they sought to train interdisciplinary teams of ICU clinicians in communication with families of critically ill patients to improve staff confidence in communicating with families and improve family satisfaction with their experiences in the ICU. This program trained a group of multidisciplinary staff (including residents) through guided readings about communication techniques, brief didactics, and case simulation exercises (role play) and found that participants had improvement in self-reported confidence but they did not find differences in overall family satisfaction in the ICU before and after the intervention [6]. Despite investigators detecting no change in overall satisfaction,

Table 26.1 Key strategies for ensuring a safe environment for communication skills training [5]

Have dedicated faculty champion(s) who focus on developing rapport with learners, setting the tone for simulation encounters, and debriefing with faculty and with learners after simulation encounters
Ensure buy-in from program directors and other clinical leaders in the training program
Ensure learners have space and time for reflection before and after the simulation encounter
Provide learners with ground rules to help set expectations, emphasizing learner-centered aspects of the activity, the role of the faculty evaluator, and provide learners with mechanisms to respond to intrasimulation crisis
Provide faculty evaluators with ground rules about feedback and debriefing, including specific, learner-specific feedback with active listening and elicitation of reflections from learners

family members did report higher satisfaction after the intervention in several important domains, including decision-making in the ICU, increased frequency of communication with nurses and doctors, and increased honesty of information.

Evidence supports the use of competency-based modules and simulation in teaching invasive procedures [7]. Many training programs currently use this learning approach for procedures such as central line placement by providing learners with specific structured components and gradually increasing responsibility. Opportunity exists to expand this procedural-training framework in innovative ways to teach house staff to respond to family needs and provide family-centered care through the family conference. We have developed and are utilizing an approach to family conference training for internal medicine residents during their medical ICU rotation that combines didactic training, observation of others performing the procedure, supervised practice with feedback, and determination of competency to perform the procedure [8]. The five components of this ICU family conference learning module are (1) residents view a brief instructional video created by VitalTalk [9] with an overview of seven components of a successful family conference; (2) residents conduct at least two supervised family conferences; (3) supervisors use a standardized teaching and evaluation form; (4) residents document the family conference in a procedure log; and (5) residents document the family conference in the electronic medical record using a note template.

Programs developed to teach house staff effective, evidence-based strategies for family communication should be careful to evaluate both learner-specific outcomes and patient and family outcomes. Communication training programs have consistently shown an improvement in clinician-reported communication skills and comfort with family communication training [4–6, 10–14], but few have examined patient- or family-centered assessments or outcomes. These constructs are important to distinguish between because trainee self-assessments of competence do not correlate with family ratings of quality of communication [15]. One randomized trial examined an educational program for residents and nurse practitioner students using didactic teaching, skills practice using simulation, and reflective discussion and found that the skills-based intervention did improve trainee self-assessments and standardized patient evaluations, but this improvement in self-assessment came without any change in the primary outcome which was patient and family ratings of quality of communication. They also found no change in patient or family ratings of quality of end-of-life care and found a slight increase in patient-reported symptoms of depression [16]. This study highlights the importance of not relying on trainee self-assessment outcomes alone when studying these types of educational interventions.

The Influence of Environment

While didactics, group discussions, simulation, and role playing all contribute to a resident's education, residency is an intense experience governed by hands-on learning. The environment in which residents train is more like a crucible than a vacuum; a great many influences come together to form the culture and the hidden curriculum [17] which shape many aspects of both training and patient care. Residents may be most influenced by their peers—other residents in training, with whom they spend most of their time. The attitudes, behaviors, and language used by attending physicians and other faculty may have a disproportionate impact, as may the views and actions of other clinicians, such as nurses and respiratory and physical therapists. Incorporation of supportive care services which focus on the family's role during acute and chronic illness, such as palliative care and social work, into the workflow of residents likely promotes more family-centered care. Beyond the impact of individuals, processes of care and hospital policies can have a profound influence. For example: Are families included in the discussions on rounds? Are families welcomed at the bedside with open visiting hours? Can families choose to be present during procedures and cardiopulmonary resuscitation, and is there adequate staff to ensure family presence is safe and supported? The promotion of family-centered care on a hospital level conveys a strong message about its importance. A recent qualitative study supported this idea that institutional culture and policy may impact the development of professional attitudes, particularly for trainees [18]. It may be that the most effective educational approach is actively working to promote initiatives to advance family-centered care within hospitals and healthcare systems. Similarly, it is likely that the policies and priorities of individual training programs have a significant impact on the importance of family-centered care for clinicians in training. For example: Are there faculty champions within the training program who model and advocate high-quality family-centered care? Are residents routinely evaluated on their ability to provide family-centered care? Is the family conference specifically evaluated as an entrustable professional activity for residents and fellows on specific rotations such as the medical ICU?

The Importance of Self-care

Perhaps even more important than the external is the internal environment, the well-being of our trainees. The impact of emotional health on job satisfaction and the quality of care by providers has become clearer over time, with effects including burnout and even suicide [19, 20]. Residents are at especially high risk of burnout, a syndrome of emotional exhaustion, depersonalization, and sense of low personal accomplishment, with a prevalence higher than 75% among internal medicine trainees [21, 22]. While it is likely that the provision of patient- and family-centered care may prevent burnout by creating purpose and opportunities for human interactions within training, it is even more likely that an emotionally exhausted and depersonalized provider will not be able to fully engage in this care [18]. Mindfulness, yoga, and other stress-reduction techniques have been offered in many residency training programs, as well as more comprehensive wellness programs which are becoming common in medical centers and universities. Indeed, there appears to be a growing recognition that the highest-quality medical care requires providers to be in touch

Fig. 26.1 Domains of wellness and examples of activities to promote self-care. Wellness is represented by the central hexagon (*rainbow*). Six domains of wellness are represented by the middle ring. Examples of self-care activities are represented in the outer ring, organized by applicable wellness domains

with their own humanity, a feat only possible if patient care is complemented by self-care [23, 24]. Figure 26.1 presents domains of wellness and potential opportunities for trainees to engage in care of the self.

The intellectual and emotional intensity of critical care medicine may be a particular risk for burnout, and residents may need additional support during their ICU rotations. The ICU curriculum can incorporate opportunities for reflection and group support, also reinforcing the concept that self-care is as important as other educational topics. One such example is "Death Rounds," a facilitated discussion about experiences with the care of dying patients [25]. Beginning at the University of Washington's Harborview Medical Center in 2000, internal medicine residents rotating through the medical ICU attended Death Rounds together near the end of the rotation to discuss specific patients who had died that month under their care. The goal of the conference was to provide the residents with a chance to share their thoughts and feelings about the difficulty of caring for dying patients and to reflect on opportunities to improve the quality of end-of-life care for both patients and their families. A survey conducted in 2002 indicated that Death Rounds was a valuable experience that improved residents' ability to cope with and care for dying patients. Indeed, Death Rounds has become a key part of the MICU experience, providing a much-needed "diastole" for the residents and attending physicians alike. The format has allowed evolution and flexibility to accommodate the needs of the medical team, including peer support and a time to remind each other to practice "intensive self-care." The success of Death Rounds and greater need for such an opportunity to support each other as a care community is reflected in its permanent spot in the curriculum in our medical ICU rotation, nearly 20 years later, and its spread to other ICU services (such as neurocritical care [26]) and other universities across the country [25, 27] and world.

The rise of the Schwartz Rounds program, an interdisciplinary discussion of the psychological and emotional aspects of patient care, at healthcare centers around the world provides a growing example of the importance of community and conversation in improving providers' ability to cope and deal with stress. Schwartz Rounds participants have endorsed the positive impact on patient- and family-centered care at the individual and institutional level [28].

Recent Guidelines and Knowledge Gaps

While a growing body of evidence suggests methods we can use to better support training of house staff in the delivery of family-centered care in the ICU, many knowledge gaps persist. The Society of Critical Care Medicine recently published updated guidelines for family-centered care in the ICU [29], endorsed by many other professional societies and groups. As one of the several domains of family-centered care, these evidence-based guidelines included examination of whether communication training programs in the ICU for clinicians, including education or simulation, improve family psychological symptoms, family ratings of quality of dying, patient- or family-rated quality of communication, family satisfaction with communication, clinician self-efficacy, or clinician psychological symptoms. They also examined the impact of family presence in a variety of settings and experiences within the ICU. The guidelines conclude that based on the existing evidence, including the known burdens to patients and families when there is poor communication and demonstrated improvements in clinician-reported skills and comfort following communication training, that ICU clinicians should receive family-centered communication training as one element of critical care training. However, the current evidence does not support one specific type of training program, and further research is needed to understand whether and how training programs can be implemented to improve family-centered outcomes. Similarly, further research is needed to better understand the impacts on clinicians, patients, and families, as open policies are adapted in support of family presence and engagement in the ICU (Table 26.2).

Table 26.2 Knowledge gaps and future research opportunities focused on teaching trainees to provide family-centered care [29]

Strive to increase use of family-reported outcomes as the standard for quality of family communication, with cautious use of self-assessment tools
Collect data on cost of implementing communication training programs
Develop more long-term follow-up studies as skills may dissipate over time
Comparison of different communication teaching modalities such as didactic training versus role play versus simulation
Further investigation of possible risks to patients such as increased depression
Measure the impact of educations/training programs on family member outcomes and ICU length of stay and costs

Conclusion

Opportunities to train providers in family-centered care are present throughout the hospital—not only in lecture halls and simulation suites but also in our team rooms, our family meeting areas, our ICU hallways, and at our patients' bedsides. Additionally, facilitating our trainees' focus on self-care inside and outside the hospital is likely to enhance both provision of family-centered care and the ability to be emotionally present and able to engage in the deeply human aspects of medicine which offer sustenance and satisfaction in our chosen profession.

References

1. Jena AB, DePasse JW, Prasad V. The declining demand for hospital care as a rationale for duty hour reform. J Gen Intern Med. 2014;29:1400–3.
2. Hurd CJ, Curtis JR. The intensive care unit family conference. Teaching a critical intensive care unit procedure. Ann Am Thorac Soc. 2015;12:469–71.
3. Curtis JR, White DB. Practical guidance for evidence-based ICU family conferences. Chest. 2008;134:835–43.
4. McCallister JW, Gustin JL, Wells-Di Gregorio S, Way DP, Mastronarde JG. Communication skills training curriculum for pulmonary and critical care fellows. Ann Am Thorac Soc. 2015;12:520–5.
5. Hope AA, Hsieh SJ, Howes JM, Keene AB, Fausto JA, Pinto PA, et al. Let's talk critical. Development and evaluation of a communication skills training program for critical care fellows. Ann Am Thorac Soc. 2015;12:505–11.
6. Shaw DJ, Davidson JE, Smilde RI, Sondoozi T, Agan D. Multidisciplinary team training to enhance family communication in the ICU. Crit Care Med. 2014;42:265–71.
7. Huang GC, McSparron JI, Balk EM, Richards JB, Smith CC, Whelan JS, et al. Procedural instruction in invasive bedside procedures: a systematic review and meta-analysis of effective teaching approaches. BMJ Qual Saf. 2016;25:281–94.
8. Whitaker K, Kross EK, Hough CL, Hurd C, Back AL, Curtis JR. A procedural approach to teaching residents to conduct intensive care unit family conferences. J Palliat Med. 2016;19:1106–9.
9. Vitaltalk. [Cited 2018 Jan 17]. Available from: http://vitaltalk.org/.

10. Boss RD, Urban A, Barnett MD, Arnold RM. Neonatal critical care communication (nc3): training NICU physicians and nurse practitioners. J Perinatol: official journal of the California Perinatal Association. 2013;33:642–6.
11. Bays AM, Engelberg RA, Back AL, Ford DW, Downey L, Shannon SE, et al. Interprofessional communication skills training for serious illness: evaluation of a small-group, simulated patient intervention. J Palliat Med. 2014;17(2):159–66.
12. Downar J, Knickle K, Granton JT. Using standardized family members to teach communication skills and ethical principles to critical care trainees. Crit Care Med. 2012;40:1814–9.
13. Hales BM, Hawryluck L. An interactive educational workshop to improve end of life communication skills. J Contin Educ Heal Prof. 2008;28:241–8; quiz 249–55
14. Meyer EC, Sellers DE, Browning DM, McGuffie K, Solomon MZ, Truog RD. Difficult conversations: improving communication skills and relational abilities in health care. Pediatr Crit Care Med. 2009;10:352–9.
15. Dickson RP, Engelberg RA, Back AL, Ford DW, Curtis JR. Internal medicine trainee self-assessments of end-of-life communication skills do not predict assessments of patients, families, or clinician-evaluators. J Palliat Med. 2012;15:418–26.
16. Curtis JR, Back AL, Ford DW, Downey L, Shannon SE, Doorenbos AZ, et al. Effect of communication skills training for residents and nurse practitioners on quality of communication with patients with serious illness: a randomized trial. JAMA. 2013;310:2271–81.
17. Downar J. Resources for educating, training, and mentoring all physicians providing palliative care. J Palliat Med. 2018;21:S57–62.
18. Dzeng E, Colaianni A, Roland M, Chander G, Smith TJ, Kelly MP, et al. Influence of institutional culture and policies on do-not-resuscitate decision making at the end of life. JAMA Intern Med. 2015;175:812–9.
19. Pulcrano M, Evans SR, Sosin M. Quality of life and burnout rates across surgical specialties: a systematic review. JAMA Surg. 2016;151:970–8.
20. Devi S. Doctors in distress. Lancet. 2011;377:454–5.
21. Dyrbye LN, West CP, Satele D, Boone S, Tan L, Sloan J, et al. Burnout among U.S. medical students, residents, and early career physicians relative to the general U.S. population. Acad Med. 2014;89:443–51.
22. Shanafelt TD, Bradley KA, Wipf JE, Back AL. Burnout and self-reported patient care in an internal medicine residency program. Ann Intern Med. 2002;136:358–67.
23. Bodenheimer T, Sinsky C. From triple to quadruple aim: care of the patient requires care of the provider. Ann Fam Med. 2014;12:573–6.
24. Linzer M, Levine R, Meltzer D, Poplau S, Warde C, West CP. 10 bold steps to prevent burnout in general internal medicine. J Gen Intern Med. 2014;29:18–20.
25. Hough CL, Hudson LD, Salud A, Lahey T, Curtis JR. Death rounds: end-of-life discussions among medical residents in the intensive care unit. J Crit Care. 2005;20:20–5.
26. Khot S, Billings M, Owens D, Longstreth WT Jr. Coping with death and dying on a neurology inpatient service: death rounds as an educational initiative for residents. Arch Neurol. 2011;68:1395–7.
27. Kitzes JA, Kalishman S, Kingsley DD, Mines J, Lawrence E. Palliative medicine death rounds: small group learning on a vital subject. Am J Hosp Palliat Care. 2008;25:483–91.
28. Lown BA, Manning CF. The Schwartz Center rounds: evaluation of an interdisciplinary approach to enhancing patient-centered communication, teamwork, and provider support. Acad Med. 2010;85:1073–81.
29. Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, et al. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. Crit Care Med. 2017;45:103–28.

Chapter 27
Child Life in the Adult ICU: Including the Youngest Members of the Family

Jaime E. Bruce and Kathleen McCue

Throughout this book, a series of chapters provide an in-depth look at the impact of the critical care unit experience on families who are facing the reality of having a seriously, perhaps terminally ill or injured loved one. These chapters are primarily contributed by professionals who are focused on the adult family members of the patient. However, it is important to be aware of a new professional group with a significant role in the adult ICU, child life. Communication issues, decision-making challenges, negative psychosocial sequelae, and traumatic grief are all components of what now may be referred to as the family intensive care unit syndrome. In order to document both the depth and intensity of this syndrome, and to plan for possible ways to ameliorate its devastating impact, we must consider the needs and reactions of children as well as adults in the family of the intensive care patient.

Child life, as an applied psychosocial service, has been available to pediatric patients and their family members on a small scale since the early 1900s. However, it was only in the 1950s and 1960s that the impact of health-care encounters on children's developmental, social, and emotional needs became well-documented in books and articles. In 1982, an organization called the Child Life Council came into existence, and individuals who worked to provide for those needs unified under the title of child life specialists. This organization is now the Association of Child Life Professionals, and it is the only group that establishes standards, educational requirements, and certification for professionals in the field of child life.

J. E. Bruce (✉)
Middle Tennessee State University, College of Behavioral and Health Sciences, Murfreesboro, TN, USA

Monroe Carell Jr. Children's Hospital at Vanderbilt, Department of Child Life and Volunteer Services, Nashville, TN, USA

K. McCue
Children's Program, The Gathering Place, Cleveland, OH, USA

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_27

This chapter will first briefly describe the profession of child life, including philosophy, mission, training, credentials, and the profession's role within the pediatric environment. The more recent movement of child life into the adult medical world will be documented, with special emphasis on child life services when families of adult patients are experiencing highly challenging medical events, such as trauma, complex and debilitating illness or injury, or end of life. Child life currently provides a wide range of services to these families, especially to the children in the family who are impacted by an adult's critical medical status. Finally, specific descriptions of the role and function of a child life specialist in an adult intensive care unit will be provided, along with tools to assist other professionals in meeting the needs of the expanded family, including any infants, children, and adolescents who are impacted by the hospitalization of an adult in the challenging environment of an intensive care unit.

Philosophy and Standards for Child Life

The Association of Child Life Professionals (ACLP) is constantly working to clarify and modernize the mission and vision of the profession. The current Mission Statement [3] is: *We, as child life professionals, help infants, children, youth, and families cope with the stress and uncertainty of illness, injury and treatment. We provide evidence-based, developmentally-appropriate interventions including therapeutic play, preparation and education to reduce fear, anxiety and pain.* In a portion of the Vision Statement [3], the settings in which child life specialists may provide their services are expanded to state: *The philosophy and practice of child life will be applicable to any health care setting and transferable to other community settings or situations in which the potential for infants, children and youth to cope, learn, and master is placed at risk.*

A significant level of training and skill is necessary to provide the services needed for at-risk populations in any of these settings. In order to assure that a minimal level of skill has been acquired by the incoming child life specialist, educational and credentialing standards have also been set by ACLP. This skill level is measured by the requirements established by the Child Life Certifying Commission, the ACLP, and a private testing agency. At this point in time, a bachelor's degree in child development, family development, psychology, counseling, or other related field plus a full semester clinical internship are the basic requirements. In order to achieve certification, it is also necessary to pass a comprehensive written certifying examination. When those standards are met, the individual is eligible to hold the title of Certified Child Life Specialist (CCLS). However, the majority of child life specialists have continued their education to achieve a master's degree or higher. In 2022, the Child Life Certifying Commission will require a minimum of a master's degree to achieve the title of Certified Child Life Specialist. At this point in time, there is no state or national licensure in the United States for a professional in child life.

Much of the early child life programming focused on addressing and minimizing the negative emotional and development consequences of an inpatient hospital stay for a child. However, during the late 1900s, child life programming expanded to include emergency services, all aspects of a child's surgical experience, outpatient and specialty clinics, pediatric hospice and palliative care, and others. Even private pediatric medical offices and dental offices found value in the utilization of child life services for their particularly stressed or challenged patients and families. Children today must face a wide array of difficult and potentially traumatic life events, and often parents and other responsible adults are not sure of the best ways to help and support the children for whom they are responsible. Child life specialists can, as a result of their training and experience, guide both children and adults to positive coping and successful outcomes.

As a result of the demonstrated success of child life professionals in the pediatric arena, the American Academy of Pediatrics has developed a policy statement on child life services. The most recent revision of the statement may be found in *Pediatrics* [1]. It includes strong recommendations for the inclusion of child life services across many different settings and concludes: *Child life services should be delivered as part of an integrated patient- and family-centered model of care and included as a quality indicator in the delivery of services for children and families in health care settings.*

Only in the last two decades has child life begun to consistently contribute to efforts to empirically document the value of various services and interventions. These services, skills, and competencies will be briefly reviewed later in this section. However, as early as 1988, a comprehensive study evaluated several dimensions of the impact of child life programming. The evaluation by Wolfer et al. [13] of a model child life program indicated less emotional distress, better overall coping during hospitalization, a clearer understanding of procedures, and a more positive physical recovery for children enrolled in the study sample. Other more recent studies [2, 5, 6, 8] have found that child life interventions in specialty areas are correlated to lessening of children's fears and producing higher parent satisfaction ratings of the total care experience.

Child Life Competencies

The Association of Child Life Professionals Official Documents [3] denote the following five areas of competency in which the Certified Child Life Specialist should be proficient: (A) care of infants, children, youth, and families; (B) professional responsibility; (C) education and supervision; (D) research fundamentals; and (E) administration.

For the purposes of this chapter, special attention will be paid to the two competencies that most frequently are connected to child life work with children of adult patients. This includes competency A (care of infants, children, youth, and families) which speaks to the clinical services of the child life specialist and competency B (professional responsibility) which reflects the interdisciplinary functions of child life.

Care of Infants, Children, Youth, and Families

The primary clinical role of the child life specialist in the health-care setting is the direct care of patients and families. The child life professional utilizes knowledge based on theories of human development, family systems, and play to address the psychosocial and developmental needs of patients of all ages and family members. Through formal and informal assessment techniques, child life is tasked with creating a plan of care that incorporates developmentally supportive interventions geared at preparing the patient and family for the health-care experience. Specialists are trained in communicating information about medical diagnoses and procedures in accurate but minimally threatening language that is manageable for children and adolescents.

Through a practice known as psychological preparation, child life specialists are able to describe medical procedures to patients and family members of varying ages, backgrounds, and levels of health-care experience. They have a basic knowledge of medical terminology, typical treatment plans, and clinical procedure that allows preparation techniques to best meet the needs of each member of the family. Sequential photographs of procedures may be utilized to illustrate what the patient and family will experience. The specialist will employ his or her knowledge of varying developmental levels and cognitive abilities to identify the appropriate combination of tools to assist each individual in the family in gaining an understanding of the experience. Throughout preparation activities, the specialist will be observing both verbal and nonverbal cues to ascertain points of distress. When distress is noted, the specialist adapts the teaching to the individual's level of tolerance. A key component of psychological preparation is instruction on coping strategies that will help the child or adult through the stressful health-care situations. Positive coping strategies such as stress reduction techniques, relaxation exercises, and distraction will promote a sense of control and feeling of being a participant in the care plan.

Professional Responsibility

The child life specialist is an integral part of the interdisciplinary team with a unique skill set and knowledge base. In this role, the specialist is charged with the responsibility to practice within "the scope of professional and personal knowledge and skill base" [3] while communicating and advocating for the needs of patients and families. The child life professional coordinates information regarding assessments and care plans with other members of the health-care team, especially psychosocial team members, through documentation in the medical record as well as participation in clinical rounds and family care conferences.

Child Life in the Pediatric Intensive Care Unit

The Pediatric Intensive Care Unit (PICU) provides care to the most critical of pediatric patients. The patients in this setting are admitted for life-altering and life-threatening diagnoses such as a traumatic brain injury, complex genetic disorders, and congenital heart defects. Many of these patients require life-sustaining medical interventions including intubation and sedation rendering them unable to benefit from the usual patient support activities provided by child life on less acute units. However child life interventions continue to be provided to:

- Parents
- Other adult family members
- Siblings on the patient
- Peers and other members of the community

When a child or adolescent is admitted to the PICU, families often request guidance and support in sharing medical information and addressing psychosocial issues for siblings, other family members, and friends. Child life professionals are also consulted to assess the multisensory environment of a PICU patient room to ensure it provides a family-centered physical setting to promote comfort, familiarity, and encouragement toward wellness. In the PICU, it is known that 5% of patients do not survive their admission [11]. Together with other members of the psychosocial support team including but not limited to chaplaincy and social work, the child life specialist plays an integral role in guiding families through the process and grief of losing a child.

Child Life in the Adult Intensive Care Unit

In a predictable transition from pediatric to adult health care, child life professionals began developing programs providing services to the children and family members of seriously ill adults. In the 1990s, many child life specialists worked in large, tertiary level hospitals and, although assigned to pediatrics, found themselves responding to requests for assistance from adult care providers. Often these requests were initiated as a result of highly distressed or emotional children visiting a seriously ill adult inpatient. (For suggestions for ways that health-care staff can further assist the children of adult patients, see Appendix A.) Because staff for adult patients often had no training or resources to assist these children, they reached out to the one professional group available who was specifically trained to deal with such issues. Very little literature was available on this topic, and a child life specialist [9] published the first book guiding both parents and professionals in dealing with a parent's illness. A publication by a physician [7] became available next, addressing the needs of children who have a parent with cancer. More recently, a comprehensive article [12] described child life consultation with staff and families when a parent is seriously ill. According to this article, 25% of cancer patients have underage children in the home, and between 3.5% and 5% of children under the age of 18 will experience the death of a parent.

One of the most common concerns of adult family members when a parent is seriously ill is how to help the children in the family. Although most research has involved cancer patients, there is much documentation of both short- and long-term negative impact of seriously ill adults on children. Phillips and Prezio [10] summarize this literature and describe an intervention program for families facing adult cancer. The program utilized child life specialists and resulted in significant amelioration of children's issues, including improved communication skills, reduced anxiety, increased feelings of security, and improved school performance. A pilot program reported by Cross and Bruce [4] describes the outcome of adding child life services to adult intensive care units and reports a high level of both family and staff agreement that child life specialists had a positive impact on parent's and families' ability to cope. Literature on needs and guidelines for child visitation to the adult ICU was summarized in this article.

At the present time, there are child life specialists providing interventions to adult patients, their children, and other family members in many hospitals. The services may be provided on a consultation basis, or child life may be an integral component of an adult patient unit with a dedicated child life professional available at all times in that particular service. Child life is most often found in intensive care services, cancer centers, and palliative care and hospice services. The remainder of this chapter will focus on the needs of children of adult patients in the intensive care unit, the role that child life can play in assisting these families, and tools for other care providers to support children in critical care environments.

Before going into specific detail regarding the services provided by child life in the adult intensive care unit, it would be useful to give an overview of the different categories of interventions that are available to patients, families, and the health-care team. Obviously, each service category is individualized to the family situation in which it is provided. All considered services are offered in a collaborative manner with the other members of the health-care team and are based on the issues and needs that are identified by the family. The following list (Fig. 27.1) provides a summary of general interventions available by child life professionals.

To better conceptualize these interventions provided by child life specialists in the adult ICU, two examples of patient and family scenarios are introduced below. The remainder of this section will describe in detail interventions relevant to each case.

Patient and Family Scenario 1

Mr. Smith is a 57-year-old male admitted to the neurointensive care unit with a traumatic brain injury sustained in a motor vehicle crash (MVC). His prognosis at this time is unclear, and he remains intubated and sedated. Prior to this accident, Mr. Smith was an active and healthy husband, father, and grandfather. He has a wife and two sons ages 10 and 12 years old. From a previous marriage, he has a 31-year-old

- Explanation of the medical situation to children and other family members
- Ongoing support for children and family members during acute hospitalization, with special attention to maintenance of normal routines and activities, such as school, work, and family relationships
- Assistance to adult family members in dealing with high-stress behaviors and other problematic behaviors in children
- Direct work with children through play, therapeutic art and counseling to manage emotional reactions to the intense medical situation
- Plans and preparation for children/family visitation and support during such visiting episodes. See Appendix B for further information on visitation
- Preparation for status change of patient, such as procedures, change in appearance, and change in mental status
- Preparation of children and family members for patient discharge, especially when discharge includes significant change in family function or the patient's role in the family
- Acknowledgment of and assistance in planning family milestone events, such as birthdays and holidays
- Legacy work with patients and other adult caregivers
- Wide range of services and interventions to assist all family members, especially children, with end-of-life situations
- Consultation regarding child/family-oriented physical environment in the ICU and the impact of sensory experiences on children
- Provision of appropriate resources, both within the hospital and after discharge or death, to continue to assist children and families in coping with the ICU experience

Fig. 27.1 Child life interventions and services in an adult intensive care unit

daughter who is mother to his 3-year-old granddaughter. Mr. Smith provides child care to his granddaughter three days a week while her mother works. In addition to his immediate family, Mr. Smith is a beloved member of the local Little League program and has been a volunteer baseball coach for many years.

Patient and Family Scenario 2
Mrs. Garcia is a 38-year-old female admitted to the medical intensive care unit with complications and severe pain related to advancing metastatic ovarian cancer. She is on heavy pain medications and has limited energy to engage with family or staff. Mrs. Garcia along with her husband and 8-year-old daughter immigrated to the United States less than a year ago. Mr. Garcia presents as a distraught and overwhelmed husband and father trying to balance work, his daughter, and time at the hospital. He has expressed reluctance to share information about his wife's condition with his daughter, although she has been present at the bedside during this and previous hospitalizations. Mr. and Mrs. Garcia speak primarily Spanish, but their daughter speaks both Spanish and English.

Child Life Services to Adult Family Members

When child life provides services in the pediatric arena, the initial contacts are typically with children themselves even when a family member is present. However, when working with the children of adult patients, the first steps in assessment always involve some discussion with an available parent or other adult family member. In Family Scenario 1, the initial assessment would reveal the wide range of children impacted by Mr. Smith's injury and hospitalization. This initial assessment process by child life would focus on the developmental level and current needs and understanding of each child related to the health situation of Mr. Smith. Mrs. Smith would probably be the primary informant regarding the needs of her two sons and could assist with any additional contacts needed in relationship to the other children in Mr. Smith's life, specifically the children he coaches in Little League.

This initial assessment with appropriate adult family members is the cornerstone of the planning for services for both adults and children by child life. Information to children about Mr. Smith's diagnosis and prognosis, plans for the children's visitation, and interventions related to specific emotional, social, and behavioral issues the children may develop would all be dependent on collaboration with adult family members and with the health-care team.

When a parent is seriously ill or injured, one of a well parent's first concerns is "How do I tell my children about this, and what do I say?" Child life is in a unique role to provide information to adults in order to empower them to appropriately inform their children about a critical medical situation in the family. Rather than asking a parent "How are your children?" which usually elicits a response of "Fine," child life will ask such open-ended questions as "What have you told your children?," "What were their emotional reactions?," and "What specific questions did they have?". It will be very important to know if Mr. Smith's two preteen sons tend to be significantly anxious, if they show their emotions openly, if they have a good social support network, if they have had any recent losses or negative medical experiences themselves, and if they are experiencing success or problems in school and other life activities. Only a parent can provide this information, and it will guide the path of future family interventions, to both the adults and the children.

Sometimes distraught parents and other adult family members need assistance in talking to children about the medical situation. Fear and distress can negatively impact providing an accurate, supportive message to children. These tough conversations can happen at the hospital, via telephone or Internet connections, or occasionally in person in the family's home. Child life often functions in the role of support person to assist the parent with the words and answers to questions needed to enhance a child's ability to cope. Mr. Smith's two sons might accompany their mother into the hospital for a meeting with child life, social work, pastoral care, nursing, and/or other medical staff, to receive the details of their father's condition. While it is likely not appropriate for the Little League team to visit the ICU, child life could provide the script needed for coaches or other fathers to explain the situation in a manner that would reduce the children's anxiety. The mother of the 3-year-old granddaughter would need a special plan based on the developmental level of her child, in order to maximize understanding. In all these situations, child life would provide parents and family caregivers with written information on helping these children emerge from this experience with trust and safety intact and with the knowledge and coping skills to face difficult times and proceed through them successfully.

Probably nothing is more distressing to adults than the knowledge that a life-threatening disease in self or spouse is progressing and that their children may have to grow up without the love, support, and teaching that the parent assumed they would be present to provide. In Family Scenario 2, Mr. Garcia is in an unimaginable state of angst, trying to balance his family responsibilities. Just as in the situation with Mrs. Smith, a thorough assessment of his daughter's knowledge and emotional status will guide the next steps in child life intervention. It may be possible and preferable to include Mrs. Garcia in this assessment if the medical situation allows, to get a sense of her wishes related to her daughter. Building a trusting relationship with Mr. Garcia will hopefully reduce the barriers that might interfere with providing the daughter with the support and education she needs.

In situations of advancing disease, it is important for child life to help parents learn how to be both honest and hopeful with children at the same time. Many parents are afraid to allow children to think about a negative outcome or a death when an adult family member is critically ill. (See Fig. 27.2.) However, the practice of child life, based on both child development theory and empirical data, makes it clear that children proceed through stress, trauma, and loss best when prepared for probable outcomes, even sad outcomes. Helping Mr. Garcia to understand that his daughter will cope best and move forward in her life best if he can be honest with her now is foundational to working with this family. Case examples, written material, and even encouragement from other parents with similar experiences may help Mr. Garcia allow more open communication with his daughter.

Another frequent task of child life in end-of-life situations is to assist either the ill or well parent with plans for legacy activities. Planning connections and messages for children even after a parent has died is painful but important work. Although this process is an emotional one, most parents find peace and comfort in preparing some sort of legacy for their children, in the event that they do not survive. These messages can take the form of cards or letters, video and audio recordings, gifts, instruction lists, and more. Mrs. Garcia may be in a position to begin this process and may need a support person by her side as she decides what messages she wants to leave for her daughter.

In summary, child life services to adult family members of an adult ICU patient always begin with a thorough assessment of the children involved. Trusting relationships with the patient, when possible, and with well family members will open the door to interventions with the children. Providing parents and others with the information they need on children's reactions to acute medical situations may empower parents to work with their children themselves, or parents may request that child life assist or take the lead in educating and supporting the children of an adult intensive care unit patient. As the critical care experience unfolds and changes, child life will monitor the family and be available to assist in helping children manage any new issues that may arise. If end of life becomes a reality for the family, child life can begin working on issues of grief and loss, can provide useful materials, and can make community referrals for continued support for the children in the family.

Birth–2 years	Beginning awareness of separation
2 years–4 years	Beginning cognitive awareness; minimal emotional response, usually imitation of adults
4 years–6 years	Increasing cognitive understanding; beginning personal emotions, including denial and empathy
6 years–9 years	Understands fully and is fascinated; strong emotional reactions, worries, and wants to avoid
9 years–12 years	Acceptance, working on spiritual meanings
12+ years	Personal responses developing; emotions may be open or hidden; may reject family religion

Children's responses to death by developmental level

Infants/toddlers

- Cannot "understand" a family crisis cognitively
- Will show distress behaviorally
- Respond to emotional distress in adult caregivers
- Distress behaviors often follow changes in routine

School age children

- Performance decline, especially at school
- Compensatory behavior, being "extra" good
- Mood discrepancy, irritability, unpredictable
- Behavior change or problem
- Psychosomatic complaints

Preschoolers

- Withdrawal
- Anxious attachment
- Denial
- Thematic play
- Fears
- Regression

Adolescents

- Acting out, especially with drugs or alcohol
- Self-criticism and low self-esteem
- Sudden or unusual school problems
- Misdirected anger
- Loss of interest in usual activities

Fig. 27.2 Children's developmental understanding of death by age

Child Life Services to Child Family Members

After a child life specialist has completed an assessment with the adult family members and the choice is made to involve children in further intervention, the specialist would begin the process of coordinating with other members of the medical and psychosocial team. It is important to take into consideration such factors as the patient's current medical status, any planned medical procedures, the atmosphere of the unit, and available space to meet with children. In one university medical setting [4], a child life specialist developed a "safety assessment" that included key stakeholders from the ICU as well as the adult family members and children related to the patient. This practice was created to ensure optimal safety and dignity for the patient, child, and unit. If, for example, the unit was running a code in the vicinity of the patient at the time of the scheduled visit, the key stakeholders would make plans to postpone the visit to a less stressful time on the unit.

Often the first intervention involves a visit to the hospital by the children. This visit may or may not include seeing the patient. It is vital that a plan is in place for where the initial meeting will occur, who will be present, and what goals the family has for the visit. A specialist would identify a neutral place, preferably outside of the patient's room and away from medical equipment and personnel, and attempt to create a low-stress environment. The specialist may bring developmentally appropriate activities such as art supplies or toys to the room as both a means of cognitive and emotional assessment and a visual cue that normalizes the hospital setting. To begin the intervention, the child life specialist would build rapport with the child while simultaneously assessing his or her level of comfort, anxiety, and knowledge of the reason for this visit. Often child life specialists will introduce their role as similar to a teacher, but one who teaches children about medical experiences and having a family member in the hospital. "Tell me what you already know about why you are here today" or "tell me what brought your father to the hospital," the specialist might ask. While the specialist likely already has this information from an adult family member, the child's perception of the visit is often different, and it is beneficial to hear the child's point of view. For more information on preparing children for a visit to an ICU, see Appendix A.

Once this in-person assessment has been completed and basic rapport has been established, the child life specialist will proceed with any number of appropriate activities. One such intervention includes medical education through facilitated play. In the case of Mr. Smith, while his sons may have received verbal information from their mother about the life-sustaining equipment being used in his care, the words and descriptions may not make sense without additional visual, verbal, and tactile information. For school-age children, the child life specialist can provide developmentally appropriate education utilizing a medical teaching puppet and real medical supplies (i.e., endotracheal tube, intracranial pressure monitoring supplies, intravenous catheters, and tubing). Photographs of larger equipment such as ventilators, VEEG monitors, and IV pumps can also be used to provide concrete visual information to the child. During such a session, equipment would be introduced individually and using simple, nonmedical explanations. For example, an ET tube can be described as a "special tube or straw used to give your dad's lungs the air that they need," and the ventilator is a "machine used to make sure he gets the perfect amount of air into his lungs and the perfect amount of air out." Children would be given the option to manipulate the equipment and ask questions at their own level of comfort. This type of activity could be simply educational or used as a psychological preparation for visitation at Mr. Smith's bedside.

In the case of Mrs. Garcia, a direct assessment with the 8-year-old daughter is also important as she has been present at the bedside during this and previous admissions, likely having overheard medical conversations in English between staff but receiving little information from her father on her mother's condition. An important aspect of this intervention will include identifying misconceptions about her mother's condition, current clinical status, and prognosis. These misconceptions should be noted and discussed with Mr. Garcia before corrections or disclosures are made to his daughter. To ensure that communication is clear and culturally sensitive, the use of a medical interpreter in conversations with both Mr. Garcia and his daughter is preferred.

When children are unable to come to the hospital for direct interaction with a child life specialist, technology (i.e., phone, Internet, FaceTime, and Skype) can be employed to provide similar assessments and interactions. Additionally, medical play supplies and supportive resources can be shared with the family to be used at home. Some child life specialists have the ability in their practice to make home or school visits, as approved by the children's parents, or refer to private practice specialists or community agencies with support services.

Families of ICU patients are often faced with the realization that their loved one will not return home immediately following discharge or may not survive this diagnosis or hospitalization. If Mr. Smith is moved to a rehabilitation facility, a child life specialist can prepare his children and grandchild for physical, cognitive, and functional differences. Furthermore, they can assist with making plans to negotiate the changes to routine at home that will be perpetuated during his continued recovery process. Although Mrs. Garcia's prognosis is unknown, memory-building activities can be initiated during her current hospitalization. Her daughter, with the assistance of a child life specialist, could engage in art activities including handprints, photography, or journaling projects that create a positive memory in the hospital as well as lasting artifacts in the event of Mrs. Garcia's death. When a parent or grandparent dies during admission to the hospital, a child life specialist can provide opportunities for memory-building activities pre- or postmortem as a way on of processing the event and memorializing the patient.

Conclusion

In this textbook, family intensive care unit syndrome is being conceptualized in depth for the first time. Although all members of an ICU patient's family are vulnerable to risk from this syndrome, the constellation most likely to be underserved are the children, grandchildren, and other minors that are significant in the patient's life. This particular group not only suffers from the immediate impact of a critical hospitalization of a loved adult but also, due to their susceptible stages of development and dependence, may carry the negative sequelae of these experiences into their later childhood and adulthood. Addressing family intensive care unit syndrome is not only about reducing immediate negative emotional responses but also about providing a preventive service to minimize mental health challenges in the future. The professional group most able to reduce the morbidity of family intensive care unit syndrome for these children is child life. In order to plan for child life services in an adult intensive care setting, consultation with the Association of Child Life Professionals (www.childlife.org) is the logical place to begin. Not only can child life provide the interventions and services needed by the children and their parents, but child life specialists can also support staff in the often emotional interactions with children who are coping with the serious illness or injury of an adult patient. With child life on the health-care team, children impacted by adult critical illness will not only avoid possible emotional and developmental pathology but can actually gain psychosocial skills to manage future life crises.

Appendix A: Tips for Helping Hospital Professionals Help Children of Adult ICU Patients

When talking to parents or family members about children:

- Determine what children in the life of the patient might be impacted by hospitalization.
- Ask open-ended questions about the children, their knowledge, emotional status, etc.
- Find out exactly what concerns the adult has about the children in the family.
- Stress the importance of honesty and age-appropriate information to children.
- Teach parents signs to watch for that may indicate problematic reactions of children.
- Offer visitation and other services as available at your hospital.
- Identify resources for children beyond the hospital and provide written material.

When interacting with children directly:

- Use language that is appropriate for the age and developmental level of the child.
- Find out from the child what he/she knows and thinks about the medical situation.
- Talk about emotions and reactions as much as about facts.
- Help the child to talk! Ask him or her about themselves, their friends, school, pets, etc.
- Use play and art to illustrate information or to allow expression of emotion.
- Explain what will be happening in the most immediate time frame, and plan to add additional information as the medical situation evolves and changes. Avoid overwhelming children with too many facts at one time.
- Provide opportunities for diversional play and art. Have simple materials like markers and paper, small toys, something for building, and something for hugging.
- Assure the child that the parent is being well cared for and you are all doing everything you can to help with recovery. However, be very careful about saying anything that could be construed later by the child as a lie.

Appendix B: Preparing Children for a Visit to a Seriously Ill Adult in ICU

From: **How to Help Children Through a Parent's Serious Illness**
Kathleen McCue, MA, LSW, CCLS

General Rule: If the child wants to visit a sick adult, and the hospital staff says it is allowed, it usually can be a positive event for both the child and the adult, with appropriate preparation and support.

Considerations to decide if the visit is appropriate:

1. Does the child want to go?
2. Does the sick adult want a visit from the child?
3. Can the sick adult tolerate a visit medically?
4. Will the hospital permit a visit by a minor child? Check the hospital rules and. then talk to the doctors and nurses about special arrangements.

A. Why should the child visit?

   (a) Opportunity to see that the adult is alive and being cared for.
   (b) Opportunity to achieve closure.
   (c) Reduce the fearful magical thinking and misunderstandings a child may have.
   (d) Reduce post-hospitalization anger and regret, especially in situations that are life-threatening.

B. Preparation at home for the visit.

   (a) Allows child to have first reactions in a safe place, away from the ICU.
   (b) Share pictures or drawings and/or describe in detail what the child will see, smell, feel, and hear.
   (c) Emphasize the emotions the child may experience: anxiety, fear, caution, and sadness.
   (d) Practice the visit: what can the child take for the adult, what can be said, can a hand be held, will the person be able to respond, what exactly will the child do when the actual visit takes place?
   (e) Things the child can do at the hospital: tell sick adult about his/her life, school, friends, activities, pets, etc.; give the adult a picture, drawing, poem, or something else created by the child; arrange the adult's cards on the wall and table or in a book; bring and distribute cookies or candy to the hospital staff; and create a communication book so that visitors can leave messages for the sick adult.

C. The visit itself.

   (a) Keep the focus of the visit on the child.
   (b) Keep the visit short so the child doesn't sit around worrying or imagining.
   (c) Help facilitate the conversation with open-ended questions to the child or prompt about the conversation or activities.
   (d) If the child is old enough, give him/her some private time with the adult.
   (e) Help the child say "good-bye," either for this visit or as a final good-bye.

D. After the visit.

   (a) Review with the child how the visit went. Help the child to feel good about anything he said or did that might have been helpful to the sick adult.
   (b) Have a picture of the adult looking healthy, to remind the child of the adult he/she will want to hold in mind.
   (c) Make a plan for any future visits or activities.

E. If the child doesn't want to visit.
    (a) Do not force a child to visit an adult in ICU.
    (b) Help the child to create something that can be sent to the hospital, a letter, poem, or picture.
    (c) Assure the child that the decision not to visit is OK, no need for guilt.

References

1. American Academy of Pediatrics. Child life services. Pediatrics. 2014;133(5). Retrieved from http://pediatrics.aappublications.org/content/133/5/e1471.full
2. Brewer S, Gleditsch SL, Syblik D, Tiejens ME, Vacik HW. Pediatric anxiety: child life intervention in day surgery. J Pediatr Nurs. 2006;21(1):13–22.
3. Child life Council. Official Documents of the Child Life Council. Arlington: Child Life Council; 2011. Retrieved from https://www.childlife.org/child-life-profession/mission-values-vision
4. Cross J, Bruce J. Child life services in an adult setting: a quality improvement initiative and implementation effort in a university hospital. Child Life Focus. 2015;33(3):13–7.
5. Fein JA, Zempsky WT, Cravero JP. Relief of pain and anxiety in pediatric patients in emergency medical systems. Pediatrics. 2012;130(5):e1391.
6. Gursky B, Kestler LP, Lewis M. Psychosocial intervention on procedure-related distress in children being treated for laceration repair. J Dev Behav Pediatr. 2010;31(3):217–22.
7. Harpham W. When a parent has cancer: a guide to caring for your children. New York: HarperCollins Publishers; 1997.
8. Madhok M, Milner D, Teele M, Finkelstein M. Child life services and patient satisfaction in emergency department. Pediatr Emerg Care. 2007;23(10):764.
9. McCue. How to help children through a parent's serious illness. New York: St. Martin's Press; 1994, rev. 2011.
10. Phillips F, Prezio EA. Wonders & Worries: evaluation of a child centered psychosocial intervention for families who have a parent/primary caregiver with cancer. Psycho-Oncology. 2016;26:1006. https://doi.org/10.1002/pon.4120.
11. Tilford JM, Simpson PM, Green JW, Lensing S, Fiser DH. Volume-outcome relationships in pediatric intensive care units. Pediatrics. 2000;106:289–94.
12. Sutter C, Reid T. How do we talk to the children? Child life consultation to support the children of seriously ill adult inpatients. J Palliat Med. 2012;15(12):1–7.
13. Wolfer J, Gaynard L, Goldberger J, Laidley LN, Thompson R. An experimental evaluation of a model child life program. Child Health Care. 1988;16(4):244–54.

Chapter 28
How to Study the Family ICU Syndrome: A Basic Approach to Research Methodology

Christiane S. Hartog

> *"…not everything that can be counted counts, and not everything that counts can be counted."*
>
> William Bruce Cameron (1963)

Why Perform Clinical Research?

While we all agree that we need to provide high-quality care, we cannot be sure of what we are doing unless we measure what we do. Measuring process and outcomes gives us a sense of knowing where we are compared to where we want to be. To design studies and to understand published study results, one must have a basic understanding of research methodology. The preceding chapters in this book have defined the scope and different angles of the problem. If we want to improve understanding and management of the family intensive care unit syndrome (FICUS), we must know how to develop and answer meaningful research questions. In this chapter, we will look at some general aspects of successful clinical research and how these might reflect on the study of FICUS.

While this chapter cannot extensively cover the subject of devising and carrying out clinical research, it will deal more specifically with the question how to study FICUS in a continuing cycle of quality improvement projects (Fig. 28.1). The important aspects that will be covered are (1) theoretical framework and the research question, (2) choosing and measuring study endpoints, (3) appropriate study designs and (4) considering complex clinical interventions.

C. S. Hartog
Department of Anaesthesiology and Intensive Care Medicine,
Charité – Universitätsmedizin Berlin, Berlin, Germany
e-mail: Christiane.Hartog@mailbox.org

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4_28

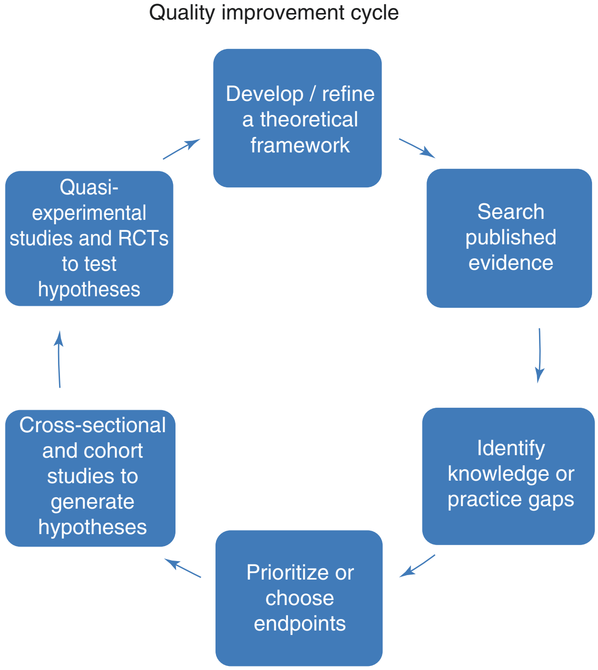


Fig. 28.1 The continuous cycle of quality improvement

Theoretical Framework and the Research Question

The first step should be to conceptualize FICUS. It becomes rapidly obvious that FICUS is a multifaceted syndrome incorporating a large variety of domains which may interact with one another in many ways. FICUS is an emerging concept and there is no universally accepted framework. Rather, different ways exist to conceptualize the problem. Future research will probably modify or converge heterogeneous concepts. It is important to remember that the kind of concept you favour will strongly determine the kind of research you will build on it. Developing a valid framework can be a research project in itself.

A potential framework which might be useful in future studies of FICUS can be found in Fig. 28.2. It is an attempt to bring together different potential conceptualizations which are described in more detail below. It is likely not complete or accurate; future research may substantially change it as our understanding of the FICUS evolves over time.

One potential conceptualization might be based on the framework offered by Netzer et al. [1].

FICUS

1. Syndrome and risk factors (maladaptive reasoning, personal and family conflicts, stressful emotions, sleeplessness, anticipatory grief and cognitive bias).
2. Person (gender, age, beliefs, values, socioeconomic status, relationship to patient, knowledge of patient wishes)
3. Clinicians (emotional strain, moral distress, humaneness, communication skills)

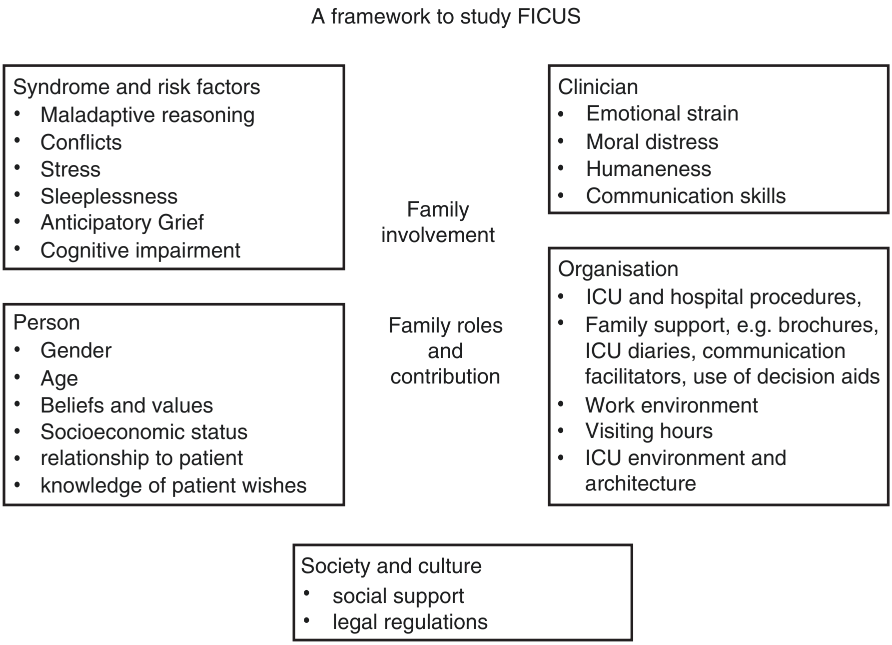


Fig. 28.2 A potential framework for the study of FICUS

4. Organization (ICU and hospital procedures; measures of family support, e.g. brochures, ICU diaries, communication facilitators, use of decision aids, etc.; quality of the work environment or ethical climate; visiting hours; ICU environment and architecture)
5. Sociocultural context (social support, legal regulations)

Some examples of potential research questions which are based on this framework:

- Do certain personal traits of the family member increase the risk for FICUS, for instance, gender, age, degree of relationship to the patient, level of education and psychological morbidity?
- Can different organizational models reduce FICUS, for instance, open visiting hours, presence of communication facilitators and use of decision aids or information brochures?
- Can interventions which reduce clinician stress mitigate FICUS?

Another way to conceptualize FICUS is to develop a framework of family involvement (based on Olding et al. [2]):

Involvement of family members in the ICU:

1. Involvement as presence
2. Involvement as receiving care and having needs met (specifically support, comfort, information, proximity and reassurance)

3. Involvement as communicating and receiving information
4. Involvement as decision-making
5. Involvement as contributing to care

Potential research questions which are based on this framework might address whether FICUS correlates positively or negatively with involvement or which type of involvement is preferable in terms of environmental impact.

A third way to conceptualize FICUS might be from the viewpoint of the roles which families play in the ICU. McAdam et al. derived these roles from qualitative research [3]:

Family roles and contributions

1. Active presence
2. Patient protector
3. Facilitator
4. Historian
5. Coach
6. Voluntary caregiver

Potential research questions based on this framework might address which roles correlate specifically with FICUS and whether empowerment of the family to fulfil these roles will have a beneficial effect.

Choosing and Measuring Study Endpoints

After you have developed a research question ("why"), you need to choose the variables which can describe exposure, intervention and outcome. In general, quality improvement in the ICU should use quality measures which, apart from being valid, the measure should also be reliable, responsive, interpretable and feasible [4] (Table 28.1). Reliable means that the measure has good retest properties and is not influenced by the person who measures it. A reliable measure yields the same results even when assessed by a different rater (inter-rater reliability) or at different times provided the variable has not changed (intra-rater reliability). A measure should also be responsive, i.e. respond to effective interventions or changes. For instance, the health-related quality of life (HRQL) measure SF-36 may not be responsive to changes due to different management of ICU survivors, because SF-36 is not specific for ICU survivors and lacks important domains [5]. An interpretable measure is easily understood by stakeholders including clinicians, ICU and hospital leadership. A feasible measure is one that can be easily collected with available resources.

However, studying FICUS requires endpoints which are family-centred. Such endpoints are novel and their psychometric properties are likely not well established. Therefore, establishing quality measures in FICUS will necessarily entail some methodological research about the properties of measures. It may be helpful

Table 28.1 Some examples of process and outcome measures

	Process measure	Outcome measure
Do patients and families care about this?	May not be important	Yes, important
Do clinicians care about this?	Yes, monitors delivery of healthcare	Yes, shows the results of healthcare
Obtain from routine data?	Sometimes	Sometimes
Useful for feedback and quality improvement?	Yes, shows what clinicians are actually doing	Yes, but indirectly because outcomes are affected by a variety of processes
Directly measures prevention?	Yes	No
Need for risk adjustment?	No	Yes
Time needed for measurement?	Less	More (long-term outcomes)
Sample size requirements?	Smaller	Larger

Modified after Curtis et al. [4]

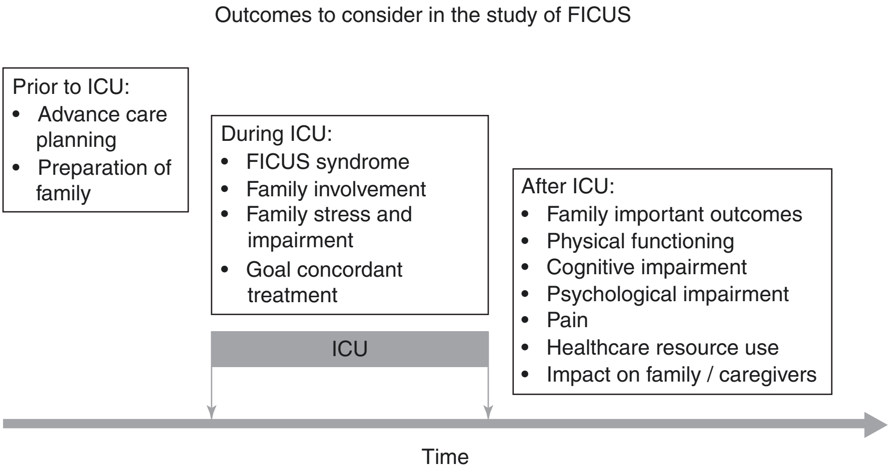


Fig. 28.3 Some outcomes to consider in the study of FICUS

to consider a timeline which starts already before ICU admission and continues beyond the ICU (Fig. 28.3).

First, there is the challenge to develop a concise but comprehensive measure of the syndrome itself, essential to determine (1) who has it and who has not and if someone has it, (2) how severely he or she is afflicted. The latter is important if you want to measure changes. A frequently used outcome in family-centred care is the mental well-being of family members. Grief, depression, anxiety, stress or helplessness can be measured by specific, validated instruments. However, more research is needed to determine which outcomes are best suited to detect the occurence and severity of FICUS and how to define a meaningful cut-off.

Further outcomes to measure are variables which are expected to have an effect on FICUS. Prior to the ICU, particularly for patients with a scheduled ICU stay, family members should be appropriately informed and prepared for their potential future role and involvement in the ICU. Advance care planning, i.e. the facilitated development of a written document which contains patient's treatment preferences, has the potential to increase compliance with end-of-life preferences and reduce family stress [6].

Goal-concordant care is one interesting new outcome which can be assessed during and after treatment in the ICU [7]. Family members want the care their loved ones receive to be concordant with patient-identified goals, respecting any treatment limitation the patient has placed on clinical care. Patient-identified goals could be return to work, comfortable in one's own home or staying alive even if this entails living in a nursery home. The incidence of goal-discordant care requires measurement of (1) patient goals, (2) treatment limitations if any, (3) treatments received and (4) judgements regarding concordance; all of these provide multiple challenges which need to be overcome [7]. Another way to approach goal concordance is to evaluate preference-sensitive decisions as opportunities for shared decision-making with families. These are treatment decisions which should trigger clinicians to clarify patient goals, for instance, a permanent feeding tube, a suprapubic urinary catheter or a tracheotomy [8]. An exploratory study of family-led research in the ICU suggests another method by which the research agenda may become further concordant with family-centric outcomes [9]. Future research will address ways to operationalize goal concordance and establish correlation with other FICUS-related measures such as learned helplessness, acute stress or moral distress of staff (just to name a few).

Several research groups have started to develop core outcome measures for intensive care which involve the patient and family perspective. Health-related quality of life (HRQL) is often used as a patient-important outcome, but generic measures like Short Form 36 (SF-36) Health Survey or EuroQol-5D (EQ-5D) have significant gaps in their coverage, for instance, cognitive functioning, relationships and family support and healthcare use [5]. Moreover, patients and families differ from researchers in their rating of the importance of outcomes after survivorship. They confer less importance to survival and more importance to pain, physical functioning and symptoms, fatigue, healthcare resource utilization and impact on family or caregivers [10]. Such outcomes may be more difficult to assess but should be preferred and evaluated for use in studies of FICUS. Other domains which are important to patients and family members are interventions to facilitate continuity of care following ICU discharge, family participation in bedside care and decision aids for end-of-life decision-making [11].

An important decision is the choice of the *primary endpoint*, as this will determine the sample calculation. The primary endpoint is obviously the most important; it is chosen to answer the research question and test the hypothesis. It also determines sample size calculation. Secondary endpoints are interesting because they provide background information. However, it must be kept in mind that the findings from secondary endpoints are only hypothesis-generating.

However, given the multidimensionality of the syndrome and the many confounders which have an impact, the challenge of selecting a single primary endpoint as well as the time point to measure it is a great one. For instance, Curtis et al. conducted a randomized controlled two-centre trial to test an intervention which used facilitators who supported communication between clinicians and families, adapted communication to family needs and mediated conflict. The primary outcome was a measure of family members' symptoms of depression, but the intervention was associated with decreased depressive symptoms at 6 months ($p = 0.017$), not at 3 months as expected; moreover, symptoms of anxiety or post-traumatic stress did not change. Thus, the result leaves open questions about the effect of the intervention on the families' emotional burden; however, secondary outcomes showed reductions in ICU and hospital length of stay in the intervention group with considerable financial savings [12]. Another challenge is the low response rates which are encountered in follow-up studies [13]. Recruiting families after the ICU can be subject to recruiting bias, with data suggesting that respondents are more satisfied with care than nonrespondents. In addition, answers may be subject to recall bias which may be particularly true when recalling specific stressors [14] or degree of compliance with patient preferences. On the other hand, recruiting families at the bedside may introduce a selection bias, as these family members are more likely to be white, of higher income and loved ones with higher acuity [15].

Appropriate Study Designs

The hierarchy of evidence places multicentre randomized controlled trials (RCTs) above observational and cross-sectional studies; however, the restrictions and challenges which are inherent in the study of FICUS, as described above, will limit the range of feasible study designs. As FICUS is an emerging concept, the study of FICUS will evolve in parallel. Initially, well-designed but lower-quality explorative studies are needed before a high-evidence RCT can be successfully designed and conducted.

Cross-sectional Studies

This type of study measures the incidence of certain outcomes, perceptions or states of being at a given time point or short period of time. It takes a "snapshot" in a general sample. In contrast to cohort studies, the sample consists of unselected participants who are not followed up over several time points. Population-based cross-sectional studies are valuable to assess prevalence of a condition or disease. Cross-sectional studies can establish hypotheses about risk factors and causal relationships. Limitations include lack of knowledge about pre-existing risk factors, length of exposure and antecedent-consequent bias, i.e. it is unknown whether the outcome is a result or a pre-existing condition.

Observational Cohorts

A cohort is defined as a group of people who share a common characteristic. Researchers often define inclusion and exclusion criteria to select participants. Cohorts can be studied retrospectively by looking back in time after the outcome has occurred or prospectively by following a cohort into the future. Observational cohort studies are useful to study risk and outcome rates and temporal relationships between outcome and exposure. Their quality is determined by how well participants represent the condition to be studied (generalizability), by how complete the cohort is at baseline (participation rate) as well as by the attrition rate during follow-up (loss to follow-up). Limitations include expense and time, given that individuals must be followed up for longer periods of time.

Quasi-Experimental Design for Improvement Initiatives

These research designs test causal hypotheses but lack the random allocation of participants to intervention and control groups. Usually, the intervention is tested against no intervention or standard of care. Participants either choose the treatment or control intervention or are assigned by administrators because the intervention is implemented as the new standard of care. This design can be used retrospectively, i.e. after the intervention was put in place, or prospectively, i.e. before an intervention is instituted. These studies are often used in quality-improvement initiatives. To account for the limitation – lack of randomization – additional statistical methods are sometimes used to create comparison groups which are as similar as possible at baseline, i.e. before the intervention, for instance, propensity score matching. While the quasi-experimental design is often used in quality improvement projects, observed differences between groups can be due to an imperfect match or secular changes over time rather than the intervention.

Randomized Controlled Trial

The RCT directly compares different treatment groups. Participants are randomly assigned to either group. In addition, validity can be increased by double- or triple-blinding (participants, statisticians and investigators). Treatment crossovers can also add to the validity but also infer the problem of carry-over effects. The stepped wedge cluster design ensures that all included trial sites will eventually benefit from the intervention [16]. The RCT is considered to provide the most direct evidence for the causal effect of an intervention and provides evidence of the highest level. However, some drawbacks exist as well. Because of stringent in- and exclusion criteria, the study population may not be generalizable to the "normal" patients in the unit. Selective analysis (including analysis of intent-to-treat rather than per-protocol) or loss-to-follow-up can diminish the validity. Subgroup analysis is often performed, but even when pre-planned, results are merely hypothesis-generating. Lastly, RCTs are costly and time-consuming.

Complex Interventions

The ultimate aim of studying FICUS is to develop, implement and evaluate interventions which will mitigate or prevent it. Such interventions will typically be complex interventions. For instance, one intervention which alleviated relatives' psychological stress after 90 days consisted of a brochure and a communication strategy, which was taught to clinicians and practised in family conferences; the control group received usual care [17]. Another intervention employed communication facilitators who supported communication between clinicians and families, adapted communication to family needs and mediated conflicts versus usual care; this intervention was delivered in the context of a multicentre RCT [12].

Complex interventions are complex because they contain a number of interactive components both in the experimental and in the control group, namely a new or changed behaviour required by those delivering or receiving the intervention, several groups or organizational levels targeted by the intervention and a range of outcomes to assess the levels of complexity; these interventions may also allow for some degree of flexibility or tailoring the intervention during the implementation [18]. It is therefore recommended to develop interventions systematically, using the best available evidence and appropriate theory, in a stepwise approach which tests each component and target to understand and control uncertainties and develop it along a line from exploratory on to pilot and then more advanced studies.

Campbell et al. recommend the following steps: (1) identifying existing evidence, i.e. finding out what is already known about similar interventions; (2) identifying and developing theory, i.e. setting up one or a series of pilot studies developing a theoretical understanding of the problem and its components; and (3) modelling process and outcomes, i.e. targeting single components or steps of the model before putting it all together [18]. In addition, you might perform a gap analysis in your unit or in several units. For instance, the gap analysis tool for family-centred care covers areas with need for improvement based on the systematic compliation of evidence [19, 20]. Moreover, patients and family members are increasingly being engaged during the planning and conduct of clinical research. This is especially fruitful when addressing healthcare delivery where patient- and family-led research has been shown to be feasible and can identify opportunities for improving care [9].

Lastly, evaluating the results of complex interventions may be difficult. As described above, the difficulties include choosing relevant endpoints and times when to measure them. To quote: “If the result is negative, we are left wondering whether the intervention is inherently ineffective (either because the intervention was inadequately developed or because all similar interventions are ineffective), whether it was inadequately applied or applied in an inappropriate context or whether the trial used an inappropriate design, comparison groups or outcomes. If there is a positive effect, it can be hard to judge how the results of the trial might be applied to a different context” [10].

Conclusions

Studying the emerging concept of FICUS requires a comprehensive research agenda. Before complex interventions can be performed to mitigate or prevent FICUS, researchers are well advised to perform explorative research and generate hypotheses based on a theoretical framework. To increase validity, patients and families are increasingly engaged into clinical research projects.

References

1. Netzer G, Sullivan DR. Recognizing, naming, and measuring a family intensive care unit syndrome. Ann Am Thorac Soc. 2014;11:435–41. https://doi.org/10.1513/AnnalsATS.201309-308OT.
2. Olding M, McMillan SE, Reeves S, et al. Patient and family involvement in adult critical and intensive care setting: a scoping review. Health Expect. 2015:1183–202. https://doi.org/10.1111/hex.12402.
3. McAdam JL, Arai S, Puntillo KA. Unrecognized contributions of families in the intensive care unit. Intensive Care Med. 2008;34:1097–101. https://doi.org/10.1007/s00134-008-1066-z.
4. Curtis JR, Cook DJ, Wall RJ, et al. Intensive care unit quality improvement: a “how-to” guide for the interdisciplinary team. Crit Care Med. 2006;34:211–8.
5. Lim WC, Black N, Lamping D, et al. Conceptualizing and measuring health-related quality of life in critical care. J Crit Care. 2016;31:183–93. https://doi.org/10.1016/j.jcrc.2015.10.020.
6. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. BMJ. 2010;340:c1345.
7. Turnbull AE, Hartog CS. Goal-concordant care in the ICU: a conceptual framework for future research. Intensive Care Med. 2017; https://doi.org/10.1007/s00134-017-4873-2.
8. Turnbull AE, Sahetya SK, Needham DM. Aligning critical care interventions with patient goals: a modified Delphi study. Heart Lung. 2016;45:517–24. https://doi.org/10.1016/j.hrtlng.2016.07.011.
9. Gill M, Bagshaw SM, McKenzie E, et al. Patient and family member-led research in the intensive care unit: a novel approach to patient-centered research. PLoS One. 2016;11 https://doi.org/10.1371/journal.pone.0160947.
10. Dinglas VD, Chessare CM, Davis WE, et al. Perspectives of survivors, families and researchers on key outcomes for research in acute respiratory failure. Thorax. 2018;73:7–12. https://doi.org/10.1136/thoraxjnl-2017-210,234.

11. Oczkowski SJW, Au S, des Ordons AR, et al. A modified Delphi process to identify clinical and research priorities in patient and family centred critical care. J Crit Care. 2017;42:243–7. https://doi.org/10.1016/j.jcrc.2017.08.008.
12. Curtis JR, Treece PD, Nielsen EL, et al. Randomized trial of communication facilitators to reduce family distress and intensity of end-of-life care. Am J Respir Crit Care Med. 2016;193:154–62. https://doi.org/10.1164/rccm.201505-0900OC.
13. Curtis JR, Nielsen EL, Treece PD, et al. Effect of a quality-improvement intervention on end-of-life care in the intensive care unit: a randomized trial. Am J Respir Crit Care Med. 2011;183:348–55. https://doi.org/10.1164/rccm.201006-1004OC.
14. Matt B, Schwarzkopf D, Reinhart K, et al. Relatives' perception of stressors and psychological outcomes – results from a survey study. J Crit Care. 2017;39:172–7. https://doi.org/10.1016/j.jcrc.2017.02.036.
15. Turnbull AE, Hashem MD, Rabiee A, et al. Evaluation of a strategy for enrolling the families of critically ill patients in research using limited human resources. PLoS One. 2017;12 https://doi.org/10.1371/journal.pone.0177741.
16. Hemming K, Haines TP, Chilton PJ, et al. The stepped wedge cluster randomised trial: rationale, design, analysis, and reporting. BMJ. 2015;350:h391. https://doi.org/10.1136/bmj.h391.
17. Lautrette A, Darmon M, Megarbane B, et al. A communication strategy and brochure for relatives of patients dying in the ICU. N Engl J Med. 2007;356:469–78.
18. Campbell NC, Murray E, Darbyshire J, et al. Designing and evaluating complex interventions to improve health care. BMJ. 2007;334:455–9. https://doi.org/10.1136/bmj.39108.379965.BE.
19. Davidson JE, Aslakson RA, Long AC, et al. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. Crit Care Med. 2017;45:103–28. https://doi.org/10.1097/CCM.0000000000002169.
20. Society of Critical Care Medicine. Guidelines. The gap analysis tool. http://www.sccm.org/Research/Guidelines/Pages/Guidelines.aspx.

Index

G. Netzer (ed.), *Families in the Intensive Care Unit*,
https://doi.org/10.1007/978-3-319-94337-4