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Legal, Medical, and Ethical Issues in Minnesota End-of-Life Care: An Introduction to the Symposium

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**LEGAL, MEDICAL, AND ETHICAL ISSUES IN
MINNESOTA END-OF-LIFE CARE:
AN INTRODUCTION TO THE SYMPOSIUM**

Thaddeus M. Pope *

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As America grays and medicine's ability to treat the sickest of patients expands, the legal, medical, and ethical issues in end-of-life care become more numerous, pressing, and intertwined. Because Minnesota's citizens, clinicians, and courts are not far from these concerns, the Hamline University Health Law Institute¹ and the *Hamline Law Review*² hosted an interdisciplinary Symposium entitled "Legal, Medical, and Ethical Issues in Minnesota End-of-Life Care."

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¹ For more information about the Hamline University School of Law Health Law Institute, please visit <http://law.hamline.edu/healthlaw/>. Hamline's Health Law Institute, founded in 2006, was recently ranked 16th among U.S. health law programs. *Best Grad Schools 2014*, U.S. NEWS & WORLD REP. (Mar. 2013). More than fifty students are pursuing one of Hamline's certificates in health law or healthcare compliance.

² For more information about the *Hamline Law Review*, please visit <http://law.hamline.edu/hamline-law-review/>.

On November 9, 2012, we welcomed more than 200 participants to the newly opened Carol Young Anderson and Dennis L. Anderson Center on Hamline University's Saint Paul campus. These participants included: attorneys, physicians, nurses, social workers, ethicists, patient advocates, legal aids, government regulators, professors, students, chaplains, and other allied health professionals. To enhance its value and interest to these diverse professionals, we qualified the Symposium for CLE credits by the Minnesota Board of Continuing Legal Education, for CE credits by the Minnesota Board of Nursing, and for CE credits by the Minnesota Board of Social Work.

Our guests came from a diverse range of professional settings, including: hospitals, government agencies, universities, non-profit organizations, law firms, and health insurance companies. They represented a virtual who's who of Minnesota healthcare and public policy organizations, including: Children's Hospitals and Clinics of Minnesota, Mercy Hospital, the Minneapolis Veterans Affairs Health Care System, the University of Minnesota, William Mitchell College of Law, Allina Health, Health Partners, United Health Group, Compassion & Choices, Medica, the American Cancer Society, Mayo Clinic, Park Nicollet, Mid-Minnesota Legal Aid, Abbott Northwestern, the Food and Drug Administration, Fairview Health Services, the Minnesota House of Representatives, North Memorial Hospital, Sanford Health, the Hennepin County Medical Center, the Minnesota Department of Human Services, and the Minnesota Attorney General's Office.

These informed participants engaged in a day-long exploration of end-of-life legal, medical, and ethical issues, specifically as they impact Minnesota. They heard from regional and national experts, both scholars and practitioners, who discussed pragmatic and provocative topics. These topics ranged from guardianship and the use of Physician Orders for Life Sustaining Treatment ("POLST"), to medical futility disputes, surrogate decision making, and aid-in-dying. Through symposium evaluations, attendees reported being over 94% satisfied with the conference content and speakers.³

In short, last November's Symposium brought various legal and healthcare disciplines together to identify problems, challenges, strategies, and solutions for Minnesota end-of-life care. This special issue of the *Hamline Law Review* is designed to recall, and indeed carry forward, the urgently important dialogues featured at the Symposium.

I. EXPRESSION OF APPRECIATION

The Symposium could not have taken place without the contributions of many people. The Law School and I wish to thank the leading scholars and practitioners who participated. We also wish to extend

³ The average score, based on 70 responses, was 4.7 of 5.0.

appreciation for the extraordinary efforts of the Health Law Institute's program manager, Kari Winter, in planning, organizing and executing the conference. Equally noteworthy are the efforts of *Hamline Law Review's* Symposium Editor Christina Becker.

The development of the Symposium also benefitted from the advice and counsel of a diverse program committee consisting of: (1) A. Kimberly Dayton, J.D., Director of the Center for Elder Justice and Policy, and Professor at William Mitchell College of Law;⁴ (2) Marjorie Schaffer, M.S., Ph.D., University Professor in the Department of Nursing at Bethel University;⁵ (3) Pat Schommer, M.A.O.L., Associate Director for the Center on Aging and the Minnesota Area Geriatric Education Center (MAGEC) in the University of Minnesota School of Public Health; (4) Kent Wilson, M.D., the Medical Director of Honoring Choices Minnesota;⁶ (5) Elizabeth M. Winchell, Editor-in-Chief of the *Hamline Law Review*; (6) Christina Becker, Symposium Editor of the *Hamline Law Review*; and (7) myself.

Furthermore, the Symposium benefitted not only from those generous individuals who helped plan and organize the event but also from those who helped moderate the several sessions. We thank law professors Barbara Colombo, Laura Hermer, Jonathan Kahn, and Jason Marisam. And we give special thanks to the event sponsors: the University of Minnesota Center on Aging and the Minnesota Area Geriatric Education Center (MAGEC).⁷

II. PRE-SYMPOSIUM THEATRICAL PERFORMANCE

Both to illustrate and to frame some of the issues that would be discussed during the Symposium, we produced a theatrical performance the evening before the Symposium.⁸ Nearly sixty people attended the performance of *Expiration Date* at the Weyerhaeuser Auditorium in downtown Saint Paul's historic Landmark Center.

⁴ Professor Dayton is coauthor of the following publications: *Advising the Elderly Client* (Thomson-West); a 39-chapter treatise on elder law and related topics; and *Elder Law: Readings, Cases, and Materials* (Lexis-Nexis 2d ed. 2003) and its companion statutory supplement. She is also the editor of the *Elder Law Prof Blog*.

⁵ Professor Schaffer is author of *Being Present: A Nurse's Resource for End-of-Life Communication*.

⁶ Dr. Wilson is also President, East Metro Medical Foundation Board. He is a former Trustee and President of the Minnesota Medical Association. He is also a former President of the Minnesota Academy of Otolaryngology, Head and Neck Surgery.

⁷ For more information about the University of Minnesota Center on Aging and the Minnesota Area Geriatric Education Center, please visit <http://www.coa.umn.edu/MAGEC/>.

⁸ This seems to be an increasingly common element of end-of-life ethics and policy conferences. For example, Compassion & Choices had Megan Cole perform *Wit* at its June 2012 conference, *Heights of Compassion - Bridges to Choice*. <http://community.compassionandchoices.org/document.doc?id=1101>.

Expiration Date is a multidisciplinary, solo theater work created and performed by Candy Simmons of Sunset Gun Productions.⁹ In it, Simmons shares the attitudes and fears that come with death and dying in America. We must all go someday, but for Lucille “someday” is now. Through a multi-character performance, layering traditional monologue, video, music, and movement, participants experienced the story of Lucille, a young woman struggling with the realities of a terminal diagnosis. Lucille’s journey offers an unsentimental, raw, irreverent, and darkly comedic peek into the approach of the end of one’s life. *Expiration Date* is a blend of fiction and personal experiences woven together with the aid of stories that Ms. Simmons collected through video interviews around the subject.

III. PRESENTATIONS AT THE LIVE SYMPOSIUM

The Symposium was comprised of seven sessions. These concerned: (A) the promise and success of POLST, (B) challenges and concerns with POLST, (C) new problems with surrogate decision making, (D) guardianship processes and procedures, (E) medical decision making for the unbefriended, (F) medical futility disputes, and (G) protecting patient choice at the end of life.

A. POLST: Promise and Success

The first and second sessions of the Symposium focused on POLST (Physician Orders for Life-Sustaining Treatment). At the end of life, patients often lose decision-making capacity to make their own healthcare decisions. For decades, clinicians and policymakers have struggled with how to assure that the treatment patients get at the end of life matches their wishes, preferences, and values. POLST is a mechanism that has proven particularly successful at achieving this congruence.¹⁰

Bernard J. Hammes, Ph.D., is director of Medical Humanities and an ethics consultant for the Gundersen Lutheran Medical Foundation in La Crosse, Wisconsin. He is also the director of Respecting Choices, an evidence-based advance care planning program.¹¹ Dr. Hammes also serves on the Executive Committee of the National POLST Paradigm Task Force¹² and as Vice President of the International Society of Advance Care Planning

⁹ For more information about Candy Simmons and Sunset Gun Productions, please visit <http://www.sunsetgunproductions.com/expiration-date.html>.

¹⁰ See Thaddeus M. Pope & Melinda Hexum, *Legal Briefing: POLST: Physician Orders for Life-Sustaining Treatment*, 23 J. CLINICAL ETHICS 353 (2012).

¹¹ For more information about Respecting Choices, please visit <http://respectingchoices.org/>.

¹² For more information about the National POLST Paradigm Task Force, please visit <http://www.polst.org/>.

and End-of-Life Care.¹³ Dr. Hammes helped participants identify several ways in which past approaches to advance directives have failed. Then, by using examples from his own exceptionally successful program at Gunderson Lutheran, Dr. Hammes described the systematic elements that are needed for future care plans to be successful.¹⁴

Edward Ratner, M.D., is an associate professor of medicine in the University of Minnesota School of Medicine. He is also the medical director for Heartland Home Health Care and Hospice. Dr. Ratner has been chairing the task force guiding the implementation of POLST in Minnesota.¹⁵ He described the development and status of POLST in Minnesota, and explained how to complete a POLST form. Dr. Ratner also encouraged participants to assist the program development of POLST programs.¹⁶

B. POLST: Challenges and Concerns

While published evidence on POLST indicates its significant effectiveness, there continue to be implementation challenges and concerns. In the Symposium's second session, two presenters addressed those challenges and identified some strategies for overcoming them.

Marshall B. Kapp, J.D., M.P.H., is a professor of medicine and law, and is Director of the Center for Innovative Collaboration in Medicine and Law at Florida State University. Among other things, this Center is the central coordinating body for the POLST program in Florida.¹⁷ Professor Kapp discussed how the POLST approach to healthcare decision making works in nursing homes. More broadly, he helped participants appreciate the role of nursing homes in the care of individuals with advanced, irreversible illness.

Stanley A. Terman, M.D., Ph.D., is the medical and executive director for Caring Advocates.¹⁸ Dr. Terman identified some key criticisms of POLST paradigm forms. In particular, he emphasized POLST's failure to respect patients' autonomous wishes important for certain clinical conditions like advanced dementia. He suggested some phrasing changes that can

¹³ For more information about the International Society of Advance Care Planning and End of Life Care, please visit <http://www.acpelsociety.com/>.

¹⁴ See Bernard J. Hammes et al., *The POLST Program: a Retrospective Review of the Demographics of Use and Outcomes in One Community Where Advance Directives Are Prevalent*, 15 J. PALLIATIVE MED. 77 (2012).

¹⁵ Lem Vawter & Edward Ratner, *The Need for POLST: Minnesota's Initiative*, MINN. MED. (Jan. 2010).

¹⁶ For more information about POLST in Minnesota, including a POLST toolkit and other resources, please visit the Minnesota Medical Association's POLST page at <http://www.polstmn.org/>.

¹⁷ For more information about the Center for Innovative Collaboration in Medicine and Law, please visit <http://med.fsu.edu/index.cfm?page=innovativeCollaboration.home>.

¹⁸ For more information about Caring Advocates, please visit <http://caringadvocates.org/>.

mitigate these criticisms. Dr. Terman also described some guides and tools that he has developed to help patients and families more successfully navigate advance care planning.¹⁹

C. New Problems with Surrogate Decision Making

Without a POLST, when the patient loses capacity, clinicians must typically look to the patient's surrogate decision makers for treatment decisions. Unfortunately, a significant body of evidence shows that surrogates frequently fail to adequately protect and promote patients' prospective autonomy.²⁰ In the Symposium's third session, we learned about some new and still-emerging challenges to good surrogate decision making.

Barbara A. Noah, J.D., is a professor at Western New England School of Law. She presented *Medical Autonomy and Pragmatism: Incorporating a Best Interests Standard in End of Life Decision Making*. She helped participants appreciate the limitations of the principle of autonomy and the substituted judgment standard which, in the United States, presumptively forms the basis for decisions to withhold or withdraw life-sustaining treatments from patients who lack decisional capacity. Professor Noah explained potential benefits, obstacles, and pitfalls of incorporating a more objective best interests approach like that used in the United Kingdom.

Maxine M. Harrington, J.D., is a professor at Texas Wesleyan School of Law. She presented *Advances in Neuroimaging and the Implications for End-of Life Care of the Patient in a Vegetative State*. She surveyed the latest developments in neuroscience and how they affect end-of-life care. For example, growing research with fMRI strongly suggests that we can meaningfully communicate with patients who have been in a vegetative state for years.²¹ Professor Harrington then described the difficulties of predicting outcomes in the persistent vegetative state and minimally conscious states. Finally, she outlined the implications for surrogate decision making.

Adam Candeub, J.D., is professor and director of the Intellectual Property, Information and Communications Law Program at Michigan State University School of Law. He presented *Health Savings Accounts and End-of-Life Decision Making*. Professor Candeub explained how the expansion

¹⁹ See, e.g., STANLEY A. TERMAN, *THE BEST WAY TO SAY GOODBYE: A LEGAL PEACEFUL CHOICE AT THE END OF LIFE* (2007); STANLEY A. TERMAN, *PEACEFUL TRANSITIONS: PLAN NOW, DIE LATER—IRONCLAD STRATEGY* (2d ed. 2011). Dr. Terman has also developed an interactive tool that entails sorting cards. STANLEY A. TERMAN, *MY WAY CARDS FOR NATURAL DYING* (2011).

²⁰ See, e.g., Thaddeus M. Pope, *Surrogate Selection: An Increasingly Viable, but Limited, Solution to Intractable Futility Disputes*, 3 ST. LOUIS U. J. HEALTH L. & POL'Y 183 (2010); Thaddeus M. Pope, *Legal Fundamentals of Surrogate Decision Making*, 141 CHEST 1074 (2012).

²¹ See, e.g., Adrian M. Owen, *Detecting Consciousness: A Unique Role for Neuroimaging*, 64 ANNUAL REV. PSYCHOL. 109-33 (2013).

of health savings accounts is leading to financial incentives that can distort surrogate decision making regarding end-of-life decisions.

Finally, Dr. Stanley Terman presented *Consensus of Substituted Judgment: A New Tool for End-of-Life Decision Making*. Traditionally, the physician asks just one person (the legally authorized surrogate) to answer “yes” or “no” in response to a question whether to accept or to refuse a treatment that may be life-determining for the patient. Dr. Terman proposed an alternative: ask several qualified surrogate decision-makers. Ask each of them to take on the patient’s mindset, when the patient was well, as they use the advance care planning tool “Natural Dying Living Will Cards.”²²

D. Guardianship Processes and Procedures

When the patient has not herself appointed a healthcare agent, when the patient has no available “default” surrogates (typically her family), and/or in cases of conflict among potential surrogates; the court might appoint the substitute decision maker (typically called a “guardian”) for the patient. In the Symposium’s fourth session, two leading experts jointly described Minnesota guardianship law and a guardian’s role as surrogate decision maker.

The Honorable Jay Quam, J.D., was, at the time of the Symposium, the Presiding Judge of the Hennepin County Probate/Mental Health Court. Robert A. McLeod, J.D., is a partner at the law firm Lindquist & Vennum. In addition to providing a primer on guardianship law and practice, Judge Quam and Mr. McCleod engaged in a lively discussion of Judge Quam’s then just-published decision in *In re Tschumy*.²³ Judge Quam had held that guardians do not have the power to terminate a ward’s life-sustaining treatment unless specifically given that power by the court. The case is now pending before the Minnesota Court of Appeals.²⁴

E. Medical Decision Making for the Unbefriended

POLST and surrogate decision making can help most of us. But some incapacitated patients have neither advance instructions nor anyone available to speak on their behalf.²⁵ In the Symposium’s fifth session, panelists discussed medical decision making for “unbefriended” or “unrepresented” patients and residents.

²² To see Dr. Terman demonstrate his advance care planning tools in a series of instructional videos, please visit <http://www.youtube.com/user/drterman>.

²³ *In re Tschumy*, No. 27-GC-PR-07-496 (Hennepin Cty. Dist. Ct. Oct. 18, 2012).

²⁴ *In re Tschumy*, No. A12-2179 (Minn. App. May 15, 2013) (oral argument).

²⁵ See generally Thaddeus M. Pope & Tanya Sellers, *Legal Briefing: The Unbefriended: Making Healthcare Decisions for Patients without Proxies (Part 1)*, 23 J. CLINICAL ETHICS 84 (2012); Thaddeus M. Pope & Tanya Sellers, *Legal Briefing: The Unbefriended: Making Healthcare Decisions for Patients without Proxies (Part 2)*, 23 J. CLINICAL ETHICS 177 (2012).

Andrea Palumbo, J.D., is an attorney with the Gores Law Office. She presented demographic data on the unbefriended population in Minnesota. Ms. Palumbo then described the scope and nature of the challenge concerning the unbefriended, describing, for example, the types of medical decisions that need to be made for these patients.

Anita Raymond, M.S.W., LISW, CMC, is a social worker with the Volunteers of America of Minnesota.²⁶ She began with the premise that guardianship should be a last resort. Ms. Raymond then helped participants differentiate among several mechanisms for avoiding or resolving the challenges of medical decision making for the unbefriended short of guardianship.

Rebecca Volpe, Ph.D., is an assistant professor in the Department of Humanities at Penn State College of Medicine. She is also the director of the clinical ethics consultation Service at Penn State Hershey Medical Center. Professor Volpe shared a new policy that Penn State developed to manage decision making for unbefriended patients.

F. Medical Futility Disputes

Mechanisms like POLST, surrogates, and guardians are largely focused on how best to assure that the patient gets the treatment she wants or that is in her best interest. But sometimes, it is medically and ethically appropriate to negotiate or to place limits on treatment requests by patients/surrogates. This issue has recently been considered by both the courts and legislature in Minnesota.²⁷ In the Symposium's sixth session, panelists addressed how disputes over non-beneficial treatment can be managed.

Victor M. Sandler, M.D., is the medical director for Fairview Hospice. He is also co-chair of the University of Minnesota Medical Center bioethics committee. He shared the University of Minnesota's futility policy. Dr. Sandler explained when and how the University of Minnesota's policy has been used.

Kathleen Meyerle, J.D., is an attorney with the Mayo Clinic legal department. She explained that the Mayo Clinic does not have a futility or non-beneficial treatment policy. Furthermore, she explained the material limits under Minnesota law on a clinician's ability to unilaterally stop life-sustaining treatment without consent.²⁸

²⁶ In 2008, VOA Minnesota received a grant from the Minnesota Department of Human Services to implement a project titled "Unbefriended Elders: Matching Values with Decisions."

²⁷ *In re Emergency Guardianship of Albert N. Barnes*, No. 27-GC-PR-111-16 (Fourth Judicial District Probate Ct. Div., Hennepin County, Minn., Jan. 14, 2011); Minn. H.F. 1565, 88th Legis. (2013).

²⁸ See, e.g., MINN. STAT. ANN. § 145C.15 ("If a proxy . . . or a health care agent . . . directs the provision of health care . . . that, in reasonable medical judgment, has a significant

Suzy Scheller, J.D. is an attorney with Scheller Legal Solutions LLC. She has represented vulnerable adults and their family members in actions against nursing homes, caregivers, assisted living, PCA agencies, and similar entities in personal injury, financial exploitation, and wrongful death claims. Ms. Scheller explained how institutional medical futility policies can pose risks to the elder population.

G. Protecting Patient Choice at the End-of-Life

In the final session of the day, participants heard from one of the country's foremost legal advocates on end-of-life issues. Kathryn L. Tucker, J.D., is director of legal affairs for Compassion & Choices, and is an adjunct professor of law at Loyola Law School/Los Angeles.²⁹ Ms. Tucker reviewed some of the most significant recent developments in law and policy impacting end-of-life choices. In particular, she helped participants to identify and assess the rights of terminally ill patients to make end-of-life choices and the duties of healthcare providers to respect such choices.³⁰

VI. THE PRINTED SYMPOSIUM

This special issue of the *Hamline Law Review* includes seven new Articles addressing the theme of the Symposium. These articles can be roughly grouped into three categories: (A) implementing POLST, (B) substitute decision making, and (C) end-of-life communication and conflict.

A. Implementing POLST

In *The Nursing Home as Part of the POLST Paradigm*, Marshall B. Kapp begins with two premises: (1) that improving the quality of care and quality of life for individuals with advanced, irreversible illness is a paramount goal of both ethics and public health, and (2) that such

possibility of sustaining the life of the principal or declarant, a health care provider shall take all reasonable steps to ensure the provision of the directed health care”).

²⁹ Compassion & Choices is the leading nonprofit organization committed to helping everyone have the best death possible. They offer free counseling, planning resources, referrals and guidance. Across the nation, they work to protect and expand options at the end of life. For more information, please visit <http://www.compassionandchoices.org/>.

³⁰ The constitutionality of Minnesota's prohibition of assisted suicide is the subject of several appellate cases. *State v. Melchert-Dinkel*, No. A11-0987 (Minn. May 13, 2013) (oral argument); *State of Minnesota v. Final Exit Network, Inc.*, (A13-0565), Lawrence Deems Egbert, (A13-0564), Roberta L. Massey, (A13-0563) (Minn. App.). According to a court order dated June 4, 2013, briefing is complete in these latter consolidated pretrial prosecution appeals, and oral arguments before the Minnesota Court of Appeals are scheduled for July 10, 2013.

improvement requires that individuals receive care consistent with their authentic, personal values and wishes.

But despite the fact that many people with advanced, irreversible illness will ultimately receive their care in a nursing home, their care too frequently deviates from that which they really want. Professor Kapp explains how the POLST paradigm promises to improve the quality of care and quality of life for nursing home residents with advanced, irreversible illness by more closely reconciling the details of their actual care with their desired care at the most crucial juncture of their lives. He concludes that POLST can and should be an integral facet of ideal nursing home care for all willing and appropriate residents.

In *It Isn't Easy Being PINK: Potential Problems with POLST Paradigm Forms*, Stanley A. Terman provides a frank, for-better-or-worse analysis of POLST paradigm forms. Ideally, POLST forms are actionable physician orders that effectively honor an accurate expression of the patient's end-of-life treatment preferences. But Dr. Terman sets forth several reasons why POLST forms may fail to fulfill their undeniably important purpose. Problems with POLST forms may result from the way the forms are completed or by the way the completed forms are used. Dr. Terman cautions that, at worst, using POLST forms may be considered immoral, unconstitutional, not reflect patients' end-of-life treatment preferences, or be ineffective. For each problem area, however, he provides a recommendation regarding how to address the concern.

B. Substitute Decision Making

In *Advances in Neuroimaging and the Vegetative State: Implications for End-of-Life Care*, Maxine M. Harrington, reminds us that many icons of the so-called right-to-die movement have been young women in the persistent vegetative state ("PVS"), such as Karen Ann Quinlan, Nancy Cruzan, and Terri Schiavo. These women are often understood to represent thousands of severely brain-injured patients whose families struggle to decide whether to withdraw supportive treatment. By definition, patients with the PVS diagnosis have lost cortical function, rendering them completely unaware and unable to perceive pain. Some commentators have argued that such a complete lack of awareness evidences a complete lack of personhood, justifying the withdrawal of treatment.

But Professor Harrington's article discusses provocative (and emerging) research that challenges many such assumptions driving and underlying the right-to-die movement. Specifically, the evolution of functional magnetic resonance imaging ("fMRI") may make it possible to detect signs of covert consciousness in consciousness-impaired patients. While this technological refinement would appear promising and worthy of pursuit, Professor Harrington tempers our excitement with the reminder that it will likely be years before fMRI is used at the bedside. Even so, we

undoubtedly await a future with improved diagnostic tools that will aid clinicians and families when making end-of-life decisions on behalf of patients with severe disorders of consciousness.

In *Two Conflicts in Context: Lessons from the Schiavo and Bland Cases and the Role of Best Interests Analysis in the United Kingdom*, Barbara A. Noah highlights an important difference between the way the United States and the United Kingdom approach making decisions on behalf of patients in the PVS. Noah focuses on a pair of high-profile cases involving patients in PVS for whom little was known about their respective individual preferences. She thereby contrasts the longstanding autonomy-centric American approach to the much different, beneficence-centric U.K. approach. In the U.K. concern for autonomy is supplemented with an open assessment of the patient's best interests. Ultimately, Professor Noah concludes that significant differences between the U.S. and the U.K. in terms of health care delivery, insurance, the role of the physician, and other cultural variables, do not undercut the strong arguments for adopting aspects of the British approach to end-of-life decision-making and dispute resolution in the U.S.

In *Peeking Inside the Black Box: One Institution's Experience Developing Policy for Unrepresented Patients*, Rebecca L. Volpe partners with Deborah Steinman, a pulmonary social worker at the Milton S. Hershey Medical Center. Professor Volpe and Ms. Steinman introduce us to the concept of the unrepresented patient, a patient who lacks decision-making capacity to give informed consent, has no guardian, and has no relevant advance directive or qualified surrogate decision maker.

Because unrepresented patients account for a significant (and growing) number of deaths in U.S. intensive care units, healthcare institutions may be well-served to develop policies that inform how decisions on behalf of such patients should be made. To that end, the Penn State Milton S. Hershey Medical Center recently developed an institutional policy guiding decision-making for unrepresented patients. Professor Volpe and Ms. Steinman describe the institutional policy that Penn State developed, along with key steps in the development of that policy.

C. Medical Futility and Other End-of-Life Conflicts

Laura C. Hoffman holds an S.J.D. from Loyola University Chicago School of Law's Beazley Institute of Health Law and Policy. In *Hospital Medical Futility Policy & the Severely Disabled Child: Is Disability a Death Sentence?*, Ms. Hoffman asks us to consider whether policymaking and decision-making in the end-of-life care context are sufficiently protective of severely disabled neonates and their families. After examining the history of both medical futility as a decision-making criterion and the hospital treatment of severely disabled neonates, she evaluates the nationwide

legislative landscape concerning application of hospital medical futility policies to cases involving severely disabled children.³¹

Ms. Hoffman identifies a growing, multi-state legislative movement to make medical futility policies more accessible and transparent in U.S. hospitals. Furthermore, Ms. Hoffman asks whether hospitals that do not disclose medical futility policies to the parents of severely disabled children, but instead vest authority for critical life decisions in the hands of medical professionals, are discriminating against these children because of severe disability. Although Ms. Hoffman pointedly argues that hospital futility policies are often misapplied or ineffectually applied in cases involving this particularly vulnerable class of patients, she concludes that the increased transparency afforded by new legislative solutions is an encouraging development.

Jim deMaine is a retired pulmonary and critical care clinician at Group Health in Seattle, Washington. He is also Emeritus Clinical Professor of Medicine at the University of Washington School of Medicine. Joi Murotani Dennett, is a clinical social worker at Group Health. In *Communicating with Patients and Families About Difficult End of Life Decisions: A Guide for Medical Providers*, Dr. deMaine and Ms. Dennett present a methodology for navigating difficult patient care discussions in the context of the family conference. Pragmatically, the authors walk their readers through a multi-step process by which these conversations can be prepared for, successfully conducted, and appropriately concluded (including recommendations for following through and following up). The approach provided by Dr. deMaine and Ms. Dennett could be an important resource for providers, new and old, as well as the institutions they represent, with the most significant benefits ultimately flowing to the patients served.

V. CONCLUSION

This special issue of the *Hamline Law Review* offers balanced perspectives from different disciplines and practice settings. And it identifies priorities for empirical and legal research. We hope that the Symposium and this special issue will assist clinicians, policymakers, and industry leaders in improving end-of-life care, by informing, guiding, or prompting the development of needed public policy, institutional guidance, and individual practice.

³¹ I recently argued that these state statutes are superfluous. The federal Patient Self Determination Act already requires hospitals to disclose their medical futility policies. Indeed, several facilities have recently been sanctioned for failing to disclose such policies. Thaddeus Mason Pope, *Medical Futility Policy Transparency* (Apr. 15, 2013), <http://www.bioethics.net/2013/04/medical-futility-policy-transparency/>.