JOURNAL OF HOSPITAL ETHICS

VOLUME 5
NUMBER 3
WINTER 2019

THE JOHN J. LYNCH, MD CENTER FOR ETHICS AT MEDSTAR WASHINGTON HOSPITAL CENTER

SYSTEMS

features

in practice

MedStar Washington
Hospital Center

editorial group

EDITOR-IN-CHIEF
Evan G. DeRenzo, PhD

SENIOR EDITOR
Christian Carrozzo, MA

PRODUCTION EDITOR
Leslie LeBlanc

MEDICAL EDITORS
Norine McGrath, MD
Jack A. Sava, MD, FACS

ADMINISTRATOR
Kahlia Keita, MA, JD

ADMINISTRATIVE ASSISTANT
Nikki Glover

EXECUTIVE DIRECTOR
Norine McGrath, MD

LEGAL EDITOR
O. Mary Dwyer, JD, MA

INTERNATIONAL CONTRIBUTING EDITOR
Daniel Sokol, PhD, GDL

MEDICAL LIBRARIANS
Jory Barone, MLS
S. Layla Heimlich, MSLIS
Fred King, MSLS

editorial advisory board

Amanda Anderson, RN, BSN, CCRN
Center for Health Media & Policy, Hunter College
Chee M. Chan, MD, MPH
Medical Director, Intermediate Care Unit, MedStar Washington Hospital Center
Zacharia Cherian, MD,
Chair of Neonatology, MedStar Washington Hospital Center
J. Hunter Groninger, MD, FAAHPN
Director Section of Palliative Care, MedStar Washington Hospital Center
Josh Hyatt, DHS, MHL, CPHRM, FASHRM
Director, Integrated Risk Management, Keck Medicine of University of South California
Jack Kilcullen, MD, JD, MPH
Attending Physician, Medical Critical Care Service, Inova Fairfax Hospital
Eran Klein, MD, PhD
Assistant Professor, Department of Neurology, Oregon Health and Sciences University and Physician, Portland Veterans Administration Health Care Systems
Jason Lesandrini, PhD(c)
Assistant Vice President of Ethics, Advance Care Planning, and Spiritual Health, WellStar Health System
Barbara M. Mitchell, RN, MSN
Director, Quality Resources & Outcomes, MedStar Washington Hospital Center
Stephen W. Peterson, MD, FAPA
Psychiatric Physician, Outpatient Behavioral Health,, MedStar Washington Hospital Center
Michael Pottash, MD, MPH
Attending Physician, Palliative Medicine, Med Star Washington Hospital Center
Ira Rabin, MD
Vice President of Medical Operations, MedStar Washington Hospital Center
Jack Schwartz, JD
Adjunct Professor and Senior Research Associate, University of Maryland Carey School of Law
Stephen Selinger, MD
Chief, Intensive Care Unit, MedStar Franklin Square Medical Center
Eric A. Singer, MD
Assistant Professor, Section of Urologic Cancer, Rutgers Cancer Institute of New Jersey, Robert Wood Johnson Medical School
Carol Taylor, RN, MSN, PhD
Senior Research Scholar, Kennedy Institute of Ethics and Professor, Department of Medicine & School of Nursing & Health Studies, Georgetown University
Leonard Wartofsky, MD, MPH
Emeritus Chair of Medicine, MedStar Washington Hospital Center

mission

The mission of the Journal of Hospital Ethics is to enhance bioethical discussion and to assist in the development of skills associated with recognizing, understanding, and managing moral uncertainties and ethical complexities in hospital practice.

The mission of the John J. Lynch, MD Center for Ethics at MedStar Washington Hospital Center is to help clinicians and other hospital professionals meet a standard of excellence in the care of our patients through education, training, consultation, policy development, and research in clinical ethics. Additionally, when appropriate, we address the ethical concerns of our patients and families directly. The MedStar Washington Hospital Center's bioethics program began in 1982. The John J. Lynch, MD Center for Ethics, subsequently established, is involved in over 300 clinical ethics consultations a year, as well as the development of internationally recognized bioethics conferences and education programming.

online access

Go to: www.medstarwashington.org. Click on: Our Hospital, The John J. Lynch, MD Center for Ethics, Journal of Hospital Ethics Online Access. Select an issue and enter the passcode. The passcode for this issue: Systems

©Copyright 2019 The John J. Lynch, MD Center for Ethics. All rights reserved. Cover photograph/graphics credit: ©iStock@ipopba.

JOHN J. LYNCH, MD
CENTER FOR ETHICS
AT MEDSTAR
WASHINGTON
HOSPITAL CENTER

JOURNAL OF HOSPITAL ETHICS

VOLUME 5
NUMBER 3
WINTER 2019

contents

ROUNDING WITH THE EDITOR

features

in practice

Systems Complexity and the Modern Hospital

Dear Reader,

Welcome to volume 5, number 3 of the *Journal of Hospital Ethics* (JOHE), the systems issue. No matter how much we would like to simplify our lives, it seems that the systems within which we have to live and work become ever more complicated. Nowhere is that more accurate than in the modern hospital. My husband, whose career was in the intelligence world, working with science and computer issues around the globe, always said that he thought hospitals were the most complex organizations: too many uncontrollable variables.

For those who prefer the worlds of research and scholarship, this fact of uncontrollable variables presents one with an indecipherable mess. Having come from the National Institutes of Health, where one of the hallmarks of clinical research is the effort to strip one's subjects of every extraneous variable possible, when I arrived at the Lynch Center 20 years ago, I fell in love with the messiness of clinical medicine.

For those of us who have worked in hospitals for most of our careers, this fact of uncontrollable variables and the ever-increasing systems complexity designed to tame them is just the everyday phenomena of the modern hospital. But only with the publication of the Institute of Medicine's (IOM) report, *Crossing the Quality Chasm*,[1] did the importance of systems come into focus. Prior to this report, the primacy of the patient/physician relationship was so strong that the systems that have grown to support the healing properties of this relationship were still in the background. No more.

Crossing the Quality Chasm, published on the heels of the eye-popping and terrifying IOM report *To Err Is Human* (TEH, henceforth),[2] plunked systems onto center stage. After the jolt felt around the world, produced by *TEH's* finding that there were approximately 98,000 preventable patient deaths a year in U.S. hospitals, more than those produced by motor vehicle crashes, did the international medical community start taking systems seriously. Reviewing progress on patient safety in 2016, 15 years after *TEH,* Provonost and colleagues found that some things have improved.[3] They still lamented, however, that "Progress towards reducing these harms has proven difficult because healthcare lacks robust mechanisms to routinely measure the problem and estimates of the magnitude vary widely. It is hard to gauge safety when healthcare uses multiple different measures for the same harm and provides limited investment in measurement, implementation and applied sciences."[4] The authors did identify, however, one success story: central-line-associated blood stream infections (CLABSIs). The 2016 article reviewed infection rates before and after *TEH,* and offered five insights into why the successes have occurred. These five are:

1. Creating a national valid and reliable measure for CLABSI and implementing a mechanism for broadly collecting and reporting these data.
2. The creation and wide adoption of evidence-based care practices.
3. Investment in advanced implementation science, with the establishment of a nationally enabling structure, to reduce CLABSIs.
4. Creation of local ownership and peer learning

communities. As the article explains, "clinicians led the work to reduce CLABSI and created clinical communities in which peer hospitals learned from each other."[5]

5. Lastly, policy makers, clinicians, and researchers aligned and synergized efforts around a common goal and measures.

Today, CLABSI infection deaths have been reduced by 80 percent.

Crossing the Quality Chasm took an even broader view. It took as its task an overview of the U.S. healthcare system writ large. The committee producing this report examined how improvements in patient care needed to be realigned; making clear that individual effort alone would not be enough. The executive summary states, "The committee is confident that Americans can have a health care system of the quality they need, want, and deserve."[6] But, the committee went on to warn, "The current care systems cannot do the job. Trying harder will not work. Changing systems of care will."[7] That is what this issue is about: systems of care.

The first path towards changing systems of care is to see how seemingly different systems within the hospital are still able to connect. One of the worst problems in hospital systems management is the silo problem. That is, persons in their own departments become completely blind to how they connect to other systems in the hospital and how their own functions can impinge on patients' well-being.

One of these areas is medical billing. It is the rare clinician who gives much thought to billing. Some clinical ethicists teach clinicians not to think about costs, but rather to only think about what is the best treatment for their patients. Others encourage physicians to take into account a patient's ability to pay for expensive discharge drug regimens. Regardless, billing is not ordinarily thought of as a bedside issue.

This matter has not gone without some scholarly bioethics attention. One of the best empirical research ethics studies on a related issue, by Danis and colleagues, explored public attitudes about discussing costs within the clinical encounter.[8] These researchers found that some persons would be willing to discuss costs with their physicians. An important precursor was Cassel and Brennan's social justice paper about medical costs and how they were becoming disproportionate.[9] They refer us back to the problem of the commons, and warn that our medical costs are consuming our resources for other important social needs. Included in this issue, Saba Fatima makes explicit and compelling arguments addressing precisely how hospital billing systems can have harmful influences on patients' well-being.

Also in this issue, Geert Craenen and Peter Koch address another aspect of systems practice in a hospital, setting these systems into the context of moral courage. The article tells the story of how a physician in the intensive care unit acted with moral courage to meet his obligation to act in the best interest of his patient, even though that meant acting counter to the preset systems the hospital had put in place to provide medically and ethically sound end-of-life care.

> *"The current care systems cannot do the job.*
> *Trying harder will not work.*
> *Changing systems of care will."*

This article epitomizes the moral courage exhibited by the physician for whom our Center for Ethics is named. As some of you may know, in Jack Lynch's name, we have created an organizational ethics yearly program that recognizes persons in the hospital who have acted with moral courage, to the extent that others recall the action and submit it for consideration to a panel of reviewers, independent of the Center for Ethics. Chosen associates are awarded at a ceremony at which the president of the hospital and Dr. Lynch's widow still speak. This is an important way to broadcast to the hospital that acting with the kind of moral courage shown by the physician in Craenen and Koch's paper is something the institution values.

The point here is that sometimes the systems we set up are the wrong systems. And perhaps it takes moral courage to take on systems that appear to be created to produce improvements but don't. This point leads me back to the article by Pronovost and colleagues. One of the insights that led to an actual improvement in patients' outcomes is that there was a national coming together to develop consistent goals with virtually universal acceptance for measurement of CLABSI infections. This agreement was absolutely necessary to assure that the rates could be tracked consistently. Right now, we have that problem in our own bioethics community. The systems that are being put in place to evaluate clinical ethicists' performance are the wrong systems. They confuse paper for patients. The elegance of chart notes has little to do with the actual effectiveness of a clinical consultation. The outcome measure is simply not the one that is needed. Nor is the goal appropriately shaped. Rather than evaluating clinical ethics consultation on whether one reads books that some like, or produces the kind of chart notes that some have spent their careers creating (as important as these things may be), the goal has to be improved patients' outcomes and the measurement of that has to be quality metrics that are established to evaluate the improvement of those outcomes

Our community needs to remember the wonderful body of work that has made George Agich one of the most important pioneers of our clinical specialty.[10] Even before there were the kind of quality metrics we now have in hospitals, George's message (I do hope I've interpreted his works and our conversations correctly) was that the value of the clinical ethicist is measured by the degree to which the clinical ethicist is seen in the hospital as a wise counselor. And the only measure of what it means to be a wise counselor by clinicians is to provide guidance that physicians can practically use to improve the outcomes of their patients.

Today, we are finally beginning to figure out how to qualitatively measure the advice of the clinical ethicist. Our hospital is a participating site in the national mortality study being conducted by the Mayo Clinic. For the first time, this study begins to identify, count, and evaluate the total number of hospital deaths occurring in participating institutions.

That hospitals didn't already do this might be surprising. Fortunately for the Center for Ethics, Cynthia Coleman has joined us. Cynthia comes from a background in hospital quality. She was immediately invited to serve on the committee that does this research. Last month, Matt Schreiber (physician lead for the research committee and vice chair of the hospital's ethics committee), added ethics consultation to the criteria to be evaluated in every hospital death. So for those deaths for which there was an ethics consult, that consult will be pulled apart in every way, not only related to the chart note, but to include interviews of those who conducted, were involved in, and received the consult. These efforts will be made to attempt to ascertain if and how the ethics consultation might have contributed positively or negatively to the deceased patient's care. From this, we expect to begin to truly create quality metrics for clinical ethics consultation.

Finally, in this issue is a piece I wrote with Jamie Watson. And because I only contributed mere morsels to something primarily written by him, I feel at least somewhat at leave to comment on it. In the article, we identify a previously invisible population that we call "decisionally isolated" patients. We thank Laura Guidry-Grimes for this conceptual terminology. The systems inside a hospital that are developed and in place for patient care are many, yet systems outside the hospital that patients also need barely exist. These systems, and/or nonsystems, interact in ways that often result in what I would consider substandard care. It is only because our president, Gregory Argyros, when acting as our chief medical officer, charged us with improving the care of our unbefriended patients, that in the course of attempting to do so, Jamie and I found we had mutual interests, most notably during our cofacilitation of a group focused on this population at the Cleveland Clinic's newly created Un-Conference. The goal of the Un-Conference, set up as a working meeting for those active in clinical ethics consultation, was to surface mutual problems with the hope of arriving at mutual solutions. It's a brilliant clinical and organizational ethics idea, and a meeting that will be continued with real expectations for innovative problem solving.

We hope that identifying this distinct population will be helpful to these patients and encourage research and scholarly interest. There are so many vulnerable patients in today's hospitals, it is as important as ever that institutions become consistent in their own mission and culture, and develop their own quality improvement projects that provide these special populations with the support they need. We hope, also, that our nascent work sparks others to look at the systems, both within the hospital and outside, and start working on the gaps in both places.

As always, we have provided cases we think are relevant to the considerations and concerns raised in the articles or by the topic of systems, more generally. And, as always, we would love to hear from you.

Sincerely,

Evan

Evan G. DeRenzo, PhD
Editor-in-Chief

References

1. Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, D.C.: National Academy Press; 2001.

2. Institute of Medicine. *To Err Is Human: Bulding a Safer Health System*. Washington, D.C.: National Academy Press; 2000.

3. Provonost PJ, Cleeman JI, Wright D, Srinivasan, A. Fifteen years after *To Err is Human*: A success story to learn from. *BMJ Qual Saf.* 2016;25:396-399.

4. Danis M, Sommers R, Logan J, et al. Exploring public attitudes towards approaches to discussing costs in the clinical encounter. *J Gen Intern Med*. 2014;29(1):223-229.

5. Cassel CK, Brennan TE. Managing medical resources: Return to the commons? *JAMA*. 2007; 297 (22):2518-2521.

6. Agich GJ. Clinical ethics as practice. *J In Bioethique*. 2009;20(4):15-24, 107.

7. Agich GJ. Education and the improvement of clinical ethics services. *BMC Med Educ*. 2013;13:41.

8. Agich GJ. Ethics consultation: Critical distance/ clinical competence. *Am J Bioeth*. 2018;18(6):45-47.

9. Agich GJ. The foundation of medical ethics *Metamedicine*. 1981;2(1):31-4.

10. Agich GJ. What kind of doing is clinical ethics? *Theor Med Bioeth*. 2005;26(1):7-24.

Opinions of Members of the National Civil (Family Proceedings) and Criminal Courts in Withholding or Withdrawing of Life Support Situations in Pediatrics

Jorge O. Selandari, MD, María S. Ciruzzi, PhD,
Adriel J. Roitman, MD, Fernanda Ledesma, MD,
Célica Menéndez, MD, and Hernán O. García, MD

INTRODUCTION TO THE TRANSLATION

The following study and qualitative analysis were first published in Argentina by the Sociedad Argentina de Pediatría in 2016. An English translation appears here for the first time. Although the descriptive study itself remains intact, this newly composed general introduction by the authoring research team (in collaboration with the editorial group of the John J. Lynch, MD Center for Ethics) has been included to provide additional context.

In Argentina, the penal system, although dogmatically subject to the principles of *ultima ratio* and minimum intervention, is often seen as the first and most forceful option against behaviors found outside the defining margins of criminal law. Although controversial, many such behaviors are often seen as more as exercises of individual freedom and personal realization than violations of the law. Nevertheless, the appeal to criminal law tends to be seen not only via judicial operators, but also in the general population, who, in the face of controversial behavior, usually resort to criminal interpretation rather than attempting to resolve conflicts through less intrusive and often more effective means.

Decisions at the end of life pose a serious challenge to criminal law, which supposes the exercise of punitive power by the state in defense of legal rights whose violation is of such magnitude that only a criminal sanction can appropriately address it. Such challenges also exist in light of civil law in considering the autonomy of a patient who is a minor, and the role of parents and/or legal representatives in decision making. Decisions made in relation to the withdrawal or withholding of life-sustaining treatment (WLST) in pediatrics can be some of the most controversial and morally challenging. These challenges are compounded by fears related to the status of decisions that are considered to be ethically optimal, even though legally questionable.

From a bioethical point of view, it is commonly understood that not everything that is technologically possible is ethically reasonable or legally binding. In turn, therapeutic obstinacy is often considered highly damaging and can also violate the principles of autonomy and nonmaleficence. However, current law (and criminal law, specifically) does not clearly embrace therapeutic obstinacy as an offence or a violation of autonomy and integrity. Many behaviors that in daily practice may result in what might be considered therapeutic harassment, and therefore tend to be avoided or limited, could also be judged by the layperson as directed to produce the death of the patient. The criminal threat appears on the medical horizon as a warning signal: it inhibits and paralyzes, preventing the clinical professional from performing the therapeutic behaviors called upon by his or her training due to fear of the consequences of an action that has unclear legal status. The *lex artis* that regulates good medical practice is inextricably linked to advances in medical science, the appropriate application of which depends on the medical circumstances of each patient *in particular*, and the professionalism and experience of the physician. Given such particularity, it is difficult to imagine a general law that could consider all of the possible therapeutic variables of every patient.

Additionally, pediatric care often assumes that the medical relationship is made up of three subjects: the physician, the patient, and his or her parents. When parents assume an active role, they often become the only expression of the child's will. Effectively, the decision-making process is handled by a third party who is not the patient and often ignores or underestimates the personal values of the child. If we include the additional intervention of yet another party in the medical relationship, such as a judge, the legal implications are further complicated.

In addition, there remains in public opinion a conceptual confusion between passive euthanasia and WLST, calling for a need to determine whether there is a single conception of these entities that has preponderance in judicial interpretation. No less important is the international media coverage of these sorts of cases, which has led to several proposals in our country calling themselves a "dignified death act" that end up superimposing existing rules, and trying to apprehend under a simple concept special and unique medical situations that—due to their complexity, not only scientific but also fundamentally human—cannot be approached unilaterally, unidimensionally, or simplistically.[1]

Based on the results of our survey, it would be appropriate to consider the proper handling of ethical issues at the end of life as a competence within the field of public health, which should be regulated primarily by scientific standards that facilitate the decision-making process, within a framework of privacy and respect for the rights of all involved. We believe that the results we obtained may assist in the training of human resources professionals, not only in the field of health but also in the field of law, facilitating an exchange of knowledge that can help avoid the legal scrutiny of appropriate medical behaviors and allow decision making to occur in a consensus environment between the health team, patient, and family. Given our results, we suggest that judicial intervention should be considered a last resort when all of the possibilities of agreeing on a course of action in relation to the pathology suffered by a patient have been exhausted. Here, the role of a hospital ethics committee is fundamental, as it allows us to apprehend the situation in a multidisciplinary way, through different scientific and legal perspectives. In principle, and supported by the findings of our survey, the ethics committee is the one called to intervene at the time of discrepancies, questions, and/or doubts about ethically appropriate medical decision making. Only when disagreements conspire against the best interest of the patient and a committee has not been able to reach a consensus should we resort to judicial intervention.

It is evident from the comments of the survey respondents that contact with real cases in highly complex pediatric practice with no reasonable possibilities of cure or improvement has shaken judicial operators who are not familiar with the elements of care that surround seriously ill children. The interviews demonstrate the anguish generated by these situations and the need felt by the respondents to offer a "technical-professional" opinion that incorporates empathy and compassion for the pain of others. Respondents often returned to a legal framing of each case while simultaneously attempting to avoid the judicialization of medical decision making.

We believe that the greatest value of the work that we are presenting lies in the interdisciplinary nature that distinguishes it. This does not emerge primarily, as is generally understood, from different medical specialties, rather from the various disciplines that together can come to understand a phenomenon as complex and multifaceted as the decision-making process at the end of life. As a culmination of that meeting, we were then able to develop medically and legally viable proposals. We believe that, beyond the particular findings of this study, this turns out to be its most significant achievement: The hospital and the university working together in the exchange of ideas, leading to the development and consensus of ethically sound public health policies.

Acknowledgment

We would like to thank Professor Juan P. Garrahan of National Pediatric Hospital, the Law School of the University of Buenos Aires, and the National Ministry of Health for their sponsorship and support of this research. The authors would also like to thank the members of the Judicial Power for their voluntary participation.

References

1. This research was completed before the Death with Dignity Act was passed by Argentine Parliament (Bill No. 26742, 2013).

Opinions of Members of the National Civil (Family Proceedings) and Criminal Courts in Withholding or Withdrawing of Life Support Situations in Pediatrics

INTRODUCTION

Medical science development, in its technological phase, has resulted in the emergence of technologies that allow sustaining life to an extent that was unthinkable not long ago. The need to limit this practice posed by the exercise of certain rights (autonomy, dignity, quality of life), the obligation to avoid causing harm (therapeutic obstinacy or patient neglect), and the increasingly active role played by patients and/or their family in the healthcare relationship make it necessary to consider how to solve these problems without harming patients or questioning the responsibility of healthcare team members. In terms of bioethics, the prevailing concept is that not everything that is technologically feasible is ethically correct. What is the approach to this matter according to the Argentine civil and criminal law? Is withholding/withdrawing of life support (WLS) legally allowed in pediatrics? Does WLS require a legal authorization in pediatrics? Is WLS in a pediatric patient a crime?

OBJECTIVE

To explore the opinion of members of the National Judiciary (NJ) regarding the approach to WLS from a legal stance.

POPULATION

Professionals working in the criminal, civil, and forensic medicine settings.

METHODS

Descriptive, cross-sectional, qualitative, quantitative, explorative study with a diagnostic analysis. The instrument used in this study was a semistructured, anonymous survey that included an informed consent (available in the appendix to this article), administered by the grant holder and/or was self-administered by research subjects themselves. The survey structure was as follows:

a. Personal and professional background.
    1. Demographic data.
    2. Professional training.
    3. Religious background.
b. Case and conceptual background.
c. Case history analysis.

The survey described three hypothetical cases based on situations generally faced by a pediatric healthcare team, and classified into three categories commonly typified in the ethical analysis of these situations. The first case was a "no chance" situation. The second case was a "unbearable" or extremely poor quality of life situation. Finally, the third case described a patient in a persistent vegetative state.[1] In addition, it was explained that all of the cases took place in a context of a good relationship, understanding, and agreement among the medical team and the patient's family.

Definition of Each Category

1. **No chance situation:** Treatment will merely delay death without significantly relieving suffering.
2. **Unbearable or poor quality of life situation:** In the face of progressive disease, additional treatment may only cause further suffering, despite the possibility it might have some potential benefit on the underlying condition.
3. **Persistent vegetative state:** Medical condition characterized by the absence of voluntary interaction with the outside world and a lack of awareness of the inner world, with no reasonable possibility of recovery after 12 months of assistance. The patient feels no pain and has no awareness, a sleep-wake cycle is present, and the patient is reflexively capable of making automatic gestures (smiling, wincing, etc), but there is no recognizable relation to external stimuli.

Table 1 is a transcription of the three hypothetical case histories included in the survey.

Items "b. Case and conceptual background" and "c. Case history analysis" in the survey provided ample space for respondents to delve into their concepts and opinions.

The study population included all judges, defenders, and prosecutors from criminal and civil justice and oral trial courts, defenders and advocates of minors and legally incompetent persons from criminal and civil justice, and forensic physicians. Only personnel from the National Judiciary and the Guardianship Office who might intervene in cases of WLS in children were included. Survey respondents signed a written informed consent form, and the study was approved by the Ethics Committee and the Institutional Review Board of Hospital de Pediatría "Prof. Dr. Juan P. Garrahan," and the Health Research Committee (Comisión

Nacional Salud Investiga) of the National Ministry of Health.

For descriptive statistics purposes, categorical outcome measures were described as a proportion and 95% confidence interval (95% CI). The univariate analysis was done using the X^2 test. No multivariate analysis was done due to the small n size ($n = 51$). Answers were qualified by two principal investigators separately, and differences were solved by consensus. Data were analyzed using the Stata 9.0 statistical package for Windows (StataCorp, College Station, Texas).

RESULTS

Between April and August 2011, 185 surveys were distributed: 135 among National Judiciary

Table 1.—Hypothetical Cases Described in the Survey

Case 1: No Chance Situation

Mariela was an 11-year-old girl with acute myeloid leukemia. The intention had been to perform bone marrow transplantation after chemotherapy. She tolerated treatment poorly and developed sepsis (severe systemic infection) and had difficulty breathing. She was intubated and connected to a ventilator in the intensive care unit, but her condition continued to deteriorate and required progressively increased ventilator settings. In spite of chemotherapy, leukemia was still active, which in her present context indicated a situation with no reasonable chances of recovery. Her physicians and parents agreed not to escalate life support (eg, use of ventilator, dialysis or invasive procedures, such as catheterization, etc) or start cardiopulmonary resuscitation in the event of a cardiac arrest. Mariela had multiple organ failure, cardiac arrest, and died; cardiopulmonary resuscitation was not attempted.

Case 2: Unbearable or Poor Quality of Life Situation

A first-time mother went into labor at 41 weeks of gestation and required an emergency c-section. She delivered a 2,700 g male infant named Ramón, who was relatively small for his gestational age. The baby was not breathing; he was resuscitated but had seizures in the following four hours. He was unresponsive and placed on mechanical ventilation (MV) until he was 32 days old. At 45 days old, he required MV once again due to apneic episodes (a temporary absence or cessation of breathing), which resulted in a respiratory infection, and required increased ventilator settings. At 65 days old, he had his first major bronchial-obstructive reaction, accompanied by crying and generalized cyanosis requiring resuscitation and sedation. These episodes were recurrent, and progressively worsened during the course of hospitalization, and in spite of several therapeutic strategies, at nine months old, he required continuous MV and had frequent bronchial obstructive reactions and seizures that destabilized him, resulting in an extensive and severe neurological injury. Medical evidence indicated, with a high degree of certainty, that if Ramón survived, he would be a quadriplegic (total loss of use of all four limbs) and have severe cognitive impairment. In this context, his physicians, nurses, and parents agreed that life support was against Ramón's best interest because such measures (need for a continuous intravenous line, airway aspiration, sedatives, and, sometimes, even paralytic drugs) only caused additional suffering and no benefits for the patient, prolonged suffering, and implied an extremely low quality of life, and that providing life support only for the purpose of alleviating the pain of losing a child was against Ramón's own dignity. Therefore, one morning, with Ramón in his mothers' arms and next to his father, was taken off MV. Sedatives were increased to manage a potential sensation of shortness of breath. A few minutes later Ramón had an apnea episode that resulted in a cardiac arrest, and he died; resuscitation was not attempted.

Case 3: Persistent Vegetative State

Pedro, a 15-year-old boy, was in a car crash and suffered a brain injury which left him in a vegetative state. He was intubated and on mechanical ventilation for more than 17 months and never regained consciousness, nor had any reaction to or interaction with the outside world. His parents asked for his endotracheal tube to be removed and to let him die in peace. Knowing Pedro, they assured that this was what their son would have wanted. Physicians removed the endotracheal tube that was connected to the ventilator and Pedro died approximately 30 minutes later.

members and 50 among members of the Forensic and Legal Medicine Board. Sixty-eight (36.76%) surveys were returned: 50 from the National Judiciary and 18 from Forensic and Legal Medicine Board. Among these 68 surveys, 17 (25%) members of the National Judiciary did not complete section "c.": seven criminal defense lawyers and 10 judges.

Descriptive data for the survey respondents are shown in detail in table 2.

Most of the 92 respondents (47, or 51%) were never involved in a WLS case. For 96.15% of the respondents (50 out of 52 completed surveys), "killing someone," "helping someone to die," and "allowing someone to die" were not the same.

Table 2.—Description of Survey Respondents (*n* = 68)

Demographic data	%	*n*	No. who did not answer
Older than 50 years	70	35	18
Married	67.31	35	17
With children	82.35	43	17
Religion	--	--	17
Roman Catholic	72.54	37	--
Atheist or agnostic	23.52	12	--
Jewish or other religion	3.92	2	--
Religious observance	--	--	20
Never	45.8	22	--
Seldom	35.4	17	--
Regularly	18.8	9	--
Profession	--	--	0
Lawyer	73.53	50	--
Physician	23.53	16	--
Dentist/psychologist	2.94	2	--
Professional experience	--	--	18
20 or more years	84	42	--
Position	--	--	0
Expert	26.27	18	--
Judge	48.53	33	--
Criminal defense lawyer	17.65	12	--
Prosecutor	1.47	1	--
Defender of minors and legally incompetent persons	4.41	3	--
Guardianship advisor	1.47	1	--
Training	--	--	0
Graduate	39.70	27	--
Post-graduate	47.05	32	--
Doctoral program	13.23	9	--

Percentages left out items that were not answered.

Among the 50 respondents who answered the section about withholding treatment versus interrupting or withdrawing treatment, 84% (42) considered these as legally separate entities, while 16% (eight) considered both situations to be legally equivalent.

Analysis of Hypothetical Case Histories

This section of the survey was completed by 48 of 51 respondents. Seventeen respondents systematically omitted this section because the National Chamber of Civil Appeals forbade judges from the civil courts to participate in the survey, alleging that they might eventually fall under prejudice should they become involved in a future case.

Table 3 summarizes the answers given to each case. Among respondents who completed this section, for Case 1, 30% criminalized the measures taken; for Case 2, 41% criminalized the measures taken; and for Case 3, 39% criminalized the measures taken.

Table 4 describes the type of crime attributed to each case.

Pooled Analysis of the Three Case Histories

In the pooled analysis of answers regarding the three cases, it was observed that 28 (55%) of the respondents did not criminalize any of the decisions made. On the contrary, 13 (25%) respondents considered that actions taken in all three cases constituted a crime; six (12%) criminalized one of the three cases; and four (8%) criminalized two out of the three cases.

Among the answers provided for the three case histories, 73.81% of the respondents ($n = 110$) agreed on the withdrawal of mechanical ventilation (MV). Also, 63.40% ($n = 97$) of the respondents focused on the need to have these situations resolved in the healthcare setting, without the need to request legal authorization. In terms of variation in the opinions regarding the existence of advance medical directives (AMD) or when the patient was an adult, most of the respondents did not modify their answer: this applied to 116 (76.8%) and 115 (77.2%) of the answers given, respectively.

Actions described in the case histories were identified with euthanasia by 47% ($n = 24$) of respondents. In this regard, Case 2 was mostly considered this way (23%, 11 respondents), followed by Case 3 (19.6%, 9 respondents). Case 1 was the one with fewest references to euthanasia (8%, four respondents).

No differences were observed in opinions in terms of religion, sex, or profession (judges, prosecutors, and defenders). A significant association was observed between working in the legal field and a higher likelihood of criminalizing any of the three cases, compared to healthcare providers, which included physicians, a psychologist, and a dentist (see table 5). On the contrary, respondents' religion (grouped by Jewish-Christian tradition or agnostic-atheist) was not associated with differences in the criminalization of decisions made ($p = 0.9$).

Qualitative results

Handwritten comments and notes made by survey respondents and the subjective findings resulting from personal interviews with respondents are available in the supplementary material (see the appendix).

DISCUSSION

WLS is a common decision made in pediatric intensive care units (PICUs) across the world[2-13] and in Argentina,[14] and, to this date, no court claims have been made in Argentina in relation to WLS.

However, the "fear of litigation"* is a factor that may have a negative impact on decision-making processes, communication with the patient's family, and their due participation in such decisions.

Actually, the fear of litigation may result, on the one side, in therapeutic obstinacy[15-20] and, on the other, in an inadequate WLS.[17,18,21] It may also affect the level of communication[22,23] and inquiry on WLS decisions with the family.

It may be believed that the existence of bioethical, medical, and legal grounds and the absence, in Argentina, of court decisions against WLS doe not justify such fears. However, this study explores, for the first time in our country, legal workers' opinions in relation to WLS and indicates that healthcare providers' fear of litigation may be justified.

Although, as expected, most respondents agreed with the decisions made in the hypothetical case histories, a remarkable number of them (45%) found one or more crimes in a setting that, as presumed by authors, posed an ethically and legally valid case of WLS, similar to those commonly observed in Argentine PICUs.[14,15,24,25]

It is striking that justice workers, regardless of their position (judge, prosecutor, defender, or advocate for minors), had such dissimilar opinions regarding medical practice in its legal significance, both in relation to the "crime-no crime" dilemma and the type of crime (intentional homicide or wrongful death, failure to render assistance, or inciting a person to commit suicide), to the point that, for the same case, both a homicide and the non-existence of a crime were proposed. Or the fact that the same practice may be criminalized as any of the four criminal definitions indistinctly.

It was obvious, during the conduct of the survey, and based on respondents' comments, that contact with real cases of severely ill patients who have no reasonable possibility of recovery or improvement in the setting of tertiary pediatric practice had made these legal workers upset. The distress caused by these situations became evident during interviews. Respondents made an effort to provide, on the one hand, a "technical and professional" opinion, but on the other hand, they had an understanding, empathetic, and compassionate position regarding others' pain. In their effort to achieve a balance, when they believed that the case constituted a crime, from a technical point of view, they also attempted to "overturn" the legal perspective and find a legal framework that would reduce the sentence, exclude illegality, or prevent accountability.

It is also worth noting, as a positive finding, that many survey respondents (63.40%) stressed the need for these matters to be resolved in the healthcare setting and that, if a third party was required to intervene other than the treating team or the patient and his/her family, they proposed the participation of an ethics committee and avoiding judicialization of the healthcare relationship.

We agree with this consideration. It is understandable that judicial involvement should be an exceptional resource, the last resort once all possibilities of agreement with the patient and his/her family regarding the management plan have been exhausted. In this regard, the role of the ethics committee is essential because it allows understanding the health-disease situation from different scientific and lay perspectives. As a matter of principle, and supported by our survey findings, the participation of an ethics committee should be requested if discrepancies, questionings, and/

---

* We refer to "fear of litigation" as the psychological "driving force" of "defensive medicine," a MESH and DeCS term defined as "alterations of modes of medical practice, induced by the threat of liability, for the principal purposes of forestalling lawsuits by patients." http://pesquisa.bvsalud. org/portal/decs-locator/?lang=es&tree_id=I01.880.604.583.524.300&term= I01.880.604. 583.524.300. Accessed December 2014.

Table 3.—Answers from Respondents Regarding Each Hypothetical Case

	Case 1		Case 2		Case 3	
	n	%	*n*	%	*n*	%
In general, agree with decisions made.	45 of 51	88	33 of 43	77	36 of 50	72
Decisions made did not constitute a crime.	35 of 50	70	29 of 49	59	28 of 46	61
Agree with no CPR.	39 of 49	80	--	--	--	--
Agree with withdrawing MV.	39 of 50	78	36 of 50	72	35 of 49	71
Would not change their answer even if patient had AMD.	40 of 51	78	41 of 51	80	35 of 49	71
Would not change their answer if the patient was an adult.	39 of 51	76	41 of 50	82	35 of 48	73
It is not necessary to request a legal authorization for WLS.	35 of 51	69	31 of 51	61	31 of 51	61
Do not agree with withdrawing parenteral hydration/feeding.	--	--	--	--	32 of 49	65
Do not agree with withdrawing enteral hydration /feeding.	--	--	--	--	32 of 51	63

n = number of respondents who answered the item. CPR: cardiopulmonary resuscitation; MV: mechanical ventilation; AMD: advance medical directive; WLS: withholding/withdrawing of life support.

Table 4.—Types of Crimes Attributed in Each Case

	Case 1		Case 2		Case 3	
	n	%	*n*	%	*n*	%
Intentional homicide	4	8	11	23	9	19.6
Wrongful death	5	10	3	6	4	8.7
Failure to render assistance	2	4	3	6	2	4.3
Inciting a person to commit suicide	0	0	0	0	0	0
Several crimes*	4	8	3	6	3	6.5
No crime	35	70	29	59	28	61.0
Total	50	100	49	100	46	100.0

* Several combinations of the four crimes listed here.

Table 5.—Determination of crime probability based on original profession

Type of profession	No case constituted a crime	1 case constituted a crime	Total for the type of profession	“Risk” rate (%)
Legal[1]	15	20	35	57.1
Healthcare[2]	13	3	16	18.7
Total cases by crime yes/no	28	23	51	45.1

NOTES

1. Attorneys, including judges, prosecutors, defenders, a scribe, etc.
2. Healthcare, including physicians, a psychologist, and a dentist. Odds ratio 5.7 (95% CI: 1.4-24), $p = 0.024$ (Fisher’s exact test).

or doubts arose regarding the medical decision-making process. Only when a discrepancy is does not support a patient's best interest, and an ethics committee is not able to establish consensus, would it be acceptable to make a legal claim.

Another remarkable finding of this study was that most respondents (73.81%) agreed to the withdrawal of MV in the three cases. The removal of MV is frequently problematic: although not initiating life support and withdrawing it have been seen as ethically and legally equivalent,[1,26-29] for healthcare teams, it is morally more challenging to interrupt a treatment than to withhold it. Healthcare providers tend to give a different psychological/emotional significance to withholding treatment versus withdrawing it.[30] The latter is usually not easily accepted among health team members, mostly because the proximity of the patient's death to the interruption of support may cause team members to feel as though they have "cause" the patient's death, even if that is not their intention.

It is understandable that judicial involvement should be an exceptional resource, the last resort once all possibilities of agreement with the patient and his/her family regarding the management plan have been exhausted.

Given that this is an original study, there are no previous studies with which to compare its results, but it is worth noting its significant limitations. First of all, the low response rate, especially regarding the most important section of the survey, the hypothetical case histories. The 27% response rate hinders the possibility of generalizing results. However, 45% of the survey respondents believed that one, two, or three of the cases were related to some form of crime. Even if those who did not complete the survey indicated that they did not detect any crime in any of the hypothetical cases—a highly unlikely polarization of opinions—12% of respondents would still criminalize decisions made.

Secondly, the survey technique may not have been sufficient to convey such complex medical concepts and situations in an effective manner to nonmedical professionals. However, respondents indicated that they were cognitively—although not emotionally—comfortable with the case descriptions and, even though this was a self-administered survey, the investigator was available to discuss and clarify any aspect that might have arisen while reading it.

Thirdly, the survey was administered before the modification in the National Patient's Rights Law, medically referred to as the "Death with Dignity Law" (May 2012), which has helped to modify the general attitude regarding these situations.

However, data supports the prevalence of this issue. For example, Marcelo Diez is an adult patient who has been in a persistent vegetative state for the past 20 years. His family has made a claim for the withdrawal of life support. An expert report by the National Forensic and Legal Medicine Board and three opinions issued by bioethics committees (Committee for the Provincial Board of Management Quality of the Secretariat of Health of Neuquén, Ethics Committee of the Argentine Society of Intensive Care, and Ethics Committee of Instituto Nacional Central Único Coordinador de Ablación e Implante) support the family's request. At present, the case has been raised to the Supreme Court because, after having been in the hands of 15 members of the National Judiciary, including different court judges, the Attorney General, etc, and even after the above-mentioned law was passed, WLS has not been authorized. We believe this case is far from being resolved.

The fear of litigation that many healthcare providers have when making end-of-life decisions regarding their patients' lives may be justified. We believe that new comprehensive clinical practice guidelines, which provide details regarding the decision-making process, as those published in other countries,[31-33] developed by healthcare providers, legal professionals, and bioethicists will help to improve the quality of care provided to patients and their families, and the health team.

CONCLUSION

Forty-five percent of survey respondents judged that the decisions made in the three cases constituted some form of crime, and this opinion was significantly associated with working in the legal field compared to working in the healthcare setting. In addition, variations in the type of crime thought to be committed were also observed.

APPENDIX

QUALITATIVE ANALYSIS

This is a descriptive study regarding the opinions of members of the National Civil (Family Proceedings) and Criminal Courts regarding withholding or withdrawing of life support situations in pediatrics.

Following are comments and/or notes made by survey respondents who indicated that they had been involved in a case of withholding or withdrawing of life support.

Judge: "I was not involved as a legal worker, but personally. I had to make a decision, together with the family, regarding the 'dignified death' of that person."

Physician: "At the Neonatal Intensive Care Unit, I have been involved in decisions regarding critically ill patients (congenital heart disease, sepsis, ventilatory failure) whose life functions and prognosis are unsustainable."

Physician: "Elderly, 84-year-old patient with brain death for more than 78 hours, multiple organ failure resulting from a hemorrhagic stroke. Life support was withdrawn."

Physician: "I had to authorize multiple organ procurement procedures due to brain death (two cases)."

COMMENTS AND/OR NOTES MADE BY SURVEY RESPONDENTS REGARDING THE THREE CASES IN GENERAL

Appeal court judge: General note on the survey: "It might seem contradictory to strongly agree with and, at the same time, criminalize an action. Legalizing euthanasia, in all of its forms, is a debt of the legislative body. In my opinion, it is necessary to set the issue in the agenda. Considering physicians (generally working in public hospitals and caring for low-income patients) have to request authorization to perform therapeutic (not punishable) abortions, they might face even more problems in these situations."

Appeal court judge: This judge indicated, in general, to agree with the decisions made in the three cases. Her general opinion was: "Every medical decision made in these hypothetical cases should be accompanied by a report of a bioethics committee."

Investigating judge: He refused to complete this section of the survey and indicated: "Taking this survey implies some sort of prejudice, delivering an opinion outside the case file."

CASE 1. NO CHANCE SITUATION: COMMENTS AND/OR NOTES MADE BY SURVEY RESPONDENTS REGARDING CASE 1

Level of Agreement and Presence/Absence of a Crime

Judge (who selected "In general, strongly agree with decisions made" and "No crime"): "To me it is clear. I share the parents' decision and the respect of the medical team for such decision. In the description of the case, I assume that parents also respected their child's will (at 11 years old a child is capable of communicating adequately). I recognize dominion over our own bodies. The single most important piece of information was what Mariela wanted. Argentina requires a regulation that, for adults, may allow for the establishment of a 'living will.' "

Judge (who selected "In general, strongly agree with decisions made" and "No crime"): "Parents are representatives of their child's will. If the decision was not vitiated, it is absolutely mandatory from a legal perspective, so the moral stance becomes irrelevant, whether allegations are made for or against it. In addition, the decision should be duly documented."

Judge (who selected "In general, strongly agree with decisions made" and "No crime"): "Family consensus and the medical report based on the impossibility of the patient's survival given her irreversible, end-stage condition, together with the decision not to do anything that may result in death, allow assuming that such alleged withholding (cardiopulmonary resuscitation) was not the cause of such result. Based on this, I agree with the last choice in the survey."

Physician (who selected "In general, strongly agree with decisions made" and "No crime"): "Physicians are not trained for a patient's 'dignified death' . . . which is as or even more relevant than a 'dignified life,' as in the case described here."

Physician (who selected "In general, strongly agree with decisions made" and "No crime"): "I believe that, in medical practice, it is necessary to deal with human omnipotence—that of the physician—and this includes considering the family's opinion and collaborating to reach consensus, preserving the doctor-patient relationship and acknowledging the limits of practice. In my opinion, parents are finally the ones that should decide, within the realms of what is reasonable."

Physician (who selected "In general, strongly agree with decisions made" and "No crime"): "If the patient's situation is that of 'no reasonable chance of recovery' and the family agrees not to escalate life support, I believe it is right to let the institution 'decide' on the end and the time for it. Otherwise, it would be a matter of obstinacy and medical and financial arrogance."

Physician (who selected "In general, somewhat agree with decisions made" and "Wrongful death"): "As per our Code, euthanasia is forbidden, so it would be a crime, even though it might be medically or clinically the most convenient thing to do."

Physician (who selected "In general, somewhat agree with decisions made" and "No crime"): "I guess that, if conditions permit, a submission should be made before the ethics committee to clearly establish (regardless of the patient's acute condition and severe multiple organ failure) whether she would have become a transplant candidate had she recovered from sepsis."

Physician (who selected "In general, strongly agree with decisions made" and "No crime"): "She had no chance at all; had the transplant been successful, who could warrant she would not have sequelae? Was it possible to ensure her an adequate quality of life?"

Physician (who selected "In general, strongly agree with decisions made" and "No crime"): "In these situations, physicians are also responsible for letting patients have a 'dignified death.' The limit of therapeutic obstinacy is that of alleviating physical pain. I have my reservations about family involvement in this decision. I have made such decisions on my own several times."

Investigating judge (who selected "In general, strongly agree with decisions made" and "No crime"): "I would decide in accordance with legal provisions and the evidence presented in each specific case, after verifying there is really no possible treatment. Once every point in the case has been verified, there would be no crime."

Judge (who selected "In general, strongly agree with decisions made" and both "Wrongful death" and "No crime"): "If a treatment that is mandatory as per the standards of the art of healing (medical protocol) is withheld, such withholding may be considered a violation to the duty of providing medical care, and the risk of death would be increased (wrongful death may be reported against physicians and parents, given that the latter act as guarantors for their child)."

Appeal court judge (who selected "In general, strongly agree with decisions made" and "Intentional homicide"): "Even though I strongly agree with the decision, as a judge, if I was asked to intervene in the case, I would consider different situations that may relieve [parties] from liability; however, from a strictly dogmatic stance, it is an intentional homicide by negligence."

Criminal defense lawyer (who selected "In general, disagree with decisions made" and both "Failure to render assistance" and "Inciting a person to commit suicide"): "A matter to consider would be what sentence would be more benign towards parents and physicians."

Investigating judge (who selected "In general, somewhat agree with decisions made" and "Intentional homicide"): "A cause for justification that rules out illegality or a cause that would relieve parties from liability. Although the case fits the definition of intentional homicide, I would always look for a justification or a cause that would relieve parties from liability: a necessity based on the case-specific circumstances."

Judge (who selected "In general, somewhat agree with decisions made" and "Failure to render assistance"): "Although this case may fit the crime punished by article 106 of the Criminal Code regarding the fact that a person unable to help herself was left to her fate, a person who should be cared for according to what was promised by physicians in the Hippocratic Oath, when faced by inevitable death, the decision to waive a treatment that would only prolong life in a precarious and arduous manner is legal. This is established in article 19 of Law 17132 regarding Medical Practice."

Investigating judge (who selected "In general, strongly agree with decisions made" and "Intentional homicide," "Wrongful death," "Failure to render assistance," and "Inciting a person to commit suicide"): "Causes for non-attributability should be considered. These are established in the Criminal Code: considering consent as a cause for justification."

Appeal court judge (who selected "In general, disagree with decisions made" and "Wrongful death"): "There are reasonable possibilities that go against an adequate legal decision regarding that there was no certain chance to continue with life. No end-stage prognosis was made."

Degree of Agreement with No Cardiopulmonary Resuscitation and Withdrawal of Mechanical Ventilation

Judge (who selected "In general, strongly agree with decisions made" and "No crime"): "I would not change my decision if parents had consented to it."

Judge (who selected "In general, strongly agree with decisions made," "No crime" and "Would change my decision"): "The patient was 11 years old, so it is assumed her maturity was enough to face 'therapeutic obstinacy.' "

Judge (who selected "In general, strongly agree with decisions made," "No crime" and "Would not change my decision"): "Minors should be heard (Convention on the Rights of the Child); however, I value parents' opinion."

Physician (who selected "In general, strongly agree with decisions made," "No crime," and "Would change my decision"): "If there is no chance, ie, no reasonable possibilities, as described in the case."

Physician (who selected "In general, strongly agree with decisions made," "No crime" and "Would not change my decision"): "The patient's decision should be respected, even if she was a minor."

Physician (who selected "In general, strongly agree with decisions made," "No crime" and "Would not change my decision"): "I do not believe autonomy should be considered, especially in terms of her age."

Physician (who selected "In general, strongly agree with decisions made," "No crime," and "Would not change my decision"): "Minors and mentally-disabled persons cannot give a valid consent. It would not change my opinion."

Investigating judge (who selected "In general, strongly agree with decisions made," "No crime," and "Would not change my decision"): "It would not change my decision because she was a minor."

Judge (who selected "In general, strongly agree with decisions made," "Wrongful death," "No crime," and "Would not change my decision"): "I would not change my decision, I would simply consider the victim's consent, the autonomy of her will to decide."

Appeal court judge (who selected "In general, strongly agree with decisions made," "No crime," and "Would change my decision"): "Although the minor is considered incompetent, based on the Convention and Law 26061, she should be heard."

Judge (who selected "In general, strongly agree with decisions made," "No crime," and "Would change my decision"): "This is an 11-year-old minor so, as in every case, she should be considered as unable to understand what she is asking for or, on the contrary, for that reason, it is more valuable."

Oral trial court judge (who selected "In general, strongly agree with decisions made," "No crime," and "Would change my decision"): "I do not agree with withdrawing or withholding artificial feeding/hydration because it is a basic healthcare procedure, not simply a treatment. A minor patient may decide on his/her preferences, and parents should decide considering such preferences."

Investigating judge (who selected "In general, somewhat agree with decisions made," "Intentional homicide," and "Would change my answer"): "Every parental decision includes a selfish component. If the patient's will was documented, the decision made by parents is an act of greatness."

Judge (who selected "In general, somewhat agree with decisions made," "Failure to render assistance," and "Would not change my answer"): "In the case of minors, their parents' or guardians' consent is valid, although it may be replaced by a legal authorization."

Appeal court judge (who selected "In general, disagree with decisions made," "Wrongful death," and "Would change my decision"): "It is a matter of legal capacity."

Change of Opinion in the Presence of Advance Medical Directives or in the Case of Adult Patients

Judge (who selected "In general, strongly agree with decisions made," "No crime," and "Would not change my decision"): "Under the same conditions: ensure the decision was not vitiated and was duly documented."

Judge (who selected "In general, strongly agree with decisions made," "No crime," and "Would change my decision"): "As long as the girl was younger. If the patient was really young or there was no consensus among the three of them (father, mother, child)."

Judge (who selected "In general, strongly agree with decisions made," "No crime," and "Would change my decision"): "I believe that the will to have a dignified death is critical."

Physician (who selected "In general, somewhat agree with decisions made," "No crime," and "Would change my answer"): "Probably in relation to advance directives."

Physician (who selected "In general, strongly agree with decisions made," "No crime," and

"Would not change my decision"): "A competent adult has a right to decide in these cases. I would ratify my decision and opinion on this subject."

Judge (who selected "In general, strongly agree with decisions made," "No crime," and "Would change my decision"): "It would clear all my doubts regarding the fact that it was adequate to withdraw treatment."

It Is Necessary to Request Legal Authorization

Judge (who selected "In general, strongly agree with decisions made," "Wrongful death," "No crime," and "No need to require legal authorization"): "Medical science is suitable to make a diagnosis and establish the necessary procedures to manage the patient and decide what is right. Legal intervention would result in a delay and complications, worsening pain and distress for the family."

Judge (who selected "In general, disagree with decisions made," "Intentional homicide," and "No need to require legal intervention"): "Physicians are forced to provide care to patients and, given a severe condition, they should dispense with parental consent."

Oral trial court judge (who selected "In general, strongly agree with decisions made," "No crime," and "No need to require legal authorization"): "I believe ethics committees and institutional review boards should be trained to intervene in these conflicts and make recommendations. It is not up to judges to decide in these cases."

Criminal defense lawyer (who selected "In general, disagree with decisions made," "Failure to render assistance," "Inciting a person to commit suicide," and "No need to require legal intervention"): "If necessary, I would request a legal authorization. For legal protection of physicians and/or family members."

Investigating judge (who selected "In general, somewhat agree with decisions made," "Intentional homicide" and "No need to require legal intervention"): "I would ask for a legal authorization so that the judge acted as a supervisor to ensure that the rights of every party involved were respected. A control of legality."

Judge (who selected "In general, somewhat agree with decisions made," "Failure to render assistance," and "No need to require legal intervention"): "A civil judge should be asked to provide an authorization only if parents had discrepancies or did not agree, but not if both the family and physicians consent to the decision."

Investigating judge (who selected "In general, somewhat agree with decisions made," "Intentional homicide," and "Need to require legal intervention"): "Eventually, the sentence may be reduced, but that would not change anything about the fact that it is a crime."

Subjective Findings

As per the individual appreciation of some survey respondents, the reference to "a situation with no reasonable chances of recovery" led them to believe that there was not sufficient certainty to justify the withholding of resuscitation.

Comments were a relevant tool: judges, in general, focused on autonomy, the patient's will, and the decision-making process by parents in the name of their children. On their side, physicians recognized that they were not trained to deal with dignified death and how to accept the family's opinion and collaborate with them. One of the physicians even stated "his doubts" regarding the family's right to intervene in the decision-making process and acknowledged that he had taken the responsibility himself and many times had made the decision on his own. Another physician, who considered this was a case of euthanasia (ie, intentional homicide), admitted that, from a medical or clinical perspective, to withhold or withdraw treatment would be the most convenient decision.

When asked to comment whether an advance medical directive would influence their decisions, it was observed that judges were more willing to agree with the minor's autonomy and the decisions made by her parents. This was not the case of physicians, who considered that minors and mentally disabled persons were not capable of giving their valid consent.

Most (76.47%) would not change their answer if the patient was an adult. At this point, judges maintained their opinion regarding the autonomy of decisions (regardless of whether the patient was a minor or an adult); physicians considered that a capable adult patient had a right to decide in these cases.

Based on these results, we found it interesting that physicians shared the medical decisions made in this first hypothetical case, and that they would have made these decisions regardless of the will of both the parents and the girl (because they considered that she was not capable of giving her own consent). To them, it seemed as though medical practice itself legalized the decision-making process, regardless of patient involvement. Also, among physicians, in general, confusion was observed regarding the difference between legal capacity and bioethics competence.

CASE 2. UNBEARABLE OR POOR QUALITY OF LIFE SITUATION: COMMENTS AND/OR NOTES MADE BY SURVEY RESPONDENTS REGARDING CASE 2

Level of Agreement and Presence/Absence of a Crime

Judge (who selected "In general, strongly agree with decisions made" and "Intentional homicide"): "The actions may be painful, but they are justified. In this case, I believe the situation should be considered from the criminal theory perspective. If actions were justified, there is no need to look for a guilty party given that it would be authorized in our legal setting."

Judge (who selected "In general, strongly agree with decisions made" and "No crime"): "This is similar to Case 1, but the minor patient in this case cannot voice his opinion. If death is considered to be a brief instant, several adverse opinions are bound to arise. If death is understood as an irreversible process, I strongly agree with the decisions made in this case."

Judge (who selected "In general, disagree with decisions made" and "Intentional homicide"): "Agreement regarding ambiguous moral guidelines expressed as 'best interest' or 'dignity,' in this case, is not enough to infer (deduce) consent. For such consent to have legal relevance, it should be signed, explained, and duly documented. Lack of consent implies a presumption against the medical team: in this case, the only 'decision' made was not to document 'agreement'; this constitutes the basis for analysis and cannot be avoided by legal workers. The absence of a signed agreement enables a criminal investigation regarding the intentional homicide hypothesis."

Physician (who selected "In general, somewhat agree with decisions made" but did not complete the section regarding crime typification): "If technological prolongation of life only extends a fateful end (Case 1), I would not even doubt about withdrawing all life support. If prolongation of life support ensures survival, I would not be capable, as a physician, to withdraw any technological life support provided to the child. I guess I would ask the hospital's ethics committee for an opinion."

Physician (who selected "In general, strongly agree with decisions made" and "No crime"): "Withholding life support parameters and preventing an additional suffering that may only result in a human being having a poor development and a very poor quality of life may be considered an act of euthanasia, in the good sense, even benevolence in this case. Likewise, I think the final decision should always be agreed upon with parents, and managed reasonably, humanely, and with common sense."

Physician (who selected "In general, strongly agree with decisions made" and "No crime"): "In the past, when such unproductive therapeutic-instrumental paraphernalia (at least in the cases described here) did not exist and death occurred 'naturally,' refraining from acting was considered a crime. Life support should be restricted only to cases for which it is considered medically favorable or when the cause of life-support requirement is potentially reversible."

Physician (who selected "In general, disagree/somewhat with decisions made" and both "Intentional homicide" and "No crime"): "Decisions should be made in accordance with present regulations, and all parties involved should participate (parents, physicians, etc)."

Physician (who selected "In general, strongly agree with decisions made" and "No crime"): "What benefit were they looking for? What about his suffering due to shortness of breath and his parents' distress? This is an example of therapeutic obstinacy."

Physician (who selected "In general, strongly agree with decisions made" and "No crime"): "My comment regarding Case 1 is also valid here. Insisting on life support, in these cases, means refusing the possibility of a dignified death."

Investigating judge (who selected "In general, strongly agree with decisions made" and "No crime"): "I would decide in accordance with legal provisions and the evidence presented in each specific case, after verifying there is really no possible treatment. Once every point in the case has been verified, there would be no crime."

Judge (who selected "In general, strongly agree with decisions made" and "No crime"): "My comment is the same as for Case 1. If the procedure withheld here was mandatory as per the medical protocol and necessary (typical) to reduce the risk of death, the case may be reported as wrongful death. Otherwise, there is no crime here: physicians are not liable—based on their protocols—to become lifesaving heroes beyond what is commonly adequate in each case."

Appeal court judge (who selected "In general, strongly agree with decisions made" and "Intentional homicide"): "Even though I strongly agree with the decision, as a judge, if I was asked to intervene in the case, I would consider different situations that may relieve parties from liability; however, from a strictly dogmatic stance, it is an intentional homicide by negligence."

Judge (who selected "In general, disagree with decisions made" and "Intentional homicide"): "Personally, I would do the same, whether I was the mother or the physician. However, if this case was brought to my court, I would not be able to avoid the intentional homicide charge."

Criminal defense lawyer (who selected "In general, disagree with decisions made," "Failure to render assistance," and "Inciting a person to commit suicide"): "A matter to consider would be what sentence would be more benign towards parents and physicians."

Investigating judge (who selected "In general, strongly agree with decisions made" and "Intentional homicide"): "A cause for justification that rules out illegality or a cause that would relieve parties from liability. Although the case fits the definition of intentional homicide, I would always look for a justification or a cause that would relieve parties from liability: a necessity based on the case-specific circumstances."

Judge (who selected "In general, somewhat agree with decisions made" and "Failure to render assistance"): "As in case 1, and although the actions described fit into the punishment provided for in article 106, National Law 17132 establishes that, in the case of a disabled person, healthcare providers should ask for the consent of that person's representative regarding the refusal to receive treatment. The benevolence principle established in the Hippocratic Oath is limited by the patient's autonomy principle and, in theory, the will of those who have a protected legal right prevails. These bioethics principles and regulations were introduced in the first conference held in the USA (Kennedy Institute of Ethics). It is worth noting that, given that this patient is a minor, his parents' consent is essential; the medical team may not agree with their decision and request for a legal ruling against it."

Investigating judge (who selected "In general, disagree with decisions made" and "Intentional homicide"): "This crime is worsened because his parents are committing it and may be mitigated by an allegation of violent emotion."

Investigating judge (who selected "In general, strongly agree with decisions made" and "Intentional homicide"): "Mitigation might be implemented: criminal theory; exculpatory factors: prohibition mistake or a different behavior cannot be required."

Appeal court judge (who selected "In general, somewhat agree with decisions made" and "Intentional homicide"): "It may be categorized as manslaughter."

Investigating judge (who selected "In general, strongly agree with decisions made," "Intentional homicide," "Wrongful death," "Failure to render assistance," and "Inciting a person to commit suicide"): "It may fit in this definitions technically."

Degree of Agreement with No Cardiopulmonary Resuscitation, Withdrawal of Mechanical Ventilation, and Change of Opinion in the Presence of Advance Medical Directives

Physician (who selected "In general, strongly agree with decisions made," "No crime," and "Would not change my decision"): "Pediatric patients should always be heard and have a chance to voice their opinion if their condition allows them to do so."

Judge (who selected "In general, strongly agree with decisions made," "No crime," and "Would change my decision"): "As I commented for Case 1, I would also ask for a consent document, and respect the patient's autonomy, will, and freedom."

Appeal court judge (who selected "In general, strongly agree with decisions made," "Intentional homicide," and "Would not change my decision"): "Given that there is no law to support the decision, it would be difficult to obtain a different ruling."

Oral trial court judge (who selected "In general, somewhat agree with decisions made," "No crime," and "Would change my decision"): "I do not agree with withdrawing or withholding feeding and hydration."

Investigating judge (who selected "In general, strongly agree with decisions made," "No crime," and "Would change my decision"): "Every parental decision includes a selfish component. If the patient's will was documented, the decision made by parents is an act of greatness."

Change of opinion in the case of adult patients Judge (who selected "In general, disagree with decisions made," "Intentional homicide," and "Would not change my answer"): "Except the 'agreements' made with the patient were documented regarding how unproductive and cruel treatments to be used are."

Oral trial court judge (who selected "Somewhat agree with decisions made," "No crime typified," and "Would change my answer"): "I do not agree with withdrawing or withholding feeding and hydration."

Criminal defense lawyer (who selected "Disagree with decisions made," "Typified as failure to render assistance," "Inciting a person to commit suicide," and "Would change my answer"): "In the case of an adult, he/she may decide what to do with his/her life."

Judge (who selected "Strongly agree with decisions made," "Typified as failure to render assistance," and "Would change my answer"): "In the case of an adult who has not signed a consent document, his family's consent should be requested."

Subjective Findings

Analyzing opinions by profession, judges in general focused on the theory of crime and many times considered that decisions were illegal (ie forbidden) but justified (either based on the patient's consent or a clinical indication). One judge focused on the fact that the agreement to withhold life support made between the medical team and the family had not been documented and, in his opinion, this implied a presumption against the treating medical team and the corresponding legal investigation. On their side, physicians focused on the poor quality of life and the scarce chance of improvement; they considered that technology use was not warranted and prolonged suffering, and highlighted that it would be a case of therapeutic obstinacy.

"Medical science is suitable to make a diagnosis and establish the necessary procedures to manage the patient and decide what is right."

A large number (23.26%) of survey respondents disagreed with the decisions made, and some of those who agreed (15.52%) considered that the case may be criminalized (intentional homicide or wrongful death most of the time). This was reflected in some of the additional notes, which considered potential causes for sentence reduction or a justification for the crime (violent emotion, necessity, etc).

The phrase "only prolonged suffering and implied an extremely low quality of life" raised concerns among respondents. Some believed that it was difficult to establish the level of quality of life while others thought it was not enough to end the child's life.

Off the record, during the interview, some judges considered that increasing the sedative dosage was the final action that caused the patient's death.

Although the patient's underlying disease was relevant in his present condition, survey respondents who disagreed with decisions made considered that taking him off the ventilator was the "cause" of his death, with the resulting legal implications.

It Is Necessary to Request Legal Authorization

Judge (who selected "Strongly agree with decisions made," "Typified as wrongful death," "No crime typified," and "No need to require legal authorization"): "Medical science is suitable to make a diagnosis and establish the necessary procedures to manage the patient and decide what is right. Legal intervention would result in a delay and complications, worsening pain and distress for the family."

Appeal court judge (who selected "Strongly agree with decisions made," "Typified as intentional homicide," and "A judge cannot authorize it"): "Physicians should know the protocol to follow."

Oral trial court judge (who selected "Somewhat agree with decisions made," "No crime typified," and "No need to require legal authorization"): "I would recommend palliative care, care for a dignified death accompanied with emotional support, community support, an understanding of suffering, and an effective pain management."

Judge (who selected "Somewhat agree with decisions made," "No crime typified," and "It is necessary to require legal authorization"): "Even if the medical team and the patient's family had given their consent, I think it would be convenient to request a legal authorization."

CASE 3. PERSISTENT VEGETATIVE STATE COMMENTS AND/OR NOTES MADE BY SURVEY RESPONDENTS REGARDING CASE 3

One judge refrained from commenting on this case because it raised concerns: "I will not comment on this case. I have doubts regarding the 'situation with no reasonable chances of recovery.' 'Reasonable' is a convention. Of course, the presence of advance directives would change my answer to the extent that they referred to this situation."

Level of Agreement and Presence/Absence of a Crime

Judge (who selected "Somewhat agree with decisions made" and "No crime typified"): "I believe that the decisions made by parents, who are affected by the health situation of their most cherished gift—a child—with the corresponding medical and therapeutic guidance cannot and should not be subjected to the opinion of a judge."

Judge (who selected "Disagree with decisions made" and refrained from commenting on the type of crime): "Before attempting to qualify the parents' behavior, which would be aggravated by their relationship with the victim and result in a life sentence, I would try to establish a different matter given the dramatic family situation. However, this case is different from the other two. I felt that parents were the ones who did not want to continue with their son in that condition. So I feel the need to look at this case from a different perspective; with the other two I had no doubts. If I had to rule in this case, I would not be able to make a linear ruling."

Prosecutor (who selected "Somewhat agree with decisions made" and refrained from commenting on the type of crime): "As far as I know, there have been uncommon cases of patients who awoke from a coma after years and recovered. I believe that in these cases the decision to withdraw mechanical ventilation and other artificial means of life support is more related to the family's interest in avoiding pain than the patient's best interest. Anyhow, I believe that if the patient dies following the withdrawal of life support, it does not constitute a crime. However, it would be a crime if the patient was breathing on his own and feeding and hydration were withheld."

Physician (who selected "Strongly agree with decisions made" and "No crime typified"): "In this case, I believe the parents' opinion is more relevant than in the other two. Anyhow, I believe these are borderline situations, hard to assess from the perspective of criminal codes. In these cases, physicians are the ones who stand up to the situation, and the main suffering is that of parents. For this reason, I believe these cases should not be brought to court, except when they involve malpractice."

Physicians focused on the poor quality of life and the scarce chance of improvement; they considered that technology use was not warranted and prolonged suffering, and highlighted that it would be a case of therapeutic obstinacy.

Physician (who selected "Somewhat agree with decisions made" and "Typified as failure to render assistance"): "In this case the withdrawal of mechanical ventilation is very difficult. Given the patient's age, I would consider he was autonomous (before the car crash) and, if he had advance directives, it might be all right to withhold ventilation in case of worsening of his condition, but if he needed it from the beginning, it would be a very difficult decision."

Physician (who selected "Strongly agree with decisions made" and "No crime typified"): "The case would fit the definition of persistent vegetative state, which is one of the clinical conditions that poses the possibility of withdrawing life support. The decision made is reasonable, even more if Pedro's opinion regarding the situation was known."

Investigating judge (who selected "Strongly agree with decisions made" and "No crime typified"): "I would decide in accordance with legal provisions and the evidence presented in each specific case, after verifying there is really no possible treatment. Once every point in the case has been verified, there would be no crime."

Judge (who selected "Strongly agree with decisions made" and "No crime typified"): "I think this case is like the other two. In this case, the risk of death was inevitable and the procedure was only delaying the result; it would not be reproachable because it neither caused nor increased the risk. It only caused it earlier and, according to some opinions, this does not constitute a crime."

Appeal court judge (who selected "Strongly agree with decisions made" and "Typified as intentional homicide"): "Even though I strongly agree with the decision, as a judge, if I was asked to intervene in the case, I would consider different situations that may relieve parties from liability; however, from a strictly dogmatic stance, it is an intentional homicide by negligence."

Judge (who selected "Strongly agree with decisions made" and "No crime typified"): "I believe this is a case established in the organ donation law."

Criminal defense lawyer (who selected "Disagree with decisions made," "Typified as failure to render assistance," and "Inciting a person to commit suicide"): "A matter to consider would be what sentence would be more benign towards parents and physicians."

Investigating judge (who selected "Strongly agree with decisions made" and "Typified as intentional homicide"): "A cause for justification that rules out illegality or a cause that would relieve parties from liability. Although the case fits the definition of intentional homicide, I would always look for a justification or a cause that would relieve parties from liability: a necessity based on the case-specific circumstances."

Judge (who selected "Disagree with decisions made" and "Typified as intentional homicide"): "Euthanasia represents the patient's right to decide how and when to die, but only seeking to relieve that person from intense suffering and merciless agony resulting from a severe and incurable disease. In Argentina, euthanasia is forbidden, unlike what occurs in Uruguay and the Netherlands, where a law has been passed to regulate it. Even though the Criminal Code projects submitted in 1937, 1941, and 1960 established that "mercy killing" should be differentiated from intentional homicide, euthanasia was not justified, it was still punishable, but differentiated based on its seriousness. Therefore, and based on current legislation, the case described here is punishable."

Investigating judge (who selected "Disagree with decisions made" and "Typified as intentional homicide"): "This crime is worsened because his parents are committing it and may be mitigated by an allegation of violent emotion."

Degree of Agreement with Withdrawal of Mechanical Ventilation, Withdrawal of Hydration and Parenteral and/or Enteral Feeding, and Change of Opinion in the Presence of Advance Medical Directives Requesting the Withdrawal or Withholding of Mechanical Ventilation or Artificial Hydration and Feeding

Judge (who selected "Strongly agree with decisions made," "No crime typified," and "Would change my answer"): "Under the same circumstances of this case, ie, if the parents knew about and agreed with his living will."

Judge (who selected "Disagree with decisions made" and refrained from commenting on the type of crime, and indicated "Would change my answer"): "In this case, the patient is a 15-year-old adolescent. It would have been important to know that he did not want to live in that condition either."

Physician (who selected "Strongly agree with decisions made," "No crime typified," and "Would change my answer"): "For (d) and (e), I believe the decision is up to the parents, and physicians should collaborate with them to reach the best possible end when there are no chances of recovery."

Judge (who selected "Strongly agree with decisions made," "Typified as wrongful death," and "Would not change my answer"): "I would also ask for a consent document, and respect the patient's autonomy, will, and freedom."

Public defender of minors and legally incompetent persons (who selected "Somewhat agree with decisions made," "No crime typified," and "Would change my opinion"): "If we assume that advance directives were made by a young adult (older than 14 years old)."

Appeal court judge (who selected "Disagree with decisions made," "Typified as wrongful death," and "Would not change my decision"): "It would be interesting to redefine the concept of pediatric patient."

Change of Opinion in the Case of Adult Patients

Physician (who selected "Strongly agree with decisions made," "No crime typified," and "Would change my answer"): "I would follow the patient's advance directives."

Physician (who selected "Strongly agree with decisions made," "No crime typified," and "Would not change my answer"): "Medicine should have a more humanistic rather than mechanistic approach. Major technological advances should not distort that approach. Technology should be at the service of life, not of death."

Oral trial court judge (who selected "Strongly agree with decisions made," "No crime typified," and "Would not change my answer"): "I would recommend palliative care. Until natural death occurs, I would privilege palliative care, including feeding and hydration."

Criminal defense lawyer (who selected "Disagree with decisions made," "Typified as failure to render assistance," "Inciting a person to commit suicide," and "Would change my answer"): "In the case of an adult, he/she may decide what to do with his/her life."

Investigating judge (who selected "Disagree with decisions made," "Typified as intentional homicide," and "Would change my answer"): "If the patient was elderly and had AMD [advanced medical directive]."

It is necessary to request legal authorization

Judge (who selected "Strongly agree with decisions made," "Typified as wrongful death," "No crime typified," and "No need to require legal intervention"): "Medical science is suitable to make a diagnosis and establish the necessary procedures to manage the patient and decide what is right. Legal intervention would result in a delay and complications, worsening pain, and distress for the family."

Judge (who selected "Somewhat agree with decisions made," "No crime typified," and "No need to require legal intervention"): "According to Molinario/Aguirre Obarrio, Pasteur was involved in a similar case (Molinario, Los delitos, volume I, page 122, Ed. TEA, 1996)."

Judge (who selected "Disagree with decisions made," "Typified as intentional homicide," and "Need to require legal intervention"): "Given that this is an action punished by criminal law, it is necessary to request authorization for each case in particular."

Subjective Findings

Among the different opinions, it is worth noting the opinion of a judge who indicated that healthcare decisions should be considered in the setting of the medical relationship, with no need to bring them before a judge. A different judge highlighted that his opinion in this case was different from that in the other two cases because he felt that the parents were the ones who did not want their son to be in that situation, and considered the selfishness component on their part. However, he stressed that, if he had this case in his court, he would probably consider the family's dramatic situation. A prosecutor indicated that withdrawal or withholding of life support was the result of the parents' interest, not that of the patient himself. He clarified that measures taken did not constitute a crime, but, if the patient had been breathing on his own, it would have been a crime to withdraw feeding and hydration. On their side, physicians considered that this type of situation should not be brought to court, except when they involved malpractice. A physician highlighted that intubation might have been withheld if that was the patient's decision, but if mechanical ventilation was needed from the beginning, he believed that the withdrawal of ventilation posed a more difficult situation.

Most respondents agreed on the withdrawal of mechanical ventilation (71.42%). However, when asked about the withdrawal of hydration and feeding, either parenteral or enteral, the level of agreement changed: most were against withdrawal (65.31% for parenteral feeding and 62.74% for enteral feeding), and this measure appeared to set the limit between what was acceptable and unacceptable regarding withdrawing or withholding treatment.

Phrases like "a situation with no reasonable chances of recovery" and "the patient is capable of making automatic gestures (smiling, wincing, etc) but there is no recognizable relation to stimuli" raised concerns among survey respondents because they led respondents to believe that the situation was not as irreversible because the patient showed some sort of stimuli response.

In general, answers related to this case were very similar to those given in Case 2 among those who disagreed with decisions made.

However, for some assumptions (22.22%), even if respondents strongly agreed with decisions made, they accepted the withdrawal of mechanical ventilation but not that of artificial hydration or feeding (enteral or parenteral).

No respondent changed his/her answer about the withdrawal of hydration or feeding (enteral or parenteral), even after explaining that one procedure was more invasive than the other.

For some assumptions, when respondents were asked if they would change their answer if the patient was an adult, they indicated that they would if the patient had advance medical directives.

General Subjective Findings

During the interviews, female respondents appeared to be much more concerned than male respondents, given that female respondents invariably identified hypothetical subjects as their own children and attempted to find a reason to prevent the prosecution of parents and physicians.

Respondents who disagreed with decisions made believed that a legal authorization would not change things because it would be as requesting an "authorization to commit a crime."

Off the record, some respondents, while chatting between questions during the interview, stated that not only would physicians be accused of the typified crime, but parents would even be accused of being co-perpetrators and receive a longer sentence according to their relationship with the victim.

In relation to the type of profession a respondent had, it is worth noting answers given by a criminal defense lawyer and a prosecutor. The defense lawyer disagreed with decisions made and criminalized actions but underscored the need to consider some sort of mitigation or waiver of liability, while the prosecutor indicated he somewhat agreed with decisions made because he considered they did not constitute any form of crime. This appears to be contrary to what was "expected" from their roles, given that a defense lawyer is believed to be more inclined to share the situations described while a prosecutor is expected to have a more critical approach.

A majority of representatives of the National Judiciary, either judges, defenders, or prosecutors, expressed, especially when making comments and even though they criminalized decisions made, the possibility of such decisions being a privileged type of crime (violent emotion) or a justified— therefore legal—behavior (informed consent provided by the patient or his/her parents in his/her name) or a behavior that, although typical and illegal, was not reprehensible, either because a different behavior could not be required, it involved a prohibition mistake, or there was exculpatory evidence available. A vast majority (88.23%) of respondents specifically stated the need to analyze the possibility of a sentence reduction and/or waiver of liability.

It is also worth noting that most respondents who criminalized one of the actions taken (73.91%) indicated that they agreed with decisions made and that they understood the situation from a human perspective, but considered it a crime from a strictly legal point of view.

Both lawyers and physicians highlighted the importance of asking an ethics committee to take part in decisions before even considering requesting a legal authorization. A major role in the healthcare relationship was assigned to these committees.

Funding

This research study was conducted with the support of the Ramón Carrillo-Arturo Oñativia Continuing Education Scholarship, granted by the National Ministry of Health of Argentina through the Health Research Committee (Comisión Nacional Salud Investiga).

Conflict of interest

None.

Authors

Jorge Oscar Selandari is an intensive care pediatrician with a specialization in health economy and management.He serves as an intensive care physician and a member of the bioethics committee at the Hospital de Pediatría SAMIC Profesor Dr. Juan P. Garrahan. Dr. Selandari is both associate professor of pediatrics and professor of pediatric intensive care at the school of medicine, University of Buenos Aires, and head of pediatrics and the pediatric intensive care unit at Sanatorio Guemes, Buenos Aires, Argentina.

María Susana Ciruzzi is a lawyer with specializations in both criminal law and bioethics. She holds a PhD in criminal law and postdoc in criminal law and bioethics. She is researcher and professor at the Law School, University of Buenos Aires and professor in the health law specialization at the school of medicine, University of Buenos Aires. In addition, Dr. Ciruzzi is head of the Administrative Brief Department, Department of Legal Affairs and member of the bioethics committee at the Hospital de Pediatría SAMIC Profesor Dr. Juan P. Garrahan, and member of the bioethics committee at the Institute of Medical Research Dr. Alfredo Lanari, Buenos Aires, Argentina.

Adriel J. Roitman is a Grant Holder at the School of Law, Universidad de Buenos Aires.

Fernanda Ledesma is Coordinator of Bioethics and a Member of the Hospital Ethics Committee at Hospital de Pediatria SAMIC Profesor Dr. Juan P. Garrahan.

Célica Menéndez is Head of Mental Health at Hospital de Pediatria SAMIC Profesor Dr. Juan P. Garrahan.

Hernán O. García is a Member of the Hospital Ethics Committee and a palliative care physician at Hospital de Pediatria SAMIC Profesor Dr. Juan P. Garrahan.

REFERENCES

1. Royal College of Paediatrics and Child Health. *Withholding or withdrawing life saving treatment in children: a framework for practice.* 2nd ed. London: Royal College of Paediatrics and Child Health; 2004:10-1, 28-29.

2. Mink RB, Pollack MM. Resuscitation and withdrawal of therapy in pediatric intensive care. *Pediatrics.* 1992;89(5): 961-963.

3. Vernon DD, Dean JM, Timmons OD, et al. Modes of death in the pediatric intensive care unit: withdrawal and limitation of supportive care. *Crit Care Med.* 1993;21(11):1798-1802.

4. Lantos JD, Berger AC, Zucker AR. Do-not-resuscitate orders in a children's hospital. *Crit Care Med.* 1993;21(1):52-55.

5. Martinot A, Lejeune C, Beyaert C, et al. Modes of death in a French pediatric intensive care unit (PICU). *Proc Eur Soc Pediatr Intensive Care.* 1994;A20.

6. Burns JP, Mitchell C, Outwater KM, Geller M, et al. End-of-life care in the pediatric intensive care unit after the forgoing of life-sustaining treatment. *Crit Care Med.* 2000;28(8):3060-6.

7. Devictor DJ, Nguyen DT. Forgoing life-sustaining treatments: How the decision is made in French pediatric intensive care units. *Crit Care Med.* 2001;29(7):1356-1359.

8. Garros D, Rosychuk RJ, Cox PN. Circumstances surrounding end of life in a pediatric intensive care unit. *Pediatrics.* 2003;112(5):e371.

9. Devictor DJ, Nguyen DT. Forgoing life-sustaining treatments in children: A comparison between Northern and Southern European pediatric intensive care units. *Pediatr Crit Care Med.* 2004;5(3):211-215.

10. Zawistowski CA, DeVita MA. A descriptive study of children dying in the pediatric intensive care unit after withdrawal of life sustaining treatment. *Pediatr Crit Care Med.* 2004;5(3):216-223.

11. Kipper DJ, Piva JP, Garcia PC, et al. Evolution of the medical practices and modes of death on pediatric intensive care units in southern Brazil. *Pediatr Crit Care Med.* 2005;6(3):258-263.

12. Cuttini M, Nadai M, Kaminski M, et al. End-of-life decisions in neonatal intensive care: Physicians' self-reported practices in seven European countries. EURONIC Study Group. *Lancet.* 2000;355 (9221):2112-2118.

13. Lago PM, Devictor D, Piva JP, Bergounioux J. End-of-life care in children: the Brazilian and the international perspectives. *J Pediatr.* 2007;83(2 sup):S109-S116.

14. Althabe M, Cardigni G, Vassallo JC, et al. Dying in the intensive care unit: Collaborative multicenter study about forgoing life-sustaining treatment in Argentine pediatric intensive care units. *Pediatr Crit Care Med.* 2003;4(2):164-169.

15. Comité de Ética Hospitalaria Hospital de Pediatría "Prof. Dr. J.P. Garrahan." Recomendaciones para la toma de decisiones terapéuticas en pacientes gravemente enfermos. *Arch Argent Pediatr.* 1998;96(6):399-403.

16. Ballard DW, Li Y, Evans J, et al. Fear of litigation may increase resuscitation of infants born near the limits of viability. *J Pediatr.* 2002;140(6):713-718.

17. Perkins HS, Bauer RL, Hazuda HP, Schoolfield JD. Impact of legal liability, family wishes, and other "external factors" on physicians' life-support decisions. *Am J Med.* 1990;89(2):185-194.

18. Bell C, Somogyi-Zalud E, Masaki K, et al. Factors associated with physician decision-making in starting tube feeding. *J Palliat Med.* 2008;11(6):915-924.

19. Piva J, Lago P, Othero J, et al. Evaluating end of life practices in ten Brazilian paediatric and adult intensive care units. *J Med Ethics.* 2010;36(6):344-8.

20. Soares M, Terzi RG, Piva JP. End-of-life care in Brazil. *Intensive Care Med.* 2007;33(6):1014-1017.

21. Garcia-Retamero R, Galesic M. On defensive decision making: How doctors make decisions for their patients. *Health Expect.* 2014;17(5):664-669.

22. Asher E, Greenberg-Dotan S, Halevy J, t al. Defensive medicine in Israel: A nationwide survey. *PLoS One.* 2012;7(8):e42613.

23. Belizan M, Meier A, Althabe F, et al. Facilitators and barriers to adoption of evidence-based perinatal care in Latin American hospitals: A qualitative study. *Health Educ Res.* 2007;22(6):839-853.

24. Ghiggi M, Chede C, Saporiti A. De lo que no se habla en la UCIP. *Arch Argent Pediatr.* 2001;99(4):337-339.

25. Ciruzzi MS. La limitación de soporte vital: ¿Derecho, Deber o Delito? Available at http://www. unesco.org.uy/shs/fileadmin/ templates/shs/archivos/TrabajosLibres-Bioetica/24.%20La% 20lmitacion% 20de%20Soporte%20vital.pdf. Accessed on March 24, 2015.

26. Comité Nacional de Terapia Intensiva Pediátrica. Consenso sobre recomendaciones acerca de la limitación del soporte vital en terapia intensiva. *Arch Argent Pediatr.* 1999;97(6): 411-415.

27. American Academy of Pediatrics Committee on Bioethics. Guidelines on foregoing life-sustaining medical treatment. *Pediatrics.* 1994;93(3):532-536.

28. Monzón Marín JL, Saralegui RI, Abizanda ICR, et al. Recomendaciones de tratamiento al final de la vida del paciente crítico. *Med Intensiva.* 2008;32(3):121-133.

29. Royal Australasian College of Physicians. Decision-Making at the End of Life in Infants, Children and Adolescents. Sidney, NSW: Royal Australasian College of Physicians; 2008. Available at https://www. racp.edu.au/docs/default-source/advocacy-library/ decision-making-at-the-end-of-life-in-infants-children-and-adolescents.pdf?sfvrsn=10. Accessed on April 1, 2015.

30. Althabe M, Ledesma F, Cernadas C, et al. Actitudes de los profesionales de salud frente a las decisiones de limitación o retiro de tratamiento en pediatría. *Arch Argent Pediatr.* 2003;101(2):85-92.

31. Berlinger N, Jennings B, Wolf SM. *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life.* 2nd ed. New York: Oxford University Press; 2013.

32. Larcher V, Craig F, Bhogal K, et al. Making decisions to limit treatment in life-limiting and life-threatening conditions in children: A framework for practice. *Arch Dis Child.* 2015;100(sup 2):s3-s23.

33. Australian and New Zealand Intensive Care Society. *ANZICS Statement on Care and Decision-Making at the End of Life for the Critically Ill.* Melbourne, Vic.: ANZICS; 2014.

Moral Courage in the ICU: A Case Analysis Using a New Approach Adapted from the Business Ethics Literature

Geert Craenen, MD, MBE, and Peter Koch, PhD

INTRODUCTION

Moral courage has received growing attention from scholars who have further developed a shared understanding of the notion and refined its role in normative frameworks. This improved understanding of moral courage promises to offer guidance in navigating difficult ethical dilemmas in a number of professional realms, including medicine. In this article we apply a multitiered framework of moral courage to an ethics consultation involving a rapidly decompensating patient in the intensive care unit (ICU). We argue that this framework provides the conceptual resources to address the morally salient features of the ethics consultation case, and thus can assist clinicians and other medical professionals in resolving dilemmas involving moral distress stemming from wayward authoritative commands. The case is as follows.

Mr. S. was a 75-year-old man in the ICU of a Veterans Administration (VA) medical center who had fulminant liver failure, acute renal failure requiring continuous dialysis, and cardiomyopathy requiring vasopressors. In addition, he had been intubated for respiratory failure. Mr. S. had been nonresponsive for most of his ICU stay.

He had been admitted weeks earlier from a nursing home for a non-STEMI (a non-ST segment elevation myocardial infarction), and had a history of dementia, liver cirrhosis, and esophageal varices, all attributable to alcohol abuse. His condition had continued to decline, including episodes of gastrointestinal and urogenital hemorrhage and acute urinary obstruction, requiring several blood transfusions.

There was a well-documented history of financial and physical abuse by the patient's family, and the previous spring, when he still had capacity to make such decisions, Mr. S. strongly voiced his wish that his family not be contacted or involved in his medical care. The note further documented Mr. S's understanding that VA policy states that, in case of both lack of capacity *and* lack of surrogates, the chief of staff should make decisions for the patient.

The ethics team was consulted to assist with goals of care decisions, when the ICU team felt that Mr. S.'s decline had become irreversible. Hospital policy is clear that first there must be agreement among the entire medical team that the medical situation is irreversible, followed by a discussion and a vote of concurrence by the ethics committee, which in turn must be approved by the director of the medical center. The team reached a consensus that withdrawing life sustaining treatment was reasonable. The plan for withdrawal did not include extubation or terminal wean of the ventilator, but merely the withdrawal of vasopressors and hemodialysis to facilitate a rapid but gradual and easy passing. The clinical ethics consultation service supported this resolution unanimously and carefully explained their reasoning to the medical center director.

The medical center director, however, refused to sign the intended plan of care, arguing that the estranged family might sue if aggressive treatment was discontinued. The director then placed a hold on the process in order to pursue legal counsel, but was unable to reach the legal department. The administration refused to share the lawyers' cell phone numbers with the ethics consultants, who then had to inform the ICU staff of the medical director's decision not to endorse their resolution. The next day, the patient's situation worsened and he started to vomit bright red blood around his endotracheal tube, acutely exacerbating the team's distress. The ICU attending physician unilaterally ordered withdrawal of the vasopressors on the strength of the ethics committee's previous recommendation, which led to the patient dying. Approximately four hours later, the form bearing the director's signature permitting the withdrawal of aggressive life-sustaining treatment did arrive in the ICU.

The ICU staff expressed great moral distress at having to see their patient die while vomiting blood, when a timelier withdrawal of aggressive life sustaining measures could have made his passing much more peaceful.

DISCUSSION

The following discussion draws upon a framework recently proposed in business ethics literature to provide a qualitative assessment of the moral courage of the two parties involved in this case. Our deliberation utilizes this framework of moral courage to contrast the actions of the ICU physician with the management of the hospital administration.

Moral Courage

Moral courage is broadly understood to be the virtue that enables individuals to act according to their own convictions despite the fear of retaliation or punishment.[1] Recent qualitative studies have augmented this definition by identifying five themes related to the measurement of moral courage:[2]

- Moral agency—the predisposition to behave ethically and work toward what is right;
- Multiple values—the ability to draw on and weigh multiple sets of values in ethical decision making;
- Endurance of threats—the conviction to do what is right or just, despite perceived or real threats to oneself;
- Measures beyond compliance—the tendency to consider more than compliance-based measures and reflection regarding what is right or just;
- Moral goals—a virtuous motivation to do what is right, as opposed to being motivated by self-interest, eg, for praise or reward.[3,4]

These five themes have been quickly adopted in the modern business scholarship as a useful means of assessing moral courage,[5-7] and Martinez and colleagues have applied them to the arena of medical ethics to develop a survey on moral courage in the healthcare field.[2,8,9] While these five themes constitute the core features of moral courage, some authors have pointed out that in contexts such as medical practice, where norms or expectations may be less explicit, it may be challenging and impractical to differentiate and measure each feature separately.[3] Nevertheless, in our opinion, these five themes, broadly construed, offer a useful lens through which to analyze the features of a complex clinical case as they pertain to moral courage.

Case Analysis

Moral agency—the predisposition to behave ethically and work toward what is right. Both the physician and the administration acted as moral agents; that is, both parties bore the capacity to deliberate upon potential courses of action, assess the ethical dimensions of each, and select one course of action over the others. The physician chose to act in a manner that reflected the sacred covenant between the physician and patient, abiding by the first rule of medicine: *primo non nocere:* first, do no harm. He exercised his moral agency to select a course of action marked by professional duties and the virtues of compassion and beneficence.

Although bound by the same covenant, members of the hospital administration chose to give primacy to "contractual" accountabilities towards other entities, such as their superiors, owners and shareholders, and the organization at large. In charitable terms, this could be understood as giving value to the virtue of prudence. Both parties, however, fulfilled the criterion of moral agency in that they were *free* to choose a course of action directed towards that which is right, even if they directed their agency in different ways.

Multiple values—the ability to draw on and weigh multiple sets of values in ethical decision making. As moral agents, both parties were tasked with identifying and balancing competing sets of values. The physician was forced to balance the values of loyalty to his superiors, fiduciary obligations to his patient, integrity as a professional, and his own self-interest. The administration was presented with similar sets of values, including compliance with their institution, fiduciary obligations to the patient, professional integrity, and organizational interests. Both exercised their abilities to weigh these values, although each balance generated a distinct course of action.

Endurance of threats—the conviction to do what is right or just, despite perceived or real threats to oneself. The decision to persevere despite threats to oneself is a hallmark of moral courage, and it is this criterion that captures a particularly salient difference between the actions of the physician and the administration. By disobeying his employer and disregarding explicit instructions, the physician risked institutional discipline, the termination of his employment, and the possibility of being reported to boards, all of which would jeopardize his career. These threats notwithstanding, he continued to prioritize compassionate care for the patient. The hospital administration also perceived a threat, namely that of legal action by the patient's family. This threat, however, was arguably nullified by the patient's stated preference to exclude his family from all aspects of his medical care, in which case, by legal default, the chief of staff should act as the patient's surrogate. The system seems to have failed to provide for this eventuality and failed to provide support or enable optimal care.

Measures beyond compliance—the tendency to consider more than compliance-based measures and reflect on what is right or just. The physician's actions exemplified measures beyond—and in fact contrary to—compliance, since strict compliance would call for the physician to abide by the orders of his superiors. While the physician could have practiced "moral escapism" by declaring himself bound by the director's refusal, he instead chose to act out of compassion and relieve the patient's acute suffering. The administration, however, sought refuge through hypercompliance by insisting on contacting the legal team despite there being no formal requirement to do so.[10] The system contributes to this with a set of requirements outlined by hospital policy regarding end-of-life decision making for unrepresented, incapacitated patients. The requirements were fulfilled by a unanimous consensus among the medical team and the ethics committee regarding a shift to palliation. However, as a matter of precaution, the administration chose to "await legal confirmation" in order to proceed with the committee's decision. In the highly litigious context of today's hospital environment, such hypercompliance is understandable even if it is, as we suggest, ethically inappropriate. The actions of the administration in responding to the perceived threat of litigation at the cost of likely prolonging a patient's suffering reflects a system whose culture relies heavily on legal support and confirmation, even *after* ethical confirmation.

> *While the physician could have practiced "moral escapism" by declaring himself bound by the director's refusal, he instead chose to act out of compassion and relieve the patient's acute suffering.*

Moral goals—a virtuous motivation to do what is right, as opposed to being motivated by self-interest such as for praise or reward. Both physicians and hospital administrators professed the same fundamental moral goals: patient-centered care, proper stewardship of limited resources, a supportive care environment, and investment in the next generation of careproviders. Self-interest, which includes institutional interests for those representing a particular institution, is one of many factors that can derail individuals and administrations from achieving these goals. Mounting financial pressures and our culture's litigious feeding frenzy, which weigh on both administrators and physicians, have caused a cultural drift from a teleological ethos of service to patients to a deontological avoidance of risk and a perceived pressure to "make good while you can." What this often means is a prioritizing of compliance over ethics by individuals and an emphasis on performance measures rather than the genuine desire to serve patients.

CONCLUSION

Drawing upon the five themes of moral courage, as developed by Leslie Sekerka and others in the field of business ethics,[3] we identified a new lens through which to examine an individual clinical consultation case. We have found Sekerka's model useful in analyzing a clinical ethics consultation and the system within which it takes place. By recognizing that authentic moral courage includes the endurance of threats, the model serves to identify the often nebulous and unnamed dangers of acting with moral courage in the face of personal consequences. Further, by identifying the professional tendency to favor compliance, the model also aided in demonstrating that, in certain cases, moral courage is required to counterbalance the growing culture of hypercompliance. Finally, this model has drawn attention to the moral goals of healthcare professionals. At a systems level, cases such as this suggest that we are witnessing a cultural drift in healthcare leadership away from patient-centered goals and towards a realm marked by compliance, performance measures, and budgetary incentives of the new healthcare executives. Moral courage has received much attention in recent business literature and is a topic from which such newly styled healthcare executives might derive some much needed inspiration in organizing our healthcare systems.[9,11-13]

Authors

Geert Craenen is an ophthalmic surgeon and a clinical bioethicist in the West Texas VA Healthcare System in Big Spring, Texas. He received his MD and an MS from the Ohio State University and his MBE from the Katholieke Universiteit Leuven with stints at the Radboud Universiteit Nijmegen and the University of Padova. His interests include publication ethics, informed consent, and the ethics of surgical simulation.

Peter Koch is an assistant professor of philosophy at Villanova University. He received his Doctorate in Philosophy from SUNY Buffalo and completed a Post-Doctoral Fellowship at Baylor College of Medicine, focused in clinical ethics. His current research interests include patient welfare, harm, and benefit, and how these philosophical notions inform ethical dilemmas in the clinical setting. Peter frequently presents his research to clinical and academic audiences both nationally and internationally.

References

1. Pianalto M. Moral Courage and Facing Others. *Int J Philos Studies* 2012;20:165-184.

2. Martinez W, Bell SK, Etchegaray JM, Lehman LS. Measuring Moral Courage for Interns and Residents: Scale Development and Initial Psychometrics. *Acad Med.* 2016;91:1431-1438.

3. Sekerka LE, Bagozzi RP, Charnigo R. Facing ethical challenges in the workplace: Conceptualizing and measuring professional moral courage. *J Bus Ethics.* 2009; 89:565-579.

4. Sekerka LE, McCrathy JD, Bagozzi RP. Developing professional moral courage: Leadership lessons from everyday ethical challenges in today's military. In: Comer D, Vega G, ed. *Moral Courage in Organizations: Doing the Right Thing at Work.* New York: Routledge; 2015:130-141.

5. Hannah ST, Avolio BJ, Walumbwa FO. Relationships between authentic leadership, moral courage, and ethical and pro-social behaviors. *Bus Ethics Quart.* 2011;21:555-578.

6. Harbour M, Kisfalvi, V. In the eye of the beholder: An exploration of managerial courage. *J Bus Ethics.* 2014;119:493-515.

7. Hutchinson M, Jackson D, Daly J, et al., Distilling the antecedents and enabling dynamics of leader moral courage: A framework to guide action. *Issues Ment Health Nurs.* 2015;36:326-335.

8. Edmonson C. Moral courage and the nurse leader. *Online J Issues Nurs.* 2010;15:1A.

9. Murray, JS. Moral courage in healthcare: Acting ethically even in the presence of risk. *Online J Issues Nurs.* 2010;15:1G.

10. Hertzberg L. Moral escapism and applied ethics. *Phil Papers.* 2002;31:251-270.

11. De Mesel B. Moral modesty, moral judgment and moral advice. A Wittgensteinian approach. *Int J Philos Theol.* 2014;75:20-37

12. Sekerka LE, Comer DR, Godwin LN. Positive organizational ethics: Cultivating and sustaining moral performance. *J Bus Ethics.* 2014;119:435-444.

13. Bagozzi RP, Sekerka LE, Hill V, Sguera F. The role of moral values in instigating morally responsible decisions. *J App Behav Sci.* 2013;49:69-94.

Physician Ethics: How Billing Relates to Patient Care

Saba Fatima, PhD

On a beautiful autumn day, I received a call at work from a neighbor who had found my uncle confused and disoriented while he was on his walk. When I arrived, I learned that my uncle had suddenly become shaky and had fallen face forward on a concrete trail. His face was badly bruised, front teeth were loose, and he was still rattled. As I assessed his condition in a state of panic, I remember thinking: "do we *need* to go to the emergency room?" My uncle was uninsured and, having dealt with his previous medical bills, I had an idea of how expensive this visit could be. Precious moments later, I chastised myself for thinking about the costs, and rushed him to the nearest ER. I found myself informing the ER physician that my uncle was uninsured and to take that into consideration when ordering tests. After the initial evaluation, to our surprise, the ER physician conceded that my uncle's syncopal event was most likely from hypoglycemia and that she would spare us the full cardiac workup. Soon after, he was discharged for home.

What is the role of physicians in such a quandary? Are there situations where they should be aware of a patient's inability to pay, or would that inevitably harm the patient's interest to be treated without bias? Can doctors holistically treat a patient while purposely remaining unaware of the patient's financial situation and of the conditions of systemic inequality in healthcare access? I argue that they cannot.

Our present system is far from adequate in terms of making healthcare financially accessible to all. The brunt of the current White House's effort to dismantle the Affordable Care Act (ACA) will be borne by lower income families and negatively impact women's reproductive health.[1] But even before this administration took office, premiums were expected to rise by 25% in some areas, Aetna had already withdrawn from the ACA health insurance exchange, and Humana and UnitedHealth Group were reducing their participation in the exchange.[2] Now, with no initiatives on the part of the government to encourage enrollment or expand coverage, it has become clear that many more people will be priced out of affordable healthcare plans, or will be left with crippling premiums or inadequate coverage.

While this article is not about the ACA, the urgency of the current social and political circumstances do prompt the sort of moral inquires that ought to lead physicians to re-examine their relationship to billing. I argue that given our predicament, in which the number of uninsured Americans is only likely to go up drastically from the current 28 million,[3] it is imperative that physicians re-evaluate many of the ethical considerations about billing that are ultimately inseparable from patients' care. For the purposes of this article, *billing* refers to the act of coding patients' procedures on part of the physician, and my concerns herein only encompass any impact such coding may have on patients' health. This thesis emerges from a commitment to the fundamental obligation that physicians have, namely to heal patients and/or manage their suffering.

ETHICAL CONSIDERATIONS

This article is not concerned about clear cases of fraud wherein a physician is willfully dishonest in billing. The focus of this article is on the structural aspects of billing that make the commitment to patients' care ethically problematic. Below, I consider three structural considerations that ought to prompt physicians to broaden their understanding of the ethical aspects of billing not to be merely about cases of fraud, but fundamentally about managing patients' health.

PHYSICIAN INCENTIVE

Medical billing serves an administrative purpose. It allows for documentation of a patient's visit and generates a charge. Whether related to an initial encounter or a follow up, medical billing can be separated into different levels of services, eg, I, II, or III, each successively worth more in revenue. Choosing which level can be based on time spent with the patient, the level of medical decision making required, or the patient's acuity. In order for the billing code to be accepted, the documentation of the encounter has to meet a minimum requirement. Electronic medical record (EMR) software often automatically populates a careprovider's note to reflect the highest level, leaving it to the physician's discretion to code the service down if need be. These codes are then used to reimburse careproviders for their services. However, often other significant financial incentives drive billing. Many large corporations and medical groups track physician employees' productivity through billing and incentivize the physicians to increase their volume and meet billing goals. A physician's livelihood can be tied closely with what is billed, whether it is in the fee-for-service model, wherein each service generates income for the physician, or a relative value unit (RVU) based model, wherein the doctor earns a base salary and receives additional compensation for productivity above a certain threshold. Although the task of billing may seem primarily administrative in nature, tying it to a physician's compensation may at least create an appearance of impropriety.

It makes sense that a physician's compensation vary with the complexity of the service offered. On the other hand, it creates the sort of environment in which a physician may code *up* reflexively. For example, entering the billing code for a urinary tract infection when there is merely an abnormal urine test, billing for chronic obstructive pulmonary disease if a patient has shortness of breath and mentioned tobacco use, or billing for diabetes *with* kidney disease, when the patient just has diabetes. Such careless billing not only wastes taxpayers' dollars and raises premiums for insured patients, but also results in patients' medical histories being recorded falsely. Here, it is important to note that the frequency of such behavior is not the core issue; rather, it is that billing systems are often set up in ways that give at least the appearance of impropriety and can foster environments that are not optimum for patients' health. As such, physicians must examine financial conflict of interests and recognize coding as an ethically relevant activity, so that they can begin to take steps to remedy such an environment.

MEDICAL COSTS AND HEALTH

One of the main reasons that billing ought to be intertwined with ethical aspects of patients' care is that lifesaving medicine is financially out of reach for many patients. This situation generates anxiety in patients regarding their ability to cover medical expenses and becomes a direct obstacle for patients and their caregivers. The thought of having your wages taken by debt collectors can further exacerbate feelings of isolation and engender resentment towards the medical establishment. According to a study by the Consumer Financial Protection Bureau, medical debt is the most common type of debt for which debt collectors contact consumers.[4] In extreme cases, financial debt can contribute toward depression and suicide. A 2015 study reported that suicide rates for adults aged 40 and 64 had increased about 40% since 1999, with a sudden increase in 2007, when the United States dipped into a historical financial crisis.[5] Researchers found that external economic factors—job loss, bankruptcies, foreclosures, and other financial problems—were present in 37.5% of suicides in 2010, up from 33% in 2005. Moreover, this study focused only on cases of "successful" suicide that were correlated with economic factors, and did not consider cases in which financial trouble regarding the coverage of appropriate healthcare contributed to medical issues such as depression.

Patients can also face moral judgment for their inability to pay their medical expenses, leaving them feeling shamed and helpless. For example, in March 2017, U.S. Congressman Jason Chaffetz commented, "Americans have . . . got to make a choice. And so maybe, rather than getting that new iPhone that they just love and they want to go spend hundreds of dollars on that, maybe they should invest in their own health care."[6] Suggesting that individuals are choosing luxury items over their own healthcare covertly aims to release the medical industry and the federal government from any responsibility for policies that sustain inequity in terms of access, and place blame squarely on the shoulders of the very people the policies are intended to serve.

Nonetheless, medical facilities often and genuinely pride themselves on practices that do not discriminate regarding patients' abilities to pay, especially in acute care settings. In emergencies treatment is neither delayed nor withheld, and is provided based on the standard of care. However, when this care results in an accumulation of insurmountable medical debt, it deters patients from following up on their care,[7] or causes them to ration their medications[8] so as to make them "last longer." Despite best intentions to disentangle the two, how billing systems are designed and managed becomes an inseparable part of what it means to care for and treat the patient.

ARBITRARY BILLING SYSTEMS

While healthcare operates within a free market in the United States, it does not seem to be driven primarily by consumers. Steven Brill writes about the business aspects of healthcare in his book *America's Bitter Pill*.[9] He documents how the determination of prices for medical procedures lacks transparency and consistency. For example, in some areas, insurance companies hold little bargaining power over hospitals that serve large portions of a local population. This is because insurance companies will be unable to sell policies if they do not include these hospitals in their coverage. In this way, hospitals hold most of the control in the negotiation of prices. Furthermore, according to Brill, the charge-description master (CDM) that lists the prices of all medical procedures, services, and goods that a hospital can provide to its patients, varies—often quite arbitrarily—across hospitals and regions. The same procedure can be billed quite differently between hospitals within the same region. Moreover, patients often have little to no knowledge of their procedural costs prior to being admitted. Even within the same facility, different insurance companies can negotiate different discounts. Besides the arbitrariness of differing insurance rates, negotiated rates are obtained by giving health insurance companies discounts off the full sticker price for that procedure. In order to demonstrate that the procedure would have cost the full sticker price, the hospital must to charge the full price to *someone*, and that someone is often the most financially vulnerable: the uninsured patient.[10] Some hospitals do offer self-pay patients discounts for full payments, but the charges are still not market driven, and are quite high for patients who pay out of pocket.

While there are many products within the general marketplace that might seem arbitrarily priced, or have high mark ups (such as the aforementioned iPhone), these products are generally not essential to one's life in the same way that access to medical care is, and consumers can choose not to buy these non-essential items. It is also true that hospitals must provide care in cases of emergency, but that care does not extend to a continuity of care for financially strapped individuals. Thus, these individuals may not have access to healthcare until their condition becomes acute. These emergent care cases act as a temporary dressing on gaping wounds, in terms of the financial cost incurred by the healthcare system and, more importantly, in terms of patients' long-term health. It should not be the case that for something as vital as true access to healthcare, we retain a "free market" framework that does not include a serious restructuring of billing practices from an ethical lens.

AN ETHICAL COMMITMENT

Critics may worry that conceptualizing billing practices as an ethical aspect of patients' care may make patients' care more consumerist. It is certainly possible that knowing the financial status of patients could certainly bias physicians to treat them differently. From the physician's perspective, although it is considered a good standard practice to be aware of which services a patient is able to access (eg, in discharge planning), being blind to a patient's billing source may seem better since the physician is providing the necessary care without discriminating on the basis of the patient's socioeconomic status. However, what a physician may not realize is that the discrimination has already occurred in the patient's selection—ie, in who comes in to seek medical care—and further social discrimination can occur in relation to a patient's subsequent inability to pay.

In an ideal world, it would seem morally intuitive for physicians to divorce themselves from such concerns in order to provide unbiased and nondiscriminatory care. However, deriving a billing system from an ideal model of the world fails to solve the very problems the system is supposed to solve. Philosopher Charles Mills[11] distinguished between two different conceptions of the ideal: ideal-as-model: these are descriptive models that represent crucial aspect of something; and ideal-as-idealized-model: these are a representation of what something *should* be like. Mills expresses that the latter conception of the ideal is problematic when it abstracts away from actual injustices. That is to say, ethical prescriptions that arise from an idealized view of the world end up not remedying the social injustices in society because their starting point abstracts away from those very inequities. However, our world is not an ideal one; social inequities do exist, many of which are institutionalized and systemic. Thus, any effort to remedy those inequities cannot begin by imagining that we live in an ideal world. Rather, we must take these inequities actively into account *while* aiming for the normative ideal. In this particular case of the healthcare system in the United States, one's access to healthcare *is* dependent on economic inequities. We can aspire for an ideal world in which physicians do not have to be concerned with issues of billing, *provided* that we are realistic about how things actually are. So any attempt to think pragmatically about what it means to treat patients ethically must consider the very reality of economic inequities in healthcare access, and not shy away from those realities under the guise of providing "impartial" care.

Some critics might also say that physicians do not have much control over the bureaucratic medical billing system. It is indeed true that physicians are quite disconnected from day-to-day feedback on how billing systems should work, and one might say that it is not their job to become actively involved in fixing this complex system. However, there have been instances when what may have seemed like bureaucratic policy changes were linked explicitly to physicians' ability to provide care to patients. One example is the general effort by physicians to advocate for gun violence research. On the surface, it may appear outside of the professional purview of a physician's obligations to get involved in the national debate on gun violence. However, in 2016, following one of the deadliest mass shootings in Orlando Florida, the American Medical Association joined the American College of Physicians and the American College of Surgeons[12] to declare gun violence a public health crisis and to push for renewed research. On a more individual basis, a 2014 *New England Journal of Medicine* editorial[13] by two pediatricians argued that doctors and other healthcare providers should act as patients' advocates and support broader policies related to family leave. They argued that such policies are linked intricately to caring for children. This is all to say that it is not odd or unprecedented to understand the bureaucracy of billing in terms of a physician's telos, especially when it directly corresponds to the health concerns of patients at large.

Any attempt to think pragmatically about what it means to treat patients ethically must consider the very reality of economic inequities in healthcare access.

It is imperative that further research be conducted on what it would mean for physicians to broaden their moral scope of practice as it relates to billing. A possible route might be that we teach this as a part of medical resident training. That would allow physicians to rethink patients' care in more holistic and comprehensive ways. It may also push physicians to be more involved collectively and individually to change our billing practices to better patients' care. This can be done through either advocacy for mandates and penalties to increase coverage[14] or advocacy for some form of single-payer system.[15] While the path forward needs an empirically based solution, it is clear that physicians cannot fully care for their patients without taking into account their patients' accessibility to care. If we stick with the current outlook on billing as not located within the purview of the ethics of patients' care, then physicians will inevitably remain enablers of, and complicit within, a broken and unethical system.

Author

Saba Fatima is associate professor of philosophy at Southern Illinois University, Edwardsville. Her research interests include non-ideal theory; social and political theory within prescriptive Islam; Muslim/Muslim-American issues within a framework of feminist and race theory; and medical humanities. She has recently published on how aspects of hospital settings, such as standards of professionalism, influence of external monitors, and emphasis on adherence to guidelines, can adversely affect the character of physicians.

References

1. Himmelstein DU, Woolhandler S. Trumpcare or Transformation. *Am J Pub Health*. 2017;107(5):660-661.

2. Johnson CY. Aetna will leave most Obamacare exchanges, projecting losses. *Washington Post*. August 16, 2016. http://wpo.st/tlJ42.

3. Clarke TC, Ward BW, Norris T, Schiller JS. Early Release of Selected Estimates Based on Data From the January–September 2016 National Health Interview Survey. *National Center for Health Statistics*. 2017. https://www.cdc.gov/nchs/data/nhis/earlyrelease/earlyrelease201702.pdf.

4. Consumer Experiences with Debt Collection: Findings from the CFPB's Survey of Consumer Views on Debt. *Consumer Financial Protection Bureau*. 2017. https://s3.amazonaws.com/files.consumerfinance.gov/f/documents/201701_cfpb_Debt-Collection-Survey-Report.pdf.

5. Hempstead KA, Phillips JA. Rising Suicide Among Adults Aged 40-64 Years. *Am J Prev Med*. 2015;48(5):491-500. doi: 10.1016/j.amepre.2014.11.006.

6. Bump P. Jason Chaffetz's iPhone comment revives the "poverty is a choice" argument. *Washington Post,* March 7, 2017. https://www.washingtonpost.com/news/politics/wp/2017/03/07/jason-chaffetzs-iphone-comment-revives-the-poverty-is-a-choice-argument/?utm_term=.f803397976a8.

7. For eg, see: Study: High Deductibles Cause Patients to Delay Care. *Robert Graham Center Research*. 2016. https://www.aafp.org/news/practice-professional-issues/20161122highdeductible.html. Or see: Steve Kukulka S. New Carepayment Research shows Americans can't afford their medical bills. *CarePayment*. February 14, 2018. https://www.carepayment.com/new-carepayment-research-shows-americans-cant-afford-medical-bills/ that reported "64% say that have avoided or delayed medical care in the last year due to expected costs."

8. For eg, see: Ricks D. Rising cost of insulin leads LI diabetics to take dangerous risks. *Newsday.* September 18, 2017. https://www.newsday.com/news/health/rising-cost-of-insulin-leads-li-diabetics-to-take-dangerous-risks-1.14196973. Or see patients' stories in Thomas K, Ornstein C. The Price They Pay, *New York Times.* March 5, 2018. https://www.nytimes.com/2018/03/05/health/drug-prices.html.

9. Brill S. *America's Bitter Pill: Money, Politics, Backroom Deals, and the Fight to Fix Our Broken Healthcare System*. New York: Random House, 2015.

10. Reinhardt, U.E. The pricing of US hospital services: Chaos behind the veil of secrecy. *Health Aff*. 2006;25(1):57-69.

11. Mills C. "Ideal Theory" as Ideology. *Hypatia.* 2015; 20(3):165-184. 166-167.

12. AMA Endorses Important Framework to Promote Firearm Safety, November 16, 2016. https://www.ama-assn.org/ama-endorses-important-framework-promote-firearm-safety.

13. Schuster MA, Chung PJ. Time off to care for a sick child—Why family-leave policies matter. *New Eng Med J*. 2014;371(6):493-5.

14. Herzlinger RE, Richman BD, Boxer RJ. Achieving Universal Coverage Without Turning to a Single Payer Lessons From 3 Other Countries. *JAMA*. 2017;317:1409-1410. doi:10.1001/jama.2017.1475.

15. See the work done by *Physicians for a National Health Program.* Available at http://www.pnhp.org/.

Patients Without Social Support Need Extra Care, Too: A Gap in the Literature; A Systems Solution

Jamie Carlin Watson, PhD, and Evan G. DeRenzo, PhD

INTRODUCTION

Patients who are capacitated but lack social support systems, such as a stable home or close relationships, can be vulnerable in some of the ways that unrepresented patients are vulnerable. For purposes of this article, unrepresented patients (sometimes called "unbefriended") are patients who are decisionally incapacitated, lack advance directives for their healthcare choices, and have no surrogate decision maker.[1] The type of patient we focus on in this article is decisionally capacitated but is otherwise similar to the unrepresented patient. These similarities, combined with new insights into the difficulties of medical decision making, suggest that these patients can share some vulnerabilities with unrepresented patients, such as more difficult advance care planning, difficulty understanding and using medical information, and limited treatment and discharge options. But since these patients have decisional capacity, it is easy to treat them the same as patients with stronger social supports. We argue that identifying and caring for this population is a systems issue and an organizational ethics problem that hospitals can address through education, policy, workflow design, and, in some cases, partnering with community organizations. We conclude by highlighting an example of a community partnership that is currently working in Phoenix, Arizona, and that might serve as a starting point for nationwide discussion.

In both of our hospitals (one a large, private, teaching and research hospital, and the other a medium-sized state academic medical center), a noticeable portion of our patient population has decisional capacity but is either homeless or lacks relationships with people who could help them with medical care. We will call these "decisionally isolated" patients.[2] We would like to introduce the concept of the "decisionally isolated patient" into the literature. Although this decade has seen a burgeoning literature on "unbefriended" or "unrepresented" patients,[3-23] decisionally isolated patients have been largely invisible in the literature. For the reasons we discuss in this article, this gap in the literature makes it harder to see these patients and understand the obstacles many of them face when hospitalized in acute care settings.

By decisionally isolated, we do not mean people who merely live alone, whose loved ones live far away, or who have close friends they don't speak with often. A person may be decisionally isolated because his or her family or friends are unavailable to hear and discuss medical decisions when the patient needs them (either because of work or unreliable communication options). Perhaps family or friends are unwilling to help with or make those decisions (whether because they are uncomfortable making such decisions, don't understand them, or have a strained relationship with the patient). Perhaps they are unqualified to make such decisions (because they are a minor, are under the supervision of a state guardian due to mental incompetence, or have a known conflict of interest with the patient's expressed wishes[24]). Thus, a decisionally isolated patient may or may not be alone in the world—such a patient may have friends and loved ones—but simply lack someone to help make medical decisions or to make medical decisions on his or her behalf in cases wherein there is a loss of capacity.

THE CHALLENGES OF DECISIONAL ISOLATION

Our understanding of how patients comprehend and use medical information has changed dramatically since 1982, when the term "shared decision making" first appeared in the President's Commission report *Making Health Care Decisions*.[25] The ideas that patients have valuable information to contribute to their medical decisions, that both patients and physicians can be biased in ways they do not easily recognize, and that most of the population struggles with low health literacy, have led to a flurry of new strategies for helping patients participate in their healthcare. These insights are being incorporated in beneficial ways throughout hospitals, from more readable healthcare forms to the use of teach-back to ensure understanding.[26,27] But there is still much to do when it comes to incorporating best practices in health literacy using hospital services (such as patient advocacy and ethics consultation) efficiently. In particular, we have work to do in identifying patients who need extra support when making medical decisions.

Knowledge Is a Social Process

The literature on the general difficulties of making medical decisions suggests at least three reasons that decisionally isolated patients may face more challenges than patients who have stronger decisional connections. First, the literature suggests that knowing is a social rather than an individual process. While classic discussions of informed consent focus on giving individual patients information they can use on their own to make decisions they perceive to be in their interests, Rebecca Kukla[28] argues that the capacity for autonomous decision making is grounded less in individual liberty and self-reliance and more in competence and responsibility. And since our competence and sense of responsibility emerges as a product of deep social dependence on, and trust in, others, we make the best decisions for ourselves when we can engage with those who share part of our past and can help us frame our current situation in light of our values. Engaging with others, in person or even online, can give us an understanding of the real practical and emotional impact of living with a particular disability, or of undergoing certain procedures—fertility treatments or chemotherapy, for instance. Such narrative and emotional knowledge is often crucial to high-quality, practical deliberation and decision making. This is a form of expertise that cannot be neatly categorized as either "factual" knowledge or knowledge of "values," but it is certainly a kind of medical knowledge that is highly relevant for patients.[28(p32)]

Further, Kukla explains that a doctor cannot engage with us in this intimate way because "this is not the kind of understanding that she gains from clinical experience—she is an outsider whose contact with her patients' lives is sporadic and mediated by a specific professional relation-ship."[28(p32)] Not only do doctors not have the relevant experience as a patient or with the particular patient, Robert Veatch[29] reminds us that doctors bring value-laden assumptions about what is medically beneficial to the table that patients might not share.[29(pp705-706)]

If knowledge is a social process and doctors can offer only minimal decision support, those who most help patients understand, appreciate, and make medical decisions are those who know them best. Thus, patients who are decisionally isolated face significantly stronger challenges to autonomous decision making than those with greater social support.

The Problem of Low Health Literacy

Second, there is a growing literature reporting that a majority of people in the United States struggle with low health literacy. Health literacy is the ability to access, understand, and use health information to make good medical decisions. People with low health literacy have a higher incidence of emergency department visits, higher medical costs, and worse overall medical outcomes.[30] What's troubling for our purpose is that, while over 80% of people in the US struggle with health information, low health literacy disproportionately affects minorities, people over a certain age, and people with little formal education.[30] To the extent that decisionally isolated patients are comprised of those with low health literacy, they are disproportionately affected by a diminished ability to access, understand, or act on health information, and we have a responsibility to address that need.

Vulnerabilities Compound

Third, we know that different forms of stress compromise decision-making capacity to varying degrees. Pain, trauma, fear, illness, the foreignness of medical language, or even the strangeness of the medical environment, can diminish patients' ability to understand information relevant to their decisions. Many patients, regardless of age or educational background, retain little of what they hear in clinical conversations. Each of these constitutes a type of vulnerability—a circumstance that renders a patient at greater risk for making poorly informed or less informed decisions.

What the social justice literature has found is that, as the number of vulnerabilities increase, they exert a compound negative effect on decision making, thereby raising the risks associated with those vulnerabilities.[31] This means we can use the number of vulnerabilities a patient experiences as a gauge for the level of decisional support they may need. While all patients face the vulnerability of their illness and perhaps low health literacy (and so require more thorough consent procedures and best practices in health literacy), when combined with homelessness or the fear of not being able to cook dinner for themselves, patients face a daunting aggregate of risks.

CHALLENGES FOR THE DECISIONALLY ISOLATED PATIENT

Advance Care Planning

Decisional isolation can present challenges similar to those of unrepresented patients. As with the latter, caring for a decisionally isolated patient in the acute care setting is a complex systems problem. One challenge is identifying patients who lack social support. Upon a patient's arrival, especially if they arrive through the emergency department, we often do not know whether they are able, or will be able, to make their own decisions.

Under the umbrella of "emergent care," a patient could move through multiple intensive care units (ICUs), and then potentially onto any of dozens of possible medical, surgical, and/or psychiatric units in the hospital before she or he is stable enough for interventions that require consent. This complex web of conditionals makes it impractical to know how many decisionally isolated patients are admitted at any given time.

Further, patients who initially seem decisionally isolated often have family or friends who arrive or are discovered by a social worker when decision making becomes imminent. There is no predictable time for an electronic medical record (EMR) flow sheet to prompt a careprovider to inquire about decision makers in the event a patient is incapacitated because every patient's trajectory will be slightly different. The only general rule seems to be: if and when a patient has or regains capacity, any discussion about his or her condition, medical needs, and likely trajectory should include a discussion of people who could support the patient in decision making or make decisions on his or her behalf, should the patient lose capacity.

Pain, trauma, fear, illness, the foreignness of medical language, or even the strangeness of the medical environment, can diminish patients' ability to understand information relevant to their decisions.

Options on living will documents are notoriously incomplete and vague, requiring a good deal of interpretation. And any specific requests can be equally unclear and even more idiosyncratic. In the absence of family members or friends with whom such documents were discussed, strangers are left to interpret what the patient intended. Further, patients are not good at thinking through the many possible contingencies, caveats, and outcomes that could affect their sense of self and quality of life. Without someone trained to talk through possible paths with them, their preferences can be overly narrow with limited nuance. And, of course, there is no one to list as power of attorney for healthcare.

Navigating the Healthcare System

One validated screening question for low health literacy asks, "How confident are you filling out medical forms by yourself?"[32] The implication is that, if you have low health literacy, then you need additional help navigating the healthcare system, including help completing paperwork, finding your way to various parts of a hospital, and adhering to your prescription regimen. A number of initiatives have been developed to help make health information easier to understand and use, including plain language writing for patients' information, teach-back techniques in the informed consent process, and simplified drug-regimen templates to reduce errors in medication dosing. But these initiatives can only help patients with the basics: understanding their health problem and how to get help. They do not help patients get a second opinion, find alternative sources of information, interpret a medical diagnosis in light of their values, or weigh the risks and benefits of a treatment plan. For those tasks, other people are necessary.

Post-Treatment Care

Perhaps the most difficult aspect of decision making for decisionally isolated patients is how to reason about their posttreatment needs. If patients need surgery, where will they recover? Will they be able to shower and dress themselves at home? How will they eat while they recover? Can they get to the clinic for their posttreatment needs or follow-up care?

Patients who have lived alone for a long time, particularly patients who have managed their homelessness with reasonable success, might not recognize the additional risks that go along with medical frailty. They might think they can call 911, but have they considered what might happen if they lose mobility or consciousness? Is there a safety net in place if no one hears from them for a day or two? These patients need someone who can help them think through these possible complications.

Perhaps a more concerning possibility is that a patient understands these risks profoundly and either refuses a treatment or chooses a suboptimal treatment on the basis of this fear, but does not explain this to the doctor. In these cases, even if there are social supports that could address these concerns, the patient will not get the opportunity to know about them.

Providing care to the decisionally isolated becomes even more complicated when their decisional capacity fluctuates or is assessed to be fairly weak. Without someone to serve as an advocate, marginally capacitated patients may exhibit behaviors such as refusal of care or refusal to communicate that may be the result of confusion or frustration, rather than authentic expressions.

CARING FOR DECISIONALLY ISOLATED PATIENTS

When patients are considered capacitated, clinicians have a disinclination to intervene in decision making, which arguably may have become ingrained through their medical training. Unless there is a complement of staff trained to identify and provide specialized assistance to patients who may need decisional support, decisionally isolated patients can languish in the hospital. A capacitated patient may ask to leave and be discharged even if no one has assessed whether the patient understands how she or he could benefit from additional care. If a capacitated patient refuses an intervention, that refusal is often accepted without further discussion, even if the patient has not been provided with the decisional support he or she would need to know whether the intervention would serve the patient's interests.

These problems suggest the need for systems that help identify and support decisionally isolated patients as they move through the healthcare system, from admission to discharge to a stable environment. In this final section, we offer four places to start addressing this gap in care.

Staff Education

EMRs are powerful data collecting tools, and if a program that flags decisionally isolated patients early in admission could be developed, this would go a long way toward thorough care planning for admission and discharge. The central question for patients to answer is simply: Is there someone who can help you make medical decisions, or could make them for you in case you lose capacity? If the answer is no, a flag could suggest a page be sent to social work, case management, patient advocacy, or the ethics consultation service.

As noted earlier, however, it is unclear where such a flag should be initiated in the workflow, or by whom. This means that, for now, identifying decisionally isolated patients is a human resource challenge that must be met through staff education. Staff should be apprised that they have the authority to ask whether a patient has decisional support or a potential surrogate decision maker at any time. And they should be aware of hospital resources to help find those answers. Clinical social workers are trained to help with complex discharge and post-op planning. Ethicists are trained to engage in discussions regarding values, to help patients reason through their realistic options, and to nudge clinicians to give patients enough time to reason and talk through their values and preferences, time that might be condensed if they are supported by people who know them well. A multidisciplinary approach to patient care can address many problems before they turn critical.

Policy and Workflow

Clinics and hospital units have distinct cultures and hierarchies. Policies and workflows that encourage regular, interdisciplinary team meetings and family meetings allow services that address social issues, such as social work and case management, the opportunity to learn early in a patients' admission whether they need additional support.

Workflows that keep documented information about family and friends, named surrogates, or durable powers of attorney for healthcare in a central or consistent location, whether physically or in the EMR, can nudge staff to collect this information and make it more noticeable when this information is missing.

Further, teams that embrace the help of ethics consultants can develop unit policies that notify ethics when decisionally isolated patients might benefit from discussions devoted to advance care planning or weighing values and preferences against risks, benefits, and alternatives.

Community Partnerships to Help Decisionally Isolated Patients

Once ready for discharge, troubles for the decisionally isolated increase substantially. Many patients are homeless or have tenuous employment and living conditions. And whatever illness brought them to the hospital may result in patients being further debilitated once their acute care needs have been met, so that returning to their previous lifestyle would be unsafe from a medical perspective.

Many patients who have been homeless, whether by circumstance or preference, want to return to the street after treatment. Those who have entered the hospital from uncertain employment or housing may be experiencing illnesses that have rendered them unable to return to that employment or housing. If a patient were incapacitated and unrepresented, social work could pursue state guardianship to help manage his or her post-discharge care. But for the decisionally isolated, capacitated patient, guardianship is not an option. So, what might be an option for the patient?

If an ideal discharge for a patient is to a rehabilitation facility, the scarcity of possible placements can result in long discharge delays. In turn, such delays can reduce a patient's window of opportunity to regain strength and functional capabilities. And by the time rehabilitation placement is found, a patient's ability to meet criteria has passed. In our experience, if there is any mention of behavioral or drug abuse problems in a patient's record, discharge efforts to outpatient healthcare systems can come to a screeching halt.

If a decisionally isolated patient, who is also homeless, is sufficiently stable to move out of the hospital into the community at large, there are few living arrangements that are set up to manage the outpatient needs of such patients, such as transportation to and from follow-up appointments, trips to the pharmacy or grocery store, and help with daily living.

For those who were homeless prior to hospitalization and who are too medically fragile to be discharged back to the street, even if that's what they want, the hospital seemingly faces an ethical dilemma. It has to balance an ethical duty to safely discharge a patient with the likely risks of detaining a capacitated patient against his or her will.

This dilemma, however, is an organizational problem of our own making, and with some careful and creative planning, there is a way out of it. Many cities already have beds that can be used by the homeless after hospitalization. But for the most part these efforts are insufficient to meet the need. During a telephone conversation with the National Healthcare for the Homeless Council, we discovered that in the District of Columbia, for example, there are only 34 male-only beds, and none for women or families; in Little Rock, Arkansas, there is only one shelter that can accommodate minimal medical needs for 200 men and 40 women (stairwells prevent them from accommodating wheelchairs). According to the council, there are approximately 70 homeless respite programs around the country. These programs all tend to be more or less patchwork efforts by persons or organizations that are designed to cobble together what resources can be brought to bear to provide respite care for homeless, medically fragile patients who are ready to be discharged. To be sure, if former patients choose and are able to leave these facilities, then no one should stop them. As Veatch[29] suggests, we must not succumb to the idea that we are the arbiters of a life that is safe or meaningful.

A program in Phoenix, Arizona, however, is something else entirely. Circle the City is a Phoenix-wide, Phoenix-hospital-wide and major-donor supported, comprehensive program (providing housing and possible employment) with 200 respite bed facilities for medically fragile, previously homeless, previously hospitalized patients.[33] Circle the City is the vision of family physician Sister Adele of the Sisters of St. Joseph of Carondelet. Addressing significant gaps in services for homeless patients, Circle the City brings together all the city's hospitals, major donors, corporate sponsors, and housing authorities, bolstered by funding from multiple social service and federal government agencies to allow patients who were homeless prior to their hospitalizations a place to rest and heal. In their materials,[33] they claim that 80% of these clients move from Circle the City into subsidized housing, not back to the street.

Such a program provides benefits all around. First and foremost, previously homeless, decisionally isolated patients have a safe, secure place to be discharged wherein they have the additional time and medical services they need to rest and heal. By working with these clients, the area hospitals have an extended reach for placement. Such a program provides the social services needed to assist clients in obtaining safe, subsidized housing and allow most to avoid returning to the street and experience continued readmissions to the city's hospitals. With a bit of community engagement, Circle the City is a model that could be emulated in many cities across the country.

NEXT STEPS

Although systems for unrepresented patients who lack decisional capacity are usually a clear pathway into court systems, pathways for the decisionally isolated patient are less clear, if they exist at all. In the District of Columbia, the next steps are to harness the reinvigorated bioethics consortium. This is a group of bioethics representatives from most of the district's hospitals who have committed to working together to solve mutually complex systems problems. From there, it will be a matter of partnering with the existing systems focused on this population, raising funds, increasing available respite beds for the homeless, and developing the extended systems partnerships needed to help clients move from homeless respite to homes of their own. In Little Rock, the next steps forward are unclear. The rural surrounding areas and limited state support for social programs make community planning difficult. Little by little, however, working to identify and support these patients on the front end can go some way toward engaging the broader community in solving this systems problem. If Circle the City is any evidence, then little by little, the state of care for decisionally isolated patients can be, if not solved, at least improved.

Acknowledgment

We would like to thank D. Micah Hester, Leslie LeBlanc, and Laura Guidry-Grimes for their comments and suggestions on an earlier draft of this article, and to Dr. Guidry-Grimes in particular for her contribution of the term "decisionally isolated" for the patient population we identify for the first time in the literature.

Authors

Jamie Carlin Watson is Assistant Professor of Medical Humanities and Bioethics at University of Arkansas for Medical Sciences (UAMS). He also works as a clinical ethicist for UAMS hospital and Arkansas Children's Hospital, and as a Plain Language Writer for the UAMS Center for Health Literacy. His research focuses on expertise, moral expertise, and clinical decision making.

Evan DeRenzo is Assistant Director of the John J. Lynch, MD Center for Ethics at MedStar Washington Hospital Center, Washington, D.C. She received her PhD in Human Development/Gerontology from the University of Maryland and was the first Senior Staff Fellow in Bioethics at the National Institutes of Health (NIH). She is retired adjunct faculty for the Johns Hopkins University, Graduate Program in Biotechnology. She is the Co-Facilitator of the ASBH's Organizational Ethics Affinity Group and chairs her hospital's ethics committee's subcommittee on organizational ethics. She holds a business process patent for tracking ethics information throughout a hospital system and is now producing the second edition of her research ethics book with Joel Moss and their additional co-author, Eric Singer, Rutgers University.

References

1. Pope TM. Perspective: Making medical decisions for patients without surrogates. *N Engl J Med.* 2013;369:1976-1978.

2. Thanks to Laura Guidry-Grimes for this helpful phrase.

3. Pope TM, Sellers T. Legal briefing: The unbefriended: Making healthcare decisions for patients without surrogates, part 1. *J Clin Ethics.* 2012;23(1):84-96.

4. Pope TM, Sellers T. Legal briefing: The unbefriended: Making healthcare decisions for patients without surrogate, part 2. *J Clin Ethics.* 2012; 23(2):177-192.

5. White DB, Jonsen A, Lo B. Ethical challenge: When clinicians act as surrogates for unrepresented patients. *Am J Crit Care.* 2012;21(3):202-207.

6. Bandy R, Sachs GA, Montz K, Inger L, Bandy RW, Torke AM. Wishard Volunteer Advocates Program: An intervention for at-risk, incapacitated, unbefriended

adults. *J Am Geriatr Soc.* 2014;62(11):2171-2179.

7. Effiong A, Harman S. Patients who lack capacity and lack surrogates: Can they enroll in hospice? *J Pain Symptom Manage.* 2014;48(4):745-750.

8. Johnstone MJ. Caring about the unbefriended elderly. *Aust Nurs Midwifery J.* 2014;21(9):20.

9. Marshall MF. Editorial: Improving guardianship processes for unrepresented adult patients who lack decisional capacity: an ethical and institutional imperative. *Jt. Comm J Qual Patient Saf.* 2014;40(9):387-388.

10. Salter B. Caring about the unbefriended elderly. *Aust Nurs Midwifery J.* 2014;21(11):55.

11. Pope TM. Legal Briefing: Adult orphans and the unbefriended: Making medical decisions for unrepresented patient without surrogates. *J Clin Ethics.* 2015; 26(2):180-188.

12. Abdool R, Szego M, Buchman D, et al. Difficult healthcare transitions: Ethical analysis and policy recommendations for unrepresented patients. *Nurs Ethics.* 2016;23(7):770-783.

13. Connor DM, Elkin GD, Lee K, Thompson V, Whelan H. The unbefriended patient: An exercise in ethical clinical reasoning. *J Gen Intern Med.* 2016;31(1):128-132.

14. Courtwright A, Rubin E. Who should decide for the unrepresented? *Bioethics.* 2016;30(3):173-180.

15. Farrell TW, Widera E, Rosenberg L, et al. AGS position statement: Making medical treatment decisions for unbefriended older adults. *J Am Geriatr Soc.* 2016;22. doi:10.1111/jgs.

16. Rakatansky H. Medical decision-making for unrepresented patients. *R I Med J.* 2016;99(10):11-12.

17. Bennett-Woods D, Abbott J, Glover JJ. Giving voice to the voiceless: The Colorado response to unrepresented patients. *J Clin Ethics.* 2017;28(3)-204-211.

18. Courtwright AM, Abrams J, Robinson EM. The role of a hospital ethics consultation service in decision-making for unrepresented patients. *J Bioeth Inq.* 2017; 14(2):241-250.

19. Buhaya MH. Unrepresent. *AMA J Ethics.* 2018; 20(8):E776-777.

20. Chamberlain S, Baik S, Estabrooks C. Going it alone: A scoping review of unbefriended older adults. *Can J Aging.* 2018;37(1):1-11.

21. Glover JJ, Bennett-Woods D, Abbott J. Colorado's new proxy law allowing physicians to serve as proxies: moving from statute to guidelines. *J Clin Ethics.* 2018; 29(1):69-77.

22. Kim H, Song MK. Medical decision-making for adults who lack decision-making capacity and a surrogate: State of the science. *Am J Hosp Palliat Care.* 2018;35(9):1227-1234.

23. Brostrom L, Johnson M. The protection of unrepresented patients in emergency care research. *Account Res.* 2018;25(1):21-36.

24. In one of Dr. Watson's cases, the patient's only relative was his sister, and the medical team learned that she was pursuing a transition to comfort care for her brother because she would inherit his pickup truck upon his death.

25. President's Commission for the Study of Ethical Problems in Medicine, Biomedical, and Behavioral Research (US). *Making health care decisions.* vol. 1. Washington, D.C.: *Congr Rec.* 1978. 124(168):S19299-300.

26. Hadden K, Prince L, Shnaekel A, Couch C, Stephenson J, Wyrick, T. Readability of patient education materials in hand surgery and health literacy best practices for improvement. *J Hand Surgery.* 2016. doi:10.1016/j.jhsa.2016.05.006. Available at: http://www.jhandsurg.org/article/S0363-5023(16)30133-2/abstract.

27. Hadden, K, Prince, L, Barnes CL. Health literacy and opioid use in orthopaedic patients. *J Surg Orthop Adv.* 2017;25(4):234-237. doi: 10.3113/JSOA.2016.0234. Available at: http://www.jsoaonline.com/archive/2016/health-literacy-opioids-orthopaedic-patients/.

28. Kukla R. How Do Patients Know? *Hastings Cent Rep.* 2007; 37(5):27-35.

29. Veatch, R. Doctor does not know best: Why in the new century physicians must stop trying to benefit patients. *J Med Philos.* 2000; 25(6):701-721.

30. Berkman N, Stacey LS, Katrina E, Donahue, Halpern DJ, Crotty K. Low Health Literacy and Health Outcomes: An Updated Systematic Review. *Ann Intern Med.* 2011; 155(2):97-115.

31. Guidry-Grimes L, Victor E. Vulnerabilities Compounded by Social Institutions. *Int J Fem Approaches Bioeth.* 2012;5(2):126-146.

32. Chew LD, Bradley KA, Boyko EJ. Brief questions to identify patients with inadequate health literacy. *Fam Med.* 2004; 36, 588-594.

33. http://www.circlethecity.org/about/.

CASE 1

Dementia and the Institutional Pressure to Discharge

The Editorial Group of the John J. Lynch, MD Center for Ethics

Complexity: **1 2 3 4**

PRESENTATION

Mr. Moore is an 87-year-old male, brought to the hospital during the early morning after calling emergency services and complaining of acute chest pain. After a brief work up by the emergency department (ED), Mr. Moore was not diagnosed to be experiencing a cardiac event. Nevertheless, the patient insisted vigorously that he was experiencing a "heart attack" and was ultimately admitted for observation and referred to an inhouse cardiologist for monitoring and further evaluation.

That afternoon, Dr. Crowell, the assigned cardiologist, began to review Mr. Moore's available medical history and noticed several documented visits to the hospital, the most recent of which included a progress note from behavioral health noting Mr. Moore as having been diagnosed with dementia. The note was linked to Mr. Moore's last visit to the ED three months ago, during which he also expressed concern that he was experiencing a life-threatening cardiac event. During this previous visit, however, Mr. Moore's complaints were noted as extending beyond concerns related to his own heart failure and included claims that his father (who was later verified to have died when Mr. Moore was a teenager) was himself presently experiencing a heart attack and that he urgently needed to bring him to the hospital.

Dr. Crowell was able to contact some of the ED nursing staff and psychiatric team involved in Mr. Moore's previous visit and confirmed, in conjunction with the available medical history, that after the previous visit's ED work up similarly revealed nothing in relation to the patient's cardiac health, the staff had contacted psychiatry for an evaluation. One of the nurses present during both ED visits commented to Dr. Crowell that, despite any protocol or standard of practice, he was surprised Mr. Moore was even admitted for further cardiac observation, given what they knew of his past medical history and what they had learned of his mental health during his previous visit. Dr. Crowell was now less concerned about Mr. Moore's cardiac health, for which he was assigned to the patient's care, but wondered if after his routine observation of Mr. Moore whether allowing him to be discharged as any other patient, ie, any other cognitively well-capacitated patient, was the appropriate thing to do.

Confident that Mr. Moore's 24-hour observation wouuld yield no cardiologic reason to extend his hospital admission, Dr. Crowell decided to use the little time he had while assigned to Mr. Moore to investigate community service options before the inevitable discharge occured. Dr. Crowell, like many hospitalists, knew far too well the constant pressure that existed to make beds available and to discharge as soon as medical evaluations failed to demonstrate the need for hospital retention or further and costly evaluation. Mr. Moore arrived by himself to the ED and, during his more lucid moments, had communicated to the staff that his only living relative was his single adult son who lived in Oregon. Although Mr. Moore claimed his son frequently visited and provided care, he had stated that he lived alone and cared for himself under a modest retirement income. Attempts to contact his son had failed. Dr. Crowell decided to contact clinical resource management, including a nurse consultant who served as a community services liaison.

The team was expected to discharge Mr. Moore in light of Dr. Crowell's assessment that there were no cardiologic concerns.

Although Mr. Moore had documented dementia, he was not demented to have been demented enough not to pass the cursory capacity assessments that had been administered so far. Therefore, the discharge planner saw no reason to hold him much longer, despite the lack of assurance that a patient with diagnosed dementia was apparently having difficulty functioning alone and had no resource for more frequent and appropriately trained care once he was home. Moreover, the nature of the psychiatric diagnosis foresaw problems in Mr. Moore's capacity to sustain any home-based self-care regimen. Although Mr. Moore was diagnosed with dementia during his previous visit, the associated discharge summary did not include instructions related to Mr. Moore's home psychiatric care, merely that there was no cardiac concern. Dr. Crowell was certain that even if the new summary included the need for home psychiatric care, there was simply no option available to provide it. To make things harder, staff members had received recent instructions from hospital administration that current monthly discharge numbers would have to be increased if the hospital was to maintain its services to an ever-enlarging number of incoming patients who did, in fact, sufficiently meet criteria for immediate and continued admission.

There were but a few hours left before Dr. Crowell would sign discharge documents and release Mr. Moore. He sat by the patient's bedside, frustrated about the patient's impending discharge, while Mr. Moore again asked about the health of his dead Father. Dr. Crowell then decided to bring back the psychiatric team, and, in addition, placed a call to the clinical bioethics department, requesting an ethics consultation. The discharge planners began contacting outside service providers while Dr. Crowell requested a new capacity evaluation to help justify and assist in the service request.

ETHICAL ISSUES

This case illustrates the systemic tension that often exists between health institutions' operational need to maintain a certain patient occupancy (number of beds available), and the opinion that certain patients are being discharged too early and without full attention regarding what sort of care they might require once they leave. Hospital systems work hard through administrative efforts to reduce length of stay via the prompt discharge of patients whose medical needs have been addressed, presumably, to the best of the institution's ability. Whether a patient is found to be in need of further medical attention or not, all appropriate and available medical care has been provided in accordance with medical diagnoses and standards of practice, or the care needed is of a sort not provided by the admitting institution, hospital administrators are tasked to help meet general institutional goals related to bed capacity, while often being the most removed from the particulars of the relevant case. This removal, however, can also be understood as systemic, ie, the symptom of a certain administrative organization. In the middle of this are those tasked with discharge planning and whose own values in relation to any particular case may or may not be in line with the values of the administrators or the attending physician and other health staff. The values that might influence meeting such difficult goals should not be dismissed as though they are only a matter of institutional avarice or the considerations of the *merely* financially driven character of hospital administrators. Without a proper administrative system that is equipped to regulate such constraints of capacity, certainly the system itself might be placed at risk or suffer in its fundamental ability to provide appropriate care.

RECOMMENDATIONS

1. Educationally, Dr. Crowell should be acknowledged by the ethicist for pausing reflectively about what he believes might be a shortcoming in the hospital's meeting its criteria for discharge and in contemplating whether general standards such as "all appropriate and available medical care" have been met in this case.

2. The ethicist can now assist Dr. Crowell in arranging a swift meeting with the psychiatrist on call, the discharge team, and the patient. This could, potentially, allow for the drafting of a comprehensive discharge summary that not only includes Mr. Moore's psychiatric diagnosis, in order to help form a more effective request for post-discharge home services, but also provides home and self-care instructions that could be transmitted to the external agency providing the care, as well as Mr. Moore's son, if he is able to be reached.

3. The ethicist can now recommend the drafting of a discharge summary and progress notation that explicitly states Mr. Moore's comprehensive condition (ie, his negative cardiac work up alongside the reasons why the discharge-by-policy criteria was insufficient in its ability to acknowledge the patient's full condition), need for post-discharge care, and perhaps most importantly, any challenges to that care, given his dementia.

REASONING

We see here both a justifiable systemic value conflict in the general administrative push to maintain basic bed capacity, and a physician who believes this is a case in which the patient's care needs have not been met—that is, that all appropriate and available medical care has *not* been provided to Mr. Moore, despite what might be immediately available at present and within the hospital's own inhouse resources. On the one hand, to characterize the hospital administration as placing in effect policies and practices that are ignorant to the struggles of particular medical practitioners would be to circumvent an attempt to more fully understand the values that drive those decisions, and, ultimately, those placed in charge of the design, implementation, and ongoing regulation of such institutional policies, ie, the very people who can assist in the correction of policies that have perhaps failed to take certain common patient scenarios under consideration in their development.

On the other hand, whereas the nurse who commented negatively on the need to admit Mr. Moore appeared to express himself merely in accordance with the hospital's administrative goals, the discharge planners are extending the goals of the administration as a matter of professional obligation, although perhaps not from shared values. Dr. Crowell is most immediately faced with a group of persons, all of whom presumably work in different capacities alongside her and other bedside care providers—they are not hospital administrators. In terms of addressing the actual and present concerns Dr. Crowell has regarding Mr. Moore's post-discharge care, it is the discharge team who is most particularly involved, positioned to make a practical difference, and from whom she might invoke a sympathetic response to the time sensitive circumstances *at hand.*

An ethicist's own reflection on this case, whatever the outcome is in terms of securing post-discharge care in Mr. Moore's particular case, should be to evaluate the conflicts that emerge within this kind of scenario in a hospital or healthcare system. The ethicist should recognize the system conflict as a distinct one, and use his or her organizational avenues for dialogue (eg, ethics committee, fellow ethicists, medical affairs, system administrators) to commence discussion on possible policy changes.

CASE 2

Patient Safety Protocols and Moral Distress

The Editorial Group of the John J. Lynch, MD Center for Ethics

Complexity: 1 2 3 4

PRESENTATION

Mrs. Patricia Carter is a 52-year-old woman, admitted to the hospital for chest pain via the emergency department. A cardiac examination revealed an urgent need for bypass surgery, which was immediately arranged. Mrs. Carter was accompanied by her husband of 25 years and their 22 year-old son, both of whom appeared to be close to her as well as responsibly involved in her care.

As the nurse assigned to the operating room (OR) arrived to escort Mrs. Carter to her surgery, she paused as she noticed the name "Patricia Holman" listed as that of the patient on her hospital wristband. The OR nurse stopped and explained to the patient that the label was mistaken and, as a matter of safety, she could no longer proceed with taking Mrs. Carter to surgery. Mrs. Carter pointed to her hanging medications, all of which had her correct name of "Patricia Carter" listed appropriately, and explained that "Holman" is her maiden name and that this had not affected her care in any way, that the attending physician was clear about the urgent nature of her bypass and to please not delay the procedure.

The OR nurse was concerned about the possibility of there being two patients of the name "Patricia Holman" in the hospital, and that the pharmacy dispensing technology that mistakenly printed the wristband could have also provided someone else's medical profile that would pose a safety risk in the OR. That is, if the wrong medications were listed, administering an inappropriate medication could put the patient at risk for morbidity or mortality. The standard processes of patient verification would be inaccurate and, in this case, the patient would not be able to participate in the verification of her own name past the point of anesthesia.

Mrs. Carter and her family appreciated the concern, but tried to assure the OR nurse that they were comfortable with the technical mistake and that they wished to proceed with the surgery right away. Moreover, the nurse had notified the cardiac surgery team. The attending cardiac surgeon and the nurse verified that the drugs hanging are for the correct patient and the surgeon emphasized that the procedure was too urgent to allow for the risk involved in taking the time to verify and correct the mistake and have the prescription device print a new wristband with the correct name. The nurse checked that Mrs. Carter's medical record number (MRN) and date of birth (DOB) on the wristband were indeed correct, therefore the probability that it belonged to another patient with the same name is quite low.

Despite the cardiac team's advice and the insistence of the patient and her family to proceed despite the technical error, the OR nurse refused to take the patient to her surgery. When she saw another nurse attempting to do so, she called the ethics department for an urgent consultation.

ETHICAL ISSUES

The ethical issues relevant to this case included:

1. Patient safety in the OR. Were the protocols well established? Were the protocols appropriate? What might ethically permit divergence from well and appropriately established safety protocols?

2. What was the ethical response to a nurse who identified a safety problem for a patient who needed emergency surgery?

3. Did the hospital have a robust program for addressing clinical moral distress?

RECOMMENDATIONS

1. Given that this patient went to surgery with an incorrect wristband, thorough documentation should be entered into the patient's electronic medical record (EMR). This should include documentation by the attending physician that the surgery was emergent and should not have been postponed to get the wristband error corrected. It should include documentation by the nurse of the incident, including the filing of a formal incident report.

2. Moral distress programming should be given to the affected team members.

REASONING

The first ethics issue requiring immediate attention is Mrs. Carter's health and safety. No matter what the problem, when professionals are involved in the care of a patient, the patient always comes first. Is this truly an emergency? Because if it is not, the error needs to be corrected before the patient goes to surgery. If it is emergent, then after confirmation that the medications are appropriate for this patient, there should be no delay in treating an emergency condition in a patient. Everything else can be worked out later. Nonetheless, to override the safety systems and take a patient with an incorrect wristband to the OR presents significant risks, and so the justification for continuing to surgery before the problem is fixed needs to be well reasoned.

Just as soon as the patient has gone to the OR, assuming that the patient's wristband has not yet been corrected, the safety systems in the hospital need to be triggered. The error has to be tracked down immediately, presumably so that the correct wristband can be placed on the patient during her surgery. But while this patient may need to proceed to the OR with the incorrectly written wristband, this nurse's safety alarm went off at the right time. She was following appropriate standards of practice to stop progress of a patient to an OR when there was an anomaly in the established protocols.

In this case, however, default protocols had not been followed, and so this information must be provided to the proper entities within the hospital as quickly as possible. The case indicated that the wristband was printed in the pharmacy, so the first call should be to that department.

Then the incident must be filed in the hospital's incident reporting system so it can go through the proper channels to be reviewed at all appropriate hospital policy and administrative levels. The cause of this mistake must be tracked down, and corrective processes put in place, so it doesn't happen in the future. Additionally, the incident must be documented thoroughly in the patient's medical record, so that any other team receiving the patient will know about the problem and can be assistive in getting the correct wristband on the patient.

After the safety issues are addressed, as an organizational matter, the nurse who spotted the error ought to be acknowledged. Not only should the nurse not have been ignored, she should have been lauded by everyone involved, including her nursing supervisor, the surgical team taking the patient to the OR, and the hospital's administration. Ethics is quality care. Excellence in care is first and foremost safe care. Catching errors and lauding those who do this is a hallmark of an ethical climate that fosters quality care.

Moral distress is endemic in today's modern hospitals, especially large, urban, teaching hospitals, and must be systemically addressed. Today, any hospital that does not have an explicit response to moral distress is behind the curve.

It is beyond the scope of this case analysis to speculate on the many factors that contribute to moral distress in clinicians, the concept itself, or to support the claim that it needs to be identified and addressed.

While the majority of recent literature on moral distress has been generated by the nursing field,[1-3] it can be found in the physician literature, as well.[4] That others ignored or minimized what this nurse perceived, rightly, to be a significant patient safety risk is an organizational ethics issue in addition to the actual threat of harm to the patient. In the eyes of the OR nurse, Mrs. Carter and her family might not have sufficiently appreciated the risk involved in undergoing such a procedure *while her hospital identification remained incorrect*. That the identifying nurse was not supported, openly, by the patient's physicians was a serious organizational ethics problem. Even if it was determined that the risk of harm to the patient in waiting for the mistake to be corrected was likely greater than the risk of harm of the original mistake, at the moment this happened, the nurse should have been thanked. If she believed she could not participate in taking the patient, she should have been respectfully allowed to step aside. Not handling the situation in a supportive way was likely to contribute not only to moral distress in this particular nurse, but across a wide swath of players in the OR system. Any moral distress must be addressed as quickly as possible. Moreover, the hospital's programmatic, systemic approach to facing and reducing moral distress must be mobilized in order to follow up on any residual moral distress that might linger on the unit.

Without this kind of well-coordinated response, it is hard to think of how the OR nurse, who acted in proper accordance with the safety protocols of the system, could be expected to continue to be vigilant of those sorts of technological and systemic gaps. An ethically sound environment calls for identifying these problems when they occur, so they can be fixed. Effectively suffocating the nurse's attempts to do so during the care of Mrs. Carter could potentially cause similar problems in the future, with harm to the patient, in addition to burnout in clinicians who know what is right but are blocked from doing it.[5]

References

1. Caram CS, Peter E, Brito MJ. Invisibility of the self: Reaching for the telos of nursing within a context of moral distress. *Nurs Inq.* 2018. doi: 10.1111/nin. 12269.

2. Mehdipour RR, Dehghan M, Nematollahi M. Nursing studetns' ethical challenges in the clinical settings: A mixed-methods study. *Nurs Ethics*. 2018. doi: 10.1177/0969733018810766.

3. Meziane D, Ramirez-Garcia MP, Fortin ML. A reflective practice intervention to act on the moral distress of nurses providing end-of-life care on acute care units. *Int J Palliat Nurs.* 2018;24(9):444-451.

4. Elton C. *Also Human: The Inner Lives of Doctors.* 2018. New York: Basic Books.

5. Fourie C. Who is experiencing what kind of moral distress? Distinctions for moving from a narrow to a broad definition of moral distress. *AMA J Ethics.* 2017;19(6):578-584.

CASE 3

Medical Team Safety and Patient Autonomy: When Principles Conflict

The Editorial Group of the John J. Lynch, MD Center for Ethics

Complexity: 1 2 3 4

PRESENTATION

Ms. Campbell was a 36-year-old woman with an advanced gastric adenocarcinoma (an invasive type of glandular cancer originating in the stomach), admitted to the hospital because of severe abdominal pain and shortness of breath (SOB). After several days of hospitalization, it looked as though the patient was no longer able to care for herself at home. Further, there were reports that her children and extended family have taken and used her pain medications, although the patient vehemently denied this. The team social worker had not yet filed an Adult Protective Services (APS) report because, given that it was unlikely that Ms. Campbell would go home, and as long as a patient was safe in a hospital, APS would not open a case. If the patient was not going home, there may have been good reason to cause additional strife within the family. Ms. Campbell, however, wanted to go home.

Ms. Campbell was a single mother. Two of her three children were adults and had moved away. They lived at a considerable distance from her and only visited occasionally when they “needed something.” Ms. Campbell strongly refused hospice care any time an attending physician sat down with her to discuss her prognosis and her wishes. The present attending had spoken with Ms. Campbell thoughtfully about her medical condition and the kind of supports that would be needed for her to return home. He expressed clearly his concern for her medical and social well-being, including her ability to manage her own basic care needs, to follow up with her appointments, or keep her prescription medications from being stolen.

Initially, Ms. Campbell appeared receptive to the medical team, but nonetheless remained unwilling to change her stance on being discharged home. After several talks with the attending, however, she decided that regardless of the outcome of her discharge, she would be unable to take care of her youngest daughter (nine years old) and wanted to seek appropriate guardianship for her. Before the patient even began to talk with a social worker about how to have guardianship for the youngest daughter set up with the patient's mother, trust completely broke down between the patient and the team. The attending physician misinterpreted the patient's interest in getting her daughter's guardianship status arranged as a sign of progress in convincing Ms. Campbell that she could not go home. When the attending began talking with the patient as if her discharge to a long-term care facility with a hospice overlay was assured, she became frustrated with what she felt were "stubborn" attempts to get her to change her mind about going home. Even though the patient was considered to be capacitated and consistent about her wishes regarding discharge, she felt badgered. At this point, she began raising her voice and repeating that she was in pain and wanted to go home to her daughter. She then claimed she would be calling her boyfriend and her mother to have them come pick her up right away.

Eventually, Ms. Campbell reached her mother and boyfriend over the phone. After these conversations, tensions between the patient and members of the team escalated. Unaware of what Ms. Campbell had told her family, when the medical team and attending physician were able to reach Mrs. Campbell's boyfriend over the phone, he became verbally abusive and threatening. In short, he threatened the staff with violence if Ms. Campbell was not given the pain medication she requested and allowed to leave as she pleased. Moreover, the boyfriend said he would be coming to the hospital and "waiting outside" by the vehicles of each of the members of the present medical staff in order to "kill them" should Ms. Campbell encounter any more resistance.

Despite her weakening medical condition and the social complexities at home, Ms. Campbell did not attempt to diminish the impact of her boyfriend's threats. Instead, she simply continued to insist on being discharged so she could return to her apartment to be with her youngest daughter.

The medical team promptly contacted hospital security to relay the threat and assure that security officers were dispatched to the floor and garage. One security officer arrived on the unit and stood inside the door. The officer reported that it had been arranged to have the team members walked to their cars by a security officer whenever they needed to get to their cars, and that security presence had been increased at the primary entrances to the hospital.

That did not, however, solve the problem. The patient insisted on leaving the hospital AMA (against medical advice), but she needed help to get in or out of bed. When the team mentioned that she needed help, Mrs. Campbell responded that her boyfriend would help her. The patient was clearly capacitated to leave AMA. Although it might have been inadvisable for a variety of reasons for the patient to go home, she insisted that her mother and boyfriend would take turns helping her.

Given all the frightening threats from the boyfriend, the team became eager for the patient to leave. The team was divided, however, about whether or not to allow the boyfriend into the hospital. The patient said she wanted him to come and help her out of the unit and into his car. Some members of the team believed that it was the patient's right to have whomever she wanted come in to help her, and with security officers posted so visibly, having her boyfriend come get her would be safe enough. Others were not so sure.

The patient was now barely speaking to anyone on the team. When she did, she appeared to be hostile and merely repeated that she was waiting for her boyfriend to come get her. At that point, the attending physician began to consider whether it was advisable to so vigorously insist that Ms. Campbell remain at the hospital or consider hospice. He became more concerned about the safety of his colleagues and staff than he was interested in attempting to convince the patient of the team's recommendations. With the whole affair was causing marked distress among the nursing staff, he called for an ethics consultation.

ETHICAL ISSUES

From a principled lens, those on the team who thought the boyfriend should be allowed onto the unit to get Ms. Campbell home did so on the basis that supporting her autonomy called for the patient to be able to exercise her moral right to have whomever she wanted to come see her. But autonomy does not always trump other relevant principles or factual considerations. In general, no one ethical principle can be held primary in every case, and will often conflict with others.

RECOMMENDATIONS

1. Do not allow the boyfriend into the hospital. Explain to the patient that the team will bring the patient downstairs to him when he arrived.
2. Have the patient tell her boyfriend to bring his

car to the front lobby entrance and that she will call him when she arrives at the lobby entrance.

3. Alert lobby security of this plan and inform them that they will be called when the patient tells the team that the boyfriend has arrived.
4. After the patient leaves the hospital, file an APS report.

REASONING

Patient autonomy is not unlimited. Although it is certainly an important ethical principle, there is not—nor has there ever been, nor is there ever likely to be—a process for deciding, in any particular situation, which of the ethical principles ought to take precedence over the others. In this case, the ethical principles in tension are (1) the autonomy of a patient and (2) justice, in terms of the safety of the staff, other patients, and hospital visitors when the patient's visitor poses a risk of harm to others. It is at this point, as for any ethical problem, that ethical judgment is required. It is up to those involved, in this case, with the assistance of the hospital clinical ethicist, to think through what is best.

Although this may puzzle some clinicians, it is only because they have learned *ad nauseam* the importance of supporting patients' rights to have visitors and to only have visitors whom they want to see. This ethical standard is a good default position, for example, when it comes to patients who might have family members who want to come, but whom the patients don't want to see.

This present case does not fit the default. The patient's boyfriend was seriously threatening. Justice (what is fair) requires that everyone in the hospital—patients, families, and staff—be kept safe in the workplace. Threats of violence simply must not be tolerated under any circumstance. This is the case whether or not a patient finds this behavior acceptable and wants such a person as a visitor—even if the visitor is documented to be the patient's power of attorney for healthcare (POAHC).

For too long, violent behavior, verbal or physical, towards healthcare workers has been ignored and/or tolerated. In an excellent review of this problem in the *New England Journal of Medicine*, Phillips[1] stated, "Health care workplace violence is an underreported, ubiquitous, and persistent problem that has been tolerated and largely ignored." For example, between 2011 and 2013, workplace assaults averaged approximately 24,000 per year, with nearly 75% in healthcare settings.[1] These events must be prevented.

Today, many hospitals have begun to take violence towards staff seriously. Although the majority of studies to date have been designed to quantify the problem, and according to Phillips, most of the studies employed weak methods, some point towards creating a hospital violence prevention climate[2] as a critical prevention strategy. From a systems perspective, this has important organizational ethics and policy implications. Organizationally, this means that all hospital systems such as education and training programs, incident reporting databases, and leadership attention must be realigned with a violence prevention point of view. Policies need to be developed and implemented that emphatically do not tolerate or ignore the problem.

For Ms. Campbell, a lack of tolerance for violence should have begun at the bedside. Staff's natural feelings of compassion for the plight of the patient should have been tempered by an appropriate concern for the safety for all involved. The patient's autonomous choices should have been superseded by the absolute requirement to protect staff.

References

1. Phillips JP. Workplace violence against health care workers in the United States. *N Eng J Med.* 2016; 374;1661-1669. 1661.

2. Arnetz J, Hambline L, Sudan S, Arentz B. Organizational determinants of workplace violence against hospital workers. *J Occup Environ Med.* 2018;60(8): 693-699.

submission guidelines

The *Journal of Hospital Ethics* adheres to the editorial standards and authorship criteria recommended by the International Committee of Medical Journal Editors (ICMJE). We welcome submissions of completed manuscripts as well as abstract paper proposals by authors with academic or professional expertise in relevant fields. Submissions on topics involving clinical bioethics broadly construed will be considered. Submissions are subject to a standard, double-blind peer-review and a rigorous internal review process. Please limit manuscript submissions to 3,500 words, and abstract paper proposals to 250 words.

For author instructions or further information regarding the *Journal of Hospital Ethics,* please contact Senior Editor Christian Carrozzo at JOHE@medstart.net

Letters to the Editor: All comments are welcome and should be addressed to the Editor-in-Chief, Evan G. DeRenzo, PhD, at *JOHE@ medstar.net.* Letters to the editor should not exceed 500 words.

editorial policy

All contributions to the *Journal of Hospital Ethics* will be reviewed for publication with the understanding that they are not under consideration, accepted, or published elsewhere. All submissions will be physician peer reviewed, with peer reviewers of other disciplines added as appropriate. The final decision on acceptance or rejection will remain at the discretion of the editorial group of the journal. The authors of all material accepted for publication will be required to assign copyright to the publisher.

Editorial Disclaimer. The contents of the *Journal of Hospital Ethics* (*JOHE*) represent only the opinions of the authors and editorial group of *JOHE.* Because *JOHE*'s goal is primarily two-fold, to be educational and to offer practical ethics guidance to busy hospital clinicians and related personnel, the contents are intended to be useful and thought provoking. All feature articles in *JOHE* are physician peer reviewed. Also, all copy is internally reviewed by our Medical Editor and members of our editorial group. Personal identifying information in cases is either removed or changed to obscure patient, surrogate, and clinician identities. Additionally, although many of the cases come from actual experience, when they are presented in *JOHE* they are more accurately thought of as composites. In that sense, all are hypothetical and created strictly for teaching purposes. Just as importantly, we recognize that the more complicated an ethical issue, the more likely it is that persons of good judgment will disagree. Thus, the opinions and perspectives offered in *JOHE* reflect only the views of the authors and editors, and do not necessarily represent the views of others within the MedStar Health system or of any other institution or organization with which any of the *JOHE* editorial group are affiliated.

Photocopy and Reprint Permissions:
No part of this journal maybe reproduced by any process or technique without written permission. For reprint permissions, contact *christian.carrozzo@medstar. net.*

subscribe

The *Journal of Hospital Ethics* is published by the John J. Lynch, MD Center for Ethics. Subscriptions are by volume; each volume consists of 3 issues.

Individual (Print & online personal access): $50*
Institutional (Print & online institutional access): $100
* ASBH members: $42.50

Back issues: $20.00 per issue subject to availability.

Subscribe now by visiting medstarwashington.org
Click on: Our Hospital, The John J. Lynch, MD Center for Ethics, Journal of Hospital Ethics, Subscription Information. Complete the electronic form and become a subscriber today.

Contact us: JOHE@medstar.net

education & awards

The Clinical Ethics Immersion is the original experiential and simulation-based education program in clinical bioethics. This program is held biannually and is hosted and directed by the faculty and staff of the John J. Lynch, MD Center for Ethics. This four-day course focuses on the institutional development of bioethics programming and practical reasoning in clinical ethics consultation. Participants round with senior clinical ethicists in intensive care units, respond to case consultation requests, and engage in discussion with invited lecturers and resident instructors. In addition, participants engage in simulated consultations with trained actors in MedStar's state-of-the-art Simulation Training Environment Laboratory.

The Ethics and Clinical Social Work (ECSW) program is hosted and directed by the John J. Lynch, MD Center for Ethics, and accredited by the National Association of Social Work for bioethics continuing education credits. The ECSW trains social workers to recognize the ethical significance of complexities that arise in the care of hospital patients, develop an understanding of ethical concepts as they relate to social work, and identify opportunities to work collaboratively with clinical ethicists. Combined case study and lecture allow participants to develop skills in ethical analysis.

The John J. Lynch, MD Moral Courage Awards, named after the founder and Medical Director of the Center for Ethics, is a biennial program in recognition of individuals who have demonstrated courage when acting against difficult and ethically challenging circumstances. Established in 2010, this program was designed as an opportunity for hospital leaders to model through exemplification the virtues they consider central to creating and sustaining an ethically sound climate in the hospital. For more information, contact the program director, Kahlia Keita at *kahlia.t.keita@medstar.net*

MedStar Washington
Hospital Center

John J. Lynch, MD Center for Ethics
MedStar Washington Hospital Center
110 Irving Street, NW
EB3018
Washington, DC 20010