VOLUME 10 NUMBER 3 DECEMBER 2024

JOURNAL OF HOSPITAL ETHICS

THE JOHN J. LYNCH, MD CENTER FOR ETHICS

ROUNDING WITH THE EDITOR

The Optimal Balance
Evan G. DeRenzo, PhD

FEATURES

A Practical Approach Towards Ethical A.I. Implementation in the Healthcare Community
Lindsey Jarrett, PhD; Matthew Pjecha, MS; Brian Carter, MD, FAAP; Gerald Wyckoff, PhD; and Mark Hoffman, PhD

Artificial Nutrition and Hydration in the Setting of Advanced Dementia: Impact of a Hospital Policy
Lynette Cederquist, MD; Ian Neel, MD; Daniel Callies, PhD; Ariadne Nichole, BA; Emily M. Ostler, BA; Khang Tong, MD; and Lin Liu, PhD

Business Ethics at the Bedside: Tracheostomy Patients, Dialysis Policies, and Creative Problem Solving
Antoinette R. Esce, MD; Ashley Dorneden, MD; Nathan H. Boyd, MD; and Jonathan Bolton, MD, MA, MPhil

Examining the Clinical Ethicist's Role as Educator
Joseph Raho, PhD; Federico Nicoli, PhD; and Paul J. Cummins, PhD

MedStar Health

JOURNAL OF HOSPITAL ETHICS

THE JOHN J. LYNCH, MD CENTER FOR ETHICS

MedStar Health

VOLUME 10 NUMBER 3 DECEMBER 2024

JOURNAL OF HOSPITAL ETHICS
THE JOHN J. LYNCH, MD CENTER FOR ETHICS

CONTENTS

CONTRIBUTORS 182

ROUNDING WITH THE EDITOR

The Optimal Balance
Evan G. DeRenzo, PhD 186

FEATURES

A Practical Approach Towards Ethical A.I. Implementation in the Healthcare Community
Lindsey Jarrett, PhD; Matthew Pjecha, MS; Brian Carter, MD, FAAP; Gerald Wyckoff, PhD; and Mark Hoffman, PhD 189

Artificial Nutrition and Hydration in the Setting of Advanced Dementia: Impact of a Hospital Policy
Lynette Cederquist, MD; Ian Neel, MD; Daniel Callies, PhD; Ariadne Nichole, BA; Emily M. Ostler, BA; Khang Tong, MD; and Lin Liu, PhD 201

Business Ethics at the Bedside: Tracheostomy Patients, Dialysis Policies, and Creative Problem Solving
Antoinette R. Esce, MD; Ashley Dorneden, MD; Nathan H. Boyd, MD; and Jonathan Bolton, MD, MA, MPhil 212

Examining the Clinical Ethicist's Role as Educator
Joseph Raho, PhD; Federico Nicoli, PhD; and Paul J. Cummins, PhD 219

MedStar Health

CONTRIBUTORS

Jonathan Bolton MD, MA, MPhil is a Professor of Psychiatry at the University of New Mexico School of Medicine. He also directs the Health Sciences Center's Institute of Ethics and is the Jack and Donna Rust Endowed Professor in Ethics.

Nathan H. Boyd, MD is a Professor, Clinical Educator Track with the Department of Surgery. He received his medical degree at the University of New Mexico (UNM) School of Medicine, completed residency in Otolaryngology-Head and Neck Surgery at Kaiser-Permanente in Oakland, and completed a fellowship in head and neck oncology and microvascular reconstruction at the University of Iowa. Dr. Boyd is currently the director of the UNM Thyroid and Parathyroid Surgery Program. He served a two year term as Chief of Staff ending in 2022. He is currently interim Chair of Dental Medicine and a member of the UNMH Board of Trustees.

Daniel Callies, PhD is Assistant Clinical Professor in the UC San Diego School of Medicine and the Ethics Program Manager for the UC San Diego Health System. Prior to joining UCSD, he was the Senior Clinical Ethics Fellow for the UCLA Health System, a Postdoctoral Scholar at UCSD's Institute for Practical Ethics, the Bernheim Postdoctoral Fellow in Social Responsibility at the Université Catholique de Louvain, and a Predoctoral Research Fellow at Harvard University. He earned his PhD from Johann Wolfgang Goethe University in Frankfurt, Germany.

Brian Carter, MD, FAAP is a pediatrician and pediatric bioethicist who practiced neonatology for 30 years. He currently sees Neonatal ICU graduates in a follow-up clinic at Children's Mercy-Kansas City to monitor their development and manage their often-complex medical needs. He is an academician and serves as the Sirridge-Family Endowed Professor of Medical Humanities and Bioethics and Chairman of the Dept. of Medical Humanities & Bioethics at the University of Missouri-Kansas City School of Medicine. He has worked in clinical ethics and performed consultations for over 30 years.

Lynette Cederquist, MD is Clinical Professor of Medicine at University of California San Diego. She is a board certified internal medicine doctor who serves as the Director of the Clinical Ethics Program for University of California San Diego Health. As part of her role she chairs the hospital ethics committee and serves as an ethics consultant. Dr. Cederquist earned her MD degree at Oral Roberts University School of Medicine. She subsequently completed her residency in internal medicine at the UCSF affiliate program in Fresno California. ***lcederquist@health.ucsd.edu***

Paul J. Cummins, PhD is an assistant professor of Bioethics in the Lewis School of Health Sciences at Clarkson University. At Clarkson he is the site principal investigator for a National Institutes of Health-Fogarty Internation Center funded program to develop research ethics capacity in the Caribbean: Caribbean Research Ethics Education Initiative and he was the project director for the National Endowment for the Humanities Connections funded project to develop an interdisciplinary minor in bioethics. Dr. Cummins earned a PhD in Philosophy from The Graduate Center, CUNY, and he has held faculty appointments at Lehman College, CUNY and Icahn School of Medicine at Mount Sinai. Dr. Cummins' research interests are bioethics education, clinical ethics, conscientious objection, and climate change.
pcumins@clarkson.edu

Ashley Dorneden, MD is from Albuquerque, New Mexico, where she completed medical school and otolaryngology head and neck surgery residency at the University of New Mexico. She currently practices as a general otolaryngologist.

Antoinette R. Esce, MD is a head and neck surgeon and current palliative medicine fellow at the Icahn School of Medicine at Mount Sinai hospital. She received a B.A. in economics and health policy as well as her medical degree from the University of Rochester. She completed residency in otolaryngology head and neck surgery at the University of New Mexico and will complete additional specialty training in head and neck surgical oncology at Memorial Sloan Kettering Cancer Center next year. She is interested in how patients and surgeons make decisions together and developing processes of care that support patient centered outcomes. ***ant.esce@gmail.com***

Mark Hoffman, MD serves as the Chief Research Information Officer (CRIO) for Children's Mercy and the Children's Mercy Research Institute. Dr. Hoffman's role is to accelerate and improve all types of research at the Children's Mercy Research Institute through resources such as data, applications and technology. Dr. Hoffman earned his BA in Molecular Biology from William Jewell College and his doctorate in Bacteriology from the University of Wisconsin-Madison, with a minor in Biotechnology. As Vice President of Research and Genomics at Cerner, he led the development of multiple large-scale software and data initiatives. In 2013, Dr. Hoffman joined the faculty at the University of Missouri Kansas City (UMKC) in the Departments of Biomedical and Health Informatics and Pediatrics and founded the Center for Health Insights at UMKC. He serves as Professor at UMKC and has an appointment as Research Professor in the Department of Pediatrics at the University of Kansas Medical Center, where he is an Associate Member of the Kansas University Cancer Center. He is also an adjunct Professor at Kansas City University. Dr. Hoffman joined Children's Mercy full time as CRIO in 2016. He leads a team of experts in software development, high performance computing, bioinformatics, data science and a group of analysts and project managers responsible for vendor provided research systems. He is a leader in AI governance at CMH and is a member of the Ethical AI Advisory group for the Center for Practical Bioethics (CPB). In 2024 he was recognized by the CPB as an" Ethics Champion" for his contributions to the Ethical AI initiative. He is an inventor on 25 issued patents, is a Fellow in the National Academy of Inventors and has received the highest awards for alumnae of William Jewell college and the Raytown School District. Hoffman serves as co-lead of the Frontiers CTSI Informatics Core and continues to conduct research using massive de-identified electronic health record data resources. He currently seeks innovative approaches to using informatics and data to improve health and research equity.

Lindsey Jarrett, PhD is the Vice President of Ethical AI Services at The Center for Practical Bioethics. Her team focuses on ethical decision making in technology development and how it impacts healthcare organizations, those they serve, and society at large. Dr. Jarrett has extensive experience in program management, research, and executive consultation across the non-profit, academic, for-profit, and government sectors. As a social scientist she has worked to provide evidence-based interventions, practices, and processes to underserved communities as they interact with the numerous systems (e.g., healthcare, education, community programs) across their life span. Her work as a clinical researcher has also improved clinical decision making for providers in the areas of opioid safety, infection control, readmission prevention, maternal mortality, social determinants of health, and post-acute care. Her work across various sectors has created several collaborative initiatives and projects to positively impact the field of clinical research and assist stakeholders in implementing evidence-based practices across healthcare, education, and program development. Dr. Jarrett holds a PhD in Therapeutic Science from the University of Kansas and currently resides in Kansas City, Missouri. ***ljarrett@practicalbioethics.org***

Lin Liu, PhD is Associate Professor of Biostatistics at Herbert Wertheim School of Public Health and Human Longevity Science in UC San Diego (UCSD), and a Statistician at the VA San Diego Healthcare System. She is the Director of the Biostatistics, Epidemiology and Research Design (BERD) unit of UCSD Altman Clinical and Translational Research Institute (ACTRI), the Associate Director for UCSD Moores Cancer Center Biostatistics shared resource, and the lead biostatistician for Health Service Research and Development (HSR&D) unit at VA San Diego. She is also the Director of MS Biostatistics program at UCSD.

Ian Neel, MD is a board-certified internal medicine doctor who specializes in caring for older adults. He serves as the clinical lead for the Geriatric Medicine Consult Service at Senior Behavioral Health at UC San Diego Health. He also is a consultant for UC San Diego's Brain Health and Memory Disorders program. He additionally serves as the co-chair of the Alzheimer's Project of San Diego. Dr. Neel completed a fellowship in geriatric medicine and a residency in internal medicine at UC San Diego School of Medicine, where he also earned his medical degree.

Ariadne Nichol, BA is a fourth-year medical student at UC San Diego School of Medicine. She completed her undergraduate degree in Human Biology with Honors in Ethics in Society at Stanford University and has done research with the Stanford Center for Biomedical Ethics.

Federico Nicoli, PhD is a Clinical Ethicist in the Hospices and Rehabilitation Departments at the Teresa Camplani Foundation in Brescia and Cremona (Italy). He works as Clinical Ethicist in the Neonatal Intensive Care Unit at ASST Spedali Civili in Brescia. Dr. Nicoli is also a member of the Center for Clinical Ethics at the University of Insubria in Varese. He obtained a Philosophy Degree at University of Milan and a Ph.D. in Medicine and Human Sciences at Insubria University with a dissertation on "A method in Clinical Ethics Consultation between normative theories and applied ethics". Dr. Nicoli's research interests include the clinical ethics consultation, end-of-life issues, the ethics of palliative care, organ transplantation, rehabilitation and ethics in neonatal intensive care. ***federico.nicoli82@gmail.com***

Emily M. Ostler, BA is a third-year medical student at UC San Diego School of Medicine. She completed her undergraduate degree at Stanford University and has done research with the Stanford Center for Biomedical Ethics.

Matthew Pjecha, MS is a consultant and co-chair of the City of Kansas City Emerging Technology Board. He works at the intersection of healthcare, policy, and emerging technology, specifically on responsible implementation of new technologies in the healthcare sector.

Joseph A. Raho, PhD serves as Clinical Ethicist at the University of California, Los Angeles (UCLA) Health Ethics Center. He is also Assistant Clinical Professor of Pediatrics in the David Geffen School of Medicine at UCLA and Vice-Chair of the UCLA Santa Monica Ethics Committee. Additionally, he has held adjunct faculty appointments in the Masters of Bioethics programs at Creighton University and Loyola Marymount University. He obtained a Ph.D. in philosophy, specializing in bioethics, from the University of Pisa, Italy (2014), and completed a post-doctoral clinical ethics fellowship at the UCLA Health Ethics Center (2016). Prior to graduate school, he worked (2006 – 2009) with the President's Council on Bioethics in Washington, DC. Dr. Raho's research interests include the professionalization of clinical ethics, end-of-life issues, pediatric bioethics, the ethics of palliative care, and organ transplantation.
JRaho@mednet.ucla.edu

Khang Tong, MS is a graduate from UC San Diego with a Master of Science in Biostatistics where he also attained his Bachelor of Science in Applied Mathematics. Khang joined the Altman Clinical and Translational Research Institute Biostatistics, Epidemiology and Research Design group in 2023 where he has been collaborating with biomedical researchers on data analysis and consultation.

Gerald Wyckoff, PhD is Director of Research and Graduate Studies/Chair and Professor, Pharmacology and Pharmaceutical Sciences at the University of Missouri-Kansas City. Modern drug discovery using silico techniques is about sifting through large amounts of data to find signals in a sea of noise and developing methodologies that do this efficiently. Dr. Wyckoff's educational background is as a molecular evolutionary geneticist, finding faint signatures of positive selection in a sea of genomic noise. This led him to become involved with large scale genomic, and later proteomic, projects utilizing a bioinformatic framework. At UMKC Dr. Wyckoff has developed collaborations with the structural biology faculty, in part to extend his knowledge of how to apply large-scale screening techniques to structure-based problems. These problems have as a common theme the development of tools to make sense out of large-scale data where noise is high, and signal is low. As part of his work, Dr. Wyckoff provides mentorship to graduate students, including in ethics related to research and mentorship.

ROUNDING WITH THE EDITOR

The Optimal Balance

Evan G. DeRenzo, PhD

Dear Readers,

Welcome to Volume 10, No. 3 of the *Journal of Hospital Ethics* (JoHE). This issue presents an array of important topics facing many in the field of clinical ethics. First, I want to focus on one that has bedeviled the field since it began. That is, what is the optimal balance between the clinical consultation obligations of a hospital clinical ethicist (CE) and her teaching activities and other assigned responsibilities? This question is one with which the field has struggled since its inception. I have personally devoted much consideration to it.

Raho, Nicoli, and Cummins in their article, "Examining the Clinical Ethicist's Role as Educator" do an excellent job of 1) sorting through where we are now in terms of what needs better assessment and, possibly, additional training for CEs, and 2) the degree to which we ought to circumscribe the enthusiasm of some CEs to ascribe benefit to the educational impact of much of the semi- and informal teaching that CEs perform. I couldn't agree more.

In addition to thinking that semi- and informal methods of teaching do play a positive role in the clinical ethics education of clinicians, and in elevating the general ethical climate of a hospital, here I concentrate on one model of such semi- and informal education. That is, when CEs join specific units for regularly scheduled clinical rounds, given my career-length interest in the potential benefits of having a CE join rounds that are part of the daily rhythm of a particular hospital unit.

Whenever I introduce myself to someone professionally, outside of clinical ethics consultation, I start with, "Hi, I'm Evan DeRenzo and I identify myself as a 2nd generation clinical ethicist." Starting by making note of the timing of my entry into the field, it is clear that I have had the benefit of learning from those who shaped the field and the privilege of living long enough to see CEs well-integrated into the hospital setting where they are (ordinarily) welcomed as eagerly anticipated partners. Especially in today's larger hospitals, CEs are normalized into a hospital's clinical program, as are pharmacists and members of the palliative care team.

While the clinical, consultative responsibilities have always consumed most of the time of the CE, my position has been that education of the clinical teams is also the job of the CE. First, there will never be enough CEs in a hospital to be present for every patient, family, or provider in need and second, because it is well established that ethics education ought to be a part of the training of physicians and nurses.[1-3]

If one believes that finding the optimal balance between the roles of clinical ethics consultation and clinical ethics educator is important, one place to merge the two, thus giving time to both, is to have CEs join regularly scheduled clinical rounds. While it is true that having a CE spend an entire morning every week attending, e.g., clinical rounds in an intensive care unit, is resource intensive, there are a range of benefits that such time allocation may produce. Raho et al. innumerate some; others are less often mentioned but may be just as important. These can be clumped as relationship-building benefits. Taking for granted that all clinicians want to provide excellent care to their patients, once the CE has offered some remark that has genuinely helped the medical team with an ethically complex patient, the CE has made a colleague for life.

Moreover, if it is the attending physician who has been helped by the CE and she lets the rest of the team know how much she appreciates having the CE join rounds, she is conveying to the rest of the team that it can be beneficial to talk with the CE. This can make the rest of the team more comfortable bringing issues in care to the attention of the CE, which often leads to increased consultations. If the CE has openly facilitated and/or supported a nurse in speaking up about an ethically challenging or morally distressing circumstance, that CE has likely strengthened the trust between herself and many on the nursing team. Joining work rounds not only familiarizes the CE with every patient on the unit that morning, it provides a venue that maximizes all members of the team and the CE getting to know each other.

Like so much in life, effective workplace performance is connected to the relationships one builds within the organization. When a CE attends clinical rounds on a routine basis, that conveys respect by broadcasting, "I want to hear how you present your patients, not just be someone who talks all the time." Attending consistently conveys to the staff that the CE is committed to assisting that particular team. By conveying respect and

commitment, the CE lays the foundations for relationships that can last for years to everyone's benefit.

The authors' call, at least indirectly, for empirical evidence of the sorts of claims I've made here in terms of the benefits of rounding, is research I couldn't support more. But there will be no research if CEs don't think the time commitment is worth figuring out how to assess the objective use of this approach in balancing clinical with educational objectives.

While the question Raho et al. raise dates back to the beginning of the field of clinical ethics, the questions raised by Cederquist et al. and Esce et. al., are not far behind. As the field of clinical ethics matured, it didn't take long to realize that there were going to be many ethically-relevant hospital policies that might already exist at any given institution, while others would be new and require not only appropriate drafting, but a hospital-wide rollout followed by education efforts likely best handled by CEs.

In the Cederquist et al. article, "Artificial Nutrition in Advanced Dementia: Impact of a Hospital Policy," the authors present a study on how implementing a new policy can assist ethically-minded clinicians in their clinical judgement. Progress in clinical practice is sometimes not well-known throughout the relevant medical community. When some practitioners are unaware of new standards-of-practice in their field, these data demonstrate the usefulness of creating hospital policies that advance adherence to improved care standards for special populations.

This article also strikes a special chord for me. Having volunteered in nursing homes from the time I was 14 through the completion of my doctoral degree and fellowship, I went from writing letters for the cognitively-intact elderly who could no longer write, to volunteering in the locked dementia units of nursing homes in Illinois, Massachusetts, Virginia, and Maryland. I not only witnessed the rise of CEs, but the standards-of-practice for the administration of nutrition and hydration for patients with advanced dementia also changed radically during these years. That is, the treatment assumption, even in relation to patients with dementia, used to be that artificial nutrition and hydration (ANH) would be provided, administered through feeding tubes. By the time my career moved from gerontology to bioethics, practice standards had changed to recommendations of withholding ANH from patients with advanced dementia.

Getting the word out about changes in consensus statements regarding treatment practices into individual, acute-care hospitals is often not a straightforward task. Who better to teach clinicians about such policies than CEs who, by my time, had answered the question in the affirmative that CEs do have an important role to play in teaching about hospital policies. And although it may be a leap of faith to believe that the teaching of CEs produces changes in hospital recommendations and treatment practices, it will be interesting to see if further research confirms this study's conclusions.

Turning to the Esce et al. article, "Business Ethics at the Bedside: Tracheostomy Patients, Dialysis Policies, and Creative Problem Solving," it is always a pleasure when we find that we have more than one accepted paper that, even if only tangentially, touches on similar topics within a single journal issue. Esce et al. address how involving CEs with policy work is as important a role as is that of clinical ethics consultation and patient-specific education, by focusing on the complications that can occur because of business practices in the outpatient setting. The authors illustrate where business pressures on both the outpatient and inpatient worlds can collide to impact, and often reduce, the quality of direct patient care.

Although this may be a contemporary problem, exacerbated by the disjointedness of a United States (US) privatized health care system, it also dates back to the beginning of the field of hospital, clinical ethics. At that time, the US healthcare system was also primarily privatized, with acute care hospitals rapidly moving from a model of charity care to one centered on research and science. The management and funding of these highly technological hospitals withstood both internal and external pressures. In the intervening years, business constraints have simply become more marked.

The article I address last is that by Jarrett et al. Artificial Intelligence (AI) was not much talked about in the medical world at the dawn of clinical ethics. Today, AI is talked about everywhere in medicine. From robotics in surgery to assisting in diagnosis, AI is moving into medicine at an ever-quickening pace. Many medical publications have policies about the use of AI, as does JoHE. Jarrett et al. make a strong case for how to set up guardrails to mitigate against some of the ethical risks AI may pose. Even though awareness of, and attempts at balancing the risks and benefits of AI is a truly contemporary problem, it brings us back to where we started.

Both Raho et al. and Jarrett et al. call for skepticism when thinking about benefits; whether it is

being overly enthusiastic about assumed benefits that have yet to be empirically well-assessed, or about the wonders of AI, the reflective CE should remember that maintaining one's skepticism is an important habit. In fact, being skeptical is a quality to which we all might well aspire.

Sincerely,

Evan G. DeRenzo, PhD
Editor-in-Chief
Journal of Hospital Ethics
John J. Lynch, MD Center for Ethics
MedStar Health, Washington, DC

REFERENCES

1. Brashers V, Haizilip J, Owen JA. The ASPIRE Model: Grounding the IPEC core competencies for interprofessional collaborative practice within a foundational framework. *J Interprof Care* 2020 Jan-Feb;34(1):128-132.

2. Cummings CL. Teaching and assessing ethics in the newborn ICU *Semin Perinatol.* 2016 Jun;40 (4):261-9.

3. Vig EK, Merel SE. Ethics education during palliative medicine fellowship. *Am J Hosp Palliat Care* 2019 Dec;36(12):1076-1080.

FEATURES

A Practical Approach Towards Ethical A.I. Implementation in the Healthcare Community

Lindsey Jarrett, PhD; Matthew Pjecha, MS; Brian Carter, MD, FAAP; Gerald Wyckoff, PhD; and Mark Hoffman, PhD

ABSTRACT: The application of Artificial Intelligence (AI) enabled tools is growing rapidly. These systems are being used to support complex decisions that can add value to society. In healthcare settings, AI assists in detecting, predicting, and monitoring health status, conditions, and behavior and assists in processes related to direct healthcare delivery. Amidst excitement, there is also growing concern around how AI can pose significant potential risk and harm across healthcare systems. How ought organizations, regulators, software vendors, and individual practitioners respond to these risks while still utilizing and appreciating the benefits of these technologies? This is the key ethical problem addressed by this paper. A solution is urgently needed in the AI space because practitioners and healthcare leaders are determined to realize the benefits and efficiencies of these technologies right now. Yet, standard processes that ensure human touchpoints, thoughtful consideration, and application of ethical principles to algorithm utilization are often underutilized or completely absent. This paper outlines an approach that brings communities together across healthcare IT, academia, ethics, and community advocacy to establish common foundations, articulate a framework for considering AI-enabled technologies, and train developers and purchasers of AI-enabled technologies to reflect on the ethical dimensions of these capabilities more thoroughly. We propose that a process and standards to guide the application of ethical considerations will offer guardrails in the use of this technology, heighten beneficence and nonmaleficence, introduce much-needed respect for autonomy, and enable paths for justice, especially among patients and families who will be most impacted by the inaccurate, inconclusive, or biased results.

KEYWORDS: Artificial Intelligence; Healthcare Community; Information Technology; Organizational Ethics

Introduction

Artificial intelligence (AI) is increasingly integrated into our digitally dependent lives. Social media algorithms track behavior and preferences, mobile devices recommend routes before they are requested, credit and housing recommendations are generated by complex systems, vehicle safety monitoring can prevent accidents, retail consumption patterns lead to product recommendations, and political and social interactions are tracked.[1] Recently, the launch of ChatGPT in 2022 rapidly accelerated the adoption of large language models (LLMs) for a wide variety of AI applications, including the generation of text that is increasingly indistinguishable from work authored by a human. The use of tools such as ChatGPT across various industries has highlighted how quickly AI can penetrate our systems, both positively and negatively.

We are at the beginning of a new era of automation and decision-making, often called the fourth industrial revolution.[2,3] As humans navigate new technologies, such as AI, there is an opportunity to ensure that they are stabilized by human morality, in order to fulfill their promise and limit their perils.[4] One of the systems in which human morality is of particular interest is the system accountable for the delivery of healthcare services to human patients. In most major care settings, especially in large healthcare organizations that have the resources to procure and deploy algorithms, AI -enabled technology may already be in widespread use. In healthcare settings, AI has shown that it can assist in detecting, predicting, and monitoring health status, conditions, and behaviors. It also may assist in processes related to direct healthcare delivery. While AI systems serve as powerful tools for automation, pattern recognition, classification, and risk prediction, they also pose significant potential risk of harm.[5] It is in this risk-benefit evaluation that has left those working in healthcare in a quandary about whether to advocate for or against the use of AI. This has created an opening for ethicists and social scientists to provide their expertise as part of a collaborative solution.

Ethicists have a clear stake in the use of AI in healthcare, as they have been integral in complex decision making and policy formation in healthcare. Therefore, the foundational principles of biomedical ethics[6,7] may provide a starting framework to employ in the rapidly evolving application of AI in healthcare,[8] because it could address the need to employ standards of right and wrong in how AI is developed and used.[9] However, there is a need to further evaluate the practical application of ethics, especially with emerging technology and the implications it has on our society. While traditional approaches to ethics have focused on individuals, actions and consequences, there is a need to evaluate structures and process-

es, and to examine the social arrangement for making decisions.[10] This social ethics paradigm could be particularly useful for the group of people working in healthcare technology who are now tasked with creating new processes of decision making for the application of AI across their industry. By leveraging a foundation of social ethics there may be more room for interdisciplinary and community-based discussions that can create a comprehensive response to the complex problem space of AI in healthcare.

We describe the lessons learned from our work with community-based participatory action on the ethical use of AI from 2021-2023. We present an iterative approach founded on community participation, compare it to related process improvement tools, and report on a community pilot. We describe the purpose of community-led design, specifically in the development of a contextual curriculum that bridges traditional clinical ethics principles and healthcare technology best practices. We outline process improvement strategies that reflect the complex lifecycle of technology design, development, implementation, and use, which exist in healthcare AI-enabled products. The recommendations provided focus on community participation and are designed to connect the distinct levels of decision-making present throughout the lifecycle of AI in healthcare, from design to use.

Background

This work is highly connected to already existing regulations, policies, standards, frameworks, and recommendations that exist in healthcare and healthcare technology to date. This connection is crucial, as healthcare is a highly regulated and standardized system, especially as it operates in the U.S.. When any new technology is introduced in a health care setting there is a need to examine how foundational ethical principles can fit into the development of standard operating procedures and how they can be extended beyond regulated compliance.[f1] We argue that current regulations, although necessary, may not be adequate for the new challenges we face with AI. Historically, systems such as the electronic health record (EHR) are governed by established regulations for privacy and security, namely the Health Insurance and Portability and Accountability Act (HIPAA). Similarly, informed consent rules are strong and well-developed.[12,13] Recently, there has been focused attention on a currently unregulated piece of technology development - the bias that lay at the base of the rules used in all types of algorithms and the decisions that may come from their use. There is growing recognition that such rules may need to be revised to create more ethical, equitable, and reliable large data sets and tools to solve complex problems in healthcare. This area of focus has activated and accelerated policy changes for AI development and use. Specifically, the Department of Health and Human Services Office of Civil Rights (OCR) published new requirements[14] to help protect people from discrimination when AI tools are used in healthcare.[15] Additionally, there have been growing initiatives and recommendations to inject ethical considerations in algorithmic development.

Over 80 AI Ethics related initiatives have published reports describing high-level ethical principles, values, and requirements for the development and deployment of AI.[16] Some of these initiatives have been used to inform healthcare policy, however there is little evidence that they offer practical guidance for ethical AI. For example, while the National Academy of Medicine published a "Healthcare Artificial Intelligence Code of Conduct" focused on privacy, ethics, accountability, and applicability[17] and other initiatives have been launched,[18] the practice of ethics and the development and adoption of AI-enabled systems appear to be largely disconnected. Currently, research and the recommendations that follow focus on specific problems from a specialist point-of-view and are not necessarily geared towards developing generally applicable ethical frameworks – particularly from the perspective of shared, collaborative decision-making in healthcare.[19]

Recommendations have often been situated in source data issues, perpetuation of biases, and the opacity of AI systems, all of which are important considerations. Existing biases are already evident in healthcare and contribute to biased and negative patient outcomes[20] which are then data points used by AI systems. These AI systems require large data sets to develop formal models[21] and often mirror biases in the data used to train them. For example, ChatGPT-4 was recently demonstrated to include race, gender, and ethnicity-based stereotypes.[22] These biases can amplify disparities related to racial, ethnic, gender, and other demographics, deepening existing societal inequities because the source data did not adequately represent the population and contain inherent limitations.[23] These limitations are often to the detriment of people of color and others who have been marginalized in healthcare and underrepresented in research.[24] AI outputs are given a degree of deference from human end-users that often perceive

such outputs as objective, having been produced by a machine rather than a person. AI systems are often opaque, defying attempts to remove bias. Without attention to ethical guidance, and its intentional application to AI, application of AI at scale may simply generate and perpetuate both old and new biases seen in healthcare systems, and there is little guidance on how to use these tools in healthcare without doing so.[25]

Despite these risks, it is well documented that healthcare may see numerous benefits in the appropriate use of AI, and "big data" research has significant opportunities to help mitigate health disparities.[26] As AI becomes more involved in the delivery of healthcare, it is imperative that the associated ethical risks be addressed so the benefits can be safely appreciated while upholding ethical principles. Regulation from the highest governing institutions may be necessary as a long-term solution, especially with increased innovation, however, the healthcare industry is currently left with educating, equipping, and monitoring their technology decisions. This necessitates the creation of ethical industry standards for the design, development, use, and monitoring of AI for healthcare to contribute to the long-term success and value of AI in medicine. As these industry standards (within healthcare and technology alike), are still emergent, organizations are left to independently establish a regulatory framework. How ought organizations, regulators, software vendors, and individual practitioners respond to these risks while still utilizing and appreciating the benefits of these technologies? This is the key ethical problem that the Ethical AI Initiative is working to address.

The Ethical AI Initiative began in 2019 and has worked with regional stakeholders and community leaders to understand the impact of AI in healthcare to develop resources and implement solutions for healthcare designers, developers, and users of AI. In addition to the collaborators in partnering organizations, our core team consisted of a mix of community leaders, technology practitioners, advocates, researchers, and healthcare providers with expertise in data science, healthcare IT leadership, care delivery, policy, change management, actuarial science, clinical research, software engineering, and disability services. Our methods for working with communities included the formation of a community advisory board, two current state assessments, semi-structured interviews with multiple community healthcare leaders, virtual meetings, two in-person workshops, post workshop satisfaction surveys, and collaborative planning meetings with stakeholders. These methods provide a practical framework for practitioners interested in creating future programming that is centered around ethical AI in healthcare.

Community Driven Design and Pilot

The Ethical AI Initiative employed a novel approach devised by healthcare IT practitioners, stakeholders, and leaders primarily residing in the Midwest region providing practical interventions focused on ethical problems that are seen at various stages throughout the AI lifecycle within healthcare. Due to these issues, caused primarily by inequitable power dynamics in healthcare and healthcare IT, we saw a need to leverage a community-based participatory model as a foundational design principle, instead of a more traditional top-down model.

Community-Based Participatory Design

Community-based approaches have long been used in the implementation of public health promotion and services, including programs centered on creating new products, tools, and services intended to improve health outcomes. Often, they have been designed to target health outcomes related to specific conditions or concerns such as smoking cessation and diabetes.[27] With the advent of Patient Centered Outcomes Research Initiatives (PCORI, in the early 2010s),[28] advances in the development of learning health networks began to identify every patient encounter as a data point. A growing body of literature emerged touting the efficacy of expanding methodologies to include more social sciences-based approaches. Community-based Participatory Research (CBPR) models afford patients and the community at-large the platform to demonstrate how varied personal interests and engagement play a key role in achieving systemic change. These models are not merely a set of methods but, instead, are an overall research orientation which fundamentally and consciously changes power relationships to eradicate the demarcation between those working on the study and those getting evaluated.[29] Further, community-based models embrace collaborative efforts among a diverse array of stakeholders who gather and use data to build on community priorities for multilevel strategies that improve health and social equity.[30]

Although limited in scope, community-based research offers as much promise outside public

health. Compared to other traditional research approaches, this method puts community members in leadership and decision-making positions. By participating in the development and design of interventions, diverse stakeholders contribute to reducing biases. To date, there has been little community-based work done in developing ethical AI frameworks; even though existing methods for review of patient-involved work (for example, Institutional Review Board guidelines) almost always demand community participation.[31] While the Ethical AI Initiative did not engage in traditional research activities, it did focus on community-based participatory action methodology and employed similar methods for the same reasons that they are useful in other settings. Using a combination of clinical ethics principles, social science approaches, an evidence-based learning pedagogy, and community participatory action techniques, the work of the Ethical AI Initiative offers a novel approach to solve the issues that arise with AI in healthcare, as other initiatives may focus heavily on technical solutions alone.[32]

Ethical AI Advisory Council

Community advisory boards (CABs) or groups (CAGs) are often a part of a community-based participatory design, especially in the early phases of a project.[33] The work of the Ethical AI Initiative began in 2019 as a community workshop with over 50 stakeholders impacted by the decisions made in healthcare IT. The workshop led to several community leaders requesting to engage in the development of practical solutions. The Ethical AI Project Team began recruitment of its interdisciplinary and intersectional group of community members for the Ethical AI Advisory Council in 2021. The recruitment process also included a matrix which examined personal and professional characteristics (e.g., gender, race, title, company) as well as expertise, power, and influence, intended to promote diversity in membership. The members were intended to be a representation of the community of designers, developers, users, and community members impacted by healthcare technology.

This group began with a core group of 20 members across healthcare technology development, healthcare leadership, patient advocacy, healthcare delivery, scientific discovery, and technologists. Industry experts in AI and stakeholders impacted by AI provide detailed insight into how ethical problems emerge in the context of healthcare. Those members with experience in healthcare technology offered practical guidance (informed by their unique roles in AI, healthcare and research, advocacy, current industry practices, and institutional norms) for how to address these problems. Additionally, they offered diverse input on framing ethical issues in a way that allows them to apply established ethical principles incorporating unique aspects of their work. After adopting a matrix and finalizing its membership, the Council held its first meeting in the spring of 2021 with ongoing monthly meetings. Meetings were facilitated by the Ethical AI Project team who translated the council's recommendations into program objectives and tasks through facilitating discussion, collecting data via surveys, and reporting progress at each meeting. This approach allowed for the community-based participatory design to be put into practice. In addition, council members volunteered to serve on subcommittees and task forces on special topics between meetings. Subcommittees formed as needed at the suggestion of the Council members. Specifically, within the first few months of the council, an education subcommittee was created to evaluate the need for educational offerings as a resource for healthcare IT professionals and healthcare providers.

Ethical AI Curriculum Development

Education is often the foundation of any successful intervention. The Ethical AI Advisory Council conducted a review of research work using Google Scholar that identified numerous papers (over 17,000 between Jan. 1, 2022, and July 1, 2023) which touched on healthcare, ethics, and AI. Limiting this to reviews focused on clinical care in the US, the search was reduced to 100 articles. Major topics were ChatGPT, image analysis tools in various fields, use of wearables in healthcare settings, addressing health inequality, health professional shortages, and detection of disease outbreaks. The variety of topics made it clear that while a need for ethics education was recognized,[34] no curricula can address the entire scope of AI in healthcare at a detailed level. This supported the council's idea to develop an ethics curriculum that focused on high-level concepts (how ethics can shape, inform, and both direct and evaluate the application of AI) rather than specific-use case scenarios (image analysis, population analysis). The goal was not to develop new subject matter experts (SMEs) in specialty fields – those stakeholders already exist within healthcare settings.

For our purposes, we saw a clear need to address the use, deployment, and monitoring of AI systems in health care settings by building curricula that addressed the various stakeholders involved in this process. When considering AI in health care, an ethical curriculum needed to address the fundamentals (what is AI, what are ethical duties, what is health care disparity) before it could assist the learner in what might be the truly desired outcomes (building and deploying AI systems that do not exacerbate disparity in healthcare; truly informed consent by patients when interacting with data collection for AI systems). Therefore, the development and analysis of our curriculum proceeded from an understanding of fundamental needs for a set of learners, using diverse learning methodologies, and utilizing assessable, measurable outcomes. The curriculum may then provide concrete first steps for healthcare IT practitioners and providers to handle the ethical considerations in their own organizational practices.

Using community-based participatory design, the Advisory Council formed two internal committees: one committee to design and develop the curriculum, and one to design the implementation of the curriculum at a community site. Both committees worked with a community consultant to develop the necessary components of the design, development, and implementation of the curriculum.

The council evaluated certain pedagogies, including the "learning by doing" pedagogy.[35] This pedagogy is an experiential hands-on approach to learning, a method most connected to the philosopher John Dewey, who believed that people should come together peacefully to problem-solve through discussion, debate and decision making.[36] This learning pedagogy was determined the most appropriate approach for the implementation of the curriculum since the path to responsible technology in healthcare needed a foundation of ethical principles and contextual application across disciplines.[37] The education committee worked with the community consultant to design modules for the curriculum, including supporting literature and resources for the future participants. A comprehensive curriculum aligned to the needs of the healthcare IT community was developed and ready for implementation in less than 6 months due to the ongoing commitment of Ethical AI Advisory Council members.

The curriculum included a didactic teaching component and a facilitation component. It was designed to teach the application of the bioethical principles of beneficence, nonmaleficence, fairness (incorporating justice and fidelity), and respect for autonomy to the development and use of AI systems in healthcare. The bioethics principles were set as cornerstones, since they are widely adopted in healthcare organizations, especially those that deliver care to patients. In addition to these principles, the curriculum addressed recurring themes of AI ethics, such as transparency, explainability, accountability and fairness.[38] Connecting the principles to AI design, development and use was designed to facilitate the development of process improvement recommendations for institutions, starting with the Pilot site. The 11 curriculum modules in order of delivery are included in **Table 1**. The modules were connected to two types of learning outcomes: problem definition and problem solving. The progression from defining the problem to solving the problem created a path from knowledge transfer to solution creation.

Ethical AI Pilot Program

Throughout the curriculum development process, the modules were grouped into sessions that could be mapped to a 7-9 hour time commitment for the participants. These sessions included a combination of didactic lectures, facilitated small group exercises, and facilitated large group discussions. To prepare for the implementation of the curriculum, the Project Team recommended a "Train the Trainer" approach[39] to align with the pedagogy of the curriculum. This approach to train the pilot site to implement the curriculum provides a sustainable model of implementation that creates engagement of our partners, but also allows for institutional support post-curriculum. Before the curriculum was implemented, the pilot site chose two co-facilitators to work alongside a trained healthcare ethics educator from an independent community ethics center. These facilitators participated in a Train the Trainer and mock workshop event created by the Ethical AI Project Team and led by the curriculum developer. The curriculum developer outlined the pedagogy, the intention, and activities of each session and how to facilitate discussion during the delivery of each module. Select members of the Ethical AI Advisory Council acted as volunteer participants so the facilitators could run through each module prior to the Pilot.

Pre-Workshop Interviews

One of the facilitators conducted semi-structured

TABLE 1: Modules by Learning Outcome Type

Module Titles (in order of delivery)	Type of Learning Outcomes	
	Problem Definition	Problem Solving
Medical Ethics, Non-Maleficence, Autonomy, and Fairness Overview	■	
Definition of AI in clinical healthcare	■	
Define Non-Maleficence of AI in clinical healthcare	■	
Define Beneficence for AI in clinical healthcare	■	
Examine AI clinical Informed Consent practices (Autonomy)	■	
Examine algorithm bias in AI clinical healthcare practices; How does bias get in there?	■	
Discuss fairness in AI clinical healthcare practices	■	
Promote explainability in AI clinical healthcare algorithms		■
Postulate ownership of responsibility, accountability, and liability in AI clinical healthcare practices		■
Select a framework for diminishing bias in the decision-making process of machine learning and algorithms used in clinical AI		■
Develop a responsible organizational approach to the implementation of clinical AI in healthcare		■

before each workshop. The interviews were designed as a pre-workshop assessment to assist the project team in understanding the current state of the organization's values, processes, procedures, and governance, as well as to document current governance and monitoring structures. The team also inquired about organizational and departmental education, specifically around ethics related education. Site A and Site B provided names, titles, and contact information for participants to the project team. With the goal of equal distribution, the project team then requested interviewees that could fit in each of the three categories of people that: 1) consider themselves decision makers of products and/or processes in healthcare IT; 2) assist in the design process of products and/or processes in healthcare IT; or 3) create products/tools in healthcare IT. The questions did not differ across categories; however, it was expected that the categories may yield different perspectives to the questions. The interviews conducted before each workshop were transcribed and analyzed to determine major themes. Since the questions were meant more to understand common practices across departments. The results of the interviews outlined the "who's, what's, where's, and when's" of decision making across the organization, specifically describing the decision points that exist in healthcare IT design, development, and implementation.

Curriculum Sessions

Curriculum sessions were delivered in the form of one on-site workshop over 2 days. The modules were divided across two half-days that did not occur back-to-back. The project team determined that the curriculum could be better absorbed by having at least a day in between that may be spent discussing the modules presented in Day 1 to colleagues, or preparing for Day 2 modules. The names and titles of the participants were shared with the project team for the purpose of email communication, interviews, assessments, and for creating workshop groups. Participants were then socially engineered into assigned seats and groups. These groups were intended to provide a balance of power, experience, and expertise. Ethical AI workshops were conducted with stakeholders at

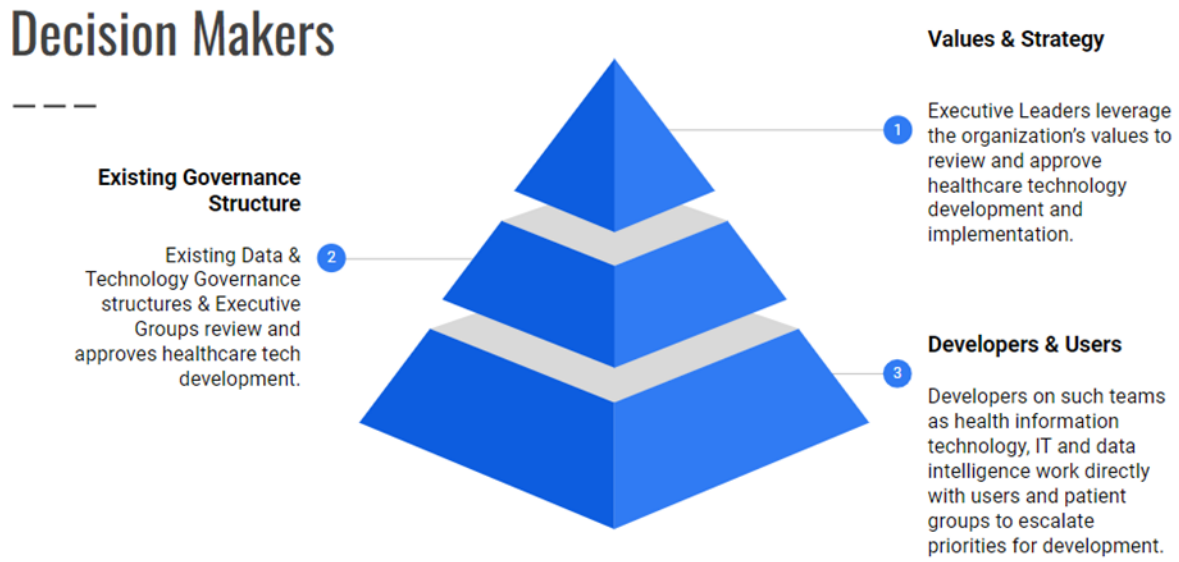
two regional medical centers. The Pilot event was held onsite at Site A, an academic medical center in the summer of 2022. The second event was held onsite in the spring of 2023 at Site B, a comprehensive pediatric medical and research center. The participants included various leaders across healthcare IT, including healthcare executives, analysts, data scientists, and leaders in research. It is important to note that both sites were volunteered by employees of those sites, who also were members of the Ethical AI Initiative Advisory Council.

Results

The program at Site A was held in the summer of 2022 and the program at Site B was in the late spring of 2023. This time gap allowed for the implementation of new AI technologies, additional recommendations in AI research, and the convening of federal officials to examine the impact of AI. Site A and Site B were comparable in participant size ranging from 12-18 participants at each site, and a sampling of participants who agreed to be interviewed. As part of the interviews, the project team identified strengths and areas of opportunity as major themes. These were also presented as part of the workshop to show the organization's potential for improvement, both at an enterprise level and in specific areas.

Common strengths across both sites included the existence of executive level guidance and expertise on data, information services, information technology and research, as well as governance structures for design, development, and deployment. Also, participants expressed an organizational level priority for privacy and security of patient data. Areas of opportunity that were common across both sites included the need for institutional definitions and standards to mitigate risk of AI enabled products, standard data management and monitoring practices, transparency, and the use of diverse perspectives in governance structures. Additionally, even though both sites had comprehensive educational platforms and streams of communication, ethics related education across healthcare IT workers was optional, and mostly unheard of.

FIGURE 1: Common Decision Makers of Healthcare IT Across Pilot Sites



As part of evaluating current state decision makers through the interview phase of the pilot program, common decision makers across each site were described. The descriptions and hierarchy shown in **Figure 1** were leveraged as part of the workshop content at each site so participants could visualize a path for ethical considerations that closely aligned to how they make decisions in their current state.

Participants at both sites were also sent an online follow-up survey related to satisfaction of the workshop itself and a 90-day post-workshop assessment to evaluate any use of the workshop in daily professional activities at their organization, and to assess if any new processes related to the ethical design, development, implementation, or use of AI had been created since the workshop. Qualitative feedback showed positive responses to the workshop, and comments to support that the organization was taking steps to consider ethical frameworks for AI-enabled products across the organization. Response rates and a sample of responses are listed in **Table 2**. The workshop at Site B informed by recommendations given by Site A participants, such as case studies embedded in the curriculum, descriptions and examples of process improvements, and the introduction of an organizational mapping activity.

TABLE 2: Sampling of Post-Curriculum Survey Responses by Site

Survey Responses	**Site**	
	Site A	**Site B**
Survey Response Rate	70%	44%
Workshop satisfaction responses (free text)	*The workshop would benefit from more guidance on setting goals and perhaps ideas for how to bring ethical AI into an organization.*	*Good content. Appreciated the philosophical setup and the hands-on nature.*
Additional feedback (free text)	*(…) the concepts and tactics require much more organizational change management within my org before we have the right support for implementation of true change.*	*The workshop was on point for our state. We'll have plenty of internal challenges, (…) one stakeholder shared that it has significantly changed her thinking and opened her eyes.*

Survey responses varied across both sites and Site B had a lower response rate. While Site B had a lower response rate to the electronic survey, the site was receptive to ongoing discussion with the Ethical AI Initiative and their executive leadership team. These discussions resulted in drafting organizational policy for the ethical use of AI as a collaborative effort from the leaders present in the workshop. Site A worked with the Ethical AI Initiative for several months after the workshop to create new committees to address the internal feedback from workshop participants. Each site continues to work with the Ethical AI initiative to examine case studies and develop policies, practices, and procedures across their organizations.

Practical Framework for the Field

Healthcare systems are continuously challenged with resource constraints and increased patient demand. The use of algorithms in healthcare is well-established as they are integrated into information technology, diagnostic mechanisms, record-keeping, and electronic health records to create efficiencies in the systems used within chart reviews, generation of patient care guidelines, and analysis of patient-related data. The rise of machine learning and, more recently, AI tools to create value within healthcare systems, maximize the use of data within them and stretch the value of scarce expertise that is predicated in part on the need to make the most efficient use of constrained healthcare resources. While bioethics is often central to decision-making in healthcare settings, broader consideration of ethical principles and virtues may not be central to the missions of organizations outside of the "normal" practices that have been enacted to protect patients and providers. As artificial intelligence technologies become pervasive in healthcare settings, providers and developers need language, tools, and organizational support to address the ethical problems they produce. Effective educational resources, best practices, and industry standards require action from diverse and interdisciplinary stakeholders.

The Ethical AI Initiative has a commitment to provide practical interventions for ethical problems

that arise at various stages throughout the development, deployment, and use of AI. Efforts to mitigate risk must exist for these tools to be used appropriately, as they potentially can improve the accuracy of diagnoses, decrease cost, and lessen the gap between research and innovation in healthcare practice.[40] As part of this effort, the initiative works to prevent harm by identifying and addressing these ethical issues before AI is deployed and developing accountability structures that can respond when things go wrong. Interventions that can be practically applied today are 1) education that defines ethical concepts and AI, 2) current state evaluation to understand areas of strengths and opportunity across organizations, and 3) process improvement recommendations to help guide organizations towards standard ethical AI practices. The interventions we propose to the healthcare IT community were developed and implemented using community driven design practices, led by a diverse group of stakeholders operating in healthcare technology. This model is recommended not only as a proactive design technique but could also be used when considering governance mechanisms. For example, after each workshop, the project team gave recommendations to each site to emphasize the importance of process improvement because education alone has limited success in creating change. The recommendations included:

* Creating ethics checkpoint meetings to understand the points in the decision-making process that may benefit from ethical considerations.

* Leveraging already existing community advisory boards to assist in decision making processes for AI design, development, and use across the organization.

* Creating ethics scorecards for their AI enabled products and ethics specific education across departments typically exempt from such offerings, such as data science, software development, and information technology services.

* Providing workshops or other AI ethics education to providers, technical workers, researchers, and various tiers of leadership across the organization.

Through our pilot program at both sites A and B, we found that these recommendations could be implemented more quickly by convening decision makers that may not typically consult each other on organization-wide decisions. Specifically, we saw this deployed as an unintended benefit at Site B, as the workshop created a new internal network of leaders committed to ethical AI. A solution ready for immediate deployment is necessary in the AI space because practitioners and healthcare leaders are determined to realize the benefits and efficiencies of these technologies. This environment will speed testing and adoption of useful and practical implementation of ethical AI in healthcare. Yet, standard processes that ensure human touchpoints, thoughtful consideration, and application of ethical principles to algorithm utilization are often underutilized or completely absent. Our approach aims to fill this gap, centering practical ethics and the incorporation of community voices most likely to be adversely impacted by unthoughtful or unguided use of the technology.[41] Further, by using community centered design, the standards and decision-making processes created by this work include equity in representation and cultural humility that can be applied to algorithm deployment and refinement over time.

Discussion

The work of the Ethical AI Initiative across two large healthcare organizations in the last two years provides a glimpse into the complex problem space of AI in healthcare and a starting point for healthcare organizations to educate themselves, create new infrastructure, and design new practices towards a solution. We found that as AI is deployed, it is often with few checks and balances beyond the technical team or reactive insights by practitioners as they uncover risks in field deployment. Also, it is often unclear who is responsible for monitoring the outputs produced by AI systems, between institutions, developers, and users. Our goal is that every healthcare organization using machine learning algorithms has a written policy and defined standards that includes the application of ethics in their decision-making process.

A key differentiator of this work and other projects focusing on the ethical use of AI is the focus on practical application. The ethical AI work is steeped in real-world application through the practical deployment of structure, governance with community voice, and standards that will adapt to changing technology and use cases over time. The work of this initiative seeks to equip developers and buyers of AI-enabled applications to make design, purchasing, and implementation decisions that are informed by ethical principles

and practices. Building the capacity of healthcare organizations, both internally and through collaboration, to select, implement, deploy, and iterate algorithms is an essential void to be filled in the field.[42] The interventions being developed in the initiative play a critical role in a larger theory of change aimed at broad adoption of ethical best practice for AI in healthcare.[43,44] The success of the initiative and related work depends on interrelationships among key stakeholders focused on equitable treatment and care for vulnerable persons in the deployment of AI in healthcare. The willingness of purchasers, developers, and clinicians to understand the long-term potential impact of AI on patient populations and balance that with their own need for AI assisted workflows demands a commitment to integrity, accountability, and justice.

Future initiatives should include an intentional approach to recruiting diverse members to design recommendations for the growing field of ethical AI. Common diversity, equity, and inclusion practices lack the infrastructure to allow for the differences in power, lived experience, and influence of many of society's communities and individuals. This initiative incorporated elements in the design of the workshop and delivery of the curriculum to ensure that participants had varying levels of power, expertise, interest, and experience, however, our participants may not have been representative of their organization. Whether based on race, ethnicity, education, socioeconomic status, gender, age, or other factors, the use of AI in healthcare impacts clinical decision-making and care. A vital component to systemic change requires that these realities be included across the decision-making pipeline, which may be a necessary disruption across the organization- from hiring to care delivery.

There is promise in intelligence, and it is not unrealistic to be excited about how it will make things in life more convenient, more accessible, and may remove barriers that have left us unable to live the life we want to live. This can be true in healthcare practices and delivery; however, this space is also a venue for incredible risk that ought to be examined with an ethical lens and practical mitigation. The risks and harms as outlined throughout the details of this pilot program underscore the need to create and incorporate industry standards in the ethical development, use, and monitoring of AI systems.

Acknowledgements

We thank all our pilot program participants for their time, energy, and their willingness to be early adopters of our work. We thank all our advisory council members who tirelessly attended multiple meetings, reviewed documents, and offered their expertise time and again. We thank our program staff and partners for navigating schedules and supporting each piece of this work. We thank our funders who financially supported this publication. We thank the organizations that hosted our workshops.

REFERENCES

1. Federspiel F, Mitchell R, Asokan A, Umana C, McCoy D. Threats by artificial intelligence to human health and human existence. *BMJ global health.* 2023;8(5)

2. Chakraborty U, Banerjee A, Saha JK, Sarkar N, Chakraborty C. *Artificial intelligence and the fourth industrial revolution.* CRC Press; 2022.

3. Velarde G. Artificial intelligence and its impact on the Fourth Industrial Revolution: A review. *arXiv preprint arXiv*:201103044: 2020

4. Graves M. Theological Foundations for Moral Artificial Intelligence. *Journal of Moral Theology.* 2022; 11: 182-211

5. Murphy K, Di Ruggiero E, Upshur R, et al. Artificial intelligence for good health: a scoping review of the ethics literature. *BMC Medical Ethics.* 2021;22(1):14. doi:10.1186/s12910-021-00577-8

6. Beauchamp TL, Childress JF. *Principles of biomedical ethics (4th ed.).* Edicoes Loyola; 1994.

7. Beauchamp T, Childress J. Principles of Biomedical Ethics: Marking Its Fortieth Anniversary. *The American Journal of Bioethics.* 2019;19(11):9-12. doi:10.1080/15265161.2019.1665402

8. Rogers WA, Draper H, Carter SM. Evaluation of artificial intelligence clinical applications: Detailed case analyses show value of healthcare ethics approach in identifying patient care issues. *Bioethics.* 2021;35(7):623-633.

9. Leslie D. Understanding artificial intelligence ethics and safety. *Proceedings of the 2019 AAAI/*

ACM Conference on AI, Ethics, and Society. 2019. doi:10.1145/3306618.3314289

10. Devon R, Van de Poel I. Design ethics: The social ethics paradigm. *International Journal of Engineering Education.* 2004;20(3):461-469.

11. Char DS, Abràmoff MD, Feudtner C. Identifying ethical considerations for machine learning healthcare applications. *The American Journal of Bioethics.* 2020;20(11):7-17.

12. United States. National Commission for the Protection of Human Subjects of Biomedical, and Behavioral Research, Research B. *The Belmont report: ethical principles and guidelines for the protection of human subjects of research. vol 1.* Department of Health, Education, and Welfare, National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1978.

13. Nagai H, Nakazawa E, Akabayashi A. The creation of the Belmont Report and its effect on ethical principles: a historical study. *Monash Bioeth Rev.* Dec 2022;40(2):157-170. doi:10.1007/s40592-022-00165-5

14. Department of Health and Human Services. Nondiscrimination in health programs and activities. *Federal Register* 89. 2024: 37522-37703.

15. Rosenbaum S, Musumeci M, Azimpoor K, Rodriguez J. Four Key Takeaways From A Health Care Civil Rights Landmark: The Final Section 1557 Rule. *Health Affairs Forefront.* 2024.

16. Mittelstadt B. Principles alone cannot guarantee ethical AI. *Nature machine intelligence.* 2019;1(11):501-507.

17. Harris E. National Health Care Leaders Will Develop AI Code of Conduct. *JAMA.* 2023;330 (5):401-401. doi:10.1001/jama.2023.12538

18. WHO Guidance. Ethics and governance of artificial intelligence for health. *World Health Organization.* 2021.

19. Char DS, Abràmoff MD, Feudtner C. Identifying Ethical Considerations for Machine Learning Healthcare Applications. *Am J Bioeth.* Nov 2020;20(11):7-17. doi:10.1080/15265161.2020.1819469

20. Agarwal R, Bjarnadottir M, Rhue L, et al. Addressing algorithmic bias and the perpetuation of health inequities: An AI bias aware framework. *Health Policy and Technology*. 2023;12 (1):100702.

21. Thirunavukarasu AJ, Ting DSJ, Elangovan K, Gutierrez L, Tan TF, Ting DSW. Large language models in medicine. *Nat Med.* Aug 2023;29 (8):1930-1940. doi:10.1038/s41591-023-02448-8

22. Zack T, Lehman E, Suzgun M, et al. Assessing the potential of GPT-4 to perpetuate racial and gender biases in health care: a model evaluation study. *Lancet Digit Health.* Jan 2024;6(1):e12 -e22. doi:10.1016/s2589-7500(23)00225-x

23. Huang J, Galal G, Etemadi M, Vaidyanathan M. Evaluation and mitigation of racial bias in clinical machine learning models: scoping review. *JMIR Medical Informatics.* 2022;10(5):e36388.

24. Zhang J, Zhang Z-m. Ethics and governance of trustworthy medical artificial intelligence. *BMC Medical Informatics and Decision Making.* 2023/01/13 2023;23(1):7. doi:10.1186/s12911-023 -02103-9

25. McLennan S, Lee MM, Fiske A, Celi LA. AI ethics is not a panacea. *The American Journal of Bioethics*. 2020;20(11):20-22.

26. Kane NJ, Cohen ASA, Berrios C, Jones B, Pastinen T, Hoffman MA. Committing to genomic answers for all kids: Evaluating inequity in genomic research enrollment. *Genet Med.* Sep 2023;25(9):100895.doi:10.1016j.gim.2023.100895

27. D'Alonzo KT. Getting started in CBPR: lessons in building community partnerships for new researchers. *Nursing inquiry.* 2010;17(4):282-288.

28. Gabriel SE. Getting the methods right--the foundation of patient-centered outcomes research. *The New England journal of medicine.* 2012;367 (9):787.

29. Lantz PM, Israel BA, Schulz AJ, Reyes A. Community-based participatory research: Rationale and relevance for social epidemiology. *Methods in social epidemiology.* 2006:239-266.

30. Israel BA, Schulz AJ, Parker EA, et al. Critical issues in developing and following CBPR principles. Community-based participatory research

for health: *Advancing social and health equity.* 2017;3:32-35.

31. McCradden MD, Anderson JA, Zlotnik Shaul R. Accountability in the machine learning pipeline: the critical role of research ethics oversight. *The American Journal of Bioethics.* 2020;20 (11):40-42.

32. Stahl BC. Embedding responsibility in intelligent systems: from AI ethics to responsible AI ecosystems. *Scientific Reports.* 2023;13(1):7586. doi:10.1038/s41598-023-34622-w

33. Godderis R, Root J. Centering Reciprocity and Accountability in Community-Based Research: How Meaningful Relationships with a Community Advisory Group Impacted Survey Development. *Engaged Scholar Journal: Community-Engaged Research, Teaching, and Learning.* 09/03 2023;9 (1):77-85. doi:10.15402/esj.v9i1.70800

34. McLennan S, Fiske A, Tigard D, Müller R, Haddadin S, Buyx A. Embedded ethics: a proposal for integrating ethics into the development of medical AI. *BMC Medical Ethics.* 2022;23(1):6.

35. Gutek GL. Philosophical, Ideological, and Theoretical Perspectives on Education. *Alberta Journal of Educational Research*. 2016;62(2):220-2.

36. Williams MK. John Dewey in the 21st century. *Journal of Inquiry and Action in Education.* 2017;9(1):7.

37. Komenda M, Víta M, Vaitsis C, et al. Curriculum mapping with academic analytics in medical and healthcare education. *PloS one.* 2015;10 (12):e0143748.

38. Weidener L, Fischer M. Teaching AI Ethics in Medical Education: A Scoping Review of Current Literature and Practices. *Perspect Med Educ.* 2023;12(1):399-410. doi:10.5334/pme.954

39. Assemi M, Mutha S, Hudmon KS. Evaluation of a train-the-trainer program for cultural competence. *American journal of pharmaceutical education.* 2007;71(6)

40. Rajkomar A, Hardt M, Howell MD, Corrado G, Chin MH. Ensuring fairness in machine learning to advance health equity. *Annals of internal medicine.* 2018;169(12):866-872.

41. Hallamaa J, Kalliokoski T. AI Ethics as Applied Ethics. Original Research. *Frontiers in Computer Science.* 2022-April-07 2022;4doi:10.3389/fcomp.2022.776837

42. Karimian G, Petelos E, Evers SMAA. The ethical issues of the application of artificial intelligence in healthcare: a systematic scoping review. *AI and Ethics.* 2022;2(4):539-551. doi:10.1007/s43681-021-00131-7

43. Alowais SA, Alghamdi SS, Alsuhebany N, et al. Revolutionizing healthcare: the role of artificial intelligence in clinical practice. *BMC medical education.* 2023;23(1):689.

44. Page K. The four principles: Can they be measured and do they predict ethical decision making? *BMC Medical Ethics.* 2012/05/20 2012;13(1):10. doi:10.1186/1472-6939-13-10

Artificial Nutrition in Advanced Dementia: Impact of a Hospital Policy

Lynette Cederquist, MD; Ian Neel, MD; Daniel Callies, PhD; Ariadne Nichole, BA; Emily M. Ostler, BA; Khang Tong, MD; and Lin Liu, PhD

ABSTRACT: Background: Despite multiple consensus statements in the literature advising against use of artificial nutrition and hydration (ANH) for patients with advanced dementia clinicians continue to offer ANH when families request it. In order to better align practices with consensus statements, we implemented a policy within our institution which stated that feeding tubes would not be offered for patients who were experiencing difficulties eating as a result of advanced dementia. Methods: We created a workgroup to develop a policy addressing use of feeding tubes in the setting of advanced dementia. Prior to implementation of the policy, we conducted a one-time cross-sectional faculty survey to assess knowledge and attitudes regarding the use of feeding tubes in the setting of advanced dementia. Approximately two years after implementation, we conducted a follow up survey to try to assess the impact of our policy. Results: In the post-implementation survey, there was a trend towards increased recognition about risks and benefits associated with feeding tubes in patients with advanced dementia. The post-implementation survey also solicited feedback regarding the policy's utility. Of the individuals who were aware of the policy, 58% reported using the policy to guide decision making, 77% found it helpful, and 32% reported unforeseen problems. Conclusions: While the feedback on impact of the policy was mixed, our results suggest that it is beneficial to have such a policy in place in order to support physicians decision making. As a result, we believe our practices better align with consensus statements.

KEYWORDS: Advanced Dementia; Artificial Nutrition and Hydration; Feeding Tubes; Non-beneficial Treatment

Background

Legal and medical institutions have historically been reluctant to set limits in the provision of artificial nutrition and hydration (ANH) at the end of life.[1] Cases are decided on an ad hoc basis, and vary widely in how they are managed.[2,3] Many contributing factors lead to highly variable management decisions and therefore potentially inequitable application of current treatment guidelines. These factors include clinician knowledge and decision making,[3,4] familial decision making often informed by religious and cultural influences,[3,5,6] and institutional drivers such as pressure to discharge patients.[7]

In addition, the dynamics of decision making regarding ANH are somewhat unique compared to other life-sustaining treatments. In the case of a decision which requires specialist intervention, there is a disconnect between the clinicians who are directly caring for the patient, and the clinicians who are asked to place the feeding tube or IV access (e.g., participation in goals of care conversations). Various specialists can be involved in the placement of PEG tubes, most often gastroenterologists and interventional radiologists. However, there are no clear guidelines on who among a patient's healthcare providers should be responsible for the ultimate decision of whether to place access for ANH.[8] There is evidence to suggest that physicians of several specialties believe there should be interdisciplinary discussion when making decisions about PEG tubes/IV access but ultimately view a patient's primary care team as having the main responsibility.[2] Indeed, patients' primary care doctors may draw upon their longitudinal relationship with their patients to make choices about PEG placement that uphold patients' desires prior to losing capacity.[9] However, the gastroenterology literature suggests a desire for those performing the PEG tube procedure to be included in decision making. Physicians who perform the requested procedures can experience moral injury by placing PEG tubes that they believe will do more harm than good.[8] Given the gap between guidelines and actual practice, there is a need for hospitals to support and empower clinicians with information on how to align their practices with evidence-based guidelines, and provide policies to guide such clinical decisions. To our knowledge, hospitals do not have policies in place which support clinicians in declining to offer ANH to patients with advanced dementia. At our institution, we have had a policy for over a decade which supports clinicians in not offering treatments which have been determined to be non-beneficial. The following is our hospital's definition of non-beneficial treatment: "Any treatment that has no realistic chance of providing a benefit that the patient has the capacity to perceive or appreciate, such as merely preserving the physiological functions of a permanently unconscious patient, or has no realistic chance of returning the patient to a level of health that permits survival outside the acute care setting." We believe that use of ANH in the setting of advanced dementia is sufficiently similar to other non-beneficial treatments such as ventilator support for a permanently unconscious patient with no reasonable hope of recovery. A person with ad-

vanced dementia lacks the capacity to appreciate the fact that they are being kept alive and are more likely to experience added suffering from administration of ANH rather than any meaningful benefit in terms of survival or quality of life. As we support limitation of other non-beneficial treatments, we felt it necessary to establish a mechanism to do the same when families request ANH in this setting. We were unable to identify another hospital which had implemented such a policy, so this was a novel approach to aligning practices with evidence driven guidelines.

Methods

A. Study Design

We first convened a workgroup to deliberate on current practices and potential solutions. The workgroup included representation from key stakeholders including hospital medicine, geriatrics, neurology, interventional radiology, palliative medicine, ethics, and gastroenterology. The consensus of this group was that in most cases of advanced dementia, ANH should not be offered. Despite that, in many cases they are still offered due to the pressures on clinicians as outlined above. The proposed intervention was to develop a policy that addresses requests for feeding tubes in the setting of advanced dementia. A policy entitled "Policy for Feeding Tube Placement in Patients with Advanced Dementia" was created and implemented in August 2021. Surveys to measure physicians' attitudes and knowledge regarding the use of feeding tubes in this setting was conducted pre- and post- policy implementation to assess the impact of the policy. This was a pre- and post- cross-sectional survey-based study within a single academic health system, conducted approximately two years apart.

B. Survey Conception

The objective of this study was to assess clinicians' knowledge, attitudes, and practices regarding the placement of feeding tubes in the setting of advanced dementia. The pre-policy implementation survey was adapted from a prior survey conducted in Israel published in 2018 looking at physician's attitudes and knowledge regarding the use of feeding tubes in the setting of advanced dementia.[10] Our adapted pre-policy implementation survey asked both closed and open ended questions including participant demographics, knowledge, attitudes, and practices. We subsequently conducted the same survey almost two years later to assess the impact of the policy and its accompanying physician education **(Graphs 1-5)**.

C. Follow Up Survey

We conducted the same knowledge and attitudes survey almost two years after policy implementation. We wanted to see if we could measure any impact implementation of a policy (accompanied by clinician education regarding the policy) might have over time **(Graphs 1-5)**. In addition to the knowledge and attitude questions, we added four additional questions to assess the impact of the policy on clinical decision making. The questions included:

1. Are you aware of the policy?

2. Have you used this policy to guide decision making?

3. Have you found this policy to be helpful?

4. Have any unforeseen problems arisen as a result of this policy?

D. Participants and Recruitment

The anonymous pre-policy implementation survey was sent via email to all faculty in the following specialties: hospital medicine, geriatrics, neurology, palliative medicine, interventional radiology, and gastroenterology at our academic medical center in 2021. The post-policy implementation survey was subsequently sent to the same faculty in 2023. We sent the survey request only one time with each survey. For both 2021 and 2023, each survey was sent to approximately 230 faculty. For the pre-policy implementation survey in 2021 we received 45 responses (19% response rate). For the post-policy implementation survey in 2023, we received 40 responses (17% response rate).

E. Policy Development and Implementation

The stated purpose of the policy was to provide guidelines for providers to follow in cases in which a family/surrogate requests placement of a permanent feeding tube in a patient who is in the

advanced stages of dementia (FAST 6d-7). The FAST dementia rating scale was selected as it has prognostic value in the care of the patient with dementia. The scale has been utilized widely for identifying patients with Alzheimer's disease that are eligible for hospice enrollment, with the Centers for Medicare & Medicaid Services having selected the FAST scale for local coverage determination of hospice eligibility. The scale identifies the FAST 7 stage as a marker of the terminal stages of Alzheimer's disease with a prognosis of less than six months, with stage six being a marker of severe cognitive decline. The following are the steps outlined in this policy:

1. Families/surrogates of patients with dementia should be educated regarding the lack of meaningful benefit, as well as risks and complications as a result of placement of permanent feeding tubes.

2. When a patient with dementia develops difficulty eating, they should be assessed for any possible reversible contributing factors. In the inpatient setting, their ability to eat should be re-assessed once they recover from any acute illness.

3. A palliative medicine or geriatrics consultation should be obtained to confirm the determination that the patient's dementia is in advanced stages with no potentially reversible contributing factors.

4. If inadequate oral intake is determined to be solely due to the progression of dementia, the surrogate/family should be informed that the patient is in the late stages of dementia. Comfort care/ hospice should be offered. They should be counseled about the option of hand feeding to provide comfort despite risk of aspiration.

5. If the patient is determined to be in FAST stage 6a-c the family should be educated regarding the fact that many professional groups advise against placement of feeding tubes in this setting. If they still elect to have a feeding tube placed, they should be advised that when the patient reaches a more advanced stage of dementia, the feeding tube could be removed.

6. At FAST stage 6d-7 a feeding tube will not be placed.

7. Palliative/comfort care will be offered at all times

8. If a patient with advanced dementia presents to our institution with an already established feeding tube that has been dislodged, as time permits, a goals of care (GOC) conversation should be conducted prior to replacing the feeding tube. If the family still desires the feeding tube, it may be replaced. If no GOC conversation was conducted prior to replacing the feeding tube, a subsequent GOC conversation should be held with the family/ surrogate regarding the option of discontinuation of the feeding tube if there is no demonstrable benefit to the patient.

9. If the family/surrogate disagrees with the application of this policy, an Ethics consult should be requested to mediate conflict per our hospital policy entitled "Non-Beneficial Treatment Conflict Resolution."

10. If despite following this process the family/ surrogate still wishes to have a feeding tube placed, they should be offered the option of seeking the desired treatment at another institution which is willing to offer it.

F. Data collection

Survey results were collected through a secure Google form and were anonymous.

G. Data analysis

Survey data was analyzed descriptively to provide a broad picture of respondent clinicians' knowledge, attitudes, and practices. We did not have a mechanism to track and measure individual respondents, so the data could not be analyzed for statistical significance.

H. Ethics approval

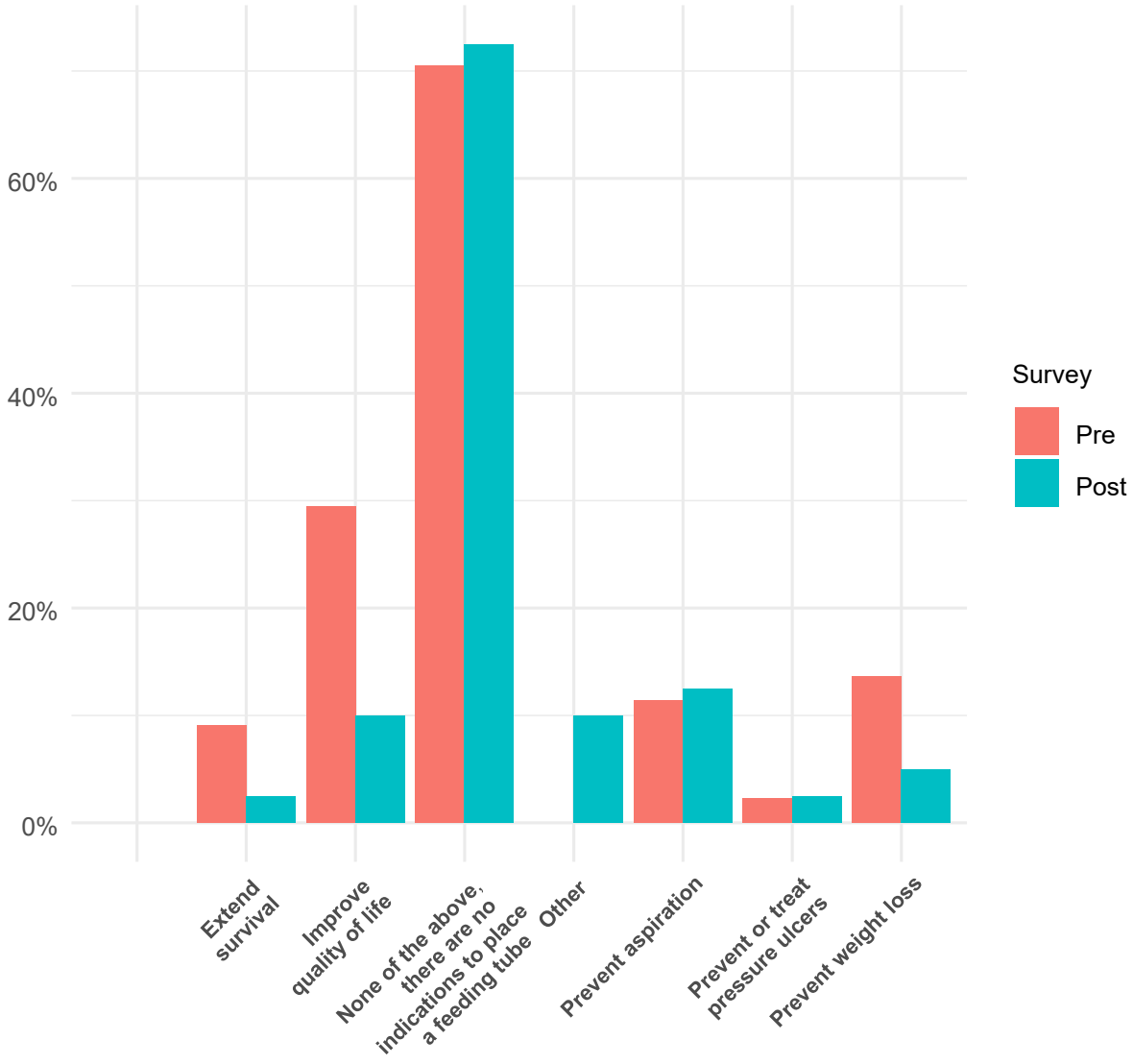
This study was deemed exempt by our institution's IRB as it met criteria for a quality improvement (QI) project.

Results

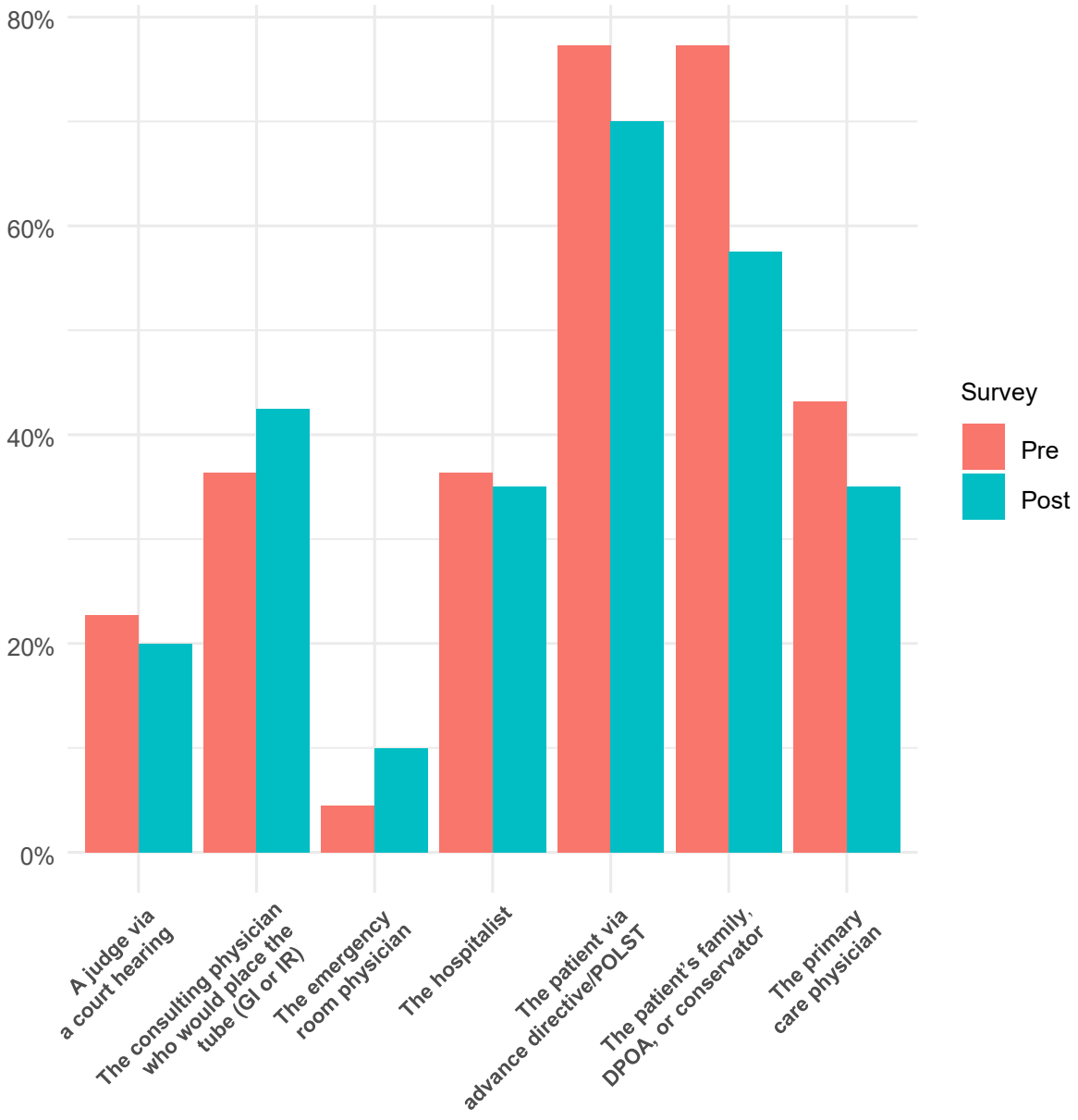
1. Pre- and Post- Attitudes and Knowledge Survey: The pre- and post- knowledge survey indicated a trend towards increased recognition of the lack of benefit and risks of harm with the use of feeding tubes/AHN in the setting of advanced de-

mentia **(Graphs 1-5)**.

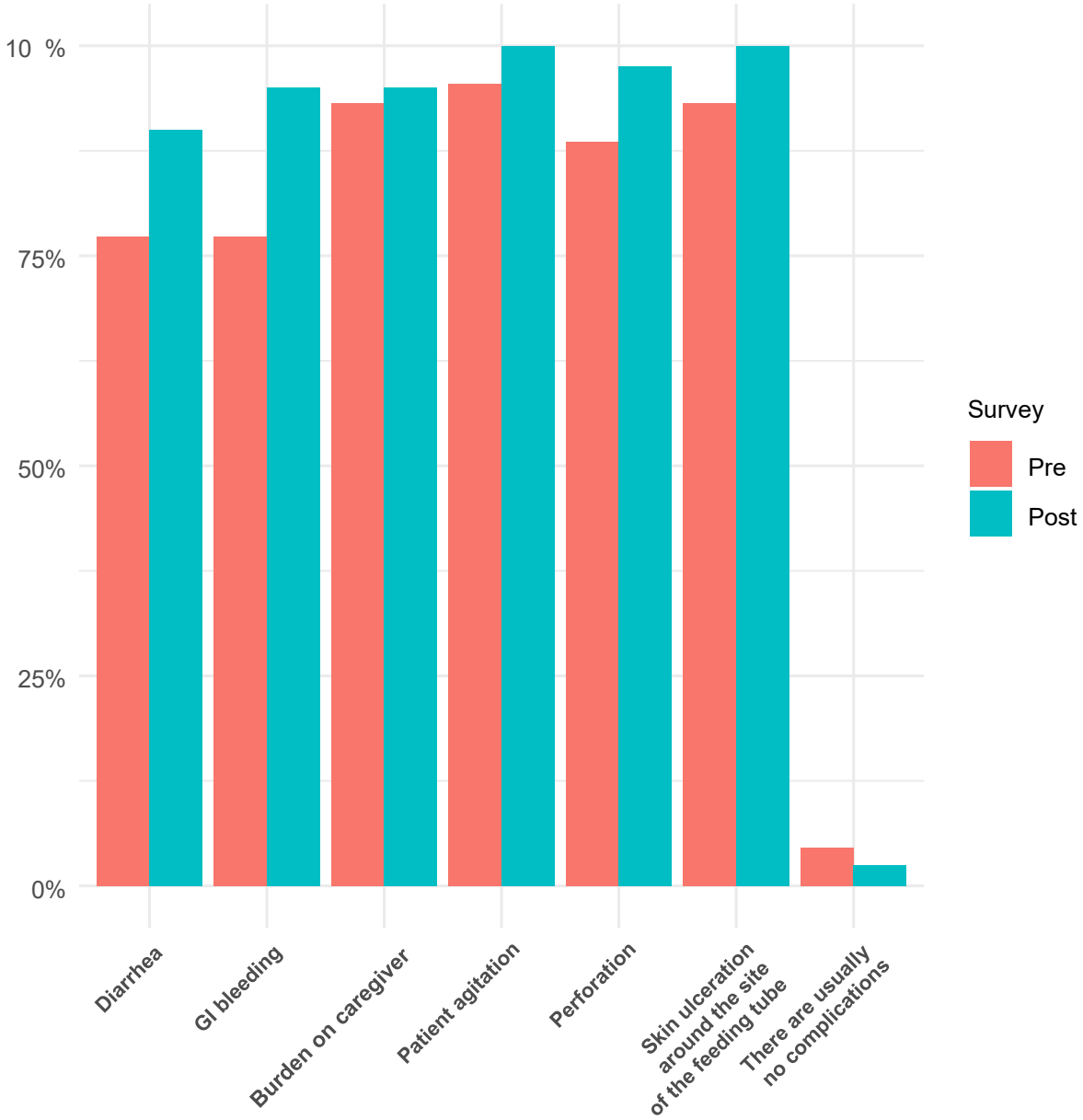
GRAPH 1: Question 1: "Which of the following are reasons to place a feeding tube for a patient with advanced dementia?" Respondents could select more than one answer.



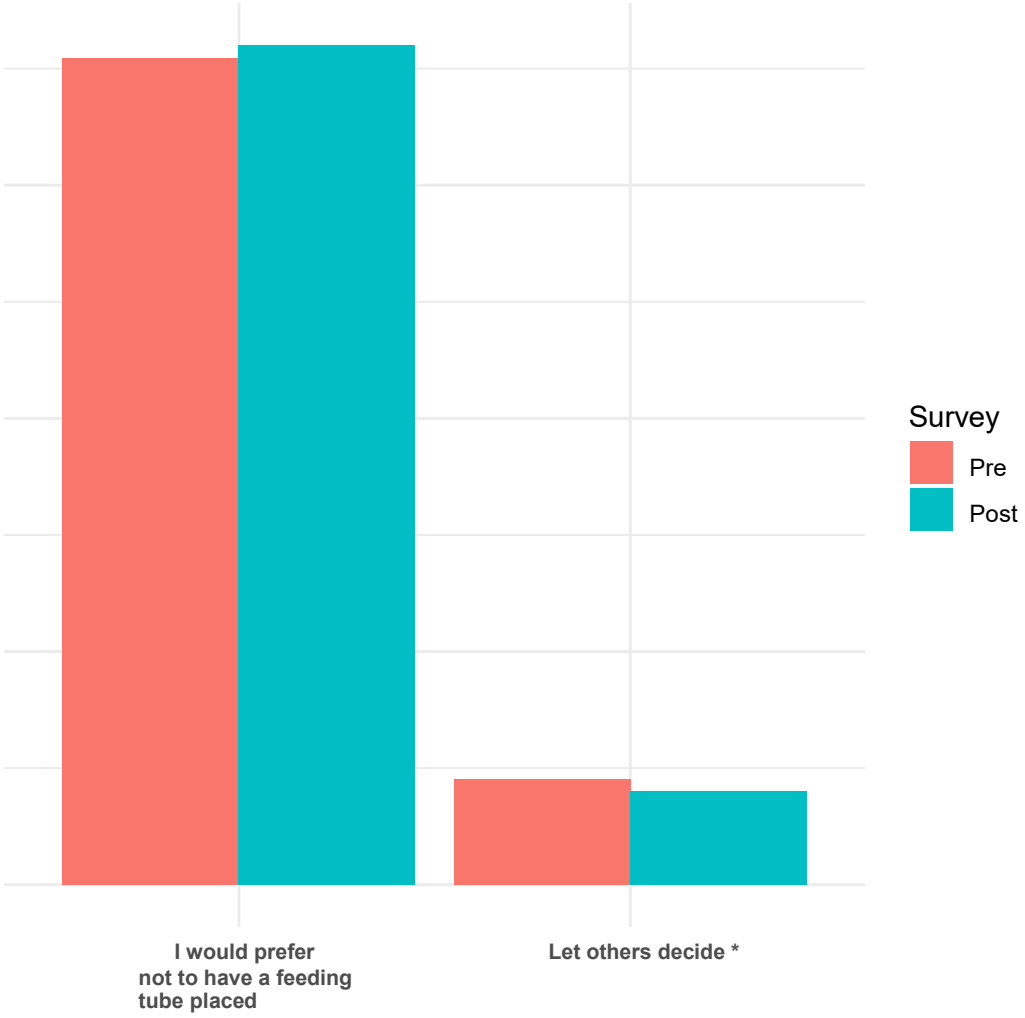
GRAPH 2: Question 2: Who should decide that a feeding tube should be placed? Respondents could select more than one answer.



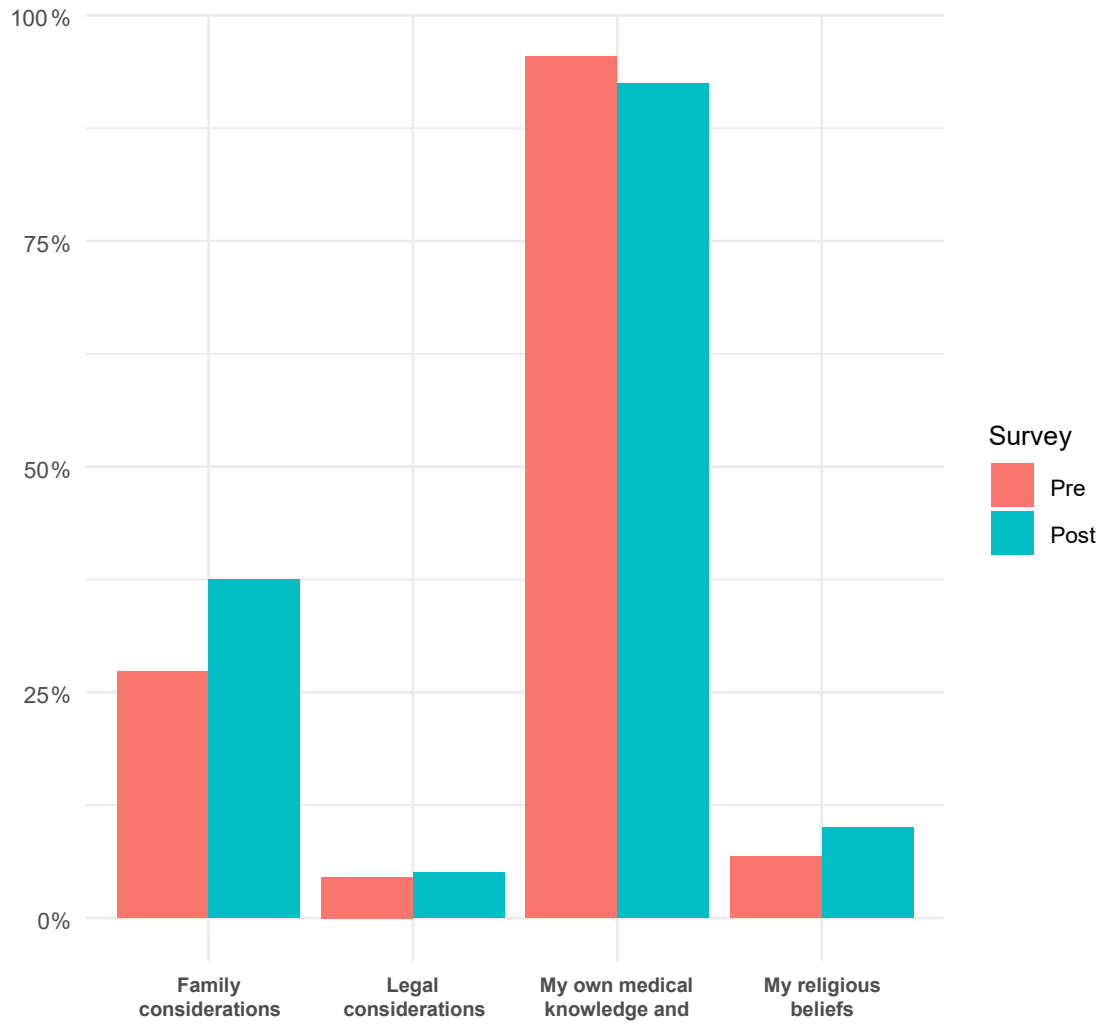
GRAPH 3: Question 3: What are the potential complications from a feeding tube? Respondents could select more than one answer.



GRAPH 4: Question 4: How do you feel about having a feeding tube placed if you or a family suffered from advanced dementia?



GRAPH 5: Question 5: What factors would affect your preference regarding having a feeding tube?



2. Follow up post survey questions to assess awareness and impact of the policy:

a. Are you aware of the policy?
Yes: 26 (65%)
No:14 (35%)

b. Have you used this policy to guide decision making?
Yes: 15 (37%) 57% of those aware of policy
No: 24 (63%)

c. Have you found this policy to be helpful?
Yes: 20 (50%) 77% of those aware of policy
No: 16 (40%.)
4 no replies

d. Have any unforeseen problems arisen as a result of this policy?
Yes: 11 (32%) 42% of those aware of policy
No: 23 (68%)

3. Unforeseen problems reported:

a. "Policy overrides decision making by the treating physician."

b. "The lack of flexibility of the policy has made it difficult to apply especially nuanced clinical situations."

c. "The hospitalist team grew defensive and upset that I cited the policy feeling it called their judgment into question."

d. "The policy creates greater conflict between the family/surrogate and treating team."
e. "The policy does not address artificial hydration." (4 respondents)

f. "Families having had different advice from other providers."

g. "The policy creates greater conflict between the family/surrogate and treating team; The policy overrides decision making by the treating physician."

h. "Because of lack of understanding of this policy, we've (IR) run into issues with referring teams."

i. "Patient families still want nutrition and ethics will override this policy."

4. Other comments:

a. "I love having a policy in place. Takes the burden off of me to some extent."

b. "Appears policy needs another round of robust debate to ensure buy in from all involved services, after which if left in place as policy (and not a guideline), it needs exclusively directive language with an alternate method to accommodate surrogate challenges."

c. "Policy step "For hospitalized patients, palliative medicine or geriatrics consultation should be obtained to confirm the determination that the patient's dementia is in advanced stages" - needs to be addressed with consensus commitment from those involved."

d. "I was ignorant that the policy exists, although it matches my practice closely. I agree with the goals of the policy."

e. "The proposed feeding tube prohibition in dementia is terrible."

f. "Language of policy is contradictory and confusing with repeated use of the word "guideline" yet also the directives such as "At FAST stage 6d-7, a feeding tube WILL NOT be placed" and "based on this policy, (Our hospital) DOES NOT OFFER feeding tube placement for patients with advanced dementia."

g. "Patients and families will still override this policy if they want the tube."

h. "I didn't know there was a policy but I know the palliative consult practice of saying its contraindicated and that's always been helpful."

Policy Revision

As a result of this survey, we have made revisions to our policy, including:

1. Changing the policy from "feeding tubes in the setting of advanced dementia" to "artificial nutrition and hydration in the setting of advanced dementia."

2. Rather than stating that ANH would not be offered, we stated that "At FAST stage 7, our hospital supports a clinician's determination that ANH

meets our hospital's definition of non-beneficial treatment and therefore need not be offered."

3. Rather than deliberating conflicts via an ad hoc ethics committee meeting, and ultimately leaving the decision up to the primary treating physician, we implemented an alternative conflict resolution process which would be done utilizing an ad hoc committee comprised of the primary attending, consulting attending who would place the ANH access, geriatrics consultant, palliative medicine consultant as indicated, and the ethics consultant, to deliberate and make the decision regarding whether ANH would be offered.

4. Amended the FAST stage when ANH need not be offered from stage 6d-7 to FAST stage 7.

Conclusions

Given the extensive data in the literature showing a lack of benefit and risk of harm, as well as the multiple consensus statements stating AHN should not be offered, there is a need to move practices closer to adopting this as an accepted standard of care practice.[11-13] We implemented this policy based on our consensus that artificial nutrition and hydration (ANH) in the setting of advanced dementia meets our hospital's definition of non-beneficial treatment and therefore physicians are not obligated to offer it.

The pre- and post- implementation survey indicated a trend in improved clinician knowledge regarding recognition of the lack of benefit and risks of harm associated with ANH in the setting of advanced dementia. There was no way to assess whether the implementation of the policy caused this trend or was merely correlated with it. But we believe it is reasonable to presume the policy may have been a contributing factor.

Perhaps most enlightening in this project was the identification of the unforeseen problems after two years of implementation:

1. Omission of artificial hydration: We realized that artificial hydration had not been addressed, which created some problems when families insisted on continuation of hydration despite requests for artificial nutrition being declined.

2. Statement that artificial nutrition would not be offered was perceived to override clinician's decision making.

3. Increased conflict between teams and with families.

Our policy revision attempted to address the first two issues. The issue of increased conflict was difficult to assess or correct with a policy revision. This might be an interesting topic of future research.

While feedback was mixed, overall it seemed that physicians felt having the policy in place supported improved decision making. While we concluded that the policy was of value, this feedback informed a revision of the policy to allow some latitude in decision making.

Although the numbers were small, it is of particular interest to note that IR faculty had the highest rate of positive response regarding whether they found the policy helpful (5 out of 6 or 83%). One might surmise that such a policy may empower the consulting physicians to be able to decline such requests and thus reduce moral distress for them.

Our intent moving forward is to create a mechanism which allows for the consulting services (GI and IR) to participate collaboratively in decision making. The somewhat more complicated decision making between primary treating physicians and consulting physicians asked to perform surgical interventions has not been studied or discussed in depth in the GI, IR, surgical or ethics literature, and is an area that is ripe for further ethical study and deliberation. It would be enlightening to study the effect of this shared decision making model on the level of moral distress for the providers who are asked to perform the interventions.

Limitations

The main limitation of this study was the low response rates (19% for the pre-survey, 17% for the post-survey). Yet both response rates are within the reported range of response rates for email distributed surveys of 15-25%. Our second limitation was the fact that we could not track individual pre- and post- responses as the responses were done anonymously. We therefore were unable to calculate any statistical data, only descriptive data. In addition, this was conducted at a single institution which was an urban academic medical center, and therefore the generalizability may be limited to the extent that the findings could be applied to other hospitals.

1. Henry B. Evolving ethical and legal implications for feeding at the end of life. *Ann Palliat Med* 2017;6(1):87–90

2. American Geriatrics Society Ethics Committee and Clinical Practice and Models of Care Committee. American Geriatrics Society Feeding Tubes in Advanced Dementia Position Statement. *J Am Geriatr Soc* 2014;62:1590–1593.

3. Fessler TA, Short TB, Willcutts KF, Sawyer RG. Physician opinions on decision making for percutaneous endoscopic gastrostomy (PEG) feeding tube placement. *Surg Endosc* 2019;33 (12):4089–4097.

4. Gillick M, Volandes A. The standard of caring: why do we still use feeding tubes in patients with advanced dementia? *J Am Med Dir Assoc* 2008;9:364–367.

5. Ladas SD, Triantafyllou K, Liappas I, Hatziargyriou M, Tzavellas E, Barbatzas C, Percutaneous endoscopic gastrostomy: adequacy and quality of information given to decision makers. *Dig Dis* 2002;20(3-4):289–292.

6. Teno JM, Mitchell SL, Kuo SK, Gozalo PL, Rhodes RL, Lima JC, et al. Decision-making and outcome of feeding tube insertion: a five-state study. *J Am Geriatr Soc* 2011;59:881–886.

7. Mitchell SL, Teno JM, Roy J, Kabumoto G, Mor V. Clinical and organizational factors associated with feeding tube use among nursing home residents with advanced cognitive impairment. *JAMA* 2003;290:73–80.

8. Roche K, Bower K, Collier B, Neel D, Esry L. When should the appropriateness of PEG be Questioned? *Curr Gastroenterol Rep* 2023;25:13-19.

9. Scott LD. The PEG "Consult" Ethics in Gastroenterology. *Am J Gastroenterol* 2005;100:740–743.

10. Punchik B, Komissarov E, et. al. Doctors' Knowledge and Attitudes Regarding Enteral Feeding and Eating Problems in Advanced Dementia. *Dement Geriatr Cogn Disord Extra* 2018;8:268–276

11. American Geriatrics Society Ethics Committee and Clinical Practice and Models of Care Committee. American Geriatrics Society Feeding Tubes in Advanced Dementia Position Statement. *JAGS* 62:1590–1593, 2014.

12. Davies N, Barrado-Martin Y, Vickerstaff V, Rait G, Fukui A, Candy B, et. al. Enteral tube feeding for people with severe dementia (Review). *Cochrane Database Syst Rev* 2021;(8):CD013503.

13. Schwartz DB, Barrocas A, Annetta MG, Stratton K, McGinnis C, Hardy G, et. al. Ethical aspects of artificially administered nutrition and hydration: an ASPEN Position Paper. *Nutr Clin Pract.* 2021;36(2):254–267.

Business Ethics at the Bedside: Tracheostomy Patients, Dialysis Policies, and Creative Problem Solving

Antoinette R. Esce, MD; Ashley Dorneden, MD; Nathan H. Boyd, MD; and Jonathan Bolton, MD, MA, MPhil

ABSTRACT: Most clinical ethics cases focus on medical decision-making dilemmas, when it is unclear what the best or right course of action is. Providers may consult the literature to better understand their medical, legal, and ethical obligations or to explore how others have handled similar situations. They may also turn to a clinical ethics consult service to help them work through the situation. The case discussed here is relatively simple from a clinical decision-making standpoint; the right thing to do for the patient was clear. However, a conflict between the interests of a patient and the managers of businesses that provide outpatient healthcare services prevented the patient's medical team from serving her interests. This conflict represents a complex healthcare problem with significant moral hazards and an example of competing organizational, business, and clinical ethics affecting bedside care. As the healthcare sector becomes increasingly privatized, conflicts in clinical, business, and organizational ethical norms will become more common, pitting individual patients and providers against corporate entities and healthcare conglomerates, where doing the right thing for the patient is not always the primary goal. This case is written from the perspective of two consultants who became involved in the case: an otolaryngologist and a clinical ethicist. An analysis of the case from competing ethical lenses follows, along with a discussion about possible ways to navigate future conflicts.

KEYWORDS: Clinical Ethics; Business Ethics; Organizational Ethics; Conflicts of Interest

Case Description

The patient is a 46-year old woman with end-stage renal disease (ESRD) requiring hemodialysis. She also has tracheal stenosis as a result of a prior intubation which requires a tracheostomy tube to bypass the narrowed segment. She was hospitalized because she could not receive hemodialysis at any regional outpatient hemodialysis center since all of these centers have policies that deny access to patients with an open tracheostomy. As a result of these policies, the patient could not receive outpatient hemodialysis, and therefore could not be safely discharged home.

The medical team had no reason to keep her in the hospital except to receive hemodialysis, which she otherwise could receive on an outpatient basis, where she would be at lower risk of nosocomial infections and medical errors. The patient's main goal was to return home. It was in this context that the primary team consulted otolaryngology in the hope that her tracheal stenosis could be resected and reconstructed, obviating the need for a tracheostomy, and bypassing the dialysis centers' exclusionary criteria.

There were three possible solutions to the patient's situation: if the patient no longer required hemodialysis; if the patient no longer required a tracheostomy; or at least one dialysis center revised its policy. Otherwise, the patient would be forced to remain in the hospital indefinitely or to regularly visit the emergency room for urgent, inpatient dialysis three times a week.

The first two options are not realistic. The patient is not a candidate for a kidney transplant and peritoneal or other home dialysis could not be safely administered given her complex, low-resource living situation. Surgically, the patient's tracheal stenosis had failed conservative management with dilation in the operating room. This left open resection with reconstruction of the airway as the only option to relieve her tracheostomy dependence. The patient has multiple medical comorbidities in addition to her ESRD, including severe obstructive sleep apnea, worsening morbid obesity, and type 2 diabetes, all of which greatly increase the risk of fatal anastomotic failure following tracheal resection and reanastomosis. The consulting otolaryngology team felt that this surgical procedure was unacceptably risky and potentially countertherapeutic.

The final possible solution was that at least one hemodialysis center revises its policy or allows this patient access as a special exception. At this point, the involved medical teams had been experiencing considerable moral distress and clinical ethics had been consulted to help navigate the situation. The dialysis centers expressed concern about caring for patients with tracheostomies due to the purported increased transmission of respiratory illnesses and the potential difficulty providing successful resuscitation in the event of cardiopulmonary arrest or dislodgment of the tracheostomy tube. Several creative solutions that would allow this patient to receive outpatient dialysis with a tracheostomy tube were suggested and thwarted including adopting standard respiratory and droplet precautions as with any other patient. In many cases, the presence of a tracheostomy eases resuscitation efforts for healthcare providers, so long as suction is availa-

ble. No dialysis center, long-term care facility, or skilled nursing facility in the state would accept the patient with her "open tracheostomy." The inpatient dialysis center was not legally allowed to provide outpatient dialysis services, even in special circumstances, due to regulations around billing through the Centers for Medicare & Medicaid Services (CMS).

Once these potential solutions were exhausted, the patient eventually left the hospital without a safe outpatient discharge plan. She now receives dialysis through the emergency department and follows with otolaryngology as an outpatient for routine tracheostomy care.

Analysis From a Clinical Ethics Lens

While the primary conflict in this case is a sociopolitical one between a patient's medical needs and regional dialysis center policies, this external conflict placed additional, artificial pressure on what would otherwise have been routine surgical decision-making. The right thing, from a clinical perspective, was clear. Although the dialysis centers claimed they couldn't safely provide dialysis for the patient, the alternative was hardly better or safer. The patient herself described considerable distress about her inability to be discharged from the hospital and her separation from her family. She was in a state of limbo. Clinicians were forced to consider and discuss interventions and medical treatments that would not otherwise be part of the standard of care.

Similarly, in an outpatient setting, this patient would never have been offered a tracheal resection and reconstruction because it does not advance her goals. Even if the patient had different hopes for her care, the procedure would not have been offered given the devastating potential wound healing complications heightened by her various medical comorbidities.[1,2] Ordinarily, the team would not include it in the list of treatment options because of the high risk and low chance for potential benefit, but in this case they felt pressure to inform the patient of the option, given the difficulties surrounding the discharge situation.

The option for tracheal resection and reconstruction is entirely elective since the patient's tracheostomy is a safe and definitive treatment for her severe tracheal stenosis and obstructive sleep apnea. Surgical norms dictate that an elective procedure should not exceed a certain theoretical level of risk. Should an invasive and potentially life-threatening surgery be considered an ethical or reasonable solution to discriminatory dialysis policies? One of the surgeon's jobs in shared decision-making is to limit the list to those that reasonably advance the patient's goals of care. A surgeon should be wary of situations that may coerce them into offering a procedure that they believe to be harmful or unsafe, regardless of their technical ability to perform it.

On the other hand, shielding the patient from this potential treatment option because of policies and politics outside of her control could be seen as paternalistic. If the patient had been seen in the outpatient clinic and inquired about tracheal resection and reconstruction, the team would have reviewed the overwhelming risks and explained why the procedure wasn't being offered. Just because the potential benefits are atypical (discharge home from the hospital), does not absolve the surgical team of their responsibility to facilitate shared decision making and completely disclose all surgical options if the patient or other team members ask about them.[3] Explaining why the high-risk tracheal resection is not an option respects the patient's autonomy and hope for beneficence, while informing her of the potential to do harm.

Both the consulting otolaryngology and primary medical teams felt the centers' policies were not based on sound clinical reasoning. Since valid concerns about patient safety could have been alleviated, it was presumed to be a managerial decision that served the business interests of the centers. One explanation that was communicated was that if patients with open tracheostomies were treated, the centers would prefer to have licensed respiratory therapists on site in case the patient developed a mucus plug. This would expose the center to additional labor costs and legal risks. However, most patients with stable, chronic tracheostomies that are not on mechanical ventilation are able to independently manage their tracheostomy care in the outpatient setting without assistance. Simple suctioning of a tracheostomy is also a skill performed by many inpatient and outpatient nurses. Patients with tracheostomies and their family members care for the tubes and complications on their own at home with minimal inpatient education. This patient did not require a higher level of care at outpatient dialysis for objective medical reasons.

Analysis From a Business Ethics Lens

It is unlikely that the outpatient care facilities in this case specifically intended to discriminate

against or otherwise harm the patient in question. Many non-profit dialysis centers set aside profits in the pursuit of patient care and have been reported to have better patient outcomes than for-profit dialysis centers.[4] That being said, nonprofit corporations do not avoid profit, they are merely obligated to reinvest their assets in pursuit of their mission. They are often influenced by the same financial incentives as for-profit companies, even if to a lesser extent. They also make up less than 10% of the dialysis market.[4] Both for-profit and non-profit dialysis centers declined to care for this patient.

Risk averse institutions need to protect themselves from liability. They also have an obligation to protect their staff and other patients from harm, which is likely where these policies came from and why they persisted. In order to protect these interests, the dialysis centers felt that a licensed respiratory therapist was required, which would not be covered through CMS since the patient did not have need for a comprehensive respiratory therapy program. A wide variety of allied health professionals can learn how to suction a tracheostomy when needed; the patient could have demonstrated it herself. The inner cannula on tracheostomy tubes is also a simple safety feature that can be removed by anyone to alleviate obstruction from a mucous plug. While part of this problem may be a lack of tracheostomy education for clinicians, or CMS billing regulations, the inability of the dialysis centers to engage in creative problem-solving warrants discussion.

Many clinical care policies at siloed medical facilities, such as outpatient dialysis centers, fail to account for negative externalities, or costs borne by others besides the decision-maker. From the perspective of the dialysis center policy maker, the decision to exclude patients with tracheostomies reduces their liability and protects their employees and patients, even from small, theoretical risk. They may lose some potential revenue, since patients with tracheostomies will not use their services, but this may be a net neutral effect, or even financially advantageous, if the business felt the need to hire additional staff to care for the patients with tracheostomies. However, the cost to patients with tracheostomies is quite high, as they now have fewer places (or in some cases, no places) to safely obtain healthcare.

One may point out that, given a competitive market, another center may arise to capture this lost revenue and specialize in providing dialysis care to patients with tracheostomies. However, this alternative is incredibly unlikely given the monopsony structure of reimbursement for dialysis care in the United States and the opposing growing oligopoly of dialysis providers.[5-7] Several models for reimbursement have been discussed and tried, and many of them, including capitation models, fee-for-service models, and the hybrid current system, make caring for sick or complicated patients less profitable and less appealing.[8,9]

This small, consolidated market does not allow for new models of care and the resulting incentives do not encourage provision of care to small groups of the most vulnerable patients. Decision makers in the business setting are not necessarily ethically beholden to their stakeholders or customers and often have a paramount legal obligation to their shareholders or their profit margin.[10] Over 90% of outpatient dialysis centers in the country are operated within this for-profit framework.[4] While some of these corporations do take care of complex patients, they only do so when it is economically favorable. While one could counter that CMS could or should properly incentivize the care of uniquely vulnerable patients, others would argue that CMS billing regulations should be grounded in both clinical and economic realities. Why should CMS reimburse for a licensed respiratory therapist if they are not clinically necessary? Does the dialysis corporation have the power to decide what is clinically indicated? What is clinically indicated and what is financially indicated for liability reasons? The business ethical framework can feel at odds with a clinical one; the for-profit dialysis center manager has a duty to first protect the interests of the corporation, and only secondarily to the patient or their treatment. Clinical and business ethics may seem antithetical some of the time.

However, real-world decision-making is not so clear cut, even in the business setting. Some posit that actual decision makers often rationalize their intuitive choices afterwards as opposed to consciously reasoning through the dilemma.[11] This intuition often relies on principles of business ethics, such as integrity, honesty, or fairness, as opposed to frameworks or theories. Others still debate stakeholder and shareholder ethics.[10] And lastly, there are often non-profit medical entities whose decision-making likely resonates more with clinical ethics than business ethics. In this space, there may be room to work with business leaders on new solutions to problems that prevent the safe and effective delivery of healthcare to patients, which is ostensibly the main societal goal for the healthcare sector.

Analysis from an Organizational Ethics Lens

One avenue for consensus building and problem-solving are large provider organizations. In the case at hand, that entity is represented by a hospital, but could alternatively be a large physician practice or healthcare center in a different context. The institution of the hospital was not directly involved in the clinical or managerial decision-making for our dialysis dependent patient with a tracheostomy, but suffered many consequences of the impasse.

The patient's length of stay far exceeded that which was necessary to stabilize and treat her medical problems. Every extra day she was in the hospital represented a direct financial loss for the hospital, an opportunity cost of additional lost income from treating a different patient, and contributed to the systemic overcrowding at the institution, negatively affecting patient and provider satisfaction. When no solution could be reached, the patient left the hospital and now returns regularly to the emergency department for urgent dialysis care on an ad hoc basis, an inefficient use of system and hospital resources.

This is another example of a negative externality. The decision of the third-party dialysis center to eschew treatment of this patient made it impossible for the hospital to safely discharge her. Facility licensing made it impossible to provide outpatient dialysis at an inpatient dialysis center. While outpatient dialysis centers are closely regulated by CMS, inpatient dialysis is regulated at the institutional level through The Joint Commission or state health departments.[12] This policy was not institutional but rather a state regulation.

Circumventing this policy or negotiating an exception at the government level would require creative problem-solving by the hospital institution. As a more radical example of creative problem-solving, the hospital may have saved money in the long run by providing funding to improve the patient's socioeconomic reality and facilitate home dialysis instead of expensive emergency room care. Current health system financing does not incentivize holistic thinking about a patient's health or the system's cost.

Negotiations with dialysis centers could be positively impacted by the active engagement of the hospital. However, despite often outsized roles in their regional areas, hospital systems are often still dwarfed by most dialysis providers, which operate at a national level.[6,7] It was felt that outpatient dialysis centers were too large to revise their policies on the basis of the political pressure exerted by a single hospital.

The ethical obligations of the hospital in this case exists at the nexus between the previously discussed business and clinical ethics. A hospital has a primary responsibility and duty to provide safe and effective care to patients, and their main liability often exists in this area of clinical practice. However, care institutions also operate as business or corporate entities in the healthcare sphere and have competing interests on the fiscal side that may affect how care is delivered.

In this case, while there appears to be a primary ethical obligation to the patient and her care, the hospital must practically weigh the institutional resource utilization of each option. The chosen option was to allow existing care management infrastructure to work on the problem despite there being no clinical solution. This played out with costs to the hospital, health system, and patient as described above. The alternatives - actively negotiating with the corporate outpatient dialysis oligopoly, lobbying the state government for a license exception, or directly funding social support for this uniquely vulnerable patient - are all time and resource intensive, which disincentivizes this more active, creative approach. The fiduciary duty to the institution could outweigh any perceived ethical obligation to go above and beyond to help this single patient, especially when the likelihood of success was low.

Discussion

This case was presented to the involved clinicians as an ethical conflict. But the dilemma was not ultimately clinical in nature. Instead, a conflict between clinical and business ethics presented itself as an institutional problem that could seemingly only be handled at the bedside. Our institution has encountered several cases exactly like the one described here: a patient with ESRD and tracheostomy dependence that cannot be safely discharged from the hospital. However, this specific kind of case is not the only example of patients and providers trapped by a conflict in clinical, business, and organizational ethics. It is just a severe one. These situations, where a small group of uniquely vulnerable patients is affected, are especially difficult to ameliorate.

Unfortunately, these conflicts will become increasingly prevalent as America's healthcare system continues to grow into an ever more balkanized conglomerate of for-profit companies primarily focused on reducing costs, standardizing

procedures, and maximizing profits. In our existing highly litigious sociopolitical context, these healthcare corporations will do whatever necessary to protect their bottom line. As previously discussed, the dialysis market in particular grows more and more concentrated, with two large for-profit dialysis corporations responsible for over two-thirds of the dialysis population.[6] These consolidations often occur beneath the existing anti-trust regulatory framework, given their character and size.[7] Large dialysis centers establish the "standard of care" for the entire industry, with smaller dialysis providers following the protocols and policies of the major centers. Similarly, hospitals continue to consolidate across geographic areas with little evidence of reduced prices; in fact, some empirical evidence suggests that cross-market mergers increase prices.[13] In these increasingly uncompetitive environments, counter-therapeutic policies like the one in this case will become easier to maintain, and the balance between clinical and business ethics will likely tilt toward the latter. The plight of individual patients and providers will become an even smaller relative consideration as healthcare institutions balance their organizational ethical and corporate fiduciary obligations.

When the care of patients is intensely fragmented and no incentives exist for separate institutions to coordinate and reduce overall risk and cost, the task of making fair, safe, and ethical medical decisions falls to the individual patient and their individual provider. In these situations, providers should present the full situation to the patient and involve them in problem solving when possible, all while being honest about the true ability to effect change from the bedside.

Meanwhile, there are opportunities for improvements away from the patient's bedside. The clinical ethics consult team, tasked with helping providers work through ethical issues, were consulted in this case because it was unclear who else there was to call. Who should be called when the conflict is beyond the scope of just clinical ethics? Perhaps an organizational ethics consult team could be created with both clinical and organizational ethics representation, with a quality and resource utilization lens, and access to legal or advocacy resources when necessary.

Many potential solutions to these types of problems require a concerted and creative problem-solving effort by institutions. Most hospital quality improvement systems are designed to improve specific metrics, often set by outside regulatory and accrediting agencies. There is no metric specifically tracking length of stay or discharge patterns for patients with ESRD and tracheostomy dependence. Each case became a clinical problem for bedside providers to solve, despite the utter lack of solutions. There is some evidence that rigid authority structures, like the bureaucratic organizational hierarchies in hospital care management and administration, stifle creative problem-solving.[14] Creativity can be structurally encouraged at both the problem identification and solution development phases of problem-solving and usually involves a holistic view of the situation.[15]

Large corporate businesses, like consolidated dialysis providers, tend to have similar structural issues when it comes to creative problem solving on the ground. However, the main barrier to problem-solving in this area are misaligned incentives. There is a strong social pressure to efficiently use resources across the healthcare system, but negative externalities cloud the incentive for individual actors to save the health system money. Traditional solutions to externality problems involve either regulations or restructured incentives through taxes or fines. However, given the complexity of the principal-agent problems in the healthcare market, a simple new law or tax is a challenging solution.[16] There are policy or community-based solutions to these problems that could be discovered with buy-in from all stakeholders including patients, providers, major healthcare institutions, and regulators, possibly on an ad hoc basis. A mechanism to track previously unknown problems and conflicts would be a start to understanding the scope of these issues. In this case, lessons can be learned from pediatric dialysis, where payers have identified children with ESRD as a group that requires special attention as they are not well suited for care within the general dialysis setting. As such, there are financial and regulatory accommodations that allow for a more tailored approach to their care.

It may be reasonable to consider that a special niche be carved out in for-profit business ethics for those engaged in the provision of healthcare. While there will always be financial realities, providing corporate healthcare leadership with principles and frameworks that reflect their obligations to both business and clinical ethics could help solve these conflicts more justly and effectively.

Lastly, providers who continue to deliver complex healthcare in a complex market economy will invariably continue to suffer moral injury when organizational ethical conflicts arise. They will also be forced to confront potential conflicts

between their professional duty as physicians and their organizational obligations as employees.[17] Including these topics in graduate medical education can encourage physician advocacy and promote resilience.[18]

Conclusion

Consolidation in the healthcare sector creates increasing conflict between clinical and business ethics. An organizational ethics lens can help explain why these conflicts often present at the bedside, with individual providers often tasked with solving them. Greater attention at the practice, policy, and regulatory level is necessary to create a healthcare system capable of solving these conflicts and providing safe, quality care for the entire population, even small vulnerable groups with unique needs.

REFERENCES

1. Maroz N, Simman R. Wound Healing in Patients With Impaired Kidney Function. *J Am Coll Clin Wound Spec.* 2014;5(1):2-7. doi:10.1016/j.jccw.2014.05.002

2. Nickel C, Segarra D, Padhya T, Mifsud M. The evidence-based preoperative assessment for the otolaryngologist. *The Laryngoscope.* 2020;130 (1):38-44. doi:10.1002/lary.27845

3. Shah N. Physicians' Role in Protecting Patients' Financial Well-Being. *AMA Journal of Ethics.* 2013;15(2):162-166. doi:10.1001/virtualmentor.2013.15.2.msoc1-1302

4. Lee DKK, Chertow GM, Zenios SA. Reexploring Differences among For-Profit and Nonprofit Dialysis Providers. *Health Serv Res.* 2010;45(3):633-646. doi:10.1111/j.1475-6773.2010.01103.x

5. Centers for Medicare & Medicaid Services. Medicare Program; End-Stage Renal Disease Prospective Payment System, Payment for Renal Dialysis Services Furnished to Individuals With Acute Kidney Injury, End-Stage Renal Disease Quality Incentive Program, and End-Stage Renal Disease Treatment Choices Model. Published online November 6, 2023. Accessed May 7, 2024. https://www.federalregister.gov/documents/2023/11/06/2023-23915/medicare-program-end-stage-renal-disease-prospective-payment-system-payment-for-renal-dialysis

6. Saeed MK, Ho V, Erickson KF. Consolidation in dialysis Markets-Causes, consequences, and the role of policy. *Semin Dial.* 2020;33(1):90-99. doi:10.1111/sdi.12855

7. Wollmann, Thomas G. How to Get Away with Merger: Stealth Consolidation and Its Effects on US Healthcare, No 27274, *NBER Working Papers, National Bureau of Economic Research, Inc.* 2020 https://EconPapers.repec.org/RePEc:nbr:nberwo:27274.

8. Anumudu SJ, Erickson KF. Physician reimbursement for outpatient dialysis care: Past, present, and future. *Seminars in Dialysis.* 2020;33 (1):68-74. doi:10.1111/sdi.12853

9. Piccoli GB, Cabiddu G, Breuer C, Jadeau C, Testa A, Brunori G. Dialysis Reimbursement: What Impact Do Different Models Have on Clinical Choices? *Journal of Clinical Medicine.* 2019;8 (2):276. doi:10.3390/jcm8020276

10. Cragg W. Business Ethics and Stakeholder Theory. *Business Ethics Quarterly.* 2002;12 (2):113-142. doi:10.2307/3857807

11. Woiceshyn J. A Model for Ethical Decision Making in Business: Reasoning, Intuition, and Rational Moral Principles. *Journal of Business Ethics.* 2011;104(3):311-323. doi:10.1007/s10551-011-0910-1

12. Kalantar-Zadeh K, Henner D, Atkinson R, et al. Inpatient Dialysis Services: Nephrologist Leadership and Improving Quality and Safety. *American Journal of Kidney Diseases.* 2021;78(2):268-271. doi:10.1053/j.ajkd.2021.03.011

13. Navathe AS, Connolly JE. Hospital Consolidation: The Rise of Geographically Distant Mergers. *JAMA.* 2023;329(18):1547-1548. doi:10.1001/jama.2023.5391

14. Maier NRF, Hoffman LR. Organization and creative problem solving. *Journal of Applied Psychology.* 1961;45(4):277-280. doi:10.1037/h0041850

15. Brewster AL, Lee YSH, Linnander EL, Curry LA. Creativity in problem solving to improve complex health outcomes: Insights from hospitals seeking to improve cardiovascular care. *Learning*

Health Systems. 2022;6(2):e10283. doi:10.1002/lrh2.10283

16. Arrow KJ. *The Economics of Agency.* Institute for Mathematical Studies in the Social Sciences, Stanford University; 1984.

17. Bolton J. Professionalism, Organizationalism and Sur-moralism: Three ethical systems for physicians. *Med Health Care and Philos.* 2022;25 (1):153-159. doi:10.1007/s11019-021-10061-0

18. Aultman J, Whipkey AJ. Moving Beyond Moral Revulsion: A Deeper Analysis of Social Justice Within Clinical Ethics Training. *American Journal of Bioethics.* 2019;19(4):67-69. doi:10.1080/15265161.2019.1572821

Examining the Clinical Ethicist's Role as Educator

Joseph Raho, PhD; Federico Nicoli, PhD; and Paul J. Cummins, PhD

ABSTRACT: Providing education is a common justification for the professional value of clinical ethicists (CEs). We argue for a cautious approach in claiming educational benefits from CEs' activities. CEs' contributions to consultation, policy development, and research are recognized, but their role as educators is less well-defined. We describe various modes - formal, semi-formal, and informal - of education CEs may provide to healthcare institutions. Formal education in a defined curriculum primarily takes place in academic medical centers. This is the most structured and measurable form of education CEs may provide because standardized assessments for this form of instruction exist. Semi-formal education, usually taking the form of ad hoc lectures and debriefings, may occur at any healthcare institution but not within a set curriculum. Semi-formal education is flexible but there are not established robust mechanisms for assessing its educational impact. Finally, CEs provide informal education implicitly and spontaneously during their clinical ethics consultations. While this is secondary to the clinical ethics consultations, adult learning theory suggests that the informal education occurring in them has a great potential. In the absence of systematic evaluations of impact, however, claims of educational benefit will be unsubstantiated. We also observe that CEs and their institutions must judiciously balance CEs' educational responsibilities with their primary consulting role to ensure they function effectively as clinical ethics consultants. We conclude that the field should include pedagogical development in clinical ethics training and develop assessment tools for semi-formal and informal ethics education to buttress claims that CEs provide educational benefit.

KEYWORDS: Clinical Ethics Education, Clinical Ethics Training, Institutional Training, Pedagogy

Introduction

This article considers education as one of the roles of the clinical ethicist (CE). CEs generally serve four primary roles: clinical consultation, policy development and review, research, and education. Broad agreement exists that CEs ought to provide education in healthcare settings.[1,2] Indeed, several recent advertisements on Bioethics.net for CE positions include education as prominent job responsibilities. Education is cited as one of the beneficial dimensions of establishing ethics consultation services. Whereas the consultative and policy roles of CEs are well-defined, less so is that of educator; our non-systematic search found nine resources that reflect on the potential of CEs to be educators.[3–11] However, it is not always clear what specific form or scope these educational efforts should take for the CE.

This essay uses the term "education" to refer to instructional activities that are intended to lead to knowledge acquisition and not merely an experience that enlightens. A person is clearly engaged in education when they teach a class as part of a set curriculum. Many CEs employed in academic medical centers are expected to do this as part of their employment contracts. Hiring CEs with this expectation will definitely carry educational benefit. Not all CEs work in academic medical centers, however, so many will not engage in this kind of educational activity. Moreover, for CEs expected to teach a class, their educational impact is limited to those who enroll in their class. Still, the literature suggests that a benefit of having a CE is education. This essay reflects on how CEs may engage in education outside of set curricula and considers the strength of this benefit. It argues that while some CEs' activities clearly deliver educational benefits, for others it is ambiguous that they do. For this reason, CEs should temper claims about the educational benefit of their work that does not comprise direct instruction.

To make the case that CEs should be circumspect in claiming educational benefit, this essay will distinguish three modes of education and describe three institutional levels at which CEs may make educational contributions. At some of these modes and levels, it is possible to establish that CEs deliver valuable education benefits. However, for other modes and levels, where much of the CE's work occurs, there are few ways to conclusively demonstrate that there are educational benefits.

Educational Contexts and the CE

Education literature distinguishes among three modes of education: formal, non-formal, and informal.[3,12] Despite Eshach's, Eaton's, and others' use of the term "non-formal," we find that its use may create semantic confusion, so we adopt the term "semi-formal" to mark the mode of education intermediate between those that are formal and informal. The activities in school settings that are subject to accreditation standards comprise formal education. Semi-formal education is structured, too, but it does not occur within a school system; some examples include conference presentations, seminars, and continuing development.[12] Informal edu-

cation by contrast is not structured and is comprised of the learning that occurs in daily experience. Formal and semi-formal educational activities are alike because their educational aim is overt, whereas with informal education, it is not. On the other hand, semi-formal and informal education share the similarity that they do not emphasize assessment of the educator's performance or the learners' assimilation of the educational content.

The employment contracts of some CEs, typically those working in academic medical centers, will dictate the education activities they are expected to engage in: teach a class; provide didactic lectures in medical or nursing curricula; lead grand rounds. And yet, CEs working in either academic or non-academic settings are often met with more casual expectations for education in their clinical practice; debriefing cases with residents, lecturing ad hoc, and responding to impromptu ethical questions. Education is also presumed to occur when clinical ethicists act qua consultant: consulting on specific patient cases; participating in team and family meetings; communicating verbal and written ethics recommendations to clinical teams; joining retrospective case reviews; and contributing to ethics committee meetings. These activities comprise all of the modes of education described in the previous paragraph. When CEs teach classes within accredited degree curricula, they are engaged in formal education.

The activities in which education is less officially prescribed for CEs are either semi-formal or informal. Ad hoc lectures and planned debriefs are semi-formal modes of education because they may exhibit structure and planning without being part of a longitudinal class or curriculum. The mode of education that occurs when a CE acts qua consultant is informal; these are events that occur spontaneously within the normal practice of healthcare (See **Table 1** on the following page for a breakdown of educational activities by CE role.)

In addition to these modes of education, CEs may engage in educational activity that has an impact at different levels, i.e., the macro-, meso-, and micro-levels. Research and scholarship on clinical ethics could be considered an educational activity because it is intended to generate new, generalizable knowledge. It is a macro-level activity because it aims at a broad influence; its goal is to expand the professions' knowledge and/or alter its practice. However, this educational activity does not directly align with the modes of education already described. Educational activities that occur in policy making have institution-wide influence and are also examples of macro-level activity. For example, CEs may serve on curriculum or training committees for their institutions, helping to set expectations for ethics training or the conduct of all students or employees. These activities are not part of the formal mode of educational activities either, though they contribute the structure necessary for it. If a CE gives a lecture as part of the onboarding process, this would be an example of an educational activity that is both formal and macro-level.

At the meso-level, the educational activities CEs perform involves interacting with and influencing subsets of their institutions' members. Sometimes CEs will accomplish this by teaching classes that are part of a curriculum and are therefore considered formal education. When CEs are invited to debrief cases with residents and their attendings, or give lectures to a department, they engage in semi-formal, meso-level education. These activities may be included in the description of the CEs' responsibilities, but their frequency is not typically codified. Instead, these are scheduled on a casual basis as CEs balance these activities against other expectations like fielding consults and teaching classes. Finally, at the meso-level, CEs engage in educational activity if they explain clinical ethics concepts as relevant in departmental meetings. This is informal education, and it is possible that even the CE fails to notice when this kind of education takes place.

Finally, the actual work of clinical ethics consultation comprises the educational activity that occurs at the micro-level. Many models exist for conducting a clinical ethics consultation, but common features include solicitation of relevant clinical information and patient preferences, identification of relevant values, norms, and laws, and an explanation of their application to the case, formulation of an ethics question or problem, a recommendation with discussion of the reasoning in support of it, and a note of the process included in the patient's medical record. At minimum, the written record will be instructive to those who read it closely, but it is likely that in the course of interacting with relevant stakeholders, the CE will provide explanations of the process that are instructive, too. In these activities, their educational potential remains covert in order to respect the sensitivity of the situation. This is informal education, and it is micro-level due to its specificity to the case on which the CE was consulted.

TABLE 1	Educational Need	Type	Example
In CE's *consulting* role	Analyze and resolve an ethics dilemma in a clinical case	Informal	Performing an ethics consultation upon request of physician
	Explain the rights and responsibilities of stakeholders	Informal	During interdisciplinary team or goals of care meeting
	Clarify recommendation	Informal Semi-formal	Discussion with consultor Additional ethics note in chart with explanation
	Clarify hospital policy	Informal	Explain the due-process steps in the non-beneficial treatment policy
	Retrospective/ prospective case review	Informal/semi-formal (depending on the approach)	During meeting, identify and provide ethical strategies for addressing future cases
In CE's *policy* role	Review current hospital ethics policies and suggest revisions if needed	Informal Semi-formal Semi-formal	Participate in discussion of policy Presentation to Ethics Committee Write a report to Ethics Committee, summarizing ethical justifications for adopting/rejecting certain proposals
	Analyze the ethical "state of the art" of a new, controversial medical practice	Semi-formal	Perform literature review, circulate academic articles, and lead discussion in Ethics Committee regarding whether to allow organ retrieval using normothermic regional perfusion
In CE's *educational* role	Offer a course	Formal	Clinical ethics course for first-year medical students
	Offer a mini-course to complement didactic offerings	Formal	Case-based ethics discussion for Resident Physicians in Pediatrics
	Offer a guest lecture to complement didactic offerings	Formal/Semi-formal	Case-based presentation to Master's-entry Nursing students
	Offer educational offering to new staff of a Department	Formal	Mandatory ethics presentation for new hires in Nursing
	Offer educational offerings to all staff members of the hospital	Semi-formal/ Informal	Monthly ethics journal club
	Mentoring trainees	Informal	During clinical ethics fellowship
	Educate new ethics committee members	Semi-formal	Orientation course with readings

Clinical Ethicists and Education

Formal Education

Formal education is the type of education that CEs can most readily point to in order to show the educational value they bring to their institutions. First, formal educational activities are, as noted, usually contractually specified. A CE's contract that includes teaching should establish the amount of time the CE's teaching activities comprises their effort. When CE's schedule courses that fill and run, this is one way in which they can show their value to the institution. This is one metric of many for establishing that CEs have provided value through their educational activities. Although enrollments are a necessary economic measure to help academic institutions apportion their resources, this does not reflect the ideal of educational value.

The paramount goal of formal education is to inculcate knowledge and skills in learners. CEs generate this value in formal education through their course instruction. Within the structure of formal education, there are several ways to evaluate whether the instruction has been valuable. First, this type of instruction includes assessments of students to determine if they have achieved the course goals. Assessments that show students have learned what the course intended them to learn indicate that the CE's instruction has provided value. Evaluations of the CE's performance as instructor are another way to establish the CE's educational value. Student evaluations can provide objective reports on some of the ways the CE performed as an instructor: provision of a syllabus; following the syllabus; explaining the standards of the course; providing timely and relevant feedback; instructor availability; etc. In addition to student evaluations, peer teaching reviews can assess the CE's value as an instructor. Peer reviews provide high level evaluation of the CE's teaching in domains like content and pedagogy. Peer reviews that are positive are strong evidence of the CE's value to formal education.

Another factor that fosters educational value from CEs' instruction is that it is part of an organized curriculum. Institutions with structured curricula often establish pedagogical standards for their course offerings and support their faculty with pedagogical development resources to meet them. CEs who engage in formal education should aim to satisfy these expectations; this will help to ensure quality education offerings from them.

When CEs are instructor of record for a course, they need time for course design and revision, preparation, grading, and meeting with students. CEs should be careful to set reasonable teaching expectations to ensure that their consulting and teaching activities are not compromised. During the term of their courses, CEs and employers may find it prudent to provide protected time for teaching when CEs are not expected to provide consultations. This can help to ensure that CEs deliver the educational value expected and consults are not subject to distraction.

The structure of formal education lends itself to creating the conditions in which CEs are able to provide value through instruction. However, demonstrating their value through instruction in formal education settings is limited to those CEs whose place of employment is in an academic medical center attached to a medical school or university. There are reasons to doubt that the conditions of semi-formal and informal education are conducive to demonstrating that CEs deliver educational value to the same degree.

Semi-Formal Education

Semi-formal education is comprised of "semi-structured" learning experiences that are not part of a planned curriculum. Some examples of this are organizing seminars or journal clubs, debriefs with residents or house staff, irregular requests for lectures from departments, or continuing development sessions for staff or members of ethics committees. CEs are likely to include these as educational activities in annual performance reviews because participant learning is an overt goal for these events. However, objectively establishing the educational benefit of these kinds of activities is ambiguous because it would rely on attendee evaluations which are unlikely to be collected at the time.

Several features of CEs' semi-formal educational work suggest that they have educational value to the learners, and, by implication, their institutions. For example, continuing development sessions usually include specific learning objectives, and the same is true of lectures. When CEs design their presentations or lectures to fulfill these learning objectives, they are observing a pedagogical principle known as "backward design."[13] As noted, CEs engaged in formal education are likely to be familiar with good pedagogy like this and use it. Whether or not CEs who do not have any responsibilities in formal education are familiar with it is uncertain. So, if sound peda-

gogy guides the development of semi-formal learning sessions, CEs are more likely to deliver high educational value. It is probable that this approach is consistent across CEs.

Other considerations from pedagogical theory suggest that the semi-formal education CEs provide is valuable. Malcolm Knowles theorized that adult learners exhibit certain traits that instructors should account for in their instruction to be effective. Knowles argues that adult learners are primed for education by a need to know, self-direction, experience, readiness, orientation, and motivation.[14] His central ideas are that (1) adults learn best when they understand why they should learn something and assume responsibility for pursuing education and (2) that instruction draws on their personal experience for examples and is applicable to tasks they must perform and problems they must solve. Semi-formal education activities that CEs perform exhibit this dynamic.

When CEs debrief with teams, provide ad hoc lectures to specialty departments or Grand Rounds, organize seminars or journal clubs, or present for continuing development sessions, their audience is likely to be receptive to learning in these formats because they are adults. Attendance at ad hoc lectures, grand rounds, or continuing development is often optional, so the learners who attend them are likely to be self-directed and internally motivated to learn about the particular topic presented by the CE. These learners also probably possess the need to know, readiness, and orientation characteristics because their choice to attend one of these sessions suggests that they appreciate that the topic is important to understand and/or they recognize that the topic is relevant to a problem they have faced or will face in their practice. In other mandatory activities, like debriefing with the house staff, the learners may not have the characteristics of self-direction or motivations, but other factors should make them receptive to education from the CE. First, any ethical issues that the CE discusses during these rounds will arise from the participants' clinical cases. Discussing ethics through their cases means that the educational activities are rooted in experience, which enhances adult learning. Often, teams invite CEs to debrief with them because they had a challenging case that created an ethics dilemma or ethics question for them. In those instances, the members of the team will need to learn how to resolve the dilemma or answer the question. They will possess readiness or orientation to learn because they are learning in order to apply a needed skill to a genuine challenge. This will be true of both junior and senior team members since healthcare practice, ethical understanding, and laws are always evolving.

Although CEs may or may not extend certain pedagogical best practices from formal education to semi-formal education activities, their learners may exhibit features conducive to adult learning, and activities themselves may align with ideals of adult learning theory, there are still considerations that prevent unequivocal endorsement of CEs' efforts as educationally valuable. In both formal and semi-formal education, a well-intentioned instructor can strive to apply best pedagogical practice or optimize the conditions for learning, but still teach poorly. In formal education, there are multiple means of assessing an instructor's performance: student grades, peer reviews, student evaluations. In semi-formal education, the same options for evaluation are often impractical. It is rare to assess if participants in a journal club or the audience at ground rounds, continuing development, or lectures have assimilated the information or skills the CEs intended to impart. Without those assessments, judgments of whether the CEs have reached their educational goals are subjective, and potentially unreliable. Unless a CE has CE colleagues who attend these presentations, the potential of peer review to judge the educational value of the activity is lost. And, even if CEs have colleagues, these colleagues may have conflicting commitments that prevent them from observing these activities. Assessment in semi-formal education is possible, but it cannot attain the same level of rigor and comprehensiveness as in formal education.

Some people may suggest that the evaluations that audiences complete at the end of grand rounds or continuing development sessions are a potential way to assess the educational value CEs provide. An analogy between student evaluations and audience evaluations supports the potential worth of these evaluations for establishing the value of a CE's semi-formal educational efforts. Despite the analogy, these evaluations are of questionable use. The analogy is weaker than it appears since student evaluations solicit answers to objective questions, such as whether feedback was timely and relevant, or the instructor was available for consultation. The evaluations that follow grand rounds or continuing development sessions tend to employ Likert scales, which tap audiences' subjective perceptions of their own learning or the presenter's quality. These measures seem unreliable, or worse, reveal a measure that is more akin to customer satisfaction.

CEs can easily report the quantity of semi-formal educational activities they perform, but quantity should not be mistaken for quality. Measuring the benefit of semi-formal educational activity can have the effect of incentivizing CEs to provide too much semi-formal education to the detriment of their consultation activity or policy work. Just as with formal education, CEs must be careful to ensure an appropriate balance of responsibilities to prevent undermining the primary activity, clinical ethics consultations.

Ambivalence may be the best perspective toward the case for whether CEs provide educational benefit through semi-formal education. On the one hand, the context in which CEs would provide this seems like an environment in which education can flourish when adult learning theory is considered. However, the same conditions make it difficult to assess the quality of these efforts.

CEs' semi-formal educational activities may be valued for other reasons, like enhancing the institutional culture. We acknowledge this and do not wish to disparage these contributions; however, at least at present, it seems unwarranted to justify the benefit of clinical ethics consultation services by citing the value of CEs' semi-formal educational work. Despite this pessimism, semi-formal education is a potential fertile environment for CEs to provide value to their institutions because many of the adult learning theory conditions are innate to teaching in a healthcare setting. If CEs continue to view educational value as one of the justifications for their services, then the profession should ensure its training and fellowship programs include instruction in pedagogy and engage in research for better methods to measure this. By enhancing CEs' readiness to teach effectively and developing tools for demonstrating effectiveness, the profession can prioritize quality over quantity in semi-formal education.

Informal Education

As noted earlier, CEs engage in informal educational activities primarily when this work occurs through their capacity as clinical ethics consultants. The majority of CEs' time is devoted to their primary responsibility of clinical ethics consultation, so their greatest opportunity to provide education is the informal education mode. However, because this educational activity is a spontaneous feature of their consulting work, it is unstructured and its educational nature obscured from potential learners, which is different from formal and semi-formal education.

An important responsibility that CEs have is to contribute their relevant ethics expertise to policy making. Sometimes, CEs are invited to policy making bodies that have broad social influence – the presence of CEs on the New York State Taskforce on Life and the Law, which collaborated with the New York State Department of Health on its 2015 guidelines for ventilator allocation during an influenza epidemic, is one example of this.[15] More locally, CEs may be asked to participate in developing or revising a healthcare institution's policy regarding conflicts over potentially inappropriate treatment, decision-making for certain patient populations (e.g., the unrepresented), or in response to new laws (e.g., medical-aid-in-dying). These are examples of macro-level activities. In policy making, CEs' role may entail explaining ethical considerations on a clinical practice or policy, offering an ethical analysis of newly available treatment options, identifying a range of ethical options for the policy committee to consider, and helping them to consider the ethical implications of a policy's implementation.

How CEs carry out these activities may bear superficial similarities to formal and semi-formal education if they use presentation strategies typical of classroom instruction or continuing development sessions. However, when CEs do this as part of a policy making committee, the educational nature of these presentations might not be transparent to the other members because policy committee members are disposed to see each other as peer collaborators. The CE, too, might not even recognize that they are engaging in education in this setting. It is unfortunate that the educational potential of these presentations is possibly obscured since instruction in the context of policy-making has many of the core features of adult learning theory. The members of a policy making committee are ready for ethics education because they will understand its need in order to develop a sound policy and recognize it as a normal feature of their professional responsibilities.

Even though policy making may be one of a CE's recurring responsibilities, it will not be as frequent as engaging in actual clinical ethics consultations which will occupy the majority of a CE's time. Within the micro-level activity of clinical ethics consultation, there is inherent potential for education. Still, the primary responsibility of CEs is to promote excellence in clinical decision-making among stakeholders who hold different and often conflicting perspectives of what should be done in a particular situation. CEs ought to en-

sure that a fair process for adjudicating these claims is being followed, and that the relevant stakeholders know and understand, to the extent possible, the applicable rules, principles, and institutional processes that bear on the consultation question. The inherent potential for education in clinical ethics consultation is derivative of and secondary to the CE's primary role as a consultant. For example, in clarifying the ethical uncertainty or problem as reported by the consultee (for clarification on the relatively subjective nature of the ethical issue, see Hynds)[16] and identifying what may be morally obligatory, permissible, or prohibited for stakeholders to do in a given context, the CE will educate consultees regarding the ethical principles or rules at play and how they ought to be applied. Similarly, the formal ethics recommendations prepared for patients' medical records will have semi-didactic form – recommendations will briefly highlight and explain relevant ethical concepts, rules, applicable hospital policies, etc., and outline various approaches to try to resolve the ethical question or concern raised by the consultee. Such formal ethics notes become an educational tool for the immediate team and future clinicians involved in a patient's care.

Although the clinical ethics consultation may be the setting that is most conducive to education considering adult learning theory, it also faces some of the same drawbacks that semi-formal education does. There is no effective way to assess if the subjects of education learned from the activity. While clinical ethics consultations services do survey their users, these surveys evaluate satisfaction with the service rather than learning.[17] It would be inappropriate to include questions about education in those surveys since the educational component of consultations is not transparent to its users and it may undermine confidence that supporting ethical clinical care is the primary goal of the service. On the other hand, many CEs review past cases by publishing peer-reviewed articles, while some consultation services follow guidance to incorporate retrospective reviews.[18–23] The internal review of consultation notes can serve the same function of peer review in formal education, which can help to support the claim that CEs provide educational value.

There is a potential pitfall to claiming there is educational value in clinical ethics consultation. As noted, some CEs may not appreciate its inherent educational potential, which means in some cases, we may oddly give CEs credit for something they do not realize they are doing. However, CEs who appreciate the potential educational value in consultations must be careful, too. For one, while the ethics consult note may be an educational tool, the CE must be cautious that in its didacticism the note does not imply it is universally applicable to all cases and misleading consultees into believing they can resolve future similar cases independently. Secondly, and most importantly, CEs must be careful never to undermine their core responsibility of clinical ethics consultation, which means that the CE must prioritize engaging with the dilemma qua consultant, and only permit the educator role to be derivative from it.[21] Striking this balance may be difficult, but it is essential to maintaining respect for the dignity of the patients on whose cases they are consulting.

The CE primarily aims to offer solutions to ethical challenges in daily clinical practice. In these cases, the CE must be careful to balance the delivery of professional expertise with education. The CE's expertise involves interpreting ethical norms in light of the particular details of each individual consultation case. The CE must also be careful to avoid suggesting that their recommendation is not constrained by principled standards. To strike the wrong balance is to put patients at risk of receiving less than an ethical standard of care that reflects uncritical conventionalism, relativism, or intuitionism on the part of health care practitioners (HCPs).

The previous section's conclusion proposed that if clinical ethics consultation professionals resolve to partially justify their services on grounds of educational value, then they should leverage the fertility of semi-formal education by developing training programs that promote pedagogical excellence among CEs and develop tools for evaluating. The same case and qualifications can be made for the semi-formal and informal education that occurs in CEs' most prominent activities, policy making and clinical ethics consultation itself. However, this may be an especially difficult challenge for informal education in clinical ethics education because of the need to ensure that the CE's consultant role is always primary.

Moral Education

Some people may envision moral education as a key part of the education that clinical ethicists provide, and which this article has not yet addressed. In this vision of ethics education, one of its aims might be to improve the ethical character of HCPs.[24–26] CEs can contribute to the moral education of HCPs when they help them to reason

through an ethical dilemma by considering their role-specific duties (e.g., "How should I act as a doctor when my pediatric patient's parent asks me not to disclose the diagnosis to the patient?") or plan on how to fulfill their duty by reflecting on the professional virtues they should embody in a situation (e.g., "What would a caring hospice nurse do to help a patient complete an advance directive?"). An alternative goal might be enhancing the ethical culture of a department or institution.[27–30] One way CEs may do this is by soliciting input about common ethical challenges faced by particular HCPs and offering educational sessions to address them. Another option is to present and discuss new ethics policies with HCPs to cultivate moral sensitivity in cases where the policy is relevant. For example, when CEs present a new policy on unrepresented patients and its ethical and practical significance, they may help a unit be attuned to this vulnerable group and initiate a protocol to support these patients sooner. Alternatively, some hospital units may have environments that inhibit HCPs from speaking up about ethical issues. At times, nurses for example report feeling unable to share their ethical perspectives with their physician colleagues. Some physicians face similar situations when their patient is being co-managed by another specialty (e.g., transplant, surgery, oncology). Research has shown that nurses and physicians in critical care settings sometimes hold divergent expectations about their respective moral obligations. In oncology, another study found that many HCPs do not discuss their ethical concerns until a crisis situation occurs.[31,32] CEs may work with certain clinician groups to foster greater awareness of ethical issues on particular units, encourage moral sensitivity to diverse perspectives, reduce barriers to a more open culture, and promote transparency and the courage to speak up proactively.

To realize the goal of moral education, moral educators must draw from a broad range of disciplines and standards. CEs are prime candidates to do this because there is an essentially interdisciplinary field that draws on a range of subjects and considerations: philosophy (i.e., ethics), clinical ethics in particular, psychology, sociology, prevailing professional guidelines, applicable laws, relevant institutional policies, etc. Furthermore, they can pursue these aims through any of the modes (formal, semi-formal, or informal) of education.

For several reasons, CEs should be cautious in claiming that moral education is also one of the benefits of their service. First, calling the development of moral habits or virtues in HCPs and fostering of ethical climates "education" may be metaphorical. These kinds of activities may be better understood as moral formation or transformation. Aristotle, for example, claimed in the Nicomachean Ethics that morality was developed through practice and habituation rather than reasoning and instruction.[33] Second, other forms of ethics instruction generally do not assume the ambitious goal of moral formation; a typical course in ethics usually does not have enhanced moral character as one of its course outcomes. So, unless clinical ethics education is essentially different from other forms of ethics instruction, there is reason to doubt it involves systemic moral formation. The point we wish to stress is that while *educating* people on what the right thing to do is and reasoning methods to determine it are important components of moral education, moral *formation* cannot occur without the process of repetition and habit that inculcates a virtue. Clinical ethics education, like all forms of ethics instruction, from the formal to informal modes, is unlikely to provide that repetition with sufficient constancy to yield a virtuous habit, and therefore moral development. A study by Schwitzgebel suggests that ethics education may thwart moral education; he found that the kinds of books that ethics professors would check out of the library were more likely to be missing than other books.[34] Third, moral education does not appear to be the monopoly of CEs. Many people try to morally improve others, so it stands to reason that the techniques people employ to do so are not solely derived from the corpus of clinical ethics. If CEs contribute to moral development, this will be an additional, but not exclusive, benefit they provide.

Two final reasons to be wary that CEs provide moral education focus on the difficulty of morally improving others. The fourth reason is that moral formation as education would require time and a durable (special) relationship between the teacher and student. If CEs are not embedded within a unit or department, they are less likely to have the regular contact needed to morally improve one another or the kinds of relationships with people where they can serve as moral mentors. Finally, outside of formal education, CEs' opportunities to provide ethics education to HCPs is mostly dependent on HCPs' recognition of their own need for it. However, those most in need of moral education sometimes are the least likely to recognize it and so those units are unlikely to invite CEs for lectures or rounds or to seek clinical ethics consultations. If this is correct, when CEs provide semi-formal

or informal moral education, the cumulative benefits will not reach their transformative potential. For all of these reasons, CEs should be cautious about claiming moral education as a benefit of their service.

Objections

Some CEs may object that we are too cautious in attributing educational benefit to informal education, which we acknowledge has significant potential for education because of all the ways in which it embodies multiple qualities of adult education theory. A major reason for caution was the lack of transparency regarding the informal education of clinical ethics work. Although it necessarily has educational potential, this can never be paramount in clinical ethics work and must always remain below the surface, which we claim inhibits its educational benefit. There are two opposing objections that CEs more confident in the educational benefit of clinical ethics might make. First, they might point out that the experience of engaging with CEs can be activating to HCPs' educational sensibility. When HCPs, especially physicians, consult one another there is a common foundation of language, vocabulary, and methods — that of medical science. Believers in the educational benefit of clinical ethics would point to our claim that CEs draw from a vast well of resources (i.e., ethics, psychology, law, etc.) in their work that HCPs are unlikely to share to the same degree. Proponents of educational benefit may argue that this will trigger an awareness in HCPs that there is opportunity for learning of which they can take advantage. If this is true, we should be more optimistic about the educational benefit of clinical ethics. This is, however, an empirical claim which requires verification; CEs should claim the benefit when they have the evidence.

An alternative response to our concern that the educational potential of clinical ethics work is not transparent is to point to the successful role of informal education in HCPs' professional training. Nurses and physicians cannot learn to practice simply through classroom instruction; their immersive and experiential learning on the floors, in clinical rotations, and residency is a vital component of educating them on the corpus of nursing and medical knowledge and the procedures and norms of clinical practice. If this is a vital part of HCPs' educations and HCPs trained in this way are effective practitioners, this is evidence that informal education is an effective mode of educating HCPs, and they can derive major benefits from informal clinical ethics education. It is impossible to deny that experience is a valuable teacher for HCPs, and this recognition lies behind our appreciation of the inherent educational potential in clinical ethics work. However, the analogy between informal clinical education and informal clinical ethics education is not total and it raises some concerns. One important difference between informal clinical education and clinical ethics education is that there are evaluations to confirm that trainees learned the lesson that these clinical experiences are designed to impart: preceptor reports; tests; licensing examinations. It is still the case that CEs have no way to evaluate if they informally educated others in their clinical ethics work.

Aside from this difference, medical educators have raised concerns about the "hidden curriculum" that lurks beneath the surface of informal clinical education.[35–39] The hidden curriculum refers to the unintended lessons students learn in their education; because they are unintended, it is possible that uninterrogated biases comprise part of these lessons. It would be a folly to assume that CEs will not unintentionally transmit systemic biases when engaged in informal education because CEs are a product of their time and culture.[40] If CEs claim informal education is a benefit of their work, they will bear special responsibility for any biased lesson they transmit. CEs should be wary of the potential hidden curriculum pitfall in informal education.

Conclusion

The educational value CEs bring to their institutions is one justification for this service, and CEs have multiple opportunities to engage in clinical ethics education, which vary by the type of institution that employs them. CEs employed at universities or academic medical centers, or some non-academic medical centers, may have the opportunity to engage in formal education. Because these activities are part of a structured curriculum, their value can be measured by reviewing student performance and student and peer evaluations. These activities are typically included in a CE's contractual responsibilities, too, so a ready measure of value is whether the CE actually teaches. It is important though for CEs to be careful not to assume too much teaching responsibility since it may detract from their primary responsibility, clinical ethics consultation. The potential value from CEs providing semi-formal and informal

education is significant because of the way it responds to the readiness of healthcare professionals to learn as suggested by adult learning theory. As with formal education, CEs must ensure that their semi-formal education activities do not detract from their consulting responsibilities. Despite both of these points, there is a need to develop reliable tools for assessing the educational quality of these activities. There may also be a need to enhance the training of CEs to include skills they can use to unlock this potential. There is a special concern about balancing the roles of consultant and educator when informal education occurs within clinical ethics consultation itself; to effectively do both may require special techniques.

There are other ways to establish the value of clinical ethicists in hospitals, but as long as the profession appeals to its educational benefit in part to justify its value, it should pursue research on enhancing and assessing the quality of teaching and the credibility of the ethicist in the semi-formal and informal education CEs perform.

REFERENCES

1. Fox E, Arnold RM. Evaluating Outcomes in Ethics Consultation Research. *J Clin Ethics*. 1996;7(2):127-138. doi:10.1086/JCE199607205

2. Bruce CR, Majumder MA, Stephens A, Malek J, McGuire A. Cultivating Administrative Support for a Clinical Ethics Consultation Service. *J Clin Ethics.* 2016;27(4):341-351.

3. Eshach H. Bridging In-school and Out-of-school Learning: Formal, Non-Formal, and Informal Education. *J Sci Educ Technol.* 2007;16 (2):171-190. doi:10.1007/s10956-006-9027-1

4. Farroni JS, Tumilty E, Mukherjee D, McCammon S, Chooljian DM, Eves MM. Emerging Roles of Clinical Ethicists. *J Clin Ethics.* 2019;30(3):262 -269.

5. Glover JJ, Ozar DT, Thomasma DC. Teaching ethics on rounds: The ethicist as teacher, consultant, and decision-maker. *Theor Med.* 1986;7(1):13 -32. doi:10.1007/BF00489419

6. La Puma J. Clinical Ethics, Mission, and Vision: Practical Wisdom in Health Care. *J Healthc Manag.* 1990;35(3):321.

7. Pellegrino ED, Siegler M, Singer PA. Teaching clinical ethics. *J Clin Ethics.* 1990;1(3):175-180.

8. Ross JW. Why clinical ethics consultants might not want to be educators. Camb *Q Healthc Ethics.* 1993;2(4):445-448.

9. Siegler M, Pellegrino ED, Singer PA. Clinical Medical Ethics. *J Clin Ethics.* 1990;1(1):5-9. doi:10.1086/JCE199001102

10. Singer PA, Pellegrino ED, Siegler M. Clinical ethics revisited. *BMC Med Ethics.* 2001;2(1):1. doi:10.1186/1472-6939-2-1

11. Walker MU. Keeping Moral Space Open New Images of Ethics Consulting. *Hastings Cent Rep.* 1993;23(2):33-40. doi:10.2307/3562818

12. Eaton SE. Formal, Non-Formal and Informal Learning: The Case of Literacy and Languages in Canada. *Eaton International Consulting, Inc*.; 2010. Accessed November 29, 2023. https:// www.academia.edu/217452.

13. Wiggins G, McTighe J. Understanding by Design. *Association for Supervision & Curriculum Development;* 2005. Accessed November 29, 2023. http://ebookcentral.proquest.com/lib/ clarkson-ebooks/detail.action?docID=3002118

14. Knowles MS, III EFH, Swanson RA. *The Adult Learner: The Definitive Classic in Adult Education and Human Resource Development.* Routledge; 2014.

15. New York State Task Force on Life and the Law, New York State Department of Health. *New York State Task Force on Life and the Law; New York State Department of Health Ventilator Allocation Guidelines.* New York State Department of Health; 2015:272.

16. Hynds JA. Ethics Consultation, Professional Praxis, and What it Means to Be a "Consultant." In: Finder SG, Bliton MJ, eds. *Peer Review, Peer Education, and Modeling in the Practice of Clinical Ethics Consultation: The Zadeh Project.* Springer; 2018. Accessed December 4, 2023. http://www.ncbi.nlm.nih.gov/books/NBK543843/

17. Filippini M, Nicoli F, Picozzi M, Latronico N. The need for clinical ethics consultation: a monocentric observational survey study in the intensive care unit (Consul.E.T.I. study). *J Anesth Analg Crit Care.* 2022;2(1):40. doi:10.1186/s44158-

022-00069-0

18. Bell JAH, Salis M, Tong E, et al. Clinical ethics consultations: a scoping review of reported outcomes. *BMC Med Ethics.* 2022;23:99. doi:10.1186/s12910-022-00832-6

19. Fox E. Strategies to Improve Health Care Ethics Consultation: Bridging the Knowledge Gap. *AMA J Ethics.* 2016;18(5):528-533. doi:10.1001/journalofethics.2016.18.5.pfor1-1605

20. Kang Y, Chao S, Battles A, Firn J. Clinical Ethics Consultation for Patients Impacted by Incarceration: A Single Center Retrospective Review. *J Correct Health Care Off J Natl Comm Correct Health Care.* Published online April 9, 2024. doi:10.1089/jchc.23.10.0083

21. Nicoli F, Cummins P, Raho JA, Porz R, Minoja G, Picozzi M. "If an acute event occurs, what should we do?" Diverse ethical approaches to decision-making in the ICU. *Med Health Care Philos.* 2019;22(3):475-486. doi:10.1007/s11019-019-09887-6

22. Orr RD, Morton KR, deLeon DM, Fals JC. Evaluation of an ethics consultation service: Patient and family perspective. *Am J Med.* 1996;101 (2):135-141. doi:10.1016/S0002-9343(96)80067-2

23. Yoo SH, Kim Y, Choi W, et al. Ethical Issues Referred to Clinical Ethics Support at a University Hospital in Korea: Three-Year Experience After Enforcement of Life-Sustaining Treatment Decisions Act. *J Korean Med Sci.* 2023;38(24):e182. doi:10.3346/jkms.2023.38.e182

24. Carrese JA, Malek J, Watson K, et al. The essential role of medical ethics education in achieving professionalism: the Romanell Report. *Acad Med J Assoc Am Med Coll.* 2015;90(6):744-752. doi:10.1097/ACM.0000000000000715

25. Shelton W, Campo-Engelstein L. Confronting the Hidden Curriculum: A Four-Year Integrated Course in Ethics and Professionalism Grounded in Virtue Ethics. *J Med Humanit.* 2021;42(4):689-703. doi:10.1007/s10912-021-09694-2

26. Kim DT, Applewhite MK, Shelton W. Professional Identity Formation in Medical Education: Some Virtue-Based Insights. *Teach Learn Med.* 2024;36(3):399-409. doi:10.1080/10401334.2023.2209067

27. Hamel R. Fostering an Ethical Culture: Rules Are Not Enough. *Health Prog.* 2009;90(1):10-12.

28. Nelson WA, Taylor E, Walsh T. Building an Ethical Organizational Culture. *Health Care Manag.* 2020;39(4):168-174. doi:10.1097/HCM.0000000000000304

29. De Panfilis L, Magelssen M, Costantini M, et al. Research, education, ethics consultation: evaluating a Bioethics Unit in an Oncological Research Hospital. *BMC Med Ethics.* 2022;23(1):133. doi:10.1186/s12910-022-00863-z

30. Westbrook JI, Urwin R, McMullan R, et al. Evaluation of a culture change program to reduce unprofessional behaviours by hospital co-workers in Australian hospitals. *BMC Health Serv Res.* 2024;24(1):722. doi:10.1186/s12913-024-11171-0

31. Pavlish CL, Brown-Saltzman K, Raho JA, Chen B. A National Survey on Moral Obligations in Critical Care. *Am J Crit Care.* 2019;28(3):183-192. doi:10.4037/ajcc2019512

32. Pavlish C, Brown-Saltzman K, Fine A, Jakel P. A Culture of Avoidance: Voices From Inside Ethically Difficult Clinical Situations. *Clin J Oncol Nurs.* 2015;19(2):159-165. doi:10.1188/15.CJON.19-02AP

33. Aristotle. *The Complete Works of Aristotle: The Revised Oxford Translation. Vol 2.* (Barnes, Jonathan, ed.). Princeton University Press; 1984.

34. Schwitzgebel E. Do ethicists steal more books? *Philos Psychol.* 2009;22(6):711-725. doi:10.1080/09515080903409952

35. Brown MEL, Coker O, Heybourne A, Finn GM. Exploring the Hidden Curriculum's Impact on Medical Students: Professionalism, Identity Formation and the Need for Transparency. *Med Sci Educ*. 2020;30(3):1107-1121. doi:10.1007/s40670-020-01021-z

36. Goldie J. Review of ethics curricula in undergraduate medical education. *Med Educ.* 2000;34 (2):108-119. doi:10.1046/j.1365-2923.2000.00607.x

37. John D, George T. Hidden Curricula, Ethics, and Professionalism. *Ann Intern Med.* 2018;169 (6):425. doi:10.7326/L18-0350

38. Lawrence C, Mhlaba T, Stewart KA, Moletsane R, Gaede B, Moshabela M. The Hidden Curricula of Medical Education: A Scoping Review. *Acad Med J Assoc Am Med Coll.* 2018;93 (4):648-656. doi:10.1097/ACM.0000000000002004

39. Lehmann LS, Sulmasy LS, Desai S. Hidden Curricula, Ethics, and Professionalism. *Ann Intern Med.* 2018;169(6):425-426. doi:10.7326/L18-0351

40. Andrews EE, Ayers KB, Stramondo JA, Powell RM. Rethinking systemic ableism: A response to Zagouras, Ellick, and Aulisio. *Clin Ethics.* 2023;18(1):7-12. doi:10.1177/14777509221094472

EDITOR'S NOTE

Each year, the *Journal of Hospital Ethics* publishes the proceedings of the International Conference on Clinical Ethics and Consultation (ICCEC). Consistent with our editorial policy, all of the abstracts included in these issues are published as provided to us by the organizers of each ICCEC meeting. We would like to acknowledge the full set of authors of four abstracts from the 2024 ICCEC meeting, some of whom were not included in those materials but should be noted for both reference purposes as well as general recognition of their work:

In relation to the presentation, "Embedding Equity, Diversity and Inclusion Principles into REB Reviews" (Vol 10, No 2, page 135), the authors are Rebecca Greenberg, Rosalind Abdool, and Anjana Sengar. In relation to the presentation, "Leaps and Bounds: Advancing Ethics Review in AI Research" (Vol 10, No 2, page 168), the authors are Anjana Sengar, Rosalind Abdool, and Rebecca Greenberg. In relation to the presentation, "A State Legislator and a Practicing Physician Walk Into a Bar… Insights From the Front Lines of Healthcare Politics and Caring for Marginalized Communities" (Vol 10, No 2, page 164), the authors are Hunter Cantrell and David Satin. In relation to the presentation, "The Role of Clinical Quality Incentives and Health Disparities in Our Communities" (Vol 10, No 2, page 139), the authors are Hunter Cantrell, Maurice Hicks, Alex Conway, and David Satin.

The Editorial Group
John J. Lynch, MD Center for Ethics
MedStar Health, Washington, DC

JOURNAL OF HOSPITAL ETHICS **Volume 10, Number 3**

AIMS & SCOPE
The Journal of Hospital Ethics (JoHE) is designed to enhance interdisciplinary discourse in bioethics, and to assist in the development of the practical reasoning and clinical skills required for recognizing, understanding, and managing moral uncertainties and ethical complexities within hospital systems and hospital practice.

EDITORIAL POLICY
The Journal of Hospital Ethics (JoHE) 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. Whereas book reviews are solicited by the Editorial Group, all other submissions to the journal will be reviewed for publication with the understanding that they are not under consideration, accepted, or published elsewhere. Authors of all material accepted for publication will be required to assign copyright to the publisher. Please limit manuscript submissions (whether intended as a feature or case analysis) to a range of 4000-6000 words, and abstract paper proposals to 250 words. JoHE adheres to the American Medical Association Manual of Style (11th Edition).

PEER REVIEW PROCESS
Submissions are subject to two double-blind peer reviews by reviewers chosen for their expertise in relation to the manuscript, prior to general acceptance. Should these two reviews result in inconsistent recommendations as to the general acceptance of the manuscript, a third reviewer will be selected for an additional double-blind peer review in order to determine the submission's suitability for publication. Reviewers follow a guided peer review process for the determination of a manuscript's acceptance, need for revision, or rejection, in addition to providing qualitative feedback (for access or information regarding this guide, please contact the Managing Editor). Editors are not involved in decisions about papers which they have written themselves. Should any member of JoHE's Editorial Group or Editorial Advisory Board submit internally a manuscript for consideration, it will undergo the same double-blind peer review process and be held to the same publication standards as any other submission.

DISCLAIMER
The opinions and perspectives offered in JoHE reflect only the views of the authors and editors, and do not represent the views of others within the MedStar Health system or other institution or organization with which any of the members of the JoHE Editorial Advisory Board are affiliated. Clinical case analyses are entirely fictional. No part of this journal may be reproduced by any process or technique without explicit written permission from the Editorial Group.

For complete information regarding JoHE's publishing policies and best practices, or to subscribe, please visit: **www.medstarwashington.org.** Click on *About MedStar Washington*, *The John J. Lynch, MD Center for Ethics*, then *Journal of Hospital Ethics.*

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

INSTITUTIONAL*……..……..$100.00
Institutional subscriptions include full network institutional access to all back and current issues via IP validation. Two print copies of each issue are also mailed to your library/institution.

INDIVIDUAL……..$50.00
Individual subscriptions include one print and one e-copy of each issue, mailed directly to the individual subscriber.

INDIVIDUAL BACK ISSUES……....$25.00
Includes an e-copy of a single back issue for non-institutional subscribers.

INSTITUTIONAL ACCESS
Institutional subscribers are able to access the full run of JoHE volumes directly from their network: Log-in from your home institution and go to www.medstarwashington.org, click on About *MedStar Washington*, *The John J. Lynch, MD Center for Ethics*, then *Journal of Hospital Ethics* to download an e-copy of any issue. Please send all subscription inquiries to: **JOHE@MedStar.net**

The Journal of Hospital Ethics is the official proceedings publication for the International Conference on Clinical Ethics and Consultation (ICCEC) and a partner journal of the American Society for Bioethics and Humanities (ASBH). Members of the ASBH will receive a 30% discount from their subscription to JoHE. All attendees of the ICCEC receive a complementary copy of the conference's proceedings.

MedStar Health
John J. Lynch, MD Center for Ethics
MedStar Washington Hospital Center
110 Irving Street, NW
EB 3108
Washington, DC 20010