

MASTER OF BIOETHICS



CAPSTONE SYMPOSIUM

May 9, 2019

Program

Welcome

Rebecca Weintraub Brendel, MD, JD

Director, Master of Bioethics Degree Program
Assistant Professor of Psychiatry, Harvard Medical School
Director of Law and Ethics, Center for Law, Brain, and Behavior,
Massachusetts General Hospital

Reflections on the Capstone Program

Christine Mitchell, RN, MS, MTS

Executive Director, Center for Bioethics
Director, Master of Bioethics Capstone Program
Lecturer on Global Health and Social Medicine
Harvard Medical School

The Circle of Mentorship

K. Babu Krishnamurthy, MD, MBE '16

Director of Epilepsy and Ethics Associate, Steward Medical Group
Assistant Professor of Neurology, Harvard Medical School

What Do Bioethicists Do?

Paul Root Wolpe, PhD

Director, Center for Bioethics
Asa Griggs Candler Professor of Bioethics
Raymond F. Schinazi Distinguished Research Chair in Jewish Bioethics
Professor, Departments of Medicine, Pediatrics, Psychiatry, and Sociology
Emory University

Closing Remarks and Invitation to Poster Presentations

Christine Mitchell, RN, MS, MTS

What Do Bioethicists Do?

Paul Root Wolpe, PhD, is the director of the Center for Ethics at Emory University, the Raymond Schinazi Distinguished Research Professor of Jewish Bioethics, and a professor of medicine, pediatrics, psychiatry, neuroscience and biological behavior, and sociology. Wolpe is president of the Association of Bioethics Program Directors, past president of the American Society for Bioethics and Humanities, a fellow of the Hastings Center, and a fellow of the College of Physicians of Philadelphia, the country's oldest medical society.



Wolpe is editor-in-chief of *American Journal of Bioethics Neuroscience*, the leading journal in neuroethics, and serves on the editorial boards of over a dozen professional journals in medicine and ethics. He publishes widely in sociology, medicine, and ethics, and has contributed to a variety of encyclopedias on ethical and bioethical issues. Trained as a social scientist—rare for an ethicist—Wolpe's work focuses on the social, religious, ethical, and ideological impact of medicine and technology on the human condition. Considered one of the founders of the field of neuroethics, he is also the founder of BEINGS, "Biotechnology and the Ethical Imagination: A Global Summit," which brought together thought leaders from around the world to reach consensus on a set of ethical principles and policy standards for human genetic engineering. Wolpe also writes and teaches in Jewish bioethics, and coauthored the guide to Jewish end-of-life issues, *Behoref Hayamim: In the Winter of Life*.

A leader in integrating the arts into education, Wolpe nurtured Emory's Center for Ethics' singular "Ethics & the Arts Program" which partners with artistic institutions to explore the use of art in ethical engagement and the ethics of artistic production and display. He was a member of the National Academy of Sciences' Responsible Science Committee that rewrote the canonical volume "Responsible Science," and cochaired the American Psychological Association's (APA) Ethics Commission looking into reorganizing the APA's ethics procedures in response to disclosure of its participation in "enhanced interrogation" collaboration with the U.S. Central Intelligence Agency and Department of Defense.

Wolpe has twice testified to the President's Commission on the Study of Bioethical Issues in Washington, D.C. A dynamic and popular speaker internationally, Wolpe has been chosen by the website Faculty Row as a "Super Professor" and by The Teaching Company as a "Superstar Teacher of America." A consultant on business ethics and the ethics of philanthropy, Wolpe was named one of Trust Across America's "Top 100 Thought Leaders in Trustworthy Business Behavior." He won the 2011 World Technology Network Award in Ethics, has recorded a TED Talk, and was profiled in *Atlantic Magazine* as a "Brave Thinker of 2011." Wolpe is a frequent contributor and commentator in both broadcast and print media, having been featured on *60 Minutes* and profiled in *The New York Times*.

Rotimi Adigun

Capstone Mentor: Ameet Sarpatwari, JD, PhD

Instructor in Medicine, Harvard Medical School; Associate Epidemiologist and Assistant Director, Program on Regulation, Therapeutics, and Law, Brigham and Women's Hospital

Faculty Advisor: Rebecca Weintraub Brendel, MD, JD

Director, Master of Bioethics Degree Program and Assistant Professor of Psychiatry, Harvard Medical School; Director of Law and Ethics, Center for Law, Brain, and Behavior, Massachusetts General Hospital

The Orphan Drug Act 1983: An Ethical Solution to the Problem of Poor Access to Effective Medicines for Rare Disease?

The Orphan Drug Act (ODA) aims to improve access to effective treatments for rare diseases by offering incentives to pharmaceutical companies to develop drugs for these conditions. Since enactment of the ODA, the number of new drugs for "rare" diseases has increased substantially, and the ODA has drawn praise as an example of successful public policy innovation. However, barriers to drug access persist including high drug costs, lack of treatments for a majority of rare diseases, and the relatively faster approval process for orphan drugs. The purpose of this capstone was to analyze the ethical basis for enacting the Orphan Drug Act and whether the ODA has significantly reduced the barrier to effective treatment for rare diseases. This study carried out a comprehensive review of relevant literature and applied four ethical theories to justify the ODA: deontology, rights based, justice, and beneficence. This capstone also used data evidence from publicly available sources and databases to analyze the effectiveness of the ODA. This study found that the ODA is ethically justifiable, however, the ODA also raises ethical problems that must be resolved. This project proposed two significant changes to the current policy on orphan drugs: first, establishing an adequate mechanism for prioritization and fair pricing of orphan drugs; second, enacting FDA approval standards for rare diseases that are comparable to those used for more common diseases.



Rotimi Adigun, MBBS, MPH, is a professor of public health at the University of Health Sciences, Antigua. He received an MBBS from the University of Ibadan, Nigeria, and an MPH from the Institute of Tropical Medicine Antwerp, Belgium. He has provided health care to at-risk communities. He received the Igbo-Eze North Local Government Award for his work on HIV stigma and is a recipient of the Belgian Directorate-Generale for Development Corporation fellowship.

Afi Alfred

Capstone Mentors: Sarah O'Neill, MBA

Retired Director, Ambulatory Operations, Beth Israel Deaconess Medical Center

Wendy McHugh, RN, MS

Clinical Nurse Ethicist, Beth Israel Deaconess Medical Center

Faculty Advisor: Christine Mitchell, RN, MS, MTS

Executive Director, Center for Bioethics; Director, Master of Bioethics Capstone Program; Lecturer on Global Health and Social Medicine, Harvard Medical School

Creating Moral Space in Community Health Care: A Wellness Initiative

Community health care centers (CHCs) were created as an effort to provide greater access to health care and to meet the needs of underserved and underrepresented populations. Most CHCs take pride in offering a wide variety of services within a local community. However, not all services available in hospitals are available in CHCs. Ambulatory settings are often overlooked when it comes to ethics consultation services, even though the ethical needs of staff and patients can be daunting and uncharted areas for CHC staff. The lack of recognition and open discussions about ethical dilemmas can leave CHC staff in a state of moral distress. This state of distress is unhealthy and can lead to professional burnout and high rates of staff turnover. This capstone project was designed to promote wellness by creating moral space for CHC staff to discuss ethical dilemmas and increase ethical awareness. A baseline survey was conducted to determine the need and interest in establishing a forum to discuss and debrief ethical concerns specific to the CHC environment. Survey results showed that 100 percent of respondents would initiate ethical consultation requests within the CHC setting, if available. The survey also revealed a knowledge deficit around ethics and the clinical ethics consultation services available through Beth Israel Deaconess Medical Center (BIDMC) or other resources. A monthly forum was established to provide moral space, open to all staff, as a means to promote healing and wellness.

Afi Alfred, RN, BSN, is the clinical manager of operations at Bowdoin Street Health Center, a member of BIDMC. She received a BS from Curry College with a concentration in nursing. She is interested in health care disparities and bioethical problems surrounding integration of spirituality and cultural humility in health care. Alfred is the recipient of the Estelle Paris Advanced Nursing Scholarship and a 2019 YMCA of Greater Boston Achievers Award recipient.



Lamees Almuallem

Capstone Mentors: Mollie Williams, DrPH

Executive Director, The Family Van, Harvard Medical School

Rainelle Walker-White, BS

Assistant Director, The Family Van, Harvard Medical School

Mariel Mendez, MPH

Community Health Manager, The Family Van, Harvard Medical School

Faculty Advisor: Bizu Gelaye, PhD, MPH

Teaching Faculty, Center for Bioethics, and Lecturer on Global Health and Social Medicine, Harvard Medical School; Assistant Professor of Psychiatric Epidemiology, Harvard T.H. Chan School of Public Health

Behavioral Health Services Accessibility and Utilization Among Family Van Clients

The Family Van (TFV) is a mobile clinic that aims to improve the health of the medically underserved, and provide curbside preventive health care coaching and screenings to various Boston neighborhoods. In 2017, thirty-seven percent of TFV clients screened positive for depression using Patient Health Questionnaire (PHQ-2) screening. Because this significant need for mental health services often goes unmet, a qualitative study was initiated to further understand clients' perspectives on the accessibility and utilization of mental health services in East Boston. Individual interviews were conducted and recorded in Spanish or English with TFV clients who were eighteen years or older and had been living in East Boston for at least three months. Interviews were coded and analyzed via NVivo. Lack of accessibility and underutilization of mental health services were associated with the presence of stigma, fear of public charge, linguistic inequity, financial and insurance challenges, and lack of knowledge of available resources. In addition, mental health issues related to legal status were prevalent, and many TFV clients chose to avoid mental health care for fear of disclosing legal information. Going forward, TFV will continue to interview clients at all four sites to gather additional data regarding accessibility and utilization of mental health services. The findings from this study are being implemented through a proposed community health worker mental health program set to begin in July 2019. The program, Healthy Roads, will focus on providing individuals with skills to improve their mental and overall physical health.



Lamees Almuallem, RT, BHS, earned her RT and BHS with honors from the University of New Brunswick, Canada. Her studies included a concentration in end-of-life respiratory care in intensive care units for adults and neonates. She most recently served as a health care settlement counselor working with refugee clients in St. John, New Brunswick. Lamees plans to pursue a PhD in health care policy.

Emily Barsky

Capstone Mentor and Faculty Advisor: Robert Truog, MD, MA

Director, Center for Bioethics, Frances Glessner Lee Professor of Medical Ethics, Professor of Anaesthesia and Pediatrics, Harvard Medical School; Senior Associate in Critical Care Medicine, Boston Children's Hospital

Attitudes towards Involving Children in Decision-Making Surrounding Lung Transplantation

Medical care has shifted from a paternalistic model towards one centered around patient autonomy and shared decision-making. In pediatrics, however, parents generally have the decision-making authority, and the role of the pediatric patient in decision-making is unclear. Studies suggest that many children with chronic disease are capable of participating in and even making medical decisions at a young age, yet physicians do not standardly involve them aside from encouraging assent. This capstone project first involved a literature review regarding the decision-making capacity of young adolescents with chronic disease. Next, an empirical pilot study was conducted, investigating physician attitudes towards involvement of children in decisions regarding lung transplant. A written survey with case vignettes was created and distributed to pediatric pulmonologists at Boston Children's Hospital to identify how physicians view the role of children in decision-making, how this is influenced by patient age and maturity level, and how potential conflict between parents' and patients' views might be reconciled. Results show that the majority of physicians believe decision-making authority rests with the parents, depending on the pediatric patient's age and not on their maturity level. Physicians are influenced by the patient's maturity level when deciding whether to convince the parents to defer to the child. They are divided about the utility of ethics consultation and psychiatry regarding assessment of a child's capacity for decision-making. Ideally, this study will lay the foundation for a prospective study exploring the attitudes of children and parents regarding pediatric participation in shared decision-making.

Emily Barsky, MD, is an instructor in pediatrics at Harvard Medical School (HMS) and a pediatric pulmonologist at Boston Children's Hospital (BCH). She received a BA from Dartmouth College and an MD from HMS. Barsky completed her pediatric residency at UC San Francisco and her pediatric pulmonology fellowship at BCH. Her clinical interests include cystic fibrosis and asthma, and she plans to pursue empirical bioethics research in shared decision-making and patient-doctor communication.



Allyn Benintendi

Capstone Mentors: Arthur Kleinman, MD, MA

Esther and Sidney Rabb Professor of Anthropology, Harvard University Department of Anthropology; Professor of Medical Anthropology in Global Health and Social Medicine, and Professor of Psychiatry, Harvard Medical School

Rebecca Weintraub Brendel, MD, JD

Director, Master of Bioethics Degree Program, and Assistant Professor of Psychiatry, Harvard Medical School; Director of Law and Ethics, Center for Law, Brain, and Behavior, Massachusetts General Hospital

Faculty Advisor: Charlene Galarneau, PhD

Teaching Faculty, Center for Bioethics, and Lecturer on Global Health and Social Medicine, Harvard Medical School; Associate Professor Emerita, Women's and Gender Studies Department, Wellesley College

Ethnography of Bioethics

Anthropology views bioethics as a culturally bound codified set of practices and techniques belonging to Western biomedicine. This capstone is a formal ethnographic study of bioethics education and the descriptive account of emerging pedagogies in a field designed to mitigate the dangers of medicine. How do practitioners, faculty, and students identify the ethical "problems" of medical care? How is bioethics taught and learned, and how is its moral discourse formed? This qualitative study included participant observation, in-depth interviewing, and interpretive analysis of data collected in the Harvard Medical School Center for Bioethics. The final product is a written account describing the historical background and interdisciplinary tensions of a local bioethics program, the covert lessons constituting the "foundation" of bioethics knowledge, and emerging pedagogy of the educational program for new ethics in the contemporary.



Allyn Benintendi, BA, is currently a qualitative researcher at Boston Medical Center. She received her bachelor's degree in anthropology from the UC Berkeley. She is interested in the intersections of medicine, anthropology, and ethics. She intends to pursue a PhD in anthropology in the future.

Rennie Burke

Capstone Mentors: Dana Pardee, BS

Director of Epidemiology Projects, The Fenway Institute at Fenway Community Health

Sari Reisner, ScD

Research Scientist at The Fenway Institute at Fenway Health; Assistant Professor of Pediatrics, Harvard Medical School and Boston Children's Hospital; Assistant Professor of Epidemiology, Harvard T.H. Chan School of Public Health

Faculty Advisor: J. Wesley Boyd, MD, PhD

Teaching Faculty, Center for Bioethics, and Associate Professor of Psychiatry, Harvard Medical School; Codirector of Human Rights and Asylum Clinic, Cambridge Health Alliance

Developing Dissemination Materials for High-Risk Human Papillomavirus Self-Swabs at Fenway Health

While literature on the effectiveness of self-swabs for high-risk human papillomavirus (hrHPV) among cisgender women exists, no research had been conducted with the transmasculine community on this topic. Given the large LGBTQ patient population at Fenway Health—one of the largest trans populations in the United States—this information could be very useful. Researchers at Fenway Health, including project mentors Sari Reisner, ScD, and Dana Pardee, BS, therefore, conducted a study exploring the effectiveness of hrHPV self-swabs for trans masculine patients. They found that self-swabs were not as effective as provider-obtained swabs, but nevertheless could be employed as a harm reduction strategy, as many in the transmasculine community are apprehensive about pelvic examinations and provider-obtained cervical swabs. This capstone project entailed taking the findings of the study and producing materials for potential patients as well as providers publicizing the findings in accessible, culturally appropriate language. Materials for patients included promotional posters, a presentation to the local transmasculine community, and a patient toolkit laying out all the information a patient would need, as well as instructions on how to self-swab. Materials for providers included a separate provider toolkit that summarized the findings with an emphasis on its place in the literature and statistics regarding its effectiveness. Looking to the future, the materials may be distributed at Fenway Health and online to help patients decide what is acceptable for them.

Rennie Burke, MA, is a medical student at UC Riverside. He received a BA in history and philosophy from UC Santa Barbara, and an MA in history from Ohio University. His current medical research explores LGBT medical education and medical humanities. He plans to apply to residencies in psychiatry and work with underserved populations following graduation.



Eric Chu

Capstone Mentor: Sang E. Park, DDS, MMSc

Associate Dean for Dental Education and Associate Professor of Restorative Dentistry and Biomaterials Sciences, Harvard School of Dental Medicine

Faculty Advisor: Spencer Hey, PhD

Teaching Faculty, Center for Bioethics, Harvard Medical School; Research Fellow in Medicine, Division of Pharmacoepidemiology and Pharmacoeconomics, Brigham and Women's Hospital

Opioid Prescription Education in Dental School: Case-based Learning Curriculum through Inter-professional School Collaboration

Dentists prescribe more opioids to adolescents than any other class of provider. This capstone explored dentists' ethical duties to their patients regarding opioid prescriptions. Many teen and young adult patients are exposed to opioids for the first time following a dental procedure such as a wisdom tooth extraction or odontogenic infection. Although dentists should not simply be anti-opioid clinicians, they should have justifiable reasons for prescribing opioids, such as severe pain not manageable by other analgesics. One of the most common ethical challenges faced by dentists making decisions about providing opioid prescriptions centers on balancing effective pain control with the risk of exposing a patient to a potential source of addiction. With Harvard School of Dental Medicine faculties, led by Sang E. Park, DDS, MMSc, this project involved analyzing data from course evaluations of dental students to measure and analyze the effectiveness of opioid prescription education. A literature review also indicated there is a deficiency in opioid education for dental students. Education about opioids is thus both critical and needed. This capstone project addressed that currently unmet need by developing a case-based learning curriculum regarding prescribing opioids. A refined version of the syllabus will be created for future utilization in dental school curriculum improvement.



Eric NagBum Chu, DMD, is a dentist at Newton Street Dental in South Hadley, MA. He received his DMD degree, magna cum laude, from Boston University Goldman School of Dental Medicine. He completed a dental externship at Boston Health Care for the Homeless Program. Chu's interest in bioethics involves the opioid crisis in dentistry, patient hospitality, and practice management. He hopes to strengthen opioid curricula in dental schools.

Hillary Chua

Capstone Mentor: Jonathan Marron, MD, MPH

Research Associate in Global Health and Social Medicine, Center for Bioethics, and Instructor in Pediatrics, Harvard Medical School; Associate in Ethics and Clinical Ethicist, Boston Children's Hospital; Attending Physician, Dana-Farber Cancer Institute

Faculty Advisor: Louise King, MD, JD

Director, Reproductive Ethics, Center for Bioethics, and Assistant Professor of Obstetrics, Gynecology and Reproductive Biology, Harvard Medical School; Chief, Division of Minimally Invasive Gynecologic Surgery, Beth Israel Deaconess Medical Center

Pediatric Oncofertility: Should Providers Discuss Fertility Preservation with Parents for Pediatric Patients with Poor Prognoses?

Offering fertility preservation (FP) to cancer patients and referrals to reproductive specialists has become the standard of care in oncology, especially as FP technologies and data about their effectiveness continue to come to light. Recently, the American Society of Clinical Oncology's updated practice guidelines recommend that providers discuss FP with all potential patients and/or refer them to reproductive specialists. Yet considerations of prognosis loom large in relation to pediatric oncology patients. Offering FP for a child who is very unlikely to survive past age 18 can seem inappropriate. Discussing FP with families can also delay urgent cancer treatment. Anecdotally, some providers do not initiate FP discussions if the patient's prognosis falls below a certain cutoff. However, decisions about referring patients for FP must balance the diverse values and interests of multiple stakeholders. These factors include medical (e.g. prioritizing cancer treatment and prognostic uncertainty), rights-based (e.g. respecting parents/guardians as co-fiduciaries of the child, and the child's right to an open future) and psychological considerations (e.g. minimizing regret/anxiety from resulting infertility). Providers should also respect families' rights to decide on FP in light of their values. Given these complexities, neither fixed cutoffs nor all-inclusive policies are appropriate. Rather, when a pediatric patient is assessed to have a poor prognosis, providers should consider initiating an FP discussion on a case-by-case basis. This project highlighted the factors that should be weighed in such an ethically complex decision.

Hillary Chua, LLB, is a graduate of King's College London, where she completed her training in medical malpractice and intellectual property law. She is a recently qualified lawyer from Singapore, and her academic work focuses on disability rights and the ethics of human germline editing. After the master of bioethics program, her aim is to help enhance clinical ethics consultation services in Singapore.



Nicholas Covaleski

Capstone Mentor: John Peteet, MD

Associate Professor of Psychiatry, Harvard Medical School; Fellowship Site Director, Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute; Physician, Department of Psychiatry, Brigham and Women's Hospital

Faculty Advisor: J. Wesley Boyd, MD, PhD

Teaching Faculty, Center for Bioethics, and Associate Professor of Psychiatry, Harvard Medical School; Codirector of Human Rights and Asylum Clinic, Cambridge Health Alliance

The Healing Power of Humility: A Literature Review

Although contemporary moral philosophy has experienced a renaissance in virtue ethics, the study of humility as a virtue has been largely neglected in this resurgence. A literature review of humility and mental health was conducted, and served as the basis for a philosophical analysis of the subject matter. Humility, according to most definitions, does not harmonize well with a liberal democratic ethos, and thus ostensibly has little place within modern American bioethics. The literature review revealed humility is a multifaceted, dynamic, and robust concept, operationalized in a variety of mental health settings, including psychotherapy, addiction counseling, pastoral counseling, and global mental health. Several types of humility, including cultural, intellectual, and spiritual, were noted. The presence of each type by both those giving, and receiving, mental health care has been found to be a key contributor to positive mental health outcomes, thus demonstrating a relationship between healing and humility. Indeed, it may be that humility is an integral part of mental health, an essential virtue to be cultivated by practitioner and patient alike. As such, it is a concept that warrants future research, both within mental health, and in bioethics, broadly speaking. The literature review and philosophical analysis in this project concluded with suggested avenues for future research.



Nick Covaleski, MTS, received his master of theological studies from Harvard Divinity School. Starting in the fall, Covaleski will begin a PhD in religion at Boston University. His research focuses on the intersections of religion, politics, and bioethics.

Anjali Fedson Hack

Capstone Mentors: Richard Blum, MD, MSE, FAAP

Assistant Professor of Anaesthesia, Harvard Medical School; Director, Simulation Education Training, Medical Director, Post Anesthesia Care Unit, and Senior Associate in Perioperative Anesthesia, Boston Children's Hospital

David Waisel, MD

Associate Professor of Anaesthesia, Harvard Medical School; Senior Associate, Perioperative Anesthesia, Member, Ethics Advisory Committee, Chairman, Fellow Selection Committee, and Main Operating Room Program Director, Boston Children's Hospital

Faculty Advisor: Rebecca Weintraub Brendel, MD, JD

Director, Master of Bioethics Degree Program, and Assistant Professor of Psychiatry, Harvard Medical School; Director of Law and Ethics, Center for Law, Brain, and Behavior, Massachusetts General Hospital

Cassandra's Curse: Physician Moral Injury in Settings of Shared Clinical Responsibility

Practicing medicine is a moral endeavor which can lead to physicians' psychological and moral distress. This project examined moral injury through a literature review and case exploration. Because existing taxonomies of moral injury are grounded in a limited concept of physician agency in clinical practice, they do not adequately account for cases of shared clinical responsibility, which is exemplified by the practice of anaesthesiologists and surgeons. Efforts to insure patient wellbeing in these settings emphasize the importance of "speaking up" and the "two-challenge rule." Inter-physician negotiation of diagnosis and management, through a process of advocacy and inquiry, is supposed to yield optimal patient outcomes, based on current evidence-based standards. While these strategies are a starting point for improved physician communication, they underestimate both the often ambiguous nature of clinical diagnosis and management, and the inherent difficulty in determining optimal clinical strategies. Clinical practice in these circumstances can lead to physician suffering which is not adequately captured by concept of a "second victim" or "moral distress." The nature of physician's moral injury in these circumstances needs to be further explored.

Anjali Fedson Hack, MD, PhD, is an independent scholar. She received an AB, MD, and PhD (sociocultural anthropology) from the University of Chicago where she completed a medicine internship. She completed a residency and fellowship in obstetric anesthesiology at the Brigham and Women's Hospital. She practiced at New York Presbyterian-Columbia University Medical Center and was director of Obstetric Anesthesia at Albert Einstein-Montefiore Medical Center. Her research has been supported by the National Science Foundation, the MacArthur Foundation, and the Social Science Research Council.



Zoe Fullerton

Capstone Mentor: Arabella Simpkin, MD, MMSc

Associate Director, Center for Educational Innovation and Scholarship, Massachusetts General Hospital

Faculty Advisor: J. Wesley Boyd, MD, PhD

Teaching Faculty, Center for Bioethics, and Associate Professor of Psychiatry, Harvard Medical School; Codirector of Human Rights and Asylum Clinic, Cambridge Health Alliance

Cognitive Bias in Case-Based Vignettes

Cognitive and implicit bias among physicians contributes to creating and perpetuating disparate health care outcomes in the United States. Research shows that while medical students enter school with general implicit biases, biased treatment decisions are learned during their medical education. The cause of this is unclear. Standardized tests are a required part of every physician's training and therefore present a potential source of learned bias. For this project, twelve vignettes were created using medical student test preparation materials. Questions were phrased so as to include insufficient details in order to definitively distinguish between two similarly presenting disease processes, one of which is stereotypically associated with a demographic group. A pilot test of five faculty members scored questions for content validity and level of uncertainty. Six questions were selected based on these scores. The survey was distributed to all MD or MD/PhD students in two versions. The first three questions of Version 1 and the final three questions of Version 2 included demographic identifiers. The versions were otherwise identical. Three demographic identifiers used were stereotype congruent. Three were different than the commonly stereotyped demographic group of the disease (counterstereotype). The project shows that in cases of uncertainty, providing demographic identifiers influences student answer choices. Statistical analysis showed stereotyped identifiers ("immigrant" or "African American") exert stronger influence on choices than counter stereotype ("Caucasian" or "businessman"). Further examination is needed into how standardized testing influences medical student understanding and diagnosis of disease.



Zoe Fullerton, BA, is a medical student at Harvard Medical School. She received her BA from Vassar College in the area of science, technology, and society. Her research for this capstone centers on the ways that different wordings of prompts can impact the answer choices of medical students and how these cognitive connections may come into play in the clinical setting. Fullerton will be returning to medical school upon completion of this program with plans to apply into otolaryngology.

Timothy Furlan

Capstone Mentor: Christine Mitchell, RN, MS, MTS

Executive Director, Center for Bioethics; Director, Master of Bioethics Capstone Program; Lecturer on Global Health and Social Medicine, Harvard Medical

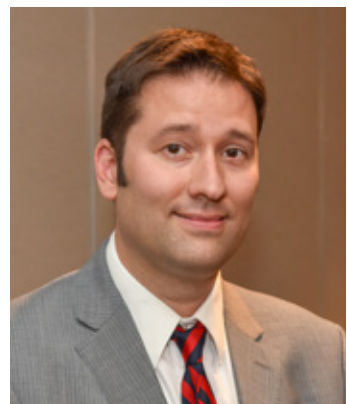
Faculty Advisor: Charlene Galarneau, PhD

Teaching Faculty, Center for Bioethics, and Lecturer on Global Health and Social Medicine, Harvard Medical School; Associate Professor Emerita, Women's and Gender Studies Department, Wellesley College

Issue Editor for Summer 2019 Issue of Harvard Medical School Bioethics Journal

Bioethics has emerged as a new interdisciplinary field of inquiry focused on important ethical issues raised by contemporary medical and scientific research and practice. Clinicians, researchers, lawyers, and philosophers have each made significant contributions. And yet, bioethics is still in the process of defining itself and being defined. The field will continue to transform and establish a professional presence. *The Harvard Medical School Bioethics Journal* aims to contribute to this conversation by publishing world-class scholarship by established and developing scholars from across the globe. In particular, the 2019 summer issue of the *Journal* will contain articles by some of the top moral philosophers and bioethicists in the world including Christine Korsgaard on animal ethics, Daniel Sulmasy on double effect, Daniel Wikler on research ethics in the developing world, and Daniel Callahan on emerging frontiers in bioethics in the 21st Century. In addition, the *Journal* will feature interviews with Kwame Anthony Appiah on naturalized moral philosophy and moral expertise, I. Glenn Cohen on medical tourism and mitochondrial replacement, a profile on the work of Michael Brescia, and George Scialabba's book review of James Davison Hunter and Paul Nedelisky's *Science and the Good*.

Tim Furlan, MA, PhD, is a visiting assistant professor of philosophy at Boston College (BC). He received his MA in the social sciences from the University of Chicago, and a MA and PhD in philosophy from Trinity College Dublin, and has held visiting doctoral and post-doctoral fellowships at the Université de Paris IV (Sorbonne), the Université de Fribourg, and the University of Athens. After graduation, he will continue his work teaching in the philosophy department as well as the new Global Public Health Program at BC.



Elicia Grilley Green

Capstone Mentor: Joshua Abrams, JD

Senior Attorney, Office of General Counsel, Partners HealthCare System, Inc.

Faculty Advisor: Louise King, MD, JD

Director, Reproductive Ethics, Center for Bioethics, and Assistant Professor of Obstetrics, Gynecology and Reproductive Biology, Harvard Medical School; Chief, Division of Minimally Invasive Gynecologic Surgery, Beth Israel Deaconess Medical Center

The Role of the Attorney on an Ethics Committee

Most hospitals have some type of committee, service, or group who are charged with discussing and making recommendations on cases involving complex ethical questions. These cases often present a web of interrelated issues that are best analyzed by a range of disciplines including medicine, philosophy, theology, and the law. The legal lens is often crucial to such discussions and has led to lawyers sitting on, and conferring with, many hospital-based ethics committees. While most experts see the advantage of having the hospital's attorney on the ethics committee, there are others in the field who disagree. Some feel that members could confuse the attorney's role, as he or she may wear multiple hats in any one ethics meeting. In addition to their legal analysis, they might offer ethical and team-based opinions, which members struggle to prioritize. Further, some worry that attorneys may voice the law in such a conclusive and aggressive manner that the overall ethical case discussion is chilled and other team members' voices are silenced. Therefore, multiple in-depth interviews of experts in the field of ethics and those who chair and organize hospital-based ethics committees and consult teams were conducted so as to better understand and facilitate the role of a hospital attorney who participates in ethics discussions and/or consultations. The results of these interviews were then systematically condensed to form a basic list of principles that attorneys can use to further develop the understanding, value, and success of their role within an ethics committee or consult process.



Elicia Grilley Green, RDH, JD, received a BAAS from the University of the Incarnate Word and graduated cum laude with a JD from Southern Methodist University. She has a legal background in public interest and health law and is admitted to the Texas state bar. Green's interests include how bioethics can be used to shape health policy and increase access to health care. After graduation, Green plans to practice health law.

Robin Jones

Capstone Mentors: Mark E. Alexander, MD

Associate Professor of Pediatrics, Harvard Medical School; Vice Chair, Institutional Review Board, Boston Children's Hospital

Susan Kornetsky, MPH

Senior Director, Clinical Research Compliance, Boston Children's Hospital

Faculty Advisor: Christine Mitchell, RN, MS, MTS

Executive Director, Center for Bioethics; Director, Master of Bioethics Capstone Program; Lecturer on Global Health and Social Medicine, Harvard Medical School

Documenting Assent: Can We Identify Challenges and Opportunities for Best Practice?

Informed consent is a foundational ethical principle set by the Belmont Report for research in human subjects. Adequate informed consent includes competence, voluntariness, information, recommendations and understanding, decisions and authorization. As children cannot legally give informed consent, parents are typically asked to give informed consent/permission, and children are ideally engaged to assent to the research. Assent is defined as a "child's affirmative agreement to participate in research." Individual IRBs are required to regulate childhood assent to research. There are, however, no standards or guidelines established for IRBs to determine capacity to assent, age of assent, or how best to document that assent was elicited. As part of a quality improvement project at Boston Children's Hospital, this capstone project included a literature review and initial review of assent documentation for studies approved by Boston Children's Hospital IRB. It was notable that the greater the risk of the research, the more often separate assent documents were used. Investigators and IRB members were then surveyed anonymously via email to review the assent process. The survey focused on the role of the independent assent document as a proxy for assent.

Robin M. Jones, MD, is an assistant professor of neurology at Harvard Medical School (HMS). She received a BA in philosophy from Yale College and an MD from the University of Connecticut. She completed pediatrics and neurology residencies at Massachusetts General Hospital (MGH), an oncology research fellowship at MGH, and a bioethics fellowship at HMS. She is interested in assent in pediatric research. She will continue to practice pediatric neurology and clinical ethics at MGH.



Joshua Joseph

Capstone Mentor: Lachlan Forrow, MD

Associate Professor of Medicine, Harvard Medical School; Director, Ethics Programs, Beth Israel Deaconess Medical Center

Faculty Advisor: Martha Jurchak, PhD, RN

Teaching Faculty, Center for Bioethics, and Instructor in Psychiatry, Harvard Medical School; Executive Director, Office of Clinical Ethics, Brigham and Women's Hospital

Clinical Ethics for the Emergency Medicine Resident: A Case-Based Curriculum

There currently exists no standardized curriculum for the teaching of medical ethics to resident physicians in emergency medicine. The chaotic environment of the emergency department, the time-limited nature of emergency care, and the socioeconomic and legal challenges surrounding the patient populations seen in the emergency department raise unique ethical dilemmas, which often cannot be addressed by formal ethics consultation. This study sought to establish an empiric understanding of what ethical challenges emergency medicine residents-in-training face, what situations are of greatest concern to attending physicians in practice, and to what extent these correlate with issues in the emergency medicine ethics literature. To this end, we conducted qualitative interviews with teaching faculty at Beth Israel Deaconess Hospital (BIDMC), Brigham and Women's Hospital, and Massachusetts General Hospital, specifically addressing the ethical challenges faced by resident physicians and recent graduates, and conducted a systematic review of the literature. Ethical issues were classified using the Armstrong Clinical Ethics Coding System, a validated system for coding ethics cases, as an a priori coding methodology. Among the top concerns of emergency physicians were issues of resource allocation, futility in end-of-life treatment, patients' decisional capacity and ability to refuse treatment, substance abuse, and moral distress. The emergency medicine literature echoed many of these concerns, as well as issues of professionalism in training, informed consent, the Emergency Medical Treatment and Labor Act (EMTALA), and involuntary treatment. A curriculum of cases has been created for residency trainees to explore these issues.



Joshua Winston Joseph, MD, MS, is an emergency physician at BIDMC and assistant professor of emergency medicine at Harvard Medical School. He received his BS in neuroscience from Columbia University, BA in Talmud from Jewish Theological Seminary, MD from University of Illinois, and MS in computer engineering from Boston University. He will continue research in clinical operations and artificial intelligence, and a Greenwall Foundation grant examining refusal of care by patients revived with naloxone.

Clio Koller

Capstone Mentor: Jordan W. Smoller, MD, ScD

Professor of Psychiatry, Harvard Medical School; Professor, Department of Epidemiology, Harvard T.H. Chan School of Public Health; Associate Chief for Research, Department of Psychiatry, and Director, Psychiatric and Neurodevelopmental Genetics Unit, Center for Human Genetics Research, Massachusetts General Hospital

Faculty Advisor: Louise King, MD, JD

Director, Reproductive Ethics, Center for Bioethics, and Assistant Professor of Obstetrics, Gynecology and Reproductive Biology, Harvard Medical School; Chief, Division of Minimally Invasive Gynecologic Surgery, Beth Israel Deaconess Medical Center

The Social and Ethical Implications of Implementing Polygenic Risk Scoring in Clinical Psychiatry

Many clinical disorders have genetic underpinnings, knowledge of which can allow physicians to identify at-risk patients and initiate measures to moderate disease onset or prevent illness altogether. Polygenic risk scoring (PRS), hailed as the future of preventative medicine, offers just that by stratifying presymptomatic patients via their genetic likelihood of developing specific disorders. While PRS has yet to enter the clinical sphere, experts predict integration of PRS in clinical practice within the next decade. In psychiatry specifically, patients benefit tremendously from early intervention, which can significantly reduce both the medical and social impact of mental illness. As psychiatry often lacks clear prognostic indicators to prompt early intervention or prophylactic treatment, PRS could prove a game changer for the field—drastically improving the outcomes of those struggling with mental health. Despite its tremendous clinical potential, the use of PRS in psychiatry also raises several ethical concerns, some traditional to genetic testing and others unique to the patient population and the complexities of mental illness. This paper examined such ethical concerns, with a specific focus on how PRS could impact both individual patients and minority populations at large, exacerbating current disparities in health care—and suggests that despite its promise, the genomics community must first address the dearth of psychiatric genomic data on populations of non-European ancestry to ensure all patients benefit once PRS reaches clinical implementation.

Clio Sophia Koller, AB, received an AB with honors in the history, philosophy, and social studies of science and medicine from the University of Chicago. She is interested in the intersection of law and bioethics, specifically concerning the social, ethical, and legal implications of emerging genetic technologies in both clinical and commercial contexts. She will attend Yale Law School in the fall.



Allura Damiana Landsberg

Capstone Mentor: Stephen D. Brown, MD

Associate Professor of Radiology, Harvard Medical School; Director, Institute of Professional and Ethical Practice, Boston Children's Hospital

Faculty Advisor: Charlene Galarneau, PhD

Teaching Faculty, Center for Bioethics, and Lecturer on Global Health and Social Medicine, Harvard Medical School; Associate Professor Emerita, Women's and Gender Studies Department, Wellesley College

Exploring the Ethical Dimensions of Medical Information

The communication of medical information is essential for informed consent and shared decision-making (SDM). Informed consent in medicine is intended to promote patient autonomy by ensuring that patients have an active role in choosing treatment options best aligned with their values and preferences. Physicians are sometimes inaccurate when predicting how much information patients desire, what content should be included, and how best to communicate it. Misalignment between the information doctors provide and what patients want may generate adverse emotional and treatment consequences. This literature review explored practical and ethical challenges related to informed consent and SDM: the balance between too much and too little information; how best to solicit patient values and accommodate their preferences; the role of physician beliefs; and the intrinsic tensions among beneficence, nonmaleficence, and autonomy. Numerous practical strategies exist for approaching the conflicting ethical considerations and promoting optimal informed consent and SDM.



Allura Damiana Nicole Landsberg, BA, received her bachelor's in neurobiology and secondary in moral philosophy from Harvard College. As an undergraduate, she completed research at McLean Hospital focused on adolescent psychopathology which culminated in a thesis exploring neural markers predictive of depression treatment response. Following the MBE program, she will be moving to New York City to pursue health policy and advocacy work before applying to MD/JD programs.

Yvette Ollada Lavery

Capstone Mentors: Mary Carol Sullivan, JD, MTS, RN

Chief Healthcare Ethicist and Director of the Initiative for Palliative Care and Advance Care Planning, Roman Catholic Archdiocese of Boston

M. Sheleagh Somers, MSW, LICSW

Teaching Faculty, Center for Bioethics, Harvard Medical School; Clinical Social Worker, Beth Israel Deaconess Medical Center

Faculty Advisor: Aaron S. Kesselheim, MD, JD, MPH

Teaching Faculty, Center for Bioethics, and Associate Professor of Medicine, Harvard Medical School; Associate Physician, Division of Pharmacoepidemiology and Pharmacoeconomics, Department of Medicine, Brigham and Women's Hospital

Religious and Spiritual Perspectives on the Bioethics of End-of-Life in Clinical Ethics and Health Policy

This capstone project included three components to gain broad experience in bioethics from religious and spiritual perspectives. First, a public policy research report on current public perception and the political landscape of physician-assisted suicide (PAS) in Massachusetts, accompanied by a strategic action memo based on the report's findings, was developed for the Roman Catholic Archdiocese of Boston to assist them with their advocacy. Second, an ethics training presentation for professionals entitled "Recognizing and Addressing Moral Struggle in Medical Decision-Making: What Does It Mean to be Morally Present to Patients, Their Families and Their Surrogate Decision-Makers?" was developed and will serve as the foundation for a sponsored continuing medical education program. It is important that clinicians receive education on addressing moral distress (or moral struggle) and providing spiritual care. This training will be presented in Massachusetts at Carney Hospital and St. James Armenian Orthodox Church. Finally, this capstone bridged the divide between abstract theory and bioethics in practice, through observing ethics committee meetings and case reviews at Beth Israel Deaconess Medical Center, Brigham and Women's Hospital, and through active participation in the Carney Hospital Ethics Committee as a community member.

Yvette Ollada Lavery, MPA, is the principal consultant at Tionchar Global. She received a BA from University of Southern California and an MPA from Sciences Po, Paris. Lavery is cofounder of the advocacy nonprofit Patients' Rights Action Fund. Her interests in bioethics include: community ethics, clinical ethics, narrative approaches, theological, religious, and spiritual perspectives, and public policy. Lavery was recognized as a "Top 40 Under 40" by the American Association of Political Consultants.



Kyungdo Lee

Capstone Mentor: Bizu Gelaye, PhD, MPH

Teaching Faculty, Center for Bioethics, and Lecturer on Global Health and Social Medicine, Harvard Medical School; Assistant Professor of Psychiatric Epidemiology, Harvard T.H. Chan School of Public Health

Faculty Advisor: Aaron S. Kesselheim, MD, JD, MPH

Teaching Faculty, Center for Bioethics, and Associate Professor of Medicine, Harvard Medical School; Associate Physician, Division of Pharmacoepidemiology and Pharmacoeconomics, Department of Medicine, Brigham and Women's Hospital

Impact of the Economic Crisis on Suicide Risk in Korea: Ethical Implications for Prevention

Suicide has consistently been a major cause of death in South Korea. The aims of this project were two-fold: to examine the epidemiology of suicide rates in South Korea using publicly available death certificates; and to evaluate the ethical dimensions of suicide prevention. Our findings and prior studies revealed that the financial crisis in 1997 was associated with a rise in suicide rates in South-Korea, but after the suicide rate peaked in 2009, the overall rates have been declining gradually. Based on this finding, it is plausible to suggest the impact of economic crisis on suicide can be largely explained by the increased risks from nondesirable changes in living conditions, mainly through unemployment. However, international studies have found this sizeable apparent impact in South Korea may not be consistent with other countries such as Iceland, which had prepared social measures to help people retain or regain jobs to mitigate negative effects of the economic crisis. This finding should be taken into account in addressing the ethics of suicide prevention. Specifically, suicide prevention interventions can be justified to prevent impulsive decisions by limiting accessibility to the means of suicide and by implementing adequate unemployment pension schemes and welfare systems to counteract negative mental health impacts of economic crisis.



Kyungdo Lee, MD, MPH, received an MD from University of Ulsan and an MPH from Seoul National University. He practiced medicine in South Korea serving vulnerable populations—including prisoners and those living in rural areas—and has focused on advocating their rights to health. His main interest lies in distributive justice issues in health policy and health inequalities. He is going to study public health ethics as a PhD student at Rutgers University.

Megha Majumder

Capstone Mentor: John Torous, MD, MBI

Director, Digital Psychiatry Division, and Staff Psychiatrist, Department of Psychiatry, Beth Israel Deaconess Medical Center; Instructor in Psychiatry, Harvard Medical School

Faculty Advisor: Rebecca Weintraub Brendel, MD, JD

Director, Master of Bioethics Degree Program, and Assistant Professor of Psychiatry, Harvard Medical School; Director of Law and Ethics, Center for Law, Brain, and Behavior, Massachusetts General Hospital

A Novel Framework for Systematic Identification of Ethical Aspects of Mobile Health Applications

The greatest civil rights issue of our time may be the challenge of fitting the round peg of clinical mobile health (mHealth) applications into the square hole of existing ethical and legal frameworks. Addressing this topic will determine whether society can reap the tremendous opportunities hidden in the big data collected by governments and cities, health care institutions and schools, social networks and search engines, while at the same time protecting privacy, fairness, equality, and the integrity of the scientific process. Currently, gatekeepers of ethical decisions range from private IRBs to journal publication standards, association guidelines, and peer review. This paper posits there is a need for a novel framework as well as an accessible assessment toolkit for the review of mHealth applications. The aim of this research was, therefore, to develop a novel framework for researchers, developers, and IRBs that enables a rapid, systematic assessment of mHealth applications. A systematic and explorative literature study provided insight into the requirements for such a toolkit—a blueprint for infusing ethical considerations into an environment as data-rich as the mHealth landscape. Existing methods were evaluated and compared to determine how they assessed mHealth applications. Results and a preliminary design of the framework were presented to experts and interviews were conducted during the design process. An artifact has been created and tested by assessing four popular mobile health applications. Further research is necessary to improve and valorize the assessment toolkit.

Megha Majumder, BA, BS, is a research associate at the Bove Lab at UC San Francisco. She received her BA/BS in public health, sociology, and chemistry at UC Berkeley. Funded by a Fulbright-Schuman Innovation Grant, her work focuses on the moral implications of a technology-infused biomedical paradigm. She will continue her pursuits in neuroscience and psychopathology at Harvard and the University of Cambridge.



Katrina Arcelia Muñoz

Capstone Mentor: Joseph T. Giacino, PhD

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Faculty Advisor: Louise King, MD, JD

Director, Reproductive Ethics, Center for Bioethics, and Assistant Professor of Obstetrics, Gynecology and Reproductive Biology, Harvard Medical School; Chief, Division of Minimally Invasive Gynecologic Surgery, Beth Israel Deaconess Medical Center

Navigating Health Care Challenges after Severe Acquired Brain Injury

Severe acquired brain injury is a catastrophic event associated with numerous health care challenges for patients and families. Despite the enormity of the problem, access to inpatient rehabilitation programs and post-acute health services has constricted substantially over the last decade. These changes have been driven by restructuring of medical authorization and health care reimbursement models, shifting the burden of care to family caregivers early after injury, resulting in significant financial and emotional distress. The primary aim of this capstone project was to produce a first-person account of the clinical, economic, and psychosocial issues faced by patients with severe acquired brain injury and their caregivers during the first year post-injury. Qualitative research methods were employed for data acquisition and analysis. This project relied on a “narrative” research design. This qualitative approach to research used semi-structured interviews and personal stories to construct narrative accounts of caregiver experiences, providing a basis for ethical reflection and learning. Top-down and bottom-up analytic approaches, including principlism and care ethics, were used to identify and unpack the bioethical issues that emerged from the challenges encountered by caregivers during the first year post-injury. Findings will be used to develop educational materials intended to increase awareness among three stakeholder groups: consumers (i.e., caregivers and patients), professionals (i.e., clinicians, institutional administrators) and the general public. These results will also serve as a first step toward policy change.



Katrina Arcelia Muñoz, BA, received a BA in neuroscience and philosophy from Bates College. As an undergraduate, she wrote an interdisciplinary honors thesis examining perceived threats brain stimulation therapies pose to the personal identities of patients with depression. This fall, she will research the social, ethical, and legal implications of deep brain stimulation and neurogenomics research in the Center for Medical Ethics and Health Policy at Baylor College of Medicine.

Elisheva Nemetz

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Faculty Advisor: Robert Truog, MD, MA

Director, Center for Bioethics, Frances Glessner Lee Professor of Medical Ethics, Professor of Anaesthesia and Pediatrics, Harvard Medical School; Senior Associate in Critical Care Medicine, Boston Children's Hospital

Controlling Death: Adolescents' Choice of Death

Physician assisted death (PAD) and euthanasia are practices that are transitioning from policy ideas that permeate our legislatures, congressional bodies, and parliaments, to a reality. Countries that allow euthanasia include Belgium, Canada, Colombia, Luxembourg, and the Netherlands. Physician-assisted death is permitted in Switzerland and a growing minority of US jurisdictions accounting for approximately 20 percent of the US population. Countries that allow for euthanasia have been transitioning to allowing euthanasia not only for adults but for minors as well. For example, Colombia, the Netherlands, and Belgium allow, to varying degrees, for minors to obtain euthanasia. Colombia and the Netherlands also allow, based on age criteria, certain adolescents to pursue euthanasia without parental consent if they demonstrate capacity. In Colombia, adolescents aged fourteen and older can request euthanasia without parental consent and in the Netherlands, adolescents aged sixteen and older must have parents involved in the decision-making process, but do not need parental consent to pursue euthanasia. There are ethical concerns regarding adolescents, euthanasia, and the lack of parental consent or involvement in the decision-making process. To come to a conclusion, a literature review of more than a hundred articles was sought and forty-two articles were identified as relevant to background information on euthanasia and PAD. All perspectives were considered, permitting independent consent and restricting independent consent, based off the bioethical lenses and ideas of capacity determinations as a heuristic, paternalism, and constrained parental autonomy. A recommendation was reached on how to move forward for euthanasia and PAD as it affects adolescents.

Elisheva "Eli" Nemetz, BA, received her BA from Yeshiva University with a major in political science and minor in biology. She is a recipient of the Benjamin and Jennie Hammer Memorial Award for Excellence in Political Science, and a dean's list scholar. Nemetz was president of the Yeshiva University Medical Ethics Society where she focused on the intersection of law, medicine, and ethics. She plans on enacting health policy change and advocating for communities with strong religious beliefs.



Matthew Riley, III

Capstone Mentors: K. Babu Krishnamurthy, MD, MBE

Director of Epilepsy and Ethics Associate, Steward Medical Group; Assistant Professor of Neurology, Harvard Medical School

Alexandra Cist, MD

Faculty Associate, Center for Bioethics, and Instructor in Medicine, Harvard Medical School; Physician, Division of Pulmonary and Critical Care Medicine, Massachusetts General Hospital

Faculty Advisor: Charlene Galarneau, PhD

Teaching Faculty, Center for Bioethics, and Lecturer on Global Health and Social Medicine, Harvard Medical School; Associate Professor Emerita, Women's and Gender Studies Department, Wellesley College

Identifying a New Model for Ethics Committee Structure and Function

Traditionally, hospital ethics committees (HEC's) have been charged with the responsibility of making recommendations when complicated ethical dilemmas arise. However, HEC's are often composed of volunteers who do not have the formal bioethics education or resources to accurately assess the needs of the stakeholders they serve, and often make assumptions about their needs instead. As service providers, it is imperative that HEC's do not simply assume how to best serve hospital stakeholders; instead, HEC's must ask directly how they can best serve. To this end, the purpose of this capstone project was threefold: (1) to identify the most robust eight to ten goals of a hospital ethics committee; (2) to identify a method that existing HEC's can use to assess the ethics needs of the hospital stakeholders they serve; and (3) to develop a survey that individual HEC's can take and modify to support the needs identified in objective 2 in order to achieve the goal identified in objective 1. The final product was a ten-question hospital ethics committee survey to be completed by hospital community stakeholders. The survey is quick to deploy, fast and easy to fill out, and simple to tabulate, which is very important for a volunteer committee that already does not have much spare time, yet wants to provide the best service that they can to the hospital community stakeholders. The survey has been successfully deployed to hospital community stakeholders at Saint Elizabeth's Medical Center.



Matthew Riley, III, BS, MDiv, received a BS in biology from Bowie State University and a MDiv from the Howard University School of Divinity. Riley's bioethics research explores the following question: What does it fundamentally mean to be human in light of emerging biotechnologies that may alter the human being at its very core? Matthew looks forward to teaching bioethics and continuing his research at the doctoral level.

Mark Robinson

Capstone Mentor: Carmel Shachar, JD, MPH

Executive Director, Petrie-Flom Center for Health Law Policy, Biotechnology, and Bioethics, Harvard Law School

Faculty Advisor: Aaron S. Kesselheim, MD, JD, MPH

Teaching Faculty, Center for Bioethics, and Associate Professor of Medicine, Harvard Medical School; Associate Physician, Division of Pharmacoepidemiology and Pharmacoeconomics, Department of Medicine, Brigham and Women's Hospital

Ethics for a Frail Subject: Systems, Technology, and a Theory of Universal Moral Impairment

From minds fatigued by too many details, to our openness to charismatic lunatics, mounting evidence reveals a crisp catalog of contextual, social, and biological impediments to our morality. What if ethics embraced this frailty? This project argued that bioethics should assume an impaired subject. This does not mean that we have no agency or are slaves to biology. Instead, how might “thinking with impairment” force a different kind of ethics? Just as disability theory showed how inaccessible buildings “impair” those with disabilities, how might, for example, requiring ethical decisions when exhausted engineer moral impairment? If long sentence structures in consent forms impair patient comprehension (such sentences tax cognition), do such forms engineer moral incapacity? Might ethics practices that ignore these limits perform ethical ableism, placing too much weight on fictions of virtue, rationality, memory, utility-calculative capacity, and too little weight on how environments and tools enable capacity? Putting forth a theory of (universal) moral impairment, and proposing a model that inserts evidence about moral limitations into a normative theory, this project proposes an ethical theory/framework that asks us to take seriously that which impairs us, why ethics without supports is impossible, the ethicality of technology, and the unique moral power inside systems.

Mark Robinson, PhD, is assistant professor at Creighton University. He received a PhD from Princeton University where he studied STS and medical anthropology, and master's degrees in social sciences and religion from the University of Chicago. His book *The Market in Mind: How Financialization Is Shaping Neuroscience, Translational Medicine, and Innovation in Biotechnology* is forthcoming from MIT Press. His second manuscript focuses on ethics, frailty, and the power of systems.



Kaila Rudolph

Capstone Mentor: Michael H. Jeong, MD

Fellow in Bioethics, Center for Bioethics, Harvard Medical School; Assistant Professor, Department of Pulmonary, Allergy, Sleep and Critical Care Medicine, Boston University Medical School; Medical Director, Medical Intensive Care Units and Codirector, Ethics Committee, Boston Medical Center

Faculty Advisor: Bizu Gelaye, PhD, MPH

Teaching Faculty, Center for Bioethics, and Lecturer on Global Health and Social Medicine, Harvard Medical School; Assistant Professor of Psychiatric Epidemiology, Harvard T.H. Chan School of Public Health

The Psychiatry-Ethics Intersection: Identifying Opportunities for Interdisciplinary Collaboration

Psychiatry and clinical ethics have distinct but overlapping expertise. The former involves identifying and managing psychopathology and decisional capacity, and the latter involves identifying moral dilemmas, conducting ethical analyses, and providing morally permissible recommendations. It can be challenging to discern where both ethical and psychiatric expertise is required; when an ethical dilemma may obscure psychopathology, or when over-emphasis on psychiatric concerns may obscure ethical issues. Given resource-allocation concerns, particularly in safety-net hospitals such as Boston Medical Center (BMC), it is critical to understand the roles of each to optimize interdisciplinary care. This capstone project characterized the roles of psychiatry in clinical ethics at BMC. A retrospective chart review was conducted for patients who had ethics consultations between January 2015 and December 2017 using the hospital ethics database and electronic medical records. Consultations were coded using the Armstrong Clinical Ethics Coding System. Chart review data was used to determine the types of ethical dilemmas most likely to involve psychiatry and psychiatry participation in ethics consultation meetings. Chart review demonstrated 65 percent of ethics consultation recipients had at least one psychiatric condition, with 41 percent undergoing psychiatric and ethics consultations during the same hospitalization. Treatment decision-making dilemmas were most associated with psychiatric involvement, occurring in 50 percent of cases, as compared to 26 percent in those without psychiatric care. As ethics consultation prevalence increased, psychiatric collaboration expanded, however, remained limited. To build upon these findings, qualitative interviews will be conducted with BMC psychiatrists to identify mechanisms to promote psychiatry-ethics collaboration.



Kaila Rudolph, MD, MPH, is a psychiatrist and ethics committee member at Boston Medical Center. She received her MD from Dalhousie University and completed psychiatry residency at the University of Toronto. She completed her MPH at the Harvard T.H. Chan School of Public Health. Her primary clinical interests include consultation-liaison psychiatry and the intersection of social determinants and acute medical and psychiatric care within the safety-net setting.

Emily Schwartz

Capstone Mentor: Kira Bona, MD, MPH

Attending Physician, Dana-Farber/Boston Children's Cancer and Blood Disorders Center; Assistant Professor of Pediatrics, Harvard Medical School

Faculty Advisor: Jonathan Marron, MD, MPH

Research Associate in Global Health and Social Medicine, Center for Bioethics, and Instructor in Pediatrics, Harvard Medical School; Associate in Ethics and Clinical Ethicist, Boston Children's Hospital; Attending Physician, Dana-Farber Cancer Institute

The Effect of Poverty on Resource Utilization in Pediatric Oncology Care

Household material hardship (HMH) is defined as a domain of poverty in which at least one of three concrete resource needs—food, housing, and energy—are unmet. HMH was previously identified in 20 percent of pediatric oncology families at diagnosis, and 30 percent of families after the first six months of chemotherapy treatment. In general pediatrics, children living in families with HMH have higher rates of infectious disease and hospitalization. While HMH is correlated with poor health outcomes in general pediatrics, standardized screening interventions can improve these measures. We hypothesized that HMH impacts resource utilization in the subspecialty pediatric oncology setting, including both psychiatry utilization and emergency department utilization. Resource utilization data was abstracted from the electronic medical records of a cohort of 415 newly diagnosed children at Dana-Farber Cancer Institute and Boston Children's Hospital whose parent/guardians completed the Psychosocial Assessment Tool as part of routine clinical care. The data was analyzed for correlation between HMH status and psychiatric evaluations and assessments, as well as emergency department visits. Poverty and HMH are highly prevalent in pediatric oncology. As such, studies that target these social determinants of health have the potential to benefit a significant population of children with cancer. The long-term goal of this study is to assess the association of HMH and health care utilization, one mechanism that may mediate documented poverty associated outcome disparities. Ultimately, the aim is to develop clinic-based interventions for the purposes of remediation and improvement of morbidity and mortality outcomes for pediatric oncology patients.

Emily Risa Schwartz, BA, BS, is a doctoral candidate in pediatric oncology at the Vrije Universiteit Medisch Centrum in Amsterdam. She received a BA in anthropology and a BS in biology from Brown University. She was granted a Fulbright Fellowship for childhood cancer research in the Netherlands. Her primary bioethical interests are in pediatric clinical ethics, particularly regarding conceptions of quality of life and processes of decision-making in pediatric oncology.



Ella Sorscher

Capstone Mentor: Brian Cummings, MD

Attending Physician, Pediatric Critical Care Medicine; Associate Chief Quality Officer, Center for Quality and Safety; Chair, Pediatric Ethics Committee, Massachusetts General Hospital

Faculty Advisor: Robert Truog, MD, MA

Director, Center for Bioethics, Frances Glessner Lee Professor of Medical Ethics, Professor of Anaesthesia and Pediatrics, Harvard Medical School; Senior Associate in Critical Care Medicine, Boston Children's Hospital

The Debate behind Clinical Ethics Certification: Implications and a Path Forward for Community and Rural Hospitals

With the recent wake-up call on the variability of health care ethics consultation in the United States, the calls for competency, oversight, and accreditation have grown louder, culminating in the American Society of Bioethics and Humanities (ASBH) offering a certification program. After examining the development and growth of clinical ethics as a field, this paper acknowledges the issues related to patient protection, professional validation, and the inevitability of certification while stressing the imminent issues hospitals and communities must address with this professionalization of clinical ethics. Through the examination of the available literature, this paper identifies that while bioethicists accept the inevitable need for professionalization, they remain divided about whether certification meets this demand. Examination of similar certification programs within the medical field provides constructive insights in clinical ethics professionalization. Moreover, this paper notes the distinctive cases and hurdles inherent to “typical” rural and community hospitals, which are often overlooked in a field dominated by academic medical centers, and examines how ASBH can meet these unique needs. Certification will potentially change the landscape of ethics consultation across the United States and transform who has moral authority to participate in clinical ethics. As bioethicists take these critical steps forward, we should walk with eyes open to the impacts.



Ella Sorscher, BA, is a MD candidate at Alpert Medical School of Brown University, planning to pursue a career in pediatrics. She received a BA in sociology/anthropology from Middlebury College. Sorscher completed a fellowship in community stewardship at Project Horseshoe Farm in Alabama. Her academic work and service focus on improving health care access in vulnerable communities, including incarcerated juveniles and immigrant populations. She is a Gold Humanism Honor Society Member.

Tan Hui Siu 陈慧修

Capstone Mentor: Christy L. Cummings, MD

Neonatologist and Ethics Associate, Division of Newborn Medicine, and Director of Medical Ethics & Humanities, Newborn Medicine, Boston Children's Hospital; Assistant Professor of Pediatrics, Harvard Medical School

Faculty Advisor: Robert Truog, MD, MA

Director, Center for Bioethics, Frances Glessner Lee Professor of Medical Ethics, Professor of Anaesthesia and Pediatrics, Harvard Medical School; Senior Associate in Critical Care Medicine, Boston Children's Hospital

On Becoming a Thought Leader in Bioethics in Malaysia: From Professional Development and Needs Assessment to Implementation

Malaysia has an active research ethics program but has yet to develop a clinical ethics platform. Clinicians are governed by codes of professional conduct and professionalism training, although ethics education remains limited. Thus, ethical discourse primarily resides in the legal and academic spheres. In practice, ethical dilemmas are often resolved through clinical team consensus, family conferences, and administrative facilitation, although this lacks formal structure and evaluation. Strong paternalistic and Asian family-orientated values infused with religious beliefs (particularly Islam) influence clinical decision-making locally. The primary purpose of this project was to master the fundamentals of clinical ethics education and facilitation in order to ultimately adapt and implement a culturally sensitive, inter-professional ethics education program in Malaysia, using a three-staged approach: professional development, local needs assessment, and implementation. The first aim, professional development, was achieved through participation, cofacilitation, and observation of activities including Boston Children's Hospital's (BCH) Program to Enhance Relational Communication Skills (PERCS) Rounds, in the neonatal intensive care unit, online self-paced ethics courses through OPENPediatrics™, BCH's Institute for Professionalism and Ethical Practice (IPEP) workshops, and Ethics Advisory Committee (EAC) meetings. The second aim, needs assessment, was to develop a survey to assess ethics knowledge and identify educational needs and potential barriers in Malaysia. Finally, the ultimate aim of this project will be to combine the first two aims to develop and implement a robust, culturally sensitive ethics education program for Malaysian hospitals.

Tan Hui Siu, MBBS, MRCPCH, is a pediatrician from Malaysia. She received her medical degree from University of Malaya, Malaysia, and professional degree from Royal College of Paediatrics and Child Health, United Kingdom. She is a Yayasan Khazanah scholar. Tan has fifteen years of clinical experience, including six years as department head, and has contributed to clinical practice guidelines and policies in Malaysia. Her interests are in child health, clinical, and organizational ethics.



Adele de Vera

Capstone Mentor: Jan McGonagle, MD

Developmental Pediatrician, Crotched Mountain Rehabilitation Center

Faculty Advisor: Christine Mitchell, RN, MS, MTS

Executive Director, Center for Bioethics; Director, Master of Bioethics Capstone Program; Lecturer on Global Health and Social Medicine, Harvard Medical School

Identifying Barriers to the Complex Care Network of New Hampshire and How to Overcome Them

The special health care needs of children who are at increased risk for a chronic physical, developmental, behavioral or emotional conditions are not currently being met through conventional health care systems in New Hampshire (NH). Primary care providers oftentimes do not have the resources to address the costly needs of these children and their families. The burden falls on the families who often shoulder the responsibilities of medical and nursing care, including care coordination and communication between health care providers, the schools, and the community. Because the state has an ethical responsibility to take care of its children with complex health care needs, the Complex Care Network of New Hampshire (CCN) was established in NH to meet this need, providing an alternative model to help families, community members and health care providers in educating and caring for children and their families with complex medical issues. Lack of knowledge of the existence of CCN is the main barrier in accessing the network. This capstone project surveyed health care providers and school nurses to determine whether or not they were aware of CCN resources. Recommendations to help the state meet its ethical obligation included adequate dissemination of information through information sessions, newspaper articles, email, and social media, with adequate periodic follow-up to all parties involved.



Adele de Vera, MD, FAAP, is a pediatrician at Monadnock Community Hospital (MCH) in New Hampshire. She received her MD from UERMMMC Philippines and completed pediatric residency at Lincoln Medical Center, NY. She founded PBJ Traveling Health Clinic, was voted a "Top Doctor" in *New Hampshire Magazine* in 2017, 2018, and 2019. She is chair of the ethics committee at MCH. She seeks to better understand ethical concerns in pediatric practice and work with local clinical ethics committees.

Monique Visser

Capstone Mentor: Martha Jurchak, PhD, RN

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Faculty Advisor: Melissa K. Uveges, PhD, MA, RN

Postdoctoral Researcher, Center for Bioethics, Harvard Medical School

Clinical Ethics Consultation: Who Calls and Why? A Review of the Literature

This capstone project consisted of a literature review regarding of who requests a clinical ethics consultation, and why, as part of ongoing research being conducted by the ethics consultation service at Brigham and Women's Hospital (BWH). The increasing complexity of modern medicine has created difficult ethical questions that require answers from patients, families, and the health care team. A recognition of the need for support outside of the legal system for solving ethics problems facilitated the development of clinical ethics consultation services. Ethics services started slowly, with physician-only requests in a limited number of institutions, to current wide-spread implementation with requestors including the entirety of the health care team as well as patients and families. As implementation of clinical ethics consultation has grown, so have the reasons for requesting such help. A review of relevant literature (and a beginning assessment of ethics service requests at BWH) revealed evolving and expanding ethics themes, inconsistency in terminology, minimal precision of definitions, and increasing diversity of requestors. Given the maturing of clinical ethics consultation services, there needs to be improved clarity of ethical themes to allow for comparisons between different institutions. This literature review is part of the BWH's analysis of their ethics service and will be used to support the creation of definitions of the ethics themes and analysis of types of consults and requestors across time.

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A Survey of the Ethics Consultation Process of Massachusetts-Based Hospices

Making up nearly half of all U.S. deaths, approximately 1.5 million people will receive hospice care this year. Many patients and families experience a relatively seamless transition through the end of life, however moral dilemmas and distress are inevitable. While there is an extensive literature regarding inpatient ethics consultation, with the most commonly cited reasons involving conflict, autonomy and surrogacy, and in end-of-life care, there is little discussion regarding home-based hospice ethics consultation. In addition, patient populations and care provision differ between hospitals and hospices. For example, the patients admitted to a hospital are confined to a medical facility, whereas home hospice care is provided by a handful of clinicians who must transport themselves to the patient's home, significantly changing the power-dynamic within a social context. This capstone project consisted of a pilot study to characterize the ethics consultation processes of Massachusetts hospices. A nine-question survey was sent to all hospices in Massachusetts, primarily through direct e-mails to medical directors or via general contact links on the hospice's website. The survey results revealed a wide variance in the local ethics consultation process for home hospice, similar to the data regarding inpatient consultation. This preliminary study suggested that there is no standardized ethics consultation process that hospices utilize and that further research and discussion are needed.



Johnson Wu, DO, is a hospice physician at Care Dimensions. He received his BS in psychology from the University of Texas at Austin and his DO from A.T. Still University in Arizona. After completing family medicine residency at UT Austin, he completed a fellowship in hospice and palliative medicine at Cleveland Clinic. He currently serves as the hospice clerkship director for Harvard Medical School's Palliative Care Fellowship Program.

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Mapping the Moral Landscape: Providing Palliative Care in Humanitarian Situations

This year, approximately 132 million people worldwide are estimated to need humanitarian aid. Palliative care, a medical subspecialty focused on minimizing pain and suffering as well as maximizing a person's quality of life, is well equipped to benefit victims of both human-made and natural disasters. Research indicates that in the year 2015 more than 25.2 million people worldwide (approximately 45 percent of all deaths) experienced symptom-related suffering during their final days. Furthermore, of that 25.2 million people, more than 80 percent were from developing regions. There is a growing body of literature calling for the implementation of palliative care in humanitarian responses. This project set out to map this dilemma. We reviewed forty articles and conducted quantitative analysis on more than fifty surveys completed by humanitarian workers. Additionally, we collaborated with an interdisciplinary team to map the most pressing population-level ethical dilemmas. The results of our work lays out the moral dilemmas involved with palliative care in humanitarian situations.

Keona Wynne, BS, is a recent graduate of Howard University where she studied biology and chemistry. Currently, her work centers around mapping the ethical issues associated with the provision of palliative care in humanitarian situations. Next year, she will begin her PhD in population health sciences at Harvard T.H. Chan School of Public Health.



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Ethical Considerations in the Transfer of “Affected” Embryos in Assisted Reproduction

Genetic testing has affected medicine in myriad ways, and the field of reproductive medicine is no exception. In the context of assisted reproduction, methods such as preimplantation genetic testing (PGT) are increasingly used to test and select for “normal” embryos unaffected by a known genetic or chromosomal disorder. While this practice itself is morally debatable, further concerns arise when testing results are inconclusive or when families request transfer of “affected” embryos. Providers are confronted with conflicting ethical considerations, including the patient’s right to autonomy, the provider’s professional conscience, and the perceived duty to promote “healthy” gestation. Despite the growth of scholarship in the field of assisted reproduction, there remains a need to address the implications of embryo transfer at the intersection of genetic testing and disability. This project sought to explore clinicians’ attitudes about and to provide a more comprehensive understanding of the ethics of transferring embryos affected by genetic and chromosomal anomalies. A qualitative survey instrument was designed to assess attitudes towards PGT, embryo transfer, and disability. Interviews were conducted with medical providers of diverse professional backgrounds—including reproductive endocrinology and infertility specialists, and providers involved in caring for individuals with disabilities. Subsequent coding and qualitative analysis revealed themes including conflicting clinical considerations, varying paradigms of health and disability, and ethical dilemmas surrounding provider identity and patient autonomy. Ultimately, this project seeks to provide information that will assist clinicians and prospective parents and guide decision-making.



Jane Zhu, BS, received a BS in physiology from McGill University. As an undergraduate, she completed research projects in cognitive science and neurobiology, for which she received the Canadian Natural Sciences and Engineering Research Council’s Undergraduate Research Award. Her academic interests include exploring the intersection of reproductive ethics, genomics, and disability. She recently presented her capstone project at the Fourth Annual Reproductive Ethics Conference at Albany Medical College. Zhu will attend medical school in the fall and hopes to continue her work at the Center.

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