CENTER FOR BIOETHICS
HARVARD MEDICAL SCHOOL

MASTER OF BIOETHICS

CAPSTONE SYMPOSIA

MAY 2 & 9, 2023

Virtual Symposium Agenda

Welcome

Kelsey N. Berry, PhD
Associate Faculty Director, Master of Bioethics Degree Program; Lecturer, Department of Global Health and Social Medicine, Harvard Medical School

Reflections on the Capstone Program with the Co-Directors

Joni R. Beshansky, RN, MPH, LP.D.
Capstone Co-Director, Center for Bioethics, Harvard Medical School; Associate Professor and Director, Health Administration Graduate Program, Boston College

Michael Ieong, MD
Capstone Co-Director, Center for Bioethics, Harvard Medical School; Director, Medical Intensive Units, Boston Medical Center; Assistant Professor on Pulmonary, Allergy, Sleep and Critical Care Medicine, Boston University Medical School

Lisa Moses, VMD, DACVIM
Capstone Co-Director, Center for Bioethics, Lecturer on Global Health and Social Medicine, Harvard Medical School; Visiting Scientist, Vertebrate Genomics Group, Broad Institute of MIT

David N. Sontag, JD, MBE, HEC-C
Capstone Co-Director, Center for Bioethics, Lecturer of Medicine, Harvard Medical School; Director of Ethics and Senior Associate General Counsel, Beth Israel Lahey Health; Co-Chair, Ethics Advisory Committee, Beth Israel Deaconess Medical Center

Invitation to Poster Presentations

Crystal Chang, MPH
Associate Director of Education, Center for Bioethics

Poster Presentation Group 1

What Do Bioethicists Do?

Mildred Z. Solomon, EdD
Director of the Fellowship in Bioethics Program, Center for Bioethics

Poster Presentation Group 2

What Do Bioethicists Do?

Keynote Speaker:

Mildred Z. Solomon, EdD

Director of the Fellowship in Bioethics Program

Mildred Z. Solomon, EdD is the director of the Fellowship in Bioethics Program at the Center for Bioethics and a professor of Global Health & Social Medicine at Harvard Medical School. She was also the president of The Hastings Center, an independent research institute in Garrison, NY that explores ethical issues in health, health care and the life sciences.

A bioethicist and social science researcher who conducts both normative and empirical ethics research, Dr. Solomon's own scholarship has focused on the ethics of end-of-life care for both adults and children, organ transplantation, research ethics particularly related to oversight of comparative effectiveness and implementation science, as well as professionalism and responsible conduct of research. She has served on committees of the National Academies of Science, on the U.S. Secretary of Health and Human Services' Advisory Committee on Organ Transplantation, and has consulted to numerous foundations and government agencies.

Before assuming the leadership of The Hastings Center, Dr. Solomon was senior director of Implementation Science at the Association of American Medical Colleges. There, she was responsible for helping the nation's academic medical centers develop their capacities in comparative effectiveness research and implementation science. Dr. Solomon earned her doctorate in educational research methods and adult learning at Harvard University and her BA from Smith College.

Erica Andrist, MD

When Duty Calls, Hang Up: The Ethics of Quitting for Clinicians

The "Great Resignation" following the SARS-CoV-2 pandemic has not spared the health sector. Resultant staffing shortages have compromised patient safety. The pandemic simultaneously reinvigorated discussions of the clinician's "duty to care," a unique ethical and legal responsibility that requires clinicians to place the needs of patients above their own interests. If a strong duty to care exists, then quitting cannot be ethical; however, this also renders clinicians infinitely exploitable by institutions and by patients. This capstone included a literature review that assessed the history and ethical underpinnings of the duty to care, and interviews with six clinicians who quit their jobs. Thematic analysis demonstrated that clinicians balance multiple competing duties with the duty to care, including duties to the self, family, colleagues, and health trainees. Being unable to effectively fulfill a perceived duty to patients because of institutional or other constraints also contributed to clinicians' decision to quit. Additionally, participants expected basic safety measures and fair compensation in return for their service. These findings indicate clinicians accept a general duty to care, but do not believe that it universally trumps other moral duties. Additionally, reported institutional constraints on good patient care and clinicians' expectations of basic protections suggest that a corresponding institutional duty to care exists. Future scholarship should articulate the upper and lower bounds of the duty to care and evaluate how institutions and the public can reasonably provide clinicians with the tools necessary to effectively serve patients.

Capstone Mentor:

Janice Firn, PhD, MSW, HEC-C, Clinical Assistant Professor of Learning Health Sciences, Co-Chief of Education Service, and Clinical Ethicist, Center for Bioethics and Social Sciences in Medicine, University of Michigan

Erica Andrist, MD, is an attending pediatric critical care physician at C.S. Mott Children's Hospital in Ann Arbor, Michigan. She completed her undergraduate work and MD at the University of Wisconsin, followed by pediatric residency at Children's Hospital Oakland and critical care fellowship at Cincinnati Children's Hospital. She is interested in clinical ethics, particularly involving end-of-life care and decision-making, extracorporeal life support, and brain death. She is also interested in the duties and responsibilities of individual clinicians practicing—as so many of us do—in structurally discriminatory, exploitative systems. After graduation, she will continue as a pediatric critical care physician, but hopefully a better one than she was prior to the MBE program.

Janet Aucoin, BASc, MSW

Shades of Grey: Sex and Intimacy for Older Adults with Diminishing Capacity

An understudied area of decisional capacity is the capacity of Long-Term Care (LTC) residents with neurocognitive impairments to participate in matters related to sex and intimacy. Sex and intimacy maintain their importance to people across the lifespan and people continue to engage in sexual behaviors after they have moved into LTC. Sexual behaviors in older adults are often perplexing to LTC staff and families because of a confluence of ageism, a paucity of organizational policies on this issue, and subjective or cultural attitudes toward sex and intimacy. In the context of decision making, no consensus exists on what to do and how to respond to sexual behaviors exhibited by cognitively impaired individuals in LTC. The aim of this capstone was to examine the theoretical constructs of consent and capacity in relation to sex and intimacy for people with neurocognitive illnesses living in LTC in Canada and the United States. A literature review suggested that there is an obligation to enable or facilitate sex and intimacy for these individuals, however, there is a lack of consensus on what that might entail when a person has diminished cognitive abilities. In the future, this capstone could develop and deploy tools or frameworks specific to evaluating a person's capacity to participate in sex and intimacy; incorporate an iteration of non-ideal theories of consent; and make policy recommendations, all of which would allow people with neurocognitive impairments to benefit from sex and intimacy.

Capstone Mentor:

Vardit Ravitsky, PhD, FCAHS, Professor, Bioethics Program, Department of Social and Preventive Medicine, School of Public Health, University of Montreal; Senior Lecturer on Global Health and Social Medicine, Harvard Medical School; President, The Hastings Institute

Janet Aucoin, BASc, MSW, is a Seniors Mental Health Clinician with Alberta Health Services, Canada. She received a BASc in philosophy and psychology from the University of Lethbridge, Canada and an MSW from Wilfrid Laurier University, Canada. Her career has encompassed academic research in cognitive neuroscience as well as clinical practice, consulting, and social work education, with a focus on the behavioural sequalae of neurocognitive and neurodegenerative disorders. Her bioethics interests include resource allocation, commodification of elder care, and pharmaceutical ethics. After graduation, Janet will utilize her bioethics training as she continues to work with and advocate for older adults and the care teams supporting them.

Rigobel Azanwi, BA, MDiv

Characterizing Moral Distress and Moral Injury Among Healthcare Chaplains

Moral distress and moral Injury (MD/MI), commonly understood as the inability to uphold personal values due to internal or external constraints and emotional harm resulting from actions that violate one's ethical beliefs, are prevalent among healthcare professionals. Recent studies, centered primarily on nurses and physicians, have identified a correlation between several mental health concerns and MD/MI and underscored the prevalence and severity of MD/MI among clinicians. Although healthcare chaplains play a significant role in healthcare teams by providing spiritual care to patients and staff during trauma, severe illness, and death, there is a paucity of data examining MD/MI among chaplains. This capstone aimed to identify the frequency and predictors of MD/MI among chaplains in the US as a first step to guide future interventions to mitigate the impact on chaplains and reduce burnout. A quantitative and qualitative survey-based study of 361 chaplains across the US used the Measure for Moral Distress (MMD-HP) Scale and Expression of Moral Injury Scale—Military version (EMIS-M) to assess MD/MI. Additionally, chaplains answered open-ended questions regarding their experiences of MD/MI. Descriptive statistics were conducted to characterize MD/MI among chaplains, and linear regression was used to assess predictors of MD/MI. Qualitative analysis examined themes regarding chaplain MI/MD. Results demonstrated that most surveyed chaplains experienced MD/MI. Predictors of MD/MI were influenced by demographic factors (age, race, religious affiliation), years in practice, and practice location.

Capstone Mentors: Tracy Balboni, MD, MPH, Professor of Radiation Oncology, Harvard Medical School; Associate Physician, Dana-Farber Cancer Institute; Clinical Director, Supportive and Palliative Radiation Oncology Service, Brigham and Women's Cancer Center;

Timothy Usset, MDiv, MPH, MA, Executive Director, Physicians Wellness Collaborative Army Reserve Chaplain; PhD Student, University of Minnesota

Rigobel Azanwi, BA, MDiv, is a Capuchin Franciscan priest and theologian. He received a BA in philosophy from L'Université Catholique D'Afrique Centrale, Cameroon, and an MDiv from The Catholic University of America. Rigo also completed a public health ethics fellowship at Tuskegee University. In addition, he has experience as a chaplain, pastor, preacher, teacher, and spiritual assistant. Rigo's research interests include moral distress/injury and global health justice. Post graduation, he will pursue a PhD in global health and social medicine to advance ethical underpinnings in emerging technologies such as CRISPR-Cas9 and teach at the post-secondary level. His hobbies include traveling, flying helicopters, skydiving, singing, playing violin, ping pong, and exercising.

Lakshmi Bharadwaj, MS

Ethical Considerations for Robotic Surgery in India

India is currently experiencing a surge in robotic surgery, with an unprecedented expansion of surgical capabilities in its major hospitals. Although surgical robots are tightly regulated in the subcontinent, ethical considerations in robotic surgery have not been included in these assessments. The purpose of this Capstone was to identify relevant ethical considerations in robotic surgery applicable to the unique constraints of Indian hospital systems. A literature review identified medical mistrust, uneven use of technology and ineffective surgical training as key ethical concerns in this area. These concerns were then examined through multiple perspectives to provide a theoretical basis for future work. Specifically, medical mistrust was analyzed through an ethics of care perspective, a justice framework was adopted for studying disparities, and a rights-based approach was utilized to examine surgical training. These critical analyses pointed to the need for deeper work, including interviews with robotic hospitalists to bridge the gap between surgical capabilities and clinical outcomes. Thus far, this capstone project has provided a theoretical basis for examining ethical considerations through bioethical frameworks. It has acted as an essential first step towards studying pressing ethical issues and has shown that multiple moral perspectives are necessary to examine these issues in a context where cultural histories have a bearing on the practice of medicine. In the future, this body of knowledge will be useful in drafting policies that integrate ethical considerations in recommendations to properly equip hospitals for the adoption of surgical robots in the country.

Capstone Mentor:

Douglas Brown, PhD, Surgical Ethics Specialist, Department of Surgery, Washington University in St. Louis and Barnes-Jewish Hospital, St. Louis, Missouri

Lakshmi Bharadwaj, MS, is a laboratory research coordinator at the Clinical and Translational Research Unit of Stanford University School of Medicine. She received a BS in biomedical engineering from University of California, Davis, and an MS in biomedical engineering from California Polytechnic State University, San Luis Obispo. Lakshmi has worked as a life science professional with a research focus on bioengineering applications in regenerative medicine. She is interested in the moral issues surrounding the use and manipulation of embryonic stem cells in biomedical research and the ethical use of surgical technologies in India. After graduation, Lakshmi will transition to a new role as a senior research specialist at Emory Medicine.

Benjamin Blevins, MD

Conflicts in Healthcare Fiduciary Relationships: Considerations for Policies in Patient Reporting

Healthcare professionals have fiduciary relationships to those who they treat. The healthcare fiduciary relationship (HFR) requires that the healthcare team act in the best interests of the patient. This relationship establishes the duties to protect privacy and confidentiality that comprise the foundation of trust necessary for effective medical care. The HFR may conflict with other professional duties such as mandated reporting to governmental agencies, particularly when such reporting can cause negative consequences to the patient and benefit no one else. An example is the reporting of substance use when there is no threat to other persons, redirecting a medical problem to the criminal justice system. This project examined whether healthcare reporting conflicts differed from conflicts in other fiduciary relationships and whether they should be treated differently. Variations among the fiduciary responsibilities of other professions, namely law, finance, corporate and military officership, in comparison to the healthcare relationship, were explored focusing on where those duties come into similar conflict with professional duties. Literature review and thought experiments were utilized to identify key conflicting obligations, concluding that competing conflicts external to the HFR differ substantially from other professions and must be treated differently. As these conflicts undermine trust necessary in the HFR for optimal communication and outcomes, this must be explicitly addressed in future policies and laws regarding mandatory and voluntary reporting of health information to governmental agencies without consent of the patient.

Capstone Mentor:

Brian M. Cummings, MD, Ronald E. Kleinman, MD Endowed Chair in Pediatrics, Medical Director, and Vice Chair, Massachusetts General for Children; Senior Medical Director, Clinical Process Improvement Leadership Program (CPIP), Massachusetts General Brigham; Assistant Professor Pediatrics, Harvard Medical School

Benjamin Blevins, MD, is a pediatric cardiologist and chair of clinical ethics and the health care ethics committee at Naval Medical Center San Diego. He received a BA in psychology from North Carolina State University and his MD from Uniformed Services University of the Health Sciences. Ben's current work focuses on military and humanitarian medical ethics, ethics education in graduate medical education, and remote ethics consultation for resource-limited settings. He hopes to expand his work in ethics education, health policy, and law. He will continue his work at Naval Medical Center San Diego until the end of his education payback commitment to the Navy.

Marta Fadda, PhD

A Narrative Analysis of Pre-admission Patient Biographies

Research has shown that incorporating biographical approaches into patient care can have considerable impact on promoting person-centered care. Eliciting patients' biographies can facilitate better outcomes, challenge biases and assumptions, enhance empathy, establish stronger relationships between patients and providers, and foster greater job satisfaction among care team members. Yet unrecognized are the specific ways the content and structure of patient biographies can shed light on essential dimensions of person-centered care . This study used narrative methods to analyze ten biographies written by patients at the request of their surgeons before their hospitalization. The narrative structures of the biographies were analyzed to understand how patients communicated the values and needs they most wanted their providers to know. The study showed that patients used multiple, distinct narrative structures to describe their personal identity and convey their need to be recognized as unique human beings. Further, patients expressed gratitude for the opportunity to provide their biographies and a deep need to form a meaningful relationship with their providers by telling them what intimately mattered to them. One strong pattern threaded through the narratives was a sense of vulnerability. Notably, this analysis demonstrated specific narrative methods patients used to convey their trust that their providers would protect their unique identities during hospitalization. Writing brief biographies at the invitation of care providers may offer a valuable tool to establish and strengthen ethically and clinically important connections at the center of person-centered care.

Capstone Mentors:

Martha Montello, PhD, Lecturer of Global Health and Social Medicine, Center for Bioethics, Harvard Medical School

Samia Hurst-Majno, MD, PhD, Physician, Bioethicist and Consultant, Clinical Ethics Council of the University Hospitals of Geneva; Director, Institute for Ethics, History, Humanities, University of Geneva

Marta Fadda, PhD, is a researcher and lecturer of bioethics at the Università della Svizzera italiana (USI) in Lugano, Switzerland. She received a BA in languages and cultures from the University of Cagliari, Italy, an MA in near and middle eastern studies from the University of London School of Oriental and African Studies, and a PhD in health communication from USI. Her work focuses on public health and clinical ethics. She received the USI Equal Opportunities Award for elucidating the social consequences of COVID-19 public health policies targeting older people. After graduation, she plans to expand her research on the use of patient biographies as a tool for person-centered care.

Sarah M. E. Gabriele, LLM

Using Exceptions in the International Intellectual Property Regime to Achieve Distributive Justice

Medical innovation has flourished in many fields, however, the results are not equally shared among patients across the globe. Indeed, low- and middle-income countries still lack widespread access to several innovative and often patented medicines that are standard practice in developed countries. This lack of access is widely perceived as an ethical and moral dilemma. Access to patented therapeutics in low- and middle-income countries has been influenced by the adoption of the Agreement on Trade-Related Aspects of Intellectual Property Rights ("TRIPS Agreement"), which provides that "patents shall be made available for any inventions, whether products or process in all fields of technology." To ensure access to these patented drugs, on the account of distributive justice values, the TRIPS agreement provides for a set of exceptions that, when necessary, might be used to allow the manufacture and production of cheaper generics. However, this rule does not explain the lack of availability of innovative medicines in low- and middle-income countries. Using patent waivers and other exceptions to international intellectual property rights is a promising solution, most recently proposed in the case of COVID-19 vaccines. However, the pharmaceutical industry and its allies have challenged these mechanisms by opposing change in the governments of developed countries. This project evaluated the role of exceptions to intellectual property rights in achieving distributive justice and proposed methods for improved implementation of flexibilities in cases such as COVID-19.

Capstone Mentors:

Aaron Seth Kesselheim, MD, JD, MPH, Professor of Medicine, Harvard Medical School; Director of the Program on Regulation, Therapeutics and Law, Brigham and Women's Hospital and Harvard Medical School

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

Sarah M. E. Gabriele, LLM, currently is a student fellow with the Petrie-Flom Center for Health Law Policy, Biotechnology, and Bioethics at Harvard Law School and a research specialist at the Program in Regulatory Therapeutics and the Law (PORTAL), in the Division of Pharmacoepidemiology and Pharmacoeconomics of Harvard Medical School and Brigham and Women's Hospital. She obtained her law degree from the University of Trento (Italy) and an LLM from Washington University in St. Louis (USA). She previously worked at Hogan Lovells in its Milan office, specializing in pharmaceutical patent litigation. Her bioethical interests focus on intellectual property law's impact on the availability and prices of medicines. After graduation, she plans to continue working as a research specialist.

Christina Gavegnano, MS, PhD

Ethical and Legal Barriers to Drug Repurposing: Paving a New Path Forward

Significant legal and ethical barriers to drug repurposing limit access to life-saving therapeutics. Drug repurposing is the process of discovering new indications of already approved drugs for use in a different disease. The aim of this capstone was twofold: 1) to identify barriers to drug repurposing across the United States and global patent law and to evaluate policy differences for off-label and compassionate use for repurposed interventions; and 2) to define a streamlined rubric of policy recommendations for ethical drug repurposing. First, this capstone undertook a systematic literature review to identify legal, ethical, and scientific hurdles to drug repurposing and examine ways to overcome these obstacles. The following barriers were identified as most salient: 1) lack of defined funding and partnership paths to pursue drug repurposing; 2) cumbersome requirements including Investigational New Drug (IND) applications to study a repurposed drug in a new indication; and 3) lack of support by drug companies due to concerns of potential risks. These limitations stymie forward progress that can save lives. Next, this capstone outlined potential policy solutions to promote public health through safe, policy solutions intended to promote public health through safe, effective and ethical implementation of drug repurposing. One example of a policy change is creation of a modified IND process specifically for repurposed drugs, leveraging known safety and efficacy data for expeditious paths to the clinic. As a next step, this capstone aspires to guide policy changes aimed at decreasing barriers to patients receiving life-saving repurposed therapeutics.

Capstone Mentor:

Aaron Seth Kesselheim, MD, JD, MPH, Professor of Medicine, Harvard Medical School; Director of the Program on Regulation, Therapeutics and Law, Brigham and Women’s Hospital and Harvard Medical School

Christina Gavegnano, MS, PhD, is an Associate Professor at Emory University. She received her BS and first MS from the University of Florida, and second MS degree and PhD from Emory University. Dr. Gavegnano directs the Gavegnano Drug Discovery Program and is the inventor of baricitinib (a treatment for viral infections). Her areas of interest include bioethical and legal obstacles to drug repurposing, and access to therapeutics. Dr. Gavegnano is the holder of numerous internationally issued patents, and has licensed her technology to Eli Lilly, which has been prescribed globally to more than two million individuals with COVID-19. After graduation, Dr. Gavegnano will pursue ongoing collaborations towards improving access to life-saving therapeutics globally.

Rachel Lipson Glick, MD

Conceptualizations of Suicide: Is the Focus on Mental Illness Limiting Possible Prevention Strategies?

Suicide, defined as self-destruction by a person who is not otherwise dying, is among the top ten causes of death in the United States. Current suicide prevention efforts are largely based on treating suicide as the result of individual mental illness. Interventions are aimed at identifying those at risk and then diagnosing and treating their psychiatric disorder. Yet suicide rates have continued to increase in this country. Since bioethics is a field interested in human flourishing, this trend is disturbing. Suicide has not always been associated with mental illness, and the contemporary medicalization of suicide has resulted in less focus on societal and environmental factors that contribute to suicide. This capstone, including a literature review and informal discussions with leaders of organized psychiatry and suicide prevention experts, explored how suicide has been conceptualized historically, and in the current era, and asked whether thinking of suicide as something beyond a manifestation of mental illness might help save lives. Findings suggest that suicide prevention, like suicide itself, is complicated. Suicide is not just an issue of psychiatric illness, although there may be a final common neurobiological pathway in the brains of those at risk. Social factors including poverty, loneliness, and access to lethal means such as guns, also contribute to suicide. Future suicide prevention efforts must combine an understanding of individual biological risk and contributing societal factors for interventions to be most effective.

Capstone Mentor:

John R. Peteet, MD, Associate Professor of Psychiatry, Harvard Medical School; Physician, Brigham and Women's Hospital; Institute Physician, Dana-Farber Cancer Institute

Rachel Lipson Glick, MD, is a retired emergency psychiatrist and clinical professor of psychiatry. She received an MD from University of Michigan (U-M) Medical School and trained in internal medicine at The New York Hospital/Cornell Medical Center and in psychiatry at Massachusetts General Hospital, before returning to U-M. At U-M she was a clinician, educator, and administrator serving as director of psychiatric emergency services, associate dean for student programs, and associate chair for clinical affairs. Her scholarly work focuses on emergency psychiatry and student mental health. Rachel is interested in ethical issues related to conceptions of suicide and approaches to suicide prevention. She plans to continue work in this area after graduation.

Haley Haldeman, BSN, RN

Exploring the Impact of Gendered Power Dynamics: The Role of the Acute Care Registered Nurse

America’s current acute health care delivery model relies upon, and is sustained by, the role of the registered nurse (RN). Despite the healthcare system’s dependence on nursing, the role of the nurse is embedded within historically gendered power dynamics that may impact the role’s perceived value and nurses’ susceptibility to moral distress. This project included three components. First, this project conducted a comparative analysis of the response to medical error in the case of RN RaDonda Vaught, who in 2022 was convicted of negligent homicide following a fatal medication error, with responses to medical error in three physician cases. Second, a review of the relevant literature aimed to determine if the gendered history of nursing created a power imbalance and showed a causal relationship to moral distress. Third, the author created qualitative survey questions to assess for moral distress caused by gendered power dynamics in acute care registered nurses. The comparative case analysis between RN RaDonda Vaught and three physicians found a significant difference in provider treatment and disciplinary action. A review of the literature suggested that there are distinct normative gender structures that have negative financial and emotional impacts on nurses. Although the literature revealed a causal link between gender norms and poor job satisfaction, no studies focused on the causal link between gendered power dynamics and moral distress. The qualitative survey questions generated in this project aim to fill the gap in literature by exploring the relationship between gendered power dynamics and moral distress in acute care registered nurses.

Capstone Mentor:

Mary McCarthy-Tiella, RN, BSN, MBE, Clinical Registered Nurse, IntelyCare

Haley Haldeman, RN, is a bedside nurse on an adult telemetry medicine unit at Novant Health in Charlotte, North Carolina. She received a BSN from University of Arkansas. Haley began her nursing career working on an acute care of the elderly unit, where she gained an appreciation of the many ethical issues surrounding the aging population. Her desire to create and improve upon ethically considerate health care policy is what led her to bioethics. She has been nominated for the DAISY Award for Extraordinary Nurses by a former patient. After graduation, Haley will continue to work as a clinical ethics consultant while continuing to explore areas of academic interest.

Carol Hawkins-Garcia, BSN, RN

Creating Awareness Among Nurses of the Value of Clinical Ethics Consultation in Every Clinical Practice Setting

Nurses in clinical care settings benefit from support when the trajectory of their patient's care becomes dissonant with perceived patient goals or when institutional issues lead to ethical and moral concerns. The literature review in this project found that clinical ethics consultations can provide a valuable resource for nurses, but that they are underutilized in patient care areas outside hospital settings, such as long-term care, home health, rehabilitation, and intermediate care settings. The findings revealed a need to enhance nurses' awareness of the value and availability of a clinical ethics consultation in any patient care setting. Educating nurses about this resource supports nurses facing ethical challenges, lessens moral distress, and leads to increased career satisfaction. Utilizing a clinical ethics consultation for ethically challenging dilemmas also enhances the professional practice of nursing and supports The Code of Ethics for Nurses. This capstone project aimed to increase nurses' awareness of the benefits of obtaining clinical ethics consultation by providing an electronic educational brochure accessible on states' Board of Nursing websites and the National Councils of State Boards of Nursing website. In order to provide high-quality nursing care within the ethical requirements of the profession, nurses in all clinical patient areas should be aware of and able to utilize clinical ethics consultation as a resource in the everyday practice of nursing.

Capstone Mentor:

Christine Mitchell, RN, MS, MTS, HEC-C, Lecturer on Global Health and Social Medicine, Center for Bioethics, Harvard Medical School

Carol Hawkins-Garcia, BSN, RN, is an appointed board member by the Texas Governor to the Texas Board of Nursing. She received her Bachelor of Science in Nursing Degree from the Texas Tech Health Sciences Center. Her professional experience as a senior director spans across policy, administration, and corporate governance for major healthcare systems and related organizations, including the United Nations and Methodist Healthcare System. Her bioethical area of interest focuses on bioethics policy within corporate governance. Upon graduating, she plans to expand her work in bioethics policy with the Texas Board of Nursing, the United Nations, and other corporate entities.

Nathan Hyde, LLB, LLM, MPA

Commercializing Biologic Materials: Ethical Challenges of Compensation in the Era of Induced Pluripotent Stem Cells (iPSCs)

The debate regarding commodifying biologic materials has been polarized around whether it exploits vulnerable populations, or instead represents a form of justice by ensuring a balanced exchange between willing parties. Many modern therapies and new cell lines have proven highly profitable, with source donors not receiving any form of remuneration. Because one cannot patent one's cells, the only legal avenue available for payment is voluntary commercial agreements. This capstone reviewed the ethics of payment for donations of biologic materials in the context of induced pluripotent stem cells (iPSCs). iPSCs create the possibility of somatic cells being reprogrammed into reproductive cells with potential greater moral and economic worth. The ethical concerns related to becoming a genetic parent without consent or compensation are heightened by the exponential growth anticipated in stem cell research requiring an influx of biologic materials to ensure supply. A comprehensive literature review revealed that whilst compensating donors for certain classes of biologic materials is permissible, courts have not attached property rights to excised biologic materials. Regulators do however encourage private commercial arrangements to compensate donors with increasing acceptance by bioethics organizations. Achieving justice for donors requires reconsidering legal property rights and providing compensation. Negotiated agreements would ensure the greatest justice, although a challenge for individual donors to monitor in commercial markets. Alternatively, justice can be achieved by compensating donors directly at the time of material excision for the intended research or clinical use.

Capstone Mentor:

Insoo Hyun, PhD, Director, Center for Life Sciences and Public Learning, Museum of Science, Boston; Member and Senior Lecturer on Global Health and Social Medicine, Center for Bioethics, Harvard Medical School

Nathan Hyde, LLB, LLM, MPA. is a Chief Executive in Canadian local government. He received his LLB from Nottingham Law School, his LLM from the University of Toronto, and his MPA from the University of York. A public-sector leader, governance expert and strategist, he has been appointed to C-Suite roles in some of Canada's largest and fastest growing municipalities. Internationally, his experience includes working with the UK Foreign & Commonwealth Office on public affairs and national policy issues. Nathan's bioethics research interest focuses on the intersection of health law and the commercialization of biological materials. After graduation he plans to establish a national bioethics consultancy and a biotech firm.

Luca Ignatowski, BS

American Policing: Using Comics to Promote Meaningful Change

Contemporary policing in the United States has provoked a great deal of concern over the past few decades, partially due to a greater tough-on-crime approach and its subsequent impact on how police both view themselves and engage with the public. Although this approach is intended to reduce the overall incidence and severity of criminal behavior, there are considerable public health repercussions of current policing practices relevant to assessing their overall effectiveness. Dialogue between police and their communities often is impeded by differences in desired outcomes, unwillingness to respect or understand diverse perspectives, and paternalism on behalf of the police. To promote reflective dialogue between groups considering the effects of policing on public health, this capstone aimed to facilitate thoughtful reflection on policy and public health through a graphic novel format that incorporated imagery and narrative to explain complex topics. The project included a literature review to understand the scope of public health issues related to contemporary policing methods and potential solutions. Current work in graphic medicine informed the format of the graphic novel created through this capstone to make it both effective and accessible. As with other graphic mediums of communication, this capstone will be used as a vehicle to disseminate information surrounding current policing trends and its public health implications, and also provide ways for the reader to reflect on their own perspectives and be better prepared to empathize and participate in conversations toward timely solutions.

Capstone Mentor:

Riley Taitingfong, PhD, Luce Foundation Postdoctoral Researcher, Native Nations Institute, University of Arizona; Leadership Team Member, Scientific Citizenship Initiative, Harvard Medical School

Luca Ignatowski, BS, earned his BS in criminal justice at the Rochester Institute of Technology (RIT). During his undergraduate career, he conducted research on community perceptions of crime and policing, medication-assisted treatment in carceral settings, and the ethics of police use of facial recognition technology at RIT's Center for Public Safety Initiatives. His bioethical interests focus on intersectionality, social determinants of health, and healthcare access in Indigenous communities. In his spare time, Luca enjoys art and illustration, video games, and spending time in nature. After completing the MBE, he hopes to work in state or federal government where he can influence public safety and law enforcement policy and practices.

Tim Janchar, MD, MFA

Everyday Ethics in the Emergency Department: A Microethical Approach

The emergency department (ED) is a unique place where patient interactions are novel, brief, and intense. Ethical decisions need to be made quickly, often without the luxury of time, consultation, or committee. Traditional ethics, which focuses on philosophical principles and often uses dramatic cases to teach theory, may not always be applicable to the ED. This capstone considered whether microethics, focusing on the quotidian minute to minute decisions practitioners make, would be a better approach for thinking about ethics in the ED. The first phase of this project involved a literature review of microethics in clinical medicine. The second phase included two parts: (a) five interviews with emergency physicians; and (b) an analysis of the information collected to identify recurring themes. Analysis showed that the majority of ED physicians rely on an intuitive reflexive process in ethical decision-making, similar to the ethos of micro ethics rather than a rational reflective approach. Findings indicated that virtue can be a bridge between these two approaches. Recurring virtues cited were adaptability, care and empathy, teamwork, patient validation, and physician transparency. Interviewees also cited ethical skills reflecting values from narrative ethics, feminist ethics, care ethics, virtue ethics, and pragmatism. This project found that using a microethical lens to identify smaller dilemmas with a contextual emphasis on relationships, attitudes, and motives can facilitate better ethical interactions between provider and patient. The pragmatic utility of the microethical approach is not unique to the ED but holds promise for its use across multiple practice settings.

Capstone Mentor:

Piroska Cornell Kopar, MD, FACS, Director and Fellowship Director, Center for Humanism and Ethics in Surgical Specialties; Assistant Professor of Acute and Critical Care Surgery, Ethics and Law Thread Lead Gateway Curriculum, Washington University School of Medicine

Tim Janchar, MD, MFA, is an emergency medicine physician at Legacy Emanuel Medical Center in Portland, Oregon and an assistant professor of emergency medicine at Oregon Health Sciences University. He received a BS in chemistry from John Carroll University, an MD from Georgetown University School of Medicine, and an MFA in visual studies from the Pacific Northwest College of Art. Tim completed an emergency medicine residency at Harbor-UCLA. His interest in bioethics centers on emergency medical care and his ongoing work after graduation will focus on the emergency room as a safety net for healthcare in the United States.

Adrienne Jones-Adamczyk, MSN, ACNP-BC

Justice in Medical Aid in Dying: Identifying Barriers to Access

Medical advances have progressed, allowing patients to live longer than ever before. However, some terminally ill patients wish to end their lives early to prevent suffering or an unbearable quality of life. Medical Aid in Dying (MAiD) started in Oregon in 1997 and allowed patients to hasten death by self-administering prescribed medications. Since then, MAiD laws have expanded to eleven US jurisdictions. Multiple safeguards were added to the legislation to help alleviate public fears and protect vulnerable populations. However, twenty-eight years of data show that these safeguards may be causing undue burdens on patients' access to MAiD. Specifically, historically patients who successfully accessed MAiD were mostly non-Hispanic whites over 65 years old with a college education and a cancer diagnosis. Yet 74% of Americans support "ending terminal patients' lives by painless means." These demographics suggest healthcare disparities and injustice in the form of limited access. This capstone project incorporated a literature review identifying the barriers to MAiD access, an immersive clinical ethics practicum focused on end-of-life cases, and interviews with key stakeholders to form a list of the most common barriers to MAiD and associated justice concerns. Some reported barriers included cost, waiting times, limited numbers of participating providers, self-administration requirements, and a lack of social support. This project's findings served as the basis for a MAiD chapter co-authored with colleagues in a book published by the Hospice Foundation of America as part of their Living with Grief series.

Capstone Mentor:

Patricia Ann Mayer, MD, MS, HEC-C, Director of Clinical Ethics, Banner Health in Arizona

Adrienne Jones-Adamczyk, MSN, ACNP-BC, is a hospice and palliative medicine nurse practitioner at Banner Health in Arizona. She received a BSN magna cum laude from Grand Canyon University and an MSN from Vanderbilt University. She is board certified as an Acute Care Nurse Practitioner and Advanced Certified Hospice and Palliative Care Nurse. Her clinical work has focused on improving goals of care conversations, symptom management, and end-of-life care. Her bioethics interests include the appropriate utilization of intensive care resources, improving communication in medicine, and educating nurses in clinical ethics. After completing the MBE, Adrienne plans to pursue a Doctor of Nursing Practice degree and work as a clinical ethics consultant.

Christina Martinka, BA, NRP

Bioethics Integration into Emergency Medical Services: A Synergistic Curriculum Aiming to Improve Clinician Resiliency and Patient Care

Prehospital providers encounter ethical tensions including consent, end-of-life care, disparities in distributive justice, administrative constraints, and exacerbations of disease related to social determinants of health. These ethical challenges are minimally addressed in Emergency Medical Services (EMS) education despite the significant risk for providers developing moral distress, which negatively impacts patient care and career longevity. This capstone aimed to address the gap in ethics education for prehospital providers by developing and implementing an EMS ethics training module focused on identification of ethical tensions and process guidance to reduce moral distress. Themes identified from a literature review and from anonymous surveys completed by paramedics about frequently encountered ethical tensions comprised the core concepts for the model. Ethics and medical education experts advised pedagogical frameworks including reflective and integrative approaches. Didactic components addressed the four principles of biomedical ethics, providing the language of ethics. Experienced clinicians and simulation experts guided scenario development requiring simultaneous management of ethical tensions and medical interventions. Realistic scenarios using manikins, scene props, and instructor role-playing facilitated identification of ethical tensions and biases and also facilitated communication techniques to overcome challenges and reduce moral distress. The module was integrated into a two-day medical training course. Thirty EMS providers with diverse experience levels and backgrounds attended. Anonymous post-course surveys recognized educational benefit from the course and expressed support for additional EMS trainings that incorporate realistic bioethical tensions with process-based solutions. Future directions include determining if EMS ethics training improves long-term clinician resiliency and patient care.

Capstone Mentor: Stephen Wood, MS, ACNP-BC, Visiting Fellow, Petrie-Flom Center, Harvard Law School

Christina Martinka, BA, NRP, is a board-certified critical care flight paramedic and CEO of Air Medical Experts, an education company serving the special operations and emergency medical services communities. She received her bachelor of liberal art degree (cum laude) from Harvard University and is a decorated member of the air medical transport sector. Her research explores the bioethical implications of rural healthcare inequities in EMS. The USN Special Warfare Group has recognized Christina for outstanding contributions as an instructor and medical adviser to the “teams.” Upon graduation Christina plans to expand education deliverables that embed bioethics into the national EMS curriculum while advocating for systemic improvements in EMS education.

Unini Odama, MD, MPH

What Does Justice Require of Us in Kidney Health?

Thirty-seven million Americans live with chronic kidney disease, while over 800,000 have end-stage kidney disease (ESKD), a devastating life-altering condition. Unfortunately, kidney health (KH) disparities and inequities abound, and the current literature does not integrate a comprehensive view of justice in KH. Justice, the fair distribution of fundamental rights, duties, socio-economic, health, and healthcare opportunities, is linked to wellbeing. The overarching goal of this project was to demonstrate how KH, health equity, and justice are inextricably linked. This work used a wide justice lens to explore the moral question of variances in KH metrics (disparities) and outcomes (inequities). A literature review unveiled widespread inequities in kidney disease risk, care, and outcomes. Diabetes and hypertension, common kidney disease risk factors, are 12-13 times more prevalent in Blacks, and ESKD prevalence in Blacks (29.8%) is quadruple that of Whites. Blacks and Hispanics are 53% and 65%, and 79% and 53%, respectively, less likely to receive home dialysis and kidney transplantation than Whites. Racism, poverty, and oppression were additional unique determinants of KH inequity identified in this work. This project illustrated the link between KH and justice with a novel justice-based KH framework, connecting normative justice theories to bioethical principles of dignity, care, virtue, and solidarity. An infographic was created to highlight the necessity for collaboration at the individual, community, organizational, and governmental socio-ecological levels. Justice requires policymakers and kidney care stakeholders to adopt a far-reaching, transparent, accountable, sustainable, and just kidney health plan.

Capstone Mentor:

Katherine Peeler, MD, MA, MBE, Medical Director, Harvard Medical School Asylum Clinic; Instructor in Pediatrics, Boston Children's Hospital; Instructor of Pediatrics, Global Health and Social Medicine, Harvard Medical School

Unini Odama, MD, MPH, is a practicing nephrologist and vice president for medical affairs at DaVita Kidney Care in Atlanta, Georgia. She earned her medical degree from the University of Jos, Nigeria and trained in internal medicine at Michael Reese/University of Illinois, nephrology at Virginia Commonwealth University, and public health at Emory. As a nephrologist in Alabama and public health director in Georgia, she focused on advocating and caring for underserved communities. She provides kidney care that prioritizes attention to eradicating disparities in kidney disease risk, care, and outcomes. She will continue to pursue her lifelong passion for kidney health justice through advocacy, collaborative justice-based framework developments, practice innovations, presentations, and publications.

Nathan Peterson, DVM

Experience with Futility Contributes to Moral Distress in Veterinary Technicians in North America

Moral distress is well documented in ICU nurses providing futile care to people. Like nurses, veterinary technicians (VTs) in North America act as immediate care providers to animals and operate under the same hierarchical constraints. To date VT experiences associated with futile care have not been examined. This study aimed to document VT experience and its relation to moral distress through a cross-sectional study that used a web-based survey distributed through the National Association of Veterinary Technicians of America. In total, 1944 VTs responded with nearly all participants (97.8%) reporting having witnessed futile care during their careers and 94.7% reporting having provided futile care. A supermajority of respondents (83.7%) reported having been asked or directed to act against their conscience in providing futile care to terminally ill patients; 80.8% reported having done so. Adverse effects on VTs associated with futile care were common with 96.6% and 83.4% of respondents reporting emotional or physical symptoms, respectively. Troublingly, 41% of respondents reported having self-medicated with drugs or alcohol and 8.1% reported having considered or attempted self-harm. These results suggest that providing futile care to pets causes significant moral distress among VTs, is associated with both emotional and physical symptoms, and may lead to harmful behaviors. Mitigating moral, emotional, and physical distress resulting from providing futile care will require the veterinary profession to engage with VTs about futile care and to develop a framework for resolving moral distress associated with providing care to terminally ill pets.

Capstone Mentor:

J. Wesley Boyd, MD, PhD, Associate Professor of Psychiatry, Center for Bioethics, Harvard Medical School; Professor of Psychiatry and Medical Ethics, Baylor College of Medicine

Nathan Peterson, DVM, is an Associate Clinical Professor at Cornell University Hospital for Animals. He received his DVM from The Ohio State University and completed an internship and residency in emergency and critical care medicine at Angell Animal Medical Center in Boston. He spent the next twelve years establishing a critical care service at a tertiary referral veterinary hospital in Los Angeles before moving to Cornell. His interests in bioethics include futility in veterinary medicine, equitable allocation of resources to patients and clients, and access to specialized care. After graduation, Nathan plans to continue his work on futility and resource allocation, and to advance bioethics training for veterinary students.

Carolyn Ringel, JD

Does Informed Consent Require Doctors to Provide Fertility Preservation Information to Transgender Patients?

When transgender individuals begin hormone therapy, they may not be aware of the potential effects on their future ability to conceive and bear biological children. The principle of informed consent demands that all patients should be informed of the potential impact of any medical intervention, such as hormone therapy, before beginning such treatment. However, there is no standard protocol within the healthcare field for delivering this specific information. This project included interviews of healthcare providers from several major hospitals about how they approach fertility counseling for transgender patients. These interviews revealed that some doctors are proactive about explaining hormone therapy's effects on fertility while others only deliver that information if the patient expresses interest in receiving such information. This project will now address that gap by creating a video that doctors and clinics can show their transgender patients seeking hormone therapy in order to deliver clear, comprehensive, and accurate information to all. The video will give patients an understanding of the potential effects of hormone therapy on future fertility, which this project confirmed through interviews of transgender healthcare providers. The video will also encourage patients to discuss the issue further with their doctor if they have questions. It is the hope and intention that this video will help make communicating fertility information to patients seeking gender-affirming hormone therapy the standard in clinics across the country.

Capstone Mentor:

David A. Diamond, MD, Professor of Urology and Pediatrics, University of Rochester Medical Center

Carolyn Baker Ringel, JD, is President of Private Client Services at The Isleworth Group, a concierge mental health consulting company. She received an AB degree in politics from Princeton University, a JD from the University of Chicago Law School, and spent a year at Queen's College, University of Oxford. She has worked as legal counsel for a Massachusetts State Senator, as a mediator, and as a family lawyer for a domestic violence non-profit organization. Her interests in bioethics include transgender health care, particularly for trans teens, and public policy bioethics. After graduation, she plans to continue consulting in the mental health and transgender health care fields and serving on an IRB.

Margaret Seater, MS, DO

How Prisons Harm Health and Injure Human Rights

Mass incarceration in the United States is one of the signature human rights challenges of our time and requires an analysis of the health harms and human rights injuries found in the U.S. carceral system. This project included searching the public health literature, Bureau of Justice data, bioethics literature, salient human rights documents, and authoritative writings to characterize the scope of these harms and injuries. This analysis suggested that incarcerated persons disproportionately suffer from, inter alia, infectious disease, physical and sexual assaults, death by overdose, lack of proper reproductive care, and inappropriate care as they age in prison. Overall, incarceration lowers life expectancy by as much as two years for every year spent behind bars. Additionally, a study in Denmark showed that children of incarcerated parents have mortality rates two times higher than peers. This evidence of harm creates a moral obligation to consider alternatives to mass incarceration. Although restorative justice programs have been in existence for decades, their lack of wide-spread uptake suggests that moving beyond retributive justice may be a political problem rather than a problem of imagining successful alternatives to mass punishment. The paper resulting from this project will provide an account of the health harms of prison and alternative conceptions of justice, compare three models of justice (retributive, restorative, and transformational), and describe a successful restorative justice program. The ultimate aim of this project is to contribute to the formation of a more robust account of the ethics of mass incarceration within the field of bioethics.

Capstone Mentor:

Joel Thompson, JD, Managing Attorney and Clinical Instructor, Harvard Prison Legal Assistance Program, Harvard Law School

Margaret Seater, MS, DO, is a general internist at the VA Boston Healthcare System. She received a BA from Grinnell College and DO, MS from the Texas College of Osteopathic Medicine. She has been a volunteer academic mentor with Boston University's College Behind Bars Program, cofounded the Resolve to Stop the Violence Project for incarcerated men, and now provides care to formerly incarcerated veterans. Her bioethical area of interest is prison-attributable health harms and injuries to human rights. The Massachusetts House of Representatives has acknowledged Margaret's advocacy in reducing community violence. After graduation, she hopes to begin a restorative justice process for veterans affected by incarceration.

Erin Sharoni, ALM

The Moral Obligation to Bear Witness: A Policy Proposal Mandating Audio-Visual Documentation of Federally-Funded Animal Use

Annually, the US agribusiness and scientific research industries kill an estimated 55 billion and 100 million animals, respectively. Many of these animals experience significant suffering throughout their existence, up to and including the killing process. This vast scale of animal use is a significant moral problem because (1) humans are not obligatory carnivores, (2) scientific results produced using animal models are poorly replicated in humans, and (3) tools and technologies exist to reduce or replace the use of animals in food and research. To explore this moral problem, the research conducted included a review of literature, public sentiment polls, and US legislation, as well as interviews with key stakeholders. Research revealed that the majority of Americans are opposed to animal cruelty, that bearing witness to suffering can result in social change, and that we have a moral obligation to bear witness to suffering. Yet, animal use operations funded with taxpayer dollars remain hidden from public view and US policy restricts opportunities to bear witness with punitive laws. This project culminated with a policy proposal mandating publicly accessible audio-visual documentation of animal suffering in federally-funded animal use facilities. The proposal is predicated on the Freedom of Information Act, which stipulates that information generated by the federal government belongs to the people. Such policy would give citizens the opportunity to fulfill their moral obligation of bearing witness to animal suffering, which may inspire much-needed social change.

Capstone Mentor:

Chris Green, JD, Executive Director, Brooks McCormick Jr. Animal Law & Policy Program, Harvard Law School

Erin Sharoni, ALM, is co-founder and CEO of a biotechnology startup that uses AI to predict Alzheimer's disease and a research associate in the NIH Bridge 2 Artificial Intelligence program. She received a BA in studio art from Wesleyan University and an ALM in biology from Harvard Extension School. Erin has spent the past nine years working at the intersection of precision health, AI, genomics, and longevity. She is passionate about ethical applications of emerging AI biotechnologies and advancing nonhuman animal rights. She has published in multiple forums including Scientific Report and Impact Ethics. After graduation, Erin plans to continue using ethical AI to advance flourishing for human and nonhuman animals.

Danielle Tarino, MA

Dignity in Data Laws: A Regulatory Framework for Restoring Medical Privacy

The principles of respect for persons and autonomy are central tenets of medical care that can be actualized through effective data privacy laws. The U.S. lacks a universal regulatory structure for health information privacy and data security that protects all health data. This capstone included a literature review that explored the bioethical issues of medical privacy and identified gaps in existing privacy law. This review showed that the current regulatory regime does not provide privacy protections for health data and commercial health technology that adequately address patient or consumer protection. The consequences for patients, providers, and the healthcare industry, in a digital age of no-privacy and hacking, are severe. The risk of identity theft that can result from a breach of protected health information leaves patients vulnerable to exploitation. Such a breach undermines the trust necessary for open communication between patient and provider. This project created an executive summary for legislative reform using an ethical-legal framework that honors obligations to patients by protecting and reestablishing fundamental privacy rights. It concluded with actionable policy proposals rooted in ethical principles, including enhanced informed consent to share data for greater transparency and updated security requirements to meet real-world cyber threats. Enhanced cyber provisions and structural protections will build trust with individuals and create safer environments for people to receive health care.

Capstone Mentor:

Brendan Abel, JD, Health Policy and Advocacy Director, Johnson & Johnson; Legislative and Regulatory Affairs Counsel, Massachusetts Medical Society; Lecturer on Global Health and Social Medicine, Center for Bioethics, Harvard Medical School

Danielle Tarino, MA, is founder and COO of the cybersecurity company Code-X. She received a BA in political science from Rutgers College and an MA from Georgetown University, where her thesis focused on ethics and issues in counternarcotics intelligence. Danielle's professional work includes privacy and confidentiality policy, addiction policy, health information technology, and cybersecurity. Her interest and passion for bioethics centers on medical privacy protections, technology, and cyber ethics. She has received multiple awards for public service from the federal government. After graduation she plans to build a portfolio of work in national cyber security policy and write professionally.

JyeMei Wong, LLM

Ethical and Legal Implications of Artificial Intelligence in Deep Brain Stimulation Treatment

The implementation of Artificial Intelligence (AI) in neurosurgery has augmented clinical tasks, improved disease detection, and advanced personalized diagnostics and treatment. However, it has also generated ethical concerns including consent and patient safety. The aim of this capstone was to provide recommendations for clinicians and medical device manufactures (MDS) addressing the ethical implications of using AI in deep brain stimulation (DBS), with a primary focus on prioritization of patient safety, the standard of care and informed consent. DBS involves implanting a brain pacemaker-like device in the brain to treat neurological disorders. The risks associated with it may include bleeding, infection, stroke, seizure, and hardware malfunction. A systematic literature review informed recommendations for use of these interventions. To ensure patient safety, clinicians ought to conduct due diligence to identify and evaluate the use of AI systems' benefits and risks, along with appropriate risk prevention and monitoring measures in DBS therapy. Proper training for interpreting and utilizing AI-generated data is also essential for the effective integration of AI into clinical decision-making processes. The standard of care for clinicians should involve following established medical protocols and guidelines and ensuring that AI systems are properly trained and validated. Similarly, MDS must prioritize patient safety when designing AI systems in DBS and disclose demographic data sets used to train algorithms to the Food and Drug Administration. As a next step, this capstone will inform a governance framework for clinicians and MDS.

Capstone Mentor:

Francis X. Shen, JD, PhD, Faculty Member and Lecturer on Psychology, Department of Global Health and Social Medicine and Department of Psychiatry, Massachusetts General Hospital; Affiliated Professor, Harvard Law School; Member, Center for Bioethics, Harvard Medical School

JyeMei Wong, LLM, is an attorney at Boston Scientific Corporation and a certified Privacy Professional. She received an LLM from the University of London, United Kingdom, and a graduate certificate in pharmaceutical regulations from Duke-NUS, Singapore. JyeMei has worked on legal and compliance matters in merger and acquisition, global clinical research, medical device regulatory approval and market access, and remote patient monitoring. JyeMei's interests in bioethics encompass the right to healthcare access and medical decision-making capacity. After graduation, JyeMei plans to assume a role on the ethics committee board at a medical institution in Singapore and be involved in advocacy work for AI-based technologies to empower ethical patient care.

Christina Yen, MD

Examining the Microethical Dimensions of Antimicrobial Preauthorization Discussions at US Hospital Antimicrobial Stewardship Programs

Antimicrobial misuse is a widespread problem that perpetuates the development of antimicrobial resistance (AMR) infections which caused nearly 5 million deaths worldwide in 2019 and are expected to cause 10 million deaths annually by 2050. In response to this trend, hospital-based antimicrobial stewardship programs (ASPs) run by physicians and pharmacists arose to counteract antimicrobial misuse. Although AMR's macroethical dilemmas are well documented, little is known about the microethical challenges of changing prescribing practices. Microethics is defined as the ethics embedded in daily clinical decision making and communication, as opposed to the broader-scale bioethical dilemmas such as end-of-life-decision making generally encountered in traditional clinical ethics. This capstone sought to identify the microethical dilemmas related to ASP preauthorization (PA), during which stewards and prescribers discuss the risks and benefits of empiric antimicrobial therapy. It developed semi-structured interview questions based on literature review findings and semi-structured interview questions were developed based on literature review findings and Arthur Frank's principles of microethics: representation (how stewards and prescribers view one another), reciprocity (how they engage collaboratively in the work's morality), and reconciliation (how they obtain feedback). Five content experts, two ASP physicians and three ASP pharmacists from different states and practice settings reviewed interview questions for clarity and content. Next steps will include IRB submission and interview administration. Going forward, the information obtained from this capstone will be used to develop pedagogy to empower and train ASPs to effectively lead PA conversations and other dialogues essential to slowing the development of AMR.

Capstone Mentor: James Brad Cutrell, MD, Associate Professor and Medical Director of Antimicrobial Stewardship, University of Texas Southwestern Medical Center and Health System

Christina Yen, MD, is an infectious diseases (ID) specialist and associate director for University of Texas Southwestern Medical Center's antimicrobial stewardship program. She received her BA and MD from the University of Southern California, completed internal medicine residency at Los Angeles County Hospital, and trained in the infectious disease fellowship at Beth Israel. Her work involves diagnostic and antimicrobial stewardship implementation. She is interested in developing antimicrobial stewardship's bioethical pedagogy. She will be a guest editor for AMA Journal of Ethics' upcoming issues on antimicrobial resistance and stewardship. After graduation, she plans to integrate ethics into her stewardship research, pedagogy, and praxis. Her hobbies are baking and scavenger hunts.

Notes

In-Person Symposium Agenda

Welcome

Rebecca Weintraub Brendel, MD, JD
Director of the MBE Degree Program, Associate Director of the Center for Bioethics, and Associate Professor of Psychiatry, Harvard Medical School; Director of Law and Ethics at the Center for Law, Brain, and Behavior, Massachusetts General Hospital

Reflections on the Capstone Program with the Co-Directors

Joni R. Beshansky, RN, MPH, LP.D.
Capstone Co-Director, Center for Bioethics, Harvard Medical School; Associate Professor and Director, Health Administration Graduate Program, Boston College

Michael Ieong, MD
Capstone Co-Director, Center for Bioethics, Harvard Medical School; Director, Medical Intensive Units, Boston Medical Center; Assistant Professor on Pulmonary, Allergy, Sleep and Critical Care Medicine, Boston University Medical School

Lisa Moses, VMD, DACVIM
Capstone Co-Director, Center for Bioethics, Lecturer on Global Health and Social Medicine, Harvard Medical School; Visiting Scientist, Vertebrate Genomics Group, Broad Institute of MIT

David N. Sontag, JD, MBE, HEC-C
Capstone Co-Director, Center for Bioethics, Lecturer of Medicine, Harvard Medical School; Director of Ethics and Senior Associate General Counsel, Beth Israel Lahey Health; Co-Chair, Ethics Advisory Committee, Beth Israel Deaconess Medical Center

What Do Bioethicists Do?

Elliott J. Crigger, PhD
Associate Professor and Director, Healthcare Administration Graduate Program, Woods College of Advancing Studies, Boston College

Invitation to Poster Presentations

Joni R. Beshansky, RN, MPH, LP.D.
Capstone Co-Director, Center for Bioethics, Harvard Medical School; Associate Professor and Director, Health Administration Graduate Program, Boston College

Poster Session

What Do Bioethicists Do?

Keynote Speaker:

Elliott J. Crigger, PhD

Director of Ethics Policy & Secretary to the Council on
Ethical and Judicial Affairs, American Medical Association

Elliott J. Crigger, PhD came to the American Medical Association (AMA) from the National Center for Ethics in Health Care at the Veterans Health Administration (VHA) in Washington, DC, where he served as chief of ethics communications with editorial responsibility for all center publications. During his tenure with VHA from 2003 to 2007, Dr. Crigger also served as a member of the development team for Integrated Ethics, a national education and organizational change initiative.

In addition, Dr. Crigger was primary staff researcher and writer for VHA's National Ethics Committee and worked with the committee to develop reports on a wide range of topics, including online patient-clinician messaging, compensation to health care professionals from industry, palliative sedation, and surrogate-clinician relationships, among others.

Prior to his appointment with VHA, Dr. Crigger was a member of the professional staff of The Hastings Center. He joined the editorial staff in 1986, becoming associate editor of the Hastings Center Report in 1988. He served as senior editor of the Report and managing editor of IRB: A Review of Human Subjects Research from 1990 to 2000, and as senior editor of the revamped IRB: Ethics & Human Research from 2000 to 2002. In addition to his editorial work, Dr. Crigger participated regularly in center research projects, including explorations of ethical issues in emerging genetic technologies, managed health care, agricultural biotechnology, and the clinician-patient relationship in cancer care and research.

From February 2003 through October 2018, he served on the Performance and Safety Monitoring Board of The HIV Center for Clinical and Behavioral Studies, NY State Psychiatric Institute and Columbia University. Dr. Crigger holds a PhD in anthropology and linguistics from the University of Chicago.

Ashlin Amano, BS

Communication and Resolution Programs (CRPs): Improving How Health Systems Respond to and Mitigate Patient Harm

Western medicine has favored defensive responses following patient harm events. Patient harm is defined as harm to a patient as a result of medical care or in a health care setting, including the failure to provide needed care. These defensive responses have created "deny-and-defend" methods learned in the formative medical school years. It was not until the 1980s that Communication and Resolution Programs (CRPs) were introduced to address this medical norm. Through a literature review, this capstone project analyzed CRP history within the United States, evidence regarding their impacts on patients, providers, learning, and costs, and finally, ethical implications of truth-telling within the clinical setting. The student also embedded with Ariadne Labs, which, in collaboration with other partners, had established a learning collaborative to help health systems implement a CRP approach. This capstone produced a package to facilitate change in institutional harm response processes to integrate into the learning collaborative. The package emphasized understanding of the aftermath of a patient's harm, learning values from the event, and deriving implications for the future. Moving forward, this capstone proposes a renaming of CRP to "Comprehensive Harm Response Program" to capture the fluid and continuous learning and healing that accompanies a medical harm event, in lieu of simply asserting that the event has been resolved. Ultimately, the goal is to implement CRPs on a wide scale so that health systems can better respond to harm and a shift in clinical culture occurs.

Capstone Mentor:

Evan Benjamin, MD, MS, FACP, Director of Community Innovation, Ariadne Labs

Ashlin Amano, BS, received a BS in biology with a minor in social work from Mount Saint Mary's University in Los Angeles. As an undergraduate, she served as president of the Honors Council and the Hawaiian Club. Her interest in bioethics stems from her undergraduate research on the emerging type 3 diabetes theory of Alzheimer's disease and her related desire to explore how advances in biology and medicine inform public policy. Ashlin received the Enright Endowed Scholarship as an undergraduate in recognition of excellence in academics and leadership. After completing the MBE, Ashlin plans to join Ariadne Labs while working on her medical school applications.

Michele Anzabi, BA

Educational Needs Assessment of Fetal Therapy Board Members

As fetal therapy centers rapidly develop and questions arise regarding the line between research and innovation, multidisciplinary ethical oversight is necessary to provide well-informed recommendations on proposed innovative fetal therapy interventions. However, evidence-based research on the educational on-boarding needs for such oversight groups is lacking. This capstone project aimed to determine the efficacy of on-boarding training for new fetal therapy board members, which included review of selected topic articles (e.g., maternal-fetal decision making, ethics of fetal interventions), access to an online resource repository, participation in a novel mock consultation, and identification of gaps in knowledge and/or skills critical for effective member participation and function of the group. Members of a newly developed, multidisciplinary, and interprofessional Fetal Therapy Board at Boston Children's Hospital completed the designed on-boarding education, then completed a voluntary, mixed-methods survey to assess self-reported knowledge and comfort levels regarding fetal therapy knowledge, ethical reasoning, and communication skills. Analysis of results remains in progress. Nevertheless, assessment of members of a fetal therapy oversight committee may help gauge efficacy of onboarding education and identify gaps in knowledge and skills useful for subsequent education and curricular development.

Capstone Mentor:

Christy Cummings, MD, Assistant Professor of Pediatrics, Harvard Medical School and Boston Children's Hospital

Michele Anzabi, BA, received a BA in health and societies with a concentration in bioethics and minors in Hispanic studies and chemistry from the University of Pennsylvania. She has furthered her interests in reproductive justice, public health, medical humanities, and clinical ethics through her work with the Shifo Foundation, Collegium Institute, MedStar Washington Hospital Center, and PERI-OD. Michele currently acts as the outreach chair for the National Student Bioethics Association. She is interested in neuroethics, clinical ethics, and health policy. Michele is the recipient of several awards, including the Mazzatenta Scholars award and the HMS Dean's Scholarship. After completing the MBE, she plans to work before applying to medical school.

Sana Baban, BA

Utilizing Quality Improvement Methodologies to Better Support Surrogate Decision-Makers in a Single Institution

Within medicine, surrogate decision-making (SDM), or making decisions on behalf of an incapacitated patient, is a common practice. The role is emotionally demanding. There remain opportunities to better support SDM and improve informed decision-making. A quality improvement (QI) approach was taken at one institution to better understand the gap between current and best practices in SDM. QI methods may be helpful for institutions to address relevant ethical issues by identifying root causes, elucidating opportunities to bridge the gap between current and best practices, and driving institutional change. Since medical institutions frequently utilize QI methods, applying this process to issues with an ethical valence can be advantageous in offering institutional leaders a familiar approach to institutional change. Based on themes in SDM, a questionnaire was created addressing important themes of decisional burden, inadequate communication, and clinician-surrogate relationship. Stakeholders who frequently work with surrogate decision makers were also interviewed. Findings suggested that decisional burden, inadequate communication with healthcare team, and conflicts in goals of care are the most prevalent challenges for surrogate decision makers. Stakeholder recommendations included increased pastoral care, enhanced social work services, and establishment of a healthcare proxy prior to a patient's loss of capacity.

Capstone Mentor:

Elizabeth Nilson, MD, MPH, Director of Medical Ethics, Attending, General Internal Medicine, Lahey Hospital and Medical Center

Sana Baban, BA, received a BA in communication sciences and disorders from the Judy Genshaft Honors College at the University of South Florida. As an undergraduate, she worked as a research coordinator at Houston Lee Moffitt Cancer Center & Research Institute focusing on smoking cessation in cancer patients and mindfulness-based interventions for caregivers of stem cell transplant patients. Sana graduated Summa Cum Laude and her most recent publication focuses on the outcomes of a randomized controlled trial to reduce smoking and alcohol use. Sana is interested in end-of-life and pediatric ethics. Her hobbies include scuba diving and skiing. After completing the MBE, Sana plans to pursue a career in medicine.

Shana Birly, BSc

Ethical Challenges and Equity in the Training of Neuroimaging Technicians (NTs)

The advent of highly portable neuroimaging devices (pMRIs) has transformed the delivery and collection of imaging data across research studies in neuroscience and may enable researchers to recruit study participants from communities traditionally underrepresented in neuroscience research. Proactive efforts to train and diversify NTs capable of conducting field-based research can advance social justice and create a level playing field for research participants. The aim of this project is to raise awareness of the limitations of the current MRI training paradigm and to develop a set of guidelines for NT. The methodology for this project included a scoping review of the literature on NT training (NTT), analysis of how publications in the field have sought to address the lack of equitable resources and opportunities for NTs, directed conversations with subject matter experts in neuroimaging to understand historical training models, and a survey of institutional imaging procedures. Findings from the literature review concluded that access to NTT is often confined to hospital employees seeking institutional certifications or to students enrolled in costly academic programs offered by for-profit universities. Neuroimaging experts confirmed these findings, voicing the need for open-source standard operating procedures or programs to increase NTs available to perform field-based research using pMRI. Addressing this training gap may contribute to expanded access to neuroscience studies and increased funding for diversity research by developing a set of guiding principles that ensure equitable access to neuroimaging technology and training opportunities for underserved communities.

Capstone Mentor:

Jonathan Jackson, PhD, Executive Director of the Community Access, Recruitment, and Engagement (CARE) Research Center, Massachusetts General Hospital and Harvard Medical School

Shana Birly, BSc, is a lead scientist at Genentech supporting neuroimmunology clinical trials. She received her BSc at San Jose State University in health sciences and psychology. Shana has worked in clinical development for almost a decade in the biotechnology industry. Additionally, she supports clinical studies on neuromodulation at Massachusetts General Hospital. Her interest in bioethics focuses on the inclusive design of clinical trials in areas of high unmet medical needs for underserved populations. After completing the MBE, Shana plans to continue her research as a PhD student. Shana's hobbies include hiking, golfing, and spending time with her puppy, Mr. Darcy.

Adam Ghiles Briki, MBBS, BSc (Hons)

The Ethical Considerations of Normothermic Regional Perfusion (NRP) as an Organ Recovery Technique in Controlled Donation After Circulatory Death (cDCD)

There is a mismatch between the number of donors and the number of organs needed for transplantation. Organ donation must adhere to the Dead Donor Rule (DDR) which stipulates that organs can only be retrieved after death, and death should never result from organ recovery. This capstone project considered the ethical permissibility of the NRP-cDCD technique which promises to increase the number of potential donors and improve the function of recovered organs when compared to established practice. A literature review was performed, Organ Procurement and Transplantation Network Ethics committee deliberations were observed, and NRP-cDCD was discussed with experts in the field. A normative ethical analysis was employed to consider the utilitarian need to increase the number and quality of organs for transplantation that is in tension with the deontological imperative to abide by the DDR. A normative ethical analysis was employed to consider the utilitarian need to increase the number and quality of organs for transplantation that is in tension with the deontological imperative to abide by the DDR. Other salient ethical considerations included antemortem preparation for transplantation and consent procedures. A lack of medical consensus on NRP-cDCD may lead to public uncertainty and a reduction of registered organ donors. This project found that the current NRP-cDCD protocols may fail to provide adequate reassurances that the DDR is not violated thereby risking the loss of public confidence in organ donation.

Capstone Mentor:

Robert D. Truog, MD, MA, Director, Center for Bioethics, Harvard Medical School; Frances Glessner Lee Professor of Medical Ethics, Anaesthesia, and Pediatrics, Boston Children’s Hospital

Adam Ghiles Briki, MBBS, BSc (Hons), is a British pediatrician. He received a BSc in biomedical science and a MBBS from St. George’s Hospital Medical School, London. He was admitted to the Royal College of Paediatrics and Child Health whilst undertaking his pediatric training. Adam has worked clinically on neonatal intensive care units and general pediatric wards. His interest focuses on navigating dilemmas that arise in the treatment of patients from the extremely premature to those on the verge of adulthood. Adam plans to build on friendships and knowledge gained from the MBE to teach and advance pediatric bioethics in the UK, alongside exploring a newfound interest in sports ethics.

Samuel L. Caraballo, MPH, MDiv

Ethical Implications of Genomic Editing for Individuals with Down Syndrome, Families, and Healthcare Professionals

In recent years, researchers have developed in vitro techniques to silence the extra chromosome in cells of individuals affected by Trisomy 21 (T21), also known as Down syndrome (DS). Following these molecular milestones, new ethical concerns exist about potential genomic interventions for this population. This project sought to (1) evaluate the ethical implications of somatic and germline editing for individuals with DS, (2) explore the attitudes and perceptions of individuals with DS and their families toward prospective genomic treatments, and (3) identify existing knowledge gaps that can guide stakeholders in making informed healthcare policy decisions of this nature. The literature review for this project showed that genomic manipulations in vitro for T21 are not easily transferable to humans. However, the quest for prospective therapeutic modifications for these individuals engenders essential moral questions about human identity. Qualitative data on parental perceptions revealed mixed results regarding the willingness to undergo molecular editing to treat loved ones with DS. Parental disposition to explore therapeutic interventions for loved ones with DS was influenced by the severity of the condition and uncertainties about individuals' future. Finally, the information generated by this project reveals a profound disconnection between the DS research agenda and the social needs of individuals and families touched by this condition. While genomic interventions could improve this population's health outcomes, serious concerns exist about the ethical ramifications involved in these potential therapies.

Capstone Mentor:

Michael J. Balboni, PhD, ThM, MDiv, Pastor, Park Street Church, Boston; Instructor at Harvard Medical School; Palliative Care Researcher, the Dana-Farber Cancer Institute

Samuel L. Caraballo, MPH, MDiv, is a Puerto Rican educator who teaches science in Massachusetts. He received a BS from the University of Massachusetts Boston, an MPH from Boston University School of Public Health, and an MDiv from Yale Divinity School. Samuel is the Pastor of First Hispanic Presbyterian Church Elim in Needham, MA. His research interest and expertise are the nexus of genomic technologies, theology, and disability. After graduation, Samuel plans to continue developing Triune Lab, a nonprofit initiative that organizes and equips faith communities to address bioethical issues affecting humans and the ecological communities they inhabit.

Carlos Dos Santos, BA

Private Equity Drives Financial Pollution and Contributes to Injustice in American Healthcare

Private equity firms (PEF) are increasing their presence and profits in the healthcare sector. PEF acquire existent healthcare organizations, deploy profit-maximizing strategies over three to seven years, and sell the acquired organization for large profit. These strategies can result in local and national market consolidation and increase healthcare costs without corresponding quality improvement. Unnecessary increases in cost contribute to financial pollution, a term describing the reverberating effects of wasteful healthcare spending. Financial pollution constrains opportunities for individuals and communities by funneling funds into health care at the expense of other public goods like education and housing. This capstone project interpreted evidence of the effect of PEFs on healthcare costs and quality through the lenses of financial pollution and justice. Towards this end, health policy and economics data on PEF practices and bioethics literature on PEF practices and the moral implications of commodifying healthcare were surveyed. The project concluded that PEF's unregulated practices contribute significantly to financial pollution and are for that reason, unethical. These effects limit opportunities for individuals and communities to develop basic capabilities argued to be essential for human flourishing and well-being, as elaborated through Nussbaum's justice-as-capabilities theory. The unique moral significance of health care ought to be protected from corporate forces seeking to benefit from the fragmented healthcare system in the United States. The author recommends increasing antitrust regulations to reduce market consolidation by PEF as well as increasing transparency of financial flows within PEFs to curb excessive profiteering.

Capstone Mentor:

Anita Wagner, PharmD, MPH, DrPH, Associate Professor, Division of Health Policy and Insurance Research, Department of Population Medicine, Harvard Medical School and the Harvard Pilgrim Care Institute; Director, Ethics Advisory Program, Point32Health

Carlos Dos Santos, BA, is a medical student at Harvard Medical School. He received his BA in molecular mechanisms of disease and in literary and cultural theory from the University of Pennsylvania. His bioethics research involves the ethical implications of increasing corporatization of American healthcare, through analyzing private equity acquisition of healthcare organizations. He additionally is interested in the ethics of involuntary hospitalization, healthcare issues affecting LGBTQI+ populations, and more broadly bridging bioethics and critical theory and philosophy. Following the MBE, he will pursue a residency in emergency medicine and hopes to work as an academic emergency physician teaching clinical medicine and bioethics.

Iyla Draw, BA

The Role of Medicaid: Delaying or Preventing Care for Patients with Severe Acne

Inequity in access to care for acne patients represents an injustice in our healthcare system. Medicaid beneficiaries comprise a large portion of the population who struggle to access dermatological care. Why should skin matter? Skin is the largest organ of the body and the suffering caused by skin conditions is not categorically dissimilar from the suffering caused by other medical conditions more commonly covered by Medicaid. This capstone project sought to analyze access to dermatological care and to identify ways to remedy existing barriers. The project began with a review of the structure of Medicaid and published literature on care delays for patients struggling from severe acne. Conversations with dermatologists delivered insight into the medical repercussions of delayed care. Semi-structured qualitative interviews were designed to understand the role of physician autonomy in restricting services to Medicaid enrollees. Despite a low response rate to interview requests, preliminary discussions suggested that dermatologists do not often deny care due to personal preferences; instead, they feel unable to offer their services due to financial burdens from low reimbursement in public insurance. This capstone project proposed that the practice of medicine is no longer in the hands of physicians because of the power the US Congress has invested in public health insurance. Future directions for this work include identifying potential solutions to care denials and delays, such as teledermatology, to expand access to dermatological care and mitigate the obstacles faced by both physicians and Medicaid patients.

Capstone Mentor:

Megan Landis, MD, Clinical Associate Professor of Dermatology, University of Louisville School of Medicine; Director, The Dermatology and Skin Cancer Center of Southern Indiana

Iyla Draw, BA, graduated from the University of Louisville with a BA in biology. She was a researcher at Dermatology Specialists Research and served as an undergraduate teaching assistant in biology. While working at various clinics to advocate for under-resourced communities, she joined a patient services company to implement strategies to administer medications to those communities. As a first generation Syrian American, Iyla also spent her summers serving the war-torn community of Aleppo, Syria. Her interest in bioethics stems from her observation of ethical challenges during her humanitarian trips, work in a patient services company, and research in dermatology. After completing her MBE, Iyla will attend medical school and integrate bioethics with her career.

Danylo Duvalko, BA (Hons)

An Overreliance on “Reason?” An Exploration of the Criteria Measured When Determining Patient Decision-making Capacity

Bioethics deeply values a patient’s autonomy in making medical decisions for themselves but denies this autonomy to patients undergoing involuntary treatment as part of civil commitment. Civil commitment, also referred to as involuntary hospitalization, results in patients being held in psychiatric hospitals against their will and often receiving treatments they do not consent to. Such paternalistic interventions are frequently viewed as necessary for the patient’s best interest. However, many patients believe their treatment was unjustified and hindered their recovery. This project examined the requirements for civil commitment, focusing on the criteria for assessing patient decision-making capacity (DMC). The process of DMC assessment was analyzed with a particular focus on the most common capacity assessment tool – the MacArthur Competence Assessment Tool-Treatment (MacCAT-T) – and how it is used to determine the capacity of patients with severe mental illnesses (SMIs) during civil commitment. The project raised critical questions about the MacCAT-T test’s emphasis on the patient’s ability to reason during the decision-making process. Since patients with SMIs often have compromised reasoning skills, and instead rely on other approaches to make decisions, the MacCAT-T test might underrepresent the ability of patients with SMIs to make decisions for themselves, and therefore overestimate the number of patients that meet the criteria for civil commitment. Further studies are needed to explore alternative decision-making models and additional means to assess DMC to ensure that no patients unnecessarily undergo civil commitment.

Capstone Mentor:

Jonathan Greenberg, PhD, Assistant Professor and Research Staff Psychologist, Department of Psychiatry, Massachusetts General Hospital

Danylo Duvalko, BA (Hons), is a recent graduate from the University of Toronto in Canada. As an undergraduate student, he studied bioethics with minors in Ukrainian literature and language, as well as Buddhism, psychology, and mental health. In bioethics, he is interested in questions of capacity and autonomy and how these concepts are applied within the mental health field. Aside from his academic pursuits, he is actively involved in the Ukrainian community locally and internationally and recently volunteered in Ukraine as part of a humanitarian aid team providing medical assistance to refugees. After completing the MBE program, Danylo plans to attend medical school.

Kamna Gupta, BS

The First Patient Project: Medical Curriculum on Empathy and Respect for Body Donors in First-Year Anatomy Lab

Medical students often are inadequately prepared for the emotional, personal, and relational experiences involved in anatomy dissections and the the relevance of these experiences to their future roles as clinicians. To address this issue, a curriculum entitled the First Patient Project (FPP) was designed and delivered before anatomy lab at Indiana University School of Medicine. Its purpose was to foster a respectful lab environment and invite thoughtful reflections on empathy, dignity, responsibility, and students' own mortality when dissecting their first patient, the donor. The FPP included the creation of an 18-minute introductory video, an invitation to engage in a discussion forum for reflection prior to dissections, and a survey to assess the effectiveness of the video and discussion forum. This capstone project included qualitative data analysis of 53 student surveys and 107 discussion forum responses from 2021 and 2022. This analysis identified that student testimonials from the video were most beneficial and gave students the confidence and humility to engage with their donors. Overall, frequently occurring themes in student responses included expressions of being grateful for the gift of donation, responsibility towards donors and future patients, and concern for dehumanizing the donor. Future iterations of the FPP could include opportunities for engagement and discourse throughout the semester, fostering in-person panel discussions with past students prior to entering the anatomy lab (in contrast to a discussion forum), and opportunities to express experiences and honor donors in a post-lab debriefing.

Capstone Mentor:

Joni R. Beshansky, LPD, MPH, PhD, Co-Director, Capstone Program, Master of Bioethics Program, Center for Bioethics, Harvard Medical School; Research Fellow in Global Health and Social Medicine, Harvard Medical School

Kamna Gupta, BS, is a third-year medical student at Indiana University (IU) School of Medicine. She earned her BS in medical humanities and health studies from Indiana University Purdue University Indianapolis (IUPUI). Prior to matriculating in the MBE, she developed medical curriculum, the First Patient Project, that focused on improving the ethical treatment of body donors in the anatomy lab. Her interest in bioethics lies in improving ethics education and training in medical school. She was recognized as a Top 10 Outstanding Student by IUPUI and received the 2020 Faculty Medal of Academic Distinction from IU School of Liberal Arts. Kamna plans to resume her medical training at Indiana University School of Medicine after graduating.

Shaojie Hao, BA

Considering Group Harms in Research: Consent Forms and Other Avenues

Current ethical guidelines for research aim to minimize risks to the participants of research and to clearly communicate during the consent process any remaining risks. It is also important to consider the potential harm to individuals not directly involved in the research, commonly referred to as "indirect harms" or "group harms." Research results can pose such harms, for example, by causing a group to be stigmatized. Without steps to prevent or mitigate group harms, research could lead to misunderstandings or even discrimination. This capstone project aimed to outlinedifferent options for promoting consideration of group harms in research. Such options include careful consideration of group harms in publishing findings (as potentially enforced by publishers), restriction of funding to projects deemed at risk of producing group harms, educational efforts targeted at researchers to alert them to the potential for group harms, and alerts in the consent process for prospective research participants regarding the possibility of group harms. To explore how often group harms are raised in consent forms, 24 consent forms and templates were reviewed. Only four mentioned group harms; one of these actually advised omitting mention of group harms unless requested by ethics committees. This review revealed that only some consent documents affirmatively attempt to address group harms. In conclusion, ambiguity persists in determining how best to address group harms in research, including whether they should be mentioned in consent forms. Further research is needed to identify best approaches and define appropriate implementation strategies.

Capstone Mentor:

Anna Lewis, PhD, Research Associate, Edmond and Lily Safra Center for Ethics, Harvard University

Shaojie Hao, BA, received a BA in economics from the University of Colorado Denver. Shaojie has used quantitative research methods to explore ethical questions surrounding big data in health care and euthanasia in China. As an undergraduate research assistant with the Bioethics Research Center at the Chinese Academy of Medical Sciences and Peking Union Medical College Hospital, she developed suggestions for the governance of euthanasia, integrating economics and legislative perspectives. Her bioethical interests lie at the intersection of ethics and public policy. As her career trajectory evolves, she intends to continue her education and pursue a PhD in bioethics or economics.

Kyle Hui

Attitudes and Experiences of Medical Students From High-Income Countries Performing Outside Their Scope of Training in Short-Term Global Health Trips

Medical students from high-income countries (HICs) participating in short-term global health trips often work beyond their level of training. To understand the underlying reasons, this capstone first conducted a literature review which identified the conflicting bioethical norms when students face situations that demand expertise beyond their scope of training: (1) beneficence and non-maleficence, (2) duty to learn and duty to care, (3) short-term and long-term social justice impacts. Few studies describe the encounters of medical students, particularly those from non-western HICs. Thus, during the second stage of this capstone, Hong Kong medical students were interviewed regarding their motivations for joining service trips, attitudes toward and experiences with practicing outside their training level, and suggestions for avoiding such situations. Results show that self-improvement, broadening exposures, and altruism were key incentives for students to join trips. While students acknowledged their limitations and agreed with the necessity of practicing within their training level in non-emergency scenarios, some still practiced beyond their scope, justifying their actions based on its perceived harmlessness, obligation to provide aid, and lenient regulations. Furthermore, no student received ethics briefings specific to their trips beyond introductions to local cultures. Based on these findings, an ‘ethics toolkit’ was created to encourage students to reflect on their motivations, be transparent about their training level, and advise trip organizers to limit expectations and work with local professionals to define student roles.

Capstone Mentor:

Noah Rosenberg, MD, MPH, Head of the Department for Emergency Medicine, University of Botswana

Kyle Hui is a third-year medical student at the University of Hong Kong. His interest in humanitarian medicine led him to serve as the president of Medical Outreachers Hong Kong. Under his leadership, the organization provided health assessments and education for populations in Hong Kong, mainland China, and Nepal. His areas of interest in bioethics include medical volunteering, global health, and clinical ethics. Kyle aims to integrate bioethics into his future practice as a humanitarian doctor or in the healthcare management sector. Upon graduation, he will return to medical school and improve its bioethics curriculum while working with local NGOs to develop more ethical global service trips for medical students.

Jaleh Jaffari, BSN, RN

Beyond Prison Healthcare: Mass Incarceration and Abolition for Bioethics

Bioethics addresses health care occurring within prisons but has not attended to mass incarceration (MI) as an ethical concern. The U.S. incarcerates more citizens than any other country. Furthermore, bioethics has not provided a system-level critique of MI, particularly focusing on structural racism. This project had two parts: examination of bioethical literature surrounding prisons and offering abolition as a new framework for bioethical analysis. Ethical themes found present in the literature emphasized individual autonomy: issues of privacy, confidentiality, surrogate decision making, delays in care, and protection of incarcerated research participants. Absent were analyses of structural racism, justice, and the impact of incarceration on communities/families. This project compared the harms of prisons using data from think tanks such as Prison Policy Initiative and Vera Institute of Justice, to current bioethical literature which does not address these identified harms on individuals, families, and communities. The second part of the project identified the moral values and norms of abolition theory in the writings of Angela Davis and Patrisse Cullors. Abolition provided a system-level analysis of MI and called for replacing harmful, racist systems with ones that address root causes, for example, providing adequate social supports instead of punitive incarceration. For example, providing adequate social supports instead of punitive incarceration. Key values of abolition that complemented gaps in bioethical discourse included prioritizing antiracism, privileging Black perspectives, emphasizing on relationships and community, and attending to justice. Next steps include continued development of abolition as a bioethical approach through modeling of its application to a MI-related problem.

Capstone Mentor:

Charlene Galarneau, PhD, MAR, Senior Lecturer in Global Health and Social Medicine, Member, Center for Bioethics, Harvard Medical School; Faculty Emerita, Women's and Gender Studies Department, Wellesley College

Jaleh Jaffari, BSN, RN, is a clinical practice manager in the neonatal intensive care unit at Swedish Hospital. She received a BSN from California State University, San Marcos. Jaleh has worked as a nurse in the NICU, as a pediatric nurse educator supporting staff development, and as a nurse leader in pediatric urgent care. Her interest in bioethics focuses on integrating concepts of health equity and social justice with policy development and staff education. Jaleh was an inaugural recipient of the Emerson Network Power Scholarship specializing in maternal and newborn care, and she also received the HMS Dean's Scholarship for master's students. After graduation, she will continue integrating bioethics and activism.

Yoo Sun “Sunny” Jeong, BScN, RN

Optimizing the Pediatric Anesthesia Informed Consent Process

Optimal pediatric informed consent promotes respect for persons, enhances parental understanding, and entails a collaborative parent-anesthesiologist partnership. The aim of this project was to gain greater insight into the pediatric anesthesia informed consent process from the perspectives of practicing anesthesiologists and health-communication experts, particularly regarding opportunities for parents to ask questions. Specifically, the goal was to create a resource tool for parents including a Question Prompt List to facilitate their questions during the informed consent process. A literature review and five semi-structured qualitative interviews were conducted with three anesthesiologists and two health-communication experts. The literature review revealed the importance of creating an environment conducive to parental empowerment, timing of the informed consent, and tailoring the informed consent process to enhance understanding. The interviews with anesthesiologists yielded three themes: time constraints impede the informed consent process, relationship and rapport with parents are essential, and parents may not fully understand the role of anesthesia. Interviews with the health-communication experts yielded two additional themes: the importance of inviting parents to ask questions and the benefits of customizing parental conversations. Based on these findings, a user-friendly resource tool for parents was developed to help facilitate discussion during informed consent processes. The tool defines familiar language, lists common side effects, and suggests questions for parents to consider. Future steps will seek parental feedback of the tool’s appeal, accessibility, and usefulness. This resource tool has potential to improve parental experience and trustworthiness of the pediatric anesthesia informed consent process.

Capstone Mentor:

Elaine C. Meyer, PhD, RN, MBE, Nurse and Clinical Psychologist, Boston Children’s Hospital; Associate Professor of Psychology in the Department of Psychiatry, Harvard Medical School

Yoo Sun “Sunny” Jeong, BScN, RN, received her BScN from McGill University in Montreal. She worked as a pediatric registered nurse and as a strengths-based nursing and healthcare coordinator at Holland Bloorview Kids Rehabilitation Hospital in Toronto prior to the MBE program. During her undergraduate education, Sunny contributed to various research projects on orthopedic and neuromuscular conditions within pediatrics at Shriners Hospital for Children - Canada. Her interest in bioethics stems from her experiences working with children with disabilities and her desire to improve the care of this population. After obtaining her MBE, Sunny will continue her training in bioethics as a fellow in pediatric ethics at Children’s Mercy in Kansas City.

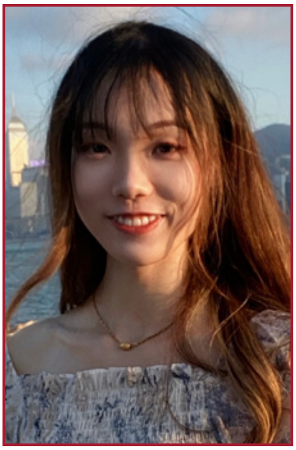
Nancy Jiang

Ethics, Virtual Reality, and Pain: Ethical Considerations in Deploying Virtual Reality for Pain Management

Virtual Reality (VR) is an emerging technology that promises to achieve effective pain management through various mechanisms, such as offering physiotherapeutic training and educating patients in mindfulness-based practice. Yet, there are no existing, well-recognized ethics guidelines or regulations that are specific to the use of VR in pain rehabilitation. This gap may compromise patients' best interests, for example by deterring researchers and clinicians from deploying VR technologies due to unclear standards for best practices. This capstone project sought to illuminate ethical tensions pertaining to VR use in pain management research and clinical care and to offer concrete recommendations for addressing the risks. The project began with a literature review and analysis. Through the lens of Beauchamp and Childress's principles of biomedical ethics framework, the project identified ethical considerations related to beneficence, non-maleficence, respect for autonomy, and justice. Prominent examples include the potential for harm such as simulator sickness and depersonalization, therapeutic misconception, and infringements on data privacy and confidentiality. Subsequently, the author developed an ethical framework for VR researchers in the form of an ethics checklist that guides their practice throughout each stage of VR pain management research. Additionally, the author developed a patient education fact sheet to aid informed decision-making when patients consider whether to enroll in VR-based studies. The fact sheet provides core information about VR research in pain management, including associated benefits and risks. Going forward, these deliverables will be introduced into real-world practice.

Capstone Mentor:

Ryan Andrew Mace, MS, Staff Psychologist, Department of Psychiatry, Center for Health Outcomes and Interdisciplinary Research, Harvard Medical School



Nancy Su Jiang is a third-year medical student at the University of Hong Kong (HKU). She represents the Li Ka Shing Faculty of Medicine at HKU as a student ambassador, volunteers in multiple ophthalmologic centers, and contributes to research related to neurovascular and ophthalmological diseases. As an advocate for ethical clinical practice, she seeks to empower healthcare leaders in addressing contemporary bioethical challenges associated with advanced medical technologies. Nancy received several scholarships for exemplary performance, including the Medical Dean's Scholarship, AIA Scholarship, and HSBC Overseas scholarship. Upon graduation, she will return to Hong Kong and finish her medical degree.

Ramya Joshi, BS

The Ethical Considerations of the Impact of Race on Access to Aortic Valve Replacement (AVR)

Despite Black Americans' high incidence rate of severe aortic stenosis (SAS) in the United States, they are less likely to undergo an AVR, the most common and effective treatment for SAS, compared to their white counterparts. For Black Americans, access to AVR is less studied than the considerations that arise once a patient has agreed to surgery. This capstone project conducted a review of the literature to assess current understandings of racial disparities in AVR, specifically investigating the roles of physician bias, patient-physician race concordance, and medical mistrust on Black patients' access to and quality of cardiovascular care in allopathic medicine. Results showed that many studies have identified structural racism, social and political determinants of health, and historical atrocities as the root of these inequities, but they have conflicting conclusions regarding the impacts of and relationships between these variables on Black patients' cardiovascular care experience. It is evident that more research is needed to draw these correlations more effectively. This project also found that the deontological mandate of medicine to "do no harm" has not translated into equity or mitigated existing structural racism, but rather has served as an ineffective normative standard that has not achieved justice. A shift to a consequentialist approach is due, wherein analyzing health outcomes and engaging affected communities in order to drive standards of care, individualize patient care, improve clinical care heuristics, and work towards more equitable healthcare.

Capstone Mentor:

Michael Ieong, MD, Member, Center for Bioethics, Harvard Medical School; Assistant Professor of Medicine, Boston University Chobanian & Avedisian School of Medicine; Medical Director, Medical Intensive Care Unit, and Co-Chair, Ethics Committee, Boston Medical Center

Ramya Joshi, BS, received her BS with honors, majoring in biological sciences and minoring in medicine in society, from Virginia Tech (VT). As an undergraduate, she worked in cardiovascular therapeutics research and served as an undergraduate teaching assistant for organic chemistry. Her bioethical interests include improving access to quality health care, improving the patient-physician interaction, and addressing the role of social determinants of health in patient healthcare experiences. She is a Harvard Medical School Dean's Scholar; a member of Phi Sigma, Phi Kappa Phi, and Phi Beta Kappa; and was on the VT College of Science Dean's List throughout her undergraduate career. After graduation, Ramya plans to attend medical school.

Kaneza Kadambaya, MPH

Compensated Living Organ Donation in the US: Ethical, Practical, and Legal Considerations

The United States (US) is experiencing an organ shortage crisis. One approach to increasing the number of transplantable organs is to implement a compensated living organ donation (CLOD) program to enlarge the pool of living donors. Understanding that federal law prohibits purchase or sale of human organs, this capstone project examined various ethical and legal perspectives regarding CLOD to determine whether such an intervention could be justified. A comprehensive literature review was performed, and multiple key informant/stakeholder interviews were conducted with transplant surgeons, ethicists, and public health experts. The project concluded that CLOD may be ethically applied as a system that provides tangible benefits to donors, equally considers the interests and well-being of donors and recipients, equally distributes risks of harm associated with organ transplantation, and respects the autonomy of donors who make informed participation decisions. A practical and ethically sound CLOD program could be well informed by how CLOD has fared in other countries, as well as by how legal, compensated egg donation has proceeded in the US. Evidence from these domains indicates that reasonable safeguards exist to protect against exploitation as applied to CLOD. Such measures would include robust informed consent, protecting vulnerable groups, and prohibiting for-profit middlemen from undermining the process. Overall, ethically justifiable approaches to CLOD exist to help mitigate the organ shortage crisis and could be an impactful way to properly acknowledge and respect the generous act of organ donation.

Capstone Mentor:

Annekathryn Goodman, MD, MPH, Professor of Obstetrics, Gynecology and Reproductive Biology, Massachusetts General Hospital

Kaneza Kadambaya, MPH, is a bioanalytical scientist at PPD, a global pharmaceutical contract research organization. Kaneza completed both a BS in pre-medical and health studies and an MPH at the Massachusetts College of Pharmacy and Health Sciences. As a scientist, Kaneza supports the process development, product strategy, and regulatory commitments of several biologics products that are currently on market. Her interests in bioethics center on the role of policy as an instrument for promoting equity and justice for marginalized communities in the United States. After completing the MBE program, Kaneza plans to continue her studies as a health policy PhD student.

Faith Kanjira, BBA

Developing a Quality Improvement Training Module for Malawian IRB Members

Institutional review boards (IRBs) are integral to the protection of human research participants as clinical research activity continues to increase in developing countries. The mission of the IRB is to protect the rights and welfare of human participants in research by independently reviewing research studies and ensuring that risks to these participants are minimized and justified by potential benefits. In the United States, IRBs are required to follow federal regulations to ensure consistency and effective application of ethical principles to research protocols. IRBs globally still face obstacles in improving the protection of research participants despite an increasing number of countries following international research ethics guidelines. Obstacles include bureaucratic delays, inconsistent approaches to review, and a focus on areas beyond the application of ethical principles to the research. To address these obstacles and needs of the Malawian IRB, this capstone project aimed to understand the IRB review process and how it achieves human subject protection. In particular, this capstone project included performing a literature review regarding research ethics review processes in the United States and Africa, attending IRB meetings at Mass General Brigham, and meeting with IRB chairs and members. The author identified the need for culturally appropriate IRB member training as an important quality improvement initiative. To meet this need, the author designed a training module for Malawian IRB members to learn how to consistently apply core ethical principles and respect local cultural values during the review process.

Capstone Mentors:

Benjamin C. Silverman, MD, Member, Center for Bioethics, Harvard Medical School; Senior IRB Chair, Human Research Affairs, Massachusetts General Brigham

Donnella S. Comeau, MD, PhD, Vice Chair, Institutional Review Board; Human Research Affairs, Massachusetts General Brigham

Faith Kanjira, BBA, received a BBA in Management from Malawi Adventist University. She worked as a regulatory coordinator with the University of North Carolina Project in Malawi and volunteered at the Malawi Ministry of Health Research department as a safety officer before joining the MBE program. Faith is a 2020 fellow of the Western Institution Review Board (WIRB-Copernicus Group) international fellows program in bioethics and ethics committee administration. Her interest in bioethics lies in improving global ethical research focusing on protecting human subjects. In her spare time, Faith enjoys reading, exploring places, and spending time with her family. After graduation, she plans to build a career in clinical trial monitoring.

Eric Kim, BA

Beyond Coverage: A Luck Egalitarian Argument for Making Orphan Drugs Affordable

‘Orphan drugs’ are drugs that are approved to treat rare diseases afflicting small patient populations. Consequently, orphan drugs typically cost more per patient. They therefore raise the consequentialist question of whether society should fund their coverage and forego healthcare goods that would benefit more people. This project began with a comprehensive literature review which revealed that current policies support the coverage of expensive orphan drugs. Subsequently, the author developed a philosophical defense for these policies based on a shared obligation to make drugs affordable and to distribute healthcare resources according to an egalitarian scheme, i.e., one that equalizes access rather than maximizes outcomes. Specifically, the author relied on luck egalitarianism, a distributive account that compensates for random factors that unjustly lead to poor welfare, such as the rarity of one’s disease. The project culminated in a manuscript in which the author argued that because disease rarity is only indirectly morally relevant to people’s claim to healthcare access, and because disease rarity itself makes a patient worse off, luck egalitarianism demands that the public pay to cover orphan drugs that may cost more than common drugs. The author also concluded that orphan drugs should be covered to make them sufficiently affordable for patients. This argument produces a more demanding obligation for society to make orphan drugs affordable than what current practice entails, as it requires a greater commitment of people’s taxes and premiums and possible increases to orphan drug coverage.

Capstone Mentor:

Leah Rand, DPhil, Research Scientist, Program on Regulation, Therapeutics, and Law (PORTAL), Division of Pharmacoepidemiology and Pharmacoeconomics, Brigham and Women’s Hospital and Harvard Medical School

Eric Kim, BA, is a fourth-year medical student at New York University Grossman School of Medicine. He received his BA in philosophy from Amherst College with an honors thesis on religion-based refusals of life-saving treatment. During his medicine clerkship rotation, he received the Clerkship Award for Outstanding Essay in Dilemmas in Healthcare after writing about the ethical difficulties of DNR orders from suicidal patients. He is interested in clinical ethics and its intersection with religion and theology. He has published his research on conscientious objections as first author in the journal *Bioethics*. After graduation, he will complete his final year at NYU and apply to an internal medicine residency program.

Francesca Minjoe Kim, MSW

Should You Trade Your Kidney for a Voucher? Ethical Implications

Organ transplantation systems involve a delicate balance between maximizing life-altering treatments for patients, preserving justice and equity for the thousands of patients on transplant waitlists, and upholding the dignity of organ donors. The growing systemic imbalance between donor supply and recipient need creates pressure to identify new ways to maximize transplants and their utility, leading to societal shifts towards accepting organs as a commodity. The Advanced Donation Program (ADP) is an innovative program that allow prospective kidney donors to donate their kidney in exchange for selecting up to five individuals to receive a voucher for a priority kidney transplant if and when one is needed. This capstone project sought to understand the evolution of the ADP, to explore its ethical tensions, and to determine its place within the Canadian healthcare system. A literature review identified ethical tensions related to exploitation and commodification of human body parts, the potential for the voucher system to undermine altruistic donation, and the equity of the voucher system. A policy brief was created to detail these ethical tensions and will be disseminated to raise awareness of challenges and opportunities in organ donation and transplantation.

Capstone Mentor:

Laura Madigan McCown, MSW, MTS, DB, HEC-C, Clinical Ethicist, Maine Medical Center

Francesca Minjoe Kim, MSW, is a registered social worker at Toronto General Hospital in Canada. She received an Honours Bachelor of Science in psychology from York University in Toronto, and a Master of Social Work from University of Toronto. She works with multiorgan transplant patients and is often involved with complex cases that present multiple ethical dilemmas. She plans to delve deeper into transplant-related ethical issues to ensure equitable patient-centered care and to alleviate clinical burnout. Francesca will continue to work as a social worker in Toronto and incorporate bioethical frameworks into her practice by leaning into the ambiguity and discomfort that arise in the clinical setting.

Hyungjin "Gene" Kim, MD, PhD

How to Promote Shared Decision-Making (SDM) in Rheumatology: Bridging the Gap Between Recommendation and Implementation

SDM is a collaborative process where patients and clinicians co-create an evidence-based management plan that aligns with patient preferences, values, and goals. SDM has been implemented as an overarching principle of the disease-specific treatment guidelines from the American College of Rheumatology (ACR) and European Alliance Association for Rheumatology (EULAR). This project aimed to identify barriers to successful implementation of SDM, to identify related ethical considerations, and to recommend strategies incorporating identified ethical concerns to overcome those barriers. A literature review was completed and professional societies' statements/guidelines addressing SDM were reviewed. Findings revealed that full implementation of SDM remains suboptimal. Ethical themes included the compromise capacity to fully respect patient's autonomy and the institution's negligence in its duty to provide adequate time for the clinician to engage in SDM. The project proposed strategies for more effective integration of SDM within rheumatology that included the following: enhanced training provisions; nurturing a collaborative environment that prioritizes patient values and cultural considerations; and, designating institutional accountability for allocating sufficient time to SDM processes through policy implementation. Next steps include engaging rheumatology societies' leadership to recognize the reported gaps in implementation with the goal of expanding guidelines/statements to include acknowledgment of these ethical tensions and provide more detailed implementation recommendations to resolve them.

Capstone Mentor:

Shahla Siddiqui, MBBS, D ABA, MSc, FCCM, Anesthesiologist Intensivist Ethicist, Beth Israel Deaconess Medical Center; Assistant Professor, Harvard Medical School

Hyungjin "Gene" Kim, MD, PhD, is a rheumatologist at Samsung Medical Center and a faculty member in the department of medical humanities at the Sungkyunkwan University School of Medicine (SKKU-SOM) in Seoul, South Korea. He currently teaches medical humanities and medical ethics at SKKU-SOM and its affiliated hospital. His passion lies in clinical ethics and global health ethics. Once he finishes his degree, his focus will shift toward teaching and researching bioethics while staying connected to peers in the field. Outside of academics, he enjoys playing cello and spending time with family.

Erica Koranteng, MBChB

Equity, Justice, and Racism: An Analysis of the Bioethics Literature

The Covid-19 pandemic and the disproportionate deaths among Black and other minoritized individuals have shed renewed light on gross injustices and health disparities in the US. Many have argued that the field of bioethics has failed to address issues related to social injustice, but limited data exist to support these claims. This project conducted a scoping review of the bioethics literature and analyzed how publications in the field have addressed social justice, racism, and health disparities, including trends over time. A focused search in PubMed revealed 548 articles addressing justice, racism, and health disparities along with bioethics. Following title, abstract, and full text review, 107 articles were found to address the topic between 1975 and 2022; of which 67 were published in the US. Fewer than 5 relevant manuscripts were published in most years. Calls to action for the field have existed consistently within the literature since the early 2000s; however, notable socio-cultural events in 2016 and 2021 appeared to lead to increased publication frequency. Several articles highlighted social injustices and provided relevant normative frameworks, with many acknowledging the need for more engagement from the field with this topic. Gaps in the literature remained in addressing the application of justice principles through the lens of bioethics as well as disparities faced by non-Black minority groups. The future of bioethics may benefit from more proactive efforts to identify and thoroughly address the abundance of social justice issues that inevitably affect health.

Capstone Mentor:

Jonathan Marron, MD, MPH, Director of Clinical Ethics, Instructor in Pediatrics, Member, Center for Bioethics, Harvard Medical School

Erica Koranteng, MBChB, is a medical officer in the internal medicine department at the University of Ghana Medical Center. She received her MBChB from University of Ghana. Erica has worked in many resource-poor hospitals and healthcare settings since receiving her medical degree and has developed an interest in the role of medical ethics in the face of limited resources. She also has a passion for patient-centered care. Upon completion of the HMS bioethics degree, Erica hopes to pursue further research in the social justice space and integrate bioethics with her medical career and advocacy work in the West-African sub-region. During her spare time, she enjoys hiking and learning about history.

Kaitlyn Lew, BS

Navigating the Bioethical Crossroads of Cancer Genetic Testing in Low-Resource Regions in Africa: What Do We Need to Consider?

Introducing modern medical technologies in low-resource regions can help reduce global healthcare disparities and foster justice and inclusion among diverse communities. Nevertheless, there are important bioethical challenges to consider for during implementation. Cancer genetic testing has the potential to identify individuals at high risk for hereditary cancers. After finding gene mutations, however, limited access to appropriate follow-up in low-resource areas limits the efficacy of the testing, and may contribute to different global standards of care. This capstone sought to examine some of the ethical dilemmas impeding just and effective implementation of genetic testing in low-resource regions. The researcher engaged with an ongoing cancer genetic testing initiative in Rwanda, conducting selected literature reviews and interviewing local professionals in Rwanda, Tunisia, and Nigeria to examine cultural barriers to informing patients about testing and prevention. Emergent themes included ensuring communication strategies appreciate the uniqueness and diversity of local communities, ensuring genomic data management, and ensuring privacy and informed consent for vulnerable populations. Prospectively engaging communities in future international genomic research can facilitate inclusive public conversations and enhance interdisciplinary work to help navigate ethical dilemmas facing cancer genetic testing implementation in Sub-Saharan Africa.

Capstone Mentor:

Lynn W. Bush, PhD, MSB, MA, Faculty, Genetics and Genomics, Pediatrics, Boston Children's Hospital; Faculty on Pediatrics and Genetics Training Program, Center for Bioethics, Harvard Medical School

Kaitlyn Lew, BS, is a research coordinator in cancer genetics and prevention at Dana-Farber Cancer Institute. She graduated magna cum laude and received a BS with honors in both biology and contemplative studies from Brown University. Her current research focuses on women's decision-making for cancer prevention. She is particularly interested in the bioethics of cancer genetic testing, informed consent, and reducing inequities in health care. While at Dana-Farber, she was awarded the Richard Boskey Ethics Award. After completing the MBE program, Kaitlyn will attend medical school in Fall 2023.

Madison Liistro, BS

Evaluating Gender-Affirming Care for Minors Through a Queer Bioethics Lens: What Needs to Change?

Gender-affirming care has demonstrated efficacy in treating gender dysphoria and has shown drastic improvements in the mental health of transgender and gender-diverse (TGD) youth, greatly reducing rates of depression and suicidal ideation in this population. Each year, a growing number of TGD minors present for gender-affirming care. Because so many U.S. states are banning this important medical treatment for minors, understanding and minimizing the non-legal barriers is critical. One such barrier is the requirement for parental consent. Cis-heteronormative bias, misinformation and lack of education, and religious beliefs are a few reasons why parents may misunderstand or be unsupportive of their child's gender identity and medical needs. Yet, a minor cannot legally consent to gender-affirming care without their parent(s)' or guardian's approval. The heterogeneous factors that influence a TGD minor's ability to provide informed consent, however, pose challenges for removing the requirement of parental or guardian approval. This capstone applied a queer bioethics framework to normatively analyze ethical dimensions of TGD minor consent without parent or guardian approval. A literature review identified a lack of ethical guidelines for TGD minors seeking medical treatment without parental consent, knowledge gaps that inhibit a clinician's ability to provide a proper assessment of risks, nuances in determining capacity for youth, insufficient gender care training of primary care physicians, and scarce educational materials for decision-making as key challenges. Normative analysis demonstrated how health care for queer individuals is unjustifiably "othering." This capstone suggested strategies to remediate this problem.

Capstone Mentor:

Jennifer McGuirl, DO, Neonatologist/Pediatrician, Ethics Consultation Service, Brigham and Women's Hospital; Member, Center of Bioethics, Harvard Medical School

Madison Liistro, BS, is a project coordinator in the Genomics Platform at the Broad Institute of MIT and Harvard. She received her BS in biology from Bates College. She facilitates research grade genomic sequencing projects for products such as whole genome sequencing, whole exome sequencing, and RNA-seq. She is passionate about the ethics of genomics and LGBTQ+ healthcare rights, especially where these areas intersect. After graduating from the MBE program at Harvard, she plans to remain in her project management position while exploring a career in genetic counseling and continuing her focus on LGBTQ+ activism in health care.

Sabryna Malik, BE, MPhil

Nanoethics Education in Medical School Programs

Applications of nanoscale science and nanotechnology are proliferating within medicine. The emerging field of nanomedicine has the potential to revolutionize personal and population health, and will substantially impact medical practice, research, and training. As nanomedicine is adopted, it is important to address the ethical and social aspects of nanomedicine including informed consent, truth-telling, and confidentiality. The purpose of this capstone was (1) to inform the development of medical curricula addressing the emergence of nanomedicine and its related ethical concerns, and (2) to promote awareness of and discussion about the challenges related to nanomedicine among healthcare professionals. An initial literature review regarding education about nanomedicine and its potential ethical implications revealed that most medical school curricula do not cover even basic nanoethics topics. The review informed the creation of a teaching module about nanomedicine and its ethical implications that can be incorporated into medical school curricula. The format is a flipped classroom module that requires students to complete pre-assigned material and participate through an online platform and live session. The module emphasizes key nanoethical concepts and critical thinking in the application of nanotechnology to health care to help physicians-in-training better analyze and resolve medical nanoethical dilemmas.

Capstone Mentor:

Todd Giorgio, PhD, Professor of Biomedical Engineering, Chemical and Biomolecular Engineering, and Cancer Biology, Vanderbilt University

Sabryna Malik, BE, MPhil, received a BE in biomedical engineering with a minor in nanoscience and nano-technology from Vanderbilt University and an MPhil in micro- and nanotechnology enterprise from the University of Cambridge. She has also enrolled in additional public health courses at Yale University. Her research focuses on the application of engineering methods to problem-solving for medical questions. Sabryna's interest in bioethics centers on ethical considerations emerging as a result of innovation in biotechnology that has fueled a rapid restructuring in healthcare delivery. She enjoys heading off the beaten track for rides through global landscapes on her all-terrain vehicle and sharing these adventures with her brother.

Cole McCabe, BA

Psilocybin's Effectiveness in Mental Health Disorders: A Proposal to Reclassify as a Schedule 4 Drug

The Comprehensive Drug Abuse Prevention and Control Act of 1970 (CDAPCA) designated psychedelic drugs, including psilocybin (the psychoactive component in "magic mushrooms"), as illegal for recreational and medical use. Under CDAPCA, the Drug Enforcement Agency (DEA) deems psilocybin, as a Schedule 1 substance, to have no medical benefit and a high potential for abuse. This capstone project examined the validity of these claims in the context of recent studies exploring psilocybin's therapeutic potential in mental health disorders, including depression, post-traumatic stress disorder, substance abuse disorder, and anxiety. It also used principlist, virtue ethics, and deontological approaches to consider the moral permissibility of psilocybin's use in psychiatric practice. A review of meta-analytic findings demonstrated that psilocybin shows potential therapeutic benefits and tolerability in mental health disorders, providing a rationale for reclassifying it to a Schedule 4 substance. Furthermore, reclassification would liberalize availability of psilocybin for use in monitored clinical settings and research, enabling production of appropriate safety data for diverse clinical populations. Finally, due to the relative lack of safe and effective medical options for patients with mental health disorders, rescheduling psilocybin facilitates ethical obligations to increase research, reduce stigma, and enhance quality of life for these populations. In the context of reclassification, careful monitoring in practice and ongoing research will remain necessary to establish ethical standards for psilocybin use.

Capstone Mentor:

Kaila Rudolph, MD, MPH, MBE, Assistant Professor of Psychiatry, Boston University Chobanian & Avedisian School of Medicine; Attending Psychiatrist, Consult-Liaison and Geriatric Psychiatry Departments, Boston Medical Center

Cole McCabe, BA, received a BA in political science from The Ohio State University (OSU). He was a psychiatric care technician at OSU Wexner Medical Center and previously volunteered at the National Suicide Hotline as a crisis intervention specialist. While a visiting student at Stanford University, he was a finalist in the Silicon Valley Innovation Academy and conducted a meta-analysis of brain activation in generalized anxiety disorder. His interest in bioethics stems from his experience working with psychiatric patients. Cole's interests in bioethics include forced medications, surreptitious administration of antipsychotics, and involuntary commitment. After the MBE program, Cole plans to attend medical school. His hobbies include playing sports and visiting museums.

Miles Meline, BA

Mental Integrity and Capabilities: Epistemological and Ethical Considerations for our Personal Use of Smartphones and Social Media

Over the past two decades, increasing use of innovative digital technologies such as smartphones and social media (SPSMs) has raised concerns about these technologies' impact on neurocognition and mental health. This capstone proposes that SPSMs may be considered direct-to-consumer neurotechnologies, given their potential to monitor or modulate human brain and behavioral functioning. Such technologies raise concerns for neurorights, i.e., principles protecting the freedom of neurocognitive functioning, and also raise epistemological and ethical questions about how individuals ought to understand and use SPSMs. To better understand neuroethical concerns related to personal use of SPSMs, this capstone explored psychiatric and philosophical conceptions of mental integrity and the impacts of individual and collective use of SPSMs on mental integrity. It found that although definitions of mental integrity vary, the concept generally refers to one's capacity to carry out successful neurocognitive functioning and the principled protection of such functioning. This capstone identified the concept of mental integrity as offering a productive epistemic framing as well as semantic efficiency (i.e., efficiency of successful understanding and explanation) to ethical reflections regarding contemporary use of SPSMs. A capabilities approach to justice was adapted to ground recommendations for personal uses of SPSMs that protect mental integrity.

Capstone Mentor:

Peter Zuk, PhD, Research Fellow, Center for Bioethics, Harvard Medical School

Miles Meline, BA, received a BA in philosophy and biology with minors in chemistry and Hispanic studies from the University of Pennsylvania. Miles has done research on topics including the efficacy of psychopharmaceutical treatments for nicotine dependency, medical decision making, the effects of expanded access programs on clinical trials, and the pedagogical role of empathy in arts education. Miles' bioethical interests broadly focus on narrative and feminist ethics, research and clinical ethics, health policy and advocacy, and social justice. Moreover, Miles is also very passionate about the intersection of bioethics, philosophy, and the biomedical sciences. After graduation, Miles plans to work within health policy as well as pursue an MD-PhD.

Gabrielle Moore, ScM

Ethical Analysis of Embryo Disposition Post-Dobbs

The *Dobbs v. Jackson Women's Health Organization* decision, which overturned *Roe v. Wade*, has not only led to state abortion bans but also has the potential to impact current regulations regarding embryos used in fertility treatment. Typical embryo dispositions after in-vitro fertilization currently include (1) donating to medical research, (2) donating for prospective adoption, (3) discarding, (4) cryopreserving, and (5) using for reproduction. If *Dobbs* is interpreted to give embryos the status of personhood, discarding or donating the embryos to medical research may become prohibited. This project undertook a normative analysis employing principlism and narrative ethics to evaluate the legal and ethical impacts of this potential interpretation of *Dobbs* on the disposition of embryos. Analyses considered the perspectives of three key stakeholders: the embryo (assuming personhood is granted), the progenitors, and society. This review concluded that, if embryos are conferred personhood, the ethical weight of principles that protect personhood would tilt the scale away from ensuring the autonomy of the progenitors and possibly away from the benefit of society. Advocacy efforts should be considered to prevent restrictions on embryo disposition and to facilitate outcomes that balance the ethical interests of affected stakeholders. Such efforts may focus on reversing the *Dobbs v. Jackson Women's Health Organization* decision and restoring federal constitutional protections for abortion, establishing legislative protections for disposition choice, or restricting the application of *Dobbs*.

Capstone Mentor:

Rebecca Feinberg, JD, MBE, MS, Teaching Associate Professor, DePaul University

Gabrielle Moore, ScM, is an administrative assistant at Mary Washington Healthcare in Virginia and a volunteer emergency medical technician (EMT). She received a BS in biology from the University of Mary Washington and an ScM in medical sciences from Warren Alpert Medical School of Brown University. She recently published on the effectiveness of pre-visit planning on PAP smear completion. Her bioethics interests include clinical ethics in medicine and dentistry, reproductive ethics, and ethics challenges that arise with biotechnological advances. After the MBE program, Gabrielle plans to work in health care and public health and pursue a career in academia.

Tomo Murayama, PhD

Application of Brain-Computer Interface Technology for Law Enforcement: Ethical Considerations

Brain-computer interface (BCI) is a developing technology that enables communication between brains and computers or machines. It translates brain signals into artificial output to manipulate external devices (e.g., prosthetic body parts) and is expected to translate digital computer inputs into brain signals. Thus, this technology can potentially revolutionize human interactions with computers and machines. Despite the positive impacts it may have, the use of BCI raises ethical concerns. For example, if others can access a user's BCI-recorded brain data, what does that mean for user privacy? This study explored the ethical issues raised if law enforcement seeks to implement BCI to enhance their investigative/operational capacities and the transparency of their activities. BCI has the potential benefit of increasing the accountability and fairness of policing by capturing officials' actions (as with body-worn cameras currently in use) and reporting individual officers' decision-making processes due to its unique feature of reading/recording brain signals. A review of the literature revealed three ethical dimensions to be considered in BCI use in health care and the military, including effects of BCI on user identity and autonomy, user choice with respect to BCI, and public acceptance of BCI. This study suggested a framework for mitigating potential ethical risks of BCI by ensuring that these ethical issues are considered as part of BCI use and policy development as well as in evaluation of BCI testing and practice results. This model would also support estimates of costs and resources required for broader BCI implementation.

Capstone Mentor:

Anthony Weiss, MD, Associate Professor of Psychiatry, Beth Israel Deaconess Medical Center

Tomo Murayama, PhD, is a technical official for National Police Agency, Japan. She received a BS, MS, and PhD in pharmaceutical sciences from Kyoto University. She also completed the Communication in Science & Technology Education & Research Program at Hokkaido University, Japan. Tomo focuses her research on chemical, biological, radiological, and nuclear threats, and robotics for preparedness and response to terrorism and disasters. She is interested in bioethical issues arising from advances in technologies, especially artificial intelligence and neuro-technologies. Tomo plans to bring knowledge and experience from the MBE program to the biosecurity sector.

Claire O’Connor, BA

Reducing Harms of Non-Racially Representative Genomic Data

Perpetuation of race-based health inequities in genomic datasets has caused considerable harm to patients and stems in part from the use of non-racially representative data throughout the drug development process. For example, the HIV drug, Abacavir, was developed using a homogenous genomic dataset. Later studies demonstrated that Black populations had a higher presence of the drug’s primary target, leading to life-threatening side effects and adverse outcomes impacting 8% of cases in Black populations. Early-stage drug discovery should serve as the starting point in promoting diverse genomic datasets to target the genetic polymorphisms that are an important source of variation in drug response among individuals. The primary aim of this capstone was to emphasize how the use of non-racially representative genetic datasets contributes to suboptimal outcomes among non-represented populations and to identify possible solutions towards utilizing heterogeneous genomic datasets. The project encompassed a literature review and case studies of drugs for which racially representative datasets were and were not used in their early-stage development with a particular focus on the outcomes impacts of this inclusion or exclusion. The results demonstrated that the use of racially representative datasets identified more safe and effective treatments for historically non-represented populations. An ethical analysis of this issue emphasized the responsibility of database owners and drug manufacturers to promote and study diverse genomic datasets as the main beneficiaries and distributors of this genetic information and their ethical obligation to prioritize equity and justice in genomics and technology.

Capstone Mentor:

Ameet Sarpatwari, JD, PhD, Assistant Professor of Medicine and Assistant Director of the Program on Regulation, Therapeutics, and Law; Brigham and Women’s Hospital and Harvard Medical School

Claire O’Connor, BA, is an education operations lead for the education team at Schrödinger, a drug discovery software company based in Cambridge, Massachusetts. She is also master’s student in English at the Middlebury Bread Loaf School of English and received a BA in history from Providence College. Her interest in bioethics developed during her internships and continuing education in ethics, education, and the power of narrative storytelling and ethical advancement in biotechnology. She hopes to improve communications in the biotech industry through a greater emphasis on literacy and educational tools. In her free time, Claire enjoys golfing, writing, and reading the latest New Yorker magazine.

Constantine “Kosti” Psimopoulos, MEd, MA

Ethics for the Clinician/Trainer/Patient in Adaptive Sports Medicine

Providers encounter unique ethical issues in disability sport and adaptive sport medicine that are relatively underexplored in the bioethics literature. Individuals with disabilities who are rehabilitating after a disease or injury may have distinct needs compared to individuals without disabilities. This scholarly project sought to explore the unique nature of disability bioethics in practice, identify how bioethics principles can be discussed in disability/ adaptive sport medicine, and develop the researcher’s practice in inclusive clinical ethics. The researcher embedded at Spaulding Rehabilitation Hospital where he apprenticed on its ethics advisory committee and observed clinical and organizational dynamics in the unique rehabilitative ecosystem. In addition, he developed focused educational programming in bioethics for Spaulding’s team of adaptive sports clinicians. This project uncovered how providers make meaning of the intricacies of adaptive sports medicine. It identified freedom of movement and self-determination as ethical goals of care and characterized rehabilitation as a domain in which quality of life (as compared to life or death) is central. Rehabilitative care was observed to be uniquely associated with the pursuit of purpose, meaning, participation, and empowerment leading to human flourishing. As next steps, the researcher will continue to develop these concepts and his own practice in inclusive clinical ethics.

Capstone Mentor:

Lynne Brady Wagner, MA, CCC-SLP, MRMC, HEC-C, Chief Learning and Diversity, Equity and Inclusion Officer, Director of the Stroke Rehabilitation Program, Spaulding Stroke Wellness Institute; Chair of the Ethics Advisory Committee, Spaulding Rehabilitation Hospital; Affiliated Faculty Member, Center for Bioethics, Harvard Medical School

Constantine “Kosti” Psimopoulos, MEd, MA, is a kinesiologist and an Equity, Diversity, Inclusion and Belonging Fellow at Harvard University. He received a BSc in health/ physical education from Aristotle University, an MEd from Springfield College, and an MA in kinesiology from The Ohio State University. Constantine has authored two book chapters on USA Olympism. His interest in bioethics focuses on disability ethics in sports medicine. Constantine is the recipient of the National Speak Out Award by SHAPE America, the Inaugural HMS Dean’s Scholarship, and the International Emerging Scholar Award from Sport in Society. Upon graduation, Constantine plans on teaching bioethics and serving on the Ethics Committee and the Adapted Sports Clinics at Spaulding.

Massoud Sharif, BS

Listening to Mothers of Children with Neurologic Illness to Explore Values and Decision-Making

When a child's neurologic function declines or never takes shape to begin with, the burden on their parents is substantial. Managing the uncertainty of clinical outcomes while grappling with implications for future impairment can make these conversations difficult to navigate. This capstone project explored the ethics of decision-making in parents of children with neurologic illnesses. A literature review grouped neurologic conditions into the following three categories: (1) neurodevelopmental disorders, (2) chronic conditions, and (3) acquired injuries. To identify broad ethical themes for future study – including the goals and values that inform decision-making – this project included informal conversations with mothers of children diagnosed with the different kinds of neurologic illness. Common themes across categories included the importance of mutual respect, flexibility, and outside support in facilitating shared decision-making. Illness-category-specific areas for follow-up included (1) the effects of labor-related health crises on mothers of children with neurodevelopmental disorders and (2) the effects of sudden change on mothers of children with acquired brain injuries. Decision-fatigue, fear, and managing uncertainty also emerged as areas for study. Future research could validate quality-of-life assessments as multifactorial – combinations of elements such as reaching developmental and rehabilitative milestones, completing activities of daily living, and having the capacity to cherish special moments. Finally, including parent perspectives across genders, input from patients (where possible), and physician impressions are avenues for future research to understand and advance decision-making on behalf of children with neurologic illness.

Capstone Mentor:

Scot Bateman, MD, Division Chief of Pediatric Critical Care and Director of the Office of Ethics, UMass Memorial Medical Center; Professor of Pediatrics, University of Massachusetts Medical School

Massoud Sharif, BS, is a recent graduate of Johns Hopkins University, where he majored in neuroscience and philosophy. As an undergraduate, Massoud studied the modulation of addictive behaviors by cannabinoid receptor systems at the National Institutes of Health. He also received the Albstein Research Scholarship to support his work at Johns Hopkins in studying post-stroke language recovery. His most recent publication explores the pathologic factors that contribute to language deficits after a stroke. Massoud's work as an emergency medical technician piqued his interest in clinical ethics, especially surrounding questions of consciousness and autonomy. After completing the MBE program, Massoud will pursue his MD at Harvard Medical School.

Tiffany Siu

Ethical Implications of Patient Selection in Low-Volume Heart Transplant Centers

Heart transplantation is a life-saving treatment for patients with end-stage heart failure. In the United States, transplant centers are regulated and funded by the Centers for Medicare and Medicaid Services. To remain accredited, transplant centers must meet specific requirements regarding center volume and patient outcome. With a smaller patient pool in low-volume heart transplant centers (LVCs), a single poor outcome significantly impacts the overall center mortality rate. This capstone project explored the regulatory and clinical pressures placed on LVCs, whether LVCs are inclined to select low-risk patients to avoid risking program suspension and the relevant ethical implications, and possible solutions to mitigate the injustice. A comprehensive literature review and non-directive interviews with heart transplant clinicians were conducted. Findings from these suggest that in addition to medical risk, LVCs tend to select patients according to outcome-influencing factors like cognitive abilities, social support, and financial stability. With limited donor hearts, selecting low-risk patients with potentially better outcomes reflects an attempt to maximize utility but create ethical concerns regarding justice, patient access to care, and resource constraints. Further studies are required to acknowledge and analyze this problem. Moving forward, modifying the oversight system to achieve a more balanced assessment of center performance would encourage LVCs to become less risk-averse, thereby increasing transplant opportunities for high-risk patients to receive marginal hearts that would otherwise be unused. This would promote equal patient access to care and beneficence, while potentially improving just allocation of donor hearts.

Capstone Mentors:

Mariah K. Tanious, MD, MPH, FAAP, Pediatric Anesthesiologist, Department of Anesthesia and Perioperative Medicine, Medical University of South Carolina; **Christoph G. S. Nabzdyk, MD,** Associate Professor and Consultant, Department of Anesthesiology and Perioperative Medicine, Mayo Clinic

Tiffany Siu is a third-year medical student at the University of Hong Kong (HKU). Her research is centered around cardiac surgery, neurosurgery, and cancer biology. Tiffany is an active volunteer in the healthcare setting in Hong Kong and Boston. Her bioethical work focuses on transplant ethics, neuroethics, and clinical ethics. Tiffany is also the recipient of numerous academic awards and scholarships. After completing the MBE, she plans to further her research in cardiac surgery while integrating bioethics into her future practice as a cardiac surgeon. Tiffany aims to promote distributive justice by contributing to healthcare reform and improving patient access to care. Her hobbies include singing and playing the harp.

Caitlyn Tabor, JD

Credible Fear Reform: A Call for Incorporation of Neuroevidence in Asylum Proceedings

Current asylum adjudication processes within the United States lack optimal procedural accommodations for asylum applicants who have experienced deep psychological trauma. Such trauma may compromise applicants' abilities to provide consistent, detailed, and linear narratives of trauma-producing events, undermining the fidelity of credible fear determinations central to asylum adjudications. The purpose of this capstone project was to advance credible fear reform towards more equitable treatment of such asylum applicants. A literature review revealed widespread immigration-related violations of established domestic and international human rights law relating to current credible fear proceedings. Deportations lack due process, and credible fear determinations, which require applicants to demonstrate genuine fear of persecution or harm, are rendered unreliable by flawed narratives, resulting in arbitrarily disparate outcomes. One solution advanced through this project is to permit introduction of neuroscientific evidence into credible fear determinations, encompassing expert testimony related to how trauma may alter brain structure and function. If permitted into asylum adjudication trainings, better understanding of the neuroscientific underpinnings of psychological trauma and how it may influence testimony may help asylum judges and attorneys understand why admitting such evidence may be material to asylum proceedings and justifiable under a human rights framework. Substantial limitations persist due to the adversarial nature of the United States legal system and the precarious role that bias plays in asylum determinations. Future directions for this work include implementation of trauma-informed training for judges and attorneys working in asylum and immigration contexts.

Capstone Mentor:

Katherine Peeler, MD, MA, MBE, Medical Director, Harvard Medical School Asylum Clinic; Instructor in Pediatrics, Boston Children's Hospital; Instructor of Pediatrics, Global Health and Social Medicine, Harvard Medical School

Caitlyn Tabor, JD, is the project director at the Center for Law, Brain & Behavior (CLBB), a neuroethics fellow at the Neuroethics Hub at Harvard Medical School, and a professor of health law, bioethics, and public health policy. She received her JD from Albany Law School in 2020. Caitlyn's scholarship centers on how justice can practically be achieved through policy reform. Her recent contributions consist of an international neurolaw training curriculum developed for the United Nations and a bioethics case-based teaching guide for medical residents created for the American Academy of Pediatrics. Caitlyn is passionate about protecting human rights and plans to continue her work post-graduation at CLBB.

Basel Tarab, MD, MHA

Toward the Ethical Provision of Patient Complaint and Grievance Systems

Patients and families may file complaints and grievances (C&G) with hospitals to express dissatisfaction with any aspect of their care or experience. In the United States, hospitals are required to respond to C&Gs according to processes regulated by several agencies, including the Centers for Medicare and Medicaid Services (CMS) and The Joint Commission (TJC). The stakeholders involved in this process, including patients and patient advocates who manage the process, may face ethical challenges while trying to reach resolutions. Particular challenges include tensions raise by patient advocates' dual commitments to patients and to the advocates' employers (i.e., the hospital) as well as the potential for disparities to occur in C&G processes and outcomes. This capstone project aimed to examine patient C&G policies and processes from an ethical perspective, focusing on the implications of C&Gs on future patient-provider relationships and the impact of patients' demographics on C&G process utilization and outcomes. This project included a literature review and semi-structured informational interviews with patient advocacy staff and leaders in selected hospitals. The results primarily revealed a lack of available data regarding C&G processes and outcomes. The researcher identified recommendations and ethical practices to reduce data gaps and inform solutions directed toward more expeditious, fair, and just C&G outcomes. Future directions for this work include developing a platform for patient advocates in Massachusetts to exchange expertise and provide recommendations to CMS and TJC to improve their existing C&G policies.

Capstone Mentor:

Sara Toomey MD, MPhil, MPH, MSc, Chief Safety and Quality Officer, SVP, Chief Experience Officer, and Director/PI, Center of Excellence for Pediatric Quality Measurement, Division of General Pediatrics, Boston Children's Hospital

Basel Tarab, MD, MHA, is a Syrian physician, patient advocate at Winchester Hospital, and adjunct faculty at Boston College. Basel received an MD with honors from Misr University for Science and Technology-Egypt and an MHA from Boston College. He completed a fellowship in bioethics at the Harvard Medical School Center for Bioethics. Basel is interested in discovering the similarities and differences in bioethics theory and practice across cultures and religions. He is the recipient of the Early Careerist Award from the American College of Healthcare Executives, the Boston College Graduates Award, and the Boston Children's Excellence Award. Basel plans on utilizing his education to conduct cross-cultural and clinical ethics research.

Alexandra Tsalidis, BA

Inside Open Payments: Examining the Public Disclosure of Payments Between Healthcare Companies and Biotechnology Researchers

Financial conflicts of interest (fCOI) in biotechnological research have serious ethical implications for both the research and the sponsoring institution. In response, the Centers for Medicare and Medicaid Services launched Open Payments (OP), a federally mandated database retrospectively publishing payments made by “applicable manufacturers” or “applicable purchasing organizations” to “covered recipients” (including physicians). This project aimed to investigate the effectiveness of OP in helping identify fCOI involving physicians conducting research. A literature review on the underlying ethics of fCOI and over 3,400 OP searches for physicians employed at Beth Israel Deaconess Medical Center were conducted. For each search, information collected included: (1) whether any payment was disclosed for 2021; (2) the total amount of “General Payments,” “Research Payments,” “Associated Research Funding,” and/or “Ownership Investment Interest”; (3) the number of “General Payments” transactions; (4) companies making the payment(s); and (5) the nature of the payment(s). Analyzing these data revealed the proportion of employees with OP disclosures for 2021, the spread of total transactions per person and of different payment types, and instances where the same entity made a research-related payment and “General Payments.” The results helped characterize the current OP landscape: most providers do not have any payments disclosed for 2021; even fewer have research-related payments; and payments are not evenly distributed. Ultimately, this project confirms the utility of OP in identifying researchers with significant financial ties to the healthcare industry, enabling further institutional risk mitigation.

Capstone Mentor:

Emma J. Kagel, JD, MBE, HCE-C, LPEC, Conflict of Interest Senior Specialist, Beth Israel Lahey Health

Alexandra Tsalidis, BA, is a graduate student at Harvard Medical School. She received her BA in law from the University of Cambridge in the UK. Alexandra is interested in the issues posed by novel technologies, in particular artificial intelligence (AI). She has worked as an AI ethics researcher at both the Shen Lab in Law, Ethics, Neuroscience & Artificial Intelligence at the Harvard Medical School Center for Bioethics and at the Ethical Intelligence Lab at Harvard Business School. She believes that bioethical frameworks can help inform how novel medical devices are implemented and regulated. After graduating from the MBE program, Alexandra hopes to contribute her ethics training to help shape a future of equitable AI development.

Elizabeth “Libby” Warner, BA

Shifting From Equality to Equity to Address Oncologic Clinical Trial Enrollment Disparities

Various clinical and research ethics frameworks promote the concept of justice, commonly understood as fairness. In clinical cancer research, the justice norm of equality, defined as equal access or opportunity, has been the prevailing standard for research participant recruitment. Recent evidence demonstrates that utilizing this standard results in racial disparities in cancer research participation. Some have therefore shifted toward a recruitment process focused on the justice norm of equity, defined as equal access or opportunity accounting for systemic social constraints, and pursuing the outcome of representativeness. These definitions and their ethical justifications have not been clearly articulated in cancer research literature. This capstone project provided precise definitions, compared and contrasted norms of equality and equity, and argued for equity-based approaches through exploration of a common trial enrollment dispute: whether a “clinically rigorous” or “representative” strategy should be used. The project undertook a literature review and comparison of recruitment strategies, exploring how current equality-based approaches have perpetuated historical disparities. It found that an equity-based paradigm for clinical oncological research participant recruitment, implemented under the aegis of a central regulatory body including multilevel interventions targeting systemic social constraints, is necessary to achieve representativeness and justice in clinical cancer research. In contrast to most existing literature, which defines participatory disparities and proposes solutions in either a wholly theoretical or practical framework that lacks reference to ethics, this project bridges the theory-to-applied gap by translating the ethical norm of equity into practice strategies to address enrollment disparities in oncology trials.

Capstone Mentor:

Andrew Hantel, MD, Member and Instructor of Medicine, Center for Bioethics, Harvard Medical School; Hospitalist, Department of Medical Oncology, Dana-Farber Cancer Institute

Elizabeth “Libby” Warner, BA, is a study start-up manager at Memorial Sloan Kettering Cancer Center. She received a BA in biology from Bucknell University with minors in Spanish, social justice, and dance. Elizabeth manages the activation process for upcoming clinical trials by collaborating with oversight committees, industry partners, and regulatory bodies to ensure that trials are activated quickly and safely. Elizabeth is interested in emerging ethical issues relating to the globalization of clinical trials, patient access to novel treatments, and social and political determinants of health. Upon graduation, Elizabeth intends to continue engaging with bioethics through her work at MSKCC and through scholarly research relating to health equity in clinical trials.

Helen Audrey Williams, BS

Bioethical Considerations for Engaging Adolescent Fathers in Positive Parenting Interventions in Low- and Middle-Income Countries

Engaging men in positive parenting interventions to combat pervasive gender norms has been found to increase closeness with their children, improve their intimate relationships, and reduce the incidence of gender-based violence (GBV). However, only a handful of parenting interventions have engaged adolescent fathers, and even fewer have been conducted in low- and middle-income countries (LMICs). This capstone project sought to explore the ethical concerns most salient to implementing parenting interventions targeting adolescent fathers in LMICs. In settings where resources are scarce, the counterintuitive approach of intervening with fathers, who may be the perpetrators of violence, prompts ethical deliberation. A literature review examined the use of parental engagement to decrease GBV. The abundance of interventions that engage mothers and, conversely, the lack of interventions for fathers in LMICs, revealed how particular ethical principles influence decisions within the field. These principles advocate promoting maternal/child beneficence and enhancing well-being through the normative lens of the capabilities theory of justice. The project also used feminist ethics to examine the implications of engaging adolescent fathers given that males typically are the oppressors in patriarchal societies. Future research should consider humanizing the work of justice by culturally anchoring interventions and integrating wider relational, sociopolitical, and contextual issues to promote gender equity and social justice.

Capstone Mentors:

Bizu Gelaye, PhD, MPH, Associate Professor of Epidemiology and Psychiatry, Harvard T.H. Chan School of Public Health, Harvard Medical School, and the Chester M. Pierce, MD Division of Global Psychiatry at Massachusetts General Hospital

Elizabeth Levey, MD, Child, Adolescent, and Adult Psychiatrist, the Chester M. Pierce, MD Division of Global Psychiatry at Massachusetts General Hospital; Assistant Professor, Harvard Medical School

Helen Audrey Williams, BS, earned her BS through a self-configured major in biology and public policy with a minor in global health from Duke University. As an undergraduate, Helen investigated the effect of cultural values on women's reproductive rights in Galle, Sri Lanka and surrounding areas. She also developed a policy framework for in-country adoption of a community-based cervical cancer screening program in Cajamarca, Peru. Helen's interests in bioethics lie at the intersection of global health and clinical medicine with a particular attunement to maternal and child health. Following her graduation from the MBE program, Helen will attend medical school.

Charlotte Wun, BSc (Hons)

Reframing BPD: A Narrative-First Approach Toward Epistemic Justice in Psychiatry

Borderline personality disorder (BPD) is a psychiatric disorder characterized by emotional, behavioral, and relational instability. Some scholars have argued that BPD is fundamentally moral: at its core, the condition entails deficits in moral character rather than clinical states of pathology. This capstone project took an analytic approach to explore this moralized conception of BPD. It began with a scoping review of the literature and traced the moralization of BPD to earlier iterations of the Diagnostic and Statistical Manual of Mental Disorders. The project focused specifically on understanding BPD's moralization within Miranda Fricker's framework of epistemic injustice. Testimonial injustice in the treatment of BPD involves the presumptive attribution of certain moral characteristics to persons with BPD that minimize their credibility—a phenomenon that is constitutive of (but extends beyond) countertransference and stigma in clinical encounters. The moralization of BPD also connects to hermeneutic injustice and a lack of conceptual resources for clinicians and persons with BPD to make sense of particular patient experiences. The project began the task of constructing a phenomenological toolkit to address the epistemic imbalance that derives from a moralized view of BPD. The toolkit will emphasize the central role of narratives and the humanistic approach of "unconditional positive regard"; these concepts will be explored in a forthcoming manuscript. Further research also is needed to elucidate the perspectives of persons with BPD and clinicians on epistemic justice and narratives in mental healthcare.

Capstone Mentor:

Douglas Knittel, MD, MBE, Clinical Assistant Professor of Psychiatry, Eastern Virginia Medical School; Assistant Professor of Psychiatry, Uniformed Services University of the Health Sciences

Charlotte Wun, BSc (Hons), is an ethics and clinical researcher at the Centre for Addiction and Mental Health in Toronto, Canada. She received a BSc in bioethics, human biology, and philosophy from the University of Toronto. Her current research focuses on medical assistance in dying (MAiD) and irremediable suffering, issues of epistemic injustice and harm in psychiatry and bioethics, and vaccine-related attitudes among youth with mental illness. Her interest in bioethics lies at the intersection of philosophy, critical theory, and mental health care. After completing the MBE, Charlotte plans to attend medical school and undertake residency training in psychiatry.

Alexis Yeung

Munchausen Syndrome by Proxy: An Ethical Toolkit for Health Care Practitioners in Case Management

Munchausen syndrome by proxy (MBP) is a condition in which a person abuses another by condition falsification. MBP often escalates to medical child abuse, where a child receives unnecessary and potentially harmful medical care at the instigation of a caregiver. Despite the gravity of these situations, MBP is difficult to identify, assess, and manage. This capstone project explored the clinical ethical dilemmas in approaching MBP cases through various principles and justifications focusing on parental consent, pediatric assent, and the best interest principle. Interview transcripts and medico-legal reports from existing MBP cases were reviewed to identify challenges in managing MBP cases from different stakeholders' perspectives. A framework was developed for healthcare professionals (HCPs) to guide decision-making processes surrounding suspected MBP cases. The project also produced a bioethics toolkit for HCPs that includes signs to look for when identifying MBP cases, moral arguments for interventions, and proposed procedures for HCPs to discuss and relieve the moral distress experienced by the health care team. The toolkit also includes a guide on how to collaborate with the child protection system when HCPs are obligated to report MBP cases. By developing a bioethical toolkit for HCPs, this project aimed to bridge the gaps in the system that allow for victims of MBP to be subjected to further harm and to prevent tragedies for which the medical system is partly responsible.

Capstone Mentor:

Catherine Ayoub, EdD, MN, RN, Nurse Practitioner and Attending Psychologist, Developmental Medicine Center; Associate Professor of Psychology, Harvard Medical School

Alexis Yeung is a third-year medical student at the University of Hong Kong (HKU). She is the founding president of the Hong Kong Medical Students' Pediatrics Association and a children's rights advocate. She is also a candidate in the Global Clinical Scholars Research Training Program at Harvard Medical School. As a child abuse survivor, Alexis focuses her work on Adverse Childhood Experiences (ACEs), pediatric ethics, philosophy, and medical education. After completing the MSc, Alexis will return to HKU to complete medical school. She hopes to contribute to trauma-informed care and child protection system reform in Hong Kong, and to integrate her bioethical experiences into her future practice.

Notes

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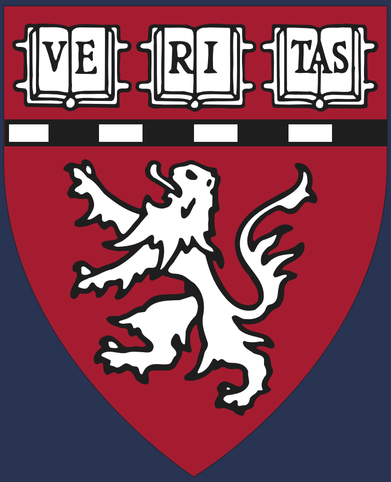

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