

Wednesday, September 18, 2024

2:00 PM - 4:00 PM, Grand B

Preconference Session: Conflict Resolution Skills for Ethics Committees (Conflict Management, Part I) Haavi Morreim
Clinical Ethics

Often, ethics consults stem not from moral puzzlement, but from conflict -- staff tensions about a complex situation, a "difficult" patient, intra-family feuds, and myriad other scenarios. Here, the optimal consult usually is not opining about ethics, but resolving conflict: exploring the situation, learning the back-stories that fuel the conflict, helping people articulate their most important priorities, and forging a mutually agreeable plan. Ethics committees and consultants must be prepared to discern what approaches and resources will best suit each consult. This workshop teaches clinical conflict resolution, including negotiation, facilitation, and assisted negotiation. The workshop begins by presenting a key "toolset" of skills, such as: managing expectations, affect labeling, normalizing, active listening, and probing for detail. These core techniques help build the trust on which successful resolution relies, thereby enabling those in conflict to reach their own workable agreements. Practice scenarios are interwoven so participants can gain comfort in using each skill. The workshop culminates in a two-part exercise focused on a complex problem of family dynamics. In Part One, small-group consult teams will "huddle" to discuss how best to approach the situation. Following a debrief, smaller pairings then conduct conflict resolution conversations. Everyone will participate in all practice exercises, followed by extensive debriefing for each. The presenter is a highly experienced and frequent mediator, both for the courts and in the clinical setting. She teaches 4-day conflict resolution/mediation trainings for clinicians, has co-taught 5-day mediation trainings designed for attorneys, and also provides full-day "communications bootcamp" trainings for residents.

2:00 PM - 5:30 PM, Grand A

HEC-C Review Course Abram Brummett, Maggi Budd, Anca Dinescu, Amanda Hine, David A. Oxman
Clinical Ethics

Developed and presented by ASBH HEC-C Review Course Task Force members, this course will provide a thorough review of the core references and four content domains through the use of sample questions and discussion about the examination content outline. The course will be highly interactive, with opportunities for attendees to test their knowledge and connect information with the content outline and core references as a review framework. The 3.5-hour session will include discussion and practice test questions for each of the following: Healthcare Ethics Issues and Concepts: Big Picture Healthcare Ethics Issues and Concepts: Clinical Encounters Healthcare Systems and Health Law Clinical Context Local Healthcare Organizations and Policies Each attendee will receive an HEC-C Study Guide featuring an extended analysis of the sample questions following the session.

3:00 PM - 6:00 PM, Grand C

Beyond case discussions: Training committee members to contribute to clinical ethics work Leah Eisenberg, Joan Henriksen
Education/Interprofessionalism

Healthcare ethics committees (ECs) benefit from including a diversity of disciplinary perspectives, but clinician volunteers likely have inconsistent education in clinical ethics. Often, committee education focuses on theoretical knowledge and case discussions with little emphasis on practical skills. Even ethics committee members (ECMs) who do not plan to lead ethics consultations should receive skills-based training so they better understand the process of ethics consultation, the complexity involved, and how the way the consultant frames an ethics question impacts the analysis and recommendations that follow. This workshop will offer accessible, dynamic tools for teaching ECMs how to structure and write ethics questions. Our time together will be interactive, using conversation, reflection, and hands-on activities to practice the discrete steps involved. Exercises will highlight the importance of naming stakeholders and their values and demonstrating how defining the action under consideration guides the rest of the consult. We will invite participants to discuss barriers they have encountered when training EMCs and share our own, including unanswerable questions, negatively framed consult requests, and the difficulty ECMs face when they "change hats" between their day job and thinking about clinical ethics. The workshop leaders are experienced clinical ethicists who regularly lead skills-based courses about ethics consultation for ECMs with a variety of disciplinary backgrounds. We have seen what works (and doesn't) when teaching ECMs what clinical ethics truly involves so they can enhance their ability to meaningfully participate on the EC.

4:30 PM - 6:30 PM, Grand B

Managing Challenging Conversations through Skilled Facilitation: Conflict Resolution Part II Autumn Fiester

Clinical Ethics

The ASBH has long endorsed the facilitation approach as the best model for ethics consultation yet many ethics consultants have not been trained in facilitation techniques. Empirical data show that the majority of US clinical ethicists hold group meetings with clinical staff, patients, and families as part of an ethics consult, even though many have not had formal training in group facilitation techniques. Having skill-based knowledge in the approaches to group interaction is especially important when tensions in the group are running high and members of the group are experiencing anger, frustration, burnout, or moral distress. This workshop will provide facilitation foundational training by teaching group management, strategies to manage difficult and contentious conversations among and between the clinical team, family members, and patients, and pitfalls to avoid that can cause a group meeting to fail. In this hands-on workshop, participants will learn how to effectively conducting complex, multi-party, and emotionally charged meetings with a diverse set of stakeholders. Careful attention will be paid to the issue of values-imposition and how to avoid it in consultation. Participants will master advanced facilitation through a combination of didactic presentations, question and response activities, and small group activities. This 2-hour interactive workshop session will be organized around 6 key facilitation skills. For each skill, there will be a short didactic presentation of the technique, followed by an interactive all-group activity to achieve mastery. The final 15 minutes of the workshop will be reserved for a concluding Q&A session.

Thursday, September 19, 2024

7:00 AM - 9:00 AM, Midway West Foyer

Breakfast

8:00 AM - 9:00 AM, Regency C

Welcome to ASBH!

Join us at this new session designed to welcome first-time attendees, new ASBH members, and those looking to make new connections at #ASBH24! Learn more about how you can maximize your conference experience from ASBH's leadership, ask questions, and forge new friendships over breakfast.

9:15 AM - 10:15 AM, Midway 9

A Cross-Disciplinary Approach to Mental Health and Substance Use Disorder Inequities

Elizabeth Pendo,

Law, Public Health Policy, Organizational Ethics

Stacey A. Tovino, Amy T. Campbell, Kelly Gillespie

In 2022, according to the National Survey on Drug Use and Health, 59.3 million adults experienced some form of mental illness and 48.7 million people aged 12 or older experienced substance use disorder (SUD) in the past year. The significant inequities in access to health care services experienced by people with mental health conditions and SUD are rooted in policies, practices, and beliefs that reflect long-standing stigma, bias, and unequal treatment. This panel will examine responses to individual, structural, and systemic forms of bias and unequal treatment that impact healthcare experiences and outcomes for individuals with these conditions from the disciplinary perspectives of law, public health, bioethics, nursing, and medical humanities. The first panelist, an expert in bioethics and law, will set the stage by discussing how mental health policy in the US could be reframed to advance collective mental health while also targeting populations with disparate experiences of trauma. The second panelist, an expert in nursing, bioethics, and the law, will examine the federal approach to controlled substance prescribing policies, including the expansion to criminalize even good faith prescribing decisions. The third panelist, an expert in medical humanities, will highlight state law issues through changing state regulation, public (mis)understanding, and other developments relating to the tele-induction of buprenorphine for SUD. The fourth panelist, an expert in law and disability theory, will provide a framework for recognizing and challenging specific forms of algorithmic discrimination that harm people with SUD, chronic pain, and other stigmatized conditions as disability discrimination.

9:15 AM - 10:15 AM, Grand A

A New Social Contract for Biobanking: The Benefits and Challenges of Using Public Deliberation to Ground Trustworthy Research

Peter Schwartz, Tom Doyle, Michael M. Burgess, Nicolas J. Oliver

Research Ethics and Social Sciences

Biobanks are collections of biological samples and information that have become cornerstones of medical research. They became common in the early 2000s after extensive discussion of the ethics of collecting biological samples and data for unspecified future research, often for unlimited time periods. One method used to identify public attitudes in this area was

Note: Please see online schedule for most up-to-date information and additional session information.

“public deliberation,” where a small group of laypeople meets for an extended period of time (e.g. 4 days over 2 non-consecutive weekends) to learn about the issues and tradeoffs and issue recommendations. Biobanks now have features that could not have been envisioned during the discussions a quarter century ago, including: the ubiquity of electronic health records to provide health information, the ability to sequence genomes, sometimes with support of private-public partnerships, the availability of massive amounts of information about biobank participants in the “big data” era, and the ability to engage participants electronically repeatedly through email, text, and other methods. These features of modern biobanks raise important questions about how to ethically collect and utilize health information, share information, sequence genomes, and return individual research results to participants. Our research team is conducting a public deliberation funded by the NIH to examine these new issues. In this panel, our interdisciplinary group will describe the complex choices involved in designing and implementing this deliberation, to illustrate the method and highlight its benefits and challenges. We will finally present the recommendations offered by the deliberants, and discuss the successes and limitations of the exercise.

9:15 AM - 10:15 AM, Regency B

Anti-Ableism in Clinical Ethics Consultation

Liz Bowen, Devan Stahl, Debjani Mukherjee, Laura K. Guidry-Grimes

Clinical Ethics

Clinical ethics consultants (CECs) are uniquely positioned to address inequities and biases in patient care and healthcare systems related to ableism. But they are not always attuned to recognize or respond to ableism, and those who do respond often encounter institutional and interpersonal resistance. This panel will identify common manifestations of ableism in the practice of clinical ethics consultation, as well as offer strategies for intervening and making constructive contributions. The panelists, a group of disabled and nondisabled CECs experienced in the work of anti-ableism, will draw from diverse disciplinary backgrounds, geographic regions, and career stages to offer practical discussions of what has worked (and what hasn't) when challenging ableism in clinical encounters, policymaking, and the culture of clinical ethics itself. The first panelist, a clinical/community psychologist and CEC who has worked on three continents, will draw on clinical examples to consider how implicit and explicit assumptions about disability are framed during ethics consultations. The second panelist, a philosopher who has worked as a clinical ethicist in several institutional settings and US regions, will suggest strategies for interrogating clinical conversations and hospital policies that are susceptible to ableist biases. The third panelist, a theologian and CEC, will discuss working with disability organizations as stakeholders in clinical ethics consultation and policy development. The fourth panelist, a CEC trained in literature and health humanities, will discuss opportunities and barriers for responding to manifestations of ableism that involve complex multi-institutional and intersectional dimensions, inviting reimaginations of the typical purview of the CEC.

9:15 AM - 10:15 AM, Regency C

Barriers Behind Bars: A Duty Towards a Dignified Death

Yelena Zatulovsky, Nicole McCann-Davis

Diversity, Disparity, and Inclusion

Persons who are and have been incarcerated with terminal diagnoses experience a plethora of poor health outcomes, both medical and psychosocial. Moreover, the multidimensional complexities of their circumstances pose particular challenges at the end-of-life creating an access inequity in hospice care for this vulnerable population. Hospice philosophy, to decrease suffering and provide compassionate care for those with life-limiting illness is at odds with this reality. Hospice agencies have yet to create collaborative relationships, decrease this disparity, and improve trusting partnerships with patients and regulatory systems. We are overdue. We need to create opportunities for collaboration, improve training for clinicians, and honor our responsibility to preserve the dignity of all patients with high-quality end-of-life care. This workshop will be a step towards that collaboration.

9:15 AM - 10:15 AM, Midway 10

Paper Session: Bridging Knowledge and Language

Health Humanities

An Empirical Perspective on Epistemic Environments as a Justice Issue for Chronic Disease Patients

Annika Nilsson

Bridging Language Effectiveness for Organ Donation

Brian D. Leland

9:15 AM - 10:15 AM, Grand B

Paper Session: Clinical Ethics: AI

Clinical Ethics

Arguing with a Ghost in the Machine - Bioethics of Health Decision Autonomy and Artificial Intelligence Benjamin Collins

The Chatting Cure?: Ethical Considerations of Unsupervised Psychotherapy Provided by AI-Powered Chatbots Seth

Zupanc

The Role of AI in Shared Decision-Making: A Patient, Physician, and a Chatbot Walk into a Consultation Room Stephanie

Kukora

9:15 AM - 10:15 AM, Jeffersonian Knickerbocker

Paper Session: Defining Benefit in Research

Research Ethics and Social Science

Evidence, Alternatives, and the Prospect of Direct Benefit

Aaron E. Segal

Navigating the Interplay Between Clinical Trial Rationality and Art Therapy Holistic Effects

Cintia Liara Engel

What's in it for Us? Revisiting How We Address Benefits in Research

James M. DuBois

9:15 AM - 10:15 AM, Midway 11

Paper Session: Equity Issues in Genetics

Diversity, Disparity, and Inclusion

Anticipatory Fatness: The Genetics of Obesity & the Individualization of Risk

Cassie Houtz

Re-envisioning Translational Ethics and Equity in Pediatric Gene Therapy

Aaron Goldenberg

Reparative Beneficence: A Queer and Crip Case Against Genetically Determining "The Best Life"

Vishnu Subrahmanyam

9:15 AM - 10:15 AM, Regency A

How Can We Expand the Canon of Reproductive Bioethics to be Inclusive of Reproductive Justice?

Diversity, Disparity, and Inclusion

Daphne O. Martschenko, Jennifer James, Faith Fletcher, Shameka Thomas

Bioethicists play a crucial role in shaping social justice discourse to address the existing inequities in health and healthcare. However, despite its roots in justice, the field of bioethics has not given due attention to healthcare inequities, especially those driven by structural racism. Moreover, it has failed to prioritize the work of scholars who focus on these issues, particularly concerning reproductive justice and its impact on minoritized groups. Reproductive Justice frameworks emphasize that reproductive choices and outcomes are shaped by one's social, structural, political, and physical environment. These frameworks also highlight the right to have children, to not have children, and to give birth and parent in safe and sustainable environments. Now more than ever, it is crucial to apply these insights in bioethical inquiry and practice. Panelists will utilize narratives and justice-oriented scholarship to center the need for discussing and actively engaging with the reproductive healthcare needs, values, and preferences of minoritized groups, namely Black women, families, and communities. Second, we highlight how these historical reflections and perspectives are fundamental in developing comprehensive reproductive bioethics frameworks, such as intersectionality to responsibly address ethical and equity issues in the healthcare of Black women. Third, we draw from three case studies to offer examples of utilizing intersectionality and reproductive justice in bioethical analyses focused on: (a) reproductive and maternal health, (b) prenatal genetics and sickle cell disease, and (c) policing and medical surveillance of Black women's bodies.

9:15 AM - 10:15 AM, Midway 5

Paper Session: Inequity at the Beginning and End of Life

Diversity, Disparity, and Inclusion

How the Other Half Dies: Health Disparities and Patient Perceptions of Clinician Bias in End-of-Life Care

Recommendations

Alexandra A. Taylor

Mitigating Healthcare Inequities thru Targeted Community Engagement: A Clinical Ethics Team Approach to Improving

LGBTQ+ Advance Care Planning

Marcie Lambrix

Prenatal Gene Editing: The Path to a Values-Based Governance Framework

Rosario Isasi

9:15 AM - 10:15 AM, Midway 1-2

Paper Session: Issues in Normothermic Regional Perfusion

Philosophy

"Honoring Humanity: The need for Transparency, in Normothermic Regional Perfusion for Controlled Donation after Circulatory Death."

Cathy L. Purvis Lively

Normothermic Regional Perfusion with Controlled Donation after Circulatory Death: Philosophical Worries Nir Ben-Moshe

Organ Procurement in The Era of Organ Recovery Centers

Amanda M. Buster

9:15 AM - 10:15 AM, New York/Illinois Central

Menu-based Surgery: When are Surgeons Just Technicians?

Megan Applewhite, Baddr Shakhsher, Sean Wightman,

Clinical Ethics

Jennifer Paruch

After a decade of training, a subspecialty surgeon develops the skills necessary to evaluate a patient and determine the operation necessary to treat the illness. Collaboratively, the goals of care are elicited, and the treatment plan is developed. For most elective operations, the goals congruent: to cure the problem – the patient then consents to surgery. What happens when the goals are aligned, but the means to reach those goals are not? What ought a surgeon do when the patient disagrees with the operation proposed contrary to the surgeons expertise? Consider the case where the operation most likely to cure a locally metastatic thyroid cancer is a total thyroidectomy with modified radical lymph node dissection. If the patient does want a cure, but insists the surgeon only remove half the thyroid, effectively choosing select parts from the "menu" of surgeon capabilities. Such conundra are arising more frequently in surgical practice, as information about patient options is ubiquitous on the internet, and the response of surgeons is varied. In this debate, questions of autonomy and paternalism will be discussed. The panel of surgeons will discuss if autonomy reigns and the surgeon should always support a menu-based approach to foster the surgeon-patient relationship; the surgeon should compromise if the patient understands the risks; the surgeon should maintain a practice where they do not offer operations that are not medically indicated; lastly beyond medical indications – only offer best medical practice for success. Just because a surgeon can, does it mean they should?

9:15 AM - 10:15 AM, Midway 7-8

Paper Session: Philosophy: Technology and Human Nature

Philosophy

AI, IVF and Singer Revisited

Thomas D. Harter

The Death of Thought in Medical Education: Bernard Stiegler, Techno-anthropology, and So-Called Artificial Intelligence

Benjamin Parks

Your Stethoscope, My Soul: What Diagnostic Technology Teaches Us About Human Nature

Andre E. Chavez

9:15 AM - 10:15 AM, Midway 3-4

Research Ethics Consultation: Xenotransplantation L. Syd M. Johnson, Anji Wall, Lainie F. Ross

Research Ethics and Social Sciences

One aspect of the question, "what does it mean to be human?" concerns whether humans are distinct from other animals. To the extent that xenotransplantation –transplantation of animal organs into humans—is possible, the separation of the species becomes less clear-cut. The ethical implications are complex and weighty. Xenotransplantation experimentation in humans also raises profoundly challenging questions about research ethics, which this panel will address. Speaker #1 is a philosopher/clinical ethics consultant who will discuss questions related to the risks of zoonotic infection: Does it violate a research subject's right to withdraw from research if they are required to submit to lifelong infectious disease surveillance? Should family members and close contacts of a subject be required to consent to ongoing surveillance? How should research-related infection risks to the public be addressed? Speaker #2 is a transplant surgeon/PhD in health care ethics who will examine using healthy subjects for first-in-human kidney xenotransplantation trials. Bringing together the purpose of first-in-human trials (safety and tolerance) with the threshold for risk in other clinical trials, may be the most rational approach to avoid therapeutic misconception that using an alternative population of end stage renal disease patients with little or no hope of human allograft transplantation engenders. Speaker #3 is a pediatrician/philosopher who has published 2 books on organ transplantation. The speaker will examine historical (Baby Fae) and current debates about whether pediatric heart xenotransplantation should be attempted when adult research is still preliminary, and will analyze its consistency with Federal Regulations for research involving children.

9:15 AM - 10:15 AM, Grand C

Paper Session: Re-visiting Abortion and Personhood Post-Dobbs

Philosophy

Abortion, Fetuses, and Imminent Personhood

Clinical and legal confusions surrounding maternal-fetal conflict in emergency medicine

Defining 'Abortion': A Need for Clarity

Joel Cox

Julia Kolak

Nicholas Colgrove

9:15 AM - 10:15 AM, Midway 6

Transformative experience, neurotechnology, and disability

Ally Peabody Smith, Lilyana Levy, Joseph Stramondo

Philosophy

Since the release of *Transformative Experience* (2014), philosophers, disability scholars, and bioethicists have explored the relevance of L.A. Paul's theory for the ways in which medical interventions bring about transformative experiences. According to Paul, there are two ways experiences can be transformative for a person: 1) epistemically transformative experiences, which give new knowledge that cannot be gained except through the experience, and 2) personally transformative experiences that alter a person's core preferences and sense of self. This panel centers the question of transformative experience on emerging neurotechnologies that target disabilities. If adopting a neural device can be transformative to a disabled person's knowledge-base or sense of self, what does that entail for how we conceptualize humanity? Panelist 1 will explain Paul's theory and discuss how cultural norms mandate that emerging medical technology transform the identity of disabled people through cure, without adequately considering whether that is a desirable goal. Panelist 2 will compare pharmaceutical interventions and neurotechnologies targeting psychological disabilities, arguing both possess transformative qualities that alter core human attributes of mind. Panelist 3 considers participant narratives from an early feasibility study for a novel visual prosthetic device, illustrating the complicated relationship between new sensory information and the ways in which using the device altered participants' senses of self. Panelist 4 will problematize the standard motivations for participant engagement in early neurotechnology studies that intervene on disabilities, which often rely on the underlying logic that using such devices are transformative in either or both of Paul's two ways.

9:15 AM - 10:15 AM, Missouri Pacific

Paper Session: Unique Perspectives on Education

Education/Interprofessionalism

Developing and Implementing STEM-Related Bioethics Curricula for High School Education

Lisa Kearns

Human Enhancement and Challenges for Opportunity Maintenance

Nicholas G. Evans

Medical Ethics and the Future of Dissection: A Scholarly Review

Amy Wang

10:45 AM - 11:45 AM, Grand C

Paper Session: Addressing Race as a Category in Medicine

Diversity, Disparity, and Inclusion

Eugenic Consequences: Evaluating Black Hardiness' Influence on the Black Patient

Kirk A. Johnson

Questioning the Use of Ancestry Labels in Clinical Genomics

Emily Peugh

Self-reported Race as a Criterion of Anti-Thymocyte Globulin induction

Julia Skibniewska

10:45 AM - 11:45 AM, Regency B

Are "Slow Codes" Ever Ethically Justified?

Abram Brummett, Gina Piscitello, Jason A. Wasserman, Parker Crutchfield

Clinical Ethics

Sometimes families will request, even demand, CPR that the treating team believes will be futile or medically inappropriate and no amount of careful discussion dissuades them. One – highly controversial – approach to such situations is the so-called "slow code," an insincere, fake, or merely performative attempt at resuscitation. In this panel, made up of three clinical ethicists and a palliative medicine physician, the prevalence and ethical viability of slow codes will be discussed. It will be argued that while slow codes clearly violate a range of ethical principles, not least of which being honesty, they may nonetheless occasionally be the least bad among available choices. The role of the ethicist in these decisions will also be discussed: Should they ever directly support such deception? Always actively oppose? Speaker one will discuss findings from an empirical study on the prevalence of slow codes in current medical practice. Speaker two will argue that while slow codes may be unethical in a vacuum, in the context of judicial and legislative overreach into medicine and medical expertise, they may represent an ethically permissible form of civil disobedience. Speaker three will argue that the

physician's decision to perform a slow code is analogous to common experiments in moral psychology, and that if the results of these experiments are valid, then the slow code is often morally permissible. Speaker four will defend the practice of offering slow codes to patients who are experiencing pressure from family to remain Full CPR.

10:45 AM - 11:45 AM

Flash Session: Artificial Intelligence

Education/Interprofessionalism

- Authentic Unintelligence in the Age of Artificial Intelligence: What if none of this matters?** Jacob Dahlke
- Ethics in AI Judgment: Bridging Human Insight and GPT's Prowess in Ethics Consultation Training and Assessment** Daniel Jenkins
- Human biases in artificial intelligence: A call for higher ethical standards in the approval process of AI/ML enabled medical devices for use diagnostic radiology** Madeline Behee
- Leveraging Artificial Intelligence for Ethical Exploration: An Approach to Enhancing Student Debate Skills** Rachel L. Budavich
- Redefining Humanity: The Ethical Imperative of Brain-Computer Interface Technology** Jiwoo Hwang
- Trust in Medical AI: Challenging the "Black Box" Problem** Arturo F. Balaguer Townsend
- Using Artificial Intelligence to Challenge Ethics of Frozen Embryos Among Undergraduates** Rachel L. Budavich

10:45 AM - 11:45 AM, Grand B

Calculating Survival: The Impact of Mortality Predictors on Medical Decision-Making Rita Dexter, Joanna Smolenski
Research Ethics and Social Sciences Meghan E. Hurley, Jennifer Blumenthal-Barby

This panel features results from a 5-year federally (AHRQ) funded engaged bioethics research project examining the impact of an algorithm-based personalized risk calculator for survival prediction in advanced heart failure patients considering left ventricular assist device (LVAD) therapy. Speakers will report findings related to patient perspectives and reactions to the personalized risk information in high stakes medical decision-making, offering a window into the practical application of algorithm-based survival and mortality predictor tools in healthcare settings. In addition, we will discuss ethical and normative considerations related to patient understanding and its impact on informed consent, as well as the implications for the right to notice and explanation of artificial intelligence (AI) in health given the rise of algorithm-based predictor tools in the healthcare space. Our interdisciplinary team combines the perspectives of various fields including bioethics, philosophy, and medical anthropology, offering us a unique approach to convey practical insights gleaned from our experience and research on the implementation of one such tool.

10:45 AM - 11:45 AM, Grand A

Caring for a patient or violating a corpse? The new brain death guidelines and unsettled questions about personhood and power Sabrina Derrington, Teneille R. Brown, Jennifer Walter, Eran Klein
Law, Public Health Policy, Organizational Ethics

The recent multi-organization consensus guidelines for Brain Death/Death by Neurologic Criteria (BD/DNC) should help reduce inaccuracy and improve consistency of clinical testing for BD/DNC, but may inadvertently worsen conflict between healthcare teams and families. At the heart of many such conflicts is a disagreement over personhood – is this person still “here” and what is owed them? The guidelines assert clinician authority over this existential question by declaring determination of brain death a “medical responsibility” and advising that “clinicians do not need to obtain consent” for testing, seeming to make irrelevant the many questions raised by incongruent ancillary tests, persistent neuroendocrine function, and variable physiologic stability and bodily integrity among patients who meet clinical criteria for BD/DNC. For the small but growing minority of families who refuse BD/DNC testing or diagnosis, when healthcare teams respond from a place of authority and unilateral decision-making it engenders or worsens distrust and can exacerbate conflict. Inability to consider or accommodate different conceptions of death puts clinicians at risk of significant moral distress when caring for patients they believe no longer are protected by person-status despite the family's perception that their loved one still deserves treatment consistent with personhood. In this panel, we will explore ethical and legal concerns raised by the new guidelines, examining what is gained and what is lost by asserting authority, ignoring ambiguity, and excluding plurality. We will offer guidance for healthcare teams and clinical ethicists and propose future directions for policy makers and legal scholars.

10:45 AM - 11:45 AM, Midway 9

Paper Session: Clinical Ethics: Appropriateness of Treatment

Clinical Ethics

An Ethic of CPR as Surgical Procedure

Kyle Karches

Clinician Experience of LVAD Deactivation

Arielle Fried

ECMO, Futility, Conscience, and 'Inappropriate Treatment': Grounding and Justifying a Policy on 'Futile' Treatment

Garson Leder

10:45 AM - 11:45 AM, Midway 3-4

Paper Session: Clinical Ethics: Unrepresented Patients

Clinical Ethics

Hospice Admission and Decision-Making for Unrepresented Patients

Timothy W. Kirk

Restoring humanity, if but for a moment: Exploring how one bioethics service works to represent the unrepresented at end of life.

Adira Hulkower

The Relevance of Ill-Being to Critically Ill Patients-Without-Proxies

Karel-Bart Celie

10:45 AM - 11:45 AM, Grand D-F

Council On Program Accreditation for Clinical Ethicist Training (COPACET): Developing Accreditation Standards for Clinical Ethics Fellowship Programs

Clinical Ethics

Ellen Fox, Cristie Horsburgh,

Renee McLeod-Sordjan, Ruchika Mishra

Development of an accreditation process for clinical ethicist training programs is now underway. A new committee called the Council On Program Accreditation for Clinical Ethicist Training (COPACET) has been created under the guidelines of the Commission on Accreditation of Allied Health Education Programs (CAAHEP). COPACET's mission is to promote the highest levels of professional competence of clinical ethicists through: • development and promotion of professional training standards; • encouragement of excellence in training program development; and • review and evaluation of clinical ethicist training programs. COPACET will soon begin drafting accreditation standards for clinical ethics fellowship programs and seeks input from various communities of interest including program directors/staff, current/former fellows, and practicing clinical ethicists. This workshop will provide a forum for all stakeholders with an interest in the future of clinical ethics training to directly inform COPACET's work. Four clinical ethicists from multiple disciplines and institutions will lead the session. After a short didactic presentation on COPACET's history, governance structure, progress to date, and future plans, participants will have an opportunity to review and discuss CAAHEP's standards and guidelines requirements and weigh in on specific questions that COPACET will need to answer. For example, what level of proficiency to perform ethics consultation should be required of graduates (e.g., ability to perform ethics consultation as a lead or solo consultant?) Should standards include specific admission criteria such as educational background, clinical experience, or personal traits? The session will emphasize active learning through interactive discussion, targeted audience feedback, and group problem solving.

10:45 AM - 11:45 AM, Midway 5

Paper Session: ELSI

Law, Public Health Policy, Organizational Ethics

Assessing the Impact of Global Human Genome Editing Governance Reports: The Persistence of Value-Based Norms

John M. Conley

Humanity in the Era of Space Exploration: Challenging What It Means to Be Human

Roel Feys

Technology Transfer and Bioethics of the Public Good in Genomic Biomedicine

Andy Murray

10:45 AM - 11:45 AM, Midway 10

Paper Session: Genetic Advances and Research

Research Ethics and Social Sciences

Genetic Revolutions & Moral Crossroads: Navigating the Moral Landscape of CRISPR's Debut FDA Approval for Sickle Cell Disease

Peyton Swanson

Honoring The Generalizables

Rafael Escandon

Narrating a journey of preparation: Longitudinal interviews with parents who received prenatal and postnatal genetic information

Sabina Rubeck

10:45 AM - 11:45 AM, Regency A

Intellectual and Developmental Disabilities and Inclusion: Ethics and Community Based Participatory Research

Diversity, Disparity, and Inclusion

Holly K. Tabor, Kara Ayers, Alex Szawranskyj, Justin Steinberg

The first panelist and moderator, a bioethicist, will describe a community-based participatory research (CBPR) project centering the voices of people with IDD. They will describe benefits and challenges to an inclusive CBPR approach to IDD, lessons learned, and future opportunities for ethicists to collaborate with IDD stakeholders and clinical researchers to promote an ethics of inclusion and translation. The second panelist, a graduate student, will describe a citizen-science project that engaged people with IDD, including those with more significant communication challenges. Teams of people with and without IDD used an app to collaboratively identify barriers in health care spaces to receiving care and suggested possible strategies to address them. This is an example of an ethics-based project focusing on tangible policy outcomes. The third panelist, a leader in a national disability advocacy organization, will describe a multi-disciplinary working group on cancer and the IDD community, the ethical implications, including around intersectionality with other underserved identities, and recommendations. This work is a model for ethically grounded engagement around IDD equity and justice across diagnoses and specialties. The fourth panelist, an IDD researcher, will describe implementation of an innovative web-based tool for research ethics training that is accessible to people with IDD. Such an approach will be instrumental to involving people with IDD in IRB reviewed projects as researchers and collaborators. The audience will engage in a discussion about innovative ways to include people with IDD in ethics research and clinical research.

10:45 AM - 11:45 AM, Midway 6

Paper Session: Philosophy: Interrogating the Concept of Health

Philosophy

**Exploring the Use of 'Functional' in Functional Neurological and Gastrointestinal Disorders
Health as the functional underpinnings of agency**

Dany Lamothe
Ian D. Dunkle

10:45 AM - 11:45 AM, Midway 11

Paper Session: Practices for Engaging Vulnerable and Underserved Populations'

Diversity, Disparity, and Inclusion

**Band-Aids and Bridges: Ethics, Risk, and Serving our Most Vulnerable
Who Should be Responsible for Finding a Surrogate for Incarcerated Patients?**

Meredith G. James
Xiang Yu

10:45 AM - 11:45 AM, Midway 1-2

Paper Session: Teaching Ethics in Graduate Medical Education

Education/Interprofessionalism

**An Ethics Case Conference for Teaching Residents an Analytical Approach to Clinical Ethics
Clinical Ethics: What, When, and How do we teach it to resident physicians?
No Time for Ethics? Implementing an Interdisciplinary Clinical Ethics Rotation for Graduate Medical Trainees**
Osipov

Holland Kaplan
Kristie Espinal

10:45 AM - 11:45 AM, Midway 7-8

Paper Session: Trust and Truth-Telling

Clinical Ethics

**Public Engagement in Medical Policymaking: Performative or Transformative?
Trust in Clinical Ethics Consultants and Clinical Ethics Consultation
Truth-telling and Devastating Disclosures: Navigating the Tension between Ethical and Cultural Obligations in Saudi Arabia.**

Casey Hall
Lauren Bunch
Ruaim A. Muaygil

10:45 AM - 11:45 AM, Jeffersonian Knickerbocker

Paper Session: Trust in AI Research

Research Ethics and Social Sciences

**Patient and Physician Perspectives on AI Transparency
Trusting AI that Echoes Back: A case against personalizing AI systems in healthcare
Voices of the Past: Voice AI's Role in Deciphering Medical Histories from Departed Kin**

Austin M. Stroud
Kristin Kostick-Quenet
Jean-Christophe B elisle-Pipon

10:45 AM - 11:45 AM, New York/Illinois Central

What can I do to help? In search of best practices for being involved with capacity assessments

Clinical Ethics

Adam Omelianchuk, Ryan J. Dougherty, Kate Luenprakansit

Healthcare ethics consultants (HECs) must help clarify relevant ethical concepts in order to resolve questions involving value uncertainty in the delivery of healthcare. One concept is decision-making capacity, the possession of which is to be determined by a responsible clinician on the basis of a clinical assessment. Yet consultations requests from such clinicians raise a question: to what extent should HECs be involved with making capacity assessments? On the one hand, it is reasonable to suppose that because HECs are not necessarily licensed clinicians, they are only to perform an advisory role in clarifying capacity as a clinical concept and recommend escalation to a more experienced clinician or service if the assessment is complex. On the other, because it is often central to their analysis in many cases, HECs tend to have expertise on the content of the four elements, how they relate to decision-specific circumstances, and what level of capacity is needed for specific treatments, which makes their perspectives valuable to clinicians. In this panel, three HECs from diverse disciplinary backgrounds will evaluate the unique contributions HECs may offer in capacity assessments with consideration to our professional role, skills, and code of ethics. Panelists will draw from our clinical experiences to construct case vignettes that highlight the benefits and limitations to their approaches. Overall, our aim is to generate discussion about the extent to which clinical ethicists should be involved in capacity assessments and what some best practices might be for documenting our involvement in a patient's record.

12:00 PM - 1:15 PM, Grand D-F

Plenary: Neural Net Aesthetics

Eileen Isagon Skyers

Plenary

In this presentation, media art curator Eileen Isagon Skyers delves into the innovative work of artists such as Amelia Winger Bearskin, Stephanie Dinkins, Ian Cheng, and Moreshin Allayari, who are using AI in novel ways to challenge and expand the boundaries of creativity. AI datasets are not neutral repositories, rather, they are coded with the biases of those who create them, thus becoming vehicles for certain narratives over others. Artists working with AI today are not only critics or observers who bear witness to this transformational moment in history—they are also active participants in world building and figuring—in reshaping or reimagining alternative futures. We hope that audience members will leave this presentation with a deeper understanding of the aesthetic and ethical implications for both curating and creating AI art.

1:15 PM - 2:45 PM, Midway West Foyer

Opening Luncheon

Networking

This luncheon is generously supported by the Institute for Bioethics and Health Humanities at UTMB. Join us in the Networking Hall for our third-annual Opening Luncheon! Grab a boxed lunch, enjoy the music, or play a few games with your fellow members!

3:00 PM - 4:00 PM, Grand C

A Primer on Epistemic Injustice and Patients with Non-English Language Preference

Diversity, Disparity, and Inclusion

Samantha A. Chipman, Karen Meagher, Amelia K. Barwise, Ryan M. Felder

An epistemic injustice is a wrong to a person in their capacity as a giver, receiver, and creator of knowledge. In healthcare, epistemic injustices can occur when doctor-patient interactions are complicated by language barriers between the parties. In this panel, we will describe a case study demonstrating ways in which epistemic injustice manifests for Hispanic and Spanish-speaking patients in settings characterized by English language dominance. The analysis provided here differentiates epistemic injustice in terms of hermeneutical injustice, testimonial injustice including, testimonial smothering, epistemic oppression, and epistemic colonialism. Building from other helpful typologies, this discussion is tailored to provide a resource for bioethicists, clinicians, and health policy makers, encouraging discussion about moving towards epistemic equity in U.S. healthcare. We focus on using epistemic injustice to name oppression and opportunities for resistance in the current healthcare environment. An overview of how patients can be treated unfairly as knowers is also situated with a broader national discourse about other forms of injustice and imperative to redress U.S. health and health care disparities. Attendees will engage with panelists about how addressing epistemic injustice in health care is a form of recognizing the full humanity of those with non-English language preferences.

3:00 PM - 4:00 PM, Midway 5

'I Know What I Feel:' Caring for Patients with Sickle Cell Disease in a Post-Cure World

Diversity, Disparity, and Inclusion

Shameka Thomas, Consuela Albright, Kristin Walters, Jada Wiggleton-Little

We propose a panel that uses storytelling as part of a Black Bioethics Framework to give voice to the lived experience of patients with Sickle Cell Disease (SCD), highlighting how their racial identity and medical trauma correlate to poorer health outcomes post-cure. For more than a century since SCD was first identified, advances in gene-editing therapy and bone marrow transplants are finally providing curative options. Even if cured of the original disorder, SCD patients seeking care for chronic pain due to persisting physical damage from the disease may experience being wrongfully dismissed, accused of drug seeking, or feel disempowered. This interdisciplinary panel session will feature reflections from a SCD patient, nurses, and a medical sociologist as well as recommendations of ways to address interpersonal and structural barriers to adequate pain management. The panel will begin with a brief discussion of trust and epistemic oppression by a philosopher and will conclude with a moderated questions and answer section. The purpose of this panel is to center the narratives of SCD patients in scholarship and clinical practice, so that our pursuit for equitable care can be more responsive to the various injustices they experience.

3:00 PM - 4:00 PM, Regency B

Paper Session: AI and Power Structure

Law, Public Health Policy, Organizational Ethics

An Ethical Framework for the Implementation of Elderly-Care AI Assistants

William J. Choi

Modeling Regulation, Regulating Models: How Stakeholders Conceptualize AI Governance in Healthcare

Zachary Griffen

Overcoming Limitations: Examining a Humanistic Approach to AI in Healthcare

Michael McCarthy

3:00 PM - 4:00 PM, Midway 1-2

Are the cases we think to be futile actually so?

Stowe L. Teti, Candyce Greene

Clinical Ethics

Much has been written about the concept of non-beneficial treatment (sometimes referred to as medical futility) and the literature is replete with studies that identify this issue as among the most common reasons for ethics consultation. In recognition of the limits of medical prognostication, this sentiment of concerns has increasingly been qualified as potentially inappropriate treatment. However, little attention has been paid to exploring that epistemic question: are the cases we think to be futile actually so? And if not, what can be learned from studying the outcomes of these patients? Epistemic and ethical questions are often intertwined; as the saying goes, "good facts make good ethics." This panel will present the current results of an ongoing QA/QI project to determine what outcomes occur in cases categorized as medically futile, or involving potentially non-beneficial treatment. Starting with a dataset of 2,418 consults conducted over the past 40 months, this panel will examine the outcomes of all 235 consults in which concerns about medical futility or potentially non-beneficial treatment were raised. By way of preview, overall mortality for the cohort was 59.1%, and while a large percentage discharged on hospice, a significant portion discharged home. There were a total of 83 permutations among cases using ACECS coding with significant differences in mortality. The panel will involve the audience in dialogue about how these data might inform ethics consultation recommendations.

3:00 PM - 4:00 PM

Building Bridges: A Readers' Theater Workshop of Imelda for Medical-Dental Trainees

Education/Interprofessionalism

Margie H. Shaw, Matthew K. Wynia, Nathan Carlin

Lisa Simon notes that, while "it is obvious that our mouths are part of our bodies,"[1] medical and dental education remain mostly distinct, as are medical and dental practices. This divide has been built through a complex amalgam of historical influences that include racism, classism, environmental injustice, and workforce inequities. There is enormous potential value in understanding these forces and moving toward the integration of oral health and general medical care. While current education and practice structures contribute to the "medical-dental divide," this session will demonstrate an educational initiative and instructional tools useful in bridging this historical dichotomy. Imelda, by Richard Selzer, addresses student and clinician experiences at the intersection of dentistry and medicine, in the context of a story that raises universal questions: What does it mean to care for a human being as a patient? What does it mean to be a patient? Does it matter what part of the human patient you understand best? Can humans be cared for in parts? How do human doctors care for other human doctors?

3:00 PM - 4:00 PM, Grand A

Paper Session: Centering the Perspectives of Marginalized Patient Groups

Diversity, Disparity, and Inclusion

A Unique Time in Neurology’s History: Recognizing Intellectual and Developmental Disorders as Health Disparities

Diana Mendoza-Cervantes

Contextualizing expressions of dissent: highlighting the importance of trauma-informed restraints policy development

Alice E. Kelley

LGBTQ+ Parents' Experiences Accessing Health Care for their Children with Developmental Disabilities

Emilee I. Coulter-Thompson

3:00 PM - 4:00 PM, Midway 9

Paper Session: Clinical Ethics: Bearing the Burden

Clinical Ethics

“Are you just a human being like the rest of us?” Leveraging the concept of human finitude to mitigate clinician moral distress and promote moral resilience.

M Jeanne Wirpsa

Bearing the Burden of Clinical Ethics Consultation: Requests, Roles, and Responses

Anna D. Goff

Regretting Doing the Right Thing: A Defense of Regret in Clinical Ethics Consultation

Nathan Stout

3:00 PM - 4:00 PM

Disease eradication: An ethical analysis of goal setting and resetting in global public health

Law, Public Health Policy, Organizational Ethics

Nathaniel Mamo, Kyle Ferguson, Thomas D. McEvoy Zafirooulos

In 1980, the World Health Organization (WHO) declared that smallpox was “eradicated.” This meant there were zero cases in the world of a disease that had killed and disabled millions. Smallpox was the first human disease to be eradicated. WHO has tried to repeat this success with polio, a disease that paralyzed children and terrified the world. Originally it planned on polio eradication by 2000, but new deadlines are set and missed as new cases emerge every year. As billions have been spent on an underperforming eradication program, questions have accumulated with costs. Disease eradication is costly, and the balance against its goods are not obvious. This panel assembles three experts to discuss the ethics of disease eradication. The first panelist will use the example of the polio eradication campaign to survey the ethics of disease eradication, moving on to discuss ethical issues specific to that campaign, with a focus on those emerging from vaccination with the oral polio vaccine (OPV). The second panelist will argue that, contrary to the egalitarian’s position that noneradication is unjust since it tolerates inequality, abandoning eradication can be justified on sufficientarian or prioritarian grounds and when we duly consider feasibility and the value of allocating resources elsewhere in global health and development. Finally, the third panelist will discuss the health economics of disease eradication, analyzing the future long-term economic benefits of disease eradication against its present costs, and how this informs the ethical decision procedure to eradicate.

3:00 PM - 4:00 PM, Midway 10

Paper Session: Gender-affirming Care

Diversity, Disparity, and Inclusion

So that One’s Soul be Tranquil: A Jewish Definition of Health and Gender-Affirming Care

Ranana L. Dine

Too Much Testosterone: Why Differences in Bodily Testosterone Levels are Insufficient to Fairly Exclude Trans Women and Girl Athletes from Competition with their Gender

Mallory R. Wietrzykowski

3:00 PM - 4:00 PM, Midway 6

Paper Session: Health Humanities

Health Humanities

Addressing ‘Big’ Questions About the Human Being: Empirical and Philosophical Findings from an Islam & Bioscience

Educational Intervention for Premedical Students

Aasim I. Padela

The Ethics of Health-Related Philanthroainment

Jeremy Snyder

3:00 PM - 4:00 PM, Grand D-F

How Psychedelics Challenge Core Assumptions about Medicine, Ethics, and Humanity

Health Humanities

Amy L. McGuire, Logan Neitzke-Spruill, Dominic Sisti, Lori Bruce

FDA is expected to make a decision about approval of the first psychedelic medicine in the US by August 2024. Psychedelics are a subclass of hallucinogenic drugs whose primary effect is to trigger non-ordinary states of consciousness. As such, they have the potential to disrupt long-held notions of what it means to be human and challenge us to think critically about transformation, the nature of healing, and mental healthcare. This panel brings together diverse perspectives from philosophy, sociology, bioethics, and law. The first panelist will discuss the current state of psychedelic use (both regulated and unregulated) in the US, examine the appropriate role of healthcare gatekeeping, and explore implications for core ethical concepts like respect for persons. The second panelist will explore the principle of agency and its importance to psychedelic facilitated self-change through interviews with psychedelic retreat-goers and will argue that ethically administering psychedelics requires a commitment to maximizing participants’ capacities to enact transformative agency. The third panelist will describe how the transdiagnostic effects of psychedelics may challenge our current system of psychiatric nosology—pushing us to reconsider alternatives to the current categorical framework of the DSM. Such a shift would have downstream effects on diagnosis, access, personal identity, and stigma related to psychiatric illness. The fourth panelist will examine understated concerns about psychedelics, argue that funders have a responsibility to care for those who suffer substantial harms, and discuss mechanisms for addressing harm, including the benefits and drawbacks of an injury compensation program.

3:00 PM - 4:00 PM, Midway 11

Paper Session: Learning Health Systems

Research Ethics and Social Sciences

Concerns and Priorities of Neurotechnology Research Participants Related to Data Sharing Mary A. Majumder

From the benches: An empirical analysis of the challenges of and opportunities for Research Ethics Consult Services (RECS) Skye Miner

Lessons for a Learning Health System: Effectively Communicating to Patients about Research with their Health Information and Specimens Kayte Spector-Bagdady

3:00 PM - 4:00 PM, Midway 3-4

Mapping Genetic Frontiers: Seeking Translational Justice in Prenatal Gene Editing

Research Ethics and Social Sciences

Megan Allyse, Marsha Michie, Rosario Isasi

Methods for genetic editing in humans show promise for addressing previously intractable genetic conditions, but considerable gaps remain in governance structures for human gene editing and its translation to clinical practice. Calls for novel governance structures for prenatal human gene editing have pushed towards values-based approaches, moving beyond traditional technocratic considerations of safety and efficacy to take into account collective normative deliberation about the ethics of prenatal intervention. This panel will discuss the concept of “translational justice” and its application to prenatal gene editing, with particular attention to two important voices historically sidelined in conversations around the future of gene editing: patients and families that might be benefited or harmed by the translation of prenatal gene editing and the scientists and clinicians who would be on the front lines of its potential clinical translation. First, a political sociologist will describe the concept of translational justice, offering a framework for empirical groundwork to guide technologies towards more equitable use in healthcare. Second, a legal/policy expert will discuss regulatory and policy frameworks relevant to the potential clinical use of prenatal gene editing and preliminary data on how scientists and clinicians conceptualize their role in this process. Third, a medical anthropologist will share data from individuals impacted by genetic conditions on their views of gene editing generally and for specific conditions. Fourth, a philosopher will moderate the panel, engaging presenters and attendees around deliberative democracy and other approaches that bioethicists can employ to integrate scientific, policy, and stakeholder perspectives into a normative framework.

3:00 PM - 4:00 PM, Midway 7-8

Paper Session: Patient Advocacy and Public Involvement

Law, Public Health Policy, Organizational Ethics

Moral Uncertainty in Community Health: Results from Qualitative Interviews with Community Health Center Clinical Leadership Carolyn Neuhaus

Patient and Public Involvement in the Medicare Drug Price Negotiation Program Leah Z. Rand

3:00 PM - 4:00 PM, Jeffersonian Knickerbocker

Paper Session: Philosophy: Empathy and Care in a Technological Age

Philosophy

Empathy as feeling: reflections on the meaning of clinical empathy in the age of artificial intelligence Ryan Lam
Empathy in Medicine: Should Healthcare Providers Empathize with their Patients? Nir Ben-Moshe
Humanity Imagined: A Bioethical Reflection on Edith Stein's Phenomenology of Empathy Tom Doyle

3:00 PM - 4:00 PM, Grand B

Paper Session: Reproduction and the Law

Law, Public Health Policy, Organizational Ethics

Born-Alive Does Not Mean Viable: Exploring the Ethical Nexus of Anti-Abortion Laws and Neonatal Care Stephanie Kukora
Rethinking the Legal and Ethical Relationship Between IVF and Abortion Katie Watson
Where Miscarriage is Manslaughter: Implications of Fetal Personhood Movements on the Legal Status of Pregnant People in Alabama Post-Dobbs Rosemary Laine

3:00 PM - 4:00 PM, Regency A

The Hastings Center's Bioethics Founders' Award

4:30 PM - 5:30 PM, New York/Illinois Central

Paper Session: AI and Ethics Education

Research Ethics and Social Sciences

Hybrid Horizons: Defining the Boundaries of Machine and Human Intelligence in AI-Assisted Bioethics Analysis Kristin Kostick-Quenet
Large Language Models take on the Situational Judgment Test: Evaluating Dilemma-Based Scenarios Jamie Chen
The risks of using ChatGPT as a moral vending machine in bioethics education: a case series William J. Choi

4:30 PM - 5:30 PM, Jeffersonian Knickerbocker

Paper Session: Alternative Perspectives in Bioethics

Research Ethics and Social Sciences

Promoting Disability Justice through better Capacity Assessment: A Tool to Evaluate Capacity to Designate a Surrogate in Patients who Otherwise Lack Decisional Capacity Devan Stahl
The Ethics of Health-Related Research with U.S. Veterans Jake Earl
What does it mean to be Human? African Religious Perspective to Personhood and the Bioethics of "Being-ness" Blessing T. Emmanuel

4:30 PM - 5:30 PM, Grand A

Paper Session: Clinical Ethics: Decision Making Capacity

Clinical Ethics

Beyond Consent: An Ethical Framework for Medical Intervention Over Objection in Incapacitated Patients Holland Kaplan
Decisional Capacity Assessments and Autonomy in Psychiatrically Vulnerable Populations Julia Kolak
Intrauterine Fetal Demise? Pierce Randall

4:30 PM - 5:30 PM, Midway 10

Paper Session: Clinical Trial Design

Research Ethics and Social Sciences

Ethics and equipoise in a phase I COVID-19 vaccine trial Liza Dawson
Moral Justification for Continuing or Stopping Clinical Trials During Wartime Vladyslava Kachkovska
Promoting Equity without Sacrificing Pragmatism?: Tough Choices for Pragmatic Clinical Trials Kayla R. Mehl

4:30 PM - 5:30 PM, Midway 3-4

Complex Ethical Issues with Organ Procurement and Donation Following Recent Regulatory Changes

Clinical Ethics

Robert Fulbright, Ruchika Mishra, Christopher Wolff, Andy Kondrat

Changes in regulatory requirements regarding organ procurement and donation have increased Organ Procurement Organizations' (OPO) incentives to maintain market share, win government contracts, and grow the number of organs procured and transplanted. These changes are felt on hospital floors as long-standing policies and standard procedures are altered to meet the current environment, yet at the same time serve to highlight the ethical challenges that predate the regulatory changes. This multidisciplinary panel with an ICU physician, clinical ethicists from different professional backgrounds, and an ethics administrator will discuss the changing landscape of organ procurement and donation in the United States, with an emphasis on best practices in the face of new challenges, and re-engaging awareness on the ethical issues that remain despite the regulatory changes. The panelists represent different health systems with multiple locations and varying patient populations. The first panelist will explore conflicts of interest between various stakeholders in the organ procurement process and the ethical challenges between OPOs, hospital policy, and clinician conscience. The second panelist will share a physician's perspective on best practices to avoid blurring the lines between the treating team and the OPOs. The third panelist will contrast varying laws governing organ procurement throughout the United States in the context of the original intent of the Uniform Anatomical Gift Act. The final panelist will discuss ethical considerations for organ donation in vulnerable populations, including patients who are unidentified and lack representation, highlighting the tensions between values and priorities held by OPOs, hospitals, and clinicians.

4:30 PM - 5:30 PM, Grand D-F

Core Competencies, 3rd Edition Listening Session (Option 1)

Alex Kon

Clinical Ethics

Join us at one of our three listening sessions to share your feedback on the current draft of our forthcoming Core Competencies for Healthcare Ethics Consultation, 3rd Edition text. The draft will be circulated through the ASBH website prior to the conference. Please come to the listening session having read the draft with feedback prepared. Our moderators are available to receive questions and feedback for use in the drafting process but may not be able to respond to all inquiries during the session.

4:30 PM - 5:30 PM, Midway 9

Paper Session: Disability and Serious Illness

Clinical Ethics

Autonomy, Disability, and Cervical Cancer Screenings

Jennifer C. Tillman

The stars inside of us: a case study on the lack of neurological disability research in adult populations and its impact on clinical outcomes

Emily Pellegrini Olson

Why the Concept of "Critical Abilities" is Misguided: Lessons Learned from the Updated Serious Illness Conversation

Guide

Joel M. Reynolds

4:30 PM - 5:30 PM, Regency B

Flash Session: Diverse Identities

Diversity, Disparity, and Inclusion

Beyond Boundaries: Navigating MAiD in LGBTQI+ Oncology Patients - Ethical Considerations and Humanistic Perspectives

Kelly Haviland

Cyborg Healthcare in Chi Ta-wei's 'The Membranes': The Queer and Disabled Patient Perspective

Nora Y. Sun

Examining the Consent Process for Gender Affirming Care

Christina L. Halstead

Made With Love & Science: Queer Reproductive and Family Ethics

Amanda Roth

Re-Claiming Autonomy: Identity, Narrative and Chronic Illness

Marion Russell

Shared Identity & Its Role in Moral Injury

Briana E. Lopez-Patino

Studying Clinicians' Response to State Laws and Institutional Policies That Restrict Pediatric Gender-Affirming Care

Laura Stamm

The Influence of the Universal Patient: Performativity in Healthcare

Briana E. Lopez-Patino

4:30 PM - 5:30 PM, Regency C

Engage Communities, but How? A Guide to Card-Sort Methods for Directing ELSI Research

Research Ethics and Social Sciences

Sara Watson, Jean Cadigan, Shawneequa Callier, Karen Meagher

Card sorting is an established but underutilized method to explore attitudes toward conceptual categories. It provides an interactive and outcome-driven technique for community engagement (CE), which can help to strengthen research

design. In this interactive workshop, we will demonstrate the card-sorting method we used to engage 3 biobank-affiliated Community Advisory Boards (CABs) in the design of our ELSI study on sociogenomic polygenic scores (PGS). These scores are developed using large datasets from biobanks to examine genetic heritability of social traits, such as risk tolerance and educational attainment. PGS for social traits are controversial. While proponents of PGS see the research as increasing our understanding of gene-environment interactions, some worry that findings could increase stigma and social disparities. These controversies reflect both attempts to move beyond, and to reinvigorate, the nature-nurture debates that contend with core questions about what it means to be human. We used card sorting to elicit CAB members' attitudes toward PGS for a wide variety of social traits and to prioritize which traits we should focus on for our ELSI study. This workshop will include a hands-on presentation of card-sort methods by providing attendees with a stack of items to group into categories. We will demonstrate the innovation and creativity inherent in card sorting activities and share tips on using the method to elicit the values and priorities of community members, research participants, or patients. In small groups, attendees will practice adapting this method for their own projects and participatory research designs.

4:30 PM - 5:30 PM, Midway 5

Equitable chances: a novel weighted lottery approach to crisis standards of care

Law, Public Health Policy, Organizational Ethics

William F. Parker, Harald Schmidt, Patrick G. Lyons, Dana Haragunani

Disasters that produce scarcity tend to fall hardest on disadvantaged communities, especially racial and ethnic minority groups. How exactly Crisis Standards of Care (CSS) protocols for triage of life-support should take this context into account remains bioethically controversial. Panelist 1, a pulmonary critical care physician and clinical ethicist, will overview the current state of CSC triage protocols in the US. They will describe how most state policies would exacerbate health inequities by relying on the racially biased Sequential Organ Failure Score (SOFA) for triage. Panelist 2, a bioethicist and health policy scholar, will introduce equitable chances, a novel weighted lottery approach that uses place-based disadvantage indices to mitigate health inequities. They will describe how the equitable chances protocol uses lottery weights carefully designed to be in proportion to the burden of the current crisis and develop a bioethical argument for this approach. Panelist 3, a pulmonary and critical care physician and data scientist, will report the results of an ICU Crisis simulation model, comparing equitable chances and SOFA-based triage protocols in a regional cohort of critically ill adults. The results will demonstrate that the equitable chances protocol saves slightly more lives than SOFA category triage and allocates more life support to disadvantaged neighborhoods. Panelist 4, a former state policymaker with experience developing CSCs, will discuss strategies for building consensus and implementing an equitable triage protocol. They will also respond to potential objections to equitable chances and consider the public reaction to the proposal.

4:30 PM - 5:30 PM, Regency A

Generative Artificial Intelligence and Scholarly Articles: A Conversation with Journal Editors

Education/Interprofessionalism

David Magnus, Mohammad Hosseini, Gregory E. Kaebnick. Laura Haupt

ChatGPT and other generative artificial intelligence (GenAI) technologies have the potential to significantly change how scholarly writing is produced, reviewed, and edited. What does it mean to be an author? What entails responsible use of these constantly evolving technologies by authors, peer reviewers, and editors? A recently published statement by several editors of bioethics and humanities journals offers a set of recommendations on this topic. Among the recommendations are that large language models (LLMs) not be listed as authors, that authors be transparent about their uses of LLMs, and that editors and peer reviewers not rely on LLMs alone to assess submitted manuscripts. During this gathering, a panel of journal editors will briefly discuss questions, values, and goals that guide the recommendations. Given the many unknowns about how the technologies will be used for scholarly publications, ongoing collaborative development of professional norms is necessary. The ASBH audience will be part of this collaborative effort. Questions for discussion will include the following: How do audience members anticipate using GenAI? In the writing and reviewing of manuscripts, how might reliance on GenAI alter scholarly communities or influence the formation of interprofessional relationships? What is the value of disclosing the use of GenAI in writing a manuscript? What responsibilities do ethicists have to educate themselves about these technologies and to limit their use in the review of manuscripts? How might the use of GenAI by authors affect diversity or equity in journal publishing?

4:30 PM - 5:30 PM, Grand C

Intersectional approach to gender, Islam, and bioethics

Diversity, Disparity, and Inclusion

Saba Fatima, Lida Sarafrazarpatafeh, Shadi Heidarifar

Our panel explores the convergence of Islamic ethics, feminism, and bioethics from an intersectional lens. The first talk focuses on the embodied nature of decision-making processes as practitioners of faith, in hopes to contribute to the broader discourse on inclusive and religiously informed bioethical perspectives. The second one explores “all-or-nothing” approaches to Female Genital Cosmetic Surgery (FGCS) procedures in women’s healthcare – particularly Muslim women – i.e., those that overemphasize either women’s autonomy so as to defend total accessibility to the procedures, or the oppressive social context affecting women as to defend the total banning of the procedures. The panel ends with a talk on why we need to add religious minorities to diversify clinical trial participants. All three talks adopt an inclusive approach to bioethics so that our discourses surrounding Muslim women are more nuanced and ethical.

4:30 PM - 5:30 PM, Midway 6

Paper Session: Issues in Healthcare Work and Exploitation

Philosophy

A Virtue Theory of Organizational Bioethics

Molly Sinderbrand

Research Participants as Workers: Solutions to Medical Exploitation

Naomi Scheinerman

The Soaring Stakes of Strikes: Is Ethical Striking Possible in Healthcare?

Mark Malcom

4:30 PM - 5:30 PM, Midway 11

Paper Session: LGBTQ+ Healthcare

Diversity, Disparity, and Inclusion

Improving Inclusive Practices for LGBTQ+ Populations

Laura K. Guidry-Grimes

Law, Medicine, and Minors: The Medicalization of Sex and Gender

Abram Brummett

4:30 PM - 5:30 PM, Grand B

Objective Assessment and Disease Models of Chronic Pain: Ethical Considerations for Stigma

Diversity, Disparity, and Inclusion

Daniel Buchman, Daniel S. Goldberg, Anita Ho, Jada Wiggleton-Little

Chronic pain is an individual and subjective condition that is often refractory to objective assessment. Chronic pain is also highly stigmatized, causing people who live with chronic pain to be disbelieved, ignored, or undertreated, perpetuating health inequities. Advocates argue that chronic pain should be considered a disease, not just a symptom of another condition, to legitimize the experience of chronic pain and reduce stigma. Research on the neuroscience of chronic pain, tools such as Artificial Intelligence (AI), and the recent changes to the ICD-11 that classifies chronic primary pain as a disease in itself, are reinforcing a disease model. However, as the history of medicalization demonstrates, disease models can increase some aspects of stigma (e.g., fear) while reducing others (e.g., blame). This panel will explore the ethical implications of disease explanations of chronic pain on stigma from clinical and population-level ethics perspectives. The panel brings together four speakers with diverse content expertise in stigma studies, bioethics, public health ethics, philosophy, artificial intelligence, and the history of medicine. Panelists will discuss the issue of pain stigma and contestable notions of objectivity from population-level and historical perspectives, how predictive analytics that prioritizes quantification in diagnosis and prognosis neglects embodied knowledge that is necessary for ethically appropriate pain management, findings from an empirical bioethics study on attitudes toward brain disease models of chronic pain on stigma, and how the presumed existence of objective measures of chronic pain may intensify epistemic injustices for people in pain from marginalized communities.

4:30 PM - 5:30 PM, Midway 1-2

Paper Session: Philosophy: Topics in Gender

Philosophy

Access and Equity in Synthetic Gametes for Same Sex / Queer Couples

Timothy F. Murphy

The Ethics of Gender Dysphoria Treatment and the Meaning of Medicine: Examining a Clinician's Obligations Regarding Gender-affirming Care

Jade R. Samanta

The Problems with “Women” and “Men”: Gendered Language and Injustice in Public Health and Bioethics

Carina Fourie

4:30 PM - 5:30 PM

Paper Session: Reasoning and Fallacies

Philosophy

Concerning Our Measures of the True-Good: What is the Role of Consensus in Bioethics?

Joseph P. Swindeman

In Search of a Unifying Theory: A Critical Typology of Clinical Reasoning in Health Professions Education Justin Mutter
The Moralistic Fallacy Fallacy Lucas J. Matthews

5:45 PM - 6:45 PM

Affinity Group Meetings

Bioethics and Artificial Intelligence, Regency A

Philip Payne, Kristin Kostick-Quenet

Cancer Ethics, Grand B

Emily Hahn, Jamie Riches

ELSI, Frisco Burlington

Daphne O. Martschenko, Elise Li Zhang, Chenery Lowe,
Jonathan LoTempio, Aaron Goldenberg, Maya Sabatello

This session invites trainees and early career researchers focused on the ethical, legal, and social implications (ELSI) of emerging technologies such as genomics and artificial intelligence. Participants will share brief presentations of their cutting-edge research, offering insights into these rapidly evolving fields. Additionally, the Center for Excellence in ELSI Research will present an overview of ELSIhub resources, materials, and events. This session will provide networking opportunities among trainees, early career scholars, funders, and mentors to support future collaborations and professional development.

Islamic Bioethics, New York/Illinois Central

Basel Tarab

LGBTQ+ Bioethics, Regency C

Theodore Schall

Reproduction, Grand C

Shameka Thomas

Student Interest, Regency B

Ariadne Nichol

The Student Affinity Group session will provide space for students and trainees to meet one another and learn about the ASBH community and ways to get involved. The interactive session will start with introductions and then transition to a discussion highlighting different bioethics and medical humanities opportunities tailored to students and trainees. The session is meant to be an avenue for discovering upcoming opportunities, networking with peers from different academic programs, and voicing what students would like to see in terms of how ASBH can support their professional development. The discussion will be facilitated by the ASBH Student Director.

Undergraduate Teaching Group, Grand A

Suzie Ciruzzi, Emily Grime, Martin Leever,
Angela Wentz Faulconer, Jason T. Eberl

"Best Ideas for Teaching Undergraduate Bioethics" "They Killed Kenny: End of Life Issues in South Park" Maria Susana Ciruzzi, JD, MSc, PhD and Postdoc Clinical Ethicist, Bioethics Program St Jude Children's Research Hospital, Memphis, TN "Utilizing AI in Teaching Ethics to Undergraduate Students" Emily Grime, DPS, MSLBE, BS, HEC-C Polk State College, Lakeland, FL "Using Cases with Purpose" Martin G. Leever, PhD University of Detroit Mercy, Detroit, MI

Friday, September 20, 2024

7:00 AM - 9:00 AM, Midway West Foyer

Breakfast

7:30 AM - 8:30 AM

Affinity Group Meetings

Conflict Resolution and Bioethics, New York/Illinois Central

Bruce Tizes

Current and Former Clinical Ethics Fellows, Regency A

Alexandra White

Environmental Bioethics, Grand C

Paul J. Cummins

The Environmental Bioethics Affinity Group works to advance understanding of the ethical implications of ecology, climate change, and the environment with individual and public health. At this year's affinity group meeting, the next leader of the affinity group will be introduced, and we will have two paper presentations from members.

Hospice & Palliative Care

Brian Carter, Janice I. Firn, Sirisha Perugu

Are You Prepared to Meet the Pediatric Palliative Care Patient Who Presents an Ethics Challenge? Children's specialty hospitals are few and far between - with some states having only one. It is not uncommon for general community hospitals and academic medical centers to provide adult-focused palliative care services. However, an occasional pediatric patient who may require palliative care services in your hospital could exceed your HPM expertise or challenge your framing of ethical challenges and their resolution. This presentation will address the need for sufficient content material and clinical exposure for the HPM clinician trainee and practitioner to address pediatric-specific HPM and ethics issues.

Military, Humanitarian and Disaster Medicine, Frisco Burlington

James Giordano

Pharmacy and Ethics, Grand A

Amy Reese, Linda B. Uchal

Update on Clinical Ethics in Pharmacy Organizations

Race & Culture/Ethnicity, Regency C

Sarah Bassiouni, Danielle M. Pacia, Donald Carter,
Jada Wiggleton-Little, Daphne O. Martschenko

In this session, we will unpack what successful anti-racist bioethics looks like and we will revisit the goals and purposes of the Race Affinity Group. Trainees and early career researchers will also present brief presentations on bioethical issues related to race, ethnicity, and culture. There will be opportunities for members to network and support future collaborations.

8:45 AM - 9:45 AM, Grand C

Abolition as an Approach to Bioethics: Uncovering the Medical Industrial Complex

Diversity, Disparity, and Inclusion

Nicolle Strand, Jennifer James, Whitney Cabey

Since the fight to end chattel slavery, abolitionists have been resolute that morally corrupt institutions deserve a level of criticality beyond that offered by reform. Slavery, they argued, need not be reformed—it required abolition. This pursuit of justice has continually evolved, with scholars like Angela Davis (working against the prison industrial complex) and Dorothy Roberts (critiquing the family policing system) identifying that many other systems require the transformative analysis afforded by the abolition framework. The pursuit of justice, including health justice, requires an abolition imaginary. While this work has more commonly centered violent state institutions like policing, scholars in the field have recently made the call that bioethics should problematize all forms of carcerality, including those embedded within healthcare. Abolition asks us to imagine a future where families and communities are safe, healthy, and free, without deprivation of liberty, coercion or oppression. It asks us to consider whether inequities caused by systems are bugs that can be reformed, or are features baked into the systems themselves. Our panel consists of an emergency physician, a lawyer, and a sociologist—all bioethicists working within academic medicine. The first panelist will describe the history of hegemonic systems and explore their relationships to healthcare. The second panelist will describe the abolition framework, and its applications within a justice-centered approach to ethical analysis of healthcare. The third panelist will offer a vision for the future that begins by confronting our assumptions about healthcare and discuss the potential for bioethics to adopt an abolitionist stance.

8:45 AM - 9:45 AM, Midway 9

Paper Session: AI and Research Ethics

Research Ethics and Social Sciences

Humanizing Algorithms: Clinician Insights into Ethical and Practical Challenges in AI-Based Survival Prediction Rita

Dexter

Moral Dimensions of Listening in Healthcare Encounters: Patient Perspectives on AI-Enabled Voice Analysis

Technologies

Michele D. Anzabi

The significance of human interaction in consent to research: remote consent, e-consent, and AI consent Mark Sheehan

8:45 AM - 9:45 AM, Regency B

Flash Session: Clinical Ethics Consultations

Clinical Ethics

An Important Seat at the Table: The Unique Role of the Genetic counselor in Health Care Ethics Consultation, Committee work and Ethics Education

Margaret Menzel

Conflicts of Reciprocity in Heart Transplantation After Brain Death: Impetus in Orthodox Communities

Elijah Wiseman

Implementing Electronic Medical Record (EMR) Orders for Ethics Consultation Requests in a Not-For-Profit, Community Hospital

Miranda Blodgett

Parental choice in the changing landscape of trisomy 18 medical interventions: How to navigate misconceptions about survival outcomes in the prenatal consult

Ryan Sanchez

The Intersection of Normative Language, Moral Status, and Personhood When Discussing the Ethical Complexities of Artificial Womb Technology

Chase Binion

The Legal and Ethical Status of DNR Tattoos

Ben Sarbey

Using Natural Language Processing as a Tool to Identify Outcome Disparities in Clinical Ethics Consultations

John C. Stys

8:45 AM - 9:45 AM, Midway 5

Paper Session: Clinical Ethics: Infectious Disease

Clinical Ethics

From Ebola to Disease X: A Survey of Clinical Leaders on the Ethics of Treating Patients Infected with Special Pathogens

Benjamin Krohmal

No vaccine, No organs? The ethics of vaccine mandates for pediatric transplant candidates

Mark C. Navin

8:45 AM - 9:45 AM, Midway 7-8

Paper Session: Communities and Justice

Law, Public Health Policy, Organizational Ethics

'Why Do You Ask?' Eliciting the Public's Moral Judgments in Bioethics Debates

Jared N. Smith

Habits of the Heart: Advancing Racial Equity in a Community Health Coalition

Lena Hatchett

Social change in an increasingly individualized, capitalized, and fragmented health system: An ethnographic study of the Open Insulin project

Nicole Foti

8:45 AM - 9:45 AM, New York/Illinois Central

Disembodied/Reembodied: Reimagining Images of Reproduction

Jaime Konerman-Sease, Lois Hendrickson

Much attention has been called to the ways in which the 2022 Dobbs decision disempowers women in medical decision-making. The decontextualization of women's experience in discussion about reproduction is not new. Its past can be found in long-18th century obstetric texts depicting the moment in medicine when reproduction and childbirth were medicalized and women were actively disembodied. As the healthcare community wrestles with the realities of healthcare inequity around reproductive and sexual health, we argue that artistic interpretation of history can help peel back the intertwining layers of medical power and social expectation to reassert the agency of female patients. Through interdisciplinary engagement between art, history of medicine, and bioethics - this project reimagines these historical medical experiences as ones in which women held onto agency in their bodies. This session will explore the product of this collaborative printed folio and exhibit titled Disembodied/Reembodied. Through viewing re-imagined flap print images and artistic reembodyments of the cadavers depicted in 18th century medical texts, presenters and participants will deconstruct the continuities of female experiences of becoming disembodied through the medical gaze in both the long 18th century and today. This folio in conversation with reproductive ethics cases invite session participants to engage in group discussion around the experience of reproduction in the United States, including the shifting legislative landscape, unequal and abysmal rates of maternal and fetal mortality, and high rates of cesarean sections.

8:45 AM - 9:45 AM, Regency C

Do Parents' Reasons Matter? The Ethical Significance and Implications of Reason-Giving in Pediatric Ethics

Clinical Ethics

Bryanna Moore, Jeremy Garrett, Erica K. Salter, Tyler Tate

In pediatrics, most acknowledge that parents' reasons for requesting or refusing medical interventions matter pragmatically; attending to parents' reasons is important for partnering effectively with families. Yet some dispute that parents' reasons matter normatively. Indeed, parents' reasons for requesting or refusing an intervention are often

deemed ethically irrelevant to whether the decision poses serious risk of significant harm to the child or falls within the zone of parental discretion (Diekema 2004; Gillam 2016). Despite some discussion of whether and how parents' reasons matter in the pediatric ethics literature, controversy surrounding this issue persists. In this presentation, we bring together ethicists and clinicians from four pediatric hospitals to explore the ethical significance and implications of parents' reasons in pediatric decision making. Panelist 1 will introduce the topic and present a hypothetical case to illustrate how parents' reasons can transform ethical analyses. Panelist 2 will analyze how reasons typically function in pediatric ethics, including summarizing key arguments for and against granting parents' reasons ethical weight when evaluating decisions. Panelist 3 will discuss what sorts of reasons parents offer in practice and how clinicians might respond to those reasons. Panelist 4 will explore the role reason-giving might play in fostering physician-parent relationships and the obligations each party may have relative to their reasons for certain decisions. Panelist 1 will then present preliminary data from a qualitative study exploring clinicians' and ethicists' views on this topic, before moderating guided Q&A with the audience.

8:45 AM - 9:45 AM, Midway 6

Paper Session: Ethics and Equity for Reproductive Health

Diversity, Disparity, and Inclusion

Enhancing the Reproductive Justice Framework to Improve Maternal and Neonatal Outcomes through Reproductive Health Promotion: Global Lessons from an Ethiopian Case

Lynette Lartey

Ethical Considerations in Expanding Eligibility Criteria for Uterus Transplant Recipients: A Scoping Review

Kimberly

Reproducing Inequity: Artificial Womb Technologies and Environmental Health Threats

Sophie Schott

8:45 AM - 9:45 AM, Regency A

Identity Defined: Exploring the Formation of Professional Identity in Clinical Ethics

Education/Interprofessionalism

Nicholas R. Mercado, Margie H. Shaw, Renee McLeod-Sordjan, Brian H. Childs

Clinical ethics consultation (CEC) is the practice of using ethical principles and theories to engage in complex interventions with stakeholders to address moral and humanistic issues. Clinical ethics consultants are professionals who conduct CEC in a variety of healthcare settings. Even though the number of degree and fellowship programs in clinical ethics has increased over time, many clinical ethics consultants continue to enter the field serendipitously, having had little or no formal training in CEC. For decades, CEC lacked standards for education and credentialing. In 2018, the American Society for Bioethics and Humanities (ASBH) launched the first nationally recognized credential for CEC: the Healthcare Ethics Consultant-Certified, or HEC-C. The HEC-C program is a step toward the professionalization of CEC by setting minimum qualifying standards to sit for a certification exam. Professional identity formation is defined as a complex and transformational process of internalizing a profession's core knowledge, skills, values, and beliefs, resulting in an individual thinking, acting, and feeling like a member of that professional community. Professional identity formation is regularly discussed in the health professions literature, particularly in medicine and nursing. However, professional identity formation in CEC is notably absent from the literature. This interdisciplinary panel will address the following questions regarding this emerging field: what is a clinical ethics consultant's professional identity? How does CEC identity relate to other professional identities? What does professional identity formation look like in CEC? What strategies can be included in training and educational programs to foster professional identity formation in CEC?

8:45 AM - 9:45 AM, Grand A

Investigating Moral Distress in the Reproductive Healthcare Workforce post Dobbs

Law, Public Health Policy, Organizational Ethics

Connie Ulrich, Mara Buchbinder, Dana Howard, Jocelyn Wascher

Humanistic caring requires providers to value and respect every patient. Loss of federal protections for abortion following *Dobbs v. Jackson Women's Health* raises concerns about the prospect of heightened moral distress among reproductive healthcare providers, many of whom face new legal and civil penalties for providing what they perceive to be necessary care. This interdisciplinary panel brings together empirical findings from two separate studies examining moral distress among providers following *Dobbs*. The panel will be introduced and moderated by a nurse bioethicist with expertise in moral distress in healthcare settings. The first panelist, a medical anthropologist, will share results from interviews with 54 obstetrician-gynecologists from 13 states with abortion bans. Participants attributed distress to the cumulative toll of being unable to provide everyday evidence-based healthcare, in addition to the acute burden of more rare and devastating cases. Second, a philosopher will report quantitative findings from a national survey of 310 abortion providers

assessing self-reported moral distress levels, comparing responses in restrictive and non-restrictive states. Although a majority (78%) reported experiencing more moral distress since Dobbs, levels were twice as high for providers in “restrictive” compared to “protective” states and higher in “surge” states. Third, an obstetrician-gynecologist in complex family planning will present key themes from a qualitative analysis of 164 responses to an open-ended question on the national survey, including distress caused by loss of professional identity when unable to use specialized training, bearing witness to patients’ and providers’ trauma, and being forced to provide substandard care.

8:45 AM - 9:45 AM, Midway 3-4

Positionality in Bioethics Research: Reporting from Within

Research Ethics and Social Sciences

Kevin T. Mintz, Lauren L. Baker, Brandy M. Fox, Asma Mobin-Uddin

Engaging communities who are traditionally underrepresented in research or marginalized in traditional power structures is increasingly becoming part of “best practices” for applied research. Many researchers who are also members of marginalized communities engage in research specifically to try and resolve or mitigate forms of injustice they observe in their communities. For many, their identity as researchers is preceded by their identities as group members directly impacted by the bioethical debates and policies they study. This panel consists of four scholars (trained in medicine, political science, and bioethics) who do empirical research from within at least one of their own vulnerable or historically marginalized identities. Each presenter will describe their research and how they balance obligations of being a researcher with obligations from within the community. Panelists will also address questions such as, What power or unique insights come from being researchers and group members at the same time? How to decide which identity to forefront? Does being a member of a certain community oblige one to be an advocate for that group? One presenter will focus on disability communities; one will discuss veterans and serious mental illness; one will address end-of-life decision making in the Muslim American community; and one will discuss medical decision making for youth in foster care. Each presentation lasts 10 minutes and there will be 20 minutes for discussion. Panelists will engage the audience by providing discussion points and inviting the audience to share their experiences as researchers engaging bioethical topics.

8:45 AM - 9:45 AM, Midway 11

Paper Session: Psychiatric Research Ethics

Research Ethics and Social Sciences

Adolescent OCD Patient and Caregiver Perspectives on Identity, Authenticity, and Normalcy in Potential Deep Brain Stimulation Treatment

Natalie Dorfman

Intracranial research in psychiatry – What are today’s ethical constraints?

Marie Nicolini

Mapping the Post-Trial Care Gaps in Deep Brain Stimulation for Psychiatric Conditions

Erika Versalovic

8:45 AM - 9:45 AM, Grand B

You Can’t Stop Me From Caring: Ethical obligations, considerations, and recommendations in responding to refusals of basic care.

Jessica Rong, Jennifer Markusic Wimberly, Sarah Vittone, Elizabeth Sivertsen

Clinical Ethics

In this session, panelists will explore the ramifications of refusal of basic care. This is an under-recognized and underappreciated problem in inpatient settings with significant impact. Basic care meets essential human needs in a compassionate manner with respect and dignity. Basic and ordinary care, aligned with current treatment goals, are of critical benefit and low burden to the patient. Basic care may include hygiene, dressing changes, repositioning, pain management and nutrition. Constraints on standards of care in clinical practice such as this type of refusal may develop into moral distress for clinicians. Exploring the role each team member has in the plan of care is essential to promoting dignity and humanity of the patient while also maintaining the moral obligations of the healthcare team. We will critique and analyze: refusal by decisionally capable patients; overt refusal by incapacitated patients, and surrogate refusal. We will examine the ethical and professional responsibilities of stakeholders and organizations to provide basic care in these cases including legal, risk, and social concepts. We will specifically explore the patient or surrogate’s role in these refusals. Recommendations will be grounded in beneficence and nonmaleficence, mitigating harms and eliciting the values and complexities underlying the refusal. Approaches will include acknowledgement of implicit biases, need for trauma informed care, and response to issues of healthcare inequities and injustice that contribute to mistrust. The ethics committee plays an essential role in establishing a culture in which all aspects of the refusal are considered to provide holistic, humane, basic care.

10:15 AM - 11:15 AM, Midway 5

Paper Session: Beyond IRBs

Research Ethics and Social Sciences

Are IRBs prepared to govern rerogenomics research? Building stakeholder-informed guidance and testing the limits of US research regulation Harlie Dion Custer

Research Ethicists Work Beyond the IRB to Integrate Justice-Based Considerations Emma Tumilty

10:15 AM - 11:15 AM, Regency C

Breaking Barriers to Belonging: A Disability Justice Framework to Using Zines as Tools To Facilitate Community in Isolation and Zine-Making As A Therapeutic Practice. Jess Walters

Diversity, Disparity, and Inclusion

A zine (pronounced like “zeen”) is a small-run, often handmade and photocopied publication of art, stories, poems, photographs, lists, instructions, recipes, reviews, or any form of expression on any subject. Zines can be made by one person or many. They can be any size and can be displayed or found anywhere...but what if zines could be used as a tool to advance health equity? This unique, interactive workshop invites attendees to experience the impact of zines first-hand. Led by a Deaf-Queer multiply neurodivergent Disability Justice advocate who turned their lived experiences recovering from dialysis and kidney transplant into a lifelong pursuit to better understand the intersections of art and health, this workshop explores how the medium of zines can be used to form community connections and zine-making as a therapeutic activity for introspection and creative expression. The presenter will share resources, provide examples of zines from a variety of perspectives, and lead the audience in a collaborative zine-making activity culminating in an opportunity to exchange zines and discuss their experiences. Prompts from the zine template will encourage attendees to reflect on their own experiences with chronic conditions and/or disabilities and creatively express their views on social justice work within the healthcare system. By providing interdisciplinary group members with the opportunity to exchange zines with one another, participants will witness and experience how this medium can be creatively used as a self-advocacy tool to share ideas and serve as a catalyst for social change.

10:15 AM - 11:15 AM, Midway 7-8

Paper Session: Clinical Ethics: Justice and Disparity

Clinical Ethics

A Justice-Driven Approach to Painful Office-Based Gynecologic Procedures Nishita Pondugula

An Ethical Framework for Addressing Complex Hospital Discharges: Articulating Organizational Commitments in Care Setting Transitions Kelly Turner

Ethical Analysis of For-Profit Market Competition and Its Impact on Live Discharge From Hospice Zachary Nylund

10:15 AM - 11:15 AM, Midway 6

Paper Session: Community Engagement in Research

Research Ethics and Social Sciences

Policy Experiments, Informed Consent, and Democratic Accountability Marcos Picchio

Who is being studied? How retrospective chart reviews can obscure "about whom" researchers obtain information Kenneth A. Richman

Why Engage Communities? Robert Steel

10:15 AM - 11:15 AM, Grand D-F

Core Competencies, 3rd Edition Listening Session (Option 2) Alex Kon

Clinical Ethics

Join us at one of our three listening sessions to share your feedback on the current draft of our forthcoming Core Competencies for Healthcare Ethics Consultation, 3rd Edition text. The draft will be circulated through the ASBH website prior to the conference. Please come to the listening session having read the draft with feedback prepared. Our moderators are available to receive questions and feedback for use in the drafting process but may not be able to respond to all inquiries during the session.

10:15 AM - 11:15 AM, Regency B

Exceptional Injustice: Interrogating Public Comments on Migrant DNA Collection at the Border

Law, Public Health Policy, Organizational Ethics

Rachel Fabi, Elizabeth Dietz, Leila Jamal

Federal regulations requiring the collection of DNA from migrants detained at the US border have faced bipartisan opposition. This cross-disciplinary panel argues that how stakeholders articulate their opposition matters for how we collectively conceive of and argue for the agency (or "humanity") of migrants. The moderator and first presenter, a public health ethicist, will provide an overview of the relevant federal regulation and current state of the practice of migrant DNA collection. She will also review the findings of a study examining the public comments that were submitted in response to the regulation's Notice of Proposed Rulemaking (NPRM), identifying key themes that emerged. The second speaker, a genetic counselor and bioethicist, will situate these findings in the context of genetic exceptionalism, which treats genetic information as more inherently personal, private, and sensitive than other data. The third speaker, a science and technology studies scholar and bioethicist, will build on these presentations and examine how taking seriously the view that it is morally wrong to collect genetic information from detained migrants generates broader conclusions about the agency of migrants and others subject to detention and incarceration. The panelists will then engage the audience in a conversation about the role of arguments for autonomy and privacy in broader debates about migrant and criminal justice, focusing on the relationship between data from public comments and conceptual analysis of federal policies that restrict autonomy.

10:15 AM - 11:15 AM, Grand A

Exploring Ethical Dimensions of Amnioinfusions for Early Anhydramnios

Clinical Ethics

David Soffer, Christy Cummings, Jena L. Miller, Kalie Steele

This cross-disciplinary panel aims to delve into the ethical considerations surrounding the use of amnioinfusions for early anhydramnios, a condition characterized by a deficiency of amniotic fluid during pregnancy. Amnioinfusions, a medical intervention involving the infusion of sterile saline into the amniotic cavity, have been employed to address complications associated with anhydramnios. While this technique holds promise, clinical trials are ongoing and uncertainty exists surrounding long-term perinatal outcomes, raising complex ethical questions that warrant thoughtful examination. The proposed panel brings together experts from diverse fields, including maternal-fetal medicine, bioethics, neonatology, and a parent advocate to engage in a comprehensive discussion on the ethical dimensions of amnioinfusions in early anhydramnios, and clinical trials. Key topics to be explored include the informed consent process for pregnant individuals, potential risks and benefits associated with the procedure for both pregnant persons and fetus, and considerations related to equipoise and research ethics. The panelists will analyze the broader implications of utilizing amnioinfusions in this context through clinical trials and ethical frameworks. Discussions will also encompass societal perspectives, ensuring a holistic examination of the ethical landscape. By fostering a multidisciplinary dialogue, this panel seeks to provide valuable insights for clinicians, ethicists, Institutional Research Board (IRB) members, and parents grappling with the ethical challenges posed by using amnioinfusions in managing early anhydramnios. Ultimately, the aim is to contribute to the development of ethical guidelines that prioritize the well-being of both pregnant individuals and their unborn children in the face of this complex medical condition and potential intervention.

10:15 AM - 11:15 AM, Grand C

Paper Session: Health Humanities: AI

Health Humanities

Narrating the Posthuman: Science Fiction and the Ethics of "Artificial" Narrators

Erik Larsen

Reading Between the Lines: Using Alice Munro's Fiction to Explore Physician-Assisted Suicide with Medical Students

Kate Luo

10:15 AM - 11:15 AM, Midway 9

Flash Session: Institutions and Law

Law, Public Health Policy, Organizational Ethics

Analyzing the Safe Third Country Agreement from a Health Justice Perspective

Megan Bailey

Assessing Personal Reflection and Professional Identity Formation in Undergraduate Medical Education

Childress

Contextualizing Unconsented Human Remains

Amanda M. Buster

Islamic Ethico-Legal Imperatives on Vaccination: An Analysis of Fatawa on Preventive Medicine

Bilal Irfan

Reconciling Legal Majority and Puberty Across Jurisdictions: Adolescent Healthcare Autonomy in Islamic Jurisprudence

Bilal Irfan

The 55-Word Story in the Pre-clinical Year Touches All Three Tenets of Professional Identity Formation Maria A. Basile

10:15 AM - 11:15 AM, Midway 3-4

Preserving Humanity in the Brave New World of Cardiac Xenotransplantation

Research Ethics and Social Sciences

Sabrina Derrington, Christopher Bobier, Leilani Graham, Amana Liddell

In a short period of time, the ability to successfully transplant genetically-modified animal organs into human bodies has gone from science fiction to reality, signaling a revolution that could save countless lives, but which evokes important questions about how humans relate to other life forms and generates new ethical complexities along the entire translational journey from clinical trials to implementation and population health outcomes. These issues are particularly weighty in the context of cardiac xenotransplantation; whether this novel therapy is ultimately a blessing or a curse will depend on how cardiac xenotransplantation is studied, offered, utilized and managed. How will investigators balance inclusion and protection of vulnerable populations as clinical trials begin? What constitutes adequate informed consent for patients and their families? How will access to porcine hearts complicate decisions around heart failure and end-of-life care, or alter allocation strategies for human organs? Will xenotransplantation reduce or exacerbate disparities for disadvantaged and marginalized patients? This diverse multidisciplinary panel, composed of a physician-bioethicist, a philosopher, a medical student and clinical research coordinator, and a heart transplant recipient and child life professional, will provide an overview of ethical concerns related to xenotransplantation research, medical decision-making, health equity, and holistic patient- and family-centered care, framed by the 2024 ASBH conference theme, "What does it mean to be human?"

10:15 AM - 11:15 AM, New York/Illinois Central

Responding to people facing dementia: Improving interprofessional learning and practice in aging societies

Education/Interprofessionalism

Nancy Berlinger, Emily A. Largent, Matthew K. Wynia, Mara Buchbinder

This multidisciplinary panel will discuss a new open-access report that foreground the needs, concerns, and choices of people facing dementia as a moral challenge for aging societies and an interprofessional learning imperative and improvement opportunity for health care providers. Most people with dementia care live outside of institutions; education and innovation concerning how to support better lives and choices for people facing dementia, and for caregivers, must engage audiences beyond hospitals. These issues are central to what it means to be human, given that ideas and values concerning what it is like to live with dementia are often accompanied by stigma, misinformation, and stark inequities in care financing. Speaker 1, a bioethics and health humanities researcher and lead editor of the report, will introduce the work in the context of ongoing research on the bioethics of aging and dementia, and will moderate discussion. Speaker 2, a health policy expert and dementia researcher, will present the report's landscape review of ethical, legal, medical, and social considerations concerning hastening death in the context of a dementia diagnosis. Speaker 3, a physician and health care professionalism expert, will discuss the landscape review's applications to interprofessionalism concerning evolving questions in primary care, hospice, and other contexts. Speaker 4, a medical anthropologist, will share empirical bioethics insights informing another paper in this report, with attention to education concerning conversations with people facing dementia.

10:15 AM - 11:15 AM, Grand B

Paper Session: Trust, Trust, and Error in AI

History, Religion, and Culture

Are We (Unfairly) Biased in Tolerating and Forgiving Human Errors Over AI Errors?

Ju Zhang

Can Healthcare Nudging Algorithms Avoid Becoming Bullshit Bots? Truth and Power in the Age of AI

Bradley Steven Thornock

Retro ad futura - Mapping a Trajectory of Trust and Sacrifice from Antiquity to Artificial Intelligence

Indica Sur

10:15 AM - 11:15 AM, Regency A

Who is talking and what are they saying? Ethical considerations when interpreting for others in healthcare

Diversity, Disparity, and Inclusion

Ana Iltis, Kirstin RW Matthews, Gianna McMillan, Shan Wang

Appropriate healthcare requires good communication between patients and clinicians. Effective communication is challenging when clinicians and patients do not share a common language, including mismatches in spoken language, or when one party is nonverbal, deaf, hard of hearing, or non-signing. Healthcare interpreters, ideally trained in language, cultural traditions, interpersonal communication, and medical vocabulary, can be instrumental in facilitating

communication. Limited attention has been paid to the ethical issues faced by trained healthcare interpreters. In addition to trained healthcare interpreters, clinicians and patients must often rely on “informal interpreters” such as nearby hospital staff, family, friends, or bystanders. This panel will examine ethical issues related to trained and informal interpreting in healthcare, such as patient safety, privacy, confidentiality, and equity and disparities. The first panelist, trained in biomedical sciences and policy, will describe categories of trained healthcare interpreters and present preliminary results of a systematic literature review identifying ethical issues trained healthcare interpreters face. The second panelist will explore issues associated with “informal interpreters” and AI-enabled services. This panelist is a bilingual philosopher with informal interpreting experience. The third panelist, a bioethicist, will present case studies and ethical issues involving interpreters of spoken and sign language. The cases will come from personal essays collected for a bioethics journal. The fourth panelist is a trained healthcare interpreter who interprets and teaches interpreting skills for a St. Louis-area nonprofit. She will reflect on the skills that healthcare interpreters need and the ethical issues the other panelists described in the context of her work.

11:30 AM - 12:45 PM, Grand D-F

Plenary: Environmental Justice, Technology, and Health Equity: Issues, Challenges, and Solutions

Sacoby Wilson

Plenary

Communities of color and low-income communities across the country have been impacted by environmental, climate, and energy injustices due to systemic racism and structured poverty. In addition, many of these communities experience a high concentration of psychosocial stressors and lack of access to high quality salutogenic infrastructure including health care infrastructure. In this session, Dr. Wilson will discuss the history of environmental justice issues in the United States including the relationship between environmental injustice and health inequity and how climate change is exacerbating these inequities. He will describe how technology in various forms has driven environmental injustice and health inequities but also will detail through examples from his work and other related scholarship, how technology can be successfully used to understand and address environmental injustice and help to advance health equity.

12:45 PM - 2:00 PM

Lunch on Own

Attendees have time to grab lunch from the surrounding area's many dining choices. Select the "Food and Drink" tab in the conference app to learn more about the available options.

1:00 PM - 2:00 PM

Affinity Group Meetings

Animal Bioethics, Missouri Pacific

Martin Fitzgerald

Astro-Ethics, Regency A

Vasiliki Rahimzadeh

Our informal session will explore emerging topics in the ethical, legal and social issues of human experimentation in space, with special attention to remote healthcare delivery using AI and digital twins. We encourage scholars with interdisciplinary interests in astrobiology, bioethics, space medicine, philosophy, and social studies of science to submit abstracts to present on the topic of AI for space. The Astro-ethics affinity group focuses on how unique features of Outer Space compel new bioethical questions related to the extreme environmental contexts, the uncertain social value and impacts of long duration human space missions, and the necessary scientific and financial collaboration across industry, defense government and public sectors for all to benefit from space exploration.

Clinical Research Ethics Consultation, Jeffersonian Knickerbocker

Caroline Morehouse, Jake Earl, Liza Dawson

This session will involve presentation and discussion of a case study of research in terminally ill patients that presents more than minimal risk without direct therapeutic benefit, but aims at advancing knowledge about novel treatments.

Feminist Approach to Bioethics, Grand C Kara Ayers, ALISON C. REIHELD, Jada Wiggleton-Little, Lindsey Grubbs, Devora Shapiro

We will have a panel of three short papers at the intersection of feminist ethics and disability ethics.

Immigration, Grand A

Brian Tuohy, Lynette Martins

Jewish Bioethics, New York/Illinois Central
Jewish Views on Autonomy and Reproductive Freedom

Carol Roberts Gerson

Law & Bioethics, Frisco Burlington

Leah Eisenberg

Philosophy of Medicine, Grand B

John Huss, Bryan Cwik, Bryan Pilkington

Is Philosophy of Medicine a Subfield of Philosophy of Science? While it is certainly possible to use the tools of philosophy of science to gain insight into the nature, aims, and scope of medicine, in this talk I will examine the view that treating philosophy of medicine as a subfield of philosophy of science places undue limits on what the philosophy of medicine can be.

1:00 PM - 2:00 PM, Regency C

Expanding the Policymaking Impact of Your Bioethics Expertise

Adam Seth Levine, Andrew Shuman

Law, Public Health Policy, Organizational Ethics

This roundtable is a follow-up from our 2023 plenary "Policymakers' Unmet Desire for Ethicists," and it is for anyone who wants to become more engaged in the policymaking process, yet is uncertain how to start. We will discuss why collaborative relationship-building, not just information dissemination, is important at these moments. We will also present new data on decision-makers' unmet desire to engage with bioethicists. Participants will be encouraged to share their own experience and vision for impacting policy. Attendees will walk away with practical guidance and tools on how to proceed — what questions to ask yourself and others, what concrete steps to take, and what challenges may arise.

1:00 PM - 2:00 PM, Midway 10

The Hastings Center: Building connections for the future of bioethics

Vardit Ravitsky, Nancy Berlinger, Virginia A.

Brown, Laura Haupt, Gregory E. Kaebnick, Carolyn Neuhaus, Danielle M. Pacia

Join us for a special session to hear about The Hastings Center's future and to meet the president, editors, and scholars. We are especially looking forward to welcoming new ASBH members and students

2:15 PM - 3:15 PM, Grand D-F

Members' Meeting and Awards Ceremony

Join us at the Annual Members' Meeting and Awards Ceremony to hear from ASBH leadership on recent updates with the Society, our plans for the year, and recognition of our volunteers and award recipients!

3:45 PM - 4:45 PM, Grand A

Paper Session: AI Ethics

Law, Public Health Policy, Organizational Ethics

Insights from a Delphi Study on Ethical Considerations Emerging with Clinical Trials of Autonomous AI

Ariadne Nichol

The Doctor Will Hear You Now? Leveraging the potential of digital voice biomarkers

Hortense Gallois

3:45 PM - 4:45 PM, Midway 7-8

Paper Session: Assessing Equitable Practices for Addressing Health Disparities and Inequities

Diversity, Disparity, and Inclusion

A Characterization of Synthetic Data Products for AI: Transparency and Ethical Values

Carole A. Federico

Fitting a Square Peg into a Round Hole: Ethical Concerns Regarding Standardized Cognitive Assessments in Healthcare

Tiffany Bystra

Racial Disparities in Involuntary Psychiatric Admissions: Ensuring Justice in the Balance between Patient Autonomy and Safety

Alexander M. McClanahan

3:45 PM - 4:45 PM, Grand B

Autism, Neurodiversity, and Inclusion: Striving for Greater Social Justice through Narrative and Supported Engagement

Diversity, Disparity, and Inclusion

Nanette Elster, Samantha A. Chipman, Kenneth A. Richman, Kayhan Parsi

According to recent data from the Centers for Disease Control, 1 in 36 children per year are diagnosed with autism. Data from several years ago identified that 1 in 45 adults is autistic. Autism is a complex phenomenon that can be

characterized in a number of ways—as a disorder, a disability, as part of neurodiversity, or as an identity. Autistic individuals are as diverse as neurotypical individuals. Autistic individuals may or may not have an intellectual disability, may or may not have communication difficulties, and may or may not have difficulties with social engagement. What many, if not most autistic adults experience, however, is a lack of inclusivity. Autistic adults experience inequity in healthcare and other key indicators of social well-being, including employment, housing, and political engagement. The panelists in this session will discuss a model of engagement that respects the relational autonomy and individuality of autistic adults and focuses on strengths rather than deficits. This panel is comprised of a graduate literature student, a philosopher, a lawyer-ethicist, and a lawyer-humanist. The first panelist is an autistic adult who will discuss how to integrate narrative into providing healthcare for autistic patients. The second panelist will discuss how the social pressure of masking autistic characteristics reflects social injustice. The last two panelists will discuss a model of supported engagement which builds upon the burgeoning concept of supported decision making, giving voice to and recognizing the substantial contributions that autistic adults can make to their communities and to the broader society.

3:45 PM - 4:45 PM, Grand D-F

Award Recipient Remarks

Hear from the awardees! Our Student Paper Award recipient will present their award-winning paper, and the 2024 Lifetime Achievement Award recipient will offer a reflection on the field and their career. There will be time for a Q&A after each speaker's remarks.

3:45 PM - 4:45 PM, Regency C

Big Little Lies: Confronting Everyday Academic Misconduct

Research Ethics and Social Sciences

Emily Hahn, Jamie Riches, Divya Yerramilli

Recently, the media has publicized major research misconduct of physicians and scientists, including insufficient conflicts of interest disclosure, data fabrication, and sexual misconduct. While these represent the most egregious infractions and erode public trust, many forms of research misconduct happen in pervasive, subtle ways, including authorship erasure/misappropriation and misuse of data. When these occur, there are no standardized ways to identify and report these instances, or consensus about consequences, resulting in patterns of unchecked bad behavior. In this workshop, we will present real-world cases including the following: 1. Authorship Erasure: A researcher has done substantial work on a project and without their knowledge, is excluded from attribution in subsequent work. 2. Authorship Misappropriation: A researcher did not verify the participation, edits, or final approval on a manuscript prior to submission. 3. Behavioral Misconduct: A collaborator or PI routinely lies to or mistreats their colleagues and trainees without crossing obvious lines of harassment. 4. Retractions: A researcher submits work for which retraction is later suggested by subsequent work, but they do not retract. 5. Data Misuse: A researcher has IRB and/or a data-use agreement for one scope of work, but then uses the data outside of the initial scope. We will engage a diverse interdisciplinary audience with real-life cases to generate strategies to better identify, report, and enforce consequences of insidious research misconduct. Audience members will participate in a collaborative dialogue examining the role of individuals, academic institutions, and other regulatory bodies in addressing, preventing, and penalizing academic misconduct.

3:45 PM - 4:45 PM, Regency A

Clickbait or Case Study: The Ethicist's Responsibility in Ethics Education

Education/Interprofessionalism

Alexandria Lescher, Jessica Ullrich

Ethics committees have long been the standard means of engaging diverse groups of hospital personnel in the work of ethics. Presenting cases within these committees is a preferred method for many ethicists to provide internal education, especially around ethical approaches, problem-solving, and other key areas of knowledge that are important for committee members to know to fulfill their roles. Particularly when cases focus on real patients, the structure and tone of these presentations can have a substantial impact on the direction of the discussion: is the case being discussed in a manner that encourages expert review, fosters quality improvement, and deepens our understanding of the human experience in healthcare? Or does the case discussion adopt a different nature, the way a book club might discuss their latest read? After a didactic introduction, speakers will debate the benefits of educational cases and the concerns that arise when well-intentioned case presentations become exploitative. Discussion will use sample case presentations to explore the conditions that might inadvertently put patients on display, and the razor-thin line between education and sensationalism. From there, each side will examine how different models of case presentation might promote high reliability, encourage committee member engagement, and improve credibility. The debate will seek to answer whether

case presentations provide education, entertainment, or both; if both are inevitable, is it worth the tradeoff or do we need another way to present cases?

3:45 PM - 4:45 PM, Midway 3-4

Paper Session: Clinical Ethics: Organ Donation/Procurement

Clinical Ethics

Children as Living Solid Organ Donors: Ethical Analysis & Model Hospital Policy Statement	Gyan C. Moorthy
Just Say No to the OPO: Boundary Setting and Collaboration in Organ Procurement	Rebecca Yarrison
Transplant Providers' Perceptions of the 6-Month Alcohol Abstinence "Rule" for Liver Transplantation	Janetta Brundage

3:45 PM - 4:45 PM, Midway 11

Paper Session: Compassion and Self-Care

Clinical Ethics

Bioethics Poetry Group: A sustainable program of expression and self-care	Jeffrey Farroni
The Role of Compassion and Moral Residue in the Veterinary Professional Identity	Lisa Moses

3:45 PM - 4:45 PM, Grand C

High Clinical Ethics Consultation Volume: A Blessing or a Bane?

Clinical Ethics

Trevor M. Bibler, Anca Dinescu, Jordan G. Potter, Kevin Dirksen

A clinical ethics program ought to provide justified, rigorous, and practical guidance about normative aspects of clinical medicine. A program that fulfills this imperative to their own satisfaction, and satisfaction of the institution, is likely a successful program. Consult volume is often taken as the cardinal metric for success. With this panel, four clinical ethics directors discuss how their services meet this aim by appealing to factors other than case volume. Panelist 1 directs a recently created program at a large community health system in the Midwest. Leading a new program with a rapidly growing consultation service, this panelist will highlight select drawbacks of focusing on maximizing consult volume, particularly for new programs with limited resources. Panelist 2 leads a large ethics consultation service for a not-for-profit, Protestant hospital in the South. He will discuss the programmatic changes that lead the service to intentionally decrease the service's consult volume, while aiming to increase the complexity of the consults. Panelist 3 directs an established ethics center at a faith-based, community healthcare system in the Pacific Northwest. He will highlight efforts to promote professionalism within an organization with multiple facilities, across the healthcare continuum. This will include a discussion of establishing value while coexisting alongside volunteer-based models. Panelist 4 leads a well-established ethics consult service at an academic, government-sponsored hospital on the East coast. She will highlight ways of assessing the added value of an ethics consult service that includes metrics such as "impact stories," consult evaluation scores, and evaluated educational activities.

3:45 PM - 4:45 PM, Midway 5

Paper Session: Philosophy: Phenomenology and Existentialism in the Clinical Encounter

Philosophy

Existentialism as a Humanist Framework for Surgical Ethics	Johan H. Lee
Is anybody there? Clinician embodiment, artificial intelligence, and the clinical encounter	Evan Beacom
Overcoming Cartesian Utilitarianism in Pain Medicine	Kyle Karches

3:45 PM - 4:45 PM, Midway 6

Paper Session: Public Health

Law, Public Health Policy, Organizational Ethics

Bioethics in Simulation: Using Quantitative Bioethics to Investigate Ethical Tradeoffs in Crisis Standards of Care

Protocols

Jonathan Herington

Public Health Ethics for Biocontainment Care

Abbey Lowe

Updating Public Health Models: Information Environment as Social Determinant of Health

Amitabha Palmer

3:45 PM - 4:45 PM, Regency B

Responsible Innovation: Exploring the Ethical Implications of AI-Powered Suicide Risk Prediction

Law, Public Health Policy, Organizational Ethics

Susannah L. Rose, Colin Walsh, Laurie Novak, Christopher Robertson

Artificial Intelligence (AI) may help save lives by proactively identifying patients at high risk for suicide. In a recently published study of 120,398 patients visits over 15 months, a newly created AI model, combined with face-to-face screening, accurately predicted patients who attempted suicide. This panel presentation will focus on ethical issues raised by implementing such models in healthcare. The first panelist is a physician, data scientist, and the lead researcher who developed this AI tool. He will discuss the development and current research using this model. The second panelist is an anthropologist who will focus on the human factors elements that are important to the implementation and ethics of such models and on the importance of value-centered design, which directly aligns to the conference theme: What Does It Mean to be Human? The third panelist is a lawyer, physician, and ethicist who will evaluate the ethical issues related to clinicians' perspectives on the use of such models. Finally, the moderator is an ethicist and clinical social worker who specializes in AI implementation and bioethics. She will facilitate discussion on the following themes: patient privacy, patient autonomy, and ethical concerns regarding bias and fairness, with an emphasis on practical recommendations. The ethics of healthcare systems limitations in mental health care will also be discussed. This panel will be engaging, encouraging attendees to participate and to ask questions. The presentation will end with a final set of recommendations that will be generalizable to other AI models in healthcare.

3:45 PM - 4:45 PM, Midway 9

Safeguarding or Gatekeeping? Historical, legal, and clinical perspectives on mandatory ethics involvement in gender-affirming care

Diversity, Disparity, and Inclusion

Theodore Schall, Jacob D. Moses, Lauren Sankary, Justin Penny

In 2024, Ohio proposed the mandated inclusion of a medical ethicist on interdisciplinary care teams providing access to gender-affirming care (GAC). While not appearing in subsequent rules, the proposal raised significant ethical questions about the appropriateness of mandated ethics involvement. This interdisciplinary panel examines how required ethics consultation can recognize ethical complexity, but may problematically frustrate justice in health care access, especially for marginalized groups. Our first presenter will describe embedded support provided to adolescent and adult gender care teams and the impact of the recent passing of Ohio House Bill 68 and the proposed rules on gender care access and delivery. The second presenter will discuss the use of ethics consultations for GAC for transgender and gender diverse patients. They will draw on their clinical experience to identify cases where clinical ethics consultation has helped promote affirming care and instances where its use could obstruct these aims of health care equity. Presenter three will provide historical context of mandated ethics consultations in other areas of medicine, including neonatology, end of life care, and other domains of politicized care in law and institutional policy. They will provide critical analysis of how ethics consultations have played a role in politicizing areas of medicine and defining areas of ethical controversy. Presenter four and the panel's moderator, will provide an overview of the concept of transexceptionalism and critique how it presents in contemporary bioethics literature on trans medicine, with a focus on work about ethics consultation.

3:45 PM - 4:45 PM, New York/Illinois Central

The Bioethics of Horror and the Horror of Bioethics

Health Humanities

Catherine Belling, Tod Chambers, Stephanie Larson

Horror, as emotion and genre, often challenges us to consider what it means to be human. This panel presents three distinct yet intersecting perspectives on the ways horror both informs and is informed by bioethics. Speaker 1, trained in literature, focuses on the meaning of "horror" as not just a genre, but the feeling for which the genre is named. Considering Frankenstein the first bioethics horror story, the presentation distinguishes between readers' horror at the monster's grotesque embodiment and Victor Frankenstein's own moral anagnorisis, his horrified recognition of the appalling implications of his success. Speaker 2, trained in religious studies, claims that cases of bioethics often read as if they were horror stories. This presentation will examine bioethics cases as being akin to what Eugene Thacker has described as "unthinkable worlds," arguing that bioethics is a field that responds not only to the morality but also to the horror of existence. Speaker 3, trained in clinical ethics consultation and 20th century fiction, draws upon the previous two papers to consider the ways popular horror can facilitate public engagement with bioethics. Using Stephen King's *Carrie* (1974) and Jordan Peele's *Get Out* (2017) the speaker will show that popular horror texts are not only a source of accessible, public-facing entertainment, but can also be read and analyzed as case studies which can, in turn, be used to encourage public-facing bioethical discussion, deliberation, and debate.

5:00 PM - 6:00 PM

Affinity Group Meetings

Bioethics & Christian Theology, Grand B Jeffrey Bishop, Daniel Sulmasy, Kristin Collier, Travis Pickell, Jaime Konerman-Sease

The Bioethics & Christian Theology Affinity Group seeks to engage contemporary works of Christian bioethics from a range of theological perspectives. Please join us for a panel discussion of *Burdened Agency: Christian Theology and End-of-Life Ethics* (University of Notre Dame Press, 2024), by Travis Pickell, PhD (George Fox University). The panel will include perspectives from prominent Orthodox, Catholic and Protestant scholars. Speakers: Jeffrey Bishop, MD, PhD (Saint Louis University), Daniel Sulmasy, MD, PhD, MASC (Georgetown University), and Kristin Collier, MD, FASC (University of Michigan).

Disability Ethics, Grand A

Laura K. Guidry-Grimes, Kara Ayers

The Disability Ethics Affinity Group will begin with a discussion of disability justice in bioethics and health humanities. As a group, we will share our strategies, our successes, and any missed opportunities for integrating the framework of disability justice in our respective fields. The second half of our meeting will be focused on getting to know one another better and forming connections.

Health Humanities Affinity Group, Regency A

Erin Lamb, Gretchen Case

This initial meeting of the new Health Humanities Affinity Group will be an active session to identify priorities and opportunities for growth within ASBH. Anyone who has participated in other affinity groups related to arts and humanities, such as Literature and Medicine or Visual Culture, is especially encouraged to join us and envision new ways to carry the work forward.

History of Medical Ethics, New York/Illinois Central

Bob Baker

Eulogizing or Expunging: Henry Beecher, Saul Krugman, and Thomas Parran Hagiographic eulogies of infamous physicians and posthumous expungements of their names are not uncommon. In 2013 the American Sexually Transmitted Disease Association (ASTDA) expunged the name of Surgeon General Thomas Parran (1892-1968) from an award, citing the President's Human Radiation Committee finding that Parran had funded experiments in Guatemala, "shoot[ing] living syphilis germs into human bodies," that he knew it would have been "ethically impossible" in the US. NYU's Medical School still eulogizes the pediatrician Saul Krugman (1911-1995), parading his awards on its website without mentioning his ethically questionable experiments on children with mental disabilities. Harvard's bioethics program and the Hastings Center responded quite differently to revelations about Beecher's ethically questionable declassified Army-CIA-sponsored Cold War LSD experiments. Harvard's program linked Beecher prize in ethics to an article weighing his contributions against his ethically questionable experiments; in contrast, Hastings Board of Directors expunged Beecher's name from its ethics prize. After a brief review of some facts about these three physicians and a summary of the Human Radiation Committee's criteria for assessing the character of people living in the past, the floor will be open for general discussion.

Philosophy, Grand C

Aaron Gray, Nir Ben-Moshe

Responsibility for the Use of Opaque Machine Learning Algorithms in Clinical Diagnosis Machine Learning (ML) algorithms are an application of artificial intelligence through which patterns in data can be discerned without that pattern being explicitly programmed. In clinical medicine, the application of ML is in its infancy. Yet results in disparate clinical specialisations show the potential for the use of ML to outperform clinicians both in accuracy and efficiency of diagnosis based on the presentation of clinical data (Jie, Zhiying & Li, 2021; Codella et al., 2015; Gulshan et al., 2016). However, it has been argued that the opacity of the ML algorithms used for diagnostic purposes makes the attribution of responsibility for negative outcomes difficult or even impossible (Floridi, 2016; Morley et al., 2020). Accordingly, their use is often thought impermissible for the reasons given by Sparrow (2007), albeit in a different context. As Koskinen (Forthcoming) argues, there is no one who can take full, informed responsibility for the use of opaque ML algorithms. Dissenting from these views, I argue that the epistemic challenges posed by diagnostic ML algorithms are analogous to existing epistemic challenges in functioning healthcare systems operating under best practices such that the standard of full, informed responsibility can be seen to be impracticably and unjustifiably high: clinicians already operate under conditions of epistemic opacity in ways which do not create responsibility gaps, and which would not meet this standard.

This includes practices of prescribing the prescription of common drugs of known efficacy which nevertheless have opaque mechanisms of action (most notably including paracetamol). Moreover, it also includes circumstances in which the cognitive limitations of physicians constrain knowledge about mechanisms of action. Indeed, even where mechanisms of actions are in-principle knowable (most notably in general medicine settings), physicians justifiably often depend on knowing the efficacy of various drugs rather than their mechanism of action. Despite the relevant forms of opacity, clinicians act permissibly – and culpably – in both sorts of case. Turning to the clinical use of algorithms, I note that the use of decision tree algorithms does not lead to responsibility gaps. Physicians have long used decision trees in general medicine (Greep & Siezenis, 1989; Podgorelic et al., 2002) to aid in determining treatment options based on probabilistic efficacy following the input of relevant clinical information. They have also been used for the purposes of diagnosing (Podgorelic et al., 2002), with much the same justification. Yet just as physicians in general medicine settings may permissibly be unaware of relevant mechanisms of action, they may permissibly be unaware of the details of how relevant complex decision tree algorithms arrive at recommendations. Importantly, the use of decision tree algorithms neither supplants physician decision-making nor undermines the appropriate ultimate attribution of responsibility. I will argue that this model of physician use of algorithms remains appropriate with respect to opaque ML algorithms. Moreover, provided that the efficacy of the opaque ML algorithm is known, the analogy with paracetamol and other effective but opaque drugs holds. Accordingly, responsibility can be attributed in familiar ways.

Public Health Affinity Group, Regency C

Jennifer C. Tillman, Andrea Kalfoglou, Carina Fourie

The aim of the Public Health AG is to create space for cross-disciplinary and collaborative thinking for ASBH members who are interested in the intersection of public health and ethics. To this end, we will host thematic roundtables for open discussion. Themes will include critical issues for public health research, identified by members of the AG prior to the meeting, as well as teaching public health ethics. We will conclude the meeting with a general discussion about our agenda and leadership for the AG in the coming year.

Rural Bioethics, Frisco Burlington

Stephanie Larson

Social Work, Regency B

Sophia Fantus

6:00 PM - 7:00 PM

Newcomers' Social

First-time attendees, new members, international attendees, and students are invited to join us for refreshments and the chance to connect with ASBH leaders!

Friday, September 20, 2024

7:00 AM - 9:00 AM, Midway West Foyer

Breakfast

7:30 AM - 8:30 AM

Affinity Group Meetings

Holocaust Genocide Contemporary Bioethics, New York/Illinois Central

Matthew K. Wynia

LatinX Bioethics, Regency A

Nicole Martinez

Literature & Medicine, Missouri Pacific

Constantine Psimopoulos

Medical Decision Making, Frisco Burlington

Emily Grime

Nursing, Grand A

Brenda Barnum, Lorri Birkholz, Linda Breslin, Shika Kalevor, Michael Martin

Our presentation “AI’s Impact on Nursing: The Good, the Bad, and the Ugly” will present participants with information on the impact of AI on the nursing profession for bedside care providers and educators.

Organizational Ethics, Grand B

Emily Grime, David Meyers

Psychiatry and Psychotherapy, Grand C

Garson Leder, Julia Knopes, Brent M. Kioud

The Psychiatry and Psychotherapy affinity group will host two presentations related ethical and conceptual issues in psychiatry and psychotherapy. Each presentation will be approximately 15 minutes, with approximately 10 minutes for questions. We will use the balance of the hour for planning future AG meetings.

8:45 AM - 9:45 AM, New York/Illinois Central

Bioethics During Wartime

Emily E. Anderson, Donal O’Mathuna, Elizabeth Dotsenko, Abdul Rahman Fares

Diversity, Disparity, and Inclusion

War creates unique ethical challenges for healthcare providers and researchers. Yet bioethics as a discipline has not actively engaged with the ethical challenges of healthcare during war. Accounts of such ethical dilemmas come not only from those operating in military or humanitarian aid contexts but also those continuing in their “usual” civilian jobs amidst armed conflict. This panel provides interdisciplinary and international perspectives on the ethical challenges of providing healthcare and conducting health research during war. Importantly, we will center the experiences of those on the ground. Our first speaker and panel moderator, an Irish expert in disaster bioethics, will review critiques of bioethics as ignoring war, introduce humanitarian ethics frameworks, and discuss their shortcomings for situations of armed conflict. Our second speaker, a Syrian empirical bioethicist, will share findings from in-depth qualitative interviews exploring the ethical challenges experienced by healthcare providers in Syria and their difficulties in applying traditional ethical frameworks for disasters within the context of revolution and war. The third speaker, an American empirical bioethicist, will share findings from another qualitative study examining ethical challenges conducting and reviewing health research during active conflicts around the world. The final speaker, a Ukrainian physician and bioethicist, will reflect on her personal experience providing humanitarian medical aid in her country since February 2022 and compare this with her previous humanitarian medical service in Iraq. Together, we hope to advance the engagement of American bioethics with the unique and complex ethical decisions required of clinicians and researchers during war.

8:45 AM - 9:45 AM, Midway 3-4

Paper Session: Clinical Ethics: Parenthood

Clinical Ethics

Compassionate Transfer and In Vitro Fertilization: Difficulties Discarding Potential Children

Olivia Schuman

Defining the Threshold of Human Birth: Ethical Introduction of Artificial Placenta (AP) and Artificial Womb (AW)

Technology in the Neonatal Intensive Care Unit (NICU)

Phillip Wozniak

Infertility, Involuntary Childlessness, and Inclusion

Amanda Roth

8:45 AM - 9:45 AM, Midway 5

Paper Session: Data and the Public

Law, Public Health Policy, Organizational Ethics

Off the Record: Ensuring Privacy Protections in Free and Charitable Health Clinics

Callie Terris

Patient privacy, transparency, and disclosure: Exploring the disclosure of hospital data sharing practices to diverse patient populations

Kayte Spector-Bagdady

What's in your voice? Examining patients' perceptions and concerns about the collection, sharing and storage of voice data

Marie-Françoise A. Malo

8:45 AM - 9:45 AM, Midway 7-8

Paper Session: Envisioning Equitable Healthcare for Marginalized Communities

Diversity, Disparity, and Inclusion

Enacting “bounded justice” through HIV integrated planning in the United States

Nivan Wadhawan

Reinterpreting Humanity in Inhumane Conditions: Ethics, Illness, and the Invisibility of Mass Incarceration

Manu S. Sundaresan

8:45 AM - 9:45 AM, Regency C

Forming Humans in Health Care: Virtue Formation for Trainees in Diverse Settings

Education/Interprofessionalism

Brett McCarty, Travis Pickell, Ethan Stonerook, Victoria Yunez Behm

What does it mean to form humans well for the work of health care? There has been an increased interest in the formation of character in medical education, and this panel explores that work beyond the education of medical students. This work, of course, raises a whole host of other questions (e.g., 'whose humanity?' and 'which virtues?'). This panel seeks to answer those questions through three case studies, with each describing the work of virtue formation within a particular setting and student population. In other words, this panel seeks answers to these major formational and philosophical questions by induction. The bioethicist moderator will begin by introducing the panelists and the questions pursued through these case studies. Next, an ethics professor will discuss a cohort-based model of character education that introduces pre-med and nursing students to virtues such as attention, compassion, and courage. The program considers these virtues in the light of healthcare settings and in dialogue with clinical mentors. A bioethics and humanities professor in PA education then will discuss a 24-month course focused on love as the primary work of patient care, and attention as the primary act of love. This course stretches students across cognitive, affective, and psychomotor learning domains to explore the ethical praxis of medical humanities at the bedside and beyond. Finally, a physician and medical educator will describe a program for medical residents that cultivates practices of attention so that residents can pursue healing and flourishing for healers and patients alike, despite malformative healthcare ecosystems.

8:45 AM - 9:45 AM, Midway 9

Hospital or Prison: Navigating Ethical Care in Incarcerated Settings

Clinical Ethics

Grace Oei, David Chooljian

Hospitalized patients who are in custody present unique ethical and legal challenges. This panel, composed of a physician-ethicist, a physician-ethicist-lawyer will present on the pertinent ethical and legal issues that may cause conflict. The discussion will use three cases to highlight disputes that can occur around confidentiality, safety, and surrogate decision-making. The cases will cover the following questions: 1. Can law enforcement block the release of health information to family members, citing concerns for patient safety? 2. Can law enforcement request attempt resuscitation/full treatment against the surrogate's wishes, citing a compelling government interest in keeping the patient alive? 3. Is the patient ethically or legally harmed when law enforcement confidentially identifies the patient's surrogate decision-maker as one of the patient's alleged victims to the patient's medical team? The panel discussion will end with resources to aid clinicians in navigating between competing ethical, medical, and legal demands.

8:45 AM - 9:45 AM, Midway 6

Paper Session: Neuroethics and Research

Research Ethics and Social Sciences

Ethical and regulatory considerations for industry-academia partnerships in the research and commercialization of neurotechnologies: Insights from interviews with neuroethicists

Tristan McIntosh

Ground Truths without Grounding: Ethical Considerations for the use of Computer Perception to Help Establish Neural Signatures of Illness

Meghan E. Hurley

8:45 AM - 9:45 AM, Midway 11

Paper Session: Philosophy: Epistemology in the Clinical Encounter

Philosophy

Anger's epistemic value for clinicians

John D. Han

Epistemological Foundations of Understanding for Informed Consent

Eleanor Gilmore-Scott

Rethinking autonomy: Is it a norm-constituted property?

Brent M. Kious

8:45 AM - 9:45 AM, Regency B

Flash Session: Psychiatric Ethics

Clinical Ethics

Antidepressant Discontinuation During Pregnancy: Navigating an Ethical Dilemma and Understanding Patient Narratives

Soham S. Shah

Creative Communication - Assessing Decision-Making Capacity in an Adult with Selective Mutism

Nicholas R. Mercado

Group-Based Psychedelic Integration Communities

Katherine Cheung

Including Incapacitated Patients in Decision Making

Ryan H. Nelson

Mental Health Crisis Plans and Psychiatric Advance Directives: Creating a Collaboratively Designed How-To Guide for Autonomous Decision Making

Virginia A. Brown

Most Autonomous Care Versus Least Restrictive Setting and the Role of Psychiatric Advanced Directives

Grayson Holt

8:45 AM - 9:45 AM, Grand C

Paper Session: Racial Bias and Fairness in Healthcare Algorithms

Diversity, Disparity, and Inclusion

De-Implementing Race-based Algorithms: Factors Influencing the Transition to Race-neutral Interpretations of Pulmonary Function

Kadija Ferryman

Rethinking Technical Algorithmic Fairness

Abdoul Jalil Djiberou Mahamadou

The Materialized Oppression of Precision Medicine

Stephanie M. Fullerton

8:45 AM - 9:45 AM, Regency A

The Ethics of Patient and Public Engagement in Drug Development, Approval, and Access

Law, Public Health Policy, Organizational Ethics Matthew McCoy, Meghan Halley, Holly Fernandez Lynch, Emily A. Largent

Patients have long sought to have their humanity recognized in drug development, approval, and access decisions, demanding “nothing about us, without us.” Patient engagement has become an ethical expectation but also raises important challenges. How much influence should patient voices carry, particularly when their preferences conflict with public health goals? For example, patients sometimes advocate for weaker standards for FDA approval, expressing willingness to accept uncertainty in favor of speedier access to therapies. In other cases, patients advocate for payer coverage of high-priced drugs despite limited evidence of benefit. Further, current approaches to including “the patient voice” risk eschewing heterogeneous patient perspectives. In this session, experts in political science, anthropology, law, and bioethics will bring their diverse perspectives to bear on these questions, alongside lived experience in patient advocacy. The moderator will provide opening remarks describing foundational issues, followed by discussion of unique tensions arising in rare disease patient advocacy around research and drug development. Next, we will discuss new empirical data examining patient engagement in FDA drug approval decisions, including involvement in advisory committees as voting members and as contributors during public comment periods. Finally, we will discuss patient engagement with payers, sharing qualitative analysis of 10,000+ comments submitted by patients, families, and the public to the Centers for Medicare and Medicaid Services in response to its proposal to limit coverage for new Alzheimer’s drugs. Across each of these domains, we will consider pros and cons of patient engagement and strategies for balancing relevant ethical considerations.

8:45 AM - 9:45 AM, Grand A

TRANSforming Autonomy: Transgender Healthcare and the Politics of Choice Under Oppression

Diversity, Disparity, and Inclusion

Theodore Schall, Rebecca Sanaeikia, Elizabeth Dietz

This panel explores and troubles the normativity of autonomy in accounts of decision-making about gender-affirming care. Presenter 1, a health services researcher, will use empirical evidence to argue that autonomous decision-making is highly constrained by administrative burden and a range of material conditions that structurally undermine access to needed gender-affirming care. Efforts to improve patient understanding of informed consent are unlikely to enhance the autonomy of decision-making about gender-affirming care due to the structural barriers to such care; trans people respond to this context by justifiably pursuing DIY care. In an examination of the “informed consent model” of gender-affirming healthcare, Presenter 2, a science and technologies studies scholar, will clarify how the informed consent model of trans medicine reveals an intrinsic normativity to conventional bioethical accounts of autonomy. Rather than merely reform systems that endeavor to enhance autonomy, we ought to interrogate the work that aspiring to autonomy itself does by requiring the demonstration of individuated, capacitated, and informed subjectivity. Presenter 3, a philosopher, offers an account of autonomy based on the situated knowledge of transgender people. Some have claimed that trans people pursue gender-affirming care as an adaptive preference and therefore are not autonomous when they choose gender-affirming care. Presenter 3 claims that arguing against autonomy of trans people is an instance of epistemic silencing, and furthermore, that the main problem is not autonomy in the normative sense. This session will invite attendees to question the quotidian use of autonomy in transgender medicine and in broader bioethical inquiry.

8:45 AM - 9:45 AM, Grand B

Weighing the Ethics of Losing Pounds: Weight Loss and the GLP-1 Agonist Medications

Clinical Ethics

Amy Hohmann, Michael DiStefano, Linda B. Uchal

GLP-1 agonists used for weight loss such as semaglutide (Ozempic®, Wegovy®) and tirzepatide (Mounjaro®) have been some of the hottest drugs on the market recently. Their promise of dramatic weight loss without the need for significant changes in diet and exercise make them an attractive solution for the obesity-related health concerns for Americans. The demand for these drugs has increased so dramatically that manufacturers are unable to maintain production, leaving diabetes patients without treatment. Compounding pharmacies have entered the market to fill the gap, but some have been cited by the FDA for supplying products that do not meet standards. Insurance payers struggle to decide whether the cost of the drug should be covered while some underinsured patients may not have access at all. Direct-to-consumer advertising of clinics and online suppliers without careful medical oversight has become common. Risks with long-term use are still unknown and patients who have not made significant lifestyle changes during treatment face the possibility of being on the medication for a lifetime. This presentation will balance the beneficence of what has been found to be true improvements in cardiovascular and other health risks with the ethical tensions that can occur when the weight-loss medication supply chain struggles with cost and supply issues, attention to medical oversight and disclosure of risk can be overlooked in favor of profitability from increasing the number of patient visits, and inclusion of adequate support for lifestyle change is not part of the weight loss treatment plan.

10:15 AM - 11:15 AM, Grand B

Paper Session: Animals and Transplantation

Research Ethics and Social Sciences

Human Enough? Organ Chips and their Ethical and Social Implications

Melanie Jeske

Kidney Transplant Candidates' Information Needs for Informed Decision-Making about Participating in a First-in-

Human Pig Xenotransplant Clinical Trial

Elisa J. Gordon

Will Xenotransplantation Mitigate or Intensify Ageism in the Transplant System?

Laura Kimberly

10:15 AM - 11:15 AM, Midway 6

Paper Session: Clinical Ethics: Patient Preference and Bias

Education/Interprofessionalism

Leaving Against Medical Advice (AMA): What's a Nurse to Do?

Joan M. Walker

Responding to Discriminatory Requests/Refusals from Patients: Healthcare Providers' Experiences and Institutional

Recommendations for Policy

Claudia Barned

Weighing Patient Preferences: Lessons for a Patient Preference Predictor

Benjamin Schwan

10:15 AM - 11:15 AM, Regency A

Disability and Human Flourishing: Re-imagining the Role of Bioethics in Promoting a High Quality of Life with Chronic Health Conditions

Diversity, Disparity, and Inclusion

Kevin T. Mintz, Jaime Konerman-Sease, Joseph Stramondo, Liz Bowen

Decades ago, disability bioethicist Anita Silvers criticized mainstream bioethics for having a “fatal attraction to normalizing.” Even though the work of Silvers and other disability bioethicists have contributed to more nuanced discussions in bioethics about the role medicine should play in the lives of individuals with chronic health conditions, our field is still grappling with what it means to have a flourishing life with a disability and how ethics and the health humanities can play a role in helping disability communities achieve the highest quality of life possible. This interdisciplinary panel will grapple with the dilemma of how bioethics in medicine should promote disability flourishing. The first panelist, a clinical ethicist with a background in theology and literature, will explore how reliance on medical technology for objective signs of illness marginalizes patients whose symptoms cannot be captured by available technology. The second panelist, a philosopher, will draw on their lived experience of disability to articulate the concept of “disability gain” and its potential to challenge the orientation of bioethics and medicine to normalize disabled bodies. The third panelist, a political scientist with cerebral palsy, will explore how families of children with rare or undiagnosed disabling conditions conceptualize how their loved ones can flourish despite significant physical, sensory, or intellectual impairments. Finally, the fourth panelist, a disability studies scholar who teaches in a medical school, will consider what it means to incorporate examples of disabled flourishing into medical education when the concept poses conflicts with some of medicine’s fundamental goals.

10:15 AM - 11:15 AM, Midway 3-4

Paper Session: Health Humanities: Death and Dying

Health Humanities

Do No Harm? Medical Students' Moral Distress Witnessing Patients' Pain and Suffering
Who Says I'm Dead? Understanding Social Death and its Intersection with Bioethics

Cara Ferguson
 Ashley Yukihira

10:15 AM - 11:15 AM, Midway 5

Paper Session: Interprofessional Ethics Education

Education/Interprofessionalism

Ethics of Pain Management in Vulnerable Populations: Details and Development of a Vital Interprofessional Graduate Course

Esther I. Bernhofer

Integrating Trauma-Informed Principles in Neonatal End of Life Care: Lessons and Opportunities from an Interprofessional Project

Erin J. Keith-Chancy

Interprofessional Ethics Education: A Virtual Approach

Caroline Anglim

10:15 AM - 11:15 AM, Grand A

Only Human After All: Reflecting on the Risky Business of Sharing Stories with Strangers

Clinical Ethics

Virginia L. Bartlett, Gretchen Case, Stuart Finder, Andrea Frolic

Ethics consultants help make sense and find meaning among the “anarchy of voices” found within any clinical context by creating space for patient, family, and clinician stories to unfold. Sharing, making sense of, and finding meaning in consultants’ own stories of clinical encounters is less commonly engaged; appreciating such stories as moral activity deserving attention is even less common. Four panelists working in clinical ethics and medical humanities thus explore the question, “What does it mean to share stories of one’s own clinical practice and experiences?” First, a practicing clinical ethicist with a background in religious studies frames the idea that writing about clinical ethicists’ own experiences is a moral activity and hence opportunity for shared reflection on clinical ethics practice – one unavailable in writing case studies. Second, a philosopher and clinical ethicist explores historic resistance to personal stories for clinical ethics work, the result of which is retreat from clinical responsibility into role. Third, an anthropologist and clinical ethicist revisits the relevance of self-reflective, embodied, situatedness for clinical practice and considers the import of critical-interpretive medical anthropology and practices of autoethnography for clinical ethics work. Finally, a health humanities scholar and educator reflects on what clinical ethicists can learn from listening to stories told by clinicians, patients, and families and how a reciprocity of stories supports and informs ethical decision-making. The second panelist will moderate discussion among panelists and audience, inviting questions, critiques, and the sharing of attendees’ own stories about storytelling in clinical ethics work.

10:15 AM - 11:15 AM, Midway 9

Paper Session: Pain Care and Opioids

Law, Public Health Policy, Organizational Ethics

Bringing an Organizational Ethics Lens to Perioperative Pain Care: Insights from a Recent Pragmatic Trial Christina M. Audeh

From Naloxone to Nalmefene? Ethical Implications for Opioid Overdose Treatment

Mark C. Navin

10:15 AM - 11:15 AM, Midway 7-8

Paper Session: Philosophy: Re-examining the Principles of Care, Beneficence, and Confidentiality

Philosophy

An Immanent Critique of Care Ethics

Lindsay "Lou" Vinarcsik

Beneficence by Convention

Aaron E. Segal

Breaching Confidentiality in Genetic and Non-Genetic Cases: Two Problematic Distinctions

Madison Kilbride

10:15 AM - 11:15 AM, Regency C

Remaking Bioethics Together

Diversity, Disparity, and Inclusion

Stephen Molldrem, Jonathan D. Shaffer, Zackary Berger, Krishna A. Chokshi

This workshop aims to expand bioethics’ horizons of political possibility. Bioethics positions itself as a neutral arbiter; indeed, ASBH bylaws forbid the association from taking “positions on substantive moral and policy issues.” This puts

bioethics at odds with institutions like the World Health Organization and United Nations, which advocate universal healthcare as a right. Bioethics' neutrality prevents it from engaging in movements to build the healthcare system that most in the field say is needed – one which is equitable along lines of race, class, gender, and sexuality; redistributes resources towards the elimination of disparities; and ensures access. Bioethics also contributes to the institutional reproduction of academic medical centers (AMCs), which generally make profits by maintaining exploitative relationships with communities which provide them research subjects, patients, workers, and revenue. Clinicians at AMCs must then treat patients in desperate straits without adequate support, while being told by employers to center social determinants of health in their practices and to further the aims of patient safety and equity. However, rarely are these commitments reflected in AMCs' behaviors toward patients, communities, or employees. Instead, burdens are borne by healthcare workers and clinical ethicists, who address issues related to patient safety, quality, and equity for some of the most marginalized. Though the clinical ethicist's job is often to disambiguate issues for individual patients, they have a valuable potential role in advancing systems-level equity. We propose to re-envision bioethics' mandate to include advocacy to address the root causes of inequities, which requires courage and consensus.

10:15 AM - 11:15 AM, Grand D-F

The Independent Ethics Consultant: Joys and Practical Realities of Working for Yourself

Education/Interprofessionalism

Wendy Kohlhase, Janine D. Siegel, Melissa Bottrell

Significant scholarship exists about the role, responsibilities, and skills required of clinical ethics consultants working as staff in organizations. Fewer articles describe the role, experience, and practice management of the independent ethics consultant (IEC) (i.e., not staff for an organization). Bramstadt (2022) described her international experience in the role, but this scholarly approach may be less reflective of the lived experience of the typical individual looking to build and maintain an independent ethics consultation practice. Questions arise around getting a “foot in the door,” working with facility staff (including an organization's ethics committee), managing access to patient records and data privacy, managing IEC practice records, quality control/peer review, billing, contracting, professional liability insurance, marketing, surviving hospital leadership changes and mergers, and a host of other items. In this panel, three IECs with a combined 35+ years of lived experience performing independent clinical and organizational ethics consultations will discuss their experience initiating, developing, managing, and potentially selling an IEC practice. Speaker 1 will describe their experience providing clinical and research ethics consultation to both community and academic facilities across three counties. Speaker 2 will describe their experience developing a practice that includes a state-run psychiatric facility and diverse community organizations. Speaker 3 will describe their experience contracting with hospitals and public agencies (federal and county) to develop ethics (clinical and organizational) programs with an eye toward building ethics skills in organizational staff.

10:15 AM - 11:15 AM, Regency B

To Be Human is to Be Vulnerable: Protecting Vulnerability in Human Subjects Research

Research Ethics and Social Sciences

Angelo Cadiente, Bryan Pilkington, Jamie Chen

To be human is to be vulnerable. Originally, vulnerability was associated with individuals with certain biologic traits, but recent shifts broadened the definition to rely on a spectrum of biologic reality, socioeconomic status, and contextual circumstance. Its purpose is to protect certain populations in research, requiring a consistent application of ethical principles; yet, its use becomes challenging as perceptions evolve: how do we balance the inclusion of diverse populations in research while also acknowledging the structural biases at play? Our panel seeks to explore the framework that defines a vulnerable research population and seeks to better understand Institutional Review Boards (IRBs) as the appropriate oversight entities. IRBs play a significant role in implementing inclusion aims; however, there is a lack of empirical data on how IRB professionals understand vulnerability and the factors that influence their decision-making, especially given the evolving scholarship. This detail is a crucial piece in the proverbial protection puzzle that determines whether vulnerable persons can be protected consistently. Our panel will feature findings of our recent study on IRB professionals' perceptions of vulnerability and its implications for research oversight. We will also explore ethical values prioritized during the review and discuss potential differences between the regulation-focused approach that IRB professionals appear to take in their oversight work and their own understandings of vulnerability within the research context.

10:15 AM - 11:15 AM, Grand C

Paper Session: Trust and Identity in Medicine

Diversity, Disparity, and Inclusion

“You haven’t studied for this”: How individuals navigate moral and ethical challenges in their role as cancer care partners

Clare Whitney

Attitudes Toward Medical Research Among Adolescent Patients and Parents of Children with Sickle Cell Disease: It’s All About Trust and Human Relationships

Liza-Marie Johnson

Ethical Moments and Professional Identity Formation in the Context of Cross-Cultural Identities

Dharshini Suresh

10:15 AM - 11:15 AM, New York/Illinois Central

What makes a Clinical Decision Support tool fair?

Law, Public Health Policy, Organizational Ethics

William F. Parker, Monica Peek, Valerie G. Koch

Healthcare systems increasingly embed “Clinical Decision Support (CDS)” tools into the electronic healthcare record. CDS tools use AI-generated algorithms to identify patients at high risk for important clinical outcomes and prompt clinicians to take specific treatment actions. Ensuring that CDS tools lead to fair treatment for patients belonging to disadvantaged groups is of critical bioethical and legal importance. Panelist 1, a pulmonary and critical care physician, clinical ethicist, and data scientist, will open the AI “black box” and non-technically explain the relevant statistical details to the audience using a case study of a CDS designed to trigger palliative care consults for hospitalized patients at high risk of death. They will introduce and apply three mutually exclusive definitions of algorithmic fairness (independence, separation, and sufficiency) to the CDS case. Panelist 2, a general internist, bioethicist, and health equity scholar, will react to these formal definitions of algorithmic fairness. They will argue that a deep understanding of structural inequity in US healthcare is essential when selecting an algorithmic fairness definition for a specific clinical situation in which a CDS is deployed to avoid biased treatment against disadvantaged groups. Panelist 3, a health law scholar, will analyze how US anti-discrimination law applies to CDS tools. They will specifically discuss which algorithmic fairness definition best aligns with the law. They will also discuss the potential legal implications for healthcare systems that ignore anti-discrimination laws when implementing CDS tools.

11:30 AM - 12:30 PM, Grand C

Paper Session: Assessing Clinical Ethics Education

Education/Interprofessionalism

Educational Needs Assessment of Fetal Therapy Board Members

Michele D. Anzabi

Pulling the Plug on Futile “Ethics” Education

James M. DuBois

Teaching Clinical Ethics for Professional Chaplaincy Competency: A Process Improvement Study

Craig D. Katzenmiller

11:30 AM - 12:30 PM, Regency C

Between Humanity and AI: What is memory? How do we connect?

Health Humanities

Ashley Hope, Juliet McMullin

A critical role of computers and artificial intelligence (AI) is the storage of information as memory and the application of memory to perform tasks. The design of computers and AI systems was greatly inspired by the human brain. Indeed, Alan Turing modeled his computer programming after the child brain. A question in medicine is whether AI’s growing abilities and capacity for memory represent a threat to physicians. We explore this in the context of psychiatry through Louisa Hall’s novel *Speak* by considering: What makes memory human? What makes connections human? The first therapy chatbot, ELIZA, launched in the 1960s as an early answer to the Turing Test of whether a machine could display human intelligence. Audiences were so captivated by ELIZA’s understanding and motivation, that its creator Joseph Weizenbaum cautioned against the projection of human traits to a computer program – the “ELIZA effect”. Yet, the advancement of therapy chatbots has continued; several are available in popular smartphone applications for mental health, leaving us to consider the space between humanity and AI. The novel, which considers life within this space, acts as a point of reflection and departure: “Before long, computers will have the capacity to store far more information than we can. But I’d remind you: one day that machine will remember your words, but it won’t ever feel them. It won’t understand them.” We posit that memory is human when it is lived and embodied, that human connection is built on memories of moments lived and embodied together.

11:30 AM - 12:30 PM, Midway 5

Paper Session: Clinical Ethics: Pediatric Ethics

Clinical Ethics

“I work with you, but I work for your child”: Clinicians’ Management of Ethical Dilemmas in Caring for Children with Food Allergies

Jill A. Fisher

Pediatric Clinician Viewpoints on Treatment Options for Infants with Single-Ventricle Physiology with and without Chromosomal Abnormalities

Benjamin R. Hauser

11:30 AM - 12:30 PM, New York/Illinois Central

Paper Session: Clinical Ethics: Surrogate Decision Making

Clinical Ethics

Surrogate Decision Making in the Aftermath of Intra-Family Violence

Patrick D. Herron

The (In)Capacity to Exclude: The Normative Value of Preferences in Surrogate Exclusion

Megan Kitts

The Volitional Approach to Surrogate Decision-Making

Pierce Randall

11:30 AM - 12:30 PM, Midway 7-8

Paper Session: Data Sharing and Industry

Research Ethics and Social Sciences

Assessing the value of patient data: A qualitative exploration of hospital/industry data partnerships

Katherine Hendy

Participant Perspectives on Data Sharing in Craniofacial Research: Qualitative Interviews with Participants with

Craniofacial Microsomia and Their Caregivers

Stephanie A. Kraft

Sharing Patient Data with Industry: A qualitative exploration of approaches and ethical considerations among academic medical centers

Katherine Hendy

11:30 AM - 12:30 PM, Midway 9

Equity and Engagement Through Innovative Research Frameworks: Results from human genomic studies

Diversity, Disparity, and Inclusion

Shawneequa Callier, Caitlin E. McMahon, Maya Sabatello, Jenny Reardon

Despite progress in articulating goals of diversity, equity, and inclusion in precision medicine and genomics research, a systematic method for assessing equity, justice, and benefit for the communities targeted for these studies remains elusive. There is a need for more research on how researchers in genomic studies, many of which involve multiple institutions, nations, and regulatory regimes, seek to establish fair and transparent partnerships with groups and communities. The panel will present an array of perspectives on what constitutes equitable community partnerships. It will draw on panelists’ research methods and expertise in various fields, including law, political science, sociology, history, bioethics, and ELSI, highlight gaps in existing work, identify challenges in implementation efforts, and illuminate innovative approaches for engaging communities of people with disabilities, research participants from the global south, and marginalized racial and ethnic groups. This multidisciplinary, multi-career stage panel will enhance attendees’ knowledge of the regulatory spaces, ethics frameworks, and complex dynamics that shape interactions between communities and institutions and present real-world examples of equity-driven research approaches designed to elevate community interests. Taken collectively, these varied presentations will highlight the potential for genomic research to recognize marginalized communities’ humanity and rights to self-determination by innovating within and intervening on the power relations that typically characterize the research ecosystems in which they exist.

11:30 AM - 12:30 PM, Midway 11

Paper Session: Ethics Engagement and Integration

Education/Interprofessionalism

Mapping Approaches to Ethicist Engagement: The VIPER Framework

Blake Hereth

Optimizing Clinical Ethics Committee Utilization in a Large Teaching Hospital: Identifying Barriers and Proposing

Solutions for Improved Patient Care

Tiffany T. Vembenil

11:30 AM - 12:30 PM, Grand A

Paper Session: Humanizing Healthcare: Dignity, De-humanization, and Refugees

Philosophy

Can Patients with Disorders of Consciousness Be Wronged?

Aleksy Tarasenko-Struc

Can We Do Ethics Without Dignity? Kierkegaard's Works of Love as a Test Case

Randall G. Colton

Humanizing Healthcare: Integrating Compassionate Practices for Refugee Well-being

Eva Regel

11:30 AM - 12:30 PM, Grand D-F

Legal Update 2024: Top 10 Legal Developments in Bioethics and Public Health

Law, Public Health Policy, Organizational Ethics

Arthur R. Derse, Paul A. Lombardo, Valerie Gutmann Koch

Each year brings important legal developments related to bioethics. This panel will discuss the latest legal trends of significance for ASBH members. This annual panel has been well-attended and popular for the past 13 years. As in the past, this year's panel will be interdisciplinary and diverse – in terms of topics covered and the speakers' areas of expertise, geographic regions, and institutional affiliations. In keeping with the conference theme, the panelists will address public discourse in the intersections of law with bioethics, public health, and society through a review of the major legal developments in areas with a range of bioethical concerns in a changing landscape of judicial, legislative, and administrative decisions and actions in bioethics-related law. Relevant recent legal developments include those affecting our diverse communities, delineating challenges and potential paths forward for individuals, health professionals, and populations at the state, federal, and international levels. Panelists will cover areas of interest to the diverse areas of expertise of the ASBH audience, representing a breadth of key areas in law and bioethics. Major legal developments addressed include: • Reproduction, assisted reproductive technologies, genomics and issues concerning vulnerable populations, e.g., individuals with disabilities (Panelist 1); • Aid-in-dying/Medically-assisted death, and withdrawal/withholding of life-sustaining treatment (including DNR and POLST orders); Brain death (including unilateral withdrawal of somatic support), fertility, and informed consent/unwanted medical treatment/conscience claims (Panelist 2); • Public health law, government regulation of behavior and research ethics (Panelist 3) All ASBH attendees are invited to discuss these emerging legal trends.

11:30 AM - 12:30 PM, Midway 6

Paper Session: Moral Distress

Education/Interprofessionalism

Clinical Ethics Needs Assessment in Pediatricians and Pediatric Residents Working in Ethiopia: A National Survey Angela Knackstedt

Differences in Ethical Issues and Moral Distress in Medical Students on Obstetrics and Gynecology Clerkship Based on Setting (Catholic vs. Public Hospital) Anita Puyear

Praise and Moral Distress

Timothy Kwiatek

11:30 AM - 12:30 PM, Grand B

Paper Session: Professionalization of Ethics Consultations

Clinical Ethics

A Methodology for Consensus in Clinical Ethics Consultation

Jamie C. Watson

Characterizing Complexity in Clinical Ethics Consultations

Eleanor Gilmore-Szott

Ethics (At Your) Service: Pros and Cons of a Broad Understanding of Clinical Ethics Consultation

John Frye

11:30 AM - 12:30 PM, Regency B

Flash Session: Research Ethics

Research Ethics and Social Sciences

A Qualitative Interview Study Exploring Ethical Issues Associated with International Surgical Teaching Collaborations in Ophthalmology Cyrus Daruwalla

Empowering Parkinson's Patients: Proactive Consent for Optogenetic Trials

Peyton Swanson

Ethics Considerations in Designing a Research Protocol with and for Women Experiencing Homelessness and Women Who Are Incarcerated Kirsten Dickens

Expressions of (Mis)trust: How trust is expressed for public health programs among African American, Hispanic/Latino, and Arab American Communities in Michigan. Dalya Saleem

Moral Resilience and Moral Injury of Nurse Leaders during Crisis Situations: A Qualitative Descriptive Analysis Alanna Bergman

Trustworthiness in Dentistry: Results from an Ethics Scoping Review

Lori Rainchuso

11:30 AM - 12:30 PM, Regency A

The "Ethics" of Clinical Ethics: The Elephant in the Room

Clinical Ethics

Matthew Shea, Joseph A. Raho, James A. Hynds, Rashad Rehman

Despite broad consensus in recent years that the purpose of clinical ethics consultation is to identify, analyze, and resolve ethical issues that arise in patient care, surprisingly little attention has been given to the question of what constitutes a distinctively ethical issue in this domain. What are we doing when we “do” clinical ethics? What does it mean to be engaged in ethics as a professional practice? When contacted by a clinician or patient, how should the ethicist understand her role qua ethicist? Is she being asked to analyze an issue of general morality, professional morality, conventional morality, or something else? At stake is the proper framing of our normative role as ethicists. Answering this meta question strikes at the core of our professional identity and remains conceptually prior to discussions of method and moral expertise. Our panel will wade into this debate. Following an introduction, the first panelist will discuss the relationship between general ethics and clinical ethics, arguing that clinical ethics cannot remain neutral on substantive, contested moral issues and should to some extent engage with general ethics. The second panelist will argue that clinical ethics presupposes some metaphysical-moral framework, especially assumptions about human nature and personhood. The third panelist will contend that clinical ethics is a second-order discipline, identifying and applying prevailing conventional rules of good practice, with room for innovation in virgin territory by organic extension of existing moral rules. Concluding remarks will draw implications for the field in light of continued efforts at professionalization.

11:30 AM - 12:30 PM, Midway 3-4

What Does It Mean to be Human in Healthcare? Empirical, Conceptual, and Pedagogical Facets of Applying “Flourishing” to Health Professional Education

Education/Interprofessionalism

Christina M. Audeh, Fabrice Jotterand, Aasim I. Padela, Jon Tilburt

In recent years, concerns regarding adverse mental health, low morale, and burnout among healthcare professionals, trainees, and students have garnered significant attention. While efforts have focused on mitigating the negative effects associated with healthcare education, training, and work, there is a growing recognition of the importance of fostering positive well-being within these spaces. Flourishing, a concept grounded in Aristotelian ethics, capability theory, and positive psychology, aims at human well-being broadly construed—including, but not limited to, happiness, relationships, mental/physical health, economic stability, and virtue. In health professional education, it proposes longitudinal collective facets of vibrant and sustainable professions beyond burnout mitigation and personal wellness strategies. Our panelists, who work as educators and researchers in healthcare and academic settings across the U.S., will offer a variety of perspectives on applying “flourishing” to healthcare work and education. They will discuss empirical, conceptual, and pedagogical intricacies of whether and how to apply flourishing in health professional education, using learners in the undergraduate and graduate medical education context. The first panelist will review empirical evidence and contemporary definitions of flourishing. The second will explore philosophical dimensions of flourishing with respect to the philosophy of medicine and how it applies to patients, communities, and professionals. The third will offer constructively critical reflections on the difficulties of applying flourishing in contemporary society. The fourth will explore the implications of prior insights for pedagogical strategies, including what is or is not/ought or ought not be the scope of a clinical teacher’s responsibility to promote flourishing among learners.

12:30 PM - 1:45 PM

Lunch on Own

Attendees have time to grab lunch from the surrounding area's many dining choices. Select the "Food and Drink" tab in the conference app to learn more about the available options.

12:45 PM - 1:45 PM

Affinity Group Meetings

Clinical Ethics Consultation, Regency B

Joyeeta Dastidar, Stowe L. Teti

Dental Ethics, Missouri Pacific

Thomas Holt, Alma Clark

Ethics and Humanities Educators in the Health Professions and Residency Training, Grand A Allison Lyle, Sheria Wilson
 The Ethics and Humanities Educators in the Health Professions and Residency Training Affinity Group session will include oral presentations that highlight innovative approaches that integrate ethics and humanities curricular programming goals.

Health and Science Policy, Grand B

Virginia A. Brown

Neuroethics, Frisco Burlington

Ian Stevens, Christopher Masciari, Daniel Moseley, Peter Zuk

The 2024 meeting of the Neuroethics Affinity Group will feature three short talks with Q&A sessions on the topics of i) treatment resistance in neuropsychiatry, ii) motivational barriers to treatment adherence and potential strategies for mitigating them, and iii) partiality toward humanity in the context of post-human enhancement: “An exploratory review of the ‘treatment resistant’ phenomenon in neuropsychiatric disorders as a normative criterion for surgical intervention” Ian Stevens, M.A. (co-authors: Gabriel Lázaro-Muñoz, Ph.D., J.D. and Joseph J. Fins, M.D., M.A.C.P., F.R.C.P.) “Motivational Barriers to Care and the Ethics of Encouragement” Christopher F. Masciari, Ph.D. “Partiality for Humanity and Prudent Vigilance about Human Enhancement” Daniel D. Moseley, Ph.D.

Pediatric Ethics, Regency A

Gitanjali Arora, Douglas Diekema, Emily Johnson, Vanessa Madrigal

Despite advances in technology, therapeutics and parent/patient inclusion in decision-making, conflict between family and the medical team does arise. In most circumstances the multi-disciplinary teams involved in these cases can work together and find common ground. In others, despite best efforts, and dedicated time, the family and team remain at an impasse. Biomedical ethics frameworks and consultants have remained at the forefront of understanding and working through these dilemmas. The harm principle, for example, has provided excellent guidance for clinicians working with parents and understanding when the parent’s view of best interest allows for unacceptable harm. During our monthly meetings, PEAG members have reported continued struggles with the nuance of when to involve Child Protective Services and what qualifies as “significant risk of serious and imminent harm” particularly when evidence based medicine does not entirely apply to the individual patient in question, thus leaving prognoses and timelines uncertain. In addition to parent refusals, many clinicians are also encountering increasing volume of parental requests for specific treatments that may or may not be evidence based. Many requests might be honored when considered neutral or having a possible benefit. Some may easily fall into a category of unquestionably harmful, allowing for no obligation on behalf of the clinician to comply. A grey zone may exist here as well, allowing for possible token of compromise with the family but leaving the clinician uncertain. Further questions ask if we apply equity in many of these uncertain cases. Do we allow the rules to bend with some parents but not with others? What attention do we give to equity when considering these challenging questions? Are we consistently asking the challenging questions that may uncover implicit bias? The session will consist of a multidisciplinary panel of national experts who will participate in a case-based discussion that covers advanced communication, trust building techniques, and how to approach situations when parents refuse recommended therapy and request non-standard therapy. Dr. Madrigal (current PEAG chair) will moderate discussion, using a mixture of (1) pre-prepared questions that are developed with Dr. Kingsley (co-chair) and the panelists, (2) live audience questions, and (3) a break out session, to generate conversation

Religion, Spirituality & Bioethics, New York/Illinois Central

Jeff Matsler

Surgical Ethics, Grand C

Sundeep Grandhe, Sabha Ganai

Our session will include discussions on critical topics in surgical ethics, including informed consent, the ethical implications of introducing new surgical techniques (with a focus on AI), end-of-life decisions and palliative surgery for terminally ill patients, and equity in access to surgical care.

12:45 PM - 1:45 PM, Grand D-F

Core Competencies, 3rd Edition Listening Session (Option 3)

Alex Kon

Clinical Ethics

Join us at one of our three listening sessions to share your feedback on the current draft of our forthcoming Core Competencies for Healthcare Ethics Consultation, 3rd Edition text. The draft will be circulated through the ASBH website prior to the conference. Please come to the listening session having read the draft with feedback prepared. Our moderators are available to receive questions and feedback for use in the drafting process but may not be able to respond to all inquiries during the session.

12:45 PM - 1:45 PM, Regency C

Narrative Medicine as Disability Justice: Using Semi-Structured Interviews to Illuminate the Stories of Healthcare Professionals with Disability and Chronic Illness

Diversity, Disparity, and Inclusion

Ben Martin, Farah Contractor

Although the CDC reports that up to 27% of adults in the United States have a disability, some studies report only 3% of physicians in the United States self-identifying as disabled. Similarly, there are limited personal accounts of healthcare professionals (HCPs) living with chronic illness. Yet personal stories of disability and illness are necessary to illuminate the breadth of intersectional identities in our professional sphere. Engaging with such stories is a unique educational opportunity to replace conventional academic hierarchies with one that honors the expertise of lived experience. Attention to the expertise of HCPs and students with disability and chronic illness will expand normative perceptions of who can and should be HCPs with the ultimate goal of dismantling structural ableism, increasing opportunities for all people to enter into the healthcare professions. Furthermore, embracing disability narratives from within the biomedical establishment will contribute to public awareness of access intimacy – in which able bodied people are asked to inhabit the world of people with disabilities – ultimately helping deepen connections between HCPs, our colleagues, and patients. We propose a highly interactive narrative medicine session to teach participants how to write stories of disability and chronic illness using information obtained from a semi-structured interview. In doing so, we aim to provide a guide for soliciting narrative information in much the same way mnemonics and lists are used as structural aids when obtaining a medical history, with an ultimate goal of increasing visibility of HCPs with disability and chronic illness.

2:00 PM - 3:00 PM, Regency A

Anatomical Dissection in Antebellum Saint Louis

History, Religion, and Culture

Andrea Thornton, Michelle Bach, Kelly Schmidt

Grave robbing has long been a topic of interest and controversy in the history of medicine. From the stories of Mark Twain to the discovery of bones in the basements of medical colleges, Americans have had to face the myth-shattering image of the outlaw scientist who has taken advantage of the dead. We believe this history forces modern day physicians to grapple with fundamental identity questions within medicine. The way that medical practitioners have treated the dead is revealing about medicine's understanding of what it means to be human. When we couple this with the clear racial bias of grave robbers, we must interrogate the assumptions embedded in our history: are some bodies human enough to be studied but not human enough to receive medical care? This panel will consider the history of anatomical dissection and the sourcing of bodies locally, at our own institutions. We ask, "What evidence exists of grave robbing in St. Louis?" and "What does that evidence mean for us today?" We come from multiple disciplines: history, theology, ethics, and medicine. After extensive review of city records and medical school archives, we believe that grave robbing was vibrant in St. Louis, and that it may even have been a distribution center for nascent medical schools in the north. In this panel we will present those findings and discuss the importance of this history for medical education today.

2:00 PM - 3:00 PM, New York/Illinois Central

Paper Session: Approaches for Supporting Health Equity

Diversity, Disparity, and Inclusion

ADVANCING HEALTH EQUITY: A Guide to Language, Narrative and Concepts – Practical Applications at an Academic Medical Center

Maria A. Basile

Do No Harm: Adopting a Community-Engaged Approach to Medical Education to Combat Ableism, Stigma, and the Dehumanization of People with Disabilities

Rachel Conrad Bracken

Shared Goals, Different Approaches: Lessons Learned from Collaboration between an Ethics Consultation Service and a Novel Healthcare Equity Consultation Service

Rachel Brownson

2:00 PM - 3:00 PM, Midway 6

Paper Session: Clinical Ethics: Trauma Informed Care

Clinical Ethics

Ethically Engaging "Complex" Patients in the Clinic: Functional Neurological Disorders, Factitious Disorders, and the (Ethical) Importance of Knowing the Difference

Devora Shapiro

Trauma-Informed Care: A Unique Framework for Consent

Stephanie Tillman

2:00 PM - 3:00 PM, Midway 7-8

Paper Session: Frameworks for Supporting Just Systems of Care

Diversity, Disparity, and Inclusion

Integrating Social Justice into Bioethics: Insights from a US-Canadian Survey of Bioethicists

Zamina Mithani

Putting Epistemic Justice into Practice: The Case of the Knowledge Encounter

Susan Lee

The Ladder of Inference as a Tool to Reduce Implicit Bias in Neonatal Intensive Care Unit (NICU) Clinical Practice

Beatrice Lechner

2:00 PM - 3:00 PM, Grand D-F

Hospital Policy Variation in Decisions to Withhold or Withdraw Life-Sustaining Treatment

Diversity, Disparity, and Inclusion

Gina Piscitello, Patrick G. Lyons, Valerie G. Koch, Michael T. Huber

Decisions to withhold or withdraw life-sustaining treatment (LST) for critically ill patients can be ethically controversial, especially when disagreements over these decisions exist among clinicians, patients, and surrogates. Sociodemographic disparities make this issue particularly fraught, especially in light of recent evidence that clinicians disproportionately make unilateral decisions to withhold LST for patients in certain vulnerable populations. For example, clinicians more often use unilateral do-not-resuscitate orders for Spanish-speaking patients and more often withhold extracorporeal life support for patients who are female, insured by Medicaid, or live in low-income neighborhoods. This panel – composed of experts in palliative medicine, critical care, clinical ethics, and law – will describe and explicate how United States hospital policies currently address decisions to withhold or withdraw LST in ethically controversial scenarios and explore how these policies ought to address these scenarios. First, we will explore the findings of a national study of American Society of Bioethics and Humanities members assessing the content of hospital policies from all 50 US states, Puerto Rico, and Washington DC. This work has demonstrated that hospital policies vary in (1) their approaches to ethically controversial scenarios amidst clinician, patient, and surrogate conflict and (2) how (if at all) they address sociodemographic disparities related to withholding or withdrawing LST. Subsequently, we will discuss important ethical and legal implications arising from the results of this study. Last, we will explore how hospital policies may be updated to better address sociodemographic disparities in clinician decisions to withhold or withdraw LST.

2:00 PM - 3:00 PM, Midway 9

Paper Session: Novel Technology Research Ethics

Research Ethics and Social Sciences

Can we just say no? Towards a Tolstoyan criterion of technological progress

Joseph Jebari

Ethical Frameworks and Digital Therapeutics

Odia Kane

Role of 'virtual' biopsies in oncology clinical trials: The potential to resolve ethical conundrums of research biopsies

Heather Whitney

2:00 PM - 3:00 PM, Grand C

Paper Session: Organizational Ethics and the Public Good

Law, Public Health Policy, Organizational Ethics

Individual Liberty and Opting Out of Mosquito Control

Casey Chmura

Protecting the public from egregious wrongdoing by physicians: Results from a policy implementation workshop with state medical boards

Tristan McIntosh

Watching the Watchers: How State Healthcare Disciplinary Boards Dehumanize Healthcare Workers

Nicole Johnson

2:00 PM - 3:00 PM, Midway 3-4

Paper Session: Pediatric Ethics

Philosophy

Reconsidering Harm in Pediatric Ethics - Dignity, The Right To Play, and The Limits of Parental Authority Christian Cintron

What Do We Owe Future Adults? Evaluating the Implications of the Right to an Open Future for Non-Therapeutic Pediatric Research

Jeremy Garrett

What is a Child? Implications for Pediatric Ethics and Child Assent

Erica K. Salter

2:00 PM - 3:00 PM, Grand A

The Clinical Ethics Consultation Benchmarking Collaborative: Year 2 and Beyond

Stowe L. Teti

Clinical Ethics

2:00 PM - 3:00 PM, Regency B

VSED as a path to MAiD: Stepping stone or quicksand?

Law, Public Health Policy, Organizational Ethics

Robert Macauley, Paul T. Menzel, Kevin Dirksen, Lisa Brodoff

Medical aid in dying (MAiD) is legal in 10 states, nearly all of which originally mandated a waiting period of at least 15 days. This requirement effectively precluded voluntarily stopping eating and drinking (VSED) from serving as the qualifying diagnosis, since the patient would have died from dehydration while waiting for the prescription. Recently, however, some states have either shortened the waiting period or allowed it to be waived if a patient is expected to die before it is completed. This has led some to endorse “VSED as a path to MAiD,” whereby a patient with a life expectancy of greater than six months—such as a person with early dementia—who initiates VSED would be eligible not only for hospice but also for MAiD, thereby sparing them the protracted process of death from VSED. In this panel, a law professor will review recent developments in state law. Then a philosopher who has co-edited a book on VSED will describe the nuances of VSED, while also exploring the respective risks to the acceptance of both VSED and MAiD from linking them. A palliative medicine physician/ethicist will then examine the complexities of VSED as providing a qualifying diagnosis for both hospice enrollment and MAiD eligibility, based on concerns for verifiability and stability of patient intention. Finally, a health care ethicist in a faith-based system will examine the complexities of VSED with intention to proceed to MAiD, when the latter (though legal by state law) is not an option in that system.

2:00 PM - 3:00 PM, Grand B

PresentationID# 2817694

What can Social Science Research Methods offer Bioethics? Case Studies from the Field

Research Ethics and Social Sciences

Melanie Jeske, Kellie Owens, Miranda Waggoner, Jill A. Fisher

As bioethics has become increasingly empirical, qualitative social scientists from the fields of sociology, anthropology, and science and technology studies (STS) have been drawn to the field. These scholars bring their insights from their home fields to their bioethical approach to studying medicine, biomedical technologies, and healthcare inequities. In this panel, we bring together social scientists from across these disciplines to examine the value social science research methods and theoretical frameworks bring to bioethics, demonstrating how such approaches can capture complex social relationships in empirical settings, elucidate nuances and heterogeneity in data, and illuminate new areas for bioethics inquiry. Focusing specifically on qualitative research methods (e.g., in-depth interviewing, ethnography, and content analysis), panelists will each present an empirical example: (1) a study of actionability and the politics of knowledge production in clinical genomics; (2) a study of the exclusion of pregnant individuals from clinical trials; and (3) a study of pediatric food allergy clinical trials. Through discussion of these examples, panelists will discuss research study design, experiences conducting their research, and specific ways qualitative social science approaches were valuable in the empirical setting and to bioethics inquiry. The panel will conclude with a discussion of challenges and limitations of integrating social science methods and theoretical frameworks in bioethics.

2:00 PM - 3:00 PM, Regency C

What would I like to say to those I am leaving behind?: A performance and dialogue about the mental health and healthcare implications of ethical will creation

Health Humanities

Hollen N. Reischer, Kristen M. Johnson

The human experience uniquely entails the psychological process of stitching together life’s highs, lows, and turning points to form a more-or-less cohesive narrative, enabling us to understand and explain who we are. We make sense of the past, interpret the present, and even forecast our stories into the future, trying to shape how we will be remembered after we are gone. One method of shaping our legacies is through “ethical wills”—documents that pass on life stories and personal values through written testimony. This session features a “verbatim theatre” performance of anonymized older adults’ ethical wills, originally written as part of a pilot mental health intervention study. The pilot study found the process of creating ethical wills improved participants’ psychological well-being pre- to post-test, and was judged by participants to be highly meaningful, validating, and motivating. Attendees will be introduced to the cultural, historical, and contemporary contexts of ethical wills; the design of the pilot intervention; and brief findings. Following the performance, attendees will be invited to participate in a close reading of ethical will excerpts and contribute to generative dialogue



about the use of ethical wills for healthcare contexts such as ethics consultations and advanced care planning. The scholarly prompts and thematic touchstones of the workshop are informed by the intersection of health humanities and clinical psychology (mental health), personality psychology (narrative identity), and developmental psychology (gerontology). Presenters have experience in psychological research, theater, creative writing, palliative care, and ethics consultation.

3:15 PM - 4:30 PM, Grand D-F

Plenary: Good Days, Bad Days, and Reflections on Reducing Workplace Violence in Healthcare Settings

Plenary

John Rozel

The hospital is a place to care and a place to heal, a place to learn and a place to teach, a place for solace in times of crisis, and a place to care for the most in need. Achieving that mission with both the exacting technical precision demanded by modern medical practice and the humanity and compassion intrinsic to a place of healing is challenging in and of itself – achieving that mission in an increasingly violent and hostile environment is one of the greatest challenges modern medicine faces. Ethicists can play a vital role in helping front line clinicians and executive leaders reconsider how they cultivate environments that are both healing and secure.

4:45 PM - 5:30 PM

Good Days, Bad Days: Follow-Up Discussion Session

Plenary

John Rozel

In this talk-back session, attendees will be able to engage with the ideas presented in Dr. Rozel's plenary, ask additional questions, and discuss the themes at greater depth.