

# JOURNAL OF HOSPITAL ETHICS

THE JOHN J. LYNCH, MD CENTER FOR ETHICS

19TH INTERNATIONAL  
CONFERENCE ON CLINICAL ETHICS  
AND CONSULTATION

**ICCEC  
2025**

**JUNE 4-7  
LAUSANNE, SWITZERLAND**



**PLURALITY, POWER, AND PATIENT CARE**  
THE SOCIO-POLITICAL DIMENSIONS OF CLINICAL ETHICS

*Proceedings of the 19th International Conference  
on Clinical Ethics and Consultation*



  
MedStar Health

# JOURNAL OF HOSPITAL ETHICS

THE JOHN J. LYNCH, MD CENTER FOR ETHICS

## EDITORIAL GROUP

### EDITOR-IN-CHIEF

Evan G. DeRenzo, PhD  
Ethicist & Editor, Emerita  
John J. Lynch, MD Center for Ethics  
MedStar Washington

### MANAGING EDITOR

Christian Carrozzo, PhD (c)  
Educator & Editor  
John J. Lynch, MD Center for Ethics  
MedStar Washington,  
Department of Philosophy  
George Mason University,  
Department of Philosophy  
University at Albany  
State University of New York

### MEDICAL EDITOR

Jack A. Sava, MD  
Chief, Trauma  
Director, Gold Surgery Team  
MedStar Washington,  
Associate Professor of Surgery  
Georgetown University School of Medicine

### NURSING EDITOR

Lucia Wocial, PhD  
Assistant Director  
John J. Lynch, MD Center for Ethics  
MedStar Washington

### BOOK REVIEW EDITOR

Patrick Herron, DBE  
Montefiore Einstein Center for Bioethics  
Albert Einstein College of Medicine

### CONTENT EDITORS

Fred King, MSLS  
Medical Librarian  
MedStar Washington

S. Layla Heimlich, MSLIS  
Medical Librarian  
MedStar Washington

### ADMINISTRATIVE ASSISTANT

Nikki Glover  
Administrative Coordinator  
John J. Lynch, MD Center for Ethics  
MedStar Washington

### EXECUTIVE DIRECTOR

Ben Krohmal, JD  
Director  
John J. Lynch, MD Center for Ethics  
MedStar Washington,  
Assistant Professor  
Georgetown University School of Medicine

## EDITORIAL ADVISORY BOARD

### Amanda Anderson, PhD, MPA, RN

Postdoctoral Fellow, United States Department of Veterans Affairs

### Amanda Bush, MA, BSN, RN

Regional Nurse Wellbeing Specialist, Center for  
Wellbeing, MedStar Health and Adjunct Professor, Berkley School of  
Nursing, Georgetown University

### Chee M. Chan, MD, MPH

Medical Director, Intermediate Care Unit, MedStar Washington and  
Assistant Professor, Georgetown University School of Medicine

### Maria Susana Ciruzzi, JD, MSc, PhD

Clinical Ethicist, The St. Jude Bioethics Program, St. Jude Children's  
Hospital

### O. Mary Dwyer, JD, MA

Assistant Professor, Department of Bioethics, Case Western Reserve  
School of Medicine

### Laura K. Guidry-Grimes, PhD

Associate Ethicist, Center for Bioethics, Cleveland Clinic and Assistant  
Professor of Medicine, Lerner College of Medicine, Case Western Reserve  
School of Medicine

### Josh Hyatt, DSH, MBE, MHL

Director, Risk Education Management & Strategy and Adjunct Professor,  
Massachusetts College of Pharmacy and Health Sciences

### Jack Kilcullen, MD, JD, MPH

Physician, Medical Critical Care Service, INOVA Health

### Eran Klein, MD, PhD

Associate Professor of Neurology, Oregon Health & Sciences University,  
and Affiliate Assistant Professor, Department of Philosophy, University of  
Washington

### Tim Lahey, MD, MMSc

Director of Medical Ethics, Infectious Disease Attending and Professor of  
Medicine, University of Vermont Medical Center

### Jason Lesandrini, PhD

Assistant Vice President of Ethics, Advanced Care Planning & Spiritual  
Health, WellStar Health

### Stephen Peterson, MD

Physician and Former Chair, Department of Psychiatry, MedStar  
Washington and Assistant Professor, Georgetown University School of  
Medicine

### Jack Schwartz, JD

Former Chief Council for Opinions & Advice, Maryland Attorney  
General's Office

### Lindsay Semler, DNP, RN

Executive Director of Clinical Ethics, Brigham & Women's Hospital,  
Harvard Medical School

### Eric A. Singer, MD

Assistant Professor, Section of Urologic Cancer, Rutgers Cancer Institute of  
New Jersey, Robert Wood Johnson Medical School

### Carol Taylor, RN, MSN, PhD

Senior Research Scholar, Kennedy Institute of Ethics and Professor,  
Berkley School of Nursing, Georgetown University

### Eli Weber, PhD, MA

Bioethics Director, Kaiser Permanente, San Bernardino, California



# MedStar Health

# JOURNAL OF HOSPITAL ETHICS

THE JOHN J. LYNCH, MD CENTER FOR ETHICS

## CONTENTS\*

**A NOTE FROM THE EDITOR-IN-CHIEF** (Page 31)

**PLENARY SESSIONS** (Page 32)

**PAPER SESSIONS** (Page 36)

Roles in Clinical Ethics (36)  
Moral Distress (38)  
Pediatric Ethics (39)  
Law (41)  
Innovative Tools (43)  
Standards and Challenges (45)  
Empirical Data (47)  
Migrant Populations (49)  
A.I. and Clinical Decision Making (51)  
Philosophy and Ethics Consultation (53)  
Gender Affirming Care (55)  
Clinical Ethics and Social Justice (57)  
Social Justice in Clinical Practice (59)  
Social Justice and Pregnancy (60)  
Discrimination (63)  
Vulnerable Populations (65)  
Equity (67)  
Sex, Gender, and Social Justice (69)  
Healthcare, Law, and Politics (71)  
Partners (73)  
Dilemmas (75)  
Clinical Ethics (77)  
Digital Technologies and Beyond (79)  
Socio-Political Issues (81)  
Contributions of Clinical Ethics (83)  
Assisted Dying (85)  
Various Topics (89)

**POSTERS** (Page 96)

**WORKSHOPS** (Page 129)

**EXPERT GROUPS** (Page 140)

\*All abstracts, their titles and content, as well as author/coauthor names, have been published as they were provided to the Editorial Group of the *Journal of Hospital Ethics* by the organizers of the ICCEC 2025, with minimal editing in order to maintain publishing standards (e.g., style, readability).



## A NOTE FROM THE EDITOR-IN-CHIEF

### Pulling Out All the (Socio-Political) Threads

Evan G. DeRenzo, PhD

Dear Readers,

Welcome to Volume 11, No. 2 of the *Journal of Hospital Ethics* (JoHE), “Proceedings of the 19th International Conference for Clinical Ethics and Consultation (ICCEC).” The meeting, held June 4-7, 2025, in Lausanne, Switzerland tackled the expansive topic “Plurality, Power and Patient Care: The Socio-Political Dimensions of Clinical Ethics.” In spite of, or perhaps because of, the far ranging implications of this topic, the meeting was, by all accounts, another highly successful ICCEC conference.

It has been wonderful to learn about so many excellent sessions presented in such a beautiful spot. As I have reviewed the abstracts, it is clear that the program’s review group set a high bar for pulling out the many threads woven through the meeting’s title, and that presenters’ works created a deeply intellectual environment for discussion of the topic’s implications and possibilities.

As you can see from the length of this volume, participants had a wealth of sessions to attend. We have done our best to organize the abstracts in a way that allows readers to follow the many intellectual threads raised by the meeting’s complex topic. I regret having been unable to make the meeting in person but am grateful for the wonderful abstracts so that any of us who weren’t there can quickly get the flavor for the expansiveness of the topic’s coverage by the presenters.

Just a very few examples include Louise Campell’s session titled, “Do clinical ethics services have a role in promoting social justice?” As one reads the abstract – and I’m sure for those who attended this session – one might have been skeptical about how the title was going to tie into clinical ethics consultation. But immediately as one reads the abstract, it is clear that the presentation’s author was seamlessly sewing the vastness of social justice considerations into the daily work of clinical ethics consultation.

Another exemplar of how beautifully sessions knit the broad brush strokes of the socio-political dimensions of clinical ethics with the micro-issues of clinical ethics consultation is Andy Kondrat’s “The fallacy of consensus: Reallocating power in ethics consultation.” What the abstract gives us is an intriguing taste for the power dynamics of the United States’ efforts at professionalization with a counter argument that, rather than drive to a specific view of standardization, leans into the details of a case’s specifics.

For my final example of the extraordinary way with which these abstracts reflect the session’s likely high-flying intellectual engagement is Stuart Finder’s “Grounding clinical ethics practice into the clinical as an inherently responsive means for responding to the socio-political.” Through the abstract we are reminded

of historical efforts at the professionalization of clinical ethics practice. Warning against losing sight of the need to understand what might be in the best interests of a particular patient and how identifying what may be ‘best’ continually bumps up against the socio-political context, to ignore the socio-political aspects of a clinical ethics consult are to rob the consult of a fulsome appreciation of what Finder aptly describes as the “texture of such contexts.”

Even for those who attended the meeting, it was likely impossible to make every session. To have this many abstracts all in the same place is exactly why we decided, with the creators and organizers of the ICCEC program so many years ago to bring the sessions of these meetings together in one place. That these proceedings have always been published under the JoHE umbrella has been a great honor and pleasure.

Now as we look forward to the twentieth ICCEC taking place next year in Cleveland, OH, we at the Lynch Center for Ethics, MedStar Health (Washington, DC) are excited to again have the ICCEC here in the United States. I am particularly excited because although I no longer make foreign meetings and avoid airports if at all possible, Cleveland is an easy train trip from Washington, DC so I can make the meeting. I look forward to doing so and catching up with my international friends at another great ICCEC meeting.

Until then, may you all have a safe, healthy, and happy year.

Sincerely,



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

**Acknowledgement:** Each year, the Lynch Center accepts a small cohort of summer volunteers that join us in order to both learn about the practice of clinical ethics and assist in various Center projects. We would like to thank Christina Lu (Georgetown University and Lynch Center Summer Undergraduate Volunteer [SUVP] for 2025), for her assistance in the production of this issue.



## **Plenary Sessions** *(Organized alphabetically by lead presenter.)*

### **Clinical Ethics Consultation (CEC) and Socio-Political Context: the Past, the Present, and the Future**

*Mark Aulisio*

This closing panel will zoom out to the bigger picture of clinical ethics consultation and its links to socio-political challenges of our time. The first part of this session will address the relationship between core competencies for clinical ethics consultation and the socio-political context in which it occurs. The format will highlight first how this has been a central part of ASBH's Core Competencies for Healthcare Ethics Consultation from its inception (1st, 2nd, and public draft of 3rd edition) and then suggest that clinical ethics consultation, indeed clinical ethics itself, is fundamentally contextual and, therefore, must remain attentive to changing features of the clinical context, particularly socio-political ones, if it is to continue to meet the kinds of needs it emerged to address. Recognising, Understanding and Managing Conflict in Paediatric Healthcare: Reflections on the Use and Impact of Mediation Skills to Support the Management and De-escalation of Conflict Between Families and Health Professionals

### **Recognising, Understanding and Managing Conflict in Paediatric Healthcare: Reflections on the Use and Impact of Mediation Skills to Support the Management and De-escalation of Conflict Between Families and Health Professionals**

*Sarah Barclay*

Conflict between parents/families and health professionals about the care and treatment of a sick child has become a significant phenomenon in paediatric healthcare. Research by the Medical Mediation Foundation found that conflict was prevalent across paediatric specialties, and particularly in neurology, general paediatrics and neonatology. The four key causes identified were communication breakdown, disagreements about treatment, unrealistic expectations/ "excessive" healthcare demands and families wishing to micromanage care. The impact of conflict can be significant and damaging for families and professionals alike, involving considerable amounts of staff time, fracturing of working relationships and a loss of focus on the child. Providing clinicians with the confidence and skills to recognise the warning signs of conflict and use mediation skills to help engage in conversations with families when conflict has arisen, have been shown to support both early recognition of conflict and its de-escalation. In this presentation I will offer some reflections on working with clinicians and families where communication breakdown and conflict have had on working relationships between family and professionals. I will also discuss how embedding the use of mediation skills in clinical teams can support families and professionals alike in navigating challenging conversations in which entrenched positions are having a negative impact on shared decision-making and constructive dialogue.

### **Plan, Safeguard, Care: An Ethical Framework for Health Care Institutions Concerning Patients, Caregivers, and Staff Who Are Migrants**

*Nancy Berlinger*

Every person needs some way to receive health care should they need it, in the place where they are. Health care institutions such as hospitals and clinics meet basic human needs by providing essential services that save lives, restore health, or manage symptoms. Yet whether and how health care institutions should provide access to health care for migrant individuals and populations is frequently unclear. These perennial challenges are intensified during periods of social and political uncertainty or turmoil concerning migration. This presentation will offer an ethical framework, grounded in familiar principles of public health and healthcare ethics and based on pandemic-era guidance developed by The Hastings Center, for healthcare institutions in different regions to explore and adapt.

### **Clinical Ethics and Artificial Intelligence: Navigating a Complex Relationship**

*Nikola Biller-Andorno*

This keynote explores the evolving relationship between clinical ethics and artificial intelligence (AI), highlighting





how AI may both support and challenge ethical practice in healthcare. It argues that while AI can assist with tasks like case summarization and provide useful tools for research and training, we cannot outsource moral judgment without compromising our human moral agency. The talk examines which elements of clinical ethics can be technologically supported and where human involvement remains indispensable. It also considers how clinical ethics can shape responsible AI use in medicine, focusing on triage and decision-support as use cases. The conclusion underscores the need for human responsibility, ethical oversight, and ongoing education to avoid overreliance on AI and to preserve the relational and interpretive nature of ethical reasoning in clinical care.

## **Racism in Medicine**

*Kevin Dzi, Kristina Wurth*

The relevance of racism in and for healthcare is immense and goes far beyond the level of individual action. At the same time, racism is a topic that provokes strong defensive reactions, is emotionally charged, and is often exploited for populist purposes. While it seems difficult for some to talk about racism and to acknowledge the existence of racist mechanisms in our societies, the issue of implicit bias is less emotionally charged and has been studied in several areas of healthcare and medicine—such as gender medicine and migrant health—revealing alarming results. In this presentation, we will explore what we mean when we speak of racism, taking into account societal and local contexts, as well as historical dimensions. We will then discuss ethical and philosophical aspects and conclude with a look at current data.

## **Resolving Conflicts in our Society: Applying International Conflict Resolution Practices to the Hospital**

*Julia Palmiano Federer*

This input collapses interdisciplinary boundaries and discusses how conflict resolution practices developed to address situations of violent political armed conflict can be applied to intercultural and political conflicts in public health and hospital settings. The input will first introduce the basics of conflict resolution mechanisms such as peace negotiations and mediation. It will then delve into specific tools for conflict resolution practitioners such as “conflict analysis,” and “process design.” In particular, the input will draw from Dr. Palmiano Federer’s research and practice supporting and studying mediation processes in several armed conflict settings, for instance in Myanmar and the Philippines. The input will end by arguing that the techniques and practices of conflict resolution can be applied to other sectors including public health, as the challenges that our global society faces (e.g. the effects of the COVID-19 pandemic, systemic racism, climate change, and other pressing public health issues) are interconnected. These challenges exacerbate as well as create new conflicts that negatively affect the communities that we serve.

## **Clinical Ethics in the Era of Climate Crisis**

*Andrew Hantel*

Climate change has profound impacts on human health and illness while healthcare delivery produces substantial waste and emissions which propagate climate change. This talk will take the “good clinical ethics begin with good facts” approach by first outlining the impacts of climate change on human health and of clinical care on the environment, which serves as the basis for why clinical ethics should care about the climate crisis. We will then consider the overarching ethical issues that arise based on the intersection of climate and health and how clinical ethics might approach them in relation to the related fields of health policy, organizational, and research ethics.

## **Autonomy and Well-being in Patient Care: How Philosophical Analysis can Provide Guidance in Cases of Conflict**

*Anna Hirsch*

Ethical conflicts that arise in patient care and are discussed in clinical ethics (consultations) often involve conflicting values, norms, and obligations. For example, the obligation to benefit a patient (from a medical-professional point of view) may conflict with the obligation to respect the patient’s autonomy – highlighting a conflict between the values of well-being and autonomy. In order to deal with these conflicts in an ethically sound way, it is neces-

sary to be sufficiently clear about what it actually means to promote patients' autonomy and to protect and foster their well-being. One approach often referred to in clinical ethics is the four-principles model of Tom L. Beauchamp and James F. Childress. While this approach can be helpful in identifying ethical conflicts and drawing attention to key obligations in patient care, it often remains too vague regarding the interpretation of core concepts on which it is based on, particularly "autonomy" and "well-being." As a result, in ethically very complex situations, the model offers limited guidance on how to interpret and weigh these obligations. In my talk, I will argue that more sophisticated philosophical theories and concepts can compensate for the conceptual shortcomings of the four-principles model. Drawing on a concrete case study, I will illustrate how such concepts and theories can deepen our understanding of autonomy and well-being in the context of patient care. This, in turn, can enhance our ability to analyse conflicts and provides arguments for specifying and balancing competing obligations. In this way, I contend, philosophical theories and concepts can contribute to robust and ethically well-founded decisions in clinical ethics (counselling).

### **Is there any Alternative...? Identifying, Avoiding, and Addressing Conflict**

*Richard Huxtable*

Despite even best efforts to hear and heed alternative perspectives, conflicts can sometimes arise in the clinical setting between (and among) clinicians, patients, and people close to the patient. The nature, sources, and complexities of conflicts vary, as do the various means of avoiding or addressing them. In this presentation, I will reflect on research undertaken with Louise Austin and Harleen Johal, in which we examined conflicts arising in England and Wales in "best interests" decision-making for patients, of all ages, who lack the capacity or competence to make decisions for themselves. The projects respectively focused on conflicts in paediatrics, especially paediatric intensive care, and in adult intensive care. In both settings, five approaches tended to be prominent, which involved looking to: the team; second (or more) opinions; clinical ethics support services; mediators; or the courts. We found that each had their merits, but also presented problems. I close with some reflections on the further work that is needed to understand not only which approaches are being used (and when and by whom), but also which should be used (and when and by whom).

### **In Favour of the Personalized Patient Preference Predictor (P4)**

*Karin Jongsma*

When patients lose capacity, their surrogates often struggle to guess what they would have wanted and many feel overwhelmed by the burden of deciding alone. In this talk, I will introduce a possible way to address these issues of surrogate decision-making: the Personalized Patient Preference Predictor (P4). This hypothetical model for predicting patient preferences would harness advances in generative artificial intelligence (AI) to create large language models (LLMs) adapted to (that is, fine-tuned on) a person-specific corpus of text. The result would be a kind of 'digital psychological twin' of the person that could be queried in real-time as to the patient's most likely preferences for treatment in any given healthcare crisis. In this presentation, I will briefly outline the technical progress that can make the P4 possible, the problems it can address and outline the reasons in favour of employing the P4.

### **Green Bioethics and Sustainable Healthcare**

*Cristina Richie*

Every medical development, technique, and procedure impacts the environment through carbon emissions. Carbon dioxide emissions contribute to climate change, climate-change related health hazards, and perpetuate social determinants of health. This talk will explore ethical issues related to the carbon emissions of health care delivery in the context of the clinician-patient relationship, such as the obligation for high carbon health care systems to reduce emissions and preserving ethical standards in the therapeutic relationship. It will use the frame of Green Bioethics- an ethical methodology that synthesizes environmental and biomedical ethics- and reflect on the nature of clinical ethics in a time of climate crisis.



## **Personalized Predictors or Preference Parrots? A Critical View on Digital Psychological Twins for Determining Patients' Preferences**

*Georg Starke*

The idea of a personalized patient preference predictor (P4) has been prominently discussed in the past year. Supposedly such a P4, based on person-specific text, can reliably predict patients' likely preferences, informing surrogate decision making for patients lacking capacity. In this talk, I will highlight some of the concerns surrounding this approach. In particular, I will discuss issues that relate to fundamental technical limitations of current large language models (LLMs) as well as to new ethical challenges that may arise from introducing a P4 into clinical practice. Finally, I will also shed light on broader inadvertent negative consequences of integrating AI into end-of-life decision making, offering further reasons why, at least for the time being, we may want to refrain from employing a P4 in clinical settings.

## **Migration Health and Strategies for Equitable Care**

*Rainer Tan*

Asylum seekers and refugees encounter significant and multifaceted barriers to healthcare, including limited health literacy, unfamiliarity with healthcare systems, linguistic challenges, medical mistrust, and discrimination. These populations also face a disproportionate burden of health issues, such as mental health disorders, infectious diseases, and worse sexual and reproductive health outcomes. The migration journey itself—along with precarious resettlement conditions—intensifies these vulnerabilities, underscoring the need to address structural determinants of health. This presentation will examine these challenges and highlight strategies implemented in Switzerland aimed at promoting health equity for migrant populations.

## **Clinical Ethics Consultation (CEC) and Socio-Political Competencies: the Past, the Present, and the Future**

*Stella Reiter-Theil, Laura Guidry-Grimes*

During the second half of the plenary, Laura Guidry-Grimes will interview Stella Reiter-Theil about her experiences and observations of the field of clinical ethics consultation, as well as the ICCEC conference series, over the years. This interview will highlight the past, present, and future of clinical ethics consultation from the perspective of clinical ethicists at different career stages. Guidry-Grimes and Reiter-Theil will discuss the sociopolitical dimensions of clinical ethics, reflecting on significant shifts in recent years that can affect health, health care, and clinical ethics work in different parts of the world. Attendees will be invited to share their experiences of the field and consider the sociopolitical aspects of their context. George Agich will moderate the discussion.



## **Paper Sessions** *(Organized alphabetically by lead presenter within each session type. Session types are listed by order of conference presentation. Please see the table of contents on page 56.)*

### **ROLES IN CLINICAL ETHICS**

#### **Workplace violence against midwives and midwifery students: moral dilemmas and challenges for Healthcare Ethics Consultation (HEC)**

*Alessia Bonaccorso*

Workplace violence (WPV) against healthcare professionals represents a global issue. Violence in the maternity setting has received little research attention, with midwives often assimilated into nurses. Few studies, primarily qualitative, have explored the effect violence has on midwifery students whilst clinical placement. Methods: An online, anonymous survey was sent via email to all members of Local Midwifery Boards in Italy and to all Italian midwifery students, investigating their experiences of WPV and bullying. Results: The findings highlight the high exposure to violence that midwives and midwifery students experience in the workplace. A total of 1059 completed questionnaires were returned by eligible participants, 687 midwives and 372 midwifery students. Forty-five percent of midwives and 27% of students reported being a victim of WPV. This was most often in the form of verbal abuse. The women's partners or other family members (65.4%), patients (21.9%), and physicians (29.1%) were identified as the main perpetrators by midwives. Midwifery students experienced bullying mostly from supervising midwives (40.2%) or other midwives (56.8%). Over half of the victims did not report and seek assistance through formal channels. Consequences of WPV included thoughts of leaving their job (27.1% of midwives) or course of study (22.5% of students) and significantly reduced gratification from caregiving. Discussion and Conclusions: Healthcare professionals face the following moral dilemmas: providing care to patients who have attacked them, manage emotions so as not to let them to interfere with care, balance the responsibility of protecting their own integrity and safety with professional duty and with respect for dignity of the patient. HEC can offer a listening space for victims and create the conditions allowing for the reporting of facts. In this listening space, ethical consultant can help to explore and resolve these conflicts through an analysis of professional and moral values. Also, HEC can help to create corporate awareness on the topic so that adequate prevention measures are implemented.

#### **Abdicating the Role of Mediator in US Healthcare Ethics Consultation: A Risky Choice**

*Autumn Fiester*

The amount of conflict between patients, families, and healthcare providers is so high in the United States that a recent consensus statement of five professional medical societies recommended embedding expert conflict management consultants in all high-volume US hospitals. From the earliest days of formal ethics consultation, the US bioethics organization, the "American Society for Bioethics and Humanities" (ASBH) deemed conflict resolution skills as a core competency for ethics consultants, making the institution's ethics service a natural locus for such conflict management experts. But over the last 25 years, clinical ethics consultation in the US has morphed into a consulting specialty similar to medical subfields like nephrology or hematology, in which the primary deliverable is knowledge-based expertise and judgment. Most US ethics consultants offer recommendations, not interventions. Even among ethics consultants with the ASBH's new formal certification (HEC-C), very few ethics consultants have any training in conflict management, despite the mandate for both in the ASBH's Core Competencies, the guiding document for the field. I will argue that this evolution (or devolution) of ethics consultation in the US may be sowing the seeds of its own demise. Over the last 10 years, US hospitals have increasingly relied on newly emerging Departments of Patient Relations to fill the void of conflict management expertise that ethics consultants could have (and, I believe, should have) filled. These new departments are typically larger and much better funded than the hospital's ethics consult service. In fact, most US hospitals have a patient relations department though many hospitals have no paid ethics consultants at all. If this trend continues, abdicating the role of conflict resolution in ethics consultation may put clinical ethics 'out of business.



## **From Conceptual to Concrete: Learning Ethics in a Clinical Ethics Committee for Medical Students**

*Lynn Gillam, Carolyn Johnston*

Medical students witness and experience ethical challenges during their clinical placements. Student Clinical Ethics Committees (SCECs) have been established in some universities globally, as an experiential learning initiative to support students to navigate and reflect on these challenges, developing skills of professional practice. In 2024, we piloted an SCEC as an enrichment opportunity for medical students at [blinded for peer review]. The staff involved in the project lead clinical ethics committees within hospitals, and aimed to replicate this experience for the medical students. Each meeting was an ethicist-led discussion of a de-identified case referred by an MD student, with case notes prepared by a volunteer notetaker. The training, referral process and model of ethics deliberation used in the SCEC reflect the real-world functioning of hospital clinical ethics committees. The student response in the pilot year has far exceeded our expectations. In order to include all enthusiastic students, we established three parallel committees each of which met online every two months. Students have submitted a diverse range of complex and perceptive referrals which have stimulated excellent discussions. The digital format strove to promote a plurality of perspectives across various clinical and geographical settings. We value this innovative learning model as a preventive form of health ethics consultation, supporting future clinicians to be better placed to respond to ethical issues, while shaping their professional and moral identities. This presentation will discuss the design and experience of the SCEC including governance, confidentiality, risk management, types of clinical ethics issues raised, and student learning outcomes. In our view, an SCEC is an effective way of bringing the workplace into ethics teaching, enabling development of practical ethics skills. It builds a cohort of peers interested in ethics and, we hope, will contribute to nurturing future leaders in clinical ethics in our context.

## **Repertoire of the Competencies of the Clinical Ethics Consultant in the Light of the European and Italian Qualifications Framework**

*Francesca Reato*

For the public recognition of the qualification of the Clinical Ethics Consultant (CEC) it is necessary to build the Repertoire of the Competencies by the European Qualifications Framework (2017) and the Italian Qualifications Framework (2018) criteria. Highlighting the clear connection to the EQF level 8, we identified and described learning outcomes of the identified competencies through knowledge, skills, autonomy and responsibility. Methods/ Materials: To reach data saturation, according to the qualitative research approach, an ethnographic study was conducted according to the principles of the "At Home Ethnography", through Participant Observation and Interviews to the Double. The interviewees are asked to imagine a hypothetical replacement by a "Double" who will take their place in the execution of the work activities and to provide him with all useful indications to cover the role of the CEC best. Results: Taking into account also the European Competencies Frameworks Entrecomp, LifeComp, DigComp and GreenComp, were identified 11 Transversal Competencies (01. Communication and Interpersonal Relationship; 02. Coping With Emotions; 03. Problem Solving; 04. Critical Thinking; 05. Decision Making; 06. Self Awareness; 07. Leadership; 08. Team Work; 09. Time Management; 10. Governance of Digital Transformation Processes and Technological Innovation; 11. Teaching Competencies) and 6 Technical Professional Specialist and Advanced Competencies (1. Determine the nature of uncertainties or moral conflicts that require clinical ethics consultation; 2. Conduct the clinical ethics consultation process in the health area; 3. Encourage the resolution of moral uncertainties and conflicts by facilitating the construction of an ethically based solution; 4. Document planned and implemented clinical ethics advice in the health field; 5. Monitor clinical ethics consultation service; 6. Improve the quality of clinical ethics consultant service). Discussion and Conclusions: The Interviews to the Double and the Participant Observation allow: tracing of the tacit routines put into place and interpreted by each Professional, through the exercise of the narration of micro actions and daily practices; identifying attitudes, knowledge, skills, emotional and intentional colors of their professional actions; identifying spaces of autonomy and responsibility; learning more about the actions and reasons for the practices of fellow Clinical Ethics Consultants.

## **Mediator or Advocate? The Role of the Clinical Ethicist**

*Lindsay Semler*

Mediation is an essential component of ethics consultation. The practice of mediation uses a neutral facilitator to foster engagement of all stakeholders and their respective interests and perspectives, and facilitate a resolution or

consensus on an ethically justifiable course of action. However, when, if every, is it justifiable for the clinical ethicist to step outside of the bounds of their role as mediator and advocate for what they feel to be the right course of action? The author will describe a case in which the interests of an incapacitated patient are discovered through interview of his wife and guardian. However, neither the wife nor the attending physician is willing to move forward with the ethically appropriate course of action to uphold the patient's previously expressed wishes. In cases like this, what are the clinical ethicist's responsibilities to advocate for the most ethically appropriate course of action? Clinical ethicists are consultants, and ultimately the decision-making rests with the clinical team and patient or family. However, when the patient cannot speak for themselves, and their loved ones refuse to do so, does the ethicist have an obligation to step outside the role of neutral mediator and instead advocate for the voice of the patient? At what point would the ethicist seek institutional or legal support to advocate for a specific course of action? The author will provide support and considerations for both perspectives, along with considerations for a deontological vs consequentialist approach to consultation recommendations.

## MORAL DISTRESS

### Who is to Blame? Identifying Responsibility and Accountability in HEC Conflict Resolution

*Donald Höpfer, Geraldine Hider*

When healthcare ethics consults require conflict resolution, consultants often encounter parties who place blame on others. In some cases, the person who is blamed is at fault, but in many cases blame is placed for behaviors or characteristics that are irrelevant to the matter at hand. Patients are sometimes blamed for their illnesses, one medical service might blame another for a perceived fault. Fault assumes failure. The act of blaming labels the one blamed as a failure, establishing an unwillingness to communicate and creating the need for conflict resolution. Sadly, it is all too easy to adopt an attitude of blaming. Perceptions of blame play out in an emotional response to moral distress. A cognitive response can offer a different perspective that can potentially draw the emphasis away from fault-finding and re-orient to resolution. Rather than engaging in placing blame, healthcare ethics consultants can identify actual responsibility and accountability. Responsibility is an attempt to define goals and processes amid uncertainty. Accountability is outcome-based and provides the basis for evaluation of goals and processes. Understood together, responsibility and accountability can provide insight into what happened, what are the consequences of what happened, and how to proceed. The presenters will demonstrate a Responsibility and Accountability model. The concepts of the model draw from a multi-disciplinary approach to clarify ethical uncertainty and emotional bias. The model reflects a real-world application process that is intended for use in clinical settings. Use of the model can aid in identifying responsibility and accountability while avoiding passing blame, thereby facilitating collaborative communication and conflict resolution.

### Can We Identify Needs for Clinical Ethics Services by Screening for Moral Distress?

*Katja Köhlmeier*

Introduction: Experiencing ethical challenges in health care can be accompanied by moral distress (MoD). Studies have shown that clinical ethics support services (CESS) can be effective in mitigating MoD of health care professionals. We explore whether a screening for MoD can be used as an indirect needs assessment for interventions by CESS. Research Question: How can structured MoD screenings be used to assess needs for CESS? Main body: We present results of an ongoing mixed-methods study and a reflection of its utility for CESS. We used psychometric test instruments for MoD screening at a German University Hospital: the Measure of Moral Distress for Health Care Professionals (MMD-HP) and the moral distress thermometer (MDT). The screened sample consisted of 143 nurses and doctors of six pediatric and neonatal intensive care units (PICUs/NICUs) (49% of the population). Between the professional groups, the level of MoD was comparably high and the most common causes were directly or indirectly associated with resource scarcity and a lack of communication. The staff of the PICUs reported higher levels of MoD. First results of qualitative interviews with 19 purposefully selected employees (nurses, doctors, psychologists and social workers) showed a variety of specific causes. For example, communication problems occurred because of a lack of spaces for interprofessional discussions and unstructured handovers, or resource scarcity was reinforced by changes in professional training and extensive documentation of patient data. The reasons for MoD go beyond case-based conflicts and point to causes of moral distress at structural levels. CESS and teams with high levels of MoD could develop needs-based interventions to tackle such causes together. Outlook: We will explore connections between the identified causes of MoD and suitable interventions based on expert interviews with clinical ethicists.

## **Moral Distress Across the Whole Treatment Team: Who Feels What and What Do They Want**

*Paul Mcloughlin*

**Introduction:** Moral engagements are a deeply inherent and intractable component of modern healthcare practice. These challenges affect not only healthcare providers (HCPs) but also patients and their loved ones, healthcare organizations, and the wider community. When these ethical uncertainties, conflicts, and dilemmas are unable to be resolved satisfactorily moral suffering ensues. Moral distress is a particular form of moral suffering experienced because of situations in which HCPs are aware of a moral problem, assume moral responsibility for the issue, and subsequently make a moral judgment as to what they believe is the right word or action to take (or not take). Healthcare ethics consultations (HECs) are often requested when significant moral distress is at play in the team. In fact, some centres now have a separate moral distress consultation service for these types of issues. **Purpose of research:** The purpose of this research was to explore the phenomenon of moral distress, through an interdisciplinary research lens, looking at the whole multidisciplinary team caring for patients requiring long-term ventilatory support. These HCPs were drawn from the disciplines of nursing, medicine, respiratory therapy, physiotherapy, spiritual care, pharmacy, and social work. This study is unique in exploring moral distress in this population and environment. **Methodology:** An interpretive phenomenological research method was employed. The Measure of Moral Distress for Healthcare Professionals (MMD-HP) validated questionnaire was completed and in-depth interviews undertaken. **Results & Discussion:** This doctoral research highlights that moral distress is not a homogeneous phenomenon of experience amongst the separate HCPs. There are significant differences in the causes, sequelae, and self reported socio-political solutions for the different team members. It is also seen that moral distress may be experienced not only by the HCPs but also by patients and families. HCPs provide personal wisdom for how we might avoid conflicts in the first place.

## **Moral Distress Debriefs: An Opportunity to Increase “Moral Peace” in the Health Context**

*Randi Zlotnik Shaul*

In this post pandemic era, rates of healthcare provider burnout are being reported at crisis levels across the globe. While many health systems are making huge financial investments into strategies to prevent their most dedicated clinicians from leaving health care, expensive solutions being dangled before the desperate eyes of hospital leadership, regularly miss a key socio-politically grounded feature of burnout. The depleting sequelae of moral uncertainty, moral distress, moral injury and even moral stress are linked to conflicts that are not surprising within social systems marked by a plurality of values. We must not become complacent, in thinking that moral compromise is solely an individuals responsibility or in thinking that interventions such as yoga, ergonomically correct chairs or even mindfulness courses, are effectively tailored to addressing these serious contributors to healthcare provider burnout. Recent research highlights an increasingly recognized bi-directional relationship between a definition of moral distress and burnout, revealing moral distress as a cause of burnout and burnout contributing to moral distress severity. There is an urgent need for a strategy to address moral distress and burnout: one that we argue, needs to be sensitive to the diverse socio-political contributors. This strategy also needs to be adaptable to a range of health care systems with various levels of ethics consultation support. Our ethics team with training in bioethics, nursing, medicine and worked together to develop amoral distress reflective debrief tool aimed at moving those experiencing moral distress to the moral peace characterized by greater clarity regarding the moral tensions at play and regarding a plan for next steps. Our presentation will describe (1) the bi-directional relationship between moral distress and burnout with particular attention to the impact/influence of socio-political challenges, (2) the self-administered or ethicist-led moral distress debrief tool and (3) the ongoing roll out and evaluation.

## **PEDIATRIC ETHICS**

### **Preventative Ethics in the Pediatric Intensive Care Unit: Implementation of a Time-Based Automated Ethics Rounding Service**

*Liza Johnson*

**Background:** Empirical evidence shows that perceptions of non-beneficial treatment and questions about goals of care cause moral distress among clinicians and are a common reason for ethics consultations. These situations arise commonly in the pediatric intensive care unit (PICU), early involvement by palliative care and ethics is recommended in professional guidelines. **Aims:** We sought to assess the feasibility and acceptability of using a time-



based automatic consult order to the clinical ethics service to facilitate the early involvement of ethics into interdisciplinary rounds as a form of preventative ethics in a subspecialty PICU. Methods: Using the capabilities of the electronic medical record (EMR), an ethics consultation order occurs automatically on ICU Day 5. Ethics reviews the patient's EMR and assigns a priority to the request (urgent-round in ICU within 48 hours, standard-round within 72 hours, or low-patient expected to leave ICU, follow remotely). An ethics rounding note is placed in the EMR following rounds unless the consultant identifies the need for a full consultation. After the initial rounding encounter, ethics follows the patient until death or ICU discharge. The Armstrong Clinical Ethics Coding System is used to track the clinical ethics issues in each case. Results/Discussion: We will present 6 months of preliminary data including demographics, reasons for ICU admission, clinical ethics issues identified and will discuss the feasibility of implementing a time-based system for the early involvement of clinical ethics into the PICU. Our anecdotal experience with ICU rounding indicates that an automatic rounding process normalizes the role of clinical ethics in the ICU setting, serves as a form of preventative ethics, is acceptable to patients and medical staff, and is not overly burdensome to the ethics service. Institutions considering a trigger-based rounding system may wish to customize their automatic triggers to suit their individual needs.

### **Proactive and Family-Centred: Changing Clinical Ethics Consultation in NICU**

*Nikolija Lukich*

Healthcare organizations strive to provide patient- and family-centred care in order to improve patient experience. Clinical ethics services can support this goal by assisting staff with challenging ethical cases as well as institutions with organizational ethical concerns. Clinical ethics services can demonstrate family-centred care by being used proactively in order to reduce various forms of conflict in clinical environments. This presentation will focus on a model being implemented in a Toronto Neonatal Intensive Care Unit (NICU), where an ethicist is working with staff and families to provide more proactive support and to predict and reduce conflict. NICUs face multiple ethical dilemmas which can lead to contention, including the decision to resuscitate and care for premature babies as young as 22-weeks' gestation, options and decisions regarding redirection of care, defining harm and suffering for infants who cannot speak for themselves, parental disagreements, and general moral distress associated with intensive care. While some cases may require reactive support from an ethicist, many of these scenarios could be addressed proactively. This is demonstrated through various actions, such as the ethicist rounding with the nursing and leadership teams on a regular basis, providing education for parents regarding their role, rights, and responsibilities, and empowering all members of an infant's team to collaborate in decision-making. While these initiatives have demonstrated success in reducing conflict between staff and parents, there are still challenges that are faced as this new model continues to be implemented, such as increasing understanding of both the purpose and limits of ethics consultation, establishing trusting relationships with parents, and balancing work with the limited resources of an ethics consultation service. Despite the challenges, however, it is clear that this model can be helpful for all NICU staff, parents, and patients in reducing conflicts and ultimately achieving more effective family-centred care.

### **Parental Experiences of DM in the Grey Zones of Neonatal Intensive Care: an International Multi-Centre Mixed Methodology Study**

*Joseph Kates Rose*

Background: In the neonatal intensive care unit (NICU), grey zones ““ situations where multiple morally acceptable decisions exist ““ often arise. Sharing decision-making (DM) with caregivers in these contexts is complex. Moral distress (MoD) is well-documented in clinicians, but caregiver moral experiences remain unknown. Aims: To elucidate caregiver moral experiences of DM in NICU grey zones, particularly, to establish whether MoD and moral schism are present. Methods: This was a mixed-methodology phenomenological study. Parents of infants who were admitted for 3 or more days between 2018-2022 and who engaged in complex conversations surrounding care plan decisions were invited to complete a survey about their experiences of DM. Bereaved families were not contacted until at least one year following their child's death. Demographic data were collected through chart review. Descriptive statistics were used for quantitative data. Qualitative data were analysed using thematic analysis, informed by the concepts of moral distress and moral schism. Results: 71 parents (80% mothers) completed the survey. Thematic analysis generated five themes: decision burdens, internal tensions, actualising beliefs and values through DM, inauthentic shared DM, and external factors shaping DM. Overall, 89% of parents wanted to be involved in DM, though only 63% felt included in that process. DM was experienced as burdensome and grey zones elicited tensions within parents about their roles and desires. Parents valued opportunities to actualise their values in the DM process. Despite the goal of shared DM, some parents felt coerced into decisions, consistent with MoD.



Extrinsic factors, such as time pressures and partner support, influenced the DM tensions. Discussion: Facilitating shared DM is complex, reflecting the need for personalised DM and sensitivity to external and internal pressures experienced. Caregivers are subject to MoD and moral schism. A nuanced approach that considers all perspectives may help alleviate tensions and better resolve DM conflict.

### **Decision-Making in the PICU: Balancing Medical Scarcity and Parental Autonomy**

*Jennifer L. Spiegel*

A nine-month-old infant was admitted to the pediatric intensive care unit (PICU) with severe hypoxic ischemic encephalopathy after drowning. Despite a tenuous initial course, he was stabilized on mechanical ventilation and nasogastric tube feeds. He was not a candidate for extubation as he did not have the cough or gag reflexes required to protect his airway. His family was left with a decision: compassionate extubation with transition to comfort care or pursuit of a tracheostomy and a gastrostomy tube for long-term care. Decision-making supports for the family included brain imaging (MRI and nuclear scans), subspecialist consults (pulmonology, neurology, physical medicine & rehabilitation, and palliative care), family meetings, medical device demonstrations, and parental support groups. Despite these measures, the child's parents were unable to make a unified decision for over a month. They identified familial discord, religion, guilt, and medical uncertainty as hindrances to decision-making. In pediatrics, parents/guardians have the responsibility to act in the best interest of their child. In most instances, they have a right to choose desired treatments and to provide informed consent for interventions. Physicians, however, should only provide care where the potential benefits to the child outweigh the possible harms. Fulfillment of this ethical mandate may be complicated by unforeseen harms, by the prospect of physiologic futility, and by moral distress. There are also system- and community-level justice considerations in fair allocation of ICU beds, ventilators, and diagnostic tests, all of which are limited resources. Would it be ethically justifiable to limit the time permitted for parental decision-making for a critically ill but stable child? What biases might influence imposition of such a time limit? What supports could be added to help both parents and health care teams in the decision-making process?

### **NICU Complex Care Rounds: A 42-Month Interrupted Time Series Study**

*Stowe Teti*

Background: The NICU presents a uniquely challenging environment: the fragility of the patients, the typically long courses of treatment, the hopes and dreams of parents, and close-knit culture can challenge the efficacy of a reactive ethics consultation format, however responsive it may be. An approach to managing value disagreements before they escalate into conflict was needed. Ethical sensitivity and everyday ethics skills needed to be inculcated into practice and embedded in culture. Aims: This project sought to measure the effects of supplementing existing clinical ethics consultation services with weekly ethics Complex Care Rounds (CCR) in our 106-bed NICU as part of ongoing consult service quality improvement. Any team member (with a focus on nurses) could nominate a case for CCR. Once weekly a multidisciplinary team would meet to discuss the cases with each attending physician in turn. Methods: A pre/post time series study design was used to investigate impact of the project with the interrupt set at six months after initiation of CCR. 110 formal ethics consults occurred in the 42-month period. Results: In the post period, the day of the patient's hospitalization on which ethics was consulted decreased from a mean of 32.8 days to 21.2 days. Average case complexity decreased from 2.4 to 2.1 on a 4-point scale. Average length of stay decreased from 73.9 days to 53.9 days. Qualitatively, we found consults involving moral distress decreased 59% while the team's willingness to question some parental choices increased 45%. Discussion: As 'basic' consults (help with goals of care) decreased, a broader variety of ethical questions emerged in the post period (as measured with ACECS codes), suggesting consults change, but volumes do not necessarily diminish with increased ethics support. This suggests CCR was effective in raising the capacity of frontline team members to identify ethical issues and manage internally or escalate accordingly.

## **LAW**

### **"Futility" Policy Revision: Addressing Power and Promoting Fairness**

*Marianne K. Bahus*

Non-suicidal self-harming is intentionally self-injuring oneself without the intention of dying. Examples include

swallowing foreign objects or taking a dangerous amount of pain medication. Individuals who self-harm often require immediate medical attention. According to Norwegian law, healthcare professionals are required to treat a patient in an emergency, even if the patient is competent and refuses treatment. This obligation is in line with the UN Convention for the Protection of Human Rights and Fundamental Freedoms, which emphasizes the right to life in article 2. Many self-harmers refuse necessary treatment, causing healthcare professionals having to use coercion to save their lives. This use of coercion and the attention the self-harmers thus receive, sometimes result in the patients harming themselves more severely on following occasions and also more frequently. The necessary medical treatment, mandated by law, appears to perpetuate negative and health-threatening behavior. These situations also require close cooperation between emergency physicians and psychologists and hence between different departments in the hospital. These challenging situations often lead to a need to seek advice from Clinical Ethics Committees (CECs). To give adequate guidance, the committee must find a way to hold the patient accountable for his or her actions and encourage the patient to choose not to harm him- or herself, without disregarding the health personnel's duty to provide emergency care and the patient's right to life. To facilitate mediation and conflict resolution, the legal boundaries must be carefully examined without compromising the obligation to act in an emergency. How far can we go in negotiating with the patient when his/her life is at risk?

### **Advantages and Limitations of a Specialist Committee Deciding on Futility in End-of-Life Treatment Decisions**

*Joan Henriksen*

In the United States, a powerful emphasis on individual autonomy and the patient as consumer has influenced the way clinicians offer choices to patients. More than a quarter of ethics consultation requests we receive involve conflicts where clinicians describe feeling pressure to provide, or continue to provide, requested treatments even when they believe those treatments will not help or may be harming the patient. Many U.S. healthcare institutions have developed policies to guide responses to conflicts that arise between clinicians and patients/families about interventions of disputed benefit. In our hospital system, the Ethics Program is responsible for this policy. In undertaking a revision of the policy, we uncovered that overall, clinicians felt unsupported by the institution and so were less willing to utilize the policy process, choosing instead to acquiesce to patient/family requests for interventions that the clinicians believed to be ineffective or harmful. Additionally, we found that across the organization, the policy had been invoked for patients with marginalized identities at a rate disproportionate to the general patient populations served in our acute care settings. These findings led us to further consider the policy through the lens of power and fairness. This presentation will frame the ethical tensions addressed in such policies in terms of expressions of power, potential for bias and justice. It will then describe practical approaches and steps we used in revising the policy. The intention was to strike a balance between supporting clinician integrity and professional judgment and honoring patient values and preferences about what goals they judge to be worth pursuing. We will encourage group discussion to learn how other healthcare systems address power imbalances in conflicts around interventions of disputed efficacy.

### **Can Mediation Avoid Litigation in Conflicts About Medical Treatment for Children?**

*Veronica Neeffes*

Conflicts between parents and clinicians about medical treatment for seriously ill children have been litigated in the courts of England and Wales for many years. Whilst the value of applying to the court lies in the resolution of an otherwise intractable conflict, litigation does have disadvantages such as the length of time before a conclusion is reached, the financial costs and the adverse effects of an adversarial process on the relationship between parents and clinicians. It is not surprising therefore that especially after highly contentious cases questions are asked how to avoid such litigation in future. Whilst judges, clinicians, academics and parents agree that improved communication between clinicians and parents could avoid future litigation, research outlining if and to what extent better communication will avoid future litigation is lacking. This study aimed to investigate the reasons why parents disagree with their clinicians in cases reaching the court and to estimate the number of cases in which mediation might have resolved the conflict and avoided litigation. Eighty-three cases regarding medical treatment decisions for children initiated either by an NHS Trust or Local Authority and reported between 1990 and 1st July 2022 were analysed. The analysis found that the three main areas of contention are different value judgments, factual areas such as the health of the child, their quality of life or burden of treatment and relational issues, i.e. loss of trust. More than half of the cases are estimated not to have been preventable by mediation because either no conflict existed (n=13) or the parental decision was based on strongly held, mostly faith-based, views unlikely to be open for dis-

cussion (n=31). The study concludes that the potential of mediation to resolve clinician-parent conflicts and thus avoid litigation may be more limited than hoped for.

### **Self-Harmers and the Right to Life: Mediation and Conflict Resolutions on a Collision Course With Law**

*Veronica Neefjes*

In England & Wales both parents and clinicians can refer intractable clinician-parent conflicts to the courts for a decision. However, given the costs of litigation, court cases about withdrawing life-sustaining medical treatment for children in England & Wales are often followed by discussion how to avoid future cases. Whilst two proposals, mediation and the introduction of a harm threshold, have received broad attention, a proposal to replace the court by a specialist review committee has not been further investigated. This study analyses the effects of a putative replacement of the courts in England & Wales by a specialist review committee using the process enacted by the futility clauses in the Texas Advance Directive Act (TADA) as a model. Briefly, under TADA life-sustaining treatment may be withdrawn when a review committee finds it is futile, and no alternative healthcare provider can be identified within a set period. The investigation first considered the advantages of the current court procedures above TADA, i.e. transparency, and suggests a modified procedure that would install a national specialist review committee modelled after TADA. Installing a national review committee to replace the court would reduce the number of court cases in England & Wales to only a few. However a national specialist review committee deciding on futility has further advantages for both clinicians and parents. Advantages for clinicians are more limited exposure to delivery of clinical care that may cause moral distress and less exposure to adverse press and social media content. Advantages for parents are that the process would establish them as ethical decision makers and offer the possibility of a transfer of care provided an alternative healthcare provider can be found. Given the advantages the feasibility of a replacement of the courts by a specialist review committee deserves further investigation.

### **Involuntary Treatment for Anorexia Nervosa: Medically Obligatory, or an Exercise in Futility?**

*Joanna Smolenski*

In this paper, I consider the case of severe treatment-refractory anorexia nervosa (AN). Given the nature of anorexia - which involves not only delusional beliefs about one's body, but also impaired cognition caused by starvation. Patients with this diagnosis often adamantly resist any efforts at treatment. In some cases, extended periods of involuntary treatment can result in positive results, even remission or cure. In others, AN patients are subjected to repeated, costly treatment against their will, which they actively resist and fails. AN can lead to intractable refusals of treatment, such that even treatment under restraint may not be enough to generate meaningful clinical improvement. Though patients may indicate that they want to live, and that they know artificial nutrition and hydration (ANH) is necessary to achieve this goal, they may nevertheless remain unable to permit its administration. They may even appear to consent to being restrained at various times, however, the level and duration of restraint necessary for potential improvement tends to be inconsistent with more general practices regarding involuntary treatment (i.e., that it should be used as briefly as possible, as infrequently as possible, and thus is generally not considered practicable for long-term interventions). Furthermore, it is not antecedently obvious that such extended involuntary treatment will even work (let alone be in the patient's overall best interest). As such, clinical ethicists are increasingly being consulted about the possibility that ongoing compulsory treatment for treatment-refractory AN- especially under restraint- may be medically inappropriate, and thus morally appropriate (or even obligatory) to withhold or withdraw, even over patient or family objection. This could bring anorexia nervosa into a hotly contested domain -that of a potentially medically-futile psychiatric disorder- and thus of particular relevance to this year's theme of HEC and conflict resolution, specifically between patients/families and providers.

## **INNOVATIVE TOOLS**

### **A Living Ethics Lab in a Rehabilitation Hospital: Concept and Initial Development**

*Arthur Filleul*

Background: Rehabilitation hospitals faced a wide range of ethical issues, such as the equitable allocation of resources to meet diverse patient needs or managing the opioid crisis in chronic pain management. These situations involve value conflicts and lead to patient frustration and clinician moral distress, contributing to staff retention

problems. In addition, administrators and clinicians lack the training and resources to help them make informed ethical decisions. Aims: LEViER is an innovative living ethics lab aimed at identifying ethical issues in rehabilitation and creating practical, actionable solutions. This project takes place at the Institut de réadaptation Gingras-Lindsay-de-Montréal (IRGLM), a major rehabilitation hospital. Theory: The project is grounded in the concept of "living ethics," a novel stance that prioritizes dialogue and collaboration. Living ethics encourages open discussions about ethical issues, focusing notably on collective and constructive problem-solving and action. Methods: This presentation will present the overall concept of the LEViER program and the results from phase 1, where semi-structured interviews and focus groups with rehabilitation administrators were conducted to identify and categorize the key ethical issues they face. These findings have laid the groundwork for phase 2, which is currently underway. This phase features participatory workshops where administrators, clinicians, patients, and their families collaborate to co-create practical solutions addressing real-world ethical issues and informing policy development. Looking ahead, phase 3 will pilot test these solutions at the IRGLM, with real-time feedback helping to refine and ensure their effectiveness and sustainability. Discussion: LEViER innovates by incorporating the perspectives of all stakeholders involved in rehabilitation care, with the aim of developing more ethically sound, contextually relevant and innovative solutions. This builds from previous like-minded efforts to propose dynamic and adaptable institutional framework to enhancing staff well-being and quality of patient care through collaboration.

### **Enhancing Conflict Resolution: The Role of Cultural Competence in Medical Interpretation During Complex Patient Discussions**

*Jamshed Khan*

Effective communication in complex medical care often requires medical interpreters, especially in multicultural settings. Cultural competence is essential also for healthcare ethics committees (HECs) when managing conflicts that arise from miscommunication or differing cultural values between patients and healthcare providers. At our tertiary care hospital in the United Arab Emirates, interpreters and our HEC bridge cultural and linguistic gaps during sensitive discussions, such as delivering bad news and goals-of-care conversations, sometimes towards end of life. This presentation recapitulates preliminary findings for a study done at our hospital around the cultural competence and emotional intelligence of medical interpreters and how these attributes contribute to conflict resolution and ethical decision-making. The presentation will discuss pre-liminary findings from a mixed-methods study at CCAD, involving surveys and semi-structured interviews with medical interpreters. While interpreters generally demonstrate strong communication skills, we hypothesize that gaps remain in their training, particularly around handling emotionally charged situations and intercultural tensions. Through the lens of clinical ethics and conflict resolution, the presentation will propose strategies for improving interpreter training. These strategies emphasize enhancing cultural sensitivity, emotional intelligence, and conflict mediation skills, all of which HECs can use to prevent or resolve ethical conflicts. The study also highlights the need for continuous professional development and a supportive environment for interpreters to manage the growing complexities of multicultural healthcare. By addressing the intersection of HEC, cultural competence, and conflict resolution, this presentation aims to contribute to a more equitable and sustainable healthcare system, aligned with the goals of clinical ethics and patient care.

### **Mandela the Ethicist: Introducing the NEMAS Transformative Mediation Framework for Clinical Ethics Consultations**

*Aloysius Ochasi*

Ethics consultants are tasked with resolving uncertainty or conflict regarding value-laden concerns that emerge in clinical situations. As such, they assume various roles in the process, with their primary roles often being those of negotiator, mediator, or arbitrator. While acknowledging the value of these methods of conflict resolution, their inherent limitations call for a revised approach. This paper introduces the NEMAS framework (Neutrality, Empowerment, Mutual Recognition, Addressing Power Imbalances, and Shifting from Positions to Interests) for clinical ethics consultations drawn from Nelson Mandela's transformative mediation during the Burundi Civil War. In transformative mediation, the mediators empower the parties to resolve their conflict and encourage them to recognize each other's needs and interests. The complex dynamics of clinical ethics consultations often mirror the challenges in high-stakes conflict mediation in the larger society, where trust, inclusion, mutual understanding, and recognition of each other's perspectives are critical. Mandela's approach in resolving the decade-long conflict between Hutu and Tutsi factions showcases the power of impartiality and inclusivity in fostering trust and collaboration that was pivotal in brokering the Arusha Peace Accords in 2000. This paper argues that similar dynamics emerge in clinical ethics consultations, particularly in emotionally charged cases involving ineffective (futile) treat-

ment at the end-of-life or complex treatment decisions. As facilitators, ethicists like Mandela must ensure that all stakeholders - patients, families, and the medical team feel heard and valued. Mandela's emphasis on neutrality, empowering marginalized voices, and addressing power imbalances aligns with the ethicist's responsibility to recognize patient autonomy while balancing clinical realities. Furthermore, Mandela's ingenious approach of shifting discussions from rigid positions to underlying interests offers a valuable tool for ethics consultations. By diffusing the tensions and guiding parties to focus on shared values such as dignity, quality of life, and compassionate care, ethicists help the parties transform their fractured relationship and agree on mutually acceptable solutions.

### **Is Narrative Ethics a Tool for Resolving Conflicts Within Health Care Ethics Bodies?**

*Morgane Romero, Nadja Eggert*

Narrative is now recognised as a tool to support carers in the face of daily challenges and to help patients cope better with their illness. In particular, it is used as a means of 'prevention and resilience against burn-out among carers,' as well as a 'prophylactic treatment' for their suffering. For patients, recounting their experience of their illness promotes a process of 'empowerment' by giving value to their stories. More generally, narrative is useful in situations marked by upheaval, such as during the COVID-19 pandemic. But if narrative benefits carers and patients, could it also be an asset in clinical ethics consultations and ethics committees? Indeed, with its existential, hermeneutic and ethical functions narrative could help to prevent and resolve conflicts of values within the medical teams that call on these bodies. However, how can narrative be integrated into these deliberations, where objectivity takes precedence over meeting the patient's needs? Who is responsible for telling the story, and on whose behalf? Is it possible to construct a collective narrative within these bodies to better represent the different perspectives? The aim of this contribution is to examine the interests, limits and conditions of possibility of using narrative ethics in the context of deliberation in healthcare.

## **STANDARDS AND CHALLENGES**

### **Ethical Aspects of Fertility Preservation for Specific Patient Groups and Their Applicability in Clinical Ethics Consultation**

*Silviya Aleksandrova-Yankulovska*

**Background:** Our report presents the first results of the ethical sub-project within the BMBF-funded Interdisciplinary Junior Researchers Center for Fertility Protection (FePro-Ulm). **Aims:** The aim of our research was the identification and ethical analysis of the ethical aspects of fertility preservation for various user groups: children and adolescents, men with cancer, women with cancer, women with endometriosis, women wishing social egg freezing, and transgender people. Our research task was to identify the specific ethical issues of fertility preservation that differentiate in various patient groups in order to reveal the potential for their application in clinical ethics consultation. **Methods:** A systematic literature search was performed in April 2024. Altogether 125 articles were identified, distributed by patient group, and further analysed from the perspective of the four principles of bioethics. **Results:** We have been able to elucidate unique ethical aspects of fertility preservation for each of the specific patient groups. These are, among others, the right to an open future and the decisional capacity of adolescents, fertility preservation as a means for cancer patients to leave a genetically related offspring, to their surviving partner, social egg freezing's effect of disturbing the intergenerational contract, the under spoken challenges of adoption and surrogacy arrangements to transgender patients as an alternative for their genetic parenthood. **Discussion:** The identified ethical aspects of fertility preservation for specific patient groups can serve as a reference point in the provision of patient-oriented fertility preservation care. Difficult cases of fertility preservation decision-making can trigger clinical ethics consultation requests. On the other side, knowledge of the group-specific ethical aspects of fertility preservation can support clinical ethics consultation for patients belonging to such a group.

### **Treatment Over Objection in Non-Psychiatric Facilities: Toward an Ethical Standard**

*Peter Bryant, James Rogers, Amir Javid, Robert Greevy, Joseph Fanning*

Treating incapacitated patients over their objection can present some of the most ethically complex and morally distressing situations faced by clinicians. Balancing the professional commitment to the patient's wellbeing with the appropriate recognition of the potential harms of forcing treatment is an evaluation that feels deeply counterin-



tuitive to healthcare professionals. The sometimes necessary use of chemical and physical restraint can transform a therapeutic intervention into an uncomfortable admixture of care, power and perceived violence. Without ethical standards for deliberation, patients may be at risk for suboptimal care or may undergo treatments that could be overly burdensome. Little is understood about how deliberations proceed for treatment over objection in non-psychiatric facilities involving non-psychiatric treatments. In 2019 Rubin and Prager proposed a guide to ethical deliberation consisting of seven questions to consider in treatment over objection, and in 2021 Fischkoff, Prager et al. reported analysis of 35 cases that showed the statistical relationship between the seven questions and the final decision made. Replicating the Fischkoff study's analytical approach, this presentation will share results from an analysis of 153 cases, all of which occurred over a 10-year period at another, geographically different U.S tertiary hospital. In addition, results from a secondary analysis will show the relationship between the final decision and three additional variables: race, ethnicity and insurance status. The implications for disparities will be discussed. Finally, this presentation will articulate how these results serve as a step in a longer-term project of developing widely-recognized ethical standards for treatment over objection in non-psychiatric facilities.

### **Including Patients in Ethics Support! When Would Perceptions About Harm and Risk Justify Reasons not to Include Patients in HEC?**

*Marleen Eijkholt*

In Europe, patient participation in clinical ethics interventions (hereafter PP) is a topic of controversy. Our empirical study has revealed that some of the objections to PP relate to perceptions about harm. Part of these are related to concerns about patient harm, but also to concerns about provider harm. For example, some of the objections against PP are related to decreased openness because of PP “a certain type of harm. In the USA, where PP is much more common, provider-related harms are not part of the reasons to reject PP. Concerns about potential patient harm, however, also appear as a reason to object to PP in the US. Still, PP is hardly a topic of controversy in the USA. In our presentation, we zoom in on our empirical findings regarding harm and objections against PP in Europe and in the US. We scrutinize perceived harms for the different stakeholders on different levels. Can we specify the concerns about harm, and how they would be embraced or rejected in the different systems. What does the lack about concern about potential harm for providers mean in the USA system, and what about concern for patient harm in both systems? We ask if and what concerns about harm can be upheld in the light of the empirical and theoretical considerations that justify PP. If we deem PP desirable for reasons of procedural or epistemic justice, we ask which cases then warrant patient participation in the light of concerns about harm. We seek to go beyond arguments of cultural differences.

### **Responding to Moral Challenges in Clinical Practice: A Qualitative Assessment of Ethics Support Needs at Three Tanzanian Hospitals**

*Bert Molewijk*

Background: Healthcare professionals (HCPs) encounter various moral challenges in clinical practice. In various countries, clinical ethics support (CES) services are developed to support HCPs. One of these CES services is clinical ethics committees (CECs): they address moral challenges faced in healthcare settings and offer support for HCPs. However, in Tanzania, CECs have not yet been implemented. For implementation purposes, greater knowledge about how healthcare professionals navigate and respond to moral challenges, their understanding of CECs, and what they perceive as key needs for implementing CECs in hospitals, are valuable. Aim: This study explores HCP ways of dealing with their moral challenges at the moment and identifies key needs for establishing CECs in Tanzanian healthcare settings in the near future. Method: We employed a qualitative research method with an explorative study design. Study participants were recruited from three tertiary hospitals. The study participants were recruited from intensive care units (ICU), emergency and internal medicine departments. A total of 38 participants were recruited. Physicians and nurses from the selected departments with more than three years of experience were included in the study. Reflexive thematic analysis (TA) was employed to analyze the collected data. Findings: The findings show that various implicit ways have been acknowledged as being useful in addressing moral challenges (e.g. regular meetings, family conferences, social welfare units, hospital procedures and guidelines, as well as consulting legal and management units). In addition, HCPs reported that a necessity exists for implementing more formal and systematic modalities to address moral challenges in clinical settings. Discussion: Based on the findings, we suggest the implementation of explicit CES services, particularly CECs, in Tanzanian healthcare settings. One of their tasks could focus on assisting health institutions in designing policies that take into equity issues in the allocation of medical resources.



## **Ethical Conflict Resolution Through Shared Decision-Making and Advance Care Planning for Incapacitated Patients**

*Ana Rosca*

Ethical conflicts often arise when caring for incapacitated patients, particularly when family members and healthcare professionals hold differing perspectives. This workshop will explore the role of clinical ethics consultation through shared decision-making (SDM) and advance care planning (ACP) in resolving these conflicts. Drawing from real-life cases, participants will learn strategies to balance the conflicting values of decision-makers. The workshop will present approaches to using ACP and SDM to prevent or deescalate conflicts when decisions must be made. Participants will engage in interactive discussions, developing skills to facilitate ethical dialogue and achieve consensus. Ultimately, this workshop aims to equip attendees with tools to better understand the complexity of these situations, ensure ethical decision-making, and mitigate conflicts in complex healthcare settings.

## **EMPIRICAL DATA**

### **The Perceived Needs for Standards and Certification in Clinical Ethics Practice in Quebec: Results From a Web-Based Survey**

*Marie-Eve Bouthillier*

**Background:** In the last decades there has been an increasing interest to define the specified training, knowledge and skills for the practice of clinical ethics (CE). The introduction of standards (code of ethics, core competencies, guidelines, certification or professional college) is a way of ensuring the quality of practice in CE. Little is known about the need for standards, in particular certification, in CE in Quebec. **Objectives:** (i) to map out the perceived need for standards and certification in CE in Quebec, (ii) to identify the parameters relevant to the development of efficient standards including certification, (iii) to formulate the premises of a certification process capable of meeting the needs identified. **Methods:** A web-based survey was sent to three groups of stakeholders: ethicists, health administrators and healthcare workers who have used CE services. The survey ran from February to May 2023, and consisted of closed-ended questions about the need for standards and certification, relevant parameters and considerations, and open comments. Data were analyzed using descriptive statistics. Open comments were subjected to thematic analysis. **Results:** A total of 89 participants responded: (44/89, 49 %) ethicists, (23/89, 26%) health administrators and (22/89, 25%) healthcare workers. They were in favor of setting standards, prioritizing certification and practice guidelines, both with (26/89, 29%) among all the types of standards presented. Priority is given to ethicists as the people who should be responsible for developing them. The creation of a professional college would be the last step to achieve in terms of standards. Three themes favored CE standards: 1) standardizing practice, 2) quality assurance of practice and 3) professional legitimacy. And two disfavored it: 1) practice limitation and 2) bureaucracy. **Conclusion:** Stakeholders showed their openness to develop standards for CE practice in Quebec. Resistance was encountered to create a professional college.

### **Implementation of the First Centralized Clinical Ethics Consultation and Support Service in Iran**

*Jan Schildmann*

**Background:** Following the constitutional court ruling in 2020, clinical ethics consultation in Germany are increasingly confronted with requests for support related to wishes for assisted suicide by patients. This study presents data of healthcare professionals and further stakeholders about (requests for) assisted suicide in Germany and explores possible contributions as well as limits of clinical ethics consultation to resolve conflicts associated with such requests. **Methods:** Online survey among applicants for an educational session on professional standards of assisted suicide. Descriptive analysis of quantitative data, content analysis of free text comments. **Findings:** 234/672 participants accessed the online survey, data of 133/234 participants were analysed. One hundred and one data sets were excluded due to lack of sufficient data for analysis (5 or less items completed). Forty-four participants were female, 84 male. Twenty-five out of one hundred and one participants reported no request for assisted suicide and 69/101 participants reported 1-3 requests during the last 12 months. Ten or more requests were reported by 13/101 participants. Fifteen out of one hundred and one participants reported that assisted suicide was performed, 11 respondents provided details. Time interval between first request and assisted suicide varied between four weeks and 24 months. Decisional capacity was assessed partially by one and partially by more than one person. In nine cases, physicians and in two cases each, lawyers and relatives assessed decisional capacity. Infor-

mation and counselling varied regarding involved professions and content. Time between ingestion or intravenous application of a lethal substance and death ranged from five minutes to seven hours. Results of the ongoing qualitative content analysis will be presented at the conference. Discussion: We will use the empirical findings as starting point for reflections on the planned professional guidance on information and counseling, assessment of decisional capacity in cases of requests for assisted suicide. In addition, we will discuss the possible role of ethical case consultation in resolving conflicts associated with requests for assisted suicide.

### **The Big Five Revisited: An Evaluation of the Most Frequent Topics in Ethics Consultations after Ten Years of Ethics Support**

*Jan Schürmann*

**Background:** Based on a new database, an earlier pilot analysis of 100 clinical ethics consultations (CECs) between 2012 and 2015 at two university hospitals in Basel, Switzerland, revealed the following "big five" of most frequent topics: coercion, care management, treatment-plan evaluation, end-of-life care, and pregnancy / assisted reproduction. Ten years later, we aim to analyze the additional CECs comparing the formal and patient characteristics as well as ethical issues of CECs with the earlier findings. **Methods:** Semi-structured analysis of the consultation reports and the feedback forms from 500 CECs conducted between 2012 and 2024 at the University Hospitals in Basel. Since the category system had been refined according to the Armstrong Clinical Ethics Coding System, the previous CECs were recoded. **Results:** Preliminary results show that the patients discussed in the CECs were on average 44.7 years old and more often female. The most common conditions were mental illnesses, congenital or genetic diseases, and neurological diseases. Half of the patients had preserved decision-making capacity (DMC), a third lacked DMC, and the rest had fluctuating or unclear DMC. Most CECs were prospective and were most frequently requested by physicians, followed by nurses, therapists, and patients or relatives. The requesting specialty was most often psychiatry, followed by gynecology, internal medicine, surgery, and emergency and intensive care. The most frequent ethical topics were treatment decision making - including coercion, opportunity-risk-assessment, and patient behavior - reproduction, and end-of-life-care. **Conclusions:** The distribution of major ethical topics has remained similar over the years, while the topic of coercion has become less frequent, especially in somatic acute care.

### **Requests for and Practice of Assisted Suicide in Germany: Data and Possible Implications for Clinical Ethics Consultation**

*Ehsan Shamsi Gooshki*

**Context:** The need for Clinical Ethics Consultation and Support Services (CECaSS) is increasing in many healthcare settings including in the Low-and-Middle-Income Countries like Iran. This paper explores the experience of providing CECaSS by Medical Ethics and History of Medicine Center (MEHMC), established in 2000 at Tehran University of Medical Sciences (TUMS), as the first centre of its kind in West Asia and the Middle East, that currently hosts a WHO Collaborating Center and a UNESCO Chair for Bioethics. MEHMC has leadership in bioethics education and research across TUMS. Based on Iran's unique integrated health system which medical education, biomedical research and providing healthcare is provided by medical universities as TUMS that have the role of regional health authorities. MEHMC provides technical ethics support to various sections of TUMS involved in education, research and clinical service. **Programming:** Using an earlier experience, MEHMC planned a centrally organized CECaSS for 5 university hospitals (3 generals, 1 heart center, and 1 pediatrics). One of the MEHMC faculty members (a clinical ethicist) was appointed as the members of the Hospital Ethics Committee (HEC) in each hospital and a guiding document for Case Presentation Conferences (CPCs) was developed. **Components:** The program included 1) Discussing ethical aspects of institutional policies in HECs 2) Providing CECaSS by the clinical ethicists assisted by volunteer PhD candidates 3) Holding a series of CPCs for more complicated cases and 4) one central CPC in MEHMC for discussing selected cases or common challenges. **Time period:** The face-to-face program started in 2017 and was terminated on February 2, 2020. However, in one general hospital it was continued during the pandemic using an online platform. **Results:** This paper explores the details of this program, most frequent cases and experiences of involved clinical ethicists involved in this process.

## The Effects of Conflict in Ethics Consultation: A Matched Pairs Cohort Study

Stowe Teti

**Background:** While conflict frequently involves value differences, the converse is not necessarily true, through HEC, value differences can be acknowledged, respected, understood, and incorporated into a cohesive, ethical care plan all parties accept. However, the resolution of conflict is multifactorial. Questions persist as to whether, and how inherent, disagreements are, comparisons between similar cases would benefit from further investigation. **Aims:** This project sought to investigate whether the presence or absence of conflict across matched sets of ethics consults could be investigated empirically. Successfully controlling for ethical issues and aggregating results across many issue types would allow for the effects of conflict to be characterized and examined. **Methods:** Mixed methods, including a retrospective review of ethics consults conducted from 2020 to 2024 at an academic medical center (n = 3000). Cases coded with identical ACECS code triads used  $\geq 10$  times were included to yield final data set of 595 individual consults in 34 cohorts (mean consults per cohort=16.4, median=11.5). **Results:** Significant differences were found around reported presence of uncooperative behavior (53.3% in conflict cases, 3.7% in values cases), average length of stay (24.6 days in conflict cases, 20.0 days in values cases, and in-hospital mortality (21.7% in conflict cases and 38.1% in values cases). Qualitatively, the case cohorts involved refusal of treatment, clinical candidacy, extent of decision-maker authority, and withholding treatment, with refusal of treatment presenting with the widest range of permutations. **Discussion:** The relationship between conflict and stalled plans of care has been posited to account for differences in length of stay, but the marked differences in mortality between the two groups bears further investigation. Patient disposition will be presented, and the presentation will address the relative rates of moral distress, professional integrity, and other qualitative considerations.

## MIGRANT POPULATIONS

### Ensuring Equity Access to Healthcare for Uninsured Patients: A Multidisciplinary Decision Model in a University Hospital

Mirela Caci, Valérie Burnens, Rachel Rutz

**Background:** International mobility and medical tourism are factors leading people to travel to Switzerland to receive specialized care. Sometimes, restrictions on the follow-up treatment in the patients' home country, particularly its unavailability, present a challenge for the choice of treatment and force patients and relatives to ask for follow-up treatment in Switzerland. In consequence, the lack of insurance coverage puts patients and healthcare professionals (HP), in a challenging position, where they navigate between significant costs and ethical tensions. **Aims:** Provide a harmonized approach to treatment for all uninsured patients through a multidisciplinary evaluation and guidance within an official transparent framework, aiming to reduce injustice based on financial means or administrative status. **Method:** In 2007, we established a multidisciplinary case management team comprising hospital managers, ethicists, lawyers, and social workers that is working with HP, patients and relatives to determine the extent of care provided addressing all administrative issues. Taking responsibility for the decision, the hospital's reference team supports patients and HP in the decision-making process. **Results:** Each year 250 to 300 patients are evaluated and solutions are found with joint health care decisions after considering clinical, ethical, financial, and any administrative issues that may arise. The expert team support professionals in complex ethical and administrative challenges, contributing to equal care access and allows HP to better fulfill their core mission. Moreover, systemic issues identified during the assessment are referred to authorities and partners allowing further developments of the health system strategy. **Discussion:** Complex financial and administrative rules for uninsured patients are often neglect by health professionals because the perceived care mission and high complexity. The situation results in injustice for patients or inappropriate cost. Expert teams can support HP and patients in making innovative multidisciplinary decisions, thus contributing to fairer access to healthcare and system improvements.

### How to Protect the Benefit and Maintain Justice for Migrant Workers: The Experience in a Clinical Ethics Committee in Singapore

Peter Chiu-Leung Chow

Singapore, as a city-state, has limited manpower, as a metropolitan, receives a large number of migrant workers for economic development. Majority of them come to Singapore working as domestic helpers and construction workers. These young migrant workers may fall sick when they work in Singapore: tropical infection, injury, auto-

immune disease etc. Although it is compulsory for the employer to pay for the migrant worker's medical insurance, the coverage is very limited. When medical care involve expensive investigations and treatments, who is going to cover the hospital bill? Employer, migrant worker agency or taxpayer? Can the employers request limited medical management and send the migrant workers back to their home countries? Knowing that they come from low-income class and the healthcare system in their home countries may not be well-developed, how should the healthcare professionals in Singapore hospitals achieve patient's beneficence, avoid maleficence, protect patient's autonomy and maintain social justice in this kind of ethical dilemma? In this oral presentation, we will present a case referral to the Clinical Ethics Committee of Changi General Hospital, Singapore. A domestic helper who required extensive investigation for possible auto-immune encephalitis. However, the employer and the domestic helper agency staff appeared in the ward suddenly requesting discharge against medical advice. We will discuss how the primary team responded to the employer and agent, the deliberation of the Clinical Ethics Committee to this dilemma and the factors of consideration by the Clinical Ethics Committee.

### **Integrating Immigrants' Cultural Traditions in Healthcare Ethics Consultation: Addressing Moral Conflicts in Prenatal Care**

*Hajung Lee*

**Background:** Healthcare Ethics Consultation (HEC) addresses moral conflicts, particularly in contexts where cultural disparities in prenatal care arise for immigrant populations. Taegyo, a traditional Korean practice focused on spiritual and emotional well-being during pregnancy, presents unique ethical challenges for Korean immigrant women, especially when integrated with modern medical practices. These challenges often involve conflicts between culturally rooted beliefs and contemporary medical advice. **Aims:** This study investigates how taegyo can inform HEC models by promoting culturally sensitive ethics consultations. The primary goal is to resolve moral conflicts in prenatal care and foster equitable healthcare and social justice by bridging cultural traditions with modern medical practices. **Methods:** In-depth qualitative interviews with Korean immigrant women and healthcare providers were conducted to explore how taegyo influences prenatal experiences and shapes moral decision-making. The study identified gaps in current healthcare systems and examined how intercultural conflicts arise between taegyo and Western medical approaches. **Results:** Findings reveal that Korean immigrant women experience both a lack of culturally sensitive guidelines and moral conflicts between taegyo and modern medical practices. Healthcare providers acknowledge the need for models that integrate cultural traditions into contemporary medical care. Incorporating taegyo and other culturally specific reproductive practices into HEC enhances ethical decision-making and fosters more culturally responsive care. **Discussion:** This research suggests that innovative HEC models that integrate cultural traditions address the ethical needs of immigrant communities, promoting equitable, culturally sensitive healthcare. This approach demonstrates how culturally grounded frameworks can enhance the practical impact of HEC, offering a model for broader application in healthcare systems serving diverse populations.

### **Health Professionals' Experiences With Uninsured Children in Quebec: A Qualitative Study in Pediatric Settings**

*Annie Liv*

**Background:** The 2021 Bill 83 (PL83) aimed to provide provincial public health insurance (RAMQ) to previously uninsured migrant children in Quebec. However, many children remain uninsured, posing ethical challenges for healthcare professionals that have yet to be thoroughly examined. **Objectives:** This study sought to explore healthcare professionals' experiences with uninsured children, focusing on the practical and ethical issues arising from the lack of insurance. **Methodology:** This qualitative research adopts a comprehensive paradigm focused on participants' subjectivity and includes semi-structured interviews with healthcare professionals. These participants were recruited through purposive and snowball sampling at Quebec's two largest pediatric hospitals. Interview topics included clinical experiences with uninsured children, the impact of lacking insurance, and strategies for overcoming barriers. The theoretical framework of social justice underpins this research, advocating for the right to healthcare for children without discrimination. Interviews were fully transcribed, and thematic analysis using inductive coding (NVivo) revealed key themes. **Results:** Between January and October 2024, 25 participants (52% physicians, 20% nurses, and 20% social workers) were recruited. Analysis identified three themes: 1) Organizational and systemic factors contribute to a lack of RAMQ for migrant children, leading to significant challenges, such as hospital bills and difficulties accessing primary healthcare services. 2) Emergency departments (EDs) become the only option for parents seeking medical care for their children. EDs are not designed to address the

healthcare and psychosocial needs of these marginalized populations. 3) Participants expressed frustration, helplessness, and a sense of injustice regarding the barriers uninsured children living in Quebec face. Ethical challenges prompt professionals to find solutions to provide equitable care, such as adapting treatments to financial limitations and life circumstances. Conclusions: Insights from healthcare professionals highlight strategies to overcome barriers. Potential systemic solutions include presumed eligibility based on residency proof, educating the healthcare workforce, and improving access to primary care.

## **Ethical Strategies for Improving the Use of Interpreter Services**

*Jamie Watson*

When a patient's primary language does not match that of a healthcare team, clinicians may struggle to establish clear communication with that patient. In those cases, interpreter services can be used to create a space wherein patients can receive information and are able to share their perspective. However, variation in availability and use of interpreters puts patients at risk of having their values and preferences misunderstood or left unstated. When values-based challenges in medical interpretation arise, clinical ethicists are often asked to support teams, patients, and families in promoting patients' interests, but there is little available guidance on how ethicists can be helpful. For example, the use of family members or friends as interpreters raises concerns about the adequacy of information conveyed by the treating team. On this same line, the use of technology by patients and families, such as cell phone applications, risks achieving mere translation rather than robust interpretation, potentially missing critical cultural connotations and norms of communication that would be understood by fluent and culturally knowledgeable speakers. In this presentation, we review current US guidelines for the use of interpreter services as well as the professional ethical responsibilities of medical interpreters. We then highlight ethical challenges in patient care unaddressed by those guidelines and responsibilities. We conclude with strategies for how ethics consultants can improve the use of interpreter services, during both policy development and review and as part of real-time care discussions. Ultimately, we aim to discuss pathways to better promote patients' nuanced values and preferences through the use of interpreter services.

## **A.I. AND CLINICAL DECISION-MAKING**

### **Artificial Intelligence in Pharmacovigilance: Considerations for Clinical Ethics and Consultation**

*Natalia Amasiadi*

The adoption of Artificial Intelligence (AI) in pharmacovigilance (the practice of monitoring and assessing the safety of medications) is transforming drug safety monitoring and adverse event detection, presenting new opportunities and challenges for clinical ethics and consultation. AI algorithms can process extensive clinical and patient-reported data, identifying potential safety issues in real-time and enabling proactive drug risk management offering significant advantages in patient safety and public health. However, integrating AI into pharmacovigilance also introduces challenges around transparency, accountability, patient privacy, and trust. One major ethical concern in AI-driven PV is patient privacy and data confidentiality. AI systems often require access to sensitive health data from diverse sources, including electronic health records, and wearable devices, which raises significant privacy risks. In clinical ethics, maintaining patient confidentiality is foundational, thus, ethical oversight is critical to ensuring that AI applications in PV adhere to privacy regulations and respect patient autonomy. Consultations with patients and ethical review bodies should incorporate clear communication on data usage, privacy safeguards, and the option for patients to consent or opt-out. Transparency and interpretability are further ethical issues central to clinical ethics and consultation. AI models are often "black boxes," making it difficult for clinicians and patients to understand how certain pharmacovigilance decisions (such as risk classifications and safety alerts) are reached. This opacity can challenge clinical consultations, as healthcare providers may lack the necessary insight into AI-derived findings to counsel patients confidently. For ethical AI deployment, developing explainable models is crucial, allowing clinicians to communicate AI-generated insights to patients accurately and responsibly. Last, algorithmic bias is one of the most pressing concerns, as AI models in PV can inadvertently reinforce existing health disparities by reflecting biases in their training data. Bias in adverse event predictions may lead to underreporting or overestimating risks for certain demographics, disproportionately affecting marginalized groups. In clinical ethics, it is imperative to address such biases, as they can lead to inequitable patient outcomes and erode trust in healthcare systems. Ensuring fairness and inclusivity in AI applications requires ongoing data audits, diverse datasets, and ethical oversight to detect and mitigate biases in real-world PV settings. In conclusion, while AI enhances pharmacovigilance by enabling more efficient and proactive drug safety measures, its ethical integration into



clinical practice requires careful attention. Clinical ethics and consultation provide essential frameworks for addressing issues of privacy, transparency, bias, and autonomy, ensuring that AI in PV aligns with ethical standards and patient-centered care. Future research should emphasize ethical AI frameworks, continuous clinician training, and multidisciplinary collaboration to support the responsible use of AI in pharmacovigilance.

### **Navigating Responsibility in the Age of Artificial Intelligence (AI): Ethical Challenges for Healthcare Ethics Consultation (HEC)**

*Christina Kalogeropoulou*

In a world undergoing rapid transformation, we are increasingly shaped by information, evolving into interconnected entities, or “inforgs.” This shift, largely driven by emerging technologies like artificial intelligence (AI), places the concept of responsibility under heightened scrutiny, especially within healthcare ethics. As AI becomes integrated into healthcare systems, healthcare ethics consultation (HEC) faces new ethical responsibilities, raising complex socio-political questions around bias and decision-making. This presentation explores how HEC can navigate these challenges, addressing and potentially redefining traditional roles of responsibility in the healthcare landscape. First, we will explore how AI reshapes responsibility by introducing both innovative tools and ethical dilemmas. Although AI systems aim to support clinicians, they often present quasi-objective claims that conceal biases and ethical implications. By examining these biases, we will question AI's role in healthcare ethics and challenge the neutrality often associated with algorithmic decision-making, emphasizing the need for HEC professionals to discern the socio-political underpinnings of these technologies. Next, we will discuss the shifting dynamics in healthcare power structures that AI introduces. With clinicians increasingly relying on AI recommendations, their role evolves from sole decision-makers to mediators between technology and patient care. Simultaneously, patients are encouraged to participate more actively in their healthcare decisions, highlighting the importance of shared responsibility and transparency. This shift challenges traditional hierarchies, calling for HEC's guidance in creating an equitable, collaborative healthcare environment. Finally, we will highlight the broader ethical implications of AI in healthcare, addressing how HEC can contribute to patient engagement, transparency, and the equitable distribution of responsibilities. By critically engaging with these new paradigms, HEC can offer insights that transcend healthcare and contribute to wider socio-political conversations around the ethics of digital disruption.

### **Using Artificial Intelligence for Proxy Decision-Making**

*Marcia MacGregor Brown, Victoria Nolan*

**Background:** The literature alludes to several studies highlighting challenges with human proxy as decision makers such as emotional burden, physician barriers, decisional conflict, accuracy, and overconfidence. However, only a small subset reported on a proxy's congruency. This study expanded on a proof-of-concept that artificial intelligence (AI) can act as a proxy decision maker with value preferences and considered its ethical implications. **Aim:** To compare the congruency of AI as a proxy decision maker with human proxies on end-of-life treatment decisions. **Methods:** Utilizing LLaMa3, an AI Large Language Model as a proxy decision tool, we recruited 15 adults and their legal decision makers as dyads to complete a value and end-of-life preference surveys for a comparison analysis. We measured the participants' overall composite value scores and collected their end-of-life preferences to use in the AI congruence evaluation. Congruency percentage was taken over three clinical hypothetical scenarios and compared between the participant with either the human or AI proxy. **Results:** The mean congruency percentage between the participant and human proxy was 44.4% (95% CI: 23.6-65.3),  $n = 12$ . Fifty percent of dyads had one or no matching responses across the three scenarios and 16% had perfectly matched responses. After the model's adjustment for prompt engineering and parameter fine-tuning, the congruency with AI and value inputs was 72.2% (95% CI: 67.4-77.0) with 67.0% matched responses. The model performed the same as the human proxy without value preferences with congruency of 45.3% (95% CI: 36.2-54.4). **Discussion:** The AI model had a 28% higher congruency as a proxy decision-maker for end-of-life treatment decisions after the inclusion of value preferences. This approach has a promising utility as a supplemental tool for human decision-making and can protect self-determination if values are pre-recorded in the event of decisional incapacity.



## Clinical Ethics at the Crossroads of Care and Emerging Technologies

*Rossana Ruggiero, Monica Consolandi*

In recent years, clinical ethics consultation has made significant strides, increasingly establishing itself as an essential component of decision-making at the patient's bedside. This evolution has been driven by the growing complexity of clinical cases, in which ethical analysis plays a crucial role in addressing dilemmas that cannot be resolved by medical expertise alone. Simultaneously, the healthcare sector has been profoundly influenced by both significant cultural changes and techno-scientific innovation, particularly the development and application of emerging technologies and artificial intelligence. Cutting-edge technologies have revolutionized diagnostics, treatment options, and patient management, offering both opportunities and challenges, while also raising new ethical dilemmas. The primary ethical concerns include issues surrounding AI-driven medical decision-making, which raises questions of accountability, the impact of technology on patient autonomy, data privacy and security risks, the depersonalization of care, and the risk of bias and fairness in AI systems. Additionally, there are challenges in ensuring informed consent when AI is involved in clinical decisions. By analyzing these new ethical dilemmas, we provide evidence that healthcare professionals who utilize clinical ethics consultation in the context of new technologies uphold the centrality of the patient, respecting their humanity and dignity, as well as the care and assistance they require. We emphasize that the thoughtful integration of clinical ethics and technology can lead to more innovative and effective healthcare practices, addressing the central question of ethics: how to act in the best interests of both the patient and the healthcare professional. The future of clinical ethics stands at a pivotal juncture, where the rapid advancements in technology raise important concerns: how to improve care and offer cutting-edge medical assistance without compromising human dignity.

## Advancing Clinical Ethics by Developing a Patient Preference Predictor With Machine Learning: A Proof-of-Concept

*Georg Starke*

**Background:** Knowing patient preferences is crucial for respecting patient autonomy and providing care in line with their wishes. Common challenges in ethics consultations arise when incapacitated patients' preferences are unknown and there are neither advance directives nor designated surrogates. In such situations, relatives or healthcare providers are asked to make decisions on behalf of the patient but frequently struggle to predict patients' preferences, creating ethical, emotional and clinical dilemmas. **Aims:** In line with the digital transformation of healthcare, ethicists have suggested that a patient preference predictor (PPP) trained with machine learning (ML) could provide a solution to this conundrum. So far, the debate lacks empirical support by an actual program. Here, we fill this gap by reporting the first proof-of-concept PPP, trained on a population sample of Swiss adults aged 50 and older. **Methods:** Using existing data from 1,814 participants of the Wave 8 (2019/2020) of the Survey of Health, Ageing and Retirement in Europe (SHARE), we evaluated several ML techniques to create a PPP, employing Shapley values to interpret the best-performing model—eXtreme Gradient Boosting Machine (XGBM). Reflecting different potential use scenarios, we trained three models: a simple model based on demographic data, a clinical model trained on data likely available in electronic health records, and a personalised model, incorporating more complex individual preferences. **Results:** Compared to couples in our sample, all three models outperformed partners in accurately predicting whether a patient would prefer resuscitation in cardiac or respiratory arrest. With up to 71% accuracy, our models also performed on par or better than typical estimates of surrogate predictive accuracy in the literature. **Discussion:** This study offers the first empirical demonstration of an ML-based PPP, highlighting both technical and conceptual limitations, and contributes to important ongoing debates regarding the ethical desirability of employing a PPP in clinical settings.

## PHILOSOPHY AND CLINICAL ETHICS CONSULTATION

### Making it Fair: Principlism, Moral Perspectivism, and Ethics Consultation

*Marco Annoni*

In this talk, I will address a critical yet underexplored issue within one of the foundational frameworks of medical ethics: principlism, or the 'four principles approach.' Despite the availability of various ethical models, principlism remains influential, with key components' such as balancing and specifying *prima facie* principles in conflicted cases' often accepted without scrutiny. I will argue that the popular form of principlism is inherently problematic,

as its decision-making framework systematically favors one stakeholder: the physician. This imbalance may lead to unjust outcomes, particularly as the gap in moral perspectives between clinicians and patients widens. Factors such as divergent cultural, socioeconomic backgrounds, and personal beliefs exacerbate this risk, making principlism more susceptible to producing biased and inequitable decisions in contentious cases. To mitigate these issues, I propose adopting a more nuanced deliberative model rooted in Sissela Bok's -Test of Publicity.- This approach involves a thought experiment designed to bridge the discrepancy of perspectives between doctors and patients. By encouraging clinicians to consider whether they would be ready to defend their decisions in front of their conscience, their peers, the public, and ultimately patients themselves, the test of publicity may aid in minimizing bias and promote fairer ethical deliberations while balancing between different moral considerations. This proposed shift underscores the need for a more equitable framework that can accommodate diverse moral viewpoints, ultimately fostering fairer and less biased outcomes in healthcare ethic consultations.

## **AI in Medicine: Ethical Challenges and the Need for a New Framework for HEC-Response**

*Hirra Hassan Rafi*

This work presents a further elaboration of bioethical principles of respect for autonomy, non-maleficence, beneficence, and justice to address the ethical dilemmas and challenges posed by the integration of Artificial Intelligence (AI) into medicine. In doing so we realize that a new bioethical framework is needed to tackle these new challenges. The new framework will guide Healthcare Ethics Committees (HECs) in addressing new ethical dilemmas. Autonomy, for instance, becomes more complicated with AI-driven precision medicine, where both patients and clinicians often struggle to fully understand decisions generated by opaque algorithms. Non-maleficence is insufficient in preventing harm when AI tools reduce human oversight and shift accountability away from humanity. Simply being beneficial does not justify AI's use, and the principle of beneficence should not apply to a tool that doctors cannot comprehend. AI is limited to its programmed data and design and is unable to account for a holistic approach to justice as human ethicists can. In response this framework introduces additional bioethical principles-transparency, privacy, accountability, and humanness-that have gained increasing importance in the era of AI. Transparency stresses that AI systems should be clear and interpretable by those making decisions based on AI's output. Privacy ensures protects patients from exploitation due to AI's vast surveillance capabilities. Accountability reinforces human responsibility in AI-assisted decision-making and prevents healthcare professionals from relinquishing too much authority to AI systems. Humanness emphasizes the need for preserving core human roles in patient care and acknowledges that morality and virtue cannot be programmed into AI systems. AI has remarkable potential, yet, it is essential that human involvement, not a cold AI, remains central to patients' clinical and ethical care, as only humans possess the capacity for being moral.

## **An Ethics Framework for the Transition to an Operational Learning Healthcare System**

*Marieke Hollestelle*

**Introduction:** In many areas of healthcare, learning healthcare systems are seen as promising ways to accelerate research and outcomes for patients by reusing health and research data. For example, in the case of pregnant and lactating people, for whom there is still a poor evidence base for medication safety and efficacy, a learning healthcare system presents an interesting way forward. Combining unique data sources across Europe in a learning healthcare system could help clarify how medications impact pregnancy outcomes and lactation exposures. While many projects have been launched with the aim of establishing such a system, the amount of operational learning healthcare systems remains limited. Given the investment of resources in these projects, a moral responsibility to pursue the transition toward a learning healthcare system falls on projects and their participating stakeholders. This paper provides an ethics framework for projects and other stakeholders that have taken steps towards building a learning healthcare system and are in the position to transition to an operational learning healthcare system. **Method:** To articulate relevant ethical requirements, we analyzed established ethics frameworks in the fields of learning healthcare systems, data intensive health research, and transitioning or innovating health systems. The overlapping content and shared values were used to articulate overarching ethical requirements. To provide necessary context, we applied the insights from the analysis to the Innovative Medicines Initiative ConcePTION project, that aims to build a learning healthcare system for pregnant and lactating people. **Results:** We identified four overlapping ethical requirements that are of significance for our ethics framework. These requirements are: 1) public benefit and favorable harm-benefit ratio, 2) equity and justice, 3) stakeholder engagement, and 4) sustainability. **Conclusion:** Although tailored to the context of pregnancy and lactation, our ethics framework can provide guidance for the transition to an operational LHS across diverse healthcare domains.

## **Taylorism and AI as Partners in Crime to Push the Care out of Health Care**

*Wim Van Biesen*

Taylorism is a management style building on componentiality and interchangeability of production tools and laborers in the production process. In this approach, each process is broken down into ever smaller pieces, until each subunit reaches a level simple enough to be performed without special skills. Labor can then be performed under managerial supervision by increasingly lesser-skilled (and cheaper) staff, who thereby also become interchangeable. Taylorism has silently been introduced into health care to increase efficiency and reduce costs, exemplified by clinical pathways, tick-box medicine and super-specialization. Taylorism is problematic from the ethical perspective as: 1. It reduces the patient to an object with a fault and the need of a technical fix, 2. it degrades the physician-patient interaction from a holistic and empathetic exchange of personal values and goals to that of an assembly line, inducing moral distress and burn-out of health care professionals, feeling they are no longer able to act in their patients' best interests. Simultaneously, the introduction of artificial intelligence (AI) and clinical decision support systems (CDSS) into clinical practice brings ethical challenges, such as 1. threatening autonomy of both patients and clinicians, 2. risking deskilling, 3. problems of meaningful control, 4. delegitimizing concerns or (unmeasurable) values of patients leading to missed opportunities to do good. Taylorism in Health Care is facilitated by the advent of AI, they fortify each other. AI enhances managerial control, and stimulates tick-box medicine, whereby high skilled health care workers can be replaced by a lower skilled worker with a CDSS. The combination risks precipitating situations where only problems that can be measured and digitalized will be addressed. This risks reducing the legitimacy and visibility of non-somatic issues, such as psychological suffering, social deprivation or human experience.

## **GENDER-AFFIRMING CARE**

### **Voice Matters: How Gender Affirming Services Builds Agency & Autonomy**

*Kimberly Eichhorn*

Background: Communication is fluid. The cultural context, message content, and communication partners dictate the voice used by the speaker to convey intended messages and meaning. For gender diverse individuals, finding a voice and communication style that is authentic to themselves can build agency and autonomy. Objective: For many transgender people, a mismatch between their voice and gender identity can lead to significant emotional distress, anxiety, depression, and even suicidal ideation. A voice that aligns with one's gender identity is a key component of self-expression and identity formation. Society often links gender identity with specific vocal characteristics (e.g., a higher-pitched voice for women). People who do not conform to these vocal norms may be subject to misgendering or social exclusion. This presentation seeks to highlight awareness to the need for access to specialized voice care in hopes of minimizing identity conflict and feelings of disempowerment. Solutions: The lack of recognition or funding for gender-affirming voice care in public health policies reflects larger gaps in the provision of comprehensive transgender healthcare. Advocating for the inclusion of voice care in public health systems can be a part of broader efforts to push for policy reforms that ensure equitable access to gender-affirming services. In regions where transgender people face legal obstacles to healthcare, the absence of voice care as part of healthcare coverage further stigmatizes transgender people and silences them. Implications: The socio-political impact of limited gender-affirming voice care cannot be underestimated, as it intersects with critical issues of healthcare access, mental health, social acceptance, and human rights. Addressing this gap in care can have a significant positive impact on the well-being of transgender and gender non-conforming individuals while also advancing broader goals of social justice, gender equality, and healthcare equity.

### **Role of Clinical Ethicists in the Shifting Legal Landscape for Gender Affirming Care**

*Laura Guidry-Grimes*

Healthcare systems in numerous countries continue to grapple with the politicization of gender affirming care (GAC) and the substantial shifts in the GAC legal landscape. These shifts have led to restrictions and uncertainty regarding the provision of GAC to adults and children, providers' ability to continue to follow best practices, insurance coverage, and institutional sustainability of GAC. The politicization of GAC is one part of numerous anti-transgender efforts, heightening the distress that adults and children alike face in schools, sports, bathrooms, and elsewhere. In this political climate, questions arise as to how best to support gender nonconforming patients, their

families, and GAC teams. Clinical ethicists have a role in this collaborative process, given the ethical implications of threats to GAC, such as healthcare access barriers, inability to refer patients to essential services, severed therapeutic relationships, misinformation, harms to patients, threats to caregiver safety, and lost public trust. We describe ways in which clinical ethicists can make impactful contributions, both proactively and reactively, in the shifting legal landscape for GAC. Our suggestions are based on our experiences as clinical ethicists in states in the U.S. that have proposed or passed laws that limit GAC. Our recommendations span across bedside consultation, institutional decision-making, and public-facing comments or testimony for broader advocacy. These recommendations for clinical ethics involvement may also aid in signaling to institutional leadership appropriate situations for enlisting clinical ethics support. We share our reflections on what efforts were well-received, such as supporting ongoing communication across teams and moral distress reflective debriefs. We discuss concerns clinical ethicists may have in taking on this role, including personal political proclivities, hesitance related to advocacy work, lack of deep knowledge of GAC, and not having established relationships with GAC teams.

## **Statutory and Regulatory Requirements, and Ethical Concerns in the Treatment of Gender Dysphoria**

*Crystal Lim*

This presentation discusses efforts by a hospital's multi-disciplinary team in developing a workflow to improve treatment for patients with gender dysphoria (GD), in response to statutory and regulatory changes. Attention is given to ethical principles guiding the workflow development, health inequality, and ethical concerns. Prior to 2018, a psychiatrist's assessment of a person as suffering from GD sufficed for the person to obtain a change in legal sex status on the national identity registration in Singapore. A regulatory amendment that year mandated that a person diagnosed with GD must be assessed by certain medical specialists to have undergone sex reassignment surgery (SRS) to effect the sex status change. The Healthcare Services Act (2020) enactment requires approval from the hospital's clinical ethics committee before a doctor can perform SRS. Thus, GD patients experience two statutory/regulatory hurdles: CEC approval prior to SRS, and mandated SRS for sex status change. However, treatment affordability limits patients' access to SRS because such surgeries are not accorded government subsidies even though subsidies are provided for hormonal therapy, psychiatry and therapy services. This policy incoherence delays cash-strapped GD patients in obtaining SRS and its concomitant legal status change, and for some, a delay for heterosexual marriage. SRS is medically justified for treating GD, a denial for subsidies reflects policy inconsistency that contributes to healthcare inequality for GD patients. Ethical concerns also arise from the following: the absence of a gender care clinic in this hospital reduces coordinated care for patients, lack of specialty training among psychologists and social workers affects competent care for GD patients, and hospital admission practice does not provide adequate safeguard for GD patients' privacy and confidentiality. Plans and steps for mitigating ethical concerns to promote distributive justice, social justice and ethically responsible treatment for GD persons are advocated.

## **Ethical Challenges Around Gender-Affirming Care Decision-Making Among Transgender Minors, Parents and Providers**

*Shilpa Surendran*

Background: In Singapore, little is known about the practice of gender-affirming care (GAC) with uncertainty in care pathways and service provision, and providers and minors appear to face specific ethical challenges. Aim: To explore the ethical challenges around decision-making in GAC experienced by transgender minors, parents and providers. Methods and analysis: We conducted in-depth semi structured interviews with 13 transgender minors, six parents and 13 providers in Singapore from February to August 2024. Data were analysed inductively using thematic analysis. Results: The ethical challenges emerged were organised into a three-phase temporal model: (1) coming out to parents, (2) interaction with the healthcare system, and (3) decision-making process. Minors delayed coming out to parents due to fears of negative reactions. When interacting with the healthcare system, minors and parents noted the lack of formal information on GAC from public hospitals, and care referral pathways varied, with some hospitals requiring additional psychiatric assessments, increasing wait times. Barriers also included providers refusing GAC due to religious beliefs, minors' age, or lack of parental consent. In the decision-making process, minors prioritised resolving the disconnect between their body and mind to live authentically, while parents prioritised protecting minors from irreversible physical changes and social discrimination. Some parents preferred alternatives or delaying decisions until their child was older. Minors with unsupportive parents either pressured them to consent or turned to unregulated sources for GAC. Additionally, providers had to balance minors' urgency for GAC with the need for thorough assessment. Some minors had unrealistic expectations, requiring providers to offer more

realistic outcomes. Multidisciplinary team discussions were valued for navigating grey areas and ensuring accountability. Providers also acknowledged the challenges in applying international clinical guidelines due to the cultural and legal differences. Discussion: This study highlights the complex ethical challenges in decision-making for GAC, as illustrated by the three-phase model.

## CLINICAL ETHICISTS AND SOCIAL JUSTICE

### **Moral Distress in the United Arab Emirates: Lessons learnt and Moral Resiliency strategies within both Healthcare Ethics Consultation Services and Medical and Nursing Practice**

*Mahwish Ahmad*

Workplace violence (WPV) against healthcare professionals represents a global issue. Violence in the maternity setting has received little research attention, with midwives often assimilated into nurses. Few studies, primarily qualitative, have explored the effect violence has on midwifery students whilst clinical placement. Methods: An online, anonymous survey was sent via email to all members of Local Midwifery Boards in Italy and to all Italian midwifery students, investigating their experiences of WPV and bullying. Results: The findings highlight the high exposure to violence that midwives and midwifery students experience in the workplace. A total of 1059 completed questionnaires were returned by eligible participants, 687 midwives and 372 midwifery students. Forty-five percent of midwives and 27% of students reported being a victim of WPV. This was most often in the form of verbal abuse. The women's partners or other family members (65.4%), patients (21.9%), and physicians (29.1%) were identified as the main perpetrators by midwives. Midwifery students experienced bullying mostly from supervising midwives (40.2%) or other midwives (56.8%). Over half of the victims did not report and seek assistance through formal channels. Consequences of WPV included thoughts of leaving their job (27.1% of midwives) or course of study (22.5% of students) and significantly reduced gratification from caregiving. Discussion and Conclusions: Healthcare professionals face the following moral dilemmas: providing care to patients who have attacked them, manage emotions so as not to let them to interfere with care, balance the responsibility of protecting their own integrity and safety with professional duty and with respect for dignity of the patient. HEC can offer a listening space for victims and create the conditions allowing for the reporting of facts. In this listening space, ethical consultant can help to explore and resolve these conflicts through an analysis of professional and moral values. Also, HEC can help to create corporate awareness on the topic so that adequate prevention measures are implemented.

### **If Not Us, Then Who? The Role of Advocacy & Activism in Healthcare Ethics Practice**

*Claudia Barned*

Background: There has been considerable debate about the acceptability of advocacy/activism within the healthcare ethics consultant's (HECs) scope of practice. Whereas some have expressed hesitation and questioned the role advocacy/activism ought to play, others argue that ethicists are inherently activists given their role in addressing moral quandaries and striving to effect change. Aims: We sought to explore this debate from an empirical lens, i.e., to understand if/how these arguments transcend geographical borders and clinical contexts. This presentation stems from a larger qualitative project examining how HECs across various public hospitals and healthcare settings in Ontario, Canada, perceive the scope of their roles. Methods: Between May and October 2024, 40 semi-structured interviews were conducted with HECs across Ontario. Using reflexive thematic analysis, we examined the perceptions of, and challenges with advocacy and activism as part of the HECs role. Results: Amidst much diversity in how advocacy/activism is construed, our analysis revealed that concerns about job security, "cancel culture", reputational risk, and a lack of moral courage are all interconnected and possibly stem from the absence of institutional protections. Canadian HECs remain much more reserved about notions of activism than advocacy. Participants situated the permissibility of each in relation to their status as clinical or academic ethicists vs. their engagement as professionals or private citizens. These themes are enmeshed in a prevailing belief that HECs should be accessible to all, which necessitates a commitment to neutrality in ethical discourse. Discussion: The differing perceptions of advocacy/activism highlight the need for clear delineation and operationalization of these terms within healthcare ethics practice. Given the criticisms of the field, and the urgent calls to action regarding racial equity and justice, these findings are instructive of how we might mobilize towards change in favour of the diverse populations served.



## **Do Clinical Ethics Services Have a Role in Promoting Social Justice?**

*Louise Campbell*

Promoting social justice involves a recognition of the need for a more equitable distribution of resources and opportunities and a commitment to identifying and redressing the structural factors which perpetuate inequity within society. As health disparities continue to widen, healthcare organisations and healthcare workers pursuing a social justice agenda need to take action to ensure that barriers to healthcare for marginalized individuals and groups are removed or minimized. Reducing inequity has become a central pillar of healthcare policy in many countries, although how this is to be achieved is often contested. The purpose of this presentation is to explore the question of whether clinical ethics has a role to play within the larger project of promoting social justice, and the challenges associated with this expanded role in an increasingly complex clinical environment. Skillful clinical ethics consultation has the potential to empower patients, families and clinicians by facilitating information exchange, scrutinizing value conflict and negotiating power asymmetries within the clinical encounter. At its most transformative, it gives voice and agency to those who would not otherwise be heard. However, while clinical ethics consultation can promote engagement with members of hard-to-reach populations, clinical ethicists committed to social justice need to go beyond this and become activists for change within their organisations. Well-established clinical ethics services are in a prime position to spearhead change, not only by influencing policy direction, but by working closely with hospital executives, administrators and health and social care professionals to ensure that the care provided to patients takes into account the enduring impact of systemic trauma, exclusion, poverty and discrimination on health and health behaviours, including barriers to accessing care. If clinical ethics can be used as an instrument of social justice, it may be time for it to become 'disruptive'.

## **Nice to Have or Need to Have? Justifications for Healthcare Ethics Consultation (HEC) in Tightening Resource Environments**

*Marleen Eijkholt*

HEC services are under an increasing threat of administrative skepticism. With global financial crises and resources for health care becoming more constraint, structural support for HEC is under closer scrutiny. Voices that deem HEC as a NICE to have instead of a NEED are growing louder. At the same time, healthcare has become more complex and moral issues have far from resolved. Environmental-, financial- and digital crises are challenging healthcare providers by creating various dilemmas that affect patient care, on managerial and bed-side level. Increased skepticism means that traditional arguments for HEC might no longer be satisfactory. Top-down accreditation norms are crumbling apart. And while the professionalization movement in the US may have contributed to making HEC more established, structural support for and professionalization of HEC is varied and still in its infancy in Europe. HEC services have existed in the Netherlands for several decades. Yet HECs are far from integrated throughout the whole system, and its development and support is threatened by tightening resources. In the past year we have established a new academic HEC network by University Medical Hospitals to bundle forces and to establish fortified justifications for HEC. One of the network's aims is to increase recognition for structural reflective and ethically supportable health care systems in which HEC is considered an indispensable NEED. This presentation will offer an insight into the first project of the network. In this project we investigated how scarcity, and social justice, issues are present in academic hospitals, and how the HEC services are engaged in the reflection on organizational and bed-side level. We examined what role HEC can play in dealing with those issues, and what this implies for the HEC's justifications and the network's role and mission.

## **Apprenticeship in Clinical Ethics and Health Justice: Reimagining Fellowship Training for a More Equitable Future**

*Kayla Tabari*

Clinical ethics fellowships have traditionally focused on developing expertise in ethical decision-making, clinical consultation, and navigating complex patient-care scenarios. However, as health disparities continue to widen and social determinants of health increasingly influence patient outcomes, there is a pressing need for fellowship programs to address the intersection of clinical ethics and health justice. This presentation will explore how our team has designed and implemented a clinical ethics fellowship-titled the Providence Center for Health Care Ethics Fellowship in Clinical Ethics and Health Justice-aimed at integrating principles of health equity and justice into the training of future clinical ethicists. In this session, we will share the process of developing our fellowship, detailing



how we structured the curriculum to ensure a comprehensive understanding the practical application of health justice in clinical settings. The session will also include reflections on the challenges we faced along the way, as well as the feedback we have received from stakeholders thus far. Finally, we will discuss how this fellowship model has the potential to influence future training programs, ensuring that clinical ethicists are equipped not only to navigate ethical complexities but to advocate for policies and practices that promote justice and equity in healthcare.

## **SOCIAL JUSTICE IN CLINICAL PRACTICE**

### **Who is More Worthy? Reimagining Equity and Moral Responsibility in Transplant Patients with Perceived Patient Induced Diseases**

*Lindsay R. Beaman*

The increasing demand for liver transplants (LTs) has amplified the challenge of ensuring equity in the recipient selection process. In the U.S. alone, one in four patients listed for LT die on the waitlist or become too sick for surgery. The scarcity of organs raises critical questions about how selection committees determine which patients are suitable for transplantation, particularly in the context of 'perceived patient induced diseases' (PPIDs). PPIDs are conditions that arise partly from behaviors considered to be within the patient's control. This presentation explores the ethical issues in using different standards for PPIDs by comparing Alcoholic Liver Disease (ALD) and Metabolic Dysfunction-Associated Steatohepatitis (MASH). ALD, caused by alcohol use disorder, and MASH, linked to obesity, can both be perceived as self-inflicted. These disorders carry significant stigma, shaped by sociopolitical narratives that influence not only public opinion, but how healthcare providers view and treat patients. This, in turn, affects transplant selection committees' decisions about patient eligibility for transplantation. Yet, their evaluation standards differ from each other. Moral perceptions of disease lead to certain patients being considered less "worthy" of life-saving organs due to the perceived controllability or moral dimension of their disease. Patients with chronic ALD are expected to maintain a minimum six-month period of abstinence from alcohol before being placed on a waitlist. Contrarily, patients with MASH are not widely required to lose weight or demonstrate changed behaviors prior to being considered for transplant. By examining ALD and MASH through the lens of patient autonomy and culpability, utility, public perception, and transparency, it is evident that current disparities in the treatment of these conditions contribute to inequities in transplant. We suggest a practical approach of aligning selection criteria across PPIDs and eliminating moral judgments in candidate evaluation. Doing so can promote greater equity in transplant candidate selection.

### **The Clinical Ethics of Contested Illness**

*Ursula Francis*

Contested illness—those whose ontology and causation are disputed within the medical community—present the paradox of an illness without an underlying disease or diagnosis. This paradox challenges the epistemic framing of the medical profession, which is to treat illness and disease as coterminous and in terms of a diagnosis. Accordingly, contested illness is often the site of epistemic injustice: unexplained symptomology is often presumed to be psychogenic, in which case patients with physiologic symptoms have an undue burden of proof thrust upon them, requiring relentless self-advocacy and provider shopping until the true diagnosis is uncovered. Conversely, psychiatric disorders that beget physical symptoms lack clinical credibility precisely because they are psychiatric in origin—another instantiation of epistemic injustice. These practices are historically linked with the subjugation of women through their hysterization, indeed, women are disproportionately affected by contested illnesses and diagnosed, often in tandem, with conversion disorder). Contested illness thus presents the question: what does justice and ethics demand of providers when confronted with these paradoxes? After situating the problem discussed above in its historical context, this paper argues that a three-pronged approach to clinical care is essential to the equitable treatment of persons presenting with contested illness. First, providers must—regardless of causation—treat a patient's symptomology and suffering as presumptively credible, effectuating epistemic justice by investing a patient's word with dignity. Second, providers must engage the problem of diagnosis with an investigative mindset, leaving open the possibility of rare disease or as-yet-undiscovered afflictions. Finally, and fundamentally, I argue for a diachronic narrative approach to patient care, which is essential to a holistic and humanist understanding of the semiotics of symptomology and, ideally, to establishing the causation that solves the paradox of an illness without a diagnosis.

## **Bodily Intervention in Pediatric Oncofertility: Considerations From Ethics and Human Rights Perspectives**

*Kristina Hug*

When cancer treatments endanger reproductive potential of pediatric patients, fertility preservation (FP) measures depend on patient's age, gender, type of cancer, success rate or risks of the intervention. When patients are too young to assent, FP decisions rest on their legal guardians. We explore FP decision-making from ethics and human rights perspectives and employ ethical and legal argumentation to study four questions: 1) What role, if any, hidden values should have in FP decision-making, especially when patients cannot be consulted due to their young age? FP is considered in the light of society's understanding of what makes a life 'complete' and what an individual should be protected from. In the bigger picture of 'completeness' of life inability to have biologically related offspring can be seen as harm or as closing one specific 'path' in life. 2) Should permissibility of bodily interventions without minors' assent depend on how certain legal and clinical possibilities to use their reproductive material are? FP choices are made under many uncertainties, e.g.: Patients' future position about importance of having biologically related offspring is unknown. Neither is their future health status and clinical chances to use cryopreserved material. Country of residence may ban reproductive services for e.g. homosexual couples or single women, and the patient may fall within these categories. 3) Should the 'disease' status of involuntary infertility refer to future condition which may or may not be experienced? FP interventions operate under the assumption that the 'disease' status of involuntary infertility reaches as far as potential condition rather than a problem experienced here and now. 4) Should children's open future be protected by the state rather than legal guardians when it comes to FP decisions? Empirical evidence suggests that parents often feel overwhelmed by cancer diagnosis and may not give FP enough consideration, in which case FP refusal could be seen as endangering child's open future.

## **Justice in End-of-life Care for Persons With Anorexia Nervosa**

*Anna L. Westermair*

Background: End-of-life (EOL) care is the part of palliative care intended for persons nearing death. In anorexia nervosa (AN), providing EOL care instead of coercing life-sustaining measures is controversial. Aims: To clearly delineate differing views and identify open questions as well as areas of possible consensus, we conducted the first-ever synthesis of the existing literature on EOL care for persons with AN. In this presentation, we will focus on results pertaining to justice. Methods: We searched EMBASE, PubMed, PsycInfo, and Web of Science for scientific publications on forgoing coerced life-sustaining measures and/or providing EOL care for persons with AN who refuse life-sustaining measures, typically artificial nutrition. As very little quantitative studies were identified, we qualitatively analyzed the material relating to relevant aspects such as conceptual questions and ethical reasoning. Results: We identified 117 eligible publications from 1984 to 2023, mainly case reports and ethical analyses. Besides beneficence and non-maleficence, reasoning was based on the ethical principle of justice. Discrimination was used as grounds for rejecting proposals of diagnosis-based ethico-legal exceptionalism such as hard paternalism. Access to care was brought up by many authors, with some arguing that EOL care endangers access to care aiming at clinical remission and others countering that AN patients should have the same access to EOL care as persons with somatic illnesses. In addition, some authors argued that providing EOL care counters stigma by acknowledging that psychological suffering can be as real and painful as physical suffering. Discussion: While the ethical debate around EOL care for persons with AN is often framed as a conflict between the ethical principles of beneficence and respect for autonomy, justice-based ethical reasoning is relevant, too, touching on discrimination, access to care, and stigma.

## **SOCIAL JUSTICE AND PREGNANCY**

### **The Quality of an Online Democratic Deliberation on the COVID-19 Triage Protocols: Results of a Canadian Public Assessment**

*Claudia Lucrecia Calderon Ramirez*

Background: During the COVID-19 pandemic, some democratic deliberations were conducted online. A few of them aimed at presenting the new critical care triage protocols to the public. Experts have recommended gathering feedback from participants to assess their quality. However, little is known about the quality of these online processes. Objectives: 1) To assess the quality of an online democratic deliberation (ODD) on COVID-19 triage protocols with public participants in Canada. 2) To determine, according to them, its transformative aspect. Methods:

This is a mixed methods study. On May 28th and June 4th, 2022, we conducted an ODD in Quebec and Ontario with a diversified target audience. At the end of deliberative session, we collected participants' views on the quality of the process. Plus, participants responded to a survey to assess the quality and identify changes in their perspectives on triage protocols (close-ended questions and written comments). Transcripts and written comments of the survey were analyzed using a thematic analysis. Quantitative data were subjected to descriptive statistical analysis. We calculated an index to determine equality of participation during the process. Results: A total of 47 members of the public participated in the ODD (20 from Quebec, 27 from Ontario). Five themes emerged: 1) process appreciation, 2) learning experience, 3) reflecting for the common good, 4) technological, and 5) transformative aspects. Of the total, 46 (98%) participants responded to the survey. Participants considered satisfactory the quality of the ODD in terms of process, information, reasoning, and video conferencing. Some participants reported at least one change of perspective on the criteria and ethical values contained in the protocols. Online modality was reported accessible and user-friendly. Low polarization was found. Conclusion: An ODD can be a promising alternative in a pandemic context, but some organizational adjustments must be considered.

### **Justifying Late Terminations of Pregnancy for Psychosocial Reasons: Restoring Social Justice for Women**

*Célia Du Peuty*

In France, women can terminate their pregnancy on the unique basis of a voluntary request only up to 14 weeks of pregnancy, later, and up to term, if doctors attest that their health is in serious danger or that their fetus carries a serious and incurable disease. Some medical teams consider unfavorable psychosocial conditions (precariousness, isolation, psychological distress, domestic violence) as -endangering women's health-, thus enabling late termination, whereas some others do not. Clinical ethics consultations about medical termination on psychosocial grounds after 14 weeks of pregnancy help identify the ethical arguments. From this experience, it seems that respect for autonomy is not useful to make decisions in this context: these women's psychosocial conditions are interpreted as a sign of limited autonomy (understood as independence, self-determination or competence). The balance between beneficence and non-maleficence is no more helpful: the maleficence of giving birth to a dead baby and the fear that women will be overwhelmed by guilt and regrets neutralizes the beneficence of accepting the request and thus avoiding a (more) catastrophic situation for the woman. Rather, the principle of justice seems to be a more promising path to justify the decision about late termination of pregnancy for psychosocial reasons, and this is so for several reasons. First these requests are legal in France, thus indicating a wider social consensus. Second, such terminations promote psychological and social aspects of health, in line with the WHO's definition. Finally, arguments about reparation are prominent in these decisions: they contribute to compensate for poor medical practices (ex: undiagnosed early pregnancies by healthcare professionals), to counterbalance inequalities in accessing abortion across the country "that contribute to the fact that women cross the 14 weeks gestation limit for voluntary access", and to make up for inadequate or insufficient public policies on women's psychological health, domestic violence, sexual education and contraception. Thus, social justice seems a less intuitive yet more powerful argument to justify women's access to late termination of pregnancy on psychosocial grounds.

### **Prevalence of Refusal to Provide Emergency Contraception to Sexual Assault Victims in Michigan Catholic and non-Catholic Hospitals**

*Andrew Eibling*

Sexual assault presents a critical public health issue in the United States, affecting 17.6% of women during their lifetimes<sup>1</sup>. Immediate medical care is essential to address the profound sequelae, including sexually transmitted infections, trauma, and unintended pregnancy. Standard care for sexual assault survivors includes pregnancy prevention through emergency contraception (EC), recommended by the American Congress of Obstetricians and Gynecologists (ACOG)<sup>2</sup>. However, Catholic hospitals, guided by their Bishop's interpretation of the Ethical and Religious Directives (ERDs) for Catholic Healthcare Services, often restrict or prohibit EC to sexual assault victims<sup>3</sup>. This study assesses the availability of EC in Michigan Catholic and non-Catholic emergency departments (EDs). Utilizing a mystery-client approach, female interviewers inquired about EC provision in 94 Michigan EDs (69 non-Catholic, 25 Catholic). The findings indicate a disparity in EC availability: 49.3% of non-Catholic EDs versus 24% of Catholic EDs provided EC. Among non-Catholic EDs that declined EC, 93.8% provided valid referrals, compared to 72.2% of Catholic EDs. Notably, 72% of Catholic EDs and 46.4% of non-Catholic EDs refused to provide EC under any circumstance, including sexual assault. The data underscore the limited access to EC in both Catholic and non-Catholic EDs, with a pronounced restriction in Catholic facilities. Additionally, those seeking EC often encounter judgment and hostility from staff, regardless of the hospital's religious affiliation. Multiple respondents

hung up on the interviewer while the interviewer was still speaking. These limitations pose a substantial barrier to comprehensive care for survivors of sexual assault, exacerbating the psychological and physical consequences of assault. While this study reveals greater restrictions to EC in Catholic EDs, the findings highlight the need for policy changes to ensure consistent and compassionate care across all EDs, regardless of religious affiliation. Future research should explore why access to EC is limited and enhance EC accessibility for all sexual assault survivors.

### **Ethical, Legal, and Social Justice Considerations of Mandatory/Routine Pregnancy Testing in the Emergency Department**

*Jenny Clark Schiff, Alyssa Burgart*

Taking a pregnancy test (PT) and learning information about one's pregnancy status (PS) is an intimate and personal activity/decision. This is especially true in the United States following *Dobbs v. Jackson Women's Health Organization* (2022), where the Supreme Court revoked the constitutional right to abortion granted in *Roe v. Wade* (1973) and returned that decision to states. This activity/decision is all the more pressing in current socio-political times following the 2024 U.S. presidential election. However, in emergency departments (EDs) across the U.S., patients who are female, female-presenting, women, women-presenting, and/or trans run the risk, without consent, of being administered PTs and learning their PS. Indeed, ED practitioners may routinely administer PTs regardless of whether their cases are emergent, urgent, or necessitate use of anesthesia. Healthcare ethics consultation (HEC) professionals should help ensure emergency department practices and policies align with what is best for patients, not only from a clinical standpoint, but also from an ethical, legal, and social justice standpoint. Our paper focuses on ethical, legal, and social justice considerations when evaluating whether PTs in the ED should be mandatory/routine for the relevant target female population. We argue that administering PTs in the ED, especially where no consent is obtained, is often: Ethically unjustifiable according to principles of autonomy, beneficence, nonmaleficence, and justice. Legally problematic (1) insofar as the results could have drastic consequences for patients depending on the state where they seek care/travel to and (2) to the extent such tests were administered without obtaining informed consent. Dismissive of females,' and often women's, accounts/testimony of their PS, if such accounts/testimony are sought out at all. Dismissive of patients' reported sexual history and preferences, which flies in the face of LGBTQIA+ rights, and economically wasteful and irresponsible on account of the widespread use of pregnancy testing in the ED.

### **How to Deal With the Criterion of Severe Mental Distress for Late Termination of Pregnancy?**

*Manuel Trachsel*

The issue of late termination of pregnancy (abortion after twelve weeks from the last menstruation) is a topic of intense debate among healthcare professionals and the public, as it involves balancing the divergent interests and needs of the pregnant person and the fetus. Some jurisdictions recognize severe mental distress as a valid criterion for allowing late termination of pregnancy. However, the unavailability of a clear definition presents challenges in clinical practice. A systematic literature review was performed to examine in which countries the criterion -severe mental distress- exists and how it is interpreted. In addition, we conducted a qualitative content analysis of clinical ethics consultation reports conducted in a Swiss university hospital. The systematic review of the literature yielded that 23 publications distributed worldwide were relevant to the question. Regarding the term -severe mental distress-, there is no uniform terminology. The indication for abortion is referred to as psychiatric, psychosocial, socio-medical, or maternal emergency. General criteria cited for risk of severe mental distress are psychiatric, psychological, embryopathic, socioeconomic, or criminological. The qualitative content analysis of 20 clinical ethics consultation reports revealed a range of ethical challenges that arise in clinical practice, namely how the risk of severe mental distress can be assessed, whether the termination of pregnancy is suitable to avert the distress, and whether the termination of pregnancy is proportionate. We identified several recurring criteria that require clarification to aid decision making, such as whether treatment options and alternatives have been adequately discussed and presented, whether the request is consistent and enduring, and whether there are causes of severe mental distress that could be eliminated otherwise. For jurisdictions that allow late-term abortion based on severe mental distress, we propose a set of guiding questions to support healthcare professionals engaging in careful decision making.

## DISCRIMINATION

### Healthcare Providers' Experiences with Discriminatory Requests/Refusals from Patients: How Can Ethicists Help?

*Claudia Barned*

Background Healthcare providers are increasingly exposed to acts of violence, harassment and bigotry from patients, their family members and visitors. When faced with such acts, there is an organizational tendency to rely on zero tolerance policies or refer to applicable guidance from regulatory bodies. Some organizations provide in-depth guidance through policy or algorithms that help direct staff on what to do, when, why, and who to contact. In lieu of substantive organizational policy, ethicists are sometimes called upon to help navigate instances where a patient requests/ refuses care from a provider solely based on their identity characteristics. Aims This presentation is part of a larger quality improvement project focused on the revision of a patient bias policy at a large Canadian academic health sciences hospital. Rooted in experiences of diverse healthcare providers, this presentation describes the forms of discrimination that oft arise in healthcare ethics consultation (HEC) on the topic, and notes the tangible ways in which organizations can better support their employees. Method 27 semi-structured interviews were conducted with physicians, nurses, occupational therapists, physical therapists, recreational therapists, and social workers about their experiences with discrimination from patients/their family. Results Participants relayed experiences with refusals owing to racism, sexism, homophobia, and islamophobia, the intersections of these and other forms of discrimination, and the ways in which these experiences were exacerbated by nuances in the work culture/ broader organization. Discussion HEC on the topic requires thorough understanding of the refusal, awareness of the organizational stance, applicable laws/policies, available supports, and institutional constraints that might impact how decisions are made and experienced by the healthcare workforce and the patients served. Where organizational responses are lacking, providers are left to blindly navigate these emotionally distressing encounters and struggle with the tensions between the duty to care and their right to a discrimination free workplace.

### Towards an Anti-Racist Clinical Ethics: Rethinking Diversity in the Hospital Setting

*Manon Chollet*

The issue of racism in hospitals struggles to gain attention despite the existence of numerous studies documenting racial discrimination in healthcare settings. The aim is no longer to demonstrate the reality of racist discrimination, but to combat it. The diversity of patients in hospitals confronts ethicists with varied practices that can lead to misunderstandings. Ethics, like any discipline rooted in the social sciences, must engage in reflective practice in relation to discriminatory phenomena. Ethics practitioners face contemporary dilemmas, which require them to gain new insights into the systemic racism that has permeated hospital settings. Sometimes, it is more comfortable to reduce the conflict at hand to its cultural dimension and to call on specialist bodies (transcultural consultations) if they exist. But the cultural dimension of hospital conflicts involving migrant patients is overestimated. At the same time, the concept of culture is often misunderstood, misinterpreted, and can even lead to discrimination. Based on two ethnographic studies in Swiss hospitals, our presentation will focus on analyzing the mechanisms of racism in healthcare and how the concept of culture is misused. Our objectives are twofold. First, we seek to prompt reflection on the contribution of sociology to clinical ethics, which still struggles to address the structural and institutional causes of racism in healthcare. Second, we aim to propose concrete adaptations and recommendations for ethics professionals to help them make decisions that take current sociopolitical realities into account, thus avoiding the pitfalls of cultural essentialism toward migrant patients.

### Measuring the Intersection of Structural Discrimination, Non-Compliance, and Implicit Attitudes in Health Care

*Jacob Dahlke*

This presentation explores preliminary research on how the widespread use of terms like "non-compliance" and "non-adherence" may reflect broader factors beyond individual patient characteristics, including structural racism, discrimination, and healthcare professionals' (HCPs) implicit biases. If true, the routine use of these terms in healthcare, in the United States or elsewhere, may be inappropriate, and alternative perspectives and behaviors should be considered. There are four arguments to support the theory described above. First is the historical context of structural racism and discrimination (SRD) in healthcare in the United States. SRD contributes to current health



disparities and outcomes among Black, indigenous, people of color (BIPOC). Concerning this specific research question, only Black patients are considered, with the full recognition that people representing all historically and structurally marginalized populations are worthy of their consideration and research. The second argument is to describe the role that implicit bias plays in HCPs' characterizations of their patients. Implicit attitudes and biases by HCPs can perpetuate pre-existing SRD in healthcare and can impact Black patients by producing or exacerbating health outcome disparities. The third argument conceptually and operationally describes the role that non-compliance plays in these encounters, including a research summary that indicates significantly disparate prevalence in characterizing Black patients as non-compliant when compared to Non-Hispanic White counterparts. Finally, the fourth argument is synthesizing the first three, with the goals to (1) establish a functional relationship between them and (2) propose initial solutions to address the underlying culture around non-compliance. By studying the intersection of SRD, implicit bias, and non-compliance, alternative practices, e.g. resetting cultural norms or policy changes, can be explored that may contribute to the overall reduction of related health outcome disparities.

### **Exploratory Research on EDI to Counter Discrimination in Hospital Settings in Canada: A Study Protocol and Preliminary Results**

*Félix Pageau*

**Background:** Discrimination not only represents a violation of the law but brings forth ethical risks for health and social services systems. We use the term 'ethical risks' defined as an action that occurs in an organization, against its politics and rules, that is problematic according to the standards in place (Begin et al., 2014). This type of risk undermines the ethical values upheld by users, staff members, the organisation, and society, as a whole. Hence, discrimination ought to be understood better, especially in the organization where it takes place. Appropriate measures should then be defined respecting Equity, Diversity and Inclusion (EDI) principles to reduce discrimination. **Aims:** Our project aims to answer: What are factors contributing to discrimination, including ethical risks? How to rally professional and organisational values preventing discrimination and sustaining EDI practices? **Methods:** This exploratory research is based on a mixed-methods approach, combining qualitative and quantitative methods in two stages. First, focus groups and individual interviews will be conducted, which will feed into a survey to understand participants' perspective on EDI and discrimination, near Quebec City, Canada. They are members of the organization as well as with users and relatives (informal care givers or concerned significant others). Our survey and interview main themes will be: the ideal of inclusion in health and social services, risk factors leading to discrimination from an individual, sectoral and organizational perspective, strategies to reduce discrimination and value EDI principles. For each theme, we will also discuss the relation between professional and organizational values. **Results:** We will present preliminary results that will have emerge from the focus-group and individual interviews. **Discussion:** Our presentation will highlight the elements identified by the participants as ethical risk factors as well as the mitigation measures allowing EDI approach to progress in a hospital.

### **Clinical Ethics Consultations and Somatic Treatment for Mental Health Patients: From Non-Discrimination to Destigmatization**

*Marta Spranzi*

Mental health patients suffer from a loss of 15 years life expectancy with respect to the general population. This is due not only to internal factors like suicide or isolation, but to persistent difficulties in accessing somatic care: obstacles to preventive treatments, time constraints in the caring for 'difficult patients', sketchy follow up, difficult social life conditions compounded by a historical separation between psychiatric and somatic institutions and medical cultures. Advocates often point to discrimination, i.e. a consistently lower level of somatic care for mental health patients, as the main cause for mental health patients' medical loss of chance. While current discrimination certainly needs a sustained societal effort to redress a persistent gap in somatic health, certain life-threatening conditions where heavy medical procedures are at stake (dialysis, amputation, transplant, etc.), raise genuine ethical dilemmas that call for a more nuanced analysis. Indeed, the patient's refusal of somatic treatment and the treatment adjustment to mental health patients' particular life conditions have to be taken into account in order to achieve real fairness. We shall draw on a few cases from our clinical ethics consultation services, in order to discuss the related notions of discrimination, fairness and stigmatization. It will be argued that unlike what a principle of non-discrimination suggests, one should not only focus on measuring these patients' health outcomes but rather on fostering an attitude of de-stigmatization, whereby these patients' voice is given the right weight in medical decisions concerning somatic care. These patients' rights should be understood in a broader sense than merely guaranteeing

equal access to somatic treatment, rather, their special outlook on the world, their right to refuse or defer treatment and their preference not to undergo treatments they consider as futile, given their life situations, should be given proper consideration.

## **VULNERABLE POPULATIONS**

### **Alone, Vulnerable, and Silent: Navigating Ethical Decision-Making for the Unrepresented Patient**

*Beverly Frase*

Hospitalized patients who lack decision-making capacity without an advance directive or legally-authorized surrogate represent an extremely vulnerable population referred to as 'unrepresented patients.' Unable to advocate for themselves and without trusted partners, clinicians and institutions have an ethical responsibility to prudently weigh treatment decisions for these patients while mitigating bias and discrimination. In the United States, limited state statutes exist that specify decision-making processes for unrepresented patients. Such laws demonstrate significant variability. This session will outline how our institution established a process to review the clinical needs of unrepresented patients through the creation of an unrepresented patient board (UPB). This procedure involves conducting advanced decision-making capacity assessments while taking into account the patient's dynamic capacity in relation to the complexity of the clinical decision. Additionally, it engages unit social workers, clinical ethicists, and law enforcement to ensure advance directives or appropriate surrogates do not exist. These efforts are performed to confirm the unrepresented status of the patient. A case-based review will highlight common challenges faced by the ethics consult service in the care of unrepresented patients including guardianship, care of incarcerated patients, and end-of-life decision-making. The membership criteria for the UPB will be reviewed including requirements for interdisciplinary clinicians, allied health professionals, spiritual care providers, legal consultants, volunteer community members, and equity, inclusion, and diversity leaders. Specific operational considerations for assembling the UPB and reviewing clinical decisions will be outlined. This includes mechanisms for timely activation of the UPB, efficient processes for reviewing clinical information with the care team, facilitation techniques for effective UPB deliberation, exploration of any evidence of prior patient advance care planning for substituted judgment, and how to proceed when consensus-based decisions are not reached in UPB deliberation. This session will promote discussion regarding social justice and equity in the care of unrepresented patients while mitigating discrimination.

### **A Wolf is in Sheep's Clothing: How Protecting the Dignity of People With Dementia Can Mask Ableism**

*Elodie Malbois*

Certain therapeutic approaches with people with dementia, such as the use of dolls or certain social robots that look like animals or children's toys, have been criticized for being humiliating and infantilizing, and therefore a threat to the dignity of their users. In this paper I argue that this argument is problematic because it is ableist. I begin by showing that dolls and robots can only be seen as a threat to the dignity of their users with dementia if dignity is understood as dignity of identity. This sense of dignity is connected to the identity of the person as grounded on their autonomy, integrity and social relations. These values are often central to our sense of identity and of worthiness and are associated with respect (for ourselves or from others). As a result, the degradation of these values is perceived as a loss of worthiness and can be seen as humiliating. Hence, when people with (advanced) dementia interact with dolls or certain robots as if they were babies or animals, their loss of autonomy and integrity becomes very apparent, which is seen as humiliating and a threat to their dignity of identity. However, this view implies that the loss of cognitive abilities is a deterioration and a loss of value and is, therefore, ableist. It is offensive and discriminatory towards people with dementia and people with intellectual disabilities. Therefore, this dignity-based argument against the use of robots should be rejected. I then discuss how clinical ethics committees should approach consultations on this issue, given that the ableist stance behind such requests is mostly unconscious but very pervasive. Indeed, because this argument is closely tied to issues of respect and humiliation, it often cannot simply be disregarded on the grounds that it is ableist.

## **Medical Decision-Making in Critically Ill Geriatric Patients: Are We Moving From Ageism to Ableism?**

*Laura Moisi*

Across the globe, media, legislators, healthcare professionals (HCPs), and healthcare organizations are increasingly concerned with gender-affirming care (GAC). More specifically, there is purported concern that patients may regret their decision of pursuing GAC. Regret is consequently framed as an outcome that patients ought to be protected from, resulting in undue challenges for patients trying to access GAC-specific interventions. These access-limiting measures constitute medical gatekeeping. Although justified at times, medical gatekeeping can risk unjustified paternalism and barriers to care. In this presentation, we first outline the ethical contours of medical gatekeeping and its relation to regret risk in GAC. We analyze the concept of regret and its role in moral deliberation, demonstrating that concerns about potential regret can be disproportionately weighted in the context of GAC and based on mistaken assumptions. We also show how the language of regret can at times act to both protect patients from undue harm, as well as overprotect patients already vulnerable to bias and undertreatment in a way that perpetuates injustice and disempowerment. We thus recommend caution when making judgements about the potential for regret in medical decision-making. Second, we discuss the practical and ethical implications for organizations and legislatures in preemptively limiting access to GAC on the basis of regret mitigation. Third, we examine the role of clinical ethicists in navigating these concerns and include strategies for responding to consults, developing embedded roles, contributing to practice guidelines, delivering education, and mitigating moral distress. We conclude that (1) not every potential for regret can or should be avoided, (2) it is not within the purview of HCPs nor legislators to eliminate patients' potential for experiencing regret, and (3) shared decision-making can address the potential for regret without unjust medical gatekeeping. The presenter/s will invite attendees to share experiences and practices and their own organizations.

## **Freak Show: How Monsterization, Isolation, and the Lure of Neurotypicalism Oppress Disabled Adults With Cerebral Palsy**

*Emily Olson*

This paper critically examines representations of deviation in human morphology within the tonal contexts of both cultural history and disability ethics, with a particular emphasis on the challenges of young adults with cerebral palsy as they transition from pediatric to adult health care systems. I suggest that the traditional model of care between pediatrics and adult medicine is fragmented and often does not match the multi-faceted needs of disabled pediatric patients as they age. Through careful reconsideration of the legacy of disability within what is arguably and historically its most stigmatized form “the freak show” as well as within modern clinical care practices, I emphasize the transitional care gap as one of many major societal manifestations of monsterization. I propose a three-pronged approach, broadly centered on availability, exposure, and standardization of transitional programs, as a potential solution for closing the identified gap in neurological disability care. Finally, I call for a reexamination of the use of the pejorative ‘freak’ in contemporary discussions of disability, suggesting that the embodiment of physical traits which are traditionally associated with a lack of health may not always clinically indicate that an individual with a disability is unhealthy, instead, impacts to physical and cognitive prowess are often only socially assumed. When these assumptions of disability-based ineptitude are made in socio-political environments by individuals in positions of power, lapses in clinical care often result. Such lapses in care can be more dangerous and damaging than the physiological harm of disability itself, especially in instances where sustained care is critical to the management of disability through the lifespan.

## **Mental Health and Vulnerability: Navigating Cognitive and Socio-Political Challenges in Health Ethics Consultations**

*Eva Regel*

Cognitive vulnerability in patients with mental health issues and trauma presents unique challenges within health ethics consultations (HEC). Information processing, decision-making, and self-advocacy limitations require a tailored ethical approach during HEC. This presentation will explore how vulnerability theory, with a particular focus on cognitive vulnerability, can enhance ethical analysis while addressing the socio-political factors that often compound these vulnerabilities and affect clinical outcomes. The vulnerability approach recognizes cognitive vulnerability as an increased risk to autonomy and justice, exacerbated by such factors as psychological trauma, mental illness, and fluctuating decision-making capacity. It expands the ethical lens to include personal vulnerabilities and

socio-political determinants, such as systemic discrimination, healthcare inequalities, and resource scarcity, all of which exacerbate these vulnerabilities. In the acute care setting, the vulnerability approach supports a framework of -relational autonomy,- which recognizes that autonomy is dynamically shaped by cognitive capacity, mental health, and the patient's social context. HEC conducted with the lens of vulnerability can adopt strategies incorporating cognitive and relationship needs, employing clear communication enhanced by trauma-sensitive language and a collaborative decision-making process to facilitate the patient's understanding and informed consent while respecting their dignity and personhood. When cognitive vulnerabilities impact decision-making, HEC can adopt empowering strategies that prioritize patient well-being while striving to maintain the patient's agency. This includes simplified information delivery, frequent check-ins, and trauma-sensitive communication that respects the patient's processing abilities and personal history. The vulnerability approach also highlights the social-political dimensions, underscoring how system issues, such as inadequate mental health resources, policy-driven barriers, and social stigma, do shape clinical ethics. Patients with mental health issues often face structural inequalities that limit access to care and support, thus intensifying cognitive and emotional vulnerabilities. Addressing these broader forces in ethics consultations will encourage clinicians to advocate for policies that alleviate these burdens, promoting justice alongside patient-centered care. The vulnerability approach offers an enriched ethical consultation framework by integrating cognitive and social-political considerations. This approach will help clinicians not only navigate the moral dilemmas arising from cognitive complexities and systemic limitations faced by patients with mental health issues and a history of psychosocial trauma but also ensure that HEC is both compassionate and contextually responsive to the unique needs and circumstances of this patient population.

## EQUITY

### **An Umbrella Review on the Ageism Older Adults Face While Seeking Healthcare Services**

*Kevin Dzi*

**Background:** Age-based discrimination, known as ageism, primarily affects older adults (OA). Despite campaigns to combat it, ageism is still a global problem. Researchers worldwide have conducted multiple reviews to summarize the data on ageism toward OA. We conducted this umbrella review because multiple reviews have collated evidence on ageism toward OA, necessitating a summary that can provide policymakers with the guidance to put in place measures that can reduce ageism in older adults' daily lives. **Objectives:** This review examines the ageism OA patients face in healthcare. Our secondary goals are as follows: 1. What contributes to ageism in OA seeking healthcare? 2. How does ageism affect OA health? 3. How well do healthcare ageism interventions work? **Methods:** This umbrella review (UR) followed the Joanna Briggs Institute (JBI) UR guidelines. **Results:** From 6 electronic databases, we found 688 records. After screening, 51 systematic reviews met our UR criteria. In the reviews, self-directed ageism (OA ageist attitudes toward oneself) was mostly determined by the OA's health status, while other-directed ageism (ageism perpetrated by others on OA) was highly influenced by the quality of contact with OA. Eleven systematic reviews examined whether health care professionals (HCP) and student HCPs attitudes toward older adults (OA) affect elderly care. Three reviews examined how scales used to measure ageism in studies could perpetuate it, and 4 examined how age discrimination in clinical trials affects OA. Six reviews examined LGBTQ OA discrimination. Ageism causes OA to stress out and avoid medical services, according to many reviews. Intergenerational contact programs have been shown to prevent ageism and promote positive attitudes toward OA in 5 reviews. A few studies have also shown that education can combat this. **Conclusion:** Ageism persists in society, including the health sector, so efforts to combat it should continue to enhance older adults' quality of life. Additional analysis of data ongoing.

### **Intersex Children: What Role Does Clinical Ethics Play Between a New Law and Traditional Medical Practices?**

*Scarlett May Ferrie*

**Background:** In response to militant demands, the French bioethics law of 2021 aimed to depathologize the situation of intersex children now called variation in genital developments. Treatment or surgery may only be undertaken in response to a compelling medical need and with the patient's consent if possible. A national commission of experts must also examine each case. **Aims:** To understand ethical arguments regarding medical decisions for children with genital variations. To explore the benefits of clinical ethics interventions. **Method:** A qualitative and multidisciplinary clinical ethics study was conducted with professionals and parents of the affected children across three specialized expert centers, along with observations of 14 discussion sessions held by the national commission

of experts. Results: 1. Parents interviewed are troubled by the lack of available treatments and by their exclusion from the decision-making process. They feel that their children are being treated as test subjects. They expect long-term medical support for their child's development. 2. The professionals interviewed feel deprived of the ability to fully assess the medical need of each intervention and they fear that this might lead to a loss of medical opportunities for children. 3. Assessing the best interests of the child is controversial between experts. Discussions can be shortened because the consensus required by law is understood as unanimity. Discussion: The break with previous medical practices imposed by the 2021 law has not fully succeeded in changing professional and parents representation. It might therefore be useful to complement laws rules with the practice of clinical ethics. Engaging in ethical reflection on a case-by-case basis would make possible to help stakeholders think about the following points: who is the patient (child, future adult, child/parents)? What does it mean to respect patient consent? Does thinking more about non-maleficence rather than beneficence help us better understand medical need?

### **Ethics Support Addressing Clinicians' Questions About Futility and Use of Finite Resources for Vulnerable "Non-Compliant" Patients**

*Carolyn Johnston, Danielle Ko*

Patients with complex medical and psychosocial challenges often struggle to follow clinical recommendations, leaving clinicians questioning whether the right course of action is to pursue treatments when engagement is low, or progress limited. We use as a starting point for discussion two deidentified clinical cases referred to our clinical ethics response group. Firstly, a patient with complex mental health issues requiring frequent endoscopies following the ingestion of dangerous items. The other a young refugee unable to attend dialysis regularly due to work obligations. Vulnerability through factors such as mental ill health, childhood trauma and challenging social conditions may cause patients to repeatedly fail the expectations of healthcare providers, sometimes fuelling feelings of hopelessness and prompting clinicians to wonder - why are we bothering? In discussions with the treating team, the clinical ethics response group explored how to balance patient care with resource limitations and sustainable service delivery. Key questions arose: Does patient vulnerability justify ongoing treatment that seems ineffective? Do certain vulnerabilities inadvertently lead to clinician bias in determining futility? We will discuss how our hospital's ethics service and committee assisted clinicians to see a way to a resolution, of sorts, by highlighting the limits of agency in vulnerable patients, exploring the meaning and scope of futile treatment, and prompting a better understanding of the patient's medical, social and personal goals.

### **Barriers Behind Bars: A Duty Towards a Dignified Death**

*Yelena Zatulovsky, Nicole McCann-Davis*

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. This session will include two key teaching methods - a didactic presentation and collaborative breakout sessions. The opening lecture will include definitions, myths, a current state of affairs and statistics, and an acknowledgement of the various challenges/disparities in providing hospice care to this population. The breakout sessions will be in three groups: Group 1 - addresses the moral experiences, including the potential for bias, in the care team and community at large. Group 2 - addresses pragmatic issues, such as regulatory restrictions. Group 3 - addresses impact on the patients, clinicians, and community. Following we will reconvene the larger group and have a report out of key themes and ideas from each breakout. The session will end with a call to action and next steps.



## SEX, GENDER, AND SOCIAL JUSTICE

### Navigating Decision-Making Dilemmas in Variations of Sex Development: The Shared Optimum Approach

*Cynthia Kraus*

In many countries, children are not legally entitled to give valid consent for medical decisions, so parents usually act as surrogate decision-makers, acting in their best interests. However, there is a growing emphasis in medical guidelines on involving children in decisions about their own health. This trend toward inclusion was sparked by the United Nations Convention on the Rights of the Child (1989) which recognizes children as social agents rather than passive recipients of adult protection. The debate on child involvement and consent to treatment has been particularly prominent in the health care management of intersex persons or individuals born with variations in sex characteristics (VSC). Regardless of the focus on patient involvement and individualization of care, medical practices in VSC continue to be parent- rather than patient-centered. This may explain why despite growing skepticism about early surgical interventions, there is no general moratorium on sex assignment surgery. Indeed, the 2006 Consensus Statement on the Management of Intersex Disorders did not rule out cosmetic surgery on the basis that it could reduce parental distress and improve bonding. Research shows that parents find it often difficult to defer surgery because they fear that it might impede their children from leading a 'normal' life. At the same time, studies highlight that intersex people who have experienced nonconsensual surgery during childhood may develop mistrust in medical providers and delay emergency and preventive healthcare visits. Healthcare professionals find it often challenging to navigate between the (future) child's and parental needs. The present presentation aims to present the shared optimum approach (SOA), a combination of best interests and shared decision-making, as a method to tackle decision-making dilemmas with parents and affected individuals over time. SOA is a process that focuses on family values and clinical facts while using a clearly and transparently defined threshold of harm.

### But What If? Interrogating the Role of Regret in Gatekeeping Gender-Affirming Care

*Jeffrey Pannekoek*

Across the globe, media, legislators, healthcare professionals (HCPs), and healthcare organizations are increasingly concerned with gender-affirming care (GAC). More specifically, there is purported concern that patients may regret their decision of pursuing GAC. Regret is consequently framed as an outcome that patients ought to be protected from, resulting in undue challenges for patients trying to access GAC-specific interventions. These access-limiting measures constitute medical gatekeeping. Although justified at times, medical gatekeeping can risk unjustified paternalism and barriers to care. In this presentation, we first outline the ethical contours of medical gatekeeping and its relation to regret risk in GAC. We analyze the concept of regret and its role in moral deliberation, demonstrating that concerns about potential regret can be disproportionately weighted in the context of GAC and based on mistaken assumptions. We also show how the language of regret can at times act to both protect patients from undue harm, as well as overprotect patients already vulnerable to bias and undertreatment in a way that perpetuates injustice and disempowerment. We thus recommend caution when making judgements about the potential for regret in medical decision-making. Second, we discuss the practical and ethical implications for organizations and legislatures in preemptively limiting access to GAC on the basis of regret mitigation. Third, we examine the role of clinical ethicists in navigating these concerns and include strategies for responding to consults, developing embedded roles, contributing to practice guidelines, delivering education, and mitigating moral distress. We conclude that (1) not every potential for regret can or should be avoided, (2) it is not within the purview of HCPs nor legislators to eliminate patients' potential for experiencing regret, and (3) shared decision-making can address the potential for regret without unjust medical gatekeeping. The presenter/s will invite attendees to share experiences and practices and their own organizations.

### A Cultural Engagement Program for Islamic Parents of Premature Children Eligible for Donor Breast Milk

*Frank X. Placencia*

Background: Fatwas (Islamic religious edicts) state that there is no religious objection to the use of donor breast milk. However, some Muslim parents continue to decline donor breast milk for their premature infant on religious grounds out of concerns over the concept of 'milk-siblingship.' Objective: This educational project teaches health care professionals how to engage Muslim parents who may decline donor breast milk for their premature infant on

religious grounds. Description: A multi-disciplinary team including members of the Neonatal ICU, women's support services, lactation consultants, hospital chaplains, and community religious leaders developed a program to address the issue of Muslim parents refusing donor breast milk. An awareness campaign including didactic lectures to healthcare providers and handouts for Muslim parents were prepared. These educational materials extend beyond the medical benefits of donor breast milk by exploring the reasoning behind the sociohistorical and religious context of milk-siblingship. We plan to implement this initiative at our main campus, and then spread it to partner institutions. Finally, a community outreach program will be conducted to improve awareness amongst community Muslim leaders and the general population. Conclusions: There exist consensus fatwas that donor breast milk is appropriate for certain premature infants. This information is not generally known by the Muslim population, nor to health care providers who recommend such strategies. Providing Muslim parents with the information for them to make the best decision for their infant is the goal of any health care professional. This educational project helps provide optimal care to this vulnerable population.

### **Trans Identity and Access to Care: Difference as a Determinant of Trust and Trustworthiness in Health Care and Clinical Practice**

*Iris Rivoire*

In the medical literature, transgender people are mainly considered through the prism of medical transitions. As a result, there is little data on their trust in medicine or their access to primary care. Yet transgender people can have the same health problems as cisgender people. It is therefore important to understand whether transgender people do, or do not, trust professionals and access primary care. The aim of this study is to understand the expectations and needs of transgender people in the context of medical consultations unrelated to medical transitions and the obstacles encountered when accessing primary care, as well as to provide an initial overview of their access to primary care. For this exploratory study, we conducted six focus groups lasting between 1.5 and 2 hours, with 21 transgender people in Geneva. Four main themes were explored: general, positive, and negative experiences, as well as the strategies used by participants. Our findings reveal that transgender people often avoid primary care due to a perceived lack of training and knowledge on trans-identity issues among health professionals. This leads to participants feeling compelled to educate doctors on these issues during consultations, which often results in negative experiences marked by discomfort, fear, or anger. Our study also reveals that participants have particularly low expectations of health professionals, mainly just wanting access to care. Participants mentioned various strategies, most of them community-based, to improve their access to care when needed. This exploratory study focused on the canton of Geneva, but similar studies are needed on national and international levels. Loss of trust despite low expectations is particularly concerning. It would also be useful to include healthcare professionals' perspectives in a broader study. Furthermore, comparing the experiences of transgender people with those of individuals facing other forms of identity-related discrimination could provide additional insights.

### **"Flipped Examination Room" - Ascriptions of Vulnerability Between Trans Patients and Their Healthcare Providers**

*Jo Steininger, Flora Löffelmann, Felix Ihrig*

Background: The history of pathologisation has left many traces in trans healthcare contexts, especially barriers to receiving healthcare. These can be explained with theories of biopower -the disciplining of non-normative bodies, which often results in breached boundaries and repudiation of agency. Aims: Our study connects to -applied transgender studies-, which centre aims to improve material conditions of trans, inter\* and nonbinary (tin\*) people's lives. In this exploratory phase of an ongoing research project, we investigated current practices and underlying beliefs about 'trans-sensitive healthcare' in Austria. We focus specifically on ascriptions of vulnerability as modes to gain back or hinder agency in healthcare contexts. Methods: Embedded in frameworks of Institutional Ethnography and Community-Based Participatory Research, we analysed recordings from one tin\* Community Team discussion and one training session for healthcare providers (HCPs) with Charmaz' Grounded Theory. Results: By depicting tin\* patients as vulnerable and themselves as the needed supporters, some HCPs practice benevolent 'pathologization,' a term we coined in combination of our findings and previous research on trans healthcare. Yet, negotiations of intimacy and responsibility as well as power imbalances can render both parties vulnerable. HCPs' own vulnerability frequently stems from knowledge gaps and expectations concerning expertise, responsibility and authority. Discussion: We argue that a caring and transparent approach to the contextual vulnerabilities in interactions between tin\* patients and HCPs is paramount. The notion of caring encounters, where being uncertain is not a flaw but a mere fact of human existence, is a transformative perspective. For a future-oriented, ethical

and sensitive approach to healthcare for marginalised, especially tin\* people, a 'compassionate gaze' is crucial. This can not only equalize power imbalances but improve health outcomes. One can conclude that tin\* people do not require 'special treatment', they require adequate treatment, e.g., medical assessments which are appropriately thorough but not intrusive.

## HEALTHCARE, LAW, AND POLITICS

### **Ethics, Globalization and Medical Travel: A Proposal for Best Ethical Practice Standards in the Care of International Patients**

*Megan Brandeland*

**Background:** Healthcare tourism has grown significantly in the last two decades. For many patients, coming to the U.S. for medical care is a final recourse for complex and serious illness. Currently, no best ethical practice standards exist in the care of international patients. **Objective:** Our objective is to propose best ethical practice standards in the care of international patients which may guide further preventive ethics work in this area. **Methods:** We completed a retrospective chart review of ethics consultations on international patients over 19-year period (2006-2024). Results were reviewed by faculty in Clinical Ethics and our International Office. For each reason for ethics consultation, we analyzed contributing factors. Using this information, we created a proposal for best ethical practice standards. **Results:** We identified 49 ethics consultations requested on international patients. The most common reasons for consultation were goals of care / 'futility' (31%), patient autonomy (29%) and allocation of resources / distributive justice (12%). Spiritual or cultural considerations were a significant aspect of the reason for consultation in 71% of cases. Five areas of best ethical practice standards for the care of international patients are proposed. (1) Clinical Care, including standardizing the patient intake process and setting clear expectations for treatments before travel, (2) Medical Records, including ensuring accurate and timely transfer of medical records (3) Language and Culture, including ensuring adequate interpreter services and patient coordinators and educating staff in cultural humility (4) Spiritual Care, including ensuring diverse spiritual care staff and support for religious practices, and (5) Financial, including review of expected costs and payment source(s) prior to travel. **Conclusion:** Ethical dilemmas arise in the care of international patients due to differences in culture, religion, expectations for medical care, and healthcare financing. We propose best ethical practice standards that may guide future preventive ethics work for international patients.

### **Conceptualising Costs: Prescribing Clinicians' Perceptions of Opportunity Cost in the Case of High-Cost Cystic Fibrosis Treatment**

*Audun Brendbekken*

**Background:** Resource scarcity necessitates priority-setting at the macro-level between groups of patients in publicly funded healthcare systems. When clinicians at the micro-level provide treatment to one patient, less resources are available elsewhere in the healthcare system. Following the advent of high-cost therapeutics for rare diseases, pharmaceutical budgets are increasing across the world. In 2022, elexacaftor/tezacaftor/ivacaftor (Kaftrio) was reimbursed in Norway for patients with cystic fibrosis through an undisclosed price agreement. The treatment is life-long, and it was publicly contested before implementation due to its exceptional high cost and expected significant effect. **Aim:** We aim to understand how clinicians conceptualize the cost of Kaftrio and its impact on availability of other healthcare services across their department and hospital. Kaftrio prescription in Norway provides a clear case for considering cost conceptualizations, as the indication was explicit, and the treatment's list price well-known. **Methods:** We conducted 18 in-depth interviews with clinicians and hospital department leaders working with cystic fibrosis and analysed data using reflexive thematic analysis. **Results:** The opportunity cost of prescribing Kaftrio is unclear to clinicians. Uncertainty about the undisclosed pharmaceutical price and to what level in the hospital budget the cost is allocated provide unclear incentives for rationing treatment. Clinicians justify providing treatment by double-counting costs and benefits which are already accounted for at the macro-level. **Discussion:** This study adds to the scarce evidence on the interplay between macro-level decision-making and its micro-level clinical operationalization. A lack of transparency obscures incentives for clinicians to ration treatment. Macro-micro level misunderstandings of costs and benefits risks skewing allocation in unintended ways. **Conclusion:** A better understanding of real-life healthcare rationing behavior at the micro-level and its interactions with intended directives from the macro level of priority-setting is needed to ensure coherent policy operationalization across levels of healthcare.

## Principled Conscientious Provision

*Abram Brummett*

U.S. law grants expansive protections for conscientious objection, while the issue of conscientious provision enjoys no legal protection. For example, a clinician who conscientiously objects to providing a prescription for birth control in a secular hospital is legally protected, but a clinician who wishes to conscientiously provide a prescription for birth control for the purpose of contraception in a Catholic hospital is not. There are three ways to respond to this conscience asymmetry. One is to offer a moral justification for the conscience asymmetry. Another is to argue for conscience symmetry, in general, which could be accomplished either by creating legal protections for all conscientious provisions or by removing protections for all conscientious objections. This talk explores a third option—legal protection for only some forms of conscientious provision in Catholic hospitals. We develop our defense of limited conscientious provision rights by rejecting the current -referral asymmetry.- The referral asymmetry refers to the fact that clinicians at secular hospitals are legally protected when they refuse to refer patients for treatments permitted at their hospital, while clinicians at Catholic hospitals are not legally protected if they provide referrals for treatments (e.g., contraception, sterilization) that are prohibited at their hospital. Our argument advances in three parts. First, we argue that conscientious refusal to refer and conscientious provision of referral should have equal legal protection. Second, we propose that referral-related conscience rights should be expanded to cover the conscientious provision of referrals. Finally, we explore the implications of expanding referral conscience rights by identifying a key principle 'the principle of comparably trivial institutional burdens' that can be used to justify legal protections for some additional forms of conscientious provision (e.g., writing prescriptions for medication abortion) without grounding legal rights for all forms of conscientious provision (e.g., providing surgical abortions).

## Should Clinical Ethicists “Put a Pin in It”? The Ethics of Wearing Social Justice Pins and Signs of Support on Hospital Badges

*Michael Lucinda Jane Greer, Jenny Clark Schiff*

Badge identification (ID) cards and lanyards provide a unique opportunity for healthcare professionals (HCPs), including clinical ethicists (CEs), to wear pins, clips, and/or stickers to outwardly signal support for social justice causes (SJs). These social justice signs (SJSs) can be affirming for patients, particularly those from historically marginalized groups (e.g. queer people, black people, women, and individuals with disabilities), who are vulnerable to social determinants of health and whose care can be compromised by HCPs with biases/prejudices. However, SJSs of support may be off-putting to, or even alienate, patients whose socio-political views conflict with views typically associated with some SJs. One might wonder whether physicians' obligations to treat their patients with non-judgmental regard (i.e., deliver uncompromised care to the homophobic, racist, misogynist, and ableist) implies an obligation for physicians not to wear SJSs. Furthermore, physicians and HCPs in general may wear SJSs merely to -virtue-signal,- potentially taking attention away from patients. Clinical ethicists comprise a special subset of HCPs with unique responsibilities and duties. It is foundational to healthcare ethics consultation (HEC) that CE's ought to demonstrate appropriate ethical concern for all patients, including the homophobic, racist, misogynist, and ableist. Therein lies the question: should CE's in patient-facing roles wear SJSs in support of SJs? Our ethical analysis focuses on sexual orientation and gender identity in particular. We connect the history of discrimination against queer people to their health outcomes and experiences as patients. We offer arguments for and against CE's wearing SJSs to signal support for SJs related to sexual orientation and gender identity. We consider, for example: what is in the best interest of patients, care-needs of pediatric patients, CE's wider geographical/socio-political/legal context, relevant hospital policies, the promotion of an inclusive professional environment, and the protection of queer and queer-questioning CE's.

## Conscientious Provision of Legal Healthcare Services When an Organization Objects

*Marika Warren*

Conscientious objection policies, common throughout North America and Europe, offer healthcare providers protection from sanctions when they are asked to provide legal healthcare services that fall within their scope of practice and the provider refuses to offer those services for conscience-based reasons. Imagine a healthcare organization that decides to stop distributing safe injection supplies for patients who choose to inject substances. The organization states that this is due to fundamental organizational values about how substance use disorder is treated. Now imagine a physician with training in treatment of substance use disorder who has admitting privileges within

that organization. This physician decides to continue distributing safe injection supplies. When threatened with loss of privileges, the physician invokes protection from sanction based on conscientious provision, stating that the provision of supplies was based in conscientious beliefs about treatment of substance use disorder and professionalism. In this presentation, I describe the structure of conscientious objection and outline paradigmatic instances when conscientious objection is invoked, including termination of pregnancy, assisted reproduction, medical assistance in dying, and gender-affirming care. I argue that conscientious provision is symmetrical to conscientious objection and demonstrate that this symmetry holds across all these types of care. This symmetry grounds a claim that conscientious provision warrants protection from punishment. I then address the reliance of the symmetry argument on the claim that organizations can have conscientious beliefs. I argue that symmetry is sufficient but not necessary to ground protections for conscientious provision, patients' claims to legal healthcare services and providers' interests in professional integrity are also sufficient. Finally, I briefly identify and address other objections, including concerns that conscientious provision could justify the provision of discredited or unproven interventions, and emphasize that the target of both conscientious objection and provision is legal, clinically indicated care that is desired by the patient.

## **PARTNERS**

### **Ethics Support Staff's Perceptions of Patient and Parent Participation in Clinical Ethics Support in Childhood Cancer care**

*Isabelle Billstein*

**Background:** There is a growing notion for patient and parent participation (PPP) in Clinical Ethics Support (CES). However, participation is increasing slowly due to complexity of execution. Therefore, we need further understanding of how to create forums and models of CES where patients and parents can participate and reflect and share their perspectives on ethical dilemmas. **Aim:** The aim was to explore PPP in CES in childhood cancer care by gaining deeper understanding of ethics support staff perceptions of the feasibility and moral appropriateness of PPP in CES. **Methods:** Ethics support staff (N=26) experienced in providing CES in Nordic childhood cancer care/paediatrics, were invited to focus group interviews (N=6). Data was analysed with qualitative content analysis. **Results:** Most participants were healthcare professionals without former experience of PPP in CES. Participants perceived that PPP in CES could deepen understanding and trust, catalyse conflicts and create dilemmas of decision-making participation. The expressed benefits of PPP in CES were overshadowed by a fear of causing participant harm. Strategies to avoid the risk of causing harm were expressed on organizational (challenge the ambiguity of ethics and CES, preparation and debriefing, create a safe environment), relational (balance care relationship, protect child-parent relationship) and individual (assess child participation, assess parent participation, assess exposure of healthcare professional) levels. **Discussion:** The appropriateness of PPP in CES depends on the situation. In cases where it can be considered, adaptation of the CES model on a case-by-case basis is important, with the starting point of applying the strategies to reduce the risk of causing harm. This study contributes to increased understanding of practical and moral challenges and benefits of PPP in CES which can be helpful when considering models to foster PPP in CES in childhood cancer care as well as other paediatric settings.

### **Patient Participation in Clinical Ethics Support Services: an Impossible Debate**

*Sara Court*

Clinical ethics support services (CESS) can assist clinicians with the resolution of moral problems that arise in healthcare. CESS discussions do not typically involve patients as participants, a matter which has recently begun to be questioned. There exists considerable variation within the category of CESS. These services can be, for instance, clinical ethics committees, individual ethics consultants or small group gatherings focused on moral reflection. While some of the differences between these services are practical, differences can also be identified that are more fundamental, for instance, in the content and practical aims of the discussions that tend to occur within these services. Some ethics services may be, for instance, particularly geared towards conflict resolution, while others may be aimed more at personal reflection. These differences seem to arise out of the diverse contexts in which these ethics services exist, not only the hospital contexts, but the different social contexts more broadly. So far, academic debate about patient participation has been localised to the context of specific forms of CESS or it has been with regard to CESS discussions as a whole. I examine three 'case studies' of different clinical ethics support services, drawing attention in particular to the different practical aims of their discussions. I then show that these aims have different implications for patient participation. In doing so, I demonstrate that patient participation can-



not be considered separately from different specific approaches to clinical ethics support, or in isolation from the contexts in which these services are embedded. Thus, it is a mistake to consider patient participation with regard to CESS discussions as a whole.

### **Bearing Witness as an Ethical Act**

*Georgina Hall*

Challenging global and local socio-political conditions including economic hardship, political uncertainty, natural disasters and cost of living pressures impact clinical care with greater demand for scarce resources, bed-count pressures, equitable distribution of costly treatment, and discharge planning. The healthcare professional increasingly feels the pinch of escalating demands coupled with rising levels of patient aggression, often leading to moral distress and burnout. When navigating ethically complex clinical situations in such trying times, standard ways of resolving challenges sometimes don't work and it can feel like there is no ethical way forward. In such instances, it is easy to overlook the substantial moral value derived from simply bearing witness to the patient's experience. This is done, often subconsciously, by healthcare professionals who walk with a patient and their families through the uncertainty, grief, doubt, and emotion of their experience. Bearing witness is active listening and not turning away from the pain and suffering of the situation. It can feel uncomfortable or inadequate for the bearer, but carries discreet moral weight and value as a unique and valuable aspect of patient care. This presentation explores the neglected ethical concept of 'bearing witness' as a powerful aspect of caring for patients and their families. It draws from established conceptual foundations in the indigenous truth-telling context and Holocaust legacy, and maps how the idea finds shape in the nursing literature. I demonstrate that there is moral value and concrete utility for both the patient and family, and the healthcare professional, in finding meaning in the space and quiet of true presence.

### **Role of Clinical Ethics in Addressing Equity for MSM Requiring HIV Pre-Exposure Prophylaxis (PrEP) in Non-Western Cultures**

*Faryal Khamis*

Establishing a clinic for pre-exposure prophylaxis (PrEP) for men who have sex with men (MSM) in non-Western cultures presents significant challenges due to religion, social stigma, legal restrictions, and healthcare inequities. This initiative addresses the urgent need for HIV prevention services that navigate cultural norms inhibiting discussions about sexual health. The clinic is designed to provide a safe and inclusive environment where MSM can access PrEP services without fear of discrimination. A multidisciplinary team trained in cultural competency fosters trust and confidentiality while addressing stigma and supporting sexual autonomy - essential elements for effective healthcare delivery to vulnerable populations. The presentation will highlight clinical scenarios illustrating ethical complexities from the perspective of an HIV physician who is also a practicing Muslim. It will explore real-world examples of ethical conflicts encountered when providing PrEP to MSM, such as when clients engage in condomless sex with multiple partners, which may clash with the personal values of healthcare providers. Ethical principles like beneficence guide providers to prioritize client health by offering PrEP as an effective preventive measure. Non-maleficence addresses risks like "prevention optimism," where perceived protection from PrEP may encourage higher-risk behaviors. Autonomy is respected by ensuring clients receive comprehensive information about PrEP's benefits and limitations, empowering them to make informed health choices. Justice emphasizes the clinic's commitment to equitable healthcare access, regardless of sexual orientation or lifestyle. Our advocacy extends beyond the clinic through our roles in the Oman National Bioethics Committee, promoting awareness of PrEP's importance in reducing HIV transmission. We engage religious leaders and legislators to reduce stigma and enhance understanding of MSM healthcare needs, ultimately striving for equitable and culturally sensitive healthcare services to effectively combat HIV transmission.

### **Patient Partnership: A Pathway to Reclaiming Civic Belonging**

*Alexandra Paré-Tremblay*

Context: The experience of severe chronic illness, constitutes barriers to civic participation and triggers processes of disqualification and disaffiliation. This marginalization process fundamentally challenges patients' sense of belonging in the civic space. Driven by the rise of health democracy, the patient partnership model advocates for the

full integration of patient engagement within the healthcare system. While patient engagement and empowerment in healthcare represent a dynamic and rapidly expanding field of research, knowledge on patients' perspectives regarding these new roles at micro, meso, and macro levels remains underdeveloped. Objectives: This research seeks to give a voice to the main actors of this partnership, allowing them to reveal if and how this clinical and organizational process impacted their care and life trajectories. This project investigates the ways in which access to patient-partner status enables patients to mobilize new adaptive processes to cope with their chronic diagnoses. Methods: An interpretive qualitative design was used to address the study objectives. In-depth semi-structured interviews, inspired by Bertaux's life-story method, were conducted with nine participants (n=9) who had taken on the role of 'patient partner.' Analysis: The life stories (n=9) were then analyzed using phenomenological interpretive analysis (IPA), in an idiographic approach. Results: Having initially endured the multiple disruptions imposed by illness, the interviewed PPs expressed a desire to reclaim their status as active, participating citizens within society. The participants reported perceiving their role as patient partners as an opportunity to respond to this essential reclaiming, providing them with a renewed sense of usefulness and confidence, as well as enabling them to build community and navigate the healthcare system more effectively. Conclusion: Partnership serves as a "negotiation of reality" for patient partners, and thus, appears to lay the foundation for reclaiming their self-esteem and their place as "full" citizens. They report engaging as patient partners in the hope of alleviating the social suffering induced by illness and envisioning a more inclusive citizenship to which they could, in turn, belong.

## DILEMMAS

### **Integrity and Sustainability: Exemplifying the Use of an Adapted Clinical Ethics Decision-Making Process in the Hospital Boardroom**

*Kevin Dirksen*

The advent of clinical ethics has proved powerful for providing increased support for ethically-challenging decision-making at the bedside and helping establish norms of practice around historically-vexing topics like the duty to informed consent and forgoing disproportionate treatment at the end-of-life. With such a great need at the bedside, many have become content with ethics staying focused on this arena: autonomy and dignity prioritized over sustainability and social responsibility, individualized dilemmas over community-based needs, personal over structural. While leaving the bedside is not the answer, adding the boardroom to an ethicist's natural habitat can help prioritize sustainable-minded goals in health care operational decision-making. We will describe our ethics program's commitment to assisting operational health care leadership in making some of the most ethically-complex decisions they face. In our experience, the kinds of operational decisions best suited for a clinical ethicist's engagement relate to: changes in the level of quality, service, and experience of patients and the community (e.g., administering anesthesia by physician-anesthesiologists to nurse-trained anesthesia providers), considering new investments in or sunseting existing health-related supports (e.g., terminating a health navigator program), allocating community benefit spending (e.g., which non-profit to provide a grant to), or consolidating services (e.g., closing a service line requiring that patients would need to access this care elsewhere). This is not to say that these decisions should be executively made by a clinical ethicist, but effectively ethicist-supported. By exploring three actual situations in the last year where our program assisted operational leaders as outlined here, we will help catalyze the relatively untapped potential that clinical ethicists have in their hospitals and health systems to engage beyond the bedside and, in turn, work toward justice, decide with integrity, and promote sustainability.

### **The St. Gallen Resuscitation Decision Algorithm**

*Ulrike Ehlers*

When patients are admitted to hospital, their resuscitation status must be determined. This is usually done by means of pragmatic medical resuscitation status decisions of 'yes' or 'no', which are made by the treating physicians on a non-scientific basis, or less frequently: at the request of patients whose advance directives indicate which medical treatments are desired or not. In particular, resuscitation decisions made by the treating physicians have the potential to cause ethical conflict, both within the healthcare staff and with relatives of patients. The content of the controversies is mainly the usefulness and the individually different predicted and defined probability of success of resuscitation. However, there are also divergences due to differing values and self-interest. Today, there are studies from which treatment and resuscitation success can be derived. There are also laws that can be used as a basis for making decisions regarding life-prolonging measures. At the St. Gallen Cantonal Hospital, a "resuscitation decision algorithm" was designed, taking into account existing ethical, scientific and medical studies and legislation. The

resuscitation decision algorithm is divided into three areas (A/B/C): Resuscitation status 'yes' (A) for patients who are resuscitated because this is promising according to scientific criteria and is not rejected by the patient. Patients receive a Resuscitation 'no' (C) if the patient does not want resuscitation or if resuscitation measures would not be sensible or successful for medical reasons. The 'Resuscitation status area B' includes patients who cannot initially be clearly classified into groups 'A' or 'C'. Here, the resuscitation status is determined based on the individual general condition, planned treatment measures and the personal values of the patient. The 'Resuscitation status decision' is made using a 5-point cascade. Previous staff surveys have been positive. A quality study will follow and will be presented at the congress.

## **Navigating Clinical Ethics Dilemmas: A New Framework for Decision-Making**

*Setareh Homami*

**Background:** Although situations with ethical dilemmas are usually frequent in clinical experiences and several models and frameworks have been introduced to address them systematically, cultural diversity and rapid technological and socioeconomic changes in the current era have caused a continuous need to review and update these decision-making tools for health care ethics training and consultations. **Aim:** The present study was conducted in Iran to develop a framework for dealing with clinical ethics dilemmas, focusing on post-intervention actions. **Methods:** In first phase, we reviewed the existing models and frameworks for dealing with clinical ethics dilemmas. Accordingly based on findings and with the consensus of the research team, a draft for the new proposed framework was prepared. The following steps included testing the draft framework on several common dilemmas of clinical ethics and some real cases in the Iranian context, evaluating its face validity by clinicians and content validity by ethicists, and finally, assessing the level of accuracy and transparency by expert reviewers. **Results:** The framework includes nine stages that start with the "Identification of the moral challenge" and "Clarification of the relevant contextual factors", it continues with the "Moral judgment" stage, "Reflection & deliberation," "Moral action," "Follow-up the decision," "Dissemination of the learned lessons," and proposing some "Modifications," and then ends with some "Empowerment actions." Some stages include several steps that need to be followed in order to resolve clinical ethics dilemmas. **Discussion & conclusion:** The development process of the current new proposed framework has some innovative aspects, such as its focus on post-intervention actions, comprehensiveness, and methodological validation. Thus, it can potentially be applicable for training and empowering healthcare professionals in clinical ethics dilemmas.

## **CES Staff's Moral Challenges Related to Confidentiality and Transparency: Needs for Moral Guidance When Offering Ethics Support?**

*Berit Hofset Larsen, Bert Molewijk*

**Introduction:** Clinical ethics support (CES) never takes place in an a-political context. In and outside health care institutions, CES seems to become increasingly vulnerable to, and involved in, political and (social) media sensitive domains. We will present two self-experienced morally challenging situations that we encountered as CES staff, including: conflicting values, protecting users of CES, CES staff and the integrity of CES itself, moral responsibilities, and, how we responded. **Norwegian case:** Staff from the maternity ward at a Norwegian hospital asked the clinical ethics committee (CEC) for advice regarding women in labor opposing recommended interventions, raising concerns about the child's welfare. A birth right activist group member, also being a journalist, contacted the hospital claiming access to all minutes from meetings - where CEC had discussed the dilemma when the mother opposes interventions in connection with pregnancy and childbirth, obstetric violence, the legal protection of the unborn child or related issues. **Dutch case:** Due to a serious incident in a Dutch hospital a patient died (not because of the illness or treatment). The head of the department asked the internal Ethics Support team for a Moral Case Deliberation to focus on the moral stress of the team members and to reflect upon various moral questions related to this tragic incident. Afterwards, the Ombudsman and the Health Inspectorate asked for the minutes from that specific MCD session, and requested an interview with the MCD facilitator. **Discussion:** After comparing the facts and moral reasoning in both examples of ethics support staff's moral challenges, we will present an innovative ethics support tool specifically developed for CES staff experiencing moral challenges when offering CES in a political context (the Confidentiality Compass). During the last part of our presentation, we will engage with the audience in discussions about future needs of CES staff for related moral guidance.

## **The Creation of an Ethical Space Within an Italian Territorial Social Health Agency to Encourage Community Welfare**

*Antonio Maria Giuseppe Staffa*

**Background/aims:** The Espace éthique d'Assistance Publique, established in 1995 by Emmanuel Hirsch in collaboration with Alain Cordier and Didier Sicard, plays a crucial role in healthcare ethics. It serves as a space for ethical reflection, professional training, and resource sharing, aimed at fostering a culture of care and supporting hospital values. It also promotes dialogue among healthcare professionals, academics, and civil society, including patients and families. Over time, similar Ethical Spaces have emerged across France, Europe, and Italy, notably through the efforts of the cultural association Spazio Etico in 2013. These spaces focus on the ethics of care, driving cultural change and promoting best practices in healthcare. A 2021 document by the CNB emphasizes the importance of Ethical Spaces in addressing vulnerability and promoting community welfare. It advocates for the creation of Community Houses, spaces where individuals, families, and associations can come together to enhance social welfare and meet the needs of vulnerable populations. Ethical Spaces are seen as key to building new care models, encouraging attention, listening, and ethical reflection within communities. **Material and methods:** An Ethical Space was then implemented within the Azienda Socio Sanitaria Territoriale ASST dei Sette Laghi through: training the identified facilitators, creating a communication channel between facilitators and employees, and identifying physical spaces. **Results:** In 2023, 12 professionals were trained as facilitators on values using the Go Wish Game, which encourages reflection on topics like Informed Consent and Shared Care Planning. In 2024, a program was launched to raise awareness among health professionals about humanizing care. Through brainstorming, key focus group topics were identified, including ethical literacy, emotional health, self-determination, professional values, respect for patient choices, equitable care, end-of-life issues, assisted suicide, caregiver loneliness, and ethical considerations in clinical practice, research, and conscientious objection. **Discussion and conclusions:** The Ethical Space was appreciated by both Facilitators and Participating Practitioners. The need for involvement of citizens has emerged. It is being considered how they can turn to the ethical space.

## **CLINICAL ETHICS**

### **The Multiple Roles of a Clinical Ethical Committee: How Do Ethics Education for Staff Impact Ethical Consultation Requests?**

*Audun Brendbekken*

**Background:** In Norwegian specialist healthcare, Clinical Ethics Committees (CEC) have been mandatory by law in hospitals since 2021, supported by a new national directive. The mandate has two main goals: to enhance health professionals' ethical awareness and competence, and to provide advisory support for ethical challenges in patient treatment and care. This study investigates whether training in case identification, ethical analysis, and structured problem-solving could reduce the need for CEC consultations by empowering staff to address ethical issues independently. Alternatively, increased awareness and knowledge may lead to greater utilization of CEC services, possibly influencing the volume and nature of requests. **Aim:** This study aims to understand whether trends in requests to the CEC change following the introduction of the CEC's educational activities. **Method:** Written records from CEC case consultations over the past 12 years at Haukeland University Hospital were analyzed using descriptive statistics. We examined the type of ethical challenges presented and the nature and extent of CEC consultations. We compared CEC consultation statistics with educational activities provided by CEC in the departments requesting these consultations. **Results:** Ninety cases were analyzed in relation to the CECs educational activities. In several departments, CEC-led training sessions resulted in an increased number of consultation requests, particularly in departments with limited previous contact with the CEC. Conversely, CEC consultations often generated requests for further educational activities, including teaching sessions, reflection group facilitation, supervision of groups and leaders, and involvement in guideline development. A general trend emerged showing fewer requests for CEC consultation and an increase in request for support in building ethics competence among staff. **Discussion:** It is essential for CECs to fulfill both their educational and advisory functions within hospitals. By doing so, they enhance staff's ethical capabilities and confidence, contributing to ethically robust healthcare services.

## Normativity and Creativity in Clinical and Organisational Ethics: What Are Ethicists' Opinions?

*Nathalie Gaucher*

**Background:** Tensions between normativity and creativity are highlighted by specific situations in healthcare, such as innovation in medicine. However, little is known regarding how creativity is utilised by ethicists in clinical and organisational ethics. **Objectives:** The objectives of our study were to: 1) describe the meaning of creativity in clinical and organisational ethics practice in Quebec, Canada, 2) develop and assess a reflexive tool to think through the role of creativity in ethics practice. **Methods:** The interdisciplinary study team developed a reflective tool based on existing literature, such as Bassot's integrated reflective cycle, and experiences as ethicists. During their annual symposium in October 2023, all members of the Regroupement de Â©thiciens du rÃ©seau du QuÃ©bec were invited to participate in a reflective workshop. They participated in small group discussions on: "according to you, what is the role of creativity in the practice of clinical and organisational ethics?" Following discussions, interested participants completed anonymous self-administered web-based surveys (LimeSurvey). Surveys consisted in: 1) a reflective tool questioning the role of creativity in a specific ethics case experienced by each participant, 2) demographic data, 3) appreciation of the tool. **Results:** Forty-one participants completed the survey. Most were less than 10 years in practice (80%), worked in urban settings (68%) and had advanced degrees (36% master's, 28% doctorate). Creativity was understood as: 1) professional competency - to respond to uncertainty, reestablish communication between parties, and create proximity, 2) method - deliberative, pragmatic and applied, proactive, reflexive, 3) reflective space - a safe and open space, both outside norms but coexisting within them. The tool's strengths included: stimulated reflection, identify positives of creativity, ease of use. **Conclusions:** Creativity is an important part of clinical and organisational ethics, at many different levels. A reflexive tool can help identify creativity in practice.

## All Caregivers: A Case Study in Implementing a New Code of Ethics at CHU Sainte-Justine

*Marie-Claude Levasseur*

**Background:** In the wake of scandals in the public service network, Quebec's government is recommending the development of codes of ethics in each health institution. These codes of ethics apply to all hospital staff and aim to disseminate the rights of users and the values of the organization, in terms of patient care and processes. Despite limited evidence of their impact on care and services, healthcare organizations invest considerable time and resources in creating them. **Aim:** This study examines the influence of the implementation of a code of ethics built via a participative process on the care experiences of patients, family members, and staff (all professions combined). **Methods:** Based on a case study, this qualitative research is conducted in the pediatric department of a specialized health care institution in Quebec, Canada, which has developed and implemented a new code of ethics since 2018. Recruitment is based on a convenience sample of participants from different professional categories, hospitalized patients and their relatives. Interviews are conducted and transcribed verbatim. Initial inductive coding is conducted and reviewed by two members of the research team (NVivo). Thematic analysis are identified according to the categories explored in the interviews and derived from the narrative analysis. **Expected Results:** From November 2024 to February 2025, 60 patients/families and staff will take part in semi-structured interviews (20-45 minutes). We assess the impact of the code of ethics on care and services from the perspective of patients, families, and employees. The presented results will guide healthcare institutions wishing to implement code of ethics as well as to measure its influence on stakeholders. **Discussion:** This study shed light on the influence of the implementation of a new code of ethics grounded on the values of patients, families and staff on the care experience.

## Framing Bias in Clinical Ethics Consultation

*Baddr Shakhsheer*

**Background:** Clinical ethics consultation may be susceptible to framing bias. Framing bias may occur when the party requesting consultation perceives and frames the ethical question in a way that influences the consultation team, including their analysis and ultimate recommendations. Framing bias is problematic because it may result in ethically unjustified or sub-optimal recommendations and has not been extensively investigated within the context of clinical ethical consultation. **Aims:** We sought to evaluate if the party asking for the clinical ethics consultation affects how the consultation service perceives the ethical question and if framing bias is introduced into the consultation process. **Methods:** Recent (1-year) graduates and current fellows of a clinical ethics training program were administered two surveys one week apart. Each survey included brief descriptions of several ethics consultation cases, the surveys were identical except for information on who initiated the consult. In the first survey, the cases



were presented such that the consultation was requested by a party other than the patient/family. We assessed the two surveys for concordance in which bioethical ethical principles were involved, and which were perceived as the primary and secondary most influential. Difference in difference analysis were used to test for concordance. Results: 14 respondents completed part one, 11 respondents completed part two. For each case, there were statistically significant differences in the ethical principles perceived to be involved by the ethics consultants, as well as the principles that were ranked as primarily and secondarily involved in the case. Discussion: These data indicate that framing is a potential source of bias within clinical ethics consultation. Consultants should guard against this by evaluating the ethical question outside of the person or entity calling for consultation.

## **Beyond Moral Distress: Understanding Moral Regret in Clinical Ethics Consultation**

*Nathan Stout*

In the clinical ethics literature, much has been written in an effort to conceptualize moral distress and to understand its impact on healthcare providers. However, I contend that the moral distress framework does not adequately characterize the experiences of clinical ethicists when dealing with hard cases. Typically, moral distress is thought to occur when an individual knows the right thing to do but is prevented from acting on this knowledge due to institutional or other external constraints on their decision-making. However, clinical ethicists are much less likely than other participants in patient care to actually encounter these constraints. Often, the clinical ethicist has no institutional or systemic barrier that prevents them from making the recommendations that they believe to be most ethically justifiable, and, so, standard accounts of moral distress often don't apply. Nevertheless, the clinical ethicist is often left with feelings of regret, or sometimes guilt, as a result of their involvement in hard cases, and these feelings can take a personal and professional toll on the ethicist. It is well documented that moral distress contributes to burnout among clinicians, but no data exists on the experience of regret among ethicists or on its long term impact on the ethics consultant. I argue that, if left unaddressed, difficult moral emotions like regret stand to have detrimental effects for the practice of clinical ethics consultation in much the same way that moral distress impacts other healthcare practitioners. I maintain that in order to prevent this, more work needs to be done to understand the negative moral emotions involved in clinical ethics consultation and their impact on the ethicist and the sustainability of his or her practice, and I propose potential pathways for addressing these issues.

## **DIGITAL TECHNOLOGIES AND BEYOND**

### **Abdicating the Role of Mediator in US Healthcare Ethics Consultation: A Risky Choice**

*Autumn Fiester*

The amount of conflict between patients, families, and healthcare providers is so high in the United States that a recent consensus statement of five professional medical societies recommended embedding expert conflict management consultants in all high-volume US hospitals. From the earliest days of formal ethics consultation, the US bioethics organization, the American Society for Bioethics and Humanities (ASBH) deemed conflict resolution skills as a core competency for ethics consultants, making the institution's ethics service a natural locus for such conflict management experts. But over the last 25 years, clinical ethics consultation in the US has morphed into a consulting specialty similar to medical subfields like nephrology or hematology, in which the primary deliverable is knowledge-based expertise and judgment. Most US ethics consultants offer recommendations, not interventions. Even among ethics consultants with the ASBH's new formal certification (HEC-c), very few ethics consultants have any training in conflict management, despite the mandate for both in the ASBH's Core Competencies, the guiding document for the field. I will argue that this evolution (or devolution) of ethics consultation in the US may be sowing the seeds of its own demise. Over the last 10 years, US hospitals have increasingly relied on newly emerging Departments of Patient Relations to fill the void of conflict management expertise that ethics consultants could have (and, I believe, should have) filled. These new departments are typically larger and much better funded than the hospital's ethics consult service. In fact, most US hospitals have a patient relations department though many hospitals have no paid ethics consultants at all. If this trend continues, abdicating the role of conflict resolution in ethics consultation may put clinical ethics "out of business."

## AI, Algorithmic (In)Justice, and the Ethics Consultant: Quo Vadis?

*Leonard Fleck*

It would be naïve to think that AI would not invade the ethics consultation process. CAR T-cell therapy has front-end costs of \$475,000 for patients with various advanced hematologic cancers. We know that 70% of these patients will gain 1-4 extra years of life from this therapy. However, the other 30% will fail to gain an extra year of life. With the goal of providing a more cost-effective and just allocation of those limited health care resources, an emerging version of AI, using multiple biomarkers, will be able to predict with 90% confidence who is in the 30% group. Imagine a private insurance company, or the NHS in the UK, is considering use of this AI protocol for purposes of saving money or re-allocation to higher priority health needs. Is such a choice just and/or congruent with a commitment to solidarity? They, and their physician advisors, are seeking guidance from you as an ethics consultant. As an ethics consultant, what will your advice be to the insurance company, or the NHS, and to the physicians on this advisory committee? Should you be functioning as a patient advocate or as a prudent steward of social resources? Is it irresponsible for the ethics consultant to leave the matter to executives, bureaucrats, economists, and other self-interested stakeholders? I will critically assess potential responses that might be offered by an ethics consultant. Spoiler alert: No easy answers will be offered. Physicians are seeking insight, not indifference. Patients need fair, affordable, effective treatment. Consequently, I will argue that timorous neutrality by an ethics consultant would not be a virtue. Likewise, retreat to the bedside would be cowardly, i.e., allowing each physician to apply the AI protocol as they saw fit, thereby risking bedside algorithmic injustice.

## Clinical Bioethics Training for Surgical and Medical Residents: The Universidad CES Experience

*Julieta Moreno Molina, Clara Cossio-Uribe*

**Introduction** Medical and surgical residents often encounter ethical-clinical uncertainties during their training. Despite the increasing complexity of clinical scenarios, medical education traditionally focuses on disciplinary knowledge, with ethical dilemmas typically addressed by ethics committees. This approach limits residents' exposure to clinical bioethics and their ability to resolve ethical conflicts effectively. **Objective** To describe the implementation and outcomes of a clinical bioethics training program for medical and surgical residents at Universidad CES, designed to enhance their ethical decision-making skills. **Methodology** Since 2018, the Clinical Bioethics Unit at Universidad CES has progressively incorporated clinical bioethics training into more than 12 medical and surgical specialty programs. The program employs innovative, student-centered methodologies, emphasizing clinical ethics deliberation methods typical of Health Ethics Consultation. Training activities include case-based learning, workshops, and guided ethical deliberation sessions. **Results** The implementation of clinical bioethics training for residents has led to a significant increase in requests for bioethics seminars in additional residency programs. Initially launched in two programs, it has now expanded to 12, including Internal Medicine, Pediatrics, Gynecology and Obstetrics, Emergency Medicine, Urology, Anesthesiology, Dermatology, Psychiatry, and Neurology. Elective rotation requests have also increased, reflecting the growing interest in clinical bioethics education. The Unit has organized two interdisciplinary events centered on clinical case presentations, utilizing bioethics deliberation methodologies. Furthermore, bioethics training has been integrated into practical settings through participation in staff meetings and clinical case reviews, fostering deeper engagement with ethical decision-making in real-world scenarios. **Conclusion** The clinical bioethics training program at Universidad CES addresses a critical gap in the ethical formation of healthcare professionals. By equipping residents with tools for ethical deliberation and conflict resolution, the program enhances competencies and fosters a culture of ethically sound medical practice. This initiative underscores the importance of integrating clinical bioethics into residency programs to prepare healthcare professionals for modern medical complexities.

## Beyond Assumptions: A Patient-Centered Approach to Faith-Based Sensitivities in Medical Treatment

*Chelsey Patten*

This presentation explores the importance of honoring patients' faith-based preferences in healthcare, illustrated by the case of a 19-year-old Muslim patient with homozygous familial hypercholesterolemia who required porcine-derived heparin for essential LDL apheresis. When nursing staff learned of the patient's faith background and raised concerns about the porcine origin of the heparin, the healthcare team faced a complex ethical dilemma: how should providers approach disclosure when an essential treatment may conflict with a patient's beliefs? Additionally, should this decision establish a broader precedent for managing similar cases in the future? This case underscores

the nuanced balance required to honor faith in patient-centered care, particularly when beliefs intersect with medical necessity. Although Islamic bioethics generally allows the use of otherwise prohibited substances in life-saving treatments with no alternatives, there is considerable diversity in interpretation. This variation underscores the importance of approaching each patient as an individual, with unique beliefs and values. Actively engaging with the patient regarding their faith-based values through the informed consent process allows providers to respect their faith commitments and foster individualized care. By tailoring discussions and honoring each patient's autonomy without presuming specific beliefs, providers can create a safe space for open, value-aligned decision-making. The policy implications of such cases extend far beyond individual instances. Healthcare serves diverse communities with varied faith-based practices requiring a systematic approach to ensure consistent respect for these differences. Standardized protocols addressing faith-sensitive treatments enable clearer, informed decision-making pathways, particularly in high-stakes or ethically complex treatments. Establishing such practices ensures transparency and consistency, allowing healthcare providers to address faith-based accommodations respectfully and proactively. This presentation explores practical strategies for integrating faith sensitivity into healthcare policies, enhancing trust and reinforcing a strong foundation for respect in patient-provider relationships across diverse cultural and religious contexts.

## SOCIO-POLITICAL ISSUES

### The Role of Socio-Political Issues in the Development and Function of Hospital Ethics Committees in Iran

*Fatemeh Bahmani*

In Iran, Hospital Ethics Committees (HECs) emerged in 1997 through the implementation of newly introduced requirements for hospitals by the Ministry of Health and Medical Education (MoHME) and developed through two phases. In the first phase, these committees were involved more in the implementation of cultural and religious values, than in clinical ethics in today's sense. However, after a while, as the first version of the Charter of Patients' Rights was approved in 2002, these committees started to change their point of focus to patients' rights gradually. The rise of the second phase of clinical ethics occurred when medical universities started to offer some post-graduate degree-based programs in medical ethics in 2008, which informed academic scholarship in the field of medical ethics in Iran. At this stage, the policymakers came to the conclusion that HECs function more effectively by the creation of central regulations and support. Hence, the MoHME established the National Clinical Ethics Committee (NCEC) in 2018, after the successful experience of the establishment of the National Research Ethics Committee and subordinate committees in universities. The NCEC soon drafted the 'Guidelines for the establishment, classification and description of duties of clinical ethics committees' and required regional health authorities to form 'regional clinical ethics committees' with the task of monitoring and guiding the HECs toward implementing medical ethics standards in the affiliated hospitals. The guidelines for clinical ethics committees brought some innovations in the field of clinical ethics to tackle the socio-political challenges faced by the HECs, leading them to function more as 'organizational ethics committees' than 'clinical ethics committees'. We will discuss the role of these socio-political issues in the development and function of HECs in Iran and argue the main issues these committees have to tackle in order to effectively address healthcare ethics needs.

### Grounding Clinical Ethics Practice in the Clinical as an Inherently Responsive Means for Responding to the Socio-Political

*Stuart Finder*

Clinical contexts are shaped by a variety of features that, when carefully examined, provide the ethical texture of such contexts. Most prominent among these are four complex and interrelated features: (a) the multiplicity of embedded and mostly unarticulated values that intimately influence (b) specific and dynamic relationships among individuals (who are mostly strangers to one another) and the roles they fulfill in the pursuit of offering (and providing) care to those suffering from disease, injury, or syndrome, care that itself must account for the (c) inherent uncertainties due to a variety of ongoing change whereby (d) what counts as 'best' is necessarily interpretive. Accordingly, when providing clinical ethics support or consultation, focus must be directed towards how these features reflect and shape what is seen as most worthwhile for those making decisions about how best to proceed. In this light, as Bliton and Finder wrote 25 years ago the main activity of clinical ethics work, as a kind of "clinical" practice, may be characterized as the "conducting of conversations" which aim "to identify by speech, and through oneself as an example, what is most worthwhile" so that those who face decisions not only may make choices consummate with their beliefs and commitments but do so in the face of having to live in the aftermath of

their choosing. On the face of it, this understanding of clinical ethics work does not appear to be concerned with socio-political considerations (social justice, sustainability, AI in healthcare, etc.). Through use of a clinical example, this paper will explore how this conception of clinical ethics work is, however, inherently a socio-political sensitive form of engagement insofar as macro-level considerations are constantly (and practically) instantiated in the micro-level context of any clinical encounter. Thus, clinical ethics work, as "clinical" must be responsive to these.

### **Bridging Ethics, Clinical Practice, and Law: The Role of SAMS Medical-Ethical Guidelines in Switzerland**

*Manya Hendriks*

In clinical ethics, coercive measures those performed against a patient's wishes or resistance go along with complex ethical and legal conflicts. While respect for patient autonomy is a fundamental ethical principle, situations arise in which a patient's refusal conflicts with medical indications, such as in emergencies like acute agitation or postoperative delirium when decisional capacity is temporarily impaired. This workshop will explore the ethical tensions between respect for patient autonomy and the perceived need for coercive medical measures. Developments in ethics, legislation, medical practice and societal values necessitate a revision of the Swiss Academy of Medical Sciences (SAMS) medical-ethical guidelines on coercive measures. The revision aims to address concerns raised by healthcare professionals (HCPs) and public inquiries, requiring a nuanced, interdisciplinary approach and to facilitate decision-making. Central to the revision is also the impact of the UN Convention on the Rights of Persons with Disabilities (CRPD), ratified by Switzerland in 2014. The CRPD Committee advocates for a radical shift from "substitution" (e.g., guardianship) to "assistance," i.e., supported decision making, raising significant ethical and practical questions about a zero-coercion framework. Through interactive panel discussions, participants will engage with these issues, exploring how updated medical-ethical guidelines can support HCPs in navigating conflicts between legal obligations, patient rights, and clinical realities. Particular attention will be given to the socio-political pressures influencing these debates, including the impact of international human rights law and national policy reforms. The workshop will be moderated by an interdisciplinary team of ethicists and HCPs involved in the ongoing revision of the SAMS guidelines, ensuring that participants reflect on the theoretical and practical medical-ethical issues of coercive measures faced by HCPs.

### **An Advanced State of Irreversible Decline in Capabilities: How Politics Impact Patient Care**

*Kristina Kekesi-Lafrance, Meredith Schwartz*

In 2021, the Canadian Criminal Code was amended to allow access to medical assistance in dying (MAiD) for a person whose death is not reasonably foreseeable. In the summer of 2023, Quebec followed by amending the Act Respecting End-of-Life Care to allow MAiD for people who are not at the end of life. One of the eligibility criteria for patients who are not at the end of life is that they must be 'in an advanced state of irreversible decline in capability'. This criterion seems to bear the load previously born by being at the end of life. Despite its weight, this ambiguous criterion becomes virtually impossible to apply in some of the more complex cases. When is a condition 'advanced'? What standard should be used to assess an 'advanced state'? We identify three different standards used in practice: (1) an objective standard relative to the typical trajectory of the illness, (2) an objective standard relative to the person and their prior capacities, (3) a subjective standard that relies on the individual's own assessment of whether their state of decline is advanced. We use fibromyalgia, a condition for which there is no objective physiological marker and known to disproportionately impact women, to discuss how power affects the application of ambiguous criteria, leaving patients and providers in a state of moral uncertainty. We look at how sexist dismissal of women's pain can negatively affect access to MAiD and reliance on ambiguous criteria heightens this risk. Through a pluralistic lens, we describe the ambiguities of applying these standards and the differences in how these standards are assessed in Quebec and the rest of Canada.

### **Plurality & Power in Paediatric Ethics: A Bioethics Service's 40+ Years of Adapting to Socio-Political Realities**

*Randi Zlotnik Shaul*

Meeting the ethics needs of a dynamic tertiary paediatric hospital requires a bioethics service that responds not only to clinical physiologically-grounded dilemmas but also to the socio-political forces shaping hospital activities. This presentation will explore the evolution of our paediatric bioethics service from the 1980s to the present, draw-

ing on insights from a historical inquiry. We will examine how our department, through its four core pillars of activity adapted to emerging challenges and opportunities, enhancing ethical decision-making and fostering a culture of ethical awareness throughout the institution. 1. Consultation: Ethical tensions often arise from the socio-political context of young people as rights holders, balancing their best interests with emerging autonomy. Over time, our consultation model has evolved from an ethics committee to a more dynamic approach, involving individual bioethicists, Clinical Bioethics Associates, and a Bioethics Advisory Committee. 2. Education: Our department has continually innovated educational approaches to address socio-political issues, including targeted in-services, monthly Bioethics Grand Rounds, and an annual Bioethics Week. Other initiatives include Bioethics-Morbidity and Mortality Rounds, fellowships, electives, and selectives, ensuring wide-ranging, hospital-wide engagement with ethical issues. 3. Policy: Today, our department plays a key role in developing frameworks, guidelines, and policies to address emerging ethical challenges, such as post-pandemic surgical prioritization and the ethical integration of new technologies. Our historical inquiry sheds light on how the department has embedded itself within the hospital's bureaucratic structures, shaping access to and influence over institutional decision-making. 4. Research: Research and scholarship in our bioethics department has historically, and presently engaged with (sometimes controversial) dialogues beyond the hospital walls on socio-political issues. These engagements, on topics like healthcare funding priorities for children, the responsibilities of the clinician-scientist, and the impact of moral distress on clinician burnout continue to be opportunities for demonstrating the value of ethics expertise.

## CONTRIBUTIONS OF CLINICAL ETHICS

### Advance Directives and Public Support for Assisted Suicide in a Population-Based Sample of Older Adults

*Solenne Blanc*

Clinical ethicists are often confronted with new societal developments and changing attitudes regarding the end of life. As evidenced by rising rates of advance directives (ADs) and memberships in right-to-die organizations, there is a growing public support for both ADs and assisted suicide (AS) in Switzerland. This study investigates the association between the completion of ADs and attitudes toward AS among older adults in Switzerland, evaluating whether older adults might be inclined to engage in ADs and, at the same time, support AS. Data from 1,523 participants aged 58 years and older were collected through the Swiss component of the representative Survey on Health, Ageing, and Retirement in Europe (SHARE) for 2019/2020. Participants were asked if they had completed ADs. Behavior toward AS was assessed using three key questions: support for AS, consideration of it, and membership in a right-to-die association. Probit regression models analyzed the associations, considering various social, health, and regional characteristics. Overall, 42% of the sample had completed ADs. Additionally, 81% supported legal access to AS, 63% considered asking for it, and 9% were members of a right-to-die association. Among members of a right-to-die a, 89% had completed an ADs. Respondents who had completed ADs were more likely to support AS ( $p<0.001$ ), consider it ( $p<0.001$ ), and be members of a right-to-die organization ( $p<0.001$ ). Conclusions: The study reveals an association between completing ADs and supporting behavior toward AS among older adults in Switzerland. When engaging in Advance Care Planning (ACP), older adults may seek clarification on assisted suicide practices. Clinicians should prepare to engage in informed discussions, ensuring that patients are well-informed about end-of-life available options. Future developments in end-of-life care planning and healthcare ethic consultations should consider incorporating these discussions and adapted documentation of both ADs and AS together.

### Medically Assisted Dying Practices: What Role for Clinical Ethicists?

*Vanessa Finley-Roy*

Background: Euthanasia and physician-assisted suicide are two forms of medically assisted dying (AD) practices that have been legalized in several jurisdictions throughout the world over the last two decades. Because of this increased trend, more individuals now have access to a self-chosen death. Despite its legalization and the diversity of frameworks governing AD, it remains morally taxing, fraught with ethical challenges. However, there is a dearth of literature regarding the specific roles clinical ethicists (CEs) may have in AD practices. Aim: We sought to address this literature gap by: 1. Gathering healthcare professionals' (HPs) and CEs perspectives on how CEs may contribute. 2. Identifying how CEs may have been involved thus far. 3. Identifying promising practices and pitfalls related to their involvement. Methods: An exploratory qualitative study using focus groups, purposive and snowball sampling. Four online focus groups were held. Groups comprised of 1) HPs involved AD and 2) CEs from Quebec and Switzerland. Data was analyzed using thematic analysis. Results: A total of 11 HPs participated which



included: physicians (n=5), a social worker (n=1), a neuropsychologist (n=1) and nurses (n=4). A total of 10 CEs participated. Five major themes were identified: 1) Previous/Current involvement in AD, 2) Specific Roles for CEs, 3) CEs competencies that are deemed useful in AD provision, 4) Operationalization of CEs involvement 5) Obstacles/Pitfalls associated to CEs' involvement in AD. Discussion: By highlighting the specific roles identified in our study and linking such roles with the competencies that are deemed necessary for CEs involved in AD, we will discuss questions and issues that pertain to the legitimacy of including CEs in AD. Promising practices and potential pitfalls related to their involvement will also be presented, considering the variability of AD practices around the world.

### **Medical Assistance in Dying in Pediatrics: What Role for Clinical Ethicists in Canada?**

*Marta Martisella*

**Introduction:** With the enactment of Quebec's Act Respecting End-of-Life Care (2015), certain adults can request Medical Assistance in Dying (MAiD). Since, there have been ongoing debates about extending eligibility to mature minors. Pediatric tertiary care hospitals, though primarily focused on children, may occasionally support young adults who request MAiD. However, the contexts of such requests and the role of clinical ethicists therein remain undocumented. **Objectives:** 1. To describe the characteristics of interactions regarding MAiD between the pediatric palliative care (PPC) team and patients or parents at the CHU Sainte-Justine (Québec, Canada), 2. To describe the role of clinical ethicists in these cases. **Methods and Analysis:** Retrospective and descriptive case study within a PPC team, gathering data from patients charts involving interactions about MAiD (2013-2023). Data included: patient demographics, illness details, palliative care and clinical ethicists involvement, and information related to the interactions about MAiD. Analyses involved descriptive statistics, structured thematic analysis. **Results:** 1) The PPC team had 11 interactions about MAiD with parents (n=8) and patients (n=3) aged from less than one year to 18 years old or older. All patients had serious pathologies and one received MAiD after reaching the legal age with the support of pediatrics teams. 2) Clinical ethicists were involved (n=5) to support interdisciplinary reflections and address any ethical issues that emerged from these discussions. **Conclusion:** Despite the current legal prohibition of MAiD for minors in Quebec, interactions surrounding MAiD do arise in a pediatric context. Given this data and the broader societal debates on the topic, clinical ethicists must adapt their practices to navigate between clinical realities and legal constraints. This presentation combines empirical data and reflections drawn from the experiences of clinical ethicists at a pediatric tertiary care hospital in Canada.

### **Understanding What Clinical Ethics Cases Are: Review and Perspectives From a Canadian Collaborative on Clinical Ethics Methods**

*Eric Racine*

**Background:** Clinical ethics involves understanding concrete moral situations and supporting meaningful discussion to identify appropriate responses. However, concepts and methods to describe cases vary between authors and clinical ethics consultation methods. We undertook (1) a review of contrasting models of consultation methods in the literature and (2) embarked on a critical and interpretive analysis of these methods by involving a large group of Canadian clinical ethicists. **Method:** Non-exhaustive literature review to identify a range of influential ideas on how to describe clinical ethics cases (e.g., with respect to terminology and definitions) and the methods recommended to understand these (e.g., grasping of medical facts, grasping context). Through participatory co-author group discussions, we explored the strengths and limitations of existing models and practices to offer a critical interpretive analysis (inspired by McDougall's method). **Results:** We identified nine families of clinical ethics consultation methods, which vary considerably with respect to the basic description of cases (e.g., dilemmas, cases, stories, morally problematic situations) and the use of moral principles in understanding cases. Recommended practices also vary greatly, especially regarding medical fact (e.g., as being 'facts' or as being 'interpretations') and the descriptions of the processes of understanding situations (e.g., as being linear or as being cyclical and iterative). Recommended practices also vary according to their methodological accounts of contexts, social and power dynamics, and emotions (e.g., as being constitutive or not of cases). **Discussion and conclusion:** We identify and discuss five issues with respect to clinical ethics consultation methods: (1) restrictive terminology, (2) gaps between theory and practice, (3) oversight of context, (4) cursory treatment of power dynamics and trust, and (5) a limited awareness of the positionality of ethicists and interested parties. This research paves the way for further steps of co-research and co-creation to develop advanced practices.

## **Repertoire of the Competencies of the Clinical Ethics Consultant in the light of the European and Italian Qualifications Framework**

*Francesca Reato*

**Background/aims:** For the public recognition of the qualification of the Clinical Ethics Consultant (CEC) it is necessary to build the Repertoire of the Competencies by the European Qualifications Framework (2008, 2017) and the Italian Qualifications Framework (2012, 2016, 2018) criteria. Highlighting the clear connection to the EQF level 8, we identified and described learning outcomes of the identified competencies through knowledge, skills, autonomy and responsibility. **Methods/Materials:** To reach data saturation, according to the qualitative research approach, an ethnographic study was conducted according to the principles of the "At Home Ethnography," through Participant Observation and Interviews to the Double. The interviewees are asked to imagine a hypothetical replacement by a "Double" who will take their place in the execution of the work activities and to provide him with all useful indications to cover the role of the CEC best. **Results:** Taking into account also the European Skills Frameworks *Entrecomp*, *LifeComp* and *DigComp*, was identified 11 Transversal Competencies (01. Communication and Interpersonal Relationship, 02. Coping With Emotions, 03. Problem Solving, 04. Critical Thinking, 05. Decision Making, 06. Self Awareness, 07. Leadership, 08. Team Work, 09. Time Management, 10. Governance of Digital Transformation Processes and Technological Innovation, 11. Teaching Competencies) and 6 Technical Professional Specialist Competencies (1. Determine the nature of uncertainties or moral conflicts that require clinical ethics consultation, 2. Conduct the clinical ethics consultation process in the health area, 3. Encourage the resolution of moral uncertainties and conflicts by facilitating the construction of an ethically based solution, 4. Document planned and implemented clinical ethics advice in the health field, 5. Monitor clinical ethics consultation service, 6. Improve the quality of clinical ethics consultant service). **Discussion and Conclusions:** The Double Instructions and the Participant Observation allow: tracing of the tacit routines put into place and interpreted by each Professional, through the exercise of the narration of micro-actions and daily practices, identifying attitudes, knowledge, skills, emotional and intentional colors of their professional actions, identifying spaces of autonomy and responsibility, learning more about the actions and reasons for the practices of fellow Clinical Ethics Consultants.

## **ASSISTED DYING**

### **To Better Understand Refusals of Medical Assistance in Dying: A Relational Ethical Approach**

*Alexandra Beaudin*

Mediation is an essential component of ethics consultation. The practice of mediation uses a neutral facilitator to foster engagement of all stakeholders and their respective interests and perspectives, and facilitate a resolution or consensus on an ethically justifiable course of action. However, when, if every, is it justifiable for the clinical ethicist to step outside of the bounds of their role as mediator and advocate for what they feel to be the right course of action? The author will describe a case in which the interests of an incapacitated patient are discovered through interview of his wife and guardian. However, neither the wife nor the attending physician is willing to move forward with the ethically appropriate course of action to uphold the patient's previously expressed wishes. In cases like this, what are the clinical ethicist's responsibilities to advocate for the most ethically appropriate course of action? Clinical ethicists are consultants, and ultimately the decision-making rests with the clinical team and patient or family. However, when the patient cannot speak for themselves, and their loved ones refuse to do so, does the ethicist have an obligation to step outside the role of neutral mediator and instead advocate for the voice of the patient? At what point would the ethicist seek institutional or legal support to advocate for a specific course of action? The author will provide support and considerations for both perspectives, along with considerations for a deontological vs consequentialist approach to consultation recommendations.

### **Medical Assistance in Dying in the Context of Mental Disorders: Co-Development of a Reflection and Discussion Guide**

*Caroline Favron-Godbout*

**Background:** Medical assistance in dying where a mental disorder is the sole underlying medical condition (MAiD-MD) is permitted in several countries and is legally scheduled to become available in Canada as of 2027. This option raises lively debate and concerns internationally, as well as the need to be prepared to deal with delicate situations related to MAiD-MD. **Aim:** To engage various stakeholders in the co-development of a support tool address-

ing concerns about MAiD-MD. Methods: Participatory action research project in four phases: 1) Literature reviews, 2) Series of 9 focus-groups with people living with mental disorders, relatives and healthcare professionals, 3) Community consultation with 10 groups of key-informants, 4) Preliminary assessment of the support tool. An advisory committee mobilizing academic, clinical and experiential expertise guided the project. Results: The presentation will report on focus-groups results supporting the co-development process. Numerous concerns were shared: 1) issues currently experienced (e.g., lack of resources, challenging care experiences), 2) needs to be addressed (e.g., to specify the guidelines and procedures that will guide MAiD-MD provision, to inform, prepare and support stakeholders), 3) complexity to be considered (e.g., particularities related to mental disorders, potential obstacles to MAiD-MD, consequences of rejected requests), 4) other sensitive questions (e.g., how to broach the subject of MAiD-MD, involve loved ones, reconcile divergent perspectives). Ideas for support were also explored, including: 1) offering better aid in living with mental disorders, 2) having prior preparation, 3) offering support, and 4) opening dialogue to ease discomfort. Discussion: The need to prepare various stakeholders to live through complex situations and to open dialogue with respect, benevolence and humility guided the development of the support tool: a reflection and discussion guide. This guide was refined during subsequent phases of the project, and the co-development process was experienced by many involved as empowering.

### **From Polarization to Reconciliation: the Role of Clinical Ethics in Redefining Medical Integrity in the Assisted Dying Debate**

*Perrine Galmiche*

In France, the medically assisted dying debate is at a turning point. An opinion of the National Ethics Council in 2022 has opened the way to a possibility of changing the law to allow a form of aid in dying. It was followed by various political and public debates, including a Citizen's Convention and a Parliamentary Report on the current law regarding end-of-life. Their conclusions acknowledged both the need for more respect for patients' autonomy and situations of suffering that do not find resolution in the current healthcare offer, as have other countries with legislations on assisted dying before them. However, a significant disagreement arose regarding whether assisted dying should be considered part of healthcare, which have sparked debates about the definition of medical integrity - a question that remains unresolved to this day. A comparison of how stakeholders use and discuss the argument of medical integrity both in the sociopolitical debate and in clinical ethics settings can help in addressing new elements on this challenge. In the French sociopolitical debate, based on an analysis of opinion columns in the press, the perception of medical integrity is very polarized. Opposite definitions are used against each other, those defending medically assisted dying considering it is compatible with one definition, and those against it affirming the opposite. In clinical ethics settings, based on a review of 7 years of clinical ethics consultations about assisted dying requests and preliminary results from a qualitative research protocol, there is no presupposed definition of medical integrity. Its contours are rather questioned in each situation by professionals, as well as patients and proxies. This reflection aims for a better understanding of the way clinical ethics can modify the use of this concept, notably by including patients and proxies' perspectives on what is a physician's role in assisted dying.

### **Psycho-Oncologists' Role in Requests for Assisted Suicide: A Qualitative Interview Study on Current State and Future Directions**

*Pola Hahlweg*

Background: Assisted suicide (AS) is a socio-political challenge. In Germany, AS is legal, but new legislation is pending. Previous legislation drafts provided for the involvement of various professional groups, including psycho-social professions such as psycho-oncologists. Psycho-oncologists have a lot of experience in dealing with seriously ill people, end-of-life decisions, and possibly the topic of AS. Their work is intertwined with ethical considerations. However, there is a lack of studies on the role of psycho-oncologists in AS, especially for Germany. Aim: The aim was to ask psycho-oncologists about their tasks and needs in AS inquiries in order to identify possible forms of participation. Methods: We conducted a cross-sectional, qualitative interview study with psycho-oncologists in Germany. Inclusion criteria were a current clinical activity as a psycho-oncologist and having talked about AS in at least one conversation with a patient. The invitation to participate was sent by email to the study team's network and via social media channels. Interested parties responded on their own initiative (convenience sample). The interviews were analyzed qualitatively using pragmatic thematic content analysis. Results: A total of N=12 interviews were conducted. Results suggest that the psycho-oncologists surveyed would mainly like to take on the role of open discussion partners, both currently and in the future. Whether psycho-oncologists should assess decision-making capacity and voluntariness was controversial among participants. The vast majority rejected par-

ticipation in realizing the AS. They were against having to take on mandatory roles. For AS work, the participants would need, among other things, a clear legal and institutional framework and specific training opportunities. Discussion: This study provides initial insights into the (potential) areas of responsibility and needs of psycho-oncologists in AS requests. It can serve as a basis for follow-up studies, e.g., with clinical ethicists as the target population. Suitable structures and training opportunities should be developed.

### **Toward a Better Understanding of the Use of Medical Assistance in Dying: A Qualitative Study With International Key Informants**

*Simon Lemyre*

**Background:** The use of Medical Assistance in Dying (MAiD) - euthanasia and assisted suicide - varies significantly across jurisdictions with such legislation. It ranges from 0.3% of all deaths in California (2023) to 7.3% in Quebec, Canada (2023-2024). Various hypotheses are proposed to understand why some jurisdictions have higher rates than others, relating to patient age, religiosity, education, socio-demographic characteristics, public awareness, eligibility criteria, number of MAiD practitioners per capita, institutional support and method used (injection vs self-administration). Few empirical studies have been published on the factors behind the increase in MAiD rates in certain countries. To assess the moral implications of MAiD operationalisation, we need to understand the factors contributing to its prevalence. **Objectives:** To better understand the factors associated with the use of MAiD in jurisdictions where the practice has existed for at least five years. **Methods:** This qualitative study uses semi-structured interviews with 50 key informants (KI) from Canada, Belgium, California (US), The Netherlands, Switzerland and Victoria (Australia) selected through purposive sampling. KI are members of a regulatory organization for MAiD or experts actively involved in MAiD. The interview guide addresses all possible factors related to the use of MAiD and has been pretested. We perform descriptive thematic analysis and make comparisons between jurisdictions. **Results:** Results revealed that factors influencing the use of MAiD can be divided in four themes: 1) laws and policies on MAiD, 2) the impact of the organization of care and services, 3) individual characteristics of people who make MAiD requests, and 4) social dimensions that influence the use of MAiD. **Discussion:** By shedding light on the factors influencing the use of MAiD, we can provide valuable insights to policymakers and healthcare providers for a more responsible delivery of MAiD. This study offers an international comparison between jurisdictions with established MAiD legislation.

### **An Integrative and Innovative Model for MAiD Equity: The Ottawa-Champlain Region Experience**

*Nikolija Lukich, Sara Oliver*

Medical Assistance in Dying (MAiD) was legalized in Canada in 2016. Since then, health care organizations have implemented MAiD procedures to address increasing volumes of requests. However, some institutions have not historically had adequate resources, preventing them from offering MAiD services. While faith-based organizations have the legal ability to conscientiously object to providing MAiD services, secular ones do not. This has raised questions regarding health equity and accessibility in a publicly-funded health care system, particularly from patients requesting MAiD who cannot be transferred to another hospital or home due to fragility. Our presentation reflects upon the use of ethics consultations in conjunction with support from a regional MAiD program and Advanced Practice Nursing (APN) to assist organizations in implementing MAiD services to meet the needs of their community. This includes robust ethics consultation and education to provide accurate and up-to-date information, to survey available resources and willing assessors and providers, to support and address fear and moral distress internally and within a small community, and establishing a set of procedures to meet legislative requirements and standards of care. Using this integrative and innovative model, combining the clinical experience of an Advanced Practice Nurse and the ethics expertise of an ethicist, ensured that patients and families were able to exercise their autonomous right to a legal health care service in an equitable manner, and hospital staff had any questions or moral distress addressed. Laying this foundation enabled the organization to implement ongoing education and support while maintaining a positive reputation within their local community of being a compassionate and patient-centred care provider.

## **Beneficence-Based Ethical Obligations in Assisted Dying**

*Georg Marckmann, Anna Hirsch*

Assisted dying usually is ethically justified by respect for the person's autonomy. However, there are also beneficence-based obligations towards persons requesting assisted dying. What beneficence requires from persons assisting in dying is far less obvious and less discussed. We will therefore explore in our contribution what role obligations of beneficence can or should play in responding to requests for assisted dying, also within ethics consultation. After a brief philosophical analysis of the concept of well-being, we will assess whether beneficence-based obligations can be used as 'gatekeeping' criteria for assisted dying. Some countries and states restrict access to assisted dying to unbearable suffering and/or treatment resistant, incurable or terminal illness. We will argue that these beneficence-based criteria are neither suitable nor justified to determine ethically legitimate assisted dying. Gatekeeping can only be justified by the protection of autonomous decisions. Nevertheless, beneficence-based obligations can play an important role in responding to requests for assisted dying. First, they require to offer appropriate psychosocial support and medical (esp. palliative) care. Professional standards of care therefore should not only include safeguards for autonomous decision-making, but also provisions of appropriate care and support for the requesting person and her families. Second, beneficence-based arguments can have an instrumental value for promoting the requesting person's autonomy. Within a shared decision-making process, they can provide an important input into the joint deliberation about the available options. Third, beneficence-based obligations can help the person who has been asked for assistance in their individual decision about whether they shall follow the request. As a conclusion, persons responding to requests for assisted dying should have specific expertise in evaluating and balancing beneficence-based obligations. Focusing more on the beneficence-based obligations ("appropriate help for the person's need") may improve the care for the requesting persons and their families and strengthen their autonomy.

## **Which Factors Influence the Evolution of the Use of Medical Assistance in Dying? A Scoping Review**

*Isabelle Marcoux*

Background: Medical assistance in dying (MAiD) is now legal in over 25 jurisdictions in 12 countries, and the numbers of requests and administrations are increasing at different rates. A few hypotheses have been suggested [1] or studied [2] in order to explain this phenomenon, but there is still no systematic assessment of the types and extent of existing evidence. As MAiD is a practice fundamentally rooted in clinical ethics, it is important to better understand the factors that influence its use while considering its evolution over time. Objective: To identify factors, including socio-political ones, associated with the use of MAiD (requests or administrations) in jurisdictions where this practice is legal. Methods: A scoping review is undertaken following the recommendations of the Joanna Briggs Institute. Nine electronic databases (i.e., MEDLINE, CINAHL, EMBASE, Web of Science) and grey literature are searched. To be included, the documents must examine factors associated with MAiD (requests or administration), focus on jurisdictions where the practice has been legal for at least 5 years, and be available online. Selection and extraction are carried out by two independent reviewers using Covidence software. Expected results: The results will enable us to determine which factors, including political and legal ones, social and cultural norms, care organization and individual characteristics are associated with MAiD and its evolution over time. We will also assess these results according to the level of existing evidence. Discussion: Knowing the individual characteristics, organizational and socio-political factors associated with requests for and administration of MAiD while considering their evolution over time, can help practitioners and policy-makers assess complex end-of-life care situations and services in their settings and jurisdictions.

## **Should Health Care Ethicists Provide Administrative Support/Leadership of Hospital Medical Assistance in Dying Programs?**

*Kathryn Morrison*

Since MAiD was decriminalized in Canada (2016), hospitals have developed local processes to respond to new or existing requests from patients. Health care ethicists have played a significant role in this development, engaging in activities such as MAiD case coordination, policy development, and education. Some hospital MAiD programs report to the administrative director of ethics, and in other cases the MAiD navigator reports to a health care ethicist. While this has resulted a high degree of ethics integration into MAiD care (with some ethicists being effectively embedded in hospital MAiD programs), it has also called into question whether these activities are within the



appropriate role and scope of a health care ethicist. This raises concerns, among other things, about the role clarity of health care ethicists when doing MAiD related work, the impact of MAiD on ethicist workload, and the effect of routine ethicist involvement on public perception of MAiD. Eight years on, the purpose of this paper is to evaluate the role that health care ethicists have had in administration of Canadian hospital MAiD programs. The paper begins by reviewing the involvement of health care ethicists in hospital MAiD services from 2016-present. The paper then analyzes the question of whether health care ethicists should provide administrative support/leadership of hospital MAiD programs by considering the following key questions: Are these activities aligned with what health care ethicists do? What are the benefits and risks? How do alternative models of administrative support/oversight compare? Are there more effective ways for MAiD programs to engage hospital ethics resources? Based on this reflection and analysis, the authors will make recommendations to enhance the quality of both ethics and MAiD programs.

## **Towards a Better Understanding of Medical Assistance in Dying in Quebec, Canada: The Mandate of the CIRAMM**

*Catherine Perron*

Since 2015, medical assistance in dying (MAiD) has been available in Quebec for people who meet the criteria of the Act respecting end-of-life care. Quebecer's growing use of MAiD places the province in first place worldwide for deaths by MAiD, ahead of all countries where it is practiced. Our team, the Interdisciplinary Research Consortium on Medical Assistance in Dying (CIRAMM), was mandated by the Ministry of Health and Social Services of Quebec to study the factors behind this increase. The factors analyzed are divided into four themes: (1) legislative comparisons, (2) societal factors, (3) personal characteristics, (4) organization of health care and services. The aims are to identify the legal, societal, individual and organizational factors that facilitate or limit the recourse of MAiD. The project comprises four cross-thematic methods (systematic review, semi-structured interviews with key informants, population-based survey and focus groups with healthcare professionals, deployed in six jurisdictions (Belgium, California, Canada, Oregon, Netherlands, Switzerland)). Specific methods will also be used for each theme: (1) realist synthesis and comparative legal analyses, (2) media synthesis and community forum, (3) individual interviews, triadic case studies and file studies, (4) literature review and system mapping. The results should provide a comprehensive understanding of the factors influencing the use of MAiD in Quebec, whether related to practices, laws, societal or personal characteristics, or the organization of care and services. Several knowledge mobilization strategies are deployed to reach different audiences: thematic information kits, briefing notes for decision-makers, policy notes for managers, practice guides for healthcare providers and infographics for the general population. By shedding light on the factors influencing the administration of MAiD, we provide valuable insights to policymakers and healthcare providers. The implications of our results extend beyond Quebec, they offer insights to other jurisdictions either with established MAiD legislation or considering similar measures.

## **VARIOUS TOPICS**

### **Is It Ever Ethical? Non-Disclosure Requests From Family, Healthcare Ethics Consultation (HEC), and Life-Limiting Diagnoses**

*Mahwish Ahmad*

Is it ever ethical to honor a non-disclosure request made by family and not share pertinent diagnostic details with the patient, especially if the patient is capacitated? What if it were an oncologic diagnosis and there were still treatments that could be offered but the family still vehemently objects to patient being told? This is a common source of healthcare ethics consultation (HEC) at our tertiary-care hospital in the United Arab Emirates (U.A.E) and a frequent source of moral distress for clinical teams, both nursing and physician-led. In this presentation, we aim to address the question whether it is ever ethical to honor non-disclosure requests by family members, highlighting the challenges in bringing Western bioethical standards to bear on non-Western contexts. The presenter/s will share an ethics consultation case that evolved at our hospital to stimulate audience discussion, aiming to highlight the conflicting values of patient autonomy and team's commitment towards non-maleficence that these requests evoke. At the razor-sharp edge between the more prevalent Western ethical norms truth-telling and first-person decision-making, and the collective sense of shared familial-decision-making prevalent in this region, the non-disclosure requests regarding end-of-life diagnoses are a true reflection of the society's norms outside of healthcare. After a description of the approach our HEC service has taken in response to these requests, discussion will focus on the associated benefits and risks/harms to all stakeholders, including inter-professional relationships, such as our palli-

ative medicine colleagues. Additionally, the session will review many of the social, cultural, religious and political dimensions underlying these family requests, share lessons learnt during the eight years our HEC has been handling such requests from global patients and offer unique best practices that reflect culturally sensitive medical care delivery for this Middle Eastern region, where these requests are the norm, rather than the exception.

### **The Lived Experience of Families of Children With 22q11 Deletion Syndrome of the Disclosure of the Diagnosis**

*Sophie Ayoub*

**Introduction:** The 22q11 deletion syndrome (22q11DS) is a prevalent genetic microdeletion disorder, presenting a wide range of symptoms that can affect nearly any body system. Identified frequently in childhood, this syndrome requires ongoing, intensive care, most often provided by the affected child's parents or primary caregivers. **Diagnosis,** whether lived positively or negatively, is an important turn point for these families, and can shape their lives significantly. **Aims:** This study investigates the fundamental aspects of the lived experience of families of children with 22q11DS during the diagnosis period. **Methods:** This interview study was a component of a broader mixed-methods research project aimed at enhancing the psychosocial well-being of individuals with 22q11DS and their families. The qualitative segment focused on insights from purposively selected families caring for children with 22q11DS. Semi-structured interviews were transcribed and analyzed using an inductive thematic approach. **Results:** Interviews with 36 families from diverse backgrounds and with children of various ages. The diagnosis was mainly delivered after birth, but a few families received it prenatally. Three major themes were identified regarding the genetic diagnosis: circumstances, reaction, and impact of the disclosure of the diagnosis. **Discussion:** An ethical disclosure requires an informed consent and a good understanding of the implications of genetic results for the future, including privacy considerations and the need to test other family members. The respect of parental and child autonomy is important to support parents' rights to informed decision-making while ensuring they understand implications for their child's health. Balancing between honesty and compassion supports parents in receiving simple information on potential health impact without overwhelming them. Clinical ethics can guide disclosing a 22q11DS diagnosis by emphasizing transparency, compassion, and clarity.

### **From Fading Myths to Conspiracy Theories: Can Ethicists Bridge Ideals of Physician-Servants and Realities of Corporate Medicine?**

*Virginia L. Bartlett*

This paper will identify frictions at the intersection where mythologies of physician roles and responsibilities meet physician realities in corporate healthcare systems and become conspiracy theories that undermine physician responsibility and disrupt sustainable practice. The paper will also explore how Healthcare Ethics Consultants might respond to the concerns that emerge from these myths and theories to open space for understanding and resistance. Part one lays out the historical roots of physician's service role, with its expectations and obligations to patients, and identifies contemporary factors that erode or become barriers to physician practice such that service seems like an idealistic myth. Part two identifies the challenges and distress physicians experience regarding their diminishing sense of profession and care within the role, and the drive to avoid responsibility that not supported, though still expected. This section will explore the trend of viewing the myth of services as conspiracy for manipulation, with and physicians pivoting to corporate medicine (venture capitalist medical groups, contracted hospitalist services) that seems more 'honest.' Part three explores places where healthcare ethics consultants can support sustainable professional practices: identifying the disconnects between such professional myths and conspiracies, and clinicians' embrace of corporate models, introducing alternate myths/sources of meaning and sustenance in practice to counter conspiracy theories about physician manipulation, normalizing recurrent and ongoing elements of these frictions within histories of professional practice. The paper will conclude with invitation to consider spaces and opportunities for discussion and ongoing forms of resistance to conspiracy theories in clinical and educational settings, and in public-facing discussion of healthcare roles and expectations.

### **Ethical Challenges in Aesthetic Medicine: Social Media's Influence in the UK**

*Sut Mo Zachary Chan*

The introduction of social media has transformed the landscape of aesthetic medicine in the UK where platforms

such as Instagram heavily influence public perception on beauty standards and cosmetic procedures. The growing reliance on social media in the field creates both opportunities and ethical challenges for medical professionals. This review aims to identify the ethical issues created with the proliferation of social media use in aesthetic medicine. A comprehensive literature search was conducted using the PubMed database to identify relevant articles on the ethical implications of social media in aesthetic medicine. The search employed the keywords -Ethics- OR -Ethical- AND -Aesthetic- OR -Social media,- covering the period from 2000 to 2024. A total of 223 articles were initially retrieved. After applying inclusion and exclusion criteria, only 220 articles were selected as they were not in English. An independent literature search was also carried out to identify the current regulations on non-surgical cosmetic procedures in the UK. This included a review of relevant governmental, professional body, and healthcare regulatory websites. The literature review identified multiple ethical challenges with the use of social media: risk of harm to patients by usage of language to obscure intentions, unrealistic expectations on beauty standards and aesthetic outcomes, misinformation to patients due to the non-regulation of marketing and lack of formal credential authentication by aesthetic influencers. Whilst the use of social media brings about its own ethical issues, the influence and potential it brings in to strengthen the patient-doctor relationship via connection and education has to be acknowledged. There needs to be regulation and licensing of aesthetic businesses in the UK to prevent the misleading of patients. Establishment of a social media guideline will standardize the information shared on platforms which will reduce misinformation and unrealistic expectations.

### **Resisting Force Through Conditional Thinking**

*Joseph B. Fanning*

Skeptics of clinical ethics consultation claim that the ethicist is merely an institutional rationalizer, a sophisticated mouthpiece for the powerful perspectives focused on the legal, political, financial and personal liabilities of contested care. Indeed, since navigating and negotiating perspectives is central to the work of ethics consultation, clinical ethicists are susceptible to the undue influence of authoritative perspectives [clinicians, patients, surrogates, administrators] whose force can undermine ethically justifiable care. A temptation to resist is to counter force with force, cashed out in strategies like "Tell the team, -Ethics thinks X-" or documenting that -Ethics recommends-. Through four selected case vignettes demonstrating different forms of perspectival power, this presentation argues that we should avoid such strategies. Rather, we should make explicit and endorse conditional thinking as a key to leveraging the authority of and responsibility to shared ethical content over against the sheer pragmatic force of statements made by powerful stakeholders. Recollecting the philosophical distinction between pragmatic force and semantic content, Robert Brandom articulates the important function of conditional thinking: "embedding a declarative descriptive sentence as an unasserted component in a compound asserted sentence strips off the pragmatic force its free-standing, unembedded occurrence would otherwise have had." Conditional thinking might appear to be a mere matter of theoretical precision but it is actually the practical lever that allows ethical content to be the fulcrum that can move power-laden situations toward ethically justified care.

### **Understanding Treatment Over Objection in Non-Psychiatric Facilities: A Review of the Literature**

*Joseph B. Fanning*

More is known about treatment over objection in psychiatric facilities because there is more legal accountability in the United States. But very little is understood about treatment over objection in non-psychiatric facilities involving non-psychiatric treatments. In the experience of the primary presenter who is an ethics consultant, these acts of care elicit considerable moral distress in clinicians and make stark the vulnerabilities of incapacitated patients who can nonetheless resist care verbally and/or physically. Isolated instances of practice guidelines authored by ethics consultants and health care professionals are valuable but a more comprehensive understanding of what is known about treatment over objection is needed. The methodology, results and analysis of selected themes within a systematic literature review of treatment over objection in non-psychiatric acute care hospitals will be presented in this paper. After the inclusion and exclusion process, twenty-four articles were included: twenty one (87.5%) were case studies and three (12.5%) were descriptive studies focused on occurrence frequency. The articles were coded for recurring themes which were analyzed for conceptual relationships. Four core themes were elucidated: 1) Assessing decisional capacity 2) Recognizing patient resistance 3) Evaluating benefit / burden profile and 4) Coordinating decisional support. The complex relationship between assessing decisional capacity and recognizing patient resistance receives significant conceptual attention because intentional resistance can be ascribed in ways that confuse the status of being decisionally incapacitated. Furthermore, the process of evaluating the benefit-burden profile in light of added burdens like mechanical restraints were contingent on the available representatives to make

decisions.

### **Is Spirituality in Medical Education a Step Towards Holistic Care or an Unwanted Avenue for Preaching? A Systematic Review**

*Phoon Jing Faye*

**Background:** Spirituality, or the core values and beliefs that make us human, is the very foundation of personhood. Unsurprisingly, it is influenced by one's upbringing, religion and socio-cultural contexts. Spirituality is similarly central to clinical decision-making, shaping patients' and healthcare providers' priorities, life goals, and perceptions of what makes a good life and death. Therefore, medical education has recently spotlighted spirituality, with some schools and residencies incorporating it into their curriculum. However, ethical concerns in encompassing spirituality into clinical care include: a) the potential of physicians' personal spiritual beliefs compromising patient care and autonomy, b) the need to respect patients' alternative spiritual beliefs and c) how much should physicians' and patients' spiritual beliefs influence clinical decision-making. Recognition of these issues can guide spirituality curricula design for medical students. Hence, a systematic scoping review of the ethics of spirituality education in medical schools is proposed. **Method:** Krishna's systematic evidence-based approach (SEBA) was utilised. Search strings were applied to Pubmed, Embase, ERIC and Scopus databases for relevant articles published on the ethics of spirituality education in medical schools from 1 January 2000 to 10 June 2024. **Results:** Reviewing the included articles identified several key domains: a) ethical arguments for and against teaching spirituality, b) the common stance on teaching spirituality, and c) how spirituality should be taught. **Conclusion:** Our findings accentuate the necessity of educating students on spirituality to counter the purely biomedical model of care and more comprehensively acknowledge the socio-cultural context of patient health. Despite the ethical challenges, it prepares future clinicians to engage with patients' values, beliefs, and existential concerns, which are often pivotal in intricate ethical decision-making scenarios, including end-of-life care, resource allocation, and informed consent. Nevertheless, further critical evaluation is needed to ensure neutrality and respect for the appropriate boundaries between physicians' personal beliefs and professional responsibilities.

### **Normothermic Regional Perfusion in Pediatric Donors: Recommended Guidelines for its Ethical Implementation**

*Alex Gariti*

The scarcity of transplantable organs relative to demand has led to the exploration of novel techniques, such as normothermic regional perfusion (NRP), to enhance organ viability. While NRP offers promise to increase the quality and quantity of transplantable organs, its implementation raises significant ethical concerns regarding the Dead Donor Rule, consent/authorization, and physician participation. These concerns are further magnified in pediatric organ donation given children's increased vulnerability and lack the decision-making authority. While these ethical challenges are widely acknowledged, numerous institutions have begun implementing NRP. This presentation explores the ethical challenges of NRP in pediatric patients and proposes ethical guidelines for institutions considering implementing NRP. Emphasis is placed on informed consent, respecting parental and cultural values, and the role of conscientious objection with the aim of fostering transparency and trust in the organ procurement process. We propose a set of guidelines institutions pursuing NRP should follow to support the ethical implementation of NRP in pediatric patients. We include a checklist institutions can incorporate into their consent process to ensure all families and patients receive the same, ethically important information.

### **Ethical Framework for Offering Fetal Interventions in Fetuses with Concurrent Genetic Diagnosis**

*Rebecca M. Johnson*

Fetal interventions are transitioning from research to clinical care globally. However, there is a lack of ethical guidance for including fetuses with chromosomal abnormalities. The authors analyze the ethical framework for expanding fetal surgery criteria by examining a paradigmatic case offering prenatal repair for fetuses diagnosed with neural tube defect (NTD) and Down Syndrome. We conclude it is ethically permissible to offer prenatal NTD repair in cases with concurrent genetic diagnoses. Utilizing the concept that the fetus can be a patient, research shows prenatal repair for NTD is clinically beneficial to the neonate while balancing the risks acceptable to the fetal and pregnant patient. Examining the balance of beneficence and non-maleficence to the maternal-fetal dyad and future neo-

nate, we conclude that performing prenatal repair should not confer additional risks to the pregnant patient or fetus without a concurrent lethal anomaly. Based on the principle of autonomy, provided the pregnant patient is presented with comprehensive information to make an informed decision, she has the autonomy to decide to undergo prenatal repair if she deems it in the best interest of herself and her fetus. Finally, based on the principle of justice, we find there is no morally compelling justification for excluding fetuses with Down syndrome. Though our ethical analysis is not intended to be limited by geography, restricted access to the full spectrum of reproductive healthcare, including abortion in many states (and approximately 40% of the global population capable of pregnancy), provides an even more compelling argument in support of our conclusion, as laws restrict pregnant patients in these areas from accessing all medically appropriate options. Considering this, the authors argue it is ethically obligatory to offer prenatal repair in fetuses with NTD and Down Syndrome. This ethical framework can be expanded through casuistry analysis to address other concurrent genetic diagnoses.

### **Doing the Right Thing Wherever Our Clients Are: A Scoping Review of Clinical Ethics Support for Community Service Providers**

*Julija Kelecevic*

In Canada, dedicated health care ethicists are mostly employed by large academic hospitals, and will sometimes contract to support smaller community hospitals. Yet the conditions giving rise to ethical issues in hospital do not disappear at discharge. Further, the locus and range of home and community service delivery make the ethical issues inherently different from those encountered in an acute care environment. An example is that the ethics of decisions to live at risk is impacted by heightened socio-economic and geographic disparities, as well as heightened communication challenges based in cultural/religious diversity. There is an opportunity to explore how ethics capacity is built among community agencies, including education, and networks of collaboration among care providers. The purpose of this scoping review is to understand the current literature on ethics support for community and social service agencies. This may include organizations that vary widely in size and focus of operation such as mental health and addictions, acquired brain injury, home care, and assisted living. This scoping review follows a 5-step approach outlined by Arksey and O'Malley, searching 3 databases (Medline, Scopus, and Web of Science). The scoping review will generate key findings, and yield recommendations for health care ethicists and ethics champions looking to implement an appropriate model of community ethics support.

### **The Fallacy of Consensus: Reallocating Power in Ethics Consultation**

*Andy Kondrat*

The push to professionalize the field of clinical ethics has grown rapidly in the United States. Examples include ASBH's HEC-C certification, the ongoing effort to update ASBH's Core Competencies, and the Clinical Ethics Consultation Benchmarking Collaborative. One prevalent argument given for these efforts is that demonstrating some level of homogeneity in the field "insofar as a shared taxonomy of ethical issues and standardized responses to them is possible" is the best means for ensuring quality in clinical ethics practice. The reasoning is that this sort of conformity is in the best interest of those requesting help from ethics consultants because it assures them of a standard of competence that, once met, empowers primary clinical stakeholders to make the best decision given the options. I argue that such standardization, however, leads to the opposite effect: it disempowers stakeholders and cedes that power to the clinical ethics consultant. In forcing stakeholders to adapt to the language and concepts of -professional(ized) ethics,- such standardization turns the power in and of discourse into a tool of those who created the language and concepts- the field and practitioners of clinical ethics. Stakeholders request ethics consultation in language reflective of their own understanding and experience of the concerns they face. Responding to their understanding and experience with taxonomies or principles that turn the request into a standard 'ethics' question that can be answered via professional consensus statements or algorithms thus does little, if anything, to help ethics consultants respond responsively to requesters' actual experience. Instead of leaning into this push for conformity, clinical ethics consultants must cede our power back to stakeholders by abandoning our specialized language and resisting standardized responses. Indeed, this should be a core component "and competency" of clinical ethics consultation if we are to truly be responsible to those requesting our help.



## **A Living Ethics Lab to Tackle Psychological Distress in Complex Chronic and Rare Diseases**

*Eric Racine*

**Background:** Ethical issues are often difficult to discuss openly in clinical settings. We report on a living ethics initiative aimed at facilitating dialogue and management of psychological distress in people living with rare or complex chronic diseases. **Methods:** This study was conducted at a highly specialized interdisciplinary clinic in Montreal (Canada), following a 5-phase living lab methodology: 1) problem identification, 2) problematization, 3) ideation, 4) enactment, and 5) appreciation. Phase 1 took the form of informal pre-project consultation with patients and healthcare providers (HCPs) from this clinic. For phases 2-5, data were collected through semi-structured interviews with patients and HCPs, as well as a brief patient survey (for phase 5). Interview transcripts underwent qualitative content analysis while survey data were analyzed using descriptive statistics. **Results:** Phase 1 led to the identification of the management of psychological distress as a key ethical and clinical issue for patients and HCPs. Phase 2 showed its association with several causes and consequences for both parties. Phase 3 led to identify 17 potential interventions to address patients' psychological distress, of which 4 were prioritized based on relevance and feasibility. Phase 4 involved the co-creation and enactment of these 4 interventions: a pre-consultation form, a repertoire of patient resources, mental health awareness ads, and a webpage. Phase 5 revealed numerous positive outcomes stemming from the project and the interventions, such as: (1) active patient involvement in clinic improvements, (2) better integration of mental health into specialized care, and (3) normalization of mental health discussions. **Discussion and conclusion:** By creating an ethical space where patients and HCPs could reflect on and discuss psychological distress, this living ethics lab initiative deepened the understanding of psychological distress and initiated a paradigm shift in a clinical setting. Participatory research methods hold great promise to make ethics live in clinical environments.

## **Preferences Regarding Location of Death in Children with Static or Progressive Encephalopathy: Bereaved Parents' Perspectives**

*Philippe Sylvestre*

**Background:** Children with static encephalopathy (SE) die more often in the intensive care unit (PICU) than others with complex chronic conditions, notably progressive encephalopathy (PE). Location of death (LOD) is considered essential in assessing the quality of end-of-life care. Bereaved parents' preferences regarding LOD for their children with SE/PE are unknown. **Aims:** To explore the experiences of bereaved parents of children with SE/PE and better understand their preferences regarding LOD. **Methods:** This convergent mixed-methods study used individual semi-structured interviews and a questionnaire with bereaved parents of children with SE/PE, who died 1-6 years prior. A distribution of diagnoses (SE/PE) and LOD (home, PICU, ward, free-standing hospice) was sought through purposive sampling. LOD preferences, planning, and concordance were explored through a qualitative naturalistic inquiry. Likert scales assessed parental end-of-life experiences and preferences. Interviews were transcribed verbatim and analyzed using thematic analysis. **Results:** Between October 2023-June 2024, 21 parents participated (16 mothers). Their children had SE (n=14) or PE (n=7) and died in various LOD. All participants (100%) found it very important to be involved, informed, discuss care objectives, benefit from care coordination. Some participants (15%) reported ability to choose LOD as "Not important/not important at all". Qualitative analysis revealed three main themes: (1) varying preferences regarding LOD, shaped by complex evolving medical needs, family circumstances and available resources, (2) relative unimportance of actual LOD for these parents, compared to other considerations such as quality of end-of-life care, minimal suffering, (3) importance of integrating LOD planning within a broader holistic palliative care approach (clarifying goals of care, navigating uncertainty, providing support/resources), to work towards goal-concordant locations of care throughout the end of life. **Conclusions:** Bereaved parents of children with SE/PE had varying preferences regarding LOD. Supporting these families through a holistic palliative care approach may be more important than planning LOD per se.

## **Ethics Consultation When Culture Collide: Setting Expectations for Clinicians and Patients**

*Jamie Watson*

A concern expressed at previous international clinical ethics conferences is that Western bioethics implies a normative mandate to adapt unequivocally the values, cultures, and approaches of a patient's current medical context to the patient's care regardless of the patient's cultural background. In the US, Canada, the UK, and Europe, this would entail prioritizing individualism, patient autonomy, and medical beneficence, even when caring for patients

who identify with cultures that value different priorities. However, a foundational element of Western bioethics includes facilitating a process that elicits patient preferences and values and ensuring their interests are adequately represented in health care conversations. When patients have social, cultural, or religious backgrounds that are unfamiliar to care teams or that come into conflict with ethical commitments or standards of care as defined in the care team's social and clinical context, the role of the clinical ethics consultant is to assist with amplifying patient values to ensure that they are given appropriate consideration in that patient's care while also helping patients and families appreciate the responsibilities of health care teams that are informed by legal and policy constraints. In this presentation, we explore three cases where a patient's cultural or religious commitments present challenges to Western standards of medical care and the role of clinical ethicists in navigating these challenges. We highlight how we, as Western-trained bioethicists, can invoke aspects of our tradition to help preserve rather than minimize a plurality of values within the constraints of medical feasibility, while acknowledging the constraints imposed by law and policy. We conclude that the ethical dangers to pluralism lie less in an oversimplified conception of Western bioethics and more in lack of training for clinical ethicists in how to facilitate rich discussions of patients' values and preferences.



## Posters (Organized alphabetically by lead presenter.)

### **Baby Steps: Growing Clinical Ethics Services for Pediatrics in a Malaysian Teaching Hospital**

*Muhamad Izwan Ab Manan, Mark Tan Kiak Min*

**Background:** The Clinical Ethics Consultation Service (CECS) was established at Hospital Al-Sultan Abdullah (HASA) in 2020. Since then, it has played a crucial role in addressing ethical issues and dilemmas that healthcare professionals at HASA face in their clinical practice. However, surveillance data revealed that requests for ethics consultations by pediatricians at HASA was significantly low- implying that the CECS at HASA was not being utilized to its full potential. **Objective:** This study aimed to identify the common ethical issues encountered in pediatric practice at HASA in order to provide recommendations on how clinical ethics services could be developed to support it. **Methods:** Key informant interviews (KIIs) were conducted with five pediatricians working at HASA. The interviews conducted via Zoom were recorded for verbatim transcription. Thematic analysis was conducted using NVivo and the transcribed data was broken into manageable and meaningful text segments for coding. Themes were developed based on the repetition of the codes. **Results:** The results were divided into three sections. Section one focused on common ethical issues encountered by the pediatricians. These revolved around issues related to clinical decision-making, surrogate decision-making, refusal of treatment by parents, end-of-life issues, and resource allocation issues. Section two focused on the pediatrician's understanding and experience of clinical ethics which yielded mixed responses while section three explored how to develop a pediatric clinical ethics support. **Discussion:** The results of this study provided meaningful insights into common ethical issues faced by pediatricians at HASA and how clinical ethics can support their daily clinical practice. While recommendations on how to grow the CECS to support pediatrics in HASA focused primarily on organizing awareness and educational programmes, it also included enhancing case consultations through participation during grand rounds, as well as developing ethical guidelines and policies related to pediatric practice.

### **When You Say “Conflict of Interest,” Do You Mean “Corruption?”**

*Gaspard Aebischer*

The concept of ‘conflict of interest’ has had a widely accepted definition in bioethics for several decades: ‘a set of conditions in which professional judgement concerning a primary interest tends to be unduly influenced by a secondary interest.’ The notion of ‘corruption in medicine,’ while covering a wide variety of realities and practices, is also based on a solid theoretical formulation: ‘the abuse of, or complicity in the abuse of, a public or private position, power or authority for the benefit of oneself, a group, an organization or other persons close to oneself, the advantages thus obtained being financial, material or immaterial.’ Despite these two distinct definitions, medical literature frequently uses one term for the other, without the boundary between the two concepts being as clearly established. What this reveals is that certain situations of conflict of interest are indeed corruption. So, what is the point of trying to identify these overlapping situations? Couldn't we be satisfied with the coexistence of the two terms, and deal with the issues on a case-by-case basis? The challenge of making a clear distinction between these two concepts is a major one: a conflict of interest is unique in that it can be properly managed if several conditions are met. Corruption, on the other hand, is a completely different matter. Distinguishing one from the other is therefore essential, not only to prevent the trivialization of certain situations of corruption seen as conflicts of interest inherent in the practice, which should then be managed rather than avoided or proscribed, but also, to limit the dangers of ‘ethical blindness’ inherent in situations of corruption, particularly at institutional level.

### **Navigating Ethical Challenges in Digital Healthcare: Strategies for Responsible Implementation**

*Abeer Al-Maamari*

Digital healthcare has revolutionized patient care and service delivery, but it also introduces critical ethical challenges that demand careful consideration. This abstract explores the primary ethical issues arising from digitalization, including privacy and data security, informed consent, algorithmic bias, accessibility, patient autonomy, and accountability for errors linked to AI technologies. The digitization of health information raises significant concerns about data privacy and security, as breaches can lead to unauthorized access to sensitive patient data. Informed consent remains essential, with patients needing clarity on how their data will be used, especially in the



context of complex AI algorithms. Furthermore, algorithmic bias poses a risk of reinforcing health disparities, as biased datasets can yield inequitable treatment outcomes. Accessibility is another critical issue, digital health tools may inadvertently exclude marginalized populations, exacerbating existing health inequities. The shift to technology-driven healthcare can also challenge patient autonomy, as increased reliance on algorithms may undermine the traditional physician-patient relationship. To navigate these challenges, healthcare organizations (HEC) must implement comprehensive ethical frameworks that prioritize data protection, equitable access, and transparent informed consent processes. Engaging diverse stakeholders, including patients and community advocates, is crucial for developing inclusive digital health strategies. Ongoing education for healthcare professionals about the ethical implications of digital tools is also essential, along with regular assessments to identify and address potential ethical concerns. By proactively addressing these ethical dimensions, HEC can foster a more equitable and trustworthy digital healthcare landscape, ultimately enhancing patient care and ensuring responsible implementation.

## **HEC for Healthcare Buildings: Bioethics Peer Review**

*Diana Anderson*

Among the most important social determinants of health are the physical determinants of health, chief among which is the built environment, the spaces in which we live and work. As our understanding of these effects has increased it has become evident that there are longstanding and novel issues in the design of healthcare facilities. The pandemic illustrated how long-term care (LTC) facility design could dramatically affect residents' survival, residents in open-ward Canadian nursing homes experienced significantly higher mortality rates than those in newer, single room designs, raising questions about risk, disclosure, and equity. Governments, facing increasing pressure to resolve problems with insufficient LTC supply, are turning to high-rise, high-density residential care solutions that, while financially palatable, run counter to evidence-based designs with lower operational costs, portending future COVID-era unpreparedness. At the other end of the cost spectrum, increasing knowledge of how architectural interventions affect people is being employed to control wandering of persons with dementia, lessen exiting attempts, and quell conflict. These approaches raise questions about evaluating dissimilar benefits and harms, freedom, and consent. Beyond basic building codes, there are no regulatory or oversight mechanisms to call upon, any solution would have to include multiple stakeholders with differing views, address complex decisions that involve value considerations. The structure of healthcare ethics consultation has proven to be a powerful method for precisely that, and here we describe our experience performing our first ethics consults for a building, which we term Bioethics Peer Review (BPR). BPR is a learning exercise that creates opportunities for decision-makers to be better and more fully informed about bioethical issues in multiple dimensions of building design and operations. BPR consists of reviewing goals, operational briefs, and design drawings at multiple stages of design completion to identify bioethical challenges. By citing appropriate evidence-based design research and posing questions for decision-makers to consider, we aim to improve the potential health and wellbeing in these facilities. As with HEC, BPR is collaborative and non-binding, reliant on morally compelling, evidence-based arguments to influence decision-makers. This presentation will illustrate the BPR method through one of our existing projects, a 300-bed long-term care facility. It will serve as an example of how the structure and methods of HEC can be applied in novel settings for the benefit of broader populations than HEC has previously served.

## **Ethics Consultation Services and Surgeons: How to Build Trust and Collaboration**

*Megan Applewhite*

Ethics consultations are commonly called from intensivists, nurses, hospitalists, and social workers, but less frequently from surgeons. Among the reasons for this fact, are: the unique trusting relationship that surgeons have with their patients and the resulting great level of responsibility that surgeons feel for their patients' outcomes. The patient-surgeon dyad is initiated at informed consent and is enhanced in the operating room where the surgeon physically intervenes on the disease and in so doing gains understanding of the patients particular pathophysiology beyond what could be gained elsewhere. This allows the surgeon to understand the patients illness on a high level distinct from any other individual, which carries both a powerful bond and tremendous responsibility. This patient-surgeon bond, positions surgeons to frequently feel their ability to navigate postoperative challenges is both most informed, and most patient-centered. Although accurate, this relationship does not eliminate the possibility of ethical uncertainty and potential conflict among caregivers and patient/surrogates. Although a formal ethics consultation can be beneficial, it is not always requested, we argue, because the surgeon does not see the ethics consultant as one who can appreciate the magnitude of surgeons responsibility to and understanding of their patient since that consultant has not lived that relationship. Unfortunately, this situation leads to barriers to patients accessing the

valuable resource of the ethics consultation service. One solution we suggest in overcoming the barriers to surgical patients having access to ethics consultations is to embed surgeon-ethicists on the ethics consult service. Over the past 20 years, we have trained over 135 surgeons in clinical medical ethics who are now at over 50 institutions and contributing in meaningful ways to justify the value of clinical ethics consultation. Intentionally educating and integrating surgeon-ethicists into leadership and consult positions enhances the comfort of those surgeons who may have previously been hesitant to seek support from the ethics service, and serves as a bridge to build trust in the ethics consult team. We believe this is due to understanding the personal experience of the intensity of the surgeon-patient relationship that leads a consulting surgeon to more confidently share the ethical or value-laden challenges that can develop. Even if surgeon-ethicists are not available at every institution, appreciating the elevated level of trust and responsibility that surgeons have to their patients is critical for building bridges between surgical and ethics consultation services.

### **Decluttering the Ethics Closet: The Impact of Electronic Health Record Systems in Clinical Ethics Documentation and Practice**

*Winifred Badaiki*

**Background:** For fifteen years, because of the absence of a centralized hospital information system, the clinical ethics team at Hamilton Health Sciences (HHS) used a mix of electronic and paper methods for documentation. These methods of documentation posed challenges regarding information integrity, data utilization, and database maintenance, among other considerations, raising concerns of quality and transparency. **Aim:** In June 2022, replacing several other documentation platforms, including paper-based documentation, HHS launched EPIC, a new hospital information system. With EPIC, patients, staff, and physicians can share vital health information and track a patient's hospital journey. The HHS ethics team migrated to EPIC by developing processes to ensure a natural documentation flow, standardization and transparency. **Methods:** The ethics team mapped the phases and processes of ethics consultation from start (placing a referral) to finish (discharge) and developed standardized templates, definitions, flowsheets, dropdown functions and free text options for each documentation phase to ensure consistency of ethics notes. We also determined the designations of ethics consultants and the availability and accessibility of consultation notes. **Results:** EPIC was successfully launched with the ethics platform ready to use. Having standard templates built for each consultation phase has resulted in ease of ethics documentation, with our notes being more concise and consistent. Conversations with staff reveal increased visibility of ethics consults, as we are able to capture every stage of the consultation process in EPIC, and teams can follow our process virtually. However, notwithstanding the successful integration into EPIC, we still face challenges, such as difficulty extracting data from EPIC, thus requiring us to track our metrics via other processes. **Conclusion:** The migration to EPIC and the creation of standard processes has transformed our consultation process and documentation. Next steps include utilizing EPIC to collect data on ethics trends, gather end-user feedback, and inform quality improvement work.

### **Show Me the Money: Comparing Industry Payments to Physicians and Advanced Practice Clinicians Across Specialties in the USA**

*Charlotte Baker*

With the inclusion of Advanced Practice Clinicians (APCs) in the Centers for Medicare and Medicaid Services (CMS) Open Payments program in 2021, alongside physicians, a more comprehensive understanding of industry payments across healthcare provider categories has become essential. The Sunshine Act, part of the 2010 Affordable Care Act, requires the disclosure of financial relationships between healthcare providers and industry to enhance transparency and address potential conflicts of interest. This study examines long-term trends in the CMS general payments database, categorizing physicians into surgical, medical, or other specialties and distinguishing between surgical and medical APCs. Our thirteen-year analysis highlights distinct payment patterns and variations among provider types. We compared distributions among surgical, medical, and other physicians, along with surgical and medical APCs. As a snapshot of trends, in 2023, surgical physicians received the highest average payment (\$635.49), followed by other physicians (\$221.95), medical physicians (\$138.40), surgical APCs (\$73.30), and medical APCs (\$41.64). Food and beverage payments were the most common across all providers and made up the greatest value for medical and surgical APCs at 56% and 41% of their total payments respectively. The predominant nature of payments varied among specialties: compensation for speaking at medical education programs dominated for medical and other physicians, constituting 35% and 37% of their total payments in 2023, respectively. Conversely, surgical physicians saw the greatest value from royalties and licenses, accounting for 54% of their total payments. These financial interactions raise ethical and socio-political concerns, particularly around conflicts



of interest and transparency in healthcare. As APCs take on a larger role in patient care, the influence of industry payments on their practice warrants scrutiny to maintain public trust. This study highlights the need for ethics support models and evaluation systems that account for the socio-political dimensions of healthcare, ensuring integrity in both practice and policy.

### **Through the Looking Glass: Where “Emerging Issues” in AI Meet Experience and Insights from Clinical Ethics Consultation**

*Virginia L. Bartlett*

This paper identifies emerging issues of artificial intelligence (AI) bias and discrimination, physician burnout, documentation, privacy, medical errors, increasing distance/disruption of clinician-patient relationship as well-trodden ground in clinical ethics consultation, creating two opportunities for learning by gazing into and out of the looking glass of AI in healthcare. First, clinical ethics consultants can use the attention an AI lens brings to these issues to refocus on how to continually engage them in the clinical and interpersonal encounters where patients and healthcare teams struggle. Integration of AI in healthcare offers a highly reflective “and hence potentially helpful” mirror for ethics consultants to look at and critically engage existing practices, interactions, and systems around these issues. Clinical ethics consultants can ask: What is peculiar or different and how so? How will patients, families and clinicians navigate this new set of tools? Are there elements of clinical ethics practice that need to expand or shift in response to AI use? Second, ethics consultants can re-examine the commitments, concerns, and values that emerge through individual, social, and communal encounters in healthcare systems. This may offer insights for those integrating AI into their healthcare practices or discovering how AI already shapes their healthcare encounters. Interrogating the taken-for-granted elements of integrating new tools like AI, with the skills and approaches developed in ethics consultation, can help AI enthusiasts and skeptics better understand emerging issues in clinical encounters. While bioethicists operating in high-level policy and regulatory domains of integrating (AI) take a macro-level look what the microchips can do, clinical encounters with AI also deserve attention from on-the-ground clinical ethics consultants who can keep a steady gaze on the curious intersection of macro issues in the micro-encounters of patients bodies and care-team interactions.

### **“Not at Home:” Insights From Case Studies on Setting Preferences in Assisted Suicide**

*Solenne Blanc*

As regulations regarding assisted dying evolve globally, requests are often accommodated within healthcare facilities. In Switzerland, only two university hospitals permit the procedure to occur within their facilities. Consequently, individuals pursue assisted suicide at home. In some instances, individuals are sent back to their homes to complete the final act, despite a stated preference for a hospital setting. Such situations raise complex ethical issues around autonomy and respect for personal preferences. However, it has been very little addressed in research and individuals' expressed preferences for the location of assisted suicide remains limited. Little is known about the difficulties individuals face when their request for an assisted suicide occurs in a location that isn't their preferred one. This study addresses this gap by examining case where individuals and their relatives residing at home, expressed a preference for the procedure to take place in a hospital. Aim: To explore individuals' preferences for a hospital setting for assisted suicide, understand this preference and document the challenges they face when this preference is not granted. Method: We conducted 4 in-depth semi-structured interviews with individuals and their relatives, at home. Data was analyzed through the reconstruction of case studies. Results: The four case studies reveal several factors influencing a preference for hospital setting: the emotional and logistical impact on family and relatives, privacy concerns, attachment to one's home, and practical implications after death. These factors were linked to significant difficulties for both family members and the decision-maker and reflect the unique Swiss regulatory context for assisted suicide. Conclusions: These results underscore the importance of setting in the request for assisted suicide. They reveal that undergoing assisted suicide at home can create substantial challenges, prompting some individuals to prefer hospital-based procedures. This study offers valuable insights for further ethical discussions on respecting individuals' preferences in assisted suicide.

## **Prenatal Workshop and Support Group for Parents of Children Who Will Come to the NICU**

*Béatrice Boutillier*

Prospective parents expecting a baby supposed to be sick at birth may experience anxiety, depression and isolation. While NICU support groups exist postnatally and have been demonstrated to have a positive impact, prenatal groups are lacking. This study describes the development of a prenatal education and support group for parents anticipating NICU admission due to prematurity or congenital issues. The workshop's format and themes were crafted through a needs assessment involving 45 parents, highlighting topics like coping with "broken dreams." These findings were used by our parent-partner group to design a presentation with pictures. The study took place in a large academic level 4 hospital. Over ten months, prospective parents were invited to participate if a NICU admission was likely, and perspectives were collected post-workshop and after one week in NICU, where recall was also evaluated. Of the 136 parents (114 pregnant women, 22 partners), 65% and 52% responded to the two surveys, respectively. Fifty-five were hospitalised in the high risk pregnancy unit and, 83 followed up in the fetal anomaly center. The mean age of the mothers was 32 years. The average gestational age at the time of the workshop was 32 weeks. During the post-workshop evaluation, parents rated it 9.6/10. Almost all agreed that the workshop was useful (98%), help to prepare the birth of the child (95%), and that exchanges with other parents were beneficial (92%). All open-ended feedback was positive, such as: 'I think it's an essential workshop for any parent expecting this type of birth. Thank you so much!' After the birth, all parents remembered it and recall topics discussed. Ninety-five percent of parents would recommend it to other parents. Open-ended responses guided improvements to the workshop content. Prenatal workshops offer valuable support to NICU-bound parents, helping them prepare for neonatal hospitalization.

## **South African Researchers' Experiences of Ethical Challenges During COVID-19 and Lessons Learned for Future Pandemics**

*Theresa Burgess*

**Background:** The COVID-19 pandemic placed significant strain on clinical research globally. Despite the availability of international guidelines to facilitate ethical conduct of research during public health emergencies (PHEs), there is limited empirical evidence that is based on the experience of researchers, particularly from the African context. A qualitative descriptive study was conducted to explore South African researchers' perspectives of ethical challenges associated with COVID-19 research and lessons learned for future pandemic preparedness. **Methods:** Twenty-two researchers from academic institutions across South Africa participated in this study. All participants were investigators on COVID-19 protocols that included observational studies, preventative and diagnostic studies, therapeutic clinical trials, vaccine trials, and implementation studies. Semi-structured interviews were conducted using a topic guide. Interviews were conducted on Zoom. A reflexive approach to thematic analysis was used to analyse data using a predominantly inductive approach. **Results:** Three main themes were identified, namely: building trust and mutual respect, maintaining ethical standards and research integrity, and setting priorities for inter-pandemic times. Researchers considered the need to advocate for post-trial access as a critical ethical obligation during PHEs. The importance of dispelling misinformation related to COVID-19 and building trust through engaging with research communities was recognised, but practically limited during the COVID-19 pandemic. Several important priorities for inter-pandemic times were identified, including promoting global equity, building African capacity for research and development, and investing in research ethics committees (RECs) and researchers. **Conclusions:** A key recommendation arising from this research is the importance of developing an inclusive community of practice in research ethics that incorporates both REC members and researchers, and provides opportunities for mentorship and collaborative, cross-disciplinary learning opportunities. Further research should aim to facilitate targeted and effective institutional investment and resources to support research development, to ensure sustainability of RECs, and to assist the growth of African research capacity.

## **Ethical Challenges of Robot-Assisted Vascular Surgery: Insights and Implications for the UK**

*Sut Mo Zachary Chan*

**Background:** Approximately 1 in 10 people in the United Kingdom (UK) have a surgical procedure each year. The introduction of robot-assisted surgery (RAS) has sparked change in the vascular field for both traditional open (vascular) and minimally invasive (endovascular) surgeries. While existing research performed has highlighted the benefits of RAS, its implementation brings about its own ethical challenges that affect multiple parties. **Aims:** This

article aims to explore the ethical issues surrounding RAS implementation in vascular surgery in the UK by drawing insights from the current literature. Methods: A literature search on the PubMed database relating to the employment of robotic technology in vascular or endovascular surgery was conducted. The search period was from 2000 to 2024 inclusive. The keywords ‘robotic’ OR ‘robot-assisted’ AND ‘vascular surgery’ OR ‘endovascular surgery’ OR ‘aortic’ were included in the search. A total of 66 records were identified. Results: The analysis unveils four main ethical issues: variable surgical skills due to the non-standardization of machines used and unregulated training, inequity and disparity in quality of service provided due to limited availability of machines, re-allocation of limited resources and added environmental burden with robot implementation and de-skilling of surgical trainees and complication of accountability from the overreliance on machines. Discussion: The implementation of a standardized training guideline in the vascular surgery curriculum and additionally as a sub-specialty would reduce the risk of de-skilling and variable surgical skills. Manufacture of robots with recyclable materials will help to reduce the environmental burden and eventual mass production of a standardized machine would help to ease the cost. At present, robot-assisted vascular surgery has no place in the UK until these ethical issues are solved.

### **Feeling Strangled: Balancing Best Interests and Public Health in a Breathless and Belligerent Patient**

*Eunice Chua*

Mdm Rani is a 64 year-old Indian lady with complex social history and poor social support. Her medical issues are chronic obstructive pulmonary disease (COPD) of severity GOLD E, hypertension, hyperlipidemia, diabetes, osteoporosis with multiple fractures from recurrent falls, alcohol and drug abuse. She actively smokes and has multiple visits to the Emergency Department, hospital-hopping and discharges against-medical-advice (AMA) mainly for her respiratory problems. At the recent admission, there was a concern of pulmonary tuberculosis (PTB) from the chest X-ray on admission. However, she refused to cooperate with proper sputum sampling and repeatedly requested for discharge after her symptoms of breathlessness had improved. Her capacity for decision-making was assessed by psychiatry, and she was deemed to have impaired capacity due to resolving delirium and underlying cognitive impairment with existing personality disorder. Her behavior in the ward was challenging to manage and she would get extremely agitated with physical restraints. The main ethical dilemma was determining best interests for Mdm Rani, whether an invasive procedure such as bronchoscopy should be done for confirmation of pulmonary tuberculosis. Treatment of PTB for her would also be challenging given her history of poor compliance to medication, she would likely have to be subject to enforced treatment in institutional care in view of public health concerns and to avoid developing drug-resistance. That would likely create significant stress on the care facility given her challenging behavior and aggression when being restrained. In addition, her repeated hospital visits due to her poorly managed COPD creates significant burden on the healthcare system, while her demands for AMA discharges result in sporadic, ineffective and costly care. Finally, there was also the ethical question of whether Mdm Rani was considered a vulnerable adult and needed to be protected from self-neglect.

### **Promoting Positive Childhood Screen Time Usage in the Age of Technology: Ethically Preserving Contemporary Youth Health**

*Zoe Cutillo*

According to the American Academy of Child and Adolescent Psychiatry, on average, children ages 8-12 in the United States spend 4-6 hours a day watching or using screens. This statistic is in significant contrast to the 1 or 2 hour a day screen time limit suggested by the American Academy of Pediatrics. Numerous studies have shown that when children regularly over consume technology, whether via video games, social media, television, etc., the impact on their health can be detrimental both physically and mentally. Typical ailments can include neck/back pain, obesity, depression, irregular sleeping habits, and a poor-self-image. This is not an occurrence limited to American children. Countries worldwide report similar impacts and statistics of youth technology overconsumption. The instinctual solution for many adults encountering children with poor screen time habits is to simply remove devices from their accessibility. While this technique often does rectify the immediate problems associated with device overconsumption, it neglects the main, overarching issue. In this technological age, children must learn to interact with screens responsibly and in ways conducive to their health. As ethicists and care providers, we are obligated to advocate for positive screen time habits. This sentiment can be justified by the principle of autonomy, and further, informed consent. To simply strip children of their technology access is often neglecting the notion that they will, eventually, use a device again, and without a complete understanding of technology’s negative impacts, outcomes may not be positive.

## **Hidden Curriculum in Medical Education: Action Research for the Development of a Participatory Reflective Tool**

*Clara Dallaire*

**Background:** Medical learners are vulnerable to the hidden curriculum (HC) which shapes their values, ethics, and professional skills. Their relational, ethical, and collaborative abilities may be best developed through reflection on their experiences. **Objectives:** The objectives were to 1) develop, test a reflective tool that examines learners' and teachers' experiences with HC in medicine, 2) evaluate this tool. **Methods:** This action research co-created a reflective teaching tool with stakeholders from the faculty of medicine for use with teachers and resident learners. A survey with program directors allowed to landscape initiatives addressing the HC. Iterative tool design with stakeholders then led to the choice of framework, "Comment soutenir la démarche réflexive?" (Charlier, et al., 2020) and format for the tool. Pre and pilot-testing to improve the tool included pre/post surveys evaluating teaching sessions. Faculty-wide implementation and evaluation will include pre/post surveys, 1-month follow-up surveys and semi-directed interviews. Survey data analysis was descriptive. **Results:** The landscape found that 28% of 66 programs did not offer training on HC to teachers or learners. From April to August 2024, three residency programs participated in pre-testing, 22 of 25 participants completed pre/post questionnaires, reporting increases in understanding of the HC (52% pre, 100% post) and mastery of reflective practice (67% pre, 96% post). The proportion of residents and teachers responding "Strongly agree" in their confidence in discussing sensitive topics with peers rose from 12% to 32% and 8% to 45%, pre/post training, respectively. Pilot study with 4 programs is ongoing, implementation and evaluation of the tool are scheduled January to December 2025. **Discussion:** This reflective teaching tool allows stakeholders to critically engage with the HC and to develop their reflective abilities. By constructively addressing power dynamics and hierarchy, this reflective approach not only enhances educational practices but also fosters a supportive, ethical learning environment.

## **Ambivalence While Training Communication of Bad News May Suggest Academic Burnout Among Medical Students**

*Lenin De Janon-Quevedo*

**Background:** Doctor-patient communication enables patients to discuss ethical concerns. To build trust, effective communication requires physicians to manage patients' emotions. Emotions also play a role in learning and can be modulated in simulation-based scenarios. Emotions arisen from interactions with simulated patients (SP) may rise difficulties. Ambivalence in interaction with SP suggests high stress level and academic burnout (AB). Our results showed that 35.6% of participants of a simulation-based workshop (SBW) on communication of bad news (CBN) had ambivalence in the hypothetical management of patients' emotions. **Aims:** 1) To identify signs of AB among student-participants of SBW who showed ambivalence to manage patients' emotions, and 2) to determine whether interactions with SP mobilize personal sensations (emotions & feelings). **Methods:** Fifth-year medical students completed a pre-workshop survey to determine prior knowledge of communication and their perceptions in hypothetical situations of CBN. Responses were deemed as "ambivalent" if participants were "not comfortable/not uncomfortable" (NC/NU) about having to manage patients' emotions. NC/NU respondents were asked to identify with Maslach Burnout Inventory-Student Survey statements without applying score. Participants registered personal sensations after simulation (S1) and debriefing (S2). **Results:** 32 surveys, 68.8% participants had previous knowledge about medical communication, and 41% self-perceived NC/NU (ambivalent) for managing patients' emotions. Among the latter, 73.3% selected the statement "I feel exhausted at the end of a day at medical school," 63.3% self-identified with the statement "I feel emotionally drained by my studies," and 56.7% selected "I think I am a good student." The modal sensation at S1 was "nervousness," and at S2 "satisfaction." **Conclusions:** ambivalent respondents showed signs of AB independently of previous knowledge about CBN. The SBW mobilized sensations among all participants. **Discussion:** A feasible way to detect student overload may be to use emotions in training communication skills, since burnout directly affects learning of clinical ethics.

## **To Disclose or Not to Disclose. What the HEC(k) Between Medical Law and Medical Ethics**

*Marleen Eijkholt*

Medical errors are a tenuous topic. The 1999 report of the Institute of Medicine: To ERR is human, has been a seminal work in the US, discussing the prevalence of errors medicine and some of the controversies surrounding the topic. The report certainly contributed to measures around error disclosure, like apology laws. Currently, I im-

agine that legislation, worldwide, surrounding reporting of errors, or ‘medical incidents’ (MI) must be quite clear and unequivocal, like in the Netherlands. In the Netherlands, in principle, an MI that has or had consequences for the patient or could have led these, must be reported to the patient. Guiding principles here are the interests of patient self-determination and trust in healthcare. However, the simplicity of the legislation and the interests that may underlie this legislation do not always fit with the unruly and complex practice of medicine. Medical errors might still give rise to questions about ethical considerations alongside the legal framework. In the context of clinical ethics, this may also raise further questions about the role of the clinical ethics advisor. In this paper we discuss a case of a dying patient with an assertive proxy. The doctor asks the clinical ethicists whether this MI should be disclosed to the patient, Would the patient like to know this? Clinical ethicists consider the legal and ethical frameworks, and struggle through the legal wording and text of the law, the intent of the law and the ethical considerations surrounding the patient's well-being.

## **Moral Measuring: Thinking or Feeling You Know How to Measure Something**

*Lara Rose Eikamp*

Problem: Measuring constructs in clinical ethics support is difficult because sample sizes tend to be small and this presents a challenge to developing measurement tools with good psychometric properties. However, next to such practical issues, there are also conceptual challenges. As clinical ethics often approaches moral reasoning as a rationalist endeavor, this can clash with other ontological approaches, one of which is a rationalist approach to moral reasoning. Surveys relying on self-report might lean into the rationalist perspective, assuming that participants' moral reasoning is explicit and conscious. Approach to Problem: Would incorporating vignette items and situational tests mitigate some of these issues? Situational tests assume behavioral consistency of participants between test and real life situations with similar characteristics and has been used for testing job suitability. One issue with introducing this into clinical ethics research is fidelity, as one could argue that no test situation can stimulate the encounter of an ethical conflict or dilemma, because it wouldn't not include the same emotional complexity. For activating such emotional complexity, theoretically, the distinction between cognitive and affective empathy might be important. Research suggests that these two kinds of empathy are not the same and have different relations to other constructs, such as emotion regulation - with cognitive empathy being related to improved emotion regulation and affective with less. Implications: Advocating for more attention to the different empathy constructs in understanding measurement challenges in clinical ethics research could lead to a better understanding of how emotions and moral reasoning interact. This might be especially important for understanding differences between subpopulations, especially in vulnerable populations such as autistic participants where the double empathy problem might suggest different ways of exhibiting empathy.

## **Clinical Ethics Consultation on a Continuum: An Examination of a Coaching Approach**

*Margot M. Eves, Joshua S. Crites, Jeffrey Pannekoek, Georgina Morley*

Although ethics consultation services (ECSs) have largely resumed pre-pandemic practices, many changed their model of operation during the COVID-19 pandemic in response to in-person restrictions, social distancing and increased organizational ethics and policy needs. In our Center, some of these changes have endured and raise important questions about quality and expectations of ECS stakeholders. The first is a sustained and still increasing consult volume along with fiscal realities that have deterred hiring additional ethicists to meet these demands. Another practice change has been the addition of a remote ‘coaching’ approach to ethics consultation in some circumstances, it prioritizes provision of specific guidance for healthcare professionals to empower them to resolve ethical issues on their own. ‘Coaching’ departs from both the standards promulgated by ASBH Core Competences and our pre-pandemic practice of meeting with most patients, families, and healthcare professionals during an ethics consultation. ‘Coaching’ is not uniformly supported among our Center’s clinical ethicists and warrants further deliberation of whether there are situations in which it is appropriate and potentially a better use of an ethicist’s time, given the constraints created by the increased consult volume and fiscal constraints. Important concerns include whether 1) a ‘coaching’ approach would adequately support stakeholders, and 2) it would negatively affect bedside support for healthcare professionals, including nurses, and our broader relationship-building efforts across the healthcare system. The ECS might benefit from refining the definitions of responses to more accurately reflect the service provided and categorize responses proportionally to the urgency and complexity of the ethical issue. In this session, the presenter will briefly describe the ‘coaching’ approach, and reflect on the practical benefits, accompanying risks, as well as engage the audience to collectively deliberate whether ‘coaching’ should be recognized along with curbside discussions and consultations in the range of clinical ethics support.



## **Filling the Gap: Does Clinical Ethics Immersion Continue to Serve the Field?**

*Margot M. Eves, Cristie C. Horsburgh, Susan McCammon, Sundus Riaz*

The Clinical Ethics Immersion Program (CLEIP) celebrates its 10th anniversary in 2025. CLEIP combines an innovative four-day learning intensive with a two-or-three-week clinical ethics immersion to offer participants experiential learning and on-the-ground exposure to the activities of the Center for Bioethics, including the high-volume healthcare ethics consultation (HEC) service. This revenue-generating program was established to meet the needs of individuals seeking HEC skill training but for whom graduate degree programs, fellowships, and intensive-only programs were either misaligned with their learning needs or impracticable. CLEIP has positioned itself as a premier program for professionals pursuing expeditious HEC experience for leadership, program building, or teaching purposes, it is not meant to substitute for comprehensive training offered by a fellowship. Specifically, participants are professionals who want to ground their teaching or scholarship in clinical practice, healthcare professionals seeking to expand their HEC skills and consultation experience or, and individuals either early in their career or exploring a career transition looking for a robust introduction to clinical ethics and HEC skills. This program is one of two sources of income for our department, and as our institution tightens internal funding, CLEIP has become increasingly important in sustaining some of our professional development activities. While CLEIP was initially developed to meet specific needs within the clinical ethics training program landscape, recent advancements in the professionalization of clinical ethics in the US prompts the need to reassess whether this program continues to fill a gap, regardless of the financial benefits. In this session, the program director will reflect on CLEIP's historical, current, and potential future contributions to the clinical ethics profession as the field continues to evolve both in the US and internationally. Attendees will be engaged in discussion, collectively grappling with questions about under what conditions (and how) the program should evolve or be discontinued.

## **Lawst in the Silence: When Lack of Legal Clarity Harms Patients**

*Margot M. Eves, Cristie C. Horsburgh, Jeffrey Pannekoek, Georgina Morley*

Law and ethics often converge at a patient's bedside in complex cases, directly affecting outcomes and sometimes creating a unique space of competing ethical and legal responsibilities. Clinical ethicists, in appropriate partnership with hospital lawyers, regularly navigate the ways in which legal and ethical determinants influence patient care. While law and ethics often align to support similar goals and decisions, in some circumstances the law may inhibit pursuit of the ethically optimal course of action, creating a "critical distance" between legally sanctioned and ethically recommended options. This critical distance is especially perplexing when promulgated by silence in the law, rather than an explicit prohibition or authorization. In those cases, the legal position can be driven primarily by risk mitigation rather than a legal analysis of statute that proportionately balances relevant ethical considerations. This is particularly concerning when a specific legal position results in harm to the patient or risks non-clinicians inappropriately infringing on a healthcare professional's clinical judgment, such as determinations about the potential clinical benefit of life-sustaining treatments. In this session, the presenter will explicate the tensions between clinical ethics and silence in the law through two case examples. The first case involved sterilization of a young adult male with developmental disabilities in which the clinical ethicist and hospital attorney disagreed about whether the physician should proceed. In the second case, the divergence in positions between the parties focused on what constituted withholding and withdrawing life-sustaining treatment for a patient for whom ECMO was emergently initiated. The presenter will conclude by discussing how clinical ethicists may navigate legal and ethical tensions in the pursuit of an ethically optimal course of action and engage attendees in considering ways in which ethics consultation may help this process, and how political and cultural tensions may affect these efforts.

## **Ethical Considerations in Research Studies With Transgender and Gender-Diverse Populations**

*Tammy Ann Fecci*

Transgender and gender-diverse (TGD) individuals are a diverse, vulnerable, marginalized population affected by negative healthcare outcomes and health indicators and many health areas remain understudied. With an increasing amount of individuals identifying as part of the TGD spectrum and requesting gender-affirming hormone therapy (GAHT) to obtain their desired gender phenotype, further investigation is needed into the potential long-term health effects of therapeutic treatment. Although self-reported data suggests that 'level of function and quality of life are improved with GAHT,' numerous TGD individuals experience low levels of function, remain vulnerable to concerns regarding their mental health, and their quality of life remains 'below that of cisgender individuals.' As

the full psychological effects of GAHT on brain health remain unknown, future research should consider cognitive domains and function, the physiological risk of gender-affirming hormonal treatment, along with psychopathology rates “development of psychological and behavioral dysfunction, behavioral mood disorders, and psychosis” in mental illness or social disorganization occurring in transgender individuals. Hence, the clinical effectiveness and ‘potential benefits’ of GAHT should ‘be weighed against largely unknown long-term’ treatment profiles of transgender young adult individuals. Further, given the potential of clinical trials to provide insight and inform our understanding into how best to accompany patients, future research studies should function as a form of accompaniment. Hence, this work illuminates the requirement for future studies in the field of transgender healthcare to address (1) the need for more conclusive information regarding the potential long-term effects of GAHT on brain health and (2) the need for accompaniment that follows the individual. Mindful of every individual's entitlement to true human flourishing, future transgender healthcare research studies should center on the dignity and freedom of the human person and serve as a centrifugal force in fostering the ability of every TGD individual to live a good life.

### **The Meaning of Experiences of Communicating About Heredity in Early Genetic Diagnosis of Muscular Dystrophy**

*Arie Fumie*

Although there have been many studies of ELSI in prenatal and preimplantation genetic diagnosis, there are few studies of ELSI in early genetic diagnosis of muscular dystrophy. When I exchanged opinions with medical professionals involved in the early diagnosis of intractable genetic diseases, experts in the humanities and social sciences, and people involved in patient associations, issue such as the difficulty of communicating with people about heredity /genetics when informing genetic test results. However, there were no studies that clarified the difficulties in "communicating (being communicated) about heredity" from both the experience of healthcare professionals who convey information and patients and their families those who receive explanations. Therefore, in order to clarify the meaning of the experience of "communicating about heredity" for healthcare professionals who provide early diagnosis of muscular dystrophy and genetic counseling, and the experience of "being communicated about heredity" for the diagnosed individuals and their families, I conducted an interview survey of healthcare professionals as the first phase of the research. This report summarizes the results of a survey of the meaning of the experience of "communicating about heredity" conducted with four genetic counselors. Five themes were derived from the study: 1) Heredity (genetic disease) is not special, 2) Understanding that it is no one's responsibility, 3) Communicating correct knowledge, 4) Communicating possibilities (future prospects), and 5) Knowing the thoughts and goals of others and not imposing the values of the medical profession. All study participants recognized that parents of children with genetic disorders have a deep sense of responsibility, and therefore they felt it was important to convey that having a gene mutation is not uncommon, that it can happen to anyone, and that having a genetic disease is not the fault of one's parents or family members and that no one can be blamed.

### **Beyond Hierarchies: Rethinking Surrogate Decision-Making with Colorado's Inclusive Approach**

*Kristin Furfari*

Background: Colorado has a unique process for identifying surrogate decision-makers for patients without identified MDPOAs who cannot name a decision-maker. Unlike many US states that use a predetermined hierarchy based on relationship priority reflecting historical definitions of family and marriage, Colorado allows any "interested person" to serve as a surrogate decision-maker. Although potential conflicts may arise in identifying the interested party, ethics consultations at a large Colorado academic medical center reveal patterns of patient and family preferences regarding surrogate decision-makers that may be broadly applicable. Aims: To determine whether the person named as surrogate decision-maker through an interested parties process would be the same if using a traditional hierarchy process, and to examine the interested parties process, focusing on the relationships of individuals considered as surrogates and the documented rationale for their selection. Methods: A review of ethics consultation requests over a three-year period involving cases where a surrogate decision-maker was identified through the ‘interested parties’ process. Documentation from medical charts, ethics notes, and internal ethics tracking will be reviewed to extract details on the surrogate identification process and the selected decision-maker. Results: More than 80% of surrogate decision-makers identified through the interested parties process have a familial relationship outside of marriage. Fewer than 20% are connected by marriage, a figure that includes ex-spouses who are often excluded from formal decision-making hierarchies in many states. Only a small portion of patients have surrogate decision-makers from relationships outside of family or marriage ties. Discussion: The findings from

Colorado's interested parties process suggest that traditional surrogate decision-making hierarchies may overlook key relationships that align more closely with patient preferences, particularly non-marital familial ties. Expanding flexibility in surrogate decision-maker selection could promote patient-centered care by recognizing diverse relational dynamics, challenging assumptions embedded in historical family structures, and informing policies elsewhere.

### **Colorado's Physician Proxy Law: Lessons in Surrogate Decision-Making and Patient Advocacy**

*Kristin Furfari*

**Background:** Colorado's approach to surrogate decision-making for unrepresented patients allows independent physicians to serve as temporary proxies, facilitating timely decisions without delays in guardianship proceedings. Decisions follow the medical best-interest standard since physician-proxies typically lack knowledge of the patients preferences. Interviews with physician-proxies reveal the contextual criteria they apply, highlighting how decisions are made on behalf of others and how implicit bias can influence approaches. **Aims:** Use qualitative methods to identify the criteria physician-proxies apply in their decision-making. Identify situations in which contextual factors may take precedence over best-interest standard. Develop best practice guidelines for surrogate decision-making when preferences are unknown. **Methods:** Structured interviews with physician-proxies explored the criteria they use to make decisions. Thematic coding revealed recurring concepts and patterns, uncovering key themes and sub-themes. **Results:** While less complex medical decisions were generally made using the best-interest standard, more nuanced decisions, particularly those involving end-of-life care, often incorporated patient-specific context derived from identity-related information in the chart. To make these decisions, physician-proxies drew on their past experiences caring for patients with similar backgrounds or social determinants of health. **Discussion:** The findings highlight the importance of diversity training for physicians to minimize the impact of implicit bias on medical decision-making. When physician-proxies draw on their previous experiences with patients seemingly similar to current cases, they may inadvertently project assumptions onto the patient. While it is essential to understand how social determinants of health affect patient needs, relying on generalized assumptions can result in unintended stereotyping, which ultimately undermines the goal of individualized, patient-centered care. Best practice guidelines for situations in which patient preferences are unknown would assist proxies in making ethical decisions and help mitigate implicit biases and stereotyping. A structured approach that balances context and objectivity can improve the decision-making process, ensuring care aligns with individual needs and values, even without explicit directives.

### **Parents Driving Too Much Medical Treatment for Their Child: Responding to the Ethical Challenges**

*Lynn Gillam, Andrew Court*

**Background:** Clinicians working in paediatric settings encounter situations where parents push for medical investigations and treatments (medical and surgical) that the clinician believes are inappropriate, because the child's symptoms do not warrant that type of treatment, or comprehensive investigations have already shown that there is no organic (physical) cause for the symptoms. If parents continue to push for investigations and treatments, and move between doctors and hospitals in pursuit of this, children can end up with interventions such as feeding tubes and ventilation, using a wheelchair, on a variety of medications, all of which can lead to functional and developmental impairment. These situations create conflict between parents and clinicians who resist, and between different clinicians with strongly diverging views about the situation. **Ethical problem:** How to recognise whether the child is being harmed by inappropriate medical treatment, and how to reduce or prevent that harm. Health professionals in our hospital reported that they were often unsure how to proceed in such cases. In particular they were unsure when to act (at what point during the course of investigation and treatment was the potential harm to the child enough to warrant action) and what to do in such situations where the parents presented as caring (rather than intentionally abusive). **Process for responding:** We have created a consultation group consisting of members of the Clinical Ethics Team together with mental health, medical and social work representatives. This group offers consultation to health professionals at our hospital who are holding such cases and value a space to discuss the conflicts and inherent dilemmas. We have developed a framework to aid the assessment of harm to a child in such situations, together with pathways to notification of appropriate cases to Child Protection that attempt to ensure a consistent and therapeutic response.

## **Enhancing Patient Autonomy: An Advance Care Planning/Advance Directives Initiative by a Healthcare Ethics Committee**

*Karen Goset*

Present a case based clinical ethics consult where the physician felt compelled to be complicit in unorthodox (and illegal) parental behavior to benefit the child. It has become increasingly common for parents and physicians to seek treatment information from social media and support groups, particularly for rare or uncommon diseases. This has led some to seek unorthodox or unproven clinical interventions with unknown safety and efficacy. In this case, we discuss parental administration of illegally obtained drug to their child, with the physician offering ongoing safety and efficacy testing without actually prescribing the medication. We will discuss the ethical dimensions of physician complicity to unorthodox behavior for direct benefit to the patient. We also discuss how publication of this behavior could negatively impact future legitimate research on unapproved medications.

## **Aid in Dying Requests: Longitudinal Processes on Diverse Levels**

*Pola Hahlweg*

Aid in dying (AID) is a complex and ethically charged topic with big socio-political impact. Germany, for example, is currently in a situation where AID is legal and largely unregulated, with regulatory clarifications pending. This leads to much uncertainty how AID requests should be cared for. In this contribution, we plan to first describe the complexity of AID processes and then propose a way to structure these processes and clarify corresponding ethical considerations in order to develop a framework and practical guidance. Every AID request is a longitudinal, iterative process that involves multiple people. It happens on the individual and interpersonal level and is influenced by the organizational and socio-political level. Besides the person seeking AID and their physician(s), many others such as relatives, nurses or pharmacists can also be involved in AID processes. Individuals involved experience various cognitive, emotional, and behavioral processes and face diverse decisions at different time points. On the individual and interactional level, AID processes can be described as including the following phases: beginning, assessment, preparation, realization, and aftercare. These phases are not necessarily consecutive and can include multiple feedback loops. In addition, good coordination, person-centered care, and inter- and multidisciplinary teamwork are important throughout. How AID processes evolve on the individual or interactional level strongly depends on institutions', healthcare systems', and society's stance on the matter. Developing a stance, policies, or even legislation on AID are longitudinal, iterative processes itself. We propose mapping the phases of AID requests and make normative specifications for each phase as a tool to structure those higher-level processes. We argue that doing so enables to clarify each step, what it entails ethically and how it should be handled. This also allows to determine who should be involved and when, including clinical ethics. An example of such a process map will be shown at the conference.

## **Navigating Challenges: The Interplay of Identity and Environment in Clinical Ethics Fellowships**

*Maram Hassanein*

A learner's journey is shaped by a multitude of interconnected factors, including the design and content of the educational program, the preceptor's role in mentorship and development, and the overall learning environment, which encompasses available resources and support systems. Additionally, global events, their media representation, and political and organizational responses further impact learners' experiences by shaping the context in which they learn. These external influences can intersect with personal identity factors such as race, ethnicity, gender, and religious affiliations which create a complex interplay that defines each learner's unique journey. In the context of Clinical Ethics Fellowships (CEFs), discussions often focus on competencies and the development of Healthcare Ethics Consultants, with limited attention to the learning environments. This presentation will explore challenges within these environments, with a particular focus on the impact of sociopolitical events on marginalized learners and emphasize the importance of safety and inclusivity in shaping both the environment and learner experience. While substantial research exists on preceptorship, the clinical learning environment, and the experiences of marginalized learners, studies specifically examining these aspects within CEF are lacking. Learners in CEFs often face challenges stemming from both external influences and personal characteristics, such as feelings of isolation, threats to their physical and psychological safety, vulnerability, and constraints on their authenticity and self-expression due to power imbalances. These challenges can lead to reduced motivation and engagement, ultimately hindering professional development. Although not unique to CEFs, these issues are particularly pronounced in

clinical ethics due to factors such as underrepresentation, inequities, and the limited availability of programs designed to support marginalized learners. This underscores the need for further research into learner experiences in CEFs and the development of environments that prioritize safety, inclusivity, and well-being. Such environments are essential for enabling learners to meet professional standards and achieve educational goals.

### **Provider Preferences and Protected Characteristics: Navigating Requests in a Pediatric Setting**

*Maram Hassanein*

Requests for alternate healthcare providers based on the protected personal characteristics of initially assigned providers are well documented in the literature. Historically, a culture of accommodation prevailed, foregrounding the needs of patients and families. However, over the last decade, there has been increased recognition of the harms to staff and risks to institutions associated with this culture. Several policies aimed at protecting staff from discrimination have been published. Now, a more nuanced approach is necessary, as growing awareness of medical racism, the benefits of racial concordance, and the complexities arising from socio-political and military conflicts have made it challenging to discern what constitutes discrimination. In pediatric settings, these requests may be particularly complex, as the emphasis on patient and family-centered care may heighten the pressure to accommodate preferences. This context is further complicated by the fact that requests are often made by substitute decision-makers rather than the patients themselves, which may necessitate escalation to child protective services. This presentation outlines institutional guidance developed by the Department of Bioethics at The Hospital for Sick Children in Toronto, Canada, for assessing whether requests based on the protected characteristics outlined in the Ontario Human Rights Code (1962) and the Canadian Human Rights Act (1985) should (or should not) be accommodated. This approach distinguishes between requests grounded in circumstances that may justify accommodation (e.g., requests based on a history of trauma) and requests that are rooted in prejudiced, racist, derogatory, or unfounded beliefs. The guideline includes considerations of capacity, justice, and equity, and goes beyond racism, sexual trauma, and religion to encompass factors such as racial concordance and socio-political trauma stemming from past and/or current conflicts. Furthermore, it also emphasizes the importance of supervisory and institutional support, along with thorough documentation and ongoing evaluation.

### **An Ethical Dilemma: Blood Product Transfusions in Situations of Physiological Futility**

*Emma Healy*

When is the provision of blood products physiologically futile? The question emerged in the care of a 79-year-old patient with multiple comorbidities who was admitted to the medical intensive care unit for hemorrhagic shock due to intestinal bleeding. After an extensive workup with 3D imaging, endoscopies, and colonoscopies, his primary medical team and subspecialists determined that the bleeding was unrepairable. Across multiple meetings, we informed the patient's family that blood products provided no long-term benefit given the persistent bleeding. We recommended transitioning to comfort measures and discontinuing life-sustaining treatments, such as vasopressors and blood product transfusions. The patient's surrogate decision makers voiced strong distrust of our assessment of futility based on a personal history of racial bias. They continued to advocate for aggressive medical management, which we provided. Over the next two months, the patient received more than two hundred units of blood products. Before he died from shock, he developed severe edema, delirium, and pain, leading to personal suffering, psychological distress among his family, and moral distress among hospital staff. This case raised several ethical questions: Did administration of blood products in this circumstance constitute physiological futility? If so, was the hospital obliged to provide the therapy as requested? How should providers navigate medical distrust, especially when patients have a history of prior discrimination or substandard care influencing their perspective? And how should physicians balance their respect for autonomy and surrogate decision-maker preferences with their obligation to prevent patient harm and promote fair access to scarce resources? Across counties, substantial differences in access to blood products and guidelines for their use exist. Similarly, approaches to the withdrawal of life-sustaining treatments vary based on religious beliefs, social constructs, and cultural values. As we present this case internationally, we hope to explore how such factors impact analysis of this ethical dilemma.



## **From Being Seen to Being Heard and Understood: Addressing Structural Vulnerability in the Hospital Setting**

*Lea Heistruevers*

**Background:** Many high-income countries, including Switzerland, have introduced universal health coverage. But there is evidence that accessing health services varies according to age, health and residence status, socioeconomic or cultural background. These determinants give rise to specific needs that must be addressed so that individuals can participate in shared decision-making processes and in setting goals of care. If these determinants are not addressed in the hospital, they will increase structural vulnerability and impact health outcomes. **Aims:** Social justice and the mitigation of structural vulnerability are relevant to the work of clinical ethics. We describe how the clinical ethics unit of the University Hospital of Zurich took on this task, which was commissioned by the hospital management. **Methods:** Following a Delphi-like approach with open-ended questions, ethics resource leaders of the hospital were guided through a process of achieving consensus on 1) how they would define vulnerability, 2) which patients they would typically consider as vulnerable and 3) what questions they would ask to assess vulnerability. **Results:** Six clusters of patient characteristics recalling structural vulnerability were identified and translated into six categories of "rights," which formed part of the hospital's ethical commitment within the newly founded 'Swiss Hospitals for Equity Network'. Likewise, the project of a 'social board' for patients in particularly precarious emergencies (e.g., undocumented migrants or people on so-called blacklists of health insurers) was also developed. **Discussion:** Clinical ethics services have the unique role of promoting social justice and raising awareness of how to address structural vulnerability in the hospital setting, assisting both administration and health professionals in fulfilling their social and political mandate to achieve universal health coverage.

## **Principled Approach to Comingled Human Remains**

*Rebekah Jacques*

Despite a large body of literature on comingled remains, the ethics of comingled human remains has been glossed over in forensic disciplines and related disciplines. Comingled human remains refers to the mixing of the human remains of two or more individuals that requires scientific study to differentiate. The causes of comingling are numerous and include trauma, human interventions, animal activity, and environmental conditions. The complexity of the forensic investigation and the skills needed for case resolution is directly related to the number of individuals. In addition, body fragmentation contributes to the difficulty since each separate fragment must initially be treated independently until it can be proven to link to another. With forensic investigations, comingling must be resolved to the greatest extent possible since it may impair personal identification of the decedents and prevents the return of remains to next of kin. Even when individual identification is not an issue, accurate sorting of individuals is critical to cultural practices and injury interpretation. Forensic disciplines are well positioned to incorporate a combination of traditional methods (e.g., death scene findings and gross techniques) and cutting-edge methodology (e.g., DNA testing) to resolve comingling. However, DNA exams in accredited laboratories are not fast and performance for the reunification of human remains to a single decedent may delay funeral arrangements. In addition, very small, fragmented remains may need to be entirely consumed for genetic material of good quality and quantity. Despite exhaustive efforts, forensic experts may not be able to sort out comingling. This presentation will use a principle-based approach in sorting a fatal motor vehicle collision dyad that resulted in comingled remains.

## **Innovating to Meet Demand: Various Approaches to Personnel and Service Delivery Models in Ethics Consultation**

*Jane Jankowski*

Providing high quality clinical ethics services in large and expanding healthcare systems is increasingly complex, involving more than just individual patient consultation. In this context, clinical ethics programs must develop operating structures and service delivery models that accommodate broader activities associated with clinical ethics work and do so across a greater geographical reach. A durable model requires balancing continued excellence in clinical ethics consultation against expectations for expansion in presence and activities such as new ethics rounds and hospital-based education that are often unaccompanied by proportional increases in personnel. This session will discuss strategies and lessons learned for sustaining ethics-related services when new locations and activities outpace department resources. Topics include utilizing technology to provide interactive hybrid education at multiple sites and recording for asynchronous viewing, managing expectations regarding how the service will be delivered.

ered by working with healthcare professionals to establish shared expectations regarding response time and accessibility of ethics consultants, and expanding the baseline skillset for non-ethicist healthcare professionals engaging in ancillary ethics work to serve in formal partnership roles. In this presentation, we will review how our orientation towards a comprehensive clinical ethics service has created challenges to keeping pace with demand as our health system has grown to include a broader geographical swath and increased utilization across all hospitals. We will share various ways we have innovated to respond to these challenges, which include a full redesign with focus on ethics knowledge and capacity-building among clinical colleagues and changes to our ethics consultation service. We will conclude with a discussion of enduring challenges before closing with a description of potential future states of scalable service delivery models to accommodate continued growth.

### **Proposed Legislation on Physician Assisted Dying in the UK Compared to the International Standards**

*Aidan Kennedy*

The United Kingdom (UK) currently lacks definitive legislation on physician assisted dying (PAD). This year, the Scottish Parliament introduced the Assisted Dying for Terminally Ill Adults (Scotland) Bill, and the House of Lords (HL) established the Assisted Dying for Terminally Ill Adults Bill, to formally legalise and create enforceable procedures around PAD in Scotland, and England and Wales respectively. To compare the UK proposed PAD bills to current international PAD legislations: Jurisdictions with active legislation permitting PAD as of August 2024 were identified and analysed to yield quantitative and qualitative results. Court decided PAD common law was an exclusion criterion. Legislatures were systematically read and compared under the following headings: consent process, minimum age of eligibility, eligibility criteria to receive PAD, reflection period length. Where minimum ages and/or reflection periods were not stated, the value was said to be 0. Twenty-two jurisdictions were analysed. Seven jurisdictions allowed passive forms of PAD and 15 legalised active forms. The average age of eligibility was 16.00. The average length of reflection period was 14.05 days, 14 jurisdictions allow this to be shortened to an average of 1.64 days. Thematic analysis of the consent process yielded the following topics: format of the request, understanding the procedure, the decision being voluntary. Thematic analysis of the eligibility criteria yielded the following topics: features of illness, considering neurodegenerative diseases, mental illnesses. The Scottish bill similarly sets eligibility at 16 years old, while England requires 18 (as is the case in all other anglo-phone countries). Similarly, both bills require a reflection period of 14 days which could be shortened to 2 days in Scotland and 6 in England. Different forms of suffering were directly mentioned but some form is implied in all international legislation and mirrored in UK bills. Irreversibility of disease is required in all legislations.

### **Cross-Border End-of-Life Decision-Making: Ethical Considerations in Repatriation and Cultural Sensitivity**

*Jamshed Khan*

What happens when a patient facing advanced heart failure wishes to forgo aggressive life-sustaining measures and return to their home country for comfort and family support? This presentation delves into the ethical complexities surrounding end-of-life decision-making through the lens of a compelling case study. The scenario highlights the critical role of Healthcare Ethics Committees (HECs) in navigating the delicate balance between respecting patient autonomy and providing appropriate medical care. By exploring how HECs can advocate for social justice and equity in healthcare, attendees will gain insights into effective communication strategies among multidisciplinary teams, patients, and families, ensuring that cultural values are honored throughout the decision-making process. This session will demonstrate how ethical obligations extend beyond clinical recommendations, illustrating the importance of compassionate care in the face of limited medical options. Presenters will also address the logistical challenges of cross-border healthcare and the vital role of ethics in ensuring equitable access to care. Ultimately this session aims to educate attendees on how HECs can proactively tackle social justice issues in healthcare, empowering patients to make informed choices about their care while maintaining dignity and respect in their final days.

### **Principle-Based Ethical Case Analysis as a Tool for Normative Conflict Resolution in Pediatrics**

*Kathrin Knochel*

Many ethical challenges in pediatric decision-making differ from those encountered in adult medicine. One of the main reasons is the triadic relationship between the child patient, the parents as surrogate decision-makers, and the

healthcare professionals. There is still considerable debate in the literature about the guiding principles about how other parents and professional should decide on behalf of child patients. Within clinical ethics consultation, it is essential to consider the specific conditions of pediatric decision-making, such as the child as a person whose capacity to decide autonomously is still developing and the parent-child relationship, which has an impact on the child's well-being. Our presentation will demonstrate how the four principles of biomedical ethics can be applied to analyze ethical challenges and conflicts within pediatric decision-making in general and, more specifically, within clinical ethics consultation. As a tool for reaching well-justified decisions, we will outline the approach of principle-based case analysis (PBCA) in the pediatric context. We will demonstrate how challenges, such as the child-parent relationship, the parental role as default surrogates, and the emerging autonomy of older children and adolescents, can be addressed by applying the PBCA to concrete case examples. After a medical workup of the case, the approach integrates the principles of beneficence and nonmaleficence to analyze the well-being of the child, then addresses autonomy-based obligations and obligations towards third parties (principle of justice). We will especially show how case-based arguments can support the balancing of conflicting obligations in the synthesis. Finally, we will discuss how such a principle-based analysis of ethical conflicts can be integrated into a more comprehensive framework for pediatric ethical decision-making.

### **What Factors Influence Families' Bereavement After a Death in Paediatric Intensive Care?**

*Anissa Lahfafa*

**Background:** The loss of a child is a tragic event for the families who face it. Pediatric intensive care units (PICU) are among the units with the most intrahospital deaths. The circumstances of death in pediatric intensive care vary greatly and can be sudden or secondary to a chronic illness. It is the responsibility of caregivers to offer a follow-up service to families to accompany and support them in their grieving process. However, there are few standards and practice recommendations on the follow-up to be carried out with families. Each unit follows and try to support families according to their needs. Depending on the circumstances of death or for organizational reasons, some families could benefit from different support after the death of their child within the same care unit. Little data exists on the factors that could influence bereavement follow up. **Study goals:** describe and analyze the practices of follow up for families of children who died in pediatric intensive care within the Sainte Justine University Hospital (Montreal, Canada). The secondary objectives are to understand the interaction between the different services involved in bereavement follow-up after a death in pediatric intensive care, identify the elements which contribute to optimal bereavement follow-up according to caregivers and highlight the barriers and facilitators of bereavement monitoring including variables linked to the child and his family. **Method:** a mixed study with a retrospective analysis over last 10 years practices (2013-2023) and a qualitative research using semi-structured interviews in focus groups with PICU staff and social workers at the Sainte Justine University Hospital. **Results:** the study is in progress, the first results will be presented during the congress (retrospective data and first results of the focus groups).

### **Navigating Difficult Conversations: A Pilot Training for Clinical Ethics Fellows in Palliative Communication Skills**

*Andrea Justine Landi*

Clinical medical ethicists are responsible for eliciting patients' values, mitigating conflict, and facilitating shared decision making, both of which require skills in palliative care (PC) based serious illness communication (SIC). A pilot training series in SIC was developed for medical ethics fellows consisting of high-impact didactics, case-based teaching, R57and role-play. This SIC training provided ethics fellows with exposure to (1) effective use of SIC frameworks and (2) using patient-tested language. **Aim:** Evaluate the impact of a SIC training on the comfort-level of ethics fellows in performing SIC. **Methods:** Fellows received a survey to evaluate their comfort level with key aspects of SIC (measured on a 5-point Likert scale (1=not comfortable at all, 5=very comfortable)). Fellows with PC training were excluded. A paired t-test was conducted to compare the level of comfort in SIC before and after the training ( $p < 0.05$  for significance). **Results:** Of the 13 ethics fellows eligible, 8 completed the survey. Four fellows had prior, but limited, exposure to SIC and PC. All fellows agreed that SIC training is relevant for their work as ethics consultants. The SIC curriculum resulted in significant improvement in the fellows' comfort level with using a SIC framework, utilizing patient-tested hope/worry statements, and exploring a patient's fears and worries using patient-tested language. Most fellows reported that the curriculum provided them with new frameworks (70%) and patient-tested language (80%) in SIC. **Discussion:** SIC training is essential for ethics fellows to develop the skills to be clinical medical ethicists. Our SIC curriculum provided effective training to improve the

comfort of fellows with performing these skills and enhanced their ability to function as medical ethics consultants.

### **Requesting Permission to Consult Palliative Care: Patient-Driven Instead of Patient-Centered**

*Andrea Justine Landi*

A 45-year-old male presents to the surgical oncology clinic for an evaluation for pancreatic cancer. A 30-year-old female is admitted to the cardiac care unit on extracorporeal membrane oxygenation. In these situations, the primary attending recommends a palliative care consultation to the patient or family for guidance in symptom management or serious illness communication, and the patients and families decline the consultation. Worldwide, a low percentage of the population in need of palliative care are receiving it.<sup>1</sup> I will discuss the barriers related to increasing access to and integration of palliative care in routine serious illness care. I will discuss my concerns regarding primary attendings and medical teams deciding they need assistance from their palliative care colleagues, yet patients and families are asked if they would be willing to have a palliative consult and it being declined. There are pervasive misconceptions regarding the role of palliative care among patients, families, surrogates, and medical teams. In this paper, I will defend my recommendation that medical teams ought to request a palliative care consult based on their own medical decision making rather than asking patients and families for permission under the ethical principles of autonomy, informed consent, beneficence, non-maleficence, and justice. Palliative care providers are best equipped to introduce the services of palliative care, build a relationship with patients and families, and perform an assessment of the patients palliative care needs.

### **Balancing Risk: Clinicians' Perceptions and Breast Cancer Screening Recommendation in Quebec**

*Alexandra Larocque*

**Background:** The literature on mammography screening often focuses on specific aspects of screening, offering limited insights into the perspectives of clinicians. The influence of clinicians' risk tolerance on their perceptions of mammography screening in Quebec has not been explored. **Aims:** This study aimed to explore 1. the perceptions of first-line clinicians on mammography-based breast cancer screening and 2. the relationship between clinicians' risk tolerance and their views on breast cancer screening. **Methods:** A descriptive, cross-sectional questionnaire was electronically distributed to family doctors, nurse practitioners, and family medicine residents in Quebec. Recruitment was facilitated through professional organizations, university departments, and regional family medicine agencies. The questionnaire included the validated Aversion to Ambiguity in Medicine (AA-Med) scale, which measures aversion to ambiguity with scores ranging from 0 to 30, where 30 indicates the highest aversion. Data analysis was conducted using SPSS v24, descriptive analyses were performed to report frequencies. **Results:** A total 105 family doctors, 45 nurse practitioners, and 37 residents participated. To discuss screening with a patient, face-to-face meetings were ranked most useful by 69.9% and group meetings ranked last by 48.9%. AA-med scores varied by age but not by profession, with higher scores at career beginnings and ends, and the lowest among those aged 40 to 50 (mean: 18.4, median: 19). Awareness of resources was low, with 24% aware and 13% utilizing them. 73% wanted more training in risk communication and 78% in breast cancer screening, with many finding overdiagnosis challenging. **Conclusion:** The findings reveal a need for more training on breast cancer screening and risk communication. Clinicians' risk tolerance appears to be influenced by their personal and professional experiences with cancer, indicating a need for further research in this area.

### **Going to Court: Exploring the Motivations of Pediatricians in Situations of Treatment Refusal Expressed by Parents**

*Bertrand Lavoie*

**Context:** In pediatric hospitals, parents may refuse the treatment plan developed by clinical teams. In Quebec, Canada, from a legal standpoint, doctors must then go to court to authorize the treatment plan, despite the parents' disagreement. However, the decision to initiate legal proceedings rests with the doctors, who may be reluctant to go to court so as not to impose an additional burden on parents already distraught by their child's condition. **Objective:** To explore pediatrician's motivations for deciding whether or not to go to court in the face of parents' refusal of treatment. **Methods:** This exploratory qualitative study is conducted in Quebec, Canada. Purposive sampling is used to recruit physicians who have experienced significant treatment refusal situations with parents. Recruitment

and interviews will be conducted and transcribed verbatim. An inductive approach will guide the thematic analysis, and independent coding will be carried out by two members of the research team (NVivo). Coding categories will be identified according to the considerations explored in the interviews and derived from the narrative analysis. Expected results: From December 2024 to March 2025, 30 participants will take part in semi-structured interviews (60 minutes). On the basis of previous studies and preliminary results, we anticipate that data analysis will identify important elements in our understanding of personal, organizational and clinical motivations for going to court or not. Conflict resolution based on out-of-court mediation, as well as clarifying expectations for families in the event of going to court, is likely to be a promising way of ensuring the well-being of everyone involved in the case, especially the child. Conclusion: This study will shed valuable light on the reasons why doctors decide whether or not to go to court to impose a treatment plan on a sick child despite the parents' refusal.

### **Value, Bridge Builder, or Obstacle? Clinical Perceptions of Parents' Religion in Complex Pediatric Situations**

*Bertrand Lavoie*

Background: In the context of paediatric care, beliefs can intervene in a complex ethical situation, and in particular be perceived (but not exclusively) as sources of interference with the work of care teams. Few in-depth studies have examined clinicians' perceptions of parents' religious values in difficult and complex clinical situations. The aim of this study is to contribute to a better understanding of clinicians' points of view, and to understand the place of families' beliefs in the ethical challenges of conflict resolution in paediatric healthcare. Objective: Exploring parents' perceptions of religion among pediatric clinicians. Method and analysis: The hospital chosen for the study is located in a large multicultural region, namely Montreal, Canada, which offers tertiary and quaternary healthcare. A total of 26 participants were recruited: 14 nurses and 12 doctors, for whom data saturation was observed. Over an 18-month period in 2021 and 2022, two types of qualitative methods were used: 24 semi-structured 50-minute interviews, and 22 ethnographic 6-hour sessions, for a total of 131 hours. Participants were doctors and nurses in hematology-oncology, neonatology and intensive care. We analyzed the data according to a thematic analysis linked to parents' clinical perception of religion. Results: We identified three recurring patterns related to clinicians' perception of parental religious values, which vary according to the child's state of health. When meeting families for the first time, clinicians tend to perceive religion as a parental value, which they try to understand despite their hesitations. In end-of-life situations, religion becomes an element that facilitates rapprochement between bereaved families and clinicians, whereas when withdrawing life sustaining interventions are discontinued, religion can become an obstacle to maintaining dialogue. Conclusion: This study provides a better understanding of the influence of religion on decision-making in a pediatric hospital, with a view to developing conflict resolution strategies.

### **Parents From a Roma Community Refusing Treatment in Paediatrics, Place of the Principle of Autonomy**

*Fleur Le Bourgeois*

The Roma are one of the most stigmatized social minorities in Europe, with a long and painful history of discrimination, persecution, and deprivation of rights, and they remain marginalized today. For clinicians, providing medically indicated treatment to some Romani children can present ethical challenges when parents refuse such care, citing religious or cultural reasons, for example. We explore the potential ethical implications for patient care through a case study involving a 4-year-old Ukrainian Roma child who was incidentally diagnosed with a genetic disorder during a routine pediatric check-up. The child required invasive testing to identify any treatable complications. Despite multiple meetings with the parents to explain the benefits and risks of the exams, they refused and left the center. The parents' refusal brings ethical concerns. Clinicians must balance principles of beneficence and respect for autonomy. The latter requires respecting the decision-making capacity of the patient or their surrogate, but parents refusal raises questions about whether the parents are acting in the child's best interests. On the other hand, autonomy requires the availability and understanding of information on the basis of which an informed decision can be made, but this leads to the question of how, when and which information is delivered to parents. The Roma community's complex vulnerabilities, including limited healthcare access, cultural misunderstandings, and socioeconomic disparities, make it difficult to establish trusting doctor-patient relationships. However, to overcome this ethical dilemma, it is crucial to foster strong relationships between clinicians and Roma parents to facilitate shared decision-making and mutual understanding, ultimately leading to improved healthcare outcomes. This ethical dilemma was the starting point for an action research project designed to question the Roma community about their healthcare expectations.



## **MD DBe HEC-C Complicit With the Illicit: How Physician Involvement Risks Condoning Unorthodox Parental Behavior**

*David G. Mann*

Present a case based clinical ethics consult where the physician felt compelled to be complicit in unorthodox (and illegal) parental behavior to benefit the child. It has become increasingly common for parents and physicians to seek treatment information from social media and support groups, particularly for rare or uncommon diseases. This has led some to seek unorthodox or unproven clinical interventions with unknown safety and efficacy. In this case, we discuss parental administration of illegally obtained drug to their child, with the physician offering ongoing safety and efficacy testing without actually prescribing the medication. We will discuss the ethical dimensions of physician complicity to unorthodox behavior for direct benefit to the patient. We also discuss how publication of this behavior could negatively impact future legitimate research on unapproved medications.

## **Prognostic Uncertainty and Shared Care Planning: A Case of a Fetus With Severe Renal Hypoplasia and Early Anhydramnios**

*Salvatore Simone Masilla*

**Introduction:** Fetal renal hypoplasia, often associated with oligoanhydramnios, can lead to significant clinical complications, such as pulmonary hypoplasia, severe prematurity, or intrauterine death. The literature indicates that in many cases, pregnancies are terminated in the presence of anhydramnios, oligoanhydramnios, or pPROM without a thorough assessment of the care needs of the unborn child. At the Policlinico "A. Gemelli," a Perinatal Hospice team employs an interdisciplinary approach that lead to Shared Care Planning (SCP). This process was supported by the involvement of clinical ethics consultants. **Aims:** To develop a more comprehensive intervention strategy in situations of prognostic uncertainty, such as early anhydramnios. **Methods:** We present a clinical case involving a fetus with severe renal hypoplasia and early anhydramnios beginning at the 19th week of gestation. The case was evaluated comprehensively by the Perinatal Hospice team, with the support of clinical ethics consultants, leading to the development of a SCP. **Results:** The prognostic uncertainty related to the severe fetal condition combined with the absence of a prenatal genetic diagnosis, prompted the multidisciplinary team to carefully evaluate the proportionality of intensive care measures in the delivery room. At 36 weeks, the ultrasound visualization of a small pocket of amniotic fluid led to the decision to provide intensive respiratory support at birth, with plans to reassess its proportionality after delivery. Upon birth, the newborn received invasive respiratory assistance and demonstrated spontaneous urination. She is currently breathing autonomously and undergoing peritoneal dialysis due to elevated creatinine levels. **Conclusions:** The prognostic uncertainty associated with early oligoanhydramnios and the potential severe pulmonary hypoplasia necessitates a multidisciplinary approach to assess possible outcomes. This process involves an ethical-clinical reflection to evaluate the proportionality of intensive treatments to be offered to the child. The SCP can help to ensure the best interest of both the mother and the baby.

## **Not Just Advisory: Clinical Ethics Committees as the Approving Authority for Innovative Salvage Treatments for Patients**

*Sumytra Menon*

It is desirable to innovate and develop new treatments if it advances the health of humans. Innovative treatments offered and administered to patients in a clinical setting by doctors engages the doctors duty to act in the patients best interests because clinical treatment is primarily to benefit the patients health. In Singapore, the treatment and care of patients by doctors is governed under a paradigm that includes medical negligence and professional misconduct. A doctors departure from the standards in the Singapore Ethical Code and Ethical Guidelines (ECEG) (issued by the Singapore Medical Council), when read with the provisions of the Medical Registration Act, may constitute professional misconduct. The ECEG (2016) states that doctors should treat patients using generally accepted methods, which means time-tested or well-documented methods, or treatments supported by a responsible body of medical opinion, which are logically held. It further adds that doctors may consider innovative therapy for their patients if certain conditions are met. In recent legislative developments, additional governance for such therapies have been provided for by licensing terms and conditions and directives, which have been promulgated under the Healthcare Services Act 2020. In this paper, the author will discuss Singapore's regulatory framework on innovative treatments administered to patients in a clinical setting, focusing on in-house manufactured cell, tissue, gene therapy products used for innovative salvage therapy, and the adjudicative role of the clinical ethics committee

(CEC) in approving such treatments. Challenges regarding the consent process, potential conflicts of interest, and the approvals required to proceed with such therapy will be examined, and the author will reflect on the role of the CEC, and whether the right balance has been struck between protecting patients and giving them a chance of a better outcome.

### **How Clinical Ethics Changed My Outlook and Made Me a Committed Citizen**

*Valérie Mesnage*

As a hospital neurologist specializing in the treatment of Parkinson's disease and related disorders for almost 25 years, I have witnessed the rise of patients' rights and emerging requests for assistance in dying, which although rare, have called into question my professional responsibility. Concerned by these requests and by the end-of-life conditions of people with neurodegenerative diseases, I joined the national center for palliative and end-of-life care with the aim of contributing to a better understanding of end-of-life conditions in France in the light of legislative developments, and to identify their strengths and limitations. But it was in clinical ethics that I found the best way to understand my place in relation to these demands, which pit self-determination against professional integrity. The practice of clinical ethics consultation on a case-by-case basis has thus enabled me to move beyond sterile postures and oppositions, by counterbalancing ethical principles. The teaching of clinical ethics applied to my practice as a neurologist has given me a better understanding of what would be required to support requests for assistance in dying for people with neurological pathologies, who are known to have a special place in countries that allow this. It was against this backdrop that I decided to become a committed citizen within a collective of healthcare professionals, to put forward my positions to both the general public and legislators, while a bill authorizing aid in dying was being examined by the French National Assembly, abruptly interrupted last June just a few days before its final vote.

### **Promoting Inclusion and/or Combating Discrimination in Ethics? Conflicts of Loyalty in Research in Quebec**

*Marie Meudec, Ana Marin*

**Introduction:** This presentation will take the form of a dialogue between two complementary perspectives - insider/outsider - centered on a case study of a project designed to advance ethics in a Quebec health and social services organization. **Case background:** Confronted with ethically troubling practices, such as ageism, the ethics department of the organization recognized the need to address the observed discriminatory practices that conflicted with core professional and organizational values. To deepen their understanding of the situation and devise ethical interventions that could foster positive change, the ethics department partnered with a research team to conduct a study on these issues. **Key issue:** During the research development phase, a critical question emerged: should the project explicitly address discriminatory practices within the organization, or should it aim to promote inclusive practices more generally? From the ethics department's perspective, a focus on inclusion was preferable, as research on discrimination could have unintended repercussions, potentially affecting trust within the organization. However, the research team saw the risk of sugarcoating the discourse, framing the project in terms of inclusion could avoid confronting the reality of discrimination. **Discussion:** This session will involve an interactive discussion between the research team's representative (outsider) and the organization's ethicist (insider), exploring the benefits and drawbacks of emphasizing a more positive, inclusive framing over a critical one focused on discrimination. This dialogue will also highlight the ethical tensions, including conflicts of loyalty, that arise when balancing organizational trust with the imperative to confront uncomfortable truths.

### **Contribution of Forensic Medicine Specialists to Clinical Ethics Consultation and Legal Advice in Iranian Hospitals**

*Vahid Moazzen*

**Context:** Ethical and legal dimensions are integral to clinical practice, where healthcare professionals in Iran frequently encounter moral distress and fear of legal repercussions due to patient complaints. Since the 1990s, hospital ethics committees have aimed to support ethics needs, with 2028 regulations mandating ethics committees at national, regional, and institutional levels. However, many hospitals lack fully developed clinical ethics consultation services, leading forensic medicine specialists (FMSs) to fill these roles, often as fee-for-service providers.

This trend is particularly common in university hospitals, where pioneering FMSs have also trained personnel for the judiciary's forensic system, which assists courts with matters like determining cause of death and conducting toxicology analyses. Problem: FMS involvement in clinical ethics consultations has prompted some regulatory interventions by the Ministry of Health and Medical Education due to their adverse effects on patient-provider relationships. FMSs' roles often transform these interactions from trust-based, ethically grounded relationships to legalistic encounters, especially in obtaining informed consent. Compounding this issue is a linguistic misinterpretation within Iran's healthcare system: 'forensic medicine' is translated as 'Pezeshki Ghanouni' (Legal Medicine), inaccurately suggesting that FMS opinions carry legal authority. This misunderstanding misleads patients and providers, fostering misplaced confidence in the legal protection supposedly offered by FMS consultations. Additionally, FMS-led consultations can obstruct the adoption of structured ethics services provided by trained clinical ethicists, partly due to conflicts of financial and professional interests. Methods: This paper examines the impact of FMS interventions in Iranian hospitals, analyzing how misinterpretations and FMS-led consultations affect clinical ethics and patient trust. Conclusion: The study underscores the need to clarify the roles of forensic medicine and clinical ethics, aligning these roles with international standards. By defining these distinctions, the paper seeks to promote patient rights and strengthen ethical standards within Iranian healthcare.

### **Vulnerability and Vulnerabilization in Healthcare: What Can We Learn From the Coronavirus Pandemic?**

*Settimio Monteverde*

Background: The concept of vulnerability is often used in clinical care and research to refer to the susceptibility and fragility of individuals or populations at increased risk of harm or neglect due to specific characteristics. During the coronavirus pandemic, the term has been widely used by public health authorities, epidemiologists, ethicists and politicians to refer to individuals or groups who may suffer disproportionately from the consequences of coronavirus disease. Problem: During the pandemic, recalling vulnerability was not only intended to highlight the fragility of human existence, it also provided a rationale for policies that aimed at addressing vulnerability through appropriate protective measures. These included prioritizing vaccines or testing options, but also implementing restrictions on freedom of movement and visiting, including visiting bans, such as in hospitals or nursing homes. Many countries are now trying to learn from how they responded to the pandemic and thinking about how to be better prepared for future public health crises. Discussion: From an ethical point of view, this process should also include an analysis of how people and groups were identified as vulnerable and, as a consequence, subjected to policy interventions. Taking the example of nursing home residents in Switzerland, we describe this phenomenon as "vulnerabilization," understood as the unilateral attribution of vulnerability in order to reduce perceived risks. One significant issue with vulnerabilization is that it reduces vulnerability to a personal attribute, obscuring contextual aspects that contribute to or exacerbate individual susceptibility. On this basis we first discuss vulnerabilization as a field of tension between externally ascribed and self-acknowledged vulnerability. Second, we argue that clinical ethicists have a moral duty to address vulnerabilization within public health policy interventions by promoting a participatory understanding of vulnerability based on both the attribution of vulnerability and the self-acknowledgment of those at risk of being harmed.

### **Euthanasia in Colombia: Expanding Legal Boundaries and the Role of Clinical Ethics Consultation**

*Julieta Moreno-Molina*

Assisted dying has been a widely discussed topic worldwide, reflecting deep socio-political, ethical, and moral positions. In Colombia, the legal framework and debate on euthanasia have evolved significantly over 30 years, with a decade of regulation within the healthcare system. However, it was only in 2021 that euthanasia became an option for individuals without proximity to death. Developing new challenges for medical doctors and interdisciplinary committees. Unlike other countries, Colombia's process includes an interdisciplinary committee as a second evaluator, verifying the medical assessments of the patient's eligibility. Additionally, the current regulation does not exclude mental illness, expanding the ethical and clinical considerations in such cases. This situation poses new challenges for healthcare professionals, who must confirm the clinical condition qualifying a patient for euthanasia and articulate this concept with the patient's perception of suffering. There is no uniform criterion or definition for a 'severe and incurable disease,' making it a concept built on the technical expertise of each medical specialty but not confined to disciplinary boundaries. When reviewed by the verifying committee, divergent perspectives on quality of life, well-being, and reasonableness can impact the guarantee of patient autonomy. Clinical ethics may have consultation has a vital role in this context, offering insights into the quality of life, non-maleficence, and proportionality. In Colombia, ethical consultants support healthcare teams handling euthanasia

requests by aiding in constructing the ‘extreme health condition’ concept, a key criterion for access to euthanasia. This contribution goes beyond theoretical bioethical debates already addressed and regulated by the Ministry of Health and Constitutional Court rulings. Instead, it provides practical guidance, ensuring decisions align with ethical principles and respect for patient autonomy while navigating evolving medical and legal frameworks. This highlights the importance of consistent ethical oversight to address the complexities introduced by broader eligibility criteria.

## **Transnational Reproductive Medicine and the Role of Clinical Bioethics: The Case of Colombia**

*Julieta Moreno-Molina*

Assisted reproductive technologies (ART) have enabled the formation of diverse family structures, challenging family and civil law, but also prompted epistemic debates on the boundaries between treating a disease, addressing a condition, or fulfilling a need. These debates occur within a framework that understands health beyond the mere absence of illness, emphasizing medicine’s role in validating the ethical use of these technologies. The global proliferation of ART intersects with issues of access, technological availability, and the moral and social validation of health tourism in Latin America, creating unique challenges. In Colombia, the legal and policy framework includes laws on infertility, reproductive tissue donation, and court rulings on the feasibility of uterine surrogacy. Notably, surrogacy is permitted without excluding foreigners, and efforts are made to encourage professional self-regulation through ethical commitments and laboratory accreditation standards. However, transnational mobility for ART services has drawn criticism due to the socioeconomic profile of users who often pay substantial sums, fostering an industry accessible primarily to those with significant financial resources. A bioethical concern is that vulnerable individuals in countries with flexible regulations may be exploited, especially concerning financial compensation and rights protection. Foreign clients frequently seek services in lower and middle-income countries with inadequate oversight systems, raising questions about the reproductive autonomy of women and reinforcing fears that ART may devolve into a commercial enterprise rather than ensuring the right to procreate under equitable conditions. Clinical ethics consultation offers a pathway to evaluate and address the ethical dimensions of ART and transnational health tourism. By fostering respect for the motivations and rationales of those seeking ART, ethical consultants can mediate between individual desires and broader societal concerns. Their role includes ensuring informed decision-making, protecting vulnerable parties, and advocating for equitable access to reproductive technologies within ethically sound frameworks.

## **Exploring the Potential of Moral Community and Moral Dialogues at Bwaila Family Health Unit in Lilongwe, Malawi**

*Tiwonge Kumwenda Mtande*

**Introduction:** Moral distress among nurses often arises from challenging work environments. However, a study conducted in the United States suggests that fostering moral community and engaging in moral dialogues can empower nurses, helping them build resilience. A moral community is understood as a group united by a shared commitment to a specific moral philosophy, grounded in the idea that individuals are both personally and professionally connected, interdependent, and mutually supportive. Whether moral community and moral dialogues could similarly support nurses and midwives in Malawi remains unclear, especially given the country's 63% vacancy rate in nursing positions and persistent challenges with material shortages, essential supplies, and other resource constraints. **Methodology:** Promoting moral community and dialogues in maternal and child care units may improve nurses' well-being and support quality care during deliveries. Our proposed project, currently unfunded, will employ participatory action research across three phases. First, we will conduct interviews with nurses and midwives at Bwaila Family Health Unit (FHU) to explore how they manage distressing situations in the maternity ward. Bwaila FHU is strategically chosen, as it serves approximately 14,000 pregnant women annually, with an HIV prevalence rate of about 10%. In the second phase, we will organize and guide nurses and midwives in moral dialogues, facilitating ethics discussions around the challenges identified in phase one. Finally, we will monitor these dialogues using the MORALDIAL framework, which is designed to train and evaluate moral dialogue systems effectively. **Conclusion:** We hypothesize that fostering a moral community and engaging in moral dialogues will help reduce moral distress among nurses in Malawi. If effective and well-received, these dialogues could be incorporated into routine nursing practice.

## **Paging Externist: Utilizing Clinical Ethicists in Patient-Engaged Care Planning to Improve Clinical Outcomes Post-Discharge**

*Allison Smith Newsome*

**Introduction:** Though hospital systems and clinical ethicists may have unique goals, one to mend current, often urgent, issues and the latter to slow the action of care to consider the larger and long-term implications of proposed treatments, they align in their mission to serve the patient. In tune with the hum of the hospital, clinical ethicists are routinely called upon in critical moments of a patient's care to offer consultation. These consult requests originate with clinicians and involve clinical ethicists as a late-stage aid. The healthcare industry has seen that including patient voices and treating the whole person improves care outcomes. I propose engaging clinical ethicists as facilitators of collaborative care planning with patients to increase their likelihood of adherence to their post-operative and post-discharge care thereby improving patient health outcomes. **Problem:** Patients may not feel comfortable sharing hurdles or concerns regarding their care plan with their clinicians and instead may fail to adhere to their follow-up treatment plan once out of their physician's sights. For instance, a physician may prescribe an oral supplement that must be taken every two hours. They are familiar with this medication and know that it is appropriate but do not mention other alternatives that are equally viable for the patient. If the patient was asked about their lifestyle and any tensions with the medication regimen, they would have shared that as a factory floor worker they may not have personal items on them nor take frequent breaks and worry they will miss a few of the scheduled pill times regularly. **Solution:** How to thoughtfully address an issue in a fast-paced environment? Be proactive. Clinical ethicists are well-situated to create guides and questionnaires to prompt clinicians' discussions with patients regarding the best care options for their full recovery. **Workshop Proposal:** Participants will have the opportunity to propose scenarios where this current gap may be addressed by a clinical ethicists' joint-care planning model, consulting patients. They will then be tasked with drafting one to three questions that could go on a guide for clinicians to discuss care options with their patients. The applicant will moderate the discussion and activity. **Conclusion:** Clinical ethicists can serve patients before the situation becomes critical and serve the care team more broadly than when disputes or acute ethical dilemmas arise. Clinical ethicists may be utilized to promote holistic healing and the consideration of external, lifestyle factors in the development of collaborative patient care-plan questionnaires and discussions for improved health outcomes.

## **Bioethics and Bioterrorism: Past, Present, and Future**

*Ioannis Nikolakakis*

The development and use of biological weapons (bioweapons) have long been a global security concern. Historically, bioweapons were linked to major powers, but smaller nations have also demonstrated the capacity to develop destructive bioweapons programs. Poland in the 1930s and South Africa later exemplify how countries with limited resources could engage in bioweapons research. These programs are significantly cheaper than nuclear alternatives, earning bioweapons the moniker of the poor man's weapon of mass destruction. Bioweapons also pose risks in civil wars and terrorist activities, particularly in regions with low budgets and technological limitations. While these weapons have potential utility, their use remains sporadic and often unsuccessful in such contexts. Furthermore, bioweapons programs have impacted medical science by advancing vaccines and treatments for diseases like anthrax, although at an ethical cost, such as during Japan's unethical experiments in World War II. Advances in technology, including AI and CRISPR-Cas9, have heightened concerns about bioterrorism. CRISPR is now accessible to individuals with minimal resources, raising fears of engineered pathogens being weaponized. Despite global treaties like the Biological Weapons Convention, regulation remains weak, necessitating stronger controls and transparency. To protect global security, the international community must prioritize ethical considerations and reinforce bioweapon regulation in the face of advancing biotechnologies.

## **To Perfuse, or Not to Perfuse, That is the Question: Community and Healthcare Professional Input on the Topic of Normothermic Regional Perfusion**

*Jeffrey Pannekoek*

Normothermic Regional Perfusion (NRP) continues to be a topic of controversy in bioethics and clinical communities. NRP is the process of reperfusing donor organs after the patient is declared dead by circulatory criteria with the aim of optimizing donor organs and increasing the number of available organs. While some healthcare systems and Organ Procurement Organizations (OPOs) in the United States have embraced this approach to organ procure-



ment, others have rejected the practice out of concerns for violating U.S. laws and ethical imperatives regarding death and donation, specifically the Uniform Determination of Death Act and the Dead Donor Rule, as well as damaging public trust in healthcare and organ donation. When our institution's Transplant Center requested an ethics evaluation of NRP, we wanted to ensure that our ethical recommendations were attentive to the evolving science and integrated community stakeholders' perspectives. Our Center for Bioethics organized a task group consisting of clinical ethicists, healthcare professionals, and community members to clarify and review the NRP process and provide ethical analysis of risks and benefits, clarify the legal permissibility, account for potential community questions and concerns, and produce a set of recommendations for our institution prior to implementing NRP. This presentation reports on the process for organizing our task group, including clarifying the procedure and the role of stakeholder input through meetings with kidney, liver, heart, and lung transplant surgeons, our local OPO, and neuro intensivists, among others. We argue that the variation in responses to NRP is best explained by reasonable yet irreconcilable differences in interpretation of the available information, including how we conceive of the limits of life and death. This pluralism is reflected in our process of developing our recommendations around this ethically complex and divisive technique for organ procurement.

### **Ethics on Record: A Study of Clinical Documentation Practices in EHRs**

*Chelsey Patten*

**Background:** Clinical ethics consultations (CEC) are essential in navigating complex patient-provider interactions marked by competing interests, moral tensions, and values disputes. Practices surrounding the documentation of these consultations vary widely internationally, influenced by institutional policies, cultural factors, and legal standards. Recent mandates, such as the 21st Century Cures Act in the United States, underscore a growing global trend toward transparency in healthcare records. Yet, practical approaches to documenting ethical recommendations remain inconsistent, impacting patient access and interdisciplinary communication. This mandate raises critical questions regarding the role and purpose of ethics documentation within Electronic Health Records (EHRs). Unlike traditional clinical documentation, which primarily records diagnostic and treatment information, ethics consultations address nuanced issues that can profoundly impact patient care, team communication, and legal transparency. Some healthcare professionals advocate for including ethics documentation as part of a comprehensive legal record, while others view its role as primarily supportive of internal consultation and decision-making. **Aims:** This study explores current practices for documenting clinical ethics recommendations in EHRs, examining the frequency and rationale behind choices such as including, excluding, or restricting access to certain information. By capturing perspectives from a geographically diverse array of healthcare systems, the study aims to identify documentation practices that balance ethical transparency with the unique needs of patients, healthcare teams, and institutional policies. **Methods:** A survey has been distributed to members of clinical ethics-related list serves and other ethics-affiliated networks, capturing geographically diverse data from ethics professionals on institutional demographics, consultant training, and credentials, documentation practices, patient accessibility, and factors influencing documentation choices. This comparative analysis will inform best practices for documenting ethics consultations in EHRs that respect ethical standards while meeting the diverse needs of all stakeholders involved in patient care.

### **Midwifery Ethics – More Diverse as Supposed to Be. Do We Need a Broader Approach?**

*Wiebke Paulsen*

**Introduction:** The field of obstetrics and support for women during pregnancy and childbirth has increasingly become a socio-political topic in recent years: Violence during childbirth, lack of autonomy, and existing underprovision jeopardize the support of pregnant, birthing and postpartum women. In Germany, midwifery training was academized in 2020 being one of the last European countries. For this change in education to achieve the desired effect, it is essential to address moral uncertainties, plurality, and potential value conflicts in the support of women in the diverse phases of birth giving. While clinical ethics in reproductive medicine and neonatology has been followed for decades, the role of midwives in obstetrics still receive little attention although many ethical challenges arise e.g. in the accompaniment of pregnant women facing potential prenatal diagnostic cascades as well as women in labor. Also it is midwives who accompany women during the stillbirth of her deceased child after a feticide, a task with many ethical dimensions. **Aims:** This project aims to widen the scope of ethical challenges encountered by aspiring midwives, their growing challenges and competences as well as their professional identity. **Methods:** Within the first 3rd year cohort of midwifery students at a large university hospital, insights from the perspective of aspiring midwives are being collected as qualitative data from group tasks using Mentimeter and written meth-

ods. Results: The ethical topics and aspects raised by the students are far more diverse (role of midwives, women's autonomy versus midwives' responsibility, professional identity) than those that have previously been in the focus of research, which mainly emphasizes women's autonomy. Discussions: These insights can lay the foundation for future ethical training, broadening the focus to include socio-political aspects like professional identity, personal ethics, structural challenges in obstetrics, and issues such as equality, gender identity, and intercultural awareness in midwives' practice.

### **Clinical Ethics Committee's Deliberation on a Complex Cystic Fibrosis: the Issue of Pregnancy**

*Renzo Pegoraro*

Background: Cystic fibrosis is a chronic, life-limiting genetic disorder that significantly affects the respiratory and digestive systems. The progression of the disease, alongside advancements in treatment modalities, raises multiple ethical and clinical challenges, including early genetic diagnosis, reproductive choices, access to emerging but expensive therapies, and end-of-life care. Advances in medical treatments have increased life expectancy and the potential for patients to consider reproductive options, but these developments come with ethical concerns related to genetic counseling, assisted reproductive technologies, and prenatal diagnosis. The impact of cystic fibrosis on parenting capacity and the long-term health of the female patient also requires careful evaluation. Aim: To present and discuss the case of a female patient with cystic fibrosis at the Bambino Gesù Children's Hospital in Rome (Italy), focusing on the ethical complexities involved in the reproductive decision-making process. Method: The clinical case was initially addressed by the Clinical Ethics Service and later by the Clinical Ethics Committee of the same hospital. The committee's discussion focused on several ethical principles, including respect for patient autonomy, beneficence, non-maleficence, and justice. The patient's mental capacity to make informed decisions was assessed, considering the potential influence of psychological distress and disease progression. Results and discussion: The case highlights issues surrounding informed consent, reproductive autonomy, and the role of healthcare providers in supporting patient-centered decision-making while considering potential risks to both the patient and the child. This case underscores the necessity of interdisciplinary collaboration, to guide complex reproductive choices in cystic fibrosis management as well as the critical role of the Clinical Ethics Committee in addressing the reproductive challenges faced the woman and the couple. This case highlights also the need for ethically sound clinical guidelines that respect patient autonomy, support informed decision-making, and consider societal implications in the reproductive health management of cystic fibrosis patients.

### **Preventing Financial Toxicity in Healthcare: Organizational & Ethical Obligations**

*Ausubel R. Pichardo*

Americans spend an estimated 3.9 trillion dollars on healthcare, with 90% of such expenses going to mental and chronic diseases like cancer. The exorbitant increasing costs of cancer treatment result in financial and psychological burdens on patients, families, and providers. This situation is called financial toxicity and resurfaces ethical dilemmas regarding the social obligations healthcare systems might have to prevent these harms. My methods include: Literature reviews. Participating in institutional policy-making committees. Exploring charity models designed to prevent financial burdens. Serving as an oncology patient navigator. Findings show that financial toxicity challenges healthcare centers in meeting institutional and patient expectations. Some providers see themselves as stewards of public resources, advocates, and financial counselors, even though that is not part of medical school curricula. Patients want to talk to their physicians about financial toxicity, but these conversations are avoided due to a lack of training and experience on the topic. Financial toxicity burdens healthcare systems and prevents patients from accessing healthcare opportunities, a human right. Policies, assessments, and new educational models are desperately needed in order to curb the increasing financial burdens.

### **The Case of Organ Donation After Euthanasia**

*Jadranka Buturovic Ponikvar*

Although limited to countries where euthanasia is legalized, organ donation after euthanasia is becoming a hot issue in the transplant community. Proponents argue that the practice brings beneficence by increasing the donor pool and by providing an ultimate meaning to the death of a euthanized donor. Opponents fear a slippery slope towards euthanizing people because of their potential as donors rather than alleviate suffering. They argue this

practice might reduce trust in organ transplantation and in euthanasia itself, thereby harming future patients (both candidates for euthanasia as transplant recipients). We argue that while efficiency and trust are important practical arguments, the mere possibility of organ donation after euthanasia, creates ethical concerns in how euthanasia may be justified. Consider a (vulnerable!) patient with mental illness who has intolerable mental suffering. As with a patient with cancer, reduction of suffering may be a justification for euthanasia in this case. However, the existence of an option to use organs from this patient crosses an ethical line if it changes the underlying motivations of euthanasia. First, according to Kant, it induces instrumentalization of this person for purposes that go beyond their benefit. Moreover, if the euthanasia procedure needs to be altered to optimize organ quality, the original intent of the patient of a 'serene death' is impeded for reasons that benefit only the organ recipient. This medicalization might also cause moral distress in the health care team. Second, patients might feel obliged to donate if refusing to do so makes them feel bad about themselves by refusing a good life to another person. The existence of the possibility to donate after euthanasia might thus obstruct autonomy of the patient as well as of health care workers. Last, there is a reduction and de-humanisation of a 'person in need' to a 'store of replacement organs.'

### **My Patient Was Dying, And I Did Not Tell Her: Exceptions to Truth-Telling in Pediatric Critical Care**

*Rebecca Propper*

A teenager was admitted to the pediatric intensive care unit after an intentional iron ingestion. She was neurological intact and conversant. She was able to vocalize her intention--to hurt herself, even though now she regretted taking the iron. Despite maximum medical intervention, she went into multiorgan failure. And despite escalating blood pressure support needs, she was calm and talkative. Her family, a Spanish-speaking one, was not present at the bedside and ongoing attempts were employed to help them return. Within hours she developed pulmonary hemorrhage and required intubation. She was calmly and clearly speaking up until that point. With almost certainty, based on her iron levels and clinical course, she would die. Prior to intubation, my words of comfort felt dishonest. Even the most sympathetic offerings I provided were powerless to revert her underlying pathophysiology. She died several hours later. I never told her she would die. The ethical imperative for truth-telling underwent a seismic shift during the 20th century. It moved from paternalism to a stronger focus on autonomous decision making of the patient. With that, the practice of nondisclosure was appropriately challenged and re-evaluated. Honesty and truth-telling are now seen as fundamental underpinning of the doctor-patient relationship. As Myers argues in 'Deception and the Clinical Ethicist,' honesty 'is the best policy without a doubt, but not an absolute one,' as he extends this argument to ethics consults. In this paper, I will defend my decision to withhold disclosure of death to this child under the ethical principle of non-maleficence.

### **Ethical, Legal and Social Issues in Diagnosis and Prevention of Childhood Melanoma**

*Costanza Raimondi*

**Introduction:** Childhood melanoma (CHM), though an exceptionally rare, presents a pressing need for early diagnosis and prevention strategies. Traditional screening methods present ethical concerns around potential overdiagnosis and healthcare accessibility. Recently, artificial intelligence (AI) technologies have been proposed to enhance early detection. However, the application of AI in this field could introduce further ethical, legal, and social issues (ELSI), particularly in privacy and data security, diagnostic accuracy, and equitable access. **Objective:** To merge insights into ELSI arising from CHM prevention and early diagnosis policies, with a focus on AI-driven tools. **Three questions are addressed:** the implications related to CHM prevention and diagnosis, to in (ultra) rare disease management, and the impact of AI applications in dermatology. **Methods:** A critical interpretive review (CIR) method was used to examine the existing literature on ELSI regarding the three focuses identified prevention and diagnosis of CHM and (ultra) rare diseases, AI-driven tools for prevention and diagnosis in dermatology. Once the review was completed, results were presented to patients, families and patient advocates during a workshop, and to a panel of experts through a Focus Group. **Results:** 26 articles were reviewed by three researchers. Merging CIR with the main workshop and focus group conclusions, ethical issues, such as diagnostic inequality, socioeconomic disparities, and risks of overdiagnosis, were identified. Overdiagnosis burdens healthcare systems and imposes emotional and financial stress on patients. AI applications in dermatology seems to introduce unique challenges, including biased training data, privacy concerns, and issues around data security, patient consent and patient literacy. Furthermore, AI-driven tools risk exacerbating diagnostic inaccuracies, particularly for underrepresented populations, and raise legal concerns over accountability in cases of diagnostic errors. **Conclusions:** This review highlights the ethical, legal, and social complexities of CHM prevention and diagnosis, especially with the integration of AI in dermatology. Addressing these issues requires patient-centered, ethically grounded policies.

The review fits into the larger goal of developing an ELSI framework for assessing innovative health technologies for prevention and diagnosis of melanoma in CAYA within the European-funded project MELCAYA.

### **Disability, Uncertainty and Quality of Life: Does Culture and Religion Matter?**

*Kumudhini Rajasegaran*

Singapore is a multi-cultural and multi-religious society. It also has a diverse expatriate community. Ethical dilemmas often surface purportedly due to cultural and religious differences between patients and healthcare providers. Three neonatal ethical dilemmas illustrate that other factors may be responsible. A child with central hypoventilation was born to physicians who requested withdrawal of treatment. They profess no religious affiliation and made their decision based on quality of life for their child and family. However, distressed healthcare professionals considered the Chinese cultural aspiration of having a 'perfect' child as a major factor in their decision. Another child with Pfeiffer's syndrome was born to Dutch parents working in Singapore. Although they consider themselves as Christian, they requested withdrawal of treatment based on the burden of therapy with an uncertain outcome for their child. Since euthanasia is legal in the Netherlands, healthcare professionals thought this to be a cultural difference that played a part in their decision. The third case involved a severely premature baby born to low-income foreign workers from a regional country. Parents requested for withdrawal due to financial and care issues, which will exist even if the child returns to parents' country of origin, as parents stay in a rural area. Although healthcare professionals do not want to consider financial issues to be a barrier to care, the harsh reality is that it is a major difficulty, particularly for foreign patients who do not have access to subsidised care here or adequate care back home. Although it may appear on the surface, that these ethical dilemmas arose out of cultural and religious differences, there are in fact other factors at play that transcend culture or religion. Acknowledging these factors would go a long way in understanding the choices parents have to consider and help reduce conflicts and moral distress.

### **Empathy Beyond Belief: Navigating Spirituality in Palliative Care Education With Sensitivity and Self-Reflection**

*Nithiya Ravindran*

Background and aims: Palliative medicine prides itself on its holistic care, aiming to alleviate physical, emotional and spiritual suffering. Spirituality has often been overlooked or conflated with religion. Whilst physicians should not impose their personal beliefs onto patients, it was found that lacking sensitivity to patients' spiritual beliefs resulted in suboptimal patient care. This is contributed by the dearth of education in this area. In order to guide the design of an educational programme to enhance sensitivity to patients' spiritual needs as they wrestle with issues of life, death and meaning, a systematic scoping review of existing literature on the role of spirituality on palliative medicine education is proposed. We aim to put forth recommendations on how best to toe the fine line of exploring patients' spiritual beliefs without being biased by one's own values and beliefs. Methods: Krishna's systematic evidence based approach (SEBA) was utilised in this systematic scoping review. Pubmed, Embase, ERIC and Scopus databases were reviewed for relevant articles published on the role of spirituality in palliative medicine education from 1 January 2000 to 10 June 2024. Results: 125 articles were identified through the SEBA approach. Key domains included: 1) the role of spirituality in palliative medicine, 2) why spirituality should be taught in palliative medicine education, 3) current educational programs for spirituality, 4) impact of educational programs for spirituality and 5) critique of teaching spirituality in palliative medicine education highlighting ethical issues, barriers and facilitators. Conclusion: Incorporating spirituality into the palliative medicine education, is pertinent for cultivating well-rounded physicians. Having self-reflective skills are as necessary as having awareness of the role of spirituality in palliative medicine education to recognise when one's own views start to compromise patient autonomy and clinical decision-making. To do this, it is proposed that a multi-modal longitudinal programme is required with a reflective component such as through the use of portfolios.

### **Innovation in Collaborative Clinical Ethics Consultation**

*Rosamond Rhodes*

Dramatic changes transformed life in the last century. People moved from close families in rural towns to far-flung locations in cities. Simultaneously, medical technologies developed rapidly. These radical changes led to the creation of healthcare ethics consults (HECs), from single experts providing services by actively communicating with

patients or families and meeting immediate staff needs for bioethics guidance. Our 1,200 bed metropolitan hospital is located at the crossroads of a highly educated wealthy population, a middle-class population, and an impoverished minority population including immigrants from around the world and undocumented individuals. Our clinical staff is supported by robust programs in palliative care, liaison psychiatry, and patient representation that respond to disputes and straightforward queries that HECs typically address. Within the institution, however, teams call our HEC service to help resolve the most complex, unusual, and intransigent issues, situations that involve wrenching moral uncertainty and benefit from a plurality of perspectives. As challenges and case volume increased, we identified circumstances that pointed our service in a novel direction. We recognized needs: (1) to respond rapidly to urgent cases, (2) to broaden our perspective on cases with patients from our diverse community, and (3) to provide ethics education for clinical staff. We tackled these issues concurrently. Since the COVID-19 pandemic, we moved from live meetings to HECs via tele-conferencing. This allows participants from across campus to gather on short notice. We broadened our perspective by broadening our membership, adding assorted medical professionals, UME and GME trainees, and community members who enrich our appreciation of patient circumstances and inform strategies with their particular experience. Given curriculum time-pressure in medical education, clinicians receive cursory ethics education. We re-designed our HEC service to meet needs for guidance while addressing educational deficits. This presentation describes how our unique HEC conducts our activities.

### **Increasing Outpatient Life-Sustaining Treatment Discussion and Documentation in a Veterans' Administration Outpatient Clinic**

*Miriam Robin*

**Background:** Life-sustaining treatment (LST) decisions are crucial for patients with serious life-limiting illnesses, often requiring surrogate decision-makers near the end of life. Despite the Veteran Affairs Life-Sustaining Treatment Decisions Initiative (LSTDI) introduced in 2018, which implemented an electronic medical record (EMR) order set for documenting patient preferences, LST documentation remains low among veterans. This study aimed to evaluate LST documentation by internal medicine residents in one Veterans' Affairs (VA) clinic. **Methods:** A quality improvement project was conducted in the APACT clinic at the Carl T. Hayden VA Hospital, Phoenix. Internal medicine residents were surveyed about their experience and comfort with LST discussions and documentation. An educational curriculum was developed using VA LSTDI resources, including lectures, video simulations, and written reflections. Data was collected through surveys and clinical informatics. **Results:** In 2021, only one LST note was completed in the VA APACT clinic. Baseline data showed that 55% of residents had not documented an LST note, primarily due to a busy clinic schedule. Additionally, 36.4% of residents felt somewhat comfortable or neutral about conducting LST discussions, with barriers including fear of patient reactions and uncertainty about the appropriateness of such discussions. Residents with lower comfort levels were mostly first-year residents. After implementing the educational curriculum, 66.7% of residents reported having or scheduling an LST discussion with at least one continuity clinic patient, and 91.7% indicated they were more likely to have these discussions in the future. **Conclusion:** The introduction of an educational curriculum on LSTs led to a significant increase in the frequency of LST discussions and documentation among internal medicine residents in the APACT clinic. LST education is an important component of postgraduate medical training, facilitating better end-of-life care decision-making for veterans.

### **Digitally Driven Proceduralization of Medicine: How Clinical Ethics Can Preserve the Role of Intuition**

*Eugenia Fiammetta Rossetti*

**Background:** The digital transformation of medicine favors the increasing use of procedural algorithms that are designed to streamline and expedite patient care but may become barriers to meaningful human interaction. Practitioners may become so absorbed in applying scales, procedures, checklists, and standard operating procedures (SOP) that they do not look beyond these and genuinely connect with the person. The utility of such procedural algorithms seems to be largely tied to the framework of evidence-based medicine, as they supposedly promote accurate and consistent diagnoses across patients though this assumption is open to debate. The ethical concern arises from the depersonalizing effect these procedures can have on both patients and professionals. Indeed, such tasks could easily be realized by computers and artificial intelligence. **Structure and arguments:** I will begin by sharing examples from clinical experience where the rigid application of procedural algorithms proved inappropriate. I will then advocate for the role of intuition in clinical practice, as discussed by Neil Levy in Neuroethics. I suggest that procedural algorithms, intended to guide consultations, can sometimes obstruct a genuine connection with the patient, ultimately reducing the quality of care. It is therefore essential to balance adherence to protocols



with intuitive, empathetic engagement. The procedures described should only be applied when they are clearly beneficial and necessary. Finally, I will reflect on how clinical ethicists could help professionals establish a wiser use of these procedures via training, guidelines, and consultation. Clinical ethics case deliberation is itself an activity that is resistant to proceduralization and can thus form a counter-paradigm. Ethics rounds might provide a space to critically assess the utility of procedures in the kinds of clinical scenarios discussed. Conclusion: This theoretical contribution argues that clinical ethics can help critically correct an inappropriate, digitally driven proceduralization of health care in a sustainable way.

## **How Can a Health Care Organization Improve Patient Care While Remaining Sustainable and Effective?**

*Rossana Ruggiero, Francesco Saverio Spiezia*

An organization endures, is credible and sustainable when it maintains, consolidates and develops both the intangible and tangible conditions that attribute credibility and legitimacy and enable it to pursue institutional purposes. Specifically, establishing valuable relationships brings back to the dimension of the organization's global action, which is fundamental to the effective pursuit of the institutional mission. In the more recent socio-political context, challenges related to economic sustainability and social justice are redefining healthcare: Healthcare Ethics Consulting (HEC) is a crucial element in addressing these challenges, promoting patient-centered care that simultaneously respects ethical and financial constraints. By integrating HECs as expert consultancies on par with other clinical disciplines, healthcare organizations can improve the quality of care without compromising economic sustainability. The role of HECs, at the intersection of ethics and sustainability, makes it possible to address issues of great moral complexity, such as justice in resource allocation and management of social inequalities. This approach not only ensures respect for patients' rights, but also improves the effectiveness of clinical decisions by avoiding unnecessary treatments and interventions that would unnecessarily burden the health care system. In addition, HECs make an essential contribution in promoting an integrated sustainability model by fostering ethical practices that reduce waste, improve efficiency, and optimize available resources. A special focus is placed on equitable access to health technologies, where HECs can prevent inequalities and new forms of vulnerability resulting from inadequate or exclusive use of these tools. The authors aim to highlight how the integration of HECs, a structural part of clinical decision making, enables healthcare organizations to achieve a balance between excellence of care and economic sustainability. HECs, not only strengthen medical action at the patient's bedside, but also help define a new paradigm of accountable and sustainable health care, in line with current socio-political challenges.

## **Ethical Dilemmas in Phase 1 Clinical Cancer Trials**

*Annina Seiler*

**Background:** Phase 1 clinical cancer trials (P1CCT) have demonstrated promising outcomes, including tumor reduction, temporary growth cessation, or complete disappearance. Additionally, P1CCTs provide early access to novel therapies, potentially bridging the gap until new treatments are commercially available. However, ethical concerns arise regarding the limited utilization of patients' right to try experimental drugs in contrast to issues like distributive justice, disparities in health literacy, implicit bias, and inadequate informed consent. Previous interventions to improve informed consent process have shown limited success, suggesting that factors such as existential distress, the meaning of hope at the end of life, therapeutic misconception, or unmet palliative care needs may influence decision-making. **Aims:** This study seeks to understand patients' motivations, understanding, and experiences in P1CCT in the era of precision medicine and how physicians balance benefits of early access to innovative treatments against the ethical challenges associated with these trials. **Methods:** A sequential mixed-methods approach will involve 30 participants in P1CCTs and their referring physicians. Participants will complete an online survey assessing mental health, quality of life, dignity, hope, loneliness, death anxiety, and spiritual distress. Semi-structured interviews will be conducted with a subset of respondents to explore their understanding of P1CCTs and the meaning of hope associated with participation in these trials. **Significance:** Terminally-ill individuals entering P1CCTs often have complex palliative care needs as they confront difficult treatment decisions in the context of disease progression and mortality. Understanding the factors influencing their participation, such as existential and spiritual distress, therapeutic misconception, and hope, is essential for improving patient care. These factors can affect patients' understanding of their prognosis and their quality of life, or achieve a goal-concordant death. This study aims to enhance P1CCT reporting, deepen understanding of the trials' impact on participants and physicians, and identify support strategies for those involved.

## **Is it Possible to Resolve and Prevent Conflicts? The Key Role of Clinical Ethics in Decision-Making at the Patient's Bedside**

*Francesco Saverio Spiezia, Rossana Ruggiero*

An ethical reasoning leading to the effective resolution of conflicts emerging in clinical practice can be carried out according to the method of American principlism, appropriately declined in the criteria of Jonsen, Siegler and Winslade. Using these criteria, the authors explore four paediatric clinical cases in order to arrive at an ethical judgement on the decisions to be made in the best interests of patients, who cannot decide for themselves. The most important challenge concerns the dialogue between clinical ethics and law, with particular reference to the decisive role of medical ethics as a *trait d'union* for recognising and operating, in the concrete case, the correct balance between the four analysis criteria. Moreover, the personalistic approach redefines life's concept and human dignity, placing each patient, a unique and unrepeatable human being, at the center of ethical reasoning. Health ethics consultation (hereafter HEC) confirms a key role in medical practice and a mediation tool in resolving emerging conflicts between the medical team and the family. The authors also underline how the HEC can ensure that the treatments undertaken are oriented towards the patient's good, avoiding the use of futile treatments that only result in a painful and precarious prolongation of life, relocating the criterion of quality of life, considering the clinical indications and contextual aspects. The authors assume how HEC can fulfil a preventive function in the emergence of conflicts, both as a guideline for medical ethics and as an effective support in identifying and resolving ethical dilemmas that often seem unsolvable. The focus of reflection remains the care relationship based on clear and fair communication between the team, patients and family members. This authentic relationship concerns ethical issues on a daily basis and is oriented toward achieving a shared plan of care and the global good of the patient.

## **Lessons From the Holocaust: Patient Advocacy in Nursing Education**

*Kelly Spriggs*

Nurses play an essential role in healthcare ethics consultations (HECs), as they are often the first to identify ethical dilemmas while acting as patient advocates. Integrating history into nursing curricula, specifically in the context of World War II, is an educational activity that enables nurses to better respond to socio-political challenges as they transition to practice. The atrocities of the Holocaust carried out by nurses exemplify the consequences of failing to advocate for vulnerable populations. Reflecting on historical experiences highlights the ethical responsibility of nurses to advocate for human rights and the equitable treatment of all individuals. Narratives of victims offer profound insight into suffering and resilience. Firsthand accounts of Jewish and German physicians and nurses grant insight into the moral predicaments faced by healthcare providers. Integrating Holocaust education into nursing education promotes ethical responsibility and nurtures empathy, compassion, and a commitment to social justice. By exploring these ethical dilemmas, nursing students are better prepared to navigate the complex socio-political challenges they will face as advocates in their practice. January 27, 2025, will mark the 80th anniversary of the liberation of Auschwitz. Moving into the future, implementing Holocaust history plays a necessary role in the pedagogy of nursing. Educators have an immense opportunity to assist students in developing advocacy through critical analysis and reflection of historical events. Educational activities surrounding socio-political issues encourage nurses and HECs to coordinate care and address systemic inequalities. With a more profound sense of advocacy, the next generation of registered nurses will be better prepared to collaborate with HECs to provide comprehensive, patient-centered care.

## **The Ethical Dilemmas of Slow and Show Codes in Healthcare**

*Eva Šteina*

**Objectives:** Most patients in hospitals in Latvia who have deterioration of the vital signs, stop of the breathing and cardiovascular collapse, get a resuscitation called Blue Code with following CPR. We discuss the following research questions: do all patients need such an escalation of treatment or the reason for treatment choice is a lack of DNR orders? What are the knowledge and attitudes of young doctors and residents in anesthesia and intensive care speciality towards Slow Code/Show Code calls? **Methods:** Anonymous questionnaire for anesthesia and intensive care residents and young doctors was developed. The pilot study was conducted between 09.12.2023 and 31.01.2024. **Results:** Anonymous questionnaire was completed by 16 participants of the pilot study. Nine respondents answered that in their hospital they observed or participated in Slow Code. Eleven respondents answered that

they do not support Slow Code/ Show Code, but 5 responded that Slow Code/ Show Code is an acceptable way of CPR in case of poor or no prognosis of survival of the patient. 14 respondents from 15 stated that Slow Code/ Show Code practice would change if it would be routine to discuss the aim of therapy and potential futility of CPR, and 12 described a Slow Code CPR as unethical. The participants also provided open responses to the questions.

### **Training Healthcare Navigators With Expertise in Variations of Sex Characteristics (VSC)**

*Jürg Streuli, Eva De Clerq*

In many countries, children are not legally entitled to give valid consent for medical decisions, so parents usually act as surrogate decision-makers, acting in their best interests. However, there is a growing emphasis in medical guidelines on involving children in decisions about their own health. This trend toward inclusion was sparked by the United Nations Convention on the Rights of the Child (1989) which recognizes children as social agents rather than passive recipients of adult protection. The debate on child involvement and consent to treatment has been particularly prominent in the health care management of intersex persons or individuals born with variations in sex characteristics (VSC). Regardless of the focus on patient involvement and individualization of care, medical practices in VSC continue to be parent- rather than patient-centered. This may explain why despite growing skepticism about early surgical interventions, there is no general moratorium on sex assignment surgery. Indeed, the 2006 Consensus Statement on the Management of Intersex Disorders did not rule out cosmetic surgery on the basis that it could reduce parental distress and improve bonding. Research shows that parents find it often difficult defer surgery because they fear that it might impede their children from leading a 'normal' life. At the same time, studies highlight that intersex people who have experienced nonconsensual surgery during childhood may develop mistrust in medical providers and delay emergency and preventive healthcare visits. Healthcare professionals find it often challenging to navigate between the (future) child's and parental needs. The present presentation aims to present the shared optimum approach (SOA), a combination of best interests and shared decision-making, as a method to tackle decision-making dilemmas with parents and affected individuals over time. SOA is a process that focuses on family values and clinical facts while using a clearly and transparently defined threshold of harm.

### **Quo Vadis? Reforming Practices on Determining Mental Capacity and Identifying Surrogate Decision-Makers in Malaysia**

*Mark Tan Kiak Min*

The dilemmas and uncertainties related to determining mental capacity and surrogate decision-making are universally recognised as one of the most important concepts in the field of clinical ethics. In Malaysia, healthcare practitioners often find both determining decision-making capacity of patients, and identifying surrogate decision makers for incapacitated patients confusing. This presentation reviews current legal provisions and guidance available in Malaysia that are related to these issues, such as the Power of Attorney Act 1949 (revised 1990), Mental Health Act 2001, and various guidelines, and discusses their insufficiency in addressing these issues. It then highlights three situations where unique challenges are encountered in the local clinical setting due to social injustices or discrimination. These situations involve (a) incapacitated patients who have legally recognised polygamous relationships, (b) incapacitated patients involved in a relationship that lack legal recognition such as overseas-registered marriages, civil partnerships and same-sex relationships, and (c) incapacitated patients who are estranged from their families, including migrants. This presentation will argue for the need of clearer guidance in determining mental capacity and identifying surrogate decision-makers to ensure equity and fairness. It will also discuss the role of clinical ethics committees in these issues to safeguard both the clinical practice of healthcare professionals and the rights of patients. It recommends the establishment of a regulatory framework with four main domains- (a) clear and objective criteria for mental capacity assessment, (b) provisions for advance decision-making while patients still possess mental capacity, (c) a ladder or hierarchy of surrogate decision- makers, and (d) provisions for appropriate surrogate decision-making standards, as well as the need for advocacy and awareness education amongst both the general Malaysian public and Malaysian healthcare professionals.

## **Surrogate Decision-Making and Ethical Dilemmas in Palliative Care: Balancing Patient Autonomy in Muslim-Majority Settings**

*Mona Tareen*

Ethical dilemmas frequently arise in palliative care, leading to conflict between patients' families, healthcare providers (HCPs), and surrogate decision-makers (SDMs). Evidence suggests that in Muslim populations, surrogate decision-making is often inadequately addressed, resulting in uncertainty, even in cases where patients retain decisional capacity. This presentation will explore the role of palliative care (PC) healthcare providers, with a focus on surrogacy and patient autonomy. The presenter will review a retrospective analysis of 50 patient charts, examining how decision-making in the United Arab Emirates (UAE) differs from that in Western societies at an academic tertiary center in the UAE. Particular emphasis will be placed on oncopalliative care, delirium, and the ethical dilemmas surrounding decision-making. Outcomes will be discussed regarding the impact of palliative care consultations and the ultimate alignment with patient and surrogate wishes. The study will highlight how family preferences and goals of care were addressed by considering the family as a whole unit in the decision-making process. The discussion will focus on the ethical principles of non-maleficence and patient autonomy, examining their intersection within palliative care. Special attention will be given to the role of palliative care consultations in addressing these ethical challenges in patients with advanced cancer in a predominantly Muslim country.

## **Patient Welfare I Palliative Care: Integrating Medical, Moral, and Spiritual Dimensions**

*Elena Toader*

Palliative care is a medical field focused on alleviating the symptoms and suffering of patients with serious or terminal illnesses, aiming to improve their quality of life. This care approach addresses the patient holistically, considering not only the physical aspects of suffering but also the emotional, psychological, and spiritual dimensions. According to bioethicist Edmund Pellegrino, the concept of patient welfare can be understood on four distinct levels, essential for effective palliative care. Medical well-being, related to the patient's physical condition, emphasizes effective pain management and symptom control, ensuring comfort within the limits of the illness. The perceived good of the patient, by focusing on what the patient personally considers beneficial, aligns palliative care with the patient's preferences, such as avoiding invasive treatments or spending more time with loved ones. Moral good aims to fulfill the ethical and moral responsibilities of the doctor toward the patient, offering care that aligns with the patient's values and respects their dignity and autonomy. Spiritual well-being, addressing the patient's need to find meaning and peace amidst suffering, involves spiritual support in palliative care, allowing the patient to explore and express beliefs that provide emotional comfort and inner peace. By integrating these four levels of welfare, palliative care offers a holistic, patient-centered approach that seeks not only to prolong life but also to improve its quality.

## **Evidence-Based on End-of-Life Decision-Making in China for Severe Brain Injury**

*Yifan Yan*

**Background:** The debate about life-sustaining treatment (LST) to maintain the prolonged survival of patients with severe brain injury in conditions of unconsciousness has arisen in China in recent years. Ambiguous medical information, cultural differences, and the lack of policies make surrogate decision-making about these issues seldom discussed in detail. **Aims:** To investigate the public's attitudes towards limiting LST for severe brain injury patients and the influencing factors, the application of medical knowledge and the clinical challenges by neurologists, and the perception and mood of family caregivers towards the patient's condition. **Methods:** Three distinct questionnaires were distributed to the public, neurologists, and primary family caregivers of patients, respectively. **Results:** We have presented these results in our published paper: less than one-third of the public agreed to limit LST for disorders of consciousness (DoC) patients in the 1123 questionnaire collected. And only 63% of neurologists correctly diagnosed the vignette case they received, with more experienced neurologists demonstrating higher diagnostic accuracy ( $P < 0.05$ ). Over 44% of family caregivers misunderstood the patient's condition, showing poor consistency with clinical diagnoses ( $\text{Kappa} = 0.217$ ,  $P = 0.002$ ), and held positive attitudes towards future recovery. During the long-term care process, over 60% of family caregivers exhibited varying degrees of depression ( $r = -0.265$ ,  $P = 0.007$ ) and anxiety symptoms ( $r = -0.273$ ,  $P = 0.006$ ), which were negatively correlated with their quality of life. **Discussion:** Most Chinese people are reluctant to limit LST for DoC patients, which may indicate a need to allocate more resources to long-term care within health policies, given the cultural differences with western countries.

We emphasize the importance of standardized education and training for neurologists, encouraging them to communicate medical information in detail with family caregivers early on to avoid unrealistic expectations. Improving the relevant procedures and laws and regulations for surrogate decision-making, e.g., advanced directives and advanced care planning, are part of future work.





## Workshops *(Organized alphabetically by lead presenter.)*

### **Developing an Ethical Framework to Guide Decisions related to Preferential Treatment in Healthcare Organizations**

*Rosalind Abdool, Vanita Fernandes, Dianne Godkin, Dian Williams*

Case Scenario: A manager's VP asks them to move a patient, whose family has made a large donation to the hospital, to a private room, this would require displacing a patient who is actively dying. The family is also requesting additional tests that are not medically indicated. Background: Every day in healthcare organizations, individuals at all levels, from the point of care to the boardroom, encounter situations related to requests/offers of preferential treatment (e.g., VIP jumping the queue in the emergency department, hiring family/friends) in which power and politics are at play. When faced with such situations, there is limited guidance on how an individual ought to respond and people may experience pressure to act in ways that are inconsistent with their own personal and professional values. Ethical issues include those related to fairness and equitable access to care and resources. A need for guidelines has been identified. Part 1 - Discussion: The workshop will begin with a facilitated discussion of ethical issues related to preferential treatment in healthcare organizations. Part 2 - Small Group: Participants will be divided into small groups to review three frequently encountered paradigmatic cases where power and politics are at play. Participants will discuss how they would approach such an ethics consultation and identify key ethical principles that should be considered. Part 3 - Prioritization Exercise: Using coloured stickers, each participant will identify what they believe are the three most important ethical principles that should be considered when addressing decisions about preferential treatment. This prioritized list of principles will be used to inform the development of an ethical framework to guide decision-making related to preferential treatment in healthcare organizations.

### **Interactive Deliberation on WHO's Clinical Ethics Guidance: A Critical Examination of Draft Content and Key Recommendations**

*George Agich, Angus Dawson, Hans Van Delden, Roli Matur, Ingrid Miljeteig, Keymanthri Moodley, Andreas Reis, Ehsan Shasi-Gooshki*

Over the past decade, clinical ethics has gained increasing prominence within the field of health ethics, especially from a global perspective. The COVID-19 pandemic, in particular, brought a range of clinical ethics challenges into sharp focus, from bedside rationing to the use of unproven therapies. While professional organisations have done a lot in this domain, the World Health Organization (WHO) has occasionally addressed specific clinical ethics concerns, but there remains a lack of comprehensive, general WHO guidance on clinical ethics. Given WHO's role in global health, the organization is well-positioned to advise and recommend member states on improving healthcare delivery and health systems through specific guidance. The upcoming WHO "Clinical Ethics Guidance" is intended to play this vital role at the global level. This guidance has been developed to support and provide broad recommendations, with a particular emphasis on governance in clinical ethics to a diverse range of stakeholders, especially member states and health policymakers. Governance is crucial for shaping systems that ensure ethical standards in clinical settings and encounters at the point of healthcare delivery. Accordingly, governance is central to this document, which addresses governance at institutional, national, and international levels. While clinical ethics encompasses many specific issues, this document focuses on key global ethical challenges and their governance and implementation. The guidance is organized into several sections. The first provides a historical background and context for clinical ethics. The second addresses key issues in clinical ethics education. The third explores clinical ethics support services, including ethics committees and consultations. The fourth focuses on policy development for ethical healthcare practices at national and institutional levels. The fifth discusses international coordination and governance. The final section offers practical recommendations for stakeholders, particularly Ministries of Health, to enhance governance and implement ethical standards in clinical settings. It is developed by an international working group (WG) comprised of experts from all WHO regions and observer organisations which was established at the end of 2023, under the supervision of a WHO internal steering committee. At the workshop, on behalf of the WHO WG (<https://www.who.int/groups/working-group-on-developing-who-guidance-on-clinical-ethics>), the team leading the guidance development will present the latest content and gather feedback from participants. The most recent version of the guidance will be shared in advance to allow participants ample time for review and meaningful deliberation.

## Resolving Ethical Conflicts in Multicultural Settings: A Structured Framework for Healthcare Professionals

*Hamed Al Sinawi, Zahid Al Mandhari, Faryal Khamis*

**Introduction:** Advances in biology and medicine have introduced complex ethical challenges, making it difficult to define right from wrong in healthcare. To navigate these dilemmas, particularly in culturally and religiously diverse contexts, an Ethical Framework was devised by the National Bioethics Committee in Oman to serve as a moral guide for medical policy and practice, rooted in its mission of service to humanity through universal ethical principles. The framework emphasizes five core values: protection of faith, life, lineage, intellect, and property supported by principles of autonomy, beneficence, justice, and non-maleficence. In cases where ethical disputes arise, this structured framework enables decision-makers to examine explicit reasons for or against particular actions, reflecting both institutional values and ethical principles. **Methodology:** This workshop uses a case-based approach to engage healthcare professionals in culturally sensitive ethical decision-making. Aimed at doctors, nurses, and senior medical students, it provides tools to approach real-world ethical conflicts thoughtfully and collaboratively. **1. Framework Overview:** Facilitators introduce the Ethical Framework, explaining its core values and principles to guide participants in aligning decisions with institutional ethics. **2. Case-Based Problem Identification:** Participants identify and define ethical conflicts within case scenarios, paying attention to relevant cultural or religious dimensions. **3. Self-Reflection on Biases and Emotions:** Participants acknowledge personal biases and emotional responses to promote self-awareness and better-informed decision-making. **4. Fact-Gathering and Analysis:** Each group assesses relevant facts, considering diverse perspectives, institutional policies, and applicable laws to ground their decisions. **5. Exploration of Alternatives:** Teams identify and assess alternative actions and outcomes, ensuring alignment with clinical goals and ethical values. **6. Ranking and Justifying Values:** Groups rank and justify values, enhancing transparency and structured reasoning in ethical analysis. **7. Decision Articulation and Implementation:** Participants develop an action plan, emphasizing clear communication, documentation, and thoughtful implementation. **8. Concluding Reflection:** The workshop concludes with a reflection on decision-making processes, biases, and interdisciplinary collaboration. **Conclusion:** This workshop equips healthcare professionals with a structured approach to resolving ethical conflicts, fostering culturally informed, patient-centered care. By integrating the proposed Ethical Framework's values and principles, participants gain tools for ethical reasoning that respect diverse beliefs and support fair, compassionate healthcare delivery.

## You Don't Know How it Feels: A Reflective Practice Workshop for Healthcare Ethics Consultants

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

Ethics consultants' personal experiences of doing ethics consultation are largely absent from professional literature or academic discussions. This strange absence limits the possibilities of having such experiences probed, interrogated, or expanded upon through self-reflection and others' critical engagement, which then can limit ethics consultants' professional development, building what may become challenges for sustainable practice for individuals and as a field. This absence also gives some weight to the decades-old criticism that consultants are non-combatants with no real understanding of the experiences that patients, families, and clinicians undergo in ethics consultations. The charge of you don't know how it feels can diminish ethics consultant's effectiveness in complex clinical encounters, conversely, an ethics consultant sharing their personal values or commitments in a consultation encounter, or focusing on their experience as consultants in publications and presentations, is often seen as transgressing professional boundaries, expectations, and decorum with too much information. Since there are few examples of and fewer opportunities for consultants to practice such uncomfortable and often unwelcome work, this workshop offers both an opportunity to reflect individually and collectively on how academic forms and professional norms constrain practice but are not definitively limiting, i.e., one can break out of those constraints, with a deliberate choice to risk and expose oneself while at the same time limiting the extent of doing so. Presenter one begins the workshop with an historical review of the collective professional avoidance of describing and expressing personal experiences with ethics consultation, within academic and clinical constraints. Presenter two explores the shadow stories in clinical ethics work, reflecting on tales that we don't tell, or can't tell, despite their deep influence on our professional experiences and practices. The workshop then offers two examples of self-reflective and creative expression of clinical ethics work. Presenter three shares poetry voicing the unspeakable in consultants' experiences. Presenter four performs a monologue representing the internal voices we hear at times in clinical encounters. Between each segment, workshop participants engage in active pauses, with invited prompts from presenters, for individual reflection and their own creative response (with creative materials provided) about what the pieces raise, identify, or put into question about their own experiences and practice as clinical ethics consultants. The workshop concludes with group reflections on the practices, challenges, and opportunities of such reflective work for ethics consultants, and an invitation for participants to share their reflections and creations from the work-

shop.

## **The Role of Clinical Ethics Consultation in Requests for Assisted Dying**

*Marie-Eve Bouthillier, Georg Marckmann, Suzanne Metselaar, Daniela Ritzenthaler, Jan Schildmann*

Assisted dying is a legal option in an increasing number of countries around the world. Legislative frameworks usually define basic elements of legitimate practice of assisted dying. Clinical ethics consultation (CEC) services are involved in safeguarding appropriate practices in concrete cases of requests for assisted dying. However, the role of CEC in assisted dying has been discussed controversially in the literature and varies considerably around the world: While in some countries CEC services are regularly involved in requests for assisted dying, they are involved just on demand in other countries. This difference in practice as well as the question what CEC services can actually contribute in requests for assisted dying raise the question what the appropriate role of CEC in assisted dying should be and how CEC should be conducted if it is involved. The aims of the proposed workshop are firstly to provide insights into current practices of involvement of CEC services and secondly to provide a forum to discuss the role(s) of CEC services and underlying reasons for (possibly differing) roles. Four short presentations will introduce the participants into experiences with CECS in requests for assisted dying from four different countries, thereby covering not only different legislative frameworks but also different socio-cultural backgrounds: Canada, Germany, Switzerland and the Netherlands. Based on these presentations, further perspectives from the participants and concrete cases, we will discuss the following guiding questions in the workshop: (1) What can or should be appropriate roles of CEC in requests for assisted dying and what limits with regard to the contribution of CECs can be identified? (2) How can CEC be conducted to contribute effectively to ethically justified practices of assisted dying? Overall, the workshop shall bring together experiences and expertise from different countries to develop perspectives about what CEC can contribute to ethically sound practices of assisted dying.

## **Globalization, Medical Travel and Clinical Ethics: Exploring Preventive Ethics Solutions in the Care of International Patients**

*Megan Brandeland, Bev Frase, Josh Overgaard, Dolly Maiti*

Background: Healthcare tourism has grown significantly in recent years. For many patients, seeking medical care abroad represents a last resort for complex and serious illness. Clinicians caring for international patients encounter a variety of ethical dilemmas. Preventive ethics is a discipline that emphasizes prevention of ethical conflicts through critical reflection on individual and institutional factors. Objectives: We propose three objectives for this workshop. First, participants will gain insight into common reasons for ethics consultations requested for international patients in the United States. Second, participants will explore proposed best ethical practice standards in the care of international patients. Third, participants will create preventive ethics solutions for the care of international patients in their own countries. Methods: The workshop will consist of three parts each focusing on one of the above objectives. Part 1: First, we will review background information on healthcare tourism and a recent study from our institution summarizing ethics consultations on international patients over 19-year period (2006-2024). Then, we will divide participants into small groups of 3-4 people to discuss sample case vignettes and share their own experiences working with international patients. Part 2: First, we will present our proposed best ethical practice standards in the care of international patients. We suggest five primary areas of best ethical practice standards including (1) Clinical Care (2) Medical Records (3) Language and Culture (4) Spiritual Care (5) Financial. After presenting these, we will divide participants into small groups of 3-4 to discuss these standards. Part 3: First, we will provide a brief overview of preventive ethics to the large group. Then, we will divide participants into small groups of 3-4 people and encourage them to propose preventive ethics solutions for the care of international patients in their own countries. We will close the workshop by coming together for a large group discussion. We will provide participants with a list of references for further learning. Conclusion: Ethical dilemmas arise in the care of international patients due to differences in culture, religion, expectations for medical care, clinical practice norms and healthcare financing. This workshop will provide participants with the opportunity to explore common ethical challenges in the care of international patients, review proposed best ethical practice standards and engage in discussion to develop preventive ethics solutions for the care of international patients in their own countries.

## **Revising ASBH's Core Competencies: What the 3rd Edition might mean for Clinical Ethics in the U.S. and Beyond**

*Joshua Crites*

The Core Competencies for Clinical Ethics Consultation, published by the American Society for Bioethics and Humanities (ASBH) is influential in the U.S. and around the globe for informing the practices of ethics consultation services and for training future professional clinical ethicists. ASBH is undertaking a 3rd edition of the Competencies, to be published in 2025, and the leaders of this workshop were involved in writing the 3rd edition at different stages of the process. While the document is an improvement over previous versions, especially in areas such as consultation models, we believe that its attempt to accommodate the broadest type of ethics consultant limits its influence to push the field forward and relegates discussion of competencies needed for advanced, high-volume, individual consultation to other venues. The aim of this revision is to highlight select changes and updates to clinical ethics practice in light of both socio-ethical and medical developments and evolutions of professionalization in the field of clinical ethics since the previous edition (2011). We will begin the workshop by reviewing some of the changes and developments as available in the current public-comment draft of the 3rd edition, notably: increased recognition of ethicists in non-consultation roles, increased attention to vulnerable populations, a move away from a full committee model as viable for consultation, advancements in professionalization of the field, and the pressing need to engage in quality assessment and establish practice standards as the field grows. We will close the presentation portion of the workshop by sharing our personal, professional perspectives, both as authors of the document as well as clinical ethicists working in the American context, specifically reflecting on implications of the 3rd edition for both formal and informal clinical ethics training and practice in the U.S. We will then engage attendees in an interactive discussion related to the influence of Core Competencies outside of the U.S. context, utilizing a 25/10 Crowd Sourcing exercise. This format drives exchange of innovative ideas through recognition of patterns of solutions shared among attendees. The goal is to clarify how current changes might affect capacity and competency building for ethics consultants globally.

## **The Aggressive SDM: Clinical Ethics Consultation at the Intersections of Safety, Vulnerabilities, and Best Interests**

*Jennifer Dunsford, Christy Simpson*

Violence in the health care environment is now so widespread as to be commonplace. Aggression and abuse toward health care providers is a significant cause of physical and psychological injury, moral distress, and intention to leave a position. Although much care-related violence is committed by patients, all too often the perpetrator is a patient's family member or significant support person. This results in a complex, morally fraught situation, which is made even more difficult when the perpetrator is the substitute decision-maker (SDM) for an incapable patient, making it impossible to simply remove them from the situation. Although professional obligations and patient vulnerabilities compel staff to continue to provide care in these situations, they do so at considerable personal risk of trauma at the hands of the SDM. Clinical ethics consultation is an important support in the resolution and prevention of situations where aggressive or abusive behaviour from an SDM poses safety risks to health care providers. In this interactive workshop, using the presenters' experience in clinical ethics consultation, we unpack the morally complex phenomenon of determining and acting in the best interests of a patient whose care is complicated by threat and/or actual violence from their SDM. Our analysis and recommendations are framed by Salient Vulnerability Theory, an emerging conceptual approach based on one presenter's doctoral research. This approach focuses on understanding aggression in the health care environment, and health care providers' decision-making processes around care in the context of violence. Using a case study to exemplify the phenomenon, this workshop outlines the problem of aggression from SDMs and explores the ethical conflicts that result. We examine the intersecting vulnerabilities of patient, SDM, and provider that create tensions in care settings, and demonstrate the application of a vulnerability lens for addressing the resulting conflicts. Using small-group discussions, we consider recommendations for ethics consultants in mediating a course of action that is both in the patient's best interests, and examines how, and in what ways, the involvement of the designated decision-maker may occur despite their behaviours that place others at risk. We conclude with a discussion of the moral distress experienced by providers in these situations.

## **Introductory Skills Workshop in Mediation: Learning the Techniques of Conflict Management for Clinical Ethics Consultations**

*Autumn Fiester*

A recent study of healthcare ethics consultation found that 59% of consults involve conflict, yet few ethics consultants receive any formal training in conflict management. Professional mediators have long possessed a unique skill set needed to facilitate difficult conversations between individuals in emotionally laden situations, generate solutions that meet the needs of all parties, and resolve conflicts that seem intractable. This skill set is increasingly being recognized as invaluable to the work of clinical ethics consultants as they navigate conflicts between and among patients, families, surrogates, and providers. Moreover, given that communication breakdown frequently lies at the root of many clinical ethics conflicts, the mediator's skills in effective communication are essential for uncovering the concerns, values, and perspectives of the parties in the conflict. This hands-on workshop will introduce the central concepts and skills needed for the management and prevention of contentious ethics conflicts. Through interactive, presentations and partner exercises, participants will learn core mediation concepts and techniques including positions vs. interests, problem-diagnosis, de-escalation, BATNA, reframing anger, thematic restatement and the ladder of inference. The workshop leader is a highly experienced mediator who has over 15 years of experience teaching conflict management to clinical ethicists, nurses, and physicians.

## **Childrens' Rights in Healthcare: How Can Participation in Pediatric and Child- and Adolescent Psychiatric Practice Succeed?**

*Sandra Hotz, Kerstin Von Plessen, Michael Von Rhein, Franck Wieber, Dominik Robin, MariSchäler, Magalie Sneed*

The right to participation of children in healthcare is defined and anchored by a legal framework on various levels. However, current practice doesn't fully comply with these requirements in Switzerland. Barriers include legal, policy-based, and healthcare aspects. Our workshop aims to present and discuss the participation of children and adolescents in healthcare, looking at very different diagnoses and settings (acute, chronic, light/heavy mental health diseases). We will discuss from a multi-professional perspective, individual, institutional and regional factors to participation and discuss capacities and constraints that facilitate or hinder the participation of children and adolescents in healthcare. In the first part of our workshop, we will exchange about the current state of child participation in health care from legal/policy, institutional and individual perspectives. To that end, a multidisciplinary approach using pediatrics, child and adolescent psychiatry, health ethics and law, public health and sociology will be used. The second part of the workshop will be organized as a group discussion exploring how the participation of children in our health care system looks like (e.g. for specific acute or chronic, physical, or psychological problems) and how changes towards a more inclusive child healthcare can be made. To conclude, an integrative discussion will take place.

## **Including the Parents'/Family Voice in Paediatric Clinical Ethics Case Consultation: Considering Best Practice**

*Carolyn Johnston, Katherine Moore, Bronwyn Sacks*

Ethics case consultations in paediatric settings do not routinely involve parents. The Nuffield Council on Bioethics (2023) notes that parents are seldom included in clinical ethics consultations. Recent legal cases highlight this lack of patient / family participation as a significant concern. In Australia, the National Health and Medical Research Council (2015) suggests consideration of the involvement of the family and/ or patient before offering case consultations and the Royal Australasian College of Physicians advocates that all patients, families, carers and clinicians have access to quality clinical ethics services. Neither gives specific guidelines. Inclusion of parents within the ethics consultation processes arguably promotes fairness, transparency and reciprocity, enabling decisions made to reflect and incorporate the values of all stakeholders. There are varying approaches to inclusion of parental views in the ethics case consultation process throughout the world. Clinical ethics services in paediatric hospitals in Australia have not yet debated the pros and cons nor the practicalities of doing so. We report on the findings of a 2023 Quality Assurance project of the Clinical Ethics Response Group (CERG) at Monash Children's Hospital. All clinicians who attended a CERG case consultation were invited to participate in a semi-structured interview, exploring views on whether and how parents should be involved in ethics case consultations. Twelve interviews were conducted. Overwhelmingly, participants expressed the importance of hearing the parental voice, to allow them to



provide information about what option(s) for treatment they considered best for their child. Suggestions included inviting families to attend CERG meetings in person, providing a written document, or meeting with an ethicist before the case consultation. There were several challenges noted to all these approaches and most interviewees favoured parents not attending in person, but rather providing a written document. Participants thought that parental involvement should be offered on a case-by-case basis, not as a default. This workshop will engage audience members in a discussion of: Current approaches of the participants institutions to inclusion of the parental /family voice in ethics case consultation. The underlying moral reasoning for parental inclusion fact finding, procedural fairness, equity? Facilitated group discussion of the benefits and challenges of different practical approaches to parental involvement. How to best accommodate and support parents, especially those with language or other limitations to engagement. Would this move the standard clinical ethics process to a mediation model? Would changes to routine practice impact the integrity of the process?

### **Disagreements Regarding Gender-Affirming Care: How Can Clinical Ethicists Contribute?**

*Marta Martisella, Marie-Claude Levasseur*

**Background:** An increasing number of youths identify as gender diverse. Such individuals may turn to healthcare professionals (HPs) for gender-affirming care (GAC). While the literature on the topic of GAC has proliferated, it is not without controversy. HPs who encounter gender diverse youth in their practice may face various ethical challenges that pertain to the initiation of GAC. Good medical practice requires that HPs be attuned to the ethical dimensions of care, the medical indications that justify treatment initiation and the legal frameworks governing informed consent. In the context of pediatric GAC, clinical ethicists may struggle to define their specific role and the potential consequences related to their involvement. How can they navigate the tension between gatekeeping practices and ethics rubber stamping in a context where numerous ethical questions may arise? **Aim and methods:** Using a fictitious clinical vignette that pertains to the ethical acceptability of initiating GAC, we propose a workshop that will highlight the ethical subtleties and challenges CE's faced throughout a consultation process. Facilitators will be intentional about creating a safe and encouraging environment for participation which aims to provide clarity with respect to finding a balance between the clinical, ethical, and legal imperatives surrounding GAC. **Implications for practice:** Requests for pediatric GAC are increasing worldwide and given the ethical issues surrounding this practice and their resulting controversies, CE's may see an increase in consultation requests surrounding this topic. Therefore, it is necessary that CE's feel adequately prepared to address the ethical challenges that arise in this context in a manner that does not harm the various stakeholders involved. Adequate preparation begins with an open and honest dialogue regarding the complexities associated with GAC. By creating a safe environment for such dialogue in this workshop, we hope to contribute to CE's reflective practice in the realm of GAC.

### **Co-developing a Casebook on Clinical Ethics in Pakistan: Local Stakeholder Engagement and Regional Collaboration**

*Rakhshi Memon, Muqaddas Asif*

In low- and middle-income countries (LMICs) such as Pakistan, there is little or no integration of bioethics into clinical training. In Pakistan, healthcare professionals have had few opportunities to learn how to recognize and manage ethical challenges arising in everyday practice. This workshop describes an ongoing process to engage healthcare professionals in different regions of Pakistan in the development of a clinical ethics casebook, modelled on a successful approach used in another Asian nation. By creating a structured, culturally relevant resource for bioethics education, this initiative has the potential to enhance professional development for healthcare workers in Pakistan and beyond, empowering them to make informed, ethically sound decisions, while fostering a culture of mentorship, reflection, and ethical inquiry in clinical practice. Panelist 1, is a British Pakistani bioethicist who has PhD in bioethics from University College London (UCL) and is an Alumni Interdisciplinary Centre of Bioethics, Yale University. She will describe project aims, including how our team is learning from and adapting an approach developed by and for Singapore's multi-ethnic society. In this approach, stakeholder meetings to identify ethical challenges arising in practice build interest and engagement and ensure that the work reflects real-world practice and ethical uncertainties. The challenges identified via stakeholder meetings become the basis of casebook materials that can support clinical teaching and learning in Pakistan. Panelist 2 is a Pakistani who has recently completed her certification in bioethics summer program from the Interdisciplinary Centre of Bioethics, Yale University. She will describe the first stage of our project, including barriers and opportunities encountered and findings from our initial stakeholder discussion. Interactive discussions with participants will enable sharing of information and resources to support similar initiatives in LMICs.

## Clash of the Titans: Ethical Conflicts When Families Reject Modern Medicine in Favour of Complementary and Alternative Medicine

*Sumytra Menon, Kumudhini Rajasegaran, Mei-Yoke Chan*

Many countries have integrated complementary and alternative medicine (CAM) into their healthcare systems as part of holistic care. Data from the World Health Organisation (WHO) shows about 50% of the population in industrialised countries regularly use some form of CAM, although it is mainly limited to outpatient care and plays a complementary role to modern medicine. Some patients however reject modern medicine completely, to the point where they may put their lives at risk. While patients have the liberty to choose their own treatments, even when others think it is not in their best interests, ethical challenges arise when patients who have not, or are unable to express treatment preferences, require modern medicine treatments to save their lives or prevent a serious deterioration in their health, and their families reject modern medicine for CAM. In this interactive workshop, the facilitators will use three cases to explore the ethical challenges faced by healthcare professionals and clinical ethics committees when family preferences for CAM place patients' health at risk, making it difficult to balance benefits and harms, and to advocate for the patient while respecting the family. Case 1: Lina, a 59-year-old woman found unresponsive on a park bench, was conveyed to hospital and diagnosed with sepsis, renal and liver failure. She lacks capacity to make any medical decisions and is unlikely to regain capacity soon. Her son, who is a Traditional Chinese Medicine (TCM) practitioner, arrived at the hospital shortly after her admission. While the doctors were preparing to intubate Lina and commence dialysis, her son informs them that Lina will only receive TCM and seeks her discharge from hospital, even when informed this may result in her suffering from preventable harm. Case 2: Kai is a 4-year-old boy, diagnosed with standard risk childhood leukaemia, which has a good prognosis with conventional chemotherapy. His parents believe that fresh air and unprocessed foods will treat his cancer. The medical team recommended chemotherapy, which the parents refused, even when informed of the good prognosis. Case 3: Mia is a 14-year-old girl diagnosed with Stage 2 osteosarcoma of the left leg. She wants to recover, return to school and see her friends. Mia has read up about her condition on the internet and prefers the modern medicine options explained by the doctors. Her parents however believe those treatments would harm Mia, and prefer CAM instead, notwithstanding the medical advice.

## “Be Wise - Prioritize!” Training and Supporting Healthcare Staff Facing Ethical Challenges Due to Resource Scarcity

*Ingrid Miljeteig, Audun Brendbekken, Helge Alsaker Solheim*

**Background and Objectives:** Resource scarcity poses major ethical challenges for healthcare providers (HCPs), who often find themselves stretched between delivering optimal patient care and adhering to efficiency demands. This challenge can lead to moral distress as HCPs both in high-, middle- and low-income countries struggle to allocate limited time and resources fairly. In Norwegian hospitals, Clinical Ethics Committees (CECs) have been mandated since 2021 to not only offer ethical guidance but also enhance staff's ethical competency, specified to also include education in relation to priority-setting of resources. Our CEC, serving around 14,000 hospital employees, has seen a marked rise in requests for training related to resource prioritization, especially following new challenges introduced by the COVID-19 pandemic. This workshop aims to: Engage participants in interactive learning methods used to train healthcare staff in addressing ethical challenges related to scarce resources. Foster dialogue and networking among attendees interested in enhancing CEC educational activities. **Workshop Structure and Activities:** Introduction (10 minutes): Overview of ethical challenges tied to resource scarcity and the role of CECs in training HCPs. Pedagogical Strategies (20 minutes): Presentation of teaching methods, learning outcomes, and evaluation strategies tailored to various healthcare roles, with evidence-based techniques for ethical reflection and decision-making. Interactive Role-Play (30 minutes): Participants will take on roles as HCPs navigating a realistic ethical dilemma in resource allocation, practicing ethical analysis, prioritization, and moral reasoning. Group Discussion (20 minutes): Facilitated dialogue on CECs' role in ethical education, with participants reflecting on the role-play, sharing institutional experiences, and discussing the impact of CEC training on staff competence. Conclusion and Networking (10 minutes): Wrap-up with an invitation for ongoing collaboration and networking among participants interested in advancing CEC educational programs. **Target Audience:** This workshop is for CEC members, healthcare educators, ethicists, and administrators focused on improving ethics training in resource-limited settings.

## **Toward Anti-Ableism in Clinical Ethics: Getting Beyond Admiring the Problem**

*Debjani Mukherjee, Laura Guidry-Grimes, Nancy Berlinger, Liz Bowen*

People with disabilities are overrepresented as patients in healthcare settings and underrepresented as colleagues. Clinical ethics consultants (CECs) are well-positioned to intervene in inequities and biases in patient care and healthcare systems, including those reflecting structural ableism. However, CECs may lack the skills to recognize and respond to ableism encountered in practice. Those who do respond often encounter institutional and interpersonal resistance. This panel will identify common manifestations of ableism in the context of clinical ethics and offer strategies for intervening and making constructive contributions. The panelists are experienced in different facets of clinical ethics work, including consulting, drafting ethical guidelines, policy development, and education. They reflect 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, clinician education, and the culture of clinical ethics itself. The first panelist, a clinical/community psychologist and CEC who has worked on three continents, will explore the dignity of risk and how decisions about who gets to take risks, how risk is defined, and how cognitive biases of the clinical ethicist can impact clinical ethics consultation. 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 bioethics and health humanities scholar who works on population aging and end-of-life care, will discuss how cultural narratives of disability and dementia intersect and diverge, and how clinical ethicists can play a role in reframing entrenched dementia narratives within clinical practice. 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 CECs to consider their roles in addressing structural ableism. The panelists will introduce several clinical cases and policy discussions drawn from their professional experiences, inviting interactive participation throughout.

## **Time to Establish Brave Spaces for Clinical Ethics Consultations? Reflection Based on a Framework Implemented in Medical Education**

*Antoine Payot, Nathalie Orr Gaucher, Clara Dallaire*

Context: Institutions are committed to protecting academic freedom and ensuring the freedom of expression for all stakeholders, both in research and teaching, especially in the context of significant cultural diversity. Many educators feel uncomfortable and at times fearful speaking about complex topics in public, where their opinions can be openly criticized and publicised, particularly with social media. In parallel, many learners are uncomfortable and hesitant to voice their opinions in the context of institutional hierarchy. It has thus become challenging to discuss complex, nuanced topics, educators and learners may prefer to remain silent rather than engage in debate, despite the importance of such discussions in addressing complex situations. The Clinical Ethics Bureau (Faculty of Medicine, University of Montreal) sought to restore educational spaces that allow for discussions on complex issues and respect for differing viewpoints. Inspired by the Brave space literature, novel tools were developed and deployed at the Faculty of Medicine to create a model of safe and authentic learning environment that encourages open and respectful exchanges. Workshop Goal: This workshop will present these novel tools and explore their use in clinical ethics consultations to facilitate debates and the exchange of ideas. Clinical ethics consultations often raise complex, nuanced ethical issues, that can at times be controversial or delicate. Consultations need to provide spaces that are safe while allowing to discuss and reflect on these complex issues, in which all stakeholders can express diverse viewpoints without fear of judgment or stigmatization. Workshop Outline: Brief theoretical presentation on the concept of brave space leading to the model of safe and authentic environment, followed by collective reflection on the importance such notions for clinical ethics consultations. Interactive plenary exploration of the different positions of stakeholders in clinical ethics consultations: Ethicists and ethics professionals, healthcare professionals, patients, families, and loved ones. Interactive plenary exploration of participants' practices concerning the creation of safe and authentic environments for clinical ethics consultations. Presentation of the creative process underlying the development of our novel tools and their use at the Faculty of Medicine at the University of Montreal. Group discussions on the practical implementation of these tools, their advantages, disadvantages, facilitators, barriers, and challenges in clinical ethics consultations. Plenary feedback session to share reflections from group discussions. Conclusion and key messages.

## Responding to Moral Complexity

*Rosamond Rhodes, Jolion McGreevy, Jennifer Finkel, Matthew Drago, Jill Berkin*

Most requests for healthcare ethics consultation (HEC) involve a single clinical service. Occasionally, they involve two different services, sometimes with conflicting concerns and views. Rarely, more than two clinical services are involved. A recent case at our institution involved three different services, namely obstetrics, pediatrics, and psychiatry. It involved a pregnant woman in the grips of an acute psychiatric crisis who denied being pregnant and refused to cooperate with recommended fetal monitoring. It also involved her severely growth restricted fetus with an abnormal placenta at risk for stillbirth or permanent disability from prematurity at extremely low birth weight. Thus, several of the most contested socio-political issues were central to the case resolution. The value conflicts embedded in the ethical analysis encompassed abortion, women's rights, fetal rights, rights of people with disabilities, parental rights, self-determination for people with mental illness, prejudice, and discrimination. Whereas everyone from the HEC and each participant from the several clinical services involved was committed to reaching a decision that served the interests of the patient, her inability to reliably communicate about her commitment to the pregnancy, her potential future child, or her priorities under the circumstances presented unusual challenges. This workshop will demonstrate our interdisciplinary, collaborative, consensus-forging HEC approach. It will involve the audience in dissecting complex ethical quandaries, navigating multiple uncertainties involved in a complicated clinical case, and piloting a HEC through the somewhat different and conflicting professional commitments of the clinicians involved. Our Ethics Committee's co-chairs, a clinician and a philosopher, will moderate the session. They will briefly describe our collective model for HEC and invite the audience to serve as HEC team members responding to the request for guidance. The moderators will, in turn, ask our institution's clinicians from psychiatry, obstetrics, and newborn medicine each to present the situation from their clinical perspective. Audience members will pose questions for the presenting clinicians. Thus, the initial workshop segment will focus on developing understanding of the psychiatric and medical situation for the woman and the fetus. Once there is preliminary agreement on the facts, the discussion will turn to resolving the moral dilemmas involved. The audience will be encouraged to raise ethical concerns and share thoughts about potential problems they foresee. Along the way, the moderators will interject clarifying comments and summary statements. Striving together, the overall aim of the group discussion will be to reach a consensus and formulate recommendations for moving forward.

## Moral Distress: Managing Conflict Within Ourselves and with Others

*Lindsay Semler*

Moral distress, or the distress that arises from knowing the right thing to do but being unable to pursue that course of action, is not only increasingly prevalent in healthcare, but also an unavoidable side effect of providing patient care in a complex care environment. Moral distress is especially common when a values conflict arises during patient care. Unaddressed, moral distress can lead to a host of negative outcomes such as burnout, impact on physical and emotional impact, and even leaving the healthcare profession. Despite a growing body of literature describing and defining moral distress, few studies have been done that provide a practical approach to addressing and reducing moral distress. This author has developed and implemented an interactive moral distress workshop that was shown to decrease moral distress and increase ethical confidence. In this workshop, participants will have the opportunity to participate in a 90-minute seminar that allows them to: 1) describe moral distress and how it differs from other types of distress, 2) use a toolkit to identify and address the ethical issues that cause moral distress, 3) engage in conflict resolution strategies, and 4) learn techniques to strengthen moral resilience.

## Réseau D'éthique Clinique International Francophone (RECIF): Comparisons, Exchanges and Collaborations

*Philippe Sylvestre*

Context: Since May 2024, the Réseau d'Éthique clinique internationale francophone (RECIF), an axis of the international francophone bioethics network, has brought together clinical ethicists from Belgium, Canada, France and Switzerland. With clinical, organizational and normative issues specific to each context, clinical ethics consultation has developed differently in each setting. This plurality of practices, in terms of processes and cases handled, offers a rich opportunity to exchange and collaborate, to learn from each other's ways of doing things and to consolidate the network. Workshop objective: We propose a workshop that will bring together an international panel of French-speaking clinical ethicists from each of the Network's teams, in order to better understand how each team carries

out its clinical ethics consultations. The workshop will be structured around a clinical vignette focusing on conflict resolution, to highlight differences and similarities in practice. The aim is to learn from different ways of approaching a similar question, to better understand how French-speaking clinical ethics teams work. Methodology: A clinical vignette will be developed by BL and PS. The vignette will be fictional but inspired by real cases observed in adult and pediatric settings, and will fit in with the Conference theme, specifically Clinical Ethics Consultation and Conflict Resolution. The vignette will be sent to a representative of each of the five clinical ethics consultations (CM at Bruxelles, RJJ at Lausanne, AP at Montréal, NF at Paris, MEB at Laval). Each team will then approach the case as they would in practice, documenting their approach precisely (Who? What? When? How?), asking questions of the authors and preparing their response and presentation for the workshop. During the workshop, we will discuss the work of each team, highlighting key differences and similarities. The five clinical ethics teams have approved the proposed approach. Workshop outline: Introduction and review of clinical vignette. Presentation of each team's approach. Open discussion with the audience to explore the differences and similarities between the approaches, in terms of the nature of the response and the process (e.g. people involved and in what order, information-gathering process, structure of deliberation, central concerns, decisional or non-decisional nature, means of communicating conclusions). Conclusions.

### **A Workshop on Interdisciplinary Collaboration and Partnership with Indigenous Patients during Clinical Ethics Consultations**

*Clara Tardif, Caterina Staltari, Gabrielle Lemieux*

The tragic death of Joyce Echaquan has highlighted the inequities and injustices suffered by Indigenous peoples in Quebec and Canada, triggering a cry of alarm throughout the Quebec health network and prompting a questioning of care practices. As a teaching hospital and referral centre for the RUISSS McGill territory, the McGill University Health Centre (MUHC) provides specialized services to the populations of the North, including 14,000 Inuit in Nunavik and 18,000 inhabitants in the Cree Lands of James Bay. These populations, often forced to travel to Montreal for specialized care not available locally, face many challenges, revealing profound systemic deficits in health care delivery. Although Indigenous people in the North account for 3000 admissions, 20,000 ambulatory visits and 2,500 emergency department visits annually at the MUHC, our understanding of their care experience remains limited. The deeply rooted discrimination faced by these patient groups can render clinical ethics dilemmas and consultation processes particularly sensitive and complex. Hence, there is a growing need for a systematic, adapted and culturally safe ethics approach to clinical cases involving Indigenous patients. Through recent clinical ethics consultations at the MUHC, we developed a pragmatic, collaborative method for cases involving Indigenous patients. At its core, this innovative method incorporates people-centered care and cultural safety approaches. It involves an active collaboration between clinical ethicists, the patient engagement quality team, indigenous allies, clinical champions and stakeholders. This collaboration aims to build a trustful, respectful relationship characterized by a keen interest in understanding the lived experience. This helps address questions surrounding social justice more adequately and avoid further contributing to trauma and discrimination of these patient groups. Throughout this process, humility and compassion are prioritized over the quick resolution of the perceived dilemma. To our knowledge, no other similar method has been reported in the field of clinical ethics. In this workshop, we first introduce the clinical ethics, patient engagement quality and cultural safety services at the MUHC. We then delve into unique challenges and questions that can arise in clinical ethics consultations involving Indigenous patients. In response, we propose a novel, pragmatic approach to these consultations. Next, we engage the participants in a case study where they can learn to apply this method in practice. We co-construct ways in which this method can be adapted and incorporated into the participants' own practices. Finally, we explore future avenues for solidifying and expanding the application of this method to other clinical contexts.

### **Situating Ethics Consultation and Overtreatment in Socio-Political Context: Reconciling Power, Plurality, and Principles**

*Jon Tilburt, Joan Henriksen*

Ethics consultants commonly encounter situations in which utilization of healthcare resources may or may not fit a patient's preferences and may or may not conform to specific notions of distributive justice. This year's conference theme is predicated on to possibility that good clinical ethics must consider broader socio-political issues, and HEC professionals may contribute an interesting view to these socio-political debates. But how, and with what vocabulary, and on what basis of expertise? In this session we will use the thorny issues raised by over- (and sometimes under-) treatment of the frail elderly as an illustrative conversational touchpoint under the conference subtheme (2)



HEC and social justice, examining in particular how inter- and intra-societal pluralism, professional power, and differential application of ethical principles get navigated in the United States and the Netherlands. Caring for frail elderly patients requires sound conversational engagement and discernment. Yet, as our case studies will illustrate, too often contemporary healthcare proceeds with a kind of clinical inertia until conflict arises. Then, in a panic, someone calls an ethics consultant. Our multi-disciplinary group of social scientists, theologian, clinicians, and ethics consultants, has been thinking, discussing, and writing together on the challenges of over- and under-treatment in the frail elderly. As we have come to learn, clinical teams face similar challenges in North America and Western Europe notwithstanding quite divergent socio-political contexts. In this 60-minute interactive session we will discuss with participants 2 case studies, one from North America, one from Western Europe, touching on common clinical situations in which an HEC might face important broader (and contested) socio-political forces influencing over- or under- treatment. We will draw upon the expertise of our multi-disciplinary panel to discuss their moral intuitions about specific cases, assess to what extent the four principles offer an adequate frame for addressing the ethical concerns raised, and what, if any, is the role of the ethics consultant in attending to, addressing (or at least naming) justice-related concerns in particular cases and how to reconcile those concerns with specific patient-centered (beneficence/non-maleficence) concerns in the work of healthcare ethics consultation.

### **Training and Assessing Ethics Support Trainees/Staff: Examining the Rationale and Practice of Two Different Simulation Methods**

*Katherine Wasson, Albert Christiaan Molewijk, Margreet Stolper*

Vital to ethics consultation and facilitating moral case deliberations is the ability to identify and analyze the ethical dimensions of a case and stimulate a dialogical moral inquiry into the moral reasoning of the stakeholders. Both involve specific knowledge, skills and a particular attitude, e.g. compassion, curiosity, openness to different viewpoints, respect for all parties. Yet, how do we train and assess clinical ethics support staff to do this work? Methods for training these specific skills in clinical ethics support are limited to date, let alone the assessment of these skills. One common approach in healthcare skills training is to use simulation-based education (SBE). Based on identified competencies, relevant skills are identified and learning objectives set for the learner. Simulation exercises allow the learner to practice in real time with trained professionals (both from ethics and health care) providing feedback. This workshop will offer two different approaches to SBE for clinical ethics support staff. First, the Assessing Clinical Ethics Skills (ACES) tool was developed based on national standards for clinical ethics consultation in the United States. It includes 12 key components, and this workshop will focus on three: identifying ethical issues and considerations, identifying the ethically (in)appropriate options in a case, and articulating the ethical rationales for each option. These steps are crucial to the process of moral decision making in ethics consultation. The ACES tool allows trained raters to evaluate learners and provide consistent, structured feedback either using formative or mastery pedagogy. Second, Moral Case Deliberation is a structured dialogue among health care professionals about their moral questions in practice. A trained and certified facilitator moderates the moral inquiry without giving advice, using one of the various MCD conversation methods. The content and the didactics of the MCD facilitator training is developed in line with the philosophy of MCD: pragmatic hermeneutics, dialogical ethics and Socratic epistemology. Central principles are: learning by doing, reflection instead of ready-made knowledge, and dialogue on dialogue. Specific self-reflection and observation forms are developed to assess the quality of the facilitator-trainees. After briefly describing both simulation methods, including the assessment criteria, workshop participants will get the opportunity to practice these approaches in small groups. The presenters will also scrutinize the pros and cons of each simulation and assessment method, and then explore if, and how to use them in participants own context.



## Expert Groups *(Group names and participants listed alphabetically.)*

### LIVING ETHICS

#### **Imagining Ethics Otherwise: Updates on Living Ethics Projects, Funding, and Activities**

*Arthur Filleul, Katja Köhlmeier, Suzanne Metselaar, Félix Pageau, Eric Racine (lead presenter), Marika Warren*

The Living Ethics International Network is pleased to invite you to an open meeting titled "Imagining Ethics Otherwise: Orientation, Projects, and Perspectives in Living Ethics." This meeting will introduce Living Ethics, highlight key ongoing projects and publications, and open the discussion on this new development. Further information: <https://livingethics.ca/>

### WORLD HEALTH ORGANIZATION (WHO)

#### **Interactive Deliberation on WHO's Clinical Ethics Guidance: A Critical Examination of Draft Content and Key Recommendations**

*Abdallah Adlan, George Agich, Ilana Ambrogi, Angus Dawson, Hans van Delden, Andreas Frewer, Lynn Gillam, Kenneth Goodman, Shija Kevin, Faryal Khamis, Otmar Kloiber, Ilhak Lee, Sana Loue, Roli Mathur, Ingrid Miljeteig, Farhat Moazam, Keymanthri Moodley, Karen Moore, Jing-Bao Nie, Lillian Omutoko, Bernardita Portales, Rouven C. Porz, Andreas Reis, Ehsan Shamsi-Gooshki (lead presenter), Ekawat Suwataroj, Mark Tan Kiak Min, Steinunn Thordardottir*

Over the past decade, clinical ethics has gained increasing prominence within the field of health ethics, especially from a global perspective. The COVID-19 pandemic, in particular, brought a range of clinical ethics challenges into sharp focus, from bedside rationing to the use of unproven therapies. While professional organisations have done a lot in this domain, the World Health Organization (WHO) has occasionally addressed specific clinical ethics concerns, but there remains a lack of comprehensive, general WHO guidance on clinical ethics. Given WHO's role in global health, the organization is well-positioned to advise and recommend member states on improving healthcare delivery and health systems through specific guidance. The upcoming WHO "Clinical Ethics Guidance" is intended to play this vital role at the global level. This guidance has been developed to support and provide broad recommendations, with a particular emphasis on governance in clinical ethics to a diverse range of stakeholders, especially member states and health policymakers. Governance is crucial for shaping systems that ensure ethical standards in clinical settings and encounters at the point of healthcare delivery. Accordingly, governance is central to this document, which addresses governance at institutional, national, and international levels. While clinical ethics encompasses many specific issues, this document focuses on key global ethical challenges and their governance and implementation. The guidance is organized into several sections. The first provides a historical background and context for clinical ethics. The second addresses key issues in clinical ethics education. The third explores clinical ethics support services, including ethics committees and consultations. The fourth focuses on policy development for ethical healthcare practices at national and institutional levels. The fifth discusses international coordination and governance. The final section offers practical recommendations for stakeholders, particularly Ministries of Health, to enhance governance and implement ethical standards in clinical settings. It is developed by an international working group (WG) comprised of experts from all WHO regions and observer organisations which was established at the end of 2023, under the supervision of a WHO internal steering committee. At the workshop, on behalf of the WHO WG (<https://www.who.int/groups/working-group-on-developing-who-guidance-on-clinical-ethics>), the team leading the guidance development will present the latest content and gather feedback from participants. The most recent version of the guidance will be shared in advance to allow participants ample time for review and meaningful deliberation.



The *Journal of Hospital Ethics* (JoHE) is a peer-reviewed academic journal devoted to interdisciplinary discourse associated with moral complexities and ethical conflicts as they relate both practically and theoretically to the provision of healthcare within hospitals and hospital systems. JoHE's annual volume consists of 3 issues, published in May, September, and December. JoHE is the official proceedings publication for the International Conference on Clinical Ethics and Consultation (<https://www.clinical-ethics.org>), and a partner journal of the American Society for Bioethics & Humanities (<https://asbh.org/resources/journals>). JoHE is published by the John J. Lynch, MD Center for Ethics, MedStar Health, Washington, DC.



#### EDITORIAL POLICIES AND GUIDELINES

JoHE adheres to the editorial standards and authorship criteria recommended by the International Committee of Medical Journal Editors (ICMJE) and is produced with guidance from the World Association of Medical Editors (WAME). We welcome submissions of completed manuscripts as well as abstract paper proposals by authors with academic or professional expertise in relevant fields. To access the full run of JoHE volumes as well as complete information regarding JoHE's editorial policies and guidelines (Manuscript Submission, Peer-Review Process, Conflicts of Interest, Data Sharing, Policy on the Use of Artificial Intelligence, Errata and Corrigenda, Editorial Disclaimer, Advertising Policy, Indexing, Open Access, Copyright, and ISSN), please scan the QR code or visit:

**[www.medstarwashington.org](http://www.medstarwashington.org)** Click on *About MedStar Washington, The John J. Lynch, MD Center*

for *Ethics*, then *Journal of Hospital Ethics*. Or simply search for JoHE's webpage directly via your preferred search engine. Please send all inquiries to [johe@medstar.net](mailto:johe@medstar.net).

#### Manuscript Submission

Please limit manuscript submissions to a range of 4000-6000 words, and abstract paper proposals to 250 words. All manuscripts should be anonymized for peer review and include an abstract of no more than 250 words. Abstracts for original studies (empirical work) should be organized in the following manner: Background, Methods, Results, Conclusions. In addition, submissions should include 3-5 keywords for greater discoverability in search engines, databases, and other indexing systems. Manuscripts should be anonymized for review and include a separate cover letter with the title of the article, name of each author, contact information, institutional affiliation(s), and a statement declaring any conflicts of interest. All submissions should adhere to the American Medical Association Manual of Style (11th Edition). Whereas book reviews are solicited by the Editorial Group, all other submissions to the journal will be reviewed for publication with the understanding that they are not under consideration, accepted for publication, or published elsewhere. To facilitate the review process, all manuscripts should be submitted as MS Word documents and should adhere to JoHE's complete set of editorial policies and guidelines as stated on this page at the time of submission. Please use JoHE's Manuscript Submission Checklist (available online) when submitting a manuscript for review. All manuscript submissions should be sent to Christian Carrozzo [christian.carrozzo@medstar.net](mailto:christian.carrozzo@medstar.net).

#### Editorial Disclaimer

The opinions and perspectives offered in JoHE reflect only the views of the authors and editors, and do not represent the views of others within the MedStar Health system or other institutions or organizations with which any of the members of the JoHE Editorial Advisory Board are affiliated.

#### Open Access, Copyright, and ISSN

JoHE is an open access journal. Given JoHE's institutional funding, its status as "Diamond" open access means no article processing fees for authors nor subscription fees for readers. Submitting authors whose work is accepted for publication in JoHE will never be asked for payment of any kind. As an open access, peer-reviewed journal, JoHE publishes its content under a version of the Creative Commons license that does not allow the material to be used for commercial purposes and prohibits that any modifications/derivations of the material be distributed (CC BY-NC-ND 4.0: <https://creativecommons.org/licenses/by-nc-nd/4.0/>). Open distribution is strictly limited to the published material as it stands without any related commercial charges or content modifications of any kind. Authors of all material accepted for publication will be required to assign copyright to the publisher. The following ISSN assignments have been made under the auspice of the Library of Congress (OCLC: 136972691): JoHE (Print) ISSN 1938-4955, JoHE (Online) ISSN 1938-4920 © Copyright 2012-2025 The John J. Lynch, MD Center for Ethics. All rights reserved.





# MedStar Health

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

Non-Profit  
Organization

U.S. Postage  
PAID

Washington Hospital  
Center