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JOURNAL OF HOSPITAL ETHICS

THE JOHN J. LYNCH, MD CENTER FOR ETHICS

Proceedings of the 18th International Conference on Clinical Ethics and Consultation & 32nd Annual Conference of the Canadian Bioethics Society

Partnering with Patients and Communities

Hosted by the Office of Clinical Ethics of the Faculty of Medicine, Université de Montréal, Canada

MedStar Health

ICCEC-CBS Montréal 2024

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A NOTE FROM THE EDITOR-IN-CHIEF

A Smart Way to Run the Show

Evan G. DeRenzo, PhD

Dear Readers,

Welcome to Volume 10, No. 2, our 7th issue capturing the proceedings of the International Conference on Clinical Ethics and Consultation (ICCEC). This issue presents the scholarship shared at this year's meeting held in Montreal, Canada, May 29-31, 2024. What a perfect time of year to be in Montreal!

This 18th ICCEC, hosted by the Office of Clinical Ethics of the Faculty of Medicine, Université de Montréal, was jointly held alongside the 32nd Annual Conference of the Canadian Bioethics Society (CBS). This kind of coordination is so smart. Working to combine ICCEC meetings with other bioethics conferences occurring in the same locale is just a wonderful way to collaborate.

And the Canadians have done it twice! Not only did they do it this year in Montreal, but the CBS and ICCEC also jointly held a meeting in Toronto in 2007. A slightly different model with the same collaborative intent was the 2008 ICCEC meeting in Rijeka, Croatia, which partnered with the 9th World Congress of Bioethics, the official meeting of the International Association of Bioethics (IAB).

Such collaborations increase prospects for participants to make new (or renewed and strengthened) collegial relationships and/or to reconnect with old friends. They also give new participants to ICCEC, and to the local (preferably national) meeting, a broader view of the field than either meeting alone can provide. Indeed, it is resource efficient in many ways; it assists colleagues with tight budgets to stretch their funds and it reduces duplication at the administrative level. All in all, it is a smart way to run the show.

Perhaps this brief history stimulates you, our readers, to create such collaborative meetings in the future. Towards that end, we have created a new way to keep you all connected. For the first time, we are providing all 2024 ICCEC/CBS meeting registrants with a free one-year subscription to JoHE, a complete volume, beginning with this issue.

We offer this volume with high hopes for such collaborations at the individual scholar, CEC practitioner, and program-administrative levels. We hope that this volume holds a special place among your reference documents for many years to come as we continue to grow our international readership.

Lastly, our sincerest gratitude to both Aron Basurto (Baylor University) and Michael Carlson (University of Virginia), our wonderful Lynch Center Summer Interns '24, for their assistance in the production of this issue.

Sincerely,

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

Compassionate Use and Research Ethics Consultation: Partnering with Clinical Teams

Mahwish Ahmad, Margot Eves

Research ethics consultation ("REC") is unique from case-based clinical ethics deliberation in that it is a distinct, longitudinal process with broader potential impact than a single patient. No area is as fertile for collaboration and partnership among bioethicists, healthcare professionals, patients, and communities than medical research. To be on the cutting edge of innovation and new medical discoveries inevitably poses challenging research ethics dilemmas that can require specialized knowledge and a dedicated research ethics review, ethics consultation, or ethics committee support distinct from review for regulatory compliance.

Our bioethicists, situated in two academic medical centers within our multi-national healthcare system, will present a comparison of approaches to providing support and help in response to research ethics queries from clinicians-scientist colleagues. Presenters will also discuss ways that the REC service differs from the clinical ethics consultation service (ECS) and how the ethicist's role differs compared to embedded service on the Institutional Review Board (IRB). As a unified healthcare system model with the motto "one (Healthcare System name)," the focus on reducing and, when appropriate, eliminating, unnecessary variation within the clinical and research ethics consultation practices is paramount.

These two ethicists' approaches to a research ethics consultation related to "compassionate use" of a research drug or device will provide an opportunity to compare the processes used in different countries in the same healthcare system. This example is particularly salient given that the research ethical issues related to compassionate use overlap with ethical issues in clinical care. As such, providing high quality REC requires working with a broad interdisciplinary team. Presenters will discuss differences in how these clinical research sites, with independent IRBs/Research Ethics Committees handle such requests and explore mechanisms to create higher reliability and synchronization. Specific attention will be given to the differing laws and regulations, as well as the cultural norms, in the two countries in which these IRB/REC entities operate. In sum, we will consider how trained ethicists are providing services to complement regulatory review and create opportunities for comprehensive research ethics consultation.

Supporting Parental Bereavement in the Neonatal Intensive Care Unit

Esther Alonso-Prieto, Susan Albersheim, Rachelle Chung, Marie Nightbird, Kelly Allison, Emily Kieran

Background: The death of a newborn is a devastating experience for parents. It is crucial to understand their perspectives on the aspects of clinical care that impact their grieving process. Objective: To identify factors facilitating and affecting parents' grieving process during and after their NICU stay. Methods: Thirteen in-depth parent interviews were conducted three months after the infants' death, with six participants interviewed again at 18 months. Participants were selected through purposive sampling, and an inductive thematic approach was used for data analysis. Results: Three months after the infant's death, the NICU experience was described as a "slow, unrelenting car crash." Four major themes emerged. Theme 1: Respect for the patient. It manifested through the nature of the care provided (e.g., compassionate, nurturing, skillful), and specific actions taken by healthcare providers (e.g., personalized blankets, gentle touching, decorated room). Theme 2: Relationships. As part of this theme parents emphasized the significance of healthcare providers establishing an authentic human connection with both them and their baby and actively engaging in the shared experience of pain. They also emphasized the importance of continuing that connection post-death as its abrupt termination added a layer to their grieving process. Theme 3: Parental decision-making authority. It referred to the importance of valuing parents' decisions, emotions, knowledge, and decision-making pace. Theme 4: Transparent communication. It emphasized the importance of using a communication style that was honest, direct, consistent, complete, inclusive of both parents and matched to the parents' experience and maturity. The second interview, 18 months later, validated previous themes and linked them to an additional theme, regret. This theme referred to how the care received impacted their conviction that they had done everything for their infant, which in turn impacted their grieving process by providing a "sense of solace." Conclusion: The study's findings highlight that the principles of respect for persons, the fiduciary relationship, parental decision-making authority, communication and the sense of parental responsibility are crucial factors in promoting healing after the death of a child in the Neonatal Intensive Care Unit.

Knowledge and Moral Authority in Paediatric Decision Making

James Anderson

Recently, a group of American bioethicists published a consensus statement on paediatric decision making in *Pediatrics* (September, 2023). The statement focuses heavily on familiar moral principles and standards. In practice, however, the core challenge in paediatric decision making is not about principles or standards, but disagreement concerning their application in particular cases. How do we decide who is right when there is disagreement between parents and physicians about what is 'best' for a child, or what constitutes a significant harm? As the authors themselves note, the consensus statement is decidedly silent on this score.

I believe we can make progress on this front by shifting our gaze to the epistemic underpinnings of our moral judgments in this context. In this talk I sketch three arguments for this thesis.

The first argument is historical. According to the standard historical narrative, contemporary clinical bioethics emerges as a response to physician paternalism. But this narrative has tended to frame medical decision making as a zero-sum game from a moral point of view. The doctrine of 'shared decision making' attempts to address this problem, but it generates more questions than answers: what is shared? Why? The underlying epistemic structure of these decisional conflicts provides answers to these questions.

The second argument is phenomenological: the character of the most difficult decisional challenges faced in paediatrics today are not primarily or solely moral in nature. When physicians reduce illness to disease, or judge quality of life in purely quantitative terms, is this accurately construed as (primarily or solely) a moral problem? When parents reject evidence-based treatment recommendations based on their personal moral convictions or false beliefs, is this plausibly construed as (primarily or solely) a moral challenge?

The third argument is normative. At least in this context, moral authority is based almost entirely on epistemic authority. Though physicians were once afforded broad moral authority, that authority is now highly restricted and tightly tied to evidence based clinical expertise. Conversely, though parents continue to enjoy broad moral authority with respect to their children, in this context their choices are highly constrained by the state of the evidence.

Ethical Principles in Providing End-of-life Transplant Patients with a Donor's Social History for Their Consideration to Accept an Organ from a Deceased Opiate Drug User: Would This Close or Widen the Gap?

Rena Arshinoff

Many critically ill people await an organ for transplantation however the need overwhelmingly exceeds the availability of this much need resource. Unfortunately, many patients die while on the waiting list. To improve this scarcity, the center for Disease Control (CDC) in the United States declared that organs may be accepted from donors who engage in high-risk behaviours such as high-risk sexual activity, injection drug use, exposure to human immunodeficiency virus (HIV), recent time spent in a prison, and receipt of clotting factor concentrates. Thorough screenings of harvested organs from deceased opioid drug users as well as the ability to treat most infections have made using these organs safe for transplantation. Moreover, most deceased drug users are young, and their organs are in better condition than those from older donors.

Despite these positive advances, stigma and fear of infection make many patients uneasy forcing them to refuse a much-needed organ and to remain on the waiting list while the organ is then offered to the next appropriate patient. This must be done in a very short period, or the organ will need to be discarded. Some surgeons believe that patients should be told about the social history of the donor while others do not, claiming that it is a breach of privacy for the donor.

This presentation will cover the application of ethical principles concerning whether transplant patients should be given such information to decide for themselves about receiving an organ from someone who used opiate drugs. The principles to be examined include autonomy, beneficence, non-maleficence, justice, accessibility, equity, and resource allocation of organs. A large question concerns whether a utilitarian methodology should be used, that is, should all safe organs be used to maximize the number of patients who receive organs regardless of whether they would choose to do so to close the gap between the need and the supply of organs? Participants will have the opportunity to express their views on this important and potentially life-saving issue during the discussion period.

Access to Patient Medical Images Online and Informed Consent: Patient Perspectives

Lauren Asaad, Maushumi Bhattacharjee, Suzanne Deliscar, Atobrhan Godlu, Zack Marshall

Background: Patient photographs from medical case reports may appear on publicly accessible image repositories without clear process for consent regarding their online dissemination. This indicates potential ethical concerns involving informed consent and privacy. Investigating patient perspectives on this topic can help engage patients and inform future ethical publishing practices.

Methods: Two patient partners joined this qualitative research project as co-researchers, following the Canadian Institute of Health Research's framework for patient oriented research. Sample recruitment was conducted through UCalgary's "Participate in Research" website, patient partners' online networks and the Newcomer Research Network conference. Online interviews and pilot coding were co-conducted with patient partners and at least one other member of our research team. Data was analyzed through reflexive thematic analysis.

Results: A diverse sample of 24 participants comprised 14 women, 7 men, and 1 non-binary person, 13 people with disabilities, with 13 people from racialized communities including African, Caribbean, Black, South Asian, Filipinx, and Chinese. Themes involved participants' expressions concerning degree of image identifiability, security and privacy risks, personal health and photography experience as a patient, psychological safety, and future recommendations.

Conclusion: Patients are directly impacted by availability of patient photographs on public online image repositories. The input of people with lived experience is crucial to informing the development of improved consent form tools, which can assist in navigating ethical dilemmas involved, and fostering ethical publishing practices.

A Content Analysis of Patient Medical Image Consent Forms

Lauren Asaad, Maushumi Bhattacharjee, Zack Marshall

Background: Patient images from published medical case reports have been found in publicly accessible image repositories, such as Google Images. It is not clear how often consent forms for the publication of patient images in medical journals mention the possibility of images circulating online. This raises ethical concerns about patient privacy and lack of informed consent.

Objectives: 1) Collect patient image consent forms from each journal in the dataset, 2) track the components included in the consent forms, 3) summarize similarities and differences across journals, 4) identify recommended elements for patient consent forms to use images.

Methods: From a random sample of 1,755 case reports published between July 2017-June 2018 and indexed in PubMed, 492 case reports included at least one patient photograph that was found on Google Images. These case reports were published in 284 unique journals. We searched for consent forms to publish patient images on each of the journal and publisher websites.

Analysis: Through a pilot scan of 5 consent forms, we constructed a data extraction table in which we could quantify commonalities and differences between consent form components.

Results: 118 journals (52.7%) included consent forms on their own or publishers' websites. Eighteen unique consent forms related to 132 journals were identified. The most common component was anonymity, and the least common component was the mention of social media.

Conclusion: 10 out of 18 consent forms mentioned photographs being available to an audience outside of the journal website, and only 3 out of 18 consent forms mentioned the possibility of the patient's images being linked to journal or publisher social media platforms. Risk related to patient anonymity was generally emphasized, however the risk associated with patient images circulating online was not emphasized or made clear, even in the forms that contained text related to social media. Consent form content varied across journals and publishers and there were many inconsistencies. A consent form checklist or standardized patient consent form could be beneficial.

Can't Keep Track of Each Fallen Robin: the Ethics Consultant's Responsibilities with Community Rejection of Intolerable Patients

Virginia Bartlett

This presentation introduces and interrogates the responsibilities of care communities and of the clinical ethics consultant for patients experiencing rejection from caregivers - both in and out of hospital - due to intolerable be-

haviors. First, the presentation shares the stories of three consultations involving three patients each with combined physical, psychiatric, and psychosocial limitations that challenged in patient care in-hospital and exhausted community resources, preventing discharge and exacerbating the distress of care providers. “Parry,” quadriplegic post-gunshot with a borderline personality, spits on nurses during the pandemic; “Brennan,” with several psychiatric diagnoses and autism, refuses nursing care and throws full ostomy bags at providers; “Joseph,” with debilitating Crohn’s, attempted suicide in hospital and now responds to clinicians only with profanities. Providers requesting ethics shared comments like “No wonder he got shot” and “He’d never have survived anywhere but here" and “I almost wish they hadn’t found him in time” - followed by immediate apologies and shame for such “unprofessional” statements - and defensiveness about “how awful it was” caring for these patients and deep frustration that there were no long-term care options in the community, such that these patients were “stuck” in an acute care hospital. Requestors hoped - and expected - ethics would “do something to help” - both for clinicians in hospital and towards finding a solution for community placement.

These stories raise questions about the responsibilities of the different, overlapping communities of care as well as the ethics consultant’s responsibilities and moral experiences in such circumstances. How can ethics consultants help bridge community and hospital teams? How can ethics consultants support staff being abused by an undischargeable patient? How can ethics consultants encourage care for a patient who has become despised and rejected by their communities of care? By sharing stories of consults, the presentation invites insights, elicits strategies, and prompts stories from the audience about potentially similar experiences in different social and cultural contexts - or whether such encounters are particular to some locations, communities, and care settings.

Beyond Individual Responsibility: Ethical Challenges in Responding to Race Correction Errors

Itai Bavli

Race categories in medicine are still used uncritically across various areas of healthcare in the United States and Canada. False assumptions about biological differences between Black and White people have led health professionals to incorporate race-based adjustments or "correction" in their treatment and diagnostic approaches. This practice involves factoring a patient's race or ethnicity into a scientific equation, influencing how they are treated. For example, in Canada, the adjustment for race in estimating kidney function, a widely adopted practice, results in an upward correction of the estimated glomerular filtration rate, consequently causing delays in diagnosing kidney issues in Black patients.

There is a growing awareness that the institutionalization of race categories in medicine can perpetuate health inequities and harm marginalized groups. Race is a social construct and not a meaningful biological concept. Pressure to end race correction in clinical algorithms has resulted in the discontinuation of this practice in various medical domains, such as kidney and lung function assessments.

Despite this progress, questions persist regarding our ethical duties in addressing errors stemming from race correction practices. Drawing on insights from bioethics concerning our responsibilities in the face of medical errors, this study delves into our moral obligation to respond to the impact of practices that have affected a large population. Specifically, the study examines the application of principles such as the duty to apologize and disclose errors to a patient, as well as taking responsibility and blame, in cases where a large population has been adversely affected by harmful medical practices.

This study builds upon existing research focused on our responsibility toward individual patients, aiming to broaden the scope by addressing our ethical obligations toward marginalized groups affected by race-based medical practices. It contends that disclosing flawed recommendations or apologizing to patients for the harmful practices is insufficient. Instead, it advocates for a comprehensive reconciliation process involving individuals from diverse racial backgrounds. This process entails unpacking and openly discussing the historical origins of structural racism within healthcare and devising strategies to prevent the perpetuation of similar harmful racial policies.

Which Ethical Questions Persist Over Time? Exploring 30+ Years of Why People Request Clinical Ethics Consultation

Mark Bliton, Stuart Finder

As Clinical Ethics makes claims to move toward professionalization, interest in codifying its history has grown. “Sociopolitical” considerations - court cases, regulatory requirements, influence of “pioneers” in the field, development of internal standards (by ASBH and CBS) - have received the most attention. How healthcare professionals and patients understood - and currently understand - “ethics” from within the clinical context has not garnered

similar attention. Examining the reasons given for why ethics consultation was requested, and tracking this over time, provides insight into the evolving concept of "clinical ethics consultation."

This paper explores several trends among reasons given for requesting ethics consultation gathered from documentation for over 1400 consultation requests from over 30 years of clinical ethics practice within different academic tertiary care contexts. During the early 1990s, for example, requests predominantly revolved around end-of-life decision-making. In comparison, since the mid-2010s, decision-making for unrepresented patients has become a more prominent issue (although end-of-life issues remain significant). Similarly, general concerns about goals of care were much more frequent 30 years ago than today. On the other hand, while disagreements about aggressiveness of interventions has been consistent, the balance between healthcare providers wanting to continue interventions that patients/families wanted stopped compared with providers seeing interventions as inappropriate but patients/families pushing to continue treatment has shifted: in the 1990s, providers wanting to continue over patient/family objections was the more common, whereas in the 2020s it's almost exclusively providers wanting to stop but patients/families wanting to continue.

Examining these findings, we show that reasons given for requesting ethics consultation often reflect sociopolitical/cultural as well as institutional considerations that are temporally bound. But perhaps more significantly, the data also reveal that the orientation toward, and understanding of, actual clinical ethics practice as held by ethics consultants also influence, over time, the kinds of reasons given by staff (in contrast to those from patients or families) for requesting ethics consultation.

By delving into trends captured by actual reasons requesters provided over the past 3 decades, we thus will demonstrate how a careful documentary study of clinical ethics' past can significantly add to the understanding of our own history- and future.

Everyday Ethics in Neonatology: Texting Parents to Help Them Cope With The Hospitalization and Maintain Hope

Béatrice Boutillier, Sarah Francoueur, Steve Turmel, Sophie Fournier, Annie Janvier

Background: Parents in the NICU (Neonatal intensive care unit) often mourn a "normal" delivery and/or baby and may experience guilt, anxiety and sadness. Neonatal hospitalizations are long and often complex, with periods of instability or stagnation. In studies, parents report that clinicians are often pessimistic and rarely focus on what is going well their children. Parents also recommended to communicate with them via texts (as opposed to flyers and websites), which has not been investigated in the literature.

Objective: The aim of this study was to describe the creation and implementation of a project to celebrate babies' achievements and progress on a weekly schedule throughout the hospital course in a large level 4 NICU.

Methods: The study took place in the largest level 4 NICU in Canada (Quebec). This project was suggested by parent partners and developed with them. The inclusion criteria were all babies who were likely to be hospitalized for more than one month, with parental consent. Parents were sent a text message every week on Fridays, including a picture, to celebrate an important weekly success, or if there was none, a message of encouragement. The corresponding "certificates" were also displayed above the baby's bed. We investigated parental perspectives about this program with a questionnaire at the end of the hospitalization.

Results: To date, 26 NICU parents received 208 certificates-texts and answered the questionnaire. The overall evaluation (on 10) of parents for this project is 9.5; 85% of parents think it has certainly or probably helped them cope with hospitalization. 90% think that the weekly frequency is appropriate. Some suggestions were made by parents and have already been implemented during the project, such as adding dates on certificate. Some parenting advice quotes for future NICU parents: "To hold on to the light at the end of the tunnel!" or "Be optimistic and above all patient." There were no adverse impacts associated with this project.

Conclusion: Sending text messages to NICU parents on a weekly basis is feasible and appreciated by parents. It celebrates their child's achievements, helps parents cope and strengthens the relationship between clinicians and parents.

Mapping the Ethical Concerns Surrounding Medical AI Throughout its Life Cycle

Guido Calderini, Athmeya Jayaram, Jean-Christophe Bélisle-Pipon, Vardit Ravitsky, Danielle Pacia, Sana Baban, Gavin Victor

Recent advancements in artificial intelligence (AI) have significantly enhanced our comprehension of fundamental biological mechanisms, particularly in genomics and precision medicine. However, the integration of novel AI models in these domains raises complex ethical, legal, and social issues (ELSI), encompassing core values such as human agency, privacy and data governance, fairness, individual, social, and environmental well-being, transparency, and accountability.

This paper addresses the gaps in current ethical evaluations of AI tools, emphasizing the need to scrutinize the ethical choices made throughout the AI development process, beyond the focus on datasets and tool effects. We also want to ensure these assessments include stakeholder engagement, integrating the perspectives of scientists, developers, clinicians, and patients, in the formulation of ethical guidelines.

To achieve these objectives, we propose an ethics-by-design approach, considering the entire life cycle of AI development. The method involves a systematic analysis of decisions, decision-makers, and decision-principles at each stage of development, incorporating stakeholders' values, expertise, experiential knowledge, and concerns.

To illustrate this approach, we will present the case of visible machine learning algorithms used to create drug response models (DRMs). Potential stakeholders of the tools generated by this project are engaged through semi-structured interviews and Delphi interviews. By centering on DRMs, this paper provides a concrete lens through which to analyze the "ethics-by-design" methodology.

Bridging the gap between abstract ethical principles and practical decision-making, we create easily applicable ethical guidelines for each step of the development process, tailored to each type of stakeholder. These resources empower developers, clinicians and patients to make informed and ethical choices, contributing to the mitigation of downstream ethical issues.

This paper offers a generalizable understanding of the AI lifecycle, providing actionable insights for scientists, developers, clinicians, and patients. By addressing the ethical challenges associated with medical AI through a comprehensive and participatory approach, we contribute to the development of practical guidelines, fostering responsible and conscientious AI development. Our findings aim to promote the ethical implementation of AI in healthcare, ensuring the alignment of technological progress with societal values and well-being.

Reviewing of Challenges and Opportunities Associated With Online Clinical Ethical Consultation

Laura Campanozzi, Francesca Reato, Emanuale Mangione, Vittoradolfo Tambone, Mario Picozzi

Background: Over the last decades, Clinical Ethics Consultation (CEC) has become increasingly relevant in healthcare as the most significant ethical activity. The growing demand for prompt and immediate responses to the ethical issues arising from daily clinical practice clashes with difficulties in arranging ethical consultations in person and in a timely way, owing to work commitments involving counselors and distances from clinical care settings. One of the main useful solutions, especially after the COVID-19 pandemic, has been the provision of online clinical ethics consultation. However, the remote approach has not been thoroughly investigated with regard to the specificities of this kind of consultation.

Objective: This study aims to analyze experiences of Clinical Ethics Consultation performed online in order to review their challenges and opportunities.

Methods/Analysis: We carried out a descriptive analysis of the existing literature and data has been collected to explore the effectiveness of the ECCs' online experiences, concerns and criticisms they raised, and proposals that have been advanced to address them, as a starting point to identify potential future steps to improve the implementation of this key ethical activity. When the related literature has been examined, the study then envisaged a multicentric survey in the field of medical ethics to integrate the state of the art with further relevant contributions from real cases.

Results and Conclusions: The analysis shows that experiences of CEC delivered online are still limited. There are positive examples via online portals, telephone, or even forums, which enable consultants to have a useful tool to discuss with colleagues at a distance in real-time. However, such experiences also raise challenges ranging from the issue of what should be shared online to the problem regarding health literacy, language and technology, and limited access to computers and the Internet, which may constitute barriers to the use and management of the Ethical Consultation by both patients and counselors. Further studies are needed to clarify in which situations online

CEC can be suggested while in others it should be avoided. The envisaged survey will be able to provide useful insights, including strategies to overcome the critical issues mentioned.

When the Default is Deficient: Lessons on Substitute Decision-Making From Structurally Vulnerable Communities

Alexandra Campbell, Lee de Bie

The substitute decision-maker (SDM) hierarchy in Ontario's Health Care Consent Act (HCCA) anoints as default decision-makers the incapable person's family members linked by blood, marriage, or adoption. Yet, as the Ontario Court of Appeal's 1999 decision in M.(A.) v. Benes recognizes, "Not all family members are close, and even when they are close, they do not always know what treatment the incapable person would want." It is past time to consider who is served and, moreover, who is most harmed, by assigning the default position of SDM to a seemingly heteronormative, procreative conception of family. This is particularly important to clinical ethics as issues related to substitute decision-making commonly present in ethics consultation.

Literature from 2SLGBTQIA+, disability, Indigenous, and racialized communities call to decolonize narrow definitions of family, reinforced in legislation and hospital practices, and to reimagine kinship and care relations in ways that support health equity. Alternatives are also being proposed within the legal sector. The Law Commission of Ontario recommended in its 2017 Final Report on Legal Capacity, Decision-Making, and Guardianship that the provincial government amend the HCCA to allow individuals to exclude family members from their decision-making hierarchy. They additionally encouraged the Government of Ontario to work toward establishing a "dedicated licensing and regulatory system for professional substitute decision-makers," which could enable people to assign power of attorney to a trusted organization. We might learn as well from the default SDM hierarchies in British Columbia and Quebec that include a close friend or interested party on the list, and from our review of Ontario Consent and Capacity Board decisions that appoint chosen family or friends instead of who would otherwise act through the operation of the hierarchy.

In this presentation, we will:

- Unpack how legal definitions of "family" and ranking of substitute decision-makers can especially harm members of structurally vulnerable communities;

- Review recommendations that encourage us to re-envision substitute decision-making; and

- Propose opportunities for enhancing ethics education and consultation related to substitute decision-making through (i) deepened equity analysis, (ii) creative and critical interpretations of SDM hierarchies, and (iii) further community engagement.

Transition Readiness Rather than Age as a Guiding Principle in Transfer Timing from Pediatric to Adult Healthcare for Youth with Sickle Cell Disease

Marie-José Clermont, Serge Sultan, Leandra Desjardins, Jade Bergeron, Barbara Fritz, Amer Yassine Hafsaoui, Nancy Robitaille, Yves Pastore, Stéphanie Forte, Nathalie Goucher, Sophie Marsolais

Transitional healthcare from pediatric to adult services is complex. It implies the shift from a family-centered to an individual-centered approach, in which youth are expected to be autonomous. This represents a challenge for adolescents and young adults (AYA) with chronic medical conditions and translates into poorer health outcomes during this period: AYA with Sickle Cell Disease (SCD) experience more medical complications, acute care utilization and hospitalizations between ages 18 and 30. Experts believe youth should not be transferred to adult services until they have the necessary skills to function independently within them. Nonetheless, healthcare systems across Canada impose healthcare transfer at age 18. Ethical tension exists between transfer as a systemic structure and individual transition readiness. Measurable parameters to evaluate transfer readiness may help identify AYA at higher risk of transition challenges and facilitate tailored interventions to help throughout transition.

The objective was to explore autonomy levels, as measured by the Transition Readiness Assessment Questionnaire (TRAQ), during transition to adult care for AYA with SCD.

A retrospective medical chart review of AYA with SCD who transferred from a tertiary care pediatric institution to a tertiary care adult hematology clinic between September 2020 and May 2023, was conducted.

Total and domain-specific scores for TRAQ surveys answered by AYA between ages 16 and 19, during routine follow-up visits at both sites, were calculated. TRAQ uses a 5-point ordinal scale, with higher scores representing

greater levels of transition readiness.

In this study, 29 AYA with SCD had completed at least one TRAQ during the study period. Median age at first adult clinic visit was 18.1 years old (17.2 to 19). The mean overall TRAQ score was 3.57 (2.56 to 4.58). The domain with the highest average score was "Talking with Providers (4.57), while the lowest was "Tracking Health Issues" (2.81).

During transfer, most AYA are still at the stage of "preparation" in the Transtheoretical Model on which TRAQ is based. Individualising transition processes by using objective measures to guide interventions may improve successful transitions for AYA with SCD.

A Call to Partner With Communities to Hear Diverse Sociocultural Perspectives on Artificial Intelligence in Healthcare

Benjamin Collins

Artificial intelligence (AI) in healthcare presents numerous ethical issues. Many of these issues are influenced by the globalization of data for AI and differentially entangled with concepts across cultures, whether among indigenous populations, immigrant populations, regionality within countries, or internationally such that it is important to consider healthcare AI in the appropriate sociocultural context. To do so requires partnering with communities to hear diverse sociocultural perspectives on AI in healthcare to: (1) Identify their needs rather than impose technological solutions when there may be other solutions or other problems with a higher priority and avoid a technological imperative whereby people feel compelled to have AI involved in their care despite concerns. (2) Recognize their moral values in matters of health, which we do not yet know in the AI context and outside the context of AI often do not align across populations such as regarding the disclosure of cancer diagnoses to patients or with acceptance of medical aid in dying. (3) Balance a discussion often dominated by big tech corporations drowning out the voices of those who are most affected. (4) Prevent problems, which are difficult to backtrack and fix, before they occur, especially the potential for negative biases and worsening health disparities of which communities will be more aware than those who develop and implement healthcare AI. (5) Determine what the communities know about healthcare AI and what they do not know, avoiding a dissonance between expectations for healthcare AI and reality, and establishing an appropriate level of trust. These partnerships should begin early, from the conceptualization of an AI, and be maintained throughout the lifecycle of AI. They should consider foremost the voice of the communities, especially hearing from those who may typically be missing from the conversation. Then to act together alongside communities, and listen again, learning what is working and what is not working. While we do not yet know what perspectives may arise or how different cultural perspectives will affect AI in healthcare, we should be aware of the importance of diverse sociocultural perspectives, especially on topics that are potentially paradigm shifting, like healthcare AI.

"First of All, I Expect to Be Treated as a Partner:" Epistemic Injustices as an Obstacle to Patient Partnership in the Medical Relationship - Towards Epistemic Justice for Patients Living With Chronic Pain

Catherine Côté, Pascale Devette

Context: Many studies highlight the invalidation experienced by people living with chronic pain. The concept of epistemic injustice, developed by Miranda Fricker, is frequently used to understand medical invalidation. However, literature on epistemic injustices is not sufficiently integrated yet to understand in depth how they interfere in the medical relationship, both through interpersonal and structural factors. Furthermore, the avenues suggested for promoting epistemic justice in the medical relationship are multiple, but do not seem to have been identified, compared, and integrated into a unified understanding.

Objective: This study aims at better understanding the mechanisms underlying epistemic injustices in the medical relationship, with chronic pain as a case figure. It also seeks to explore possible avenues for promoting epistemic justice in the medical relationship, both at the interpersonal and structural level.

Methods: Seventeen narrative interviews were conducted with people experiencing different painful conditions with the aim of exploring their experiences of epistemic injustices with healthcare practitioners, as well as their experiences of validation. The interview guide was co-constructed in partnership with a researcher, a clinician, and a patient partner. A focus group was also organized with patient partners to validate and enrich the analysis.

Analysis: The verbatims of the interviews were analyzed following the reflective thematic analysis approach proposed by Braun et al. to identify both the mechanisms producing epistemic injustices and the factors contributing to validation. A critical literature review was performed to identify and compare avenues to promote epistemic

justice in healthcare.

Results: Several mechanisms are identified as contributing to epistemic injustices, including oppression systems, distribution of epistemic authority, the biomedical model, language, institutional opacity, and the organizational factors. These mechanisms also hinder healthcare partnership. Avenues for promoting epistemic justice are analyzed and compared. They include virtuous, structural, narrative, cognitive, and partnership approaches, as well as resistance strategies.

Conclusions: The patient partnership approach seems transversal to the identified avenues and is therefore an important approach to facilitate the implementation of epistemic justice, itself ethically necessary to tackle social health inequities.

Domains of Complexity in Medical Assistance in Dying (Canada): The Challenge of Reported Suffering and Moral Distress

Phillip Crowell

Background: With the introduction of MAiD in the Canadian context there have been nuanced relationships between palliative care and MAiD provisions everything ranging from conflicted, ambivalent, opposed, collaborative, cooperative and integrated. Within this mix of practice experience and relationships there are occasions when providers report moral distress about how the process, procedures, assessment, and communication unfolds that generates an experience identified as moral distress.

Objective: The definition of moral distress over many years has been under constant review, revision and debate. Our objective is utilize the more recent moral distress literature raising the important question do the instruments for measuring and defining moral distress adequately fulfill the task? The strong indication is that the instruments fail in a number of ways. A prime reason is that the assessment of the facts in the situation are incorrect. The second important issue and question that is raised, "is the distress moral, and therefore, is it justified as moral distress?"

Methodology: We examine the arguments regarding justified or unjustified moral distress and the typical experiences of moral distress identified, and then assess the standard for adjudicating a legitimate moral distress. A test case is offered for examination regarding palliative care and MAiD in order to measure and assess moral distress legitimacy. We assess the inflection points of moral distress and the equilibrium point for an advanced ovarian cancer patient considering MAiD.

Analysis: The types of moral distress that arise for healthcare providers within the context of MAiD assessment and provision are identified, such as lack of resources/supports in terms of symptom management, psychological-spiritual, logistical or equipment supports. There can also be lack of understanding of the specifics of the patient situation or misinterpretation of the basic facts.

Result: Utilizing the concept of "justified or unjustified moral distress" an examination of moral distress in relation to MAiD is rendered in the light of this case, recognizing that unjustified moral distress occurs.

Conclusion: Justified or legitimate moral distress in MAiD cases, as in other significantly moral distressing situations, often emanate from shortcomings in organizational functioning, workplace operations, and communication processes.

Patient Autonomy, Substitute Decision-Making and the Normative Value of Prior Expressed Wishes

Frank Curry

Among the stated aims of Ontario's Health Care Consent Act, 1996, one central purpose is to 'enhance the autonomy of persons for whom treatment is proposed' by "requiring the wishes with respect to treatment… expressed by the person while capable… to be adhered to" (HCCA 1.c.iii). This commitment finds explicit expression in the principles of Substitute Decision Making, set out in HCCA 21.1, stating: "if the person knows of a wish applicable to the circumstances that the incapable person expressed while capable… the person shall give or refuse consent in accordance with the wish."

Precisely how SDM's adherence to a patient's prior expressed wishes enhances their autonomy is unclear, however. And there are strong reasons to question the reliability of such wishes as sources of normative guidance in substitute decision making.

In this presentation I survey four such reasons:

a. the excessive-vagueness problem (in which the relation between what one wishes and what one would consent to is unclear);

b. the ambiguity of the statute (specifically having to do with what 'the circumstances' encompass);

c. the indexing of values problem (viz. the epistemic impossibility of knowing another's hierarchy of values);

d. the SDM as core to a patient's values (wherein the SDM is asked to make decisions as though their primary importance to the patient is of no normative significance).

My contention is twofold:

1) that the possibility of adhering to 'prior capable wishes' is less straightforward than contemplated by the Act; and

2) that the effort to make substitute decisions on the basis of them does little to enhance patient autonomy.

This is not to suggest that prior capable wishes ought to be considered irrelevant when making decisions on behalf of incapable patients, however. Rather, it means such wishes could be down-graded both in their legal and normative status, and weighed among the other considerations the Act sets out as relevant to making decisions on behalf of incapacitated patients.

Living Ethics: Introduction to the Concept and Discussion of Current Experiments

Bénédicte D'Anjou, Gabriel Saso-Baudaux, Eric Racine

Moral questions are vital questions because they concern what is esteemed to be the best choice, the best action and, ultimately, the best life to live. Wolf and Moreno argue that bioethics has contributed to moving ethics toward more experience-based and user-oriented ethics theory and methodology. Despite this, current ethics approaches remain an incomplete lever for human development and flourishing. This context led to the development of a "living ethics stance", by a collective of Canadian clinical ethicists, patient-partners, scholars, and healthcare professionals. In its first sense, a living ethics stance designates a form of ethics attentive to human experience and the role played by morality in human existence. In its second sense, a living ethics stance represents an ongoing effort to interrogate and scrutinize our moral experiences to promote adaptive responses which enact their flourishing as authentic ethical agents. Living ethics pulls from insights found in pragmatist, hermeneutics and narrative ethics notably. It holds specific theoretical, methodological, and practical implications in various areas of health ethics activity such as clinical and organizational ethics, health policy and public health, health ethics research, and learning and teaching health ethics.

The first speaker will provide background and an overview of the concept of a living ethics and of current projects. The second speaker will present in greater details the activities of a living ethics laboratory. The audience will learn about two living ethics experiments: a first dedicated to appropriate levels of care in an intensive care unit, and a second on psychological distress in complex and rare diseases. The third speaker will present ongoing progress in the international development of a living ethics stance. Given the panel content and objectives, the audience will have the opportunity to learn about the development of this orientation codeveloped by a large interdisciplinary group. Each of the three presentations will last 12 minutes with 3 minutes for questions specific to each talk. Then a final 15 minutes will be left to exchange on the overall panel and the strengths and limitations of living ethics.

Clinical Research in the Anthropocene

Jeff D'Souza

A necessary condition for a study to be deemed ethically acceptable is that the potential benefits to individuals and society outweigh the potential risks. This calculation has typically focused on a select subset of individuals (i.e. participants), been largely based on the present state of affairs, and has concentrated on direct benefits and harms impacting humans. This has resulted in (i) a number of people and communities wrongly excluded from a proper risk-benefit calculation, (ii) ignoring the full impacts of research on future generations, and (iii) a dismissal of the wider environmental impacts of clinical research on climate change, and the resulting effects of climate change on human health.

In this presentation, I highlight the importance of considering environmental concerns within the research ethics

review process, and the significance of meaningful community engagement to ensure that new requirements are implemented in a fair and equitable manner so that important clinical research is able to be carried out in a timely fashion, and so that certain communities, countries, and regions conducting clinical research are not disproportionately negatively affected. In addition, I introduce a new ethical requirement that would mandate researchers to (i) calculate and disclose the associated carbon footprint of their research, and (ii) develop a mitigation plan to ensure that their study achieves net-zero carbon emissions.

For far too long we have underappreciated the unintended consequences that research conduct has had on climate change and human health. To make matters worse, the carbon footprint of conducting medical research is largely produced by individuals and groups in the Global North, while the impacts have disproportionately burdened individuals and communities in the Global South, who are currently experiencing some of the worst climate change-related environmental catastrophes in human history. The time for change is now.

Suffering of Long-Term Care Residents With Dementia: Perceptions of Health Care Assistants

Serge Daneault, Amélie Du Pont-Thibodeau, Émilie Allard, Andréanne Côté, Mathieu Moreau

Background: Most residents in long-term care facilities suffer from major neurocognitive disorders, and many are unable to verbalize their suffering. Health care assistants (HCA) are by far the group of caregivers who spend the most time at residents' bedsides. Yet we know little about their perception of suffering.

Objectives: The aim of this exploratory study was to understand how HCA conceptualize the notion of suffering, and to describe how they assess it in people with major neurocognitive disorders.

Methods: Semi-structured interviews were conducted with 6 HCA working day, evening, or night shifts. The verbatims were then analyzed using a qualitative approach inspired by grounded theory.

Analysis and results: HCA conceptualize suffering as a change. This may be in relation to an initial state of calm (as opposed to agitation), to a previous cognitively intact state (as opposed to major neurocognitive disorders), to a state of well-being (as opposed to residents' expression of negative emotion) and to a state of satisfaction (as opposed to residents' unmet needs). The perception of suffering therefore aims to identify these changes. Thus, the role of the HCA is based on knowing the resident. Their competence is relative to their experience.

Violence is present in long-term care facilities. It represents an obstacle in the perception of suffering since it acts to depreciate the role of HCA. It also magnifies the loss of meaning that HCA experience in the face of suffering, eroding their ideal as caregivers. This erosion contributes to their developing defense mechanisms that distance them from residents.

Conclusion: Since suffering expresses itself through change, its recognition requires the establishment of a longitudinal relationship with residents. This demonstrates the importance of team stability and underlines the fact that assessing suffering is an ongoing process, not just a one-off event.

Envisioning the Discipline's Future: A Community-Centered Perspective on Clinical Ethics Fellowship Recruitment

Lee De Bie, Maram Hassanein

In line with the conference theme, we accept and support that clinical ethics ought to be engaged with communities. Yet, experience in patient and community engagement is not generally recognized as a valuable form of expertise that is prioritized in recruitment decisions for clinical ethics. Therefore, our goal is to discuss recruitment to the discipline, with particular emphasis on a future that promotes and reflects community engagement.

Underrepresentation of diverse groups and the lack of community engagement in clinical ethics pose significant challenges. Clinical ethicists from minoritized communities can provide crucial insights to diversify perspectives in clinical ethics and healthcare, and to enhance commitments to health equity. Moreover, community-engaged ethicists play a vital role in strengthening the healthcare system's capacity to foster trust and safety with diverse communities and to recognize and respond to their needs. These opportunities are forfeit when members of minoritized communities are underrepresented within the discipline.

We focus on recruitment to clinical ethics fellowships as they are often a gateway to the discipline; the question of "whom to select as fellows" is inherently intertwined with the vision of "what bioethics should evolve into"? The pedagogic decisions within fellowship programs hold political consequences. For example, choices made during intake and within the program influence the composition and future of the field. Due to the lack of intention and

focus on diversification and community engagement, the recruitment and retention process often sustains the status quo, resulting in the selection of individuals who closely resemble those already established in the field. This self-reinforcing process, leads to future cohorts that are less likely to prioritize diversification and community engagement. Unfortunately, such choices have contributed to a lack of community engagement and inequitable representation within the discipline.

Simulation-Based Learning: A Way to Integrate Communication Training, Ethics and the Patient's Feedback

Lenin De Janon-Quevedo, Silvia Birnenbaum, Gerardo Perazzo, Rubén Revello, Jimena Paz, Ivanna Saldívar

In Simulation-based Experiential Learning (SBEL) students are encouraged to solve complex problems using controlled settings that replicate real-life scenarios. SBEL is useful in training communication skills where truthfulness and empathy embody ethical values such as compassion and prevention of harm. Moreover, interpersonal relationships arisen during simulation can mobilize sensations (emotions, feelings) allowing trainees to perceive vulnerability of the patients and driving them to use ethical approaches to improve clinical communication. Objectives: 1) Determining previous knowledge on medical communication (PKMC) among medical students (MS); 2) Recognizing sensations of MS during communication of bad news (CBN). Methods: From 2019 to 2023, 161 MS in the 5th year of the M.D. Program participated in an 8-hour workshop on CBN. Technical aspects of medical communication and the SPIKES protocol were previously reviewed, and PKMC was determined via a survey. Then, participants role-played the communication of death of a loved-one or breaking of a poor-prognosis diagnosis to simulated patients. Role-plays were recorded on video. Immediately after simulation, the MS were asked to register their sensations (S1). During the debriefing, the participants thoroughly analyzed the videos and once again registered their sensations (S2). Results: 67% of MS self-perceived as proficient in CBN; 58% felt uncomfortable during CBN; 51% self-described as uncomfortable and 37% as neither comfortable nor uncomfortable (indifferent) to cope with the emotions of the patients. Arithmetic Mode (M) of S1 was nervousness and M of S2 was satisfaction for fulfilled duty. In S1 predominated emotional and negative sensations compared to S2. Other sensations in S1 were comfort, fear, stress, calm; in S2: calm, compassion, empathy, growing. Conclusions: Most of the MS self-perceived as proficient but uncomfortable during the CBN and when coping with the emotions of the patients. A group of MS felt indifferent to manage the patients' emotions. The sensations differed from S1 compared to S2.

Vulnerable Voices in Moral Case Deliberation: Learning from Patient Participation in Dutch Clincal Ethics Support

Janine de Snoo, Margreet Stolper, Bert Molewijk

Background:

In Clinical Ethics Support services (CESs) in the Netherlands, patient and family involvement is not yet a common practice. However, the voice of patients and family members is essential in order to fully understand the patient's perspective. The patient perspective is explicitly considered when doing Moral Case Deliberation, the main form of CESs in the Netherlands.

Objectve:

To deal with this discrepancy of explicitly inquiring but not physically inviting the patient and family, several initiatives are currently done to improve patient and family involvement in MCD. One of these initiatives is our project on patient and family participation in our hospital. In our project, we investigated the attitudes, concerns and ideas about patient and family participation in CESs to gain a better understanding of the challenges in patient participation in CESS and develop an approach to strengthen the patients' position in MCD.

Methods:

We conducted qualitative interviews with healthcare professionals, patients, family and facilitators of MCD. We also organized a pilot MCD session including both healthcare professionals and family members, to observe and learn about actual experiences. Lastly, we led focus group meetings with patients and healthcare professionals to reflect on our findings and develop plans to implement actual patient participation in MCD.

Analysis:

Interview findings were analyzed according to Grounded Theory methodology. Preliminary categories and overarching themes were discussed in the focus group meetings to finalize the findings.

Results:

At the conference, we would like to specifically focus on one of our findings: vulnerability. First, this vulnerability concerned the patients and family as they do not possess the medical information in an equal way as healthcare professionals and might feel overwhelmed by the presence of many medical staff members when joining a dialogue about their moral case. On the other hand, vulnerability also concerned the healthcare professionals, as they might feel reluctant and disturbed in maintaining their professional attitude to share their core feelings and thoughts about a case.

Conclusions

In order to make CESs and MCD more inclusive, we need to consider how vulnerability should be taken into account when organizing shared dialogues among people.

Factors Affecting Deceased Organ Donation in Bangladesh

Md Shaikh Farid

Organ transplantation is a life-saving medical procedure that offers hope to patients with end-stage organ failure. In Bangladesh, like many other countries, the demand for organs far exceeds the available supply, leading to a substantial gap between those in need and those receiving transplants. This paper explores the multifaceted factors influencing deceased organ donation in Bangladesh, shedding light on the complexities and challenges within the country's organ transplantation landscape. First, cultural and religious beliefs play a significant role in shaping attitudes toward organ donation. Bangladesh's diverse population encompasses various religious traditions and cultural norms, which can either facilitate or hinder the willingness to donate organs posthumously. Understanding and respecting these beliefs are essential for effective educational campaigns and public outreach. Second, awareness and education campaigns about organ donation remain limited, contributing to a lack of understanding among the general population. A comprehensive strategy that engages with both healthcare professionals and the public is needed to bridge this awareness gap. Furthermore, addressing misconceptions and raising awareness about the importance of organ donation can promote a more favorable attitude towards it. Third, the legal and regulatory framework surrounding organ donation and transplantation requires further development and enforcement in Bangladesh. Establishing clear guidelines, strengthening the regulatory infrastructure, and ensuring ethical practices are critical for building trust among potential donors and recipients. Fourth, economic factors also influence deceased organ donation. The financial burden associated with organ transplantation can deter individuals and families from consenting to donation, highlighting the importance of accessible and affordable healthcare services. Fifth, healthcare infrastructure and expertise must be expanded and enhanced to facilitate organ retrieval and transplantation. The shortage of qualified transplant surgeons, lack of transplant centers, and inadequate post-transplant care pose significant challenges in meeting the demand for organs. Finally, addressing unethical practices such as organ trafficking and ensuring transparency in organ allocation are crucial steps to maintain the integrity of the organ donation system in Bangladesh. In conclusion, the factors affecting deceased organ donation in Bangladesh are complex and multifaceted, encompassing cultural, religious, legal, economic, and healthcare-related dimensions.

Obstacles to Timely Decision-Making for Unrepresented Critical Care Patients without Capacity: A Single-Center Qualitative Study

Francisca Finkel, Claudia Sotomayor

Background: Unrepresented patients are defined as those who have neither an advance directive nor a surrogate decision maker. This demographic accounts for up to 16% of ICU deaths. These patients are some of the most vulnerable and they often are marginalized populations. The persistent challenges in obtaining consent for medical treatment on behalf of these individuals remains problematic and it brings questions about ethics and patients' rights because of the risks involved. The American Thoracic Society/American Geriatrics Society (ATS/AGS) published a policy statement in 2020 that proposes five ethical goals and six recommendations to navigate medical treatment decisions for unrepresented patients in the ICU. We encountered that even though this policy statement is compelling, it is difficult to implement in our hospital system due to legal limitations. We also found that the ethics consultation service is often called to help navigate the decision-making process in these patient population.

Aims: To improve the quality of care for this patient population, we designed this interdisciplinary quality improvement project that aims to explore different healthcare professionals' understanding of the management, policies, and procedures of the decision-making process for incapacitated unrepresented patients in the Intensive Care

Unit. After learning from the different stakeholders, the secondary aim is to develop a process flowchart to improve the decision making process for incapacitated unrepresented patients at our institution.

Methods: This is a interdisciplinary qualitative improvement project. A needs assessment survey was sent to ICU personnel included: nursing staff, physicians, social workers, patient advocates, case managers and risk managers. This was paired with a one hour focus group of 10 people with representation from different professions: physicians, nurses, social workers, attorneys and ethicists.

Preliminary results: We received a total of 50 responses. 62% of the healthcare professionals think that this patient population does not receive the standard of care. 50% of the healthcare professionals are unaware of the guardianship process. 68% of the healthcare professionals are unaware of our state's code of law regarding guardianship. 84% of the healthcare professionals agree that a flowchart is needed to improve the quality of care provided to these patient population.

Building Trust in Neurological Research Through Listening and Community Engagement

Paul Ford, Lauren Sankary, Jada Wiggleton-little

For research institutions to accomplish their most transformative research projects, they must engage communities in new ways that engender trust. Bioethicists have skills in communication, facilitation, education, and research to further evolve these activities. In recent years there have been wonderful strides toward engaging the community through representation on boards, community health centers, and public health initiatives. Although large national initiatives like "All of Us" have been successful in engaging diverse populations in research, community engagement efforts need to be undertaken locally to ensure research is responsive to specific interests of communities. This ethicist-led initiative provided a process for engaging local community partners around shared priorities and interests to connect research priorities to local needs. Drawing on principles of Participatory Action Research (PAR), we engaged community partners to address barriers to inclusion of underrepresented communities in neurological research through focus groups, collaboration, and educational activities. The project builds on relationships developed with key community stakeholders during a previous year of educational collaboration. Several populations were included during the initial phases, including individuals affected by incarceration, those identifying as being part of the LGBTQA+ community, and those in under-resourced communities directly adjacent to the main hospital. The project was led by an ethics fellow and two ethics faculty members. The presentation will focus on lessons learned in applying traditional clinical ethics skills and applying research ethics processes to meaningfully engage community groups outside the clinical setting.

A Participatory Action Research Study on Transition Care to Promote Flourishing in Youths With Chronic Conditions (Parachute)

Anne Fournier, Marie-José Clermont, François Ouimet, Rocio Gutierrez Rojas, Eric Racine, Juliette Durocher

Background and objectives: Transition from pediatric to adult care is a challenging moment in the life of youths living with a chronic condition. Many transition programs are oriented towards maximizing compliance and treatment adherence, thereby placing high moral value in autonomy and independence. However, there is a need to expand the focus of current research and interventions to engage youths as persons with preferences and aspirations to a flourishing life. We undertook a participatory action research study (Parachute) to better understand the needs and aspirations of youths with respect to transition care, including their well-being and flourishing. Our work culminated in the development of short thematic videos and a dialogical workshop for clinical teams.

Methods and analysis: The current steps - on which we will also be able to report partly in May 2024 - include the co-development of transition video content with youths and a participatory workshop for healthcare professionals based on our study results. Semi-structured interviews (N=54) were conducted via Zoom and audio recorded with youths, parents and healthcare professionals recruited from four clinics in a pediatric hospital. An online survey was tailored to assess transition readiness and a series of questions about needs and priorities for transition (e.g., expectations, preferences for modalities of transition) with comparative perspectives between youths and parents.

Results and conclusions: Concerns about the transition of care cluster around: (1) apprehension about adult care; (2) lack of clarity about the transition process; (3) emotional attachment to pediatric healthcare professionals; (4) significance of the coinciding transition into adulthood. Fourteen salient concerns (e.g., knowledge and information about transition, parental involvement in healthcare) were identified with corresponding recommendations to address them. These salient concerns touched upon important dimensions of human flourishing (e.g., environmental mastery, autonomy). We will discuss the implications of our findings, including new survey results and video content, available by the time of the meeting. We will also take this opportunity to reflect on the value and challenges of participatory action research in the context of transition.

Developing and Evaluating Clinical Ethics Frameworks at a Canadian Academic Psychiatric Hospital: Approaches to Knowledge User Engagement

Zahra Hasan, Marina Salis, Lee de Bie, Alannah Vila, Faisal Islam, Daniel Buchman

Clinical ethics frameworks are applied during clinical ethics consultation (CEC) to support patients, families, clinicians, staff, and ethicists navigate the ethical decision-making process. In a previous project, we conducted an analysis of 37 Canadian clinical ethics frameworks, comparing their substantive content and procedural development. While most institutions have mechanisms to evaluate their CEC services, only 8.1% identified distinct processes to evaluate their clinical ethics framework. During quality improvement interviews, practicing healthcare ethicists identified barriers to conducting evaluation including a lack of resources, ethics capacity, and awareness of ethics services. Congruent with our findings, the CEC literature lacks data on diverse knowledge user perspectives, including patients, families, and structurally vulnerable populations (e.g., racialized groups). Because clinical ethics frameworks are a downstream mechanism of CEC, these frameworks must be informed by evidence from a diverse range of knowledge users to understand how these frameworks support ethical decision-making and for whom.

In our current project, we are applying quality improvement and qualitative research methods to develop and evaluate a clinical ethics framework at a Canadian academic psychiatric hospital. The project is overseen by an advisory group comprised of patient and family representatives, clinicians, and staff. In this presentation, we will describe: (1) our methodologically diverse approach to knowledge user engagement, and (2) the enablers and barriers we encountered in this process.

Our project design is grounded in a developmental evaluation using data from our current ethics framework to inform any revisions. To understand clinician perspectives, we will conduct a pilot comparative analysis of both frameworks during CEC. We will also conduct focus groups with patients and families to understand their perspectives on the strengths, limitations, and goals of both frameworks. Our organizational engagement strategy includes consultations with clinical, organizational, and equity-focused leadership groups across the institution. Once we have generated an updated framework, we will conduct continuous quality improvement evaluations to further our understanding of context- and population-specific needs.

By prioritizing relationship-building and fostering trust with groups that are underrepresented in CEC data (i.e., patients, families, and equity-focused leadership), we strive to develop a clinical ethics framework that best supports all those who may benefit from CEC.

The Balancing Act: Parents' Experiences of Procedural Holding in Hospital

Sage Hay, Jenny O'Neill, Sharon Kinney, Stacey Richards, Meaghan Hawley, Fiona Newall

Background: Common clinical procedures in the paediatric hospital setting often require children to undergo some degree of holding. Holding children for procedures is widely accepted as necessary to complete the intervention in a timely and safe manner, however we know that there are also some negative consequences of holding for children and their parents. There are limited studies that capture the experiences of the parents, which is crucial to understand the risks and benefits guiding our practice. Objective: To explore parents' experience of holding children for clinical procedures in a tertiary paediatric hospital in Melbourne, Australia. Method:This is a qualitative exploratory study. Parents of children who had undergone a non-invasive clinical procedure during their hospital admission between October and December 2022, were invited to participate in a semi-structured interview. Analysis: Interviews were audio recorded, transcribed, and analysed using Braun and Clarke's reflexive thematic analysis. Results: Eight parents were interviewed, whose children ranged in ages from 3-months to 14-years. Key findings from understanding the parents experience, highlighted that parents have multiple roles during a procedure, with an overarching theme of parent as a protector. The parent's roles included being a comforter, a helper, and an enforcer, with parents often moving between different roles throughout a procedure. The varying roles suggest that parents are balancing their desire for their children to feel safe, holding as a comforter; with wanting to get the procedure done, and therefore holding as an enforcer. Conclusion: This study provides valuable insight into the complexity of the parents' position in supporting their child during a procedure in hospital. It emphasizes the need to recognise and understand the multiple roles parents take on, with the overarching role of parent as a protector. By understanding these roles, clinicians can support parents to minimize inappropriate holding and distress.

Me, Myself, and (Q)I: Review and Improvement Strategies for Lone Ethicists

Joan Henriksen

Excellent healthcare ethics consultants value accountability in their practice. The American Society of Bioethics and Humanities' Code of Ethics and Professional Responsibilities for Healthcare Ethics Consultants notes that competence "requires a commitment to subject one's work to peer review and scrutiny for quality improvement." It can be challenging to develop a rigorous system of review and quality improvement in settings outside of large academic medical centers. Many professional ethicists work alone, serving as the single ethics expert in healthcare organizations. What can peer review even mean in those circumstances?

There are not standard mechanisms for sharing cases and notes across organizations, so utilizing outside professional ethicist peers is not practical yet. In our experience, clinician volunteers on existing ethics committees have responded variably to participating in quality review. Some are reluctant, saying "we are not ethicists, who are we to review a specialist's practice?" while others are eager to weigh in with big ideas about how consults should go. Neither approach provides the meaningful review we would hope for.

This presentation will share our experience of designing and refining a quality review system for ethics consultations. People who volunteer for ethics committees typically enjoy hearing cases, but in a busy consult practice, case conversation can easily fill all committee meetings to the exclusion of other work. To begin our quality improvement process, we identified a small group of committed clinicians and added a separate meeting outside the full committee. Our review method evolved from summary explanations by the ethicist to a clinician-led and template-based discussion.

For our program, the key ingredients in building a robust improvement culture have included preparing committee members with intensive education on consult process and scope, assigning individuals to only one or two cases so they have time for a deep dive each month, providing a structured tool to guide the review, asking for questions and ideas and then taking those seriously. Even without multiple professional ethicists, clinical ethics programs can promote accountability. This presentation will share lessons, structures, and tools for developing quality improvement and review within ethics programs filled with clinician volunteers.

The Blood Of The Covenant Is Thicker Than The Water Of The Womb: The Ethical Obligation to Respect Chosen Families for Surrogate Decision Making

Patrick Herron

When patients are unable to make their own medical decisions, healthcare professionals have a legal and ethical duty to identify a surrogate. Historically, immediate family members have been called upon because they are assumed to have the strongest relationships as reflected in the commonly used saying, "blood is thicker than water."

For many persons, family is not defined by DNA. Literary scholars have pointed to alternate interpretations of this text as noted in this abstract's title to reflect an alternate meaning in which the bonds of friendship or the covenant voluntarily establish between persons has greater significance than involuntary kinship. While societal perspectives of what constitutes a family has evolved, individuals whose personal knowledge and insights regarding a patient's values and preferences would meet expectations for being ethically appropriate surrogates are not legally recognized or at best, deemed less qualified than persons biologically related. If the justification for identifying a surrogate is to respect a patient's autonomy and promote their best interests, then healthcare professionals have an ethical duty to honor those relationships that reflect the deepest bonds the patient has chosen to be their family.

Such relationships established outside of the parameters of biological or legal bonds are more frequently described as chosen family. The term has its foundational roots in the LGBTQ+ community. First written about by Kath Weston who analyzed the historical conditions, social meaning, and political implications of gender and sexual minorities who often experienced rejection and estrangement from their families of origin and in turn appropriated the language of kinship to represent an ethics of care amongst individuals often in the context of health and illness experiences. Chosen kinship is not unique to queer communities though as this call for care giving and mutual support outside of traditional bio-legal relationships is seen in other marginalized and disenfranchised communities. Traditional nuclear familial relationships are the basis for many states' and provinces' hierarchical frameworks for appointing surrogates for health care decision making but such a narrow structure denies the ethical legitimacy of chosen families and persons who are best suited to make decisions for the patient.

Redesigning and Expanding the Role of Community Members in Hospital Ethics

Jane Jankowski, Cristie Cole Horsburgh, Joshua Crites, Jennifer Katlen, Margot Eves, Susan Cash

The Center for Bioethics in our large healthcare system initiated a project two years ago to redesign how community members and healthcare professionals engage in and with ethics activities. This redesign included replacing hospital ethics committees with two integrated groups—the Ethics Ambassador Network or EAN (composed of healthcare professionals) and the Network for Connecting Communities and Bioethics or NCCB (community representatives).

Focusing on the NCCB, the presenters will discuss challenges the traditional ethics committee structure poses to meaningful community member participation from diverse and underrepresented groups. The presenter will then describe how community members instrumentally contributed to developing the core structure of the NCCB with those challenges in mind, including membership and recruitment, purpose, and charter. This structure provides opportunities for more meaningful engagement; the presenters will specifically outline the bi-directional relationship created between ethics programming and NCCB members as community partners via two primary functions: (1) amplifying and integrating diverse community perspectives into departmental initiatives (internal-facing) and (2) driving community-based activities and external-facing outreach. Through these functions, the NCCB aims to enhance the Center's partnership with the communities served by the organization and begin (re)building trust. Examples of departmental initiatives we anticipate NCCB members contributing to include quality assessment initiatives for the improvement of clinical services, development or revisions of ethics-related institutional policies, and project-oriented working groups. Community-based activities and outreach may include representing the Center for Bioethics at healthcare events, hosting community educational events, speaking engagements (e.g., at community service organizations, churches, senior and recreation centers, etc.), and providing tools that help address ethical issues in healthcare. In the past year, NCCB members have created patient-facing materials regarding medical decision-making, participated in events to amplify awareness of advance directives, and applied for a grant to hold a community summit to raise awareness of clinical ethics. To empower NCCB members to fulfill these functions, they also receive education and training in healthcare ethics, including quarterly brown bags and virtual ethics case discussions (alongside healthcare professionals). The session will conclude with the presenter highlighting successes and challenges experienced during the first two years of the program.

Ethical (and Equity) Implications of Guidelines Against The Use of Breastmilk Among People Living with HIV: A Violation of Equity and Ethics?

Thivia Jegathesan, Tomisin John, Mark Yudin, Michael Szego, Clara Juando-Prats, Douglas M. Campbell

Background: A parent's decision around the use of breastmilk to feed their newborn is deeply rooted in moral attitudes and values around infant feeding. People living with HIV (PLWHIV) experience additional moral conflicts when making infant feeding decisions for their newborn due to the stigma associated with an HIV diagnosis. While the World Health Organization encourages the use of breastmilk among PLWHIV in developing countries, the American Academy of Pediatrics discourages the use of breastmilk. This creates additional moral tensions and

conflicts among PLWHIV.

Objective: The primary objective of this study was to obtain a better understanding of PLWHIV's ethical values around infant feeding and experiences interacting with the health system during their pregnancy and shortly after birth. The secondary objective was to critically evaluate current guidelines around the use of breastmilk among PLWHIV with PLWHIV's reported lived experiences.

Methods: A critical qualitative study using participatory approaches with semi-structured interviews was conducted with PLWHIV who recently gave birth at an urban center. Using an ethics of care approach, inductive thematic analysis was applied to analyze interviews to identify ethical and equity implications of current breastfeeding guidelines among PLWHIV and whether these guidelines were justified.

Results/Analysis: 10 PLWHIV consented and completed semi-structured interviews. Three major ethical themes emerged; 1) It was important for PLWHIV to be able to make autonomous decisions around the use of breastmilk for their newborns based on their own values, and perspectives. In addition, they wanted to be informed about the risks however it was important to them to be able to make the final decision. 2) PLWHIV reported moral conflicts when deciding whether or not to breastfeed when balancing multiple perspectives from their family, culture, perceived societal norms and previously reported risks to their newborn. 3) Some PLWHIV reported feeling recommendations against the use of breastmilk or risks of using breastmilk was limiting their autonomy. Conclusion: The use of breastmilk is a deeply cultural, social, and personal choice; restrictions to these decisions violate equity and PLWHIV's autonomy. As a next step, patient partners will be consulted to inform recommendations around the use of breastmilk among PLWHIV.

AI in the Ethics Committee: Appraising the Role and Quality of ChatGPT for Ethics Consultation

Daniel Jenkins, Christian Vercler, Andrew Barnosky, Janice Firn

Background: Artificial Intelligence (AI), particularly widely available public models like ChatGPT, has revolutionized the generation of human-like thought processes and text. Across healthcare, the integration of AI in decision-making processes is increasingly pervasive. However, the intersection of AI and clinical ethics consultation remains relatively unexplored.

Objective: To assess ChatGPT's capacity to evaluate ethical dilemmas and produce rigorous analysis, discussion, and actionable recommendations.

Methods: Ethics consultation notes from a tertiary, academic medical center were randomly selected and de-identified. Notes contained a brief medical summary, description of the ethics concern/values disagreement, ethical analysis/discussion, and recommendations. A clinical ethics dilemma was chosen randomly from the consult database as a test case. We trained ChatGPT using three separate 'chats' with one, two, or five unique notes and asked it to produce an ethical analysis/discussion and recommendations for the test case. We conducted this same series again but gave ChatGPT only the ethical analysis/discussion and recommendation sections from the training notes to learn from. Two independent raters scored ChatGPT's ethics consultation documentation using the validated Ethics Consult Quality Assessment Tool (ECQAT).

Analysis: We calculated interrater reliability and trends in ECQAT scores for each 'chat' session.

Results: When trained with full notes ChatGPT's ECQAT overall holistic rating score for each 'chat' was 2.5 for one note, 1.5 for two, and 2.5 for five. When trained using only the ethical analysis/discussion and recommendation sections, ChatGPT scored 3 for one note, 2 for two, and 1 for five. There was 87.5% agreement between raters on the acceptability of ChatGPT's ethics consultation documentation.

Conclusion: ChatGPT's capability to process ethical dilemmas reveals a correlation between the extent of exposure to relevant case material and the quality of ethical analysis and recommendations produced. While scores varied, when provided with comprehensive consultation information, ChatGPT produces moderately effective ethical analyses and recommendations. The lower scores achieved when ChatGPT was trained solely on the ethical analysis/discussion and recommendation sections indicate that contextual understanding plays a substantial role in performance. Extensive training or alternative methods to achieve higher reliability and ongoing human oversight are needed if ChatGPT is used in ethics consultation.

Patient Engagement in Genomics Research: A Personal Utility Approach

Ralf Jox, Brenda Bogaert

Background

An important part of patient engagement is helping persons develop resources and knowledge to be able to act on their health. In the case of genetics and genomic research, the return of research results gives the opportunity for patients and their families to gain access to treatment, to better understand risk factors, as well as to better plan their lives. While guidelines have been developed based upon expert consensus, the patient's perspective has largely been absent. In this research, we gathered patient perspectives and mobilized the concept of personal utility to better understand patient perspectives.

Objective

The objective of the research project was to explore and document patients' perceptions of research return of genome analysis results, including their expectations, needs, and implications for relatives. The project also had a practical aim, namely to improve guidelines and practice on the return of genetic and genomic information in clinical research at the university teaching hospital in Lausanne, Switzerland.

Methods

The study design was qualitative, consisting of semi-structured interviews with patients while they were awaiting their test results for patients who had a family history and/or suspected genetic origin to their illness. This project was part of a wider study which aimed to identify monogenic forms of cardiomyopathies and/or canalopathies as risk factors for cardiac arrest.

Analysis

The data was analyzed thematically by several researchers and coding was input into MAXQVA software to help organize data and facilitate interdisciplinary exchange between researchers.

Results

Our results highlight patient perspectives on the return of genomic results in the context of sudden cardiac death. Our data closely correlates with literature on personal utility, including cognitive outcomes, behavioral outcomes, and affective outcomes. Overall, our study contributes to better understanding patient engagement in genomic testing and in particular the personal utility to them of the return of genomic results, including what to do with incidental findings and negative results.

Comment Peut-on Protéger la Santé Sexuelle de Nos Usagers? - How Can we Protect the Sexual Health of Our Residents?

Kristina Kekesi-Lafrance, Meredith Schwartz

Sexual health is part of our overall health, and some even speak of a right to sexual health. Yet we're not all on an equal footing when it comes to meeting these needs. For example, residents our health and social care facilities (long-term care, assisted living homes for people with disabilities) can rarely form relationships in the typical way by going out into the community to meet people. Some turn to health care professionals and request access to the services of a sex worker. In particular, some of them want to hire a sex worker with experience working with people with disabilities. However, current legislation does not allow such services to be solicited. Some family members or professionals are prepared to take the risks associated with solicitation on behalf of the person with disabilities, but most residents are on their own to cope. As a result, health care professionals generally lack the tools to navigate these situations. Can a healthcare facility tolerate such a practice? How can this service provision be safely managed? Are there clinical alternatives to meet these requests? Are there ways of collaborating with community resources to meet the needs of our residents? Sex workers are themselves members of our communities, but the legal barriers in place make their full integration and collaboration difficult in this context. What happens to the resident's sexual and mental health if we refuse their request? How can we facilitate access to overall health, and include them throughout the process? We propose to present a multidisciplinary portrait of the situation at its current stage, and to provide some food for thought for the future. The aim is to encourage dialogue on the issue, explore some common solutions and continue to normalize the taboo subject of sexuality among our residents.

Building Legitimacy Online: An Ethnography of a Facebook Support Community for Canadian Women with Fibromyalgia

Jenna Kerr, Carey DeMichelis

Background: Women with fibromyalgia (FM) - a contested illness category characterized by chronic widespread pain - are faced with the challenge of communicating the legitimacy of an invisible affliction in order to access adequate medical care. Recent studies of online chronic pain support communities reveal how digital connectivity can be utilized for coping and navigating access to care. At present, however, minimal research has explored the dynamics of private online spaces.

Objectives: To explore the various ways that Canadian women with FM go about legitimizing and coping with a contested condition, and the role that online community plays in these efforts.

Methods & Analysis: Through ethnographic observation in a private Facebook group (pseudonymized as "Fibro Women Canada") and in-depth interviews with five of its members, we explore how women come to be seen as legitimate (or not) in the eyes of their healthcare providers. Our arguments stem from an interpretative phenomenological analysis.

Results: Attending to the moral stakes of seeking biomedical recognition, we illuminate the strategies that these women devise within their online community to construct themselves as credible patients who are deserving of care. We find that Fibro Women Canada functions as a backstage environment that supports two distinct, yet interwoven, forms of legitimacy-building: (1) illness literacy, and (2) identity work.

Conclusions: We argue that FM produces a crisis of legitimacy, a crisis of identity, and a crisis of morality for its sufferers; within these, the illness burden is compounded by complex inter- and intra-personal relations of (dis) trust and epistemic harm. Fibro Women Canada strives to guide members on a path to moral repair and care justice.

Facilitators and Barriers Towards Establishing the Clinical Ethics Committee in the Tanzanian Context

Shija Kevin Kuhumba, Trygve Johannes Lereim Sævareid, Albert Christiaan Molewijk

Background: Moral dilemmas are an inseparable part of daily clinical practice in healthcare. In the clinical setting, ethical dilemmas contribute to the complexity of decision-making for healthcare providers. Clinical ethics committees (CECs) have been developed in healthcare settings to support healthcare professionals, patients, relatives, family members, and community members by analyzing value conflicts related to clinical practice.

Over decades, hospitals in Europe and North America have increasingly introduced CECs with different models of consultation and structures. In Sub-Saharan Africa, a few countries have implemented CECs in the hospital setting. Tanzania has not yet established CECs. Thus, implementing sustainable CECs in hospitals requires understanding facilitators and barriers.

Objective: This paper explores the existing facilitators that would guide the effective implementation of CECs in hospitals and provide foresight for the barriers that might impede the effective implementation of CECs in Tanzania.

Methods: This study used qualitative research methods. Data was collected in three hospitals. Researchers recruited study participants in intensive care units, emergency, internal medicine, and surgical departments. This study used the in-depth interview method for data collection. A total of 35 participants, including physicians, nurses, and hospital administrators were recruited for this study.

Analysis: The present study employed a thematic analysis approach in analyzing data.

Results: The study participants identified several facilitators that could support the establishment of CECs. These facilitators are categorized as follows: structural, institutional, national, research and academic, community, as well as existing partnerships and networks. While participants demonstrated keen interest and readiness for establishing CECs, they articulated several potential barriers that might hinder establishing and implementing CECs in hospital settings in Tanzania. The identified barriers are limited financial resources to implement CEC activities, time constraints among healthcare professionals to attend CEC meetings, inadequate availability of trained ethicists, clinical ethicists, and bioethicists, lack of willingness to report ethical issues, lack of awareness of CEC functions, and roles among healthcare professionals, hesitation from hospital management, perceiving a CEC as a disciplinary, and fear of breaching confidential information discussed in a CEC meeting.

Conclusion: All participants attested to the paramount importance of CECs in addressing moral dilemmas and ethi-

cal challenges.

The Health and Welfare Commissioner's Consultation Forum: A Deliberative Body That Helps Identify and Analyze Ethical Considerations Related to the Performance of the Health and Social Services System

Maude Laliberté, René-Pierre Turmel, Sarah Thibodeau, Ariane Quintal, Georges-Charles Thiebaut

Background: The Health and Welfare Commissioner (CSBE) assesses the performance of Quebec's health and social services system. Due to the system's complexity, a variety of perspectives must be taken into account to understand it. The CSBE incorporates the views of the population into its performance assessment, in particular through the contribution of its Consultation Forum, made up of 16 citizens and 9 experts from various regions of Quebec.

Objective: Integrate ethics and stakeholder perspectives into the CSBE's work by identifying and analyzing values and ethical considerations based on the Forum's work

Method: Non-systematic review of scientific and grey literature, as well as discussions with experts in ethics and public participation

Analysis: The procedure chosen to support the deliberative process was ethical deliberation. An inductive ethical analysis was also carried out on the basis of the deliberative reports to identify, define, and analyze the values and ethical considerations mobilized.

Results: Ethical deliberation is a process of arriving at reasoned positions based on a diversity of views expressed by members on an issue or item submitted to them. To do so, members are invited to openly discuss the issue. This exercise, focused on the collective interest, is based on relevant and objective information, while taking into account members' personal experiences and values. The views expressed by members must be aimed at improving the health and welfare of Quebecers through their interactions with the health and social services network. They must also be pragmatic and take into account the system's limited resources. The values and ethical considerations identified are then triangulated with the literature to draw out societal values and identify systemic ethical issues. The results of ethical deliberation thus shed light on the CSBE's work.

Conclusion: Public participation through the Forum's deliberations brings an ethical perspective to its analytical framework and its work on the performance of the health and social services system. The deliberative approach allows us to see ethics as an exercise in mobilizing experiences and values to offer an inspiring yet pragmatic perspective.

Beyond Medical Facts: Decision-Making in the NICU

Elizabeth Lanphier, Uchenna Anani, Carey DeMichelis

Background: The parent-physician dyad has primarily been the focus of ethical research on shared decision-making in the Neonatal Intensive Care Unit (NICU). However, multiple stakeholders, including other members of the NICU healthcare team are invested and may influence these decisions. There is limited empirical research on the "behind the scenes" interactions and decisions that shape shared decision-making. Moreover, there is little understanding on how contextual features such as social and political determinants of health may or may not influence healthcare provider decision-making in the NICU.

Objective: To explore (1) how multidisciplinary NICU providers, individually and collectively navigate decision-making, and (2) the ways social and political differences between families influence healthcare provider decision-making in the NICU.

Methods: Using a focus group design, multidisciplinary teams of NICU providers were asked to review a highly contested ethical scenario: a hypothetical case of a neonate with severe neurological impairment from hypoxic ischemic encephalopathy. Each focus group received the same medical information regarding the patient; however, the social information provided regarding the family (including SES, first language, access to care, religious background, family structure, and community supports) were intentionally varied.

Analysis: We present a comparative thematic analysis of this qualitative focus group data. Our analysis focuses primarily on the issue of continued intervention, and is underpinned by a constructivist theory of knowledge production.

Results: Our analysis reveals important differences in the way focus group participants: 1) construct medically appropriate care; 2) respond to parental requests for continued intervention; and 3) incorporate the family's educa-

tion, income, geography, medical literacy, and active presence on the unit in their deliberations. These findings suggests systematic variations in which families are seen as capable, whose wishes are likely to be accommodated, and when withdrawal over objection is most likely to occur.

Conclusion: Our data suggests systematic variations in NICU providers' willingness to compromise/accommodate family requests for continued treatment. It challenges the common belief that medical facts alone dictate the plan of care for patients, revealing instead the way non-clinical data can shift the interpretation of medical facts.

Document Analysis on Breast Cancer Screening in Quebec, Ontario and Canada: How Do We Communicate Relevant Information?

Alexandra Larocque, Nathalie Gaucher

Background: The information made available to women invited to participate in screening mammography is crucial to obtaining informed consent. Expert recommendations on breast cancer screening are not always consensual and may be difficult to follow for non-experts. The objective of this research was to analyze the information made available to women.

Methods: A document analysis was conducted using the READ method. Documents published between 1999 and 2023, from Quebec, Ontario, or Canada, containing the keywords "breast cancer screening" and "screening mammography" and available on the Internet were included in the analysis. All documents were analyzed using a 16-category grid developed for this analysis.

Results: 51 documents were identified and included (Qc: 16, On: 11, Can: 24). 11 documents were excluded. Very few women from the public were indicated as part of the drafting committee (8%), but the majority of contributing experts were women (54%). 42% of the documents were considered inaccessible using the Flesch-Kincaid score. Benefits were mentioned more often than the risks (90% vs 37%). Several documents confused screening and diagnostic tests (15%). Women under the age of 50 were overrepresented (81%) and racialized women underrepresented (57%).

Conclusion: This analysis shows that biases exist in the design of these documents, in the presentation of information and in the message conveyed to women, which could influence their decision-making. Promising practices were identified, such as presenting both risks and benefits and including women in the conception of the documents.

Influence of Possible Parental Proximity on Reasonable Treatment Decisions in Pediatric Intensive Care

Fleur Le Bourgeois

In France, the decision to withdraw or limit life-sustaining treatment (WLST) in pediatrics is a medical decision. The discussion is mainly based on medical criteria, but not only. Healthcare professionals (HCP) are going to have to argue using conscious and/ or unconscious projections. In pediatrics, the projection of parent involvement with their child, and the importance given by HCP to this implication, could be critical elements in the WLST decision. To what extent does the projection of parental involvement in the care project influence the WLST decision?

In a French pediatric intensive care unit, HCP were asked to fill out an electronic survey which presented a vignette. It was a 2-month-old patient whose neurological, digestive, and respiratory prognosis were uncertain. The patient was dependent on mechanical ventilation and parenteral nutrition. Five situations were presented, each with a different scenario of parental context: unknown parental context, parents living near the institution, parents living abroad, a single mother living 1h from the institution and the child was an orphan. The parent(s) deferred to the decision of the healthcare professionals trusting them. HCP were asked to decide between continuation of artificial organ support for an undetermined time in long-term care institution (LTCI), palliative support care until death or no decision.

Fifty-eight HCP completed the questionnaire. When parental background was unknown, the decision was balanced between all alternatives (continuation of treatments 38%, WLST 33%, no decision 29%). When the parents were living nearby the LTCI, 64% of HCP decided continuation of treatments, conversely, if the parents were living far away or completely absent, a WLST was decided by 64 and 79% of HCP respectively.

The quality of the bond between parents and their sick child is difficult to quantify and predict. However, the possible absence of a relationship, or the difficulty in developing one seems to be a pejorative factor in HCP's projection, of the child's future situation. Even if those non-medical factors are important to consider, they can sometimes lead to mental shortcuts. To limit these biases, HCP should be trained in ethics of care, and be helped by

ethics consultation during meetings.

The Contribution of a Hospital-Based Organizational Ethics Program to a Balanced, Shared Decision-Making Approach

Suzanne Longpré, Gabrielle Lemieux

The McGill University Health Center (MUHC) has developed an Organizational Ethics program to address recurring ethics dilemmas that risk having significant institutional impact. The program includes an Organizational Ethics consultation service, provided by the MUHC's Centre for Applied Ethics, as well as the Organizational Ethics Advisory Council (OEAC), which includes a patient-partner and is chaired by the MUHC's Associate President and Executive Director.

Balanced, shared decision-making

Three decades of clinical ethics consultations have revealed the importance and frequency with which patients, family members and teams encounter difficulties with the shared decision-making model, as well as numerous obstacles to preventing and managing situations of potentially inappropriate care. The OEAC therefore developed and promoted a renewed approach to shared decision-making that clarifies roles and responsibilities and offers ethics guidance with the aim of balancing equally legitimate values that are in tension. The approach is consistent with the most recent guidelines for consent to care jointly developed by the Quebec medical and legal professional associations, in addition to further promoting relational ethics and people-centered care. It also states the values prioritized by the MUHC regarding potentially inappropriate care (e.g. patient's best interests, professional integrity, distributive justice) and how the institution will provide support in a consistent and aligned manner.

Ensuring appropriate care

More recently, the OEAC has elected to develop institutional policy and support the development of mechanisms that promote care appropriateness. An Organizational Ethics working group, comprised of a patient-partner, senior management, medical leaders and an ethicist, will rely on patient experience feedback, a recent literature review and benchmarking data to fulfil its mandate. The MUHC's Pediatric and neonatal non emergent tracheostomy decision-making policy, which establishes a multidisciplinary process and medico-ethical criteria for decision-making in complex situations, will serve as a model for the development of intervention-specific mechanisms.

Increasing Ethicist-Patient Engagement: The Role of Narrative and Literature in Clinical Ethics Education

Georgia Loutrianakis

Some of the core competencies identified by the American Society for Bioethics and Humanities as necessary for ethics consultations (such as moral reasoning, interpersonal skills, and ethical assessment and analysis) are significant, but difficult to develop without practical experience. However, bioethics graduate students who wish to pursue careers in clinical ethics consultation may find such practical opportunities difficult to come by. In this presentation, I explore the strengths and limits of the incorporation of narrative literature education in bioethics graduate programs for the teaching of skills that are crucial for ethicist-patient engagement in the clinical space, but difficult to quantify, such as close listening and empathy.

Within medical and other health professions' education, it's widely recognized that exposure to narrative literature can help students learn how to interpret "what is being said" even when meaning is not expressed directly, how to think about moral values in the clinical space, and how to draw attention to and encompass different perspectives. Despite the integration of narrative medicine into medical and health profession studies, there is little discussion of its use in clinical ethics education.

I will analyze the relationship between goals in clinical ethics consultation, according to the American Society for Bioethics and Humanities' core competencies, and provide examples of narrative and literature studies that can help students and trainees build related skills. For example, a large goal of clinical ethics consultation is to "identify and analyze the nature of value uncertainty or conflict." Using texts like "It's Over, Debbie" and *Borrowed Time: An AIDS Memoir* by Paul Monette can provide students with insight into the concrete process of balancing ethically laden values by studying how to respect language and adopt differing points of view. Another important goal in clinical ethics consultation is to "build principled ethical resolutions." Works like *The House of God* by Samuel Shem and *When Breath Becomes Air* by Paul Kalanithi can instruct how to facilitate the resolution of conflicts by teaching how to integrate isolated phenomena so that they suggest meaning and how to understand one story in the context of other stories.

Medical Assistance in Dying in a Pediatric Context: A Mixed-Methods Research in a Canadian Pediatric Tertiary Care Hospital

Marta Martisella, Marc-Antoine Marquis, Audrey Stypulkowski, Claude Julie Bourque, Marie-Ève Bouthillier

Background : In 1999, a pediatric palliative care (PPC) team was established at CHU Sainte-Justine (CHUSJ) in Montreal. While its primary focus is pediatric care, it also provides support to a few young adult patients who, under specific conditions since 2015, may request Medical Assistance in Dying (MAiD). However, these types of requests, as well as the perspectives of healthcare professionals who receive them remain understudied.

Objectives : 1) To describe and analyze healthcare professionals' perspectives regarding these requests. 2) To describe the characteristics of cases involving interactions regarding MAiD between the PPC team and patients or parents and to create a typology and clinical vignettes to support the PPC team and training needs.

Methods and Analysis : 1)Thematic analysis was conducted by extracting emerging themes from semi-structured individual interviews with both members of the PPC team (N=10) and team collaborators including parent partners (n=14). 2) Critical documentary analysis of archives (2013-2023).

Results : 1) Central themes identified from the interviews included 1) current issues, 2) anticipated issues and measures to be taken if MAiD criteria expand to minors, 3) conditions for the acceptability of care, 4) healthcare professionals' concerns and 5) role of stakeholders. 2) Since 2013, the PPC team received 11 MAiD requests from patients (n=3) or parents (n=8). These requests have been implicit (n=2), exploratory explicit (n=5), and direct explicit (n=4). They were initiated when the patient was at the end of life (n=6), during acute deterioration episodes (n=2), or in the context of gradual decline in their condition (n=3). Patients suffered mainly from oncological (n=4), genetic (n=3), metabolic (n=2) or neurological diseases (n=2). One patient died with MAiD after reaching the legal age of 18 years old, with the continuous support of the PPC team.

Conclusion : This study provides new knowledge and avenues to guide MAiD practices in pediatric care, both in the present and in the future should eligibility criteria expand to include minors. These findings represent an essential initial step in establishing a solid understanding of this complex issue, paving the way for future research involving patients and parents.

Establishing Testimonial Justice: Rebuilding Trust in Black Maternal Health

Rochelle Maurice

Morbidity and mortality rates in perinatal care culminate to one bleak statistic: Black pregnant and birthing people are at least three times more likely to experience death or severe illness. Many studies examine social determinants of health to understand the disparities in the rates of morbidity and mortality in perinatal care; however, there is a significant relational component that can provide important insight to these disparities. Trust is at the centre of this relational component. While some studies identify distrust as a theme, it is often examined in the context of Black patients not trusting their care providers. However, there has been evidence that the lack of trust in Black birthing people's reports have led to troubling outcomes. From personal stories to documentaries, it has been well documented that the ways in which Black birthing people's credibility about their embodied knowing have been diminished. Despite finding compensatory ways to demonstrate that their testimony should be trusted, Black birthing people continue to be confronted with the same experiences of diminished trust. This is an important area for exploration, as the lack of credibility afforded to Black people historically still exists in perinatal care spaces, thus impacting birthing outcomes.

Many organizations have implemented implicit bias training and established equity, diversity and inclusion departments as a means for broadly addressing inequities in healthcare delivery. However, these approaches are inadequate for comprehensively attending to the specific issues faced by Black birthing people and their interactions with healthcare providers. Using Black Feminist Thought, Reproductive Justice, and Testimonial Injustice as organizing theoretical frameworks, I will examine trust in the encounters between Black birthing people and their care providers to shift the perspective on the understanding of diminished trust in these contexts. I will then discuss how understandings of trust and trustworthiness still disproportionately burden Black pregnant and birthing people. Finally, I will re-conceptualize trust building at the interpersonal level in birthing spaces, highlighting the ways in which community can contribute important foundations for the relationship between Black pregnant and birthing people and their care providers.

Attitudes Towards Disease Model Explanations of Chronic Pain Among Canadian and US Adults Without Chronic Pain: Ethical Implications for Stigma

Iris Coates McCall, Rachael Bosma, Chris Lo, Javeed Sukhera, Jennifer Chandler, Emeralda Burke, Dwayne Patmore, Brooke Magel, Zahra Hasan, Karen D. Davis, Daniel Buchman

Background: Chronic pain is a highly stigmatized condition. Some argue that advances in neuroscience and recent changes to ICD-11 pain classifications support the idea that chronic pain is a disease rather than merely a symptom, and that this may help reduce stigma. However, evidence from the brain disease model of addiction suggests that it may inadvertently increase aspects of stigma. It is unknown whether labelling chronic pain as a disease will have similar unintended ethical implications.

Objective: Determine the pervasiveness of a brain disease explanation of chronic pain and investigate its impact on the degree to which adults without chronic pain stigmatize others who live with chronic pain.

Methods: We randomized 508 Canadian and American adults without chronic pain to vignettes about a fictitious person (Sam) whose physician explains that their chronic pain is due to i) no physical cause; ii) biological, psychological, and social factors; iii) a disease; iv) a brain disease; or v) a brain disease and biomarkers, accompanied by a picture of a brain. Participants then responded to survey questions to measure their judgments of stigma using a modified composite social distance score, estimated pain level, pain exaggeration, trustworthiness, and sympathy towards Sam.

Analysis: We analyzed survey responses using Kruskal-Wallis tests, a Mann-Whitney U test, and Beta and Linear regression models to understand how the contrastive manipulation of the vignette affects responses.

Results: Compared to the no physical cause vignette, participants who viewed the disease and brain disease vignettes perceived Sam's pain to be greater, had more sympathy, were more willing to help Sam, and thought Sam was less likely to exaggerate and more likely to be telling the truth about their chronic pain. There was no statistically significant difference in social distance towards Sam based on the vignette.

Conclusions: Our results suggest that disease and brain disease explanations of chronic pain may influence some dimensions of stigma. To further understand the nuances of chronic pain related stigma, we will conduct qualitative interviews with people with chronic pain and healthcare professionals to explore the meaning and significance of a brain disease model of chronic pain on stigma.

Bringing the Voices of Children and Youth into Ethical Deliberations Concerning Artificial Intelligence in Healthcare

Abdullahi Mohamud, Melissa McCradden

Background:

A scoping review of the literature identified very few studies that sought to understand the perspective of children and youth on artificial intelligence (AI) in healthcare. It is vital to gather the perspectives and perceptions surrounding the ethical use of these tools with respect to children and youth.

Objective:

To characterize patient perspectives on the critical ethical considerations involved in the use of AI in healthcare research and clinical practice.

Methods:

A 2-hour virtual multi-method workshop was conducted via Zoom for Healthcare to collect both quantitative and qualitative data. We reached out to individuals from our previous pediatric healthcare studies, and eight consented to participate in this research. Among the participants aged 10-14 years old, three were female, two were male, and three chose not to disclose their gender.

Analysis:

All participant responses from the audio-recording transcripts, interactive slides text, and Zoom chats were combined and inputted into an excel document to create one dataset. Two team members lead the content analysis of the dataset. Quantitative data are presented as descriptive statistics while qualitative data are represented textually.

Results:

The mean (SD) age of the eight children and youth participants was 12 (1.4) years. An inductive approach revealed

ten key themes regarding their views on the use of AI in healthcare settings. These themes included 1) the use of health data from research participants, 2) health research data enrollment type, 3) viewpoints on sensitive data types, 4) inter-hospital data sharing, 5) organizational trust in healthcare organizations, 6) awareness of the conditions for participating in clinical AI research, 7) recognizing the vulnerability within pediatric clinical populations, 8) potential harms and consequences, 9) recognizing the bias that can occur with utilizing AI within this field, and finally 10) the perceived role of doctors in the age of AI.

Conclusions:

The findings from this study explore the critical need to explore and amplify the perspectives of children and youth when considering integrating AI in the healthcare setting. It is pertinent that their unique perspectives are acknowledged and included in both the research and clinical space.

The Strength of Avoiding Right and Wrong. Using Dialogical Ethics Support and Action Research for Fostering Psychosocial Safety

Bert Molewijk, Charlotte Kroger, Eva van Baarle

Strengthening psychosocial safety in the workplace and educational contexts is increasingly prominent within healthcare and teaching programs at medical faculties. Worldwide, the #MeToo movement has drawn significant attention to issues like (sexual) harassment, bullying, and power abuse. A psychosocially safe working and learning environment is not only morally imperative but also essential for fostering interdisciplinary professionalism and a positive learning climate. Furthermore, research indicates that a lack of psychosocial safety in the workplace and educational settings may lead to increased sick leave and employee turnover.

A traditional response to incidents and scandals related to psychosocially unsafe environments typically involves: A) Establishing clear norms that define what is morally wrong and morally appropriate (e.g., within policy documents and codes of conduct); B) Implementing various educational programs and interventions that explain what psychosocial safety means in practice and what behaviors are considered inappropriate; C) Creating a specific reporting structure for employees and students to report negative experiences. Paradoxically, this heightened attention to psychosocial safety can either make people more judgmental of others' behavior or make employees, especially leaders or supervisors, uncertain about what is currently deemed morally appropriate, such as when giving critical feedback or making jokes.

In response to requests from two clinical wards, the Ombudsman's office (along with confidentiality officers) and our Ethics Support Group (providing clinical ethics support services and research) have been called upon to develop and pilot a participatory action research program with dialogical ethics support, comprising two phases: A) attending three dialogues facilitated by 2 facilitators, and B) harvesting and initiating employees' suggestions to strengthen their psychosocial safety.

During our presentation, we will first provide a more detailed overview of the program's structure. Second, we will focus on a particular philosophy and perspective on ethics support, emphasizing the use of the inherent epistemological uncertainty within ethics by prioritizing dialogue and moral inquiry rather than aiming for definitive moral norms. This approach can help create a safe atmosphere when discussing sensitive and vulnerable issues. Third, we will delve into one specific newly developed conversation method for a dialogical ethics support: the "grey zone."

Counterbalancing Polarization in Healthcare Through Moral Distress Reflective Debriefing

Georgina Morley, Cristie Horsburgh, Laura Guidry-Grimes, Lauren Sankary, Natalie Weigand, Laura Longbrake, Jennifer McLellan Johnson, Margot Eves, Joshua Crites

The healthcare climate feels increasingly politicized and polarized, exacerbating healthcare workers' (HCWs) experiences of moral distress. In the US, legal constraints in the provision of abortion care and gender-affirming (adolescent and adult) care have resulted in HCWs experiencing moral-constraint distress because they are unable to provide care that is consistent with the standard of care, patient safety, respect for persons and individual choice. Other HCWs have expressed moral-constraint distress because they feel obligated to provide care inconsistent with their personal values and political beliefs. In this workshop, we will describe our structured approach to facilitating Moral Distress Reflective Debriefs (MDRDs), which have been utilized in our large US healthcare system to facilitate over 60 MDRDs to ~350 HCWs since 2019 in response to these (and other) polarized and morally distressing issues. The aims of MDRDs are to provide morally distressed HCWs with a safe space to share their moral perspectives, explore the basis of their beliefs, better understand the moral event causing distress, and engage in perspective-taking.

The rise of disinformation around abortion care and gender-affirming care, which include unsupported claims about 'reimplanting' rather than terminating ectopic pregnancies, adolescent 'peer contagion,' and patient regret perpetuates concerns for stigma, bias, and discrimination. In this context, clinical ethicists facilitating MDRDs must balance tensions between HCW's right to conscience claims with their obligations to address stigma and bias that compromise patient care. Workshop leaders will provide an overview of the MDRD process, describing how facilitators strive to mitigate the negative effects of moral distress through discussion, reflection, empowerment, and a sprinkling of ethics education. We will describe additional measures implemented to optimize the safety of the moral space when exploring polarizing ethical issues and methods used to validate experiences of moral distress while balancing the affirmation of diverging values with challenging fear- or stigma-based beliefs or assumptions. Audience members will be able to practice facilitating aspects of an MDRD. The session will conclude with a reflection on how we supported HCWs who expressed worries about providing abortion or gender-affirming care with further education that was tailored to skill-building and increasing their confidence.

Navigating Barriers to Meaningful Connections: Unraveling the Impact of Stereotypes and Listening Across Differences

Debjani Mukherjee, Fahmida Hossain

As clinical ethicists, the importance of partnering with patients is recognized, and meaningful connections are foundational to excellent consultation practice. This paper, co-authored by Bengali-speaking clinical ethicists with diverse religious, national, and generational backgrounds, draws on their unique experiences to collectively explore the potential dynamics hindering connection and collaboration. The authors will explore the challenges posed by social or moral disparities between patients and healthcare providers, particularly in instances where trust is compromised, stereotypes prevail, and effective cross-cultural communication is neglected.

In healthcare, trust forms the bedrock of successful encounters. When this trust is eroded from either the patient or provider perspective, a chasm may emerge, impeding effective collaboration. Drawing on their personal and professional experiences, the authors will describe clinical scenarios where stereotypes—preconceived notions and biases— may hinder the establishment of a genuine, mutual understanding between the two parties.

Stereotypes, whether based on cultural, social, or personal factors, can perpetuate miscommunication and reinforce simplistic ideas about the other. Strategies to recognize, address, and engage with stereotypes will be explored, emphasizing the importance of fostering cultural competence and awareness among clinical ethicists.

The first author will examine the use of narrative-based approaches. Narratives have the power to dismantle stereotypes by humanizing both patients and providers, fostering empathy, and promoting a more nuanced understanding of diverse perspectives. The second author will critically examine the role of implicit and explicit biases. She will focus specifically on brief, often emotionally charged, clinical ethics encounters, and consider the challenge of making judgments and processing complex information.

Together the authors emphasize how active, empathetic listening is indispensable in building bridges and fostering understanding between patients and providers, especially when faced with conflicting social or moral judgments. Practical approaches to enhance listening skills and promote cultural humility are discussed, providing a roadmap for clinical ethicists to navigate the complexities of patient partnership in diverse and multicultural settings.

Hindering or Helping: Focus Groups With Key Stakeholders on Patient Participant in Urgent Decision Making by Clinical Ethics Support Services

Katherine Murdoch

Background:

Clinical ethics support services (CESS) often deliberate when there is time for discussion. This becomes more challenging when there is an urgent decision. Patient involvement in clinical ethics remains a contentious issue without uniform practice regarding if, how, and when they should be involved. There are challenges to including patients in ethics support services and preference to do so depends on the individual service. Understanding patient involvement in the context of urgent decision making has yet to be explored.

Objectives:

The main objective was to understand clinical ethics support service member and clinician viewpoints on patient involvement in the context of urgent decision making by CESS.

Methods:

Three stakeholder groups were recruited - CESS members in England, Doctors in England, and CESS members in the United States. Participants in England were recruited by dissemination of the study online. International participants were contacted via email. This resulted in a sample size of 13 participants.

Analysis:

The focus group transcripts were analysed using reflexive thematic analysis, which took an iterative approach to coding and theme development. Resulting themes encompassed codes generated from all three focus groups.

Results:

The theme, 'hindering or helping' describes the uniform view of the importance of patient and/or family representation by all three groups of stakeholders. However, the ways in which their involvement was facilitated varied. CESS members in the United States routinely involved the family directly by discussion with the clinical ethicist. However, CESS members in England and doctors viewed patient and/or family involvement in committee meetings as a barrier to open discussion. Instead, CESS in England would seek ways in which involvement could occur, such as a written statement, advocation by the clinical team or a CESS member.

Conclusions:

The clinical ethicist model appears to support direct patient involvement in the consultation process, in comparison to the clinical ethics committee model. There were direct differences in support between CESS members in England and in the United States. However, these results are limited by the small sample size and small number of viewpoints represented.

Considerations for Community Engagement in Artificial Intelligence in Africa: A Review of Literature

Harriet Nankya

Artificial intelligence (AI) is poised to impact Africa in several ways; promising to reduce inequality, alleviate poverty, and improve access to public services like health and education. There are however, challenges to AI in Africa given a vast digital divide, electricity and internet cuts, high rates of poverty and brain drain. This is coupled with ethical concerns of fears of data colonialism, potential exploitation of African data without equitable benefits, among others. Such distinctive challenges necessitate the development and application of AI solutions tailored to the African local needs through community engagement.

This paper is a review of literature on community engagement in AI in Africa from varying sites including Google, Google scholar, and PubMed. The search items were: community engagement; artificial intelligence, community engagement in AI, community engagement in AI in Africa. The literature was analyzed thematically through categorizing it into major themes by a team of two bioethicist and one expert in AI.

AI ethics should engage with the cultural diversity in Africa. Additionally, Africa has rich moral traditions built around core values of interconnectedness, solidarity, communality and respect, conceptualized in ethical frameworks such as Ubuntu. These and other relevant African value-systems should form the central focus of AI value alignment in Africa.

AI is considered foreign to Africa since the expertise in it mostly comes from the developed countries. This potentially increases the inferiority of Africans to make input to AI research and development. Because of this low literacy for AI in Africa, the protection of the rights of the communities is basically the role of research ethics committee. While this approach may be regarded as paternalistic and non-empowering to communities, it still has a role in many indigent communities in Africa in which individuals may be coerced into study participation.

Initiatives like; Science for Africa and the African Observatory on Responsible Artificial Intelligence, policy (in Uganda) have focused their endeavors, visibility of Africa in AI research.

Engaging Africa communities, offering training solutions, understanding local issues and their unique needs is hoped to help create an avenue for developing more inclusive AI technology.

What Exactly Is The Medical Ethicist's Role When Family Members Refuse Organ Donation After Brain Death Determination?

Paola Nicolas

In accordance with the Uniform Anatomical Gift Act and the laws of New York State, medical staff members are prohibited from approaching the patient's next-of-kin to obtain consent for organ/tissue donation. Only the Organ Donor Network representatives may approach the patient's next-of-kin for consent to organ/tissue donation. This paper will discuss the case of a brain dead 33-year-old patient, after a re-rupture of aneurysm, who appears to be an organ donor per his driver license, however his family argues that the deceased recently changed his mind and explicitly expressed his desire to be buried "intact." What is the clinical ethicist's role in those situations? Whereas the Revised Uniform Anatomical Gift Act explicitly reaffirms that if a donor has a document of gift, there is no reason to seek consent from the donor's family, how do we approach situation where family members argue that patient's wishes have changed? This paper will evaluate in particular the legal implications of considering medical ethicists as medical staff members in case where the family objects to organ donation. If medical ethicists are indeed considered as clinicians, does that mean that medical ethicists are always and unconditionally prohibited from engaging with family members about organ donation? Are there cases where ethics consultant's engagement with family members is not only appropriate, but also necessary? We will discuss two different views: (i) medical ethicists, as clinicians and hospital employees, should never engage with family members about organ donation since it would constitute a direct conflict of interest; (ii) medical ethicists could, in some rare circumstances, offer mediation between UNOS representatives and family members. This paper will map the legal and ethical concerns posed by ethics consultants' involvement in organ donation conversations and will elaborate strategies to be advocates for the deceased and their family members while being compliant with local hospital policies and state laws.

Patient Portals: An Open Door to Patient Engagement

Emily Oleynik

Health care organizations in Canada are rapidly moving toward digitization of patient records. Laboratory results, medical imaging, and clinical documentation are increasingly recorded and stored in a digital format. Allowing patients and caregivers access to these digital health records through "patient portals" encourages patient engagement and partnership in their care. Patients are able to view results at any time and however many times they wish; show results to other practitioners and organizations; and track results and trends. However, there are some potential harms to patients. Some practitioners raise concerns about releasing results to patients in real-time, suggesting in part that viewing digital test results or documentation without guidance of a healthcare professional may be distressing for patients, and may create unnecessary anxiety for patients who might already be experiencing a worrying health condition. Despite these concerns, immediate access to digital records for patients supports engagement and partnership.

Healthcare organizations should empower patients to view all digital test results in real-time, regardless of whether a healthcare professional has seen the results or is able to provide timely counseling to the patient. The literature indicates there are benefits to patients in accessing their results independently, as well as research that indicates a profound patient preference for viewing digital test results independently in real-time. With real-time access to their records, patients are able to prepare for upcoming appointments, alert clinicians when they think something might be wrong, and have a greater understanding of what is happening with their care. Real-time results release may contribute to a feeling of partnership, rather than a sense of paternalism from the healthcare team, who may hold back results based on the assumption that results will be too distressing for patients. There is strong evidence for the benefits to patients who are able to view digital test results online in real-time, but negative impacts cannot be ignored. Mitigative approaches are suggested for some of these negative impacts, such as setting expectations for patients when viewing digital test results, and providing accurate, plain-language interpretations alongside the digital record.

Patient Opinions About AI-enabled Voice Monitoring in the Hospital Room

Joel Pacyna, Michele Anzabi, Susan Curtis, Austin Stroud, Journey Wise, Richard Sharp

Background: Hospitals are increasingly exploring mechanisms to leverage AI to improve the effectiveness of patient monitoring in inpatient settings. One such mechanism is through the real-time processing of patients' voices and other sounds recorded by ambient listening devices installed in patients' hospital rooms. While this use of AI-enabled monitoring has the potential to be a highly effective enhancement to inpatient care, little is known about patients' receptivity to monitoring by continuous ambient listening devices in the context of hospitalization. For

example, we know little about whether patients will view this kind of monitoring as intrusive, or equivalent to an unwanted third-party that eavesdrops on private, intimate conversations between patients and providers, family members, etc. No data are available on whether patients may resonate with some of the proposed benefits of this kind of monitoring, or whether they feel it will enhance or detract from their experience in the hospital.

Methods: We conducted focus groups with patients and discussed using acoustic and linguistic voice processing in hospital room settings. Focus groups were semi-structured and followed a moderator guide.

Analysis: Recordings of focus groups were transcribed and analyzed qualitatively.

Results: We conducted 15 focus groups (n = 107 patients). Patients expressed divergent opinions about the use of acoustic-linguistic voice processing in the hospital room. Some patients appreciated the benefits of proposed safety and convenience conferred by continuous ambient voice/sound analysis, while others enumerated potential concerns or harms that might result from acoustic-linguistic surveillance. For example, several participants suggested that family members would no longer feel able to debrief privately with the patient about difficult aspects of the patient's care. Other patients suggested that continuous recording of the voice during a time of unusual vulnerability was inappropriate.

Conclusions: Implementing real-time AI-enabled acoustic-linguistic analysis in inpatient hospital care in a way that is respectful of patient needs and values will require normative evaluation informed by patient and provider input. We highlight patient concerns as well potential parameters described by patients that may inform an ethical implementation of this kind of technology.

Engaging South Asian Communities in Québec and Ontario on the Ethical Dimensions of Personalized Breast Cancer Screening

Manisha Pahwa, Ananya Banerjee, Ryoa Chung, Elizabeth Anne Kinsella, Tajinder Kaura, Simerpreet Sandhanwalia, Matthew Hunt

Breast cancer screening policies are developing into personalized approaches that use individual risk factor information, sometimes including genetic data, to create tailored breast cancer screening plans. The aim of personalized approaches is to optimize the balance of benefits and harms of breast cancer screening. Ethical implementation of personalized breast cancer screening (PBCS) policies requires consideration of not only benefits and harms, but also, potential effects on existing breast cancer inequities. In Canada, one important inequity is that South Asian people have more late-stage breast cancer diagnoses, and therefore a greater burden of breast cancer morbidity, compared to non-South Asian people. If PBCS policies are to play a role in ameliorating this inequity, they need to be responsive to the needs, values, and lived experiences of South Asian communities. This includes responsiveness to what South Asian communities self-determine as benefits, harms, and ethical issues of PBCS; lived experiences of breast cancer and health care; and social contexts in which PBCS plays out. Research about PBCS ethical issues in Canada has concentrated on informed consent, equity of screening access, and genetic discrimination from the perspectives of the public, policymakers, and primary care providers. However, these ethical issues are unlikely to fully map on to the needs of equity-denied groups, whose voices and values are underrepresented in the literature about PBCS ethics. This epistemic injustice hinders the implementation of PBCS policies in ways that contribute to equity in breast cancer prevention for South Asian people. Pluralistic ethical frameworks and social values about breast cancer screening and the use of genetic information in health care have been articulated worldwide. Yet little is known about what South Asian people in Canada, a large and diverse constellation of communities with a disproportionate burden of breast cancer morbidity, self-determine and experience as potential ethical issues regarding PBCS. This knowledge can inform efforts to reduce the burden of breast cancer for South Asian patients, families, and communities. This understanding may also widen the scope of bioethical issues in Canada and enrich existing theories and frameworks for addressing health equity for culturally diverse groups in Canada.

Screening for All at High Risk, Except Some: Public Ethical and Social Values About Lung Cancer Screening in Ontario, Canada

Manisha Pahwa, Julia Abelson, Lisa Schwartz, Paul A. Demers, Katrina Shen, Meredith Vanstone

Background: Lung and bronchus cancer was diagnosed in an estimated 31,000 people and caused approximately 20,600 deaths in Canada in 2023. Population-based lung cancer screening policies are being more widely implemented in Canada to reduce lung cancer mortality. Public ethical and social values are key to screening implementation.

Objective: This research aimed to elucidate public ethical and social values about population-based lung cancer

screening policies in Canada.

Methods: This empirical bioethics project used qualitative description methodology. Members of the public in Ontario, Canada aged 55 to 85 years, an inclusive target age for population-based lung cancer screening, were recruited from family medicine clinics, social media, and researchers' networks using purposive sampling. Using a semi-structured guide informed by ethical issues in cancer screening and principles of population-based disease screening, participants were interviewed via telephone or Zoom where they were asked to identify and provide their perspectives on potential ethical issues and to describe their values-based reasoning for how ethical issues should be addressed in policy.

Analysis: A hybrid inductive-deductive qualitative content analysis was used to develop codes and categories with minimal interpretive inference.

Results: Participants (N=26) were mostly women aged 61-70 years with post-secondary education and previous/no history of commercial tobacco smoking. Participants rationalized their enthusiasm for screening by the principle of beneficence for individuals (lung cancer mortality prevention, information about lung health) and society (cost-savings for health systems). When asked about the ethical dilemma of who should be screened, participants supported current screening of only high-risk individuals; however, participants believed that this should be inclusive of a range of lung cancer risk factors. Expanding screening for occupationally exposed populations and people with a family history of lung cancer was favoured over offering screening to people who currently smoke commercial tobacco.

Conclusions: Participants' biases in favour of screening and against screening for certain social groups should be addressed in policy by providing transparent and accessible information about benefits and harms and creating non-stigmatizing programs with equitable access for people who currently smoke commercial tobacco. Otherwise, screening may widen inequities in lung cancer mortality and create more harms than benefits.

Proposal for a Patient-Engagement Approach that Considers Issues of Inclusion, Diversity and Awareness for Sickle Cell Disease

Yves Pastore, Nathalie Gaucher, Evelyne Doyon-Trottier, Jessica Darilus, Gabrielle Bujold

Context : Several health inequalities affect patients with sickle cell disease (SCD). In this study, we sought to develop a research and care improvement program for pediatric SCD that was rooted in the needs and realities of children and their families. We believed patient-engagement and patient-partnership would be suitable approaches to build this program. Methods: In this paper, two theoretical concepts are drawn to propose a patient-engagement model for healthcare professionals : (1) patient-engagement in healthcare, and (2) well-known issues of inclusion, diversity, and power in SCD. Empirical data was obtained from an action research study exploring engagement issues raised by clinicians, youth and their families, through focus groups in a tertiary care pediatric institution with a dedicated SCD clinic. This study was co-designed with a partner-parent and informed by a provincial SCD patient association. Themes explored included: (1) priorities for education, recognition, and awareness of SCD, (2) how all parties envision an approach to collaborative work that considers democratic representation; (3) issues of inclusivity, diversity, and power in partnership work; and (4) how an institutional initiative should engage with community partners to foster patient engagement in clinical, research, and advocacy initiatives. Findings: Empirically, the study focused on institutional practices that could foster patient-engagement to address power imbalances in the clinic. However, our findings found that, in order to truly engage with youth and families in partnerships, clinicians had to understand engagement beyond the clinical setting, and learn to consider families' social backgrounds and community experiences. We therefore suggest that patient-partnerships in SCD should develop simultaneously at the individual level (within patient-clinician encounters), at the institutional level (with institutional care pathways that are responsive to SCD families' experiences and focus on their priorities), and at the community level (with clinicians advocating for improved awareness regarding SCD) in the voice given to SCD. Conclusions: Patient-partnerships can take many forms. In the case of SCD, a patient-engagement model was shaped by its social and structural aspects. Clinical encounters are just one aspect of how we engage with families and community partners and foster patient engagement in clinical, research and outreach initiatives.

Ethical Preparedness: AI and the Survivability of Research Ethics Boards

Angel Petropanagos, Dylan McKibbon

If one uses a Large Language Model (LLM) to generate a protocol, consent form, and/or other research documents, is one still a researcher? If Research Ethics Boards utilize LLMs for ethical discernments, can it really be said that

ethical perspectives have been thoughtfully considered? Could LLMs replace REBs altogether?

The recent surge in the prevalence of LLM software applications, such as OpenAI's ChatGPT, ought to prompt urgent discussion in the field of clinical research. Myriad concerns include data privacy and security, informed consent, data validity and biases, equity, research grant exploitation issues, and more. Amid these discussions, this paper probes a crucial inquiry: are research ethics boards adequately equipped to grapple with the ethical intricacies stemming from the integration of LLMs in clinical research?

We maintain that the widespread adoption of LLMs introduce profound ethical challenges for REBs. We begin by presenting an LLM-generated mock study, followed by a 'mock REB assessment' conducted by an LLM, to illustrate ethical issues related to the use of AI for research ethics. We demonstrate the speed, ease, and consistency with which LLMs can already generate materials for an REB process and problematize the use of such technology in research. We then summarize the findings from our narrative literature review and describe ethical challenges that may impact researchers, research participants, and REBs. Ultimately, we suggest that despite evolving regulations, the creation and adoption of a research-specific LLM may be necessary to address some of the ethical challenges.

The presence and advancement of LLMs pose significant ethical challenges for REBs. We urge proactive engagement with these considerations and advocate for broader discussions related to potential ethical safeguards and the creation of research-specific LLMs that can help to navigate the challenges introduced by the integration of LLMs into the field of research ethics.

Digital Compassionate Care Principles in VCA Design for Mental Health

Geneviève Rouleau, Jean-Christophe Bélisle-Pipon, Zoha Khawaja

Voice-based AI Conversational Agents (VCAs) in digital mental health care could represent a way to respond to the current and future shortage of mental health services and inadequate supply of resources. These agents use advanced voice analytics to decipher emotional cues, tonal variations, and speech patterns, offering diagnostic and predictive information as well as therapeutic solutions. The voice-centric approach of VCAs echoes the natural conversational flow experienced in human-to-human clinical settings, potentially fostering a sense of digital therapeutic alliance. Thereby, such VCAs can act as auxiliary devices to support overburdened clinicians while also democratizing healthcare, especially for those who face physical, financial, and geographic barriers to accessing care facilities. Yet, while their promise is immense, so are the ethical implications they introduce. A key concern is a therapeutic misconception arising when patients misperceive VCAs' machine-driven feedback imbued with human compassion and wisdom, imperiling the trust inherent in therapeutic bonds. This is coupled with the potential feeling of being under ceaseless surveillance, deterring open expression. The great benefits offered by VCAs come with plausible unintended consequences which warrant responsible and trustworthy development that considers a patient-centric approach, emphasizing digital compassionate care. In this talk, we explore and argue that VCAs' design must be grounded in compassionate and ethical digital healthcare principles which include, but are not limited to, establishing trust through transparency about the VCAs' capacities and data handling processes, upholding patient autonomy by cultivating relational communication, and ensuring that there is a clear understanding about the VCAs limitations when it attends to patient needs and suffering. To truly realize the transformative potential of VCAs in mental health and enhance users' well-being, care, and quality of their therapeutic relationship, it is imperative that compassionate and ethical-centric approaches be central to the VCAs' development.

Characterizing Experiences of Moral Distress Among Medical Interpreters in Canada

Marwah Sadat, Rouba Isshak, Fern Brunger

Background: Interpretation is an important element of making medical encounters more accessible. Few studies have explored the ethical conflicts and power dynamics that interpreters navigate in their essential roles.

Objective: The purpose of this study was to identify and describe the moral labour and ethical dilemmas that medical interpreters may experience in the Canadian healthcare system.

Methods: This project analyzed data already collected as part of a broader study on patient and provider perspectives on newcomers' experiences of marginalization in the Canadian health care system. Community members who are patients and interpreters were collaborators. Critical and interpretive post-structuralist ethnographic approaches were utilized to examine how power intersects with culture in the experience of marginalization. This sub-study focused on the perspectives of medical interpreters.

Results and Analysis: Here we report on the moral distress experienced by professional interpreters as they encounter ethical dilemmas in the context of interpretation. We focus on participant narratives describing when moral distress was experienced, and the reported reasons behind the moral distress. Moral distress occurred when the interpreter: was known to the patient; had extra information that they could not/were requested not to tell the physician; felt they were not interpreting adequately; and felt that the healthcare provider was navigating the encounter poorly. The reasons behind the moral distress were thematically categorized as ethical dilemmas related to: (1) power imbalances between health care providers and interpreters; (2) emotional proximity to the patient; and (3) role conflict and associated conflicting lines of accountability with respect to relationship to the provider versus to the patient.

Recommendations: Three main recommendations are provided, centering on training for providers and interpreters with respect to: (1) power relations; (2) the logistics of interpretation; and (3) accountability.

Conclusion: Moral distress may occur in several ways among interpreters working in the Canadian healthcare system. Reasons behind this moral distress should be addressed to improve the quality of care provided to patients and the quality of professional life for interpreters.

From George Floyd to Daunte Wright: Reporting From the Epicenter of a Cultural Movement

David Satin, Erika Kaske

Background: George Floyd's death in Minneapolis, MN, catalyzed the largest international protests in history, prompting the deployment of widespread crowd control measures. One year later, Minnesota witnessed the police killing of Daunte Wright, followed once again by protests met with crowd control weaponry. Police use of less-lethal weapons for crowd control, including kinetic impact projectiles and chemical irritants, can lead to significant morbidity and mortality.

Objective: Community reaction to injuries sustained by protesters and continued inaction by policymakers prompted our systematic characterization of trauma during the George Floyd and Daunte Wright protests.

Methods: We screened 15,375 encounters for adult or pediatric trauma from M Health Fairview Hospital, North Memorial Hospital, and Hennepin County Medical Center (Minneapolis, MN) within 2 weeks of each protest. Care Clinics, Urgent Care, and the Emergency Department with ICD10 codes S00-T59 or patients with "riot" or "rubber bullet" or "tear gas" or "protest" or "projectile" in patient notes comprised the inclusion criteria. Injuries not related to less-lethal weapons or officer violence were excluded.

Analysis: The total number of injured protesters and their Injury Severity Score (ISS) served as our primary outcome. To report injuries, we followed the STROBE (Strengthening the Reporting of Observation Studies in Epidemiology) guidelines.

Results: 103 patients sustained injuries from police use of projectiles, chemical irritants, or batons. Injuries to the head, face, and neck were most likely to require surgical intervention. Full clinical outcomes, including an ISS "heat map" and patient demographics such as race, ethnicity, age, and gender will be presented.

Conclusions: Police use of less-lethal weapons for crowd control can cause severe injuries requiring surgical intervention. Injuries were sustained to the head, neck, and face, suggesting inaccurate or wrongful use of these weapons, according to the 2020 United Nations Guidelines. The consequences of each injured protester deepen the rift between our communities and those sworn to serve and protect. We call for the continued collection of standardized clinical data from all protests to inform outcome-oriented discussions among our communities and policymakers.

The Paradox of Protective Isolation: Trauma Informed Care Considerations From the Perspectives of Children and Youth

Jami-Leigh Sawyer, Faye Mishna, Randi Zlotnik-Shaul, Eric Bouffet, Michael Saini

Background: Medulloblastoma is the most frequently occurring malignant brain tumour among children. Depending on the severity of their disease, some children and youth require intensive treatment. To guard against possible infections during treatment, children and youth are required to live in a protective isolation room in hospital for a timeframe that spans many weeks to months.

Objective: Giving voice to children and youth is one of the highest goals in bioethics. This study was unique in that its objective was to explore this intensive treatment experience from the perspective of children and youth

directly.

Method: A database maintained by the neuro-oncology program at a large urban children's hospital was consulted to generate a list of all patients who were currently being treated or had been treated with Protocol SJMB03. From this list, participants were contacted who met the inclusion criteria.

Analysis: Eight participants took part in in-depth interviews either in person or via telephone. In an attempt to reach the depth required for an interpretive phenomenological design (IPA) whereby the participant "tells their own story, and the interviewer listens," second interviews were conducted with all eight participants during which new questions were asked and previous responses expanded and/or clarified.

Results: Findings highlight children and youths' subjective experiences of their treatment experience including: 1) the paradox of hospital isolation rooms, 2) becoming numb to the physical pain of treatment, and 3) their interactions with hospital staff.

Conclusion: Gaining insight into how children and youth perceive their treatment experience is vital to informing healthcare policies and practices, including the provision of ethics consultations and services. Better understanding how children and youth perceive staff during treatment is critical to inform trauma-informed care practices so that children and youth feel physically and emotionally safe, as trauma informed care is ethical care. Study findings are timely and significant, as the COVID-19 pandemic highlighted the critical need to better understand and address the impact of isolation for children and families.

"Is This Worth Using PPE for?": A Qualitative Study of Resource Allocation Decisions Navigated by Frontline Critical Care Providers During the Covid-19 Pandemic.

Alison Scholes, Monica Molinaro, Asiana Elma, Deborah Cook, Lawrence Grierson, Meredith Vanstone

Background:

Insufficient resources and dynamic infection control policies made it necessary for frontline Critical Care Providers (CCPs) to make frequent ethical decisions throughout the COVID-19 pandemic. Many of the ethical decisions included allocating scarce resources to optimally prioritize patients, resources, and clinician time. The transition from usual patient-centered care to care centered attending to infection control mandates and rationing resources forced CCPs to make a barrage of bedside decisions as they balanced competing demands while trying to uphold high standards of care.

Objective and Methods:

Using a qualitative case study approach, we aimed to document the type of decision, reasoning used, and impact of ethical decisions made by frontline CCPs during the pandemic. We conducted twenty-five semi-structured interviews with CCPs (e.g., physician, nurse, respiratory therapist, physiotherapist) and administrators employed in a single community Intensive Care Unit (ICU) in Ontario. Within the ICU, triage protocols had been circulated, institutional policies were continually revised, and multiple sustained surges in COVID-19 admissions were experienced.

Results:

Resource allocation decisions within CCP's clinical practice were ubiquitous and diverse. The constraints imposed by the pandemic and multiple provincial and organizational policies formed the context that necessitated these decisions. As CCPs reflected on their decision-making, they described reasoning corresponding to a wide variety of ethical theories, most commonly utilitarianism and virtue ethics. They consistently prioritized values of CCP safety and individual patient well-being when particular principles were invoked. The actions they described taking as a result of these decisions included prioritizing and timing clinical tasks and adapting their practice patterns. Although these situations commonly evoked stress, frustration, and other negative emotions within CCPs, various positive internal responses were also described, including team cohesion and feelings of self-efficacy and resourcefulness.

Conclusion:

Analysis of bedside resource allocation-derived decision-making helped to illuminate a variety of challenges that CCPs faced during the COVID-19 pandemic, driven by institutional policies and pragmatic limitations. Insights from this study highlight how these ethical decisions are an inherent part of clinical practice and how they have the potential to create positive professional development on the heels of adversity.

What Community Members and Local Stakeholders Valued in How Organizations Closed Humanitarian Assistance Projects in Six Locales in the Philippines

Lisa Schwartz, Matthew Hunt, Revka Perez, Mayfourth Luneta, Shelley-Rose Hyppolite, Handreen Mohammed Saeed, Isabel Munoz Beaulieu

Background: Humanitarian projects are intended to be temporary emergency responses. If poorly planned or implemented, project closure can lead to a range of harms, especially when these are rushed, do not engage with communities, or lack transparency. There remains uncertainty, however, about what ethical project closure entails, and most analyses have examined it from the perspective of humanitarian organizations. Therefore, we conducted a study to investigate the perspective of people living in communities that have received humanitarian aid.

Objective: To explore experiences and perceptions of members of six communities in the Philippines regarding the closure of projects, including what they consider to be the characteristics of an ethical humanitarian project closure.

Methods: The study was guided by interpretive description methodology and carried out in communities that received humanitarian assistance following typhoons, volcanic eruption and armed conflict. Data collection was conducted by local civil society organizations who took part in the project's Advisory Board and supported by the Center for Disaster Preparedness. In total, we conducted eight focus groups with community members who had received humanitarian aid and 34 key informant interviews with community, government, and religious leaders (101 participants). We developed synopses that summarized ideas, created concept maps, and undertook a framework analysis. Provisional findings were shared with the Advisory Board through virtual sessions, and feedback was received at an in-person event in the Philippines.

Results: We identified seven elements that community members described as valuable when closing humanitarian projects: transparency, collaboration between organizations and local leaders, participation of community members, sustainability, continuity of connections with the community, closures that preserve relationships, and support for communities to be prepared for future crises.

Analysis: The experiences of how communities experience project closure invites humanitarian organizations to consider their duty of care towards communities in a way that critically engages with the temporary nature of humanitarian action.

Conclusions: This study sheds light on ethical project closure from an understudied perspective: that of affected communities. It explores their values, concerns, and priorities- advancing new avenues to think how, even after the departure of humanitarian organizations, projects do not necessarily end for communities themselves.

Acknowledging Family Members' Complex Bereavement Experiences Following Medical Assistance in Dying (MAiD)

Kristie Serota, Daniel Buchman, Michael Atkinson

Background: Individuals who choose to receive medical assistance in dying (MAiD) usually involve their family members and close friends in the process. While most Canadian research has found that family members are generally supportive of their loved ones' MAiD decision and have positive experiences, a small number of studies have indicated that MAiD bereavement can present unique challenges. Research from Switzerland and the state of Oregon, jurisdictions that have legalized processes for assisted dying, indicates that family members' MAiD bereavement can be negatively impacted by disagreement, conflict, and moral dilemmas.

Objective: The current study was designed to explore the factors complicating family members' MAiD bereavement in Canada and how care may be improved for those experiencing MAiD bereavement.

Methods: Drawing upon narrative and care ethics approaches to critical qualitative research, we conducted 12 narrative interviews with MAiD-bereaved family members and close friends who encountered disagreement, family conflict, or differences in understanding regarding MAiD.

Analysis: Participants' stories were analyzed using critical narrative analysis.

Results: Participants resided in Alberta, British Columbia, and Ontario. We conceptualize these individuals as having complex MAiD bereavement experiences. Our analysis generated five factors that can complicate the MAiD process and bereavement: family discordance, internal conflict, legislative and eligibility concerns, logistical challenges, and managing disclosure and negative reactions. We also identify the roles of emotional pain and disenfranchised grief in participants' stories.

Conclusions: Based on the narrative data, we discuss several improvement opportunities for enhancing the care provided to family members before, during, and following the MAiD process.

How Would the General Population Have Allocated Pediatric Intensive Care Resources to Adults in the Context of the COVID-19 Pandemic?

Naomi Singh, Nathalie Orr Gaucher, Marie-Ève Bouthillier, Claudia Lucrecia Calderon Ramirez, Karell Laporte

Background: An ethical consensus regarding how to allocate pediatric intensive care (PICU) resources in the context of the COVID-19 pandemic, which disproportionately affected adults, has not been reached. Understanding local social values is essential to inform the design and implementation of prioritization protocols.

Objective: The objective of this study was to explore the general population's perceptions and values on the use of PICU resources to treat adults during the COVID-19 pandemic in Canada.

Methods: An online democratic deliberation (DD) exercise was held with adults from Ontario and Quebec, Canada. Participants took part in two days of information sessions and deliberations; consensus was not sought. Questionnaires investigating participants' values and preferences on the allocation of PICU resources to adults were completed before and after the DD. Questionnaires were developed by an interdisciplinary team of researchers, and included multiple choice, Likert scale items, and open-ended items. Questionnaire analyses included descriptive reports of frequencies; participants' pre- and post-DD responses to Likert scales were compared using Wilcoxon sign tests, using SPSS (v.24, IBM Inc).

Results: In the spring of 2022, 57 participants participated in day 1 and completed the pre-DD questionnaire, while 47 participated in both days and completed the pre- and post-DD questionnaires. Participants' age range varied from 18 to 92 y.o and 74% had completed post secondary education. Most participants wanted to participate in the DD in order to influence the opinions of other group members on the issue of triage protocols (76%). Following the DD, there was a significant increase in the acceptability of using a pediatric triage protocol to allocate resources (84% pre-DD to 93% post-DD, p=0.049). It was also noted that "best chance of survival" was a favored allocation of PICU resources approach when choosing between two children. Most participants believed it was "unacceptable/most unacceptable" to not use pediatric resources in case of overwhelming demand in adult ICUs and that it was "acceptable/most acceptable" to share some pediatric resources

Conclusions: This study provides insight into how the general population in Canada assesses the ethical tension between maximising the use of intensive care resources and protecting pediatric ICU resources.

Meeting Clinical Criteria: Practical and Ethical Challenges in Gender Care for Minors

Meaghan Storey

Children and minors under the age of majority have become a focal point for anti-trans rhetoric and mobilisation globally. In Canada, anti-trans protests took place across the country in September 2023 with many protestors citing the protection of children as part of their cause. One of the ways anti-trans groups seek to 'protect' children is by limiting access to gender services and medical interventions, such as puberty blockers and gender affirming hormones, until these children are adults. From a clinical point of view, withholding or delaying access to gender services does not have this protective effect - research shows that preventing access to gender care has significant detrimental effects to minors' health and well-being. Instead, clinicians rely on clinical guidelines and criteria for accessing care to ensure treatment is appropriate for a given patient. Clinical criteria can therefore act as a safeguard or gatekeeping measure, setting out the parameters for accessing gender services. This session will consider what happens when patients know and try to meet clinical criteria in order to access gender services. What are the practical and ethical implications when patients try to meet clinical criteria, particularly for marginalised minors navigating an increasingly hostile social and political environment? Moreover, how might ethical considerations of patient autonomy, patient safety, and justice be balanced in this clinical setting? By considering the role clinical criteria might play in a paediatric gender service, this session aims to highlight ethical considerations for clinical practice in light of current gender affirming and informed consent models of care.

Working With Community Research Councils in Precarious Socio-Political Times

Meaghan Storey

Methods of coproduction and community collaboration are increasingly used in research at stages of research de-

sign, data collection, and data analysis. Working with community members through the different stages of research provides important perspective on epistemic harm and critical understanding of what is at stake for community members. For transgender and gender diverse communities, involvement and input in research is increasingly important as anti-trans sentiment and legislation steadily rises globally. Recently in Australia, The Children's Hospital at Westmead in Sydney published a controversial paper regarding patients accessing their gender service. Many of these patients and their families have since spoken out saying this paper not only misrepresented their treatment at the hospital but put forward a damaging and harmful narrative about transgender and gender diverse children. It is clear there are practical and ethical reasons for researchers to work in collaboration with marginalised communities to produce meaningful and impactful research. However, there may be important additional ethical considerations that come out of working with transgender and gender diverse communities at this point in time. This session will look at the benefits and challenges of working with community groups on socially and politically sensitive research by using the presenters current PhD research on access to gender care for minors in Australia as a case study. The presenter will highlight how community collaboration played a role in considerations around framing research questions, potential narratives around participants and community members, confidentially, and dissemination strategies. Though research impact and outcomes cannot always be controlled, this session aims to discuss ethical and practical considerations for conducting research collaboratively with community groups at a hostile and turbulent socio-political time.

Parental Experiences and Preferences for Decision-Making in the Management of Their Febrile Young Infant: Insights From a Mixed-Methods Study

Philippe Sylvestre, Paul L. Aronson, Alexandra Yannopoulos, Cassandra Poirier, Nathalie Gaucher, Brett Burstein

Background: Recent guidelines for the management of febrile young infants recommend that when appropriate, decisions regarding lumbar puncture (LP) and hospitalization should incorporate parents' preferences in a shared decision-making (SDM) process. However, little is known regarding parental preferences for involvement in these decisions, and limited information is available to guide clinicians how to engage in these discussions.

Objective: This study aims to discern parental preferences in SDM concerning the management of their febrile young infant.

Methods: This was a sequential explanatory mixed-methods study, using a cross-sectional questionnaire followed by qualitative focus groups with parents of infants aged ≤60 days, evaluated for fever at a tertiary pediatric Emergency Department between May 2020 and May 2022.

Analysis: Parental expectations, stressors, and desired level of decisional involvement were assessed using multiple-choice and 6-point-Likert scales. Questionnaire results informed the qualitative naturalistic inquiry into parents' decision-making experiences and preferences for LP and hospitalization.

Results: During the 24-month study period, 432/665 eligible families (64.9% response rate) completed post-discharge questionnaires. Few parents anticipated the need for hospitalization (20.8%) or LP (10.2%), and these were selected as the most stressful aspects of management. No family identified lack of decisional involvement as the most important stressor during their visit, though nearly all (97.5%) wanted to be involved in management decisions. Six focus groups with a subset of 17 parents revealed main themes: (1) varying parental preferences for decisional involvement depending on the strength of the medical recommendation; (2) importance of involving parents throughout their child's ED care; (3) need for tailored information; and (4) importance of supportive relationships. Parents reported that even though decisions regarding LP and hospitalization were usually made by the medical teams, they felt involved in the discussions about their child.

Conclusions: In this mixed-methods study involving parents of febrile young infants, LP and hospitalization were the most unexpected and stressful aspects of care. Understanding individual family expectations and tailoring information in relation to the strength of medical recommendation is necessary to guide SDM for febrile young infants.

An Argument Towards a Pluralist Concept of Vulnerability

Marco Tang

Outside of bioethics, vulnerability generally refers to having a higher probability of being harmed, e.g., children, and the homeless. In research ethics, although different accounts of vulnerability exist, universities, hospitals, national and international institutions agree that the concept is useful in research ethics, e.g., the Tri-Council Policy

Statement and the Nuremberg Code. Vulnerability frameworks outline the distincts harms that potential participants can incur and how researchers can respond. However, institutions disagree on how to operationalize vulnerability, i.e., its definition, scope and how it can inform research ethics guidelines. Many in the literature aim to provide vulnerability with greater conceptual grounding by creating frameworks. Some are skeptical of its utility. In particular, some claim that research ethics boards and institutional review boards would be better off focusing on other relevant concepts, e.g., consent and minimal risk, to assess research-related harms rather than vulnerability since its broad. I, however, take a step back. I aim to explain the source of the disagreement rather than creating a new framework. More specifically, I will argue that the disagreement regarding operationalization is due to the failure to appreciate vulnerability as an amorphous concept. The paper will be divided into three sections. I will first summarize and evaluate common accounts of vulnerability. In the second section, I will do two things. I will argue that vulnerability is amorphous because the aspects of vulnerability and the relations each aspect has with each other cannot be adequately captured by a singular frame of reference. I will then argue that pluralism may be a possible solution - vulnerability must be seen with multiple frames. Lastly, I will respond to some objections. Professional and applied ethicists cannot create, implement, act on and advise others on ethics-informed policy without understanding the limitations of the demands of policy and ethical concepts. Understanding the relationship between the nature and demands of ethical concepts and policies allows us to write better policies.

Integrating Gender Data Into Electronic Health Records to Foster Inclusive Healthcare Partnerships With Transgender and Non-Binary Patients

Clara Tardif

Transgender and non-binary (TNB) people face significant levels of inequality when receiving health care. These disparities can be grouped into three major categories: health status, access to care and quality of care received. These inequalities have been linked to poor documentation of gender identity and expression in the health records of this patient group. A proposed solution to combat the disparities faced by TNB patients in the healthcare system is to better document this gender data in all electronic health records (EHRs), in addition to birth-assigned sex data. Hence, this initiative could improve the health care provided to this group of patients.

This presentation specifically focuses on how this initiative could represent a way to foster inclusive partnerships with TNB patient communities. We begin by addressing the global risks and potential benefits of this EHR alteration through a queer ethics framework, an approach that is specifically designed to address the unique needs and experiences of LGBTQI+ patients. Through this analysis, we identify opportunities for engaging gender-diverse patient communities in the decision-making process related to the implementation of this change. We highlight how this measure could represent a way to create more gender-affirming clinical environments and involve TNB patients more in personalizing and improving the health care they receive. To conclude, we find that fostering inclusive healthcare partnerships with gender minority groups is both a potential outcome of this change in EHRs and an important part of the process, for pursuing this analysis and potentially changing policies.

Upstream Community Interventions for Clinical Ethics Consultations: Advance Care Planning for Patients With HIV

Callie Terris, Emma Tumilty, Lesley Sommers, Jeffrey Farroni

Advance care planning and advance directives are valuable tools for proactively thinking about, discussing, and documenting someone's healthcare preferences. Yet, stigma, discrimination, and a lack of information remain barriers to completing advance directives for persons living with HIV. Ethical issues involving information disclosure, goals of care, and treatment decisions, may arise when a person living with HIV becomes incapacitated and requires a surrogate decision-maker.

Clinical ethicists are uniquely equipped to prevent issues that arise with medical decision-making. They can empower persons living with HIV to make informed decisions about their healthcare and ensure their wishes about medical treatments and information disclosure are respected by proactively educating community members on advanced care planning and directives. The literature discusses physician and other non-physician clinicians' roles in educating community members about advance care planning and directives; however, it has yet to explore how clinical ethicists can prevent future ethical dilemmas by increasing advance care planning and directive awareness and knowledge within the community.

This presentation describes how our clinical ethics service identified a critical need for advance directives among persons with HIV and then partnered with a community organization to provide a stepwise educational intervention. We discuss the benefits and challenges of utilizing clinical ethicists to promote conversations about advanced

care planning and directives with persons living with HIV in the community. This presentation concludes by emphasizing that advanced care planning and directives are not solely for end-of-life scenarios but also promote patient-centered care and protect the autonomy of persons living with HIV.

Hearing the Patient's Voice: A Pre- and Post-Pandemic Analysis of the Clinical Ethics Consultation Practices within Pediatric Intensive Care Settings

Alangoya Tezel, Janice Firn

Background: Keeping the patient at the center of the ethics consultation process is paramount. There is heated debate regarding best practices for achieving this goal. Ethicists disagree about whether and under what circumstances the consultant should speak with the patient and/or surrogate. During the COVID-19 pandemic, new barriers were introduced to meeting patients and/or surrogates at the bedside, including new social distancing guidelines, hospital visitor policies, and scarce hospital resources.

Objective: To compare the consultation practices and primary ethical issues raised across pediatric intensive care settings in the years before and after the COVID-19 pandemic.

Methods: Retrospective review of ethics consultation notes for patients admitted to the pediatric intensive care unit (PICU), pediatric cardiothoracic ICU (PCTU), and neonatal ICU, of a quaternary academic children's hospital between January 2016 and December 2022. Consults were divided into pre-COVID (2016-2019) and post-COVID (2020-2022) cohorts.

Analysis: Conceptual content analysis was used to determine what proportion of consults involved speaking with patients and/or surrogate decision-makers, and to characterize the primary ethical issue and contextual features contributing to each case. Consults were coded by hand and analyzed using descriptive statistics.

Results: Eighty-five consults were identified; 57 were pre-COVID and 28 post-COVID. On average, more consults were received yearly in the pre-COVID period (14/year) as compared to the post-COVID period (9/year). Medical futility was the most common primary ethical issue raised in both cohorts (25%), followed by goals of care for the pre-COVID cohort (19%) and surrogate decision-making for the post-COVID cohort (19%). Despite having lower consult volumes and receiving more consults regarding surrogate decision-making, post-COVID consults elicited the patient's voice less often (7%) as compared to pre-COVID consults (23%). The majority of post-COVID consults did not document a reason for not meeting with the patient or surrogate (82%) as compared to roughly half of pre-COVID consults (58%). Of the reasons identified to not meet with patients and/or surrogates, parental preference was the most common (43%) across cohorts.

Conclusion: Further research on the impact of the COVID-19 pandemic on ethics consultations is needed to safeguard against unintentional changes in practice that may limit the patient's voice.

Predicting and Preparing for the Future of Babies Born Extremely Preterm: Parents Give Recommendations to Clinicians

Émilie Thivierge, Rebecca Pearce, Thuy Mai Luu, Magdalena Jaworski, Anne Synnes, Claude Julie Bourque, Annie Janvier

Background: Parents of extremely preterm children face many challenges and uncertainties. The information and support provided by clinicians -both before and after birth- is invaluable to help them make informed decisions about their child's future.

Objective: To explore the information needs of parents of extremely preterm infants. Methods: All parents of infants born <29 weeks' gestational age and seen for neonatal follow-up between the ages of 18 months and 7 years were consecutively recruited over a one-year period. Parents were asked: "Knowing what you know now, what do you wish doctors would have told you about prematurity before and/or after your child's birth?" Answers were analyzed using mixed methods by medical professionals and a patient-partner. Results: 45% of the 249 parents (98% participation rate), were satisfied with the medical information and support they received. Prenatally, 16% felt that more practical information was needed in term of the function of babies born preterm (not only diagnoses), some parents would have liked prematurity to be mentioned in their normal pregnancy follow-up. 19% of parents wanted to know more about the life-trajectory of babies in the NICU, as well as how they could be part of the team to help their baby. 22% wished discharge to be improved, to be better prepared for the future: "BPD does not help. We would have liked to know what leaving on oxygen meant, that she should not go to daycare, the risk with infections, RSV shots, sleeping problems many preemies have. This could have been done weeks before we

left the hospital." Fourteen percent wished they had known more about resources for psychosocial support. Parents (14%) wished for clinicians to be more optimistic and to give them hope: "Before birth, I would have liked to know that most micro preemies do well." Conclusion: Although half the parents are satisfied with information and support received, the other half recommends improvements, mainly to make it positive and practical. Diagnoses did not help parents prepare for the future prenatally, in the NICU or at discharge, but function and what parents could do (in a practical fashion) did.

Patient Partner Disengagement: When Patient Partners Consider Quitting

Laura Tripp, Mary Anne Levasseur, Carolyn Canfield, Caitlyn Ivany, Myles Leslie, Paula Rowland, Meredith Vanstone, Julia Abelson

Background

As partnering with patients and caregivers becomes routine in health settings, there is an ethical imperative to facilitate high-quality engagement. Patient partners may wish to stop engaging for many reasons, including harmful circumstances or practices; identifying contributing factors that lead patient partners to consider quitting their roles can make engagement practices more ethical.

Objective

To use Canadian Patient Partner Study (CPPS) data to understand why patient partners consider quitting their roles and whether these reasons implicate an ethical obligation from the health system organization, staff, or other patient partners.

Methods

CPPS data sources used to understand patient partners experiences and reasons for considering quitting included: (1) an online survey of patient partners working in the Canadian health system which asked if respondents had considered quitting their role and if so, what prompted that; and, (2) qualitative descriptive interviews with patient partners about their experiences. Data collection approaches were co-designed with patient partners.

Analysis

Open-ended survey comments were inductively analyzed to describe the reasons that prompted quitting considerations. Interviews were analyzed via conventional content analysis to identify considerations of, incidences, and impacts of quitting.

Results

40% (213) of survey respondents and 71% (15) of interviewees identified that they had considered quitting their patient partner role. Rationales for considering quitting centred around personal reasons (e.g., health issues, caregiving, finances), demands of the role (e.g., lack of fit, overwhelm, unrealistic expectations) and challenges of the role (e.g., interpersonal challenges, emotional tolls, poor engagement practices). Many of the reasons provided by interview and survey respondents centred around fatigue, a sense of futility due to a lack of impact, emotional strain, lack of support and role ambiguity, factors that have been associated with burnout.

Conclusions

Patient partners are engaged by the health system to share their lived experience, perspectives and skills to create a more patient-centred system. The CPPS results, however, suggest that many patient partners also suffer from or are at risk of suffering burnout because of inadequate engagement practices. This poses several ethical questions that are critical to address as the health system continues to expand and prioritize roles for patient partners.

Pop! The Bioethics Podcast: Promoting Patient Partnership and Community Engagement by Exploring Bioethics in Popular Media

Jessie Van Leeve, Casey Rojas

Emergent responses to the COVID-19 pandemic contributed to a general disconnect in communication between healthcare, academic, and public communities across the globe. The resultant lack of cohesion in public messaging gave rise to widespread fatigue exacerbated by misinformation and frustration with healthcare systems. Today, public mistrust remains a serious impediment to patient care and population health outcomes, calling us to take seriously the task of improving the ways we engage patients and communities as partners in understanding healthcare practices, issues, and bioethical challenges. For a vastly diverse audience, popular media can play an

invaluable role in generating awareness of, and inviting participation in, consideration of complex ethical issues. Media in all of its various forms is digestible, immersive, and accessible for broad audiences, and its narratives engage and transport people in ways that generate empathy. When health and other educational messages are integrated into pop culture mediums, they have the power to promote awareness and influence attitudes about contemporary health and socio-cultural issues. The use of health messaging in entertainment is well documented, but media remains underutilized as a tool for creating stronger, more open dialogue among patients and communities. Pop! The Bioethics Podcast attempts to explore the integration of bioethical issues in entertainment as a way of bridging the gap between experts and the public. Over ten episodes, this podcast captures the perspectives of several experts who speak to bioethical topics and challenges such as healthcare decision making, reproductive and research ethics, mental health and addiction as they appear in popular film and television. Through this example, our presentation will demonstrate the value of utilizing media as a strategy for patient engagement. Bioethical issues are often highly technical, critically nuanced, and emotionally charged such that holding conversation on these topics is uncommon in daily life; however, these concepts are pervasive amongst the media we consume every day. By identifying the bioethical aspects of media with which people are already familiar, this project aims to make complex bioethical questions more accessible to the public and, in doing so, promote meaningful collaboration between media, healthcare professionals, and the communities they serve.

Track-2 Medical Assistance in Dying (MAiD): A Print Media Discourse Analysis

Caroline Variath, Ashley Wood, Lara Jeletzky, Nova Heartland, Josephine Varghese

Background:

Medical Assistance in Dying (MAiD) for persons whose death is not reasonably foreseeable (Track-2) is an ethically charged, contentious topic. Introduced during a global pandemic that strained healthcare resources and intensified the workload of providers in Canada, Track-2 MAiD necessitates an enhanced support system for both healthcare professionals and patients navigating this intervention. The expansions to the MAiD legislation have raised concerns among disability and mental health advocates about the potential for misuse of MAiD. To ensure safe and effective Track-2 MAiD processes, it is important to understand community perspectives on and representations of Track-2 MAiD. Analysing media discourse on Track-2 MAiD will shed light on social contexts that influence perspectives as well as the relationships between media representation and normative understandings about Track-2 MAiD.

Objectives:

Our main objectives are to collate information on experiences with and concerns about Track-2 MAiD and critically examine the public discourse on Track-2 MAiD in Canada.

Methods:

A systematic search of Canada's largest news database (Canadian NewsStream) will be conducted. Search terms include MAiD, natural death is not reasonably foreseeable, and Bill C-7. News articles from the search will be screened against inclusion/exclusion criteria independently by team members.

Perspectives on Track-2 MAiD is a complex social phenomenon which requires an in-depth evaluation of language, social contexts, and power relations. Critical discourse analysis will be used to analyse the print articles that meet the inclusion criteria. This print-media review does not require ethics approval.

Implications and Dissemination Plan:

This work-in-progress will help establish foundational understanding of our community's ethical perspectives and experiences regarding Track-2 MAiD. The findings will illuminate ethical and moral challenges from diverse viewpoints. Additionally, our findings may shed light on resources and practices that support clinicians, and challenges with access to and implementation of Track-2 MAiD.

Based on our findings, we plan to compile specific guidelines and best practice recommendations pertaining to Track-2 MAiD processes. Our findings will be disseminated widely through collaborations with local, national, and international end-of-life organisations, facilitating the sharing and distribution of this resource.

Building a More Empathetic Professional Student Community: Unexpected Data From the COVID-19 Pandemic

Hailey Warner, Jack Goldstein, David Satin

Background:

The healthcare literature consistently finds decreasing empathy and increasing burnout throughout healthcare and other professional student training. It is a robustly reproduced fact that students begin more empathetic than their age-matched peers, yet complete their training far less empathetic. Very few, brief interventions have ever been documented to even temporarily alter this dynamic. We predicted that the stress of the COVID-19 pandemic would worsen medical student burnout and empathy. We were wrong.

Objective:

To assess medical students' burnout and empathy during the COVID-19 pandemic at one of the largest public medical schools in the United States of America.

Methods:

Pre-COVID and COVID student survey results from September 18th, 2018 through November 22nd, 2021 were compared across domains of burnout and empathy. We used the Oldenburg Burnout Inventory (OBI) to measure burnout and the Interpersonal Reactivity Index (IRI) to measure empathy. Surveys completed before the March 14th, 2020 transition from in-person to virtual curriculum constituted the Pre-COVID cohort, and those completed after constituted the COVID cohort.

Analysis:

Categorical scores were compared with chi-square tests while numerical comparisons were made with the nonparametric Wilcoxon rank-sum test. Analysis included overall scores and sub-groups according to gender, medical school graduating class (classes of 2021-2023), and year of medical school (MS1-MS4.)

Results:

3,985 surveys were analyzed between the Pre-COVID (2,047) and COVID (1,938) cohorts. Overall during COVID, burnout decreased (from 21.84, 95% CI 21.53-22.15 to 20.94, 95% CI 20.57-21.32, $p<0.001$ on the OBI) and empathy increased (from 22.42, 95% CI 22.21-22.62 to 23.43, 95% CI 23.21-23.64, $p<0.001$ on IRI). All subgroups with decreased burnout had increased empathy, attributable to changes in the exhaustion and engagement sub-scales of burnout.

Conclusion:

Contrary to expectations, medical students were less burned out and more empathetic during COVID compared to Pre-COVID. In subgroup analyses, the temporal relationship with curricular changes was a better explanatory fit than changes in the COVID pandemic stage. We postulate a curricular "Goldilocks" zone that balances a limited virtual curriculum to decrease student exhaustion with in-person experiences to increase student engagement - the net result of which could build a more empathetic professional student community.

Practicing Healthcare Ethicists and Medical Assistance in Dying: What Should We Be Doing?

Marika Warren

Since the legalization of medical assistance in dying (MAiD) in Canada, practicing healthcare ethicists (PHEs) have been involved in its delivery in a variety of ways. The upcoming legalization of MAiD when mental disorders are the sole underlying medical condition causing irremediable suffering has generated renewed discussion related to MAiD, especially regarding ethical concerns related to vulnerability and structural inequities. Given these conversations, it seems a productive moment in which to explore normative questions related to how PHEs should be involved in the provision of MAiD.

In this presentation, I will first outline the different roles that PHEs can find themselves in regarding MAiD, recognizing that in most jurisdictions PHEs play multiple roles related to MAiD. I distinguish how PHEs can contribute to (a) retroactive oversight and review, (b) proactive decision making and approval, (c) policy and procedure development, and (d) support and guidance, using examples from a range of jurisdictions where MAiD has been legalized. I will also describe some of the constraints on PHE involvement with MAiD delivery, including geographic disparities, and human resource limitations.

In the normative section of the presentation, I explore what PHEs can uniquely contribute in each of these roles

and identify what I see as some of the implicit messages about the relationship between ethics and MAiD contained in these various framings of the PHE role. I will compare MAiD with other complex, high-stakes situations in health care, such as living donor transplantation and end of life decision making, to determine whether there are ethically relevant differences between these situations that would provide justification for a different degree or kind of PHE involvement in MAiD provision.

Finally, I will bring the descriptive and normative discussions together, proposing a series of questions to ask when a service or organization is determining the role that PHEs will play in MAiD delivery.

Patients with Somatic and Psychiatric Comorbidity in Clinical Ethics Support

Charlotte Wetterauer, Jan Schürmann, Manuel Trachsel

Background: Patients with somatic and psychiatric comorbidity are a highly vulnerable patient population, which can lead to complex treatment situations from both a medical and ethical perspective. As somatic and psychiatric patient care structures are still mostly physically separated, adequate treatment of the multifaceted needs may be further complicated.

Objectives: The aim of the present study was to investigate the ethical issues that arise at the interface of somatic and psychiatric patient care, the needs for action, and how these can be addressed in specific recommendations.

Methods/Analyses: Records of 204 clinical ethics consultations (CECs) provided by a clinical ethics support service at a somatic and a psychiatric university hospital, were analyzed. The frequency of CECs requests regarding comorbid patients, their formal, demographic, and clinical characteristics, and the main ethical issues were assessed. In addition, 11 semi-structured interviews with selected staff members of the two institutions were conducted and analyzed.

Results: 47 of 204 CECs (23 %) involved comorbid patients. The three most common ethical issues were decisions about coercive measures (36.2 %), life-sustaining measures (21.3 %), and dealing with problematic patient behavior (12.8 %). The interviewees stated that there is a need for action regarding the appropriate consideration and treatment of patients with comorbid somatic and psychiatric illness.

Conclusions: The frequent presence of patients with somatic and psychiatric comorbidity often leads to ethical questions and to insufficient attention by one or more medical disciplines. In addition to improving individual competencies, it is imperative to promote structural collaboration and to increase the presence of the other discipline within one's own health care institution. In summary, the following three main recommendations were derived: (1) joint treatment planning, i.e., consideration of mental illnesses in somatic treatment planning; availability and awareness of referral reports; protocols defining the appropriate points for involvement of specific stakeholders in therapeutic planning, and patient participation; (2) knowledge and use of each other's medical disciplines in one's own institution (e.g., C-L psychiatrists); and (3) active promotion of interdisciplinary basic knowledge.

"I have to put myself in their place:" Exploring the Moral Significance of Empathy in Humanitarian Palliative Care Through Narratives From Cox's Bazar, Bangladesh

Rachel Yantzi, Md Hadiuzzaman, Kathryn Richardson, Puspita Hossain, Sakib Burza, Lisa Schwartz

Background:

Within Médecins Sans Frontières (MSF) and the humanitarian aid sector more broadly, there has been an increasing focus on the importance of palliative care. The MSF Goyalmara Hospital in Cox's Bazar, Bangladesh offers the highest level of paediatric and neonatal care available in the Rohingya refugee camps. Efforts are underway to integrate palliative care, yet little is known about the moral experience of staff who offer palliative and end-of-life care in this context.

Objective:

The purpose of this study was to understand the moral experiences of MSF staff who are involved in providing palliative and end of life care to children, neonates, and their families.

Methods & Analysis:

This focused ethnography was conducted between March-August 2021 at Goyalmara Hospital. Data collection involved participant-observation, individual interviews (22), focus group discussions (5), and analysis of protocols and other documents. Interviews and focus groups were audio-recorded, translated, and transcribed. A coding

scheme was developed, and data coded using NVivo 11. Using ethnographic stories, we will explore how staff engaged empathetically with patients and their families, as well as the moral significance and limits of empathy in this context.

Results:

Sympathy and empathy, as well as Bangla concepts with similar meaning such as shohanubhuti and shohomormita, were central to how MSF staff understood good palliative care. Yet staff struggled to engage empathetically with patients and families due to linguistic and cultural differences, time constraints, and perceived expectations of professional distance. Some staff worried that frequent exposure to child death was causing them to lose capacity for empathy, while others experienced emotional distress when patient deaths reminded them of their own experiences of loss. Staff expressed concern that empathy and other forms of emotional support were not a substitute for quality medical care.

Conclusion:

Given the inequities and material deprivation of humanitarian contexts, empathy should be understood as necessary but not sufficient for good palliative care, as a precursor to compassionate and concrete action to improve the quality of life of patients and families. Humanitarian organizations have an obligation to ensure that staff have the supports needed to avoid secondary trauma and compassion fatigue.

Leveraging the Lived Experience of Youth Leaders: Authentic Ways to Partner

Heather Burns, Jessica Chan, Dolly Menna Dack

Youth-aged patient partnership has had a long history at Holland Bloorview; in fact the Youth Advisory Council is celebrating more than 25 years in existence. In 2012 we sought to create a comprehensive approach to our organizational efforts to engage with youth-aged patient partners (Youth Leaders). Three streams of engagement work were brought together to create the Youth Engagement Strategy (YES). These streams are: the Youth Advisory Council, the Youth Mentorship Program and paid work opportunities.

In this 60minute workshop, a comprehensive overview of the structures and processes that have led to the success of the YES, and highlights of projects that the Youth Leaders have been involved with in the areas of Research, Policy, and Organizational strategic work will be shared. By fostering a culture of partnership and collaboration the Youth Engagement Strategy has actualized the hospitals' core values in the creation of the framework and activities undertaken. By fostering a culture of collaboration, we creatively transformed ideas into impact.

The workshop will elucidate the approach undertaken to foster authenticity, honour the youths lived experiences and create a successful partnership. The workshop presenters will include the Manger of the Youth Engagement Strategy and two Youth Leaders who have been involved in range of YES projects.

Audience members will participate in short activities to reflect on meaningful engagement with patient partners and what small steps can be undertaken to either improve partnerships with patients or begin these partnerships in their local environment.

Fostering Moral Communities: An Interactive Workshop on Developing Metrics to Measure the Success of Novel and Traditional Clinical Ethics Programs

Joshua Crites, Laura Guidry-Grimes, Cristie Horsburgh, Jane Jankowski

Absent resources to meet increased demand and an expanded scope of ethics activities in the United States, many U.S. ethics committees struggle to provide quality ethics services that meet institutional needs. Scholars have been calling attention to these challenges in the literature for more than 20 years, offering various strategies for reinvigoration in light of the ways in which ethics committees have been falling short of their original aims.

After several years of attempting reinvigoration within our own healthcare system, we comprehensively redesigned ethics programming in collaboration with healthcare professionals, hospital leadership, and community members. The new structure has two complementary networks, one for healthcare professionals and one for community members, coordinated through our department and replaces traditional ethics committees. Paramount in this process was creating metrics that would help us measure success or determine when we might need to course correct within the new structure to avoid previous structural ineffectiveness and inefficiency. We drew from the few but excellent examples of measuring ethics committee and ethics network activities in the clinical ethics literature but found a relative dearth of comprehensive approaches to measuring whether ethics work is having its intended effects. We believe that, regardless of utilization of ethics committees or other structures, more ethics programs engage in assessment efforts than is reflected in the literature and that attendees at this conference especially would benefit from sharpening and sharing those experiences through this workshop.

Facilitators will outline the structure and goals of the workshop before reviewing our redesign (and the challenges it seeks to address) and introducing the metrics we have employed in measuring success (15 min). Facilitators will then lead breakout groups through a modified "Discovery & Action Dialogue" exercise consisting of the following stages: (1) Sharing of current experiences in measuring ethics activities with breakout groups (10 min); (2) Development of individual plans for incorporating metrics presented in this session within home institutional setting, either by sharpening current approaches or developing new ones (20 min); (3) Report out of key takeaways and next steps within the larger group, with opportunity to further refine action plans (15 min).

Cases That Haunt Us: Revisiting Progress and Looking Forward

Paul Ford, Kaarkuzhali Krishnamurthy, Denise Dudzinski

The phrase "cases that haunt us" has been a part of the bioethics lexicon since the publication of Complex Ethics Consultations: Cases that Haunt Us in 2008, inviting ethicists to consider the affective dimensions of ethics consultation. Fifteen years later, this panel will reflect upon the evolving practice of clinical ethics consultation. What remains salient and instructive about the way ethics consultations were conducted in 2008? What has changed? What should change? As we emerge from a global pandemic, do the same issues haunt us? With special attention to equity, diversity, and inclusion, members of the panel will reflect upon the types of cases captured in several themes from the book to answer these questions. Each panelist will present less than 10 minutes about the current progress made and the hopeful trends in addressing the affective components of ethics consultation. The remaining time will be facilitated discussion from the audience. The three panelists are experienced consultants (more than 50 combined years of ethics experience) who practice in geographically diverse areas (West, Mid-West, and Eastern United States) and in three separate health systems. In addition, the panelists are from philosophy, religion and medicine by discipline and have diversity by culture and gender. The interactive panel will invite attendees to discuss and debate what haunts them- past, present, and future.

When the Darkness Falls What Can You See?

Andrea Frolic

At the 2011 ICCEC meeting, I performed a dance with my collaborator Victoria Slager. The piece--"Body of Work"--explored ethics consultation as an embodied practice, challenging its characterization as primarily philosophical or cognitive. Using music, poetry, case narratives and movement, we depicted the healthcare ethics consultant's (HEC's) engagement with patients, families, clinicians and leaders. "Body of Work" revealed the physical/emotional impact of bearing witness to stories of trauma, loss, injustice and death on a daily basis.

In the intervening years, my work has undergone radical renovation due to a confluence of global events, including: the introduction of MAiD in Canada; the COVID-19 pandemic; and the epidemic of burnout amongst healthcare providers. These disruptions presented creative opportunities, as well as chronic moral injury. Equally, my personal life was rocked by deaths of friends (including Ms. Slager), as well as injuries which led me to give up dance. I imagine every HEC could recount a litany of personal, local and global seismic events that forever changed who they are and how they practice.

Objective:

The most pressing moral issue I experience in my work mirrors the most pressing issue I face in my personal life: how to cultivate individual and collective post-traumatic growth? That is, how do we endure and find hope amidst the cataclysms of contemporary life

Methods:

This workshop will unfold in three parts. First, a multimedia dance performance explores grief, moral injury, meaning and hope in the work of healthcare. Second, participants reflect in small groups on how the piece expresses some of the challenges facing HEC's collectively. Third, large group discussion will gather our collective wisdom about the sources and expressions of hope in healthcare, and practices to cultivate purpose and growth in our HEC work.

Analysis, Results, Conclusions:

In this interactive workshop participants will explore: 1) how HEC identities and practices are altered by both global and personal traumas; 2) the role of hope and its sources in our work; 3) how we renew ourselves as professionals to enable our own sustainability and the renewal of the beleaguered health systems we support.

Aid in Dying: Partnering With Patients and Communities

Pola Hahlweg, Ralf Jox, Marie-Eve Bouthillier, Thaddeus Pope, Stella Reiter-Theil

Aid in dying (AID) can be understood as an umbrella term for end-of-life practices that intend to hasten someone's death - at their voluntary request, with capacity to make decisions, and with the help of another person. Depending on the context, this includes (clinician-)assisted suicide and voluntary euthanasia. We conceptualize AID as a longitudinal, iterative process including communication and decision-making about and possibly the performance of AID.

AID processes and their implementation are highly complex and remain ethically challenging. Among the open questions are:

1. Should AID be part of the routine healthcare setting or be organized in another (private or professional) setting?

2. Should healthcare (ethics) institutions partner with community groups like AID advocacy groups? If so, how?

Some countries like Canada already have answers through their laws. Others, like Germany, Switzerland, and the United States are less decided or still finding their way. Depending on the answers, we must answer additional questions such as who should initiate and lead conversations about AID.

This workshop explores the pros and cons of AID decision processes being organized as part of routine healthcare, in other professional settings, or in the private sphere of individuals considering AID. In addition, we reflect on collaboration between the different settings and on who should bring up AID in conversations. Brief statements by stakeholders from different countries and healthcare settings will be followed by a 30-minute interactive panel discussion moderated by Stella Reiter-Theil and Ralf Jox.

Thaddeus Pope will present the work of AID advocacy groups in the United States and their collaboration with healthcare (ethics). Pola Hahlweg will show the chances and challenges Germany currently experiences when facing the task to re-regulate AID and Ralf Jox will add the Swiss perspective. Marie-Ève Bouthillier will share Canada's experience, where AID is a statutory part of healthcare, and discuss the consequences for the issues raised above. Through this interactive and multi-perspective format, we aim to map out different aspects to consider, challenges, and practice examples to approach an answer to the question whether AID should be included in routine healthcare and who should initiate communication about AID.

Cultural Differences in Pediatric Palliative Care: Shared Decision-Making

Chantal Joren, John Lantos, Erwin Khoo, Eduard Verhagen

The World Health Organization has called the provision of pediatric palliative care (PPC) "a medical and moral necessity." WHO estimated that 21 million children around the world could benefit from PPC. But the development of PPC programs can be influenced by legal, political, cultural, religious and economic factors that are different in every country. PPC patients usually have complex diseases that require complex and high-tech care. Decision-making is challenging as new innovative treatments change prognostic estimates. The prevailing paradigm for communication is "shared decision making" (SDM) in which the doctor's role is the share knowledge and help parents make decisions that align with their values. But SDM requires a delicate balance between a more directive, paternalistic approach and a more open-ended, autonomy-oriented approach. SDM has a strong theoretical basis but it can be difficult to operationalize in practice.

In this interactive workshop, international experts in PPC will discuss the ways in which PPC has developed worldwide. They will present cases that illustrate the complexity of SDM and the ways that it may conflict with cultural or religious expectations. The experts will highlight approaches that are widely endorsed across cultures as well as practices that are unique to certain cultures. We will present best practices from around the world and highlight ongoing controversies.

The workshop will provide participants with a broad understanding of the challenges and potential solutions enabling a more comprehensive approach to SDM in PPC. Dr. John Lantos will introduce SDM around the world together with Chantal Joren. Polling and group discussion will be used. Dr. Erwin Khoo will talk about SDM in Malaysia. A case exercise in small groups will be used to enhance the learning experience. Prof. Dr. Eduard Verhagen will lead the group in discussing difficult cases. Examples from around the world will be used. Chantal Joren will provide a Dutch perspective on SDM, as well as helpful tools. Dr. John Lantos and Prof. dr. Eduard Verhagen will lead the group in discussing implementing best practices.

The Art of Care: Towards a New Paradigm of Caring Art in Relationship

Philippe Karazivan, Tiffany Clovin, Marie-Pierre Codsi, Morganne Masse, Caroline Wong, Marie Leclaire

The era we live in, with its rapid societal changes, the acceleration of digitalization, the reasoning power of artificial intelligence, and the unprecedented environmental crisis, makes it urgent for us to explicitly and collectively define the human faculties we wish to cultivate to care for individuals, communities, and the environment.

In this participatory workshop facilitated by a patient partner, a physician, and a psychologist, we will freely inquire into what enables the cultivation of the art of care, drawing from various examples from the clinical practice

of family physicians, residents, medical students, and patient partners. Narratives and images of the art of care will serve as a basis for discussions. We will explore current representations and norms surrounding the art of care within the medical culture, paying attention to their biases and limitations. We will integrate biomedical perspectives, patient experiential knowledge, and insights from the humanities. The aim is to reexamine the epistemology of care and identify opportunities for innovation.

We will propose that one remedy for the overwhelming intensity of the modern world is to become aware of what we can do together—care, think, repair, and build connections—and to have the courage to increase their visibility today by embracing a plurality of perspectives and co-constructing with patients.

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Clinical Ethicists as Expert Witnesses: A Workshop Based on the Experiences of Clinical Ethicists and Lawyers in Pediatrics

Bertrand Lavoie, Anne De Ravinel, Marie-Claude Levasseur, Armand Antommaria, Nathalie Gaucher

In the 1980s and 1990s, North American ethics committees developed, in part, in response to court cases and the desire to keep ethical issues out of the courts. In the last several years, clinical ethicists have been called to testify in court in various contexts, including litigation over gender-affirming medical care in the United States and a case regarding pediatric decision-making in Quebec.

This workshop will explore clinical ethicists' roles in courts and how clinical ethicists can be credible expert witnesses. Discussants will explore the concept of a legitimate testimony as a clinical ethicist and the idea that theoretical ethical reasoning can be considered expert testimony. Given the exceptional presence of clinical ethicists in courts in North America, this workshop will present ethicists' experiences in the various phases of litigation including preparing for trial, testifying in deposition and at trial. A multidisciplinary group of discussants will facilitate engagement of participants.

Deciding With Children: A Challenging Ethical Ideal

John Massie

Deciding with children (DwC) describes an ethical ideal of including children in healthcare decisions. This is based in the ethical principle of respect for persons, and is supported by the rights of children (UNCRC). DwC is a

process that should occur throughout a child's healthcare journey by considering the child's evolving preferences, values, interests and capacity, with the goal of developing an independent decision-maker. DwC can be tricky to implement, with challenges including: the willingness of the child and their parents to engage and involve the child in the decision-making process, interpreting the child's expressed wishes, determining the child's best interests and the extent to which these are served by honouring the child's decision, and balancing competing interests and voices.

In this interactive workshop we will consider the ethical principles that underpin DwC and then engage with the challenge of operationalising DwC through two cases, with audience participation.

Introduction and Ethical Theory: Professor John Massie, Clinical Director Children's Bioethics Centre, Royal Children's Hospital, Melbourne.

Case 1: Fertility preservation in a 10 year-old boy with leukaemia.

Presented by Dr Jenny O'Neill, Clinical Nurse Consultant Bioethics

Moderated by Ms Sharon Feldman Clinical Ethicist

Simon is a 10 yo boy, recently diagnosed with acute lymphoblastic leukaemia. He has a good chance of survival with chemotherapy, but it is likely to impair fertility. Simon is pre-pubertal; the best chance of preserving fertility is testicular biopsy with cryopreservation of the tissue and later in-vitro stimulation to induce sperm. His parents want the biopsy, but Simon clearly states he does not want this procedure.

Case 2: Below-knee amputation for a 13 year-old girl with a vascular malformation.

Presented by Dr Georgina Hall Clinical Ethics Educator

Moderated by Ms Sharon Feldman Clinical Ethicist

Wynona is a 13 yo girl with a congenital vascular malformation of her left leg, predominantly affecting her tibia but also including the distal femur. The vascular malformation has progressed through her childhood and is now causing skin ulceration, pain and bleeding. The only medical option is below-knee amputation which Wynona vigorously opposes. Her mother is unwilling to consent without Wynona's assent.

Determining Intolerable Suffering in the Context of Advance Directives for Euthanasia: A Debate on Quebec's New Legislation Regarding Advance Requests for Medical Assistance in Dying

Mathieu Moreau, Tim Holland

In 2023, the Quebec government passed legislation enabling advance directives for euthanasia (often referred to as advance requests for medical assistance in dying - MAiD - in Canada). Once the legislation becomes effective, Quebec will join the Netherlands as being the only two jurisdictions that permit advance requests for MAiD for conscious patients lacking capacity to consent to the procedure.

In the Netherlands, to receive MAiD a physician must be able to objectively note the presence of intolerable suffering. By contrast, in Canada, the patient must experience intolerable suffering as defined by the patient's subjective experience. The new Quebec legislation departs from Canada's previous subjective focus and has included stipulations more in keeping with the Netherlands requirement for objective evidence of suffering. This draws attention to one of the most central ethical dilemmas facing care decisions in patients who lack decision-making capacity: Do we look directly at the patient before us to determine what is in their best interests (e.g., do we rely on objective evidence of suffering), or do we rely on the interests of the person who drafted the advance request (e.g., what qualifies as suffering is determined by the subjective forecasting of the patient drafting the advance request). This dilemma pulls into stark contrast the omnipresent tension between beneficence and autonomy. An understanding of the pitfalls involved in applying an advance request could guide its drafting as part of an informed partnership with patients.

This workshop will involve a debate between two physician-ethicists. Dr. Mathieu Moreau, consulting physician on the Quebec legislation, and member of the Bureau de l'éthique clinique at Université de Montréal, will defend the legislation's objective focus. Dr. Tim Holland, chair of the Advance Request Working Group for the Canadian Association of MAiD Assessors and Providers, and Head of the Bioethics Department at Dalhousie University, supports the subjective perspective. Both are MAiD providers since the procedure became legal in Canada. The debate will begin with a poll of the audience and will be followed by an audience discussion on the issue. Facilitators will be intentional about creating a safe and encouraging environment for trainee participation.

Counterbalancing Polarization in Healthcare Through Moral Distress Reflective Debriefing

Georgina Morley, Cristie Horsburgh, Laura Guidry-Grimes, Lauren Sankary, Natalie Weigand, Laura Longbrake, Jennifer McLellan Johnson, Margot Eves, Joshua Crites

The healthcare climate feels increasingly politicized and polarized, exacerbating healthcare workers' (HCWs) experiences of moral distress. In the US, legal constraints in the provision of abortion care and gender-affirming (adolescent and adult) care have resulted in HCWs experiencing moral-constraint distress because they are unable to provide care that is consistent with the standard of care, patient safety, respect for persons and individual choice. Other HCWs have expressed moral-constraint distress because they feel obligated to provide care inconsistent with their personal values and political beliefs. In this workshop, we will describe our structured approach to facilitating Moral Distress Reflective Debriefs (MDRDs), which have been utilized in our large US healthcare system to facilitate over 60 MDRDs to ~350 HCWs since 2019 in response to these (and other) polarized and morally distressing issues. The aims of MDRDs are to provide morally distressed HCWs with a safe space to share their moral perspectives, explore the basis of their beliefs, better understand the moral event causing distress, and engage in perspective-taking.

The rise of disinformation around abortion care and gender-affirming care, which include unsupported claims about 'reimplanting' rather than terminating ectopic pregnancies, adolescent 'peer contagion,' and patient regret perpetuates concerns for stigma, bias, and discrimination. In this context, clinical ethicists facilitating MDRDs must balance tensions between HCW's right to conscience claims with their obligations to address stigma and bias that compromise patient care. Workshop leaders will provide an overview of the MDRD process, describing how facilitators strive to mitigate the negative effects of moral distress through discussion, reflection, empowerment, and a sprinkling of ethics education. We will describe additional measures implemented to optimize the safety of the moral space when exploring polarizing ethical issues and methods used to validate experiences of moral distress while balancing the affirmation of diverging values with challenging fear- or stigma-based beliefs or assumptions. Audience members will be able to practice facilitating aspects of an MDRD. The session will conclude with a reflection on how we supported HCWs who expressed worries about providing abortion or gender-affirming care with further education that was tailored to skill-building and increasing their confidence.

Aspirations and Realities for Ethical Partnerships: Experiences in Humanitarian Health Research

Isabel Muñoz Beaulieu, Puspita Hossein, Rachel Yantzi, Sonya de Laat

Background:

Considerable initiatives exist to support equitable research partnerships in settings where partners are differently positioned relative to power. Humanitarian and global health research include strong examples of this. Over the past decade, initiatives have emerged to establish fair, equitable and effective research partnerships including the Principles for Global Health Research from the Canadian Association for Global Health, the Canadian Institutes for Health Research's Framework for Action on Global Health Research, and from the United Kingdom, ELRHA's Partnerships Review: Research for Health in Humanitarian Crises. The commitments inherent in these initiatives have helped orient collaborations and promote relevant and robust findings. Despite this, structural barriers and frustrations persist, including unequal recognition of research contributions, allocation of funding, data sovereignty, and access to research networks (e.g., conference fees, travel visas).

Objective:

The workshop has two main aims: (1) explore experiences of working in collaborative humanitarian health research, and (2) identify what worked and what did not in efforts to continue promoting and effecting power redistribution strategies in research broadly.

Discussion:

Being a workshop on partnership, there will be three pairs of presenters, each focusing on one of the following themes: initial stages of a partnership, during research, and concluding research / furthering collaborations. For the workshop's first 20 minutes, presenter pairs will have 5-7 minutes to introduce their partnership experience with a focus on its successes and challenges.

Interaction:

Breakout lightning discussions will allow participants 8-10 minutes to talk with each presenter-pair. The discussions allow participants to delve deeper into presenters' experiences and explore ways in which values expressed in existing guidelines and best practices can be further embedded in partnered research.

Results:

Expected outcomes of the lightning discussions includes sharing, as a group, final reflections on the barriers and enablers that support or stunt aspirations from becoming realities. The workshop will conclude with 10 minutes to hear from participants and to reflect on the interconnections between initiatives at the different stages of research.

Conclusions:

The workshop provides a strong foundation for gaining insights into developments, actions and ongoing challenges in fostering fair, equitable and effective partnered global humanitarian health research.

Community Partnerships in Sickle Cell Disease: Success of Novel Therapies Depends on the Relationships We Build

Frankline Onchiri, Yvonne Carroll, Kim Sawyer, Liza-Marie Johnson

Patients with sickle cell disease (SCD) suffer from serious morbidities and are at risk for early mortality. The disease disproportionally impacts racial and ethnic minorities, with 90% of individuals identifying as Black. Patients with SCD can experience structural inequities in healthcare as well as bias from individual providers during routine clinical encounters, both of which can result in suboptimal care and may foster mistrust. Given the serious disease burden and significant morbidity, curative therapies are urgently needed. Presently fewer than 10% of patients have access to curative matched sibling bone marrow transplantation. Haploidentical donor transplantation and gene therapy are two investigational approaches in early-stage clinical trials. Best practices for communication with SCD patient-family stakeholders about these novel interventions are lacking. Given the historical mistreatment of minority participants in clinical trials, there is an ethical imperative to develop innovative, culturally competent approaches for engaging with individuals who will be offered novel 'high risk potentially high reward' therapies where long-term risks remain to be established. This multi-disciplinary panel will present our experience working with an advisory council of SCD patients and parent caregivers using a community based participatory research approach. Through a series of surveys and focus groups we have gathered community perspectives, and our panel will outline recommendations for communicating with vulnerable and underrepresented minority patients and families. A patient stakeholder with SCD (FO) who participated in this partnership will share his perspective.

We will use a combination of didactic presentations, videos, and knowledge probe questions for the audience. We will engage participants in a dialogue about the presented material and elicit their lived experiences, using a quick think / Socratic questioning approach if necessary. Both our advocacy expert (YC) and patient (FO) will present material for objective 1, while our communication expert (KS) will present information for objective 2, with the physician-ethicist (LMJ) and patient (FO) sharing information for objective 3 with visual aids. Each section will allow opportunity for interaction with the final 10-15 minutes of the hour for questions and formal group discussion with participants.

The Development of Safe and Courageous Educational Spaces in a Medical Faculty

Antoine Payot, Clara Dallaire, Julie Desmeules, Julie Cousineau, Vincent Jobin, Miriam Loulou, Louis-Philippe Thibault-Lemyre

In our rapidly evolving social environments, establishing and promoting safe educational spaces within our academic institutions and training sites calls for thoughtful adjustments of our attitudes and approach to equity, diversity and inclusion. The concept of a safe space, well described in medical or educational literature, carries the risk of leading to a leveling and sterilization of the content discussed to protect the interlocutors and avoid offending certain sensitivities. Although these risks are real, the muting of certain important discussions for healthcare training, whether cultural, social, historical, political, or religious, is not a desirable outcome for learners.

One of the objectives of a university academic environment is to promote a respectful, constructive, and sometimes courageous dialogue on complex issues, even if some arguments of the dialogue may seem contrary to certain societal trends. With the objective of promoting and maintaining psychological safety and allowing for open dialogue and the debate of complex issues, we propose the creation of a "courageous space" within a safe learning environment.

Within these courageous spaces, students and professors would have the academic freedom to address difficult and complex subjects while cultivating open-mindedness, respect, nuanced discussions, and consideration.

Learning Objectives:

Define the concept of pedagogical safety and its characteristics. (CD, JC)

Explore strategies for recognizing our own biases, values and beliefs within a courageous and safe space in an educational setting. (JD)

Propose the creation of safe and courageous spaces through a contract of mutual consideration established between teachers and learners within the various educational sectors of a medical faculty. (AP, ML)

Discuss the issues, benefits, risks, and limits of such an approach within a medical training program. (all presenters with audience)

Methods:

A 60-minute workshop consisting of small group discussions alternating with large group plenaries. A training tool for participants (teachers and learners) will be proposed and discussed. The sharing of experiences and potential tools from different participants will be encouraged.

Authors are clinician-educators (AP, JD), clinical ethicists (AP, JC), specialists in pedagogy (JD, CD), patient-partner (CD) and medical student (ML).

Workshop facilitators will be available after the event for debriefing as needed.

A Toolkit for Working With At-Risk Patients Expressing Desire for Discharge

Jordan Pelc, Omar Ghaffar, Jesstina McFadden, Shannon Roberts, Sameera Khalid, Rosanna Macri

Although there is a plethora of literature on patients leaving against medical advice, across Canada there is a lack of similar guidance when patients with cognitive impairment, who are medically stable but have ongoing personal care needs (i.e., "at-risk patients") seek discharge when their care team recommends they remain admitted. With the population aging and the continued lack of community resources, the legal and ethical considerations, such as patient autonomy, professional responsibility and liability, authority to detain or restrain, and defining and managing risk are nuanced and the best course of action is not always clear. This can cause significant moral distress for all involved.

In an attempt to fill this gap, a quality improvement project was initiated with a core change team which included a hospitalist, a psychiatrist, a lawyer, a bioethicist, and a bioethics research student. A practical framework to facilitate in-the-moment decision-making when an at-risk patient is expressing a desire to leave an in-patient setting and return to community was developed and piloted with a range of stakeholders. This framework is based on Ontario law, but its principles are applicable broadly across Canada. It outlines four options that health care teams can use, alone or in combination, to help determine what to do. When evaluating options, it is important to consider the patient's specific circumstances, values and wishes.

This workshop will be facilitated by the hospitalist physician and bioethicist from Sinai Health who, with colleagues, developed this framework. The framework which includes guiding legal and ethical principles, along with considerations for communication strategies and internal resources will be reviewed and applied to a case. Participants in this workshop will then have an opportunity to work in groups on a variety of provided cases and apply the framework in real-time. They will then present their case review to the entire group to facilitate further discussion and learning.

Facing Dementia in the Community and the Clinic: New Challenges for Aging Societies

Thaddeus Pope, Zoe Ritchie, Kate de Medeiros, Nancy Berlinger

This interactive, multidisciplinary, transnational workshop will share a body of new work that considers dementia as a signal ethical challenge for aging societies globally, calling for fresh thinking and collaboration among bioethics, health humanities, and health and healthcare policy concerning how to support better lives and choices for people facing dementia, and for caregivers.

This topic is relevant to the conference theme: people with a dementia diagnosis or symptoms, or at increased risk of this strongly age-associated condition, constitute a community that is largely based outside of clinical settings. Engagement with people facing dementia, including caregivers, happens in primary, specialty, hospital, and residential care settings - and in homes and neighborhoods. Engagement with ideas and values concerning what it is

like to live with dementia happens at many levels, often accompanied by stigma or misinformation.

Speaker 1/Moderator, a U.S.-based researcher in bioethics and health humanities, will introduce two new open-access publications from ongoing work on population aging: 1) a report centered on a landscape review of ethical, legal, medical, and social considerations concerning hastening death in the context of a dementia diagnosis, and 2) a preview of a forthcoming volume of original essays on cultural narratives about dementia. Speaker 1 will then, as moderator, engage with perspectives from other speakers as follows:

Speaker 2, a U.S.-based expert in EOL law and policy and a co-author of the landscape review noted above, will discuss applications of this work to clinical and legal practitioner discussion and policy development concerning evolving questions in the US, Canada, and other aging societies.

Speaker 3, a Canada-based trainee, will offer examples of academic and media narratives concerning Canada's expanded MAID criteria, with attention to transnational discourses.

Speaker 4, a Canada-based social gerontologist and a co-editor of the volume of essays noted above, will offer a critical perspective that introduces participants to non-clinical approaches to thinking about aging, including experiences of living with dementia and progress toward equity in dementia care.

Methods: We will reserve 20 minutes for facilitated group discussion following four 10-minute presentations. We will share materials via print and QR code.

Involving Patients and Relatives in Health Care Ethics Support (HCES): Standard or Exception?

Stella Reiter-Theil, Ralf J. Jox, Jan Schürmann, Georg Marckmann, Katherine Wasson

Health care ethics support (HCES) has developed primarily as a service for health care professionals. Yet, patients, their surrogate decision makers, their relatives, and other users of the health care system are involved in most ethical problems arising in clinical care and may have ethical questions themselves. Consequently, the standard recommendations regarding HCES, such as the Core Competencies of the American Society of Bioethics and the Humanities, state that these stakeholders should be involved in and have access to HCES. In practice, however, involving patients and their relatives in HCES is not generally established, and practices vary widely. In some institutions, it has become part of routine practice, in others it is not encouraged or not even imaginable. Even at the theoretical level, there is controversy about whether, when and in which way patients and relatives should be involved in HCES. Is this controversy substantial? How can the diversity of practice be explained? Are there legal or cultural factors to consider?

In this workshop, we want to stimulate a lively exchange with the international audience based on three complementary inputs. The aim is to facilitate an informed attitude among conference participants about the question of involving patients and relatives in HCES.

Moderation: Stella Reiter-Theil (Basel, CH), Ralf J. Jox (Lausanne, CH)

Speakers:

1. Jan Schürmann (Basel, CH): Mapping the field and professional experiences

2. Georg Marckmann (Munich, DE): A reluctant view: conceptual and pragmatic counterarguments

3. Katherine Wasson (Chicago, USA): Arguing in favor: routine and rules of practice

Structure:

5 min introduction: The moderators will ask questions to the audience via Wooclap (real-time online survey tool) to elicit their practices and attitudes.

10 min for each presentation

20 min discussion with the audience

5 min closure: The Wooclap results will be displayed, together with the results of a final question on attitude change.

CAPHE-ACESS Code of Ethics

Marika Warren, Amanda Porter, Rosalind Abdool, Helgi Eyford, Jill Oliver

The Canadian Association of Practicing Healthcare Ethicists - Association canadienne des éthiciens en soins de santé (CAPHE-ACESS) was established in 2009. The purpose of this group was to professionalize and standardize the scope of practicing healthcare ethicists (PHEs) in Canada. In support of this aim, it was determined that a Code of Ethics would serve as one important product to develop.

Over the past few years, a sub-group of CAPHE-ACESS members, the Values Product Working Group (VPWG), developed a Code of Ethics for Canadian PHEs. In developing it, the group used a deliberative engagement methodology which supports a democratic, consensus-seeking process. The purpose of this workshop is to engage in conversations about the methodology used to develop the Code of Ethics and to address questions about implementation and continued collaboration amongst those interested in PHE professionalization. The workshop will have 5 parts:

Part I. Introduce the deliberative engagement methodology used to develop the Code of Ethics (10 mins)

Part II. Describe themes emerging during stakeholder engagement (5 mins)

Part III. Review the current Code of Ethics and proposed next steps in deliberative engagement (5 mins)

Part IV. In a small group, discuss the VPWG's proposed next steps to finalize and implement the Code across Canada (25 mins)

Part V. Discuss how workshop attendees can collaborate on professionalization initiatives moving forward (15 mins)

This workshop is interactive with opportunities for questions and discussion throughout. A think-pair-square-share process will be used to structure the small group discussion, when active engagement is most essential to the success of the workshop. Additionally, there will be opportunities for attendees to provide additional responses via a survey (accessible via QR code).

The final plenary discussion will explore whether and in what ways workshop attendees can collaborate on professionalization initiatives for Canadian PHEs. Insofar as all attendees have an interest in PHE professionalization, the continued conversations and engagement will be of benefit to all.

Developing a Code of Ethics for Practicing Healthcare Ethicists in Canada

Rosalind Abdool, Jill Oliver, Helgi Eyford, Amanda Porter, Andria Bianchi, Marika Warren

For at least the last fifteen years, professionalization has been discussed among those engaged in clinical and organizational ethics support in Canada. Professionalization has also been a concern for colleagues in other jurisdictions, but it was important to create a code of ethics that captured the specifically Canadian approach to healthcare ethics.

Foundational documents, including values statements and practice standards, are central to professionalization. A deliberative engagement methodology was adopted by the membership of the Canadian Association of Practicing Healthcare Ethicists - Association canadienne des éthiciens en soins de santé (CAPHE-ACESS) to guide the development of foundational documents for professionalization. The poster will enumerate the steps in the deliberative engagement process and then describe how those steps were (and will be) implemented to create the draft Code of Ethics.

The poster will highlight how differences of opinion were addressed in the development process as well as themes and questions that emerged in feedback from CAPHE-ACESS members. The poster will also identify how developing a code of ethics prompted revisions to the deliberative engagement methodology.

The poster will conclude with reflections from members of the working group regarding the strengths and challenges of using the deliberative engagement methodology to create the draft CAPHE-ACESS Code of Ethics.

In addition, this poster will offer opportunities for engagement, letting viewers rank the values listed in the Code of Ethics using repositionable notecards and a QR code for survey relating to possible processes for ranking. This is designed to offer experiential learning around both conceptual and procedural challenges inherent in the work necessary to create a code of ethics.

Analyzing Ageism in Healthcare AI: The Hidden Biases of Electronic Health Records

Belinda Alievska

This paper examines biases in physician-authored electronic health records (EHRs) and their impact on epistemic injustice in healthcare, with a focus on elderly populations. The use of Natural Language Processing (NLP) in healthcare, while aiding in EHR transcription and processing, unintentionally heightens the risk of bias and inaccuracies, adversely affecting vulnerable groups. Such biases in EHR data pave the way for AI tools to inherit and perpetuate systemic disparities, leading to inequalities and unfair healthcare outcomes.

The concept of vulnerability in healthcare is explored, highlighting how elderly patients, particularly women and people of colour, face testimonial injustice due to ageism and stereotypes. Elderly patients' inherent vulnerability, compounded by discriminatory healthcare practices, often leads to inadequate and unequal treatment.

The paper additionally discusses how implicit biases of healthcare providers affect the language in medical reports and the quality of care patients receive, with treatment decisions varying based on age, race, and gender. These biases are not only evident in EHRs but also influence the development of medical AI tools trained on such data.

Miranda Fricker's concept of epistemic injustice is used to conceptualize the frequent dismissal of elderly patients' experiences and testimonies in medical settings, often due to age-related stereotypes. This form of injustice is believed to extend to medical AI, as biased EHR data result in AI healthcare algorithms that inadequately represent or address elderly patients' needs.

In conclusion, the paper stresses the importance of proactive efforts to reduce biases in physician-authored reports and AI tool development in healthcare. Recognizing and addressing these biases is essential for equitable healthcare outcomes and the effective use of AI in medical practices. A comprehensive approach to understanding and counteracting these biases is advocated, aiming for a more inclusive and equitable healthcare system for all, particularly the vulnerable elderly.

Developing a Moral Empowerment Program to Address Moral Determinants of Providers' Wellbeing and Contribute to Healthcare Effectiveness and Sustainability

Esther Alonso-Prieto, Angel Petropanagos, Viva Swanson, Vanessa Mueller-Prevost, Jessica Fee, Amy Blanding, Davina Banner, Drew Clark, Alice Virani

Health care workers (HCWs) are experiencing alarming burnout rates, as evidenced by studies and institutional surveys on wellbeing. Burnout severely impacts HCWs, patients, and the healthcare system. Therefore, interventions to address its root causes are needed. Recent literature highlights that moral distress, that is, the psychological discomfort HCWs experience when they can't act in alignment with their moral values, is contributing significantly to burnout. Despite its negative connotations, moral distress can also have instrumental value. Thus, if properly addressed, it may facilitate the identification of gaps in organizational processes, contribute to personal and professional growth and ultimately lead to enhancing patient care and HCWs' job satisfaction. This is the core premise behind Northern Health Moral Empowerment Program's (NH-MEP). NH-MEP is an evidence-informed, practice-based, and organization-wide educational approach to promote moral empowerment among HCWs. It is evidence-informed because it builds on ethical theory to explicate HCW's experience of moral distress and the process of moral empowerment. It is practice-based because it integrates conceptual knowledge delivery with hands-on application. It is organization-wide as it is inserted in the broader context of the Northern Health Authority in BC. In this presentation, we will outline the program's theoretical foundations and discuss our approach to its design, implementation and evaluation identifying opportunities and recommendations for future work. This presentation will be of interest to those engaged in delivery, planning, and evaluating healthcare initiatives, along with patients and the public with an interest in moral empowerment in health care.

Sometimes Immature Minors Need to Hear Their Genetic Results: A Recommendation for Parent-Expert Collaborative Counseling

Veronica Andric

Sometimes an immature minor needs to hear their genetic results. However, the values underpinning precision medicine and family-centered care are rarely considered in the context of result disclosure. In general, there exists a lack of guidelines and regulations surrounding how, rather than which, results ought to be returned to patients. This is currently of particular concern in the field of genetics which is often associated with precision medicine and is becoming increasingly used in the pediatric setting. Experts often rely on parents or guardians to steer the ship with regards to disclosure of findings to their children. This undermines the family-centered care that is touted in many pediatric hospital settings and disregards beneficence in the name of parental autonomy. How results are shared with young patients can have potentially long-term medical, social and psychological consequences for both parent and child. The goal of this investigation is to arrive at an approach for disclosure of genetic findings in this context that is in line with the values of precision medicine and family-centered care. Ideally, the final recommendations will also be applicable to other subspecialties of medicine with some finessing. To achieve this, we explore the uniqueness of the immature minor patient, facing early onset of symptoms and invasive interventions at a young age, in the results disclosure phase. This involves considering the strengths and limitations of the parental role in this context and the responsibilities of genetic experts in facilitating these discussions. The final recommendation will seek to maximize benefits and minimize harms while respecting parental autonomy. Finding the right language and managing the practical questions and emotional responses that may arise is best approached through a collaborative parent-expert counseling session rather than turning to a "hands-off until asked otherwise" mentality. A parent can be leaned on for their knowledge of the child while an expert has the benefit of their technical background and experience. In this way, the parent is also supported through a potentially challenging experience. This recommendation for collaborative counseling serves to enhance precision-medicine and family-centered values through its application to results disclosure.

Green Inhaler Adoption, Climate Change and the Sustainability of Medicine: Navigating an Ethical Clinical Approach

John Appleby

Medicine is among the most environmentally destructive industries on the planet and is a major contributor of greenhouse gas emissions. One source of emissions is the use of metered dose inhalers, which use hydrofluorocarbon (HFCs) propellants that are exponentially more potent greenhouse cases than carbon. For example, in the UK, over 50 million inhalers are prescribed each year and 70% of those are meter dose inhalers. As a result, these inhalers make up approximately a quarter of general practice emissions, and constitute at least 4% of the greenhouse gases produced by the National Health Service (NHS). Given the urgent need to reduce healthcare's impact on

climate change, in this paper I ask what the ethical implications are of policy changes that could be used to encourage a clinical shift towards 'green inhalers', such as dry powder inhalers (which do not use HFC propellants). There are three main options available to policy-makers and clinicians. The first is to no longer offer meter dose inhalers to patients as an option. The second option is to allow the patient to choose whether or not they want to switch from a meter dosed inhaler to a dry powder inhaler, based on their own values and preferences. A third option entails preserving patient choice, but to also employ incentives, nudges and tools from behavioural economics to try and steer patients toward green inhaler choices. In considering these options, I argue that ultimately a hybrid model of the above three options is preferable. In particular, I recommend an approach that encourages green inhalers through incentives and education, while also allowing the limited use of meter dose inhalers for instances where there is a risk of harm to patients who refuse to switch. From an ethical point of view, I argue that attempting to preserve patient autonomy and maintain existing standards of care is essential to cultivating patient trust in new sustainable healthcare initiatives, such as the increased use of 'green' inhalers.

Understanding Attitudes and Beliefs Regarding COVID-19 Vaccines Among Transitional-Aged Youth With Mental Health Concerns: A Youth-Led Qualitative Study

Alexxa Abi-Jaoude, Daniel Buchman

Background: People living with mental health concerns experienced a disproportionate burden of COVID-19 globally. While vaccination against COVID-19 is a key public health strategy, vaccination rates among transitional-aged youth (TAY; 16-29 years) remain low. TAY with mental health concerns represent a vulnerable population in the context of COVID-19 because this population experiences stigma and discrimination. Those who contract virus face barriers to timely care which increases COVID-19 related morbidity and mortality. Specialized education and health promotion efforts are necessary to mitigate these inequities and promote population health.

Objective: The objective of this study is to understand the attitudes and beliefs towards COVID-19 vaccines among TAY with mental health concerns.

Method: We conducted in-depth qualitative semi-structured interviews with TAY living with mental health concerns and with family members. We explored perceived susceptibility to COVID-19 infection; severity of having COVID-19; benefits, consequences, motivations and barriers to vaccine uptake. Interviews were transcribed and then coded.

Analysis: We applied Braun and Clarke's approach to thematic analysis, generating four major themes: 1) factors underscoring trust in COVID-19 vaccines; 2) mental health influences and safety considerations on vaccine decision-making, 3) key sources of vaccine-related information; and 4) factors influencing information-seeking and uptake.

Results: Factors underscoring trust included trust in the vaccines, health care providers, and government. We also identified several moderating factors that influenced vaccine trust. This included the ways that the TAY's lived experiences of mental health directly and indirectly influenced their decision to take the vaccine. We also identified the sources of vaccine-related information that TAY sought out to support their decision-making, including friends/family; mainstream news; social media; health care providers; health care organizations and government. The findings of this study illuminate the complex factors that influence TAY's decision-making regarding COVID -19 vaccines, and several factors that can help to achieve widespread vaccine coverage and control the spread of COVID-19.

Conclusion: While this study was conducted in Canada, findings may be relevant to the global COVID-19 vaccination effort. Our next steps include co-creating a youth-specific resource and a clinical conversation guide that is an inclusive public health approach to promote equity in COVID-19 vaccine uptake.

Clinical Ethics Education: A Model for Developing Training Opportunities in Clinical Ethics

Megan Bailey, Jessie Van Leeve

In the realm of professional clinical and organizational ethics, a formal academic background in bioethics is just one piece of the puzzle for future ethicists. Practical training in a clinical setting is critical to develop the knowledge, skills, and competencies necessary for practicing healthcare ethics. Clinical ethics training programs help learners to bridge the gap between bioethics in theory and in practice. As senior clinical ethics interns with academic backgrounds in ethics, in addition to our experiences connecting with programs across Canada and working with the Ethics Quality Improvement (EQI) Lab at William Osler Health System in Brampton, Ontario, we have gained valuable insight into the benefits associated with experiential training and we now look to identify

key elements of our training experience with the aim of highlighting an effective model for quality-driven ethics education.

Training opportunities in ethics not only immerse individuals in diverse clinical spaces, they enable future practicing ethicists to build a portfolio of experience that includes consultation, policy development, education, teaching, and research. These programs give trainees opportunities to work with frontline staff, physicians, patients, and families to address a variety of challenges that arise in healthcare settings.

The commitment to creating quality-driven training programs for future ethicists calls for the development of a responsive learning environment, specifically one grounded in adaptive leadership, capacity-building activities, change management principles and quality improvement. Training programs designed with these keystone elements in mind do not merely expose prospective ethicists to a range of ethics services, they support the cultivation of effective communication, values-based conflict mitigation, and interpersonal skills through discussion, project-based activities, and clinical rotations. This approach has the effect of generating a strong theoretical and practical foundation for quality-driven ethics practice. It goes beyond theoretical knowledge, equipping practitioners with the tools needed to address complex ethical issues in real time.

As academically trained bioethicists, passionate about clinical ethics and patient-centered approaches to care, our experience has revealed to us the strong value associated with training programs that use these elements to bridge the gap between theory and practice and foster a comprehensive education experience for future clinical ethicists.

Transforming Clinical Ethics in Practice: Proactive vs. Reactive Approaches and the Nexus of Patient-Centered Care

Megan Bailey

In the current context of clinical ethics practice, there is the opportunity to shift towards a proactive approach to patient care that redefines how clinical ethics functions within an acute care setting. The shift towards a proactive approach is an opportunity to reshape the landscape of patient engagement within the realm of patient care.

In this presentation, I will address what a proactive vs reactive approach to clinical ethics is and the dynamics of this transformation. In doing so, I will explore how consultations can be reimagined with a proactive model of patient care and engagement. This shift stems from a quality improvement approach to clinical ethics that shapes clinical ethics through ongoing development, implementation, assessment, and refinement of strategies, tools, and resources. This approach recognizes the value of education, training, patient and family engagement, as well as interdisciplinary collaboration.

Traditional clinical ethics practice operates within a reactive framework, responding to ethical dilemmas as they arise during the course of patient care. This approach utilizes rigid ethical decision-making frameworks and foundations in moral philosophy as a means to approach ethics within the clinical context. There is an increasing recognition of the need for a proactive approach that engages patients in ethical discussions before critical decisions are required to be made.

This presentation seeks to address the benefits of patient-centred care associated with this paradigm shift by examining and offering insights into the evolving dynamics of ethical engagement in clinical settings. The presentation will further address what factors to consider when working on proactive approaches to clinical ethics and the creation of these types of tools. By embracing a proactive approach to clinical ethics, ethicists can honour patient-centred care by promoting enhanced autonomous decision-making within the healthcare context. The approach presented in this presentation contributes to the ongoing discourse on patient-centred clinical ethics, ultimately promoting a more inclusive and collaborative approach to ethical decision-making in healthcare.

Silent Triage During the COVID-19 Pandemic and Beyond: An Observational Study in a Swiss University Hospital

Ghislaine Behaghel, Kevin Dzi, Kristina Wuerth, Daniela Ritzenthaler, Ralf J. Jox, Rachel Rutz Voumard

Background: The COVID-19 pandemic has urged health care systems worldwide to reflect on the allocation of intensive care measures. While the Swiss government has never officially announced a triage practice, there may have been pre-hospital ‘silent’ triage reducing the numbers of transfers to emergency departments (ED).

Aims: (1) To assess evidence for silent triage during the past COVID-19 waves in Switzerland regarding transfers to ED. (2) To investigate the decision-making process underlying silent triage from the perspective of nursing homes.

Design: This is a single-center observational study in a Swiss region where the incidence of COVID-19 infection was among the highest in the country.

Methods: (1) A retrospective quantitative analysis of data from a university hospital has investigated differences of ED transfer of patients over 65 years before COVID (November 2019 to January 2020), during the first COVID-19 wave (November 2020 to January 2021) and after COVID-19 (November 2021 to January 2022). (2) Directors and chief nurses in nursing homes of the referral region have been asked to participate to an online survey focusing on their experiences regarding ED transfer and collaboration during the COVID-19.

Results: The retrospective data set consisted of 7840 patient cases. Mean age was 79 years (SD 8.4) and median length of hospital stay was 5 days: these were not significantly different between the 3 periods. We did not find any association between age, place of residence, and COVID-19 status with the number of ED transfers before, during and after COVID-19. Among the 21 survey participants from nursing home, 29% mentioned that transfers had been refused in acute situations and 47% noticed an earlier return to the nursing home, mainly justified by resource scarcity or an alternative of plan care in the nursing home. Before COVID-19, 57% did not fear any shortage of resource, while after COVID-19 the majority perceived a high fear of triage.

Conclusion: Our study did not find any indicators of silent triage during the first COVID wave in this region. However, nursing home expressed changing perceptions and practices regarding hospital transfer and increasing fear of resource scarcity and triage since.

Management of Demands of Potentially Inappropriate CPR and Life-Sustaining Therapies: The View of Quebec Clinicians

Vincent Béland, Mathieu Moreau, Philippe Rico, Yiorgos A. Cavayas

Background: In this era of shared decision-making, requests of potentially inappropriate treatments (PITs) by families is a frequent dilemma in the intensive care setting. PITs are associated with substantial costs and human impacts for patients, families and healthcare workers. There is great variability in how jurisdictions handle demands of PITs. There are no previous studies on the approaches of Quebec doctors regarding demands of PITs.

Objective: To evaluate the approaches and perspectives of Quebec physicians regarding demands of potentially inappropriate CPR and life-sustaining therapies (LSTs).

Methods: An electronic self-administered survey will be sent to the 300 physicians working in an intensive care unit in the province of Quebec. Decision-making is assessed in 5 fictional scenarios of intractable disagreements about withholding or withdrawing PITs for patients with very poor prognoses. Likert-like scales are used to assess the magnitude of PITs, techniques used for managing PITs and opinions regarding withholding and withdrawing PITs against patients' will.

Analysis: The primary outcome is consensus of clinicians, defined as an agreement ≥ 80%. Secondary outcomes are subjective appropriateness of care and variability of agreement and degree of treatment intensity according to epidemiologic factors: Hospital, age, base specialty, religiosity, and weeks per year working in ICU.

Results: In a pilot survey of the 15 intensivists of our institution, response rate was 80%. Among 12 respondents, 10 (83%) estimated that PITs were a frequent challenge and 11 (92%) that guidelines were not clear enough to adequately manage PITs. There was disagreement regarding withholding and withdrawing CPR or LSTs against patients' will. In the scenarios, among doctors choosing to provide the LSTs, the majority (n=8; 70%) thought it was not medically indicated. Recurrent themes in the qualitative analysis were difficulty of shared decision-making in acute situations, plurality of values, fear of conflicts or pursuits and short trials of LSTs as a potential solution.

Conclusions: We suspect that the ethical and legal framework around PITs in Quebec is challenging to clinicians, leading to heterogeneous approaches and more self-assessed inappropriate treatments. The pan-Quebec survey will take place in January 2024 and results will be presented at the conference.

Cognitive-Communication Adaptations in Ethics Consultation: Strategies for Patient Engagement, Communication Access, and Just Inclusion

Shelly Benjaminy, Elissa Larkin

Disability ethics is anchored by a commitment to an inclusive process that uplifts the autonomy of individuals with disabilities and promotes justice and equity. At base, effective clinical ethics interventions facilitate reciprocal en-

gagement between stakeholders, be they patients, families, providers, administrators, or policy makers. A profound challenge arises when a central stakeholder, the patient, has a disability that limits how they convey and access information, and thereby how they engage in their health care decision-making.

Cognitive-communication disability is a clinical category that encompasses the impact of altered thinking and linguistic skills on an individual's ability to engage in information exchange. Cognitive-communication disabilities can affect how a person comprehends and expresses information, as well as their non-verbal interaction skills. Cognitive-communication disabilities affect people across the age continuum and include a wide variety of diagnoses, such as autism spectrum disorder, traumatic brain injury, Parkinson disease, and dementia.

Worldwide systematic reporting is limited, but the median global incidence of adults 50 years of age or older living in the community with cognitive impairment is estimated to be 19%. That number only increases when children and young adults are included. Further, symptoms of long COVID can include both linguistic and cognitive dysfunction. Therefore, there is a growing need for practitioners, including healthcare ethics consultants, to acquire the knowledge and skills to accommodate the needs of persons with cognitive-communication disabilities. This is particularly critical in clinical ethics practice, where accurate communications are at the heart of high-stakes and potentially life-altering decisions.

We explore justice and equity as core values in clinical ethics consultation and highlight the imperative for fulsome inclusion of individuals with cognitive-communication disabilities in clinical ethics consultation. Drawing on a case-based approach from our ethics consultation experience and best practices from the speech and language pathology scholarship, we describe cognitive-communication challenges and illustrate evidence-based supported communication strategies that can be integrated into clinical ethics consultation. Accommodations for individuals with cognitive-communication disabilities uplift patient voices and promote the autonomous and just inclusion of individuals in key moments of their healthcare journeys.

The Plight of Being a Proxy in the ICU

Anissa Berger, Arlene Davis, Kenton Dover, Rimma Osipov, Jean Cadigan

I will present a first-person narrative exploration of the experience of a heath care proxy speaking on behalf of a critically ill patient in the ICU to explore the underappreciated but critical role proxies play. Patients' loved ones are asked to step into the role of proxy and make many difficult decisions. We argue that medical teams and the ethics consultants who work with them have an obligation to consider not only the work of proxies but their preparation for the role. Do providers explain to proxies what their role entails? How can proxies be supported throughout the decision-making process to represent the patient's preferences? Proxies have varying levels of "cultural health capital," a term used by Janet Shims to describe a set of skills and knowledge that can be leveraged by patients [or their proxies] to navigate the health care system. Research suggests that while proxies with higher cultural health capital are more confident in their interactions with providers and in their involvement in the patient's care, those with lower cultural health capital can find communicating with providers and decision-making more difficult. Providers may also use language that affects how the proxy considers the patient's preferences when making decisions. For example, providers may tell a proxy that a patient "needs" a life-prolonging intervention, misleading them into thinking that pursuing this intervention is the best course of action, without reflecting on whether the patient desired life-prolonging measures. It is also crucial to acknowledge the emotional burden of being a proxy for a patient in the ICU. In many cases, proxies are tasked with making critical decisions and it is reasonable that they will bring in their emotions during health care interactions and decisions. Amanda Gengler demonstrates how emotions can be valuable information throughout the decision-making process; emotions can be constructed to help proxies make their decisions and feel more confident about them. Although the literature on the provider-proxy relationship is emergent, it is essential that teams and clinical ethicists consider these perspectives in working with proxies in the critical care setting.

The Bridge to Nowhere: Unraveling Litigation of Non-Beneficial Care Offers in Canada

Marc-André Blier

Background: Critical care units in Canada employ advanced life support therapies including invasive ventilation, renal replacement therapy, and hemodynamic support aiming to return patients to their premorbid level of functioning. While these admissions are often lifesaving, critical care therapies have potential of harm including physical, cognitive, and psychiatric sequelae. The resources required are extensive compared to a routine hospital stay and the frequency of critical care usage is increasing year over year, increasing the importance of justice-based resource allocation. Patient selection for admission to critical care is therefore key to a well-functioning unit. Nev-

ertheless, patients, despite having predictors of poor outcomes or goals inconsistent with life support technology, continue to be inappropriately admitted to critical care settings.

Fear of litigation by patients or substitute decision makers (SDMs) contributes to physicians' offers of non-beneficial therapy, as acquiescing to requests is often deemed easier than discussing the therapy's non-beneficial nature and the conflict, including litigation, which may result.

Objectives: This project aims to identify themes of non-offer situations that result in litigation, identify what is ethically at stake in acquiescing to requests for non-beneficial therapy, and propose strategies to improve communication and understanding in end-of-life discussion with the goal of high-quality patient care.

Methods: retrospective, qualitative analysis of medico-legal complaints against Canadian physicians derived from data from a national CMPA database of medico-legal complaints. This included closed cases involving physicians of all specialties across Canada from 2018-2022 with patient end-of-life outcome.

Analysis: Thematic analysis of CMPA data results looking specifically for circumstances leading to complaints and litigation.

Results: Following manual review, 94 out of 36,950 cases involved allegations against physicians at end-of-life and met criteria. In 50 of the 94 cases, experts agreed with physician's care and no issues were identified. The most common leading factor for both allegation (49%) and modifiable contributing factor (28%) was communication breakdown between physician and patient/SDM.

Conclusion: Of the 44 cases that had contributing factors, most reasons for concern are modifiable through education and training and offer an avenue for education to minimize conflict between physicians and SDMs.

Ending "Ignorance" in Patient Partnerships: Toward Greater Inclusion of Vulnerable Groups

Brenda Bogaert

Background : While patient partnerships have been increasingly advocated for under the auspices of health democracy, not enough consideration has been given to the patients who represent their fellow citizens in healthcare policy, research, and education. On the one hand, we appear to have moved beyond the debate of whether or not they will be representative of the population as a whole and accepted that a truly objective representation is impossible. Instead, we are recognizing the value of individual experiences, expertise, and life stories. These are promising developments to help us advocate for the value of patient engagement in healthcare and research. However, we still have a blind spot: we have not done enough in the recruitment stage - as well as other stages of their involvement - to include vulnerable groups. In practice, this means that their knowledge has not been integrated into decision making and that we are largely still "ignorant" of their perspectives.

Methods : The field of ignorance studies, which refers to the study of how and why diverse knowledge does not "come to be," or is ignored or delayed, has considerable developed since Proctor's influential study in the late 1960s on the communication strategies of the tobacco industry to hide information or confuse the public. It has helped to show how ignorance can be produced in an involuntary manner or due to the choices of diverse actors.

Analysis : We propose to use this concept to think about the problem of inclusion in patient partnerships today and what we can do about it.

Results : Using the field of ignorance studies, we will show the "diversity" problem in the recruitment and involvement of patient partners (in particular those citizens coming from vulnerable groups) and why this is a problem ethics and for knowledge production.

Conclusions : We will give strategies/ideas to discuss with the audience - and in particular with patient partners present - to include vulnerable groups, including identifying facilitating factors or barriers to involvement of a more diverse public. Our proposition is therefore the start of a reflection on how to move out of this ignorance.

Colombian Parents' Perspectives on Adolescent Consent in Sexual and Reproductive Healthcare and Research

Julien Brisson

Background: The issue of adolescent consent in research and healthcare is ethically complex, especially in the context of adolescent sexual and reproductive health. Striking a balance between adolescents' evolving autonomy and parental values can be challenging. This tension is particularly pronounced in Colombian settings with elevated

rates of adolescent pregnancies and HIV/STIs. This research aims to investigate Colombian parents' viewpoints on adolescent consent in sexual and reproductive healthcare and research.

Methods: Data collection will start in January 2023 and will utilize a mixed-methods approach, incorporating semi -structured interviews and surveys. Participants will include parents of adolescents aged 10-19 years residing in the Colombian department of Antioquia, encompassing both the city of Medellin and the surrounding rural areas. The quantitative data will allow to determine if there are correlations between participants' demographics and opinions about adolescent consent. The qualitative interviews will allow participants to share their thoughts and experiences on the subject in details.

Analysis: A thematic and cross-sectional analysis will be conducted to assess potential differences in perceptions of consent for adolescent boys and girls among fathers and mothers.

Results: The preliminary main findings collected between January-May 2023 will be presented.

Conclusion: In the field of bioethics, there is no consensus on the extent of adolescent autonomy and the point at which parental consent becomes unnecessary for their decision-making. This lack of clarity is evident in the diverse parental consent policies globally, including variations within the Canadian context. The results of this study aim to provide insight into the perspectives of parents on the issue of adolescent consent, contributing to the development of informed and comprehensive policies.

Where Do I Belong? Leveraging Arts-Based Activities to Share Stories of Growing Up With a Disability

Heather Burns, Dolly Menna Dack, Jessica Chan

The Holland Bloorview Kids Rehabilitation Hospital's Youth Engagement Strategy has created a unique opportunity for the youth leaders (youth-aged patient partners) to explore, develop and share their lived experiences through art. In the last five years, five arts-based projects have used a variety of mediums including artist's choice mixed media, photography, and podcasts. These projects aim to scaffold the gap that exists in disability representation in the arts and seeks to share experiences of young persons with disabilities in meaningful ways by exploring social exclusion, access to supports and services, and youths' agency. The most recent project, *As I Live and Breathe* is a collection of short stories written by authors with lived experience of disability. The stories cover a wide range of topics and highlight how, even though disability is a deeply personal experience, there are common themes within the experiences of disability.

This virtual writing project began in February 2022 and consisted of workshops focused on writing styles, utilizing writing exercises and prompts, peer critique and discussions that were grounded in current experiences of living in, and growing up as a young disabled person in Toronto. On December 1, 2022 the book was launched in celebration of International Day of Persons with Disabilities.

This presentation will include an author reading by a Youth Leader from their short story in the As I Live and Breathe collection . Interactive Publicly available links to each of the arts-based projects will be shared with the audience to provide opportunities for them view, listen and read the content of these projects.

The Youth Leaders who participated in these projects are all current or former members of the Holland Bloorview Youth Engagement Strategy. The Youth Engagement Strategy is for youth aged 14-29 who are current or former Holland Bloorview clients who wish to use their lived experience to create change for future generations of kids and youth with disabilities.

AI Moratoriums and Medicine: What the Digital Revolution Can Learn From the Genetic Revolution - Hype, Panic, and Action

Guido Calderini, Vardit Ravitsky, Jean-Christophe Bélisle-Pipon

The healthcare sector is at the forefront of the debate surrounding the use of artificial intelligence (AI) and its potential impact on human society. At the same time, the creation of more powerful AI tools, particularly in the form of generative AI and large language models (LLMs), has created misgivings among the general public and in academia, culminating in the calls for moratoria on the further development of more potent engines. Should we see the recent misgivings and societal questioning as a reactionary trend that would jeopardize the progress of AI, or as proof of wise prudence that would enable balanced and sustainable growth, or maybe something else entirely? To answer this question, we can learn from similar debates surrounding other historically disruptive technologies. Through my presentation, I will present a framework of technological development based on a comparative analysis between the "AI revolution" and the "genetic revolution." This historical approach can help us to better under-

stand —and subdue— the dynamic interplay between the techno-progressive and techno-skeptical discourses that create alternating waves of hype and criticism in the realm of AI. Through my analysis, I identify three intellectual currents (1) transhumanism, (2) bioconservatism, and (3) bioliberalism and explain how they interact to shape debates surrounding new tools in medicine. Based on an analysis of similar trends for AI, I will show that current calls for moratoria are a sign of unproductive panic following two decades of unchecked techno-optimism. To ensure the responsible development and adoption of AI in healthcare I will defend the need to develop an institutional (technoliberal) approach that considers both benefits and costs seriously and creates a framework that minimizes risk while maximizing public benefit. I will also make the case that the contributions made by technoconservatives in identifying fundamental human concerns have not been given enough consideration and explain why and how they can be integrated into an institutional framework.

Ethical and Practical Challenges: Limits of Familial Responsibility for Patients who Make "Bad" Decisions

Mei Yoke Chan, Kumu Rajasegaran, Sumytra Menon

In many countries, including Singapore, legislation and professional ethical codes support the right of competent patients to make healthcare decisions that their family members or doctors consider "bad." This reflects bioethical thinking that emphasizes individual autonomy, where a competent and rational person can independently decide what happens to their own body. Singapore is a family-centric multicultural and multireligious community, shaped by Confucian principles and Western influences, where people have a range of attitudes on who should make treatment decisions. Nonetheless, family involvement in treatment decision-making for competent patients in Singapore is not uncommon, especially for older patients, and generally accepted by healthcare professionals in practice as long as it is supportive of the patient. This paper focuses on patients with borderline competency who may have limited insight into the implications of treatment options, and who may be especially vulnerable and prone to making decisions others would consider contrary to their best interests and reflecting insufficient understanding. These patients may have personality or mental health disorders, for which they have repeatedly declined professional guidance. The ethical tensions and practical challenges faced by the individual, their family as well as the clinical team will be discussed. This would include the emotional toll on the family, potential avoidable financial and caregiving responsibilities and the limits of the family's obligations when such "bad" decisions leads to serious consequences. The extent of the family's duty of care during these challenging circumstances will also be discussed.

How Should Novel Salvage Therapies Be Assessed for Ethical Appropriateness?

Mei-Yoke Chan, Titus Lau, Kumudhini Rajasegaran, Sumytra Menon

Since the Human Genome was sequenced in 2003, new technologies in genomics have given rise to the nascent field of precision medicine. Treatment is tailored to patients' genetic or molecular profiling with the promise of optimizing efficiency and/or therapeutic benefit. However, as with any new scientific advancement, precision medicine has the potential to improve health outcomes but also raises ethical questions. Since most of these therapies are "personalized," the gold-standard of randomized controlled trials to assess utility, cannot be applied. In Singapore, clinicians apply to institutional Clinical Ethics Committees (CEC) for ethical approval to use these novel therapies, which are untested, albeit backed by basic scientific evidence, as a last-ditch salvage option for patients. This begs the question whether CECs are the most appropriate gatekeepers since the members are not content experts and rely on clinicians who have biases of their own. There is also a potential for CECs to be a loophole, circumventing the more stringent evaluation by research IRBs. Some examples of cases that were brought up to CECs include novel in-house manufactured chimeric antigen receptor T-cell products, and living-donor intestinal transplantations, which while considered standard of care elsewhere, have not been done here. In some countries the Hospital Exemption rule and Expanded Access programmes have been established to facilitate patients' timely access to novel therapies that are either off-trial or not suitable for commercialisation. Singapore is currently exploring ways to efficiently but safely evaluate the clinical and ethical utility of such novel therapies so that patients can also have timely and ethically appropriate access to them. This may be preferable to relying on CECs only to assess. In addition to scientific experts and ethical and regulatory representatives, it might be beneficial and inclusive to have industry representatives as well as community or patient advocate representatives so that every voice that may be impacted by the adoption of any new evaluation method of such novel therapies, is heard. Finally, while it is not the intention to impede scientific progress, there should still be rigorous regulatory frameworks with which to assess the safety and necessity of such therapies.

How Do Clinical Ethicists and Ethics Interns Feel? A Narrative Review

Téa Christopoulos, Oluwaseun Sobode, Thomas Milovac, Sam Moshiri, Dylan McKibbon, Jessie Van Leeve, Megan Bailey, Angel Petropanagos, Jill Oliver, Paula Chidwick

Background: As interns, we've observed clinical ethics consultations and noticed that we've experienced emotional responses following consultations, particularly those on difficult topics such as end-of life decision-making. We pondered: Are emotional responses following ethics consultations typical for interns or clinical ethicists? What is this emotional experience? Is there a cumulative aspect of these emotional responses that warrants investigation? While there's extensive literature on the role and nature of emotional responses for many frontline healthcare providers, such as nurses and physicians, relatively little exists on the emotional experiences of clinical ethicists. We maintain that understanding the experiences of emotions related to ethics consultation can be important for both interns and clinical ethicists, given the challenging and value-laden healthcare contexts in which ethics consultations often occur.

Objectives:

To demonstrate a gap in the literature with respect to the presence/role of emotions experienced by clinical ethicists and their interns.

To advocate for empirical inquiry to better understand the emotional aspects of clinical ethics consultation work.

Methods: We conducted a narrative review, searching scholarly journal databases, and grey literature. We searched for articles that focused on clinical ethicists, emotions and consultations and summarized articles that spoke to emotional aspects of clinical ethics consultation work.

Results: Although much research exists on the emotions of HCPs, there is a paucity of such research pertaining specifically to clinical ethicists and interns particularly in the context of ethics consultations. There's also a lack of descriptive and empirical literature that identifies the cumulative emotional impact of work by clinical ethicists over extended periods of time, which warrants further investigation.

Conclusions: There's a need for more nuanced attention to the role that emotions play during and following clinical ethics consultations. We advocate for empirical studies focusing on the presence, identification, and management of the emotions of clinical ethicists before, during, and after consultation. Our review is the first part of a descriptive study that will employ a survey to gather empirical evidence on this topic. To our knowledge, this is will be one of the first empirical investigations of emotional implications for clinical ethics consultations for interns and ethicists.

A Call to Partner With Communities To Hear Diverse Sociocultural Perspectives on Artificial Intelligence in Healthcare

Benjamin Collins

Artificial intelligence (AI) in healthcare presents numerous ethical issues. Many of these issues are influenced by the globalization of data for AI and differentially entangled with concepts across cultures, whether among indigenous populations, immigrant populations, regionality within countries, or internationally such that it is important to consider healthcare AI in the appropriate sociocultural context. To do so requires partnering with communities to hear diverse sociocultural perspectives on AI in healthcare to: (1) Identify their needs rather than impose technological solutions when there may be other solutions or other problems with a higher priority and avoid a technological imperative whereby people feel compelled to have AI involved in their care despite concerns. (2) Recognize their moral values in matters of health, which we do not yet know in the AI context and outside the context of AI often do not align across populations such as regarding the disclosure of cancer diagnoses to patients or with acceptance of medical aid in dying. (3) Balance a discussion often dominated by big tech corporations drowning out the voices of those who are most affected. (4) Prevent problems, which are difficult to backtrack and fix, before they occur, especially the potential for negative biases and worsening health disparities of which communities will be more aware than those who develop and implement healthcare AI. (5) Determine what the communities know about healthcare AI and what they do not know, avoiding a dissonance between expectations for healthcare AI and reality, and establishing an appropriate level of trust. These partnerships should begin early, from the conceptualization of an AI, and be maintained throughout the lifecycle of AI. They should consider foremost the voice of the communities, especially hearing from those who may typically be missing from the conversation. Then to act together alongside communities, and listen again, learning what is working and what is not working. While we do not yet know what perspectives may arise or how different cultural perspectives will affect AI in healthcare, we should be aware of the importance of diverse sociocultural perspectives, especially on topics that are potentially

paradigm shifting, like healthcare AI.

The Role of Substitute Consent for Sexual Assault Evidence Kits for Incapable Persons

Eoin Connolly, Nikolija Lukich, Rosanna Macri, Lauren Honan

The decision to collect forensic evidence using a Sexual Assault Evidence Kit (SAEK) from an incapable person who is believed to have recently experienced sexual assault is fraught with ethical complexity. Generally speaking, SAEKs are not considered treatment under the Health Care Consent Act, and therefore the standard hierarchy for substitute decision making does not statutorily apply. However, individuals who have experienced sexual assault often present to emergency departments and sexual assault clinics. During their care, one of the supports that is often offered is a SAEK administered by a health care practitioner. If the individual is unconscious or incapable for whatever reason, this gives rise to challenges in identifying an appropriate proxy decision maker to provide consent for a SAEK, if substitute consent is appropriate at all. In the absence of clear policy and or legislative guidance, hospitals are faced with inconsistent practices and feelings of moral distress amongst health care workers. In determining whether or not consent should be sought and from whom, organizations rely on ad hoc decision making consisting of institutional values and varying individual opinions. In order to support those involved in non-treatment related decisions, such as this one, hospitals must engage in ethical analysis to address a lack of procedural support.

During this presentation, we will use case examples to discuss the nuances of "substitute decision making" for the collection of forensic evidence using SAEKs from a person unable to provide consent. We will then explore the potential role of the "Substitute Decision Maker (SDM)" in these scenarios, and suggest 1) considerations healthcare professionals should reflect on when determining from whom to seek consent, and 2) considerations an SDM should weigh in determining whether or not to consent to the use of a SAEK.

With little legal and clinical guidance on how to proceed, an ethical analysis of substitute consent for SAEKs should be informed by the principles of trauma-informed care. This analysis should attempt to minimize the risk for further re-traumatization or harm but at the same time respect the person's autonomy to the greatest extent possible and serve their overall best interests.

The Clinical Ethics Consultation Service in the Neonatal Intensive Care Unit at the Fondazione Policlinico Universitario "A. Gemelli" IRCCS in Rome: Report and Data Analysis

Barbara Corsano, Salvatore Simone Masilla, Giovanni Vento, Patrizia Papacci, Simonetta Costa, Costanza Raimondi, Dario Sacchini, Antonio Gioacchino Spagnolo

Introduction: Neonatal Intensive Care Unit (NICU) is a peculiar area in which the values at stake require appropriate evaluation in order to guarantee the pursuit of the best interest of the newborn. Clinical Ethics Consultation (CEC) in NICU represents a useful support not only to facilitate the decision-making process, but also to identify and resolve ethical issues raised by the intensive-invasive practice offered in this department to extremely fragile patients.

Objective: The aim is to present the experience of the CEC service within the NICU of the Fondazione Policlinico Universitario "A. Gemelli" IRCCS in Rome (FPG).

Methods: Through a retrospective survey we analyzed: 1. the number of CECs requested and performed d by the CEC Service in NICU from 2016 to today; 2. the form taken by the consultation (standard ethics consultation or Shared Document for healthcare ethics planning); 3. the ethical issues at stake.

Results: The number of CECs in NICU increased over time from 3 in 2016 to 19 in 2022. They make up 20% of the total amount of CECs performed in the same period of time. The number of CECs requested (74) is bigger than the number of newborns for those the neonatologists request the CEC (42): this disparity shows the nature of a step -by-step decision-making process. Cases coming from the perinatal hospice (19) indicate the presence of the ethics consultant already in prenatal phase. The prevalence of standard ethics consultation (56) compared to the drafting of SDs (14) indicates that support is often requested in emergency situations. From the analysis of the ethical issues at stake, the proportionality of treatments is one of the prevalent issues.

Conclusions: The growing number of CEC requests underlines the increasingly important role that clinical ethics consultation plays within such a delicate context as the NICU, where the beginning and end of life often coexist, generating ethical dilemmas within the healthcare team and the patient's family.

The Ethical Challenges Posed by Spiritual/Religious Requests in the Clinical Context: A Clash of Cultures

Philip Crowell

Background: From a historical perspective issues of spirituality/religion (S/R) have clashed with medical culture on a wide array of issues. However, in recent years, in the clinical context, there has been a paradigm shift in mental health and addictions, with spiritual health programs recognized as effective, and in palliative medicine, spiritual care is included as an essential goal.

Objective: In the presentation of two cases, the goal is to explore the intersection of spirituality and values in conjunction with the ethical challenges to offer patient/person centered care in response to patient or family requests that are outside the norm. The first case is a young man, Sam, with advanced cancer who is exploring his own sense of spirituality. He wishes to follow a path of Buddhist and Indigenous rituals and is requesting psychedelics, but has some history of substance use disorder. The second case involves an end of life scenario in the pediatric ICU with a child suffering a tragic brain injury and is on life supports. Brain death tests have confirmed that withdrawal of life supports is medically appropriate. The team has indicted to the mother (Muslim), that they will withdraw life support in the next 24 hours. She requests for more time, in order to connect with her "religious and spiritual resources."

Method: Using the theme of patient preference, quality of life, medical indicators and contextual factors an assessment is rendered on both cases beginning with the cultural, spiritual and mental health issues.

Analysis: Focuses on addressing the suffering of patient and family as well as the ethical questions concerning accommodation and recognizing the bias that misjudges the "drawing of the lines."

Result: In recognizing the variety of religious, cultural and spiritual requests, the central question is what is in the "best interests" of the patient or family when considering risks to the patient or in the second case the trauma and mental health risks to traumatized grieving mother because of an "expedited" withdrawal.

Conclusion: Ethical challenges in respecting divergent cultural-religious and spiritual requests for care are mitigated by education on pluralism, ethical accommodation and spiritual care inclusion.

Nudging in Clinical Consultations: The Balance of Framing and Trust

Ian Doherty

Ethics consultations present the opportunity for doctors, patients, and their family members to discuss and understand what matters to the patient. This dialogue is especially helpful when there is a conflict about treatment options. These decisions require each party to understand their values and the potential treatment options that align with those values. Deciding to disclose potential treatment options can become a tenuous job rather quickly. Doctors can be choice architects and can frame the treatment options in a way that nudges the patient or surrogate decision-maker toward a particular option. Doctors must walk a fine line between nudging or manipulating a patient or surrogate decision-maker toward a particular option. Doctors ought to be familiar with how framing decisions can alter an individual's deliberative process. Moreover, apart from the probabilities that are disclosed, doctors should be mindful of how their relationship with their patients can impact framing. This paper will examine the role nudges and trust play in clinical consultations. When doctors frame treatment options for a patient, they can take advantage of the patient's cognitive biases or rely on trust in the relationship with their patient. Utilizing and overcoming a patient's cognitive bias through nudging can lead to a patient selecting the optimal treatment for their ailment. While doctors may use the trust built up in their relationship with the patient and not need to rely on framing. When doctors utilize trust within the relationship, they respect their patient as a person and not just as an individual who makes decisions. Ultimately, relying on trust within the relationship steers clear of the paternalistic and autonomy-violating critiques that are leveled against nudges.

An Inexpressible Relationship

Stéphanie Dollé, Jacinthe Pepin, Sylvie Gendron

Background: The experience of caring for brain-injured patients and their loved ones when treatment discontinuation becomes an option raises serious questions for intensive care nurses. In that particular moment of an uncertain prognosis and altered or even non-existent relationship with an unconscious patient, ethical questions arise regarding a person's preferences in terms of autonomy and quality of life. Without reciprocity, how does one care for the Other, what is the purpose of care and its existential significance? In such circumstances, nurses are deeply challenged, feel disrupted and express emotional pain.

Objective: To describe and understand how intensive care nurses experience care with brain-injured patients and their loved ones when treatment discontinuation becomes an option.

Methods: An interpretive descriptive qualitative study inspired by narrative inquiry principles was conducted with 11 intensive care nurses of different age groups, gender, experience and organisations. The resultant stories were further analysed via thematic analysis (1) followed by complexity-based systemic conceptualization methods (2).

Results: 1. Nurses experience care as a reflexive practice activated by the uncertainty and incomprehension that arise in these particular moments, as well as by vulnerability, ethics, the search for meaning, and their caring relation with patients and their loved ones. 2. Care is a complex living system that evolves in an ecology of action and relations, its temporality, and with a meaningful purpose. These inter-related dimensions and interactions between carers and persons cared with, in space and time, both influence and guide. the eco-organization of care towards a shared ends-in-view: the highest good, whatever it turns out to be.

Conclusion: Based on this conceptualisation of care, it is possible to discern the nature of the relationship between brain-injured patients, their loved ones, nurses and other health care professionals when treatment discontinuation becomes an option. This relationship evolves in a systemic and a non-linear fashion and is essential to the purposeful organisation of care towards a unique and ethical end despite the unpredictability of the moment. Further research in other contexts will help refine this inexpressible, but intelligible and lived, human relation.

Healthcare Access for Asylum Seekers Under Deportation Arrest: Ethical Challenges for Healthcare Workers in Quebec, Canada

Adélaïde Doussau

Rejected asylum seekers are exposed to complex clinical and organizational ethical issues when seeking access to care, as they fall under deportation arrest and often go underground. This generates ethical dilemma for health professionals as well.

In this project, we have reviewed the ethical challenges related to the access to care of this group, based on sociopolitical and health literature. We aimed at identifying the ethical and logistical issues faced by caregivers and healthcare organizations.

Those situations raise issues regarding legal status, equity, and distributive justice. A large gap in understanding the context of those situations, and the resources available has been reported.

This exploratory study indicates that doctors as independent workers (as opposed to other health professionals working in the public sector), independent specialized community resources, and public hospitals are best able to meet the care needs of rejected asylum seekers. Additionally, it is urgent to raise awareness and train caregivers on these issues.

Revisiting CanMEDS After the Pandemic: Do Canadian Physicians Need a New Set of Ethical Competencies?

Mark Downing, Tiffany O'Donnell, Kirstin Borgerson

The COVID-19 pandemic changed the practice of medicine more than any other event since the Royal College of Physicians and Surgeons of Canada (RCPSC) implemented its current framework, CanMEDS, for establishing professional competencies in 19961. The relationships that physicians have with patients and health care systems have shifted, and as a result what it means to be a physician is changing too. The RCPSC has released a list of eleven 'Emerging Concepts' for updating CanMEDS to address the changing times. We used these concepts to guide a qualitative study around curriculum development that involved interviews with 25 tutors of the Professional Competencies unit at Dalhousie Medical School. Common themes that emerged that were recommended as areas to prioritize include: Equity, Diversity, Inclusivity (EDI) and Social Justice; Critical Reasoning; Resource Allocation; Artifical Intelligence, Virtual Care, Data Informed Medicine and Adaptive Expertise; and Cognitive Overload, Burnout and Physician Humanism.

At the centre of professional identity formation for physicians is the patient relationship, which has traditionally rested on the principles of beneficence, non-maleficence and autonomy. A number of recent social events, particularly the COVID-19 pandemic, have shifted the focus away from the physician-patient relationship towards questions around justice, and several of the RCPSC Emerging Concepts have a strong justice lens: EDI and Social Justice; Anti-racism; Indigenous Health; Planetary Health; and Complex Adaptive Systems. The RCPSC has traditionally emphasized *advocacy* and *stewardship* in medical education, however these competencies are often inade-

quate when one has to make decisions with finite resource or when there are competing tensions. We argue that a stronger focus on the theories of justice, particularly social justice, in medical education will equip physicians with the skills to better address these emerging concepts and practice more effectively within a complex medical system.

A Moral Calculus: The Limits of Obligation in Violent Care Encounters

Jennifer Dunsford

Violence is ubiquitous in healthcare environments. The experience of violence raises practical and ethical questions about the duty to provide care in the context of risk, including weighing obligations around providing care in spite of the risk of being hurt, and avoidance of personal harm by retreating from the situation.

Using constructivist grounded theory, the presenter's doctoral research explores how nurses make decisions in the context of violent situations. Preliminary findings from this study suggest that the experience of abuse or aggression from patients and visitors can have significant and varied implications for nurses. These data lend support to the idea that decisions around whether and how to care for violent or potentially violent people tend to hinge on the vulnerability of both patient and nurse. Nurses describe a wide range of traumatic encounters, from racial discrimination to credible threats against the person, to physical and sexual assault. Patterns in nurses' responses to violence and the subsequent interactions with aggressive people are also varied, as for many, incidents of violence create doubt about their choice of careers, and almost invariably impact how they provided care subsequently.

This poster outlines themes identified from interviews conducted with nurses about their experiences of workplace violence. The core category of salient vulnerability was generated from the data, including the role of vulnerability in weighing conflicting priorities and managing exposure to violence. Participants describe considerations that factor in to decisions about the right course of action as balancing vulnerabilities, which includes categories of personal and patient factors, values, environmental elements, and the availability of supports and tools. The experience of moral distress will also be addressed. The intent of this work is to develop practical tools and strategies for reducing the incidence and impact of workplace violence in health care contexts, and to promote healthy work environments free from abuse and aggression.

Real-Time Delphi: A Dynamic, Interactive and Efficient Consultation Method for Ethicists

Charles Dupras

In this presentation, I will outline the advantages of the new real-time Delphi consultation method for empirical inquiries in ethics. Like the conventional Delphi, the real-time Delphi is a mixed qualitative and quantitative method for obtaining the opinion of experts or stakeholders with a good knowledge of a specific topic or set of circumstances. It is based on an iterative approach that allows participants to hear the opinion of the group before the end of the study, and to revise their answers in the light of others' perspectives. The Delphi method enables the group to move towards consensus, but also to identify areas of persistent disagreement that merit special attention. The classic Delphi study is widely recognized for its ability to support the development of concrete recommendations and decision-making in complex situations. It offers three major advantages: consultation is entirely online; asynchronous, so that participants can take part at a time that suits them best; and semi-anonymous responses, meaning that people's identities are known only to the research team and not to other participants. This last feature encourages free expression by all, minimizing the undue influence of power or authority relationships on responses. Unlike the conventional Delphi, which relies on several rounds, the real-time Delphi relies on technology that enables simultaneous aggregation of responses and immediate feedback as soon as a response is submitted. This approach promotes dynamic interaction between participants, reduces waiting times between rounds, and reduces attrition during the study. As an example of the method's application, I will present the outcomes of our team's experience with Calibrum's platform Surveylet in the context of a consultation we recently conducted on the governance of research ethics in Canada. I will also advise on the kind of studies and other patient engagement activities which could most benefit from employing the real-time Delphi method within clinical ethics.

Lessons Learned from Addressing Moral Distress Within a Provincial Health System

Katherine Duthie, Victoria Seavilleklein

Background: The prevalence and incidence of moral distress in healthcare has increased significantly because of the COVID-19 pandemic and its lingering effects. Pandemic policies and mandates amplified the tension between meeting the needs of individual patients and minimizing harm to the greatest number of people. As the pandemic has waned, staff continue to experience moral distress related to increased system demands and greater patient

complexity within a context of staff shortages and proportionally fewer systems resources. This presentation will describe the response of our provincial clinical ethics service to the increased need for moral distress supports in Alberta.

Methods: In early 2021, members of Alberta Health Services' (AHS) Clinical Ethics Service (CES) initiated several projects to enhance the service's capacity to provide moral distress supports to AHS's 120,000 member workforce. We completed a comprehensive literature review to develop an Ethics Brief that reflects the most current theory and evidence in the literature. Drawing from this literature and existing tools, we developed a Moral Distress Debriefing Tool. We then engaged in a quality assurance process with AHS staff and community members to test and revise this tool. In 2022, we launched an organization-wide survey for the broader AHS community to inform and guide our efforts.

Outcomes: In response to widespread community feedback, we developed a one-hour combined education/debriefing session and have provided over 70 such sessions to teams and programs throughout AHS. We also initiated an organization-wide panel debrief on the commonly-identified struggle with family and visitor restrictions, implementing many of the known organizational strategies to mitigate moral distress. This novel event sparked collaborative discussions across multiple portfolios. We have also developed a resource guide, anticipatory moral distress sessions, and moral distress display tables at site-wide events to facilitate ongoing conversations and real-time support to staff members.

Lessons Learned: During our presentation, we will describe the many lessons we have learned while engaging in this work, including the importance of timing, participant input and organizational context. Our goal is to help other ethics services deliver effective interventions to prevent or mitigate moral distress among the staff and physicians in their organizations.

Where I End and You Begin: Teaching Good Boundaries in Medical Education Using Critical Phenomenology

Nathalie Egalité

This paper outlines the ways in which philosophical scholarship in critical phenomenology can inform the teaching of good boundaries in medical education. Professional boundaries between physician and patient denote the limits between individuals and their behaviors in the therapeutic relationship. Setting boundaries involves determining what is appropriate or professional in fulfilling one's traditional clinical role. Poor professional boundaries negatively impact care by compromising the ability to act in the patient's best interest, fostering unhealthy attachments, and undermining trust. They can also cause interpersonal harms for providers leading to the neglect of personal responsibilities, compassion fatigue, and burnout. The ambiguous clinical role of medical students as well as the need to balance what is owed to learners makes the teaching of good boundaries challenging.

I argue that the concept of intersubjectivity - developed by Edmund Husserl and expanded by the critical contributions of phenomenologists such as Maurice Merleau-Ponty, Frantz Fanon, and Lisa Guenther - proves useful in refining the understanding of what boundaries mean and their significance for medical ethics. Critical intersubjectivity situates the mutual exchange of thoughts, feelings, and perspectives in a reflexive awareness of both one's subjective position and interpretation of worldly phenomena; in addition to highlighting the importance of empathy required for interconnectedness and building community, it requires cultivating a sense of how social structures impact beyond the boundaries of one's perceptions. In the teaching of ethical issues pertaining to self-disclosure, critical intersubjectivity helps students recognize differing perceptions of what is suitable from the points of views of physicians and patients. As a conceptual tool, it further highlights the unique features that change with each patient and context of care, the effects of cultural influences, and the implications of power, hierarchy, and institutional constraints in clinical interactions. Critical phenomenology, with its rich theoretical treatment of the self in relation to others, is valuable for teaching medical students about professional boundaries.

Patient Participation in Clinical Ethics Interventions: (Non)-Justifications, Barriers and Incentives From an International Study

Marleen Eijkholt, Janine de Snoo-Trimp, Bert Molewijk

Patient participation in clinical ethics interventions (CEI) occurs in 73-96% of the cases in the USA, according to a recent study. But outside of the US participation seems much less common. In Europe, for example, participation of patients in clinical ethics support interventions seems rare.

We conducted an international survey querying the reasons for or against patient participation. We sought to exam-

ine what justifications existed for and against participation, in various countries and parts of the world. We particularly scrutinized the reasons or justifications challenging patient participation in clinical ethics interventions in-depth.

In this paper we reflect here on the outcome of our survey. We scrutinize and reflect upon the differences and similarities in approach towards patient participation, in the international context. We query if the reasons forwarded for and against participation in CEI can be upheld. Finally we will ask what barriers and facilitators can be identified and how they could be addressed. In our proposal we seek to go beyond arguments about cultural differences.

What Does Education Have to Do With Ethics Consultation Services, and How Does This Relate to Patient Participation in Ethics Consultation?

Marleen Eijkholt

Ethics services are often attributed three functions: policy formation, consultation and education. The education function has been connected to the clinical ethics consultations (hereafter: clinical ethics interventions (CEI). That is to say, the education function of CEIs has been researched, at least to some extent, and some of it has been endorsed. Yet, several questions still exist around this function. For example, where does the education function come from and how far does it go? Who is to be educated, how, and on what? We are particularly interested if claims around the education function could give rise to a (moral) obligation for education. This includes the question if there is anyone who could extend a claim for the education function, and by what means? Our query is based on the concern that patient participation in CEI has been opposed and resisted in several countries and regions. We therefore wonder if a patients could have a moral right and claim to be educated via ethics consultation, just like health care providers. Could opposition to patient participation in CEI be rebutted by a claim for education and information about CEI?

Ethical Considerations of Gestational Surrogacy in the Wake of Dobbs v Jackson: Where do We Go From Here?

Sophia Fantus, Priyanjali Chakraborty

The Dobbs v Jackson Women's Health Organization Supreme Court decision has triggered state-wide regulations impacting abortion care nationwide, introducing civil and criminal repercussions for pregnant people, family and friends, and healthcare staff. The legal and ethical implications of this decision have been addressed in both legal and academic spaces. Yet, there is an omission as to how such restrictions will impact the practice of gestational surrogacy. Although the U.S. has varied state laws regarding the legality of surrogacy, there are now questions as to the whether it is even ethical to pursue surrogacy. The U.S. is bearing witness to increased maternal morbidity rates, maternity care deserts, barriers to postpartum care, and a rise in newborn and infant deaths. Prior ethical interpretations of surrogacy have posited that it is a form of procreative freedom; it is a practice that grants new opportunities for LGBTQIA+ persons, single men and women, and those with histories of illness or trauma to have families. The question now becomes at what cost?

Our presentation will consider perspectives of surrogates and the complexity of third-party reproduction and bodily autonomy in the aftermath of Roe v Wade. Broadly, are these restrictions on maternal healthcare further acts of discrimination against LGBTQIA+ families and persons experiencing infertility? The audience will be engaged to deliberate on whether it is ethically justifiable for intended parents to seek surrogacy in the U.S., whether surrogacy ought to remain legal, and whether states with maternal care deserts ought to prohibit surrogacy altogether. The presentation will end by asking how the current political climate in the U.S. may ultimately encourage cross-border surrogacy to Canada and the responsibility of international intended parents to uphold protections of surrogates. Dobbs v Jackson and the recent slew of court cases demonstrates the physical, emotional, and psychological long-term impacts of becoming pregnant in the U.S. and on the reproductive health of underserved populations, including women of color and women living in rural settings. These factors shed light on the new ethical decisions surrogates and intended parents must make to protect themselves, their families, and their providers.

Implications for Ethicists on Medical AI Development and Deployment in Healthcare

Sophia Fantus, Lu Tang, Jinxu Li

Background: Artificial intelligence (AI) is transforming healthcare delivery and patient care. AI has the potential to optimize workflow, provide earlier and more accurate diagnoses, and reduce errors and unanticipated patient

events. Guidelines that facilitate ethical decision-making in practically applying medical AI are rooted in higher-order theoretical frameworks, omitting the perspectives and experiences of actual stakeholders. Identifying empirical work on the knowledge and attitudes of medical AI ethics may lead to mechanisms that can clarify the role of ethicists in practice.

Objective: The purpose of this presentation is to report findings from a systematic review of published empirical studies of medical AI ethics to inform future practice considerations for ethicists.

Methods: Supported by PRISMA, the research team searched databases for published peer-reviewed empirical qualitative and/or quantitative studies from 2000 to 2022 that focused on ethics. Articles were evaluated by types of AI technologies, geographic locations, stakeholders (e.g., patients, clinicians, AI developers), research methods, ethical principles, and major findings.

Analysis: Thirty-six studies were included (published 2013-2022). This presentation will focus on exploratory studies of stakeholder knowledge and attitude toward medical AI (n=21) to identify stakeholders' ethical concerns that ethicists may need to address across health systems.

Results: Findings show that stakeholder concerns predominantly involve issues related to responsibility, data security and privacy, patient and clinician autonomy, and clinician-patient engagement. Although, ethics has shown to have a small effect on the success of adopting medical AI, results show that both patients and clinicians have ongoing concerns about the use of AI in healthcare and its impact on trustworthy relationships and effective communication across care teams, patients, and families.

Conclusions: To inform ethical AI development, there ought to be reciprocal dialogue between ethicists, healthcare teams, and patients. Ethicists ought to be involved in the design, research, development, implementation, and interpretation of medical AI products. In practice, ethicists ought to consider how the application of medical AI may contribute to ethical dilemmas, encounters of moral distress, and conflictual relationships between care teams and families. This presentation will discuss the inclusion of medical AI in decision-making frameworks to analyze short- and long-term implications on family-centered care.

Ethics Schmethics: Film as a Discourse With the Public on Clinical Ethics Issues

Jeffrey Farroni, Emma Tumilty

Popular culture such as film is one of the primary means by which the public is exposed to nuanced ethical issues in patient care, research, and public health. The aim of this podcast series is to illuminate ethical issues in the medium of film that captures their philosophical and practical complexity in an accessible way. Episodes are ~30 minutes and comprised of film synopsis, highlighting filmmaking and storytelling techniques, exploration of bioethical issues, and directed interviews with relevant stakeholders. The podcast provides a combination of bioethical analysis, some scientific information, and real-life experiences, as well as some humor to be relatable and engaging. Topics can be experienced in ways that strengthens one's understanding of the complex and challenging issues facing health care providers, translational researchers, and public health officials through the medium of podcasting. The format is based on another series we produced that focused on a single patient with each episode exploring a different aspect of her story, including her background, experiences undergoing cancer treatment, and revealing thoughts from her own self-reflection. We have previously shown that student listeners are more engaged in the material than they would be during a case presentation, class, or seminar. The current podcast series expands on this impact and is produced for the wider public. We will discuss key considerations in starting a podcast for public audiences, with philosophical, technical, and practical advice. Combining narrative ethical inquiry techniques with popular media such as film and podcasts allows for greater success of translational bioethics activities such as the development of patient empathy skills, reflection, and professional identity formation. It is also an excellent way to engage the public and foster broader discourse on complex bioethical issues.

Medical Assistance in Dying in the Context of Mental Disorders: Perspectives of People Living With Mental Disorders, Relatives and Healthcare Professionals for Ethical Support

Caroline Favron-Godbout, Catherine Perron, Eric Racine

Context: Medical assistance in dying (MAiD) is evolving rapidly in Canada. One of these developments concerns the possibility of requesting MAiD when a mental disorder is the sole underlying medical condition (MAiD-MD). This possibility raises concerns and a need to be prepared to deal with the complex situations that can arise when MAiD-MD is considered.

Objectives: To co-develop a support guide to help people living with mental disorders, their loved ones, and certain healthcare professionals in their reflections and delicate discussions about MAiD-MD.

Methods: Participatory action research design based on 3 key phases: 1) focus-groups aimed at identifying the concerns of people living with mental disorders, relatives, and healthcare professionals, then involving these people in the development of a draft support guide, 2) a community consultation aimed at soliciting 10 to 15 groups of key informants for comments and ideas to complete the support guide, 3) a preliminary use and evaluation of the support guide.

Analysis: Thematic content analysis of focus group transcripts was done using MAXQDA software. Triangulation of perspectives enabled the identification of shared concerns, needs, and ideas. Perspectives specific to each group were also identified. An advisory committee made up of two patient-partners living with a mental disorder, a family member, three bioethicists, and a clinical ethicist trained in social work and involved in MAiD oriented the development of the support guide, using suggestions from the focus groups. The advisory committee supported the guide's ongoing adaptation throughout the project.

Results: This presentation will highlight concerns, needs, and ideas put forward by key stakeholders to promote ethical support through MAiD-MD. These concerns include various worrying factors that could lead to requests for MAiD-MD when other options exist, a difficult line to draw between MAiD-MD and suicide, a fear that requests won't be taken seriously, and discomfort at having certain delicate discussions. Needs and ideas include the importance of considering loved ones in the process, instilling hope, and informing, preparing, and supporting the various stakeholders.

Conclusion: We will reflect on the results acquired thus far and on the participatory research experience on such a sensitive topic.

Every Child, Everywhere, Deserves Peace

Asma Fazal

The proportion of children residing in war areas has increased by 74% in the past ten years. Many countries are seeing more violent conflicts this decade than they had in the previous 30. As a result, over 20 million children have been forced to relocate. Up to 85% to 95% of the casualties in recent wars are of civilians, and more than 50% of those are children. Not only can conflicts and wars cause a great deal of mortality, but they also cause enormous terror, economic harm, and mass relocation. War kills and uproots countless numbers of children annually, psychologically weakens thousands more, destroys essential resources like food, clean water, shelter, healthcare, and schools, and denies them access to social and economic opportunities that are thought to be essential to their well-being. Protecting children is the most fundamental norm of war, yet it is being disregarded everywhere from Afghanistan to Mali to Palestine, Israel, Libya, and beyond. Children cannot thrive without peace. Since fair and just societies safeguard children, it is our moral duty to shield them from conflict areas. The cornerstone of global health is justice. Human rights are legally guaranteed and serve as a safeguard against acts that violate people's basic freedoms and dignity. These rights encompass political, economic, social, and civil rights and are relevant to all people. International human rights law recognizes that everyone has the right to health care, including children living in conflict zones. Children cannot wait for the peace process to start; efforts must be taken to put an end to these terrible wars. We need to double our efforts to put a stop to these armed conflicts, but we also need to make sure that children are not attacked. An entire generation of children is in danger from these ongoing conflicts. Our time is experiencing a moral crisis, and we must never accept this as the new normal. It is our duty to build these children a future free from harm because every child, everywhere, deserves peace.

Patient as a Person: Treating Unrepresented Patients Ethically

Asma Fazal

Unrepresented patients have no surrogate or advance directive to guide their medical decision-making when incapacitated. A majority of these unrepresented are homeless, mentally disabled, or socially isolated. Some of them are elderly too. This is society's most vulnerable population that does not have a voice. However, medical decision -making for these marginalized patients frequently lacks minimal safety measures to protect them from harm. Thus, there is a high risk that healthcare decisions made on their behalf can be biased, uninformed, unethical, or unsympathetic. Nevertheless, regardless of being incapacitated, such vulnerable patients are entitled to have appropriate medical decisions made on their behalf that are in their best interest. This respect for the inherent dignity of the human person, regardless of race, gender, disability, and social status, is the cornerstone of ethical medical

practice. We propose developing an institutional policy to outline decision making process for this highly vulnerable subgroup of patients.

Crisis Pregnancy Centers - Falsehoods and the Religious Practice of Medicine

Rebecca Feinberg

Access to abortion is limited in many countries around the world and further exacerbated by the presence of Crisis Pregnancy Centers (CPCs). CPCs present themselves as clinics that provide free pregnancy consultation services, but in fact are pro-life, anti-abortion pulpits. The falsehoods and overt lies disguised as medical advice pose a greater danger in an environment where access to the full range of reproductive healthcare is legislatively limited. This presentation will explore the ethical quandaries presented by the behavior practiced in CPCs that involves the provision of fundamentally false information. From the outside CPCs appear to be legitimate medical institutions, but in fact, they rarely employ people with medical training. It should be noted that these employees often wear white medical coats, giving the false appearance of a credential in the medical field. The spurious lies told within CPCs are not regulated under medical practice standards because CPCs are not regulated medical institutions. This allows CPCs to advance falsehoods under the guise of medical practice. Adding to the egregious nature of CPCs is the fact that they target vulnerable minorities. In the developed world, CPCs establish in low-income neighborhoods and neighborhoods of color and are progressively moving into the developing world as well. As the number of CPCs continues to increase worldwide, access to clinics that provide the full range of reproductive care is simultaneously diminishing. Given that CPCs disseminate inaccurate information about time sensitive medical procedures, they are a health hazard, obscuring access to a service that heavily impacts health outcomes. This presentation provide an ethical analysis of CPC activity and their ability to limit women's reproductive justice and include recommendations to restrict the overlap between CPCs and legitimate medical institutions.

Facilitation Methods for Partnering With Clinicians and Others in Ethical Deliberation: The Critical Dialogue Model

Sharon Feldman, Lynn Gillam

In clinical ethics consultations, ethicists bring moral reasoning to bear on concrete and complex clinical ethical problems by undertaking ethical deliberation in collaboration with others. The reasoning process involves identifying and clarifying ethical values which are at stake or contested, and guiding clinicians and sometimes patients and families as they think through ethically justifiable courses of action. There is however ongoing debate about the methods an ethicist can use to do this ethical deliberation work, and in particular, how they include meaningful partnerships with clinicians or others in the ethical reasoning processes.

In this presentation, we describe the Critical Dialogue Model of ethics facilitation; a series of seven steps a clinical ethicist can use to guide collaborative deliberation on a clinical ethics case. 'Critical' denotes an intention to encourage clinicians and others present at a clinical ethics consultation to think about moral questions associated with clinical care in a deliberative and analytical way, rather than relying on intuition or private conscience situated within professional authority. 'Dialogue' is used to denote the process of collaborative communication between people to foster shared understanding of an ethical problem and to purposefully scaffold moral agency and growth in those involved.

The facilitative methods aim to not only identify ethically justified responses to ethical questions but also to assist participants to gain greater moral clarity, understanding and confidence in responding to ethical challenges as independent moral agents. Notably, these educative goals are analogous to key goals of classroom philosophy teaching, including to foster students' ability to draw from theories and concepts to develop logical arguments, and to engender their moral development through collaborative ways of discussing, listening carefully and articulating views. Given these analogous goals, clinical ethicists can draw upon teaching and facilitation methods used by philosophy educators.

By describing in detail the facilitation methods an ethicist can use, and linking them to educational literature, we aim to advance the scholarship of clinical ethics facilitation methods and to demystify the process of how ethicists can purposefully involve and empower others in ethical deliberation work within clinical ethics consultations.

Co-Learning With the Community: Mental Health First Aid Training Project

Paul Ford, Sundus Riaz, Jane Jankowski

In 2022 the Center for Bioethics at our organization partnered with community leaders to address a continuing mental health crisis affecting persons living and working in our city. This project was initiated by the specific request from community members to have mental health first aid training and a desire for our organization to develop ongoing partnerships with meaningful community initiatives. In our own practice as clinical ethicists we see the effects years of mental health neglect can have on patients, and through meaningful dialogue with community members a three-part project was initiated to build skills and knowledge related to mental health. This presentation will explain the key elements of the initiative and the considerations that informed this community focused program.

Initial steps focused on strategies for acknowledging skepticism towards and distrust of institutions by joining stakeholder conversations with members of a neighboring community to assess and address barriers and buy-in. Carefully planned community-based training sessions for Mental Health First Aid (MHFA) were held with a deliberate attendee mix that included both healthcare professionals and community members as co-learners. Finally, a summit event was held with local institutions, service agencies and community leaders to create a consortium of individuals to help communities address mental health with an actionable plan for sustainable programming support.

The goals of this initiative were met or exceeded. A goal of hosting 5 MHFA trainings was exceeded with a total of (11) sessions hosted due to demand and the addition of Mental Health First Aid for Youth training. The target of training 100-120 individuals was more than doubled, with a total of (250) individuals completing a training. The pre and post survey results showed (statistically significant increase in key learning objectives covered in the MHFA trainings. The summit convened (200) individuals representing (60) community facing organizations to engage in structured problem-solving break-out sessions and networking for program awareness. The project earned awards at the organizational and state levels, and the partnership with community leaders has been sustained.

Refusal of Standard Treatment for Cancer by Parental Substitute Decision Makers

Michelle Fornasier

There have been many North American cases of refusal of standard treatment for cancer for a minor by substitute decision makers (SDMs) for cultural or religious reasons. Many of these cases involve going to court, which is often a negative experience and ruptures the patient-clinician relationship. This can be morally distressing for both the healthcare teams involved and the patients' families. Further guidance should be available to clinicians to support existing standard decision-making tools to reduce the amount of harm to the patient and moral distress to their families and the healthcare teams. It is important to develop a standardized protocol to help mediate this ethical complexity.

Here, I examine the refusal of standard care for cancer by SDMs, focusing on the subjectivity of harm and multiple meanings around what is "best" for a child. I argue, agreeing with Diekema, that the best interest standard is best used as a guidance principle, while the harm principle serves as a better interference principle. To support my argument, I apply the best interest standard and harm principle to 4 cases and outline what the perceived harm was to the parents and to the clinicians in each case. I rely on the scholarly literature in ethics and pediatrics, supplemented by news media. I take as a starting assumption that the goal in mediating these cases should be to avoid going to court. I conclude by recommending that the best way to navigate this ethical complexity is through the explicit use of cultural brokers.

Navigating Parental Vaccine Hesitancy: Primary Care Practitioners' Approaches to Discussing COVID-19 Vaccination

Micaela Forte, Maxwell Smith, Jacob Shelley

Background: Vaccine hesitancy among parents has contributed to reluctant uptake of many vaccines, including COVID-19 in children, and the re-emergence of vaccine-preventable illnesses in Canada such as measles, meningitis, and varicella. Parental vaccine hesitancy has also triggered recent court cases due to familial conflicts around the COVID-19 vaccine. Discussing vaccination with the child's primary care practitioner (PCP) is often at the root of these court cases, thus necessitating communication strategies for PCPs to describe the importance of vaccination in primary care. PCPs are a trusted source for parents to receive health information and therefore actively in-

fluence parental attitudes towards vaccination. However, the ways PCPs describe how they navigate the best interests of the child provides a novel and important context to explore and understand approaches to vaccine hesitancy, specifically with the use of ethical reasoning and tools.

Objective: This research aims to: 1) explore how primary care practitioners navigated parental COVID-19 vaccine hesitancy during the COVID-19 pandemic, and 2) consider the complexity of ethical tensions, if any, related to navigating children's best interests that arose when discussing vaccination with parents.

Methods & Analysis: 8-10 PCPs (family physicians, pediatricians, and nurse practitioners) who practice in Ontario are being recruited for semi-structured, qualitative interviews. Critical realism methodology will guide methodological approaches. Braun and Clarke's method of thematic analysis and NVivo software will support data analysis.

Results & Conclusions (forthcoming): This knowledge will help improve understanding of how ethical considerations related to 'best interests' are faced by PCPs when discussing vaccination with vaccine-hesitant parents. Additionally, a deepening understanding of the reasoning and decision-making tools used by PCPs can enhance vaccine decision-making for future health emergencies, and what practical recommendations can be implemented to assist healthcare professionals in their approaches to vaccine-hesitant parents. The results have the potential to aid in navigating vaccine hesitancy during (inevitable) future pandemics, as well as be applied in alternate contexts such as childhood HPV and other vaccinations.

Agreement on Scope of Ethics Consultation

John Frye, Aaliyah Eaves, Leah Jeunnette, Haavi Morreim, Robert Guerin

Background:

Clinical ethics services that provide real-time consultation in patient care are increasingly available in American hospitals. However, the clinical ethics services still significantly vary from institution to institution. With projects such as the Quality Attestation Portfolio, and the new HEC-C certification program, there is a growing movement toward ensuring practitioners of ethics consultation should be take place with greater consistency. This research captures one aspect of the current state of variation in clinical ethics consultation services, the extent to which the practitioners view their role narrowly or broadly.

Objective:

To assess the extent of consensus among clinical ethics consultants regarding the scope of their practice

Methods:

An online survey was distributed on various clinical ethics listservs. Twelve case narratives were presented, with 27 questions of potential tasks to help resolve uncertainties or conflicts. Respondents indicated on a 5 point Likert scale whether each task fell within the scope of a clinical ethics services.

Analysis:

ORDANOVA was used to analyze the extent of consensus on the individual case responses, allowing each question to receive a consensus rating of Good, Moderate, Fair, or Poor. The Mann-Whitney U Test was used to assess whether demographic variables resulted in different distributions of case responses.

Results:

Sixty-seven respondents had experience in an ethics service. There was at least fair consensus that 15 tasks were appropriate for a clinical ethics service, while only 2 tasks were generally agreed to be inappropriate. 7 tasks had a fair consensus around neutrality (neither appropriate nor inappropriate), while 3 tasks had poor consensus.

Demographic variables tended to cluster into two groups: (A) solo consultants with 50+ consults per year, salary support, and more hours advance training, and (B) volunteer consultants who did not have HEC-C, who tended to be licensed in another professional role. Group A was associated with more tasks being within the clinical ethics scop of service, and higher consensus, while Group B was associated with the opposite.

Conclusions:

While scope creep remains a concern, the association of broader scope with advanced training and certification may simply reflect a different or new approach to ethics consultation.

The Impact of Racial Bias on Ethics Consults Regarding Non-Beneficial Interventions

Kristin Furfari

Background: It is well-documented that bias infiltrates healthcare and influences the behaviors of healthcare providers. A systematic review demonstrated that healthcare professionals' racial bias leads to increased diagnostic uncertainty, decreased patient-centeredness, poorer communication, and undertreatment of pain for Black patients. Studies have demonstrated differences in the provision of therapeutic interventions for Black patients and other racial minorities. Specifically, these patients are less likely to receive interventions, ranging from high-technology interventions to basic diagnostic and treatment procedures. While the impact of implicit racial bias is well-documented regarding healthcare interventions, less is known about the impact of racial bias on the work of clinical ethics consultants.

Objectives: This project attempts to describe the role of racial bias on the request for ethics consultation regarding non-beneficial interventions. Non-beneficial interventions (NBI) are defined as those in which the harms of treatment outweigh perceived benefit. The AMA Code of Ethics states that physicians are not required to provide interventions that, in their best medical judgment, cannot reasonably be expected to yield the intended clinical benefit. Since medical judgement is influenced by bias, it is likely that decisions regarding NBI may also be impacted. Methods: All ethics consult requests regarding NBI at an academic medical center were reviewed over a three-year period. Patient demographics were extrapolated from the electronic health record. Demographic data for ethics consults about NBI specifically were compared to demographic data for all ethics consults and all patients receiving inpatient-level care. Statistical analysis performed using t-test.

Results: Race is a significant factor in ethics consults for NBI, with 44% of all NBI consults for Black patients. In comparison, Black patients represent only 24% of all ethics consults and even fewer of all hospitalized patients. A similar trend is observed with other racial/ethnic minorities including Hispanic, Asian, and Pacific Islander.

Conclusion: Racial bias influences ethics consult requests regarding NBI at an academic medical center and ethics consultants must be aware of this impact. One role of the ethics consultant is to call attention to the presence and impact of bias. Collaboration with community partners may aid in earlier recognition and mitigation of biases.

Effective Partnerships for Antimicrobial Stewardship: The Role of Trust

Grace Gabber

Antimicrobial stewardship (AMS) is typically understood as the optimization of antimicrobial use through programs and interventions to curb the emergence of antimicrobial resistance (AMR). The responsibility for AMS is often placed on individual healthcare providers to use antimicrobials appropriately through interventions like infection prevention and control, and optimal prescribing practices. In this way, antimicrobials are often viewed as a resource entrusted to specific actors, like clinicians, for their responsible use and management.

While conventional AMS is an important part of ensuring appropriate antimicrobial use, its focus on the technical problem of individual clinician decision-making tends to overlook the structural drivers of AMR. As such, institutional-, system-, and national-level approaches to AMS are needed to manage this critical resource. There have been increasing calls for and developments of global collaboration between disciplines, industries, sectors, organizations, and states to respond to AMR and undertake AMS at a level higher than the individual clinical decision. However, little work has been done to clearly articulate guiding principles to ensure these collaborations are effective, sustainable, and sufficiently outline what good stewardship involves.

This presentation will review models of AMS partnerships to describe what is currently being done to collaboratively address AMR. I will then argue that the development of trust must be at the center of AMS collaborations and formal partnerships. These partnerships include actors such as healthcare providers and health agencies, veterinarians, agricultural and pharmaceutical industries, governments, funders, and others working across the One Health spectrum. Partners need to be able to trust one another in multiple ways. For example, they must trust each other's commitments to AMS, their expertise, competency, and capacity to carry out required activities, and that partnering will be mutually beneficial. Trust is also critical for responsible data sharing on AMR epidemiology, and the surveillance and monitoring of antimicrobial use. Any lack of trusting partnerships threatens the sustainability and effectiveness of interdisciplinary, intersectoral, and international partnerships to address AMR. AMS cannot be merely about the responsible management of antimicrobials entrusted to relevant actors - it must also involve the development of trust between these actors to ensure the partnerships are fruitful.

Indigenous Meaningful Participation in the Work of Governmental and Government-Related Organizations Involved in Health and Social Services

Martine Gagnon-Robitaille, Mathieu Bujold, Amélie Blanchet-Garneau

Context:

In Canada, health inequalities disproportionately affect Indigenous peoples. As a result, Indigenous participation in the work of governmental and government-related organizations involved in health and social services is an ethical imperative. Many health organizations wish to commit to meaningfully working with Indigenous, recognizing their rights to self-determination and to actively participate in the quality and sustainability of the health system. However, at the level of governance in health and social services, the concrete design and operationalization of meaningful participation with Indigenous peoples in the work and decisions remain sparsely detailed.

Objective:

This study aims to document the initiatives, issues, and facilitators for Indigenous participation in the work of Canadian governmental and government-related organizations involved in health and social services.

Method:

A multi-phase qualitative approach has been initiated. First, an environmental scan of websites and reports from federal and provincial organizations was conducted to identify initiatives aimed at facilitating Indigenous participation. Second, a scoping review was conducted to document the issues and facilitators for Indigenous participation.

Analysis:

A content analysis of grey literature and scientific articles was conducted using a hybrid (deductive/inductive) approach. From a deductive viewpoint, an initial coding dictionary was established based on the conceptual framework of the International Association for Public Participation (IAP2) and Gregor, S. (2006) exploring the following questions: what (initiative), who (stakeholder), why (reason), how (issues and facilitators). Throughout the analysis, the coding evolved inductively by following an inter-rater agreement process.

Preliminary Results:

Regarding the environmental scan, the review of 25 governmental sites, 47 government-related organizations sites, and 27 Indigenous organization sites identified 284 information sources (reports and web pages) presenting initiatives aimed at Indigenous participation. The scoping review identified four scientific articles detailing initiatives, issues, and facilitators for Indigenous participation in the governance of health and social services in Canada. This poster presents the thematic synthesis of the results of these two phases.

Preliminary Conclusion:

This study highlights the need to further explore Indigenous participation at a macrosystemic level. A next phase of qualitative data collection aiming to better understand the issues and facilitators of Indigenous participation in the Quebec context will be conducted. A knowledge user committee including an Indigenous organizational partner is being developed. The information synthesized in this

descriptive analysis will provide guidance for future initiatives aimed at strengthening meaningful Indigenous participation.

Forced Treatment in the Era of Antimicrobial Resistance: The Legislative Landscape in Canada

Kayla Gauthier, Maxwell Smith, Jacob Shelley

Background: Antimicrobial resistance (AMR) is one of the top global public health threats facing society. One cause of drug resistance is the failure to complete a course of treatment. To prevent drug resistance, forced treatment has been employed in the past for multi drug-resistant tuberculosis (TB) treatment nonadherence, and is legally permitted in some jurisdictions for TB and other virulent diseases. However, limited attention has been given to the ethical justification of forced treatment in a context where diseases with AMR are becoming increasingly common. In this presentation, we explore the legislative landscape of forced treatment for infectious diseases to anticipate ethical considerations that may arise for the future management of pathogens with antimicrobial resistance. Objective: This presentation reports a content analysis of the current Canadian legislative landscape of forced treatment, and aims to identify key ethical values and rationales for forced treatment in the laws identified. Methods: A scan of Canadian federal and provincial legislative documents related to forced treatment. Results and

Conclusion: Using Canadian legislation as a case example, this work will advance our understanding of the extant legal provisions for forced treatment that may apply to future pathogens with AMR, which in turn will aid in navigating preparedness for future AMR threats.

Embedding Equity, Diversity and Inclusion (EDI), Antiracism, and Anti-Oppression Principles and Considerations Into an Ethical Framework

Dianne Godkin, Rosalind Abdool

Trillium Health Partners' (THP's) Regional Ethics Program led a quality improvement project to enhance its IDEA Framework to more explicitly address EDI, antiracism, and anti-oppression. Various groups that included people with diverse backgrounds and experiences at THP, including patients and families, were given an opportunity to complete a short survey encompassing demographic and open-ended questions to seek their feedback on the IDEA Framework. Survey responses revealed gaps within the IDEA Framework and recommendations for modifications were provided (e.g., editing language to be more accessible and inclusive, placing a greater focus on lived experience, including a section on key lessons learned). Other improvements included enhancing the IDEA Framework by further developing its ability to address organizational (systemic) ethical issues, in addition to clinical ethical issues that arise in relation to individuals at the point of care.

This work is innovative as it aims to expose where bias, power and privilege lie within ethical issues in healthcare systems and explicitly addresses these issues and concerns. This includes ethical concerns such as implicit bias, discrimination and harassment, reflexivity in care, as well as re-defining and re-imagining ethical principles (e.g., autonomy, beneficence, justice, non-maleficence, integrity, trustworthiness, confidentiality).

The project initially sought feedback from THP's Circle on Antiracism and Inclusion, followed by the THP Ethics Forum. These groups were comprised of THP staff, professional staff and learners who, in totality, represent many different lenses: multiple programs (i.e., patient care programs), disciplinary backgrounds, roles, sites, shifts, demographics and intersectional lived experiences. Project co-leads also sought input from members of THP's Patient and Family Partner Program.

In this presentation, we will showcase the work that we have completed thus far to meaningfully engage with relevant parties across THP and its community. Having made a number of revisions to the IDEA Framework in response to the engagement, we will also discuss the steps we are taking to evaluate these changes. We aim to measure the impact of the revisions to the IDEA Framework on awareness and responsiveness to EDI, antiracism, and anti-oppression principles and considerations in relation to ethical issues.

Embedding Equity, Diversity and Inclusion Principles into REB Reviews

Rebecca Greenberg, Anjana Sengar

Equity, Diversity and Inclusion (EDI) are important principles in both the ethical conduct of research involving participants, and the review of research by Research Ethics Boards (REBs). In upholding the basic principles of respect for person, beneficence and justice, it is clear that more equitable, diverse and inclusive research is essential to conducting impactful research. What remains unclear is how to operationalize EDI in practice and how an REB should apply an EDI lens in the research ethics review process. Trillium Health Partners (THP) REB endeavoured to make EDI meaningful in its review of research submissions. To achieve this goal a working group was formed to oversee the development of an EDI checklist. THP REB engaged in: 1) environmental scan, 2) literature review, and 3) review of relevant research ethics standards to inventory the current landscape with respect to EDI and REB review. An REB reviewer checklist was developed that includes: i) key considerations that REB members should look for in their review, ii) justification for such items on the checklist, iii) considerations for operationalization of such items, and action steps for researchers.

With any evolving practice THP REB aims to be consultative and collaborate with their research community. The THP REB created a pathway for input on the application of the checklist from their users. Through consultation with users, we aim to ensure the finalized checklist will be balanced to meet the needs of the research community while upholding the values of EDI. Obtaining feedback identifies barriers to implementation so they can be addressed in conjunction with the checklist roll out. As such, the THP REB has begun the process of engagement with the research community to present its findings and solicit feedback from its users.

Prior to the full implementation of the REB EDI checklist, THP REB will actively seek out opportunities for increased feedback; streamlining existing reviewer checklists; providing education on the EDI checklist for users; and piloting the checklist with users' input. In our presentation we will discuss the pathway for developing an EDI

REB Checklist, our preliminary considerations and feedback received from our research community.

Avoiding Patient Abandonment: A Pathway to Ethical Resolutions in Situations of Untenable Patient-Surgeon Relationships

Leah Gudex, Hannes Prescher, Jaclyn Mauch, Christian Vercler

Background: A trusting partnership between patient and surgeon lies at the core of a successful therapeutic relationship and clinical outcome. However, there are conditions that can jeopardize this partnership and create an ethical dilemma for the surgeon, who is guided by a moral obligation to care for the patient without causing unnecessary harm. We present a case of a patient with borderline personality disorder (BPD) refractory to psychiatric care, who directly undermined the surgical team's effort to reconstruct her self-inflicted wound with repeated acts of self-mutilation. The surgical team was confronted with the challenge of achieving ethical resolution to the therapeutic relationship to prevent further delivery of futile care while avoiding patient abandonment.

Objective: Investigate previously published work on the ethics of therapeutic discharge and guidelines for care in situations of untenable patient-surgeon relationships.

Methods: A systematic review of the literature was performed, and principles of clinical ethics were applied to current evidence in the context of our clinical scenario.

Results: There are no published ethical guidelines for resolving a therapeutic impasse in patients suffering with psychiatric illness that directly undermines the patient surgeon relationship, in particular when terminating the relationship can exacerbate the psychiatric illness. Patients with BPD are prone to both mutilation and fear of abandonment, which can perpetuate a cycle where a patient may repeatedly self-mutilate to maintain the relationship with the physician. We applied the ethics principles of treatment futility, nonmaleficence, beneficence, and patient abandonment to develop a set of guidelines for navigating precarious post-operative patient relationships.

Conclusions: Guidelines for terminating patient relationships are well-established. However, this may not always present the most ethical path to resolving therapeutic challenges in surgical patients with comorbid psychosis. Instead, maintaining a trusting relationship based on firm boundaries and expectations with patients who fear abandonment is the best strategy to prevent further mutilation and harm. Temporizing care until stabilization of the psychiatric illness has been achieved can lead to a successful treatment outcome. However, if these efforts are exhausted, therapeutic discharge is ethically permissible and may be necessary to disrupt the maladaptive cycle and prevent potential harm to the patient.

Decision-Making Processes on Aid in Dying: An International Scoping Review

Pola Hahlweg, Zoe Henning, Claudia Martens

Background: Aid in dying (AID) means supporting a person in hastening their death voluntarily. Despite a trend toward legalization of AID in many countries, the current medical culture struggles to accommodate AID.

Objective: We aimed to explore the current state and needs regarding AID decision-making processes from multiple professional perspectives.

Methods: This scoping review synthesized the current scientific understanding of AID decision-making processes. We searched Web of Science, PubMed, and CINAHL. After screening of titles and abstracts and eligibility assessment of full texts, data was extracted and synthesized from the final set of records with a structured excel sheet.

Results: We identified n=109 publications. We found a great variety of participants of AID decision-making processes. Some records described professionalized and/or team-based approaches. Several process phases (beginning, assessment, preparation, realization, aftercare) and overarching themes such as coordination, patient-centered care and multidisciplinary teamwork were described. Throughout the process, a range of decisions were described that need to be made by different stakeholders. This complex process requires appropriate communication skills. For example, the aim to go from vague requests to informed decisions in a shared process and the need to fulfill patient-centered care need and procedural requirements. The records also showed facilitators and challenges for such processes. Examples of facilitators were a trusting pre-existing relationship between patient and clinician, guidelines, and an open, curious, caring, and non-judgmental attitude. Examples of challenges were power imbalances between patients and clinicians, subjective interpretations by clinicians, and the need for clinicians' self-reflection.

Conclusion: The knowledge gained in this study can structure future research on AID and inform the socio-

political debate and implementation efforts in routine healthcare.

Matters About Life and Death: Palliative Care Communication About Aid in Dying Requests, When Aid in Dying is Illegal

Pola Hahlweg, Catherine DesRoches, Kathleen Lee

Background: Aid in dying (AID) is illegal in Massachusetts, USA. Nevertheless, patients might inquire about AID and palliative care clinicians are a likely audience for such requests. Being asked about AID, when it is not a legal option, presents clinicians with particular ethical challenges.

Objective: This study aims to explore how palliative care clinicians in Massachusetts communicate about AID requests and their needs to feel well equipped for such conversations.

Methods: We conducted a qualitative interview study with n=16 palliative care physicians and nurse practitioners in Massachusetts. We asked about their experiences with and needs regarding communication about AID with their patients. Data was analyzed with qualitative content analysis.

Results: Preliminary results suggest that palliative care clinicians in Massachusetts do encounter AID requests, albeit seldom. If they do, many participants focus on exploring and understanding the underlying suffering. To do so, they try to clarify the request with open questions and a non-judgmental, curious attitude. In the following, they often try to offer legal alternatives in order to relieve suffering. Other times, patients/family members need reassurance that palliative care does not mean hastening death. Participants voiced the need to have inner clarity about one's own attitudes and boundaries. These boundaries should also be openly communicated with people requesting AID. Furthermore, a need for guidelines regarding legal and communication aspects were mentioned and open reflection and supervision about AID within healthcare teams were seen as crucial. Final results will be presented at the conference.

Conclusion: The results of this study shed light on how palliative care clinicians communicate with their patients about AID, if AID is illegal, and what needs they experience. The results can inform efforts to improve communication about AID requests, in palliative care and beyond.

Treating Achondroplasia: What Are the Consequences?

Georgina Hall, Sharon Feldman, Monica Cooper, Lynn Gillam

Achondroplasia is a genetic disorder of disproportionate short stature, which is also associated with life-threatening complications and multiple social consequences. There is some evidence that Vosoritide, a new drug still in its early stages of use, when administered in childhood can improve growth and subsequently reduce medical complications of achondroplasia. This sound like a good thing, but there are some adults with achondroplasia who hold the perspective that achondroplasia is an identity and not a disease that warrants treatment. This raises the possibility that there may be parents unwilling for their children to have Vosoritide, even though it could improve their child's quality of life and reduce the risk of death, because it would undermine or take away the child's identity.

In this presentation, we will discuss this ethically challenging scenario, raising a number of ethically relevant considerations, including:

1. Zone of Parental discretion - Currently, there is no long-term data to prove that there will be a reduction of death or serious medical complications with Vosoritide. Therefore, in the absence of evidence, parent refusal may be acceptable. When the evidence is conclusive, parental refusal of Vosoritide for their child could be considered unethical because it would amount to causing harm to the child, which is beyond the limit of parental authority.

2. Identity - Objectively speaking, Vosoritide will not "change" children with achondroplasia to the extent that their identity would be lost. Children would still have achondroplasia, and have its characteristic features, but with have less severe complications.

3. Communication with parents - Knowledge translation of new scientific information about medical treatments that are deeply incongruent with a person's worldview and identity will not be readily absorbed or accepted. Time and patience is needed for people to be able to reflect, re-think and consider what feels right.

Conclusions:

Dealing with this ethical challenging scenario in practice will require acceptance that cultural and social matters

will be part of a dynamic process of engagement and negotiation with families.

We Can't Just Hold'em Down Anymore - Ethical Challenges in Adolescent Consent to Immunisation

Georgina Hall, Jenny O'Neill

There is broad consensus that vaccination nurses wouldn't physically force or hold down a typically developing adolescent who was refusing their scheduled adolescent vaccinations, even if a parental consent form was signed. This makes moral sense and feels intuitively like the right thing to do, but is it the right thing to do, and what is lost?

This presentation will use a case study of a 15 year old refusing the Men ACWY vaccine offered through the Australian School Immunisation Program to unpack and explore the assumptions, competing claims and ethical implications of accepting a young person's vaccination refusal, including:

- How do nurses assess and understand a young person's capacity to make this decision for themselves?

- If holding is a technique often used to administer vaccination in younger children- what age is the tipping point to accepting a young person's refusal, and what's the rationale? (Is restraint of young people always ethically problematic?)

- Is vaccination justifiable for something that arguably does not provide the individual with a direct and immediate health benefit?

- What impact does this have on parental autonomy in pediatrics?

The presentation will conclude with some variations on the scenario which add extra ethical complexity, in order to challenge audience members further, including situations where the young person has cognitive delay or disability, or seeks vaccination against or without parental knowledge or consent.

Clinical Ethics Education Through Applied Drama Improvised by Professional Actors

Kenji Hattori

In this paper we explicate the significance of introducing applied drama into clinical ethics education. Being inspired by Augusto Boal's "theatre of the oppressed", we have developed and implemented two specific types of applied drama suitable for fostering trainees' clinical ethics competencies: clinical theater and clinical etude. The former is, here, to be focused on. The trainer presents a case to the trainees in the form of a drama instead of medical document or narrative. The drama is played by several professional actors. The trainer stops the play midway through and encourages the trainees to point out problems and to respond to patients and their family members by taking on the role of a medical professional in the play. The actors respond immediately to what the trainees express. After several rounds of such improvisational communication, feedback and comments are exchanged among all of the trainees, the actors, and the trainer. Clinical ethics support such as clinical ethics committees and ethics consultation is the macro clinical ethics behind the ward, so to speak, while clinical theater is the lived micro clinical ethics. The well-trained, non-medical actors can improvise without a script and spontaneously play the roles of patients and their families in response to the trainees' every move. Communication manuals and protocols are of little use when faced with a real person with a mood, personality, values, and so on. The trainees learn a lot from clinical theater, where they are extemporarily expected not only to think about and judge various ethical issues, but also to respond with appropriate expressions. We present the details of how the clinical theater was implemented, the reactions of the trainees, and the specific strengths and challenges of this fruitful educational method.

Communicating About COVID Vaccines in the Age of Conspiracy: Comics Create a Connection

Joan Henriksen, Leah Eisenberg

We live in a time of unprecedented access to information, not all of it factual. It is a constant challenge to separate the wheat from the chaff, the boring-but-accurate from the engaging-but-completely-wrong. This task has been amplified during the height of the COVID-19 pandemic, when people were physically isolated and spending a lot of time online, looking for facts they felt they could trust amidst a deluge of constantly evolving scientific knowledge. The release of COVID-19 vaccines in late 2020 was largely recognized by the scientific community as an astounding achievement resulting from decades of prior research, new funding sources, and some luck. However, many individuals were apprehensive about these vaccines, and the apprehension seems to have been amplified

by two years of reports about less-than-ideal efficacy coupled with dozens of conspiracy theories blaming everything from infertility to stroke on the vaccines. Good ethics start with good facts, so how can ethicists help people access good facts about the vaccines?

This presentation will detail the process of producing two short educational comics addressing common vaccine concerns undertaken by a creative team of a cartoonist with health communication expertise and two clinical ethicists. The goal of this process was to provide readers with accurate and understandable information about COVID-19 vaccines in an encouraging, accessible, and inviting format. We will discuss why we believe the time invested in developing such materials will pay off in increasing the public's understanding of and comfort with COVID-19 vaccines, and why comics can be an important tool for communicating ethics.

The Role of Clinical Quality Incentives and Health Disparities in Our Communities

Maurice Hicks, Alex Conway, David Satin

An intractable feature of many healthcare systems is the disconnect between financial incentives and patient needs. This is particularly salient in the USA, where heterogeneous healthcare funding mechanisms coupled with wide socioeconomic disparities have proven to harm patients from marginalized communities. Our community-based participatory research group conducted three studies to understand and address the role of clinical quality incentives and health disparities in our local communities.

In 2018, the Somali-Latino-Hmong (SoLaHmo) community advocacy organization convened a group of community leaders to understand diverse communities' perspectives on healthcare quality. Three themes emerged: 1) Quality clinics utilize structures and processes that support healthcare equity. 2) Quality clinics offer effective relationships, education, and health promotion. 3) Funding based on current quality measures perpetuates health inequities.

In 2020, we investigated this third theme to identify design features of quality measurement incentive programs that could potentially reduce health inequities. Our systematic literature review of 180 articles identified 6 design features: Two of these features, risk adjustment and clinic stratification for patients' socio-political drivers of health (SDOH), have strong evidence for reducing disparities and are already used by some programs. Two design features, pay-for-improvement and exception reporting, have some evidence and are occasionally used. The final two design features, disparity-reduction metrics and population-specific metrics, are experimental but show promise.

In 2022, using a novel frequency-based approach to literature searching, we documented a significant fall in the volume of "pay-for-performance" (P4P) publications and a commensurate rise in "value-based purchasing" (VBP) publications. While P4P explicitly pays for achieving defined quality metrics, VBP folds these quality payments into the overall payment system. Baking quality measurement into the system of reimbursement can better align healthcare finance and clinical quality, but it can also obscure sources of health disparities created by the system itself.

The healthcare journey that began with a disconnect between financial incentives and patient needs now faces a new challenge to health equity. Vigilance in diagnosing and addressing the sources of health disparities, including those arising from the healthcare system itself, is an ongoing project. Diverse communities' perspectives must be central to the discussion.

Building Competency in Clinical Ethics

Geraldine Hider, Donald Hoepfer

The presenters developed and refined an innovative ethical assessment model for clinical practice that applies three levels of ethical analysis to situations of moral weight. Clinicians are trained to perform physical assessments. This ethical assessment model has practical application for clinicians to perform ethical assessments and to ethically engage with patients and colleagues. Clinicians who integrate this model in their practice illustrate the capacity to engage in effective and balanced ethical decision-making. Moreover, clinicians who integrate this model in their practice build the competency to use those same skills when faced with circumstances that can produce moral distress.

The Ethical Assessment Model these presenters will demonstrate is appropriate in all situations where ethical decision-making is needed. This study utilized a qualitative case study method involving focus groups, interviews, and surveys. The study was conducted over a five-year period. Study participants could make sense of the model and

proved equally adept at applying the model to various case studies. Having been instructed in the Ethical Assessment Model, study participants identified their own moral reactions, demonstrated increased awareness of ethical skills, and demonstrated increased capacity to discuss reasons for their choices in ethical decision-making.

Instructing health care professionals in performing ethical assessments and in identifying the difference between ethical assessment and their own moral reactions has implications for reducing instances of moral distress.

Should Canada Ban Tobacco for the Next Generation?

Riel Hishon

Use of tobacco is the leading cause of preventable death in Canada and has negative effects on every organ of the body. It is related to conditions such as cancer, respiratory diseases, and cardiovascular diseases. Nicotine in tobacco is physically and psychologically addictive. It raises levels of dopamine in the brain, increasing pleasure. This can cause emotional dependence where individuals use tobacco to manage unpleasant feelings. The percentage of Canadians who smoke cigarettes has been declining but persists. As of 2020, approximately 13.9% of Canadians aged 12 and above were daily or occasional smokers. Canada aims to reduce tobacco use to less than 5% of the population by 2035. To do so, the government plans to include warning messages on filter paper of cigarettes in addition to cigarette boxes. New Zealand and the United Kingdom have gone even further. New Zealand has introduced laws banning the sale of tobacco to anyone born from 2009 onwards. The United Kingdom plans to raise the age for buying tobacco each year so that anyone currently 14 and under will never legally buy it. While this seems like a positive step towards improving population health, it presents bioethical issues related to autonomy, beneficence, non-maleficence, and procedural justice. Should the government tell people they can't smoke cigarettes? Will this lead to a larger black market of cigarettes or higher rates of vaping and illegal drug and alcohol use? How should we situate tobacco in the context of illegal drug laws? I will examine these questions through a literature review and use a principlism framework to argue that Canada should introduce legislation similar to the United Kingdom and New Zealand.

Striving to Close the Advance Directive Completion Gap With and Alongside Marginalized Communities

Cristie Cole Horsburgh, Jennifer Katlen, Margot Eves, Georgina Morley

Advance directives are a vital tool to equip loved ones and healthcare professionals with information about patient preferences to honor their end-of-life preferences. The literature is peppered with studies evidencing that Black patients complete advance directives at a lower rate than White patients. This disparity in advance directives completion rates raises concerns that Black patients are at a greater risk than White patients of receiving treatment inconsistent with their individual preferences.

When reviewing hospital code blue event (aka medical emergencies involving an adult) data at a small community hospital, we found that Black patients are less likely to have completed advance directives than White patients, even though they make up the majority of patients that we serve. In a chart review covering a 2-month period, approximately 16% of Black patients and 53% of White patients had advance directives. For patients who had more than one cardiac or respiratory arrest or rapid response event in the 2-month period analyzed, 50% of White and 29% of Black patients had documented advance directives. The empirical work of Barargan et al. (2021) suggests that the reason for lower completion rates is due to mistrust and discrimination experienced by Black patients in healthcare settings.

Recently recognized by the Lawn Institute as the most Socially Responsible Hospital in the state, the team drew from successful strategies to improve rates of advance directive completion. While previous efforts have focused on formal education outreach programs, we engaged with our local community through formal outreach efforts (including our Network for Connecting Communities and Bioethics) and informal networks to discuss advance directives and explore barriers to completion. These discussions occur in a familiar setting, often when working alongside community members to meet a community-identified need, and are part of our efforts to organically build and develop trusting relationships with the community we serve. The events also provided opportunities for individuals to complete and scan their documents into the electronic health records system. In this presentation, we will present our strategies to engage community members in advance directives completion, impact on completion rates, and share our goals to expand our program.

Bacon, Egg and Cheese With a Side of... Bioethics?

Adira Hulkower

The field of bioethics is engaged in ongoing discussions regarding the definition of the clinical ethics consultant's role, the criteria for claiming the title of a clinical ethics consultant, and the nature of expertise in clinical ethics. The American Society for Bioethics and the Humanities has outlined a list of core competencies, equipping clinical ethics consultants to effectively navigate and address complex ethical issues encountered in clinical practice. These competencies include ethical theory and methodology, analytical skills, and communication skills. However, neither a solid grounding in the principles of bioethics and the foundations of moral philosophy, nor mastery of the art of communication can fully prepare the clinical ethics consultant to respond to moments such as when a patient says, "please don't leave me, I'm scared," or "you're the only person I can trust," or when a family member calls begging for help because they cannot afford a funeral.

In these instances, the clinical ethics consultant may grapple with the dissonance between their personal and professional values and ask themselves: "What is my role here?" "Who am I to this patient?" These instances often force the clinical ethics consultant to confront conflict between personal and professional values, prompting questions about their role and identity in such situations, potentially resulting in moral injury. This tension is amplified by the boundaries set by clinical ethicists, presenting themselves as partners to patients but with limitations.

The story of Ms. C, initially refusing dialysis, serves as a prime example. What initially was a routine bioethics consultation unfolded into a scenario where I found myself offering intimate care—hand-feeding her bacon, egg, and cheese sandwiches and providing comfort during painful procedures. This narrative sparks an examination of whether the role of a bioethicist extends to that of a caregiver. By delving into caregiver literature and theories of professionalism, I aim to scrutinize the implications, for the profession and for patients, when clinical ethics consultants navigate these complex, intertwined roles.

Protecting the Dying Public in the Organ Recovery Process

Brian Jackson

The deceased donor organ recovery system in the United States is complex and includes organizations that function at a national (United Network for Organ Sharing/UNOS), regional (organ procurement organizations/OPOs), and hospital level. At each of these levels, entities involved in organ recovery share dual responsibilities for ensuring maximal utilization of organs and for ensuring that fiduciary obligations to the donor are met. While UNOS focuses primarily on the equitable and efficient distribution of organs and the hospital where the donor dies focuses primarily on the well-bring of the donor and their family, OPOs often find themselves uncomfortably caught between these two sometimes conflicting responsibilities. Recent changes to federal law have shifted the balance between these responsibilities too far toward the maximization of organ recovery and away from the responsibility toward the donor.

Changes to the Centers for Medicare and Medicaid Services (CMS) Conditions of Participation for OPOs (42 CFR 486), which went into effect in August 2022, were designed to "increase donation rates and organ transplantation rates." The regulations accomplish this goal by changing accountability metrics for OPOs and by placing OPOs in direct competition with each other to improve those metrics. These changes focus exclusively on improving system efficiency without providing balancing measures to ensure that the rights and well-bring of donors are protected.

At a theoretical level, these changes reduce deceased people to a means to achieve the end of successful transplantation for another person. People who have died may be seen as potential organ donors rather than as people, even by well-intentioned members of OPO teams. At a practical level, these changes encourage the rapid adoption of new technology, even when the adoption may need additional ethical scrutiny. This has played out in the adoption of normothermic regional perfusion (NRP) by many OPOs, often without consulting with the public and donors' hospitals. Similarly, efforts to increase donation by expanding first-person authorization for donation's application to donation after cardiac death (DCD) are likely reflective of the new law's incentives. To address these concerns, policy makers should add accountability measures related to protecting donors into the new regulatory framework.

Trans Autistic Experiences of Epistemic (In)justice in Gender-Affirming Health Care

Kai Jacobsen

Background: Transgender people are much more likely to be autistic than the general population. Research indi-

cates that autistic trans people experience significant barriers to accessing healthcare, especially gender-affirming health care such as hormones and surgeries. While research into autism and gender diversity is increasing, most is conducted from a pathologizing framework that fails to incorporate the voices of trans autistic people themselves. As several US states have cited the high prevalence of autism among trans people as justification for banning gender-affirming care, neurodiversity-informed and trans-affirming research on trans autistic people's needs and experiences is urgently needed.

Objective: The research questions are: What are trans autistic people's positive and negative experiences with accessing gender-affirming health care? What are the impacts of these experiences on trans autistic people's lives? How can gender-affirming health care providers better support trans autistic people?

Methods and Analysis: I conducted qualitative semi-structured interviews with 12 autistic adults who had accessed gender-affirming care in Ontario in the past five years. Participants were recruited from trans and autistic social media groups and community organizations. I analyzed these interviews using reflexive thematic analysis. The specific analysis presented will focus on ethical considerations and recommendations for healthcare providers working with trans and/or autistic clients.

Results: Participants described numerous experiences of health care providers not taking their knowledge, desires, and needs seriously. Participants felt that stigmatizing ableist attitudes entrenched in society led providers to underestimate and discredit autistic people's capacity to understand and make decisions about their own care. Consequently, many participants did not trust the health care system and avoided disclosing their autism or avoided care altogether. However, participants also described positive experiences in which health care providers acknowledged the limits of their clinical knowledge, listened deeply, and collaborated to support a decision-making process that centred the client's autonomy and embodied knowledge.

Conclusions: Epistemic humility—the ability to recognize the limitations of one's expertise and the value of other sources of knowledge—is an important clinical skill for health care providers working with trans autistic clients. Shared decision-making with marginalized individuals requires epistemic justice to achieve truly collaborative, patient-centred care.

Exploring the Ethics of Forensic Genetic Identification of Human Remains Recovered From Indian Residential Schools Unmarked Burials

Rebekah Jacques

The Indian residential school system resulted in more than 150 federally sponsored and church-run residential schools for approximately 130 years across Canada. Changes to the Indian Act made it compulsory for Indigenous children to attend these schools where thousands of children died; many of which never returned home. Their families were often inadequately informed or never informed of the circumstances around their death or place of burial. For most of the schools' history, the practice was not to send bodies of children who died at school to their home communities. Instead, they were often buried in the cemetery at the residential school. The identities of those who died is not fully known. Today, these abandoned cemeteries are vulnerable to accidental disturbance and there is interest by some families, Survivors, and communities to identify any human remains that are recovered following exhumation. Forensic disciplines offer indispensable set of skills, knowledge, and expertise to resolve complex the humanitarian process of identification. The ethical, humanitarian and legal reasons for the establishment of the identity of human remains include the need to know, especially for families, for legal proceedings and for ceremonial and burial rites purposes. Identification is a process that utilises a variety of sources and the most reliable means of identification is DNA comparison between living biological family members and human remains. Genetic identification of the human remains of Indigenous children recovered from residential school cemeteries highlights the intersection of science, Indigenous law and Canadian law, death investigation bioethics and Indigenous ethics. This presentation will explore the ethical issues around forensic genetic identification and non-identification.

Cultivating Ethical Practice to Improve Quality Care, From Bedside to Boardroom

Kim Jameson, Kristina Smith, Julia Gill, David Migneault, Bethan Everett, Lorraine Blackburn

An extensive review of the Vancouver Coastal Health (VCH) Ethics Services was undertaken in 2020-2021 to understand how to better meet the needs of patients/families, staff, medical staff, and leaders when facing moral uncertainty, discord, and/or distress at all levels of healthcare delivery, from bedside to boardroom. This session will outline the review process led by a steering committee comprised of VCH staff, leaders, and public members

using a mixed methods approach to re-imagine a model of Ethics Service that could effectively achieve our mission "To cultivate and support a culture and practice of ethical responsibility and accountability throughout VCH." We will reflect on the changes that have been implemented over the last two years and the shift of focus from a reactive towards a preventative ethics approach. This has included an emphasis on building ethics knowledge and skills, community of support, and meaningful collaborations with other support services (e.g. Equity, Diversity & Inclusion, Adult Protection, Privacy, Indigenous Health, Quality and Patient Safety, People Safety, People Wellness). The session will engage the audience on how we ought to integrate optimal measures in ongoing assessment of Ethics Services to promote safer, quality, and ethical care delivery across the continuum of care including our rural, remote, and urban sites and all levels of our health care system.

Considering the AAP's Statements on Informed Consent and Pediatric Decision Making for a Patient With Complex Needs

Rohit Jaswaney

In 2016, the American Academy of Pediatrics updated their statement on informed decision making, highlighting how informed consent in pediatrics may be approached with broader considerations of parental decision making beyond the best interest standard. Consensus recommendations on pediatric decision making were proposed in 2023, emphasizing six key aspects that captured the reach and bases of responsibilities that parents and clinicians hold towards a pediatric patient.

We use the updated statements to illuminate issues in complex decisioning for a 3-year-old child with quadriplegic cerebral palsy and intractable epilepsy who was offered a tracheostomy due to persistent obstructive apnea exacerbated by seizure episodes. In the provision of tracheostomies for medically complex children in critical care, the informed consent process often discusses acute risks and benefits of undergoing the intervention, perhaps with less attention on several essential questions related to transition out of the ICU: To what extent should providers inform families of the anticipated challenges of home tracheostomy care? In an environment where community/home nursing support is limited, should we anticipate and discuss with a family an outcome that may include them being unable to care for their child?

This case introduces the parent's hesitations to pursue tracheostomy during the initial informed consent process and subsequent conversations that eventually led to the tracheostomy. It then explores the months-long process of teaching the parent about tracheostomy care, and considers the possibility that the parent will not be able to demonstrate the level of care expected by the team. And when a parent is told they cannot care for their child at home, it creates a significant breakdown in trust between the parent and the medical system, and a prolonged hospital stay while searching for a safe disposition plan. How do the AAP's statements on informed consent and pediatric decision making apply along this trajectory? How do their attempts to unite respect, beneficence and justice inform the treatment decisions and outcomes for our patient as described? It is through this exploration that we hope to better understand how to support our families through the difficult decision-making process surrounding the offer of a tracheostomy.

fMRI and Neuroprognostication in the Critical Care Period After Pediatric Brain Injury

Rohit Jaswaney, Ghallia Kaouk

Neuroprognostication seeks to predict the trajectory of recovery for patients following severe brain injury. Newer technologies such as functional MRI (fMRI) provide a new lens to understand a patient's brain activity, however, as are with any prognostic tools, these studies present with significant limitations. In pediatric populations, after serious brain injury, parents are often faced with difficult medical decisions such as the pursuit of medical technologies like tracheostomies to continue the recovery process when it aligns with a family's goals of care. Consensus recommendations on pediatric decision-making were recently proposed by the AAP, emphasizing six key aspects that captured the reach and bases of responsibilities that parents and clinicians hold towards pediatric patients. How may our conclusions from fMRI studies and their use in neuroprognostication influence how families approach decision making during the critical care period?

We present the case of a 7-year-old girl who suffered an extensive ischemic stroke secondary to sickle cell disorder requiring partial lobectomy resulting in an acute comatose state (GCS 3). In the initial weeks following the event, parents discussed considerations for withdrawal of care, stating concern for ongoing suffering and their views on quality-of-life which included the ability to walk and talk. An fMRI was completed for neuroprognostication which identified intact brain activity in locations related to motor skills, which was interpreted by family as an opportunity for the patient to return to her pre-event function. The family subsequently opted to pursue tracheosto-

my and gastrostomy tube placement to aid in recovery, medical devices they had initially stated were incongruent with their views on quality-of-life. The patient's subsequent course was complicated by ventilator dependence and significant dysautonomia without a clear path towards the ability to sustain life without these medical technologies.

The case raises several ethically salient issues in the use of imaging technologies to assist with pediatric neuroprognostication during the critical care period after significant brain injury. How can pediatric critical care providers appropriately support families in the shared decision-making process with our current abilities to interpret fMRI studies? It is our hope that this case will be able to explore these topics further.

The Ethics of Compassionate Use in Fetal Interventions

Rebecca Johnson, Caitlin Sutton, David Mann

Physician-scientists routinely attempt to use the expanded access pathway, more commonly called compassionate use, of a drug or device as justification for providing "lifesaving" interventions to a fetus with a "lethal anomaly" that does not qualify as a participant under a clinical research trial.

Using language such as a "lifesaving" intervention instead of "potentially life-altering" feeds into a therapeutic misperception. This subtle distinction, offering "patient treatment using a life-saving innovative intervention" rather than offering participation in a "potentially life-altering innovative intervention" is ethically inappropriate. Using an experimental intervention outside of a research protocol as compassionate use remains innovative, i.e., it is research without formally collecting data. A few countries, including the United States, require physicians who want to use a drug or device for compassionate use to seek approval from the research ethics committee prior to use, because the safety and efficacy of the investigational drug or device being used have not been thoroughly studied. Therefore, the ethics of research, not clinical care, would apply.

The authors will argue that fetal centers should offer interventions proposed under compassionate use on a case-by-case basis only if there is a morally compelling reason for doing so and with the approval of an ethics committee that has evaluated the risk-benefit profile; otherwise, a voluntary moratorium on such interventions should be imposed.

Transitioning Pediatric Tracheostomy From the Hospital to the Community: What is Fair for Different Families?

Benny Joyner, Arlene Davis, Catherine Trub

Tracheostomy can be a life-extending procedure in children for whom there is a successful pairing between the hospital setting and the community. However, the decision surrounding tracheostomy often focuses on clinical indications within the hospital setting. In highly resourced US healthcare centers, children receive tracheostomies for a variety of reasons, including upper airway obstruction, chronic respiratory failure necessitating long-term mechanical ventilation from traumatic, non-traumatic and genetic causes, and musculoskeletal insufficiency. How can we fairly account for the importance of community in decision-making that occurs in hospital settings?

A tracheostomy requires constant care and monitoring long after a child leaves the resources of the hospital—requiring coordination among physicians, home nursing, and parental caregivers. To illustrate the salience of setting and resources consider Vanessa, a 3 year old girl with a severe brain injury, intractable seizures and muscular weakness since birth who presents with recurrent aspiration pneumonias related to frequent choking episodes. Vanessa's mother is a single parent with 3 older children. She does not speak the primary language used at the hospital. While Vanessa has had home nursing services in the past, her mother's disagreements with staff has resulted in agency refusals to provide home care. Tracheostomy is considered for improved airway management but there is concern in the setting of limited community support. Her mother is hesitant to consent, as a tracheostomy would mean that her daughter would not be able to safely live in her home without nursing or a second caregiver, neither of which are available to her due to social factors.

Fairness, under the justice principle, suggests that this child should be treated like similarly placed patients. Physicians would offer parents a tracheostomy for children when doing so would reduce the risk of aspiration and frequent lung infections. Access to home nursing care would be an essential element of the plan. In most instances, parents could accept or decline the procedure. However, fairness is harder to assess for parents where we worry that decisions are unduly influenced by their limited social support and by language barriers.

Ethical Engagement With Youth With Disabilities in Patient-Oriented Research: Sharing Lived Experience Safely

Shafniya Kanagaratnam, Mathias Castaldo, Genevieve Sutherns, Linda Nguyen, Keiko Shikako, Sakiko Yamaguchi

Background: The Critical Ethical Engagement with YOUth (CEE YOU)! in patient-oriented research team is comprised of two research trainees, two youth with brain-based disabilities, and a research assistant. We have been working together to co-create training resources to support researchers' development of partnerships with youth with disabilities. When partnering with youth with disabilities, various ethical challenges, such as unequal power relationships, vulnerability and confidentiality of sharing lived and living experiences, and tokenism, may arise. Our reflexive discussions explored ethical considerations when engaging with youth with lived experience in disabilities in research.

Discussions: Researchers who value lived experience as expertise can make research more inclusive by inviting youth with diverse backgrounds and experiences to be involved throughout the research process and be intentional to address power imbalances in the youth-researcher relationship. By building trust and providing capacity building, youth with lived experience can become active research partners who may play a role of protagonists to publicly share their stories. However, youth are more vulnerable when it comes to sharing their lived experience as they may share more than what is expected. They may not know how and to whom they are sharing their stories and may feel unsafe about the implications of sharing. When sharing results, certain unique conditions could make the information identifiable in the disability community. It is critical for researchers not only to be open to listening to youth's diverse ideas but also to be mindful of the potential effects of sharing youth's lived experience on youth themselves, their families, and communities.

Conclusions: The lived experience of youth with disability can facilitate creation of new knowledge to inform policies, services, and research, and effective knowledge mobilization. However, challenges with confidentiality may arise when unique conditions and experiences of youth are shared. Researchers may have to consider their ethical responsibilities to ensure: 1) safety for youth when sharing their experiences, 2) transparent communication of who the audience is and how the lived experience is shared, 3) seeking consent from youth before sharing, and 4) protection of sensitive information, to mitigate unintended consequences of youth's sharing of their lived experience.

Ethics of Co-Design: Strategies for Improved Shared Decision-Making and Meaningful Partnerships in Paediatric Complex Care

Caitlyn Kaziev, Francine Buchanan, Shamama Raza, Peter Gill

Patient-centered care is important in yielding positive health outcomes, particularly in the era of precision child health, where the values, preferences, goals, and unique experiences of children and their families ought to be at the forefront of care planning and delivery. Shared decision-making (SDM) is one facilitator of patient-centered care that allows patients, families and caregivers, and their healthcare providers (HCPs), to communicate and work collaboratively to ensure the child's care aligns with their personalized needs. There are immense benefits of SDM, including improved hospitalization experiences and outcomes. For children and youth, there are added benefits including improved coping mechanisms, improved communication and decision-making skills, enhanced knowledge in healthcare, and positive impacts to their developing autonomy and capacity. Despite these benefits, there is a lack of SDM in practice, particularly for children and youth with medical complexity (CMCs). Some of these barriers can include uncertainty about the child's needs, knowledge gaps on implementation, uncertainty regarding the child's capacity and desire for involvement, concern around navigating conversations, and power imbalances between families and HCPs.

To better understand the prevalence and impact of SDM in paediatric complex care (PCC), we must first understand the experiences of SDM for patients and families. To achieve this, a co-design research study was created involving HCPs and parents of CMCs. While the aim of this study was to ideate strategies for improved SDM during hospitalization, it is also important to consider the ethical implications of collaborative research, specifically within PCC. As such, this presentation aims to evaluate the ethics of co-design methodology, particularly as it relates to family experiences and the impacts of meaningful engagement on their interactions and hospitalization, as well as assess whether this co-design study was able to reduce barriers to SDM. Through a literature search of current practices and a thematic analysis of the co-design study, it was evident that collaborative research is a valuable experience. By working with patient partners to understand their needs and experiences, participants felt that they were valued members of their child's team, and felt optimistic about the future of SDM and PCC.

In the Context of Mitochondrial Replacement Therapy, Does Genetic Manipulation Produce Triparental Children in the Eyes of the Law?

Kristina Kekesi-Lafrance

In the context of in vitro fertilization (IVF), when preimplantation genetic diagnosis reveals that the egg donor carries a mitochondrial mutation, the mutation may be neutralized with the introduction of a third party's healthy genetic material. This technique is called mitochondrial replacement therapy (MRT). If a healthy embryo emerges from MRT, it will have a triple genetic background and, thus, three biological parents. However, in the context of MRT, does genetic manipulation produce triparental babies in the eyes of the law? Although MRT has been legal in the United Kingdom (UK) since 2015, MRT falls under the prohibited activities of Canada's 2004 Assisted Human Reproduction Act. Nevertheless, I propose to provide an answer to this question for the Canadian context, should MRT one day become legal.

First, I'll briefly explain the science behind MRT and discuss the ethical issues raised by this technology. MRT challenges our binomial model of conception by raising complex ethical, legal and social issues (ELSI). Second, following my review of the law in both the UK and Canada, I argue that biology itself is not sufficient to establish parenthood. Third, while current legal frameworks of family law mostly remain biparental (especially in Quebec), I'll show that two Canadian provinces derogate from this principle. Thus, I conclude that unless there is an intention from the mitochondrial DNA donor to be a parent to the child, MRT itself does not produce triparental children under the law based solely on the sharing genetic material with said child. In other words, MRT could produce tri-parenthood under law, only in the provinces that allow for more than two parents.

Canada needs to thoroughly review its provincial parentage laws to make sure they are in tune with current social practices. The ever-evolving nuclear family and the development of new technologies for assisted reproduction will continue to introduce unforeseeable questions in family laws. Legal fictions have often favored intentional and social relationships to ensure the stability of families. In the name of the best interest of the child, the introduction of germline modifying technologies in fertility treatment should follow the same path.

Unpacking the Hype: Public Online Discourses of CAR T-Cell Therapy

Mary Kelly, Henry Llewellyn, Valerie McDonald, Kieran O'Doherty, Lynda Balneaves, Annette Hay, Jennifer Bell

Background:

Chimeric antigen receptor (CAR) therapy is a highly innovative and promising next generation cell editing technology. Discourses surrounding CAR T-cell therapy proclaim it as a "revolutionary" breakthrough in cancer care, offering an opportunity for cure for those with relapsed or refractory disease and limited treatment options. Some authors argue the "hype" associated with CAR T-cell therapy has obscured the provision of balanced information about the risks and benefits for individual patients to make informed treatment decisions. Balanced information is also required for publics to determine an acceptable level of risk in relation to the expected benefits of this technology, and in weighing the opportunity costs for finite healthcare budgets.

Objective:

This research explores and critically evaluates the online information available to the public regarding CAR T-cell therapy, with attention to explicitly considering the ethical issues, values, and perspectives advanced therein.

Methods:

We reviewed publicly accessible information about CAR T-cell therapy available online using Google search. Documents were subjected to qualitative thematic analysis. We examined the discourses surrounding this technology to identify the implicit and explicit values and understandings communicated.

Results:

Fifty-one webpages primarily from the United States, Canada, South America and Asia were included in this review. Webpages represented a variety of players including industry, healthcare organizations, news organizations, patient advocacy associations, academic and government or non-profit organizations. Four themes characterize the information presented about CAR T-cell therapy: patient stories of success, magic, and hope; medical science explainers; ethical discussions and complex arguments; and economic perspectives.

Conclusions:

A nuanced appreciation of the online discourses of CAR T-cell therapy will take seriously the complex interplay of scientific information, implicit and explicit values, and ethical norms. Further, acknowledging the larger medical-

industrial complex and players allows for interrogating how power is concentrated within these discourses and which voices dominate, and how these voices may portray, conceal, disclose, sequester or mobilize the stories being told. Such understandings are important because online discourses influence public perceptions, which relate to societal trust in science and public acceptability of new medical technologies, as well as inform individual patient expectations and choices about healthcare treatments.

Physicians' Perspectives on End-of-Life Interventions

Mikaela Kim, Joelle Robertson-Preidler

Background: During goals-of-care discussions, conflict may arise when families and physicians disagree on end-of-life decisions. Physicians are sometimes reticent to offer interventions for patients near the end of life, often invoking concerns about medical futility, harm, or inappropriateness. However, patients and families may not understand a physician's rationale for refusing to offer treatments when the alternative is death. Having deeper insight into how physicians decide when to offer treatments can help physicians and clinical ethicists improve transparency and bridge communication gaps during goals-of-care discussions.

Purpose: This qualitative study aims to identify factors that physicians consider when deciding whether to offer interventions for patients near the end of life.

Methods: We conducted in-depth semi-structured interviews with physicians representing different specialties to capture perspectives on various types of interventions that might be considered at the end of life (e.g., surgery, dialysis, chemotherapy, and cardiopulmonary resuscitation). Interviews were transcribed and analyzed using thematic analysis to identify emerging themes.

Results: Twenty-five physicians participated in the study, representing specialties in surgery, oncology, nephrology, intensive care, or emergency medicine. Participants described various factors they consider when deciding whether to offer or recommend treatment for patients near the end of life. These considerations fell into five themes: patient baseline characteristics, likelihood to cause harm, likelihood to achieve a goal, patient and family values, and clinician and institutional factors. Most participants discussed basing these considerations on evidence-based medicine, experience, and respect for patient autonomy. However, many considerations were also influenced by physicians' subjective assessment of harm, benefit, reasonable treatment goals, and their perceived duty to the health care system.

Conclusion: Physicians consider various factors when making end-of-life decisions, including physician-specific factors. Variability based on factors that are not patient-based may have implications for equitable and patient-value-informed decision-making. Transparency and improved communication regarding physicians' decision-making rationale could help bridge communication gaps and support informed decision-making.

Genomic Horizons: Safeguarding Women's Reproductive Autonomy in the Age of Gene Editing

Maria Klimenko

Currently, uterine transfer of a genetically modified human embryo is illegal. However, the legal standing of such genetic research did not stop the 2019 incident in China, when a woman gave birth to genetically modified twin girls. This is a signal of further possible advancements in the realm of gene editing research.

The central question posed is: To what extent are women's reproductive rights affected by burgeoning gene editing research? In this presentation, I discuss three key points that highlight the risk posed to women's reproductive rights within the context of pregnancy involving genetically modified embryos, assuming the procedure is safe and effective, emphasizing the need for comprehensive discussions.

Firstly, the voluntary participation of women in carrying genetically modified embryos may introduce societal pressures due to the potential benefits (i.e., chronic disease prevention), potentially compromising reproductive autonomy. If some women choose not to undergo the procedure, despite its safety and anticipated benefits, they may experience marginalization and their reproductive rights may be impacted.

Secondly, if a woman decides to abort a pregnancy involving a genetically modified embryo, the principle of autonomy must be upheld to the highest standard. The right to abortion must play a big role in ethical discussions involving reproductive autonomy in the context of gene editing.

Lastly, it is likely that there will be a certain level of involvement from third parties, such as clinic staff, government entities, and/or others at various stages of a woman voluntarily carrying a genetically modified embryo. In

order to preserve the reproductive rights of women, the extent of third-party involvement or control must be discussed in order to safeguard women's reproductive rights.

As the scientific community continues to tread forward in gene editing research, initiating dialogues on the impact of these advancements on women's reproductive rights is imperative. I call for a proactive approach to navigate the complex ethical landscape that accompanies developments in gene editing research.

Reporting of Health Equity Considerations in Vaccine Trials for COVID-19: A Methodological Review

Roger Kou, Sarah Lopes Sadafi, Rachael Principato, Laura N. Anderson, Romina Brignardello-Petersen, Lawrence Mbuagbaw

Background: Randomized controlled trials (RCTs) on COVID-19 vaccines has served as the evidence base for public health decision-making. While it is recommended that RCTs report results by health equity stratifiers to reduce bias in healthcare and gaps in research, it is unknown whether this was done in COVID-19 vaccine trials.

Objective: To critically examine the use of health equity stratifiers in COVID-19 vaccine trials.

Methods: We conducted a methodological review of published COVID-19 vaccine trials available in the COVID-NMA systematic review database through February 8, 2023. Based on the PROGRESS-Plus framework, we examined the following health equity stratifiers: place of residence, race/ethnicity, occupation, gender/sex, religion, education, socio-economic status, social capital, age, disability, features of relationships, and temporary situations. We assessed each study in duplicate according to three criteria for comprehensive health-equity reporting: 1) describing participants, 2) reporting equity-relevant results, and 3) discussing equity-relevant implications of trial findings.

Analysis and Results: We reviewed 144 trial manuscripts. The most frequently used PROGRESS-Plus stratifiers to describe participants were age (100%), place of residence (100%), gender/sex (99%), and race/ethnicity (64%). Age was most often used to disaggregate or adjust results (67%), followed by gender or sex (35%). Discussions of equity-relevant implications often indicated limited generalizability of results concerning age (40% of studies). Half (47%) of the studies considered at least one health equity stratifier for all three criteria. No trials included stratifiers related to religion, socioeconomic status, sexual orientation, or features of relationships.

Conclusions: Health equity stratifiers were infrequently used in COVID-19 vaccine trials to describe participants, report equity-relevant results, and discuss equity-relevant implications. Considering the health disparities exacerbated during the pandemic, increased uptake of PROGRESS-Plus in RCTs would support the characterization of health inequities and help inform actions to improve health equity.

Reporting of Race and Ethnicity in Trials Published in the Canadian Medical Association Journal: A Methodological Study

Roger Kou, Yulika Yoshida-Montezuma, Fatima Sheikh, Valentina Antonipillai, Sandra Ofori, Roma Dhamanaskar, Omotola Olasupo, Jasdeep Brar, Margret Lo, Lisa Schwartz, Laura Anderson

Background: In health research, the terms "race" and "ethnicity" are frequently used to characterize study participants, often interchangeably and with diverse definitions. The use of these concepts has also evolved over time due to societal influences and practices in academia. In February 2023, the Canadian Medical Association Journal (CMAJ) published new guidance on the reporting of race and ethnicity for articles submitted to CMAJ. This new guidance is welcome as progress is made towards improving equity in health and research. However, the distinctions between "race" and "ethnicity" remain unclear and little is empirically known regarding the methods and rationale for using race and ethnicity data in research.

Objective: To evaluate how race and ethnicity are reported amongst original research articles and examine researchers' purpose for collecting these data about trial participants.

Methods: We conducted a methodological review of experimental and interventional studies published in the CMAJ between 06/2003 and 06/2023. Ineligible studies were reviews or studies of observational, case-control, or simulation design. We systematically searched Medline and Web of Science. We screened and extracted data in duplicate using Covidence. Data extraction items were based on the published CMAJ guidelines and refined through piloting. Key outcomes included i) how "race" and "ethnicity" were reported in studies, ii) how this data was collected from participants, iii) author rationale for collection and use of this data, and iv) how authors integrated race and ethnicity into analyses, results, and discussions.

Analysis and Results: Our search yielded 4153 records and 167 records were reviewed in full text. Data extraction is ongoing. Frequencies and percentages will be used to summarize the number of studies within subcategories for each outcome. We will narratively synthesize and compare findings to the February 2023 CMAJ guidelines.

Conclusion and Implications: In this evaluation of the use of race and ethnicity in health research over a 20-year period, we hope to prompt reflective discussions regarding the important distinctions between race and ethnicity and how these concepts may be applied in research in a manner that is thoughtful, respectful, and useful in advancing our understanding of health.

Representation in Action: Integrating the Patient's Voice Into a Behavioral Health Ethics Committee Infrastructure

Leslie Kuhnel, Ken Timmerman

Renowned patient advocate Judi Chamberlin is credited for integrating the motto "nothing about us without us" within the mental healthcare arena. Her use of this term underscores the important idea that "no policy should be decided by any representative without the full and direct participation of members of the group(s) affected by that policy." This idea serves as the foundational principle for representation in action within our Behavioral Health Ethics Committee (BHEC) infrastructure.

When our BHEC was originally convened nearly two decades ago, one voice we knew we needed at the table was that of someone with lived-experience of mental illness. Initially, we invited a representative from the Behavioral Health Consumer Advisory Group to serve as a BHEC ad hoc member. Over time, this evolved into standing BHEC membership by Peer Support representatives who have been successful in their own recovery journey, and now help others experiencing similar situations.

Peer Support representatives have contributed significantly to BHEC discussions about practice and care delivery, policy development, and ongoing professional education, addressing such topics as:

- Assuring patient access to medical records, long before legislated Open Medical Records requirements.

- The development of psychiatric advance directives, including shaping state legislation.

- Minimizing stigma and bias towards persons with mental health diagnosis.

- Adopting person-first language appliction4 and trauma-informed-care practices across healthcare settings.

- Developing policy for decision-making on behalf of unrepresented patients without capacity; and most recently, considering practical, sensitive ways to identify patients at risk for harmful or violent behavior without further trauma, marginalization, or stigmatization.

Integrating this representative voice into BHEC conversation has provided unique collaboration opportunities. According to one Peer Support representative, "when talking about ethics, it has always been important that the voice of those we are serving be heard. I always feel heard; and many times my suggestions changed the conversation and led us in different directions on our way to meaningful destinations." Without the unique perspectives brought to the table by Peer Support representatives, our BHEC would be missing this critical representative voice in our various deliberations and initiatives.

Development of Quality Indicators for Ethical Deliberations of the Health and Welfare Commissioner's Consultation Forum

Maude Laliberté, Karina Côté, Stella Carine Kengne Tine, René-Pierre Turmel, Georges-Charles Thiebaut

Background: Due to the complexity of the health and social services system, a variety of perspectives must be taken into account to understand it. This is why the Health and Welfare Commissioner (CSBE) has chosen to assess the system's performance by integrating three areas of analysis: numerical analysis, governance and public policy analysis, and ethical analysis. Ethical analyses include an ethical deliberation process conducted by members of the Consultation Forum. However, we have noted a lack of consensus or theoretical framework for identifying guidelines to help ethical deliberations run smoothly.

Objective: Develop quality indicators for ethical deliberation to provide clear guidelines for the proper conduct of deliberations by the Forum's citizen and expert members to foster their engagement and the emergence of a diversity of views.

Method: First, the concept of ethical deliberation was defined. Then, indicators were developed as part of a non-

systematic literature review.

Analysis: The quality of the publications included was evaluated using validated assessment tools. Subsequently, the "candidate quality indicators" with empirical or theoretical support were extracted, either those already identified in the literature or descriptive elements with the potential to become indicators. The indicators were then grouped and described by a thematic statement and a proposed measure. This approach reduced the initial number of 38 indicators to a final list of 6.

Results: As a result of the work presented above, the following quality indicators for ethical deliberation were developed: impartiality and transparency; adequacy of resources; clarity and structure; collective interest; diligence; inclusiveness and diversity.

Conclusion: Quality indicators for ethical deliberation were presented to Forum members to guide the conduct of ethical deliberations. These indicators also led to the design of a survey to measure the perception of the quality of ethical deliberations at Forum sessions to support continuous improvement and strengthen mechanisms for public participation within the CSBE.

Ethical Considerations When Choosing and Justifying the Theme of a Self-Initiated Project: The Practices of the Health and Welfare Commissioner

Maude Laliberté, Ariane Quintal, Sarah Thibodeau, Myriam Ben Dahmen, Georges-Charles Thiebaut

Background: The Health and Welfare Commissioner (CSBE) is a public organization that can initiate work without requiring a mandate from the Government of Quebec. While this practice of self-initiation reflects an independence that enables the CSBE to adapt to contemporary challenges, the choice of a project raises ethical considerations. For example, the choice may be subjective, may not be in line with internal resources, or may duplicate the work of another publicly funded organization. The use of selection criteria strengthens the integrity and effectiveness of the self-initiation process.

Objective: Develop a clear and transparent method for choosing and justifying the theme of a self-initiated project and for arbitrating between multiple themes when required

Method: Work such as conceptual development and a literature review were undertaken to define criteria for selecting themes for self-initiated projects. Workshops were held to refine their compatibility with CSBE's organizational values, mandate, and mission.

Analysis: The choice of theme is the prerogative of the person holding the position of Commissioner. However, this choice must be based on scientifically valid and socially legitimate information, in keeping with the CSBE's mandate and organizational values.

Two categories of criteria were developed. The first category concerns the importance of a problem. This refers to the importance of health needs (e.g., incidence, prevalence), the problem's social importance (for the population, on the political agenda), and the perception of issues regarding the value of services offered to the target population (accessibility, response to needs, efficiency, citizen concerns, stakeholder expectations).

The second category relates to the ability to act. This refers to the ability of stakeholders to act on an issue, the feasibility of the assessment (availability of data, complexity of the assessment), and the relationship with the external environment (e.g., network competing on the same theme or supporting our analysis).

Results: A decision-making chart was created with a three-level rating scale. An inter-judge analysis allows for arbitration when required. In addition, the establishment of a substantive ethics process allows for an exploratory literature review that provides an overview of ethical considerations, values, and contextual factors to facilitate the choice of theme based on its social importance.

Conclusion: A rigorous self-initiated methodology can strengthen public confidence by demonstrating the CSBE's commitment to its organizational values and mission to improve the health and welfare of Quebecers.

The Term "Layperson" Ought to be Supplanted by "Public Representative"

Shamima Lasker

A cross-sectional pilot study was done on 50 Ethics Committee (EC) Members where 50% were laypersons. The objective was to understand the perception of EC members regarding the term "laypersons." Of 962% EC had females as laypersons. Only 4% of cases EC had a male layperson. The qualification of most of the layperson was

graduate (55%) and Minster (33 %). Only 5% of laypersons were 12 class passed and 1% had a Ph.D. Of 55% EC members felt the presence of layman is imperative whereas 95% of laypersons felt that their presence was important. However, in 90% of cases, both the EC and the layperson themselves felt that the layperson did not take part in the discussion in the EC meeting though, in 70% of cases, laypersons attended the meeting. Most of the laypersons attend the meeting due to respect (70%), gathering knowledge (28%), and meeting with an educated person (2%). In response to the question of how would you feel if the term "layperson" had been changed? Of 65% of EC members answered the term "layperson" should be changed whereas 93% of laypersons felt the term should be changed. However, of 65% of laypersons felt the team should be "public representatives" whereas 35% of laypersons preferred "patient representatives" instead of "layperson." On the other hand, 65% of EC members felt the term should be "public representatives" instead of "laypersons." We can conclude that majority of the EC members of Bangladesh felt if the term layperson world has changed to "public representative" more males would be interested in acting as "layperson." There were numerous cases of modifying nomenclature for good meanings, e.g., research "subject" to "participant." If the nomenclature "layperson" is changed to "public representatives" it will have dual importance. On the one hand, this will strengthen their favorable perception within the EC, on the other hand, their sense of dignity and self-esteem will help them serve the EC more effectively to protect the participants.

Normativity and Creativity in Clinical and Organizational Ethics: A Scoping Review

Claudia Lucrecia Calderon Ramirez, Marie-Ève Bouthillier, Claude Julie Bourque, Nathalie Orr-Gaucher

Context: Clinical and organizational ethics (COE) was developed as a response to emerging ethical issues in health care due to technological advances and constant changes in society. COE uses both normative frameworks to guide interventions and creativity to seek innovative solutions to complex problems.

Objective: To identify in specialized publications the integration of creativity and normativity in the practice of COE.

Methods: According to Arksey & O'Malley's method, a comprehensive review was conducted in seven electronic databases (PubMed, Medline, EMBASE, Web of Science, PsycINFO, EBM reviews and CINAHL complete). Gray literature was also included. Inclusion/exclusion criteria were: publications from 2013 to 2023, in English/French, with keywords (clinical ethics, organizational ethics, creativity, normativity). Covidence software was used for data management. Descriptive statistics were used. Thematic content analysis was applied to the included articles.

Results: Of the 586 publications identified, 115 were duplicates and 421 did not meet the inclusion criteria. Of the 50 full-text publications, 22 were excluded, resulting in 28 articles for content analysis. The studies were heterogeneous and varied in terms of intervention, study population and reported outcomes. No articles addressed the integration of creativity and normativity in COE practice. Publications focused on three areas: 1) ethical questions arising from specific clinical situations (human reproductive technology, stem cell use, neuroscience, and mental health, among others); 2) ethical issues raised by innovation in medical practice; and 3) the place of normativity and creativity in organizational ethics.

Conclusion: The integration of normativity and creativity into the practice of COE is an emerging concept that deserves to be further explored.

Retrospective Review of Ethics Consultations on International Patients at a Global Destination Medical Center: What is the Role of Preventive Ethics?

Dolly Maiti, Amanika Kumar, Bev Fraser

Background:

International patients seeking medical care in the United States represent a diverse population with unique needs. Clinicians caring for international patients face ethical dilemmas due to differences in culture, religion, expectations for medical care, clinical practice norms and healthcare financing.

Objective:

We conducted a retrospective review of all ethics consultations on international patients at a global destination medical center over 18-years (2006-2023). We aimed to examine patient characteristics and describe the most common clinical ethics questions arising in this setting.

Methods:

Patients were identified by from an existing prospectively-maintained database established by the Office of Clinical Ethics at Mayo Clinic. Inclusion criteria included having a home address from an international location. Demographic, medical, psychosocial, and ethics consultation data was abstracted from the medical record. Data was summarized with descriptive statistics.

Results:

Amongst all ethics consults, 42 international patients were identified. The majority of ethics consults were placed on adult patients 88% with n = 34/42 (81%) from Middle Eastern countries and n = 29/42 (69%) speaking Arabic as a primary language. The majority of patients identified as Muslim n = 33/42 (79%). The embassy of Saudi Arabia or UAE provided funding for n = 21/42 (50%) of patients. The most common primary diagnoses were malignancy n = 20/42 (48%) and neurologic n = 7/42 (17%). The most common primary reasons for Ethics Consultation were religious or cultural issue n = 15/42 (36%), goals of care or 'futility" n = 13/42 (31%), and financial issues affecting allocation of resources and/or access to healthcare n = 8/42 (19%). Palliative care was involved in 57% of cases. In 33% cases, the patient died in the U.S. and in 48% of cases, the patient returned to their home country alive.

Conclusion:

The most common ethical dilemmas for international patients were religious or cultural issues, goals of care or 'futility" issues, and financial issues affecting allocation of resources and/or access to healthcare. Preventive ethics activities to address these dilemmas may include improved cross cultural ethics education, greater investment in spiritual care resources for Muslim patients, earlier involvement of palliative care, and improved transparency and policies regarding fiduciary responsibility for international patients.

Prognosis and Disability

Natalie Martin

In the philosophical and scientific literature, work on prognosis centres around the discussion of end-of-life care. In cases of disability, well-formed prognoses are essential for patients to make important personal and treatment decisions.

The goal of this research is to expand the bioethics literature on prognosis. Instead of drawing on examples from end-of-life, I discuss chorionic villus sampling (CVS) and amniocentesis. These tests are performed in the first or second trimester of pregnancy and use cells from the placenta or amniotic fluid to analyze fetal chromosomes. Patients use the results of these tests (for example, a diagnosis of Down syndrome) coupled with prognostic estimates from their genetic counsellors to make critical decisions about their future.

I discuss and analyze this case and argue that it gives good reason to think prognoses in cases of disability are distinct. Disability prognoses require estimates both about the course of a patient's illness and their expected quality of life. I draw out normative recommendations for prognosticators that arise from this analysis.

There are normative implications for healthcare professionals who prognosticate, especially in cases where they are evaluating quality of life. First, a prognostic assessment in the case of disability is more likely to be made based on ableist beliefs or attitudes, which value able-bodied lives over disabled ones. These ableist attitudes are often based on unwarranted bias. Those who prognosticate about disability, I argue, have a responsibility to be actively anti-ableist. Second, we require an expanded understanding of who prognosticates. In the case of prenatal testing for Down syndrome, genetic counsellors offer prognostic information, not physicians. Existing literature overlooks this prognostic plurality despite reports that nurses are often involved in the communication of prognoses. I argue that education about prognoses must reach beyond physicians to genetic counsellors, social workers, and nurses. Finally, prognoses are always crafted with and for others. For healthcare providers to consider the factors which might impact a patient's prognosis, prognoses are best delivered in the context of shared decision-making, where information moves from healthcare provider to patient and vice versa.

The Shared Document for Healthcare Ethics Planning, a Tool for Shared Care Planning: Report and Evaluations

Salvatore Simone Masilla, Barbara Corsano, Costanza Raimondi, Dario Sacchini, Antonio Gioacchino Spagnolo

Introduction: The shared document (SD) for healthcare ethics planning is an expression of shared care planning

(SCP). The Clinical Ethics Consultation Service of the Fondazione Policlinico Universitario "A. Gemelli" IRCCS (FPG) of Rome uses it as a decision support tool that on one hand meets the needs of the doctor-patient/family relationship and on the other grants the appropriate respect for the autonomy of the subjects involved.

Objective: The aim of the present work is to analyze the use of SDs at FPG during the years between 2016 and 2023.

Methods: Through a retrospective analysis of the CECs carried out in the last seven years, the following items were highlighted and analyzed: the number of SDs drafted compared to the total number of CECs carried out, the departments that requested the use of SD, the nature of the ethical issues at stake, the age of the subjects involved, the pathologies for which the SD was requested.

Results: There has been an increase in the of SD for SCP at FPG. The total number of SD in these 7 years are 115, but the number of SD per year has increased drastically, considering that 5 SDs were drafted in 2016. This data could point to the effectiveness of the tool for SCP from the healthcare professionals' point of view, and also to the increased awareness of the healthcare professionals about requesting support in their decisions, precisely through the use of SDs. The cases' context, basic pathology and prognosis give us an indication of when the approach offered by the SD is more appropriate: all those cases had favorable conditions for SCP, such as the right timing and the possibility of a discussion both within the healthcare team and with the patients and/or their families.

Conclusions: In Italy the topic of shared care planning has taken on a greater role following Law 219/2017 on informed consent and advanced directives. In the experience of the CEC Service at the FPG in Rome, SD offer a useful tool to support the SCP process, bringing together the healthcare team's orientation with the patients' needs and autonomy.

Is Carrier Screening for Cystic Fibrosis Justified in the Era of Highly Effective Modulators?

John Massie

Cystic Fibrosis (CF) is traditionally described as the most common childhood onset, life-shortening inherited condition. It has a carrier frequency of around 1/25 people of European descent. It is possible to detect carriers before they have an affected infant using gene mutation analysis (reproductive genetic carrier screening, RGCS). RGCS has been recommended by peak bodies in a number of countries, and CF is usually one of a number of inherited conditions screened for at the same time. RCGS is promoted on the basis of offering reproductive couples choice about having an affected infant. The inclusion of CF is RCGS panels has been justified on basis that CF is a childhood onset, life-shortening condition. However, the new highly effective modulators facilitate the mutated gene-product (cystic fibrosis transmembrane conductance regulator, CFTR) to function sufficiently well to overcome the life-shortening lung disease that characterises CF. The modulators are CFTR gene mutation specific, and are effective for about 90% of people with CF. The CFTR modulators are licenced from the age of two years, at which point few children have established CF lung disease, and for some that do, their changes have been reversible. Most patients seem to respond to the modulators, and few have to stop because of side-effects. The modulators are taken orally, twice daily. The CFTR modulators are relatively new so that there is not long-term data to know if this effect will be maintained for decades. There are some CF complications that are apparent at birth such as pancreatic exocrine insufficiency, meconium ileus and absent vas deferens, but all have effective treatments, and none are life-shortening.

"Don't Tell My Kid They Are Dying:" Requests for Withholding Information From Pediatric Patients

Virginia McLaughlin, Andrew Ross

The death of a child can be a devastating event for families, communities, and healthcare providers. These unfortunate situations can be made more difficult for healthcare providers when they are asked by parents to hide their child's terminal prognosis from the patient, even by means of deception. Such parental requests for deception, while infrequent, can cause tremendous distress for the entire healthcare team. While each situation is unique, parental rationales for deception may include: that the child will not understand and/or will only be harmed by the disclosure; the obligations of the parents to protect their child; and/or belief systems that would align with not disclosing a terminal prognosis. The ethical tension in this type of circumstance lies between the healthcare providers' obligation to honour the parental decision-making, and competing obligations towards truth-telling and optimizing the agency of the child in healthcare decisions. While parents are rightfully given wide latitude to make decisions on behalf of children who are not mature minors, there are limits to what providers should honour, especially where significant harm occurs to the child. This presentation will explore the potential harms in these types of cas-

ses, the underlying broader social norms that permit deception of children, the weight of the emerging capacities of the pediatric patient in considering this request, and practical solutions for teams and clinicians.

Community Engagement for Ethical, Legal, and Social Implications Study of Sociogenomics

Karen Meagher, R Jean Cadigan, Sara Watson, Shawneequa Callier, Lia Kaz, Anya Prince

The expanding field of sociogenomics integrates genetic and social science data to understand the interplay between genes, environment, and human behaviors. Such research, using big data from a variety of biological and social science resources, raises questions about how research findings are used and carries implications for all groups who may be affected by the findings. Sociogenomics aims to measure the aggregate contribution of hundreds or thousands of genetic variants associated with an outcome of interest, creating a "polygenic score" (also called a "polygenic index"). Specifically, sociogenomics utilizes genetics to predict socially mediated, non-medical outcomes, such as income and educational attainment, opening doors to a variety of applications beyond medical care. The sociogenomic research agenda is controversial, with some arguing that it will greatly enhance social science research and lead to improved social and behavioral interventions, with others arguing that it can entrench reductionist explanations and harkens back to eugenics. Regarding the development and use of polygenic scores for social traits, community views on the use of this data are important partly because the advent of sociogenomics is an example of future research that was not predicted at the time of biobank participants' provision of broad (i.e., long-term and nonspecific) consent. In line with CTSC Principles of Community Engagement, we describe a community-engaged research project to better understand views toward this emergent use of data, including the attitudes of both biobank donors and non-donors. We began community meetings with a broad list of social traits for which polygenic scores have been developed, including reproductive behaviors, aggression, and risk tolerance. By employing a card-sort approach, community advisory boards in three geographic locations helped our team prioritize five of these traits for additional study of the ethical, legal, and social implications of sociogenomics. This engagement approach exhibited the strength of eliciting values of card sorters and study team experience provides an example of a participatory approach to mixed methods research design. In addition to describing team experience, this presentation provides attendees with a user guide to adapting card sort methods for community engagement goals, including eliciting community values and ascertaining community priorities.

Screening for Social Drivers of Health: Clinical and Organizational Ethics Implications

Michael Miller

In 2024, hospitals in the United States will be required to screen patients for Social Drivers of Health (SDOH) and report positive rates to the Centers for Medicare & Medicaid Services (CMS) as part of the Hospital Inpatient Prospective Payment System (IPPS). This reporting expands the collection, reporting, and analysis of standardized data; a priority of CMS' Framework for Health Equity. The implementation of this patient screening tool and its framing as a quality metric raise ethical questions in both clinical and organizational realms. In this presentation, I will articulate some of these questions and encourage participants to anticipate these questions as this screening is implemented within their own organizations. I will also explore solutions to sustainably support internal and external stakeholders in their efforts to screen for SDOH and promote health equity.

The Ethics of the Electronic Health Record and the Potential Application of Blockchain Technology

Kamalpreet Minhas

The digitalization of medical records has brought forward paramount convenience for health care providers and patients alike. Medical records have acted as clinical repositories, legal documents and communication tools that have facilitated care. Historically, medical records have existed in silos, often existing as paper documents in a single location accessed by a handful of healthcare practitioners and exchanged by simple means. Though, with the government-incentivized adoption of electronic health records in the United States of America and Canada, ethical concerns regarding privacy and confidentiality have been exacerbated. The electronic health record has offered significant value to patients. However, it highlights a need to consider the social and economic ramifications that vulnerable health data may have. The role of legislation, specifically the Health Insurance Portability and Accountability Act, complicates the conversation of privacy as organizations infiltrate the doctor-patient relationship with increasing digital innovation. As technologies like blockchain are introduced as potential safeguards to these ethical contentions, information sharing, ownership, and regulation become pivotal discussion points with electronic health records.

Equitable Child Health: Enabling Broad Ethical Inquiry in Pediatric Care by Understanding the Clinical Parameters of Social License for Reuse of Clinical Data

Abdullahi Mohamud, Melissa McCradden

Artificial intelligence (AI) technology in pediatric healthcare is one domain where the exclusion of children and youth from discussions of social license has fundamentally limited our understanding of the phenomenon. There is great promise for impacting the current landscape of patient care with the adoption of these AI technologies. Upon review of the current literature there were only a few studies that aimed to comprehend the viewpoint of children and youth on AI in healthcare Since children and youth are the dominant future healthcare consumers, understanding their views is crucial to the robustness and sustainability of our characterization of social license.

Our team developed a web-based survey study exploring the views, values, and moral intuitions of youth regarding AI use in healthcare and comparison of views to standard (non-AI) care. We engaged with youth advisors to provide valuable insights during the development of the content and structure of the survey.

Ongoing broad recruitment of youth in the community is being carried out using social media, newsletter, and mail -out lists. We plan on providing a descriptive account of their responses and for 3 scenarios participants will be randomized to two conditions (AI or non-AI vignette). Responses will each be compared using group-based statistical comparison.

The goal of this study is to define and describe the 'social license' guiding the ethical use of artificial intelligence in healthcare. Social license in this case refers to the conditions by which youth judge the use of AI to be justifiable.

Artificial Intelligence and its Potential Impact on the Doctor-Patient-Health Team Relationship

Evangelina Mollar, Carmen Larsen

A better patient-healthcare team relationship can be achieved by leveraging technologies that make communication easier from the patient's viewpoint and access to a broader pool of knowledge for the healthcare provider. These technologies are part of the Artificial Intelligence portfolio of tools. AI can complement the patient-healthcare relationship by providing greater information on similar cases. A critical part of the healthcare team is the medical ethics consultant or committee member.

In medical ethics, digital platforms and AI tools can support oversight, prevention and intervention when the patient or family members disagree with the medical options presented. Digital tools that help medical ethics practitioners track and assess medical dilemmas are extremely useful in creating a reference of what was said and done, and key stakeholders for the patient. Documenting assessment, investigation and communications is key in a resolution to a medical ethics dilemma. In this case, AI tools are used by the medical ethics practitioner or the ethics review committee to identify previous similar dilemmas and examine how they were addressed and with what degree of success. Bioethics cases can vary in complexity: the background, mental capacity, co-morbidity factors, culture and ethnicity, religious beliefs influence the approach to an ethical dilemma.

Bioethics committees, often called upon to deliberate and propose solutions to medical ethics dilemmas, stand the most to gain from digital documentation and AI aided research.

Digital platforms that incorporate artificial intelligence provide ethics committees with well delineated processes and checklists, foster transparency, reliability and agility in medical ethics committee work, enhance patient engagement and significantly improve quality of care, arguably reducing risk of legal claims.

The future is today. While AI can help in improving access to care and the health care team's pool of knowledge, ethical issues still prevail and must be addressed. AI cannot replace the healthcare provider's patient-centric approach but can help reduce patient wait times to resolve a medical concern, complementing and improving the patient-doctor relationship, ensuring ethical oversight and personalized care that doctors and healthcare teams can provide.

Learning From Queer Community Responses to Mpox: Solidarity During Public Health Crises

Michael Montess

In this paper, I consider the lessons we can learn about solidarity from queer community responses to the recent mpox outbreak. This solidarity has led to a relatively successful community response to mpox, which is in contrast to the many challenges experienced during other recent public health crises, including COVID-19 and HIV/AIDS.

Gay, bisexual, and queer men were disproportionately affected by mpox at the beginning of the global outbreak during the summer of 2022 in Canada and the United States and there were worries that mpox could become the next epidemic or pandemic. However, the response of queer communities, including listening to public health advice, getting vaccinated, and changing behaviours, is credited as playing an important role in helping us get mpox under control in North America and preventing a wider public health crisis. Solidarity is cited by public health experts and political leaders as an important part of our responses to such crises and philosophers are increasingly referring to solidarity as an important concept in bioethics. Barbara Prainsack and Alena Buyx highlight three different tiers of solidarity: interpersonal solidarity, group solidarity, and institutional solidarity. Public health responses to COVID-19, HIV/AIDS, and mpox have demonstrated different ways of building solidarity, the different roles each tier plays in our responses, and the different challenges to building solidarity. First, we seemed to use institutional solidarity during COVID-19 in a top-down approach that overlooked interpersonal and group solidarity as individuals and groups sometimes struggled to follow public health guidelines. Second, we seemed to use interpersonal and group solidarity during HIV/AIDS in a bottom-up approach because governments and public health institutions were initially unresponsive to the crisis. Finally, we seemed to have learned lessons from both HIV/AIDS and COVID-19 in our societal responses to mpox, which demonstrates the importance of each tier of solidarity, especially group solidarity. The responses of queer communities to mpox in particular show the power of leveraging solidarity within different groups depending on the public health crisis and the importance of promoting whichever tiers of solidarity are most relevant for continuing to improve our responses to these public health events.

Addressing End-of-Life Conflicts With Community Advance Directive Education

Ray Moseley, Marcia Brown

Background:

Advance directives have become the standard way to express end-of-life treatment wishes and conflict has been cited as an important barrier to its creation or implementation. Furthermore, conflict around advance directives has been linked to low health literacy and miscommunication, but interventions addressing this in the underserved population are rare. We undertook a pilot study to evaluate the unique needs and feasibility of a community intervention within minority faith communities.

Methods:

After approval from the University of Florida Institutional Review Board, we invited our hospital chaplains and other community academic partners to refer individuals to participate in a research workshop on Conflict and Advance Directives Education (CADE). The virtual intervention held three sessions: Overview of Conflict, Overview of Advance Directives, and a practice session in three conflict management skills. The skills taught were listening, self-reflection, and the AEIOU technique. The CADE workshop lasted approximately 3 hours per cohort and a facilitator guide was provided to minimize variability. Participants were then asked to take an optional feedback survey of the training.

Analysis:

A mixed method approach was applied to this research intervention. Descriptive statistics calculated the demographics and a qualitative technique garnered themes from the workshop participants.

Results:

A total of 27 consented and 26 attended the workshop. There were 6 cohorts where 62% were female, 46% were between 25-34 years, 77% were non-Hispanic, and 30% provided feedback. Out of those who responded to the questionnaire, most agreed that the subject matter was useful, 88% felt that they brought a positive attitude, and 75% felt they actively participated on a score of >75 of 100. On the qualitative section of the survey, the respondents noted: importance of end-of-life conversations, urgency in having their end-of-life plans documented, and the need for choosing a surrogate promptly. For the conflict management skills, they found the listening and the AEIOU techniques most useful.

Conclusion:

The addition of conflict management skills to advance directives education appears to be doable and CADE as a community intervention shows promise in this setting.

Keeping Our Options Open: The Need for Specialized Paediatric Palliative Care in Ontario in Response to the Growing Normalization of MAID

Sam Moshiri

Canada has implemented safeguards to ensure that medical assistance in dying (MAID) is not accessed in a way that could diminish one's autonomy. One example of this is that adults seeking MAID must be informed by the practitioner of available and appropriate means to relieve their suffering through other means like counselling and palliative care.

I argue that, unlike adults, MAID should not yet be considered to be offered to mature minors, as this patient group's autonomy is currently compromised due to the lack of specialized palliative care. Ensuring all available and appropriate means to relieve suffering is a challenge with mature minors, as specialized paediatric palliative care in Ontario is limited. A report by the Ministry of Health and Long-Term Care of Ontario states that expertise in paediatric palliative care currently exists within only five major hospital organizations in Ontario. As a result, access to this specialized care is limited for those who do not live in proximity to these major hospital organizations. This includes those living in rural and remote communities.

This presentation will also consider counterarguments to this position on MAID for mature minors. First, it will consider that some may argue that it is both ethically and legally responsible for mature minors to access MAID. Second, it could also be argued that by not offering MAID for mature minors, they are being subjected to suffering that adults would not be subject to, as they are assumed as capable, autonomous individuals.

If MAID is being offered to mature minors without any proportionate palliative care options, this raises issues of distributive and procedural justice. The lack of availability of robust paediatric palliative care in Ontario is unjust, which impacts the autonomy of a mature minor's decision to receive MAID. It would be incautious of the government to move forward with this legislation before ensuring other means are readily available for these young patients. Gaps in our healthcare should not limit us to one option when others exist. If we want children to have the same opportunities as adults, palliative care should be no exception.

A 20-Year Review: Qualitative and Quantitative Trends in Bioethics Consultation Through the 21st Century

Nancy Nam, Nicholas Salupo, Jeffrey Kaufhold¸ Megan Grant

Background and Objectives: To address the difficulty of recruiting qualified ethicists, Fraser Health Ethics Services (B.C., Canada) is developing an ethics fellowship program to train and support the hireability of systems-level and clinically trained ethicists. This presentation details the development process of the fellowship and aims to contribute to the conversation on standardization and professionalization in the field of bioethics.

Methods: Fraser Health pulled from different sources to assess current best practices and inform the structure and curriculum that their fellowship should adopt. The academic literature pertaining to postgraduate ethics programs and grey literature, namely websites of ethics programs and job postings for clinical ethicists in North America, were reviewed. Interviews of 7 fellowship directors, 10 mentors, and 7 past fellows from across Canada were conducted. Where available, program outlines were consulted. This fellowship also builds on Fraser Health's existing bioethics course and other capacity-building efforts within the organization.

Results and Analysis: Preliminary thematic analysis of the environmental scan reveals variability in the fellowships' eligibility criteria, stipend, goals, length, syllabus, activities and opportunities, research component, site rotations, number of supervisors, areas of specialization in ethics, assessment practices, and measures of success. Notably, the applicability of the American Society for Bioethics and Humanities' Core Competencies and Certification (HEC-C) to the Canadian context is questioned. The program leads and preceptors stressed the importance of flexibility, such as adapting to the fellow's prior experience and skills, revising the fellowship's duration, and adjusting the fellow's tasks and projects based on their needs, progress, and interests, consultation requests received, and supervisors' availability. Barriers to the success of ethics fellowships include: funding, cost of living, logistics of rotations, events like a pandemic, inadequate supervision, and lack of support for the mentors in terms of time management, added responsibilities, and pedagogical approach.

Conclusion: In light of these considerations and recommendations, Fraser Health's fellowship aims to be launched in the Fall of 2024. By thoroughly documenting its development process, Fraser Health Ethics Services hopes to respond to the desire for shared curricula and educational tools in the bioethics community and foster collaboration among ethics services across the country.

Advance Care Planning: A Communal Approach

Nico Nortje

Advance Care Planning (ACP) conversations is seen as a cornerstone of modern healthcare and needs to be supported. Advance care planning has been heralded, as a mechanism, to support patient rights, autonomy, and dignity in a patient's healthcare trajectory. However, research indicates that the uptake thereof is limited, regardless of various campaigns and legislation.

Various gaps in ACP adaptation within systems have been identified. This presentation will give an overview what a comprehensive tertiary cancer center has done on a systems level to encourage better ACP conversations and align it with better goals of care conversations. In 4 years, ACP documentation has increased from around 19% to well over 80%. ACP conversations can only be successful if patients are also made aware of the importance thereof. Information will be presented on a plan of integrating a patient-centered ACP solution via MyChart in the electronic health record.

It is evident that early and empathetic engagement with patients should be focused on the alignment of expressed wishes with what is medically viable. Furthermore, it is argued that family members must be involved as much as possible, in a culturally sensitive setting. ACP conversations should be normalized, and all healthcare providers have a role to play.

Artificial Intelligence and Moral Disengagement: Considering the Influence of Interactive Algorithmic-Based Ethical Decision-Making and Agentive Wellbeing

Aloysius Ochasi, Kirk Mensch

Artificial intelligence (AI) has become an undeniable source of paradigmatic influence on human beliefs, attitudes, intentions, and behaviors. Individuals are increasingly relying on artificial intelligence to make decisions in the organizational work context as well as personal decision-making, the two contexts not being mutually exclusive. In this article, we explore previous research that offers insights into the potential risks related to individual well-being and human flourishing generally, and the pluralistic organizational context specifically. Additionally, we examine the relationship between the use of Generative and Predictive AI and the potential perils related to an increased propensity for an individual to disengage from their moral self-sanctions and previous research that supports the connection between moral disengagement, cognitive dissonance, cognitive distress, and self-harm. In healthcare, for instance, AI algorithmic recommendations or predictions for diagnostic procedures, risk assessment, and prognostication may influence healthcare providers to defer to AI's response even if the provider has ethical reservations. If healthcare providers remit their moral agency to AI, it may diminish their agentive responsibility for the consequences of that decision and increase a propensity for the disengagement of their own moral self-sanctions. Furthermore, questions about transparency and accountability arising from the difficulty of deciphering the reasoning behind an AI system's recommendations or predictions (Black-box problem) raise ethical dilemmas that undermine the autonomy of individuals to make informed, morally sound decisions as rational agents. We submit that AI can perpetuate the sociopsychological phenomenon known as displacement of responsibility, a mechanism of moral disengagement, and incite a shifting of agentive responsibility by sanctioning attitudes, intentions, and behaviors inconsistent with the agent's moral schema and underlying beliefs. Finally, we offer recommendations on how moral agents can remain vigilant and reduce the uniquely elevated risk that AI poses regarding the propensity for moral disengagement.

Beyond the Home of the Bioethicist: An Ubuntu-Inspired Model for Effective Clinical Ethics Consultation through Community Engagement

Aloysius Ochasi, Levi Nkwocha

Health inequity and disparity in the United States have continued to provoke core concerns in bioethicists due to their subtle infiltrations into the clinical settings, often propelled by intense personal biases and aggressive cultural orientations. Patients from historically minoritized groups are more likely to undergo ethics consults than patients identifying as white, arising from cultural or communication differences between clinical teams and families. However, the vast majority of ethics consultants are whites who are directly or indirectly employed by the health system in which the committee is situated. Such structural factors and the predominantly white makeup of ethics consultants create the perception of bias, conflicts of interest, suspicion, and distrust among patients and families who see ethics consultants as extensions of the inherently-biased medical establishment.

In response, this paper argues that a bridge of trust can be built between providers and patients of color by a com-

munity engagement inspired by an Ubuntu humanness model, on the one hand, and a patient-based communication improvement plan for the providers, on the other hand. Ubuntu is a South African ethical concept that represents a general notion of universal interdependence, solidarity, and communalism. It advocates for human interactions that nurture sharing and building trusting relationships filled with mutual compassion, respect, listening, and affirming others. As a go-between in the patient-provider relationship, the core interpersonal skill required for ethics consultation can be deployed in bold outreach to the historically minoritized groups to build trust capital they can leverage when ethics consults arise. Such outreach characterized by empathic listening, openness, solidarity, and cultural sensitivity can also reorient the providers to foster trust and connectedness between them and the affected communities. We propose that the Ubuntu community engagement model can be replicated nationally to mitigate mistrust between providers and minority communities.

Evaluating Research Integrity Awareness: An Assessment Among Botswana Research Institutions

Lillian Aaca Okui, Kaizer Ikgopoleng, Mpho Zwinila, Abia Sebaka, Ngozana Seonyatseng, Tumalano Seketo

Background: Research integrity is essential for the ethical practice of research and public's trust in researchers and their findings. Research institutions have a responsibility to educate and establish mechanisms to ensure compliance with research integrity principles. Regulatory officers from Botswana Ministry of Health research unit and two leading research organizations, conducted a survey assessing the understanding of research integrity principles among their research teams.

Objective: To evaluate the level of knowledge of essential research integrity principles among researchers in three Botswana-based research institutions.

Methods: A comprehensive online self-administered questionnaire was used to assess research integrity knowledge. The questionnaire consisted of twenty multiple-choice questions covering but not limited to, peer review, authorship, research misconduct, and financial conflicts. A total of 118 researchers from the three research institutions participated in this study

Analysis: Descriptive statistics were calculated, summarizing the responses to each question. Frequencies and percentages were reported to present a clear picture of the participants' level of awareness and understanding of research integrity principles.

Results: A 90% response rate was achieved. Less than half (42%) of the respondents were fully aware of the fundamental concepts of research integrity. Peer review (12%) and financial conflicts (13%) were the most deficient areas. Approximately one-third of the participants exhibited limited understanding of authorship (36%) and research misconduct (37%). These findings suggest that there are substantial gaps in research integrity knowledge, with less than 50% of the respondents fully comprehending the general principles of research integrity.

Conclusions: This study highlights notable knowledge gaps among researchers in Botswana regarding research integrity principles. These findings underscore the importance of continued efforts to enhance awareness and education in research integrity where deficiencies were observed. Addressing these gaps can contribute to a more robust and ethically sound research environment in Botswana's research institutions.

A Systematic Literature Review of Non-Financial Conflicts of Interest in Research and Publication: Building a Community Standard

Devin Orchard, David Bauer, Philip Day, Marc Tunzi, David Satin

Background: Attention to conflicts of interest (COIs) in healthcare research has increased exponentially over the past two decades. Although financial COI has an extensive literature, publications about non-financial conflicts of interest (NFCOIs) are comparatively rare. To date, no published systematic review of NFCOI in research and publication exists.

Objective: To systematically 1) summarize the NFCOIs literature about healthcare research and publication, and 2) identify issues of community consensus and contention.

Methods: 621 articles were reviewed for inclusion and exclusion by 2 independent reviewers (DAB, DAO) with a third (DJS) settling any disagreements. Articles were then included if they discussed NFCOI in general or a specific form of NFCOI such as academic, intellectual, personal, or political conflicts, in the context of research or publication.

Analysis: The final dataset consisted of 205 articles coded for type and content according to the Relevance, Appro-

priateness, Transparency, and Soundness (RATS) criteria of qualitative research. Analysis proceeded using Grounded Theory, developing results through consensus across three independent reviewers (DAB, DAO, DJS).

Results: We found a heterogeneous literature with three fundamental disagreements about (1) whether NFCOIs should even be understood to be COIs; (2) whether NFCOIs need to be addressed in research, or if they are distractions from the real concern of financial COIs; and (3) whether NFCOIs should be managed with disclosure or with other strategies. Despite these disagreements, the balance of evidence and arguments favored that (1) NFCOIs are a meaningfully distinct entity in research ethics, (2) they require management, and (3) disclosure is necessary but not sufficient as a management strategy.

Conclusions: This review demonstrates a need for communities of researchers, reviewers, and editors to engage in active dialogue toward consensus on the diagnosis and treatment of NFCOI in healthcare research. If this issue isn't addressed, biased data will continue to enter the evidence base, inaccurately informing the actions of clinicians, policymakers, and advocacy groups - undermining the trust that patients and communities place in our academic healthcare institutions.

Implementing an Interdisciplinary Clinical Ethics Rotation for Graduate Medical Trainees

Rimma Osipov, Diya Jost, Arlene Davis, Jean Cadigan

How can we bring clinical ethics to the busy world of residency? Although ethics curricula are well-established in undergraduate medical education, residency presents a complex set of challenges: clinical workloads, competing educational priorities, and a lack of specialized expertise among preceptors. Conventional GME ethics curricula rely primarily on the didactic and tend to be siloed by specialty. All these factors can become barriers to developing and maintaining robust educational experiences in clinical ethics for medical residents.

We describe an adaptable model for a clinical ethics rotation implemented at our institution in 2020 that addresses some of these challenges. Designed primarily by one of the authors during her medicine-pediatrics residency, the rotation has thus far enrolled 15 residents from across training programs. With the cooperation of GME program directors, the rotation is supported by the institution's Center for Bioethics and Hospital Ethics Committee (HEC). The faculty advisor and preceptors are members of the HEC's Clinical Ethics Service.

Residents from across specialties have joined the rotation and adjusted its duration and goals to suit their clinical schedules and academic interests. Each resident meets with a HEC preceptor to develop a personalized plan based around 3 pillars: didactics in the foundations of clinical ethics, practical ethics experiences, and a project or educational presentation for a broader audience. All residents engage in a set of core readings on the history of clinical ethics, models of ethics consultation, and ethical theory. These readings are discussed with an HEC facilitator at the end of the rotation in the context of their experiences. All residents attend HEC meetings, shadow ethics consultations, and attend ethics rounds in various critical care settings. Resident projects have ranged from preparing case presentations for national ethics conferences, to peer education for community outreach around vaccine hesitancy, to creating a database of films and TV shows for ethics teaching. The rotation is available for 2-6 week blocks, with residents offering a descriptive evaluation upon completion. The rotation has been well-received with most residents describing an increase in their ethics knowledge and level of interest.

"What if Someone Else had Shot Him?" Code Status After Suicide Attempts in Patients With Longstanding DNR Orders

Rimma Osipov, Paul Ossman, Alissa Hutto, Anissa Berger

What values, precedents and guidelines ought to be considered in honoring a pre-existing DNR in a patient admitted after attempted suicide? We present 2 amalgamated cases, based on 5 ethics consults at a single hospital over 4 years. In the first case, Ms. M, an 89 year old woman with a history of severe COPD, chronic pain, and possible new lung malignancy was admitted after an intentional overdose. She has no psychiatric history, and has had a DNR for over 1 year. After stabilization she remains delirious but is expected to improve. Her daughter, who is her healthcare decision maker reports that her mother desired to be DNR due to untreated pain and poor quality of life. Psychiatry was consulted and recommended suspending her DNR so as not to be complicit in her suicide should she decompensate. The second case involved Mr. H, a 78 year old brought to the ER after a self-inflicted gunshot wound. He has multiple chronic illnesses and a history of depression. He remains minimally responsive with concern for anoxic brain injury. He has had a DNR for several years, and his wife/HCPOA wants to honor it. These cases illustrate a concern likely to become more frequent as the population ages: how can medical teams balance autonomy and beneficence/non-maleficence in caring for patients with long-standing DNR orders who attempt

suicide. Accepted practice in the field of psychiatry is to view a suicide attempt as sign of compromised capacity, which raises concern that not offering full resuscitation to these patients would be ethically unacceptable. Brown et al. argue that honoring DNR status can be ethically permissible in certain circumstances and propose a decision algorithm that centers on the question "If this were not an attempted suicide, would a request to withdraw care be reasonable?" We test this algorithm against the cases of Ms. M and Mr. H. We argue that with an emphasis on interdisciplinary conversations that are inclusive of patient's surrogate, it is possible to address many of these cases in a way the respects patient's values while protecting them from unnecessary harm.

Patient Partner Narratives

Alexandra Paré-Tremblay, Christian Jetté, Aline Bogossian

Context:

A growing body of research has focused on the partnership model of care. Most of it examines the efficiency, as well as the facilitating and limiting factors associated with the integration of Patient Partners at macro, meso, and micro levels of healthcare systems. Since little research has questioned the perspectives of those involved in the partnership, this research explores the lived experiences and participation of chronic patients who have become 'Partners'. Based on the premise that the Patient Partnership approach underlies the empowerment and self-actualization of patient partners, it seeks to understand how (or if) patient partnership contributes to altering the meaning patients ascribe to their life trajectory, as well as to their care trajectory.

Objectives:

This project aims to explore the various partnership narratives that emerge from the testimonies of chronic patients as they relate to their experience as Patient Partners. It seeks to reveal how this experience has influenced their relationship towards their illness/diagnosis, their bodies, and the healthcare professionals they encounter.

Methods:

In-depth semi-structured interviews, inspired by Bertaux's (1997) life story method were conducted with nine participants who had acquired the title of 'Patient Partners'.

Analysis:

The life stories (n=9) were then analyzed using Interpretative Phenomenological Analysis (IPA), following an idiographic approach.

Results:

In light of their experience as Patient Partners, the participants recounted having attributed a renewed meaning to the experience of illness, to their bodies, and to the healthcare professionals encountered throughout their complex care trajectories. The partnership experience appears to have contributed to transforming their identity, as well as their sense of self.

Conclusion:

The introduction of partnership into their care and life trajectories seems to provide a lasting meaning to "life beyond," as well as serving as a catalyst in the quest for meaning prompted by the experience of illness.

How Are Pediatric Tertiary Care Hospitals Structured to Respond to the Needs of Children With Medical Complexity During Acute Deteriorations? A Landscape Study in Canada

Julia Parreira Pinto, Tammie Dewan, Sophie Marsolais, Alexandra McKinnon, Sadaf Ghanbari Miandoab, AJ Côté, Evelyne D.Trottier, Graham Thompson, Samina Ali, Nathalie Gaucher

Background: Children with medical complexity (CMC) represent the most fragile children; they have many unmet health needs. Institutional structures and complex care (CC) programs are important to improve their care, posing an important organisational ethics problem.

Objective: To identify the organizational and administrative resources available for the care of CMC in Canadian tertiary care pediatric hospitals and to assess how physicians believe these resources are adapted to the specific urgent needs of CMC.

Methods: Key informants representing complex care (CC) and pediatric emergency medicine (PEM) services from

15 pediatric tertiary care hospitals in Canada completed cross-sectional structured questionnaires. Participants were identified through national research networks and by snowball sampling. Utilizing the Lime Survey web application, two questionnaires (one for PEM, one for CC) were develop based on a literature review (Burns methodology). Verbal questionnaires were administered via a secured teleconference application or completed digitally. Descriptive data were generated using Excel and SPSS v.29.

Results: From 09/2022 to 09/2023, 93% (28/30) key informants completed questionnaires (15 PEM, 13 CC). Across the 15 sites, 12 had a CC program/clinic. Information about established CC programs was available for 10 sites, from participating CC informants: 4/10 offered outpatient services; 6/10 offered inpatient and outpatient services; 8/10 offered last minute appointments. CC informants reported offering an ED consultation service at 8/10 sites, while 6/12 PEM participants reported access to this service. CC informants reported that their program rarely offered consultations during weekends (2/10) or nights (1/10). PEM informants reported good access to documents to help with continuity of care including emergency care plans (13/15), medical history (14/15), goals of care (13/15). To improve the care of CMC, informants most often suggested improved access to documentation, improved access to CC teams, and specific ED structures for CC patients.

Conclusions: There exists wide variation in the structures caring for CMC and their availability in case of acute needs. National collaboration between CC and PEM teams may facilitate the design of programs to improve the acute outpatient care of CMC.

Information About Clinical Ethics Consultation on Hospital Websites

Melina Peshoff, Jacob Earl, Elizabeth Lanphier, Ben Krohmal, Magdelynne Lowy, Marion Danis

Background: Previous studies show that 80% of U.S. hospitals offer clinical ethics consultation (CEC) and nearly all allow patients or their representatives to request this service. This aligns with best practice guidelines and with evidence that patients and surrogates believe they would benefit from CEC, though they initiate only 4% of all consults. Lack of accessible, relevant information about CEC might explain this low uptake, but there has been no systematic investigation of how U.S. hospitals communicate externally about CEC.

Objectives: 1) Determine the prevalence of information on public-facing hospital websites regarding availability of CEC; 2) Describe characterization of CEC availability to patients and surrogates, and their function, cost, staffing, and request procedures.

Methods: We apply a standardized website search protocol to confirm whether 100 hospitals in the U.S. have publicly available information about their CEC services and to qualitatively assess information about such services for patients and families. We chose a list of "top hospitals" in the U.S. to reflect those academic and non-academic institutions most likely to have robust CEC services in line with best practices. For hospitals without CEC information identified on their website, the study team will follow up by phone to confirm existence and availability of services.

Analysis: Quantitative data about incidence of websites with publicly accessible CEC information will be compared with data from prior studies about hospital-reported availability of CEC. Qualitative data from all identified websites will be coded and thematized by the study team and compared with prior studies about patient and surrogate concerns regarding CEC.

Results: Preliminary data show that half had available information about CEC services, availability to patients, and contact information. The other half either did not have detectable information about CEC services (12%), or information did not indicate how to request CEC or that patients and families could place requests (38%). Remaining data collection and analysis is ongoing with results reportable by May 2024.

Conclusions: Although this study is limited to 100 U.S. hospitals, findings will support recommendations for enhancing publicly available information about CEC availability to align with best practices and improve patient and surrogate engagement.

Assessing Innovative Health Technologies for Secondary Prevention and Diagnosis: The MELCAYA Project

Costanza Raimondi, Pietro Refolo, Dario Sacchini, Bettina Ryll, Violeta Astratinei, Laura Sampietro-Colom, Paula Closa

In childhood, adolescence and young adults (CAYA), melanoma is under-studied and non-existing tailored clinical guidelines and standardized approaches lead to a very low diagnostic accuracy. The European funded MELCAYA

project aims to understand risk factors and determinants of melanoma to improve the prevention, diagnosis and prognosis of melanomas in CAYAs through a strong international consortium with experts from 10 countries in different disciplines (oncology, pediatrics, ethics, policy making), and sectors (academic centers, SMEs, hospitals, patient associations).

Within the numerous aims of MELCAYA, an ELSI framework for assessing innovative health technologies for secondary prevention and diagnosis of melanoma in CAYA will be developed by the ethics team of Università Cattolica del Sacro Cuore (UCSC) with a sound contribution of Asociatia Melanom Romania (AMER) and Melanoma Patient Network Europe (MPNE) as patient organizations active on national and European level, respectively.

Patient engagement (PE) in MELCAYA, particularly within work package 7: health care system strategies implementation to inform policy and ethical dimension. PE fulfills two main objectives: 1. to increase the probability of implementing melanoma early detection technologies. 2. to ensure transparency and accountability towards those for whose benefit the project is primarily conducted and society at large.

UCSC performed a critical interpretive review of literature about the assessment of health technologies for secondary prevention and diagnosis of melanoma. A fruitful partnership between the ethics team and Patient Organizations was established within the Patient Engagement Plan (PEP), consisting of regular communication and face-to-face interactions with patients and patient advocates to collect input and discuss their real-life experiences. These regular activities will be completed with Virtual Focus Groups (VFG) to identify Ethical, Legal and Social Issues that are not found in the literature or addressed by it, as well as a workshop at the MPNE conference in March 2024.

We will share the preliminary results obtained during the virtual focus group and the AMER/MPNE joint workshop with patients, families and patient advocates.

Based on these results, an ELSI framework for assessing innovative health technologies for secondary prevention and diagnosis of CAYA melanoma will be developed.

HIV Molecular Cluster Analysis and Non-Domination

Pierce Randall

Public health authorities now use molecular analysis to detect the patterns of HIV spread within a community. When a patient is tested, a genetic analysis of their sample can be used in conjunction with other positive tests to map a pattern of HIV outbreak clusters. Though this information cannot reliably prove that one individual infected another, it is possible to identify patients as belonging to the same infection cluster with this technique.

This practice raises significant ethical concerns. Many populations at high risk for acquiring HIV come from vulnerable populations: persons with injection drug use disorder, unhoused individuals, men who have sex with men, and incarcerated persons. Adding to the potential vulnerability of these groups, many states still have laws criminalizing wrongful HIV transmission. The vulnerability of populations at risk for HIV spread, as well as laws criminalizing wrongful HIV spread and the social stigma surrounding HIV, create a substantial privacy concern for members of these groups, since their genetic information may be shared with government agencies and could even make them liable for prosecution. Compounding this problem is that patients are neither routinely informed of nor consent to the use of their sample for molecular cluster analysis.

In this paper, I propose a principle of non-domination for public health ethics, drawing on republican political theory. The use of genetic data for public health, I argue, is permissible only if it will not subject the person whose data is collected to the arbitrary will of others. The non-arbitrariness condition, for republican political theorists, may be satisfied if there are robust procedures in place that ensure that the agent in question (in this case, a public health authority) reliably tracks the interest of those whose data they are collecting. Unfortunately, I argue, there are not robust procedures that ensure that many public health authorities in the US reliably make decisions in ways that track the interests of vulnerable and marginalized groups—for example, in states that criminalize HIV transmission. There is a pro tanto case in these jurisdictions against molecular cluster analysis without disclosure.

Artificial Intelligence and Clinical Ethics: The European Context

Dario Sacchini, Salvatore Simone Masilla, Pietro Refolo, Costanza Raimondi, Barbara Corsano, Antonio Gioacchino Spagnolo

Introduction: According to the first definition, Artificial Intelligence (AI) is “a field of study that combines com-

puter science, engineering and related disciplines to build machines capable of behaviors that, if observed in humans, would require intelligence" (McCarthy). The literature indicates that on the one hand AI offers a series of opportunities, on the other hand risks.

Objectives: Identify the ethical aspects raised by the advent of AI and the impact on clinical practice as well as on decision-making processes in the European context. What are the implications for clinical ethics consultancy?

Methods: A review of the literature available on the PubMed database was carried out regarding the subject of this contribution. A review of current guidelines and regulations that guide clinical practice is also conducted.

Results: The ethical issues in the healthcare field related to AI concern the privacy and security of personal data, the issue of trust in AI by healthcare professionals and citizens/patients, the responsibility in case of incorrect use of AI. Furthermore, the ethical attention on healthcare AIHTs currently focuses on "carer robots," diagnostics, precision medicine. With reference to the classic ethical principles in bioethics, the following emerges. According to the principle of Beneficence, AI should be developed for the common good; according to the principle of non-maleficence, AI must not cause damage while respecting privacy and security. In relation to the principle of respect for autonomy, it is necessary to pursue the balance between the decision-making power that we reserve for ourselves and that which we delegate to "artificial agents," while always leaving the possibility of deciding open to us. According to the principle of justice, it is necessary to eliminate any possible discrimination by trying to identify benefits to be shared. Finally, an unprecedented ethical factor emerges relating to explicability, or rather "responsible intelligibility," which means clarifying what is being done and identifying ethical and legal responsibility for any damage.

Conclusions: the impact of AI on clinical practice becomes increasingly compelling, so much so that it requires the support of ethics in order to resolve new ethical issues involved according to an appropriate value horizon.

Nurturing Moral Community Using a Novel Moral Distress Peer Support Navigator Tool

Lauren Sankary, Georgina Morley

Moral distress is a pervasive phenomenon in healthcare for which there is no straightforward 'solution.' Rhetoric surrounding moral distress has shifted over time, with some scholars arguing that moral distress needs to be remedied, resolved, and eradicated, while others recognize that moral distress can have some meaning and positive value. In this presentation, we argue that moral distress has positive value as a warning sign and that experiences of moral distress signal the presence of an ethical issue related to patient care requiring deeper exploration, rather than evidencing identification of the 'right' course of action. Recognizing the importance of supporting healthcare professionals experiencing moral distress using multiple modalities, we describe a step-by-step approach toward mitigating the deleterious effects of moral distress while promoting action to attend to underlying ethical issues. The peer support navigator tool provides concrete action steps, drawn from theory, for healthcare professionals to utilize independently or alongside peers to mitigate moral distress. The steps and guidance within the tool are predicated on a broader conceptualization of moral distress that divorces moral distress from 'knowledge' of the 'right' action and reorients individuals towards perspective-taking and dialogue. Focusing on perspective-taking and dialogue promotes actions that contribute to ethical climate and generating a moral community in which healthcare professionals are supported in navigating moral distress and can offer that support to others. We briefly describe the four steps users are guided to take to effectively support a healthcare professional experiencing moral distress, illustrating each step in the context of a case example: 1. Information gathering, 2. Interrogating emotions, 3. Perspective-taking and 4. Dialogue. This structured approach focuses initially on the micro-space but has the potential to influence the macro-space through dialogue, thereby nurturing effective teamwork to foster moral community.

A State Legislator and a Practicing Physician Walk Into a Bar… Insights From the Front Lines of Healthcare Politics and Caring for Marginalized Communities

David Satin, Hunter Cantrell

Drawing on the experiences of a retired state legislator and a practicing Canadian/American physician, this session will explore the ways in which the United States of America's (USA's) for-profit healthcare system persists within the gridlock of politics. Through vignettes, data about access and care denial, and an insider description of the political landscape, attendees will gain a nuanced understanding of how (1) insurance corporations, (2) pharmaceutical companies, and (3) hospital systems influence policy and clinical practice to the detriment of marginalized communities across the USA.

These three players often point fingers at each other to explain why healthcare costs continue to rise while patients

suffer. However, a lack of regulation has allowed for perverse incentives in healthcare to pre-dominate the industry, resulting in entities without direct involvement in patient care inventing new ways to profit. At the same time, these entities effectively practice medicine without a license by controlling patient access to services. We will review specific topics as exemplars of political gridlock ranging from prior authorization, hospital billing, pharmaceutical price gouging, administrative bloat, and the heterogeneous insurance framework.

As countries with single-payer systems around the world continue to explore the privatization of services, this discussion will serve as a global cautionary tale of the ways for-profit healthcare exacerbates inequities in community health.

From George Floyd to Daunte Wright: Reporting From the Epicenter of a Cultural Movement

David Satin, Erika Kaske

Background: George Floyd's death in Minneapolis, MN, catalyzed the largest international protests in history, prompting the deployment of widespread crowd control measures. One year later, Minnesota witnessed the police killing of Daunte Wright, followed once again by protests met with crowd control weaponry. Police use of less-lethal weapons for crowd control, including kinetic impact projectiles and chemical irritants, can lead to significant morbidity and mortality.

Objective: Community reaction to injuries sustained by protesters and continued inaction by policymakers prompted our systematic characterization of trauma during the George Floyd and Daunte Wright protests.

Methods: We screened 15,375 encounters for adult or pediatric trauma from M Health Fairview Hospital, North Memorial Hospital, and Hennepin County Medical Center (Minneapolis, MN) within 2 weeks of each protest. Care Clinics, Urgent Care, and the Emergency Department with ICD10 codes S00-T59 or patients with "riot" or "rubber bullet" or "tear gas" or "protest" or "projectile" in patient notes comprised the inclusion criteria. Injuries not related to less-lethal weapons or officer violence were excluded.

Analysis: The total number of injured protesters and their Injury Severity Score (ISS) served as our primary outcome. To report injuries, we followed the STROBE (Strengthening the Reporting of Observation Studies in Epidemiology) guidelines.

Results: 103 patients sustained injuries from police use of projectiles, chemical irritants, or batons. Injuries to the head, face, and neck were most likely to require surgical intervention. Full clinical outcomes, including an ISS "heat map" and patient demographics such as race, ethnicity, age, and gender will be presented.

Conclusions: Police use of less-lethal weapons for crowd control can cause severe injuries requiring surgical intervention. Injuries were sustained to the head, neck, and face, suggesting inaccurate or wrongful use of these weapons, according to the 2020 United Nations Guidelines. The consequences of each injured protester deepen the rift between our communities and those sworn to serve and protect. We call for the continued collection of standardized clinical data from all protests to inform outcome-oriented discussions among our communities and policymakers.

Making Way for Community-Based Ethics Champions and Consultants Through a Healthcare Ethics Basics Course

Jami-Leigh Sawyer, Jeffrey D'Souza, Shannon Buckley, Winifred Badaiki, Andrea Frolic

Background: Healthcare staff in community hospitals tend to rely on their peers/colleagues to navigate ethics issues, rather than external ethics supports. As a result, we identified a growing need to develop local ethics champions to provide informal consultation to address ethical issues within their organizations.

Objective: The Regional Ethics Network (REN) in Ontario, Canada, launched a Healthcare Ethics Basics Course designed and offered to health professional staff across five hospitals, who identified interest in strengthening their capacity to act as ethics champions. The goal was to provide baseline education about ethical concepts and theories as they apply to healthcare, to teach participants how to analyze ethical dilemmas using an ethics framework, and to increase capacity utilizing local ethics resources and tools. The intention was to enable ethics champions to be the first point of contact for frontline staff experiencing moral distress or ethics questions, and to function as a bridge to more formal ethics consultation services.

Methods: Launched in September 2023, the on-line Healthcare Ethics Basics Course is comprised of ten, 30-60 minute, asynchronous modules, plus a weekly community of practice meeting for participants to reflect on content

and engage in case analysis. Twenty-nine staff, physicians and leaders participated from October 2023-December 2023. Following completion of the course, all participants will be invited to engage in focus group sessions scheduled for January-February 2024. During these qualitative feedback sessions, course participants will be asked to describe their overall experience of the design/delivery of the course, as well as how it has impacted their confidence in addressing ethical dilemmas/issues using tools and skills learned in this program.

Analysis: A grounded theory approach will be used to analyze focus group transcripts. Major themes will be identified and explored.

Results: Results presented will include themes garnered from both experiences of participants and facilitators, as well as recommendations for process and content improvement.

Conclusions: Perspectives described in this presentation will outline the benefits and challenges of offering a virtual learning opportunity designed to increase capacity and promote ethics champions within organizations. Recommendations to others undertaking similar capacity-building endeavours will be shared.

Embryo Transfer Without Intention of Pregnancy: Assisting Patients in Their Search for Symbolic Meaning

Olivia Schuman

Meaningful partnerships with patients includes giving considerable weight and taking seriously their preferences and values, even if they are atypical or not in alignment with the healthcare team. This is relevant is considering requests for an uncommon alternative to embryo disposition called Compassionate Transfer (CT).

Some context: More than one million embryos are frozen in storage in the USA. Patients with more embryos than they need for creating their family often have difficulty deciding how to dispose of their "potential children." Many feel undecided or unsatisfied with the available disposition options, which include donation to others or laboratory disposition. Consequently, an estimated 20% of patients simply keep their embryos frozen indefinitely.

Patients typically discover CT through word of mouth and internet sources. It is a procedure whereby in vitro-created embryos are thawed and transferred into the patient's body during an infertile window, resulting in the loss of the embryo. Although some physicians consider the procedure "a waste of time, money, and a farce" that produces the exact same end result as laboratory disposal, patients who request it report that the option feels more personal, natural or respectful than laboratory disposal.

Although CT was estimated to be offered in less than 5% of clinics in 2003, studies report that about 19% of fertility patients would be likely to elect this option. As awareness of this procedure grows, clinics will have to confront the question of whether to perform the procedure, and if so, whether to offer it as a standard option.

The objectives of this paper are to: Situate CT within a larger context of the medicalization of reproduction, where patients' own intuitions or preferences about their bodies are secondary to those of the medical team. Relate how patients' subjective understanding and sense of embodiment plays an important role in the ethical assessment of this procedure. Emphasize the partnership of the medical team in co-creation of the symbolic and performative meaning of CT. Explore how to assess requests for CT from patients without a uterus.

What a Culturally Competent Clinical Ethicist Should - and Should not - Do

Jan Schürmann, Susanne Schmidt, Manuel Trachsel

Background:

Language, cultural identity, values, or migration experiences of patients, family members and health care professionals have a significant impact on health care. In individual cases, this can lead to the perception of moral conflicts and thus to requests for clinical ethics support (CES) services.

Objectives:

To explore the role of clinical ethicists in moral conflicts related to the diverse cultural backgrounds of persons working in or using health care services, and to clarify how culturally competent CES should look like.

Methods/Analysis:

Based on a conceptual reflection on the relationship between culture and ethics and existing models of cultural engagement in CES, the aspects of culturally competent CES were analyzed.

Results:

Recommendations - dos and don'ts - for culturally competent dealing with moral conflicts are suggested in three areas: First, in the area of attitudes which includes awareness of one's own and others' cultural identity, reflection on behavior in the cultural context, humility about what one thinks one knows about cultural identity, avoiding cultural bias, respect for and appreciation of cultural identities, and a commitment to health equity. Second, in the area of the consultation process which includes advocating for professional linguistic or transcultural interpreters; showing and promoting respect for cultural identities; exploring cultural identities and values; performing a change of perspectives; promoting understanding of different cultural identities; analyzing the cultural aspects of the moral problem; respecting cultural values within the framework of patient will and quality of life; confronting unwarranted discrimination, stigma, and racism; promoting open dialogue about options for action and compromise; and defining and justifying the boundaries of the responsibility of professionals. Third, in quality management, the aim is to build networks with specific cooperation partners such as diversity management, interpreting services, and spiritual care, and to promote cultural competence in education and training.

Conclusions:

Clinical ethicists should be sensitive, reflective, empathetic, respectful, and fair in addressing culturally related misunderstandings, value differences, discrimination, or value conflicts - in other words, they should be culturally competent - and thus contribute to the resolution of culturally dependent moral issues in health care.

Inclusion of Rohingya Perspectives in the Healthcare Decision-Making Process in Bangladesh

Lisa Schwartz, Gillian Mulvale, Olive Wahoush, Puspita Hossain

Background:

Bangladesh is hosting approximately one million forcibly displaced Rohingya from Myanmar; however, it is not a signatory of the 1951 UN Convention on refugees and is not mandated to provide “refugee” status and associated rights to them. Settled in overcrowded camps, the Rohingya cannot access the national healthcare system without prior permission, and primary healthcare is only available through national and international NGOs with few options for transfer of care to the community. Decisions about healthcare priorities are mostly taken centrally by the government and humanitarian sector representatives. In this context, few opportunities exist for the Rohingya to participate in decision-making.

Objective:

To understand how the relative power of various interest groups influences the inclusion of Rohingya perspectives in the health policy and decision-making process.

Methods:

This study was set in Cox’s Bazar, Bangladesh and guided by Interpretive Description methods. We conducted 23 key informant interviews by purposively sampling individuals from government and non-government decision-makers, health administrators, program implementers, activists from the Rohingya diaspora, and researchers.

Analysis:

Alford’s structural interest framework, expressed through the political concepts of interest and power, was used to illustrate the interests of various actors regarding the healthcare decision-making process. We followed a concurrent data collection and analysis approach and identified deductive codes based on the theoretical framework, while inductive codes emerged from the data.

Results:

The emergent nature of the humanitarian response and program cycle design did not allow for an adequate level of engagement with the Rohingya, which compromised the inclusion of their perspectives. The government’s interest in not providing refugee rights while hosting the Rohingya and the humanitarian sector’s interest in being an ally to them and having more power in the decision-making process left little room to serve the interests of the Rohingya, who wanted to make independent choices regarding their healthcare.

Conclusion:

Due to the lack of political and organizational power, the interests of the Rohingya are not addressed in the decision-making process. Healthcare is one of the fundamental rights, and it is essential to identify approaches that include their perspectives to ensure their access to equitable healthcare services.

Leaps and Bounds: Advancing Ethics Review in AI Research

Anjana Sengar, Rebecca Greenberg

The application of Artificial Intelligence (AI) in healthcare is an emerging field with a plethora of ethical challenges. As with any new technology or practice, recognition of and management of ethical issues often lag behind the emerging field due to a lack of adaption of normative guidelines. As such, THP's REB recognized that there is a significant gap in REB reviewer AI foundational knowledge to perform comprehensive and appropriate ethics reviews. REB reviewers struggle with knowing which additional questions to ask, and which standard questions may or may not be applicable given the type of research being conducted (modelling versus staged clinical deployment).

THP's REB Chairs have endeavored to gain further knowledge about AI at large, and to develop a robust awareness of the types of ethical issues that can be encountered at all stages in the life cycle of AI research. Through engaging with AI researchers, other REBs and REB members and AI Ethics experts, THP's REB is in the process of developing an AI-specific checklist to guide our REB reviewers through the novel types of questions that can arise in AI research ethics. This process includes engaging and re-engaging with AI relevant parties to pilot the checklist and ensure that relevant ethical concerns are captured in AI research ethics reviews.

In this presentation, we will outline the steps taken to explore AI research ethics review, present key ethical considerations unique to AI research in healthcare and highlight the challenges we have encountered along the way.

Sepsis Policy: The Role of Patient and Families in the Policy Process

Fatima Sheikh, Victoria Chechulina, Alison Fox-Robichaud, Lisa Schwartz, Kali Barrett

Background: Sepsis accounts for 48.9 million cases and 11 million sepsis-related deaths worldwide. In 2013, New York passed "Rory's Regulations," requiring all hospitals to develop protocols for early identification and treatment of sepsis. Despite the reported improvement in sepsis mortality in New York and similar policies around the world, there are no similar sepsis policies in Canada. Here, we explore a distinguishing feature of Rory's Regulations, the impact of patients and families on the policy process, to understand how it led to the transformation of sepsis practices in the US and its relevance for Canada.

Objectives: (1) identify and describe the ideas, interests, institutions, and external factors that led to Rory's Regulations; and (2) describe a scoping review of sepsis policies, clinical practice guidelines, and health professional training standards.

Methods: To guide the analysis of Rory's Regulations, we conducted a retrospective document analysis using the "3I+E" framework. Relevant sources of information were identified through a literature search of academic databases; a review of publicly available policy documents and government websites; and a review of news media.

To analyze the current landscape of sepsis policies, we conducted a scoping review and environmental scan. Policies, guidelines, or training standards related to sepsis identification, management, and/or reporting, published since 2010, and available in English/French, were included. Individuals with lived sepsis experience were involved in all stages of the review.

Results: Although the interplay of institutions, interests and ideas contributed to the decision to enact Rory's regulations, the unexpected death of Rory Staunton facilitated the passage. Barriers to implementing similar policies include the failure to justify a policy response and lack of coordination with existing policies.

In the second phase of this initiative, we present data from the scoping review and environmental scan. Following systematic searches in five databases, 1329 sources of evidence were included in the first screening phase and 38 sources of evidence have been included in the final analysis.

Conclusions: Understanding what other countries have done to address sepsis, the role of patient and public involvement, lessons learned, and the current policy landscape in Canada is important to develop future policy.

The Role of Patient Advocates in Medical and Research Ethics

Christina Sisti

With the rise of patient advocate inclusion in medical and research trials, it is vital to elevate their role and expand the ethical considerations in all realms of health care. Patient advocates have experienced the effects of illness and, therefore, have a unique perspective on prospective research and clinical trials. The ethical responsibility of includ-

ing patients and caregivers in deciding the impact research or clinical trials will have is vital. Nevertheless, building on their role, the next step is elevating patient advocates to the position of educator and developer of curricula for medical and research students and professionals. A curriculum that fails to teach the patient perspective from the viewpoint of a patient or caregiver negates the ethical duty observed in grant review programs.

"Staff, Please Leave the Room:" Low-Intervention Birth Plans and Ethical Considerations

Kristina Smith, Kim Jameson, Julia Gill, David Migneault, Bethan Everett

In the past year at Vancouver Coastal Health Authority which operates in remote, rural and urban sites, there has been a notable increase in ethics consultation requests to support healthcare providers with patients' low-intervention birth plans. Low-intervention birth plans may include minimal medical interventions such as delivering a baby with little to no pain medication and/or fetal monitoring. Some healthcare team members report significant moral distress over how to uphold respecting the patient's choice for a low-intervention birth plan especially when complications arise that threaten the health and safety of both patient and fetus. This session will introduce a case scenario in which a patient is admitted to acute care in labour with a low-intervention birth plan including no oxytocin, no epidural, and minimal fetal monitoring. Over the course of the delivery, the patient requests only her birth attendant, who is not insured or licensed, to be in the room and for all other staff to leave. We explore the ethical considerations in this case, including duty of care to the mother and fetus, worldviews from a relational ethics perspective, risk of harm and ethical criteria to assess risk, informed consent and refusal, and moral distress and injury. We provide clinical and organization-level recommendations for healthcare teams and patients, with a specific focus on acute and community team collaboration that may best support low-intervention birth plans that align with patients' values.

Using Relational Ethics to Approach Equity in Palliative Care

Kristina Smith, Kelli Stajduhar

Evidence suggests that people experiencing inequities and who are highly marginalized (e.g., people impacted by racism, sexism, discrimination, stigma, mental illness, substance use issues, disability, and the effects of homelessness; also referred to as structurally vulnerable) often die alone, in pain, not receiving the care they need. Some research even points to highly marginalized people not feeling worthy of care. The need to consider equity in the context of palliative care has recently emerged but little attention has been paid to how ethical decision-making generally, and relational ethics, specifically, could provide guidance in the care of highly marginalized people who are on a palliative trajectory. Relational ethics offers a model of care and decision-making framework that emphasizes how clients, healthcare providers, and larger social structures are interwoven, and acknowledges that one's background and relationships influence their choices. Relational approaches in the context of palliative care for highly marginalized people has the potential to provide a lens to better support the delivery of equitable palliative care. This session will explore relational ethics as a way to approach equity in palliative care in order to support clients facing structural vulnerabilities. Clinical exemplars for how a relational ethics approach might be used to promote equitable access to palliative care will be explored, highlighting how such approaches have the potential to better align client wishes with their needs and to ensure decision-making and care delivery is trauma-informed, harm reduction focused, and culturally sensitive.

Modelling the Impact of Different Conceptions of Justice on Population Health Outcomes

Maxwell Smith, Brendan Smith, Christine Warren

Background and Objective: Health inequities are differences in health that are 'unjust.' Yet, despite competing ethical views about what counts as an 'unjust difference in health', theoretical insights from ethics have not been systematically integrated into epidemiological research. Using diabetes as an example, we explore the impact of adopting different ethical standards of health equity on population health outcomes.

Methods: We conducted a risk prediction modelling study using the nationally representative 2015-16 Canadian Community Health Survey (n = 75,044, 54% women). We used the Diabetes Population Risk Tool (DPoRT) to calculate individual-level 10-year diabetes risk. Hypothetical weight-loss interventions were modelled in individuals with overweight or obesity based on each ethical standard: 1) health sufficiency (reduce DPoRT risk below a high-risk threshold (16.5%); 2) health equality (equalize DPoRT risk to the low risk group (5%)); 3) social-health sufficiency (reduce DPoRT risk <16.5 in individuals with lower education); 4) social-health equality (equalize DPoRT risk to the level of individuals with high education). For each scenario, we calculated intervention impacts,

diabetes cases prevented or delayed, and relative and absolute educational inequities in diabetes.

Results: Overall, we estimated that achieving health sufficiency (i.e., all individuals below the diabetes risk threshold) was more feasible than achieving health equality (i.e., diabetes risk equalized for all individuals), requiring smaller initial investments and fewer interventions; however, fewer diabetes cases were prevented or delayed. Further, targeting only diabetes inequalities related to education reduced the target population size and number of interventions required, but consequently resulted in even fewer diabetes cases prevented or delayed.

Conclusions: Using diabetes as an example, we found that an explicit, ethically-informed definition of health equity is essential to guide population-level interventions that aim to reduce health inequities. This presentation will further explore how this methodology can help to enhance work on health equity in public health.

"Invincible Indecision:" Problematizing the Relationship Between Choice and Decisional Capacity

Joanna Smolenski

The requirement to obtain informed consent from patients has been a feature of medical care since approximately the 1950s, when the term "informed consent" first appeared in the seminal court decision of Salgo v. Leland Stanford Etc. Bd. Trustees. However, not all patients are permitted to provide such consent. Prior to asking a patient to consent to a given procedure, that patient's decisional capacity must be assessed, which is standardly taken to require the patient to be able to demonstrate understanding, appreciation, reasoning, and the communication of a choice with respect to a given medical intervention. For a physician to deny that a patient has decisional capacity is for them to deny that that person is able to provide legitimate informed consent to the intervention in question at a particular time. Because capacity is both time- and decision-dependent in this way, "it can vary with circumstance; for example, a patient can have the capacity to make small, straightforward decisions such as consenting to take a new medication, but may lack the capacity to consent to a high-risk abdominal surgery." As such, determining capacity is part of the task of a physician at the bedside, and will depend - at least in part - on the nature of the intervention that the patient is being asked to undergo.

In this paper, I will consider the question of capacity assessment, and ask if there are circumstances under which failing to meet one of the dominant criteria for decisional capacity - namely, the ability to communicate a choice - nevertheless fails to undermine a patient's decisional capacity. To do so, I will begin by introducing a case in which an otherwise apparently capable patient failed to communicate a choice regarding her treatment. I will argue that under certain circumstances like these, not communicating a choice could in fact be seen as more consistent with the remaining three criteria for decisional capacity, and better exemplifies appropriate understanding, appreciation, and reasoning than selecting between the available options. As such, patients who exhibit what I call "invincible indecision" may retain their decisional capacity while remaining undecided.

We Are What We Repeatedly Do: An Aristotelian Perspective on Clinical Ethics Consultation

Joanna Smolenski

While first introduced as a practice in the late 1960s and early 1970s at The Pennsylvania State University, the New Jersey College of Medicine (now the University of Medicine and Dentistry of New Jersey), and the University of Wisconsin, clinical ethics consultation has come to be a widespread practice in American hospitals, with ethics consultants found in 86.3% of all hospitals (and 100% of all hospitals with more than 400 beds). Despite its increasing pervasiveness, clinical ethics consultation is still a relatively nascent field that is defining itself in real time, and disagreement remains about what exactly the practice of consultation is, as well as who ought to be empowered to do it and under what circumstances. Contrary to other views that have been defended in the literature - notably, the "facilitation," the "moral expertise," and the "mediation" models - in this paper, I will argue that the best framework for viewing the work of a clinical ethics consultant is an Aristotelian model, which sees clinical ethics expertise emerge from the repeated practice of ethics consultation under the mentorship of an experienced, expert practitioner.

In order to make this argument, I will first provide an overview of the Aristotelian model, explaining Aristotle's notion of teleology and how it relates to his views on virtue. Once this background has been established, I will make the case for clinical ethics consultation to involve the type of expertise that can be inculcated in an analogous manner to Aristotle's proposal for the inculcation of virtue. In particular, I will focus on the importance of knowledge for virtue in Aristotle's account to help explain the uncovering or discovery element of clinical ethics work. This view, I suggest, best captures the flexibility of the expertise inherent in clinical ethics and helps make sense of the variety of disparate tasks that fall under the umbrella of "consultations" in ethics practice, both within

and across institutions.

Innovations in Clinical Ethics Support - Lessons Learned From Developing Ethics Support Tools

Margreet Stolper, Janine De Snoo-Trimp, Bert Molewijk

Well known types of ethics support to support healthcare professionals with their moral challenges are ethics consultants, ethics committees and moral case deliberations. Despite the advantages of these types, these forms also have specific disadvantages: they are often only case oriented, they require de participation of quite some participants (which is often difficult to organize), it may require quite some time, and the harvest of the case oriented support is often not transferred into more thematic forms of ethics support which might help other healthcare professionals when being confronted the same thematic focus.

Ethics support tools aim to provide practice-oriented and sometimes normative guidance when dealing with moral challenges related to a specific theme. They are tailored to a defined healthcare setting. They often contain conceptual, procedural and normative elements from earlier moral case deliberations and focus groups on the theme. In addition, insights from the literature can get inserted. Ethics support tools are designed for low-threshold availability and independent and easy use, individually or in teams (often without the help of ethics support staff).

We have developed several thematic ethics support tools in the last years and see the value of this for those working in practice. Yet, we also experienced challenges and encountered difficulties when working on these projects. We would like to present: 1) reasons for developing ethics support tools, 2) our specific approach to developing ethics support tools, and 3) presenting some examples of different kinds of ethics support tools, and 4) the lessons learned, including facilitators and barriers.

Gender-Affirming Care for Transgender Individuals: A Scoping Review of Ethical Considerations

Shilpa Surendran, Michael Charles Dunn, Hui Jin Toh, Chuan De Foo, Teck Chuan Voo

Background: Gender-affirming care for transgender individuals raises various ethical issues for healthcare providers. A review of these ethical issues yet to be published can be useful as reference work for healthcare providers, policymakers, and ethicists working in this emerging area of healthcare.

Objective: To identify the main ethical issues and review arguments related to gender-affirming care management of transgender individuals.

Methods and analysis: We conducted a scoping review of normative and empirical literature in January 2023 using a single database. The search yielded 1271 publications. After removing duplicates and initial screening, 311 publications underwent full-text review and were analysed inductively guided by the Qualitative Analysis Guide of Leuven.

Results: A total of 70 publications were included. A majority (72%) of the included publications were published in 2019 or later. These publications had a limited geographical focus, with 36 and 17 originating from USA and UK respectively, 5 from Australia, 6 from Canada, and none from Asia. A majority of the publications (65%) were centred on transgender minors, while the rest addressed issues related to all transgender patients. Five ethical issues were identified: involvement of minors in giving consent for gender-affirming care, parental involvement in decision-making, models of gender-affirming care and care management, access to fertility preservation, and funding provision for gender-affirming care. The arguments deployed to defend positions in favour or against the issues drew mostly on the principles of autonomy, beneficence and non-maleficence.

While justice and welfarist-based arguments were somewhat less prominent, they gained parity with arguments based on autonomy, beneficence and non-maleficence when addressing issues related to models of gender-affirming care and care management, and access to fertility preservation. Analogous reasoning was frequently employed to bolster various arguments.

Conclusions: The identified publications present a well-rounded perspective, with support and opposition to ethical issues largely focused on decisions around gender-affirming care for transgender minors. Yet, when using the same ethical principles, the polarity of these arguments implies that a principle-based approach must treat relevant principles with nuance, relying less on analogous reasoning. There is also scarcity of empirical evidence presented to justify the deployment of beneficence and non-maleficence-based arguments.

Gene Editing and Responsibility for Poor (Genetic) Health

Ryan Tonkens

Sickle cell anemia has been successfully treated in clinical research in the U.S., and has now been approved by UK's Medicines and Healthcare Products Regulatory Agency for this purpose. It is reasonable to suggest that other monogenetic diseases will be treatable by the use of gene editing in the future.

Based on the information about public opinion on the use of therapeutic gene editing, it is fair to assume that some people who have access to gene editing will nevertheless choose not to use it, even for therapeutic purposes.

Here we evaluate the Genetic Responsibility Argument: the view that people who choose not to use safe, effective and affordable therapeutic gene editing can justifiably be given a lower priority in access to health care resources (e.g. alternative, less effective treatments for sickle cell anemia), or charged higher fees, because they are "responsible for" their own medical need, because of their refusal to use gene editing.

We argue that the Genetic Responsibility Argument needs to be taken seriously: (1) Many bioethicists endorse a version of this view in related contexts, such as people causing their own end stage liver disease; (2) the use of therapeutic gene editing technology could be seen as a "golden opportunity" to improve one's health, and choices to forgo such "golden opportunities" may be met with disdain; (3) part of the allure of therapeutic gene editing is the hope that it will help decrease disease burden and thereby reduce health care costs, thus mitigating ongoing issues with stretched health care systems—people who choose not to use this technology thereby fuel the problem.

We consider two potential responses to the Genetic Responsibility Argument, namely that people have the right to refuse medical treatment, and that "liberal eugenics" requires that people's decisions about the use of gene editing be free from undue pressure. Ultimately, we conclude that the plausibility of these responses is likely to be contentious, and that there is need for further research, and urgent review of key policies (e.g. Canada's Genetic non-Discrimination Act).

Examining the Ethics of Communicating AI-Predicted Risk to Patients and Clinicians

Emma Tumilty, Avery Koi, Amy D. Waterman

Artificial intelligence/machine learning (AI/ML) can be applied to the analysis of big data to identify characteristics of patients at higher risk of having poorer health outcomes before the poor outcome occurs. For example, in Texas, AI/ML analysis was used to develop indices from electronic medical record (EMR) data to predict kidney patients' level of risk of never beginning transplant evaluation, becoming wait-listed for transplant, and becoming ineligible for transplant due to illness progression. Populations more likely to fall into medium and high levels of risk for "drop-out" include marginalized populations and those managing greater social determinants of health (SDOH).

With this new knowledge available, health systems are putting support services in place to impact the trajectory of patients' experience to enable more patients to get waitlisted and receive transplants. However, questions arise about the potential impact of patients and their transplant clinicians knowing the level of expected risk ahead of time. There are risks of compounding inequities when data models can predict which groups of patients are less likely to succeed in situations where transplantable kidneys are scarce. It is also unclear how patients might react to receiving information about their likelihood of success and drop-out risk early when their issues relate to factors beyond their control. Finally, it is also unclear how to present a group-derived risk index to an individual patient to ensure informed decision-making.

We provide an overview of ethical issues in communicating risks to clinicians and patients in this setting. We make recommendations that address individual and system-based responsibilities as well as potential safeguards that could be considered to reinforce both. We also use Luna's conception of "cascading vulnerabilities" to discuss how to think about communication with patients.

When applied justly, AI-supported risk prediction has the potential to help health systems intervene early to reduce drop-out and improve health outcomes for all patients. Since communicating risks of this kind can also lead to the possibility of compounded harms and inequities, careful ethical consideration when applying these indices to actual patient decision-making is needed.

Moral Distress in Post-Pandemic Paediatric Health Care Communities: Sequelae and Strategies

Lucy Turner (Bower), Randi Zlotnik Shaul

In the post-pandemic period, sequelae of moral distress make it an essential consideration for health care professionals (HCPs) whose communities are fractured. Moral distress is the psychological distress which occurs when one is forced by external constraints to witness or take part in an action that threatens personal integrity and compromises moral beliefs. When experienced repeatedly, the negative effects of moral distress have significant ramifications including burnout, emotional exhaustion and increased intention to leave practice.

Prior to the COVID-19 pandemic, moral distress was reportedly higher in paediatric settings. The pandemic created a perfect storm for moral distress and factors unique to paediatrics such as prioritization of adult populations, restrictive family presence policies and patient and family isolation led to rapidly rising moral distress amongst paediatric communities, such as Toronto's Hospital for Sick Children (SickKids). Patients at SickKids often require multi-disciplinary care; HCPs must work together to forge meaningful partnerships with patient and family communities through child and family-centred shared decision-making. However, sequelae of moral distress such as depersonalization and empathy fatigue threaten effective engagement with colleagues, patients and families.

Popular messaging around resilience places too much accountability on HCPs who feel they have failed by experiencing moral distress. We propose that the response to moral distress should shift the focus from individuals towards community accountability and supported interdependence. The Mental Health Commission of Canada's 2022 survey highlights the importance of building strong health-care communities, reporting that unhealthy, unsupportive team environments act as a barrier to protection from moral distress. Ethics consultations and debriefs which enhance ethical competence and communication facilitate protection against moral distress.

We will describe existing ethics resources at SickKids such as moral distress debriefs, Health and Wellbeing strategies developed in consultation with the Bioethics Department and Care and Reflective Ethics Dialogue (CARED) in which bioethicists provide informal support at the bedside as part of an effort to embed ethics support within hospital communities. We will identify the barriers staff face in accessing support and discuss how these could be approached to optimize interventions. We conclude our presentation by discussing future strategies to mitigate moral distress at SickKids.

Loss of Decision-Making Capacity and Access to MAiD: Paradoxes and Challenges

Caroline Variath, Elizabeth Peter, Dianne Godkin, Lisa Cranley

Background:

Under Bill C-14, numerous individuals initially deemed eligible for medical assistance in dying (MAiD) were unable to receive MAiD following a loss of decision-making capacity due to the final consent requirement. The introduction of the waiver of final consent amendment (Bill C-7) to MAiD legislation in 2021 aimed to enhance access to MAiD for those vulnerable to capacity loss after being deemed eligible. Our study explored the experiences of healthcare providers with eligible patients' loss of decision-making capacity and subsequent ineligibility for MAiD, as well as their perspectives on using the waiver of the final consent amendment to provide MAiD.

The objective of this presentation is to highlight several paradoxes and challenges in the experiences and perspectives of healthcare providers in the context of MAiD for eligible patients who are at risk for or have lost decision-making capacity.

Methodology:

This study received ethics approval from the University of Toronto Research Ethics Board. Employing critical qualitative research, we conducted semi-structured interviews with 30 participants, including physicians, nurses, nurse practitioners, and social workers, representing various healthcare settings across Canada. These participants shared their experiences with patients losing capacity and subsequent ineligibility for MAiD. A voice-centred relational approach, guided by a feminist ethics theoretical lens that focused on power, relationality, and moral agency, was used for data analysis.

Findings:

Our study shed light on socio-political factors that influenced access to and experiences with MAiD. We identified four main paradoxes within the MAiD context: 1) the expansion of MAiD legislation without addressing socio-political barriers to patients' access to MAiD; 2) perceptions of power overshadowing the vulnerabilities and challenges experienced by MAiD team members, 3) the impact of opposition from some palliative care stakeholders on the seamless access to both palliative care and MAiD; and 4) using a patient-centred approach while inadequately

understanding the influence and meeting the needs of family members.

The findings carry significant implications that address practice and access-related issues as well as further legislative expansions. Our findings may enhance experiences with MAiD and contribute to the overall quality of end-of-life experiences for patients, family members, and healthcare providers.

What Can Ethics Do When Resources Are Chronically Scarce? Reflections From a Paediatric Hospital

Kayla Wiebe, Roxanne Kirsch, Randi Zlotnik Shaul

As we emerge globally from the absolute resource scarcity brought on by the pandemic, it has become clear that we - healthcare systems, practitioners, and partners - need to approach questions regarding the allocation of everyday healthcare services in ordinary degrees of resource constraint with ethical rigour and sustained attention that we gave to triage during the pandemic. One striking, local example, are the paediatric surgical waitlists in Canada. In Ontario alone, the waitlists have reached nearly 12 thousand, with children waiting longer than adults for many vital surgeries, and two thirds waiting past their designated clinically safe window of time. Delays in paediatric surgery mean missing developmental milestones, increased invasiveness in surgical intervention, and can pose permanent disruptions to quality of life and functionality.

In this presentation, we explore this example of 'normal' resource constraint and raise the question: what is the appropriate role of ethics work in these contexts? We present the results from a comparative analysis we (the authors) conducted in early 2023, where we surveyed several ethics frameworks and guidelines to support surgical prioritization in Canadian paediatric hospitals. Notably, we found consensus on key ethics principles: relevance, transparency, inclusivity, equity, non-maleficence, and prima facie prioritizing of clinical urgency.

While this was encouraging, a further troubling point of consensus emerged through our analysis and discussion: when the norm is that resources are chronically scarce, and clinical urgency is prioritized above all other factors, 'elective' (scheduled) cases cannot be completed. This results in countless patients for whom surgery is certainly not 'optional,' but who will not die without it, left languishing on the waitlist. Can ethical prioritization (via frameworks or guidelines) realistically resolve this problem? What can ethics offer when the problem just is that prioritization must occur within a context of devastatingly insufficient resources?

We present a case study to illustrate this problem, and conclude by suggesting roles for ethics work, such as advocacy, problematizing the status quo of urgency-first prioritization, and collaboration with paediatric health partners, the public, and family advisors, to generate solutions.

Ethical Advocacy: Confronting Racism With Bioethics

Rianne Williams

Bioethics is rapidly advancing to support decision-making and ensure that practices are performed to benefit society as a whole. Though this section of interdisciplinary studies is rather young, it provides a unique perspective and opportunity to advocate for historically underrepresented and marginalized groups. Whether this be in education and medicine to law and politics, the bioethical lens can be used to evaluate shortcomings in a specific manner and propose solutions that should benefit all persons.

In the past, Bioethics has had a strong emphasis within a multitude of areas on how an ethical lens can be used to navigate complex situations. Taking things a step further, this poster will explore how bioethicists can and should utilize their expertise for advocacy, specifically when it comes to racism.

An introduction to how racism perpetuates safety and public health concerns within the African-American community will be reviewed to identify the problem. Then, the case that some of society's most challenging ethical and moral dilemmas directly impact the health and welfare of its most vulnerable individuals can be made. To further explain this reasoning, an ethical, empirical, and philosophical analysis will take place to examine how this fits into the scope of a bioethicist's practice. Finally, the steps that can be taken moving forward to navigate advocacy in the field will be discussed. Specifically, advocacy can be implemented through outreach strategies and training implementations while acknowledging the limitations at hand. This poster will aim to explore the detriments that racism poses to the African-American community and how bioethicists have the ability, and moral obligation, to mitigate these impacts.

Applying a Stoic Compatibilist Theory of Responsibility in the Context of Addiction Treatment

Maxwell Wiltzer

The two traditional models of addiction - as either a moral failing or neurobiological disease - and their corresponding attributions of total responsibility or lack thereof on the part of addicts, have faced criticism in recent years. The former model holds addicts fully responsible while failing to appreciate addiction as a uniquely challenging disorder resulting from particular human biological, neurological, environmental, economic, and social vulnerabilities. Meanwhile, the latter, which medicalizes addiction, risks disempowering addicts in their own recovery by discounting their responsible agency. Maintaining addicts' sense of responsibility has proven to aid recovery.

In response, hybrid approaches to addict responsibility, which attempt both to maintain addicts' sense of responsibility and also foster a degree of moral leniency or compassion, have emerged. Hanna Pickard's "Responsibility Without Blame" approach, which advocates holding addicts accountable for their behaviour and employing "detached" rather than "affective" blame is one example. These approaches capitalize on the recovery benefits of preserving addicts' sense of responsibility, while avoiding the detrimental effects of blame on recovery. However, to justify this framing of addict responsibility, these approaches often have readers either adopt unintuitive beliefs about the nature of blame or buy into controversial models of addiction. This is not ideal, especially since the success of such approaches hinges on the ability and likelihood of addiction treatment professionals digesting and buying into them, so they can be put into practice.

In this presentation, I will argue in favour of a novel hybrid approach to addict responsibility. My proposal will suggest that we apply a different theory of responsibility to addicts, inspired by Stoicism. Rather than viewing addicts as operating in the same responsible reality as non-addicts, I argue that, for the sake of addiction treatment, we view addict responsibility through a compatibilist lens, which more appropriately reflects the nature of addiction. With this approach, blame would have no serious or intuitive role to play in assessments of responsibility, and treatment specialists would continue to value and respect addicts' status as moral agents and meaningful partners in their own recovery: a win-win for addiction treatment.

Between Politico-Institutional Constraints and Medical Needs: The Definition of Emergency for Seriously Ill Asylum Seekers Without Health Insurance in Switzerland

Kristina Würth, Daniela Ritzenthaler, Rachel Rutz Voumard, Ralf J. Jox

Of the 23.9 million people who fled their home countries at the end of 2018, around a third (7.7 million people) came to Europe. With the creation of the Schengen area with its open internal borders, Europe established a common security policy to tighten the EU's external borders and created a common European asylum system (CEAS). To date, this has determined that the asylum procedure must be carried out in the European country that the refugee first entered and where health insurance is consequently also provided. However, European countries are highly diverse and have different political, economic, and social profiles, which is also reflected in the healthcare system. For asylum seekers, depending on the host country, this can result in barriers to accessing healthcare services (e.g., due to language barriers, lack of support, discrimination), which in cases of serious illness can have a drastic impact on prognosis, life expectancy and quality of life. While EU residents are also entitled to medical care in other EU countries, this option is only if the illness is unexpected and requires emergency treatment before their return. Against this background, we present an exemplary case at a Swiss university hospital in which an asylum seeker hosted in Italy, who is highly vulnerable (for reasons including his young age, language barriers, traumatization, a potentially lethal illness, lack of social networks and homelessness), stays in Switzerland and is admitted to the emergency ward due to acute complaints related to cancer. While the definition of an "emergency" permits immediate treatment acute symptoms (e.g., pain), a medically indicated cancer treatment was not provided as it did not fulfil the definition of emergency treatment. The patient is informed that he must return to Italy for oncological treatment, which he initially refuses, mentioning access difficulties (e.g., linked to the language barrier). After several months of not receiving cancer treatment, he consents to return to Italy. One year later, the patient comes back, without having been treated, with a grown tumor, severe pain and suffering from mental exhaustion. The case will be analyzed from the perspective of healthcare ethics and political ethics.

Inclusive Family Care: Tending to Ethical Tensions Around Family Treatment in Pediatric Mental Health

Daniel Wyzynski

This presentation examines ethical challenges surrounding parental treatment in paediatric mental health settings,

utilizing case-based discussions to illuminate ethical tensions around inclusive family-centered care. The presentation will focus on the SPACE and Circle of Security interventions, which are designed to address child/youth mental health symptoms through modifying parental behavior. The primary ethical inquiry centers on how to facilitate parental treatment in acute care pediatric mental health settings. Elements explored will include consent, confidentiality, privacy, treatment documentation, and hospital admission from both a clinical and organizational ethics lens.

A pivotal dilemma emerges regarding the implications on consent for treatment when interventions target a caregiver, but outcomes are measured on a child. The presentation explores arguments for when (if at all) a child's consent for such interventions is necessary. This presentation will argue that, when feasible, a child's autonomy ought to be respected through a meaningful consent process. However, scenarios will also be considered where parental treatment may be conducted independently without providers disclosing the child's PHI, challenging the absolute need for the child's consent.

This presentation delves into broader policy implications of independent parental treatment in hospital settings, bringing attention to treatment documentation and consent requirements. The appropriateness of hospital admission becomes uncertain when caregivers seek treatment for themselves based on their child's acute mental health needs. A counterargument suggests that, in specific cases, parental treatment may proceed without the child's consent, emphasizing therapeutic intent to support the family unit.

Highlighting challenges in policy and legislation, the presentation advocates for breaking down silos in mental healthcare settings to facilitate holistic family-centered treatment options. Within existing legislation and system limitations, ethical justification for parental treatment without the child's consent may be sufficiently supported under specific conditions, but systemic change is needed to adequately meet the mental health needs of our population.

"I Wanted to Do This Research so I Could Offer Something to Patients:" Moral Experiences of Health and Research Personnel Involved in COVID Research During the First Wave of the Pandemic

Rachel Yantzi, Matthew Hunt, Sandra Moll, Olive Wahoush, Takhliq Amir, Eliza Yadav, Lisa Schwartz

Background:

Research has a critical role during emerging pathogen pandemics such as COVID-19, yet clinical care and public health priorities may be in tension with research priorities, creating moral distress among researchers and clinicians.

Objective:

The study aim was to understand the moral experience of health and research personnel with the production and utilization of COVID-19 evidence during the first wave of the pandemic.

Methods & Analysis:

This qualitative study was guided by Interpretive Description methodology. Between May and September 2020, we conducted 26 semi-structured online interviews with healthcare professionals, investigators, research staff, and a medical professional practice leader based in Canada (20), United States (2), South Asia (1), and Europe (3). Interviews were audio-recorded, transcribed, and inductively coded using NVivo software.

Results:

Five themes emerged from our analysis that characterize participants' moral experiences of COVID research: 1) striving for evidence-based practice in the absence of evidence, 2) struggling to balance speed, rigour, and ethical standards, 3) advocating for patients in the rush to develop COVID evidence, 4) bearing the burdens and risks of conducting COVID research, and 5) feeling part of something bigger.

For many participants, research was seen as something they could offer their patients as they grappled with the lack of evidence to guide practice early in the pandemic. Given the perceived moral significance of research, participants experienced tension between the need to build evidence quickly while respecting methodological and ethical research principles and regulations. Participants were concerned about the well-being of patients and families invited to participate in COVID research given the fear surrounding COVID and the absence of family members in clinical departments, as well as the burdens placed on clinical staff in COVID departments. Despite the complexities of conducting research during COVID, many participants saw research as a way they could contribute to the pandemic response.

If I Wasn't the Researcher, I Could Have Been a Participant: Reflections on Conducting Ethnographic Research During a Protracted Humanitarian Crisis

Rachel Yantzi, Md Hadiuzzaman, Kathryn Richardson, Sakib Burza, Lisa Schwartz

Background:

Palliative care is increasingly recognized as an important component of comprehensive humanitarian healthcare, yet humanitarian organizations continue to face obstacles to its integration. In 2021, Médecins Sans Frontières (MSF) undertook an ethnographic study to understand the moral experiences of staff involved in providing palliative and end of life care in the Rohingya refugee camps in Cox's Bazar, Bangladesh. Within MSF, ethnographic research plays an important role in developing contextually responsive interventions but is typically performed by dedicated anthropologists. In contrast, the lead researcher for this study occupied multiple roles including researcher, nurse, and palliative care program implementer.

Objective:

The aim of this presentation is to explore how the ethnographer's social location, roles, and relationship to the research topic impacted the research process, and the ethical implications of this research approach.

Methods & Analysis:

The main study was a focused ethnography, conducted between March-August 2021 at Goyalmara Mother-Child Hospital. Data collection involved participant-observation, individual interviews (22), focus group discussions (5), and analysis of guidelines and other documents. This sub-analysis was inspired by auto-ethnographic methods and involved emotion-focused coding, reflective memo writing, and analytic discussion with co-authors.

Results:

As an international staff nurse, researcher, and palliative care program lead, I was simultaneously insider and outsider to the study context. I sought to understand the staff's conceptualizations and experiences of palliative care, while at the same time I played an important role in informing their conceptualizations and experiences. Moving between emic and etic perspectives provided a valuable analytic tool to understand certain findings such as the contested role of protocols and guidelines in palliative care related decision-making. Simultaneously, multiple roles and layered power differences increased the ethical complexity of the study and required frequent exploration with co-authors with different positionalities.

Conclusion:

Research conducted by individuals who occupy multiple roles may be necessary or beneficial in humanitarian contexts; however, important ethical tensions must be considered. It is critical that ethnographers engage in frequent reflection and discussion with differently positioned collaborators so that multiple roles become a valuable analytic tool rather than a source of bias.

Who Should be Responsible for Finding a Surrogate for Incarcerated Patients?

Xiang Yu, Pierce Randall

Hospitals have an obligation to make reasonable efforts to find a surrogate for each patient if the patient is determined to lack decision-making capacity. However, for concerns about safety and security, hospitals that serve correctional facilities sometimes enter into agreements with those facilities that the hospital shall refrain from contacting the patient's family or friends and that it is instead the responsibility of the correctional facility to find a surrogate for the patient. In this presentation, we describe ethical challenges that arise from such agreements, based on the experience of one hospital in New York State with such a policy.

First, such agreements violate a hospital's obligation to look for a surrogate for each patient who lacks capacity, regardless of their incarcerated status. Second, correctional facilities' interest in doing what's best for the facility may interfere with the obligation to find a surrogate. For example, a potential surrogate may be expected to choose to forgo life-sustaining treatment on behalf of a patient, while it may be in the best interest of the facility to keep the patient alive to avoid the appearance that the patient was harmed or killed at the facility. In a scenario like this, the correctional facility may have an incentive to limit their efforts in finding that surrogate and may instead prefer medical decisions be made by physicians or a guardian, even though the surrogate is the person who knows the patient best.

We propose that it should be the responsibility of hospitals rather than prisons to contact potential surrogates of an incarcerated patient. This is because incarcerated patients should be treated as patients when they are in the hospi-

tal and are entitled to the same quality of care that is provided to any other patients in the hospital. However, it is reasonable for prisons to request that non-medical information (e.g., the patient's location) not be shared with surrogates and that individuals implicated in past criminal behavior not be contacted. Accommodating these requests is fully compatible with the hospitals' obligation to locate a surrogate for any patient who needs one regardless of their incarcerated status.

The History of Bioethics at The Hospital for Sick Children (SickKids): A Story of Service, Collaboration, Leadership and Adaptation

Randi Zlotnik Shaul, Zoe Ritchie

Among the many academic disciplines that contribute to bioethics, including philosophy, theology, law, sociology, and anthropology, some scholars have articulated that one remains conspicuously absent- history. Our presentation will discuss and report the findings of a research project aimed at recounting the history of bioethics activities at SickKids as its staff and colleagues navigated the place and purpose of bioethics within the institution from 1970-2023. Our project involved empirical historical description utilizing a wealth of primary and secondary sources to elucidate how the hospitals' ethics culture and activities evolved in tandem with significant trends in paediatric bioethics. We will have several primary sources we used in our analysis on hand for attendees to view and inquire how each contributed value to the project. In our presentation of results, we will focus on critical points of change and organizational adaptation we were able to discern in our project. These include the move from an ethics committee approach to the introduction of a Bioethics Department in 1991, discourse spurred from the Olivieri debacle in the late 90s, and the introduction of the Clinical Bioethics Associate role in 2010. We will engage attendees with highly contemporary issues in the field of paediatric bioethics our historical inquiry spurs novel re-engagement with including (1) the practical and theoretical implications for a bioethics department embedded within a healthcare institution, (2) the culture of practicing ethics in a pediatric hospital, and (3) the value in understanding how ethics capacity evolves within an organizational context. As the field of bioethics continues to move towards a form of professionalization, understanding the field's development is critical to understanding where it is headed. Institutional memories and culture are often passed down from person to person, as was the case at SickKids before we embarked on this project. Our presentation will offer an open, collaborative space for attendees to learn from our experience undertaking a historical inquiry into practices at SickKids allowing space for them to consider the utility of a historical inquiry into the ethics practice at their respective healthcare organizations.

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