Compulsory isolation for tuberculosis: Are patient's rights sufficiently protected? A comparison of the law and its applications in England, the Netherlands and South Africa.

Marleen Bakker[1]
[1]*Erasmus MC, Rotterdam, the Netherlands, , Netherlands*

Biography:
Dr. Marleen Bakker is trained as a pulmonologist after a PhD on lung cancer research, and has been working as a staff member at the department of Pulmonary Diseases of the Erasmus Medical Center, Rotterdam, the Netherlands since 2002. Since 2004 that department started a cooperation with the department of Pulmonary Diseases of Groote Schuur Hospital, Cape Town, and since 2014 with the department of Pulmonary Diseases of Tygerberg Hospital, Cape Town. She specialized in infectious diseases with special interest in cystic fibrosis and tuberculosis. In the field of tuberculosis she works together with the Public Health Clinic Rotterdam. She participates in tuberculosis teaching programs for pulmonologists, fellows and public health doctors. She finished her Master in Bioethics and Medical Law in London, UK, in 2019 with the thesis "Compulsory isolation for tuberculosis: Are patient's rights sufficiently protected? A comparison of the law and its applications in England, the Netherlands and South Africa".

Introduction: Forced isolation for infectious tuberculosis is a threat to the basic human right of freedom. Public Health Laws should therefore carefully weigh the rights of the public to the rights of the patients. The Siracusa principles underlying the laws are: the threat to the public is serious, caused by a disease mentioned in the law and cannot be averted in any other way; the patient does not agree to any voluntary action. Application of the law has to fulfil criteria of proportionality, subsidiarity and effectivity.
Methods: This study compares the English, Dutch and South African law on forced isolation, its application and confinement through law text, case law, interviews and literature search.
Results: England and the Netherlands are low incidence, high income countries with (very) limited numbers of resistant tuberculosis. Of the three countries, the Dutch public health law (applied 3 times a year) poses the biggest threat to the rights of the patients as there is an unlimited length of the order, no clarity on the grounds for abrogation, no right of appeal and no central notification. In England (6 forced isolations/year) only the extension to non-infectiousness can be considered a threat to patient's rights. South Africa has a very high tuberculosis incidence, including high numbers of multi- and extremely drug resistant tuberculosis, in a resource-poor setting. The public health law (2017) is well aligned to human rights, but does not seem to be used in a TB epidemic where criteria of proportionality, subsidiarity, and effectivity cannot be met. Confinement of the Dutch law allows for criminalisation of patients, and for catastrophic costs through high fines in both England and the Netherlands.
Conclusion: From the 3 countries, the Dutch law poses the biggest threat to human rights and needs to be urgently aligned with human rights.

Sharing Health Data for Precision Medicine: An Exploration of Ethical Concerns in Singapore

Angela Ballantyne[1], Ing Wei Khor[1], Dr Tamra Lysaght[1], Serene Ong[1], Owen Schaefer[1], E-Shyong Tai[2], Vicki Xafis[1]

[1]National University of Singapore, , Singapore, [2]National University of Singapore & National University Hospital, , Singapore

Biography:

Associate Professor Ballantyne's research interests include exploitation, research ethics, the ethics of pregnancy and reproductive technologies, and secondary use research with clinical data. She has worked in schools of Medicine, Primary Health Care and Philosophy in New Zealand, Australia, England and the United States; and as the Technical Officer for Genetics and Ethics at the World Health Organization in Geneva. In 2018 and 2008 she was a Visiting Scholar at the Yale University Interdisciplinary Center for Bioethics. She was President of the International Association of Bioethics (2016-2017).

Introduction: Precision Medicine (PM) offers the promise of improving clinical care by tailoring disease treatment and prevention to individual patient factors such as genetics, lifestyle, and environment. PM requires many patients to share biological samples and de-identified health information. Both national governments and international consortia recognise the pressing need to articulate norms for responsible clinical data sharing to encourage patient participation. Singapore is a noteworthy case study in integrated data.

Methods: We conducted 10 focus groups (ranging from 6-10 participants) in Singapore (May-June 2019) exploring ethical concerns over participating in a hypothetical PM programme and identifying potential governance strategies. We used thematic analysis.

Results: Singaporeans: (i) want to maintain some control over the storage, use and sharing of data and samples; (ii) draw on previous high-profile data breaches in assessing the risks of participating in PM; and (iii) expect anticipated personal and public health benefits to offset the perceived risks of participating in PM. Participants were more inclined to trust certain government agencies to secure the data and ensure it is shared responsibly; more so than the private sector (with particular concern noted about access by health insurance providers).

Discussion: Results were consistent with prior research (in other jurisdictions) showing that some patients will participate in PM without the need to re-consent each time the data or samples are accessed. Successful development of PM will need to address the legacy of data breaches and Singaporean's complex trust relations with the government.

Conclusion: Understanding what oversight mechanisms might affect participation in PM can assist with the design of trustworthy governance systems. Ethical decision-making frameworks for PM must draw on traditional ethics principles such as privacy, confidentiality and consent; whilst also expanding the boundaries of clinical ethics to engage new concepts such as responsible governance, patient and public trust, and social licence

Perceptions of ethical decision making in relation to participation/non participation in ethics case reflection rounds among healthcare professionals caring for children with cancer

Cecilia Bartholdson[1], Margareta Sandeberg[1], Bert Molewijk[2], Associate Professor Pernilla Pergert[1]
[1]Karolinska Institutet, , Sweden, [2]VU University Medical Center Amsterdam, , Netherlands

Biography:
Cecilia Bartholdson is a paedaitric nurse specialist and a clinical researcher. Her thesis (2015) was about clinical ethics in childhood oncology and her research has since then involved studies about the ethical climate, moral distress and how ethics case reflection rounds impact paediatric oncology care. She has been a visiting postdoc at VU medical centre in Amsterdam and is now a visiting researcher at the same institution. Furhtermore she is the head-supervisor of a Phd-student who is doing her doctoral studies regarding a moral compass in paedaitric oncology. Her closest collaborators are Dr. Pernilla Pergert, Dr. Margareta af Sandeberg and Dr. Bert Molewijk.

Introduction. Paediatric oncology difficult ethical decisions are made in daily practice. During organised/spontaneous ethics case reflection (ECR) rounds the healthcare team can deal with ethical issues. However, the ECR rounds are usually not formal decision making forums. The overall aim of this study was to describe perceptions of decision making in relation to participation/non participation in ECR rounds among healthcare professionals (HCPs) caring for children with cancer.

Methods. HCPs, including medical doctors (MD), registered nurses (RN) and nursing assistants (NA) at three units at a University Hospital in Sweden, were invited to answer a study-specific questionnaire. Questions concerned ethical decision-making in relation to a specific patient case in three different scenarios: A) Being present in the ECR round, B) Not being present, C) No ECR round was conducted. In each case/scenario, HCPs rated perceptions on the following items: 1) involvement, 2) possibility to influence, 3) formal responsibility, 4) shared responsibility, 5) understanding of the ethical issue/decision.

Results. All, except item 5, were scored significantly higher when HCPs (N=89) participated in the ECR round. HCPs' perception of involvement in decisions, possibility to influence and responsibility decreased when they were not present during the ECR round and when no ECR round was conducted. HCPs' understanding of the ethical issue/decision was in general high regardless of being present in the ECR round or not. Even if participants were not present in the performed ECR round, the understanding of the decision was higher than if no ECR round was conducted.

Discussion/ Conclusion. As the research has demonstrated participation in ECR rounds, compared to non-participation, results in perceptions of greater possibilities to be involved, to influence and to have formal/shared responsibility for ethical decisions in patient care. Thus, performing and participating in ECR rounds will most likely improve teamwork and ultimately the quality of care.

Freedom from "Want" in Clinical Ethics: Challenging American Values of Choice and Desire

Virginia Bartlett[1], Andy Kondrat[1]
[1]*Center for Healthcare Ethics, Cedars-Sinai Medical Center, , United States*

Biography:
Virginia L. Bartlett, Ph.D., is the Assistant Director of the Center for Healthcare Ethics and Associate Professor in Biomedical Sciences at Cedars-Sinai Medical Center, Los Angeles, California (USA). She serves as a clinical ethics consultant, provides ethics education across the medical center and community, serves on institutional, local, and national boards and task forces, and researches the practices and contexts of clinical ethics consultation. Her current scholarly projects include interdisciplinary ethics education, ethical challenges in caring for unrepresented patients, and responsibility in clinical ethics consultation practice.

Due to ways unarticulated theoretical frames underlying any use of language often unconsciously shape how people think and make evaluations, and subsequently how they engage with others, the language people use matters. This may be especially true in ethics consultation work, where everyday and technical languages often become enmeshed – or even entangled. Ethics consultants may unintentionally use less-than-helpful language – especially if they have not probed or challenged the theoretical frames underlying taken-for-granted word choices – which may then ultimately lead to more contention among consultation participants, not less.

To illustrate this challenge, our presentation explores one simple, yet problematic, example: the everyday language of "want" and ways its use (especially by healthcare professionals, including ethics consultants) exacerbate rather than ameliorate the moral challenges of healthcare decision-making. We argue that asking "what patients want" is the wrong frame for ethics consultations, and that the language of "want" – with its deeply American foundation of individual choice and desire – is nonsensical in the context of healthcare decisions. No patient wants to be in the hospital, actually wants to undergo any medical interventions, or even wants to see healthcare providers. Every patient is, however, wanting in the sense of lacking or in need of something – and the ethical mandate is to find out what may be wanting and whether available interventions make sense toward serving that deficit or meeting that need. We argue that instead of getting caught by the common language of what patients "want" – understood as desire or choice – clinical ethics consultants share responsibility for the more careful and robust work of identifying a patient's goals, values, and preferences in the context of wanting. Presenting the example of "want" invites the audience to identify other values underlying clinical ethics language that could be challenged.

A principled ethical approach to intersex paediatric surgeries

Prof Kevin Behrens[1]
[1]*Steve Biko Centre for Bioethics, , South Africa*

Biography:
Kevin Behrens is an Associate Professor at the Steve Biko Centre for Bioethics, University of the Witwatersrand. He holds a doctorate in Public Philosophy and Ethics from the University of Johannesburg and a Masters in Applied Ethics for Professionals from Wits. He has also been awarded the Postgraduate Diploma in Health Sciences Education.

Kevin is the Academic Head of the PhD programme in Bioethics and Health Law, and the Unit Head for the unit "Foundations of Bioethics" in the MSc (Med) in Bioethics and Health Law programme.

His research interests lie in the area of Applied Ethics, in particular in Bioethics and Environmental Ethics. A major emphasis in his work is on applying African moral philosophical notions to ethical questions.

He has published widely in international and national journals and is the Editor-in-Chief of the African Journal of Business Ethics. He holds a rating of "Established Researcher" (C1), from the National Research Foundation.

He has been appointed as an expert bioethicist to the Clinical Expert Advisory Panel of the Council for Medical Schemes for the period 2018-2020, and is a member of the Research Ethics Committee of the Council for Scientific and Industrial Research.

Surgery for intersex infants should be delayed until individuals are able to decide for themselves, except where it is a medical necessity. In an ideal world, this single principle would suffice and such surgeries could be totally prohibited. Unfortunately, the world is not perfect, and, in some places, intersex neonates are at risk of being abandoned, mutilated or even killed. As long as intersex persons are at such high risk in some places, any ethical guidelines for intersex surgeries will need to take these extreme risks of harm into account.

I, therefore, argue for five basic principles that ought to inform ethics guidelines for surgical interventions in intersex children, specifically in contexts in which such children are at risk of significant harm. What I set out to come up with is a set of principles that do not completely prohibit surgery, but only allow it where a strong case can be made for its necessity, in the best interests of the child, and where there is some kind of oversight to prevent misuse.

The first principle is that interventions as drastic as these surgeries should only be performed when there is strong evidence that they are beneficial and not harmful. The second principle is that surgeries should normally only be performed in cases of true medical necessity. Principle three is that surgeries should normally be delayed until such time as the intersex person is mature enough to assent to treatment or decide against it. Principle four is that the conventional ethical requirements regarding truth-telling apply equally to intersex children as to anyone else. The final principle is that where physicians or parents think that surgery is in the best interests of the child, the burden of proof lies with them.

Advance directives (AD) in clinical ethics consultations: a means to defuse potential conflicts regarding end-of-life decisions

DENIS BERTHIAU[1], Nicolas Foureur[1]
[1]*APHP Clinical Ethics Center, , France*

Biography:
Berthiau Denis, associate professor, of law at the University of Paris ; consultant to the APHP Clinical Ethics Center.

Advance directives (AD) in clinical ethics consultations: a means to defuse potential conflicts regarding end-of-life decisions

AD aim to enhance patients' autonomy. However, patients usually do not write them, for different reasons: difficulties considering death, anticipating what are going to happen, translating personal preferences into medical choices…
Despite these reluctances, AD are widely promoted in nursing homes. It can be explained by the fact that AD, as a legal tool, appear useful to defuse conflicts about medical decisions, particularly in decisions regarding end of life. For example in France, it was suggested in the recent and famous "Vincent Lambert case" that if V. Lambert had written AD, it would have reduced legal appeals.
The clinical ethics center from Assistance Publique - Hôpitaux de Paris, France recently conducted a qualitative study on AD discussions in 4 nursing homes (47 residents). The study shows that discussions about AD and their redaction between patients, relatives and healthcare professionals reduce conflicts around medical decisions at the end of life.
Similarly to AD, clinical ethics consultations can help stakeholders to focus on the patient's wishes, interests or values. Sometimes, it can help him to express or write AD, and in the end participate in reducing the possible conflict about medical decisions.
But neither patients nor relatives use or focus on AD if they are only about "treatments quantity" rather than "quality of end of life". The balance to be respected between medical and the non-medical aspects in these discussions is particularly difficult to find. This intervention will show why our clinical ethics consultations, multidisciplinary because led by both caregivers and non-caregivers, offer an interesting and replicable model, notably to discuss AD.

How emerging communication technologies impact clinical ethics

Marietjie Botes[1]
[1]*University of Kwa-Zulu Natal, , South Africa*

Biography:
Dr Marietjie Botes has exchanged a 20-year career as attorney specialising in the intersection between law and technology in the fields of Health-tech, Fin-tech and Biotech for academia in 2019. She joined the Health Law and Bioethics group of the University of Kwa-Zulu Natal, South Africa as a senior postdoctoral researcher and focused on genetic research regulation, privacy issues relating to health information, data sharing and related intellectual property rights, gene editing and stem cell therapy whilst lecturing Medical Law, Human Rights and Ethical Theories at the School of Health Sciences. Since the COVID-19 outbreak Dr Botes became actively involved in pandemic preparedness and management research, writing the section about the pandemic's impact on human rights in the Country Report on governmental leadership, governance and the implementation of measures to combat COVID-19 in South Africa. Dr Botes is also serving on the panel of experts of the Academy of Sciences of South Africa (ASSAf) to investigate, advise and write consensus reports on the Ethical, Legal and Social Issues (ELSI) related to Advanced Therapies such as gene therapy and stem cell research.

She will be joining the IRiSC Sociotechnical Cybersecurity Interdisciplinary Research Group at the SnT - Interdisciplinary Centre for Security, Reliability and Trust at the University of Luxembourg in April 2021.

During the COVID-19 pandemic emerging communication technologies have been repurposed to track, trace and alert infected people or people exposed to other infected persons. The goal of communication technologies repurposed for pandemic management is to disrupt the infection chain, empower people to take responsibility for their own health and safety from infection, to lessen the burden on medical treatment centers, equipment and ultimately decisions about the allocation of scarce and lifesaving resources such as ventilators, which comes with its own ethical dilemmas. The South African government created mobile tracking and tracing application, COVID Alert SA, based on smartphone technology, but regardless of the fact that this app does not collect any personal information and allows for anonymous alerting the uptake of the app is extremely poor. One of the main reasons for this is people's general lack of trust in government, largely based on the fake news epidemic that emerged in parallel with the COVID 19 pandemic. To stop the circulation of fake news, government was criminalised the 'publishing of any statement through any medium including social media with the intention to deceive any other person about measures by the government to address COVID-19'. Many health workers welcomed these measures as the spreading of fake information presented difficulties when trying to introduce community-testing initiatives which impact infection rates and numbers in treatment facilities. Balancing privacy rights with other constitutional rights while engaged in a vast program of tracking and tracing is not an easy task. The crux of the matter is tat people fear what they don't understand and this knowledge void can be filled with the innovative use of communication technologies to make the application of downstream clinical ethics easier during a pandemic when time to contemplate, debate and consider emergency and lifesaving ethics is a luxury.

Beyond borders of the permitted ethical and legal boundaries : the case of a complex factitious disorder

Valerie Badro[2], Marie-Eve Bouthillier[1], Annie Descoteaux[3], Michelle Pimont[3], Brigitte Rouleau[2]
[1]Faculty of Medicine, University of Montreal, , Canada, [2]CIUSSS du Nord-de-l'Île de Montréal, Hôpital Jean-Talon, Montréal, , Canada, [3]MSc, , Canada

Biography:
Professor Marie-Eve Bouthillier, is the Head of the Ethics Centre of the CISSS the Laval, a regional health care organisation North of Montreal, Québec, Canada. She is also co-director of the Programs in Clinical Ethics at the Faculty of Medicine of the University of Montreal. She teaches clinical ethics and supervises several master's and doctoral students. She has been practicing clinical ethics for over fifteen years now and has facilitated thousands of complex ethical cases. Her research focuses on communication, palliative and end-of-life care and medical assistance in dying.

Introduction:
Patients with a factitious disorder are rare, but this serious psychiatric condition raises many clinical, ethical and legal issues such as respect for confidentiality, the judicious use of resources, associated costs, appropriate care, and the integrity, autonomy and best interests of the patient. For example, symptom simulation can lead to long hospitalizations where many tests are performed at very high cost, and a significant amount of inappropriate treatment may result. If the patient refuses access to his previous medical file, all investigations may be repeated again and the same merry-go-round can continue. By constantly crying wolf, the patient may no longer have his or her complaints taken seriously. This could lead to the abandonment of investigations when the patient has developed a real pathology from which he or she could ultimately die.
Methods:
We present the story of a patient with a factitious disorder, experienced by our team of clinical ethicists in Canada, Montreal. We will recall the process and analyze our ethical support work framed in a Canadian perspective. In a following step, we will analyze the case from a different ethical and juridical perspective, taking a Swiss framework of ethical support into account.
Discussion:
We will (i) identify and analyze the ethical issues of a complex factitious disorder, (ii) show the benefit of going beyond one country's normative framework and thus, highlight certain cultural elements by adding a rather international perspective to the case, and (iii) reflect upon the role of the clinical ethics team in a situation of great complexity and perceived absurdity.
Conclusion:
Complex cases in psychiatry can lead the team beyond borders of the permitted ethical and legal boundaries. Crossing this border can have a significant moral impact. This adds to the complexity of the case and its constructive resolution.

Sometimes, in managing serious mental illness, compulsion is the least worst option - Consideration of Norwegian laws related to the use of coercion in the health and care sector

Berit Brinchmann[1], Eliabeth Sveen Kjølsrud[2]
[1]Nord University, , Norway, [2]NSF, , Norway

Biography:
RN, Phd, Professor in Nursing and Health Care Ethics.
Nord University, Bodø and Nordland Hospital Trust, Bodø Norway.
Norwegian Board of ethics for nurses.
ICN international working Group for ICN Code of Ethics.

Historically, unnecessary coercion has been used in psychiatry. This has demeaned and damaged the patient and its use should be reduced.
A Commission has presented proposals for amendments to the laws relating to the use of coercion in the health and care sector in Norway (NOU 2019:14).

The Commission's ethical perspective is that:
Everyone has the right to:
1. Self-determination in personal matters
2. Protection from violation of their rights
3. Necessary health and care services
4. Respect for their fundamental human rights

The proposal says: "Involuntary medication is an extremely invasive measure with potentially severe adverse effects."
"…. a proposal is made for an option to reserve oneself against treatment of mental illness using specific or all types of anti-psychotics for up to ten years. It is a prerequisite that the person has previously suffered psychosis and has been treated with anti-psychotics".

The Commission's ethical perspective is founded on the rights of, and obligations toward, the individual. We will argue for a law taking greater account of utilitarian and consequence-ethical arguments, in which the individual's rights are seen in a wider perspective considering all the affected parties. Lack of coercion can be damaging to the patient and inappropriate for him, his carers and society. A person with a serious mental illness treatable with anti-psychotics, who, after treatment, is considered competent to decide and can therefore stop his medication. This can lead to renewed psychosis.

The discussion is also based on relational autonomy.
People are socially rooted, their identities formed within the context of complex interactions and social determinants. Although individuals are independent, their autonomy is influenced by conditions shaping their capacity for autonomy. Decision-making is not just a matter of choice but must be seen in social and situational contexts.

The State versus Peter Sean Davison: Is this the death of assisted dying in South Africa?

Mark Blockman[2], Theresa Burgess[1]
[1]*Centre for Medical Ethics and Law, University of Stellenbosch, , South Africa,* [2]*Division of Clinical Pharmacology, Department of Internal Medicine, Faculty of Health Sciences, University of Cape Town, , South Africa*

Biography:
Theresa Burgess started her career with a BSc (Physiotherapy), followed by a BSc (Med)(Hons) and PhD in Exercise Science, all from the University of Cape Town. In 2011 she was awarded a NIH Fogarty Fellowship in Bioethics and with this support, successfully completed a MHSc (Bioethics) at the University of Toronto in 2012. She is part of the ARESA Bioethics Leadership Program, and is registered for a PhD in Clinical and Research Ethics. Her PhD topic is 'An ethical analysis of female adolescent sexual and reproductive health care and research in South Africa'. She teaches bioethics and neuromusculoskeletal and sports physiotherapy to undergraduate and postgraduate students in the UCT Faculty of Health Sciences. She is also the programme convenor of the MSc in Exercise and Sports Physiotherapy. She serves as the Deputy Chair of the Faculty of Health Sciences Human Research Ethics Committee; is a member of the Department of Health's National Health Research Ethics Council, and also serves on the Hospice Palliative Care Research Ethics Committee.

Professor Marc Blockman holds a BPharm (UCT) with distinction, an MBChB (UCT), an MMed (Clinical Pharmacology) (UCT) and a Postgraduate Diploma in International Research Ethics. He is an Associate and Council Member of the College of Clinical Pharmacologists of South Africa. He is a Professor in the Department of Internal Medicine, and a consultant specialist in the Division of Clinical Pharmacology at Groote Schuur Hospital and the University of Cape Town (UCT). He is recognised as an expert on International, National and Provincial Drug Policy. He serves as an International Consultant for the World Health Organisation, assessing drug policy and drug regulation in many countries and advises on the implementation of remedial systems where appropriate. He serves on the South African Health Product Regulation Authority (SAHPRA) as a Council member, as well as Chairperson of the Pharmacovigilance Expert Committee and as a member of the Clinical Expert Committee. He has chaired the South African Essential Drugs Programme since 2008. He is an Executive member of the Provincial Government of the Western Cape's Pharmacy and Therapeutics Advisory Committee (PTC) and is chair of Groote Schuur Hospital's PTC. He chairs the Western Cape Provincial Government's Antimicrobial Stewardship Committee. He is a member of the Western Cape Provincial Government's Clinical Guideline Advisory Committee, to assess Clinical Service Packages within the Province. He is a consultant expert to medicines formulary development committees in both the private and public sectors in South Africa and has special interests in the cost-effectiveness of medicines, pharmaco-economics and drug utilisation review. He exemplifies a strong culture of evidence-based medical practice, demonstrated by his involvement in the teaching and application of the evidence-based ethos. He is a well-respected lecturer and was awarded the Distinguished Teachers Award from UCT. He is Chair of the UCT Faculty of Health Sciences Human Research Ethics Committee, as well as chair of various data safety monitoring committees (DSMBs). He is also chair of the UCT Senate Ethics in Research Committee. He is also a member of the UCT Faculty of Health Sciences Professional Standards Committee.

Introduction:
Assisted dying is controversial and the subject of much debate. Physician-assisted dying is illegal in South Africa. Peter Sean Davison was convicted of three counts of murder for assisting individuals to die; including: a quadriplegic medical doctor who suffered debilitating neuropathic pain following a motor vehicle accident; an individual suffering from motor neuron disease; and one with catastrophic brain injury, who could only communicate with eye movements. Death was caused by a concoction of drugs;

asphyxiation and/or helium deoxygenation; and pentobarbital respectively. However, Davison is not a medical doctor and is not qualified to perform medical procedures. None of the three families wanted Davison to be prosecuted for assisting their son or brothers to die. We aim to interrogate how this case might influence current thinking about assisted dying in South Africa.

Discussion:
This case introduces additional complexity to the assisted dying debate because of the actions of a non-medical professional. Proponents view Davison as a 'good Samaritan' and argue that his actions uphold the rights to dignity and freedom, and individual patient autonomy. But these actions need to be balanced with both the right to life, and the potential harms of assisted dying, particularly by non-medical professionals, in the South African context. A further complexity is the assessment of individual capacity to make the decision to die: can capacity only be assessed by medical professionals, and how might their individual values influence the outcome of a capacity assessment?

Conclusion:
Peter Sean Davison's conviction represents a multi-layered and profound cultural shift in the debate around legalising assisted dying in South Africa. We argue that a greater understanding of the diversity of views of assisted dying is needed to determine how we can protect the weakest while enabling the freedoms for the strong in our society.

The defence of therapeutic privilege in England and Wales: is the new test of information disclosure for informed consent hailing patient autonomy or an inadvertent return to paternalism?

Claudia Carr[1]
[1]*University of Hertfordshire, , United Kingdom*

Biography:
Claudia Carr is a Senior Lecturer in Medical Law and Ethics at Hertfordshire Law School at the University of Hertfordshire. She is the author of a number of books, three on Medical Law and Ethics and one on Criminal law, together with a number of articles. Having started her career in private practice, representing London hospitals in their clinical negligence claims, she moved into academic law and has been the module convener for Medical Law and Ethics at Hertfordshire Law School for a number of years. She is now studying for her PhD at Middlesex University and her research area is the defence of therapeutic privilege in informed consent. Her other roles at HLS include deputy LLM programme leader and Wellbeing Leader. Her other special areas of interest are end of life and Jewish (Halacha) law.

Originally formulated by the courts in the US, the defence of therapeutic privilege enables a doctor to withhold information from a patient, where they believe that disclosure could result in serious physical or psychological harm.
Therapeutic privilege has been cited in cases in the courts of South Africa, Canada, Australia, the US and in England and Wales. Whilst it is rarely referred to, it is even rarer for the defence to be successful yet; the defence survives.
In 2015, the Supreme Court in England and Wales finally introduced informed consent for medical treatment, putting the 'particular patient' at the heart of the decision-making process for medical treatment.
The Montgomery judgment retained the defence of therapeutic privilege, albeit in a limited form and still largely undefined. The defence, now renamed therapeutic exception and confirmed by General Medical Council guidance, must not be abused in a way to permit doctors to impose their notion of best interests on their patient.
The emphasis is now on communication of material risks with the patient, to enable the patient to reach their own conclusion regarding medical treatment. Paternalism has been replaced with autonomy and, the 'Bolam' test has now been rejected in its entirety for information disclosure for informed consent.
Yet, it is recognised that to comply with the new test of information disclosure, clinic times will be longer, with the additional risk of increased stress and anxiety on patients. This applies equally to those capacitous patients with intellectual disability, who could find the environment of additional information, often complex in nature, increasingly challenging.
In these circumstances, this paper will explore whether, the defence of therapeutic exception may now find a foothold in England and Wales and the introduction of informed consent may result unintentionally, in new found paternalism.

Do Reasons Matter? A Consideration of Faith, Culture and Gender in Pediatric Treatment Disagreements

Amy Caruso Brown[1]
[1]*SUNY Upstate Medical University, , United States*

Biography:
Amy Caruso Brown, MD, MSc, MSCS is an associate professor in the Center for Bioethics and Humanities and the Department of Pediatrics, Division of Pediatric Hematology/Oncology at SUNY Upstate Medical University. Dr. Caruso Brown was educated at the University of Virginia (BA, 2002), Emory University (MD, 2008), the University of Oxford (MSc, 2008), and the University of Colorado (MSCS, 2014). She subsequently completed residency training in general pediatrics (Children's Hospital of Philadelphia, 2008-2009; University of Colorado, 2009-2011) and fellowship training in pediatric hematology/oncology (University of Colorado, 2011-2014) and is board-certified in general pediatrics and pediatric hematology/oncology. At SUNY Upstate, she is the co-director of Patients to Populations, a required justice-centered bioethics course for first-year medical students. She is also a clinical ethics consultant and practicing pediatric oncologist. Her research interests include cultural dimensions of treatment refusal in pediatrics; the impact of social media on trust and communication between physicians and families; and the question of how medical students understand and enact social responsibility as part of their evolving professional identities, across societies and healthcare systems.

Introduction: How health-related decisions should be made for children who are seriously ill and who should make such decisions is a major topic of discourse in pediatric bioethics. One issue that resists consensus is the question of whether parental reasons for or against specific decisions matter or whether judgments should rest solely on assessment of the child's best interests or risk of harm.
Discussion: I argue first that reasons do matter, on three grounds: (1) that they are inextricably tied to families' perceptions of potential benefits and harms of therapies and thus essential to the development of compromises and avoidance of unilateral decision making; (2) that an understanding of reasons can predict the potential harms of unilateral decision making (that is, what might happen to the child if parents are compelled to accept an intervention they oppose or if they have a desired intervention withheld?); and (3) that careful consideration of reason has the potential to mitigate biases in healthcare and society. I then consider the inevitable corollary: is it ethical to permit a family to receive or to decline an intervention for a specific cultural, spiritual, or religious reason, when another family, from a different culture, faith, or tradition, would not be permitted to do so? Under what conditions might such a decision be permissible? Finally, I explore the converse question: when parents' culturally or religiously bound reasons for disagreement are rooted in gender bias, should an otherwise permissible decision be overridden?
Conclusions: In some cases, a decision falls within the zone of parental discretion, yet the biases that lead to the family's decisions may interfere with their ability to give voluntary, informed consent (or refusal). In such circumstances, ethics consultants may recommend legal action in order to protect the child's rights.

That rare occurance when a family requests an ethics consult

Cynthia Coleman[1]
[1]*Medstar Washington Hospital Center , , United States*

Biography:
Cynthia Coleman is a senior clinical ethicist at the John J Lynch, MD Center for Ethics at Medstar Washington Hospital Center is Washington, DC. She is also adjunct faculty at The George Washington University. She earned her Doctorate of Bioethics in 2018. Cynthia practiced as an Registered Nurse for 30+ years. Her areas of practice included Emergency Medicine, Palliative Care and Hospice. As a full time ethicist at Medstar, a high risk obstetric center, she responds to ethics consults on actively laboring women, Neonatal Intensive Care Unit, and outpatient consults.

Family/patient-initiated ethics consults are uncommon. When the medical team requests an ethics consult, the patient/family is told about the process, the goals of the consult, and invited to participate. The medical team typically understands what they are seeking when an ethics consult is called, but does a patient or family member understand? Is education on the process/goals/and communication the same? Or ought it be enhanced? When a family requests a consult, are they owed the opportunity to see the consult they requested? A case study will be shared where a family regretted calling ethics. Audience interaction will be sought to analyze the case and explore answers to the questions posed above.

Building a model for Clinical Ethics Committees in a Cancer Center: the Italian case

Paolo G. Casali[3], Chiara Crico[1], Gabriella Pravettoni[2], Virginia Sanchini[2]
[1]Department of Oncology and Hemato-Oncology, University of Milan, Milan, Italy, , Italy, [2]Applied Research Division for Cognitive and Psychological Science, European Institute of Oncology, Milan, Italy, , Italy, [3]Istituto Nazionale Tumori, Milan, Italy, , Italy

Biography:
I am a 4th year PhD student from the European School of Molecular Medicine and I work in collaboration with the two main cancer centers of Milan (European Institute of Oncology and the National Cancer Institute). The abstract I would like to present is the main part of my project, which has the aim of building a model for a Clinical Ethics Committee in the hospitals I'm working in.

Introduction
Clinical Ethics Committees (CEC) represent an ever-increasing presence in hospitals and care centers. In many countries, including Italy, CECs are still under development and a devoted regulation is still lacking. The aim of this study is to investigate how ethical reflection is implemented in the daily clinical practice of a cancer institute, in order to develop a CEC tailored on the actual needs of its healthcare staff and stakeholders.
First, we assessed the real impact CECs have in clinical practice, by carrying out a systematic review of studies evaluating CEC's performance and effectiveness.
Then, we conducted an exploratory qualitative study to gather and analyze experiences with ethical issues in clinical daily practice, requests and expectations regarding potential ethics support of key members of an Italian cancer institute.
Methods
The systematic review was conducted according to the PRISMA guidelines. All the relevant literature published up to July 2019 was retrieved in the databases PubMed, Ovid MEDLINE, Scopus. Only studies addressing CECs as a topic and providing any form of evaluation were included.
For the qualitative study, a thematic analysis of 21 semi-structured interviews from healthcare professionals, Ethics Committees members, Patient Advocacy Group members was performed.
Results and conclusion
29 articles were included in the systematic review, providing both qualitative and quantitative measures. Consultation resulted as the most evaluated service provided by CECs. Satisfaction, categorized as the perception of utility and efficacy of consultation services was used as a qualitative measurement; quantitative research focuses on composition of CECs, adherence to a given methodology or to CECs' recommendations.
The results of the qualitative study show an agreement in identifying the common ethical issues in a cancer institute: above all, clinicians' poor communication skills and ethics literacy, decision-making in uncertain prognosis, transparency of clinical information. The educational role of the CEC is deemed to be crucial, and the flexibility and multidisciplinary nature of its composition seem to be key elements in meeting the needs of stakeholders.

New Frontiers: Navigating Medical and Ethical Uncertainty in the Neonatal ICU

Philip Crowell[1]
[1]*British Columbia Children's Hospital, , Canada*

Biography:
Philip Crowell, PhD in Philosophy, University of British Columbia Medical Ethics Theme Leader Faculty of Medicine; Clinical Assistant Professor Dept. of Pediatrics in Hematology/Oncology; British Columbia Spiritual Health Leader for BC Cancer Agency, BC Children's and Women's Hospitals

Introduction: Neonatal medicine is a realm where scientific innovation has drawn praise but also significant criticism. The path of innovation and new frontiers in the Neonatal ICU has sometimes ignored conventional wisdom and has garnered success in the form of babies who survive serious complications. The controversy in the success is the quality of life for these newborns and their future prospects for health and some measure of normalcy. This paper will introduce the best interest standard, the harm principle and the 'good enough' approach specific to the neonatal context. Using a complex case from the NICU we analyse the substitute decision making process focusing on a route between the best interest standard and the harm principle while recognizing that cultural influences shape these concepts.
Discussion: In the midst of NICU resuscitation and daily maintenance it is extremely difficult to define the point where life becomes "intolerable" or "extremely grievous" for the infant, or where benefits are outweighed by burdens. It makes sense that parental views about decision-making should carry some weight because their interests overlap with those of the infant (D.Wilkinson). Parental interests may also carry independent weight in decisions because of the substantial impact on the interests of parents and other family members if a child survives with very severe impairment. Here, there is need for a supplemental argument about the welfare of parents as caregivers and the erosion of their "practical identities" (Lindemann-Nelson & Frader).
Conclusion: Where there is significant (2nd order) prognostic uncertainty, there must be moral consideration of the strong chance that an infant will survive in a state that is negative or harmful. Where there is moral uncertainty about harms to an infant we should allow parents to make decisions, known as the "zone of discretion", but within limits.

Heart Transplant After Circulatory-Determined Death: Exploring New Frontiers

Jacob Dahlke[1], Marian Urban[2]
[1]*Nebraska Medicine, , United States,* [2]*University of Nebraska Medical Center, , United Kingdom*

Biography:
Jacob Dahlke is a clinical ethicist and the Director of the Office of Healthcare Ethics at Nebraska Medicine in Omaha, NE (USA). Jacob is a graduate of The Bioethics Program at Union Graduate College – Mt. Sinai School of Medicine, and has additionally contributed to the medical ethics field in Vermont and Colorado, and is a part of the first cohort of nationally credentialed bioethicists through the American Society for Bioethics and Humanities. Jacob's primary interests in bioethics include advance care planning, LGBTQ+ and feminist ethics, and healthcare professional wellness as it relates to moral distress and moral injury.

There is currently a seismic shift occurring in the United States in how people think about death. Access to medical aid in dying continues to expand across states. Court cases continue to challenge the legal definition of death, including the relevance of its permanence and irreversibility and even the often variable criteria itself used to determine death. This all leads to practical issues in health care, including the utilization of resources dedicated to people who are considered alive in their current condition or location, but would otherwise be considered dead in another state.

These factors have profound implications in a highly specialized area of health care: organ transplantation. One the most challenging organs in transplant is the heart. Procuring hearts only after neurological death determination of death limits efforts to increase the number of available hearts. Hearts from donation after cardiac determination of death (DCDD) are potentially ethically challenging. Restarting heart circulation after death has potential to conflict with longstanding criteria that death is irreversible and permanent, and with some beliefs that death only occurs when the heart stops (versus the brain's failure to function).

A DCDD method of procuring hearts via ex situ repurfusion – re-establishing blood flow in a removed heart inside a specialized device – was first used by a pediatric transplant program in Colorado (USA) in 2009 and later in adults in Australia. A new in situ technique has been recently pioneered by surgeons in the United Kingdom that repurfuses the heart in a deceased donor prior to its removal and transport to the donor recipient.

This session will (1) describe the technical differences of both methods; (2) explore ethical justifications, limitations, and other considerations of the in situ technique; and (3) recommend how transplant programs might implement such innovative but potentially ethically challenging techniques.

What are the health-related obligations of a host state towards detained asylum seekers?

Angus Dawson[1]
[1]*Sydney Health Ethics, , Australia*

Biography:
ANGUS DAWSON | Professor of Bioethics and Director
Sydney Health Ethics | Sydney School of Public Health

THE UNIVERSITY OF SYDNEY
Level 1, Medical Foundation Building K25 | The University of Sydney | NSW | 2006
T +61 2 8627 0964 | F +61 2 9036 3436
E angus.dawson@sydney.edu.au W http://sydney.edu.au/medicine/sydney-health-ethics
Twitter: @PublicEthics

Joint Editor-in-Chief: Public Health Ethics: http://phe.oxfordjournals.org

Leader of Politics and Ethics of Infection (EPI) Node, Marie Bashir Institute:
http://sydney.edu.au/mbi/research/nodes/politics-ethics.php

Australia has implemented a system of 'off-shore' detention and processing for asylum seekers who arrive by boat. Such asylum seekers, often fleeing persecution and torture, are not subject to a legal sentence but are detained for many years for 'processing'. This is has been condemned by a number of UN agencies and is in breach of international law. Many of the detainees have substantial health needs as a result of past torture, a traumatic journey and a seemingly endless detention itself. The relevant clinical health needs of this population are not being met. In this paper I seek to explore a series of related questions that arise from this situation. What are the health-related obligations of a host state in such a case? What is the appropriate standard of health care for this group? Who is bound by such obligations? How, if at all, are considerations of deterrence, security and cost relevant to determining the relevant standard of care? I draw upon the literature relating to the provision of health care in prisons and the standard of care debate in international research ethics to provide a number of arguments for why we should support, at the very least, the idea of equivalence between the host population and detained refugees in relation to health care standards. My conclusions have implications for other countries receiving asylum seekers.

Moral distress, decision-making and ethical climate at the ICU during the first wave of the covid-19 pandemic: directions for ethics support

Janine de Snoo-Trimp[1], Bert Molewijk[1], Mark van Zuylen[1]
[1]*Amsterdam UMC, , Netherlands*

Biography:
Mark van Zuylen is a resident in anesthesiology at the Amsterdam UMC, location AMC in the Netherlands.

Janine de Snoo-Trimp works as a postdoc researcher on Clinical Ethics Support in the Amsterdam UMC, location VUmc, in the Netherlands.

Bert Molewijk is a professor in Ethics Support and Quality of Care in the Amsterdam UMC, location VUmc, in the Netherlands.

Background
The COVID-19 pandemic caused extreme working conditions in healthcare. ICU workers were confronted with many moral dilemmas like balancing their own personal safety whilst still providing good patient care. This might result in moral distress and negatively impact job satisfaction and turnover rates. It is important to support healthcare professionals to deal with these moral dilemmas, with ethics support services, good team cooperation and a positive ethical climate.
For this support, input from ICU workers on what type of ethics support they envisage is needed. Rather than collecting 'dramatic' moral dilemmas only, it is crucial to also focus on the positive lessons-learned from ICU workers themselves, in order to help them to deal with these challenges in the future.
We will present a survey among ICU workers at the Amsterdam UMC during the first wave of the COVID-19 pandemic, regarding 1) moral distress and team cooperation; 2) moral dilemmas around end-of-life decisions; and 3) their lessons learned and needs for ethics support.
Methods
A survey was sent to all healthcare professionals who had worked at the ICU during the first wave of the COVID-19 pandemic in the Amsterdam UMC – Location AMC and contained parts of existing scales for moral distress and decision-making.
Results
About half of the respondents reported that they experienced serious worries about the provided quality of care in general. Furthermore, about thirty percent reported emotional stress. At the same time, team cooperation, solidarity and less bureaucracy were valued very positive. We found quite some significant differences between doctors and nurses. Several concrete suggestions were made on what they would like to maintain and what they would like to change for the next wave(s).
Discussion
We will suggest several implications of both the critical and positive findings; for ICU workers ICU managers and for ethics support.

Presenting the New European Moral Case Deliberation Outcomes Instrument: The Euro-MCD 2.0.

Janine de Snoo-Trimp[1], Riekie de Vet[1], Bert Molewijk[1], Mia Svantesson[2], Guy Widdershoven[1]
[1]Amsterdam UMC, location VUmc, , Netherlands, [2]Orebrö University, Orebrö, , Sweden

Biography:
Janine de Snoo-Trimp is a junior researcher at the department of Medical Humanities at the Amsterdam UMC, location VUmc in Amsterdam, the Netherlands. She is about to finish her PhD on Outcomes of Moral Case Deliberation, a study that tested an instrument for evaluation of Clinical Ethics Support in three European countries. Other research projects in which she is involved include ethical issues in the allocation of hospital beds, shared decision-making in gender affirmative care and impact of clinical ethics in care for people with intellectual disabilities.

Background:
Clinical ethics support (CES) services aim to help healthcare professionals in dealing with ethical challenges. It is important to know if and how CES services achieve their presupposed goals. Therefore, evaluation is needed to gain insight in the value of CES. Evidence-based methods for evaluation are yet still scarce. In 2014, the Euro-MCD instrument was developed to assess outcomes of Moral Case Deliberation (MCD). Several field studies within a PhD project using and testing this instrument have recently been performed to validate and improve it.
The aim of this presentation will be to present the revised Euro-MCD Instrument.

Methods:
The revision process involved an integration of empirical findings and reflective dialogues among the research team and with MCD experts. Empirical findings included both quantitative and qualitative results from the field studies among healthcare professionals from Sweden, Norway and the Netherlands. We reflected on these findings, using relevant ethical theories and concepts. We decided about new domains, reformulations, removing and adding of items in iterative dialogues.

Results:
The revised Euro-MCD Instrument involves a re-categorization and less items which are almost all reformulated. The revised instrument consists of three preliminary domains covering MCD outcomes: 1) Moral Competence, 2) Moral Teamwork and 3) Moral Action.
At the moment (Oct 2019), the research team is finalizing the revised instrument. Final content will be presented at the conference.

Discussion:
We think the revised Euro-MCD Instrument is an empirically sound, theoretically solid and feasible instrument that may be used to optimize MCD practices, training of CES professionals and contribute to evaluation research in general. Although initially developed for MCD, it might be applicable for other types of CES as well.

Svantesson et al. (2014). Outcomes of Moral Case Deliberation – the development of an evaluation instrument for clinical ethics support (the Euro-MCD); BMC Medical Ethics.

TransLife: Development of a smartphone app to predict and improve rates of suicidal ideation among transgender persons

Oleksandr Dubov[1]
[1]*Loma Linda University, , United States*

Biography:
Dr. Alex Dubov is an Assistant Professor of Bioethics and Public Health at Loma Linda University. He has completed his doctoral studies in Bioethics at Duquesne University (advisor: Dr. Henk ten Have). His post-doctoral studies were at Yale University School of Public Health (mentor: Frederick Altice). His research interests lie at the intersection of public health (HIV epidemiology and prevention) and decision-making science (social and cognitive factors that influence risk, decision-making, and health behavior). His research was supported by the NIH and USAID.

Transgender people have an extremely high prevalence of suicidal ideation and suicide attempts. In the US, the lifetime prevalence of suicide attempts among this group is estimated to be as high as 41.0%, compared to 4.6% in the general population. Research is limited on factors that account for variability in suicide risk and associated mental health concerns among transgender persons.
In this presentation we will report on the mHealth suicide prevention phone app TransLife designed with the help of transgender people. The app will provide users with resources intended to promote resilience and cope with minority stressors. Additionally, the app will allow researchers to collect longitudinal data that will be used to create a comprehensive model outlining the process and series of psychosocial mechanisms leading to suicidal ideation in transgender people.
We will present the beta version of the app together with results of focus group discussions. In addition to the main feature of the app – structured mood tracking, the users of TransLife can access a variety of resources. Mood tracking allows users to record their mood and track health activities (sleep, energy, etc.) to identify patterns in their mental health. Researchers will be able to use these entries to create a large training dataset. This dataset will be analyzed using deep neural networks to develop a deep neural net classifier for early detection of suicidal risk. Given a series of mood entries the model will predict likelihood of the next entry being worse or suicidal. In addition to presenting the app, we will also discuss ethical concerns in creating an AI powered model of suicidal ideation as well as using mobile apps as passive data collection devices. The issues of big data collection, privacy, confidentiality, and informed consent pertaining to the mobile app deployment will be discussed.

Ethical Dilemmas Relating to the Management of a Newborn with Down Syndrome and Severe Congenital Heart Disease in a Resource-Poor Setting

Ama Kyerewaa Edwin[1], Frank Edwin[2], Summer McGee[3]
[1]School of Medicine, University of Health and Allied Sciences (UHAS), Ho, , Ghana, [2]School of Medicine, UHAS, Ho; National Cardiothoracic Centre, Accra, , Ghana, [3]University of New Haven, Connecticut, , United States

Biography:
Dr Ama Edwin has an MB ChB from the University of Ghana Medical School (1994), an MPhil in Clinical Psychology from the University of Ghana (2001) and a Doctor of Bioethics from the Loyola University, Chicago, USA (2015). She helps health professionals and allied scientists meet a standard of excellence in health care through consultation, teaching, policy development, and research in bioethics.
As a bioethicist/clinical ethics consultant, she is committed to patient safety and excellent patient care and helps clinicians and healthcare institutions improve patient safety and reduce medical errors and their impact. She works with clinicians to improve care outcomes by delivering quality patient-centered care, facilitating clinician-patient communication, and addressing ethical dilemmas arising from patient care. She supports specialty areas, such as Intensive Care Units that are often fraught with ethical issues in identifying and addressing these issues. As a palliative care clinician with a focus on end-of-life care, She provides supportive care to patients to enable them live as well as they can for as long as they can, even though they have a serious illness. She also helps patients with terminal illnesses and their families complete their relationships and face death with a positive outlook.
Dr. Edwin has a passionate desire to see scientific and ethical multinational research done in LMICs and serves on national and international Ethics Review Committees. She teaches health law and ethics, and medical ethics to medical students and physician assistantship students and research ethics to residents in the Faculty of Medicine of the West Africa College of Physicians in Ghana. Her research interests include ethical dilemmas in clinical practice, end-of-life ethics, mental health ethics, research ethics, health law and ethics, public health ethics, and humanitarian ethics. She has several peer-reviewed publications, and presentations in national and international conferences.

Introduction

"The doctors have done me wrong. They should have allowed this child to die." These are the words of the mother of a 9-month-old child with Down syndrome and complete atrioventricular canal defect to the pediatric heart surgeon to whom her baby had been referred.

Decision-making regarding treatment for newborns with disabilities in resource-poor settings is a difficult process that can put parents and caregivers in conflict. Despite guidelines that have helped to clarify some of the medical decision-making in Ghana, there is still no clear consensus on the specific moral criteria to be used.

This is a case study of a mother who expressed her wish that her child with Down Syndrome should not have been resuscitated at birth. It explores the ethical issues at stake in both her misgivings about the resuscitation and her unwillingness to consider surgical repair of a congenital heart defect.

Discussion

Knowing that children born with Down syndrome are able to pursue life's goals, should our treatment of congenital heart defects in such children be considered morally obligatory, even in resource-poor settings like Ghana? Treatment decisions for critically ill newborns in resource-poor settings are difficult, and can put parents and caregivers in conflict. In making such decisions, it is important to determine who the decision-makers are and the appropriate moral criteria by which they will be guided. While parents are the primary

decision-makers for newborns with disabilities, they may not always make morally sound decisions in the face of resource scarcity, lack of social support, or lack of understanding about their child's prognosis.

Conclusion

Healthcare providers, with the help of clinical ethicists can ensure that appropriate care is given to such newborns. However, providers must exhaust dialogue with parents, including ethics consultations before invoking the intervention of Ethics Committees or the Courts.

Normative, theoretical and practical perspectives on patient participation in Clinical Ethics Support (CES) Services from Dutch CES staff

Janine de Snoo-Trimp[2], Marleen Eijkholt[1], Bert Molewijk[2]
[1]LUMC, , Netherlands, [2]AmsterdamUMC, , Netherlands

Biography:
Marleen Eijkholt is a senior lecturer at the Leiden University Medical Centre. Her research interests include clinical ethics, and the legal and ethical aspects of experimental treatments, reproductive medicine and neuroscience.

Patient and family participation (hereafter: PP) has been recognized as an important issue in Clinical Ethics (and Law) Support Services (CES). Yet, despite the wide variety of practices globally, PP in CES practice is rarely studied in detail. In Europe PP is not unequivocally endorsed. Practices vary from region to region, and per type of support. They vary from being non-existent, to patients being a full conversation partner. And while PP seems to be on the rise, there is no data to confirm this. In North America, on the contrary, participation seems more or less standard. The assumption being that PP is important for reflection about, and determination of, morally appropriate care.
In light of the increasing interest for and prevalence of CES in Europe and the Netherlands, we aimed to study the practice, ideals and challenges of PP in CES in the NL. Hence, we piloted and surveyed Dutch ethics support staff on the topic of PP. Through various professional networks (such as the National Network for Ethics Support (NEON) and a Dutch ethicist email-list), we invited individuals to participate in our a survey. Our survey comprised a total of 25 open and close-ended questions, focused on four themes related to PP in CES, including queries on 1) the goals of CES, 2) the status quo of PP in CES, 3) the ideals concerning PP in CES, and 4) the needs around (challenges in) PP in CES. During the writing of this abstract we had received around 100 surveys.
During this presentation, we will report the preliminary findings on the 4 themes, including the correlations between the different views held depending on the professional position and the type of institution. Our data will eventually allow us to research and compare practices on a European and international level.

Procedural justice, and objections against patient participation and chart review. Culture, justice and practice of clinical ethics consultation

Marleen Eijkholt[1]
[1]*Leiden University Medical Centre, , Netherlands*

Biography:
Marleen Eijkholt is a senior lecturer in the department of Medical Ethics and Health Law at Leiden University Medical Center in the Netherlands. Her background is eclectic, but primarily based in law and ethics. After doing research, teaching and clinical ethics consulting in different countries around the world, including the United States, Canada, the United Kingdom and France, she has returned to work in the Netherlands. Marleen's work lies in health law, clinical ethics, bioethics, research ethics and neuroethics. Her work includes diverse topics, such as reproductive rights and experimental treatments. She has published several papers and chapters about topics such as reproductive rights, placebos, stem cells, Deep Brain Stimulation and ethical reproducibility in national and international journals.

The argument of procedural justice (PJA) requires to take account of all relevant views in clinical ethics case consultation (CEC). It demands that pertinent views should be carefully considered and examined, including for their contributions and biases, as part of due process. Hence, in our view, the PJA calls for two procedural steps. First, patients should participate in CEC, so that their views can be studied through an ethically informed lens. Second, medical chart notes should be studied and read by the ethics consultant, for the same reasons.

Our view about the PJA and its implications for the CEC context is, however, controversial. Although the PJA was already coined in the 1980's, the argument does not seem to have been convincing so far in the European context. In Europe, patient participation in CEC is limited and contentious, even if practices are changing. Examination of chart narratives by ethics consultants, moreover, seems rare. Charts remain unexamined, per the authors' personal experience and the lack of European literature on this practice. On the contrary, in the USA these two interventions seem to be standard practice.

In this paper we will outline how the PJA relates to these two steps. We will also describe how the PJA has developed. Further we scrutinize the objections against the two practices, and outline how the PJA should be read in the European versus the American context. We will hypothesize that some objections have been cultural. For example because of particular views in the EU vs USA on the patient-physician relationship, autonomy, and patient privacy. We will ask if how the PJA weights in the different cultural settings, and will submit that previous objections need to be set aside. We will argue for the adoption of these two practices in both settings as a matter of justice.

Addressing ethical issues around confidentiality in Mental Healthcare: How can Metz's Ethics of Friendliness help?

Cornelius Ewuoso[1]
[1]*University of Johannesburg , , South Africa*

Biography:
Cornelius Ewuoso is a Postdoc Fellow at the Department of Philosophy, University of Johannesburg, South Africa. He was a Consolidoc Fellow at the Department of Philosophy, Stellenbosch University; a recipient of the Santander/Ethics and Society Scholarship for Theories and Application from Fordham University; an international visiting fellow at the Institute for Medical Ethics and History of Medicine, Ruhr-Universitait, Bochum; the Center for Biomedical Ethics and Law, KU Leuven; the James F. Drane Institute of Bioethics, Edinboro University of Pennsylvania and a recipient of the Master of Science in Bioethics scholarship award of the West African Bioethics Training Programs

This study argues the thesis that a set of guidelines grounded in Metz's ethics of friendliness can usefully supplement current codes and guidelines, and be of assistance in providing legitimate reasons for breaching patient's confidentiality in mental healthcare.

Mental healthcare professionals have a dual obligation to maintain patient's confidentiality and to report dangerous individuals, who might harm others. Professionals who fail to report such individuals contribute to violence towards others.

Studies have shown that a serious conflict can occur between these obligations. A decision to maintain confidentiality may (negatively) impact others' safety. The 2014-Sasebo 15-year-old school girl murder in Japan, is an example. Before the murder, the professional examining the assailant warned authority that she might commit murder but concealed her name, considering it a duty to maintain confidentiality. Japanese Criminal Law, as is the case with many Laws, states that doctors should not disclose patient information obtained within the clinical context without legitimate reason. The laws in Japan and in many regions, are unclear about what exactly constitutes legitimate reason. To date, ethical codes have equally failed to clarify the necessary conditions for breaching confidentiality. This gap is significant.

Consistent with the ICCEC 2020 sub-theme "Exploring Diversity in Philosophical approaches on CECs", this study shows how Metz's ethics of friendliness (based on the under-explored African philosophy of Ubuntu) which mandates one to end unfriendliness – in which individuals in communal relationships no longer identify and exhibit solidarity with one another, or act in ways that are more likely to be of good – before promoting new ones, may be used to develop some guidelines that clarify the necessary conditions for breaching confidentiality. Specifically, this study shows how a mental healthcare professional may justifiably disclose patient's identity if this is necessary to end unfriendliness on the part of the patient.

Gender-based violence among Rohingya refugees- a case of global child protection.

Dr Asma Fazal[1]
[1]*Childrens Hospital and Clinics of Minnesota, , United States*

Biography:
Dr. Asma Fazal completed her medical degree from Hamdard College of Medicine, Karachi, Pakistan. After completing her specialist pediatric training in Ireland, she received membership of the Royal College of Physicians of Ireland in 2011. Over nine years, and after working in different parts of the world, Dr. Fazal has gained extensive clinical experience in general and subspecialty pediatrics.

Due to her growing interest in ethical issues in pediatric patient care, Dr. Fazal joined the University of Toronto and completed MHSc in Bioethics in 2019. Her bioethics education and training opened a new career pathway for her, and she joined Children's Minnesota Hospital as a Clinical Ethics Fellow in September 2020.

Besides providing ethics consultations, Dr. Fazal is passionate about ethics education, policy-making, and academic research. Her research interests are substitute decision making, the best interest of a child, consent and capacity, patient confidentiality, moral distress among healthcare professionals, ethical issues involving refugees and migrants, and organ transplantation.

Rohingya people, a stateless Muslim minority group in Myanmar, is facing the world's fastest-growing humanitarian crisis since 2017. Over 1 million people, including 720,000 children, are affected by this decade long conflict. Extreme cruelty and discrimination have forced millions of Rohingya refugees, mostly women and children, to flee across the border into Cox's Bazar, Bangladesh, making them vulnerable to family separation, abuse, exploitation, arrest, detention, and trafficking. The magnitude of violence has been much higher among women and adolescent girls. They had experienced horrific acts of gender-based violence from the Myanmar army before they fled, which like other refugee camps in other parts of the world, continued in Cox Bazar as well but on a larger scale. As a result, there has been an increased incidence of genital injuries, unwanted pregnancies, unsafe abortions, and sexually transmitted infections. Most of the victims cannot access sexual and reproductive health services due to stigma and healthcare costs. Public health and aid agencies have been focusing on treating physical trauma, infectious diseases, water, and sanitation, which improves refugees' overall health. However, little attention is paid to issues like child protection and gender-based violence resulting in lack of workforce and funding to deliver child protection and sexual and reproductive health services to the Rohingya women and girls in need. This paper argues that the brutality against Rohingya women and girls is due to their refugee status and ethnic affiliation and is deeply rooted in the beliefs, attitudes, and structures that tolerate gender-based discrimination. This wide range of gender-based abuse requires special attention from healthcare providers, local and international policymakers, and aid agencies because if this issue is left unaddressed, it will lead to a vicious cycle of untreated social disease of gender-based violence Rohingya girls, depriving Rohingya women and girls of their fundamental human rights.

Clinical Ethics Consultation at the Intersection of Emerging Technology, Informed Consent for Research, and Complex Language Barriers

Janice Firn[1], Andrew Shuman[1], Kayte Spector-Bagdady[1]
[1]*University of Michigan Medical School, , United States*

Biography:
Dr. Janice Firn's research focuses on interprofessional education and collaboration, clinical ethics, and clinician moral distress, burnout, and resilience. Her expertise includes clinical ethics, implementation of evidence-based practice in clinical settings, palliative and end of life care, and qualitative methods research.

Ph.D., Palliative Care, Lancaster University, 2016
M.S.W., University of Michigan, 2004
B.S., Michigan State University, 2001

Informed consent to medical interventions requires disclosure of information about the proposed intervention, the purpose of the intervention, and potential consequences and alternatives. But regulations approach this discussion completely differently dependent upon whether it transpires in the clinical or research context. Informed consent to clinical research, in particular, can conflate and confuse these two contexts. The challenges of informed consent for research, especially those involving experimental technologies, are widely documented. For patients who speak languages different than their clinicians in particular, ensuring sufficient patient understanding for informed consent in these situations is especially difficult. In addition to the necessity of meeting the ethical requirements of informed consent, there are legal and regulatory requirements for professional healthcare interpretation services both in clinical care and research. But for rarely spoken languages, these services may be limited or unavailable. This session explores the role of clinical ethics consultants when mandates for provision of healthcare interpretation services, experimental technologies, research regulations, and immigration and cultural issues intersect. These themes are elucidated in the context of a complex case involving informed consent for an experimental airway splint for a critically ill infant whose parents' native language is on the UNESCO list of languages in risk of extinction.

Investigating the Views and Experiences of Fetal Medicine Practitioners Offering Late Termination of Pregnancy in the Western Cape.

Jantina de Vries[1], Sydney Francois[1], Nakita Laing[1], Andrea Palk[2]
[1]University of Cape Town, , South Africa, [2]University of Stellenbosch, , South Africa

Biography:
Sydney completed her BSc in Human Physiology, Genetics and Psychology at the University of Pretoria in 2015, before going on to complete her BSc Hons in Human Genetics at Stellenbosch University in 2016. She completed her MMedSc in Genetic Counselling at the University of Cape Town in 2020. Sydney chose to pursue a career in genetic counselling as it marries her fascination with human genetics with a desire to connect with and help people. She has an interest in bioethics, particularly the ethical issues around medical genetics.

Introduction: Fetal medicine practitioners (FMPs) make decisions about the appropriateness of a late termination of pregnancy (LTOP) based on their assessment of the severity of the prenatal diagnosis while also taking into account the practical, legal and ethical aspects. This study aimed to investigate the views and experiences of FMPs involved in LTOP decision-making in the Western Cape and how these views may guide LTOP decisions. Specifically, the research questions guiding this study aimed to investigate FMPs views on the Choice on Termination of Pregnancy Act (CTOPA), No. 92 of 1996, as well as their attitudes towards the provision and ethics of LTOP.

Methodology: Six semi-structured, individual face-to-face interviews were analysed using an interpretive phenomenological framework. Transcripts were managed using NVivo 12 software.

Results: Participants believed that the CTOPA is based on the principle of gradualism and that while women have reproductive choice, TOP becomes progressively restricted as gestation advances to protect the fetus. However, they felt that the specified cut-offs in the CTOPA are arbitrary and open to interpretation and believed there is a need for further documentation to guide practitioners as to which conditions should be considered for LTOP. When making a decision to offer LTOP, participants considered various factors including fetal age, whether a feticide was required and the prognosis. Participants considered that conditions which qualified as severe were untreatable and would have a significant, long-term negative impact on the individual's functioning and quality of life. Participants felt that LTOP was justified to prevent suffering for both the future child and for the parents. However, they did not believe that LTOP was justified to prevent all disability. Lastly, participants valued societal consensus and believed that decisions around LTOP needed to be made by multidisciplinary teams to ensure objectivity, as well as to share the moral burden.

Is PrEP a genuine tool of empowerment? A discussion based on a qualitative study in the two years following the implementation of PrEP in France.

PERRINE GALMICHE[1], Foureur Nicolas[1]
[1]*Clinical ethics center (Assistance Publique - Hopitaux de Paris), , France*

Biography:
Perrine Galmiche is a philosopher who specialized in medical ethics. She is currently working in the Assistance Publique - Hopitaux de Paris Clinical ethics center and the National center for end-of-life and palliative care in France.

PrEP can sometimes be presented “as a lifestyle choice and not a biomedical tool” to incite its use in populations highly affected by the HIV epidemic, notably adolescent girls and young women in South Africa. Others argue that PrEP as a biomedical tool raises ethical concerns: prescription of a pill to heathy people; no preservation from other STI; risk of sexual disinhibition. Then, can PrEP be used to enhance patient autonomy, or is it necessary to consider it through the lens of the medical benefit-risk equation?
The study led by the Parisian Clinical Ethics Center to better understand how PrEP users and health professionals experienced PrEP in the two years following its implementation in France can help apprehend this question. 52 semi-directive interviews were conducted (31 PrEP users, 21 health professionals). The users were all-but-one homosexual men; three were migrants (in France for less than 5 years).
One physician who had female migrant patients in a sexual health center considered that prescribing PrEP went against her patients’ autonomy – PrEP being a tool allowing them to keep living in precarious conditions. Male PrEP users rather said that PrEP helped them gain more autonomy in their sexuality, even if some of them could be vulnerable concerning psychoactive products for example. Professionals considered PrEP to be always medically valuable for the patient but remained worried about public health issues, and questioned whether it was part of their responsibility to talk about sexuality with their patients. Professionals have to know why they are prescribing PrEP for it to be in the best interest of the patient and enhance his autonomy.

An African Philosophical Account of Moral Status

Dr Wandile Ganya[1]
[1]*Stellenbosch University, , South Africa*

Biography:
Wandile Ganya
Stellenbosch University
wandiganya@gmail.com

Generally, questions on ethical judgment emanate from the province of entities that enjoy moral status. It is therefore unsurprising to learn that the concept of moral status assumes much centrality in the formulation of moral theories and principles which inform ethical judgement.
In this paper I argue, contra atomistic conceptions, for an African philosophical account of moral status which better comprehends the complexity and landscape of clinical ethical consultation in Sub-Saharan Africa. I will discuss an account of African moral theory and community as a moral entity in the scope of reproductive health and emerging technologies.

Issues with the South African Choice on TOP Act in the context of fetal anomalies diagnosed late in pregnancy

Lut Geerts[1], Mike Urban[1]
[1]*University of Stellenbosch, , South Africa*

Biography:
MBChB, FRCOG, BScHons (Human Genetics), Dip Fetal medicine (UK)
Qualified as obstetrician in Belgium and currently registered as a subspecialist in Maternal and Fetal Medicine in South Africa.
Principal specialist and Lecturer in the Department of Obstetrics and Gynaecology and Head of the O&G Ultrasound and Fetal Medicine Unit of Tygerberg Hospital, University of Stellenbosch.
Chair of the Fetal medicine Module of the MPhil in Maternal and Fetal Medicine, University of Stellenbosch.
President of the South African Society of Ultrasound in Obstetrics and Gynaecology since 2013 and serving on the council of the South African Society of Obstetricians and Gynaecologists and its' expert opinion panel.
Author of 4 chapters in international books and more than 35 peer reviewed articles.
Main interests are prenatal screening and diagnosis, management of complicated pregnancies and education in ultrasound and fetal medicine.

With improved access to obstetric ultrasound and prenatal diagnostic services, severe fetal abnormalities are diagnosed more frequently but often only after fetal viability is reached. The Choice Act permits late termination for severe abnormalities but the flawed and vague wording of the Act is open to wide interpretation and has resulted in the inconsistent offering of TOPFA across the country. As a public health care facility, we felt it was essential to develop a deeper understanding of the underlying intention and principles of the Choice Act in this regard and to translate this into a policy for our drainage area that is fair, consistent, ethical and transparent.
After extensive reading on the subject of late TOPFA, multiple focus group discussions between professionals with different backgrounds within the perinatal medicine field firstly resulted in the formulation of clinically relevant interpretations of terminology used in the Act, including “termination” and the place of feticide procedures and “fetal malformation”. Our interpretation of the Act is that the presumption is in favour of life but that this inherent respect for life is not absolute but rather potentially rebuttable, but only for increasingly grave reasons with advancing gestation.
We based the definition of “severe” on ethical principles and the expected outcomes for the prospective child within the local health care and social context. The deliberations resulted in selection criteria to differentiate between conditions for which late TOPFA after viability would be offered in our unit or not and the ethical principles behind this selection. The policy document received wide Input from many parties of interest and is endorsed by the clinical ethics committee of the hospital. It has been extremely helpful in running a fair and ethical service in our unit and may be instrumental in developing a national policy on this matter.

Moral Challenges in Transgender Care: A Thematic Analysis Based on a Focused Ethnography

Marte Fleur Antonides[2], Annelou de Vries[1], MD MA Karl Gerritse[1], Laura Hartman[1], Bert Molewijk[1], Annelijn Wensing-Kruger[1]

[1]Amsterdam University Medical Center, , Netherlands, [2]Vrije Universiteit Amsterdam, , Netherlands

Treatment teams providing transgender-affirming medical care are inherently faced with various kinds of moral and ethical dilemmas and questions, which are becoming even more pressing due to increasing treatment numbers and public attention for transgender care. Little is known about what kinds of moral and ethical challenges manifest in clinical practice. The aim of the present research was to map the moral and ethical challenges of healthcare professionals working in a specialized multidisciplinary transgender care center. Over a period of 7 months, during a focused ethnographic study, data were collected through participant observation of multidisciplinary team meetings, observation of individual psychodiagnostic assessment sessions with clients, and analysis of transcripts and reports of a series of moral case deliberations. A thematic content analysis of the data identified various implicit and explicit moral and ethical challenges around the following six themes: (1) assessing eligibility; (2) content of treatment; (3) sequential order of the treatment steps; (4) role of the clinical guidelines; (5) differing notions regarding gender identity, and (6) decision-making process. Our research provides a detailed insight into the way healthcare professionals experience these moral and ethical challenges and how they are related to (local) guidelines, the multidisciplinary character of GD care, and its inherent implicit and explicit gender norms. Our findings suggest that good transgender care may profit from continuous multidisciplinary deliberation of and sensitivity toward the normative dimension of transgender care. The presentation ends with recommendations for ethics support mechanisms in transgender care.

Addressing Provider Distress & Resiliency: The Synergistic Relationship Between Clinical Ethics Consultation Services and CISM

Tyler Gibb[1], Amy Morrison-Maybee[2]
[1]Western Michigan University Homer Stryker M.D. School of Medicine, , United States, [1]Bronson Healthcare Group, , United States

Biography:

Presenter and Co-Authors
tyler s gibb, JD/PhD
Program in Medical Ethics, Humanities & Law
Western Michigan University Homer Stryker M.D. School of Medicine
1000 Oakland Drive
Kalamazoo, MI 49008
tyler.gibb@med.wmich.edu
269.337.4400
Presenter

It is no secret that healthcare providers at all levels are suffering. Rates of burnout, compassion fatigue, job dissatisfaction, and suicide are alarmingly high across most countries. Often, requests for clinical ethics consultations (CEC), where such services are available, are centered on particularly troubling cases, families, patients, and team conflicts. The moral and emotional burden on both providers and clinical ethicists of these cases is significant. Despite the increasing interest in standardization of core competencies and formalization of training programs of clinical ethicists, clear gaps in expertise exist and are likely to remain. Unfortunately, this lacuna in competence often aligns with the most troubling of cases. CECs are often called upon to provide support for providers experiencing emotional, professional, existential, and moral distress. Despite the varied backgrounds of CECs, helping providers to defuse, debrief, and process distressing situations is often outside of their professional training or competence. However, professionals with this critical skillset and training exist and can effectively augment CEC services. CISM team members receive specialized training in how to help individuals, generally first-responders and other high-stress professionals, in defusing high-stress situations, providing one-on-one interventions, and in processing and debriefing traumatic experiences—critical to supporting reliance, professional well-being, and healthy emotional adjustment. This presentation will describe the synergistic relationship between Critical Incident Stress Management (CISM) teams, who possesses these critical skills and training, and CEC services. This presentation will describe the types of training CISM team members receive, provide case examples of when CEC and CISM teams have worked together, and how CISM teams and training might augment other CEC efforts.

BEdR: Getting Better at Bioethics Education

Amy DeBaets[2], Marin Gillis[1]
[1]Florida International University College of Medicine, , United States, [2]Hackensack Meridian Health, , United States

Biography:
Marin Gillis is a philosopher, bioethicist, and medical educator. She is chief of the Division of Ethics, Humanities and the Arts (DEHA) at the Herbert Wertheim College of Medicine (HWCOM) at Florida International University. She has published in the area of ethics and medical biotechnologies but is more recently devoted to the scholarship of medical and interprofessional health education. Leadership in education includes directing the USA Working Group of the international Cambridge Consortium for Bioethics Education and co-chairing the Ethics and Humanities Educators in the Health Professions affinity group at the American Society of Bioethics and Humanities (ASBH). Recently, she has cycled off a three-year term on the Steering Committee for the American Association of Medical Colleges (AAMC) Group on Women in Medicine and Science (GWIMS). Dr. Gillis is a full Professor in the Department of Humanities, Health, and Society, a Faculty Associate in the FIU Women and Gender Studies Program, and a past fellow at the FIU Honors College.

BEdR: Getting Better at Bioethics Education
Introduction: Education is one of three main deliverables of a hospital ethics committee, that also include consultation and policy-making. We know very little about what makes bioethics and humanities education effective. We do know that existential burnout and moral distress among trainees and clinicians- two of the primary learning outcomes often associated with bioethics and medical humanities interventions- are rising. Improving the design and delivery of bioethics education interventions is a need.

Discussion: Bioethics Education Resources (BEdR) www.bedr.education is a project of the international Cambridge Consortium of Bioethics Education and consists of a free webinar series, now in its second year, on conducting educational research in bioethics for health professionals and trainees and a free open-source collection of peer-reviewed teaching resources. https://www.bedr.education. Its goals are: 1) Training bioethics educators in best practices in conducting education research; 2) Reviewing and disseminating effective and innovative educational interventions for health professionals in medical ethics for use at other institutions. We have given two national-level workshops on designing and submitting educational resources for peer review and hosted one webinar series to date with a second starting in January 2020. Feedback on these initial activities has been uniformly positive and participants indicated significant increase in their comfort in their ability to formulate a research question in bioethics education, utilize qualitative, quantitative, and mixed methods research, and identify suitable venues to publish scholarship of teaching and learning in bioethics.

Conclusion: In this session we will walk participants through the resources and how to submit their own teaching resource.

Treatment, Fair Equality of Opportunity, and the IAAF Eligibility Regulations for Female Classification

Susan Hall[1]
[1]*Stellenbosch University, , South Africa*

Biography:
Dr Susan Hall is a lecturer in the Philosophy Department and Centre for Applied Ethics at Stellenbosch University. Her PhD dissertation focused on the ethics of biotechnological human enhancement, and her research interests include Bioethics and Environmental Ethics. Her current areas of research are ethical issues raised by technology in various contexts and medical ethics in sport.

The IAAF Eligibility Regulations for Female Classification, which govern the participation of athletes with DSDs in certain athletic events, have recently been upheld by the Court of Arbitration for Sport, a judgement which South African middle distance runner Caster Semenya is appealing. These regulations raise questions about fairness in sport, but importantly, they also raise medical ethics concerns, given that medical professionals will necessarily be involved in their implementation. One of these concerns, raised in an open letter by the WMA, has to do with whether the interventions required by the regulations are legitimate medical treatments. The IAAF has insisted that they are, and implicitly seems to subscribe to a 'normal function' model of medicine in support of their position. However, the discrepancies between this model, as outlined by Normal Daniels, and the regulations proposed by the IAAF, reveal two things. Firstly, while the moral motivations of medicine for both the normal function model and the regulations have to do with fair equality of opportunity, these motivations are skewed in the latter case, in that the intention is not to achieve fair equality of opportunity for the patient, but for others in her reference class. Secondly, an examination of the constitution of the category of normal functioning under the regulations shows that they amount to a form of sex verification which the IAAF claims to have abandoned.

Social media and the impact on the medical decision in Taiwan: Past, now and future

Jack Tien-Yu Huang[1]
[1]*NTUH, , Taiwan*

Biography:
Current position:
* Hepatologist, Far Eastern Memorial Hospital, New Taipei City, Taiwan
* Master degree in Department of Medical Education & Bioethics / Graduate Institute of Medical Education & Bioethics, National Taiwan University College of Medicine
* Assistant Professor in Ming Chuan University, Taiwan
** Guest Lecturer in Medical Bioethics, Peking Union Medical College, Peking, China*

Social media had became important parts of life today. While lots of medical information is shown on the social media, with no reviewing system about the contents in Taiwan, many people are affected deeply, no matter right or wrong, about their medical seeking behavior and the interaction with doctors. On the other hand, many doctor's daily practice is changed by social media. The aim of this study is to analyze the impact of social media on clinical practice and the patient doctor relationship in Taiwan.

We survey the medical information on the Facebook, Twitter, Instagram, Youtube and Internet news in Taiwan. We chose three most popular articles about medical information according to the click through rate (CTR) and gave them to different ages of doctors with different specialists and different working places (medical center, local hospital or clinic). We had depth interview with them and analyze the transcript.

The education in Taiwan about media literacy is lacking for general population. Also, the medical education about digital professionalism is scarce. All the interviewees admitted that due to the effects of social media, they changed their medical practice even if they knew it was wrong to do so. Over-treatment or under-treatment were quite common in Taiwan. The root cause analysis showed that the peer effect, afraid of medical dispute and the legal issue, and lacking medical knowledge other than their specialists are the most common causes. The impact of social media on clinical practice affected the medical practice in doctors, medical seeking behavior in general population, patient doctor interaction and the process of share decision making. However, due to the characteristics of the media, the information is usually not complete. Education about the media literacy on general population and the digital professionalism on doctors are both important in Taiwan nowadays.

Inpatient Deaths of Children With Cancer: What Do We Know About DNAR and CPR?

Hanna Allen[1], Justin Baker[1], Liza-Marie Johnson[1], Chen Li[1], Zhaohua Lu[1]
[1]*St. Jude Children's Research Hospital, , United States*

Biography:
Dr. Liza-Marie Johnson is a physician-bioethicst who received her MD and MPH from Tulane University and a Masters in Bioethics from Clarkson University. She completed her pediatric residency at Tufts University in Boston and pediatric oncology fellowship at St. Jude Children's Research Hospital in Memphis. Dr. Johnson is an assistant member and Program Director of the Oncology Hospitalist Program at St. Jude Children's Research Hospital. As a bioethicist, Dr. Johnson is engaged in clinical and research ethics consultations. She serves as Chair of both the Hospital Ethics Committee and Institutional Review Board at St. Jude. Dr. Johnson's academic scholarship focuses on parental decision-making in both clinical and research contexts. She is well published in both pediatric oncology and bioethics with a national reputation in the arena of Pediatric Bioethics.

Introduction: Death in children with malignancy may result from refractory disease or acute complications during therapy. End-of-life research commonly focuses on palliative care; however, little is known about the medical interventions received in the last week of life from the overall cohort of children who die from cancer or related complications. We sought to describe the inpatient medical management of children with cancer during the last week of life.
Methods: Retrospective chart review of inpatient pediatric oncology deaths, examining the medical record for interventions at the time of death as well as 7 days prior to the event. The record was reviewed for use of chemotherapy, acute events, intensive care unit (ICU) admissions, initiation or limitation of life-supportive medical therapies, and code status.
Results: Of 344 inpatient oncology deaths (mean age = 11.32 years), DNAR orders were common (76%), despite 51% of deaths occurring in the ICU. Of the 83 children without a DNAR order, 32 (39%) did not receive CPR at death due to guardian request. Only 12% (n = 39) received CPR at the time of death; however, location of death in the ICU (Odds Ratio = 17.2, CI: 6.06-48.88, P<0.0001) or lifetime admission to the ICU (Odds Ratio = 4.637, CI: 1.40-15.36, P<0.006) was associated with a significantly increased likelihood of CPR.
Discussion: The most common reason for CPR at death was a potentially reversible cause of arrest. Having previously had CPR decreased the likelihood of CPR at death, either due to written DNAR or parent refusal. Very few patients received CPR during their terminal event and lack of a formal DNAR did not guarantee that potentially non-beneficial CPR would be performed.
Conclusion: Further analysis is needed to better understand other factors that impact the decision to have a DNAR or initiate CPR at death.

Promoting the establishment of Clinical Ethics Committees in Africa

Siti Kabanda[1], Anita Kleinsmidt[1], Sharon Kling[1], Keymanthri Moodley[1], Adetayo Emmanuel Obasa[1], Leza Soldaat[1]
[1]*University of Stellenbosch, , South Africa*

Biography:
Siti Kabanda is currently working on a research project at the University of Stellenbosch, Centre for Medical Ethics and Law.
The research project is assessing the establishment of Clinical Ethics Committees in Africa. Siti has MPH and MSc (Cell biology). Her current research interests include public health and ethics.

Background: Healthcare in the 21st century is fraught with ethical dilemmas. Advances in life-prolonging technologies have created dilemmas that are important, value-laden and highly complex. With increasing awareness surrounding the ethical dimensions of clinical practice, Clinical Ethics Committees (CECs) are being established in order to provide consultation services to ensure high standards of ethical practice in the clinical environment. CECs are common in the United States and Europe. However, in Africa, there is limited information on the existence and functionality of CECs. In some regions in Africa, resources are constrained and access to healthcare professionals is suboptimal rendering the need for sound clinical ethics decision-making even more pressing. The aim of this study is to establish baseline data regarding the existence of formal CECs in Africa.
Methods: An online survey was sent to health professionals and academics involved in bioethics in African countries. This was followed up with telephonic in-depth interviews. Descriptive statistics and thematic analysis were used to analyse the data.
Results: A total of 91 participants (representing 30 African countries) responded to the survey. Of this sample 74% (67/91) indicated that they do not have established CECs in their institutions. This was due to lack of resources, training and awareness of CECs. Most respondents 88% (59/67) indicated that they would be interested in establishing CECs in their countries. Participants suggested that they will need funding, capacity building and training in establishing CECs.
Discussion: Preliminary findings suggest there is a confusion between research ethics committees and CECs. Thus, the need for the establishment of CECs or clinical ethics consultation services in Africa. This study aims to assess how CECs can be implemented or strengthened to improve the quality of healthcare in Africa. The study is ongoing.

End-of-Life Decision-Making in Family Meetings: Strategies for Understanding and Addressing Cultural Imperatives

Dr. Shaylona Kirk[1]
[1]*N/A, , Japan*

Biography:

Dr. Shaylona Kirk is a physician and bioethicist currently living in Okinawa, Japan, providing bioethics consulting and training services for healthcare organizations. She is also an expert faculty member for the American College of Preventive Medicine. Dr. Kirk received her M.D. from the University of Arizona, an M.A. in Biomedical and Health Ethics from Arizona State University, and an MPH from the University of Florida. She completed a Clinical Ethics Fellowship at California Pacific Medical Center. Prior to moving to Japan, Dr. Kirk worked as a full-time bioethicist for the Program in Medicine and Human Values for the Sutter Health System in San Francisco, CA and the greater Bay Area. Dr. Kirk has also practiced as a preventive medicine physician, served on numerous ethics committees, functioned as a consultant and educator for the Arizona Bioethics Network, and worked as an ethics consultant for the Health First Hospital System in Florida.

The vibrant, multifaceted city of San Francisco is home to a multitude of ethnically diverse communities with a staggering number and variety of cultural experiences represented in its patient population. Consequently, clinical ethicists in that city as well as in similar settings around the globe often encounter cultural contexts, especially spiritual beliefs, family dynamics, and social traditions, that play an important role in end-of-life decision-making. Frequently, a properly facilitated family meeting is the most productive and efficient vehicle for reaching agreements that reduce stress while respecting and accommodating, as much as possible, the patient's cultural heritage. To achieve this goal, clinical ethics consultants should be trained to: 1) avoid making cultural assumptions through the development of cultural humility and, 2) take the steps necessary to learn about the relevant cultural values directly from patients and their families. Cultural humility occurs when we admit our limited knowledge about another person's culture and uphold a patient-oriented position in relation to their cultural identity. Like any interpersonal relationship skill, it requires guided self-reflection and significant, directed practice in recognizing our own cultural biases and sincerely conveying reverence for expressed cultural imperatives. Strategies helpful in exploring core cultural values with patients/families include: 1) Asking open-ended questions to invoke the patient's story and how it interrelates with family and community, 2) Affirming the right to express cultural views, 3) Reflective listening and summarizing to clarify the CEC's accuracy of cultural comprehension, and 4) Asking for permission to inform about options that are clinically and ethically appropriate. Such an approach supports medical teams in mitigating pressure from families to provide non-beneficial treatments and promotes cooperation and agreement in end-of-life decision-making. It also serves to focus the family on what matters most to them, saves time by reducing cultural misunderstandings, and promotes trust between patients, their families, and the healthcare team.

Live and let die: The living will in SA law

Melany Hendricks[2], Anita Kleinsmidt[1]
[1]*Stellenbosch University, , South Africa,* [2]*Stikland Hospital, , South Africa*

Biography:
Anita Kleinsmidt is a senior lecturer at the Centre for Medical Ethics and Law at the Faculty of Medicine, University of Stellenbosch. She formerly practised as an attorney in Johannesburg.

Melany Hendricks is Chief Clinical Psychologist at Stikland Hospital, Bellville. She is currently studying towards a PhD in constitutional law.

Euthanasia and assisted suicide are currently illegal in South Africa. Some patients use advance directives – 'living wills'– to indicate their choices. The Supreme Court in Clarke v Hughes NO without commenting directly on the legality of the living will, stated that 'the patient's wishes as expressed when he was conscious should be given effect to'. The Health Professions Council of South Africa recommends that patients should be encouraged to use living wills. We will discuss 3 cases that came before a hospital ethics committee in the Western Cape, where doctors were faced with living wills. These cases highlight the ethical dilemmas that clinicians face when dealing with living wills. In case 1, the signature on the document did not appear genuine, highlighting the dilemma of effecting a choice with permanent consequences on the basis of a document with uncertain origins. Case 2 presented a similar dilemma where a patient with disseminated testicular cancer had deteriorated to the point of requiring intubation and ICU care. A formerly estranged family member produced a signed and witnessed living will. The doctors elected to continue with intensive care. The patient recovered consciousness and disputed that he had signed the document. In case 3, a patient with previous stroke and right hemiplegia unexpectedly required admission to ICU post-sigmoidoscopy, requiring long-term ventilation. His wife produced a living will indicating refusal of intubation, which the surgeons were uncertain about acting upon. Here the issue was not the authenticity of the document, but the vagueness of the language in a situation not forseen by the patient. Living wills are drafted to provide clarity and guidance when patients are unable express their wishes themselves. However, the current legal situation is nebulous and open to abuse, leaving doctors to exercise their judgement on the efficacy or futility of treatment strategies.

Cross-cultural considerations in paediatric clinical ethics consultation at the end of life

Sharon Kling[1], Kurt Maart[3], Keymanthri Moodley[2]
[1]Department of Paediatrics and Child Health, Stellenbosch University, , South Africa, [2]Centre for Medical Ethics and Law, Stellenbosch University, , South Africa, [3]Senior Medical Manager, Tygerberg Hospital, , South Africa

Biography:
Sharon Kling is an associate professor in the Department of Paediatrics and Child Health at Stellenbosch University. She has an MPhil in Applied Ethics and is currently enrolled for a PhD in Clinical Ethics Consultation. She is a member of the Clinical Ethics Committee at Tygerberg Hospital in Cape Town.

"A pluralist, cosmopolitan society is a society which not only accepts difference, but actively seeks to understand it and to learn from it. In this perspective, diversity is not a burden to be endured, but an opportunity to be welcomed." Aga Khan IV, 2015.

Different belief systems influence interactions between healthcare providers (HCPs) and patients and their families. South African HCPs are trained in western medicine and may not understand the deeply held beliefs and values of patients and families from different cultures.

A 3-month-old baby had been ventilated since birth in the Neonatal ICU. He was diagnosed with surfactant Protein B deficiency, for which no therapy is available. The baby was expected to die imminently. The parents were counselled and requested that a traditional healer visit the baby and administer herbal medicine to him. The hospital's Clinical Ethics Committee (CEC) was consulted.

Should the parents' wishes and beliefs be respected despite the potential risk of causing harm and suffering to the baby? If the HCPs would not permit herbal medicine to be administered to a baby with a good prognosis, should they permit it for a terminally ill baby? Should a waiver of legal liability be sought if permission was granted for the administration of the traditional medicine?

The CEC was unable to achieve a consensus opinion. The clinical team refused permission for the herbal medicine to be administered.

Reflection on this case evokes a feeling of disquiet. What harms would have resulted from allowing the parents to do everything possible for their dying child? The outcome implies a lack of cultural humility, which constitutes an approach to resolving power imbalances and respecting others' rights by engaging in dialogue with them. It also holds implications for the functioning and composition of the CEC.

A plea for patient virtues in the clinic

Jos Kole[1]
[1]*Radboud university medical center, , Netherlands*

Biography:
J.J. (Jos) Kole is assistent professor in 'ethics and philosophy of healthcare' at the Radboud university medical center in Nijmegen (The Netherlands). Trained as moral philosopher (PhD), Jos has diverse clinical ethical roles in the Radboud university medical center. He teaches ethics and philosophy of healthcare to medical (and other) students and residents. Apart from that he also does research, especially in professional (virtue) ethics and concerning 'the virtuous clinic'. Jos also regularly functions as moral case deliberation facilitator on the ward in the clinic.

Patient-ethics (that is, ethics concerning the moral responsibilities of patients towards others and themselves) and especially patient virtue ethics are still largely neglected topics in clinical ethics. The positive claim defended in this paper is that more clinical-ethical attention should be paid to patient ethics and patient virtues, to enable all members of the moral clinical community to flourish, each in his/her own way, in response to one's own circumstances and context, to the extent possible given these circumstances.

To defend this claim I first (re)introduce patient ethics and, more specifically, patient virtue ethics, in dialogue with the relative small body of literature on both topics (see e.g. Miles, 2019). Then I discuss arguments why neglect of this type(s) of ethics is undesirable and more attention should be paid to this approach.

An important line of argument will be that a patient (virtue) ethical approach corrects the current onesided focus in bio- and clinical ethics on professionals as ‘moral agents’ and patients as ‘moral patients’ (object of moral concern). It stresses the consequences of the idea that clinics are moral communities in which all members, both patients and professionals, can and should be considered as both moral subject and moral patient.

The paper ends with a research agenda that shows the interesting and inspiring questions that still have to be answered in further patient (virtue) ethical research in a clinical context.

This paper is part of a larger research project 'Towards a virtuous clinic?' that was introduced in a keynote-lecture at ICCEC 2019 in Vienna.

Philosophies of Front-Line Clinical Ethics: Responsibilities for Education and Consultation

Virginia Bartlett[1], Andy Kondrat[1]
[1]*Cedars-Sinai Medical Center, , United States*

Biography:
Andy Kondrat, PhD, is a Clinical Ethics Consultant in the Center for Healthcare Ethics and Instructor of Biomedical Sciences at Cedars-Sinai Medical Center in Los Angeles, California. He received his PhD in philosophy from Loyola University Chicago, and his BA in philosophy from Boston College.

In the United States, many Clinical Ethics Consultation Services regularly round with clinical teams as part of their practice. This rounding often has two kinds of "preemptive ethics" aims: first, seeking to avoid last minute "crisis consults" that are called in order to "put out fires"; second, supporting education and the development of a "culture of ethics" within the institution. In addition, such rounding offers clinical ethics consultants important opportunities for learning about the concerns, culture, communication, and clinical teaching that occur in particular units, which can offer helpful information when ethics consultation requests subsequently arise. Such rounding, however, can also create tensions for ethics consultants when clinical encounters raise or highlight moral and ethical challenges which are themselves not understood by clinicians as concerns that would compel an ethics consultation. When this occurs, core questions of responsibility arise for ethics consultants reflective of both institutional and performative practices of clinical ethics consultation.

To illustrate, our presentation begins with a brief description of a clinical teaching moment rife with typical, even recurrent issues about physicians' clinical responsibilities, in which an ICU attending physician seems to be "teaching the wrong thing" while undercutting the culture of ethics we hope to foster. Specifically, in this teaching moment, the physician both models and makes explicit that "temporary peace and moving on" are to be valued over identifying and responding to unit or system-based causes of patient-team conflict. Against this frame, four different roles that ethics consultants might embody in response (observer, diplomat, guerilla, and cavalry) are outlined. After exploring some of the philosophies and commitments underlying each role, we invite the audience to identify and consider potential benefits and risks of each response in trying to address the "moral moment" of a given encounter.

Rare Diseases, health care access and the South African National Health Insurance Coverage

Mariana Kruger[1]
[1]*Department of Paediatrics and Child Health, Faculty of Medicine and Health Sciences, Stellenbosch University, , South Africa*

Biography:
Mariana Kruger is a paediatric oncologist and ethicist. She is currently a full professor and executive head of the department of Paediatrics and Child Health at Tygerberg Hospital, Stellenbosch University. She is past African Continental President for the International Society for Paediatric Oncology (SIOP). She has publications in paediatric oncology, paediatric HIV, research ethics, several chapters in books and has been editor and author of an African research ethics guidebook with the title "Research Ethics in Africa: A Resource for Research Ethics committees" (Co-editors: Drs Lyn Horn and Paul Ndebele) .
She is a founder member (2003) and co-principal investigator of South African Research Ethics Training Initiative (SARETI), funded by Fogarty International Center, NIH, USA, which aims to build African research ethics review capacity (currently in 3rd funding cycle) and an honorary professor in the School of Applied Human Sciences (Discipline of Psychology), University of KwaZulu-Natal. She has served on several ethics review committees (including as either chair or deputy chair for the last 10 years) and is currently a member of the Stellenbosch University Senate Ethics Review Committee, Stellenbosch University.

The management of rare diseases poses major challenges for any health care system, as resources are limited in low and middle income countries, of which South Africa is one. Resource allocation in healthcare in these countries is usually done using a utilitarian approach to ensure that the greatest number of persons benefit from the available resources. The focus is on the burden of diseases, especially prevention and treatment of common diseases. In the case of rare diseases, the access to expensive therapies are decide on a case-by-case basis by referral to the local clinical ethics committee to assist in the decision-making, using the principles of beneficence and distributive justice. The key question is whether it is ethically justified to only use this approach, especially as South Africa is in the process of establishing National Health Insurance (NHI), which will ensure that all South African citizens have access to essential health care, regardless of socio-economic circumstances or monetary contribution. A fair system should ensure that no one is left behind and that persons suffering from rare diseases should also gain access to essential medicines for their conditions, especially under the "Rule of Rescue". This paper will explore the various pathways the NHI can use to support healthcare access for persons suffering from rare diseases, exploring the underlying ethical arguments for healthcare resource allocation according to the principle of distributive justice. Furthermore, national rare diseases guidelines will guide clinical ethics committees with the tough decision-making involved for the management of rare diseases and should be developed.

The use of social media by health professionals: Ethical and legal pitfalls

Brenda Kubheka[1]
[1]*Drs B Kubheka and partnerts Inc., , South Africa*

Biography:
Dr. Brenda Kubheka
MBChB, PDBA, Dip Proj Mngt., MBA, Clin Ethics cert. and Phd candidate
Ethics and risk management lead
Health IQ Consulting

The use of social media as a communication and networking tool has increased globally. It provides a platform for building social and professional relationships that can be used by anyone with internet access, including healthcare professionals. It has brought benefits of facilitating social and professional networks and has disrupted geographical barriers. It has enabled the spread of information wider and faster compared to traditional communication channels. The use of messaging applications like WhatsApp have brought efficiencies in communication amongst colleagues, professional groups, including support groups. These platforms bring ethical and legal challenges for health professionals, especially when communicating with or about patients, which includes sharing pictures and clinical information. Confidentiality and privacy are owed to patients and other stakeholders like colleagues and employers, both online and offline. A professional's online behaviour is subject to ethical and legal standards in spite of the "online disinhibition effect" of lowered social restraints experienced during online activities. Creating awareness about this cyberpsychology phenomenon is a critical proactive measure in managing risks associated with online activities. Social media posts and messages have a life of their own, which may leave permanent digital footprints and may attract negative consequences. Critically, young trainees bring their entrenched digital habits when joining medical schools therefore accentuating the need for social media training amongst trainees and professionals. There are benefits associated with the use of these platforms and professionals ought to acknowledge corresponding risks.

Exploring diversity of values in ethical decision-making

Prof. Axel Liégeois[1]
[1]*KU Leuven (University of Leuven, Belgium), Leuven, Belgium*

Biography:
Axel Liégeois is full professor of care ethics and practical theology at the Faculty of Theology and Religious Studies, KU Leuven, Belgium.
He holds the Chair of the Brothers of Charity for Theology, Mental Health and Disability. He is also posted as ethical advisor to the Brothers of Charity in Gent, Belgium, where he coordinates clinical ethics committees, gives ethical advice and ethical education.
His research, teaching and services focus on ethics in spiritual care and in the care for people with mental health problems or intellectual disabilities. His passion is to train and empower people in ethical deliberation, so that they can make responsible decisions based on the ethical model 'values in dialogue'.
In addition to articles in journals and contributions to collected volumes, he is co-editor of "'After You!' Dialogical ethics and the pastoral counseling process" (Leuven: Peeters, 2013), co-editor of "Autorité et pouvoir dans l'agir pastoral" (Namur/Paris: Lumen Vitae, 2016), and author of "Ethics of Care: Values, Virtues and Dialogue (Values in dialogue. Ethics in care" (Newcastle upon Tyne: Cambridge Scholars Publishing, 2021).
A selection of his publications can be consulted and downloaded at the webpage https://theo.kuleuven.be/values-in-dialogue

Introduction. Decision-making in clinical ethics is philosophically based on an assessment of fundamental values or principles. Beauchamp and Childress discerned four 'principles of bio-medical ethics' (2019): respect for autonomy, beneficence, non-maleficence and justice. Specifically for the care of people with mental illness or with intellectual disability, we have designed a framework of ten fundamental values in our book 'Ethics of care: values, virtues and dialogue (Cambridge Scholars Publishing, 2021): support and protection (traditional values); autonomy, privacy and well-being (emancipatory values); participation, justice and sustainability (societal values); and trust and solidarity (relational values). A decision is ethically justified when the stakeholders in care, through dialogue and driven by virtues, obtain a reasonable or proportional assessment of values.
Discussion. Inevitably, such philosophical frameworks are marked by the Western culture in which they were developed. We can ask whether we can also work with these values when we are involved in intercultural and interreligious encounters in Western or non-Western care facilities. Many stakeholders in care have a background in various cultures and religions: care users, their families and care providers. At first glance, people from many cultures and religions acknowledge these values, but they make different evaluations and set other priorities. Closer examination often reveals that implicit values play a role: values form a non-Western culture and values interwoven with a specific religion, such as related to the honor of the family or the community, or the woman-man relationships, or religious customs or rules. That is why we have extended the philosophical framework of ten fundamental values to include a free space for a specific cultural or religious value. The stakeholders in the ethical decision-making can make a specific value explicit at this free place and include that cultural or religious value in the assessment of all values at stake.
Conclusion. By adding a specific cultural or religious value, we integrate the diversity of values into the philosophical basis of clinical ethics.

What and how do trainees learn in a course to become facilitator MCD?

Wieke Ligtenberg[1], Bert Molewijk[1], Margreet Stolper[1]
[1]*Amsterdam UMC, , Netherlands*

Biography:
Wieke Ligtenberg is junior researcher the department of Ethics, Law and Humanities at Amsterdam UMC. She works with Margreet Stolper en Bert Molewijk.

In Europe Moral Case Deliberation (MCD) has been developed as an established form of Clinical Ethics Support (CES). The latest years there is globally an increased interest in MCD. Amsterdam UMC offers a solid training program based on experiential learning. For more than a decade it trained more than 1200 (healthcare) professionals to be facilitator MCD. In the training trainees are expected to practice MCD and the role of facilitator in their own work context. Various tools and didactical methods are used to assess trainees and indirectly the quality of CES they provide. One of those tools is an assessment form in which trainees reflect upon their skills and attitude as a facilitator MCD. The trainees' learning goals play an important role in this reflection process and are part of the assessment form. The learning goals reflect not only the learning process of the trainee but also provides insight in the quality of the MCD facilitation process. Next, it provides information for trainers in mentoring the trainee and about what to set on the agenda in the training sessions. To gain more knowledge about the learning process of trainees and specifically about the difficulties and troublesome parts they experience in facilitating MCD, we started a study that analyses the assessment forms of 750 trainees. Part of the study is a qualitative research on the learning goals of trainees in which we try to find answers on the questions: how do facilitators develop their role as a facilitator? What or where do trainees experience difficulties and how does goal setting change with increasing experience? In the presentation we will present a brief overview of our training program and its theoretical background, the assessment form and preliminary results.

AI-Assisted Decision-making in Healthcare

Dr Tamra Lysaght[1], Hannah Yeefen Lim[2], Vicki Xafis[1], Kee Yuan Ngiam[1]
[1]National University of Singapore , , Singapore, [2]Nanyang Technology University , , Singapore

Biography:
Dr Lysaght is Director of Research and Phase Director of the Health ethics, Law and Professionalism (HeLP) program at the Yong Loo Lin School of Medicine at the Centre for Biomedical Ethics, National University of Singapore. She has expertise in empirical bioethics and experience in using both qualitative and quantitative research methods to inform normative questions pertaining to emergent biotechnologies and the biomedical sciences. Her work focuses on emerging health and biomedical technologies, including stem cell research and regenerative medicine, precision medicine and genomics, Big Data and AI in healthcare.

Artificial Intelligence (AI) is set to transform healthcare. Key ethical issues to emerge with this transformation encompass the accountability and transparency of the decisions made by AI-based systems, the potential for group harms arising from algorithmic bias and the professional roles and integrity of clinicians. These concerns must be balanced against the imperatives of generating public benefit with more efficient healthcare systems from the vastly higher and accurate computational power of AI. This paper focuses on how these issues arise with the development and implementation of AI-assisted clinical decision support systems (CDSS). Our analysis suggests it is important that developers and implementers of AI-assisted CDSS put in place control mechanisms to protect individuals and groups from harms arising through these tools. At the same time, these controls must not be so restrictive as to prevent the public benefits they can also deliver for health systems.

Is Institutional Conscientious Objection to Gender-Affirming Interventions Ethically Justifiable?

Janet Malek[1]
[1]*Baylor College of Medicine, , United States*

Biography:
Janet Malek, PhD is an associate professor of medicine and medical ethics at Baylor College of Medicine's Center for Medical Ethics and Health Policy and the director of the Houston Methodist Biomedical Ethics Program. In these roles, Dr. Malek designs and teaches ethics and professionalism programs for Baylor residents and medical students, conducts research on the implementation of genomic sequencing into clinical practice, and carries out ethics consultation and other ethics activities throughout the Houston Methodist Hospital System. She also serves as the Past Chair of the Board of Directors of the Academy for Professionalism in Health Care. Her research focuses on issues related to clinical ethics, genomic and reproductive ethics, and professionalism education.

Introduction: In the United States, a movement toward protection of religious freedom has gathered strength in recent years. At the same time, a pattern of institutional mergers between religious, predominantly Catholic, and secular facilities is emerging, leading to increasingly centralized, religiously-based decision making about access to medical procedures. These factors are creating a care environment increasingly hostile to patients seeking gender-affirming intervention, even as the demand for such treatments is growing. More people are identifying as gender diverse and new data is giving health care providers a better understanding of the risks faced by this vulnerable population as well as the significant medical benefits associated with gender-affirming interventions. The colliding trends of growing interest in gender-affirming intervention and decreasing number of institutions willing to provide such therapies raise ethical questions about how healthcare institutions should balance these conflicting considerations.

Discussion: This presentation explores whether healthcare institutions can be ethically justified in creating policies against providing gender-affirming interventions. Competing institutional obligations to promote their patients' well-being as well as to protect vulnerable populations conflict with such policies. Further, there are reasons to question whether refusals to offer gender-affirming interventions are based on genuine conscientious objection or on prejudice. The tension between these considerations and claims about the need to respect healthcare providers' deeply held moral beliefs will be described and evaluated.

Conclusion: The arguments supporting access to gender-affirming interventions and the doubts about decisions to decline to offer these interventions support a conclusion that healthcare institutions should avoid establishing policies or practices that restrict the delivery of appropriate care for transgender patients on the basis of conscientious objection. If they proceed with doing so, additional measures must be taken to help mitigate the possible impact that such practices may have on a growing, vulnerable population.

With twins who's benefit is most beneficial?

David Mann[1]
[1]*Baylor College of Medicine, , United States*

Biography:
I'm a Pediatric and Obstetric Anesthesiologist, practicing at the Texas Children's Hospital in Houston. My clinical interests involve providing anesthesia to both the pregnant woman and her fetus during fetal surgical interventions.

My professional training includes a BS in physics from Juniata College, an MS in medical physics from the University of Pittsburgh, an MD from the Drexel University College of Medicine, and a DBe from Loyola-Chicago in Bioethics. My current academic title is Associate Professor of Anesthesiology, Medical Ethics, and Pediatrics at the Baylor College of Medicine.

I'm the Associate Chief of the Clinical Ethics Consult service. As an important practical interest, I chair the Fetal Therapy Board (Ethics Committee for the TCH Fetal Center) where we review fetal surgical interventions that are too novel to warrant IRB approval.

My presentation will explore possible ethical support, or lack thereof, for performing an EXIT to airway procedure for the benefit of one twin while imposing risk/burden upon the co-twin under the pregnant woman's informed consent. The fetal lesion is a large neck mass that completely obstructs the airway; the fetus would not survive ex-utero without an artificial airway prior to surgical resection of the mass.

An EXIT to airway procedure involves exteriorizing the uterus, making a hysterotomy (uterine incision), exposing the effected fetal head, and inserting an endotracheal tube (breathing tube) into the airway while the fetus is still supported by the placental circuit (before the umbilical cord is cut). For a singlet pregnancy, this procedure is standard of care at our institution. For a twin gestation with only one effected twin, the unaffected twin assumes significant burden (risk) during the procedure that is intended to benefit only the co-twin.

Classically the unaffected twin would not be subjected to any burden for the co-twin; however, in an era of genetic selecting of an embryo based on donor match compatibility, this prohibition may no longer hold.

Can machine learning algorithms provide care? The case of apps for mental health and well-being

Nikola Biller-Andorno[1], Tania Manriquez[1], Manuel Trachsel[1]
[1]*Institute of Biomedical Ethics, , Switzerland*

Biography:
Tania Manríquez holds a BA in Social Anthropology (University of Chile), an MA in Global Ethics (King's College London) and is conducting her PhD in Bioethics at the University of Zurich.

As a social anthropologist and ethicist, she has developed qualitative methodologies and conducted in-depth interviews on development, human rights and global health topics in Africa, Europe and Latin America. She has experience as a consultant and researcher in projects for the World Health Organization, UNICEF, the European Commission, the Center for Development and Cooperation (NADEL, ETH Zurich), the Center for Child Well-Being and Development (University of Zurich) and the Human Rights Centre (University of Chile).

Tania is currently developing the project "Global Health Ethics Platform", an interactive website coordinated by the Institute of Biomedical Ethics at the University of Zurich. In this platform experts will share and discuss cases on global health ethics and conduct cross-cultural analyses. She also works as a researcher in DIPEx Switzerland in the module "Experiences on Intensive Care Unit".

Introduction
Although most people with a mental health illness respond well to psychotherapy or medication, there is a need to increase access to care, to improve existing treatments, and to develop new ones. Digital mental health might be a tool to meet these needs. This research tackles key ethical discussions regarding the development and use of apps for mental health and well-being based on machine learning algorithms – supervised, unsupervised and semi-supervised.
Research questions
- Can machine learning algorithms be a means to provide care?
- Does the use of machine learning algorithms affect the relationship between mental healthcare professionals and patients?
- Does the use of machine learning algorithms affect public trust in mental health professionals?

Discussion
I introduce two distinctions. First, it is key to know the degree of control that developers have over machine learning algorithms – and therefore over the apps based on them. Second, we also need to know what functions are performed by machine learning algorithms in a given apps (e.g. pattern identification, prediction making, interventions).
These distinctions help us address the potentials and risks associated to machine learning apps. On the one hand, they may offer an unprecedented potential for public health. They may help cultivate relationships between patients and mental health professionals, support and complement the practice of caregiving, and encourage people to contact mental healthcare professionals. On the other hand, apps may expose users to psychological and physical harm, create a false sense of security, disrupt relationships between mental health professionals and patients, or undermine trust in mental healthcare.
Gaps
Available literature on digital mental health has not yet addressed the ethical discussions that arise from apps based on different types of machine learning algorithms.
Remarks
I will present my conceptual work and the advances of the empirical part of my project.

Should abortion laws in Malawi and South Africa be based on religion or human rights?

Francies Masiye[1]
[1]*Stellenbosch University, , South Africa*

Biography:
Francis Masiye is a graduate in Bioethics and Health Research Ethics from the University of Cape Town and the Johns Hopkins Bloomberg School of Public Health. He is currently working as a Health Research Ethics Coordinator at the Stellenbosch University in South Africa and he is a doctoral candidate in Clinical and Research Ethics in the Centre for Medical Ethics and Law at the Stellenbosch University in South Africa. *Francis has published several papers and book chapters in bioethics and health research ethics in the Springer Journal of Theoretical Medicine and Bioethics, BMC Medical Ethics Journal, the British Journal of Medical Ethics, Journal of Organizational Ethics and the Oxford University Press. His scholarly interests are in Health Research Ethics, Bioethics, Public Health Ethics and Medical Anthropology.*

Introduction: Statistics indicate that 20 million pregnant women opt for unsafe abortions due to restrictive laws on abortions worldwide. 97 % of the unsafe abortions occur in sub-Saharan Africa. Malawi is one of the countries with restrictive abortion laws and has one of the highest maternal mortality rates in the world. On the contrary, South Africa has enacted the Choice on Termination Of Pregnancy Act (TOP) which allows women to have safe abortions. The TOP has assisted in reducing rates of maternal morbidity and mortality in South Africa. However, in both Malawi and South Africa, there is resistance to current abortion laws by both human rights activists and religious leaders. Therefore, this presentation will analyze and compare Malawi's Abortion Law and the South African TOP with the goal of reaching a compromise between the conservative (religious) and liberal (human rights) views on abortion.
Discussion: Strong ethical debates on abortion center on the moral status of the fetus and when life begins. While most religions are against all forms of abortion on account that the fetus has moral status and life begins from the moment of contraception, human rights activists argue that the fetus has no moral status until birth and that life begins at birth. These debates have influenced current abortion laws in both Malawi and South Africa. This presentation argues that abortion laws should neither be based on religion nor human rights views. It suggests a moderate view on abortion. This moderate view will act as a compromise between the conservative and liberal views on abortion.
Conclusion: The moderate view on abortion is the "lesser of the two evils" between the conservative view and liberal view on abortion and it may benefit both religious leaders and human rights activists in Malawi and South Africa.

Strengthening Clinical Ethics Consultation in Malawi: A call to develop teaching tools, capacity and promote awareness

Titus Divala[2], Francis Makiya[4], Limbanazo Matandika[1], Joseph Mfutso-Bengo[1], Lucinda Manda Taylor[1], Maxwell Yohane[3]

[1]Centre for Bioethics in Eastern and Southern Africa, University of Malawi, College of Medicine, , Malawi, [2]Helse Nord Tuberculosis Initiative,Department of Pathology,University of Malawi,College of Medicine, , Malawi, [3]John Hopkins Project, , Malawi, [4]Queen Elizabeth Central Hospital; Ministry of Health and Population, , Malawi

Biography:

Limbanazo Matandika is a research fellow at the Center for Bioethics in Eastern and Southern Africa (CEBESA) and a PhD student specializing in Research Ethics at the University of Malawi, College of Medicine. A holder of Master of Social Science degree in Health Research Ethics (2017) from the University of Kwa Zulu Natal in South Africa, through the South Africa Research Ethics Training Initiative (SARETI). She is an early career bioethicist with vast exposure and experience of ethical issues emerging in settings with limited resources like Malawi. Limbanazo have previously worked with clinical research Institutions and Research Ethics Committee (REC) in Malawi. As part of her PhD training, she is involved in developing teaching materials and teaching research ethics and research integrity modules to both postgraduate and undergraduate students.

Her main interest in research ethics includes; informed consent, focusing on communication strategies, bio-banking, ancillary care, research integrity and embedded empirical ethics. She is passionate about exploring various approaches aiming at providing awareness and promoting ethical practises and conduct.

Background

The practice of providing health care unearths “ethically important moments” and these include the difficult, indirect, and frequently unpredictable situations. The response of health care providers (HCP) to such ethically challenging situations is important because it determines how the principles of autonomy, beneficence and justice are upheld. Such response therefore needs to be guided by an assessment of the ethical concern supplemented with the application of ethical principles and guidelines, however such guidance is rare in Malawi and the Africa region. The best guidance is one that comes from the local setting presenting ethical issues in real time and reflecting HCP’s ethical competence on case management.

Clinical practice is a rich, yet underutilized resource for such information as clinical practice experiences are not documented. Ethical dilemmas in clinical practice form part of everyday challenges for HCP especially in setting with limited resources, diverse, stressful working environments due to epidemics, diverse cultural norms and values and in populations with high illiteracy levels. Documentation of ethically important moments presents great opportunities to enhance ethics training and case management, therefore documentation of real time ethical experiences and encounters is of great significance.

Proposed Approach:

We propose to create a continuous system of generation and utilization of ethical guidance from clinical interactions to clinical training by setting up “ethical directory reports”. The reports would facilitate ethical mapping, digestion, documenting and analyzing of ethical issues in real time. The documented cases will be discussed and shared during ethics seminars with medical students and HCP. We anticipate the approach will be sufficient to provide future HCP with the necessary tools, skills and attitude to respond and address diverse ethical challenges in real time and relevant to their settings.

Parental decision-making in paediatric precision medicine: ‘best interests’ by design?

Melissa McCradden[1]
[1]*The Hospital for Sick Children, , Canada*

Biography:
Melissa McCradden is a Bioethicist with the Department of Bioethics at The Hospital for Sick Children (SickKids). Melissa holds a PhD in Neuroscience (McMaster University) and a M.HSc. in Bioethics (University of Toronto). In her role, she provides clinical and organizational consultation, gives education to staff and trainees, participates and leads policy development, and conducts research. Melissa’s research focuses on novel technologies, including artificial intelligence, machine learning, and precision medicine. She is particularly interested in how to responsibly evaluate these new technologies from an evidence perspective, integrating research ethics and evidence-based medicine. This work involves exploring the accountability of clinicians, informed consent in paediatrics, and public and patient/family perspectives about AI. These projects involve a unique integration of ethics, computer science, and paediatric healthcare.

Precision medicine offers the intended aim of delivering healthcare targeted to the individual on the basis of genetic, biologic, and other factors, often with the aid of artificial intelligence or machine learning approaches. Embedded in the semantics is an inherent connotation of 'precision' as determinative, with many scholars noting the epistemic authority and ontological confusion this term may invoke. Quantitative evidence also suggests we may have cognitive biases toward automated solutions and those that rely on more data sources. Given these biases, precision medicine prediction poses a particular challenge for pediatrics where the 'best interests' standard guides decision-making.

Additional challenges to decision-making include the limitations of evidence. Despite the de facto authority of precision medicine, there is limited evidence suggesting a population-based advantage to the precision approach in terms of clinical outcomes. That is to say that the predictions may be accurate in terms of their computational task, but not always in predicting the true clinical outcome. Moreover, there are extant limitations to following the prediction, including availability of safe, effective therapeutic agents.

I will consider precision medicine approaches by analyzing the current state of the science against the ethical framework of best interests. I will highlight current advantages and limitations, and how we might incorporate these technologies into the framework without neglecting the importance of other factors contributing to a best interests decision (e.g., psychosocial, cultural, spiritual wellbeing, and the child as the centre of a family). I will then explore recommendations for discussions with patients and families with the goal of counteracting the described biases and centring the conversation on the holistic notion of best interests. Like current interventions, precision medicine approaches must be weighed by the strength of evidence, certainty about outcomes, and patient/family values - not just predictions.

Standards of Surrogate Decision Making and Gender Affirmative Therapy for Pediatric Patients

Katherine Mendis[1]
[1]*CUNY School of Medicine, , United States*

Biography:
Katherine Mendis is Clinical Professor and Director of the Bioethics Curriculum at the Sophie Davis School of Biomedical Education/CUNY School of Medicine in New York City, where she administers a vertically and horizontally-integrated ethics curriculum for students enrolled in the BS/MD program. A former Ethics Fellow at the Icahn School of Medicine at Mount Sinai, she is also a PhD candidate in Philosophy at the CUNY Graduate Center.

Recent literature has produced a vigorous debate over which theoretical standard(s) for surrogate decision making are best suited to resolve disputes between providers and parents over treatment decisions for pediatric patients. (Rhodes & Holtzman 2014, Gillam 2016, Bester 2018, Pope 2018, Kopelman 2018) Analysis typically focuses on cases involving treatments for serious or life-threatening illness excluding reproductive or mental health care, as many jurisdictions allow for expanded self-determination for adolescents seeking the latter categories of care. Interventions that comprise gender affirmative therapy (GAT) for children and adolescents with gender dysphoria--which includes puberty-blocking agents (PBA), cross-sex hormones, and surgery—present a rich opportunity to broaden and deepen the conversation about the limits of parental discretion over medical decision making. Arguments for and against overruling parental objections and expanding access to GAT for children and adolescents have thus far focused the structural supports necessary to expand access to GAT (Boskey & Marron 2019), whether GAT is standard care (Laidlaw et al 2019), and applying one theoretical standard for surrogate decision making: the Harm Principle. (Diekema 2004, Priest 2019, Notini et al 2019).

This presentation will build on the discussion about parental refusal of GAT and the Harm Principle, and consider alternative theoretical frameworks for assessing the boundaries of parental discretion and the normative obligations of surrogate decision makers. I will focus on three standards that have been the subject of recent debate: the consensus Best Interest Standard, the Not Unreasonable Standard, and the Zone of Parental Discretion. I will assess what each standard prescribes with regard to overruling parental refusal of GAT, and the theoretical implications that application to GAT poses for each standard. This analysis suggests that overruling parental refusal of GAT may not be justifiable at this juncture.

How should the 'privilege' in therapeutic privilege be conceived in decision-making about treatments for patients with compromised capacity?

Alastair V Campbell[1], Vikki A Entwistle[1], Sumytra Menon[1], Johannes van Deiden[2]
[1]Centre for Biomedical Ethics, Yong Loo Lin School of Medicine, National University of Singapore, , Singapore, [2]Julius Center for Health Sciences and Primary Care, University Medical Center Utrecht, Utrecht, Netherlands, , Netherlands

Biography:
Sumytra Menon is Senior Assistant Director at the Centre for Biomedical Ethics, Yong Loo Lin School of Medicine, National University of Singapore. She is Co-Director for the Clinical Ethics Network + Research Ethics Support (CENTRES) initiative, which offers educational activities in clinical and transplant ethics to enhance capabilities in ethics committees work in Singapore. Sumy is a lawyer by training, and her particular research interests are in healthcare decision-making, the law on mental capacity and at the end of life.

Therapeutic privilege is a defence that may be available to doctors who fail to disclose to the patient relevant information when seeking informed consent for treatment if they have a reasonable belief that providing that information would likely cause the patient concerned serious physical or mental harm. In a landmark judgment, the Singapore Court of Appeal introduced a novel interpretation of therapeutic privilege, identifying circumstances in which it might be used with patients who did not strictly lack capacity but might be inclined to refuse recommended treatments. In this paper, we explore the conceptual and practical challenges of this novel interpretation of therapeutic privilege. We propose that more emphasis should be placed on forms of shared and supported decision-making that foster the autonomy of patients with compromised mental capacity while being mindful of the need to safeguard their wellbeing. The kind of privilege that doctors might need to invoke is one of time and supportive expertise to ensure a flexible, responsive approach calibrated to the individual patients' needs. The provision of such service would extinguish the need for the novel therapeutic privilege proposed by the Singapore Court of Appeal.

The Duty to Rescue the Rescuer: COVID-19, Moral Trauma and Societal Obligation

Valerye Milleson

Biography:
Valerye Milleson is the Manager of Clinical Ethics for Ascension Tennessee and Ascension Alabama. Prior to joining Ascension she completed a clinical ethics fellowship at UCLA and was a Clinical Ethicist at Inova Health System. She holds a PhD in Philosophy and MS in Biology from Arizona State University, and her research interests include topics such as clinical ethics, narrative medicine, moral repair, and ethical issues in chronic illness.

The professed moral duty to rescue or respond to individuals in need of aid is longstanding in healthcare ethics. Historically, there has been an apparent default position placing any such duty to rescue onto individual healthcare practitioners. However, this default presents several potential challenges, both personally and professionally, many of which have been especially highlighted during the recent and ongoing COVID-19 pandemic. Areas where this is most apparent include: moral distress and compassion fatigue; work environment and patient safety; duties to self and personal health, safety and wellbeing; and moral injury and trauma. Each of these areas are explored in turn, with particular attention to the moral injury and trauma resulting from how this default duty impacts healthcare practitioners within the current COVID-19 context. A restructuring of the duty to rescue is then proposed which involves balancing it across: (1) individual practitioners; (2) the healthcare profession(s) more broadly, in terms of clear professional standards on the scope of a professional duty to rescue; (3) specific healthcare organizations, by way of taking on the burden of rescue at an institutional level, enacting policies that place limits on rescue requirements of employees and putting into place system-level supports to help sustain them; and (4) society more broadly, positing a positive duty for society to support these limits on rescue requirements and further implement programs that enable moral repair and post-traumatic growth. This transformed duty, it is argued, is necessary to meet the demands of contemporary healthcare and help 'rescue' the rescuer.

The Next Frontier: Sub Saharan African Countries' Clinical Ethics Committees Preparedness for the Fourth Industrial Revolution

Boitumelo Mokgatla[1]
[1]*Internatioanl AIDS Vaccine Initiative, , Botswana*

Biography:
Boitumelo Mokgatla is a global health leader with extensive experience in leading Policy, Advocacy, Access and Regulatory Affairs for HIV, TB and Malaria complex multi-lateral, multi-country and multi-donor funded Public Health Research (including clinical trials) across Africa.
With over twelve years broad experience as a clinician, researcher and a manager, she spent the last twelve years in several senior leadership positions in Africa; currently as the Associate Global Director for Policy, Advocacy and Regulatory Affairs at the International AIDS Vaccine Initiative (IAVI), prior to which she was the Africa Programs Director for the Council on Health Research for Development (COHRED). Through these positions, she led access, policy, and regulatory oversight for HIV, TB, Malaria and neglected tropical diseases projects across 22 sub-Saharan Africa countries.She has worked closely with strategic global health and research and development partners including; public private partnerships (AERAS, PATH); pharmaceutical companies (Pfizer), regional economic communities (SADC, NEPAD); a spectrum of funders (USAID, BMGF, DFID, and EDCTP); civil society organizations and advocacy coalitions (e.g South African Health Technologies Advocacy Coalition (SAHTAC), governments and academia.

Introduction
The advent of the fourth industrial revolution (4IR) is increasingly shifting the paradigm of healthcare system in developing countries. Remarkable developments in information technologies and artificial intelligence (AI) coupled with advances in biological sciences; including genetics, reproductive technologies and neuroscience, are unprecedented in scope, velocity and impact, with endless possibilities and potential disruptions. Most Sub-Saharan African (SSA) countries are starting to grapple with the disruptive potential of the 4IR and Clinical Ethics Committees (CECs) increasingly have to deal with these new challenges in digital medicine.

Discussion
While 4IR offer extraordinary opportunities like; great promise to cure diseases, reduce healthcare costs by proactive prevention and health promotion, accelerate generation of potential molecular targets for accelerated drug development and accurately monitoring individual patient through advances in AI, it also disrupts the entire healthcare system. As a result, number of challenges persist, such as; impacts on the workforce, strains on privacy and freedom of expression, impact on the doctor-patient care and its continuity and other critical clinical ethical issues such as; what limits - if any - should be placed on genetic technologies, who owns the data, who can access it and how is it regulated.

Most SSA countries are starting to grapple with the disruptive potential of 4IR. The 4IR places a new burden to the healthcare systems in addition to competing healthcare priorities in respective countries. It is critical to ensure that SSA countries are prepared at clinical level with established and well capacitated CECs for sound ethical oversight.

Conclusion
The 4IR is a revolution where a fusion of technologies blurs the line between the physical, digital transformation and biological spheres of healthcare. Preparing the SSA countries' CECs for the 4IR, is as critical as securing key global health governance and equity, to not do so, would be ethically irresponsible.

Theory and practice of integrative Clinical Ethics Support: a joint experience within gender affirmative care.

MD MA Karl Gerritse[1], Laura Hartman[1], Giulia Inguaggiato[2], Bert Molewijk[1], Annelijn Wensing-Kruger[1], Guy Widdershoven[1]
[1]Amsterdam University Medical Center, , Netherlands, [2]University of Oslo, , Netherlands

Clinical ethics support (CES) aims to support health care professionals in dealing with ethical issues in clinical practice. In this paper we describe five key characteristics of, what we have called, an integrative approach to CES; 1. Positioning CES more within care practices, 2. Involving new perspectives, 3. Creating co-ownership of CES, 4. Paying attention to follow up, and 5. Developing innovative CES activities through an emerging design. These five characteristics are based on both experiences in cooperating with a team for transgender care and theoretical reflections about clinical ethics support stemming from pragmatism, hermeneutics and organizational and educational sciences. In the presentation we compare this approach to the integrated approach to CES developed in the US and the hub and spokes strategy developed in Canada. Furthermore we reflect on how an integrative approach to CES can help to handle some of the challenges of current CES.

Systematic evaluation of two years of ethics reflection groups. Changes over time regarding employees' attitudes, user involvement, team cooperation and the handling of disagreement

Olaf Aasland[3], Reidun Førde[3], Almar Kok[2], Bert Molewijk[1], Reidar Pedersen[3]
[1]Centre Medical Ethics, University of Oslo, , Norway, [2]Amsterdam UMC (VUmc), , Netherlands, [3]University Oslo, , Norway

Biography:
Bert Molewijk (1966; RN, MA, PhD) is professor of clinical ethics support both at a) the Department of Medical Humanities at Amsterdam University Medical Centres (location VUmc), and b) the Centre of Medical Ethics, University of Oslo. He is team leader of the team Ethics & Philosophy and member of the management team of the department in Amsterdam. His main tasks are (supervising) (PhD) research, training and consultancy related to ethics support and moral case deliberation. His main interest is in developing innovative ways for integrative ethics support and monitoring and fostering the contribution of ethics support to quality of care, team cooperation and moral competence. He is co-founder and coordinator of the European Clinical Ethics Network (ECEN; since 2005) and the Dutch Network for Ethics Support (NEON; since 2016). He is also member of the executive board of the European Association of Centres for Medical Ethics (www.EACMEweb.com).

Background: Ethics reflection groups (ERG) or moral case deliberations (MCD) are increasingly used in health care as a form of clinical ethics support (CES). ERGs are often evaluated with a focus on evaluating ERG itself yet not on the impact of or change due to ERGs. Within a larger study implementation and impact of ERG was studied with use of various qualitative and qualitative research methodologies. In this presentation we present findings of the quantitative research.

Research question: Are there changes over time after two years of ERG regarding employees' normative attitudes with respect to the use of coercion, user involvement during the use of coercion, team cooperation and the handling of disagreement?

Research method: Repeated cross-sectional survey at seven wards within three different Norwegian mental health care institutions (T0-T1-T2).

Results: In total, 817 surveys were included in the analyses. Of these, only 7.6 % (N= 62) have responded at all three points in time, while 76.8 % (N= 628) responded only once. Over time, adjusted for ward and profession, respondents agreed less that coercion is a form of care or security. Furthermore, respondents thought they involved patients and their family significantly more often in situations of coercion and they reported that the constructive of disagreement within the team significantly improved. More frequent ERG participation seemed associated with a more critical attitude towards the use of coercion and higher scores for user involvement, team cooperation and the constructive handling of disagreement, yet differences between ERG participation were generally small in absolute terms.

Conclusion: Structural participation in ERG seems to contribute to changes in attitudes, user involvement and team cooperation. Studying changes over time and trying to find a relationship between CES interventions and outcome is difficult yet important and need to be further developed in future CES evaluation research.

At what cost? The biopolitics of visitation restrictions in a pandemic and what it means for clinical ethicists

Bryanna Moore[1]
[1]*Institute for Bioethics and Health Humanities, University of Texas Medical Branch, , United States*

Biography:
Bryanna Moore is an Assistant Professor at the Institute for Bioethics and Health Humanities and Department of Preventative Medicine and Population Health at UTMB in Galveston. She has a PhD in Philosophy from Monash University and a Bachelor of Arts with first class Honours in Philosophy from the University of Queensland in Australia. Dr. Moore completed postdoctoral fellowships at the Center for Medical Ethics and Health Policy at Baylor College of Medicine in Houston and the Children's Mercy Bioethics Center in Kansas City. Her research interests span clinical ethics, medical decision-making, pediatric ethics, end of life issues, virtue ethics and moral psychology.

The COVID-19 pandemic has led many hospitals to adopt strict visitation policies that limit who can enter the hospital, at what times, for how long for, and in what proximity any visitors can be to patients. That is, such policies constrain visitors' ability to occupy certain therapeutic, social, and moral spaces that they were previously allowed to occupy. Exceptions to these restrictions have been granted, usually for family members of patients who are at the "end-of-life", "imminently dying" or require "special circumstances". The ebb and flow of the pandemic has seen the relaxing and tightening of these policies; sometimes, overnight, loved ones can go from being allowed at bedside to not being allowed to set foot inside the front doors.

Drawing upon biopolitical theory, in this presentation I critically interrogate the role of visitation policies during a pandemic and the operationalization of categories like "end-of-life" by policymakers. I show that the boundaries of categories like "end-of-life" are socio-politically constructed; policymakers have drawn those boundaries in different places, depending on institutions' politics and values. The mutable nature of these policies raises important ethical questions about modalities of power in healthcare and how the purported benefits of these kinds of "protections"—enforced in the name of patient and public health—are being weighed against the harms they may create. I conclude by proposing some recommendations for clinical ethicists who, I argue, have an important role to play in advocating for fair and transparent policies and decision-making processes in this challenging context.

From Karen Ann Quinlan to Jahi McMath: A Half-Century of End-of-Life Care Debates in the USA

Dr. John Moskop[1]
[1]*Wake Forest School of Medicine, , United States*

Biography:
John C. Moskop, Ph.D., is Professor of Internal Medicine and Wallace and Mona Wu Chair of Biomedical Ethics at the Wake Forest School of Medicine, Winston-Salem, North Carolina, USA. He chairs the Clinical Ethics Committee at Wake Forest Baptist Medical Center and is a core faculty member in the Wake Forest Bioethics Graduate Program. From 1979 through 2009, he was a faculty member in the Department of Medical Humanities of the Brody School of Medicine at East Carolina University. Dr. Moskop is author of more than one hundred articles and book chapters on ethical issues in emergency medicine, death and dying, the allocation of health care, and other topics in bioethics. His book Ethics and Health Care: An Introduction was published in 2016 by Cambridge University Press. Dr. Moskop is a member of the Ethics Committee of the American College of Emergency Physicians and of the Ethical and Judicial Affairs Committee of the North Carolina Medical Society.

Disagreements about medical care near the end of life have always been a major impetus for clinical ethics consultation. To assist in resolving these conflicts, clinical ethics consultants need a clear understanding of available options for end-of-life care and of the moral and legal status of those options. This presentation will situate conflicts about end-of-life care within the broader context of the evolution of end-of-life care over the fifty-year history of American bioethics. The presentation will defend the following three bold claims:
1. End-of-life care options have undergone an almost total transformation over the past half century.
2. Moral controversies in end-of-life care played the leading role in launching the field of bioethics.
3. Moral controversies in end-of-life care remain the most visible, and some of most vexing, issues in bioethics today.
The presentation will begin with a comparison of available end-of-life care options today and fifty years ago. It will then provide a brief review of the course and current status of five prominent end-of-life-care debates in ethics and public policy in the United States, over abortion, “brain death,” “natural death,” “physician-assisted suicide,” and medical futility. It will compare this history to similar debates over end-of-life care in South Africa.
The presentation will revisit the five bold claims listed above to summarize the evidence for them. It will conclude with a look ahead at the future of the five prominent end-of-life care debates.

Ethics consultation for patients with limited English proficiency in a U.S. hospital: Does language barrier prompt unique ethical conflict, or does language barrier uniquely complicate common ethical questions?

Janice Firn[1], Eman Mubarak[1], Eman Mubarak[1]
[1]*University of Michigan Medical School, , United States*

Biography:
Dr. Naomi T. Laventhal is a Clinical Associate Professor in the Department of Pediatrics and Communicable Diseases in the Division of Neonatal-Perinatal Medicine, and in the Center for Bioethics and Social Sciences in Medicine (CBSSM). She completed her residency in pediatrics, fellowships in neonatology and clinical medical ethics, and a master's degree in public policy at the University of Chicago. She serves as a Faculty Ethicist in CBSSM's Clinical Ethics Service, providing clinical ethics consultation throughout the University of Michigan hospital system. She cares for critically ill neonates in the Newborn Intensive Care Unit at C.S. Mott Children's Hospital and serves as the director of the Neonatology Prenatal Consultation Clinic, which provides anticipatory guidance and supports decision making for women with pregnancies complicated by congenital anomalies and expected preterm birth. Her research interests are in neonatal bioethics and clinical research ethics, and her current work focuses on the prognostic value of healthcare providers' predictions of neonatal outcomes. She serves on the American Academy of Pediatrics Committee on Bioethics.

Introduction:
Patients with limited English proficiency (LEP), even when aided with medical interpreters, must navigate a distinct set of challenges within the healthcare setting. Unpublished data from the University of Michigan showed that non-English speakers are disproportionately represented in preventive ethics rounds discussions. The purpose of this study was to investigate whether and how a patient's non-English speaking background is presented in ethics consultations across the age spectrum. We sought to explore the themes underlying how these patients' cases were discussed in these contexts and how information was communicated to inform medical decision-making.

Methods:
We performed a retrospective conceptual content analysis of ethics consultation notes between June 2015 - October 2019 regarding adult and pediatric patients with a language barrier at Michigan Medicine.

Results:
Of 445 ethics consultations, twenty-one relevant cases were identified, thirteen of which dealt with issues surrounding end-of-life care. Fifteen cases identified at least one instance of miscommunication, acknowledged lack of communication by the healthcare team, or lack of comprehension by the patient. Language barriers between patients/families and the healthcare team caused recurrent challenges: difficulty in disclosing information, concern about compromised patient autonomy, and patient mistrust in the healthcare system.

Discussion:
In these cases, communication between the healthcare team and the patient/family with LEP was often negatively affected, either directly or indirectly due to the language barrier. Ethical issues were further complicated by and in some instances arose uniquely because of impaired communication. We identify distinct aspects of ethics consultation for patients with LEP that warrant continued attention and investigation.

Conclusion:
Clear communication between the healthcare team and the patient/family is necessary to support patient autonomy and informed decision-making, particularly in situations of ethical complexity. Particular attention to the needs of patients with LEP is warranted to support comprehensive, compassionate, and balanced ethical consultation for these patients.

Ethical challenges in kidney paired donation in Switzerland – the orphaned recipient

Valerie Luyckx[2], Thomas Mueller[1]
[1]University Hospital, Zurich, , Switzerland, [2]Institute of Biomedical Ethics and History of Medicine, University of Zurich, , Switzerland

Biography:
Prof. Thomas Mueller, MD, PD is a professor of nephrology at the University Hospital in Zurich, Switzerland, where he is the medical lead for the kidney transplantation programme. He obtained his MD degree from Marburg University in Germany and his training and specialisations in Internal Medicine, Intensive Care and Nephrology in Marburg. He completed a nephrology research fellowship at the Brigham and Women's Hospital, Harvard Medical School in Boston. He has has a strong research interest in organ quality for transplantation and evaluation of living donors for transplantation, and had published widely on these topics, ranging from the laboratory bench to microarray technology and clinical research. He is a member of the Declaration of Istanbul Custodian Group (DICG) which advocates strongly against organ trafficking. He has been a member of the ethics committees at the University of Alberta Hospital in Edmonton, Canada and at the University Hospital in Zurich, Switzerland.

Kidney transplantation is the optimal treatment for patients with end-stage kidney disease. For many years an immunological 'mismatch' within the donor-recipient pair represented an insurmountable barrier, and the recipient needed to wait (often years) for a deceased donor (DD) kidney. Recently kidney paired-donation (KPD) "chains" have gained acceptance. Pairs of incompatible donors and recipients are entered into a (national) computer-based algorithm that iteratively identifies the most compatible new recipient-donor pairs within the pool.

Kidney transplantation poses many ethical challenges including resource allocation, not doing harm, respecting autonomy and transparency. In addition, KPD is associated with greater complexity of informed consent, and a specific potential harm to an "orphaned" recipient (OR), i.e. when for an unforeseen reason a kidney allocated to a specific recipient becomes no-longer available (e.g. damaged in surgery or transport), but their donor has already donated to the third party recipient. This recipient loses their "bargaining chip" for a future KPD, and still requires a kidney. The decision about which kidney to allocate fairly to this individual, and when, is complex, especially as it impacts others on the DD waiting list: Should the OR receive the next available DD organ? Should they receive the next altruistic LD organ? Should they wait like everybody else on the waiting list? Global policies regarding organ allocation to an OR were investigated. Of the 13 national KPD programs, 70% prioritize the OR for the next DD and/or LD kidney. Three programs do not have a specific allocation policy in place. One program does not allow any prioritization and requires the OR to go on the normal waiting list. Given this variability, transparency, solidarity and accountability are important in national policies, which also require legal ratification and uniformity of implementation, to ensure maintenance of population trust, a necessary component of any transplantation program.

Restorative Practice through Medical-Legal Partnership: An Innovative, Collaborative Approach to Health Inequity and Healing

Janet Goode[2], Lauren Mutrie[1]
[1]*Northwest Permanente at Doernbecher Children's Hospital, , United States,* [2]*Attorney at Law, , United States*

Biography:
Lauren Mutrie, MD, MSc is an Associate Professor of Pediatrics with a background in academic medicine, global health, and medical-legal partnership. Her career has centered on advocacy for children made vulnerable by poverty, and she divides her time between clinical practice, teaching, and program development in global health and medical-legal partnership.

Medical-Legal Partnership (MLP) is a collaborative, interdisciplinary approach to health in which trauma-informed medical and legal care are integrated within health systems and communities. MLP's possess powerful social and legal advocacy capabilities that serve as preventative and curative medicine for patients whose social determinants of health (SDH) anchor them in poverty and illness. MLP embodies Ubuntu, allowing for enriched inter-professional collaboration that enhances the ability of healers to remove the social and legal barriers to health for children and families living in poverty. Originating in a rural health center in Mississippi in 1967, the MLP movement has evolved to include over 300 internationally recognized partnerships between health and legal care teams all over the world. In this presentation, we discuss the medical, social, and legal pathologies associated with poverty as well as persistent inequities for poor families across the globe. We then introduce MLP as a holistic, globally adaptable collaboration that uniquely addresses the SDH in pediatric health care settings, thereby reducing health inequities, improving health outcomes, and supporting policy reform. We further examine MLP as an empowering educational tool for health and legal care providers, including clinical ethics consultants and committee members, engaging the entire care team in the health issues of vulnerable populations, developing greater respect for diverse perspectives, and harnessing the healing power of social justice. Finally, we discuss MLP as a standard of care that can be accelerated in and adapted to low- and middle-income countries.

Impact of Caring for Terminally Ill Children on Physicians: A Systematic Scoping Review

Ahmad Bin Hanifah Marican Abdurrahman[2], Natalie Pei Xin Chan[2], Clarissa Wei Shuen Cheong[2], Jeng Long Chia[2], Min Chiam[6], Annelissa Mien Chew Chin[3], Chong Yao Ho[2], Muhammad Raihan Jumat[5], Nur Haidah Ahmad Kamel[2], Lalit Kumar Radha Krishna[7], Joshua Tze Yin Kuek[2], Stephen Mason[4], Cheng Han Ng[2], Dr Jun Xuan Ng[1], Lisa Xin Ling Ngiam[2], Yun Ting Ong[2], Lorraine Hui En Tan[2], Xiu Hui Tan[2]

[1]Ministry of Health, , Singapore, [2]Yong Loo Lin School of Medicine, National University of Singapore, , Singapore, [3]Medical Library, National University of Singapore Libraries, Singapore, , Singapore, [4]Palliative Care Institute Liverpool, Academic Palliative & End of Life Care Centre, University of Liverpool, United King, , Singapore, [5]Duke-NUS Medical School, National University of Singapore, , Singapore, [6]Division of Cancer Education, National Cancer Centre Singapore, , Singapore, [7]Division of Supportive and Palliative Care, National Cancer Centre Singapore, , Singapore

Biography:

Jun Xuan Ng is from the Class of 2020, Yong Loo Lin School of Medicine, National University of Singapore. As a junior doctor entering this profession at a time like the COVID-19 pandemic, he experiences first-hand, the wide range of impacts aptly described in this study. Every day at work, he seeks new inspiration on how to shape our personhood for the better. The author isn't looking to revolutionise practice; he just wishes to make each patient's lives a little bit better, one small step at a time.

BACKGROUND

Caring for terminally ill children in Pediatric Palliative Care (PPC) has complex and lasting effects upon the personal psyche, familial ties, professional identity, and societal roles of healthcare workers. Physicians who are, regardless of cultural beliefs, constantly exposed to the stressful circumstances surrounding death and dying are prone to succumbing to its effects. Despite this, the scope of these effects remains poorly understood, leaving many unsupported physicians struggling to cope.

METHODS

This systematic scoping review adopted a novel Systematic Evidenced Based Approach (SEBA), which applies interpretivist analysis to construct meaningful perspectives. Krishna's Ring Theory of Personhood (RToP) was utilized as a framework to capture individual physicians' perspectives of personhood over time and in diverse settings, within four concentric rings (Innate, Individual, Relational and Societal rings).

RESULTS

13,424 titles and abstracts were screened, 188 full-text articles were evaluated, and 39 articles were included. A wide range of impacts, predominantly negative than positive, were recorded across the four rings of personhood. On one extreme, the physician is plagued with pessimism, negative emotions, and has strained personal and professional relationships. On the other hand, the physician may experience personal and professional growth with a vastly positive outlook on life.

CONCLUSION

By understanding how a physician's personhood is molded by his/her own experiences with care provision, we can enhance holistic and longitudinal assessment and support of physicians in PPC, especially during trying times like the COVID-19 pandemic. There is a need to enhance physicians' resilience via support services aimed at reflecting, reframing, and resolving inner conflicts, driving positivity for growth. To that end, a tool that builds upon the understanding proffered from the above data, which can help identify at-risk/distressed physicians would be an important first step in mitigating the harmful effects of terminal care provision on physicians in PPC.

Goals of Care and ethics

Nico Nortje

Biography:
Dr. Nortje is a Clinical Ethicist and assistant professor, Department of Critical Care, at the University of Texas MD Anderson Cancer Center, Houston. Nico is also the Director of Goals of Care and End-of-Life at the Hospital.

It is recorded that most of medical litigation is due to a break in communication between patients/families and their health care providers. The COVID-19 pandemic has exacerbated the need for good communication during these unprecedented times and has placed the issue of goal concordant care at the front and center of all healthcare institutions and training centers, worldwide.
At our institution A Goals of Care Rapid Response Team (GOC RRT) was establish as an extension of the usual CEC service to help primary oncologists with these discussions. The GOC RRT is a multi-disciplinary team who brings various levels of expertise to the conversation and coaches the oncologist through a specific conversation guide. The objective of the GOC RRT consultation is to promote realistic patient and family understanding of the patient's medical situation, prognosis and treatment options from a trusted oncologist, supported by supportive care and ethics expertise in facilitating such communication, in an effort to ensure that the care the patient receives is consistent with a well-grounded understanding of potential medical benefits and risks and the patient's GOC. This approach has been translated into a more formal training approach and all faculty have access to the training, as well as GOC RRT. Both the structure of these conversations and educational formats will be discussed during the presentation.

Comrades-in-arms in the COVID war

Shannon Odell[1]
[1]*University of Cape Town, , South Africa*

Biography:
Dr Shannon Odell is a post-graduate lecturer in Palliative Medicine at the University of Cape Town and works as a private palliative care provider in the southern suburbs of Cape Town.

The devastation of the COVID-19 pandemic on humanity and the need for a strategic, cohesive global response to the virus have been likened to war in political rhetoric and experiential discourse of health care providers and surviving patients. It is a compelling metaphor recognising an enemy, soldiers, the home-front, traitors and the experience of a "bad" death. The more than two million people worldwide who have died due to this novel virus are casualties in this war, many dying in isolation and fearful. Deliberation is given as to whether the "war on COVID-19" can be considered metaphorically jus in bello, and in doing so, consider and identify all the autonomy insurgents and socio-economic health aggravators. Advancing the war analogy further, it is questioned whether sentiments of military ethics accompany this metaphor in influencing our reconciling the enormous death toll with the proportionality of our resolve for universal health coverage, securing a reasonable chance of defending the vulnerable, improving the legacy of socio-economic injustices and implementing palliative care. Possible warning signs are explored that these war-mongering manoeuvres guise formidable authoritarianism for sound public health ethics; and camouflage nationalism for utilitarianism. Recently, the unequal deployment of the COVID-19 vaccine armamentarium amongst countries and within countries might possibly signal a Pyrrhic victory for communitarianism with distributive justice as collateral damage. It is not convincing that the war metaphor is the best use of a population-level bioethical azimuth.

Quest for Family Harmony in Ethical Decision Making in Health Care Among Indigenous Kenyans

Stephen Muhudhia Ombok[1]
[1]*The Nairobi Hospital, , Kenya*

Biography:
Name: Stephen Muhudhia Ombok
Tittle: Dr.
Institution: The Nairobi Hospital, Kenya.
Email: drmuhudhia@gmail.com,
Twitter: @drmuhudhia1
Facebook: Stephen Muhudhia

Dr Stephen Muhudhia Ombok is an Adjunct Professor of Bioethics, Trinity International University, Illinois, USA, and Co-director of Africa Bioethics Initiative. He was the "International Bioethics Scholar of the Year 2018" Trinity International University.
He is a Consultant in Biomedical Ethics and Clinical Ethics at The Nairobi Hospital, and Chair of the Hospital's Clinical Ethics Committee. Dr Muhudhia is a member of the Scientific and Ethics Review Unit (IREC) of the Kenya Medical Research Institute
And also serves as faculty for Cbec-KEMRI Bioethics Training Initiative which conducts training on clinical, public health and research ethics.
He has a Masters degree in Bioethics and Health Law from the University of the Witwatersrand, South Africa and Post Graduate Diploma in Biomedical Ethics from Sindh Institute of Urology and Transplant, Pakistan.
Dr Muhudhia is a specialist paediatrician based at The Nairobi Hospital, Kenya and a visiting consultant paediatrician to Gertrude's Children's Hospital, Aga Khan University Hospital and M.P. Shah Hospital.
He served on the Board of World Vision Kenya and was the Vice Chair for 3 years. He served as Country Director for Life in Abundance Kenya (LIA Kenya), a health and development NGO, from 2005 to 2008.
He is a member of the Institute of Directors of Kenya. He has a certificate in Corporate Governance and a certificate in Advanced Leadership from the Haggai Institute, Singapore.

Ethical decision making in health care can be complex and may be influenced by social, cultural, religious, and economic factors. Various ethical theories are considered in search for suitable basis for making decisions. Principles of ethics proposed by Beauchamp and Childress are often applied with various degrees of weightings. In this principlism approach the principle of respect for persons, autonomy is usually the most dominant ethical value.
In Kenya and several African Countries, the concept of autonomy in decision making is complex. Decisions are more collective with strong input from nuclear and extended family members. Religious people are often consulted by families. The application of the principle of respect for persons often involves respecting the family and social support systems that the person relates closely to.
A desktop study using philosophical methods was carried out to explore the major factors that influence ethical decision making in health care in indigenous Kenyans. The main factors considered were disease affecting a patient, socio-cultural, economic and religious factors. The role of the concept of "Ubuntu" was analyzed. Ubuntu is a philosophical concept encompassing the relational and communitarian lifestyle common in indigenous African societies. After analysis of literature an argument was developed posing that the most significant factor in decision making, during periods of serious illness, is a quest for family and communal harmony. This is an important finding for members of Hospital clinical Ethics Committees in Africa. The knowledge is valuable in analyzing ethical dilemmas and providing culturally and socially appropriate solutions.

From Pond Ripples to Subway Maps: Towards a Relational Disclosure Account of Genetic Risk Information to Family Members

Serene Ong[1]
[1]*National University of Singapore, , Singapore*

Biography:
erene is a PhD student at the Centre for Biomedical Ethics, National University of Singapore. Her research interests include familial disclosure, data sharing, and the ethics of genetic testing and emerging technologies.

For patients with a hereditary condition, the familial aspect of the condition raises the issue of disclosure to family members at risk of carrying that same condition. In the traditional model of disclosure, disclosure depends firstly on the patient giving informed consent to release information, and subsequently on individual family members giving their informed consent to receive that information. This model is problematic because it presumes that individuals within a family, including the patient, are autonomous agents independently making rational decisions about whether to disclose or receive information that potentially affects all of them. However, individuals are not truly independent agents, and the decisions they make are better understood within socially inter-related contexts. Moreover, disclosure hinges on the patient's consent; yet at-risk family members are affected by the patient's disclosure both personally and socially, and the implication of the current model whereby the interests and choices of family members may be excluded from consideration altogether seems ethically unjust. The problem in reconciling this tension is that the traditional model prioritises the personal autonomy of patients without accounting for the interests of others who may benefit or be harmed from the disclosure. Currently, there are moral arguments for and against disclosure, and little guidance for clinicians on whether and how they should counsel patients on disclosing genetic test results to at-risk family members. Building on the feminist conception of the relational self, I propose to develop an alternative relational account of disclosure that takes into account the social environments that influence a patient's decision about disclosure, and the familial linkages resulting from shared genetic data. With increases in the use of genetic testing, moral dilemmas in familial disclosure of genetic risk information are likely to become more common, and a relational approach to disclosure could assist in reconciling the tensions.

Context-specific situations important to capture moral distress – a national cross-sectional study in paediatric oncology

Associate Professor Pernilla Pergert[1], Cecilia Bartholdson[1], Margareta Sandeberg[1]
[1]*Karolinska Institutet, , Sweden*

Biography:
Pergert is associate professor (Docent) of Pediatric Care Science and research group leader at Karolinska Institutet. She studies the two very closely related areas of intercultural care and clinical ethics in paediatric cancer care. The research aims at increasing knowledge about care situations involving different cultures/languages and situations with ethical issues, and how healthcare professionals could be supported to deal with theses situations. Studies in clinical ethics explores clinical ethics support, ethics case reflection (ECR) rounds, moral distress and the ethical climate in paediatric cancer care. Pergert is involved in the International Society of Pediatric Oncology (SIOP) as a member of the scientific committee, the nursing committee as well as the Nurse Specialist of the Global Initiative of Childhood Cancer. She is a member of a Nordic working group on ethics in paediatric oncology offering ethics support, for example, a training of facilitators of ECR rounds in collaboration with Dr Molewijk from Amsterdam UMC. She is also a new member of the steering board of the European Clinical Ethics Network (ECEN).

INTRODUCTION: Paediatric oncology involves a threat to the child's life and extended stress on the family. This affects the care culture and the situations in which healthcare professionals' (HCPs') experience moral distress. The Moral Distress Scale-Revised (MDS-R) has been translated and culturally adapted to Swedish paediatric oncology. Cognitive debriefing revealed five not captured situations:1) Lacking time for conversations with patients/families, 2) Parents unrealistic expectations, 3) Not talking about death with a dying child, 4) Performing painful procedures, 5) Deciding on treatment/care when uncertain. The aim was to explore experiences of moral distress in these five situations.
METHODS: HCPs at all paediatric oncology centres were invited to participate. Focusing on the added situations, descriptive statistics and non-parametric analysis were performed. A MDS-R score for each item was calculated (intensity multiplied with frequency).
RESULTS: Participants included 278 HCPs: registered nurses (RNs), medical doctors (MDs), and nursing assistants (NAs). NAs reported significantly higher intensity than the others on all added items. RNs reported significantly higher frequency on situations 1-4 and MDs reported higher MDS-R score than the others on situation 5. In situation 1, intensity was moderate/high and frequency high among all, with RNs rating the highest MDS-R score. Item 1 had the second highest MDS-R score of all 26 items for all groups. Regarding situation 2, the level of disturbance was low, but it occurred often, with RNs rating the highest MDS-R score.
DISCUSSION: The results indicate that the added items are important to capture moral distress in paediatric oncology. Recently a more generic questionnaire was developed to measure moral distress. However, we would argue that the context/culture is relevant, for example, the added situation about talking with a dying child is quite unusual in some care settings.
CONCLUSION: To capture moral distress, some items need to be context-specific.

Don’t Throw Autonomy Out with the Bathwater

Associate Professor Constance Perry[1]
[1]*Drexel University, , United States*

Biography:
Dr. Constance Perry is an Associate Professor in the Health Administration Department within the College of Nursing and Health Professions. She received her doctorate in philosophy from the University of Buffalo, specializing in biomedical ethics and completed a fellowship in Clinical Ethics from Loyola University in Chicago. She has published articles and book chapters, and given presentations on a wide variety of subjects, including ethical issues in pregnancy, research ethics, autonomy, personhood, animal experimentation, and clinical ethics consultation. Besides teaching and other service commitments, she Co-Chaired the Hahnemann University Hospital Clinical Ethics Committee and serves as the ethicist for the Drexel University IACUC and the FIMR-HIV Panel for the greater Philadelphia area.

This talk will present some of the major criticisms of autonomy in clinical ethics. These criticisms raise important points for clinical ethics that need to be addressed. I will argue that clinical ethics consultants (CECs) do not need to jettison or even significantly weaken autonomy’s role in clinical ethics. Rather, CECs should adapt their practices to nurture and empower autonomous capacity.

Autonomy’s role in bioethics has been criticized by many. Some criticisms include that autonomy is:
• A tool of privilege, brandished by those who have the freedom and resources necessary for options;
• An isolationist denial of the interconnectedness of individuals in society;
• A myth that denies social and biological realities;
• A disguise used by the powerful to hide conditions which disempower vulnerable populations.

These criticisms present a challenge to clinical ethics practice, especially in the United States where autonomy is highly influential.

Many of the critics represent vulnerable or disenfranchised groups in society and bioethics (e.g. women, minorities, resource impoverished, etc.). If clinical ethics consultants (CECs) wish to be inclusive, equitable, accurate and empowering, they need to consider and respond to these critiques. I will demonstrate that they criticize an overly simplified view of autonomy.

In conclusion, this discussion will present some of the criticisms of the overly simplified view of autonomy. These critics raise important issues to which clinical ethics practice needs to respond. Using preventive ethics consults and expanding the function of the CEC beyond the hospital, I will demonstrate how CECs can promote a richer understanding of autonomy, including the responsibility to empower individuals, enhance communication and promote issue deliberation and problem solving in populations.

Authenticity of Informed consent in Anaesthesia

Dr Helet Potgieter

The National Health Act in South Africa states that a health care provider must take all reasonable steps to obtain the user's informed consent (Gazette and Goverment Gazette 2003), therefore informed consent for the administering of Anaesthesia is a prerequisite before anaesthetising a patient. The delicate task of conforming to both the ethical and legal requirements of informed consent has prompted an investigation into the conundrum of whether authentic informed consent truly authentically exists in Anaesthesia? The ethical dilemma faced by the anaesthesiologist and by me personally during my practice of Anaesthetics has necessitated an investigation. In order to asses these dilemmas in anaesthesia the thesis examines the origin en establishment of the precept of informed consent in both biomedical ethics and the law. Investigating the concept of autonomy, and the development of respect for autonomy as a principle of biomedical ethics it elucidates the move away from paternalistic approach to medicine to the now patient centered approach.

To expound the unique nature of the informed consent consultation where the anaesthesiologist finds themselves in, anaesthesia as a speciality is examined and from this investigation leads to discovering the unique moral status of the anaesthetised patient, a transient ethical state unlike any other in clinical medicine.
The ethical dilemma faced by the anaesthesiologist, is investigated with the guidance of bioethical principles and current thought leaders in the informed consent bioethical environment.

In an attempt to find ethical solutions to the dilemma of informed consent we face. ethical alternatives to informed consent in Anaesthesia are investigated. Phronesis and the ethics of responsibility, virtue ethics, as well as medical professionalism offers some solutions to the ethical dilemma that could alter the concept informed consent in anaesthesia as it currently exists. The important influence that the unique moral state of the anaesthetised patient infers upon the patient has interesting potential implications for the obtaining of informed consent in Anaesthesia. Lastly practical solutions to satisfy the responsibility of current legal and ethical guidelines faced by the Anaesthesiologist to obtain informed consent for the administering of Anaesthesia are be investigated, while facing the reality that the challenge of acting ethically and accepting that, despite obstacles, it is a strive to the ideal.

Sledding in Canada: Down the Slippery Slope of Medical Assistance in Dying (MAiD)

Professor Daryl Pullman[1]
[1]*Memorial University, , Canada*

Biography:
Daryl Pullman is Professor of Bioethics in the Faculty of Medicine, and Director of the Centre for Bioethics at Memorial University in Newfoundland and Labrador, Canada. He has over 20 years of experience in clinical ethics consultation and is currently a clinical ethics consultant with the Provincial Health Ethics Network for Newfoundland and Labrador. In 2019 he received a Lifetime Achievement Award from the Canadian Bioethics Society. Daryl has published widely on both research and clinical ethics and has an on-going academic interest in the concept of human dignity and its role in moral discourse.

In June of 2016 Canada passed legislation to permit Medical Assistance in Dying (MAiD). In the same month the state of California passed into law the End-of-Life Option Act effectively legalizing physician assisted death (PAD). California's population is larger than Canada's (38 million versus 36 million), yet there have been 8 times as many deaths in Canada due to MAiD than have occurred in California due to PAD over the same time period. Nevertheless there are continuing calls in Canada to further liberalize the law to permit even more individuals to have their lives ended with the assistance of a health care professional. Indeed, at the time of this writing media reports are circulating about the distressed family of a 61 year old man suffering from clinical depression, who was euthanized by a physician without consultation with his family. Even the most liberal interpretation of Canada's loosely drafted legislation does not permit mental illness as a condition eligible for MAiD, yet it isn't clear that any legal recourse to the steady expansion of the MAiD criteria in Canada are forthcoming.
In this talk I will discuss some of the factors that are contributing to the increasingly liberal interpretation of MAiD legislation in Canada, and to the potential threats it creates for the mentally ill, those suffering from dementia, and other vulnerable populations. At a time when many jurisdictions around the world contemplate introducing assisted dying legislation there are important lessons to be learned from Canada's descent down this slippery slope.

The "Shared Document" as a tool used in clinical ethics consultation in Obstetrics/Gynecology Area: data, results and perspectives of Clinical ethics consultation Service at “Agostino Gemelli” Teaching Hospital, Rome (Italy)

Barbara Corsano[1], Dario Sacchini[1], Antonio G Spagnolo[1]
[1]*Institute of Bioethics and Medical Humanities – Università Cattolica del Sacro Cuore, Rome, , Italy*

Biography:
Prof. Dario Sacchini, MD, MA, PhD, is Associate Professor of Bioethics at the Institute of Bioethics and Medical Humanities at Università Cattolica del Sacro Cuore (UCSC), Rome - Italy. He specialises in clinical ethics, research ethics and IRBs, management / organizational ethics, HTA. He has authored several publications. He is involved in international research projects.

Objectives. This contribution is aimed at showing the experience of Clinical Ethics Consultation (CEC) Service provided by Institute of Bioethics & Medical Humanities (IBioMedH) of Università Cattolica del Sacro Cuore (UCSC) for the Obstetrics and Gynaecology (Obst/Gyn) Area of “Agostino Gemelli” Teaching Hospital, Rome (Italy), from 2000 to 2019.
Methods. The data about CECs are gathered both from electronic database of IBioMedH-UCSC and “Gemelli” Intranet.
Results. Through January 2000 up to October 2019, 332 CECs totally were performed. One hundred of them were carried out for Obst/Gyn Area.
Clinical conditions of pregnant women for which CEC was requested are: ectopic pregnancies (30 cases); severe phoetal malformations, even associated to genetic syndromes (23); maternal pathologies in pregnancy (6); severe Intrauterine Growth Restriction (IUGR) (5); cancer in pregnancy (4); Premature rupture of membranes (PROM) (4); Hemolysis, Elevated Liver enzymes, and Low Platelet count (HELLP) syndrome (4); Pre-eclampsia (2); twin pregnancies with one dead phoetus (2); ovarian tissue cryopreservation (2); septic abortion by chorioamnionitis (1).
CECs was requested also for gynecologic diseases as false positive beta-hcg in gynecologic cancer (15), proportionality of treatments in terminal gynecologic cancer (1), blood transfusion in Jehovah’s witness with anemia and methrorragia due to cervical myoma (1).
72 CECs were delivered as written documents, as usual in clinical consultations (including summary of clinical condition, ethical question to be addressed, ethics consultant opinion) in clinical record, while 28 CECs were carried out as “shared document” of advanced care planning – as also recommend by recent Italian Law 219/2017 – especially regarding dilemmatic clinical conditions in which more than one clinical orientation can be ethically justified. In this case the document is signed in by patient/surrogates, health care professionals involved, and clinical ethics consultant.
Ethical issues/challenges/perspectives are analyzed and discussed.

Human Organ Transplant Law in Pakistan- A Bridge to Nowhere!?

Dr Sarosh Saleem[1], Nidi Ilyas Shamsi[2]
[1]Shalamar Medical & Dental College, Lahore, , Pakistan, [2]The Indus Hospital, Karachi, , Pakistan

Biography:

Dr. Sarosh Saleem is Assistant Professor and founding Head of Bioethics Department at Shalamar Medical & Dental College, Lahore, Pakistan. Dr. Saleem is a trained Pediatrician and Pediatric Ethicist. She has established Hospital Ethics Committees at various hospitals of Pakistan and has formally introduced Clinical Ethics Consultation Training as well Undergraduate Bioethics curriculum in Pakistan. Her areas of interest are socio-cultural diversity in healthcare, moral distress, Clinical Ethics Consultation and Bioethics education.

Introduction:

Human organ trafficking is a huge ethical concern, globally. Transplantation of Human Organs and Tissues Act, 2010 was enforced in Pakistan to curtail organ trafficking. This law suggests serious punitive actions against those found involved in human organ trafficking. The act permits only a blood relative to donate organ. Kidney transplantation is the most common form of organ transplantation in Pakistan, hence, this law raises ethical concerns for patients and healthcare providers, in this context.

Discussion:

Laws of a country are reflective of social, cultural and religious norms prevalent. Pakistan has a huge burden of patients with End Stage Renal Disease, requiring renal transplant. Corneal, bone marrow and other organ transplants are also being done but at a smaller scale. However, challenges arise due to limited number of donors. Neither every patient has a blood relative who fulfills the criteria of an organ donor, nor every blood relative volunteers to donate. Social pressures on young female donors, particularly, are immense. Culturally, females are considered homemakers and expected to raise children after marriage. A young daughter, sister and even a wife is often not allowed by family or spouse to become an organ donor, despite her own willingness.

In a paternalistic society where individualism is overpowered by 'relational autonomy' and where the legal boundaries restrict poor patients in need of organs, is such a law not restrictive to social justice? Instead of facilitating the patients and healthcare providers, is it leading us to nowhere?

Conclusion:

The Act of Human Organs and Tissues transplantation is not only restrictive but also not aligned with the social and cultural values of Pakistan. The Act needs revision and adequate consideration of social and ethical aspects of challenges faced by organ donors and recipients in Pakistan.

“We are pretty sure we can never say never”: Ethical implications of communicating genetic risk & uncertainty in the South African healthcare context

Dr Megan Scott[1], Jennifer Watermeyer[1], Tina-Marie Wessels[2]
[1]Health Communication Research Unit, School of Human & Community Development, University of the Witwatersrand, , South Africa, [2]Division of Human Genetics, Department of Pathology, University of Cape Town, , South Africa

Biography:
Megan Scott is a genetic counsellor based in Johannesburg, South Africa, and a PhD candidate at the Health Communication Research Unit (HCRU) at the University of the Witwatersrand. Her research focuses on communication practices within healthcare, with a particular interest in medical genetics, informed consent, and the impact of context on the interactional dynamics of patient-healthcare provider consultations.

Introduction:
Genetic counselling (GC) consultations are inherently complex due to the nature of the information provided and making risk-related decisions under uncertainty. Contextual influences including socioeconomic, linguistic, cultural, literacy and institutional variables may create further interactional difficulties. There is a paucity of research on the process of GC communication in non-western contexts, and how genetic specialists perceive this experience.

Methods:
This project focuses on risk and uncertainty communication in South African genetic clinics, using the lenses of complexity theory and Tronto’s work on ethics of care. Data includes 18 video-recorded GC consultations and 12 interviews with genetic specialists. Qualitative methods including conversation analysis and thematic analysis are utilised.

Results and Discussion:
Communication challenges exist within South African GC consultations due to theoretical ideals versus the reality of practice. GC principles such as complete disclosure of all relevant information and the need to maintain non-directiveness in consultations appear to create ethical tensions. This is despite their intention to facilitate informed decision making and enhance patient care. Patients may feel overwhelmed by the information provided and unsure about a decision, especially when seeking advice. Their lifeworld realities may also impact their reaction to genetic risk information. Alternatively, specialists may feel conflicted by their personal perception of a particular risk and the expectation to remain neutral. Specialists may also be unsure whether patients have found the information conveyed to them beneficial when they provide little or no response. Collectively, these factors exacerbate uncertainty and its management in the interactional space.

Conclusion:
GC in reality is not as straightforward as is suggested in theory and may include several ethical tensions. Further research and debate are necessary, including finding context-appropriate frameworks and approaches that enhance and facilitate patient decision-making and care, yet alleviate some of the complex communicative challenges faced by genetic specialists.

Out of Sight, Out of Mind: Suffering of Non-Covid Patients During the COVID Pandemic

Nuzhat Irfan Malik[1], Dr Sarosh Saleem[2], Nida Ilyas Shamsi[1]
[1]The Indus Hospital, Karachi, , Pakistan, [2]Shalamar Medical & Dental College, Lahore, , Pakistan

Introduction:
Covid 19 pandemic has exposed both public and healthcare professionals to many unprecedented ethical challenges. As the emergency and critical care professionals faced many morally challenging situations, the primary healthcare clinicians also dealt with situations beyond comfort. These ethical dilemmas created moral distress that many were not familiar with.
Discussion:
The patient-clinician encounter took an absolutely new meaning in 2020 when the world observed a lock-down. The physical touch was restricted by screens of gadgets through which the clinicians engaged with patients while at home. The lockdown meant many patients stayed at home instead of visiting their physicians either for a diagnosis of what was making them sick or to continue the therapy they had been taking to stay well. In this paper, we share a case of a patient suspected of gastrointestinal malignancy, advised imaging and biopsy for confirmation but was restricted to the home. A follow-up call by the Primary Healthcare Physician (PCP) reveals that the patient had passed away at home, undiagnosed. The PCP consoled the family but approached the Clinical Ethics Committee, questioning the responsibility of clinicians and the healthcare system toward 'non-covid' patients during the pandemic. The PCP suffered from moral distress of not being able to provide due care to her patient.
Conclusion:
The COVID-19 pandemic has posed many ethical questions for clinicians. The inequitable distribution of healthcare resources has instigated moral distress among clinicians. The institutions must look into the more equitable distribution of resources and introduce steps to mitigate moral distress among clinicians.

Design Ethics for Artificial Intelligence in Health Care: A Review and Proposed Framework

Joseph Donia[1], Jennnifer Gibson[1], Dr. Jay Shaw[1]
[1]*University of Toronto, , Canada*

Biography:
Dr. Jay Shaw is a Scientist at the Institute for Health System Solutions and Virtual Care at Women's College Hospital and Research Director of Artificial Intelligence, Ethics and Health at the University of Toronto's Joint Centre for Bioethics. He is also an Assistant Professor (Status) at the Institute of Health Policy, Management and Evaluation at the University of Toronto.

Introduction: A variety of approaches have appeared in academic literature and in design practice representing "ethics-first" methods for the design of technologies such as artificial intelligence (AI). These approaches generally focus on clarifying the normative dimensions of design, and outlining strategies to more strongly incorporate ethical decision-making throughout the design process. However, only recently has attention been devoted to comparing these approaches on their practical and normative characteristics, and very little attention has been paid to their application to health-related AI in particular.

Discussion: We identified 17 approaches to design ethics, ranging from normatively "weak" approaches to normatively "strong" approaches. Normatively weaker approaches included "value-sensitive design", which emphasizes identifying and incorporating the values of the local design team throughout the design process. Normatively stronger approaches included "critical making", which attends to the concentration of power and the possibility that technologies might increase domination and inequality on a global scale. We map these design ethics strategies onto the design of artificial intelligence technologies in health care, outlining the range of institutional realities that require attention if design ethics is going to be effective in the design and deployment of AI for health.

Conclusion: We suggest that design ethics must consider a range of institutional realities that lie outside of the design of the AI technology itself, such as the epistemic privilege of evidence-based medicine, the complexity of organizational relationships within health systems, and existing public beliefs about surveillance and public health. Design ethics for health-focused AI can inform more ethical applications of AI when acknowledging the challenges of how AI will be deployed in specific cultural and policy contexts around the world.

Egyptian Organ Transplantation law. Ethical Issues

Dr. Hany Sleem[1]
[1]*National Hepatology and Tropical Medicine Research Institute (NHTMRI), Cairo, , Egypt*

Biography:
Hany Sleem
I am the coordinator of ENREC, The Egyptian Network of Research Ethics Committees which was created in 2008 to raise the harmonization between Research Ethics Committees (RECs) in reviewing research proposals and to augment sharing of information and intellectual resources, policies and review strategies. I have working experience in the field of Dermatology that started 18 years ago. I am now the Head of the dermatology department in NHTMRI. I was selected to be a member of the IRB of NHTMRI and I received a scholarship for a Two-month certificate course in Research Ethics at the University of Maryland, Baltimore, USA. After my return from the USA, NHTMRI Dean assigned me NHTMRI IRB Chair, which I occupied for 10 years.
Moreover, I also contributed as a founding member of the Egyptian Society of Healthcare Development (ESHD), an Egyptian NGO aiming at strengthening research and research ethics,In conjunction with being the Vice-chair of the IRB at the National Hepatology and Tropical Medicine Research Institute (NHTMRI), Cairo. As well as the Co-PI the Middle East Research Ethics Training Initiative (MERETI).

Egyptian Organ Transplantation law. Ethical Issues
Introduction:.
The issuance of Egyptian Organ Transplantation law No.5/ 2010 and then its executive regulations is the reason for reducing accusations of theft organ or deceiving donors. On the other hand, it has raised many other ethical issues, such as the exposure of donors to financial temptation in order to donate their organs under difficult economic conditions.
Thus I aimed to explain the system of work in one of the institutional ethics committee for organ transplantation in one of the Egyptian liver transplant centers.
Methods /Results:
The emerging organizational structure according to the Egyptian law for organ transplantation will be described in addition to the strengths and controversies that face the practical application of the law including the Tripartite Committee on transplant Ethics located at each center of transplant.
In the non-relative donor, additional protection steps against any coercion or deception like registration of the donation process through official institutions (Recorder of deeds and police station) will be needed according to the law
The acceptance of the law for non-relative donations allows the existence of implicit organ trading that may include brokers.
Discussion:
The section of the law is devoted for deceased donor transplantation (DDT) is still inactive due to technical problems in dealing with brain stem death cases and the establishment of a refined administrative system to document legal and ethical procedures.
Activating DDT will allow more patients to be treated with fewer ethical dilemmas
In other hand if (LDT) will continue, additional governance points for the donation of non-relatives will be necessary to prevent hidden organ trading
Activation of ethics committees for organ transplantation is also a necessity to resolve any ethical problems that arise.

The ethical duty of practitioners in their interactions with third party funders

Howard Snoyman[1]
[1]*Discovery Health Medical Scheme, , South Africa*

Biography:
Howard Snoyman is an attorney and an ethicist, holding both LLB and MSc. Med. (Bioethics and Health Law) degrees, and has attained the title of Certified Deal Architect through the University of Tennessee, Knoxville. Since leaving practice, he has worked for a private complementary medicine manufacturer, a listed health / wellness / pharmaceutical company and is currently the Head of Legal and Ethics for Discovery Health Medical Scheme, the largest private healthcare insurer in South Africa. He also serves on the board of the Marketing Code Authority, a self-regulatory body established by the pharmaceutical industry, to determine the bounds of fair and ethical marketing and promotional activities relating to pharmaceutical products and medical devices in South Africa.

Howard is a member in good standing of several esteemed bodies, including:
• the World Association for Medical Law;
• Golden Key International Honours Society;
• Institute of Directors of South Africa (IoD);
• Corporate Counsel Association of South Africa (CCASA); and
• *The Ethics Practitioners Association;*

Practitioners around the globe are effectively bound to uphold two universal standards, namely:
1. Treat the patient in accordance with clinically appropriate interventions, as the circumstances may dictate; and
2. Such interventions may need to be constrained in accordance with prevailing funding parameters, regardless of whether the funding is sourced from the State, privately insured or paid out of the patient's own pocket.

Whilst the first standard is generally well understood and practiced, the second is an aspect that may require a greater degree of scrutiny.

There are generally three types of practitioners that contravene legal norms and standards in their interaction with funders, namely those:
1. that intentionally act unethically / illegally to derive personal benefit to the detriment of the funder;
2. that intentionally act unethically / illegally to assist patients in the bona fide belief that their beneficent end justifies their unlawful means; and
3. that negligently act unethically / illegally on account of not understanding both the substantive and procedural limitations that they are bound to act within.

Regardless of which of the above categories an errant practitioner falls into, the effect is the same - a constraint on the funder to provide optimal benefits for a maximal number of its members / constituents, given the unfortunate reality of a finite pot of resources from which to source such funds. When these financial resources are limited, the result is a diminished access to healthcare, which is of serious concern to society as a whole.

Fraud, waste and abuse of restricted financial resources are scourges that need to be actively combated by all stakeholders in the healthcare delivery chain. With this in mind, practitioners should seek out

opportunities to improve their understanding of their legal and ethical obligations in their particular jurisdiction.

Nudges in Clinical Medicine: Navigating the Tension Between Individual Liberty and Population Health Benefits

Mr. Derek Soled[1]
[1]*Harvard Medical School, Harvard Business School, , United States*

Biography:
Derek Soled, MSc, is a MD/MBA candidate at Harvard Medical School and Harvard Business School. A recipient of the Henry K. Beecher Prize in Medical Ethics, his research focuses on ethical tension in health policy. Derek has worked on public health interventions and clinical ethics in the United States and worldwide. He is also the author of over 20 peer-reviewed articles, abstracts, and chapters on clinical medicine, care delivery, and ethics. Derek has a master's degree in medical anthropology from the University of Oxford, where he won the Nautilus Prize for his dissertation on culturally compelling public health. In 2016, he graduated summa cum laude and Phi Beta Kappa with distinction in sociology and molecular biology from Yale University.

Libertarian paternalism describes the concept of nudging, which Richard Thaler and Cass Sunstein define as steering individual decision-making while preserving freedom of choice. By framing choices (or altering the environment) to trigger automatic cognitive processes in favor of a desired outcome, the nudge encourages an individual to choose a particular option or behave in a certain way. In medicine, libertarian paternalism has gained widespread attention, specifically regarding interventions designed to promote healthy behaviors. Some scholars argue that nudges appropriately balance autonomy and paternalistic beneficence, while others claim that nudges exploit cognitive weaknesses and, therefore, must be considered coercive. This analysis further explores the ethics of libertarian paternalism in clinical medicine and public health, focusing on several contemporary nudges that use opt-out defaults and incentives. Moreover, in light of the COVID-19 pandemic, taking advantage of individuals' decision biases and using them as starting points for designing preventive interventions that use nudges, such as masking, social distancing and sanitation stations, all relate to these ethical tensions. Utilizing the frameworks of Feinberg voluntary choice, Kantian autonomy, and genuine informed consent, this analysis concludes that nudges do in fact infringe on individual liberties when knowingly used in clinical medicine. However, despite their limitations, nudges are ethically justified when there is a clear public health benefit to the manipulation of choice.

The COVID crisis and the boundaries of doctors' perception of their own mission

Nicolas Foureur[1], Milena Maglio[1], Marta Spranzi[1]
[1]*Center for clinical ethics, Paris, , France*

Biography:
Marta Spranzi is associate professor of history, philosophy and ethics of science at the University of Versailles St-Quentin-en-Yvelines medical school, and a clinical ethics consultant and research at the "Center for clinical ethics" at the Paris university hospital trust AP-HP (http://ethique-clinique.aphp.fr/clinical-ethics-consultation/)
Her research focuses on epistemological issues underlying empirical and clinical ethics (what is a case and what is its normative relevance, 'ordinary humanity', the natural and the artificial), end-of-life and other prominent clinical ethics issues, and moral philosophy (Le travail de l'éthique: decision médicale et intuitions morales, Mardaga, 2018).

The triage dilemma during the ongoing COVID crisis is usually construed as a choice between an egalitarian approach focused on the care of each individual patient and a utilitarian perspective accepting to sacrifice individual chances in order to maximize total well-being. In France there has been a general uproar about the very possibility of prioritizing patients according to non-medical criteria. However, as we learnt from follow-up interviews from a previous study about of intensive care doctors' perception of "withdrawal and withdrawing practices" in the ICU, during the crisis, individual patients' "loss of chance" and the impossibility of following purely medical criteria was a daily reality. Stakeholders construed their moral dilemma as an insoluble and existential predicament of a double allegiance to two radically different commitments: to the patient as a concrete person, or to a collective entity. In the first part of the paper we shall give examples of the way the dilemma was formulated by practitioners themselves. In the second part of the paper, we shall describe ways of dealing with those incompatible commitments. Whereas some advocated externalizing priority decisions a committee or a political entity, others thought it was their duty to assume an enlarged role themselves. This latter group was also divided, as to how to characterize their mission: some describe the necessity of a "paradigm shift", the exceptional, war-like, circumstances bringing about a different standard of care, some others construed their predicament as sharpening the dilemmas of current practice, the crisis serving as a sort of "magnifying glass" in time of shrinking resources and a reduced timeframe even indicting ways to improve normal practice. In the conclusion, each of us will give arguments in favor of either of these two options, and thus introduce the discussion.

Engineering life: new biotechnologies call for a paradigm change in bioethics

Carlo Casalone[3], Bruno Dallapiccola[4], Daniel Müller[2], Renzo Pegoraro[3], Carlo Petrini[5], Ralf Stutzki[1], Marco Tartaglia[4], Tom Ward[1]
[1]University of Basel , , Switzerland, [2]ETH Zurich, , Switzerland, [3]Pontifical academy for life, , Italy, [4]Ospedale Pediatrico Bambino Gesù, , Italy, [5]Bioethics Unit, Istituto Superiore di Sanità, , Italy

Biography:

Dr. Deepak Sarma is a professor of Indian religions and philosophy in the Department of Religious Studies and holds a secondary appointment in the Department of Bioethics in the Medical School at Case Western Reserve University, Cleveland Ohio. Sarma is the author of Classical Indian Philosophy: A Reader, Hinduism: A Reader (2008), Epistemologies and the Limitations of Philosophical Inquiry: Doctrine in Madhva Vedanta (2005) and An Introduction to Madhva Vedanta (2003). Sarma attended the University of Chicago Divinity School, where he received a PhD in the philosophy of religions. His current reflections concern bioethics, cultural theory, racism, and post-colonialism.

What implications does diversity have for the field of clinical ethics? Can "western" principles be incorporated in “Hindu” contexts? And, can “Hindu” principles be incorporated in “western contexts”? The changing, osmotic, and humanly constructed boundaries around world communities, religions, and peoples demand that philosophical diversity is incorporated in decision-making processes by CECs. If philosophical diversity is not then are the decisions made by CECs merely instances of “western” imperialism? Are they merely a covert continuation of colonial complexities on post-colonial contexts? But if philosophical diversity is incorporated, couldn’t some positions conflict with ideas and ideals of social justice, foundational to “western” ideas of a universal bioethics?

The presenter will ask these and related questions concerning the consequences of cultural relativism from the perspective of Hinduism. Hindu social systems, theories about women, and concerns with purity are instances where non-western practices conflict with secular ideologies. How does one decide what to include and what to exclude? And, in so doing, is the claim (or desire) to incorporate philosophical diversity merely nominal or superficial?

After addressing the issues in the theoretical, I will examine these and other instances with the goal of provoking conversation about how to do (or not to do) bioethics in an increasingly cosmopolitan and globalized world and whether or not Hindu" principles can be incorporated in the decision-making processes by CECs.

The Need to Establish Clinical Ethics Committees (CECs) in Liberia

Cecelia Morris[1], Mr. Jemee Tegli[1]
[1]*UL-PIRE IRB, , Liberia*

Biography:

Jemee K. Tegli works for the Liberian-US Clinical Research Partnership Program under the name "Partnership for Research on Vaccines and Infectious Diseases in Liberia (PREVAIL) since 2014 and currently serves as Director of Operations. He previously worked with the University of Liberia-Pacific Institute for Research and Evaluation (UL-PIRE), a prevention research center from 2007 – 2014 in various capacities navigating from Capacity Building Manager to Center Director. Mr. Tegli currently serves as the Coordinator of the UL-PIRE Institutional Review Board. In past years, he implemented research and capacity building grants from the National Institutes of Health (NIH), European and Developing Countries Clinical Trial Partnership (EDCTP), World Health Organization (WHO), etc. He has a background in Regional Science, Bioethics, Research Ethics, IRB Administration, Social Mobilization Engagement & Communication. He is an alumnus of the Bioethics Fellowship program at the Western Institutional Review Board (WIRB)-Copernicus Group, Puyallup, Washington, USA; and the Berman Institute of Bioethics at John Hopkins University, USA. He is a member of the National Research Ethics Board of Liberia (NREB). He also serves as a Board Member of the Liberia Center for Outcome Research in Mental Health (LiCORMH). He is also a member of the Technical Working Group on Ethics of the West Africa Integrated Vector Management Programme (WA-IVM). He has written and contributed to numerous publications and study abstracts that have been presented and published in international journal and conferences. He is a contributing author of the book "Research Ethics in Africa - A Resource for Research Ethics Committees. Chapter 9, Informed Consent in an African Context."

INTRODUCTION

Attention to clinical stewardship and governance, typical in many low-resource settings are important issues to be addressed and strengthen. In Liberia, there are about twenty-two provincial hospitals with no CECs few of which facilitate research. The upsurge of patients inflow seeking medical care couple with ethical dilemmas encounter are glaring. These facilities lack appropriate capacity in clinical ethics review, monitoring and regulation on clinical procedures. The use of international best practices for protection of patients and caregivers is nominal. The need to establish a CEC at John F. Kennedy Medical Center is needed at this time.

DISCUSSION

There are social, cultural and public attitudes towards the medical profession and a growing emphasis on patient choice and decision making. Occasionally, health professionals and patients may disagree about values or face choices that challenge their values. There is a regulatory framework in Liberia that guides clinical research activities. However, there is no national clinical ethics guidelines even though there are semblance in these facilities. Therefore, working with the JFK Authorities to establish a CEC is important. It will address gaps and create opportunities for clinicians and institutions to use best judgments regarding the protections of patients. Issues about informed consent, risks/benefits, end of life procedures, and palliative care are critical areas of interest. A structure approach to assist health professionals in identifying, analyzing and resolving ethical issues that arise in clinical practice is required.

CONCLUSION

Liberia will gain a lot in the establishment of CECs at JFK (the largest referral hospital) and others. Clinical ethics is an evolving field that can provide a structure approach in assisting patients in making informed decision during clinical care. Engaging with the JFK Authorities on this subject which they are aware of can be a concrete approach in establishing it here.

Patients on social media -Supportive guidelines for an ethical and legal approach

Cecilia Bartholdson[2], Lisa Törnudd[1]
[1]*Crown Princess Victoria Children's Hospital and Dep. of Biomedical and Clinical Sciences, Linköping University, , Sweden,*
[2]*KBH, Karolinska Institutet, , Sweden*

Biography:
Lisa Törnudd is a paediatric oncologist at Crown Princess Victoria Children's Hospital, Linköping University Hospital, Sweden. She is the chair of the Nordic Society of Paediatric Oncology and Haematology and Nordic Society of Paediatric Oncology Nurses joint Working Group on ethics as well as the chair of the Paediatric Ethics Board in the South-east Region of Sweden.

Introduction
An increasing number of patients share their experience of illness and healthcare on social media. This has raised possibilities but also challenges. Many seem to be more comfortable sharing through their computer-screen than face-to-face. Following blogs etc might give healthcare professional a better understanding of patients and therefor enabling them to provide better care. However, patients might also share experiences where they have been or felt medically or personally mistreated. The commentary fields are often supportive, but might also include hateful remarks towards the healthcare system or a specific healthcare professional. An elevated number of ethical concerns where brought to our ethics counsel involving both legal and ethical questions concerning freedom of speech, slander, professional secrecy, integrity, children's rights, amongst others.

Methods
The regional pediatrician ethics board held a workshop with lawyers, human resource professional, ethicists, physicians and nurses with the aim to construct a document to provide ethics support and legal guidance concerning patients and parents social media activities.

Results
A document stating legal facts, responsibility of the employer as well as ethical values that needs to be considered in these situations was constructed.

Discussion
A workshop could be held at the national level to get a wider perspective. More research is needed to examine how patient's activity on social media affects care and caregivers. Moreover, values and norms in the patient blogosphere needs to be explored.

Conclusion
The explosive expansion of social media is shifting norms concerning integrity, truth, responsibility and freedom of speech. This phenomenon will grow further and we have a responsibility to enhance benefits and minimize harm. Care providers need to be equipped with tools to handle these situations and enabling them to provide a good care-relationship with their patients.

Online clinical ethics support: Potential benefits and risks

Dr. Manuel Trachsel (MD, PhD)[1], Julia Stoll[1]
[1]*University of Zurich, , Switzerland*

Biography:
Manuel Trachsel (MD, PhD) is the head of the Clinical Ethics Unit at the University Hospital of Basel, the University Psychiatric Clinics Basel, and the Geriatric University Clinic FELIX PLATTER Basel, Switzerland. He is a Research Associate at the Institute of Biomedical Ethics and History of Medicine, University of Zurich, Switzerland.
Dr. Trachsel has been trained in medicine (MD), clinical psychology (PhD), and philosophy/ethics at the University of Bern, Switzerland. In 2014, he has been a visiting research fellow at the Bioethics Center of the University of Otago, New Zealand, and in 2016/2017, a research fellow at the Cedars Sinai Medical Center in Los Angeles, CA.
Dr. Trachsel has been awarded with the 2020 Mark S. Ehrenreich Global Prize in Healthcare Ethics Research by the Pacific Center for Health Policy and Ethics, University of Southern California.
Dr. Trachsel's research areas include the philosophy and ethics of psychiatry and psychotherapy, the intersection of psychiatry and palliative care, ethical challenges with regard to coercive measures in psychiatry, clinical ethics support services in psychiatry, medical decision-making capacity, and informed consent. He is a published author of more than 70 scientific papers, book chapters, and books including articles in JAMA, The Lancet Psychiatry, The American Journal of Bioethics, The Journal of Medical Ethics, The British Journal of Psychiatry, and Frontiers in Psychiatry among others. Furthermore, Dr. Trachsel is the lead editor of the Oxford Handbook of Psychotherapy Ethics.

Clinical ethics support services (CESS) cannot only be provided in the classical face-to-face setting but also over distance using technology such as the internet. Online CESS can have many potential benefits and risks for healthcare providers, patients, and CESS providers. Analogous to findings from a recent review on online psychotherapy, potential benefits of online CESS could be (1) increased access to CESS and service flexibility; (2) advantages related to specific ward or hospital characteristics (e.g., remote location); (3) convenience, acceptance, and increased demand; or (4) economic advantages. Potential risks of online CESS could be (1) confidentiality and security issues; (2) CESS providers competence and need for special training; or (3) legal issues (e.g., transnational CESS). These and more potential benefits and risks are discussed and illustrated with examples from clinical practice.

Medical futility and communication, as old as the Hippocratic Oath.

Jewel Jacob[2], Dr. Roopa Verghese[1]
[1]The Center for Bioethics, New Delhi, , India, [2]MGM Muthoot Healthcare, , India

Biography:
Dr. Roopa Verghese, is a senior consultant obstetrician and gynecologist by profession who went on to do her Masters in Bioethics from Trinity International University, Chicago. After working for 14 years in all over northern India in remote locations under the aegis of Emmanuel Hospital Association she has now shifted to Muthoot Healthcare in rural Kerala as a full time obstetrician and gynecologist. She also has an added responsibility of being the Deputy Medical Superintendent of the Hospital.
Being among the first few trained and qualified bioethicist in India she contributes to the pioneering work for the Center for Bioethics as a part time consultant. Presently she as a faculty of TCB along with CMC, Vellore are engaged in setting up the curriculum for the first every post graduate course in bioethics in India. She strives to practice bio ethically relevant obstetrician and gynecology in rural India given the socioeconomically and cultural difference between the countries of her educational and origin. She is a keen activist representing women's rights on a much wider platform.

Medical futility is a concept commonly used to describe medical therapy that has no known or anticipated immediate or long-term benefit for a patient. The concept of futility has existed since the time of Hippocrates and has become the predominant dilemma for many end-of-life situations. Doctor-patient communication is an issue that is attracting more and more attention within the international scientific community, stimulating an interest involving many different health contexts, from academic to medico-legal ones. Today, clinicians grapple with ethical conflicts and concepts in their daily practice. Many healthcare providers use the concept of medical futility when they are talking with patients and families who are in a quandary about their loved one's care. Doctor-patient communication is therefore an extremely up-to-date topic, the problematic of which may already be discerned in Western medicine in the so-called Hippocratic Oath.
In this paper an overview of medical futility and its relation to doctor-patient communication is discussed along with the importance of every physician and, more in general, how every health operator should learn to communicate effectively in the course of his/her medical training.

Should Hospital Scrubs be Scrubbed from the Public? An Ethical Inquiry and Policy Recommendations:

Kevin Whitford

Scrubs worn outside of the hospital setting represent an immediate and insidious threat to public health. A systematic review of the literature reveals that of nearly two dozen studies assessing the pathogenic hazards of hospital scrubs continues to be a pervasive and ubiquitous challenge among hospital settings. Nearly a decade ago, the Committee to Reduce Infection Death, a nationwide educational campaign to stop hospital-acquired infections, took major steps to curtail the spread of pathogens by medical workers. The recommendations implored hospitals across the United States to implement policy that would not only supply clean uniforms but additionally bar workers from wearing their scrubs outside the hospital setting. While many institutions implement policies governing use and disinfection, statistics reveal that they are vague and rarely enforced. While the health hazards attributed to microbes and pathogenic sources are well documented, the implicit power differential characterized by the appearance of scrubs outside of the clinical setting represents a paternalistic model that abuses public trust and exploits the provider-patient relationship. Few studies have explored the underlying drivers correlated with power dynamics and paternalistic phenomena. We explore research findings and hospital policies that are informed by unconscious conflation of the wearing of professional uniforms with perceived patient and public trust. We propose that all institutions engaged in clinical care put in.place scrubs attire policies for employers addressing wearing of scrubs outside of their practice area, We also recommend that an accreditation body, such as the Joint Commission on Accreditation of Healthcare Organizations and/or the Federation for State Medical Boards create policy oversight and implementation for healthcare systems to ensure national standardization of the wearing of scrubs. We do not propose punitive consequences but rather supportive measures to promote thoughtfulness of policies for healthcare workers that may be globally recognized, applied universally, and implemented across practices.