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THE JOHN J. LYNCH, MD CENTER FOR ETHICS AT MEDSTAR WASHINGTON HOSPITAL CENTER



Proceedings of the 14th Annual International Conference for Clinical Ethics Consultation: Clinical Ethics and Changes in Healthcare (ICCEC 2018)

Hosted by the the Institute of Medical Ethics at the
Mathematical Institute, Oxford, United Kingdom

[faculty](#)

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mission

The mission of the *Journal of Hospital Ethics* is to enhance bioethical discussion and to assist in the development of skills associated with recognizing, understanding, and managing moral uncertainties and ethical complexities in hospital practice.

The mission of the John J. Lynch, MD Center for Ethics at MedStar Washington Hospital Center is to help clinicians and other hospital professionals meet a standard of excellence in the care of our patients through education, training, consultation, policy development, and research in clinical ethics. Additionally, when appropriate, we address the ethical concerns of our patients and families directly. The MedStar Washington Hospital Center's bioethics program began in 1982. The John J. Lynch, MD Center for Ethics, subsequently established, is involved in over 300 clinical ethics consultations a year, as well as the development of internationally recognized bioethics conferences and education programming.

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A Note from the Editor-in-Chief

Dear All,

Welcome to the third of the *Journal of Hospital Ethics's* published proceedings of the annual International Conference for Clinical Ethics Consultation (ICCEC). As the sponsor journal for the proceedings of the ICCEC meetings, we present to you the abstracts of ICCEC 2018 at Oxford. As an attendee, I know firsthand how wonderful this meeting was. The meeting program and materials were excellent; thorough and elegantly presented. The presentations were also excellent, and the engagement among participants throughout Q&A sessions and during breaks was lively, and extended the utility of the formal presentations into making new collegial connections and international friendships. The diversity and breadth of international attendance was a delight.

The skill in organization of the sponsoring United Kingdom (U.K.) groups was superior; everyone's needs were met cheerfully and to the very end. Also worthy of note, those who needed extra mobility assistance, such as I, were provided that extra help with the kindness for which one would always hope.

And as usual, thanks go to George Agich and Stella Reiter-Theil for their continuing assistance and support. Thank you, additionally, to Phil Greenwood, Chief Executive at the Institute of

Medical Ethics, and others in the U.K. and the U.S. who have assisted with the preparation of these proceedings.

We hope you find this third *Proceedings* a useful resource and a reminder of another wonderful ICCEC meeting. As is now our practice, we will have print copies of this issue distributed to the attendees of ICCEC 2019. I look forward to meeting and talking with as many of you as possible in Vienna.

Sincerely,



Evan

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

Faculty of ICCEC 2018

The Names of Presenters at ICCEC 2018, with Abstract Numbers

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Conference Program

A Listing of the Presenters by the Date of Their Presentation, with Abstract Numbers

AGENDA | Thursday, June 21

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- 8:45 a.m. **Welcome address**
Dr. Wing May Kong, Chair, Institute of Medical Ethics
Professor Stella Reiter-Theil and Professor George Agich
- 9:15 a.m. **PLENARY 1: Philosophical foundations of clinical practice: Does clinical ethics need theory**
Session Chair: Professor Raanan Gillon
- From principles to stories . . . and back again? Personal reflections upon theorizing in clinical and biomedical ethics**
Professor Bobbie Farsides
- The inescapable presence and relevance of theory in the practice of clinical ethics support: The case of emotions**
Dr. Bert Molewijk

PARALLEL SESSIONS

1 A: Clinical ethics and saw—Chair: Michael Parker

- 11:45 a.m. **Symposium: Clinic, court, or committee: In the best interests of the critically ill child?** **1040**
Richard Huxtable, Giles Birchley, Helen Irving, Vic Larcher
- 12:35 p.m. **Oral presentation: When ethics and the law conflict in clinical ethics support services** **1073**
G. Owen Schaefer

1 B: Ethics case consultation: Sharing experience—Chair Karen Le Ball

- 11:45 a.m. **Symposium: Helpfulness in clinical ethics consultation notes** **1022**
Marleen Eijkholt, Devan Stahl, Stella Reiter-Theil, Jurgen Wallner
- 12:45 p.m. **Oral presentation: Uncertainty in clinical ethics consultation recommendations** **1018**
Paul Cummins, Federico Nicoli, Joseph Raho, Rouven Porz, Mario Picozzi

1 C: Clinical ethics services: Roles, boundaries, and strategies—Chair: Anne-Marie Slowther

- 11:45 a.m. **Oral presentation: Protecting CEC's autonomy: Institutional virtue as the courage to sacrifice institutional autonomy. One way forwards?** 1059
Raj Mohindra
- 12:05 p.m. **Oral presentation: Can clinical ethics committees be a legitimate actor in bedside rationing?** 1051
Morten Magelssen, Kristine Baerøe
- 12:25 p.m. **Oral presentation: How hard to push? The challenge of addressing organizational ethics** 1032
Laura Guidry-Grimes
- 12:45 p.m. **Oral presentation: Encountering "ethics" in clinical versus administrative contexts: Peer learning, peer review, and responsibility** 1010
Mark Bliton, Stuart Finder

1 D: Ethics dilemmas and ethics cases: Reviewing and experiences—Chair: Reidun Førde

- 11:45 a.m. **Oral presentation: What ethical issues arise at a rural regional medical center? A quantitative and qualitative analysis of clinical ethics consultations from 2007 to 2017** 1055
Jessica Miller, Jonathan Wood
- 12:05 p.m. **Oral presentation: Clinical ethics dilemmas in a low-income setting: A national survey among physicians in Ethiopia** 1054
Ingrid Miljeteig, Frehiwot Berhane, Ole Norheim, Dawit Desalegn, Marion Danis
- 12:25 p.m. **Oral presentation: Ten-year review of ethical topics and themes arising from referrals to a well-established clinical ethics committee** 1019
Paquita de Zulueta, Gareth Tudor-Williams, Selena Knight
- 12:45 p.m. **Oral presentation: Translating clinical ethics in trenches: Experiences from a developing country** 1076
Nida Shamsi, Sarosh Saleem

1 E: Values at the end of life—Chair: Ruth Horn

- 11:45 a.m. **Case study: When a son refuses palliative care for his dying mother: Conflicting interests at the end of life** 1048
Danielle Ko
- 12:10 p.m. **Oral presentation: What does dying with dignity mean when euthanasia is requested by a life-sentenced prisoner? Ethical issues** 1067
Lucie Opatrny, Mathieu Moreau, Marie-Eve Bouthillier
- 12:30 p.m. **Oral presentation: How should hospital ethics committees address surrogate requests for imminent death organ donation?** 1001
Mahwish Ahmad, Jordan Potter

- 12:50 p.m. **Oral presentation: Who leads in the final dance? Patient information and autonomy in the case of advanced cancer “ideals and realities”:
A qualitative study** **1034**
Berit Hofset-Larsen and Reidun Førde
- 2:15 p.m. **PLENARY 2: Translating clinical ethics across global contexts**
Session Chair: Dr. Maureen Kelly
- A glimpse into ethical dilemmas, discussion, teaching, and capacity building in Ethiopia**
Dr. Ingrid Miljeteig and Dr. Dawit Desalegn
- Clinical ethics in a low-resource setting: The perspective of hospital staff working in a charity healthcare organization in Cambodia**
Dr. Claudia Turner

PARALLEL SESSIONS

2 A: Different approaches and influences on ethics consultation—Chair: Prem Fade

- 4 p.m. **Case study: Advocating for patients with profound intellectual and multiple disabilities at the end of their lives: Reframing a case through the lens of an ethics of care** **1056**
Valerye Milleson, Katherine Brown-Saltzman
- 4:25 p.m. **Oral presentation: Charlie Gard: How the “court of public opinion” may influence future end-of-life decision making** **1007**
Neera Bhatia
- 4:45 p.m. **Oral presentation: A systematic review of typologies used to characterize clinical ethics consultations** **1002**
Armand Antommaria, Jennifer deSante-Bertkau, Michelle McGowan

PARALLEL SESSIONS

2 B: The color of medicine: confronting the problem of racism in clinical settings —Chair: Nneka Sederstrom

- 4 p.m. **The color of medicine: Confronting the problem of racism in clinical settings** **1075**
Nneka Sederstrom, Rachel Hardeman, Shelly Nauertz, Maurice Sholas, Joel Wu

2 C: Ethical challenges in paediatrics—Chair: Carwyn Hooper

- 4 p.m. **Case study: Pediatric case examination: Undocumented parents in rural America** **1072**
Hellen Ransom
- 4:25 p.m. **Oral presentation: Who decides? Exploring the impact of governmental authority on the treatment of borderline viable infants in the United States** **1042**
Sasha Jorgensen-Muga, Ingrid Miljeteig
- 4:45 p.m. **Oral presentation: Medical innovation in a children’s hospital: “Diseases desperate grown by desperate appliance are relieved, or not at all”** **1012**
Joe Brierley

2 D: Moral expertise from international perspectives—Chair: Symposium leader

- 4 p.m. **Moral expertise from international perspectives** **1087**
Jamie Watson, Jennifer Flynn, Salla Saxén

2 E: Ethical challenges and ethics support in intensive care—Chair: George Agich

- 4 p.m. **Case study: The burdens in the interpretation of the ethical criterion of the proportionality** **1065**
Federico Nicoli, Alberto Giannini, Nicola Latronico, Giovanni Zaninetta, Mario Picozzi

- 4:20 p.m. **Oral presentation: The best interest of the child in the case of not complete acceptance by the mother** **1085**
Vittoria Viganò, Emanuela Constanzo

- 4:40 p.m. **Oral presentation: Implementation and evaluation of ethics in multidisciplinary ICU rounds** **1070**
Prabalini Rajendram, Robert Guerin, Marguerite Augustine, Katheryn Weise

- 5 p.m. **Oral presentation: Clinical inertia in critical care: lessons from ethics consultations** **1086**
Margaret Waltz, Sara Scarlet, R. Jean Cadigan, Casey Olm-Shipman, Arlene Davis

AGENDA | Friday, June 22

9 a.m. **PLENARY 3: Extending the boundaries of clinical ethics practice**
Session Chair: Michael Parker

Mitochondrial donation and reproductive choices
Professor Alison Murdoch

Extending the boundaries of clinical ethics practice
Professor Mark G. Kuczewski

PARALLEL SESSIONS

3 A: The complexity of communication in clinical ethics—Chair: Stella Reiter-Theil

10:45 a.m. **Symposium: Truths, conceits, and moral entanglements when telling (and listening to) clinical stories: the challenge of re-presenting ethics consultation** 1027
Stuart Finder, Virginia Bartlett, Mark Bliton, Jürgen Wallner

11:35 a.m. **Oral presentation: A role for clinical ethicists on ventricular assist device eligibility committees** 1031
Laura Guidry-Grimes

11:55 a.m. **Oral presentation: Culture, context, and communication in gynecological cancers in India** 1079
Kalyani Subbiah, Jaya Danta, Arima Mishra

12:15 p.m. **Case study: Mixed messages: Tattoos and a schizophrenic patient** 1009
Ted Bitner, Marcia McKelligan, Lauren LeFebvre, Tara Wales

3 B: Advance decision making and its consequence—Chair: Richard Huxtable

10:45 a.m. **Case study: What part of “No” don’t you understand?** 1053
Annette Mendola

11:05 a.m. **Oral presentation: Approaches to resuscitation decisions: When does empirical evidence of harm lead to an ethical imperative to change practice?** 1029
Zoe Fritz, Anne-Marie Slowther, Rachel Warren, Gavin Perkins

11:25 a.m. **Oral presentation: Translating to advocacy and policy: Reflections on ethical and practical issues with promoting advance directives and advance care planning** 1014
Hui Yun Chan

11:45 a.m. **Oral presentation: Evaluating ways to conduct do not resuscitate/do not intubate conversations with terminal patients: Is a paternalistic approach ethically favorable?** 1052
Kristen Mathias

12:05 p.m. **Oral presentation: What’s the harm in CPR? The ambiguity of harm in code status discussions** 1049
Peter Koch

- 12:25 p.m. **Oral presentation: Property rights over cadaveric organs and tissues in an “opt out” system of organ donation in Australia and New Zealand: How important are the next of kin?** **1008**
Neera Bhatia

3 C: Ethical challenges and ethics education—Chair: Georgia Testa

- 10:45 a.m. **Oral presentation: Cross-cultural topics in daily clinical encounters: An ethnographic study reveals ethical challenges outside ethics consultation** **1088**
Kristina Maria Würth, Wolf Langewitz, Sylvie Schuster, Stella Reiter-Theil
- 11:05 a.m. **Oral presentation: Beyond the actor and simple personal recollection: Partnering with patients, the new clinical ethics teaching standard** **1021**
Amelie Du Pont, Vincent Dumez, Philippe Karazivan, Antoine Payot, Alexandre Berkesse
- 11:25 a.m. **Oral presentation: Field notes from the front line: Postgraduate medical ethics education in the UK** **1068**
Andrew Papanikitas, David Molyneux, Selema Knight, Laura Machin
- 11:45 a.m. **Oral presentation: Published coma/brain death simulation utilized to assess neurology residents and medical students** **1003**
Diana Barratt, Maryam Shakir, Rebeca Martinez, Amparo Gutierrez, Farah Fourcand
- 12:05 p.m. **Oral presentation: Legal cases or thought experiments?** **1036**
Dieneke Hubbeling

3 D: Ethical challenges of medical innovation—Chair: Nina Hallowell

- 10:45 a.m. **Oral presentation: Incidental findings of misattributed paternity discovered through whole exome sequencing: An old ethical problem with a new twist** **1057**
Valerye Milleson, James Hynds
- 11:05 a.m. **Oral presentation: Navigating uncharted territories: Interdisciplinary ethics collaboration in innovative clinical practice** **1071**
Prabalini Rajendram, Michael O'Connor, Margot Eves
- 11:25 a.m. **Oral presentation: The ethical challenges of providing innovative treatment to children** **1083**
Marianne Tinkler, Ian Thomas, Giles Birchley
- 11:45 a.m. **Oral presentation: Ethical issues of gamete donation in Islam: Shia and Sunni perspectives** **1026**
Md Shaikh Farid
- 12:25 p.m. **Oral presentation: Genomics in research and practice: Is there a need for a new ethical approach in the clinic?** **1045**
Angeliki Kerasidou, Ruth Horn, Nina Hallowell, Ingrid Slade, Michael Parker
- 12:25 p.m. **Oral presentation: Opening Pandora’s box: Ethical uncertainty surrounding the handling of incidental findings generated in genomic sequencing** **1035**
Joseph Home

- 1:45 p.m. **PLENARY 4: Ethical responsibilities at the interface of health and social care**
Session Chair: Alastair Campbell
- Ethical responsibilities and fairness at the intersection of health and social care**
Jacquelin Chin
- Slow ethics for elder care**
Ann Gallagher

PARALLEL SESSIONS

4 A: Educational innovation in clinical ethics consultation—Chair: Andrew Stanners

- 3:30 p.m. **Symposium: Filming clinical ethics consultation: Using video technology for research, education, and community information** **1043**
Ralf Jox, Kurt W. Schmidt, Katherine Wasson, Stella Reiter-Theil
- 4:20 p.m. **Oral presentation: The making (and successful failure) of a pilot project assessing the use of videoconferencing technology to deliver ethics consultation** **1017**
Joshua Crites, Cristie Horsburgh, Hilary Mabel, Bethany Bruno
- 4:40 p.m. **Oral presentation: Teaching and learning beyond simulation: Innovative experiential curriculum in clinical ethics consultation** **1023**
Margot Eves, Susan McCammon

4 B: Clinical ethics beyond the acute care setting—Chair: Carwyn Hooper

- 3:30 p.m. **Symposium: Is there a place for clinical ethics consultation outside of the hospital setting?** **1020**
Kevin Dirksen, Tyler Gibb, Devan Stahl, James Hynds
- 4:20 p.m. **Oral presentation: Unique and evolving ethical challenges faced by a community palliative care service preparing for the implementation of voluntary assisted dying** **1047**
Danielle Ko, Janet Phillips, Jane Sullivan
- 4:40 p.m. **Oral presentation: Bridging clinical and system ethics: Opportunities for responsible advocacy** **1033**
Anita Ho

4 C: Patient autonomy and shared decision making—Chair: Ruth Horn

- 3:30 p.m. **Oral presentation: Patient centered care, autonomy, and choice** **1005**
Zackary Berger, Leah Rand
- 3:45 p.m. **Oral presentation: Shared decision making and ethics: A political approach** **1006**
Zackary Berger, Samuel Scharff, Douglas Opel
- 4:00 pm. **Oral presentation: Rethinking the assessment of decision-making capacity** **1044**
Juliana Kan

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4:35 p.m.	Oral presentation: Clinical ethics committees and consultation services as moral spaces to reduce moral distress Georgina Morley	1064

AGENDA | Saturday, June 23

- 9 a.m. **PLENARY 5: Empirical ethics and clinical practice**
Session Chair: Anne-Marie Slowther
- Presentation of Hans Shwager award**
Stella Reiter-Theil
- Translating empirical ethics research into clinical ethics support service:
What role should research outcomes play when giving practical ethics advice?**
Mikey Dunn
- From practice to research to practice: A (case) study in psychiatry**
Stella Reiter-Theil

PARALLEL SESSIONS

5 A: Responding to different cultural and moral perspectives—Chair: Maureen Kelley

- 11 a.m. **Symposium: How should clinical ethicists respond to discordant moral
points of view in an increasingly contentious time?** **1082**
Anita Tarzian, Reidun Førde, Marian Danis
- 12 noon **Oral presentation: Muslim perspectives on palliative and end of life care:
Empirical ethics research analyzing perspectives of service users and providers** **1080**
Mehrunisha Suleman

5 B: Autonomy, human rights and conscientious objection—Chair: Raj Mohindra

- 11 a.m. **Oral presentation: Where clinical ethics meets human rights:
An observation study in adolescent forensic psychiatry** **1074**
Jan Schuermann, Christiana Perler, Wiebke Paulsen, Mara Muehleck,
Stella Reiter-Theil
- 11:15 a.m. **Oral presentation: Another way to understand autonomy in psychiatry?** **1028**
Nicolas Foureur
- 11:30 a.m. **Oral presentation: Learning from conscientious objections for medical aid in
dying (MAID): Implications for practice from the recent Canadian experience** **1011**
Marie-Eve Bouthillier, Lucie Opatrny
- 11:45 a.m. **Oral presentation: Conscientious objection and medical duties in case
of suicide assistance requests** **1038**
Samia Hurst
- 12 noon **Oral presentation: Exploration of an important counterclaim in the
conscience-based refusal debate** **1069**
Clint Parker

5 C: Non-standard settings and non-standard treatments—Chair: Daniel fu-Chang Tsai

- 11 a.m. **Case study: Complex treatment decisions: Two case studies from a U.S. jail** **1030**
Monica Gerrek, Oliver Schirokauer

11:25 a.m.	Oral presentation: Exploring the standards of care and ethical duties for traditional and complementary medicine practitioners in Malaysia Mark Tan Kiak Min	1081
11:45 a.m.	Oral presentation: The Trojan horse of patient choice in complementary medicine use: How autonomy and bioethical imperialism puts the public at risk in Australian pharmacy practice Eleanor Milligan, Helen Irving, Jenny Jones	1058
12:05 p.m.	Oral presentation: A different kind of care: Ethical and practical issues when doctors practice complementary and alternative medicine (CAM) or have patients who use CAM Kanny Ooi	1066

5 D: Global perspectives on clinical ethics—Chair: Jacqueline Chin

11 a.m.	Oral presentation: What is urgent? Rights of access to healthcare and their limitations in the case of illegal immigrants Samia Hurst	1039
11:20 a.m.	Oral presentation: A cross-sectional qualitative SWOT analysis of the need for clinical ethics consultation service in Malaysia Erwin Jiayuan Khoo, Siew Houy Chua, John Lantos, Meow-Keong Thong, Zilfalil Bin Alwi	1046
11:40 a.m.	Oral presentation: Managing ethical challenges around incidental information within clinical context: Insights from an African ethico-cultural system Cornelius Ewuoso	1024
12 noon	Case study: Decolonising medical ethics education in South Africa: Reflecting on the past 15 years Keymanthri Moodley	1060

5 E: Equity and transparency—Chair: Morten Magelssen

11 a.m.	Oral presentation: The mechanics of the “accountability for reasonableness” (A4R) framework: An experience of its use in establishing fairness in accessing renal replacement treatment in South Africa Mohammed Rafique Moosa	1063
11:15 a.m.	Oral presentation: Did improving procedural fairness in the allocation of dialysis access by application of the “accountability for reasonableness” in South Africa have the desired outcome? Mohammed Rafique Moosa	1062
11:30 a.m.	Oral presentation: Reflecting on priority setting for anesthesiology in concurrent emergency surgeries Yi-Ting Fang, Daniel Fu-Chang Tsai	1025
11:45 a.m.	Oral presentation: Ethically permissible inequity in access to experimental therapies Bryanna Moore	1061

12 noon	Oral presentation: The problem with transparency Geert Craenen	1015
5 F: Exploring the workings of clinical ethics consultation—Chair: George Agich		
11 a.m.	Oral presentation: Where is the ethical substance in ethics consultation? Louise Campbell	1013
11:15 a.m.	Oral presentation: How to assess the quality of a facilitator of moral case deliberation? Concepts and didactical methods Margreet Stolper	1078
11:30 a.m.	Oral presentation: quality improvement: Translating business practices into strategies for clinical ethics Joshua Crites, Marguerite Augustie, Paul Ford, Jane Jankowski, Hilary Mabel	1016
11:45 a.m.	Oral presentation: “It was awful, let me tell you”: On the necessity and impossibility of sharing and learning from stories of failed consultations Virginia Bartlett, Stuart Finder	1004

Authors and Abstracts

Authors and Abstracts from ICCEC 2018 Listed by Abstract Number

1001

How should hospital ethics committees address surrogate requests for imminent death organ donation?

Authors:

Mahwish AHMAD, MBBS, MPH (presenting author), Cleveland Fellow in Transplant Ethics, Cleveland Clinic Department of Bioethics
Jordan POTTER, PhD, Cleveland Fellow in Advanced Bioethics, Cleveland Clinic Department of Bioethics

Imminent death organ donation (IDOD) is the practice of procuring organs (usually a single kidney) from a living donor prior to the impending and planned withdrawal of life-sustaining therapies in terminal, imminently dying, and/or permanently unconscious patients. This innovative practice was developed to ensure the procurement of at least a single kidney from willing donors who are not optimal candidates for donation after cardiac death. This practice can occur in patients with or without decision-making capacity, although IDOD in incapacitated patients requiring surrogate consent is more ethically controversial than IDOD in capacitated patients. In 2016, after analyzing the practice of IDOD in incapacitated, neurologically devastated patients that do not meet death by neurological criteria, the United States' Organ Procurement and Transplantation Network's ethics committee concluded that there were too many risks and unknown factors to recommend this form of IDOD as a standard practice at this time; however, they also advised that there may be specific circumstances where surrogate consent for IDOD can be ethically justifiable.

Given that this practice requires significant surgical burdens, offers no objective benefit to the incapacitated, imminently dying patient, and has potential ramifications for public backlash, surrogate requests for IDOD should be handled delicately and be elevated to the level of a full hospital ethics committee to investigate the ethical appropriateness of such an intervention. This presentation will provide practical guidance to hospital ethics committees to aid their ethical analysis and response to such requests. It will also include discussion of specific factors and characteristics of the clinical and psychosocial contexts that hospital ethics committees should probe in their investigation, and several distinct scenarios will be delineated to serve as examples of ethically appropriate cases of surrogate consent to IDOD.

1002

A systematic review of typologies used to characterize clinical ethics consultations

Authors:

Armand ANTOMMARIA (presenting author), Professor, Cincinnati Children's Hospital Medical Center
Jennifer DESANTE-BERTKAU, Assistant Professor, Cincinnati Children's Hospital Medical Center
Michelle MCGOWAN, Associate Professor, Cincinnati Children's Hospital Medical Center

Background: Given the debate over appropriate development and content of consultation typologies, we conducted a systematic review of the literature to describe the typologies used to characterize clinical ethics consultations.

Methods: We identified empirical studies of clinical ethics consultation that report the types of ethical issues from PubMed and references. We screened articles based on titles, and then full text. We extracted institution name, institution type, study population, data collection period, number of consultations, primary outcome measure, method of deriving the typology, and typologies; and coded the typologies.

Results: We reviewed 438 articles and 30 fulfilled our inclusion criteria. Studies were conducted in Australia ($n = 1$), Germany ($n = 1$), Japan ($n = 1$), Norway ($n = 1$), Switzerland ($n = 1$), and the United States ($n = 25$). The majority of studies were conducted at academic medical centers ($n = 17$). We identified 27 unique typologies that each contained five to 47 categories (mean = 18). The most common categories were do-not-attempt-resuscitation (DNAR) orders (19, 70 percent), capacity (18, 67 percent), withholding (18, 67 percent), withdrawing (17, 63 percent), and surrogate or proxy (16, 59 percent). Only seven (26 percent) of the typologies contained all five of the most common categories. Some codes were related to ethical principles, for example, autonomy and justice, or ethical issues, for example, DNAR orders, capacity, advance care planning, informed consent, and privacy or confidentiality. Other codes referred to decision making in general, for example, decision making and goals of care; decision-making dynamics, for example, withholding, withdrawing, refusing, and demanding; or types of interventions, for example, DNAR orders, life-sustaining treatment, and palliative care, without specifying specific ethical issues.

Conclusions: Typologies used to characterize clinical ethics consultation exhibit significant heterogeneity and several conceptual limitations. For example, many of the authors included multiple, conceptually distinct topics in a single typology. Development of a common typology may advance the field of clinical ethics consultation.

1003

Published coma/brain death simulation utilized to assess neurology residents and medical students

Authors:

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Farah FOURCAND, MD, Neurology Resident, Georgetown University Medical Center

Mandates set by accrediting bodies are a driving force in research of education within the clinical setting. Recently, neurology residency programs were required to assess and document the competency of residents in the following: effectively leading family meetings, analyzing and managing ethical issues in complex clinical situations, and demonstrating the compassionate practice of medicine, even when in disagreement with patient/family member. A new initiative will require medical schools to document that students can be trusted to effectively communicate with patients/families while respecting autonomy and anticipating and interpreting emotional responses. As part of this workshop, we will present our published coma/brain death simulation, which has effectively trained and evaluated over 400 medical students and 30 residents. During the presentation, the setting is a staged intensive care unit with a mannequin as the patient and intensive care unit (ICU) monitors projected on the screens. A trainee interacts with a distraught “family member” and the patient’s prognosis is extremely poor. The trainee must break bad news, offer appropriate treatment options including withdrawal of care, and address end-of-life issues. The audience will evaluate the trainee’s performance, according to the accrediting bodies’ standards. Discussion will be led by directors of a neurology residency program and neurology clerkship, a neurology resident, and an ethicist.

1004

“It was awful, let me tell you”: On the necessity and im/possibility of sharing and learning from stories of failed consultations

Authors:

Virginia L. BARTLETT (presenting author), Assistant Director, Center for Healthcare Ethics, Cedars-Sinai Medical Center

Stuart G. FINDER, Director, Center for Healthcare Ethics, Cedars-Sinai Medical Center

It is a fact of clinical ethics practice that not all ethics consultations start well, go well, or end

well. Given increasing attention for demonstrating high quality in clinical performance, a crucial—and practical—question is whether it is possible to actually tell the story of an ethics consultation that went poorly, that is, to give, share, and hear accounts of less-than-ideal or even poor practice, without falling into several readily available tropes and traps that prevent learning and engagement. Such “tropes and traps” include at least the following: (1) challenges associated with giving such accounts and issues of accuracy, truthfulness, excuses, and “chest-beating”/mea culpas; (2) challenges associated with sharing such an account, including the risks and benefits of utilizing different formats, venues, and audiences (what may be thought of as the politics of this “entrustable” profession); (3) challenges associated with hearing such accounts and common reflexive efforts to dismiss “inexperience, offer pet methods, arm-chair coaching, or absolution as ways to minimize impact/importance (but also support colleagues). The aim in presenting this case scenario, therefore, is thus not merely to explore the issue of our responsibility as ethics consultants for giving, sharing, and hearing these kinds of stories as part of our ongoing clinical practice—even and especially in the face of such challenges—but actually to engage in such exploration, as practiced during this session.

A scenario will be presented of an ethics consultation for an unrepresented patient. Although all of the process requirements are filled, the parties to the consult do not seem interested in addressing the substantive considerations made explicit by the ethics consultant. Indeed, they are overtly dismissed as unimportant. Does it—should it—matter to anyone other than the ethics consultant?

1005

Patient-centered care, autonomy, and choice

Authors:

Zackary BERGER (presenting author), Associate Professor, Johns Hopkins School of Medicine
Leah RAND, Fellow, Ethox Center, University of Oxford

Autonomy is a central principle of medical ethics, that can come into conflict with other principles, for example, justice, in the setting of increasing pressure on health systems to guide patients' choices to those that are most cost effective. One manifestation of autonomy is patient-centered care (PCC), which places patients, their

preferences, values, and needs at the centre of clinical decisions. Healthcare systems are adopting PCC as a core tenet in their design and explicitly mentioning the principle as a motivator for quality improvement and training.

In this paper, we ask what happens to PCC when clinical options are limited (either because there are no clinical options or they have been restricted)? We argue that although PCC by its definition prioritizes and considers patients' values and decision making, it does not depend on a strong concept of autonomy. That is, although patients may not be able to act on their values, PCC is possible even in cases of limited choice. This account of PCC draws on elements of shared decision-making models that consider patients' values but not unchecked patient choice. To show how PCC can be practiced in a context of restricted choices, we look to examples of health systems that have dual commitments to both PCC and resource stewardship. The success of PCC rests not on a concept of patients' autonomy but on the relationship between the patient and provider. Thus, as healthcare systems seek to implement PCC, they can do so without foregoing population coverage goals.

1006

Shared decision making and ethics: A political approach

Authors:

Zackary BERGER (presenting author), Associate Professor, Johns Hopkins School of Medicine and Johns Hopkins Berman Institute of Bioethics
Samuel SCHARFF, MD/PhD Student, Johns Hopkins University School of Medicine, Johns Hopkins School of Medicine
Douglas OPEL, Director of Clinical Ethics, Seattle Children's

Shared decision making (SDM) has been characterized as an ethical desideratum in the redesign of healthcare systems, further establishing respect for the patient as an individual as fundamental to patient-clinician interactions. Yet SDM makes implicit political claims, which require evaluation in the local contexts where SDM is applied. For instance, in one common formulation, SDM involves (a) a scientifically expert clinician and patient deliberating together regarding (b) a decision with equally valid options according to objective criteria (equipoise) so that (c) the option chosen conforms with the patient's clarified values and preferences. In this formulation, patient

and clinician meet for an interchange of information, beliefs, and emotions as atomized individuals operating in an unstructured, apolitical encounter. Excluded from this model, however, are considerations of power (how clinicians in dialogue with biomedicine, state, and society decide what counts as “equipoise,” and how their options as independent actors are constrained by a political-social milieu) and independent agency (what it means when patients, at various degrees of disadvantage, are assigned the burden, or opportunity, of choice).

Considered even more broadly, SDM frameworks do not include the ethical prequels and sequels of such decisions. What social determinants “count” as healthcare decisions, or are susceptible to SDM, is relevant to its employment as an ethical approach to repairing patients’ lives and systems. Whether housing, political representation, financial resources, and insurance are topics for which SDM can be brought to bear is a question that can be addressed only outside its framework.

Our presentation seeks to make the political assumptions in SDM more transparent. In doing so, we will apply insights from ethics and the history and philosophy of medicine to suggest opportunities for linking the possible benefits of SDM to a clinical setting embedded in a more complicated social world.

1007

Charlie Gard: How the “court of public opinion” may influence future end-of-life decision making

Author:

Neera BHATIA, Senior Lecturer, Deakin University, School of Law

Last year the case of terminally ill British infant Charlie Gard attracted international attention, including the President of the United States Donald Trump and the Pope. Charlie suffered a rare genetic condition, and his parents wanted to take him to the U.S. to undergo experimental treatment (nucleoside therapy). His parents and some medical experts believed that experimental therapy could provide a small chance of improving his quality of life, although no cure.

Nevertheless, Charlie’s treating doctors at Great Ormond Street Hospital (GOSH) and several courts all concluded that the withdrawal of life-sustaining treatment was in his best interests. Charlie’s parents eventually agreed to withdraw treatment, and he passed away in July 2017 in a hospice.

The case, unfortunately, became a media circus, in which the “court of public opinion” played a large role in advocating for “Charlie’s best interests.” Yet, some questioned whether the influence of social media and political pandemonium shifted the focus away from his “best interests” towards the interests of others.

Determining whether withdrawal of life-sustaining treatment is in the best interests of a critically ill infant is not a novel issue, even for the courts. Nevertheless, the manner in which the Charlie Gard case was so publicly conducted could potentially have global ethical, policy, and legal implications for cases in the future, particularly concerning medical treatment decisions for critically ill infants and children; or, more broadly, the role society should play in medical treatment decisions.

I will highlight three features of the case that could play a role in future treatment decisions: (1) the use of social media to influence medical treatment; (2) the use of crowd funding to support experimental treatment(s), especially with an ageing population, where the distribution of finite healthcare funds are critical; and (3) the rejection of the paternalistic (“doctor knows best”) relationship, shifting towards an anti-establishment movement.

1008

Property rights over cadaveric organs and tissues in an “opt out” system of organ donation in Australia and New Zealand: How important are the next of kin?

Author:

Neera BHATIA, Senior Lecturer, Deakin University, School of Law

Compared to other developed nations, Australia and most notably New Zealand have some of the lowest rates of organ donation. Both countries operate under “opt in” systems of organ donation, in which organs are procured only from persons who had consented to donation before their death. Organ procurement may increase under an “opt-out” system of donation, which presumes that all persons have consented to donate organs their after death unless they have declared their objection, and their next of kin would be unable to veto organ procurement.

In a recent effort to increase rates of organ procurement, some countries, including Wales and France, have introduced soft “opt-out” systems, with others soon to follow. Despite positive pub-

lic opinion, Australia and New Zealand have not.

An “opt-out” system involves two questionable presumptions. First, that the deceased person would have agreed to donate organs before death. Second, the assumption of the applicability of the legal principle that, at common law, there is no property in a human corpse. Case law commencing with *Doodeward v. Spence* (1908), demonstrates that tissue extracted after death and preserved by “work and skill” acquires attributes of property. This principle is readily applied to organs procured after death. Arguably, organ procurement after death should be subject to the agreement or refusal of the next of kin.

When legislative reform is improbable, common law can be more effective. Recognition of property rights of the next of kin in relation to ownership of organs and tissues could be incorporated into current legislation, providing greater clarity and certainty to the existing manner in which organs are procured. A future “opt-out” system in Australia or New Zealand could also mean legislation recognizing common law property rights of the next of kin in the organs and tissues of the deceased, and seeking their consent.

1009

Mixed messages: Tattoos and a schizophrenic patient

Authors:

Ted BITNER (presenting author), Professor of Psychology and Neuroscience, DePauw University
Marcia MCKELLIGAN, Professor of Philosophy, DePauw University

Lauren LEFEBVRE, Emergency Department Nurse, Washington Medstar Hospital Center

Tara WALES, Emergency Department Nurse, Community Health

Using two emergency department (ED) cases, we will generate discussion of concerns that arise when there is uncertainty about the meaning or legitimacy of a patient’s refusal of treatment. Our goal in the session will be to lead the group to consider what principles professional caregivers should follow in such situations to insure that patients’ wishes are respected.

The first case involves an apparently lucid patient with advanced prostate cancer. He is brought to the ED by his sister because of a sudden decline in his condition. The patient has previously received treatment for his cancer, but his current prognosis is poor. The patient states clearly that he does not wish any further treatment for

his cancer and hopes instead to be admitted to hospice care. However, the patient is schizophrenic. His father and his oncologist want the patient to continue with treatment. Both believe that because of his mental illness, the patient is not competent to make the decision to forgo further treatment and that therefore his expressed wishes may be disregarded.

The second is the widely publicized case of a man who was picked up off the street unconscious and taken to a Miami ED where staff discovered “DO NOT RESUSCITATE” tattooed on his chest. The attending physicians’ first impulse was to act cautiously and initiate resuscitation efforts, on the grounds that to fail to do so was to make an irreversible choice that might not conform to the patient’s wishes. However, the hospital’s ethics consultants advised against resuscitation on the grounds that the tattoo expressed the patient’s “authentic preference.”

The discussion will center on the important moral and epistemic differences between these two cases so as to shed some light on the problems involved in determining and responding to patients’ true will in situations of ambiguity.

1010

Encountering “ethics” in clinical versus administrative contexts: Peer learning, peer review, and responsibility

Authors:

Mark BLITON (presenting author), Director of Medical Bioethics, Kaiser Permanente Los Angeles Medical Center

Stuart FINDER, Director, Center for Healthcare Ethics, Cedars-Sinai Medical Center

Ingredient to ongoing debates regarding certification of individual ethics consultants and accreditation of clinical ethics educational programs are deeper questions about how best to evaluate ethics consultation practice. In this paper we take up such questions against the background of the recently curtailed attestation project by the American Society for Bioethics and Humanities (ASBH) and the ongoing efforts to credential individual ethics consultants. We direct attention toward an element in the evaluation debate that is often ignored: the role and influence of administrative and bureaucratic values. We are particularly interested in how such values shift focus from moral reasons and actions to effective fulfillment or completion of institutionally authorized and designated procedures, whereby “ethics” becomes a set of pro-

cedures performed to satisfy bureaucratic accountability. In particular, we address how the increasing drive toward utilizing quality improvement (QI) measures and metrics as a, if not the, primary means for establishing organizational worth of clinical service shapes what counts as “good” clinical ethics practice, and, as a result, we argue, the kinds of ethical concerns frequently encountered on the clinical level are likely to gain institutional acknowledgment only if and when they can fit into such QI-based standardized metrics. Accordingly, problems, issues, concerns, and topics designated as “ethical” do not seem to match, or at a minimum are remote from, the experiential dimensions of face-to-face interactions—interactions that frequently provide clues for identifying the values that people hold most worthwhile in clinical situations. Crucial factors that prompt requests for clinical ethics consultation then become obscured, replaced by bureaucratic language and concepts of quality. We thus identify the need to support meaningful notions of peer review and peer learning by which clinical ethics consultants not only share experiential accounts of actual clinical ethics practice but gain understanding of practice through shared dialogue and mutual investigation.

1011

Learning from conscientious objections for medical aid in dying (MAID): Implications for practice from the recent Canadian experience **Authors:**

Marie-Eve BOUTHILLIER (presenting author),
Chef Centre d'éthique/Professor, CISSS de Laval/
University de Montreal

Lucie OPATRYN, MD, Director of Professional
Services, Vice-president, CISSS de Laval

Background: Medical aid in dying (MAID) has been legalized in Quebec, Canada, since December 2015, under the act respecting end-of-life care. This new law sets out an overall, integrated vision of palliative and end-of-life care, including MAID for voluntary consenting adults under certain criteria. MAID consists in the administration of drugs to patients at the end of life who have unbearable suffering. Under this new law, physicians may refuse to provide MAID only when it involves their conscientious objection. However, they must notify the executive director (or designated person) of the institution of the patient's request. The authors have been gathering data, both qualitative and quantitative, about physicians' re-

fusals to provide MAID since the implementation of this new practice.

Objectives: The first objective of this presentation is to show the prevalence of conscientious objection among physicians who faced a MAID demand and the motives behind the objection. Data was collected through a survey ($n = 207$) of all physicians practicing in an administrative healthcare region as well as semi-structured interviews with physicians in that region who refused to provide MAID ($n = 22$). The second objective is to discuss the implication of these results for medical practice and program development.

Results: Survey results showed a widespread acceptance of MAID (78 percent) among Quebec physicians in the studied region. However, there was a high rate of refusal (77 percent) to perform MAID by physicians in this same region. The reasons for this significant discrepancy were explored in the qualitative part of the study, and will be presented. The authors hope to use the results in order to:

1. Improve reasonable access of MAID to patients,
2. Better support physicians, and
3. Make sure this practice is sustainable.

1012

Medical innovation in a children's hospital: "Diseases desperate grown by desperate appliance are relieved, or not at all"

Author:

Joe BRIERLEY, Director of Paediatric Bioethics
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Ormond St. Hospital

A balance needs to be struck between facilitating compassionate access to innovative treatments for those in desperate need, and the duty to protect such vulnerable individuals from the harms of untested/unlicensed treatments. We introduced a principle-based framework (2009) to evaluate such requests and describe its application in the context of recently evolved U.K., U.S., and European regulatory processes.

Our quaternary children's hospital clinical ethics committee (CEC) received 24 referrals (20 individual, four group) over a five-year period (2011-2016). The CEC-rapid response group evaluated individual cases within 48 hours; the main referers being hematology/oncology, immunology, or transplant services (14). Most requests were for drug/vaccine/pretrial access (13) or biological/cel-

lular therapies (eight). The majority of individual requests were approved (19 of 20); neutral or negative opinions were given in five, including three group requests.

Recently evolved regulatory processes share common criteria and conditions to our framework including: demonstration of clinical need, sound scientific basis with lack of viable alternative, risks-benefit/best interests evaluation, arrangements for fully informed consent, no compromise of arrangements to test treatment for licensing purposes, and consideration of resource implications.

There are differences between individual processes and with our framework, with respect to procedures, scope, application format, costs, and obligation to make available all outcome data.

Our experience has emphasized the need for an independent, principled, consistent, fair, and transparent response to the increasing demand for innovative treatment on a compassionate basis.

We believe that there is a need for harmonization of the recent proliferation of regulation and legislation in this area.

1013

Where is the ethical substance in ethics consultation?

Author:

Louise CAMPBELL, Lecturer in medical ethics, National University of Ireland, Galway

Clinical ethics as a practical discipline is characterized by the use of a structured approach to analyzing ethically challenging or “unsettled” cases which is based on a robust method for gathering information and an acknowledgment of the value-laden nature of healthcare. Identifying ethically justifiable solutions in situations that pose ethical challenges requires scrutiny of the clinical decision-making process itself: its context, the values and assumptions that underlie it, the conflict generated by competing avenues of action, the rationale provided for the decision, and the responsibilities of the decision makers. Several tools exist for the clarification and resolution of these difficult cases. These tools emphasize the importance of process, yet it remains unclear whether procedural requirements alone—fairness, transparency, inclusivity—are sufficient to justify the recommendations put forward by clinical ethics services. The purpose of this paper is to examine to what extent the process of clinical ethics consultation is underlain by more substantive ethi-

cal commitments: commitments represented by a range of theoretical principles and approaches which implicitly legitimate the outcome of the consultation process.

1014

Translating to advocacy and policy: Ethics, advocacy, and policy: Reflections on ethical and practical issues with promoting advance directives and advance care planning

Author:

Hui Yun CHAN, Lecturer in Law, University of Hertfordshire

Advance directives (AD) and advance care planning (ACP) are tools that allow patients to express their treatment preferences when they are no longer competent to decide for themselves. ACP is promoted in several countries, including New Zealand, the U.S., and Canada, and is based on the principle that a patient has the right to exercise his/her autonomy. An example where ACP has been promoted nationally is the annual Conversations that Count Day in New Zealand that is intended to encourage discussion about future care planning.

However, there are several factors to consider in promoting the use of ADs and ACPs, particularly in a diverse population. This exploratory paper considers the ethics of promoting ADs and ACPs through advocacy and national policy. It examines the ethical and practical issues with promoting ACP and why awareness of these issues is important for patients, their families and healthcare professionals. These include autonomy and cultural considerations in healthcare decision making. For example, the perception that people would want to engage in ACP may be misconceived, as some patients may prefer that their families make the decisions about their care. Another hurdle could be if the healthcare professional is unfamiliar or uncomfortable with the concept of ACP. Additionally, there are questions about the legal effect of ACP and AD, where countries treat ACP and AD on different legal standing. Recognizing these ethical and practical issues will facilitate a better understanding for clinical ethicists and policy makers in promoting ACP and translate into improved discussions and decision making between patients, their families, and healthcare professionals.

1015

The problem with transparency

Author:

Geert CRAENEN MD MPH, Clinical Ethics
Consultant, WTVAHSC

Recently, the *American Journal of Bioethics* devoted half an issue to discussing the Physician Payments Sunshine Act. This act, enacted by the U.S. Congress in 2010, purports to promote greater transparency of physicians' financial ties to industry (big pharma and device manufacturers), enabling the patient to make a more informed selection.

This act is a farce on two separate levels. Practically, it is so full of loopholes, after the big pharma lobby had the final word in the editing process, that it makes Swiss cheese feel solid. The data are near inaccessible, so that virtually no one makes use of it.

More importantly, on a conceptual level, it completely misses the boat. It is a classic example of clinical ethics blindly copying mechanisms from research ethics, without giving thought to the underlying values those mechanisms are supposed to serve. In research, billions of dollars are needed to promote the progress of medical knowledge. Until a buffer is created between industry sponsors and scientists, such as an anonymous funding clearinghouse, the best safeguard we have to prevent undue conflicts of interest is indeed complete transparency about the researchers' financial relationships with industry. As things stand, this is a reasonable gold standard.

But in clinical practice, no such relationships are needed. It is perfectly possible, and the vast majority of clinicians do this every day, to practice medicine without any financial ties to industry. Transparency in clinical practice, therefore is a decoy, a way to deflect attention away from what really matters. In clinical practice, the gold standard is not transparency, it is *independence*.

As long as bioethicists and clinicians continue to waste time debating transparency, big pharma has already won.

1016

Quality improvement: Translating business practices into strategies for clinical ethics

Authors:

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Driven by institutional priorities and preferred modes for demonstrating quality, over the past two years faculty and fellows in our department and serving on the ethics consultation service (ECS), in conversation with hospital leadership, have begun to learn the "language" of demonstrating and improving quality, utilizing methods and tools common to the business sector (including the business of healthcare). To our knowledge, tools such as SWOT (strengths, weaknesses, opportunities, threats) analysis, strategic agenda management, and the plan, do, check, act cycle have not been applied regularly by ethics departments or ECSs. In discussing our experiences with learning how to apply these methods and tools to our ongoing quality improvement efforts, we will argue that it is both possible and beneficial to translate these business-oriented methods into meaningful tools that can be applied to the "products" of clinical ethics activities (for example, consultation, education, scholarship). We will discuss both the challenges we have faced in aligning with the larger institutional goals and the (sometimes unexpected) benefits we have experienced, including enhanced understanding of our own purpose and mission, clearer identification of milestones demonstrating quality improvement, and the application of various tools to assess whether or not those milestones are achieved. In doing so, we aim to equip attendees with strategies for employing similar concrete quality improvement tools at their home institutions, where they may be facing similar impetus from hospital leadership to align with institutional priorities and goals, as well as shifting trends in demonstrating quality and impact of clinical ethics activities within the institution.

1017

The making (and successful failure) of a pilot project assessing the use of videoconferencing technology to deliver ethics consultation

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As healthcare systems globally face a trend of consolidation, there is growing demand for clinical ethicists to provide cost-effective care to more patients in healthcare systems composed of multiple facilities across greater distances. The utilization of telehealth technology may be one way to address this challenge, but this perspective is not without detractors, as clinical ethics consultation often involves exploring value-laden, emotionally difficult issues that some may view as best discussed in person. However, without testing this presumption, healthcare institutions may be forgoing opportunities to expand the reach of, and create efficiencies in, clinical ethics consultation. This presentation will describe the creation, results, and ultimate discontinuation of a pilot project aimed at assessing the feasibility and effectiveness of using videoconferencing technology for family and team meetings in the intensive care unit of a community hospital situated within a large healthcare system in the United States. The project surveyed more than 20 healthcare providers and family members involved in ethics consultations regarding their experiences and views on the use of virtual ethics consultation. The presenter will describe the development and operationalization of this project, as well as challenges faced, such as the organizational and logistical difficulties around the availability of telehealth equipment, the resource limitations in implementing the project design, and the ways in which the sensitivity of certain clinical ethics consultations restricted data collection. Ultimately, these barriers prohibited adequate data collection to assess feasibility of this model of ethics consultation. Nevertheless, the insights generated make the project a success, and the presenter will highlight the many lessons learned that can be applied to telehealth efforts in clinical ethics consultation going forward.

1018

Uncertainty in clinical ethics consultation recommendations

Authors:

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Four bioethicists who work in diverse healthcare environments, Italy, Switzerland, the United States—California and New York—engaged in a review of an ethics consultation from one of their institutions. Despite relying on different theoretical approaches (principlism, casuistry, narrative ethics, care ethics) to clinical ethics consultation (CEC), the bioethicists were able to achieve relative consensus in their recommendations. A common theme in the various analyses was uncertainty. Clinical ethicists help those who consult them to cope with uncertainty in clinical medicine and the ethical issues arising from it. Clinical ethicists are fallible, but their recommendations carry an authority that obscures the uncertainty they confront in forming them. In this oral presentation, we will first present the case and our points of agreement concerning the ethics recommendations. Then each of the four bioethicists will identify a node of uncertainty in his ethical analysis of the case that could have led to a discordant recommendation. Each bioethicist will explain why this point in the analysis generated uncertainty for him and how he resolved it. The uncertainty the bioethicists confronted involved:

1. Interpreting a possible inconsistency in the surrogate's consent to some treatments,
2. The possibility the patient would return to consciousness and regain decision-making capacity,
3. Whether attempts to resuscitate the patient should be limited,
4. Whether the patient's infirmity satisfied legal conditions for withdrawing life-sustaining treatment.

The aim of this presentation is twofold. First, it will reveal the complications that CEC recommendations obscure. Second, by illuminating the nodes at which consultants confront the limits of their training, it may help to identify new areas for research and instruction.

1019

Ten-year review of ethical topics and themes arising from referrals to a well-established clinical ethics committee

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Background: The Imperial College NHS Healthcare Trust Clinical Ethics Committee (CEC) is one of the longest serving U.K. CECs, and meets monthly to discuss clinical-ethical cases referred from its four hospitals, as well as reviewing institutional protocols, policies, and public health directives.

Aims: This study aims to identify and categorize the ethical topics and themes arising from cases referred to the CEC over the past 10 years, and to ascertain whether there has been a qualitative change in the types of cases and themes arising over time.

Method: Detailed minutes of CEC meetings from 2008-2017 were reviewed. Cases were categorized according to primary and secondary ethical and/or legal topics. A broader thematic analysis was undertaken to explore the main ethical themes and the framework used for case-analysis and decision making. Triangulation was undertaken as part of the analysis.

Results: Preliminary results identified the most commonly raised topics as: decision making for patients lacking capacity, vulnerable patients' consent and refusal, control of information, and the scope of the duty of care. These were consistent across the years. Broader themes included challenges in ascertaining net benefit particularly in the context of uncertainty, the scope of autonomy, and distributive justice. The framework used for case analysis was broadly casuistic, adopting a case-based "bottom-up" approach, comparing and contrasting with other similar cases and drawing upon relevant ethical and legal principles.

Conclusion: This study offers a detailed typology of cases referred to a CEC over 10 years. The regular recurrence of certain ethical topics and themes demonstrates that these continue to challenge healthcare professionals. The informal application of a casuistic approach highlights the "four quadrants" (Jonson, Siegler, and Winslade) as a useful framework for CECs to use for case analysis. This study provides material for future educational training of CEC members and for healthcare workers in hospital trusts and other settings.

1020

Is there a place for clinical ethics consultation outside of the hospital setting?

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In the United States, ethics consultation in the acute care setting is becoming more common and is even recommended in consensus statements by professional societies (American College of Physicians ethics manual, Society of Critical Care Medicine guidelines). Less attention, however, is paid to ethics consultation in other areas of the healthcare system, from the emergency room to the outpatient setting (for example, primary care clinics, outpatient surgeries, community health providers), and rural contexts. We posit that ethical questions, issues, and conflicts emerge wherever patients receive care, and are not confined to intensive care units or the acute hospital setting or to certain specialties (that is, palliative care, oncology, neurology). Because ethics consultation is increasingly viewed as an important tool to address value-related conflict in the inpatient setting, we wonder whether the same will be true in the future of other care settings from those listed above to same-day routine care, and even telemedicine. In this presentation, we provide examples of actual ethics consultations from practicing clinical ethicists that were requested outside of the inpatient environment. We explore these questions in order to begin the conversation about whether ethics consultation should be expanded to wherever patients are cared for by healthcare professionals, and what shape outpatient ethics consultation, or rural clinical ethics, might take. We also include a cautionary perspective on the panel in order to identify and discuss objections to expanding clinical ethics consultation outside the acute care setting.

Panelist 1: Within the hospital and without. Illustrating that ethical issues can continue after a patient is discharged from the hospital or before a patient ever reaches the hospital, we discuss two

actual situations when a health system's ethics consult service was called about the same patient-care scenario, yet in a different setting. Case 1: Patient admitted to a general medical ward then cared for by in-home services. Case 2: Patient cared for in the community by a hospice team then is admitted.

Panelist 2: In the emergency care setting. When a patient presents to a hospital *in extremis* and before being hospitalized as an admitted patient, emergency care physicians and nurses address a variety of ethically challenging situations. Whether ethics consultation is available immediately/STAT or retrospectively, we address common scenarios where clinical ethics expertise is sought in the emergency room.

Panelist 3: In rural areas. Non-urban settings often lack the resources needed for ethics consultation, however, ethical conflicts are inherent to the setting, especially conflicts of interest and clinician burnout. How do we balance the available resources with the need for clinical ethics expertise in these areas?

Panelist 4: A cautionary perspective. Why inpatient clinical ethics consultation cannot necessarily be translated to a context outside of the hospital setting.

In summary, this symposium will allow audience members to see what clinical ethics consultation can look like outside of the hospital, with the opportunity for dialogue with audience members regarding theoretical and practical considerations involved in offering clinical ethics consultation in new settings.

1021

Beyond the actor and simple personal recollection: Partnering with patients, the new clinical ethics teaching standard

Author:

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Clinical ethics teaching has been essentially focused on improving the quality of patient care while empowering clinicians and other healthcare professionals, all the while excluding the patient as a partner in problem solving. The University of Montreal is an international leader in the development of patient partnership science and prac-

tices. According to this approach, the patient is a *bona fide* member of the healthcare team, recognized as an actor of care. The university has embraced this change in paradigm, and patient partnerships are now fundamental in the clinical setting, as well as in teaching and in research. The clinical ethics curriculum at the faculty of medicine has been reformed in this perspective. A new curriculum has been coconstructed, codeveloped and is cotaught with patient-partners. This symposium will present why partnering with patients has become fundamental and crucial for the clinical ethics curriculum. The following symposium will be chaired by one of the founders of the patient-as-partner approach.

1. The patient-as-partner approach in clinical ethics: Presenter 1. Discuss its origins, the philosophy behind the patient-as-partner approach, the conceptual framework in which it has been developed, as well as its impact on the shared decision-making process that occurs in the clinical setting. Distinguish how this approach is fundamentally different from patient-centered care and how it can improve clinical ethics education for caregivers and clinical ethicists.

2. Ethical challenges of medical students: the role of patients: Presenter 2. Based on empirical studies, presentation of the main ethical challenges facing medical students at different levels. Put into perspective the role and contribution of patients in these challenges, offering new and novel opportunities for teaching and learning.

3. Benefits and challenges of integrating patients in teaching: Presenter 3. Discuss the many tangible and symbolic benefits of integrating patients-as-partners in clinical ethics teaching. Present some of the major challenges associated with this integration, such as issues of legitimacy, as well as some of the pitfalls. Detail certain strategies that have proved efficient in overcoming these obstacles, and bring a critical perspective on how certain of those strategies can have unintentional effects.

4. The patient as a clinical ethics teacher: challenge and success: Presenter 4. Illustrate this partnership, outlining two workshops that were developed as part of a new clinical ethics curriculum. Present a narrative ethics workshop that is offered to all specialty residents at the University of Montreal, as well as a workshop that is offered to all medical clerks in which they learn how to recognize and address situations that have caused them moral distress. Outline the role of patients-as-partners in both these workshops as well as their invaluable contribution.

1022

Helpfulness in clinical ethics consultation notes

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How should we formulate clinical ethics consultation (CEC) chart notes to be most helpful, while being mindful about professional boundaries? Should CECs state recommendations, such as: It is ethically permissible that . . . , or should ethics consultants adopt more procedural formulations, along the lines of: Empower the patient by offering him . . . ?

Often times medical providers are used to reading notes of their fellow consultants in the form of conclusions, such as: “Patient is in kidney failure. Palliative care recommends x dosages of morphine.” However, ethics consultants hardly ever find themselves faced with a clinical scenario that allows for such “simple authoritarian” conclusions, let alone that authoritarian conclusions are undesirable within the framework of our profession.

While discussions around CEC ethics “expertise” continue to offer inconclusive answers, and the field still lacks clear answers as to the method of consultations, or the type of expertise that consultants should bring, whether interventions and answers should be conceptual, prescriptive, procedural or normative, we ask the question: How can we phrase the most helpful recommendations for eager and vulnerable healthcare providers that are not philosophers?

In this symposium we will have offered one clinical scenario to four different contributors, two U.S. and two European-based ethics consultants, and have asked them to write recommendations. In addition, we will ask each contributor their considerations about the question: What makes a recommendation helpful, while maintaining professional standards? Our analysis of the conclusions and their helpfulness will be situated in both a U.S. and an international context.

Paper 1 will adopt a conceptual lens and examine how to balance clarity and brevity with the educational function of recommendations. The rationale given for a recommendation can help providers understand the ethical considerations necessary to make future decisions regarding similar cases.

Paper 2 will explore the scenario through an empirical lens. After disseminating the scenario and collecting the recommendations of several U.S.-based clinical ethicists, this paper will explore the results from a constant-comparison analysis, having searched the data for patterns of intersection through labelling and coding, and having developed theories of helpfulness.

Paper 3 will focus on recommendations in an Austrian context, in an explicit facilitative approach towards ethics consultations.

Paper 4 will address the Basel approach of ethics consultations. Here, the conclusion section is a key component of the note, but the note also regards the requestor and information about the outcomes of the joint ethical discourse about various options, including the consensus and the open questions. Rather than an approach based on “recommendations,” conclusions in the Basel method include statements about an explicit agreement between requestor and participating parties. As the advice is a part of the process leading to this outcome, the consultation notes adopt a different interpretation of helpfulness.

1023

Teaching and learning beyond simulation: Innovative experiential curriculum in clinical ethics consultation

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Despite efforts to define and measure quality in clinical ethics consultation, few areas of consensus have been reached. One principle held in common is that high-quality ethics consultation requires expanding beyond theoretical knowledge into a specialized and practical skill set. Yet most educational offerings do not provide an opportunity to practice ethics consultation skills beyond observation or simulated scenarios. This presen-

tation will describe an innovative, experiential curriculum that develops ethics consultation skills in the tertiary care clinical setting.

The curriculum comprises a short intensive didactic component that uses a wide variety of teaching methods to establish learners' assessment and analysis skills, an intermediate length individual practicum in which ethics consultations are performed with direct mentorship of process and interpersonal skills, and a long-term collaborative consultation relationship that consolidates competencies as learners return to their home institutions.

Presenters will demonstrate how the program's skills-building exercises, workshops in note writing, interactive seminars, and experiential learning exercises correlate to the ethics consultation competencies endorsed by American Society for Bioethics and Humanities (ASBH). The first presenter (curriculum developer and faculty) will present the educational rationale and discuss the logistics and feasibility of immersing learners in the clinical setting. This presenter will share aggregate data about the participants' background, motivation, expectations, and outcomes to illustrate the impact of participating in real-time clinical ethics consultation on a high-volume clinical service. The second presenter (participant and clinical ethics consultant) will discuss the unique challenges and benefits of a high-volume, intermediate-length clinical immersion and will focus on the ASBH process skills of triage, facilitation, and systems-based practice, which are rarely directly experienced in clinical ethics educational programs.

Attendees will benefit from the presenters' complementary perspectives on clinical ethics consultation education and the development and assessment of practical skills in the lived environment.

1024

Managing ethical challenges around incidental information within clinical context: Insights from an African ethico-cultural system

Author:

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This project aims to argue the thesis that a set of guidelines, firmly rooted in a particular interpretation of African moral theory, specifically Ubuntu moral philosophy, will do a better job than

current medical ethics frameworks in addressing ethical challenges around incidental information in health professional-patient clinical interactions.

Incidental information, such as information with significant personal or health implications within the clinical context, raise unique challenges for medical professionals. For example, withholding information regarding misattributed paternity accidentally discovered in HLA (human leukocyte antigen) testing for organ compatibility may be seen by a patient as a violation of his/her right to know. Contrarily, disclosure when a patient has not requested such information (and when establishing paternity is not the purpose of the patient's clinical interaction with the physician) may be taken by the patient as a violation of his/her right "not to know." Resolving these moral challenges remains a herculean task for healthcare professionals and teams.

African moral theory contains an under-emphasized value for addressing these ethical challenges around incidental information within the clinical context. I am interested in contributing this knowledge and enhancing healthcare professional-patient relationships. I note here that this study builds off of two previously completed systematic reviews that aimed to answer the question, "What models for enhancing health professional-patient relationships exist in Ubuntu philosophy?" In this study, I shall be applying what I have learnt—from the completed systematic reviews—about the model which exists in Ubuntu moral philosophy for enhancing health professional-patient relationships to address ethical issues around incidental information in the clinical context.

If the results of this study are adopted by clinical ethics support systems, it will greatly enhance them, as well as greatly enhance health professional-patient relationships.

1025

Reflecting on priority setting for anesthesiology in concurrent emergency surgeries

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Allocation of scarce or limited medical resources is a persistent ethical challenge and has been deliberated in different clinical situations. As an anesthesiologist, which surgery should be prioritized and given an anesthesia intervention before others is a constantly encountered challenge in daily practice. In this presentation, we will use two clinical situations to explore the question, “Who has the priority to the scarce resource, the anesthesia intervention, in concurrent emergency surgeries of different surgeons?” and develop ethical principles and practice strategies.

The setting is emergency operation rooms of a regional hospital, a common site of ethical challenges of resource allocation in Taiwan. We will deliberate using the scope of a hospital policy, made by the operating room management committee, to determine the levels of emergency for various surgeries, to use in solving conflicts between the surgeries of different surgeons.

We will also reflect on human resources issues from the perspective of articles 3, 24, and 25 of the Universal Declaration of Human Rights.

No single principle is sufficient to assign priority to limited resources, including human resources. Thus, our purpose is not to criticize, but to clarify ethical analysis by weighing several principles: first-come, first-served; youngest first; instrumental value; sickest-first; reciprocity; and number of lives saved, for allocation during decision making during emergency situations.

In conclusion, with the hope that after we deliberate regarding the various ethical principles and policies in the form of a chart, inter-professional communication in setting priorities for concurrent emergency surgeries may become more reasonable and precise, avoiding prejudice and private complaints, and to help medical staff (especially nurses) gain a reasonable limitation of working hours and periodic holidays with pay as mentioned in the Universal Declaration of Human Rights, to provide safer patient care.

1026

Ethical issues of gamete donation in Islam: Shia and Sunni perspectives

Author:

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Assisted reproductive technologies (ARTs) have been practiced in Muslim societies within

married couples since their introduction, but there are divergent views over the issue of third-party gamete donation among Shia and Sunni clerics. This paper elucidates the different views of Shia and Sunni clerics concerning gamete donation and examines ethical issues involving gamete donation in Islam. The paper was based on examining the available literature and some primary sources, that is, the relevant verses from the Quran and Hadiths, the religious verdicts of Shia and Sunni clerics. The literature was retrieved from databases such as PubMed, Web of Science, BioMed, and Google Scholar, using the key words gamete donation Islam, sperm donation Islam, egg donation Islam, assisted reproduction Islam, and ARTs Fatwas Islam. The study found that Sunni clerics are totally against gamete donation. They argue that gamete donation is a breach of the marital contract between husband and wife, and assert that it confuses paternity, kinship, descent, and the Islamic law of inheritance. In opposition to Sunni clerics, leading Shia clerics in Iran, such as Ayatollah Khamenei, made a religious decree that legitimized gamete donation with some conditions. Although his ruling paved the way for gamete donation, it has evoked certain reactions from other Shia scholars, as Shia clerics from other countries are not in agreement with him. The individualistic usage of *ijtihad* [individual reasoning], rather than collective deliberations, has resulted in a diversity of opinions among Shia clerics concerning gamete donation. The diversity of these views has also led to a reasonable flexibility in usage of gamete donation. However, solely based on religious decrees, gamete donation has been practiced in a vacuum of a legal and ethical framework without foreseeing the well-being of donor children. The paper argues that lack of laws and guidelines on ARTs raise many ethical concerns about gamete donation in Islam.

1027

Truths, conceits, and moral entanglements when telling (and listening to) clinical stories: The challenge of re-presenting ethics consultation

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Listening to and telling about peoples' experiences and stories is central to clinical ethics consultation. How to do so responsibly, and learn from such stories, are questions equally central to clinical ethics practice. Different approaches to, constructions of, and aims for telling clinical stories range from the more phenomenologically oriented critical reflections on practice and probing of "truths" of clinical accounts (best epitomized in the work of Richard Zaner) to ongoing debates over case write-ups in portfolios for purposes of education, training, and certification of ethics consultants (as epitomized by the recent ASBH attestation effort). With such variety of approaches, constructions, and aims for telling clinical ethics stories, attention is surely demanded to address what we actually learn from such stories, as well as better (and worse) ways for that learning to occur. Such is the focus of this panel.

Specifically, this panel is designed to examine, through exposition and demonstration, why and how we tell clinical stories "to each other and to ourselves" and what such stories might teach us when we engage their "conceits," that is, the narrative devices and code words used in any retelling/re-presentation. Speaker one introduces the topic to be addressed and sets the frame for what will follow. Speaker two critically interrogates the notion of presentation as a constructed account. Speaker three presents an ethics consultant's experience with a post-suicide-attempt patient's caregivers, highlighting truthful elements of clinical practice. Speaker four reflects on how conceits of that (and any) story may capture audiences' attention and possibly distract, or even misdirect, from the truths such stories intend to portray. Speaker one then suggests some re-framing questions in light of which the panel will engage the audience about (1) ways we learn together, through sharing and representing unqualified uniqueness of people, actions, emotions, and relationships that occur at the core of clinical ethics practice; and (2) the scope of commitments, both our own and others, revealed in those devices and code words used to compose and tell clinical ethics stories in the various contexts in which we tell and listen to such stories (clinical, institutional bureaucratic, professional conferences, et cetera).

1028

Another way to understand autonomy in psychiatry?

Author:

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As a CESS (clinical ethics support service), we carried out a prospective and qualitative study on involuntary hospitalization in psychiatry between 2014 and 2016 in three psychiatric wards (one traditional hospitalization ward, one ward focused on ambulatory care, and one psychiatric emergency unit). The goal was to understand the stakeholders' perceptions and ethical arguments about involuntary hospitalization. Teams of two researchers conducted interviews with patients, relatives, psychiatrists and nurses. The role of surrogates and advanced directives in psychiatry were also discussed with the interviewees.

For 42 cases, 161 semi-structured interviews were conducted: 35 with patients, 30 with relatives, 37 with psychiatrists, and 19 with nurses.

Main results:

- Patients didn't consider consent for hospitalization as the main issue. They emphasized the feeling of being violated as persons: forced treatment, physical coercion, boring and violent atmosphere in the hospital.
- Relatives denounced the lack of medical anticipation that could prevent the involuntary hospitalization. During the hospitalization, they wanted to be recognized as the main interlocutors by healthcare professionals.
- Healthcare professionals justified involuntary hospitalizations by medical arguments, in the best interest of patients. Nevertheless, their respective beliefs and habits about consent and coercion dictated various ways of care.

Discussion: Protective provisions of the law and patients' rights don't seem to be sufficient to resolve the ethical dilemma between respect for patients' autonomy (considered as self-determination) and the need for psychiatric care. Beyond self-determination and necessity of care, patients demand to be respected as human beings. We suggest that autonomy for these patients could be considered also in terms of personal integrity, meaning more respect for their humanity or their dignity as individuals living among others. It implies more consideration for the person and his/her needs and creating more relationships between all

the people involved (debriefing with patients, advance directives in psychiatry).

1029

Approaches to resuscitation decisions: When does empirical evidence of harm lead to an ethical imperative to change practice?

Authors:

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Gavin PERKINS, Professor of Critical Care Medicine, Warwick Medical School and Heart of England NHS Foundation Trust

The mandate to change clinical practice requires two elements: evidence of harm of the current practice, and evidence of superiority of an alternative.

Evidence that the most common approach to resuscitation decisions, the “do-not-attempt-cardiopulmonary-resuscitation” (DNACPR) documentation, creates ethical challenges and can contribute to patient harm has been identified and synthesized. This occurs through inconsistent and poor conversations, and the misinterpretation of DNACPR to mean that other treatments should not be given, resulting in inequities of care.

In response to this, we worked with patients and clinicians to develop an alternative approach: CPR (cardiopulmonary resuscitation) should not be considered in isolation, but rather as one aspect of holistic care for an individual patient. A single-centre study identified an improvement in conversations and patient outcomes.

We presented evidence of the harms associated with DNACPR and the potential benefits of an alternative approach to the U.K. Parliamentary Health Committee. They recommended: “that the Government review the use of DNACPR orders” including whether resuscitation decisions should be considered in the context of overall treatment plans.

The Resuscitation Council (U.K.) supported the development of a unified national approach based on best international evidence

Best international evidence was incorporated, existing ethical issues with DNACPR were explicitly addressed, and an applied Scanlonian con-

tractualism process was adopted in order to ensure the interests of patients and clinicians were met. The resulting Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) encourages early conversations with patients about overall goals of care, before making clinical recommendations of what treatments (including attempted resuscitation) should be given in an emergency.

We argue that, while further evidence is required to mandate a change to ReSPECT (evaluation in six sites is ongoing), a change in practice can be driven by an ethically and empirically robust approach to developing an alternative.

1030

Complex treatment decisions: Two case studies from a U.S. jail

Authors:

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In the United States, jails are institutions where individuals are housed while they await trial or sentencing, or are serving time for an offense punishable by less than a year of incarceration. Treatment decisions in a jail, as in most medical settings, are significantly influenced by concerns related to consent, adherence and follow-up, and finances. These factors, however, take on new dimensions in a jail, in large part because patients are incarcerated for short periods and providers often know neither the length of their stay nor where they will go after jail.

In this talk, we describe two cases in which providers struggled with a treatment decision for a patient in jail. The first involved a 51-year-old man who, while out of jail on bond, was diagnosed with and underwent surgery for an anaplastic oligodendroglioma. His bond was subsequently revoked and he returned to jail to await trial. The jail’s medical staff then had to decide whether or not to provide a generally effective, but extremely expensive, regimen of chemotherapy and radiation. The question of whether to proceed was complicated by the patient’s numerous comorbidities and the possibility that he might be convicted and have his treatment discontinued if he ended up at a long-term prison.

The second case we consider is that of a 54-year-old man who was brought to the hospital from the jail with stroke symptoms. Imaging revealed

severe stenosis of the left vertebral artery, and discussion ensued about possibly stenting the vessel. A few small studies suggest that this intervention may be of benefit, but the procedure is still considered unproven. In this case, providers had concerns about offering the patient the surgery because of the uncertainty regarding its impact, the challenge of arranging post-operative rehab, and the difficulty of obtaining valid consent.

1031

A role for clinical ethicists on ventricular assist device eligibility committees

Author:

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Eligibility criteria for ventricular assist devices (VADs) are not as rigid or clear as those for solid-organ transplants, and clinical ethicists may be asked to serve on VAD eligibility committees to help determine whether certain patients should be considered for VAD implantation. Through this role, clinical ethicists can help set precedent for the VAD team in thinking about future cases and also establish the ethos of the team. Clinical ethicists can provide valuable insights during this process, as I will illustrate with an actual case that threatened to set troubling precedent. In this case, Mrs. S was admitted to the hospital after reporting that her husband turned off her medication pump in her sleep. She told the medical team that her husband of the last 40 years had always been emotionally abusive, and he enjoyed seeing her ill. At this point of her medical deterioration, Mrs. S needed a VAD to increase her longevity and improve her quality of life. The VAD eligibility committee decided against the implantation because of her unsafe home situation. In the words of her cardiologist, Mrs. S was being “double victimized” by being denied the VAD for this reason. Initially, some members of the medical team were focused on her questionable capacity to report abuse and make decisions, and the patient narrative was reduced and largely dismissed. When the ethics team was consulted for our recommendation, we broadened the scope of moral concern to include features of the patient’s vulnerability, possibilities for enabling her autonomy, and the moral urgency of responding to her reports of abuse. This case demonstrates the ethical complexity of VAD eligibility and how support from clinical ethicists can make a positive impact in these deliberations.

1032

How hard to push? The challenge of addressing organizational ethics

Author:

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Clinical ethicists generally espouse a commitment to organizational ethics, but what this concretely means can be difficult to discern. Over 20 years ago, Robert Lyman Potter emphasized the important work that bioethicists have to contribute to organizational ethics, which he defines as the intentional use of values to guide the decisions of a system, which implies that members of a cooperative group have articulated and reflected on a set of values and have accepted them as normative for the culture of that organization. In the course of their work, clinical ethicists in a hospital environment will frequently see preventable ethical conflicts and avoidable moral costs. Clinical ethicists have a unique vantage point in being able to pinpoint troubling patterns and trends that could be emerging, such as those related to resource use, work environment, miscommunication and missing documentation, cultural incompetence, personal biases, and training deficits. When these broader issues arise in a particular case, clinical ethicists are often stuck in determining the boundaries of their professional role. Clinical ethicists face pressures to be “politic” and not too intervening, leaving certain messes to other services who should take responsibility for them. But when the clinical ethicist has identified certain problem areas and communicated them to the proper individuals, and it becomes evident that no one will take responsibility for those problems, then how hard should the clinical ethicist push? What sacrifices and risks are an inherent part of clinical ethicists’ professional obligations? In addition to worries about overstepping our professional boundaries, there are also worries about other services relying too heavily on ethicists taking responsibility for problems that they should learn to address themselves. I analyze these tensions with case examples, and I suggest how clinical ethicists should think about their professional duties regarding organizational ethics.

1033

Bridging clinical and system ethics: Opportunities for responsible advocacy

Author:

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Clinical ethicists and ethics committees are regularly tasked with resolving ethical issues around individual patients, or discrete treatment matters that arise from dyadic therapeutic relationships or conflicts that are caused by individual circumstances. However, as institutional policies, professional practices, funding schemes, and other socio-systemic factors often frame or contribute to bedside dilemmas, many clinical ethics scenarios reflect meso and macro weaknesses in fulfilling patient needs. With careful documentation and analysis of consultation patterns, ethicists and ethics committees can occupy a unique vantage point to alert the organization and system of such challenges and barriers, and to advocate for positive change accordingly.

Nonetheless, questions abound as to whether or how ethicists/ethics committees may advocate for change. This presentation will critically explore systemic features that can promote or hinder not only ethically appropriate care, but also ethicists' ability to advocate for improvement. First and foremost, there is a fundamental question of whether ethicists can remain objective in analyzing and clarifying ethical issues while advocating for certain positions or interests of particular parties. Moreover, ethicists/ethics committees occupy a delicate position within a healthcare organization. Ethicists are generally hired by institutions and provide guidance as per clinical teams' requests. The extent to which ethicists can advocate for a patient's or family member's interests or desires that meet resistance from a healthcare team is thus unclear. Informed by the concept of a learning organization, this presentation will explore how an organizational and system ethics approach can guide ethicists and ethics committees regarding responsible and responsive advocacy without compromising appropriate forms of objectivity. Going beyond an individualist approach, this presentation will propose an upstream, pro-active and integrative approach to advocate for not only organizational and system improvements, but also ethical care for various populations.

1034

Who leads in the final dance? Patient information and autonomy in the case of advanced cancer ideals and realities:

A qualitative study

Authors:

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Background: Respecting patients' autonomy has become both an ethical and a legal obligation in Norwegian healthcare. In cases of advanced cancer and short life expectancy, ethical dilemmas related to life-prolonging treatment may occur, due to uncertain outcome and troublesome side-effects. The realization of patients' autonomy relies heavily on open and honest communication with patients. The aim of this study was to gain knowledge about healthcare professionals' perspectives on patients' autonomy in decisions about life-prolonging cancer treatment.

Methods: Semi-structured, individual interviews were conducted with five physicians, as well as focus group interviews with seven nurses, on a cancer ward at a Norwegian university hospital. A qualitative content analysis was conducted.

Results: In principle, all participants agreed that respecting patients' autonomy is an ideal that must be kept high. Despite this, the autonomy of patients with advanced cancer is not always upheld in practice, due to insufficient or biased information in favor of more treatment, and thus, lack of free choice. Other patients' self-determination sometimes extends beyond Norwegian law and guidelines when they strongly request life-prolonging treatment, despite poor medical justification. The nurses believed that they often had a more realistic picture of the patient's condition and preferences, and saw it as their task to be the patient's interpreter and advocate.

Conclusions: Both too much and too little weight on patients' autonomy seems to cause more life-prolonging treatment. Nurses should have a central role in decision making, and may contribute to enhanced patients' involvement and more appropriate treatment intensity by bringing relevant information into the discussions. Continuity in relationships with patients is essential for building trust and knowledge of patients' preferences, both of which are important conditions for good decision-making processes. Management

must accommodate work cultures and arenas where open discussions in cross-disciplinary teams about difficult decisions can take place.

1035

Opening Pandora's box: Ethical uncertainty surrounding the handling of incidental findings generated in genomic sequencing

Author:

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As whole-genome and whole-exome sequencing techniques become more accessible, their application within both medical research and clinical practice has significantly increased. This has led to substantial gains in our knowledge surrounding the genetic components of disease, pathogenesis, and prognosis. This, in turn, has allowed us to develop targeted treatments, with the ultimate goal of improving patients' outcomes.

However, as with everything within the field of medicine, each intervention comes with some risk. In the case of genomics, this is in the form of so-called incidental findings. Incidental findings are not a new concept in medicine; however, due to the nature of genomic information, this one investigative test has the potential to reveal huge quantities of unwarranted information about patients, their future health risks, as well as possible risks to genetic relatives. In addition to health-related findings, sequencing may also lead to significant revelations around biological parenthood of both patients and their offspring.

This leads to difficult questions for clinicians: Do we inform patients, or not? This is further complicated when a patient does not consent to receive additional results, but the clinician finds an easily treatable but otherwise life-limiting finding. Such cases call to question the validity of traditional approaches to beneficence, autonomy, and consent, with some ethicists suggesting the principle of solidarity supersedes all other ethical considerations. Such a position has created heated debate with those who champion individual sovereignty above paternalism.

Not only is there little consensus within academic bioethics on the subject, there is little regulatory guidance to help direct doctors in such situations. The complexity of these findings leads to significant uncertainty for both clinicians and researchers, in an area which is only going to grow in the future.

1036

Legal cases or thought experiments?

Author:

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In ethics there is a debate whether one should focus on rules developed from more general principles or on cases, and in those discussions cases tend to be real cases, either legal cases or clinical ethics cases. However, one can also use fictitious cases, analogous to thought experiments in philosophy. Usage of a particular type of case has advantages and disadvantages.

Using legal cases or actual clinical ethics cases has the advantage that the cases are realistic, as they have actually happened, but the disadvantage that the law is not a "self-sufficient, integrated and self-interpreting system of doctrine." Furthermore, legal cases are often influenced by extraneous factors, and one cannot always recognize this by focusing on the argumentation.

Thought experiments have the advantage that one can focus on distinctive features of particular cases, because one can make slight variations, or one can focus on hypothetical cases that will never happen in practice. In this way one can demonstrate which factors are important, and it may also be possible to develop an overarching theory clarifying various thought experiments. However, a disadvantage is that thought experiments are often not realistic, there may be different results in different cultures, and external validity is limited.

There is a place for thought experiments in ethics, and for real cases, and one probably needs to use both types of cases in comprehensive ethical studies.

1037

Safe enough: Exploring ethical issues in the complex discharge

Author:

Adira HULKOWER, Chief, Bioethics Consultation Service, Montefiore Medical Center

Ethics consultation services are frequently consulted regarding conflicts over safe discharge. Patients with decision-making capacity who refuse a safe discharge plan have the option to sign out against medical advice. Challenges arise when patients without capacity refuse the recommended discharge plan and wish to return to an environment that treating staff believes to be unsafe. An

added layer of complexity arises when patients lack decisional capacity to refuse, but are able to clearly express the values and preferences that motivate their refusals.

I will present the case of Mr. K, a 66-year-old man with chronic obstructive pulmonary disorder (COPD) who was living independently prior to admission. Because of his worsening COPD and new need for continuous oxygen, as well as his use of cigarettes, the primary team determined that he would not be safe at home and recommended nursing home placement. Mr. K was adamant that discharge home was the only plan he would agree to. Psychiatry was consulted, and the consultant determined that Mr. K lacked the capacity to refuse a safe discharge plan, because he could not understand the need for continuous oxygen and the risk he would pose to himself through non-adherence.

Through an exploration of the ensuing consultation, the attendees will be introduced to concepts from the social science literature that discuss the importance that “home” and “risk-taking” play in identity formation and preservation. Together we will explore what it means to be safe and challenge the conventional medical understanding of safety as relating solely to the body. Ultimately, I will argue that sometimes the most ethical discharge plan is not the safest discharge plan.

1038

Conscientious objection and medical duties in case of suicide-assistance requests

Author:

Samia HURST, Professor, Geneva University Medical School

Persistent controversy surrounds end-of-life decisions, in particular assisted suicide and euthanasia. Switzerland allows suicide assistance if it is offered without selfish motive and even when it is practiced by nonphysicians. As in all countries allowing assisted dying, the issue of physicians' involvement and duties, and of conscientious objection, is a difficult one.

This presentation will focus on the Swiss discussions regarding physicians' duties and on the difficulties arising in ethics consultations for cases of assisted-suicide requests.

Although Switzerland, in recognizing no entitlement to suicide assistance, seems to facilitate issues of conscientious objection by never assigning a duty to provide this assistance, difficulties

nevertheless arise. First, the extent of liberty-rights, as opposed to entitlements, is not clearly understood in clinical practice. Second, the distinction between assisting suicide and caring for patients who request suicide is often misunderstood, and with it the extent of medical duties in such cases as well. Third, some of these duties, such as the evaluation of decision-making capacity and the exploration of alternatives, are difficult to disentangle from individual physician's agreement or disagreement with the suicide-assistance request. Finally, although conscientious objection could apply to suicide assistance itself, as well as to caring for patients who request it, these are different categories of actions to which it is not required to adhere or object simultaneously.

The scope and limits of medical duties in the situation of suicide-assistance requests should be understood clearly by clinicians. As illustrated through cases presented for ethics consultation, confusion on several of these points is prevalent and can have adverse consequences for patients and healthcare professionals. Swiss mechanisms for ethical guideline development allowed these experiences to bear on revising policies applied by Swiss physicians to suicide-assistance requests.

1039

What is urgent? Rights of access to healthcare and their limitations in the case of illegal immigrants

Author:

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Increasing migration flows lead healthcare systems to growing tensions regarding access to care for illegal immigrants. Ethical and political disagreements center on whether migrants are to be excluded from access to healthcare resources to which only legal residents have contributed, or whether their access should be guaranteed on the basis of shared humanity. Despite their apparent incompatibility, common ground does exist between these positions. As a result, healthcare access does exist, even for illegal immigrants and very restrictive countries. The scope of this access, however, is under constant pressure.

In Switzerland, where anti-immigrant policies have gathered strong public support for decades, a right to access is nevertheless guaranteed. A Swiss Supreme Court decision, grounded in constitutional rights, confirmed that urgent care should be guaranteed. What constitutes “urgent” care, however? Urgent is usually understood to

denote a situation akin to the rule of rescue: a person is in dire need of immediate help, failing which she will die—or come to grievous harm—in a very short time. “Urgent” can thus be understood to have three components: the lack of possible delay for effective action, the severity of the harm, and the rapidity of the ill effects in case nothing is done.

Are these three components sufficient? Are they cumulatively required, or can an intervention be urgent in the absence of one or more of them? This paper will explore different cases to examine the scope of the criterion of urgency in determining requirements for access to care for illegal immigrants.

1040

Clinic, court, or committee: In the best interests of the critically ill child?

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Conflicts can arise in the clinic when a decision must be made about (not) providing life-sustaining treatment to a critically ill child. Even with careful communication, clinicians and parents will sometimes differ in their assessments of what the welfare or “best interests” of the child requires.

Some such conflicts are amenable to resolution in the clinical setting; others, however, fall to be decided in a court, as occurred in the U.K. cases of Charlotte Wyatt (2005), Ashya King (2014), and Charlie Gard (2017). The Gard case was particularly fraught, generating significant (worldwide) media attention and the interventions of international leaders. In that case, the parents wished to try an experimental treatment overseas, but the courts ruled that this was not in the best interests of the child. The courts did, however, recommend that efforts be made to resolve disputes prior to recourse to the law.

In this symposium, which is proposed by the U.K. Clinical Ethics Network and comprises three presentations, we explore the roles that might be played not only by courts, but also by clinical eth-

ics committees (CECs), in seeking to resolve such disputes.

1041

Facilitating moral resilience in the ICU:

A participatory action research partnership with ethics consultation services

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Issues of moral distress across healthcare settings and its impact on the quality, safety, and efficacy of care and retention of clinicians and nurses has been widely studied in recent years. While several research projects have articulated notions of moral distress and characterized its effects, few have found ways to address its varied root causes and develop mechanisms that promote moral resiliency at the individual and health-system level. This presentation will describe the role of clinical ethicists in facilitating moral resiliency through a partnership with the Moving from Moral Distress to Moral Action in Intensive Care Units research project.

This participatory action research project involved the development and testing of a moral conflict Assessment (MCA) tool, authored by J. Chevalier, in three intensive care units (ICUs) within hospitals in Vancouver, B.C. We report findings from MCA assessments done at one hospital between May 2017 and September 2017. Data were collected during one group interview with five nurses and one respiratory therapist, and three individual interviews with two physicians and one social worker. Participants’ discussion of moral distress centered on cases pertaining to decisions related to end-of-life care in the ICU.

Facilitated by a clinical ethicist using the 10-step MCA tool, we describe the current moral climate by characterizing the behavior that is causing moral distress, its effects on the participants, their current responses, and the different values, interests, and personal or relational issues involved. Contextual factors that help or hinder the participants’ ability to act according to their moral conscience are also considered. The reported discussion ends with recommendations for new responses and metrics to measure success. Reports

were provided to participants and the ICU leadership team to highlight issues causing moral distress and proposed action plans.

1042

Who decides? Exploring the impact of governmental authority on the treatment of borderline viable infants in the United States

Authors:

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In high-income countries, new technologies and knowledge have altered, and continue to alter, the boundaries of how to define the borderline viable neonate. Recent studies have reported that survival rates for infants born at gestational ages (GA) 22 to 24 weeks vary across countries, but range from 0 percent to 18 percent (GA 22 weeks) to 40 percent to 67 percent (GA 24 weeks).

Despite the increase in survival rates over the last 20 years for extremely premature infants, the outcome for the individual infant remains uncertain and, therefore, the decision to initiate resuscitation continues to be a complex one, with numerous medical and ethical aspects. Who should hold the final authority to make that decision is a key question that has yet to be answered definitively and remains fraught with the potential for conflict.

Traditionally, parents have been viewed as the surrogate decision makers for minor children, on the assumption their decisions are in the best interests of the child. In the United States, however, federal legislation in the form of the Child Abuse Prevention and Treatment Act (CAPTA), the Born-Alive Infants Protection Act (BAIPA) and subsequent judicial decisions appear to have placed that authority in the hands of the government. In doing so, the government imposes decisions on physicians and parents while simultaneously disregarding physicians' knowledge and the concept of parental autonomy. Moreover, in legislating one specific treatment possibility with few exceptions, the government may increase the potential for conflict while ignoring the best interests of the neonate. The potential consequences of such overarching governmental policy may serve as a cautionary tale to other governmental bodies that are attempting to solve medical and ethical complexi-

ties for which there exists no firm medical consensus. This paper explores the impact of CAPTA, BAIPA, and subsequent judicial decisions through the lens of parental autonomy and two different interpretations of the best interests standard.

1043

Filming clinical ethics consultation: Using video technology for research, education, and community information

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A key activity of clinical ethics support consists in chairing case discussions in different healthcare contexts. Given these complex communication settings, the video and broadcasting technology that is widely available today could help in training clinical ethicists, informing the public, and performing research on ethics consultation (EC). Yet it raises multiple ethical and methodological concerns, for example concerning confidentiality, the validity of simulated case discussions, and the possibility of evaluating performance on video. In this international symposium, four experienced clinical ethicists present different EC projects involving video technology:

Presenter 1 (Munich, Germany): Ethics case consultation on video—a qualitative research project on the course and outcome of consultations. The first presenter will show the results of a qualitative research study that used videotaped simulated EC with a standardized case, invariable role actors, and three different consultants. The study elucidated the core of EC, identified the key nonverbal elements of successful EC, and found that the personal style of the consultant has a higher impact on EC outcome than the theoretical model applied.

Presenter 2 (Basel, Switzerland): Addressing (unexpected) challenges in ethics consultation. Using video for education. This presenter used the

videotapes from the same research project for educational purposes in the leading certification course of clinical ethics consultants in Germany, and for in-house training. By contrasting the approaches of the three different consultants, the videos can be used to teach core elements of EC, such as the opening, the closure, or the management of an emotional outbreak of a relative participating in the EC.

Presenter 3 (Chicago, U.S.): Assessing Clinical Ethics Skills (ACES): a video-based education and evaluation tool. The ACES project is being used to evaluate the interpersonal skills of students and clinical ethics consultants, using simulated ethics cases and a scoring sheet developed by experts. The ACES tool is also available online to train ethics consultants in recognizing and applying these skills. The project, the various experiences gathered so far, and the scientific evaluation will be presented and discussed.

Presenter 4 (Frankfurt, Germany): How the ethics committee can help you—creating a movie on ethics consultation. The fourth presentation will feature a film specifically developed to inform the general public about clinical ethics support, its objectives, aims, structures, and roles. This film responds to the need to make EC more widely known in the general public in order to promote its use and its development as a professional field.

After the four short presentations, a joint panel discussion will address the promises and challenges of using video technology in clinical ethics. There will be ample opportunities for the audience to pose questions, give comments, and discuss with the presenters.

1044

Rethinking the assessment of decision-making capacity

Author:

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Mr L is a 68-year-old gentleman who was admitted for a cerebrovascular accident, complicated with post-stroke depression. During his admission, he developed wet gangrene of his left toe. He was referred to an orthopedic surgeon who advised ray amputation of the toe [removal of diseased toe and metatarsal]. Mr L declined, and a psychiatrist assessed him for lack of decision-making capacity due to inability to retain information or comprehend the risks versus benefits of the operation. Due to the risk of life-threatening sepsis, the medical

team decided to proceed with the amputation in the patient's best interests. As the patient was wheeled down to the operating theater, he struggled and shouted that this was his body, he should decide for himself, and he does not want the amputation. Both the anesthesiologist and orthopedic surgeon were uncomfortable with proceeding with surgery and subsequently held off the operation. This case raised questions as to whether our current method of assessing mental capacity is accurate and adequate.

Determining an individual's decision-making capacity is fundamental to obtaining informed consent for and respecting refusal of medical treatment. Mental capacity acts in most countries have agreed upon four abilities that constitute capacity: understanding information, retaining that information, weighing up options with reasoning, and communicating a choice in relation to a specific decision. Current instruments for assessments do not take into account coercive factors that may influence patients' judgment, including strong emotions, relationships, and financial pressures. There is also no guidance on when it is appropriate to delay treatment-related decision making, or evaluating and treating reversible causes of cognitive impairment and communication disorders. We propose a comprehensive framework to assess decision-making capacity for medical treatment incorporating the above factors, to give physicians clarity and confidence to make appropriate and ethical clinical decisions, and to balance respect for patients' autonomy and acting in their best interests.

1045

Genomics in research and practice: Is there a need for a new ethical approach in the clinic?

Authors:

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The genomic revolution and the ability to process big data sets has opened up new possibilities in medicine. The combination of genomic infor-

mation with other types of data such as medical history, laboratory tests, diet, environment (aka digital phenotype), can make it possible to answer more complex questions regarding prevention, diagnostics, and treatment of disease. The hope is that in the near future, as the amount of data as well as the analytic and computational capacity of new tools increase, more diagnoses (and treatments) will be forthcoming, and researchers will have a better idea on where to concentrate their efforts.

The realization of the genomic and big data promises in medical practice, however, will raise new ethical challenges in the clinic. The potential for genomics to be utilized in clinical care strongly depends on the availability of data. A large amount (volume and velocity) and different types (variety) of reliable data (veracity) that can be analyzed in a continuous cyclical process between research and practice is necessary for this potential to be actualized. The cyclical and iterative process between research and clinical application, however, challenges established practices and theoretical conceptions of professional duties and obligations. The application of genomics and big data methods in the quest for more accurate diagnoses and treatments, in which the interaction between research and clinical practice comes ever closer, creates important new ethical challenges in the delivery of genomic medicine. It is, therefore, important to consider whether existing ethical frameworks in research and clinical practice are adequate to guide clinical genomic practice, or whether a new ethical approach will need to be developed.

The symposium will address the aforementioned question by discussing the following topics:

1. Ethical challenges in the prenatal context: research informing practice—Presenter 1
2. Ethical issues in genomics and big data research: some clinical implications—Presenter 2
3. Genomics in research and in medicine: professionalism in the new context—Presenter 3
4. Clinical genomic medicine: is there a need for a public health ethics approach?—Presenter 4

The chair will draw conclusions based on the presentations and discussion regarding the need for a new ethical approach in genomics and big data research and practice.

1046

A cross-sectional qualitative SWOT analysis of the need for clinical ethics consultation service in Malaysia

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Clinical ethics consultation service (CES) is fast becoming a cornerstone of healthcare settings in many developed countries. Yet such services remain undeveloped in low- and middle-income countries. It is recognized that the introduction of CES poses challenges. Malaysia is a multicultural and multilingual society, and its diverse religions, values, interpretations, and perceptions further complicate the introduction of CES.

Key clinicians attending a national congress workshop completed a cross-sectional qualitative strengths, weaknesses, opportunities, threats (SWOT) analysis. The aim was to gain insight into clinicians' mind sets and expectations and their professional environments. We also wished to promote initiatives leading to the introduction of formal CES.

Clinicians agreed that these services (CES) can improve quality of care, reduce healthcare costs, and advocate for patients and providers. The analysis highlights constraints with regard to a sufficient critical mass of relevant expertise and restricted opportunities for training in bioethics. The opportunities lie in education and curriculum development, as well as the availability of dedicated proponents and local champions. Cultural barriers, limited resources, lack of awareness, differences in opinions, fear of litigation, and the destructive influence of social media are seen as threats to the successful introduction of CES in Malaysia.

This study illustrates the value of involving stakeholders when introducing CES in a multicultural middle-income country. The critical issues identified will inform the strategic directions for the delivery of CES at a national level. The meth-

odology used in this study could be applied to other developing countries or institutions with multicultural populations.

1047

Unique and evolving ethical challenges faced by a community palliative care service preparing for the implementation of voluntary assisted dying

Authors:

Danielle KO (presenting author), Palliative Care Consultant and Clinical Ethics Lead, Austin Health
Janet PHILLIPS, Strategy and Operations Manager, Melbourne City Mission Palliative Care
Jane SULLIVAN, Psychologist, Melbourne City Mission Palliative Care

Community palliative care services look after patients with advanced progressive illness. The intimacy of the home environment often means that intense relationships form quickly between staff and patients, providing a safe space to address difficult and confronting issues such as the desire for hastened death.

In November 2017, Victoria became the first state in Australia to pass voluntary assisted dying (VAD) legislation, and it comes into effect in June 2019. This presentation will discuss the unique and evolving ethical challenges faced by our service in the lead up to the implementation of VAD.

Whilst it is anticipated that VAD will only be requested by a small percentage of patients, there are potential widespread implications for our service, which is team-based, multidisciplinary, and small. There is a wide range of views on VAD amongst the staff. Therefore, key ethical challenges are how to: continue to uphold our institutional value of supporting patients' choice and control, best support staff with a wide range of values and beliefs, maintain high-quality and consistent clinical care, and ensure strong working relationships with colleagues regardless of their views on VAD.

The processes and strategies implemented by our service in response to these challenges will therefore be discussed, and are aimed at ensuring that staff are supported throughout this period of uncertainty and anticipatory anxiety. These include: active encouragement of the service leadership and individual clinicians to consider and determine their ethical positions of VAD, facilitation of open and respectful dialogue between clinicians with differing views, and increased support from our clinical ethics committee.

1048

When a son refuses palliative care for his dying mother: Conflicting interests at the end of life

Authors:

Danielle KO, Palliative Care Staff Specialist, Clinical Ethics Lead, Austin Health

This presentation is an interactive discussion of the end-of-life care of a patient whose son was unable to accept that his mother was dying. A complicating factor was that this case occurred in a jurisdiction where the law governing the right to refuse medical treatment specifically excludes the refusal of palliative care.

Mrs A was a non-English speaking Chinese woman in her 70s who was admitted to hospital with acute neurological deficits. Her diagnosis remained elusive for several weeks, during which time she deteriorated from ambulant and independent to being bed bound and confused, with increasing difficulty swallowing and talking. Mrs A was eventually diagnosed with a malignant brain lesion. Shortly after chemotherapy and radiotherapy were commenced, Mrs A's condition deteriorated and it became clear to the healthcare team that she was dying. Palliative care was consulted to assist, but nursing and palliative care were refused by her son, her legally appointed agent. Mrs A died following a sustained period of poor symptom relief, including significant agitation.

This case prompts us to consider a number of important ethical issues and questions. First, in what circumstances is it ethically appropriate to place the interests of family over those of a dying adult patient? In clinical practice, this occurs on a frequent basis, and it is important to consider the ethical bases of such decisions. A second, less commonly discussed but important issue is what weight should be placed on the distress of healthcare staff when they are making decisions in ethically challenging cases? In this case, the wider healthcare team experienced great distress knowing that better palliative care could have been provided. Should this distress be factored into decision making, or do healthcare staff need to accept that deviation from their notion of a "good death" is not necessarily ethically inferior?

1049

What's the harm in CPR? The ambiguity of harm in code status discussions

Author:

Peter KOCH, Assistant Professor of Philosophy, Villanova University

Clinical ethics consultations are frequently initiated to resolve disagreements between the medical team and a patient's family regarding the patient's code status. These conflicts are particularly challenging when the family insists that the medical team attempt cardiopulmonary resuscitation (CPR) despite the reservations of the healthcare professionals involved. In these circumstances, physicians often communicate their unwillingness to perform CPR in terms of "harm," explaining that any resuscitation attempts will likely cause grave harm without any meaningful benefit. In this paper I discuss the theoretical foundations of harm underlying such conversations, drawing upon a distinction between experiential and non-experiential harms. I then argue that these different understandings of harm may account for miscommunication between the family and team, as each implies a different set of ethically relevant harms. Recognizing this distinction allows clinical ethicists to better elucidate the concerns of both healthcare professionals and families regarding the harms of CPR, which may assist in bringing resolution to such conflicts. Furthermore, given the ambiguity of harm, clinical ethicists may benefit from directing conversations away from harm-based justifications for CPR refusal, instead relying upon notions such as dignity or professional obligations.

1050

Lifting the cloak of professional invisibility: Understanding the experience of compassion fatigue, vicarious trauma, and moral distress for medical interpreters and scribes

Author:

Leslie KUHNEL, Regional Ethicist, CHI Health

The experience of moral distress, compassion fatigue, and vicarious trauma has been a focus of concern within a variety of healthcare professions in recent years. In the nursing profession in particular, turnover rates, burnout, staffing shortages, and medical errors have all been linked to these experiences. In response, many organizations have developed debriefing strategies and other types of staff support to acknowledge and address these problems.

There are some professionals within the healthcare team, however, who, by their professional standards of practice, are called to demonstrate a unique type of "invisibility" in the healthcare setting. Medical interpreters, for example, are expected to maintain neutrality and to essentially become invisible within the communication exchange between patient and provider. Medical scribes, as well, are expected to serve in this "invisible" role, sometimes from an unobtrusive location within the exam room, and other times from a different removed location altogether. For these professionals, the experiences of hearing a devastating diagnosis, interpreting a traumatic situation, or capturing a disturbing exchange within chart documentation are similar to those of nurses and other ancillary professionals, yet interpreters and scribes are often rarely included in follow-up debriefings or case reviews.

In this presentation I will discuss the results of a study of healthcare team members burdened with a professional expectation of invisibility in the clinical interaction. I will also share strategies for addressing their unique experiences of moral distress, compassion fatigue, and vicarious trauma. Finally, I will suggest further areas of research, and ideas for adapting various codes of professional ethics to reduce the impact of expected invisibility within specific healthcare professions.

1051

Can clinical ethics committees be legitimate actors in bedside rationing?

Authors:

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Kristine BÆRØE

Background: Rationing at the clinical level—bedside rationing—entails complex dilemmas that clinicians and managers often find difficult to handle. There is a lack of mechanisms and aids for promoting fair decisions, especially in hard cases. Reports indicate that clinical ethics committees (CECs) sometimes handle cases that involve bedside rationing dilemmas. Can CECs have a legitimate role to play in bedside rationing?

Methods: The theoretical assumptions of the accountability for reasonableness framework (A4R), developed by Daniels and Sabin, are explored and modified in order to make the framework suitable for legitimate decision making at the clinical level. Within these frames, we discuss how CECs can contribute to enhanced legitimacy in

bedside-rationing decisions according to both the epistemic and the procedural dimensions of A4R. Through brief case vignettes we outline several potential roles that CECs may play, and then discuss whether these might contribute to rationing decisions becoming legitimate. In the process, key prerequisites for such legitimacy are identified.

Results and discussion: Legitimacy places demands on aspects such as the CEC's deliberation process, the involvement of the stakeholders, transparency of process, the opportunity to appeal decisions, and the competence of the CEC members. CECs might be legitimate advisory actors in bedside-rationing decisions and appeals, provided they: (1) adequately represent stakeholders (that is, healthcare providers responsible for treatment, adversely affected patients, and other patients who could benefit from the opportunity costs); (2) deliberate in a systematic manner, drawing on relevant clinical, ethical, and legal arguments; and (3) allow for transparency with respect to the deliberation and conclusions. Thereby they might strengthen the legitimacy of some of the rationing decisions clinicians have to make.

Conclusion: CECs can have a well-justified advisory role to play in order to enhance the legitimacy of bedside-rationing decisions.

1052

Evaluating ways to conduct do-not-resuscitate/do-not-intubate conversations with terminal patients: Is a paternalistic approach ethically favorable?

Author:

Kristen MATHIAS, Medical Student, Baylor College of Medicine

By United States federal standards, terminal illness is defined by a condition with an associated life expectancy of six months or less if the illness runs its natural course. In patients with terminal illnesses, a crucial component of end-of-life discussions entails determining if the patient would want to forgo cardiopulmonary resuscitation and/or intubation in the event that the patient's heart stopped beating. The manner in which these do-not-resuscitate/do-not-intubate (DNR/DNI) conversations are held is highly variable and often contentious. Some physicians adhere to an autonomy-centric approach, in which DNR/DNI status is a decision left up to the patient after the benefits and consequences of each option are clearly elucidated. Other physicians prefer a paternalistic approach, in which the physi-

cian clearly states what he or she believes is best and alters the patients' care accordingly. Still others prefer a hybrid approach, in which a physician advocates a course of action for a patient, but ultimate decisions regarding DNR/DNI status are left up to the patient. Although the Western approach to DNR/DNI conversations tends to emphasize autonomy, the literature surveying patients' and physicians' attitudes toward these conversations may suggest that a paternalistic approach is ethically preferable. The aim of this discussion is twofold: to evaluate autonomy-centric, hybrid, and paternalistic approaches to DNR/DNI conversations and to argue ultimately that the paternalistic approach to DNR/DNI conversations is most ethically favorable, because it tends to reflect patients' preferences, helps to counteract known biases in decision making that undermine the realization of patients' values, and is logical, given that the burdens of resuscitation and intubation for terminally ill patients are not outweighed by the benefits.

1053

What part of "No" don't you understand?

Author:

Annette MENDOLA, Director of Clinical Ethics, University of Tennessee Medical Center

The patient, a 48-year-old nurse, was admitted for elective hernia repair. Apart from the hernia and some asthma, he was in good health, working full-time, and looking forward to going on his annual fishing trip with friends that summer.

He had diligently completed an advance care plan (ACP) two weeks earlier, which identified his son as his surrogate, with his mother as the alternate. In addition to checking boxes about resuscitation and artificial nutrition, he had handwritten that he would accept a ventilator short-term if necessary, but clarified: "I do not authorize placement of a tracheostomy." To underscore this, he had added "No trach!!"

After his surgery, he suffered a set of unexpected complications, including acute respiratory distress syndrome (ARDS). After a few weeks, his prognosis was uncertain; he was still encephalopathic and ventilator-dependent. To continue ICU care safely would require a tracheostomy, as leaving the endotracheal tube in place much longer could result in severe, permanent damage to his trachea.

His son, and some of his providers, noted that, as a nurse, the patient would have known what

he meant when he completed his ACP. They observed that he had gone out of his way to hand-write “No trach!!” and must have had his reasons for doing so. They were uncomfortable going against a recently executed, unambiguous directive from an informed, competent patient.

His mother, and other providers, however, doubted he had considered the current situation when he gave that direction. They reasoned that he’d previously been healthy and had chosen to have surgery in order to get better, which was still possible—but unlikely unless he receives a tracheostomy soon.

Among other themes, case analysis will explore the concept of moral luck in evaluating decision making in clinical ethics.

1054

Clinical ethics dilemmas in a low-income setting: A national survey among physicians in Ethiopia **Authors:**

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Ole NORHEIM, Professor, University of Bergen, Norway

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Background: Few studies describe health workers’ ethical challenges in low- and middle-income countries. Our objective is to explore what dilemmas Ethiopian physicians experience most frequently and to describe these dilemmas based on their own narratives.

Method: A sequential, exploratory, mixed-method design was used. A national survey was conducted amongst physicians from 49 public hospitals using stratified, multistage sampling in six regions. All of the physicians in selected hospitals were invited to complete a self-administered questionnaire. Descriptive statistics were used. Template analysis, a type of thematic analysis, was used to analyze the qualitative data.

Results: In total, 587 physicians responded (91 percent response rate), and among them, 200 provided narratives about ethical dilemmas they experienced. Twenty-four types of dilemmas in nine predefined categories were sorted according to frequency. Dilemmas related to shortage and distribution of resources, inability of patients to pay,

and welfare implications for families due to medical treatment decision were reported to occur often or sometimes by 93 percent, 85 percent, and 82 percent of physicians, respectively. Dilemmas concerning reproductive health, disclosure issues, cultural understanding, and health illiteracy were also frequently reported. Observing unethical behavior by colleagues was common. Few doctors (less than 10 percent) reported dilemmas concerning limiting life-prolonging treatment or euthanasia. Respondents described a strong sense of ethical concern and a lack of guidelines and regulations that might guide their handling of their dilemmas.

Discussion: Ethiopian physicians encounter a great variety of ethical challenges. Their narratives reveal the stark work environment and the lack of guidelines and regulations needed to guide ethically sound behavior. There is an urgent need of training in ethics, decision making, and also in self-compassion.

1055

What ethical issues arise at a rural regional medical center? A quantitative and qualitative analysis of clinical ethics consultations from 2007 to 2017 **Authors:**

Jessica MILLER (presenting author), Professor, University of Maine

Jonathan WOOD, Pediatric Intensive Care Lead Physician, Eastern Maine Medical Center

As the field of clinical ethics matures, more practicing ethicists are working with hospitals of various sizes within larger healthcare systems. The vast majority of retrospective analysis of clinical ethics consultations has been conducted at large urban hospitals, typically academic medical centers. There is limited data on the type and number of ethics consultations conducted across different settings. To address this gap, we conducted a retrospective review of 60 ethics consultations from 2007 through 2017 at Eastern Maine Medical Center, a 400-bed tertiary care facility. We analyzed demographic data regarding the patients and conducted a content analysis of the ethics consultation summaries, coding the frequency of ethical issues and key ethical issues in each case. We also explored the elements of hospital size and geographic and economic setting that affect the specific character of consultations on issues such as withdrawing and withholding life-sustaining treatment, determining patients’ decision-making ca-

capacity, and potentially unsafe hospital discharges. Our findings offer new data to inform the education and training of clinical ethicists regarding the ethical issues that arise in practice at a regional medical center in a suburban setting that serves a large rural area.

1056

Advocating for patients with profound intellectual and multiple disabilities at the end of their lives: Reframing a case through the lens of an ethics of care

Authors:

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Katherine BROWN-SALTZMAN, Co-director, UCLA Health Ethics Center

End-of-life decision making is a challenging situation for many patients and their families. For patients with profound intellectual and multiple disabilities (PIMD) this challenge is often compounded by the patient's inability to express a choice (whether due to their intellectual disability or a comorbid condition such as deafness, blindness, or mutism) or the fact that they have one or more complex diagnoses characterized by prognostic uncertainty. In such instances, clinicians generally turn to family for guidance in determining whether to pursue or forego certain medical interventions in light of a patient's known preferences or perceived quality of life (QOL). However, when there is no family, and when assessment of preferences/QOL is potentially non-directive, questions about appropriate treatment goals present no clear answers, sometimes prompting the need for ethics consultation. For our presentation, we consider the case of a 40-year-old female with a history of blindness, psychosis, and severe developmental delay who, after undergoing a lifesaving procedure, was dependent on trach/ventilator assistance and tube feeds. It was deemed unlikely that she would be liberated from either intervention, and it was evident that her machine-dependence and hospitalization were causing the patient great distress. Additionally, while she had no available family to guide the team, her caretakers indicated that the patient's primary enjoyment in life involved the comfort and enjoyment of eating, suggesting that continued treatment that might negate these possibilities could be inconsistent with what the patient herself would want, or otherwise inconsistent with

her overall QOL/best interests. We reflect on how we and the team approached this case, considering such questions as: How do we as clinical ethicists advocate for patients with PIMD at EOL? How much should QOL assessments influence decisions for these patients? and When and where might an ethics of care approach enhance our advocacy capabilities in these cases?

1057

Incidental findings of misattributed paternity discovered through whole exome sequencing: An old ethical problem with a new twist

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The ethical question of how best to deal with findings of misattributed paternity discovered through an unrelated test or treatment is not new. In particular, debate surrounding the appropriate response to incidental findings of nonpaternity revealed during genetic counseling has existed for decades, with the general trend—albeit a not uncontroversial one—being either not to disclose the findings at all, or to disclose to the mother only, leaving her to decide whether and how to relay the information to others. As we enter into a new genomic era, however, in which there is increased use of multi-gene/whole-genome sequencing, a greater push for genetics-based personalized medicine, and direct-to-consumer genetic tests more readily available, one might ask whether extant trends can (or should) be maintained. In the case of clinical exome/genome sequencing especially, where decreased cost and improved bioinformatics have led to increased medical utility, but where there is as yet no professional standard, the old ethical problem of misattributed paternity returns to the fore, bringing with it new concerns advanced by the new technology, as well as prompting a re-visitation of earlier assumptions about what clinicians ought to do when faced with these incidental findings. Focusing on the case of a pediatric patient whose clinical situation led the team to pursue whole-exome sequencing for diagnostic and therapeutic purposes, which led to an incidental (nontherapeutic) discovery that the patient's presumptive father was not biologically related and prompted the team to request an ethics consultation, our presentation looks at this

problem and reflects on our role as ethicists therein, considering such questions as: Whose information is at stake here? Who, precisely, is the patient? Is there a right to know (or not to know) about the misattributed paternity? Is withholding the finding practically possible? and Would such withholding undermine patient care?

1058

The Trojan horse of patient choice in complementary medicine use: How autonomy and bioethical imperialism puts the public at risk in Australian pharmacy practice

Authors:

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Helen IRVING, Paediatric Oncologist, Lady Cilento Childrens Hospital
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In 2017, the Pharmaceutical Society of Australia (PSA) released a revised Code of Ethics which states, “a pharmacist will only purchase, supply or promote any medicine, complementary medicine, herbal remedy or other healthcare product where there is credible evidence of efficacy and the benefit of use outweighs the risk.” The Pharmacy Board of Australia’s Code of Conduct further defines good care as “providing treatment options based on the best available information and not influenced by financial gain or incentives” and “practising in accordance with the current and accepted evidence base of the health profession, including clinical outcomes.”

While it may seem self-evident that registered health professionals should only promote effective treatments, many pharmacists and pharmacies continue to supply products that do not meet this professional standard. Indeed a recent Australian consumer investigation found that between 30 percent and 50 percent of pharmacists’ surveyed recommended unproven complementary treatments, in direct contradiction of the professional obligations outlined above.

The discourse of respect for patients’ autonomy runs strongly through debates on the use of alternative, complementary, or unproven treatments. The justification that if consumers make an informed choice to buy products of unknown, or known-poor outcomes, their choice should not be impeded by health professionals. Perversely, the discourse of respect for patients’ autonomy aligns with the commercial imperatives to sell

products regardless of their efficacy, and in direct contravention to the professional obligations outlined above. This creates significant conflicts of interest that are detrimental to patient care.

In the complex environment that shapes modern pharmacy practice, this presentation will explore the ethical tensions between patients’ choice, professional self-interest, trustworthiness, the commercial drivers of practice, and the profession’s need to maintain public trust. It will also unpack how paying deference to autonomy has become a strategy to justify lowering professional standards of practice, while claiming patient-centered care.

1059

Protecting CECs’ autonomy: Institutional virtue as the courage to sacrifice institutional autonomy: One way forwards?

Author:

Raj MOHINDRA, Consultant and Chair ethics committee, Freeman/RVI, Newcastle upon Tyne

The Newcastle upon Tyne—U.K. Clinical Ethics Committee (CEC) began in 2000. It is integrated into the organizational structure of the Trust. It has high-level institutional support and an active work stream. However, its success raises a question:

How can such integrated committees protect their most valuable asset, autonomy, from organizational group think?

Solutions may lie:

1. In the selection of the committee. However, guidance about committee structure is relatively unclear.
2. In qualities possessed by the members. A statement of required core competencies does exist. These competencies are divided into skills, knowledge, and personal competence. However, the ability to remain objective about organizational norms is a distinct additional competence.
3. Members embracing the virtue of courage. But vision must come first, followed by the courage to challenge those institutional norms.

One alternative option is reported here: the appointment of a CEC chair that works at an entirely different NHS (National Health Service) organization. External members often sit on clinical ethics committees. However, it is extremely rare in the U.K. to find such an established CEC with a chair from another organization.

This move has been approved by the clinical director and the board of the Trust. The courage is institutional. The win for the organization is that it will get the ugly truth, like it or not.

The separation thesis asserts that business ethics possesses a separate morality. Is the move here a rejection of the separation thesis or an alignment of medical and business ethics?

If this is a possible solution, can and should it be the basis for systematic development at a national level? In the context of the U.K. NHS, that would seem entirely possible. However, that would require both vision and courage from NHS England.

1060

Decolonizing medical ethics education in South Africa: Reflecting on the past 15 years

Author:

Keymanthri MOODLEY, Head and Director, Centre for Medical Ethics and Law, Stellenbosch University, South Africa

Globally, most curricula in bioethics are based on Greek philosophy. Consequently, many teachers in bioethics adopt this approach in different regions of the world. While the origins of Western philosophy are attributed to ancient Greece, some argue that Western philosophy may actually have its origins in the Kemetite civilizations of ancient Egypt, North Africa. Various literary sources indicate that philosophy thrived in Egypt from around 3,400 B.C. to 343 B.C. From 500 to 300 B.C. a period of intense intellectual activity was occurring in various parts of the world. Consequently, the history of Western philosophy is contested in the literature. African philosophy, Confucian ethics, Buddhist and Hindu philosophy, and Middle Eastern philosophies have all posed fundamental questions about the meaning of life.

Medical ethics education on the African continent is in need of curricular reform. The Centre for Medical Ethics and Law, Stellenbosch University, has embarked on a process of such reform in response to calls from student activist groups to “decolonize” medical education. This paper will describe ways in which African philosophical thought impacts decision making in healthcare, especially since notions of personhood in traditional African settings are relational, communitarian, and extended. This has important implications for consent processes and end-of-life dilemmas. Diversity is the hallmark of communities in South Africa. Pedagogics in medical ethics must

therefore embrace diverse philosophical systems in teaching and learning to empower young clinicians to function in multicultural contexts.

1061

Ethically permissible inequity in access to experimental therapies

Author:

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Clinical ethics services are increasingly receiving case referrals regarding access to experimental therapies. Sometimes, patients or their families seek access to an experimental therapy that has not been subsidized by any government scheme, and for which no local clinical trial is underway. If the patient or family can cover the cost of the therapy, should a public hospital administer that therapy to that patient, when other patients with the same condition at the same hospital will not receive the therapy because they cannot privately fund it? All else being equal, that patient may benefit from receiving the therapy without making the position of any other patient worse. In economics, this is what is referred to as a Pareto-improvement. However, in the context of public healthcare systems, treating only one patient with an experimental therapy, when others might also benefit from it, evokes a troubling sense of inequity.

In this presentation, I will examine the relevance of Pareto principles and the “levelling down” objection to ethical deliberation about patient or family-initiated requests for experimental therapies. While facilitating access to an experimental therapy may benefit a patient without making any other patients worse-off, this does not dispel ethically relevant considerations concerning equity. When deliberating about cases involving inequity, clinical ethics services and committees must balance directly improving the position of individual patients with avoiding contributing to inequities more broadly. In this presentation I will argue that inequity can be ethically permissible, but only if satisfies two conditions: firstly, the decision to provide this special treatment for one patient must have a strong likelihood of contributing to future equity; and secondly, this must be done in a way that shows respect for the patients who do not receive the experimental therapy. I will illustrate my argument with a case study.

1062

Did improving procedural fairness in the allocation of dialysis access by application of the “accountability for reasonableness” in South Africa have the desired outcome?

Author:

Mohammed Rafique MOOSA, Executive Head, Stellenbosch University

South Africa is a middle-income country facing immense sociocultural challenges. Both communicable and noncommunicable diseases take a heavy toll on human lives. Chronic kidney disease is increasing, and the demand for dialysis and kidney transplantation has reached unprecedented levels. The public-sector health system cannot meet the growing need, and rationing has been implemented since the initiation of dialysis in the country. Initial informal allocation strategies resulted in unfair selection favoring whites, males, the employed, and married. We then implemented a priority-setting protocol developed using the “accountability for reasonableness” framework, applying the basic premise that patients accepted for dialysis had to be transplantable. Kidney transplantation is cheaper, offers better survival and quality of life, and frees up dialysis spaces for new patients. Patients who need but do not receive dialysis die. The priority-setting process involved stakeholders including staff, lawyers, patients, and ethicists in an iterative process. The process resulted in a formal policy promulgation. We analyzed outcomes of its application at two teaching hospitals in Cape Town. Over seven years, 25 percent of the 1,101 patients assessed were accepted for dialysis at Tygerberg Hospital. Patients accepted were younger, employed, married, and not diabetic. At Groote Schuur Hospital, over five years, 48 percent of 564 patients were accepted with similar predictors of acceptance. Availability of resources impacted differences in acceptance rates between the two hospitals. Psychosocial factors (for example, poverty, substance abuse) continued to play key roles in the selection of patients. While every effort was made to minimize the impact of factors that patients had little or no control over in development of the prioritizing policy, the reality was that these factors ultimately did determine the fate of patients needing dialysis. To solve social issues and achieve equitable access to the limited dialysis facilities in South Africa, physicians need to advocate beyond health.

1063

The mechanics of the “accountability for reasonableness” (A4R) framework: An experience of its use in establishing fairness in accessing renal replacement treatment in South Africa

Author:

Mohammed Rafique MOOSA, Executive Head, Stellenbosch University, South Africa

South Africa is one of the most unequal societies in the world, evidenced by its consistently high Gini index. Approximately 15 percent of the population access good medical treatment through private health insurance. The remaining 85 percent must compete for public health services that are struggling to cope in a society grappling with a quadruple burden of disease, including a rising tide of chronic kidney disease. South Africa has been offering dialysis and kidney transplantation since the 1960s, but has always limited access to treatment by rationing. Initial selection for the treatment was never formalized, resulting in biased allocation favoring patients who were white, younger, employed, and married. Appreciating the unfairness of the process, nephrologists agreed to work on a priority-setting policy that was fair, and defensible morally, ethically, and legally. With approval of the Health Department, a priority-setting process was launched employing “A4R” principles. The team decided on the basic premise that all patients selected should be suitable candidates for kidney transplantation, as the superior form of treatment in terms of cost effectiveness and outcome. The team then developed eligibility criteria using published and local data known to correlate with success of kidney transplantation, to select patients. The criteria were ordered in a hierarchical fashion. Where data was lacking, the experience of the team with the local environment proved useful. The set of criteria was then shared with all relevant stakeholders, including public representatives, and amended iteratively over several months. The guidelines were formally adopted as government policy in February 2010. A4R stresses transparency, review, and appeal. The process has withstood the scrutiny of the South African Human Rights Commission following a patient appeal. Ongoing review has resulted in a revised policy in 2016, which will continue to be monitored to improve equitable access to dialysis in South Africa.

1064

Clinical ethics committees and consultation services as moral spaces to reduce moral distress

Author:

Georgina MORLEY, Doctoral Student, University of Bristol

Moral distress (MD) has become an increasing focus of research. However, most of this research has been conducted in North America, whilst research in the United Kingdom (U.K.) remains extremely limited. This presentation reports on an empirical ethics study from the U.K., which aims to develop a coherent account of MD amongst U.K. nurses, to understand more about the concept itself and to provide recommendations about how we ought to respond to it. I will provide empirical findings from interviews with critical care nurses ($n = 19$), analyzed using Van Manen's six activities for interpretive phenomenology. I will present a Moral Distress Model developed from these empirical findings, and highlight how narratives of moral uncertainty, constraint, and conflict suggest that current understandings of MD are too limited. Jameton's original and subsequent definitions must be broadened in order to meaningfully capture U.K. nurses' experiences of MD. Given this broader understanding of moral distress, I will suggest three ways in which we could use clinical ethics committees and consultation services as moral spaces to alleviate moral distress amongst nurses and potentially all healthcare professionals. Firstly, because of the prevalence of ethical uncertainty, I will suggest that nurses need more comprehensive ethics education and support to teach them skills in moral deliberation to formulate moral judgements. Secondly, and concurrently, I will suggest that we need to prepare nurses for moral failure, so that when they inevitably face moral dilemmas they will recognize that it is not always possible to get moral decisions "right." Finally, I will suggest that we need more ethics resources that can provide moral spaces in the U.K. to facilitate interdisciplinary ethical communication and mitigate the effects of moral distress.

1065

The burdens in the interpretation of the ethical criterion of the proportionality

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The burdens related to a specific treatment play an important role in defining the criterion of proportionality in patient care.

The term "burdens" refers to those aspects with a psychosocial and physical nature, since, in certain contexts, the economic aspect is not the main one. The fundamental issue concerns the subjects on whom these burdens fall (that is patients, family members, and community).

The aim of this work is to analyze, through the presentation of two clinical cases, two different perspectives in which the issues of burdens become decisive in determining whether to withdraw a medical treatment. The first case focuses on the patient's point of view while the second considers that of the relatives.

Is it justifiable that patients decide for themselves—the degree of resistance varies from person to person—if a treatment is no longer physically bearable due to its side-effects (neoplastic therapies should come to mind)? Is it equally acceptable when one's refusal is due to the existential burdens that fall on family members? Moreover, if the patient is incompetent, what weight should be given to the caregivers' wish to withdraw a treatment? It is important to remember, that in the care of a person, even if that person cannot recognize anyone, all of the stakeholders still share a responsibility.

It is necessary to verify whether, and to what extent, it is possible to cope with these situations in order to overcome them: the underlying risk is endorsing a culture that rejects and excludes vulnerability as a fundamental human condition, considering it an obstacle to a life that is worth living,

that cannot include the fatigue and the burden of being taken care of by others.

1066

A different kind of care: Ethical and practical issues when doctors practice complementary and alternative medicine (CAM) or have patients who use CAM

Author:

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Complementary therapies are used alongside conventional medical treatments but are not an integral part of it, while alternative therapies are used instead of standard medical treatments. Jointly referred to as complementary and alternative medicine, patients use CAM for different reasons. For example, CAM is often more compatible with a patient's values and beliefs because it seemingly offers a holistic way of treating illnesses and managing symptoms. Further, some patients turn to CAM for greater control over their treatment, and because of a perceived power disparity in the doctor-patient relationship.

Despite a growing use of CAM, its risks and benefits are not always understood, and there is often little scientific research to support the efficacy and safety of many CAM therapies. In addition, there is widespread misconception that CAM is safe because it is "natural." However, some CAM therapies can cause adverse reactions and delay a patient's decision to seek medical treatment. CAM can also be harmful psychologically and financially, when money is spent on treatments with extravagant claims.

This paper explores the tension between conventional medicine and CAM, when doctors practise CAM and/or have patients who use CAM. It argues that such practitioners are first and foremost doctors, so they should be held to the same professional, legal, and ethical obligations as any other doctor. This includes proper record keeping, prescribing treatments that are clinically warranted, and being respectful of other health practitioners who are involved in the patient's care. Several cases when there have been concerns about a doctor's CAM practice will be discussed. The paper also highlights key areas in the Medical Council of New Zealand's revised statement on CAM, which is intended to help patients make informed choices about their mode of treatment, and which doctors practising CAM must adhere to in order to safeguard themselves and those they treat.

1067

What does dying with dignity mean when euthanasia is requested by a life-sentenced prisoner? Ethical issues

Authors:

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Background: In Canada, euthanasia is referred to as medical aid in dying (MAID). Canada has a short history of practicing MAID; it was first legalized in the Province of Quebec in December 2015, and subsequently in the rest of Canada in June 2016. As a result, clinicians have not yet experienced the range of complex ethical issues that have been described by countries with decades of practice such as the Netherlands and Belgium.

In Canada, Correctional Services provide some healthcare, including a comprehensive palliative care program. However, for certain medical conditions such as surgery or intensive care, this is available to prisoners only in a hospital setting. Certain prisoners express the preference to receive palliative care in the community. The requests for palliative care outside prison walls are evaluated by the Liberation Commission (LC), which evaluates the risk of the prisoner to society perspective and decides accordingly.

Theoretically, prisoners have also the right to ask for MAID, but it has been decided after reflection by the Correctional Services that this would not occur inside the prison, for various reasons.

Objectives: To discuss the first case of MAID requested by a life-sentenced prisoner in Canada. This prisoner requested, and was denied by the LC, the right to receive palliative care in the community due to being considered an active threat to public security, even at the last stage of his life. Facing the refusal of the community palliative care, the prisoner asked his physician to receive MAID, which would be given outside the prison.

Discussion: This case raises complex ethical issues that will be identified and discussed through the history of P, a 45-year-old life-sentenced prisoner who suffers from a treatable lymphoma.

1068

Field notes from the front line: Postgraduate medical ethics education in the U.K.

Authors:

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We present postgraduate medical ethics education (PGMEE) for doctors as a key but neglected form of clinical ethics support in the U.K., only some of which is provided by clinical ethics committees (CECs). This symposium presents three elements of PGMEE: ethics education for newly-qualified doctors, ethics education in specialist training programs, and ethics education as an element of medical continuing professional development (CPD).

Each presenter will reflect on firsthand experiences of ethics education in these settings in the U.K.

Presenter 1 will outline current provision of ethics education for Foundation Year doctors. These are the first two years of practice, when doctors are pluripotential in terms of career. These doctors are simultaneously accountable for their decisions and at the lowest level of the medical hierarchy. The formal provision for ethics and law has, over the two years, been described as “an hour for ethics” and is dependent on the availability of local enthusiasts. Presenter 1 is currently leading a national survey of British Foundation Year doctors’ ethical learning needs.

Presenters 2 and 3 will outline the current provision of ethics education for speciality training, offering general practice as a case study. Whilst ethics is explicitly threaded into the British Royal College of General Practitioners’ (RCGP) curriculum, provision of education linked to this is variable, occasionally formally taught, but mainly covered in course work (overseen by general practice trainers with no guaranteed special training for this). Presenter 2 is an experienced RCGP examiner, and Presenter 4 is an academic GP trainee.

Presenter 4 will discuss ethics education as CPD. This has two broad aims amid a plethora of modalities: (1) Ethics education for specific roles such as teaching ethics to students, ethics committee work, commissioning, and leadership roles.

(2) Ethics education to support daily practice as a doctor. Presenter 4, who will also chair the symposium, has direct involvement in multiple forms of postgraduate ethics education including from CEC work, online education, and a postgraduate diploma.

We will collectively offer a rationale for the translational (explicitly linking academia, education, and practice) development of PGMEE with reference to existing research. This highlights a mismatch between a good theoretical grasp of medical ethics and doing the right thing in practice, variation of ethics’ inclusion in medical school curricula, variation of doctors’ experiences of ethics education as undergraduates and postgraduates, and a pervasive hidden curriculum. We note with concern the ramifications of this for healthcare quality and patients’ safety. We also note international research findings that previous ethics education is associated (in qualitative studies of ethics support) with better ability to access clinical ethics support. Yet, in postgraduate settings, the time allocated to ethics in postgraduate curricula is more pressured and haphazard, but this is set against increasing ethical responsibilities of doctors. In this symposium we showcase the U.K. experience of PGMEE and invite international colleagues to share knowledge and good practice, and aim to stimulate future research questions and potential collaboration.

1069

Exploration of an important counterclaim in the conscience-based refusal debate

Author:

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In some countries, physicians can refuse to provide a legally permissible medical service within their scope of training because they believe it would be morally wrong to do so. These types of refusals can be met with the following counterclaim: Regardless of their personal moral beliefs, physicians ought to provide the requested medical service. One might ask, however, What does it mean when we say that physicians ought to do something that they believe is morally wrong? In this presentation, I will explore three ways of explicating this counterclaim. First, the counterclaim can be understood as an expression of the subjective desires of the counter claimant, or as an expression of the negative emotions the counter

claimant would experience if these desires were unfulfilled. (“I desire that the physician provide the service,” or “If the physician doesn’t provide the service, I will feel frustrated, angry, et cetera). Second, the counter claim can be understood as a straightforward objective claim about the physician’s moral obligations. On this explication, the counter claimant is simply disputing the physician’s original claim: “Providing this service is not morally wrong; it is, in fact, morally required.” Third, the counter claim can be understood as an objective claim about the physician’s professional obligations and the relative status of these obligations, compared to the physician’s moral obligations. On this explication, the counter claimant asserts that even if the physician has a moral obligation to not provide the service, he or she has a professional obligation to provide it, and that professional obligation should trump. Each of these ways of explicating the counter claim carries with it implications that will also briefly be explored in the presentation.

1070

Implementation and evaluation of ethics in multidisciplinary ICU rounds

Authors:

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The value of integrating ethicists into intensive care unit (ICU) culture is understudied. To correct this omission, we systematically studied the impact of incorporating an ethicist and an ethics rounding tool in new, weekly multidisciplinary rounds in several ICUs. The goal of rounds was to enhance ethical culture by promoting education about ethical issues and encouraging providers to pro-actively avoid ethical dilemmas. To study the impact of the intervention, we measured providers’ baseline understanding of ethical issues, comfort with the Ethics Consultation Service (ECS), and frequency of communication with families.

Baseline data reveal gaps in knowledge and practice that could be improved if ethics integration is successful. For example, only 50 percent of the respondents reported that they always identify a surrogate decision maker on the day of admission when the patient lacks decision-making

capacity, and 14 percent of providers reported that they are not familiar with the process of requesting an ethics consult. We will follow up with a six-month post-intervention survey to assess whether integrating an ethicist and an ethics rounding tool influenced culture change.

In this presentation we will provide conference attendees with research results, an ethics rounding tool, and an evaluative method to assess the efficacy of this tool for quality assurance. The knowledge gained from this presentation promotes a fundamental goal of clinical ethics: educate and empower providers to resolve particular ethical issues independently, reserving the ECS for more complex ethical dilemmas. The knowledge gained also aligns with emerging institutional goals toward evaluation for quality assurance in clinical ethics.

1071

Navigating uncharted territories: Interdisciplinary ethics collaboration in innovative clinical practice

Authors:

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Margot EVES, Clinical Ethicist, JD, MA, Cleveland Clinic

First used in neonates in the 1970s, extracorporeal membrane oxygenation (ECMO) is now utilized as a salvage or bridge to therapy for adult patients with cardiac failure. More recently, with the development of specialized ECMO referral centers and advancements in technology, the use of veno-venous ECMO for refractory hypoxemic respiratory failure has steadily gained acceptance. However, for its use in such clinical scenarios, there is limited data on efficacy and appropriate criteria for patient selection. When combined with a high degree of ambiguity regarding prognosis and treatment, the expansion of indications and the use of ECMO places the patient in a particularly vulnerable situation. This creates unique ethical challenges for the medical team.

In recognition of the ethical complexities associated with the use of ECMO in this susceptible patient population, a working committee was formed to establish an ECMO care pathway. The committee included a subgroup comprised of an ethicist, a cardiothoracic anesthesiologist and critical care physician, and a medical critical care phy-

sician, who were tasked with delineating the ethical quandaries present in ECMO. This presentation reflects the work of this interdisciplinary ethics subgroup. It identifies the ethical challenges created by the innovative use of ECMO in the clinical setting, and describes a practice model of preventative ethics for pro-actively addressing these challenges. The model also emphasizes the need to engage the patient and/or surrogates throughout the trajectory of ECMO, including the three phases of treatment: initiation, continuation, and discontinuation. This model of preventative ethics not only blends expertise from different subspecialties, but also serves as a guide to clinical practice for ground-breaking therapies such as ECMO in settings with limited resources.

1072

Pediatric case examination: Undocumented parents in rural America

Author:

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This case study explores the complexities involving immigration status and the complications surrounding pediatric intensive care patients. Rural populations typically encounter many healthcare challenges insofar as they lack healthcare coverage, have a higher incidence of poor health, and experience exclusions from healthcare services. Couple these challenges with providing adequate care to a pediatric patient whose parents are fearful and hesitant to seek healthcare, leaving the medical team facing a moral dilemma of how to treat a child with the looming contextual presence of mistrust and deportation.

HT was a two-month-old male who presented to the pediatric intensive care unit (PICU) after he experienced two cardiopulmonary arrests and seizure-like activity. Upon presentation, the healthcare team placed HT on a ventilator; due to significant respiratory compromise, he had poor muscle tone and was flaccid. HT's father was employed on a tobacco farm, but insisted that he washed his hands frequently and removed his clothing and bathed after work before touching the children. When the team asked HT's father to talk to his boss to find out what chemicals HT could have been exposed to, he eluded this topic and made several excuses, which was thought to be due to fear of losing his job. Multiple unsuccessful attempts were made to obtain a list of working environmental exposures.

HT's case is wrought with complications, the primary one being how to provide care to an infant whose parents are afraid to provide personal information because they are anxious that this information might be used against them. There are many challenges that will have to be addressed. The first to be examined are the controversies surrounding purposefully excluding certain populations from healthcare access and the establishment of fair healthcare resolutions.

1073

When ethics and the law conflict in clinical ethics support services

Authors:

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From time to time the right thing to do may also be illegal. Or at least, it may be unclear whether an illegal option is the most ethically justifiable action. For example, a jurisdiction may prevent publicly funded hospitals from performing a termination of pregnancy, but a practitioner wishes to offer such a procedure in the best interests of a particular patient. Or a jurisdiction may outlaw homosexual relations, and require reporting of any such instances, but this would substantially undermine the doctor-patient relationship.

This paper addresses the question, What should ethics support personnel do when reviewing a case when one option is potentially illegal?

To be sure, ethics support services cannot justifiably recommend an illegal course of action. Such would compromise their institutional standing, as well as unfairly pressure practitioners to risk legal sanction.

But nor should ethics committees see legal limitations as a "conversation stopper." While it is important for the potentially illegal nature of a particular option to be discussed, it should be left open whether this means it should not be pursued. To recommend legal deferral would be to impose a particular view of the moral authority of the law, one that practitioners in certain contexts may reasonably reject. Instead, the ethical considerations of a potentially illegal option should be thoroughly explored. It is for the requester of ethics support services to determine for themselves whether, in a given case, violation of the law is ethically justified.

1074

Where clinical ethics meets human rights: An observation study in adolescent forensic psychiatry

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Stella REITER-THEIL, Head, Department Clinical Ethics, Psychiatric University Hospitals Basel, University Basel, Switzerland

Background: In 2011 the first department of adolescent forensic psychiatry (AFP) in Switzerland was established. Its goal is to treat juvenile offenders with mental illness to enable social integration with minimal delinquency and maximal autonomy. In this setting, caregivers face ethical issues on different levels: contextual issues known from forensic ethics, issues of clinical ethics, and general issues of civil or even human rights. This study aims at filling the gap of empirical studies exploring ethical aspects in AFP, highlighting their structure of normative specificity.

Methods: The study includes a systematic literature research on ethical aspects in AFP, a qualitative content analysis of observations of 39 AFP team meetings, and an ethical analysis.

Results: Our study confirmed several ethical issues found in the literature. The spectrum of ethical issues as addressed within the AFP meetings can be categorized in six main types: (1) self-determination, (2) well-being, (3) professional duties, (4) moral competencies, (5) diagnostics/assessment, and (6) justice. Regarding these issues, different levels of normative specificity can be distinguished: individual values, contextual norms, bioethical principles, social norms, civil rights, and human rights. Five ways of team communication were identified: report, evaluation, discussion, follow-up, and task concerning five types of involved stakeholders (individual, patient-other, social environment, institution, society).

Discussion and conclusions: Ethical aspects are pervasive in the practice of AFP. It is important to enable caregivers to identify and address ethical issues relating to different levels of generality, to communicate them properly, and work on them with appropriate methods. AFP may benefit from a categorical system of ethical issues to structure, train, and complete the ethical awareness of caregivers in clinical practice. As challenges such as human rights issues can hardly be covered in clinical routine, regular team opportunities for addressing such issues are put to discussion.

1075

The color of medicine: Confronting the problem of racism in clinical settings

Authors:

Nneka SEDERSTROM (presenting author), Director of Clinical Ethics, Children's Minnesota
Rachel HARDEMAN, Assistant Professor, University of Minnesota

Shelly NAUERTZ, Senior Diversity and Inclusion Consultant, Children's Minnesota

Maurice SHOLAS, Senior Medical Director, Rehab Services, Children's Minnesota

Joel Wu, FELLOW, Clinical Ethics, Children's Minnesota

In an increasingly connected global community, the problem of racist behavior by patients towards medical professionals appears to be an increasingly common phenomenon. Recent publications have identified this issue, and examples of this behavior are appearing with growing frequency.

The problem of racist patients is an issue situated at the intersection of clinical practice and institutional policy. It's also a problem that can occur in any part of the world. Specifically, the issue concerns how healthcare professionals and institutions should act to promote and affirm the dignity and interests of healthcare workers and patients in a situation where a patient or a patient's parents express preferences, or makes choices, on the basis of explicit racial prejudice.

There are two aspects of the problem that remain underdeveloped: (1) The prevalence and effects of racist patient behavior are not well characterized; and (2) Institutions lack policies to effectively address the problem of racist patient behavior.

This panel will address both issues from four different perspectives:

First, Dr. Rachel Hardeman will characterize the experiences of physicians who have experienced racist patient behaviors, based on initial findings from “The Color of Medicine” study. She will aim to situate our understanding of these interactions within the context of the current socio-political climate, and the observation that the healthcare enterprise is not immune to the effects of the racist rhetoric that has been increasingly common since the 2016 American presidential election.

Second, Joel Wu will present recommendations for institutional practices that address the problem of patient racism. The patient/provider relationship is not merely a transactional engagement; rather, the dignity of both parties engaged in the healthcare context implicates mutual rights and duties. Patients’ “rights and duties” documents may provide a useful instrument to simultaneously notify patients of their rights while informing them of their duties to healthcare providers as persons.

Third, Shelly Nauertz will discuss the development and implementation of diversity and inclusion strategies in a healthcare organization. In addition, she will identify institutional barriers to racial equity and inclusion, and opportunities to overcome those barriers.

Fourth, Dr. Maurice Sholas will discuss the conflict between a medical professional’s duty to serve all patients and the psychosocial harms and offenses to dignity that follow from racist patient behavior. As professionals, physicians enter into a special obligation to provide care to all members of the community. That commitment to unbiased care for all is at the heart of medicine and an integral component of professionalism. However, when a provider’s care is rejected by a patient on the basis of race, that rejection implies that regardless of education or competence, that provider is unworthy to provide care. Thus, the provider is demeaned both as a professional and as a person, while holding a professional obligation to help those who would refuse their help.

The panel will be moderated by Dr. Nneka Sederstrom, who will bring together the impact this topic has on the organizational ethics of an institution.

1076

Translating clinical ethics in trenches: Experiences from a developing country

Authors:

Nida SHAMSI (presenting author), Assistant Professor, Family Medicine, Indus Health Network, Pakistan

Sarosh SALEEM, Assistant Professor, Head of Bioethics Department, Shalamar Medical College, Lahore

Healthcare providers have to follow a certain ethical code to help them in making correct decisions. This requires a vital background knowledge and understanding of ethical challenges in healthcare provision. Over the past years, healthcare ethics has become a growing area of focus, as it benefits the healthcare community in its decision-making processes. Hence, the pressing need for familiarity with the ethical dimensions of healthcare is accepted worldwide. The United Nations Educational, Scientific, and Cultural Organization (UNESCO) made the ethics of science and technology one of its five priority areas. Pakistan is a country of huge cultural diversity, with many ethnic groups and socioeconomic strata. The Pakistan Medical and Dental Council (PMDC) has proposed having bioethics as a mandatory part of the medical curriculum. However, it does not provide a much-needed framework for answering moral questions and fulfilling healthcare responsibilities with confidence for the future. There also remains an enormous gap in this area, owing to a lack of trained professionals and formal training in Pakistan. In this setting, even limited resources and a skeptical attitude towards clinical ethics could not stop a group of healthcare professionals who were bent on creating an ethical environment in a free of cost, tertiary care hospital of Karachi, Pakistan. The authors share their experience of self-education, capacity building, and promoting ethical behaviors in healthcare providers while reflecting on strategies used to achieve this purpose. Beginning with small, informal, interactive, case-based discussions and growing to well-organized workshops on clinical ethics, and independent ethical practices, to ultimately developing a hospital ethics committee (HEC), all efforts were directed towards introducing an ethical climate in the organization and beyond. Currently, the initiative is getting more technical and complex, with care being provided by multidisciplinary teams. The paper presents a narrative of authors’ experience

of challenges faced, goals achieved, and plans for the future.

1077

Shared decision making with people with intellectual disabilities (ID): A solution for impasses in clinical ethics?

Author:

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People with intellectual disabilities are inadequately involved in the decisions made regarding many aspects of their lives, including healthcare decisions. Little research has been done to improve this situation. Findings from an empirical study that explored healthcare professionals' views on how shared decision making can be applied with people with ID might contribute to closing this gap.

Five main themes were identified in the data:

1. Different understandings of what it means to share decisions with people with ID.
2. Differences in what kind of decisions can be shared with people with ID.
3. Uncertainties about and different approaches to capacity.
4. Provision of information and presentation of choices and options.
5. The patient-healthcare professional relationship: identifying and addressing challenges.

The appropriate model of making healthcare decisions with people with ID needs to provide a balance between overprotection and over-empowerment, adequately involve family members and carers, and leave enough space for informal capacity assessment.

While it is not possible for people with ID to participate in all healthcare decisions, the process of identifying the limits of which decisions people with ID should be enabled to participate in should include additional factors beyond mere capacity assessment. This paper presents the complexity of healthcare decision making for people with ID and argues that in order for shared decision making to happen with this group, the existing models of shared decision making need to be appropriately adapted.

Healthcare decision making with people with ID *per se* is ethically problematic, and many clinical ethical cases refer to this issue. More research

is needed to establish whether sharing healthcare decisions with people with ID, actively involving them in the decision making process, might contribute to lesser emergence of those cases.

1078

How to assess the quality of a facilitator of moral case deliberation? Concepts and didactical methods

Authors:

Margreet STOLPER, PhD, Senior Researcher, VU University Medical Center

Background: Moral case deliberation (MCD) is a form of clinical ethics support (CES) that offers a methodical structured conversation among participants about a moral issue from one of the participants. MCD is facilitated by an ethicist or someone that has followed a solid training program. But a training program does not guarantee a qualitatively good MCD or facilitator of MCD. Despite increasing attention on the conceptual clarification of what it means to be “a good facilitator of MCD,” tools and methods for practical examination to assess the quality of a facilitator of MCD are hardly available.

Aim: To clarify the theoretical viewpoints of “a good facilitator of MCD” and describe didactic methods to assess the quality of a facilitator of MCD.

Results: Based on literature on theoretical viewpoints on MCD and years of experiences in training facilitators of MCD, we developed, during the past decade, an assessment procedure in which we make use of different ways to assess and qualify facilitators of MCD. In this presentation we will present four methods: (1) A questionnaire in which the concept of a good facilitator of MCD is operationalized into concrete and feasible behavioral terms and can be used for reflection, (2) the use of mentorship and (3) a portfolio, and (4) a formal assessment at the end of the training program.

Discussion: We conceived the development of an assessment process not as a simple deductive translation of existing theories. We experienced that using some instruments that contain a normative view on the concept of a “good facilitator” were not sufficient to determine a good facilitator of MCD. Moreover, there was a risk of ignoring contextual factors and using it as a golden standard. To assess the quality of MCD facilitators requires a dialogical process and demands a combination of several methods.

1079

Culture, context, and communication in gynecological cancers in India

Authors:

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Background: The burden of noncommunicable diseases on low- and middle-income countries is an openly acknowledged concern today across the world. Practice and research are invested in finding more integrated solutions to this global challenge. However, the myriad grey areas surrounding the efficacy of health interventions continue to daunt both practitioners and practice. In an era of evidence-based medicine, the challenge to build context-specific, long-term, self-sustaining programs and interventions that enhance health choices and decisions and promote health and well-being remains.

Aims: Existing gaps in the literature need to be understood better when designing health interventions and promotional campaigns. In India, women's cancers, especially gynecological cancers, have several deep silences surrounding them. The danger of looking at women's cancers as merely diseases with clinical prognoses, trajectories, and goals results in ethical ramifications in contexts when health is intrinsically tied to familial, cultural, and social well-being. Norms place heavy, though often unspoken, expectations on women in their roles as sexual partners in marriage and primary responsibility for the continuance of family lineage through reproduction. Gynecological cancers can impact the reproductive and sexual health and choices of a woman. Consequently, the additional fear and stigma they elicit can directly mitigate efforts to manage them clinically. Information seeking and information providing become more complex in such a scenario for patients and healthcare providers.

Implications: The inter-linkages between the social reality and the clinical reality in women's cancers has to be fully understood before healthcare providers and women can openly address related challenges in the spectrum of cancer care. This paper is reporting on a current research project on the subject, and will attempt to trace how a particular cultural context, India, can work more harmoniously with its clinical context with

the support of vigilant and well-informed health communication.

1080

Muslim perspectives on palliative and end-of-life care: Empirical ethics research analyzing perspectives of service users and providers

Author:

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Every community has its own religio-cultural understanding of death, its rites, rituals, and beliefs. Although there is a growing Muslim population in the U.K., many of whom either access or provide healthcare services within the NHS, very little is known about the beliefs, processes, and practices they use in relation to death, dying, and remembrance. In this presentation, I will share findings from an empirical study that offers a thematic analysis of 50+ interviews with Muslim patients and families, as well as doctors, nurses, allied health professionals, chaplains, and community faith leaders across the U.K. The themes include ethical challenges raised by the reconciliation of beliefs and practices in Muslim communities when they encounter the health service, the role of faith leaders and religio-cultural commitments in the understanding and articulation of values around death and dying, such as acceptance and hope. The presentation will also explore how attitudes and practices amongst Muslim communities in the U.K. is changing, and how such inter-generational transitions in the beliefs, processes, and practices in relation to death, dying, and remembrance may impact access to health services and the practice of professionals delivering care.

The study reports that Islam, its texts and lived practice, finds growing importance within the U.K. end-of-life care discourse, as there is an increasing Muslim population and burgeoning interest in the role of faith and spirituality in healthcare decision making. It also indicates that patients and practitioners alike rely on multiple moral sources to make decisions, and face moral anxiety and frustration when these different moral sources are in conflict. An ethical analysis of such tensions will be presented, with an evaluation of the normative implications for health systems, healthcare services, providers, and users.

1081

Exploring the standards of care and ethical duties for traditional and complementary medicine practitioners in Malaysia

Author:

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Traditional medicine and remedies still maintain a huge influence in Malaysia, especially among the less educated, the elder generation, and those living in more rural areas. Their widespread popularity prompted the Ministry of Health to assign a special division in 2004 to oversee the incorporation of traditional and complementary medicine (TCM) into the national healthcare system. In order to better regulate these TCM services, the Traditional and Complementary Medicine Act was introduced and gazetted for enforcement in 2016.

Problems arise when TCM practices that are meant to complement modern medicine become treated as alternatives instead. In addition, despite claiming to be a part of “medical practice,” TCM practitioners are generally not held with the same level of accountability and liability as healthcare professionals practicing modern medicine.

Even though the TCM Act aims to mirror the structure within the Medical Act 1971, some of its provisions appear to be problematic when they are compared to modern medical practice. The main problem pertains to the duties of TCM practitioners. According to the TCM Act, practitioners have a choice of disclosing information to either patients, their guardians, or a representative. Moreover, they are not obliged to refer their patients unless an acute medical emergency occurs. Subsequently, patients whose symptoms cannot be resolved will eventually present to hospitals at a later stage, albeit with more advanced diseases and more serious consequences. It is also unclear as to the amount of liability TCM practitioners will be held accountable for should complications arise.

Examining aspects of the doctor-patient relationship and their origins in both forms of medical practice, this presentation argues that patients should expect the same standards of care and ethical duties from both TCM and modern medicine practitioners if TCM claims to be actual medical practice.

1082

How should clinical ethicists respond to discordant moral points of view in an increasingly contentious time?

Authors:

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Historically, clinical ethics consultation grew out of a need to resolve questions and conflicts that arose as medical practice offered increasingly powerful interventions such as dialysis, intensive care, and organ transplantation. Ethics consultation satisfied the need to find approaches to guiding and sharing responsibility for tough decisions.

Clinical ethicists have come to rely on several approaches such as deliberation, negotiation, and mediation to resolve disagreements. However, there are an accumulating number of developments that seem to challenge the adequacy of the approaches we have taken to resolve moral disagreements. As Jonathan Haidt has suggested, people differ fundamentally in their moral values in a way that we have difficulty reconciling. Attitudes about what we owe each other in a humane society have been heatedly debated recently. Fundamental concepts such as death that, for a period of time, had a widely accepted definition based on neurologic criteria have been contested lately. While the prominent philosopher John Rawls argued disagreements should be resolved by bringing only widely shared reasons, such an approach may yield indeterminate and inconclusive answers. Added to these values conflicts is a growing tendency to boost claims through the use of fake information. Our ability to carefully validate information is limited by the extent to which we rely on shared knowledge that is difficult to verify.

Can these challenges be adequately addressed by the approaches we have come to rely on to resolve disagreements in clinical ethics consultation? There are many issues that clinical ethicists address, such as reproductive rights, rights of parents to make decisions for their children, access to health insurance, and healthcare for refugees, that the public disagrees about vehemently. The panelists will describe the challenge posed by the lack of common ground and consider how the field of clinical ethics might respond.

1083

The ethical challenges of providing innovative treatment to children

Authors:

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The use of innovative medical treatments poses many ethical considerations in a resource-limited environment. “Evidence” of benefit is often required before administration of a novel therapy is sanctioned. In the context of children with rare, life-limiting, or terminal diseases, it is highly unlikely that any high-quality “evidence” will ever be produced, yet how to proceed when no such evidence exists—and who should decide? To what extent can extrapolation of perceived benefit from trials of a therapy in a similar, but crucially, not identical clinical setting, or even results from laboratory-based experiments be transferred to an individual patient who may be in desperate need? Even if an innovative therapy is administered, how do we know when to continue and when to stop? How do we balance the potential benefit to future patients, in terms of a gain in scientific knowledge, against the rights of a patient to be protected from being used simply as a “means to an end”? How can we avoid “decision transference” in which—in the face of intense pressure to “try something/anything” from relatives, support groups, or social media campaigns—the challenging decision of whether to start a therapy is simply transferred to whether it should be continued or withdrawn?

In this presentation, we will describe our experience of dealing with requests for innovative treatments, illustrating it with the case of a terminally ill 11-month-old baby who was referred to our clinical ethics committee for consideration of whether it was ethically acceptable for the baby to receive an innovative therapy on a compassionate-use basis. We discuss the ethical issues that such cases raise, and describe how, by using a framework similar to that described by Brierley and Larcher, ethics committees are able to address the points listed above.

1084

The Patient Self-Determination Act and its challenges to ethics consultation in Taiwan

Author:

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In January 2016, the Patient Self-Determination Act (PSDA), which is the first of its kind in Asia, was announced and scheduled to be in effect in three years in Taiwan. This act allows a competent adult to appoint a surrogate or to set up an advanced directive (AD) that records the adult’s decisions regarding the refusal of life-sustaining treatment (LST) and artificial nutrition (AN) in five clinical conditions, including end-of-life status, permanent vegetative status, irreversible coma, severe dementia, and in unbearable unresolvable suffering. This presentation will introduce the process of legislation and its debates, the characteristics of the act, and the possible challenges when practiced in the future, especially from the perspective of ethics consultation. The author will point out that only the “negative right” of refusing life-sustaining treatment is protected in the PSDA, not the “positive right” to demand active euthanasia or assisted suicide. The actualization of this act can enhance the protection of patients’ autonomy and their medical welfare, especially in an East Asian culture in which the family’s decision is not uncommonly taken as superior to the patient’s, even overriding the patient’s decision. However, because the act requires that a competent adult make an AD before any of these five clinical conditions occur, those who are already in PVS or an irreversible coma, and severely demented patients who did not complete an AD or appoint a surrogate will not be able to refuse LST and AN. This population was estimated to be around 200,000 persons in Taiwan. This will be the next challenge, after the legislation of PSDA in Taiwan. A possible solution to this predicament will be proposed as well.

1085

The best interest of the child in the case of not complete acceptance by the mother

Authors:

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Anna Emanuela COSTANZO, PhD, Clinical
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Despite the flourishing literature discussing ethical issues related to neonatology, the literature is scarce in regard to the attitude of the medical team towards a mother who is not completely accepting of a premature or ill baby. The ethical issue is when a mother has legally recognized her baby, but does not fully accept his/her health condition, and insistently cares about or even hopes for the baby's death from complications.

Our work aims to present a possible ethics (and legal) consultation in Italy to protect the baby's best interest without forgetting the mother's needs and burdens. The ethics consultation could be useful during one of the following moments: pregnancy, if previous mental health disorders or risk of a premature birth are assessed; hospitalization, if the woman shows signs of rejection towards her baby; and at the baby's dismissal from the hospital.

During the pregnancy, the main question is if and when a gynecologist can warn the pediatrician/neonatology unit, the psychologist and/or the partner regarding a possible difficulty of the mother to accept her baby.

During the hospitalization, some questions are: Firstly, if and when pediatricians may talk with the partner or family about the mother's problem without obtaining her consent. Secondly, what should be the attitude of the physicians towards these women? Should the doctors try to encourage them to be involved in the care of their baby, even though they want their baby to die? A third aspect to consider is whether a medical team can keep the baby hospitalized longer than the necessary, to gain time to assist the bonding between the mother and the baby.

Finally, just before hospital dismissal, the question is whether the pediatrician can warn the general practitioner or social worker, knowing that the mother is not completely accepting her child.

1086

Clinical inertia in critical care: lessons from ethics consultations

Authors:

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The clinical inertia literature often focuses on its classic definition: the failure of clinicians to initiate and intensify therapies. Yet clinical inertia can also include clinicians' failure to stop or reduce therapies. Here, we examine how both types of inertia operate in critical care units (ICUs) in the context of ethics consultations. Our analysis relies on data from two sources. First, we use observations of ethics case discussions in medical and pediatric ICUs to determine how clinicians talk about inertia, such as feeling that their hands are tied—that interventions are “past futility,” or that there has been “a lack of progress” in decision making. These descriptions often revolve around feelings of powerlessness, poor communication, frustrations with surrogate decision makers, and questions about the appropriateness of interventions. Second, we utilize a retrospective chart review of ICU patients for whom ethics consultations have been requested. These data include demographic characteristics and characteristics of illness (mechanical ventilation, inotropic therapies, presence of delirium), as well as possible indicators of inertia such as code status, identification of a surrogate, and documentation of family meetings or advance planning. We examine whether and how these indicators of inertia have been altered (or not) post consultation. In doing so, our work informs the understudied phenomenon of inertia in critical care, and highlights how the ethics consultation may act as an intervention to help eliminate inertia and change the course of clinical care within this context.

1087

Moral expertise from international perspectives

Authors:

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Jennifer FLYNN, Assistant Professor of Bioethics, Memorial University

Salla SAXËN, Graduate Student, University of Eastern Finland

There is growing international interest in academic and clinical education designed to develop skills in clinical ethics consultation (CEC), particularly in moral decision making. This phenomenon has raised questions among scholars and

medical professionals about the nature and plausibility of anyone's possessing such a skill, particularly, whether ethics professionals should be treated as experts who can offer authoritative advice. In this symposium, scholars from three countries—Canada, Finland, and China—explore some of the conceptual and practical implications of moral expertise for clinical practice.

Presenter 1: I start with the question, is CEC ever moralistic (and if so, is that problematic)? The clinical ethics consultant could be viewed as making moral judgments, and also as advocating certain moral standards, in the course of her consultative work. Each of these activities opens the door to charges of sanctimony and moral presumption. I argue that aspects of CEC can sometimes be perceived as moralistic, and that those perceptions can and should be reduced. The clinical ethicist's moral expertise can help her do this. Second, I urge that ethics consultation sometimes requires (or at least can allow for) a certain kind of moralism, and that this is tied to the required moral expertise of the clinical ethics consultant.

Presenter 2: Irrespective of whether the practice of CEC is generally accepted, the nature of moral expertise continues to be a contestable concept. Instead of arguing whether clinical ethics consultants possess such expertise, I envision a third way of understanding the nature of moral expertise in ethics consultation: as the locus of an inherent paradox. I argue that moral expertise in clinical ethics consultation is built on an inner ideological struggle between pluralism and expertise—inclusion and exclusion—and that this built-in tension forms the core of the paradox. However, I claim that this paradox does not lead to a paralyzing contradiction, but instead, can be embraced positively, as a guarantee of keeping moral space open. Moreover, I argue that putting too strong emphasis on consensus as a professional ideal of CEC may actually threaten the fostering of open social space for moral discussions.

Presenter 3: In Western philosophical discussions, the debates on moral expertise often concern whether moral opinions come to us with a certain level of guarantee that they are true—we doubt whether moral expertise possess the justifiable right of telling us to do X and not to do Y. In ancient Chinese philosophical discussions, there are moral experts in the form of sages (*shengren*), who command a body of moral values and have knowledge or techniques recognized by a community. However, for ancient Chinese sages, moral experts do not necessarily have the right to tell

people they should do X or should not do Y. Nor does the status of moral expert presuppose that others should always listen to their advice, especially when facing dilemmas. Through the ideas of Confucius and Zhuangzi, I examine questions regarding what ancient Chinese moral experts tell others when facing dilemmas.

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Cross-cultural topics in daily clinical encounters: An ethnographic study reveals ethical challenges outside ethics consultation

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Background: Cultural expertise has found entry into medicine and medical education across nations (for example cultural competence). In ethics consultation (EC), issues typically associated with culture are often part of the problems. But what problems arise in clinical encounters that do not lead to EC, but are managed in daily routine?

Methods: A total of 32 out-patients (16 of Albanian and 16 of Turkish origin) were accompanied during their interactions with hospital staff (participant observation) at a Swiss University Hospital (USB). Semi-structured interviews were conducted with all actors involved in a clinical encounter (patients, front desk staff, nurses, physicians and interpreters, as required). Data were analyzed for content analytically using MAXQDA. Patients' and healthcare providers' perspectives were triangulated.

Findings: Patients and physicians revealed difficulties in two areas: (1) "treatment adherence" and (2) "interactions and relationship." Triangulation of perspectives showed differences in perspectives. Physicians perceived non-adherence to be rooted in deficiencies of patients, for example, lacking medical knowledge. Patients revealed another set of reasons, especially personal fears associated with the fulfillment of therapeutic instructions. Regarding interaction and relationship, physicians experienced difficulties in reaching

common ground with migrant patients and with their “exaggerated ways of behaving” (pain expression, personal demands). Patients felt they were not being taken seriously and even discriminated against by staff members.

Discussion: The divergence of patients’ and physicians’ perspectives on basic matters such as adherence or interactions and relationship is significant. It shows not only that ethical challenges arise in daily work, even outside ethics consultation, but reveals also that clinical staff need training for cross-cultural encounters. Ethics consultation should include the topic in the curricula more explicitly and help clinicians to cope with the ethical challenges that arise.

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