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

Proceedings of the 13th Annual International Conference for Clinical Ethics Consultation: Clinical Ethics and Changes in Healthcare (ICCEC 2017)

Hosted by the the Centre for Biomedical Ethics, Yong Loo Lin School of Medicine, National University of Singapore, with Major Support from the Singapore Ministry of Health

faculty
The Names of Presenters at ICCEC 2017, with Abstract Numbers

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

authors and abstracts
Authors and Abstracts from ICCEC 2017, Listed by Abstract Number

exhibitors and sponsors
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MedStar Washington Hospital Center

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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CENTER FOR ETHICS
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A Note from the Editor-in-Chief

Dear All,

Welcome to the second of the *Journal of Hospital Ethics's* published proceedings of the annual International Conference for Clinical Ethics Consultation (ICCEC). As our work of being the sponsor journal for the proceedings of the ICCEC meetings continues, we present to you the abstracts of ICCEC Singapore 2017. By all accounts, the Singapore meeting was outstanding. From the first page of the beautifully designed meeting program to the closing presentations, particularly those of the award winning abstracts of Salla Saxén and Keikki Saxén (Best Abstract #1), and that of Mark Tan Kiak Min (Best Abstract #2), the first ICCEC in Southeast Asia was an impressive success.

The diverse spectrum of international attendance was impressive and inspiring, with contributions to the conference from all of the following countries: Australia, Brazil, Canada, China, Finland, Germany, India, Ireland, Israel, Malaysia, Nepal, New Zealand, Republic of Cameroon, Romania, Saudi Arabia, Singapore, South Africa, Switzerland, Tanzania, the Netherlands, the United Kingdom, and the United States. Our own Center's representative at the meeting, Laura Guidrey-Grimes, confirms that not only were the presentations widely representative of clinical ethics consultation (CEC) around the globe, but so too were the conversations among meeting attendees outside the formal sessions. These more informal conversations, she tells me, were wonderful exchanges across many countries and cultures.

I expect to attend the ICCEC 2018 Oxford meeting this summer and the tentatively planned ICCEC 2019 Vienna meeting the following year. Thereafter, our Senior Editor, Christian Carrozzo, will make one or more of the following ICCEC meetings. Both Christian and I are committed to encouraging future ICCEC keynote speakers to turn their talks into short articles to be included in future proceedings.

Perhaps overdue, I would like to thank George Agich and Stella Reiter-Theil for having jointly imagined and brought to life what is now the regularly occurring and internationally respected ICCEC conference. George and Stella are owed a debt of gratitude from the global CEC community. In no small part because of the ICCEC meetings that they have created, established, and nurtured, the practice of CEC is not a disjointed, nationally silo-ed conglomerate of providers. Rather, and in no small part because of the ICCEC, we are a global community of providers who are in communication with each other, who seek to strengthen the ethically sound care of patients and families in all healthcare settings, and to ethically support those who provide care to such patients and families. Through our discussions at the various ICCEC meetings, we collaborate in advancing the field of CEC around the world in ways that are collegial, scholarly, and innovative. I know I speak for all of us in thanking George and Stella for the great service they have provided the international CEC community and the many national and regional CEC communities nestled therein.

Finally, we would like to thank the many kind persons, in both Singapore and the US, who have assisted us with the preparation of these proceedings. They include Owen Schaefer and Sumytra Menon of the National University of Singapore, Kahlia Keita of our Center, and Leslie LeBlanc,

President, University Publishing Group Consulting. Without your help and the assistance of many others, these proceedings would have been much more difficult to produce.

With that, we hope you find this second *Proceedings of the ICCEC* an excellent 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 2018. I look forward to meeting and talking with as many of you as possible at Oxford.

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 2017

The Names of Presenters at ICCEC 2017, 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** May 25 Abstract #

8:30 a.m. **Opening Ceremony and Welcome Address**
Guest-of-Honor: Associate Professor Benjamin Ong (Director of Medical Services)

9 a.m. **PLENARY 1: Clinical Ethics and Changes in Healthcare**
Session Chair: Professor Alastair Campbell

Working Well with Less? Considering Ethical Responses to Diminishing Healthcare Budgets
Professor Vikki Entwistle

Patient Involvement in Big Data Research: How it All Fits Together
Professor Johannes Van Delden

Knowing When is Enough: A Policy to Promote Ethical Management in End-Stage Organ Failure
A/P Chin Jing Jih

PARALLEL SESSIONS

Informed Consent—Chair: Chin Jing Jih

11 a.m. **Symposium: Overcoming Professional and System Barriers to Achieving Patient-Centered Informed Consent** **1034**
Sucharita Hota, Peter George Manning, Teck Chuan Voo, Jacqueline Chin

12 noon **Oral Presentation 20: Institutionalized Consent: A Mask to Protect "Patient Autonomy"** **1068**
Supriya Subramani

12:20 p.m. **Oral Presentation 10: Awareness, Attitude, Understanding, and Perceptions Towards Informed Consent Among Patients Attending Tertiary Care Hospital in Kerala, India** **1038**
Sabin Katpattil

Education—Chair: Stella Reiter-Theil

11 a.m.	**Symposium: Using Humanities to Promote Empathy and Encourage Ethical Attitudes: A Faculty Development Symposium** Pablo G. Blasco, Graziela Moreto, Leo Pessini	**1005**

End of Life: Special Panel on Assisted Dying—Chair: Johannes Van Delden

11 a.m.	**Oral Presentation 20: Exploring the Interface Between Palliative Care and Physician-Assisted Death: Growing Tensions Between Policy, Ethics, and Clinical Practice** Linda Sheahan	**1065**
11:20 a.m.	**Oral Presentation 20: Should Incarcerated Persons Be Allowed to Access Legal Assisted Death?** Eric Wasylenko	**1074**
11:40 a.m.	**Oral Presentation 20: What Can Ethics Consultation and Committees Contribute to the Development of Appropriate Standard for Physician Participation in Assisted Death?** Alexander Capron, Sunita Puri	**1009**
12 noon	**Oral Presentation 20: Moral Heuristics in End-of-Life Treatment** Alex Dubov, Whitny Braun	**1017**

Pediatrics and Adolescents—Chair: Chay Oh Moh

11 a.m.	**Oral Presentation 20: The 11 Year Olds Who Want Their Legs Amputated** Merle Spriggs and Lynn Gilliam	**1067**
11:20 a.m.	**Case Study 20: A Mother's Benevolent Deception: One Mother's Request to Keep Her 16-Year-Old HIV-Positive Son Ignorant of His Medical Status** Whitny Braun, Alex Dubov	**1007**
11:40 a.m.	**Oral Presentation 20: The Ethics of Fertility Preservation for Prepubertal Children: Should Clinicians Offer Procedures Where Efficacy Is Not Proven?** Rosalind McDougall, Lynn Gillam, Clare Delany, Yasmin Jayasinghe	**1047**
12 noon	**Oral Presentation 20: Ethical Choice Architecture? A Framework for Neonatal Life/Death Decision Making** André Kidszun	**1040**
12:20 p.m.	**Oral Presentation 10: Balancing Compassion and Honesty: A Case Study in Communicating Difficult and Unwanted News in Pediatric Medicine** Nneka O. Sederstrom, Maurice Sholas	**1063**
1:30 p.m.	**PLENARY 2: Clinical Ethics Support for Changing Healthcare Practices and Contexts** Session Chair: A/Professor Anita Ho	
	How to Sustain (and Grow) Your Hospital Ethics Service in a Time of Tight Budgets Dr Matthew Wynia	
	Addressing Stigma: Lessons for Clinical Ethics Committees Dr Lee See Muah	

The Rise and Fall of Clinical Ethics in Taiwan
Professor Daniel Fu-Chang Tsai

PARALLEL SESSIONS

Neuroethics—Chair: Yonghui Ma

3:30 p.m. **Symposium: A Cross-Cultural Examination of Pain: Conceptual, Practical, and Clinical Ethical Challenges** **1018**
Marleen Eijkholt, Nneka O. Sederstrom, Daniel Fu-Chang Tsai, Yonghui Ma

4:30 p.m. **Case Study 30: Clinical Neuroethics: Cracking Brains and Healthcare Systems** **1019**
Marleen Eijkholt

Clinical Ethics and Contexts—Chair: Roy Joseph

3:30 p.m. **Symposium: Aid-in-Dying Session** **1055**
Mathew Pauley, Jana Craig, Theresa Drought

4:30 p.m. **Oral Presentation 20: Sowing the "SEED" for a Supportive Decision-Making Model** **1035**
Kim Jameson, Soodabeth Joolaee, Daniel Buchman, Anita Ho

Diverse Perspectives: Religion and Policy—Chair: Lynn Gillam

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Farid Md Shaikh

3:50 p.m. **Oral Presentation 20: Decisional Capacity and Autonomous Choice with Regard to the Jehovah's Witnesses Blood Policy: A Study in Justified Paternalism** **1056**
Daryl Pullman

4:10 p.m. **Case Study 30: Jehovah's Witness and Liver Transplant: Ethical Dilemma** **1053**
Shirijit Nair, Niamh Conlon

4:40 p.m. **Oral Presentation 20: Should Brain-Death Certification Be Hastened in a Presumed Consent System for Organ Donation?** **1073**
Teck Chuan Voo, Shahla Siddiqui

4:50 p.m. **Oral Presentation 10: Ethically Important Moments in Newborn Screening for Cystic Fibrosis** **1016**
Clare Delany, John Massie

Advance Care Plans and Advance Directives—Chair: Lee See Muah

3:30 p.m. **Oral Presentation 20: Reconciling the Science of Medical Advancements at the End of Life with the Art of Dying Well: Advocating for the Introduction of Legislation on Advance Decisions in Malaysia** **1070**
Mark Tan Kiak Min

3:50 p.m. **Oral Presentation 20: An Actual Advance in Advance Directives: Moving from Patient Choices to Patient Voices in Advance Care Planning** **1022**
Stuart Finder, Virginia Bartlett

4:10 p.m.	**Oral Presentation 20: Developing Medical Student Entrustment in Advance Care Planning: Challenges and Lessons Learned** Marin Gillis, Sanaz Kashan, Chris Degnon, Marcos Milanez	**1028**
4:30 p.m.	**Oral Presentation 20: The Weight of Expectation: Challenges in Implementing Advance Care Planning** Sumytra Menon, Marike Kars, Johannes Van Delden	**1050**
4:50 p.m.	**Oral Presentation 10: Who Makes the Decision? Assisting Clinicians When Advanced Directives Conflict with Surrogate Decision Makers** Sarah Kleinfeld, Mary Colleen O'Rourke	**1041**

AGENDA | **Friday** May 26

9:00 a.m. **PLENARY 3: Changing Attitudes to End-of-Life Care**
Session Chair: A/Professor Jacqueline Chin

Changing Concepts of Personhood in Geriatric Oncology
Dr Lalit Krishna

Ethical and Legal Debates in End-of-Life Care in Japan
Dr Hitoshi Arima

Delivering Primary Palliative Care in the Hospital: A New Pathway to Guide Professional Practice
Dr Nancy Berlinger

PARALLEL SESSIONS

Clinical Ethics Support—Chair: Anne Slowther

11 a.m. **Symposium: A Comparison of Clinical Ethics Consultation Methods and Their Grounding Values** **1013**
Geert Craenen, George Agich, Jos Kole, Nneka O. Sederstrom

12 noon **Case Presentation 30: Ethics Consultation Involving Potentially Unsafe Discharges: Use of an Ethics Rubric for Assessing Discharge Readiness** **1042**
Nicholas Kockler

End of Life—Chair: Jacqueline Chin

11:20 a.m. **Oral Presentation 20: Are Palliative Care Patients Too Vulnerable to Participate in Research? Perspectives on an Ethical Dilemma** **1052**
Jessica Moore, David Hui, Donna Zhukovsky, Elizabeth O'Toole

11:40 a.m. **Oral Presentation 20: Ethics of Health-Related Quality of Life Influencing End-of-Life Decision Making and Futility of Care in Burn Patients** **1039**
Anjay Khandelwal, Monica Gerrek, Oliver Schirokauer

12 noon **Oral Presentation 10: To Treat or Not Treat Without Legitimate Consent: Challenges of Cancer Patients with Mental Illness and Changing Capacities** **1014**
Philip Crowell

12.10 p.m. **Oral Presentation 10: Healing Conflict? Mediation in End-of-Life Care** **1059**
Amy Salapak

12.20 p.m. **Oral Presentation 10: Applying Motivational Interviewing in End-of-Life Care Planning: A Pilot Study** **1010**
Helen Chan, Ps Ko, Pt Lam

Mental Health and States of Mind—Chair: Wong Kim Eng

11 a.m. **Oral Presentation 20: Family Members' Experiences with and Views on Coercion in Mental Healthcare and the Possible Role of Clinical Ethics Support** **1033**
Marit Helene Hem, Reidum Norvall, Hilde Lindemann

11:40 a.m. **Oral Presentation 20: Defending the Right to Starve: Hunger Strikers and the Right to Refuse Treatment in Israel** **1044**
Zohar Lederman, Shmuel Lederman

11:20 a.m. **Oral Presentation 20: Evaluation by Case Series: Top Themes of Ethics Consultations in Psychiatry as Compared to Somatic Medicine** **1058**
Stella Reiter-Theil, Jan Schürmann

12 noon **Oral Presentation 20: Slow Ethics . . . Two Years On!** **1037**
Jenny Jones, Eleanor Milligan

Ethical Deliberation—Chair: Marin Gillis

11 a.m. **Oral Presentation 20: Outpatient Ethics Consultation: How Can Ethics Consultants Support Healthcare Professionals and Patients in Decision Making?** **1071**
Sandra Thiersch

11:20 a.m. **Oral Presentation 20: Impact of Moral Case Deliberation in Contemporary Healthcare Institutions: An Integrative Review** **1031**
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Pablo G. Blasco, Ismael Ramirez-Villaseñor, Graziela Moreto

12 noon **Oral Presentation 10: Ethical Issues in Clinical Practice: A Survey of Clinicians' Experiences and Views about Clinical Ethics Support** **1025**
Giuliana Fuscaldo, Melissa Cadwell, Kristen Wallis, Lisa Fry

12:10 p.m. **Oral Presentation 20: Virtues of Moral Case Deliberation Moderators** **1043**
Jos Kole, Jelle Van Gurp

12:30 p.m. **Special Session**
Session Chair: Ms Sumy Menon

Breaking News: Singapore Court Adopts New Standard of Care for Medical Advice
Ms Kuah Boon Theng, Professor Richard Huxtable, A/P Chin Jing Jih

1:30 p.m. **PLENARY 4: Using Innovative Treatments and Modes of Health Service Delivery**
Session Chair: Assistant Professor Voo Teck Chuan

Limits of Patient Autonomy and Vulnerability in Clinical Innovation
Dr Tamra Lysaght

Responsible and Irresponsible Medical Innovation with Stem Cells
Professor Jeremy Sugarman

Clinical Ethics Support: A Useful "Ethical Scaffold" for Innovation in Health?
A/P Ainsley Newson

PARALLEL SESSIONS

Clinical Ethics Challenges—Chair: Biswas Agnihotri

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Care—Chair: Keymanthri Moodley

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4:30 p.m.	**Oral Presentation 20: Why Do Ethical Standards Drop Among Interns in Medical Settings? Ethical Erosion in Medical Psychology as a Test Case for Other Medical Professions** Rebecca Reicher-Atir, Sigal Levy, Rooty Yavor	**1057**
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Innovation—Chair: Richard Huxtable

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4:10 p.m.	**Oral Presentation 20: Assessment of Clinical Ethics Oversight in Tanzania** Daima Bukini, Aboud Muhsin	**1008**
4:30 p.m.	**Oral Presentation 20: Bridging the Gap: E-Ethics Joins Other Specialities in Medicine to Provide Distance Consultation** Margot Eves, Joshua Crites, Cristie Horsburgh	**1020**

9 a.m. **PLENARY 5: Globalization, Migration, and Cross-Border Healthcare**
Session Chair: Sumytra Menon

Cultural Competence and Its Ethical Implications for Cross-Border Healthcare
Dr Ilhan Ilkilic

International Migration of Human Resources for Health: Clinical Consequences and International Responsibilities
Professor Leonardo de Castro

From the Abstract to the Real: Through the Lens of Living Related Kidney Donation in Pakistan
Dr Farhat Moazam

PARALLEL SESSIONS

International Perspectives on Clinical Ethics Consultation—Chair: Sharon Kaur

11 a.m. **Oral Presentation 30: Clinical Ethics Consultations at an Academic Hospital in South Africa: Challenges and Opportunities** **1051**
Keymanthri Moodley

11:30 a.m. **Oral Presentation 20: Pitfalls and Potentials of a New Clinical Ethical Consultation Service: An Experience from Turkey** **1012**
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Difficult Decisions—Chair: Owen Schaefer

11 a.m. **Symposium: Alfred Schutz, The Stranger, and the Unending Challenge of Engaging Ethics in Clinical Contexts** **1023**
Stuart Finder, Virginia Bartlett, Mark Bliton, Stella Reiter-Theil

12 noon **Oral Presentation 20: What Kind of Neutrality? Keeping the Ethics in Ethics Consultation** **1030**
Laura Guidry-Grimes, Jamie Watson

Conflict of Interest—Chair: George Agich

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Kyle Anstey, Trevor Theman

1:20 a.m. **Oral Presentation 20: Is Consumerism a Fetter on Medical Ethics?** **1004**
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11:40 a.m. **Oral Presentation 20: Do Doctors Over-Investigate Patients for Their Own Incentives? A Prospective, "Randomized" Data Survey in an Indian Metropolis** **1015**
Jayanta Das, Krishnendu Mukherjee

12 noon **Oral Presentation 20: A Doctor in the House—Ethical Considerations When Doctors Treat Themselves and Those They Are Close To** **1054**
Kanny Ooi

Migration and Humanitarianism—Chair: Leonardo de Castro

11 a.m.	**Case Study 20: Providing Care for Patients Without Documentation: An End-Stage Renal Disease Case Study** Jeffrey S. Farroni, Jennifer Zirkle, Selwyn O. Rogers, Jason R. Ross	**1021**
11:20 a.m.	**Oral Presentation 20: Ethics in Humanitarian Services: Reflection from the Earthquake in Nepal** Ramesh P. Aacharya, Sanjeeab Tiwari, Tirtha Shrestha	**1001**
11.50 a.m.	**Oral Presentation 10: Medical Migration in Global Context: Ethical Issues Regarding the Integration of Cultural Diversity** Elena Toader	**1072**
12 noon	**Oral Presentation 20: How Do Cancer Patients Face the Approach of Death? What Do They Ask, Then, of Medicine?** Véronique Fournier, Phillpi Bataille, Sandrine Bretonniere, François-Xavier Goudot	**1024**

Pediatrics

12 noon	**Case Study 30: Case Discussion: An Adolescent Requesting Removal of IUD Without Parental Involvement** Lynn Gillam	**1027**

Authors and Abstracts

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1001

Ethics in Humanitarian Services: Reflection from the Earthquake in Nepal

Authors:
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Tirtha SHRESTHA, Tribhuvan University Teaching Hospital, Nepal

The Nepal earthquake was one of the biggest natural calamities of the year 2015. This paper is an attempt to explore the ethical issues involved in the humanitarian services rendered during the crisis and thereafter. Principles of biomedical ethics are discussed in relation to the relief activities immediately following the disaster and subsequent long-term rehabilitation activities. Incorporating ethical principles into the response to disasters is of vital importance to ensure that healthcare complies with professional norms and ethical standards, and is in tune with the medical needs of the local culture. In crisis situations, beneficence is prioritized, while nonmaleficence and autonomy tend to be ignored. Justice, particularly distributive justice, deserves due attention in the context of limited resources, not only during the emergency phase but also during the phases of rehabilitation and planning for the future. The discussion on the principle of justice touches upon public health components such as vulnerable populations, environmental ethics, and justice for the future. Principles of biomedical ethics must be respected even when working under crisis conditions, so that the health services rendered comply with professional norms and ethical standards, and are in consonance with the medical aspects of the local culture. Embedding ethical principles in every aspect of healthcare, including disaster preparedness plans, is of vital importance. The ethical challenges faced while responding to disasters can be minimized with the help of the preparedness plan and by the ongoing orientation of the plan to authorities concerned, including those at the grass-roots level.

1002

Exercising Autonomous Choices

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With the introduction of respect for the principle of autonomy in medicine, the informed consent model has acquired the status of legal standard. Exercising autonomous choice, however, is often challenged, thus transforming a well-elaborated legal norm into a common source of ethical dilemmas. The aim of this report is to present and discuss practical difficulties in the application of informed consent legal framework in Bulgaria.

Methods: Cases retrieved through application of adapted METAP methodology for clinical ethics consultation are analyzed through the lens of current national and international legal and ethical

frameworks. Content analysis of legal documents is performed. Approval of the institutional ethics committee has been obtained.

Results and discussion: The provisions of informed consent are included in the Bulgarian Health Act. Medical procedures without the consent of the patient are possible only in cases when the patient's life is endangered. If the patient/legal representative refuses emergency intervention, it still can be performed by the decision of the hospital manager. The same is valid for the cases of advance directives. In practice, this means that even in an autonomous state, a patient cannot refuse resuscitation. Another problematic area is the influence of relatives over a patient's decision. Two such cases will be discussed: a 31-year-old woman in premature menopause needing a donor's ova for in vitro fertilization (IVF) and a 76-year-old patient suffering from dizziness episodes who needs closer observation and care. The last case, together with a case of a 78-year-old patient whose sons opposed his decision to undergo a cardiac operation, will be additionally discussed through the lens of the overlapping confidentiality issues.

Conclusion: The available legal framework aids medical professionals, but it does not prevent ethical dilemmas. Ethically sound decisions require that clinicians be familiar with legal provisions, but equally important is the development of an ability for moral reasoning.

1003

Professional Courtesy, Equity, and Partiality

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Kyle ANSTEY (Presenting Author), Alberta Health Services, Canada
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Physicians sometimes provide services within the scope of their own practice to other healthcare professionals. In Canada, such "professional courtesy" is prevalent, but often criticized as constituting improper preferential access to the public healthcare system. Engaging in professional courtesy is often labelled as an unmanageable conflict of interest: however, granting that a physician's primary obligation is to existing patients, the nature and management of the conflict deserves further scrutiny.

A primary obligation to existing patients can be respected if professional courtesies are extended outside normal working hours; any direct or opportunity costs incurred by the treating physician do not delay or displace any current insured patients; and any further care needs identified for the professional extended the courtesy should be addressed based on need and urgency alone.

Accepting that a physician's primary obligation is to existing patients, what is his or her secondary obligation in a "universal" public healthcare system? Do obligations to equity or stewardship within the public system come before or after considering obligations to one's colleagues within that system? Physicians might be able to supply impartial moral reasons for preferring the interests of colleagues in specific contexts, such as prioritizing scarce resources in extreme circumstances to maintain the system's capacity to care for all patients. However, it may also be both understandable (and even expected) that they act partially by advocating more strongly and more directly for access by their colleagues.

We report on how our analysis of these competing obligations informed development of new professional courtesy guidance for physicians in Alberta, Canada.

1004

Is Consumerism a Fetter on Medical Ethics

Author:
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The rise of consumerism is regarded as one of the fundamental developments shaping health service rendered in the present day. There is a conceptual distinction that can be made between the respective roles of the "patient" and the "consumer" of healthcare. The "patient" has been regarded historically as occupying a subject position, with implications of dependency and unquestioning compliance with medical expertise. In medical ethics, doctors are expected to work in the interest of their patients, and this commitment is fundamental. However, this emphasis on social control and the "docile" body is felt to be less appropriate when considering the present day "consumer" of healthcare services. Health policy initiatives appear to endorse a view of service users who are becoming more "empowered" in their relationships with health professionals. Today, despite a strong tradition of medical ethics, doctors, like other professionals, have conflicts of interest and sometimes breach their fiduciary obligations. This paper examines the reasons behind the lack of confidence in the "doctor-patient" relationship today, and whether the accountability of doctors is questionable in this era of consumerism in which health services are seen as a commodity.

1005

Using Humanities to Promote Empathy and Encourage Ethical Attitudes: A Faculty Development Symposium

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Empathy has to do with deeply understanding the other, and is a path to bridge scientific knowledge with compassion for better caring. Can empathy be taught? To care with empathy implies having an understanding of the human being. In life, the most important attitudes, values, and actions are taught through role modeling and example, processes that act directly on the learner's emotions. Because people's emotions play a specific role in learning attitudes and behavior, educators cannot afford to ignore students' affective domain. Although technical knowledge and skills can be acquired through training with little reflection, it is impossible to refine attitudes, acquire virtues, and incorporate values without reflection. Learning through the humanities stimulates a reflective attitude in the learner. On the other hand, medical school faculty face challenges when they teach and have few opportunities to share them and reflect with their peers. Usually when teachers discuss educational issues with their colleagues, they spend most of their time talking about problems, rather than nurturing themselves. As teachers, we need to formulate new paradigms in education, learn how to share our weaknesses and frustrations, and find resources to keep up the flame and energy for a better teaching performance. The humanities could be incorporated in faculty development strategies because they provide useful peer reflective scenarios. They also provide a tremendous spectrum of attitudes that are required to build ethics and professionalism. Here we present a successful experience in faculty development: How to use the humanities—including brief readings, pieces of art, music, and some movie clips—that illustrate complex moral choices, and how to use each to stimulate comment and reflection from the audience. Participants will learn how faculty can be creative in using the arts and humanities to empower their teaching and more effectively reach students, to promote a reflective attitude that helps to build ethical attitudes and professionalism.

Speaker 1, a PhD, will discuss research in medical education and how to use movies to educate health professionals. He will show how to use the humanities in medical education—with particular emphasis on the use of movies, in particular, a recent movie about Hannah Arendt—which demonstrates that reflection is the key to incorporating ethical attitudes into daily practice. When reflection is lacking, physicians lose their ethical perspective—not because they are malicious, but because they keep working, get into the scientific process, neglect details, and ignore the patient's world. They just stop thinking.

Speaker 2, a PhD, will consider research on empathy erosion in medical students. Her research points out how the affective component of empathy declines during the years of medical school. To prevent empathy erosion, the use of humanities to educate students' emotions could be a valuable resource in teaching ethics and professionalism.

Speaker 3, a well-known, global bioethicist, will describe his broad experience in teaching compassionate care, end-of-life issues, and critical decisions in bioethics, and how the humanities can help in this endeavor.

1006

Using Movie Clips to Teach Medical Ethics: From Emotions to Attitudes through Reflection

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To care implies having an understanding of human beings. In life, the most important attitudes, values, and actions are taught through role modeling and example, a process that acts directly on the learner's emotions. Because people's emotions play a specific role in learning attitudes and behavior, educators cannot afford to ignore students' affective domain. Life stories and narratives enhance emotions, and therefore set up the foundation for conveying concepts. Learning through aesthetics—in which cinema is included—stimulates a reflective attitude in the learner. Movies provide a narrative model, framed in emotions and images, that is grounded in the everyday universe and stimulates a reflective attitude in the learner.

They offer a quick and direct teaching scenario in which specific scenes point out important issues and emotions are presented in accessible ways. In this context it makes sense to use movie clips because of their brevity, rapidity, and emotional intensity. Bringing clips from different movies to illustrate or intensify a particular point fits well with the dynamic and emotional nature of students' experience. As audiovisual resources permeate our current culture, opportunities for teaching with cinema are well-suited to the learner's environment.

Fostering reflection is the main goal in the cinematic teaching set. The purpose is not to show students how to incorporate a particular attitude, but rather to promote their reflection. Reflection is the necessary bridge to move from emotions to behavior. The audience will understand the cinema teaching methodology, especially the movie clip variation, and learn how to apply this methodology to help students be more reflective and promote empathic attitudes, enrich professional values, and develop well-rounded qualities as human beings. The authors have developed the movie clip methodology for almost 20 years. References can be found at http://sobramfa.com.br/eng/articles/movies-in-medical-education/).

1007

A Mother's Benevolent Deception: One Mother's Request to Keep Her 16-Year-Old HIV-Positive Son Ignorant of His Medical Status

Authors:
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This paper presents the case of a mother in New York City who brought her intellectually delayed 16-year-old son into the emergency department for a recurring ear infection. She asked to speak to the physician privately and revealed to the physician that her son had been born HIV-positive and that she had kept that fact from him for the last 16 years. She told her son that his medications were actually vitamins and had instructed his other physicians in the past to keep his HIV status from him. The emergency department physician felt that the pretense the boy was not HIV-positive was no longer an act of benevolent deception, but potentially a public health issue, as the boy may now be sexually active. The physician wanted to tell the boy his status and educate him about the risks associated with engaging in sexual activity, as well as managing his own condition; however, the mother was adamant that the boy remain ignorant of his condition, and threatened to sue the physician and hospital if the physician disclosed the boy's condition. An ethics consultation was requested. As there was not a legal precedent for this type of situation, the hospital ethics committee decided to move forward with full transparency in their interactions with the boy. This case study and presentation will pose the following questions: (1) What are the limits of benevolent deception? (2) What are the ethical obligations of a healthcare professional to inform a sexually active minor with an infectious disease? (3) Is it truly in the best interest of a patient to withhold information that will inevitably be revealed and result in potential emotional trauma?

1008

Assessment of Clinical Ethics Oversight in Tanzania

Authors:
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In many hospitals in Tanzania, ethical dilemmas and conflicts occur. Despite their prevalence, relatively little is known about their magnitude, nature, and how they are resolved, if at all. Moreover, in resource-constrained healthcare institutions, there are higher chances that patients' rights and privacy may be violated, and that patients may not be involved in making decisions about their own health. Interestingly, there are many protocols and frameworks to protect the rights and welfare of human subjects of research, but very little has been done to protect the interests and rights of patients in clinical care. We aim to determine the magnitude and nature of ethical conflicts and dilemmas in healthcare institutions in Dar es Salaam, Tanzania. We also want to explore whether healthcare workers and institutions are adequately prepared to handle ethical conflicts, and thereafter recommend the best approach in handling these issues. A mixed method design was used to collect information from healthcare workers and institutions providing clinical care. A survey was conducted to determine the magnitude of the problem and it was followed up with focus group discussions and in-depth interviews with healthcare workers. The construction of the survey questionnaire was guided by the result of the focus

group discussions during an Ethics in Research and Clinical Practices Workshop in March 2014 in Dar es Salaam, Tanzania. The results reveal a high incidence of clinical ethics conflicts and the lack of any form of clinical ethics consultation in the participating institutions. We used the results to develop a framework to guide clinical ethics consultation in Tanzania.

1009

What Can Ethics Consultation and Committees Contribute to the Development of Appropriate Standard for Physician Participation in Assisted Death?

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Ethics consultation has been an essential element in the development of legal rules, clinical practices, and ethical standards regarding decisions about care at the end of life since 1976, when the New Jersey Supreme Court upheld Karen Ann Quinlan's parents' right to have her disconnected from a ventilator, provided that the diagnosis was confirmed by a hospital ethics committee. Soon, hospitals across the country were appointing ethics committees (and later, ethics consultants) to help resolve disputes over withdrawal of life-support. Disagreements at first involved physicians' rejecting the insistence of patients (using an "instruction" or "appointment" advance directive) or the next-of-kin of incapacitated patients, when the length or intensity of care be limited when recovery was unlikely. More recently, this pattern has been reversed when a medical team concludes that a patient will not benefit from further "futile" treatment, but the next-of-kin wants "everything done" to prolong life. Ethics consultants have played a major role through their involvement in such decisions and analysis in developing the relevant ethical and legal principles. Yet, at least in the US, the legalization of physicians' participation in assisted suicide has not followed this pattern. Ethics consultation has largely not occurred, since decisions about self-administered death arise in an outpatient context, while consultation is mostly found in institutional settings. In this presentation, we argue that ethics consultants and committees, with their familiarity with decisions that lead to patients' death in the context of withholding or withdrawing treatment, could pay a useful role in addressing the great differences in the rules that apply in this context (eg, the requirement that the patient act directly and unaided, the necessity of the certainty and imminence of death, the requirement of the patient's current capacity, and, above all, the criminal law context of the act).

1010

Applying Motivational Interviewing in End-of-life Care Planning: A Pilot Study

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Objective: This study attempted to introduce motivational interviewing (MI) into the advance care planning (ACP) process so that clinicians could work with patients through their ambivalence towards ACP.

Background: Given the complexity of end-of-life care issues, clinical experience suggests that patients usually remain skeptical about planning for future care in advance. Our previous studies revealed that the level of readiness towards end-of-life care planning varied, as that proposed in the Transtheoretical Model (TTM). MI is a person-centered counselling skill grounded in TTM that aims to engage people in identifying resistance and perceived barriers to behavioral changes. It has been widely applied to promote disease self-management behaviors.

Methods: The MI-tailored ACP program was pilot tested at a palliative care clinic. Ten patients were recruited to the study. In addition to a satisfaction survey to examine its feasibility and acceptability, individual semi-structured interviews were conducted with participants to understand their experiences with the program. The data collection process is still in progress.

Conclusion: Thus far, the participants shared that the program enabled them to clarify their concerns and fears and provided an opportunity for them to explore their care goals and formulate the plan of action.

1011

From Clinic to Community: Teaching and Doing Ethics in Care Work

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Proposal: Clinical ethics education, well-established in hospitals, may also be organized to serve community physicians. While it is axiomatic that healthcare work is ethically challenging, healthcare ethics, as an enterprise, has paid far less attention to the ethics education needs and challenges of community professionals who do "care work." For nurses, physicians, social workers, case managers, and others who provide care to people with serious chronic conditions in home, long-term care, and ambulatory care settings, clinical ethics consultation services may be non-existent, or accessible only via hospital admission. Given the realities of ageing societies and the migration of many medical interventions and forms of care into nonmedical settings, what does clinical ethics owe to those who do care work? This symposium will draw on international expertise to explore (1) the specific differences and challenges that community professionals face concerning practical ethical decision making in different settings, and (2) emerging models for education and ethics support that can assist these professionals. Such services need to respond to distinctive features of ethics in community settings: (1) Many community-level ethical challenges in the community setting arise from system-level concerns, eg, resource allocation, program scale up in response to changing social demographics, rather than "bedside" decision making. (2) Responsibility for care is distributed among a large number of individuals, including nurses, physicians, care assistants, "paraprofessional" workers (often migrants), volunteers, family members, and friends, and often among different healthcare and social care organizations. (3) Many community care workers are not educated or supported within healthcare training paradigms that offer opportunities to learn how to make ethical judgments and work with colleagues to resolve ethical issues arising in their care setting(s) in the context of ageing societies. Panel participants have been selected for their expertise in both topics. Three 10-minute presentations will be followed by 20 minutes of discussion.

Presentation 1: Ethics in the community: novel challenges; novel decisions. This presentation will introduce the special challenges of ethical decision making and support in the community, drawing on lessons learned from a recently completed ethics practice development project in Singapore, and other research into the challenges of supporting people with long-term and chronic health conditions outside the hospital setting.

Presentation 2: Ethics done communally: sharing decisions with family members and other caregivers. This presentation will explore the reality of shared ethical decision making among different professional actors and "informal" caregivers, including paid workers and family members. The duties and obligations of different caregivers and the implications of these duties for ethical responsibility, education, and support will be highlighted.

Presentation 3: Modelling ethics support for the community. The ethical distinctiveness and practical features of community-based care raise questions about whether and how standardized approaches for ethics consultation and committee work can be developed for the community setting. This presentation will explicate a community networking approach to these challenges.

1012

Pitfalls and Potentials of a New Clinical Ethics Consultation Service: An Experience from Turkey

Author:
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Although clinical ethics consultation (CEC) has been a routine component of healthcare in North America and Europe for decades, it is almost "unborn" in other countries. It could be claimed that, as of the year 2010, CEC was almost absent in Turkey, except for some sporadic examples. Considering this problem, the goal was to establish a CEC service at Uludag University Centre for Health, Practice, and Research (UU-CHPR), located in Bursa, the fourth most populated city of Turkey. In the first phase, a cross-sectional survey was conducted to determine the quantity and quality of CEC needed. It was found that there was a substantial unmet need for CEC services, and that the majority of clinicians stated that they would use CEC in a variety of situations. In light of this needs assessment, a hospital ethics committee (HEC), comprised of 11 members, was established

in 2012 within the UU-CHPR. Its directive about structure and functions states that its main functions are "case consultation, policy review, and education." Three years after the establishment of the HEC, retrospective research on requests for CEC was conducted to examine how the HEC was utilized by healthcare workers and patients, and its effects on providing guidance on dilemmas and improving healthcare. Two-thirds of the requests were from patients, and their issues largely related to right to health, patients' rights, and claims of infringement of professional obligation in the context of specific cases. Requests for CEC, on the other hand, comprised only 6.1% in total. Since the HEC members did not undergo any specific training in ethical analysis in general, they are prone to making mistakes in both spotting the existence of ethical problems and determining justifiable options with due regard to relevant rights and obligations, when confronted with a range of options. The members, who are mostly clinicians, may adopt a paternalistic perspective, and tend to protect their colleagues. The absence of healthcare workers other than physicians on the HEC, as well as patients' representatives, makes it difficult to express different views and to have these views taken into account. The prioritization of legislation in the process of decision making shifts the weight to existing legislation when there is any mismatch between ethics and legislation. In addition to these, perhaps the most important source of problems is giving priority to economic considerations in decision making. In spite of these difficulties, the HEC still has a meaningful role to play in improving healthcare and reducing cases of violation of rights. In this sense, primary objectives should include (1) increasing requests for consults, or more correctly utilizing the HEC, (2) ensuring continuous improvements in HEC decision-making processes, and (3) strengthening the implementation of decisions of HEC policy/guideline development. Promoting the HEC as a consultancy service by organizing activities to inform clinicians and patients will boost awareness. In addition, it may be rewarding to train clinicians in recognizing and finding solutions to ethical problems in their daily practice. Ensuring the participation of all parties in moral deliberations, as much as possible, could provide more accountability and trust, and therefore increase requests for ethics consults. There is a need to conduct research—preferably qualitative studies—in order to gain insight about clinicians' mind set, expectations, and the conditions surrounding them, and to develop initiatives accordingly. In addition, what must be done in order to prevent the emergence of many problems is to promote, in the longer term, a culture that integrates CEC into all available services. It can be envisaged at this point that health policies will play a crucial role besides institutional support.

1013

A Comparison of Clinical Ethics Consultation Methods and Their Grounding Values

Authors:
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George AGICH (Presenting Author), Bowling Green State University, United States
Jos KOLE (Presenting Author), Radboud Universiteit Nijmegen, The Netherlands
Nneka O. SEDERSTROM (Presenting Author), Children's Hospitals of Minnesota, United States

The panelists will present their specific clinical ethics consultation methods and explore the grounding values for each method. Grounding values will be compared for congruence/dissonance, and each panelist will explain how his or her method will serve these values in future.

Introduction: I will argue that there can be a diversity of methods of doing ethics consultation, but all of them should be anchored in ethics consultation as a reflective practice. A method must guide the actions of consultants; it is thus not just a normative conception or statement of guidelines or procedures. Any adequate method should address the following elements: the interpretation or diagnosis of the ethical questions or problems, the communicative actions of the consultant in the case, the practical and normative foundation for the guidance and recommendations made, and the critical analysis of and reflection on the actions undertaken in the consultation.

1. The Nijmegen Method: This method, developed in Nijmegen (The Netherlands) starts from the idea that we all have moral experiences in daily moral life in the clinic that need to be articulated to understand their meaning and their normative and motivating force. Exploration of this meaning starts with a "close reading" of the scripted text of the case at hand. Rather than "solving moral problems," this method explores the plurality of perspectives, the influence of context and the hidden assumptions that color our moral experience and understanding. This leads to deeper understanding of what is going on in the case at hand

from an ethical perspective and cultivates moral wisdom.

2. The CASES method: The CASES method was developed at the National Center for Ethics in Health Care of the US Department of Veterans' Affairs. It was designed to operate in the specific environment of a government health service, based on solidarity with former military service members. The CASES method serves to respect the moral concerns of healthcare providers, patients, and their families with a somewhat incongruous blend of respect for persons expressed as autonomy as well as compassion, and solidarity by and with a larger population.

3. Pediatric consults: In this presentation I will discuss using ethics consultation as a means to convince parents to act in their child's best interest during end-of-life discussions. Ethics is frequently consulted due to the clinical teams' need to convey difficult messages and, sometimes, their inability to effectively communicate their recommendations. When dealing with parents of a dying child, it is infinitely harder to have conversations about values and best-interest standards in the face of such grief, so clinicians seek ethics consultation to play the "bad guy." Being able to successfully address end-of-life decision making within the context of parental autonomy is a delicate dance that clinical ethics consultants must master.

1014

To Treat or Not Treat Without Legitimate Consent: Challenges of Cancer Patients with Mental Illness and Changing Capacities

Author:
Philip CROWELL, BC Children's Hospital, Canada

The challenge of caring for patients with severe mental illness entails significant ethical conundrums, especially when there is comorbidity such as cancer. One daunting hurdle is having patients agree to and comply with treatment. Add to this inquiry the pediatric element of adolescent patients with developing capacity who face cancer and psychiatric morbidity. Our notions of capacity and competency are tested in many ways because of complex contextual factors. In some jurisdictions, legislation limits any treatment going beyond the psychiatric treatment without the informed consent of the patient. When children (adolescents) are in these precarious conditions, it is tempting to impose additional treatments given their developmental stage, lack of life experience, and the effect of the disease on their cognitive processes. This presentation will explore notions of capacity in the light of the intersection of mental illness and cancer. A case is made for adults to make their own medical decisions, even when encumbered by mental illness. But with children, our ethical argument for additional protection and treatment has legitimacy because of very specific "best-interest" arguments when children are deemed incapable to provide consent to treatment.

1015

Do Doctors Over-Investigate Patients for Their Own Incentives? A Prospective, "Randomized" Data Survey in an Indian Metropolis

Authors:
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Krishnendu MUKHERJEE (Presenting Author), Dillons Kidney Foundation, India

There is a popular perception amongst a section of the public in India that doctors, especially professionals in the private sector, over-investigate patients for incentives. While these incentives may or may not be purely materialistic in nature, it is widely believed that doctors often do this to generate more "revenue" for privately funded establishments. Sensational stories in the popular media fuel this perception, which is, in turn, potentially detrimental to trusting doctor-patient relationships and subsequently may adversely affect patients' compliance with treatment advice. However, no rigorous scientific research has been performed to test this hypothesis. This study aims to involve a selected group/forum of nonmedical (lay) participants and select three to four private establishments and the doctors who are empaneled therein. As a control arm, two charitable/public institutions will also be studied. The members of the nonmedical group (investigation forum, or IF) will decide on the dates of inspection and select the institution. This data collection exercise will be done on the same day (within 24 hours) of the selection. A double-blinded, lucky-draw system will be used to select the institution on each day. The IF will accompany the principal investigators to the institution and also randomly select five to 10 bed numbers. The team will then visit these patients, obtain consent, and record three parameters; (1) principal symptoms, (2) working/provisional diagnosis and the line of management, and (3) the list of investigations performed. Data analysis will be done transparently with specialists not involved in the said patient care/institutions and by consulting current medical literature. Necessary clearances from ethics committees and consents by

institutional review boards (IRBs) has already been obtained, and the composition of the IF have been finalized. If the study shows a definitive statistical trend, a second phase will be undertaken.

1016

Ethically Important Moments in Newborn Screening for Cystic Fibrosis

Authors:
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In research ethics contexts, ethically important moments have been described as "the difficult, often subtle, and usually unpredictable situations that arise in the practice of doing research" (Guillemin and Gillam 2004, p 262). Addressing them requires reflexivity about researchers' role and judgments, and sensitivity to everyday ethical dimensions of research practice. We suggest a similar need for clinician reflexivity within newborn screening for cystic fibrosis. This screening is well-established and considered ethically appropriate. It reduces morbidity, prevents prolonged diagnostic odysseys for families, and offers a chance to engage in genetic counselling. It also complies with original screening criteria proposed by Wilson and Jungner (1968). However, meeting accepted criteria does not remove all potential ethical issues. There are a range of "subtle, and sometimes unpredictable situations that arise" in the "doing" of newborn screening for cystic fibrosis. We present a framework for promoting clinicians' reflexivity and ethical sensitivity for newborn screening. The framework complements the criteria set by Wilson and Jungner (1968) and highlights a series of ethical alerts to raise awareness of possible ethically important moments as infants move through the cystic fibrosis newborn screening paradigm.

1017

Moral Heuristics in End-of-Life Treatment

Authors:
Alex DUBOV (Presenting Author), Loma Linda University, United States
Whitny BRAUN (Presenting Author), Loma Linda University, United States

This presentation will discuss the role of moral heuristics in judgments about life-sustaining treatment in an intensive care unit (ICU). We propose that end-of-life treatment intensity in a given ICU can be influenced by a number of moral "rules of thumb" or heuristics. Moral heuristics are a set of strong, stable, and immediate moral beliefs. These beliefs are not results of a deliberative process. They are, rather, fast and frugal decision rules or decision norms that produce judgments quickly based on limited information. Most research on heuristics has been conducted by psychologists in the area of risk and probability estimates. This work deals not with moral questions, but with some factual issues, such as judgments of frequency, probability, and risk. We propose that in a similar fashion, when confronted with a complex moral issue, people resort to moral heuristics and simplify their judgments by using what is familiar to judge what is unfamiliar. Decisions to limit or forgo life-sustaining therapy are areas in clinical practice in which moral heuristics can be particularly relevant. One in five US patients dies during or shortly after an ICU stay. A number of studies demonstrate striking variability in these decisions (sixfold) even after adjusting for patient and ICU factors. Ideally, these decisions should depend on the goals and preferences of families, survival estimates, quality-of-life considerations, and illness severity. However, recent research suggests this variability is not driven by the factors above, but, rather, by decision-making norms deriving from hospital or ICU cultures. Assuming that moral heuristics are results of these cultural decision-making norms, we discuss a number of relevant moral heuristics, such as commission/omission distinction, means-to-an end/end-in-itself distinction, rule of rescue, and decision ownership.

1018

A Cross-Cultural Examination of Pain: Conceptual, Practical and Clinical Ethical Challenges

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Pain is a relevant clinical problem, but also a social construct that is impacted by culture, environment, and gender. As a result, it would not be

surprising if pain is perceived, framed, and treated differently across cultures. However, minimal literature exists on cross-cultural examinations of pain, and this panel seeks to fill this gap. The phenomenon of pain is complex and entails conceptual, practical, and clinical ethical challenges. Conceptual challenges arise, for example, from the distinction between pain and suffering. Practical challenges arise from tensions between objective and subjective components of pain, and clinical ethical challenges arise in cases when surrogates desire adjustment of pain medications for an unconscious patient. For example, if a surrogate asks to remove pain control so the patient regains some consciousness, this could conflict with providers' perception that the pain should be treated and that consciousness is less important.

Some authors have identified the social construct of pain in differing ideas about when it is "appropriate" to express pain, which pain is "appropriate" to express, and how it should be treated. Since the 1990s, pain has been framed as the fifth vital sign in the US, as an essential component of a patient's status, and something that should be reduced at all costs. In turn, this construction and the sensitivity for the pain narrative has been labeled as one of the major causes of the 2016 US "Opioid-Epidemic." The question is whether such an epidemic could arise elsewhere in the world. Some Western historical discourse around pain is composed using references to religious and spiritual components of pain; enduring pain could be seen as a means of communicating with God or as having a redemptive component. Certain Christian perspectives, in particular, have long emphasized dualistic thinking to address the spiritual versus physical components of pain. Such rhetoric is obviously contextual. This panel seeks to examine these various challenges in the framing of pain across cultures. By exploring cases and concepts, it will examine the meaning of pain, the various challenges of the pain discourse, and varying approaches towards pain through a cross-cultural lens. In addition, it focuses on questions such as: What is the relevance of pain in the clinical setting? What (in)abilities do patients and surrogates have to address pain in the clinical setting? How is pain treated? and What concepts frame the importance of pain?

Paper #1 seeks to describe some of the ethical, legal, and social implications of pain treatment in the US , adopting a historical and comparative lens.

Paper #2 discusses pain and freedom from pain as a right that must be respected for all, from an American point of view.

Paper #3 examines the practice of pain control in end-of-life care, and the meaning of suffering in a Taiwanese context, while reflecting upon the cultural values that influence such clinical practice.

Paper #4 focuses on tensions between patients' health and welfare, versus beliefs that impact developments of effective pain management strategies in the Chinese context, as shaped by traditional philosophical and ritual backgrounds.

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Clinical Neuroethics: Cracking Brains and Healthcare Systems

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Based on a real-life scenario involving a military veteran with PTSD (post-traumatic stress disorder) and TBI (traumatic brain injury), I explore some clinical ethical issues evolving from emerging neurotechnologies. In this scenario, a veterans hospital (VA) requests a civilian hospital to perform an fMRI (functional magnetic resonance imaging) for an indication that has not been accepted in the civilian system of healthcare. This raises ethical concerns about differences in clinical translation of neurotechnologies and the lack of cooperation between services that deal with brain disorders. The fragmentation of the brain sciences may adversely impact a patient's interests in receiving speedy and adequate care. Moreover, this scenario reveals systems-level problems that create obstacles and concerns about safe discharge due to labeling illness, potential unnecessary use of expensive resources, and delays due to these concerns. In this paper, I will examine three issues. (1) I will address question of how to accommodate the patient's best interests in this case, given divisions between neurology and psychiatry and the silo-ing of different departments. I will consider concerns about pushing off difficult, time-consuming patients on each other. (2) I will scrutinize clinical criteria for the appropriate use of fMRI by focusing on the relationship between matters of scientific efficacy and value-laden considerations about the patient's best interests. I will include ethical concerns related to the translation of technology in differing healthcare systems, such as public healthcare systems versus other systems like the VA. (3) I will ask about the range of inter-

ests that should be taken into account in the use of fMRI in a hospital. Should they go beyond the strictly clinical? Should we allow the translation of a technology from bench to bedside sooner to facilitate the transfer of patients as in the present case, irrespective of the continuing methodological and scientific debates?

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Bridging the Gap: E-Ethics Joins Other Specialties in Medicine to Provide Distance Consultation

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As various forms of technology become increasingly integrated into the provision of healthcare, it seems only appropriate that clinical ethicists should consider how such technology might be leveraged to conduct clinical ethics consultation and education. Such technology is currently used by medical specialties to reach patients located in geographically more remote locations (eg, a wellness "check-in" for an elderly patient who lives 90 minutes from her doctor's office and cannot drive herself or find transportation, provide greater "on demand" care (eg, an "urgent care" visit for persistent cold/flu symptoms), assist with care at healthcare facilities where personnel resources do not include a particular needed specialty (eg, psychiatry consult for a nursing facility without a psychiatrist on staff). Not only does this approach meet the "convenience" demands of patients' busy modern lives, it also increases the cost efficiency of high-impact, low-burden healthcare related activities. Within our own healthcare system, we developed an electronic platform to provide ethics consultation support to hospitals within the healthcare system and to support developing ethics programs or programs with limited resources or that do not have formally trained ethicists at facilities outside the system. As distance/tele-medicine has done for intensive care units, e-ethics provides an innovative way for larger healthcare systems to meet the clinical ethics needs of multiple facilities without hiring multiple ethicists. In this presentation, we will discuss the development of our e-ethics program and platform, including challenges/lessons learned, and future directions.

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Providing Care for Patients Without Documentation: An End-Stage Renal Disease Case Study

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An estimated 11.7 million undocumented immigrants live in the US. Current federal and state policies significantly limit an undocumented immigrant's access to healthcare. Policy efforts in the US to address chronic health needs, like end-stage renal disease (ESRD) treatment, are denied for this segment of the population. Even recent legislation like the Affordable Care Act, which aimed to increase healthcare access, has further marginalized undocumented immigrants. The culmination of these legislative efforts leaves healthcare institutions and medical teams to grapple with treating undocumented patients, which may challenge our professional and moral duties to provide the best standard of care. We present a case in which an undocumented patient was in danger of losing vascular access for dialysis in his management of declared ESRD. The current approach to care was to have a patient wait until a critical need arose, due to the limited fashion in which care is mandated and reimbursed by applicable state and federal policies. The patient would arrive in emergent need of dialysis, have a temporary catheter placed, be dialyzed, and then the catheter would be removed and he would be discharged. This cycle would be repeated when the urgent need arose again. Concern grew within the team that vascular access might become compromised to the point that dialysis would no longer be possible. We adopted a rights-based capabilities approach that considered the patient's vulnerability in society. Our ethical framework views undocumented immigrants as integrated participants in our society and rejects the notion that they represent "the Other" in our community. We were able to convene a multidisciplinary working group whose aim was to develop a creative strategy for optimizing similarly situated ESRD patient. This approach recognized the pragmatic reality of limited resources and constraints imposed by the state and, in fact,

reveals the economic efficiency of providing non-emergent ESRD care.

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An Actual Advance in Advance Directives: Moving from Patient Choices to Patient Voices in Advance Care Planning

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Since living wills emerged 40+ years ago, challenges with advance directives (ADs) have been documented across healthcare settings and among different patient populations and cultures, especially the perpetual challenge of guiding clinical care utilizing pre-selected "choices" about specific interventions. Indeed, most ADs focus on choices regarding broad themes ("prolong life/do not prolong life," eg, which, lacking context, prove to be of limited meaningfulness) and whether or not to utilize particular interventions (cardiopulmonary resuscitation, mechanical ventilation, eg, about which most laypersons know little). Whether by foundational frame or decades-long misunderstanding in medicine and bioethics, or different societal customs, these ADs identify decision making for initiating, continuing, or withdrawing medical interventions as a patient responsibility—creating a burden for which most patients are unprepared and limiting healthcare providers' responsibility to mere technical application or customer service. At our institution, significant efforts have focused on embracing the unique and complementary responsibilities of patients (articulating their goals, values, and preferences) and physicians (using medical expertise to reach patients' goals) to enable appropriate plans of care. This includes restructuring our AD form to more accurately represent a patient's values as the frame within which physicians are responsible for determining appropriate care. Rather than specifying interventions, the AD makes patients responsible for specifying what matters to them and what they value in terms of function, interaction, and the level of acceptable burden, thus providing clear goals for clinicians to pursue—or, when goals are not reachable by available medical interventions, to acknowledge and allow for logical shifts to what may be achieved, including, in end-of-life contexts, care focused on respect and dignity. Using an engaging, multimedia PowerPoint, this presentation will outline how the simple shift in framework becomes a profound shift regarding patients' and providers' responsibilities, and ultimately, an advance in the realm of advance directives.

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Alfred Schutz, The Stranger, and the Unending Challenge of Engaging Ethics in Clinical Contexts

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The concept of clinical ethics consultants (CECs) functioning as strangers was an influential idea early on in the clinical ethics literature in the US (see, for instance, Agich, Barnard, Churchill, Hoffmaster). As CECs have become more common in the US and Europe, however, that discussion has receded. Nonetheless, attention to this motif deserves to be renewed and insights retrieved, especially as Singapore, along with other nations, nurtures its own response to clinical ethical issues.

Within that influential idea is a rich set of learnings likely to help people interested in cultivating the field of clinical ethics in cultural settings that have similarities to, but also significant differences from, the US and European contexts. More specifically, as explored in the generative work of sociologist-philosopher Alfred Schutz, the role of the stranger illustrates the ways by which, and through which, core commitments, values, and beliefs that are embedded in the practices and languages of different groups may become highlighted. For example, Schutz says the stranger is someone who "has to place in[to] question nearly everything that seems to be unquestionable to the members of the approached group." Acknowledging that CECs are often cast into the role of stranger—they are a new and different kind of "careprovider"—they have the opportunity to learn what counts as "taken for granted" and as typical "thinking as usual," and what serves as the "believed in" reality for the various individuals composing the different groups in a given clinical situation. Accordingly, an ongoing challenge for clinical ethics (and CECs) is to reflect on those important beliefs that underwrite various practices, while also engaging in discovery and learning about those sets of beliefs that are operating within the approached group. This

panel will explore these themes in the following way: The first speaker introduces the history and themes of "the stranger" in clinical ethics literature to briefly reflect on how and the extent to which this notion continues to be relevant. The next speaker summarizes Schutz's concept of stranger and identifies attributes that contribute recognizing and exploring a diversity of standpoints and meanings. Particular emphasis will be directed toward the movement from outsider to insider as useful for investigating the activities of clinical ethics consultation, whether these activities occur at the organizational level, in relation to clinical encounters in different units in a hospital, or among a variety of professional groups and practices. In that light, the third speaker turns explicitly toward the context of clinical and professional experiences of CECs, giving examples and opening up the conversation by asking questions about the role of CEC and about the influence the presented concepts might carry forward in the discourses organized around the role and development of clinical ethics consultation.

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How Do Cancer Patients Face the Approach of Death? What Do They Ask, Then, of Medicine?

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When cancer progresses and patients reach the point where no more curative treatments are available, the doctor-patient relationship often becomes strained. Doctors refer their patients to the palliative care team, but patients most often resist this. Their reluctance persists even when patients are referred to palliative care earlier, with the hope that, in doing so, they might better accept it later, when they will definitely need terminal care. Thus, doctors still wonder, in France as in other countries, how best to help their cancer patients prepare for their coming death. As a CESS (Certificat d'Etudes Supérieures Spécialisées), we implemented a research study to help answer this crucial question. We conducted individual, in-depth qualitative interviews with 47 patients who were at an advanced stage of cancer (M: 21, F: 27; mean age: 65 years; mean length of the disease: five years, interviewed between one and three months before death). They all had been told that no curative treatment remained available to them, and that they could now be best cared for by the palliative care team. We found that most of the patients were not interested in talking about death, even when they were perfectly aware that they might die soon. What was crucial for them was to keep up a feeling of hope and to remain connected to the dynamics of life up to the very end. Without hope, experiencing life is impossible to sustain, they said. For this reason, for the most part, patients asked for more chemotherapy, even when doctors had clearly refused to provide it, in light of a negative beneficence/maleficence balance. For patients, to continue chemotherapy maintained hope and allowed them to live relatively peacefully up to the very end. We will detail the results of the study and discuss them from a clinical ethics point of view.

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Ethical Issues in Clinical Practice: A Survey of Clinicians' Experiences and Views About Clinical Ethics Support

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There is ongoing discussion in Australia about the need for and the type of clinical ethics support (CES) suitable for hospital settings. We investigated the type of ethical issues encountered by clinicians in a large regional Victorian teaching hospital, how clinicians address these issues, and what type of CES they would find helpful. Hospital staff were invited to complete a validated survey, administered online. Approximately 8% (368) of all clinical staff completed most, or all, of the 20 Likert scale, multiple choice, and free text questions. 57% (208/363) of respondents indicated that they often or occasionally have ethical concerns in clinical situations. 69% (245/357) of respondents agreed or strongly agreed that ethical issues could be better handled, and 82% (294/358) indicated that there are some ethically complex situations where

more support might be helpful. The most frequent options selected for type of support were: having regular educational seminars on ethics and law (187/313, 60%), more "in-service" training or education (171/313, 55%), having an individual ethics and/or legal expert available for advice (162/313, 52%), and having an advisory group (155/313, 50%). Consistent with international developments, our research supports the development of clinical ethics capacity and the implementation of clinical support services.

1026

The Ethics of Living Skin Donation

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The use of living skin donors for the treatment of various conditions including burn wounds, scalp avulsion, and breast reconstruction is an uncommon occurrence in the US, but one that raises significant ethical concerns. Although living solid organ transplant centers in the US are required to implement informed consent procedures and to provide an independent advocate for living donors, to ensure their best interests and rights are protected, there are no such similar rules in place for living skin donors. Yet, living skin donors face many of the same challenges that living solid organ donors face, including healthcare concerns, financial considerations, the need to provide informed consent, psychosocial issues, and possible inducement, coercion, or other pressure. In fact, some of these issues may be of greater concern for living skin donors than for living solid organ donors. For example, because living donor skin grafts are not considered transplants, surgery on the living donor is not covered by insurance. In the case of donation for breast reconstruction, the decision to donate might be further complicated by the fact that, unlike in any other living donation, the donor receives a cosmetic benefit by undergoing the procedure (abdominoplasty). Finally, perhaps the most important concern in living skin donation is that the majority of donors are monozygotic twins or triplets. The pressure on these individuals as savior siblings may be greater than on any other kind of living donor. Our conclusion is that in settings such as the US, in which the protections given living skin donors fall short of those afforded living solid organ donors, the rules and policies governing donation should be expanded to ensure that the interests of living skin donors are addressed.

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Case Discussion: An Adolescent Requesting Removal of IUD Without Parental Involvement

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This is an interactive discussion of a case (suitably de-identified) that was referred to our clinical ethics service several years ago. The circumstances were medically straightforward, but socially complicated. It raised some ethical issues and questions that we have continued to ponder, including questions about the nature and ethical significance of competence in adolescence, whether refusal of treatment is ethically different in this regard from request for treatment, and whether the interests of people other than the patient can ever be given ethical weight in a treatment decision for an adolescent. In brief, the case involved a 15-year-old girl who presented to the emergency department alone, with abdominal pain, and requested nonstandard treatment of chronic constipation. She refused standard non-invasive methods of management, and wanted a manual disempaction under general anesthetic, a procedure that she had previously had done. She then asked for her IUD (intra-uterine device) to be removed under anaesthetic at the same time. She was adamant that her parents not be contacted. Her medical records showed that she had the IUD inserted with parental consent approximately six months earlier, and that she given birth the previous year, at age 14.

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Developing Medical Student Entrustment in Advance Care Planning: Challenges and Lessons Learned

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While physicians believe that end-of-life care and advance care planning (ACP) conversations are important, they frequently report that they find them uncomfortable and do not know what to say. To support ethical practice in healthcare through respecting the primacy of patients' welfare and patients' autonomy, training of clinicians in ACP is warranted. We developed a longitudinal educational intervention to develop a learner competency in ACP to meet this need. Such interventions will ultimately improve patient care in a significant ways and will foster providers' resilience in the face of what has been typically regarded as distressing. We will present our strategies, challenges, and lessons learned. Our intervention is focused on a concrete target: students will become competent to discuss advance directives with patients and families and to accurately document the patient's goals of care, in particular. A core team of educators determined the knowledge and skills needed to arrive at this competency. We located course and clerkship opportunities across the entirely of the undergraduate medical degree, so as to not add any required learner hours, and created a yearly schedule of faculty and staff development sessions on ACP. We also consulted educators whose learning objectives dovetailed with ours.

Strategic and process management skills are necessary to develop a longitudinal competency-based curriculum and must included in the calculation of workload: (1) managed communication is key amongst faculty and staff across a variety of courses; (2) educational information technology is necessary, as a competency dashboard is helpful; (3) faculty and staff development must be managed; (4) fostering a commitment to use shared language and definitions (eg, shared decision making, serious illness) across the medical school is also essential.

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Development and Deployment of a National, Online Supplement in Research Ethics: A Brazilian Experience

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Brazil is a continental country with over 200 million inhabitants and with a high turnover of research ethics committees (REC) members, who often receive inadequate support from institutions for their maintenance. There are currently 765 RECs in Brazil, and it is estimated that they comprise over 5,000 members. Despite the number of people involved in the ethical evaluation of research, there is a shortage of educational materials that target these members. Therefore, a Brazilian National Supplement was developed on the online platform TRREE (Training and Resources in Research Ethics Evaluation), in order to bring together information on research with human beings in a single document, adapted to Brazilian laws and regulations. This paper aims to describe the researchers' experiences in the design of the Brazilian National Supplement.

Results: The Brazilian National Supplement consists of educational and advisory material in ethics in research with the objective of helping qualify REC members to carry out ethical evaluations of research projects. It consists of 100 topics in 10 major areas, using the TRREE model. The working team consisted of 10 people from different professions and areas of activity and two experts who were responsible for reviewing all the material. The development of the material lasted 18 months, and legislation on ethics in research in Brazil was included. The Brazilian National Supplement will be available, at no charge, online through the TRREE Platform, http://elearning.trree.org.

Conclusion: Developing and deploying a national supplement in research ethics is a complex task. Specific steps should be followed for the educational material to be valid, and people must be available to work in a multi-professional team. Financial resources are essential for the provision of a national affordable online supplement. Despite the challenges, building a source of local educational material on research ethics is a feasible and necessary activity.

1030

What Kind of Neutrality? Keeping the Ethics in Ethics Consultation

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Many ethicists and healthcare providers are skeptical of the idea that ethicists can speak

authoritatively about ethical matters in practical contexts. Part of the worry is that when ethicists attempt to speak authoritatively, they end up ignoring the complexities of practical settings. Another worry is that ethical decisions are not the sort of decisions on which one person can authoritatively advise another. This skepticism has led to describing ethics consultation in the weakest possible terms, consulting that aims at conflict resolution and cultural and religious understanding within the constraints of organizational values. Although neutrality is often considered a virtue for how ethics consultation should be done, this approach falls into "hyper-neutrality." We delineate types and degrees of neutrality that often go overlooked. The implications of the hyper-neutrality approach are evident in the consultation process, the content of the recommendations, and the language used in ethics chart notes. We demonstrate how this approach can subtly affect ethics consultation by working through established consultation methods and cases. We argue that a hyper-neutral approach undermines the central motive for and potential benefits of enlisting ethics consultants, and that we should either refrain from identifying such practices with ethics or develop a robustly ethical conception of ethics consultation. Further, we argue that, with some careful distinctions and a firm sense of the limitations of ethical expertise, skeptical worries can be allayed and a robust sense of ethics consultation with proper neutrality can be supported.

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Impact of Moral Case Deliberation in Contemporary Healthcare institutions: An Integrative Review

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Over the past decades, multidisciplinary deliberations have been used to address moral questions and dilemmas that arise in patient care. Such deliberations have developed into a specific form of clinical ethics support, with various methods available. There is, however, little generalized empirical or conceptual evidence for the impact of those deliberations—partly because of the variety of ways in which the phenomenon is described in practice and in research (moral case deliberation, ethics meetings, ethics rounds, ethics consultations, etc). We conducted an integrative literature review on this rich phenomenon of "moral case deliberation." Because of the variety of terminologies that are used we executed an extensive search strategy to cover the field. We (qualitatively) analyzed both empirical (eg, observational, case, or evaluation) studies, which provide information about the current practice, as well as conceptual (eg, philosophical) papers, which provide statements about possible impact and results. In our presentation we will provide an overview of the following:

- Types of moral case deliberation and terminologies used to describe these,
- Expectations and conceptual assumptions for moral case deliberation by healthcare professionals, facilitators or researchers,
- Empirical evidence for the impact of moral case deliberation, for example on quality of patient care, ethical competence, professional well-being or interprofessional communication within a team,
- The relation between these expectations and assumptions, and the empirical evidence.

Often in contemporary fragmented and pluralistic healthcare institutions there is a lack of time and opportunity to thoroughly reflect on dilemmas together. With our review we hope to contribute to a shared understanding of moral case deliberation. This review provides support for implementation of moral case deliberation and may help convince stakeholders of its value. At ICCEC we would like to present our conclusions and discuss with the audience the basis and benefit of moral case deliberation in healthcare institutions.

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Difficulties in Approaching Individuality in Clinical Ethics

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The orientation to individuality or to the concrete ethical issues of each individual case, with its specific circumstances, is vital for clinical ethics. And yet, due to apparent obviousness, little attention has been paid to how it is possible for

ethicists to approach the individuality of the case at hand. This question is the topic of this paper. The first light in modern clinical ethics, against a principles-based biomedical ethics, was the revival of casuistry introduced by Jonsen and Toulmin. It is arguable, however, that casuistry is based on a typological way of thinking, in that it puts each case in question at a certain point between the two poles, paradigmatic cases in the typological matrix as a grounding. Without such a patterned tableau as a whole, a given case would be floating, and the method of casuistry itself would be impossible. Thus we should admit that, in casuistry, paradigmatic types have precedence over each individual case. Then how is it possible for ethicists to access and prioritize each individual case? We can utilize a psychological and hermeneutical work (1895-1896) by Dilthey, in which he explored the way to approach particular individuality, but in vain. In this paper, tracking down Dilthey's thought on individuation and homogeneity as a clue, and working toward an alternative, we argue for the legitimacy of the banner of clinical ethics, which claims approaching specific individuality of a given case as its the essential feature.

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Family Members' Experiences with and Views on Coercion in Mental Healthcare and the Possible Role of Clinical Ethics Support

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The use of coercion in mental healthcare not only influences the individual patient, but the whole family. However, there are few studies exploring family members' experiences with and views on coercion, and the (moral) dilemmas they face. The aim of this narrative study is to explore experiences with and views on coercion and involvement in care from the perspective of family members.

Methods: The empirical material includes three extensive semi-structured focus-group interviews and one individual interview with 20 adult relatives of adults with various mental health problems and experiences with coercion. Participants were recruited through next-of-kin organizations from the southern and eastern parts of Norway. Data were collected in 2012 and 2013 and analyzed using a thematic and dialogical narrative analysis drawing on a family ethics perspective.

Findings: Family members held various views on coercion, influenced by their practical experiences with coercion over time. We found four major themes of dilemmas in their stories: (1) the ambiguity of coercion, (2) their struggle to keep connected and establish collaboration, (3) worries and distress regarding compulsory care, dilemmas regarding initiating and exercising power, and (4) coercion.

Discussion: Family members' views and dilemmas should be broadly explored utilizing family and triadic perspectives. Coercion can reduce burden, but also adds burden by creating strains on family relations, dilemmas, (moral) distress, and retrospective regrets. These dilemmas are enhanced by lack of information, involvement and/or low-quality care.

Conclusion: There is a need to develop sufficient support and voluntary alternatives in the home to prevent coercion. Further, it is important to improve compulsory care and to support family relations when coercion takes place. Health personnel should provide more guidance and balanced information regarding coercion in order to increase family members' abilities to make informed decisions. Clinical ethics support could play an important role regarding the necessity for establishing dialogue and cooperation among stakeholders.

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Overcoming Professional and System Barriers to Achieving Patient-Centered Informed Consent

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The case of *Montgomery v Lanarkshire Health Board* (2015) in the United Kingdom has led to a growing interest in how healthcare institutions can promote better patient-centered consent processes. This symposium will focus on the development and implementation of informed patient decision-making policy at an academic teaching hospital

in Singapore, the National University Hospital (NUH). Four speakers, comprising members of the NUH Clinical Risk Management team, Hospital Ethics Committee, and Bioethics Centre will address the following topics, with 15 minutes for audience questions.

1. Determining the value basis and systemic implications of an informed consent policy. This presentation will briefly explain the reasonable patient standard from the case of *Montgomery v Lanarkshire Health Board,* and its implications for practice at the professional and system levels. It reviews the requirements of high-value, shared decision making between professionals and patients, the benefits and costs, and efforts to incentivize its implementation in practice.

2. Reasons for, and barriers to, achieving patient-centered informed consent at an Asian University Hospital. This presentation will report on the development of a quality improvement initiative for achieving patient-centered informed consent at the NUH, a tertiary care hospital, and a survey of healthcare professionals and administrators in NUH departments on their perceptions of the reasonable patient standard for informed consent, shared decision making with patients, and an analysis of participant feedback on reasons for and against, and barriers to, achieving this in practice.

3. Developing patient decision-making tools for improving informed consent to treatment at an Asian University Hospital. Patient decision-making tools or aids aim to improve patients' knowledge, understanding of risk, and participation in care decisions. Certification of patients' decision-making tools depends on best available scientific evidence on the risks attached to medical treatments and procedures, and capturing patients' values and preferences. This presentation focuses on a small-scale controlled trial of two decision-making tools for informed consent for elective surgery and/or an elective medical procedure at the National University Hospital in Singapore. Expert reviews of the two patient information leaflets (PILs) will be conducted for scientific accuracy, and face validity will be tested. A mixed-methods study combining a tool for measuring patient participation in decision making and a qualitative interview study will be conducted to assess the impact of PILs on patients' knowledge, accuracy of risk perception, and level of active participation in treatment decision making. The presentation will report on the work of the NUH with potential certifying authorities to incentivize systems improvement for achieving informed patients' decisions.

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Sowing the "SEED" for a Supportive Decision-Making Model

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Background: Despite the centrality of individual autonomy in Western bioethics, many clinical ethics dilemmas involving patients of diverse backgrounds highlight the need for attending to relational factors in considering treatment decisions. However, few relational tools exist to help healthcare providers (HCPs) support patients and families though complex decisions in ways that truly respect their agency.

Methods: This presentation focuses on findings from a multiphased Canadian qualitative study examining intersecting factors affecting patients' and families' abilities to make complex healthcare decisions between 2012 and 2016. Based on interviews with 41 HCPs, 86 patients, and 41 family supportive decision makers (SDMs) of diverse backgrounds in Vancouver, we developed a relational supportive decision-making model. Using treatment decision case examples, we then conducted three focus groups with 18 nonphysician HCPs and an additional eight physician interviews in Vancouver and Toronto.

Results: Based on HCPs' feedback, we refined a four-step iterative "SEED" model of relational decision making: (1) **S**eek collateral information, (2) **E**ngage in conversation, (3) **E**xplore options and preferences, and (4) **D**ecide with patient/SDMs, document, and debrief. The model provides HCPs with practical strategies, trigger questions, communication recommendations, and available resources for each step to engage patients and families. It embeds supportive and collaborative approaches at the interpersonal and system levels. By helping HCPs gather relational and contextual information regarding patients, the SEED model is designed to help anticipate the needs and resources that are necessary to support healthcare decisions that are made in relational and social contexts.

Conclusion: An iterative relational model may facilitate collaborative decision making that can empower patients and families in therapeutic encounters. Prospective collaborative studies including medical teams, patients/SDMs, and clinical ethics committees/consultants may also help to explore the long-term effectiveness of preventing decisional dilemmas at the bedside.

1036

Clinical Ethics Services in Tertiary Pediatric Hospitals in Australia and New Zealand: A Survey of Presence and Function

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Background: Ethical decision making in pediatrics is complex. A formal clinical ethics service (CES) can support clinicians and families in this often challenging arena. CESs are a relatively new concept in Australian and New Zealand healthcare, but are considered important by accreditation bodies for quality healthcare delivery, and are mandated in some countries internationally. There is, however, a paucity of evidence on which to base the development and operation of CESs. A description of existing services is a key step in developing consistent standards.

Objective: To explore the presence, purpose, function, and governance of clinical ethics services in tertiary pediatric hospitals in Australia and New Zealand.

Methods: One key person from each of eight tertiary pediatric facilities completed a 28-item, descriptive, quantitative survey about the person's local organization's approach to CES provision.

Results: 88% of facilities have access to a CES. All services provide clinical case consultation; 86% provide education, policy, and guideline development; and 57% undertake original ethics research. Case consultation practices are heterogeneous, with just over half of the services having a written policy for how consultations are conducted. Only three services always documented the consultation in patients' medical records. None of the services reported being funded by their local health service. Most rely on funding from charitable organizations and in-kind support from clinical staff and partner universities.

Conclusions: There is wide heterogeneity in how CESs operate in Australian and New Zealand pediatric hospitals. There is a need to develop consistency of practice, such as clear guidelines for consultation and for documentation of case discussions. Funding models for CESs need to be developed. Further research to describe and analyze case consultation processes, define core competencies for CES members, and understand activities in nontertiary, general hospital and community health settings where children are managed is required.

1037

Slow Ethics . . . Two Years On!

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At ICCEC 2015, we presented a case study of Jane, a young woman in her early twenties living with borderline personality disorder and a history of persistent and extreme self-harm. Over the past 10 years, Jane damaged her body to the point that multiple surgeons agreed that further surgery would not be in Jane's best interests. In 2015, we sought to further understand the appropriateness of palliation for patients living with chronic, life-limiting mental illnesses as well as to clarify the role of the Clinical Ethicist within the context of this particular situation. In this presentation we revisit Jane's story two years on. Jane's case was referred to the appropriate statutory authority, which determined that Jane had the capacity to make her own decisions. Should Jane lose capacity, her mother was acknowledged as her substitute decision maker. Following this assessment, Jane was discharged and cared for by her mother with some community support. In recent months, Jane re-presented with the request for comfort care only. After extensive consultation, her care was transferred to the palliative care team, and Jane was admitted to the palliative care unit. Staff found it difficult to care for Jane. Her challenging behaviors, perceived "dividing" of staff, caused a considerable disharmony and distress amongst the practitioners, particularly nursing staff. A number

of Compassion Cafés were facilitated to assist staff build to their capacity to care not only for patients such as Jane, but also to strengthen their self-awareness, self-care, and ability to respond appropriately to the multiple other complex and challenging situations encountered in the contemporary healthcare setting. In this presentation, we will discuss the role the clinical ethicist played in providing both consultation services and the facilitation of Compassion Cafés—a concept similar to that of Sautet's Café philosophique.

1038

Awareness, Attitude, Understanding and Perceptions towards Informed Consent among Patients Attending a Tertiary Care Hospital in Kerala, India

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Introduction: Patients' autonomy is an imperative issue in the health service area. It is known that patients' awareness of legal and ethical issues related to the consent process is often limited. The present study was therefore conducted to ascertain patients' awareness, attitudes, and perceptions regarding informed consent.

Methods: A structured interview schedule was developed and handed out to 343 patients attending the general surgery department at a tertiary care hospital in Calicut from January 2014 to June 2015.

Results: 88% of participants believed that they had no right to change their mind after signing the consent. 61.6% trusted their doctor to do the right thing and did not mind what happened to them provided they were made better. Level of understanding was satisfactory in only 32% of patients.

Conclusions: A great deal of misconception regarding the legal status of consent was seen. The study concludes that there are vast discrepancies in informed consent as perceived by patients. Current consent procedures seem inadequate as a means to express autonomous choice, and their ethical standing can be called into question.

1039

Ethics of Health-Related Quality of Life Influencing End-of-Life Decision Making and Futility of Care in Burn Patients

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Simply stated, health-related quality of life (HRQOL) is an individual's or group's perceived mental and physical health. These challenges are taken to the extreme in burn patients. The relationship of HRQOL with end-of-life care and futile care are well understood and clear. There are only a few articles discussing end-of-life (EOL) care and futility in burn patients; the majority of the articles essentially revolve around similar cases, and the articles that do discuss futility revolve mainly around survival. No article discusses the influence of HRQOL on EOL care or futility. However, there are significant ethical impacts of having HRQOL influence EOL and futility of care that are unique to burn patients. These ethical impacts include: burn patients are frequently not capable of making autonomous decisions about their own HRQOL, and the burn team may need to act on behalf of the patients. In addition, due to their unique injury, burn patients tend to focus on their current state as an indicator of HRQOL without realizing the potential for change in the future; therefore their view of HRQOL may be biased. The impact of cosmetic versus functional quality of life needs to be addressed, as treating these as equals could lead to an ethical fall out. The authors provide detailed analysis of each of these points with recommendations on how to address the influence of HRQOL on EOL decision making and futility of care.

1040

Ethical Choice Architecture? A Framework for Neonatal Life/Death Decision Making

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Shared decision making (SDM) to withhold or forgo life-sustaining treatment in neonatal intensive care is a significant matter of research and ethical debate. In current approaches, a number of distinct problems are incompletely addressed. Parents—the primary decision makers—request different degrees of participation and support in decision making. They are emotionally stressed and often have insufficient time for informed decision making. They struggle with translating medical facts into something meaningful to them, and are frequently faced with concealed value judgments and caregivers' treatment preferences. Probabilistic medical knowledge, moral values, and also the way choices are presented impact SDM. Ethical choice architecture merges these

aspects into a comprehensible and transparent framework that is concerned with helping parents to make decisions that serve the best interests of their affected infants and their families. Ethical choice architecture is based on three main pillars. (1) The scientific basis of medical information, including prognostic uncertainty and different levels of evidence, needs to be disclosed. Ethical choice architecture expects that caregivers are willing to support parents in a way that is most appropriate for them, irrespective of the caregiver's own moral and medical preferences. (2) Value judgments should be recognized and avoided or at least be communicated in an explicit and transparent manner. (3) Choice architecture techniques should deliberately be deployed. This may comprise: adjusting quantity and quality of medical information (eg, decision aids), framing of options (eg, defaults), giving feedback (eg, coherence), and narrative co-construction. Ethical choice architecture is a noncoercive, nonpersuasive, but structured and transparent approach that supports parents to the degree they request. It inheres a libertarian paternalistic view and a corresponding understanding of relational autonomy. In summary, a reliable and practical approach to neonatal life/death decision making is presented that takes human behavioral psychology and paternalism into account.

1041

Who Makes the Decision? Assisting Clinicians When Advanced Directives Conflict with Surrogate Decision Makers

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Mr N is a 98-year-old male nursing home resident with a medical history of dementia, congestive heart failure, atrial fibrillation, and a chronic subdural hematoma. He was admitted to the medical center due to a heart failure exacerbation, his ninth similar hospitalization in the preceding year. His hospital course was complicated by acute delirium that was attributed to interval worsening of his subdural hematoma. Review of records revealed that Mr N completed an advanced directive in 2009, which stated his desire to forgo life-sustaining resuscitation in this case. In addition to Mr N's prior advanced directive, there were conflicting reports in the chart regarding the presence of a court-appointed guardian and/or conservator, documentation suggesting that Mr N's son was his healthcare power of attorney, and documentation indicating alternating reversal of wishes by the patient and his guardian regarding resuscitation multiple times, even in the preceding calendar year. Further concern was raised when the suspicion arose that the guardian was not authorized to make proxy healthcare decisions. Court documents were not immediately available to the team. When Mr N's condition acutely worsened, a clinical ethics consult was requested to address the discrepancies regarding his prior wishes, his current code status, and the appropriate surrogate decision maker. This case highlights the challenges that clinicians face when they attempt to identify the correct surrogate decision maker, particularly when the distinctions between types of advanced directives and surrogate decision makers are not evident. It also emphasizes the role that organizational ethics and systems play in individual decisions. As increasing numbers of geriatric patients age to a greater risk of dementia and need for court-appointed guardians, this issue of balancing patients' autonomy and system efficiency is very important, and indicates a need for pervasive systems-based interventions related to end-of-life care issues.

1042

Ethics Consultation Involving Potentially Unsafe Discharges: Use of an Ethics Rubric for Assessing Discharge Readiness

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Many ethics consultations require prudence in navigating tensions between respecting autonomy and professional duties to benefit and protect patients from harm. A common example of this in our practice setting is an ethics consultation involving a potentially unsafe discharge. In such circumstances, providers and discharge planners often recommend that the patient be discharged to a facility that may be able to better accommodate nursing care needs and continue care that began in the hospital. However, in some cases, providers request an ethics consult when patients decline a recommended disposition and express a preference to go home or to a place that professionals perceive to be less than optimal, or unsafe. The role of ethics consultation in such cases is often to find a way to negotiate the values behind such expressed preferences by the patient and the professional commitments of caregivers. Sometimes, such negotiation is unable to establish a viable

option that meets all value commitments. When such "viable" options are not feasible, ethics consultation may provide moral confidence that such a discharge is safe enough and ultimately respects the patient's autonomy and sufficiently fulfills or demonstrates professional obligations to protect patients from harm. This paper outlines the development and application of a rubric to assess a patient's discharge readiness through the lens of an ethics consultation wherein competing values and professional duties are in tension.

1043

Virtues of Moral Case Deliberation Moderators
Authors:

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Considerable attention has been paid to the "competencies" that clinical ethicists need to acquire in order to do their work "professionally." Far less explicitly mentioned are the "virtues" that would support professional clinical ethicists to do their work properly. In this paper, we focus on clinical ethicists' role as moderators in clinical moral case deliberation (MCD). We argue that an explicit virtue ethics approach towards moderating is both desirable and necessary. Taking a specific MCD that was recently moderated by a colleague in our clinic as an example, and taking into account observations of and retrospective reflections on multiple MCDs by colleagues, we analyze and argue dialogically how the virtues of the moderator may play an essential role in the successful proceedings of this MCD. We will concentrate in our analysis on the interplay of the four cardinal virtues: prudence, justice, temperance, and courage. In our presentation, we will elaborate on the possible added value of the concept of virtue and the concept of competence. The intrinsic relation between virtues and the internal goals of a MCD, and the close relation between emotion, attitude, skill, and judgment in virtue. In addition, we will discuss how the cardinal virtues support the role of the moderator. This paper is the first step of a larger empirical-ethical project to explore whether and why virtues are important for MCD-moderators and other participants, which virtues are important, and how we can cultivate them (if they are important). We will follow two tracks that contrast and support each other: (1) an empirical explorative approach towards daily practice of MCD in our clinical wards and (2) a philosophical-theoretical track focusing on theoretical insights concerning virtues. We invite attendees of our session to join us in our dialogue on the role of virtues in MCD.

1044

Defending the Right to Starve: Hunger Strikers and the Right to Refuse Treatment in Israel
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In 2015, the Israeli Knesset passed the Force-Feeding Act that permits the director of the Israeli Prison Authority to appeal to the district court with a request to force-feed a prisoner against his or her expressed will. A recent position paper by top Israeli clinicians and bioethicists, published in Hebrew, advocates for force-feeding by medical professionals. The paper presents several arguments to support its assertion. In this presentation, we posit three interrelated questions: (1) Do prisoners have a right to hunger strike? (2) Should governing institutions force-feed prisoners and/or is it ethical to force-feed prisoners? (3) Should healthcare professionals force-feed prisoners? We will focus on the first and third questions. We first briefly provide several arguments to support the right of Palestinian prisoners to hunger strike. Next, we critically review the arguments presented in the Israeli position paper, demonstrating that they are all misguided, at best. Lastly, we briefly present arguments against force-feeding by medical professionals, the most common (and strongest) being the patient's right to refuse treatment.

1045

Health Research in Humanitarian Crises: Towards a Post-Research Ethics Framework
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Distinctive ethical challenges regarding the conduct of health research in humanitarian crises have been identified and addressed in the current research ethics literature. However, despite significant contributions, widely accepted guidance on the issue is lacking. Given that existing ethi-

cal guidelines do not readily translate to health studies in challenging situations that are rapidly changing, when immediate attention and response is required, research investigators, IRBs (institutional review boards), and other stakeholders who are involved in these unique circumstances must consider decision strategies that are different from those used in "normal" settings. It follows then that a humanitarian research ethics framework in light of evolving situations is necessary to provide guidance on how research protocols should be developed and assessed. What should be the ethical principles that guide research in these circumstances, when there is great vulnerability and pressing humanitarian needs. A balance between therapeutic access and scientific endeavor should be achieved. This presentation will describe the initial findings of our project: "Post-research ethics analysis: a tool for ethical reflection and sharing lessons learnt from health research in humanitarian crises," which aims to improve good ethical practice by gathering evidence on actual experiences of research ethics issues by researchers, research ethics committees, and other stakeholders when conducting health research in humanitarian settings. We will present the fundamental ethical issues raised in research in humanitarian settings, as they are identified in the current literature, and discuss the limitations of current guidelines and regulations to provide an effective tool of guidance to those involved in such studies. We will then explain how our project seeks to address existing gaps by developing, testing, and establishing a tool to analyze and share ethical challenges encountered in health research in humanitarian crises.

1046

Ethical and Social Issues in Fecal Microbiota Transplantation

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Fecal microbiota transplantation (FMT) has demonstrated efficacy and is increasingly being used in the treatment of patients with recurrent clostridium difficile (C. diff) infection. Despite a lack of high-quality trials to provide more information on the long-term effects of FMT, there has been great enthusiasm about the potential for expanding its applications. However, FMT presents many serious ethical and social challenges that must be addressed as part of a successful regulatory policy response. In this paper, we draw on a sample of the scientific and bioethics literature to examine clusters of ethical and social issues arising in five main areas: (1) informed consent and the vulnerability of patients, (2) a determination of what a "suitable healthy donor" is, (3) safety and risk, (4) commercialization and potential exploitation of vulnerable patients, and (5) public health implications. We find that these issues are complex and worthy of careful consideration by healthcare professionals. The desperation of a patient should not be the basis for selecting treatment with FMT, and the patient's interests should always be of paramount concern. Authorities must prioritize development of appropriate and effective regulation of FMT to safeguard patients and donors, promote further research into safety and efficacy, and avoid abuse of the treatment.

1047

The Ethics of Fertility Preservation for Prepubertal Children: Should Clinicians Offer Procedures Where Efficacy Is Not Proven

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Young children with cancer are treated with interventions that can have a high risk of compromising their reproductive capacity. Techniques aimed at maximizing reproductive potential for these children are being developed and evaluated. "Fertility preservation" for children who have not yet reached puberty involves surgically removing and cryopreserving reproductive tissue prior to gonadotoxic therapy or gonadal decline, in the expectation that strategies for the use of this tissue will be developed in the future. Fertility preservation for prepubertal children is ethically complex because these techniques lack proven efficacy for this age group. Current guidance from professional bodies is insufficient, and clinical practice varies substantially from center to center. The key question addressed in this paper is: When, if ever, is it ethically justifiable to offer fertility preservation surgery to prepubertal children? We present the ethical concerns about prepubertal fertility preservation, drawing both on the broader

literature about pediatric fertility preservation and our experience discussing this issue with clinicians in clinical ethics case consultations at the Royal Children's Hospital, Melbourne. We argue that offering the procedure is ethically justifiable in certain circumstances. For many children, the balance of benefits and burdens is such that the procedure is ethically permissible but not ethically required; it is the parents' decision to make. We suggest that an ethical approach to prepubertal fertility preservation requires more than reliance on research ethics protocols. We argue that clinical ethics processes are useful to assist clinicians to engage with the ethical issues and enable each case to be examined individually, and describe the clinical ethics process that evolved at our hospital.

1048

Gamete Donation: Islamic Sunni and Shia Perspective

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Artificial reproductive technologies (ARTs) have been practiced in Islamic societies by married couples since their introduction. However, there are divergent views over the issue of gamete donation among Sunni and Shia scholars. This paper illustrates the different views of Sunni and Shia Muslims surrounding gamete donation practices, and ethical issues involving gamete donation in the Islamic world. The study was based primarily on a combination of examination of available literature and some primary sources, ie, relevant verses from the Quran, relevant *hadiths,* and various *fatwas* of Sunni and Shia religious clerics. The literature was retrieved from various databases such as Web of Science, PubMed, BioMed, Philosopher's Index, and Google Scholar, using the following key words: egg donation Islam, sperm donation Islam, assisted reproduction Islam, gamete donation Islam, and *fatwas* and ARTs Islam. The study found that Sunni religious scholars are totally against third-party donation and argue that third-party donation is a breach of the marital contract between husband and wife. They also assert that it confuses kinship, descent, paternity, and the law of inheritance, and may lead to incest among the offspring of donors. On the other hand, the Iranian Shia religious scholar, Ayatollah Khamenei, proclaimed a *fatwa* permitting gamete donation with certain religious conditions. His *fatwa* has paved the way for gamete and embryo donation and has evoked certain reactions from other Shia scholars. Recently, the Iranian parliament passed an act on embryo donation. But the conditions stipulated by Shia religious scholars in their *fatwas* contradict the general practices of gamete donation. This paper argues that the lack of laws and guidelines on ARTs raises many ethical concerns about gamete donation. When based only on religious decrees, gamete donation has been practised in a vacuum of legal and ethical frameworks without consideration of the well-being of a donor child.

1049

Narrative Ethics and the Response to Suicide Threats

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Speaker 1 presents case studies of suicide threats and attempts. She compares the responses of medical personnel to patients who make serious and completed suicide attempts to threats or gestural attempts made repeatedly by people who have not actually made an attempt or who have only made mild attempts. One representative male patient drinks heavily and when his partner kicks him out of the house, he presents to the emergency department (ED) where he seeks shelter, food, and care, stating he is suicidal. Using his case and others, we discuss the ethical options for how to respond to repeated threats of suicide. Within the American/Maine health system, patients like this can present repeatedly with threats of suicide that resolve in several days. Medical personnel express their anger at such patients for overutilization of resources. When we adopt a narrative perspective and collect the stories guiding behavior, these patients appear to be optimizing available resources. Questions arise as we seek solutions. Should the number of times a person presents to the ED with claims of being suicidal be limited? Can we establish levels of suicidal risk for which we will not intervene in a litigious society like the US?

Speaker 2 moves this discussion to indigenous suicide attempters in Canada and how we can address them. A total of 54 patients were interviewed in depth. The mean age was 21.0 with a standard deviation of 6.1 years. Psychotherapy proceeded with 27 of this group. Twenty-four of

these patients made no further suicide attempts. No patients completed suicide. Psychotherapy lasted an average of nine sessions, the range being one to 16 sessions. Frequency ranged from weekly to monthly. Of the patients who did not engage in psychotherapy, 21 attempted suicide again at least once. Average length of follow up was 15 months, while the range was from five to 19 months. Medication was available to these patients if desired. Twelve patients chose to take medication (primarily SSRIs), five from the group who did not choose psychotherapy, and seven from the group who did. Review of the life story interviews revealed three common plots/themes preceding suicide attempts: (1) The break up of a relationship, usually sudden, unanticipated, involving a third person. (2) Being publicly humiliated by another person(s), accompanied by high levels of shame. (3) High levels of unremitting, chronic life stress (including poverty) with relative isolation.

Speaker 3 reviews five common strategies successful in psychotherapy with Aboriginal suicide attempters: (1) Create delays and alternative pathways from the habitual thinking that occurs before a suicide attempt. (2) Among these alternative pathways, create a sense of narrative agency of being a person with other options for revenge and other ways to show people how great the hurt has been. (3) Build narrative competence by assisting the Aboriginal suicide attempter to build and rehearse stories of positive futures, face-saving when necessary. (4) Find islands of humor. (5) Engage culture and elders to the extent possible. We conclude with discussions about responses to suicide threats that balance cost and effectiveness.

1050

The Weight of Expectation: Challenges in Implementing Advance Care Planning

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This paper focuses on a qualitative study conducted in Singapore that explored the perspectives of 61 doctors, nurses, medical social workers, caregivers, and patients with life-limiting conditions, on advance care planning (ACP). A dominant theme that emerged from the study was participants' expectations. Patients' and caregivers' expectations regarding ACP conversations were dominated by genuine concerns such as making the wrong decision, causing the patient to lose hope, and not burdening family members. Healthcare professionals' expectations, to a limited extent, reflected those of patients and caregivers. They expected that ACP conversations might burden family members and cause patients to lose hope, but they were also concerned that ACP may not be beneficial if it is not legally enforceable, and it may not be helpful to some patients, such as those who refuse to make decisions, preferring instead to defer to the family member who is paying for treatment. ACP has been introduced to give patients a structured and supported opportunity to express their future preferences for healthcare, and thereby respect their autonomy. However, ACP also has the potential to significantly disrupt the settled expectations of healthcare professionals, patients, and caregivers, with respect to decision making at the end of life. This paper will explore the societal and legal framework that created these expectations and allowed them to flourish, and consider steps that could be taken to sensitively and successfully implement ACP.

1051

Clinical Ethics Consultations at an Academic Hospital in South Africa: Challenges and Opportunities

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A clinical ethics committee (CEC) comprised of 11 members, was established eight years ago at an academic public hospital in Cape Town, South Africa, with two goals—first, to assist clinicians with difficult decision making in the face of ethical dilemmas, and second, to develop policy on critical and recurrent dilemmas in the hospital. The CEC meets quarterly for a formal discussion and on an *ad hoc* basis, at the bedside, for urgent referrals and consults. When possible, the CEC meets with the treating medical team, the patient, and family members. Most of the referred cases to date have involved withdrawal of treatment. Other cases have included termination of pregnancy, Jehovah's Witnesses who refuse blood transfusions, and other treatment refusal such as amputation, treatment of foreign nationals, HIV testing and treatment, pediatric consent, and the use of off-label drugs or innovative therapies in the clinical setting. Policy development on refusal of blood transfusions and withdrawal of treatment have

been prioritized over the past two years. Since its inception, the CEC has continued to play an important role in the hospital and is in use by various departments; the medical, surgical, and neonatal intensive care units (ICUs) call on the CEC most frequently.

1052

Are Palliative Care Patients Too Vulnerable to Participate in Research? Perspectives on an Ethical Dilemma

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Good medical practice requires evidence of effectiveness to address deficits in care, strive for further improvements, and justly allocate scarce or finite resources. Those who deliver palliative care are dedicated to providing the highest quality of care that supports all of the needs of the patient as a person. Scientific advances in this field are partially limited by perceived ethical challenges that distinguish dying patients as a vulnerable population who require special protections, thus limiting their participation in research. For example, only 13% of studies in the palliative care literature involved patients in the last month of life. There has been debate of this issue in the literature for almost 15 years, leading to the conclusion that, provided investigators compassionately apply ethical principles to their work, research involving palliative care patients is justified. Our panel, consisting of bioethicists, palliative care physicians, and clinical investigators, will discuss many important themes related to conducting research in palliative care populations, including (1) the needed precautions for research in a perceived vulnerable population, balanced with the need for an evidence base for quality of care and access to the best options (Moore and Zhukovsky); (2) unique burdens and benefits (Zhukovsky); (3) concerns regarding informed consent, voluntariness, and decision-making capacity (O'Toole); (4) logistical difficulties (Hui); (5) conflicts of interest (Hui); and (6) rigorous review of research proposals (Hui and O'Toole).

We will revisit the debate regarding what constitutes vulnerability, what protections are necessary, how this can be balanced with access to and general advancements in quality improvements, and the importance of conscientious scientific design and rigorous review, by presenting both sides of the argument. Ultimately, although there is concern about research in what is widely considered a vulnerable population, research that has been rigorously reviewed for adherence to regulations that are meant to protect all research participants and provide access to quality care should be permitted. At the conclusion of this presentation the audience member will be able to: (1) Recall the elements of good research design that have been identified by others as areas of concern for the ethical conduct of research in a participant population considered to be vulnerable. (2) Articulate arguments as to how and why research can be conducted in the palliative care patient population, even at the end of life. (3) Integrate sound ethical approaches regarding clinical research into their own palliative care practices.

1053

Jehovah's Witness and Liver Transplant: Ethical Dilemma

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Background: Jehovah's Witnesses present a unique challenge in medical management. Religious concerns play significant role in the clinical decision making of these patients. The issue of transplantation is not straightforward and is compounded by the refusal of blood transfusion. Transplantation itself was not allowed for Jehovah's Witnesses until the 1980s. Witnesses view a decision to transplant as an individual choice, under the assumption that no blood is transfused. We present an unusual case of an ethical dilemma of a Jehovah's Witness who is being considered for an orthotropic liver transplant.

Case report: A 58-year-old male Jehovah's Witness was diagnosed with hepatitis C cirrhosis and decompensated liver disease. The patient has grade 1 encephalopathy post-trans jugular intrahepatic Porto systemic shunting. Patient has a modified end-stage stage liver disease score of 9. He has a history of intravenous drug abuse but is currently clean. He lives with his wife and daughter and has a good family support. His pre-operative investigations are normal. He has been discussed at the multidisciplinary meeting for orthotropic liver

transplant. The salient points of the meeting are follows:

- Meeting attended by transplant surgeons, anaesthetist, psychiatrist, hematology, hepatology
- Patient will accept only cell saver or synthetic blood products
- Patient is happy for liver transplant
- In the meeting it was said that liver transplant would improve the quality of life of this patient.

Discussion: This is a unique case in terms of professionalism and the ethical issues involved with religious-belief-driven clinical decisions in treatment for Jehovah's Witnesses. First, refusal of blood transfusion for a liver transplant surgery that involves significant blood loss, putting the life of patient at risk; second, giving an organ, which itself is precious and rare, to someone for whom there is high risk of organ failure due to patient autonomy.

1054

A Doctor in the House—Ethical Considerations When Doctors Treat Themselves and Those They Are Close To

Author:
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Having a doctor in the family is often regarded as beneficial, as there is easy access to medical advice and care. It is common for doctors to treat themselves and those they are close to, and some doctors even consider it their right to do so. However, such care arrangements are not without pitfalls. Primarily, being in a close relationship with someone and being their doctor simultaneously can impair a doctor's judgement about the correct diagnosis and course of treatment. The lack of clinical objectivity can, in turn, lead doctors to treat problems that are beyond their skill and competence or to be pressured to do so by someone close to them. Other pitfalls include trivializing or overtreating a medical condition, failing to document the care provided, and making assumptions about a person's medical history and personal circumstances such that the doctor avoids asking sensitive questions or omits to take a full history and to examine the patient. Consequently, despite good intentions, doctors may not provide the best quality treatment to those they are close to. This paper explores the ethical issues that arise when doctors treat themselves and those they have a close relationship with. It argues that in the vast majority of clinical situations, doctors should not engage in such care arrangements, and explains why it is important for doctors to have their own general practitioner. Several cases when doctors have been censured by the Medical Council of New Zealand for engaging in self-treatment or in treating those they are close to will be discussed. The paper concludes by outlining exceptional circumstances when it may be appropriate for doctors to treat themselves and those they are close to, and what measures they should take, in those instances, to safeguard themselves and those they treat.

1055

Aid-in-Dying Session

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In October 2015, the End of Life Option Act legalized physician aid in dying (PAD) (also commonly called physician-assisted suicide) in California. Hospitals, healthcare providers, and health agencies then had until mid-June 2016 to decide whether they would opt in or opt out of providing PAD and create policies and work flows to respond to requests when the law became active. Kaiser Permanente (KP) is the largest managed care organization in the United States, and its two largest regions are in California, accounting for 11 million members, divided fairly evenly between northern California (NCAL) and southern California (SCAL) (together, roughly 28% of the population of California). Although each region is a part of the parent organization, the regions operate with significant autonomy. KP in California had two advantages in responding to the new law: (1) KP had experience providing PAD in its Pacific Northwest regions (Washington State and Oregon), and (2) KP had clinical ethics leadership in both of its regions to provide direction. KP NCAL and SCAL worked independently and collaboratively to prepare for PAD.

This one-hour symposium will include ethicists from the NCAL and SCAL regions and will seek to provide insight into the regions' processes, approaches, moral concerns, and strategies for addressing PAD. With thousands of doctors in the Permanente Medical Group, and thousands of potentially qualifying patient-members, ethicists

at KP were in the middle of a storm of evolving attitudes toward death, the practice of medicine, and changing institutional policies. California is the fifth state to legalize PAD, and it is thought that adoption will now accelerate in other states.

This Symposium will break down as follows: three speakers, speaking for combined total of 30 to 35 minutes, leaving 25 to 30 minutes for panel discussion and questions. The speakers and their specific topics are as follows.

Speaker 1 will speak specifically on the work done preparing for PAD roll out in NCAL, collaboration with SCAL and other healthcare organizations, and obstacles faced. Specific attention will be given to the role ethics played in the process.

Speaker 2 will speak on the 11-months-later perspective. KP has been collecting both quantitative data and qualitative information about the PAD experience. Moreover, the ethics committee will begin a review process at the six-month mark to address concerns, processes, and unforeseen matters regarding PAD. ICCEC 2017 occurred 11 months after PAD went into effect in California, and relevant information will be provided on nearly a full year of work.

Speaker 3 performed a values clarification exercise with approximately 150 physicians prior to and as the legislation went into effect, in an effort to establish a baseline of physicians feelings about PAD, and to help guide policy implementation. The speaker will present her findings as well as information on the learnings in Southern California.

1056

Decisional Capacity and Autonomous Choice with regard to the Jehovah's Witnesses Blood Policy: A Study in Justified Paternalism

Author:
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The position of the Jehovah's Witnesses (the Watch Tower Society) on the refusal of blood transfusion has long been a matter of consternation for healthcare providers. Although the courts have ruled that the decisions of competent adults must be respected, and healthcare providers have come to appreciate the need to care for the whole person—including respecting beliefs that may appear irrational or harmful—dealing with individual believers can still be a source of moral distress. The Watch Tower Society has done an admirable job of establishing hospital liaison committees to educate healthcare providers about its beliefs with regard to alternative, bloodless surgical procedures, and to support Jehovah's Witness believers in navigating the healthcare system. Nevertheless, many still struggle with whether it is ethically appropriate to challenge individual believers about their beliefs and/or to attempt to persuade them otherwise. In this paper I revisit the question of autonomous choice and justified paternalistic intervention as it pertains to members of the Jehovah's Witness faith. Central to the argument is the general claim that identifying with a particular faith community does not entail that one subscribes to every particular belief. This is true for Roman Catholics, Muslims, Buddhists, and virtually any faith tradition. While the official orthodox position of the Watch Tower Society with regard to that church's beliefs is one thing, the specific beliefs of any individual Jehovah's Witness could be quite another. Hence it behooves healthcare providers to explore the individual beliefs of particular patients and to engage in debate when necessary. I argue that such paternalistic intervention can be justified, and in some instances may even be morally required.

1057

Why Do Ethical Standards Drop among Interns in Medical Settings? Ethical Erosion in Medical Psychology as a Test Case for Other Medical Professions

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A previous study found that psychology interns in medical institutions tended to ignore ethical issues more at the end of their internship than at the beginning. This lowering of ethical standards, termed ethical erosion (EE), was found to be a risk factor for moral distress (MD). Consulting relevant others has proven crucial to coping with ethical conflicts. The current follow-up study examined reasons for EE and interns' patterns of consultation regarding moral and ethical concerns. Findings indicate that the three leading reasons for EE are as follows. (1) Fearing damage to self ("my professional future is in the hands of my seniors, so I had to keep quiet") (M=3.77, SD=0.172). (2) Obeying authority due to pressure and submission ("my seniors pressured me into falling into the conventional behavior patterns") (M=3.6, SD=0.152). (3) Avoiding conflict or confrontation ("I knew what the right way to act was but felt uncomfortable doing so") (M=3.48, SD=0.177). Those reasons

for EE correlate with interns' preferences regarding whom to consult. For example, the more interns feared damage to self, the more likely they were to consult with friends or family outside a medical institution, while the more interns complied with authority as matter of principle rather than pressure, the more they tended to consult in-house supervisors. The findings are organized according to notions of ethical silence and the distinction between two styles of assimilation ethical norms: (1) blind obedience versus open-minded-adherence and (2) the idea that ethics is a never-ending project among all the medical professions.

1058

Evaluation by Case Series: Top Themes of Ethics Consultations in Psychiatry as Compared to Somatic Medicine

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Background: Clinical ethics support (CES) in psychiatry, especially its acceptability, is still developing. Its evaluation can strengthen the quality and reputation of the field. Evaluation research on CES in psychiatry is even rarer than in somatic medicine.

Approach: What are the top issues brought to ethics consultation (EC) in psychiatry in comparison to somatic medicine? This question was investigated in a series of 50 psychiatric and 50 somatic cases of EC on demand. Classification of themes and evaluation judgments were made by at least two researchers.

Results: Among the 100 cases, the top five themes were (1) coercion (28%), (2) care management (24%), (3) treatment plan evaluation (17%), (4) end-of-life-care (16%), and (5) pregnancy/assisted reproduction (12%). In EC in psychiatry, the most significant ethical issue is coercion (34%), followed by care management and treatment-plan evaluation (both 20%). In EC in somatic medicine, the top three ethical issues concern (1) end-of-life care (28%), (2) pregnancy/assisted reproduction (22%), and (3) coercion (20%). The issue of decisional capacity was given in 34% of all EC in somatic cases, while only in 10% of all EC in psychiatric cases; competence was more often impaired or questioned in EC in psychiatry (40% resp. 22%) than in EC in somatic medicine (24% resp. 12%). In total, a patient's competence is either unclear, impaired, or not given in 77% of all EC cases. Feedback from requestors as to whether CES was helpful was positive in both fields (100%).

Conclusions: As EC in somatic medicine and in psychiatry focus on partly different topics, ethics consultants need to prepare for handling these themes competently. Learning from the advanced evaluation of CES in somatic medicine is certainly useful for CES in psychiatry, although EC in psychiatry does require specific adjustment.

1059

Healing Conflict? Mediation in End-of-Life Care

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End-of-life care presents myriad challenges for healthcare institutions, clinicians, patients, and their families. Factors such as advances in medical technology, different opinions as to prognosis and treatment, and various cultural and family dynamics all have the potential to create a climate of high emotion, dissension, and conflict. In an acute critical care setting, there is often limited time and expertise for institutions and clinicians to focus on dealing with conflict, as well as the medical and ethical complexities that may arise in end-of-life decisions and care. Such tension is frequently required to carefully balance the desires of the patient with the often-conflicting wishes of family members and surrogate decision makers. It is often said that 10% of conflicts are due to differences in opinion and 90% are due to the wrong tone of voice. Mediation provides a powerful means to allow parties in a dispute to communicate and to be heard. It presents an opportunity to assist parties to identify issues, recognize interests, develop options, and consider alternatives to empower them to make decisions in an effort to reach an agreement and resolve the dispute. This presentation will identify the nature, causes, and the cost of conflict in end-of-life disputes. It will explain the process of mediation and the role of a mediator. This presentation will then explore how mediation can be used as an effective tool to resolve conflict, and to establish agreement in order to deliver the best quality end-of-life care for the patient.

1060

Personalized Medicine Challenges Boundaries Between Research and Care: Could Ethics Consultation Provide Answers?

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Personalized medicine, sometimes labeled as a "new paradigm for healthcare," refers to the tailoring of care according to patients' individual attributes, especially in relation to their genetic and molecular profile. In practice, this personalization means moving toward treatments that have been targeted to small patient groups, potentially subcategorizing the patients into ever-smaller groups, as understanding and technologies improve. In order to personalize treatment according to patients' genetic profiles, patients would have to go through much closer genetic screening during the span of their treatment. For example, since the genetic profile of cancer cells changes as the disease develops, the need to constantly analyze patients' genetic profile is raised. How does this affect the traditional roles of the different kinds of professionals involved? Should scientists' findings routinely influence treatment? These scenarios challenge traditional boundaries between research and care, as typically the lines have been drawn between scientific advancement and individual health benefit. Even though participating in research may have the potential to lead to individual health benefit for patient-research subjects, health benefit should not be the reason to participate in medical research. Blurring the lines between treating a patient and carrying out scientific research raises many ethical questions—for example, concern for potential hidden conflicts of interest—as it may be harder for outsiders to distinguish treatment goals from research interests. As personalized medicine brings clinicians and scientists closer to each other, flexible structures may be needed to allow free flow of communication, moving between the IRBs, clinical ethics committees, patients, clinicians, and scientists in cases that raise conflict or concern. We suggest that when visible, traditional lines of communication become blurred, creating bridges of communication and identifying ethical issues may be roles suited for ethics consultation services.

1061

Incidental Findings and Data Sharing: From Perspectives to Consensus Policy

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The growth of genetic testing for clinical purposes worldwide has raised a number of ethical concerns, including the reporting of incidental findings (ie, findings not originally sought in a test or intervention but that may be relevant to the patient) and sharing of clinical data with researchers. Absent formal legal regulations, resolving these issues requires institutions to develop local policies. Consensus policy guidance is desirable, because it (1) provides institutions with a well-reasoned and informed framework; (2) creates consistency, leading to less arbitrary differential treatment based on institution; and (3) is more likely to be taken up, due to its consensus nature. In this paper, we report on a Singaporean project that uses empirical evidence to develop such local consensus policy guidance. After analyzing the latest literature on incidental findings and data sharing, we developed a structured focus group approach. Stakeholders (both clinicians and patients) were presented with a set of circumstances and policy options, and asked to discuss and justify their policy preferences. We also report on the outcomes of follow-up stakeholder workshops that were facilitated in Singapore with the purpose of generating consensus on key aspects of incidental findings and data-sharing policies. The workshop and focus groups then formed the basis for a set of consensus policy white papers for adoption by Singaporean institutions. Our findings and experiences will be of interest to those studying the ethics of incidental findings and data sharing, particularly those from countries that are also in the process of developing locally tailored ethics policies related to clinical genetic testing.

1062

Explaining Ethics Consultations in a Video

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Although clinical ethics consultation (CEC) has been established in our hospital for years and is well known to long-standing staff, patients and next-of-kin usually have their first contact with CEC as the result of an (unplanned) stay in the hospital. Even if somebody has informed them about it beforehand, it is still difficult for next-of-kin to

imagine what will happen during a consultation because of the stress they are under and the decisions they have to make. Having often experienced this problem, the Ethics Committee at our hospital decided to make a video showing the course of such a consultation. This video is available to next-of-kin or other interested parties on the internet and can also give hospital staff a better insight into the procedure. For the Ethics Committee, it was not only the finished video that was important, but also the creative process and the writing of the screenplay: the video shows an anonymized consultation in which all the participants play themselves; only the two family members are played by members of staff. But which elements of an ethics consultation was the video to highlight? Which elements were particularly important? Which elements required further explanation? In writing a screenplay for the internet, all of the participants were forced to reach an agreement about the central content and principal message of the video, in the full knowledge that their underlying approach or method would become public. One of the things that came out of this process was the importance of the right "atmosphere" in a consultation, and that this atmosphere—and not only the contents of the consultation—should be captured in the video. Technical support (filming, sound track, editing) was provided by professionals. Following an introduction, the talk will include a presentation of the video (six minutes) and a report of the experiences resulting from its use.

1063

Balancing Compassion and Honesty: A Case Study in Communicating Difficult and Unwanted News in Pediatric Medicine

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The culture of medicine has evolved from a paternalistic to a more patient/family-centered model. That change has done much that is positive for the patient-doctor relationship. However, it has introduced challenges to the practice of medicine; chief among them is a barrier to communicating information that is difficult for patients and their families to receive. There is such a high value placed on keeping patients and families happy, that caregivers actively or subconsciously avoid topics and information that are perceived as hurtful, even if they are essential to the management of the case at hand. This paradox will be discussed in this case study regarding post-critical-care maintenance and rehabilitation in conflict with parental autonomy for decision making. Understanding the role of surrogate decision makers and communicating difficult and unwanted news for patients who suffer significant injury and require long intensive-care management is the point of this case study. As we will describe, the pendulum swing from paternalism to a more family/patient centered approach can, at times, be a hindrance to good-quality clinical interventions.

We will look at this new problem through the lens of a severely ill child and his mother's refusal of standard rehabilitation post-ICU. This is a case of a young male with metastatic medulloblastoma that resulted in a high cervical spinal cord injury. He received chemotherapy and radiation therapy such that his survivability from an oncological standpoint was strong. However, the spinal cord injury left him dependent on a ventilator and without functional use of his arms and legs. Based on standard scoring and classification, it was predicted that his paralysis was significant and durable. However, the patient's mother rejected the validity of that assessment and forbade the treatment team from revealing the diagnosis and prognosis to the patient, which led to compromised care and his eventual death.

1064

No One Should Die Alone: A Discussion on Neonatal End-of-life Practices When Parents Are Absent

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For most families, an infant's birth is a time of pure joy, but the lives of some neonates (babies under 28 days of life) are filled with hardships. Many of these neonates are admitted to the neonatal intensive care unit (NICU), a time that is highly stressful and emotional for all involved. For some babies, the beginning of life and end of life occur close together, and when parents are facing the death of their infant, the distress can be overwhelming, leading to a crippling sadness for both families and the team providing care for

the infant. The clinical team often provides not only medical care, but also focuses on "making memories" for the family before and after the infant's death. This includes, but is not limited to, maximizing bonding time, making molds of the baby's hands and feet, bathing the infant, and photographing the newborn. These rituals are important for the infants, families, and staff, but what about the neonates who are not able to have their parents with them? Data indicate that babies who are able to be held skin-to-skin with a parent are calmer and less distressed, a goal that is of utmost importance at the end of life. How do we deal with the added stress of not having parents nearby when a child dies? Understanding how to address the clinical team's distress, the possible distress of the patient, and navigating absent parents is a multidisciplinary team goal. Through the lens of two cases of neonates facing the end of life without parents present, our panelists will address the ethical, psychosocial, palliative, and clinical complexities involved in the care of these infants. The death of babies is a global tragedy. These cases will highlight some of the issues that are unique to dealing with end-of-life care in neonates at a Children's Hospital in the Midwest of the US.

1065

Exploring the Interface Between Palliative Care and Physician-Assisted Death: Growing Tensions Between Policy, Ethics, and Clinical Practice

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The issue of physician-assisted death (PAD) remains highly contested. This said, an increasing number of jurisdictions around the world have introduced legalized assisted death in the form of physician-assisted suicide (PAS) and/or voluntary euthanasia (VE). This shift in the international context toward a more widespread acceptance or endorsement of assisted death is coupled with an under-explored tension in clinical practice arising from palliative and end-of-life care practitioners. The international literature indicates that physicians who are more likely to deal with dying patients are less likely to support legalized PAD. The question of why this is so has not yet been adequately explored empirically. This paper will revisit the ethical arguments for and against legalized assisted death, touch on the international experience of assisted death in jurisdictions where it has been legalized, and examine the recent shifts toward acceptance of end-of-life practices related to hastening death (both in ethics and the law), in the context of best-practice palliative care.

1066

When the Bosses Do Not Like Your Ethics Consult Recommendations

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Clinical ethics committees function as independent unbiased bodies that are consulted for a variety of clinical ethical dilemmas that clinicians may face. These ethical/moral tensions may arise in the care of the patients and may involve end-of-life decision making; conflicts with surrogates or within the medical team; questions about professionalism; general questions about patients' privacy or confidentiality; and questions about ethical practices in the workplace, that is, human resources, resource allocation, or the business practices of the institution. Although traditionally employees do not raise issues that compromise their position in the workplace, there are times when advocating for a patient may come in direct conflict with the senior management of a hospital. I share a case of a foreign worker who presented to a hospital with chest pain and was found to have a liver tumor. The surgeon offered resection; however, the patient could not pay for the procedure. An ethics consult was requested, and a unanimous recommendation of surgery was the reply from the CEC. The senior management of the hospital, however, took exception to this, as they were not in agreement with this reply, and rebuked the CEC.

1067

The 11 Year Olds Who Want Their Legs Amputated

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Doing things to alter children's bodies or their appearance when it is not medically necessary is controversial. Examples include infant male circumcision and cosmetic genital surgery for infants at the request of parents. A recurring theme in these debates is the idea of leaving the decision to children when they are old enough to make their own decisions. We are presenting two very specific examples of a child (both 11 years old) for whom the decision to have a major surgical alteration to their body was their own. One decision was based on appearance concerns and the

other was about physical function. Both wanted to have a leg amputated under circumstances when it was not medically necessary. Neither was what is generally considered to be a "mature minor." A key feature of these two cases is uncertainty—uncertainty about what was best for the child, what the child will think in the future, and how much weight to put on the desire of an 11 year old. In particular, these cases prompt us to think about how to balance children's current distress with possible future distress. This is important to think about. It is central to the work of clinical ethics committees and clinical ethics consultants in the pediatric setting, where having to balance these things is common. These cases also highlight the important role for children in decisions about their immediate and long-term interests—without the need for misleading or potentially damaging pronouncements about their competence.

1068

Institutionalized Consent: A Mask to Protect "Patient Autonomy"

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Consent discussions can be traced across most human interactions in society. There is an ocean of literature on the concept of informed consent based on different contexts and applications. Context plays an important role in understanding the concept of consent. This paper is an exercise in conceptual and empirical analysis. It will identify what court judgments, surgeons, patients, and patients' family members mean when they refer to consent in medical practice. This paper applies qualitative research methodology using content analysis to contested consent court judgments and in-depth interviews of the participants listed above. The major goal of this paper is to examine the significance and functionality of the consent expected and applied within legal and medical practice in India. This paper argues, based on this analysis, that institutionalized consent is observed, and it is a tool to protect physical autonomy, as it protects bodily integrity or physical well-being, which underscores respect for a patient's right to information. I will elaborate on how respect for a patient's autonomy is encapsulated within the physical well-being of the patient. In this paper, I question the ethical and legal basis of institutionalized consent, and argue that it does not protect patients' autonomy as an intrinsic value. I further analyze and examine its role within legal and medical practice and present my argument that, to value consent—for it to be a morally transformative transaction—it should go beyond institutionalized consent. Thus, this paper explores the present understanding and application of consent within medical and legal practice in the Indian context.

1069

Trade-Off Between Health Informatics Access and Dissemination and Zika/Ebola Epidemics' Ethical, Social, and Medical Issues

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The devastating and complex complications of the Zika and Ebola epidemics have exposed flaws in the global surveillance architecture dealing with cross-border health pandemics. This paper examines the impact of access to and dissemination of information-technology-based health informatics data and the effects of the Zika virus/Ebola epidemics on care delivery before, during, and after response to the epidemics. We found that information-technology-based health informatics are evolving, as are minimum global standards for open access to and sharing of relevant data on epidemics and information on the risk of communication of the diseases.

The most common goals during viral epidemics are public awareness, health promotion and education, counselling and guidelines regarding the surveillance of symptoms, and response to epidemics, to reduce and avert further transmission. The use of mobile communication devices raises issues of personal data security, privacy, and confidentiality. The use of health informatics via open channels (eg, Tweeting, public image-sharing websites, public forums) and individuals' posting of sensitive information present potential threats to personal and community informed consent and security, misinformation, and stigma.

There is need to develop legal, social, and medical guidelines and regulations. We found that the management, planning, and delivery of healthcare services had been documented and, for the Zika virus, that these played a critical role in raising awareness of travel restrictions and delaying pregnancies in women of reproductive age. The effective use of personal protective equipment against infection was communicated through cultural practices, communication with affected individuals, the training of health responders, advocacy, and monitoring and evaluation. The Zika and Ebola epidemics highlight the importance of ethical practice, the dignity of patients, and the process of seeking consent while solving and forecasting the unforeseen and emerging negative consequences of viral epidemics. Addressing these areas—including medical and socio-ethical issues regarding privacy and confidentiality, security, informed consent, autonomy, the accuracy of information, stigmatization, and marginalization—allow better preparedness and response.

1070

Reconciling the Science of Medical Advancements at the End of Life with the Art of Dying Well: Advocating for the Introduction of Legislation on Advance Decisions in Malaysia

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End-of-life care decision making in Malaysia is difficult because of the multi-cultural and multi-religious aspects of its population. This becomes even more challenging, as most patients rarely communicate their wishes regarding treatment beforehand. How can we know what treatment patients want and how can we be sure that we are really acting in their best interests? The answer lies in planning for our death, which, first, requires patients to have a conversation with someone else about this topic, and, second, to have it in some recorded form. In attempting to advocate for the introduction of legislation on advance decisions (AD) that is currently lacking in Malaysia, this presentation first explores some different forms of ADs currently available, including living wills, advance directives, lasting powers of attorney, and the physician orders for life-sustaining treatment (POLST) forms. This is followed by a brief consideration of current AD legislation in the United Kingdom and Singapore, in addition to other relevant Malaysian legislation and guidelines. The presentation subsequently highlights some of the current medical, legal, ethical, and social aspects of end-of-life care in Malaysia that will help determine the best possible approach to implementing AD legislation here. A stepwise approach is then suggested to overcome this problem. The first step of is to encourage people to talk about their wishes and life values. The second step is to work to improve the communication skills of all of the parties involved in end-of-life care. The third step is to legislate provisions for AD.

We conclude by identifying and examining how legislating ADs may subsequently impact decision-making practices on end-of-life issues in Malaysia. This includes the possibility of changing current consultation practices to implement a shared decision-making approach, and the prediction of an increase in demand for palliative care services.

1071

Outpatient Ethics Consultation: How Can Ethics Consultants Support Healthcare Professionals and Patients in Decision Making?

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Context: In 2012, an outpatient ethics consultation was founded by a multidisciplinary team in Bavaria. The target group contains family doctors, nursing home staff, relatives, and patients. During the last three years, 48 case deliberations were made. In addition to the deliberation of cases, an outpatient ethics consultant will want to act in a preventive way. This includes qualifying capable persons to make the "right" medical decision when patients are not able to consent. One possibility is to prepare advance directives for patients. Another approach is to educate healthcare professionals' awareness about prevailing legal norms, especially the mental capacity act in Germany. But how can ethics consultants manage this job? And what are the expectations of the target groups?

Method: To answer the preceding questions, three qualitative-guideline-oriented interview studies with 32 persons were made between 2013 and 2015. Ethics consultants, members of the Bavarian outpatient ethics consultation service, and persons who requested a case deliberation were interviewed. In 2015, a questionnaire study with local family doctors was conducted.

Results: Ethics consultants offer additional education to healthcare professionals. The consultants also offer informative meetings in nursing homes about advance care planning. Ethics consul-

tants reported that nursing home residents, as well as nurses, were very glad about and thankful for the informative meetings. Sometimes the nursing home residents and even their relatives decided to prepare an advance directive after the meeting.

Discussion: There are many possibilities for ethics consultants to work in a preventive way. People are often grateful for the offer. But there are also problems. Sometimes the offers aren't well advertised, or persons, especially family doctors and nurses, are afraid of taking advantage of the offer. Ethics consultants' participation in nursing rounds is often not permitted.

1072

Medical Migration in Global Context: Ethical Issues Regarding the Integration of Cultural Diversity

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In our globalized world there are increasingly close, unavoidable contacts between different societies and cultures, and doctors who migrate are faced with the problem of integrating cultural diversity. An example of one ethical problem is how migrant doctors can maintain their own values and genuine respect for a variety of values, traditions, and experiences in various professional and social situation. We analyzed the main ethical issues that arose where the issues of globalization, the migration of doctors, and multicultural medicine met. To present realistic picture, we analyzed information from participatory observation and comprehensive interviews conducted during job fairs for doctors—Career in White—with staff representatives of the recruitment companies, physicians present at the job fairs, and physicians who had experience with migration or intended migrate. All aspects of our empirical work will be reported in the literature.

In conclusion, we highlight situations that appear to be representative of how migrant doctors adapt and integrate their professional cultural diversity. We identify, present, and analyze how migrant doctors may discuss fundamental values in meetings with patients who have different ethnocultural backgrounds.

1073

Should Brain-Death Certification Be Hastened in a Presumed Consent System for Organ Donation?

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In view of competing conceptions of what it means to be dead, the debate on brain death within transplantation ethics has focused on the normative issue of whether this is the appropriate point for deeming a person dead for the purpose of human organ transplantation. Less has been said on the "technical" aspects of brain-death testing and certification, which can be clinically and ethically challenging. Brain-stem death causes a series of pathophysiological changes, such as hypernatremia, which need to be managed to enable brain-death certification. As a prelude to organ procurement, brain-death certification (BDC) can thus be difficult and circuitous, and subject to variable performance. On the one hand, rapid control of hypernatremia can be the cause of brain death itself. On the other hand, delays in BDC can affect the viability and quality of the organs procured, and cause distress to already distraught families.

In this paper, we discuss the process for BDC, and the moral issues raised by BDC delays, under Singapore's presumed consent donation system as set by its Human Organ Transplantation Act (HOTA). We use two cases to discuss these issues, with a focus on the conflict between families and intensivists that may be caused by delays in BCD and a lack of knowledge of HOTA. This serves as background for consideration of a protocol to "hasten" or avoid delays in BDC as a form of donor management. We examine autonomy, best interests, and family-centered care as ethical grounds for this protocol. We conclude that these concepts support the hastening of BDC under certain conditions: intensivists' recognition of deceased organ donation as part of their professional responsibility, and the need to inform the public of the intricacies of BDC as part of public education on HOTA.

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Should Incarcerated Persons Be Allowed to Access Legally Assisted Death?

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Jurisdictions that have legalized assisted death incorporate clinicians in all or some of the process steps. In some jurisdictions, the formal healthcare system coordinates policies, regulations, training, and provision. Even though assisted death may not have been explicitly justified, and is open to criticism, it may be considered part of healthcare

in these jurisdictions. The health of, and healthcare for, incarcerated persons is subject to declared principles promulgated in at least some countries. Several of those also have legalized assisted death. But the standards for healthcare delivery have not generally contemplated assisted death within prison health programs, despite the recognized aging and chronic health challenges of prison populations. This leaves patients/prisoners subject to potentially discriminatory treatment arising from non-equitable access to a legitimized service that non-incarcerated persons can avail themselves of. It also leaves health providers at the mercy of idiosyncratic policies, regulations, and program provisions when faced with the vexing practical issues and ethical uncertainty at the intersection of prison health and assisted death. Further, incarcerated populations have been shown to have high rates of mental illness and drug addiction, two situations that impact on the autonomous choosing precepts that underlie assisted-death regulations. Together with the potentially unique coercive influences inherent in incarceration, assisted-death considerations are therefore even more challenging to sort out. This paper will explore: (1) potential grounds for supporting differential access to assisted-death between incarcerated and non-incarcerated individuals, considering specific vulnerabilities that are exposed by incarceration, (2) potential arguments in favor of equitable access, and (3) ethics considerations that health personnel might bring to bear in their deliberations with patients who are incarcerated and who may wish to consider assisted death.

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