

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



Hosted by The Center for Ethics at MedStar Washington Hospital Center

Proceedings of the Twelfth Annual International Conference for Clinical Ethics Consultation: Caring for the Ethically Complicated Patient (ICCEC 2016)

Hosted by the John J. Lynch MD Center for Ethics at MedStar Washington Hospital Center

faculty

The Names of Presenters at ICCEC 2016, with Abstract Numbers

Conference program
A Listing of Presenters by the Date of their Presentation, with Abstract Numbers

authors and abstracts

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mission

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

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

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

VOLUME 4 JOURNAL OF NUMBER 3 HOSPITAL ETHICS

Proceedings of the Twelfth Annual **International Conference for Clinical Ethics Consultation:** Caring for the Ethically Complicated Patient (ICCEC 2016)

Hosted by the John J. Lynch MD Center for Ethics at MedStar Washington Hospital Center

A Note from the Editor-in-Chief Evan G. DeRenzo, PhD

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A Note from the Editor-in-Chief

Dear All,

It is with much excitement that the Journal of Hospital Ethics (JOHE), presents its first proceedings of the International Conference for Clinical Ethics Consultation (ICCEC). Just as exciting, moving forward, *JOHE* is going to be the official proceedings journal of the ICCEC, printing an IC-CEC proceedings issue after every conference.

As most of you know, the John J. Lynch MD Center for Ethics at MedStar Washington Hospital Center hosted the ICCEC 2016 in Washington, DC, May 19 through 22. After that meeting, the JOHE team had the idea of publishing the proceedings of the conference. That idea ultimately evolved into *JOHE* becoming the official journal of the ICCEC.

Once the ICCEC founders, George J. Agich, PhD, and Stella Reiter-Theil, PhD, decided they liked and would support the idea, the work began in earnest. Over the years, sometimes ICCECs have occurred yearly, sometimes every other year. Regardless of the natural scheduling of future meetings, the proceedings of each meeting will be published in *IOHE*.

Why do we at the John J. Lynch MD Center for Ethics (hereafter, the Center) think it important to have the papers presented at the ICCECs documented in this way, and why do we think that *JOHE* is an ideal place to house the proceedings? Let me take these two questions in order.

First, the ICCEC is a particularly important meeting for the clinical ethics community. The ICCEC, never a membership organization, is a recurring conference to bring together, specifically, the global clinical ethics consultation (CEC) community. Through these conferences, those individuals (often those very few individuals) engaged in CEC in countries around the world have had an intellectual home in which to discuss, with like-mindeds, their work and progress with clinical ethics in their locales.

There has also always been a secondary goal of the ICCECs: to shine a spotlight on those few programs around the globe in which clinical ethics is actually practiced. By each ICCEC being hosted by a different program in a different country, the programs are able to further educate the field about the variations in clinical ethics programs and practice, deepening the field's appreciation for how and where clinical ethics is advancing internationally.

It is this dual purpose of the ICCEC project that combined to make *JOHE* an ideal publication to publish the ICCEC proceedings. JOHE, like the ICCEC, is solely focused on clinical ethics. From JOHE's beginnings, our mission has been to be an educational tool to advance the practice of clinical ethics.

Our vision for each *IOHE* proceedings is to be in two parts. One part will be to publish the abstracts of each presentation. The second part is to include short, JOHE-length papers representing the presentations of the keynote speakers and the award winners.

This first issue is not going to encompass the totality of both parts of this vision. To make the deadline of getting the proceedings ready for the ICCEC 2017 in Singapore, this first proceedings issue only contains the abstracts tied to the meeting schedule. We finalized plans for the 2016 proceedings too late to ask the 2016 speakers and award winners to write for this issue. But we plan to contact these colleagues in the near future to

work out a process to allow for publication of their ICCEC 2016 work.

Here we start preparing the ICCEC 2017 Singapore participants for our next proceedings. For everyone on the program who has provided an abstract to the Singapore meeting organizers, and completes a release form allowing us to publish your abstract, we look forward to publishing the abstract in the 2017 proceedings. To the 2017 ICCEC keynoters and award winners, please consider turning your talks into *JOHE*-length articles. You'll see in the inside front cover of this issue that we

ing, for the participants of that next meeting. Each issue will include preparatory instructions and explanations so these processes become routine.

The hard copy we supply here is a gift to the participants of the 2017 ICCEC from the John J. Lynch MD Center for Ethics at MedStar Washington Hospital Center. We imagine that perhaps at this point you are wondering why we are providing the proceedings free. We can explain in two words: community education.

We believe that archiving the work and disseminating everyone's efforts will be of benefit to

At the point at which an individual is in relationship with a clinician, particularly a physician, that relationship carries with it ethical obligations and responsibilities.

have a limit of 3,500 words, give or take. We are eager to start producing these proceedings, creating an archival treasure of the wonderful world of the ICCEC.

Finally, I'd like to introduce to you the members of our *JOHE* group with whom ICCEC participants may be interacting. If you are a keynote speaker or an award winner, our *JOHE* Senior Editor, Christian Carrozzo, MA, will likely be your contact for shaping your talks into relatively short papers for the proceedings in which the talks were given. (To the keynoters and award winners for ICCEC 2016, Christian will be contacting you soon.)

Production of the proceedings, as well as moving *JOHE* forward, is now in the skilled hands of the University Publishing Group of Hagerstown, Maryland. Your contact there is Leslie LeBlanc, President, in case any production questions arise.

Since we have never done this before, we are facing a sharp learning curve. The plan is that we shall work with the ICCEC local organizing teams to obtain the files of all abstracts, so that, other than making certain we have your permission, this postmeeting work should be invisible to the ICCEC participants until the proceedings are published.

Once published, we shall send an electronic copy to all of the presenters and participants of the proceedings meeting. We shall also send hard copies of the proceedings to the next ICCEC meetstrengthening connections throughout the international clinical ethics community. The Center has long been well known for this kind of work. Having created our Clinical Ethics Immersion course, and *JOHE* itself, for the same purpose, we are long committed to advancing clinical ethics in the world of hospitals, patients and their families, and clinicians around the globe.

Further, and in the spirit of upholding the ethical value of transparency, there are many ways that a publication can spend its marketing dollars. There will only be some ways, however, for *JOHE* to spend marketing dollars that are consistent with our education mission. And so, each proceedings will include information about how to subscribe to *JOHE*. By subscribing to *JOHE*, each recipient of the ICCEC proceedings will receive the full volume of *JOHE* at a discount.

If not, however, ICCECers will still receive free the electronic version of ICCEC proceedings of the year of one's own participation, and a hard copy of the proceedings at registration for the next ICCEC. We hope this creates an additional incentive to keep going to ICCECs, wherever around the world they take place.

Finally, and just as importantly for us, whether or not this new project for *JOHE* garners any new subscribers, we at the Center will have demonstrated to our own leadership, who have been so consistently supportive of the Center's work for decades, that we have made an honest attempt to have another one of our educational projects produce a small funding stream back into the Center to help reduce the support burden running a Center such as ours costs.

Regardless, we are thrilled to be producing and disseminating the proceedings of our ICCEC 2016 and all future ICCECs as a service to our colleagues around the world. And so, I think this is enough of an ICCEC proceedings introduction for now. Please remember that this is a work in progress. If you have any questions or concerns, please do not hesitate to contact us.

Our email is *johe@medstar.net*.

Our *JOHE* Administrator, Kahlia Kéita, MA, JD, will be happy to answer your questions.

Before turning this note over to the proceedings, however, I'd like to make a few comments on the topic of ICCEC 2016: the ethically complicated patient.

Of the many interesting and important insights on approaches of care to, for, and of, the ethically complicated patient that ICCEC speakers produced, the one I want to note here is the different perspectives that the participants brought to the phrase "ethically complicated patient" itself. Participants wondered just what it was we meant by the phrase "ethically complicated" patient. Given that it is our Center from which this term-of-art has emanated and is now floating out into the clinical ethics, medical, and academic communities, it is worth a moment or two to muse on its meaning(s).

A few years ago I attended a meeting at the National Academies of Science on the Complicated Patient. What the conference organizers meant by the term was strictly medical. I sat through the meeting waiting for the speakers to raise ethical issues that were part of the complexities of the medicine, but they never did. One physician in the audience did, but neither the speakers nor most of the audience knew how to react to his ethics interjections, and so his comments, which seemed to me to be among the most important of the day, gained no traction at all.

Of course I returned to the Center and reported on the meeting. That report led organically to discussions in which we coined the term. (I'm not sure if we did actually or not; to make a firm determination I'd have to really research it, which I haven't. If anyone has any examples of other or previous uses of the term the "ethically complicated patient," please send it our way and we'll definitely publish it.)

Nonetheless, we, at the Center, think of the ethically complicated patient as: A patient with multiple ethical issues, one or more of which are causing difficulties or producing barriers or creating additional complications for the medical team to care for the patient in a way that produces the best medico-psychosocial outcome(s) for the patient.

At the Center, we train our house staff and other clinicians, Center rotating medical residents, academic interns, and visiting scholars that caring for all patients has ethical implications. At the point at which an individual is in relationship with a clinician, particularly a physician, that relationship carries with it ethical obligations and responsibilities. Acting out these obligations and responsibilities creates various implications. Space does not permit me to explore these claims, but there are vast literatures that do. Suffice it to say that at the Center we see every patient/clinician relationship grounded in the ethical responsibility of the clinician to act in the best interest of the patient. That's where an ethically uncomplicated case starts. Anything past this starting point, anything that interferes with excellence in patient care, produces for us an ethically complicated case.

Now that doesn't mean that every ethically complicated case rises to the level of a CEC. If it did, we would need an army of clinical ethicists. As it is, our Center handles approximately 300 CECs a year, which stretches us to the max.

Rather, this illustrates the operationalization of the Center's educational mission. We see our job as joining forces with our senior clinicians to teach our junior clinicians how to provide ethical excellence in care, just as they are expected to provide technical excellence in the science of care. It is the skilled combination that is the art (ie, the ethics) of medicine.

It is never at question that all patients, as well as their families and friends, are owed excellence in care, and that the clinicians who care for them are owed an ethically sound climate in which to practice. That, for us, is ethically straightforward and uncomplicated. It is when the ethical issues that are part and parcel of the care of any sick human combine in the unique ways that reflect the uniqueness of each human, and that combination, or something about the patient, combines with systems or processes of the hospital in a way that impedes excellence in care, that we consider a particular patient ethically complicated.

That clinical way in which we view the ethical complexities of our patients seemed to us to be organically manifest in the majority of the presentations at ICCEC 2016. The many ways in which ICCEC 2016 participants talked about their patient cases or the systems and/or processes they were highlighting to improve patient care, were completely consistent with what we, at the Center, had envisioned for the ICCEC meeting we were so happy to host last year.

And so, with that brief reflection back on the previous ICCEC, we at the John J. Lynch MD Center for Ethics hope you all have a wonderful ICCEC 2017 in beautiful Singapore. Although I am so sorry to be unable to make the meeting (having made most in the past), this year our Center will be very well represented by our clinical ethicist, Laura Guidry-Grimes, PhD.

If you see Laura, she'll be happy to talk to you about this new *JOHE*/ICCEC project. We look forward to working with each of you in the years and ICCECs ahead.

Sincerely,

Evan G. DeRenzo, PhD

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Faculty of ICCEC 2016

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Morgan, Timothy, MD	1070		
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Pavlish, Carol, PhD	1017		
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Rosenthal, M. Sara, PhD	1048*		
Rothke, Danielle, DNP	1005		
Rudolph, Dawn, MSEd	1007		

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Conference Program

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

AGENDA | **Thursday** May 19

Pre-Conference Workshop

11:00 a.m. Conflict Management Skills for Working with the Complicated Patient

Autumn Fiester, PhD

2:30 p.m. Integrating Quality Improvement Measures into Ethics Consultation

Kelly Armstrong, PhD; Thomas V. Cunningham, PhD; Joseph B. Fanning, PhD

AGENDA | **Friday** May 20

Session I: Main Session

8:00 a.m. Welcome and Introduction

Nneka O. Sederstrom, PhD, MPH

8:15 a.m. **Opening Remarks from ICCEC Founders**

George J. Agich, PhD; Stella Reiter-Theil, PhD

8:30 a.m. Care for the Ethically Complicated Patient - Cases from Around the Globe

Thalia Arawi, PhD; Anne L. Dale Ave, MD; Juan Pablo Beca, MD; Yael Zonenszain, PhD(c)

10:30 a.m. Keynote: Caring For the Ethically Complicated Patient in a Publicly Funded Health

Service

Anne M. Slowther, DPhil

11:30 a.m. **Questions and Discussions**

Anne M. Slowther, DPhil

Session II: Breakouts

Abstract number

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12:45 p.m.	Differing Ethical Perspectives on Assisted Suicide (Panel) Moderator: Laura K. Guidry-Grimes, PhD(c) Panelists: Katherine Brown-Saltzman, MA, RN; Stella Reiter-Theil, PhD; Anne M. Slowther, DPhil	1001
2:15 p.m.	24 & Ready to Die: Using Emily's Narrative to Teach about the Ethics of Allowing Euthanasia for Patients Who Suffer from Severe and Incurable Distress, including Psychological Disorders (Case Study) Carol R. Taylor, PhD	1002
2:45 p.m.	Ethics Consultation for the Under-Cared for Patient: Reducing Ethical Disparity in Clinical Ethics (Case Study) Barbara L. Chanko, RN	1003
Breakout B		
12:45 p.m.	Representing the Unrepresented: State Law, Institutional Practices, and the Role of the Ethics Committee (Panel) Moderator: Joan M. Henriksen Hellyer, PhD Panelists: Felicia Cohn, PhD; Leah Eisenberg, JD	1004
2:15 p.m.	Does Suicidal Ideation Invalidate Advance Care Planning Choices to Forgo Life-Sustaining Treatments? (Case Study) Thomas D. Harter, PhD	1005
2:45 p.m.	Are We Tired of Serving the Psychiatric Patients? A Home Case Study from South India (Case Study) Michael Jothirajan, PhD	1006
Breakout C		
12:45 p.m.	End of Life Decisions for People with Intellectual Disabilities (Panel) Moderator: Dawn Rudolph, MSEd Panelists: Marisa C. Brown, MSN, RN; Samantha Crane, JD	1007
2:15 p.m.	Logic Modeling: A Tool that Clinical Ethics Programs Should Know About (General Session) Ellen Fox, MD	1008
Breakout D		
12:45 p.m.	Capacity Building for Ethics Consultation in Ethiopia: What Can We Learn from a Low Income Setting? (Case Study) Frehiwot Berhane Defaye, MD, PhD(c); Dawit Desalegn, MD	1009
1:45 p.m.	The Ethics of End-of-Life Palliative Sedation of Children (Case Study) Anders Castor, MD, PhD	1010
2:15 p.m.	The Limits of Surrogate Authority (Case Study) Jill Watanabe, MD, MPH	1011

2:45 p.m.	Maintaining Dignity in the Dying Super Obese Patient: End-of-Life Care for the Super Obese (Case Study) Nneka O. Sederstrom, PhD, MPH	1012
Breakout E	(Individual Paper Presentations)	
12:45 p.m.	Clinical Bioethics in Mexico: Difficulties, Challenges and Opportunities Elizabeth de los Rios, PhD	1013
1:05 p.m.	Communication Skills for Consensus Building Methodology: Considering of Ethically Complicated Cases Kumiko Yoshitake, PhD	1014
1:25 p.m.	Conscience and Role Conflation: Moral Distress of Clinical Ethicists Marleen Eijkholt, PhD, JD	1015
1:45 p.m.	Variability in Decision-Making and Outcomes in Infants with Significant Neurologic Disorders in Three NICUs David K. Urion, MD	1016
Session III:	Breakouts	
Breakout A		
3:30 p.m.	Changing the Climate: Lessons Learned from Instituting an Interdisciplinary Team Based Ethics Assessment (Panel) Moderator: Katherine A. Brown-Saltzman, MA Panelists: Carol Pavlish, PhD; Ellen Robinson, PhD; Jennifer Tamir, RN	1017
5:00 p.m.	When God's Plan and the Medical Plan are Mutually Exclusive: Can Parents Refuse Organ Transplantation Based on Religious Beliefs? (Case Study) Wendy S. Moon, MS	1018
5:30 p.m.	Sedating Patients with Dementia to Solve Aggression: Ongoing Ethical Challenges (Case Study) Carol R. Taylor, PhD	1019
Breakout B		
3:30 p.m.	Palliative Care for Psychiatric Patients: A Role for Ethics Consultation? (Panel) Moderator: Marie-Eve Bouthillier, PhD Panelists: George J. Agich, PhD; Mark P. Aulisio, PhD; Stella Reiter-Theil, PhD; Jan M. Schuermann, MA	1020
5:00 p.m.	An Exploration of Curriculum Development and Ethics Education in Residency Education: The Frame of Medical Ethics, Consent and Moral Distress (General Session) Katie Adams, MD; Patrick McFarlane, MSN-APRN; Jeremy Werth, MD	1021
Breakout C		
3:30 p.m.	Diversity of Clinical Ethics Consultation Services in the United States: Variance of Roles and Organizational Expectations in Various Stages of Program Development (Panel) Moderator: Ashley Stephens, MA Panelists: Andrew Childress, PhD; Becket Gremmels, PhD; Jason Lesandrini, PhD(c)	1022

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5:00 p.m.	Falling Through the Cracks: Patients with Both Somatic and Psychiatric Diseases (Case Study) Tanja Löbbing, M.mel.	1023
5:30 p.m.	Donor's Versus Relative's Genetic Material in a Case of IVF (Case Study) Silviya Aleksandrova-Yankulovska, MD, PhD	1024
Breakout D		
3:30 p.m.	Do We Force a Patient to Have Dialysis? (Case Study) Mary Caldwell, MA	1025
4:00 p.m.	Cosmetic Quality-of-Life: Who Decides When a Patient Can't? (Case Study) Anjay Khandelwal, MD	1026
4:30 p.m.	Miracles, Money, and a Compromised Surrogate (Case Study) Marcia A. McKelligan, PhD	1027
5:00 p.m.	A Case of Attempted Suicide in Huntington's Disease: Ethical and Moral Considerations (Case Study) Jean T. Abbott, MD	1028
5:30 p.m.	Managing Conflicts between Clinicians and Surrogates (Case Study) Barbara L. Chanko, RN	1029
Breakout E	(Individual Paper Presentation)	
3:30 p.m.	Ethical Considerations in the Use of the Internet to Obtain Patient Care Information David J. Alfandre, MD, MSPH	1030
3:50 p.m.	Brain Death: Expanding Duties to Accommodate Objections Thaddeus M. Pope, JD, PhD	1031
4:10 p.m.	Rich in Detail, Poor in Content: Excavating the Ethical Complexities in (Presumably) Clear Clinical Language Virginia L. Bartlett, PhD	1032
4:30 p.m.	Continuous Palliative Sedation for Intractable Existential Suffering Alina Bennet, PhD; Elijah Weber, PhD	1033
4:50 p.m.	Membership Recruitment in Healthcare Ethics Committees Anya Prince, JD	1034
6 :05 p.m.	Closing Remarks and Introduction to Evening Programming	
6:15 p.m.	SPECIAL FILM VIEWING: The Oral History of Healthcare Ethics: Volume 1: A Life in Clinical Philosophy: A Conversation with Richard M. Zaner	

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AGENDA | **Saturday** May 21

Session IV: Main Session

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8:00 a.m.	Conference Announcements Nneka O. Sederstrom, PhD, MPH	
8:30 a.m.	Keynote: Ethical Principles and Ethical Muddles Daniel Callahan, PhD	
9:30 a.m.	Questions and Discussions Daniel Callahan, PhD	
10:00 a.m.	Healthcare Ethicists in Canada: Who Are We and What Do We Do? Michael Campbell, MHSc	1035
10:20 a.m.	Exploring the Impact of Values on Advance Care Planning in a Multi-Cultural and Multi-Religious Asian State Sumytra Menon, LLB, LLM	1036
10:40 a.m.	Certification of Healthcare Ethics Consultants: The German Model Ralf J. Jox, MD, PhD	1037
11:20 a.m.	Intensive Care for Organ Preservation: Ethical Considerations Anne L. Dale Ave, MD; Jack Kilcullen, MD, JD, MPH	1038
Session V: I	Breakouts	
Breakout A		
1:00 p.m.	Sleepless Nights: The Ethics Consults that Continue to Haunt (Panel) Moderator: Tyler S. Gibb, JD, PhD Panelists: Kevin M. Dirksen, MSc, MDiv; Margot M. Eves, JD, MA; Ryan F. Holmes, PhD(c)	1039
2:30 p.m.	Hospital Ethics Consultation: Can They Provide Impartial Recommendations for a Patient and/ or Surrogate, without Compromising the Organization that Employs Them? (Case Study) Fernando Gutierrez III, BA	1040
3:00 p.m.	Ethical Issues Arising from Terminal Discharge of Patients (Case Study) Sumytra Menon, LLM, LLB	1041
Breakout B		
1:00 p.m.	On Behalf of the Unrepresented: Does This Homeless Patient Lack Capacity? (Case Study) Miriam P. Cotler, PhD	1042
1:30 p.m.	Caring for the "Unrepresented Patient": Strategies to Avoid Moral Distress and Substandard Care (Panel) Moderator: Jean T. Abbott, MD Panelists: Debra Bennet-Woods, EdD; Thaddeus M. Pope, JD, PhD	1043

3:00 p.m.	Assuming too Much, Assuming too Little: Addictions, Clinical Ethics, and Complexity (Case Study) Daniel Z. Buchman, PhD, RSW	1044
Breakout (
1:00 p.m.	Death at the Beginning of Life: Can We Withdraw Life Support on a Pregnant Patient? (Panel) Moderator: Joan M. Henriksen Hellyer, PhD Panelists: Felicia Cohn, PhD; Leah Eisenberg, JD	1045
2:30 p.m.	Aging with Chronic Illness (Case Study) Jacqueline L. Chin, PhD	1046
Breakout I		
1:00 p.m.	Evaluating the Interpersonal Skills of Clinical Ethics Consultants: Assessing Clinical Ethics Skills (ACES) Tool Launch (General Session) Katherine Wasson, PhD, MPH	1047
2:00 p.m.	Building and Using a Tool for Ethically Complex Cases: The Moral Distress Education Project (General Session) M. Sara Rosenthal, PhD	1048
Breakout I	E (Individual Paper Presentations)	
1:00 p.m.	Power of Attorney for Research: The Need for a Clear Legal Mechanism Jennifer A. Bell, PhD	1049
1:20 p.m.	Ethical Complexity of POLST Implementation: Should the POLST Be Treated Differently than Other Physician's Orders? Laura B. Webster, BSN	1050
1:40 p.m.	Caring for Patients with a History of Illicit Intravenous Drug Use: Parameters of Ethical Obligations from Bedside to Boardroom Nicholas J. Kockler, PhD, MS	1051
2:00 p.m.	Ethical Complexity: Toward a More Effective Diagnosis and Response F. Daniel Davis, PhD	1052
2:20 p.m.	How Neutral Should the Clinical Ethics Consultant Be? Alessandra Gasparetto, MA	1053
2:40 p.m.	Beyond Ethics Consultations (ECs): Building an Ethics Environment in a Children's Hospital Brian S. Carter, MD	1054

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Session VI: Breakouts

Breakout A

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3:45 p.m.	Addressing Racism and Discrimination in Clinical Ethics (Panel) Moderator: Marion Danis, MD Panelists: Akilah Jefferson, MD, MSc; Anita J. Tarzian, PhD, RN; Yolonda Y. Wilson, PhD	1055
5:15 p.m.	ECMO and Miracles: Setting Expectations (Case Study) Ashley Stephens, MA; Trevor M. Bibler, PhD	1056
5:45 p.m.	Giving In: The Capable Patient Who Defers (Case Study) F. Daniel Davis, PhD; Joseph A. Raho, PhD	1057
Breakout B		
3:45 p.m.	Less Discussed Everyday Issues of End of Life Care Ethics (Panel) Moderator: Silviya Aleksandrova-Yankulovska, MD, PhD Panelists: Ralf J. Jox, MD, PhD; Renzo Pegoraro, MD, MPH	1058
5:15 p.m.	Teaching Conflict Engagement Skills in Clinical Ethics (General Session) Evan DeRenzo, PhD; Lauren Edelstein, MA; Kahlia T. Kéita, MA	1059
Breakout C		
3:45 p.m.	Providing Treatment of Erectile Dysfunction in Ethically Complex Cases (Case Study) David J. Alfandre, MD, MSPH	1060
4:15 p.m.	Gaining Ground: The Ethical Space between Consent and Assent (Panel) Moderator: Katherine Wasson, PhD, MPH Panelists: Andy Kondrat, MA; Debjani Mukherjee, PhD; Preya S. Tarsney, JD	1061
Breakout D		
3:45 p.m.	A Delirious or Disqualified Demand of Physician Assisted Suicide (PAS)? (Case Study) Veronique Fournier, MD, PhD	1062
4:15 p.m.	Should We Keep Louise in the Hospital with Forced Treatments and Contention, or Should We Take the Risk of her Attempting to Commit Suicide Outside the Hospital? (Case Study) Nicholas Foureur, MD	1063
4:45 p.m.	Should the Medical Team Let Mr. Ali Suffer during his Agony as his Wife Demands, in Accordance with their Cultural and Religious Values? (Case Study) Francois-Xavier Goudot, MD	1064
5:15 p.m.	Smoking on Oxygen: A Double Edged Sword (Case Study) Laura S. Johnson, MD	1065

Breakout E (Individual Paper Presentations)

3:45 p.m.	Tell Me Your Story Robert J. Barnet, MD, MA	1066
4:05 p.m.	Rebooting a Broken Relationship: Developing a Process for Implementing Care Agreements in a Children's Hospital Pamela G. Nathanson, MBE	1067
4:25 p.m.	Countertransference and the Clinical Ethics Encounter: What, Why, and How We Feel during Consultations Michael J. Redinger, MD, MA	1068
4:45 p.m.	Ongoing Evaluation of Clinical Ethics Consultations as a Form of Continuous Quality Improvement Rebecca Volpe, PhD	1069
5:05 p.m.	A Protocol for Prioritizing Hepatitis C (HCV) Treatment: An Ethical Framework for Scarce Resource Allocation that Can Be Useful for Ethics Consultation Kenneth A. Berkowitz, MD	1070
5:25 p.m.	Guidelines for Managing Complex Cases Involvling Extracorporeal Membrane Oxygenation (ECMO) Courtenay R. Bruce, JD; Trevor M. Butler, PhD; Ashley Stephens, MA	1071
6:15 p.m.	Top Poster Award Announcement and Closing Remarks	
AGENDA	Sunday May 22	

Session VII: Main Session

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7:50 a.m.	Conference Announcements Nneka O. Sederstrom, PhD, MPH	
8:00 a.m.	"Top Poster Award" Oral Presentation Topic will be selected from the Top Posters that will be onsite on Friday and Satura	ay
8:20 a.m.	Cultural Challenges Faced by Clinical Ethics Consultation in Mexico Yael Zonenszain, PhD(c)	1072
9:50 a.m.	Ethical Challenges Facing Advance Care Planning in Singapore Shahla Siddiqui, MD	1073
10:50 a.m.	Lost in the Law: Where's the Patient? Legal Impediments to Ethically Optimal Treatment Margot M. Eves, JD, MA; Josh Crites, PhD; Lauren Flicker, JD, MBE	1074
12:10 p.m.	Closing Remarks & Looking Ahead to ICCEC 2017 in Singapore George J. Agich, PhD; Stella Reiter-Theil, PhD; Nneka O. Sederstrom, PhD, MPH	

Authors and Abstracts

Authors and Abstracts from ICCEC 2016, Listed by Abstract Number

1001

Differing Ethical Perspectives on Assisted Suicide

This panel presents multiple perspectives on assisted suicide (AS) in different countries. The first panelist will emphasize that choice is not intrinsically valuable, so we should consider how adding AS to end-of-life options may or may not support autonomous decision making. In the US, we are still striving to improve end-of-life care, so offering AS should be analyzed against the backdrop of an imperfect health care system. The second panelist will discuss the passage of the new law in California, exploring concerns about our professional obligations to patients and our professions. She will analyze the concept of control that often seems to be the crux of the arguments in the US and what is lost when that becomes the focus. The next panelist will provide reflections on the recent UK parliamentary debate on AS, focusing on the arguments on both sides with respect to the concept of vulnerability. She will discuss the ambivalent position of UK law with discretion ultimately left to the Crowne Prosecution Service, which has a potential discriminatory effect. Our last panelist will share perspectives from Central Europe. Lay organizations offer AS with little public control in Switzerland; Germany's liberal legislation has recently been changed to prohibit Swiss-style AS; Austria has instituted restrictive legislation. The role of clinical ethics support will be illustrated by recent university hospital guidelines on responding to patients' questions regarding AS.

Author: Laura K. Guidry-Grimes, PhD(c), MedStar Washington Hospital Center, Washington, DC, USA Co-Authors: Stella Reiter-Theil, PhD, University Hospitals Basel, Basel, SWITZERLAND

Anne M. Slowther, PhD, Warwick Medical School, Coventry, UK

Katherine Brown-Saltzman, MA, RN, UCLA Health Ethics Center, Los Angeles, CA, USA

24 & Ready to Die: Using Emily's Narrative to Teach about the Ethics of Allowing Euthanasia for Patients Who Suffer from Severe and Incurable Distress, Including Psychological Disorders

In November 2015, the Economist invited subscribers to visit their film site to watch "24 & Ready to Die," a narrative about Emily, a young woman who found life unbearable and requested physician assisted dying under Belgium's euthanasia law. The release of this narrative followed an influential article in The New Yorker entitled "The Death Treatment" by Rachel Aviv (June 22, 2015) critiquing euthanasia as a "treatment" for incurable psychological suffering. While many are adamantly against any physician involvement in suicide or euthanasia and others adamant proponents of the same, the majority of us are unsure of what we ought to think and believe about these as options in a moral society, about what role physicians and other clinicians should play in counseling and assisting, and about what the criteria should be, including whether or not incurable psychological suffering is sufficient ground for a request to end one's life. This session explores how ethicists might best use a film like "24 & Ready to Die" to invite moral reflection and discourse about these topics.

Discussion questions:

Should assisted suicide and euthanasia be al-

lowed for patients who suffer from severe and incurable distress, including psychological disorders?

- In what way, if any, should clinicians' beliefs about assisted dying inform what they say or don't say when counseling patients who want to control how and when they die?
- What value does a film like "24 & Ready to Die" have in educating the public about assisted suicide and euthanasia?

Author: Carol R. Taylor, PhD, Georgetown University, Washington, DC, USA

1003

Ethics Consultation for the Under-Cared-For Patient: Reducing Ethical Disparity in Clinical Ethics

Bias in ethics consultation has increasingly been recognized in the literature. Ethics consultants frequently, even if unwittingly, share the stigmatizing attitudes of their professional and/or ethics colleagues toward marginalized populations such as patients who smoke, have substance use disorders, or have a criminal history of sex offense. The dominant medical and/or institutional culture may consider such groups as "difficult patients," a label that often leads the treatment team and at times the ethics consultant to discount or disregard the individual preferences, interests, or rights of these individuals. Patients in these groups are better characterized as "difficult to help," and frequently are not only under-cared for clinically but also ethically. This paper will present paradigmatic ethics consultations involving these under-cared for patients as a means of clarifying the core value conflicts that bias and strong emotions can obscure and confound. We will discuss how the ethics consultant often serves as an advocate for these patients by facilitating a process-based approach to resolving ethical conflicts in a way that is patient centered, systematically considers the values perspectives of each involved party, and balances the values perspectives with the legitimate safety and quality interests of the practitioner and institution. Such an inclusive approach to ethics consultation can help reduce ethical disparity in the care of patients who are difficult to help.

Author: Barbara L. Chanko, RN, MBA, VHA National Center for Ethics in Health Care, New York, NY, USA

Co-Authors: Cynthia Geppert, MD, PhD, DPS, New Mexico Veterans Affairs Health Care System, Albuquerque, NM, USA Kenneth A. Berkowitz, MD, VHA National Center for Ethics in Health Care, New York, NY, USA Marilyn Mitchell, RN, BSN, VHA National Center for Ethics in Health Care, New York, NY, USA

1004

Representing the Unrepresented: State Law, Institutional Practices, and the Role of the Ethics Committee

A 52-year-old male was found unresponsive in a parking lot and was transported by ambulance to the hospital for evaluation. The patient has not been seen previously in this hospital. No prior history is available and no friends or family accompany him. Bystanders in the parking lot stated that he was acting oddly, witnessed him collapse, and called 911. A police investigation turns up several individuals claiming to be the patient's friends, but no family. After interviewing the patient's friends, no surrogate decision maker emerges. All of the friends state that the patient was a private person and never shared his beliefs or preferences regarding health care, and none feel comfortable representing his wishes.

An 89-year-old female arrives in the emergency room, transported by a concerned neighbor who found her wandering around the neighborhood unable to state her name or where she lives. She is disheveled and frail. Medical assessment suggests advanced dementia. The neighbor states she does not know the patient well and cannot assist with contacting family or suggest anyone else who might help the patient. A social worker determines that the woman has outlived her family, has been living alone for some time, and has been neglecting her own basic needs. No friends or family are identified to assist with medical decision making. The social worker refers the patient to the public guardian's office, but knows this process will take at least six months. She is concerned the patient may not live that long.

Though very different situations, these patients share a common and growing problem. Neither has decisional capacity nor a surrogate. Without advance directives or family or friends to assist with decision making, nothing is known of their values or treatment preferences, making even the simplest medical decisions complicated.

The 1987 Hastings Center Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying called attention to the issue of the unrepresented, incapacitated patient, recognizing it as a "one of the most difficult problems in medical decision making." Despite years of attention,

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there remains no consensus on the proper solution. Among the approaches to decision making that have been adopted are default consent laws, judicial authorization for treatment, temporary medical treatment guardian, public guardianship, surrogate decision making committees, and reliance on institutional committees. Ethics committees frequently have a role in decision making for these patients.

Three clinical ethicists, practicing in different states will explore their very different institutional approaches to medical decision making for their unbefriended patients. One state addresses the issue in its default surrogate consent law, relying on physicians and ethics consultants or two physicians for decision making. In another state without specific requirements in the law, a state court recently ruled that a law allowing nursing homes to make medical decisions on behalf of certain mentally incompetent residents is unconstitutional, raising questions about practices in other health care institutions. In the third state, state law is silent on surrogate decision making altogether, providing no legal guidance. Each institution has developed a policy to assist these patients. The panelists will discuss their varied approaches to the cases described above, the development of their institutional policies, and questions that persist with each approach. Participants will be invited to consider their institutional approaches, explore the ethical implications of the variations, and the appropriate role of the ethics committee. A full case presentation will be offered as the basis for an interactive discussion.

Author: Joan M. Henriksen Hellyer, PhD, Mayo Clinic, Rochester, MN, USA

Co-Authors: Leah Eisenberg, JD, University of Arkansas, Little Rock, AR, USA

Felicia Cohn, PhD, Kaiser Permanente, Anaheim, CA, USA

1005

Does Suicidal Ideation Invalidate Advance Care Planning Choices to Forgo Life-Sustaining Treatments?

Ethically, patients with capacity may electively forgo otherwise life-sustaining treatments, such as medically assisted nutrition and hydration. However when an interactive person who is refusing treatment appears to lack decision-making capacity, whether to honor the refusal may be ethically unclear. Traditionally, suicidal ideation frustrates a person's treatment decision-making capacity. In this case presentation, we discuss a middle-aged

patient who suffers from severe cerebral palsy, speech impairment, spastic quadriparesis, depression, and anxiety, and who has been fed primarily via a feeding tube for the past few years. After doing advance care planning, the patient was voluntarily admitted to our behavioral health hospital for suicidal ideation. She subsequently refused tube feedings, stating that she is tired of living her life and ready to die. The patient agreed to restart tube feedings after her primary provider threatened to seek a court order mandating the patient receive tube feedings on grounds she is suicidal. In particular, we will explore what contextual features of this case ought to drive decision-making, whether to honor the patient's refusal, and how to make ethical sense of the threat to override the patient's refusal of tube feedings on the belief that suicidal ideation invalidates her refusal. We will further question the role advance care planning might play in this case and in the general population of those with severe mental health diagnoses.

Author: Thomas D. Harter, PhD, Gundersen Health System, La Crosse, WI, USA

Co-Author: Danielle Rathke, DNP, Gundersen Health System, La Crosse, WI, USA

1006

Are We Tired of Serving the Psychiatric Patients? A Home Case Study from South India

Traditional Indian families have adopted the joint family system. Since modernization began, the nuclear family system began to dominate over the joint family tradition. Was there any change in the attitudes of the separatists? The answer is no. The Indian families still enjoy the pseudo-joint family system. In this case study, the authors have identified 10 families in different economic conditions, different religions, different ages, and different castes. Different castes have their own value system. Different religions have their own practical teachings. The different economical conditions reveal their diversity in the social system. The objective of the study was to find the attitude of those who provide help to psychiatric patients who are not in a position to make decisions on their own. Closed-door interview was conducted under video coverage. The results point out that the healthcare providers are happy serving the special child as God-given gift. Most of the healthcare providers were the parents, daughters, and daughter-in-laws of the patients. This study revealed that daughterin-laws play a significant role in building up the families who were studied in this project. It can be concluded that the Tamils in India are not tired

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of looking after the ethically challenged patients. **Author**: Michael Jothirajan, PhD, Arul Anandar College, Tamil Nadu, INDIA

1007

End of Life Decisions for People with Intellectual Disabilities (Panel)

[No abstract available.]

Moderator: Dawn Rudolph, MSEd

Panelists: Marisa C. Brown, MSN, RN; Samantha

Crane, JD

1008

"Logic Modeling": A Tool that Clinical Ethics Programs Should Know About

Clinical ethics programs (CEPs) differ in many ways, but often face similar challenges. One problem that is common to many CEPs that they feel they need more staff time or other resources, but have a hard time convincing their organizational leaders and stakeholders of their value.

One thing that can help CEPs with this problem is to develop a "logic model" (also called program theory, program matrix, conceptual map, impact pathway, or theory of change). A logic model is a management framework or tool that has been widely used by non-profits, government, funders, and evaluators. The idea is to follow a specific method to construct a visual depiction of the logical relationships between the program's planned activities and its intended outcomes. The logic modeling process engages stakeholders to build a shared understanding of the need for the program, what it does, and how it makes an impact. The process also enables programs to communicate more clearly and succinctly; produces a tool that can be used as a guide for program planning, management, and evaluation; and often leads to rapid improvement by uncovering program gaps.

This session will introduce audience members to logic models and how to develop them. The session will emphasize active learning and group interaction, challenging participants to apply elements of the logic model process to their own programs.

Author: Ellen Fox, MD, FOXETHICS, Arlington, VA, USA

1009

Capacity Building for Ethics Consultation in Ethiopia: What Can We Learn from a Low Income Setting

Building local capacity in clinical ethics and conducting research on clinical ethical challenges has not been prioritized in most low-income countries. In this session we will describe the current status of clinical ethics in Ethiopia and describe a cooperative endeavor to develop clinical ethics teaching and consultation in this diverse sub-Saharan country. Marion Danis moderates the session, and presenters are Dawit Desalegn (MD and former dean at the Addis Ababa Medical School), Frehiwot Berhane (MD, PhD-candidate) and Ingrid Miljeteig (MD, associate professor in medical ethics at the University of Bergen, Norway, and responsible for the capacity building project in collaboration with Ethiopian partners) We aim to activate the participants: First we hope our examples from a neglected area within the field of clinical ethics consultation—capacity building in clinical ethics in low income settings, will stimulate discussion on how we can best share experiences of decades long attempts to improve healthcare workers ethics competence in high income countries with our colleagues in low income contexts in an efficient and ethically acceptable way. Secondly we will invite the participants to reflect upon what models of ethical support services and training/teaching can be beneficial in settings with extreme resource scarcity, lack of skilled healthcare workers and high disease burden. We prioritize 30 minutes for discussion.

Author: Ingrid Miljeteig, DO, University of Bergen, Bergen, NORWAY

Co-Authors: Dawit Desalegn, MD, Addis Ababa University, Addis Ababa, ETHIOPIA

Frehiwot Berhane Defaye, MD, University of Bergen, Bergen, NORWAY

Marion Danis, MD, PhD, National Institutes of Health, Bethesda, MD, USA

1010

The Ethics of End-of-Life Palliative Sedation of Children

When cure or meaningful prolongation of life is no longer possible, relief of suffering is the overriding goal. Sometimes standard palliative treatments may fall short of this goal, however, and end-of-life palliative sedation to unconsciousness (PS) may be considered a last resort. We cared for a 4-year-old boy with a brainstem tumor. In spite of all curative treatment efforts the tumor slowly but steadily progressed. All tumor-directed therapy was eventually abandoned, and efforts were focused on providing comfort. The child lost his

ability to speak and communication became very difficult. He got difficulties swallowing, noisy breathing and was believed to be in pain. The child was admitted for titration of pain medication and assessment of breathing problems. In the course of a few days his condition deteriorated with noisier breathing and signs of continuing pain. The child seemed distressed and anxious, but the severity of his suffering was difficult to assess. PS was begun a week after admission, and continued for two weeks before he died. In the discussion of this case we wish to focus on what the scope of indication ought to be, from an ethical point of view. What kinds and degrees of suffering, if any, would warrant PS in young children? To what extent should the foreseen length of PS matter? And what does caution dictate when there is significant uncertainty about how much time there is left, the severity of suffering and/or the child's level of awareness?

Author: Anders Castor, MD, PhD, Skåne University Hospital, Lund, SWEDEN

Co-Author: Linus Broström, PhD, Lund University, Lund, SWEDEN

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The Limits of Surrogate Authority

We present a series of cases to illustrate the ethical limits of surrogate decision making and propose an approach to addressing conflicts with surrogates. While a substituted judgment standard is prioritized over the best interest standard for adult, previously decisional patients, we argue that there are times when a best interest standard should be used instead. For example, ethical concerns arise when a previously healthy patient suffers a devastating trauma and family members serving as surrogates ascribe their fear of long term disability to the patient. In the name of substituted judgment, surrogates may prematurely request terminal withdrawal. During the first weeks postaccident, clinicians seek diagnostic and prognostic information and monitor the patient's recovery. We argue that during this period, a best interest approach may be warranted for both providers and surrogates. Appeals to substituted judgment are often premature in the midst of significant clinical uncertainty or when starkly counter to uncontested standards of practice. Instances in which surrogate authority should be limited include unsubstantiated rationale for irreversible treatment decisions; decisions that are known to be inconsistent with the patient's preferences or values; and decisions in which a surrogate has imposed his or her own values or has a conflict of interest. In such cases

the physician must act in the patient's best interest even over the objection of surrogates.

Author: Jill Watanabe, MD, UW Medicine Ethics Consultation Service, Seattle, WA, USA

Co-Authors: Diane Timberlake, MD, MA, University of Washington, Seattle, WA, USA

Laura Webster, RN, MA, University of Washington, Seattle, WA, USA

Denise Dudzinski, PhD, MTS, University of Washington, Seattle, WA, USA

1012

Maintaining Dignity in the Dying Super Obese Patient: End-of-Life Care for the Super Obese

The epidemic of obesity is getting worse in the US, and the new category of the "super obese" has raised significant care constraints for hospitals, in particular how to appropriately care for these patients when they are dying. This case study will highlight the extreme measures of care that was undertaken in order to maintain the dignity of a super obese patient at the end of their life, including the additional assistance to family that ordinarily would not be in the realm of clinicians. The strain of resources needed to care for a patient of this size in an ICU setting, and the burden of figuring out goals of care when standard procedures are not able to accommodate the patient's girth, is a major source of moral distress for all clinicians. Addressing the families' inability to see the truth in the limitations of care and having severely unrealistic expectations of outcomes makes communication very challenging. Many feel that the duty to care for these patients should not be at the expense of the care of others. Others argue that each patient requires the best that can be given, regardless of the distributive justice arguments. Nonetheless, in end-of-life cases with the super obese, clinicians' duties must extend to after the patient's death in order to maintain dignity. The ethics of caring for this unique population is much underrepresented and for clinicians in the US, this is a serious gap needing to be filled.

Author: Nneka O. Sederstrom, PhD, MPH, MedStar Washington Hospital Center, Washington, DC, USA

1013

Clinical Bioethics in Mexico: Difficulties, Challenges, and Opportunities

Ever since 2013, I have had the interest of implementing Clinical Bioethics in Mexico, this came up during my stay at the Cleveland Clinic where

I had the opportunity of being in close contact to clinical bioethics while doing an observership at the Department of Bioethics; it was then when I realized this did not exist in my country: neither the education to be a clinical bioethicist nor the practice inside hospitals.

In this space, first I share my own experience since then trying to implement this in my country by preaching and teaching the concept of "clinical bioethics" mainly in the academic field (where I currently work). I also describe some difficulties in the understanding and acceptance of the concept mentioned. Secondly, I comment on my experience since 2014 as a member of the Bioethics Committee at Hospital General de México, "Dr. Eduardo Liceaga," one of the largest hospitals in Mexico with around one thousand three hundred beds. Thus, I have been gathering all the difficulties, challenges and opportunities ever since its institution.

Three are the main areas in which these difficulties have been presented to us: the professional, cultural and practical-economical aspect. The first referring to the absence of education and preparation in the field of bioethics as members of these Committees, the second shows the ignorance on the functions and issues that a Committee is created to assess and study, this coming from health care professionals, patients and families; finally, the third one identifies practical issues such as care for emergencies, urban difficulties like traffic and insecurity in the country and risks of attending calls. The economical aspect is also studied here.

Finally, I will share briefly my project on creating a private ethics consultation service, which I started in January 2015 and its development, so far, in the Mexican reality.

Author: Elizabeth de los Rios, PhD, Anahuac University, San Antonio, MEXICO

1014

Communication Skills for Consensus Building Methodology: Considering of Ethically Complicated Cases

There are many ethically complicated contexts in clinical settings such as organ donation and withholding treatment. Ethical training for medical staff is required for the development of practical skills for resolving such cases. The extent of ethical training, however, varies between medical institutions without basic guidelines in Japan. The author has been engaged in ethical training for medical staff since 2005. This training includes not only an understanding of ethical theory, but also an understanding of the employment of the consensus

building method. The consensus building method is a creative process in which stakeholders share their opinions and their deep reasons for a satisfactory resolution. The purpose of this study is to consider application possibilities for the consensus building method through actual cases which include ethical issues. The subjects are resident nurses in Japanese public hospitals. Upon receiving ethical training and a lecture on the consensus building method, they organize ethical meetings for development of communication skills in their hospitals. This presentation intends to describe some of the facets of consensus building communication skills, and shows how they were used in actual cases. Ethical issues are also considered as well as whether or not this method is appropriate under certain conditions or in certain contexts. This study yielded results that prove the validity of the consensus building method.

Author: Kumiko Yoshitake, PhD, Tokyo University of Technology, Tokyo, JAPAN

1015

Conscience and Role Conflation: Moral Distress of Clinical Ethicists

Recognition for clinical ethicist (CECs) moral distress is still developing. CECs engage in plenty of situations where content or the CECs' multiplicity and conflation of roles creates a risk of moral distress.

My paper considers several scenarios, where I ask if and how the CECs moral distress should be accommodated. (1) A CEC is invited as a representative of the system to speak at an LGBTQ conference about a provider's hypothetical refusal to treat LGBTQ individuals. However, that the scenario is not so hypothetical and the CEC finds the refusal bordering unacceptable discrimination. How to address concerns about injustice with the CEC's role in the system? (2) Aside doing cases, the CEC also supports morbidity and mortality conferences. In the M&M conferences, discussions reveal an error in one of the CEC cases. The error has not been disclosed to the patient and the physicians try to silence the issue upon asking. How to address the concerns about the non-disclosure in the dual role? (3) A CEC has traditionally embraced sanctity of life principle. Their State adopts legislation that legalizes PAS. Could the CEC invoke a conscientious objection?

While distressed providers can talk to CECs or can defer to conscientious objections in some case, I examine tools for CECs. The Code of Ethics for Professional Health Care Consultants refers to

"preserving integrity" as a fall back mechanism. But does it offer CECs enough or what are potential alternatives?

Author: Marleen Eijkholt, PhD, Davidson College, Carolinas Medical Center, Charlotte, NC, USA

1016

Variability in Decision-Making and Outcomes in Infants with Significant Neurologic Disorders in Three NICUs

Neurological disorders represent a substantial proportion of the complications of prematurity (Volpe), as well as complications in the perinatal period for full term infants (Hill). Decision-making in the Neonatal Intensive Care Unit (NICU) around initiation or withdrawal of intensive care treatments often revolves around the current and likely future neurological function and capacity of the newborn infant. In addition, a large percentage of the consultations in a fetal care center also revolve around probable or likely neurological outcomes of findings, either through advanced genetic technologies, imaging studies, or both. Thus, in both these settings, discussions around the initiation or withdrawal of medical technologies are significantly influenced by the perceived likely neurological outcome for a given infant. Who has these discussions with family, and their mastery and knowledge of the literature regarding likely outcomes is central to decision making. In addition, individual providers' beliefs and attitudes regarding children with neurological difficulties is likely to influence advice given to families.

This study reviews the course of two groups of infants. In the first set, premature infants with left middle cerebral artery stroke in the perinatal period were identified at different NICUs. Through the use of process maps, the consultation and decision making were represented, and outcome choices identified. In a similar fashion, prenatal consults with similar findings of inferior vermian cerebellar hemorrhage were identified, who received care at one of the three NICUs. Again, through the use of process maps, the consultation and decision making were represented, and outcome choices identified.

In both groups, despite similar clinical presentations, process and outcomes varied significantly.

This suggests that the observation first made by Driscoll pertains forty years later. It is very different from the experience in adult critical care medicine. In the 1970s approaches to adult stroke varied widely between institutions. In the 2010s, however, with the advent of evidence-based guide-

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lines, differences in practice are minimal between units.

The implications and possible explanations for the persistence of variability despite evidence regarding prognosis in the setting of NICUs will be considered.

Author: David K. Urion, MD, Boston Children's Hospital, Boston, MA, USA

1017

Changing the Climate: Lessons Learned from Instituting an Interdisciplinary Team Based Ethics Assessment

How might one implement an interdisciplinary protocol that encourages dialogue on "ethic-related risks" in complex situations? The panel will explore our experiences in assessing the effectiveness of an evidence-based ethics protocol in six ICUs at three major US hospitals—UCLA, MGH, and Mayo Clinic. The purpose of the protocol is to identify patient, family, and situational risk factors known to contribute to ethical conflict, so interventions can be introduced earlier. Juggling the need for an efficient model and a way to engage clinicians in change and learning led to insights and recommendations for implementing a daily ethics assessment. Although such a project might appear straightforward, a range of obstacles surfaced. The challenges ranged from translating research based language into risk averse language compatible with an electronic medical record, to obtaining multiple IRB approvals, to engaging leadership, to maintaining consistency across sites while being contextually sensitive. Further obstacles to be addressed include: overcoming initial reservations about what was perceived to be a time-consuming task, disrupting routines and interdisciplinary relationships, and requiring clinicians to view an online orientation module. Our lessons learned speak to the complexity of trust, cultures of avoidance, implementation fidelity, the difficulty of altering habits and sustaining change, supporting moral courage and overcoming the skepticism that we can successfully address ethically complex situations through early team dialogue. Integrating clinical ethics innovation into healthcare is essential in improving care for patients, their families and decreasing moral distress and disengagement, in clinicians.

Author: Katherine A. Brown-Saltzman, MA, UCLA Health Ethics Center, Los Angeles, CA, USA Co-Authors: Carol Pavlish, RN, PhD, FAAN, UCLA School of Nursing, Los Angeles, CA, USA Ellen Robinson, RN, PhD, Massachusetts General

Hospital, Boston, MA, USA Jennifer Tamir, RN, MSN, CNL, UCLA School of Nursing, Los Angeles, CA, USA

1018

When God's Plan and the Medical Plan Are Mutually Exclusive: Can Parents Refuse Organ Transplantation Based on Religious Beliefs?

An 8-month-old female had new-onset jaundice. Laboratory evaluation revealed she had developed acute liver failure. Non-invasive testing for the etiology was unrevealing. She rapidly deteriorated, with rapidly rising liver enzymes. However, she continued to appear "well" to her parents,. It was recommended that she be placed on the liver transplantation list. It was felt that delaying the listing might jeopardize the chances of receiving an organ. The parents refused listing and were not open to the idea of transplant. Parents were undocumented immigrants from Central America, and neither could communicate in English. Both mother and father were spiritual with an expressed belief in God. Their belief system was rooted in trust in rituals and prayer as a form of healing. They were open about their beliefs, and shared that they were confident that God would heal her. In the past, the patient's brother had jaundice, which was managed in this manner with resolution of illness. Parents were seen as caring individuals who were advocating for what they believed was their child's best interest. Given the lack of a clear etiologic diagnosis for the liver failure, they could not see the relevance of such aggressive therapy in this context. The PICU team requested an ethics consultation regarding how to proceed in the setting of a medically indicated liver transplant for acute liver failure in a minor when her parent's beliefs are not aligned with the medical plan.

Author: Wendy S. Moon, MS, Mayo Clinic, Rochester, MN, USA

Co-Author: Juliana Perez Botero, MD, Mayo Clinic, Rochester, MN, USA

1019

Sedating Patients with Dementia to Solve Aggression: Ongoing Ethical Challenges

Violent behaviors are a not infrequent occurrence with certain types of dementia. When individuals with these types of dementia become violent, their families often seek to place them in a residence with a memory care unit and specially trained caregivers. In some cases heavy sedation is needed to resolve the behavioral problems. While the sedation "solves" the behavioral problems, it can

also severely compromise general functioning. In this case presentation, a composite case drawn from several real family scenarios, will be used to illustrate two significant ethical challenges. See the questions below. Care will be taken to identify the special challenges and moral distress of both family and professional caregivers and to suggest strategies for addressing these challenges.

Discussion questions:

- When sedation is used to "treat" aggression and violence in patients with certain types of dementia, is the resulting harm of impaired functioning justified by reduced violence?
- If impaired functioning results in the resident needing to be hand fed (a resident who can safely swallow and who enjoys eating but whose brain fails to instruct him to move food and drink to his mouth) can caregivers acquiesce to a surrogates demand not to hand feed the resident because "he would never want to live this way."

Author: Carol R. Taylor, PhD, Georgetown University, Washington, DC, USA

Co-Author: Robert Barnet, MD, MA, Georgetown University, Washington, DC, USA

1020

Palliative Care for Psychiatric Patients: A Role for Ethics Consultation?

There are a growing number of cases in which patients with psychiatric illness are deemed appropriate for palliative care or hospice placement. Recent years have seen appearance of several articles addressing this possibility. However, this is still a taboo subject. This raises the question of whether consideration of the limitations of healthcare and the appropriateness of palliative care and hospice placement may now be following a similar trajectory in mental and behavior healthcare as they did in other areas of medicine, albeit at a much later date. This panel will address the difficult ethical issues raised by psych-driven palliative care or hospice placement. The panel will include: (1) an overview of the tension between treating psychiatric illness and recognizing the appropriateness of palliative care or hospice placement, i.e., allowing the patient to die, for this specific population; (2) a case discussion that suggests the need to seriously consider palliative care or hospice for a patient with serious psychiatric and somatic illness triggering uncertainties of what condition might be termed "end stage"; (3) a case discussion that suggests the need to be extremely

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cautious about the transition to palliative care or hospice for patients with severe psychiatric illness; (4) a case discussion of whether there is a role for ethics consultation in helping to deal with such issues; and (5) open discussion among the panelists and audience of the issues raised.

Author: Marie-Eve Bouthillier, PhD, CISSS de Laval, Laval, Québec, CANADA

Co-Authors: Jacques Quintin, PhD, Universite de Sherbrooke, Québec, CANADA

Stella Reiter-Theil, PhD, University Hospital Basel, Basel, SWITZERLAND

Jan M. Schuermann, MA, University Hospital Basel, Basel, SWITZERLAND

Mark P. Aulisio, PhD, Case Western University, Cleveland, OH, USA

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An Exploration of Curriculum Development and Ethics Education in Residency Education: The Frame of Medical Ethics, Consent, and Moral Distress

Our residency program participated in the design, delivery and educational evaluation of an Association of Family Medicine Residency Directors (AFMRD) and Society for Teachers of Family Medicine (STFM) and American Academy of Family Physicians (AAFP) National Residency Curriculum Resource (RCR) curriculum titled "Consent within the frame of medical ethics." It is a presentation focused on activating and developing knowledge of medical ethics, procedures around consent, and case studies including assessment of moral distress. This presentation will focus on the process of curriculum development in residency ethics education, and will share process of focus groups and the evaluations of the curriculum and outcomes from the pre test/ post test competency testing preliminary data (n=26) which suggests some areas for future study in terms of ethics curriculum development and measures around "competence."

Author: Patrick McFarlane, MSW, MA, MSN-APRN, Eastern Maine Medical Center Family Medicine Center and Residency Program, Bangor, ME, USA

Co-Authors: Katie Adams, MD, Eastern Maine Medical Center, Bangor, Maine, USA

Kristin Thom, DO, Eastern Maine Medical Center-Bangor, Maine, USA

Denae Kershner, DO, Eastern Maine Medical Center-Bangor, Maine, USA

1022

Diversity of Clinical Ethics Consultation Services in the United States: Variance of Roles and Organizational Expectations in Various Stages of Program Development (Panel)

[No abstract available.]

Moderator: Ashley Stephens, MA

Panelists: Andrew Childress, PhD; Becket Grem-

mels, PhD; Jason Lesandrini, PhD(c)

1023

Falling Through the Cracks: Patients with Both Somatic and Psychiatric Diseases

Within the last decade more than 400 clinical ethics consultations (CEC) on demand were performed in the EvKB in both the somatic and the psychiatric sector. Some patients suffer from severe somatic as well as from serious psychiatric diseases. At worst, one or both of these conditions might endanger not only their health but also their lives. In a CEC these complex cases are demanding for all participants. Frequently, the regular therapy of the psychiatric disorder may also aggravate the somatic disease, or vice versa. Patients in such situations fall through the cracks due to the inability of any single department to meet all treatment requirements on its own. As a consequence, the scope of action is often limited and harm to the patient may result out of this dilemma. Furthermore these patients often do not have the capacity to consent. However, their participation in or at least their toleration of a demanding treatment are essential factors for its success. The ethical lines of conflict lie especially between the poles of beneficence and non-maleficence. But also distributive justice of scarce resources is an important aspect, because these patients need intensive support resulting in less attention of others. The complex situation in these CEC is illustrated by a case report from our practice. On the basis of this example the underlying values, conflicts of obligations and ethical arguments are analyzed and ways to act in concert are presented for discussion.

Author: Tanja Löbbing, Master of Medicine, Ethics and Law, Ev. Krankenhaus Bielefeld, Bielefeld, GERMANY

Co-Authors: Klaus Kobert, MD, Ev. Krankenhaus Bielefeld, Bielefeld, GERMANY

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Donor's Versus Relative's Genetic Material in a

Introduction: One of the widely discussed problems in assisted reproduction is related to the importance of genetic relationship between the child and the future parents.

Objective: We aim at presenting and discussing a case of a 31-year-old woman in premature menopause applying for IVF with donor's ova.

Methodology: Adapted METAP methodology and accompanying materials were presented to the leader of the team of the reproductive center "Radost"-Varna who had passed courses of bioethics and business ethics thus being appropriately prepared for the application of the methodology. The leader of the team organized ethical case discussions at place. Feedback was received through an original self-administered questionnaire.

Results and discussion: Two options regarding donor's ova were available to the patient – anonymous donation or patient sister's donation. Seven participants took part in the ethical meeting: the patient, her husband and her sister, physician, psychologist, embryologist and a midwife. The discussion resulted in a decision in favor of the usage of relative's material. This option was strongly supported by the patient's husband and sister while the treating team rather supported the anonymous donor option. The main arguments of the family were: reluctance to raise child from unknown donor; fear of undesired child's features; chance for close relation to the biological parent. Re-assessment was not planned.

Conclusion: METAP methodology helped mainly in the clarification of the problem and gaining confidence in the rightness of the decision. All participants were satisfied of the ethics meeting and on their own opinion they reached decision easier. Further revision of the instruments is necessary.

Author: Silviya Aleksandrova-Yankulovska, MD, PhD, Medical University of Pleven, Pleven, BUL-**GARIA**

Co-Authors: Toni Vekov, Medical University of Pleven, Pleven, BULGARIA

Alkan Emin, MD, Medical University of Pleven, Pleven, BULGARIA

1025

Do We Force a Patient to Have Dialysis?

Jan is a 37-year-old woman admitted for renal failure. She is a Type I diabetic. She has been admitted 4 times in the past year. She has significant cognitive deficits. Her IQ is 58. She has spent most of her life in institutions (foster care, hospitals, prison, or care facilities). She does not have decisional capacity, and has a court appointed guardian. There is no family. In the hospital she has stolen needles, scissors, and items belonging to other patients. She has harmed herself; a sitter was assigned to stay with her. She refuses medication. She asks to smoke. She cannot comply with dialysis, often leaving before a treatment is complete. She is unable to understand the consequences of her refusal, i.e., she states she wants to live, but cannot understand she needs treatments/ medications to live. Repeated attempts to help her understand have not been effective. While she is legally incompetent, her doctors want to preserve autonomy to the degree possible. The physician requests ethics consultation. Questions: How do we reconcile what she wants with her behavior in order to respect autonomy? What level of autonomy can she exercise given her deficits? Do we sedate her for dialysis? Are we committing assault if we force dialysis? Are we causing harm? What is in her best interest? What would a "reasonable person" in this situation want? Is it "reasonable" to refuse dialysis? How can we address quality of life? How we address caregiver moral distress?

Author: Mary Caldwell, MA, Mission Health, Asheville, NC, USA

Co-Author: John Watford, MD, Mission Health, Asheville, NC, USA

1026

Cosmetic Quality-of-Life: Who Decides When a Patient Can't?

A 49-year-old female with 47% total body surface area full-thickness burns and a severe smoke inhalation injury was admitted to the burn unit. The burns included many areas of 4th degree burns over her face and right arm. She was initially mechanically ventilated, sedated and lacked capacity. She was estranged from her father, but had three close friends. The patient's injury was a survivable and functionally recoverable one that would provide the patient with a reasonable quality of life, although numerous surgeries and extensive therapy would be necessary. Her friends were adamant the patient would not want to live with a severely disfigured face and above-elbow amputation. They demanded the medical team remove the ventilator and let the patient die. The patient's father consented for the necessary surgeries since he was her next-of-kin. One of the

patient's friends begged an ethics fellow to force the team to withdraw the ventilator. Numerous ethical questions were presented to the clinical ethics consult service. Should the friends be permitted to act as her surrogate since the patient had been estranged from her father? How could the team determine if the friends were making decisions based on substituted judgment or what they believed were in the best interests of the patient? Is cosmetic quality-of-life (QOL) equal to that of functional QOL? If so, should it have an equal bearing on decision-making in cases like this?

Author: Anjay Khandelwal, MD, Institute of Burn Ethics, Cleveland, OH, USA

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Miracles, Money, and a Compromised Surrogate

Using an ethically complex case we will generate discussion of concerns that can arise when a surrogate's capacity to act in the patient's interest is compromised. Our goal in the session will be to lead the group to identify the morally problematic elements of the case and to explore how professional caregivers in such situations might act within ethical constraints to insure an optimal outcome for the patient.

The case involves a patient whose niece has durable POA. The patient has been in critical care for 30 days at the time her physician recommends withdrawal of life support. The niece, who is ill herself, devoted to her aunt, and financially dependent on her, wants treatment to continue and offers religious reasons for her choice. A consulting psychologist determines that the niece has significant emotional problems. A chaplain and the physician attach different motives to the surrogate's decision. To break the deadlock, an estranged daughter is brought into the situation at which point the niece relents and life support is withdrawn.

Discussion questions will include:

- How can health care providers determine when a surrogate is not an adequate representative of the patient's autonomous wishes?
- 2. How much deference should be given to surrogates' judgments when it is suspected that they are unreliable decision-makers?
- 3. What are the ethically acceptable options avoiding paternalism, coercion and harm—for moving a surrogate towards an optimal decision?

Author: Marcia A. McKelligan, PhD, DePauw University, Greencastle, IN, USA

Co-Author: Ted Bitner, EdD, DePauw University, Greencastle, IN, USA

1028

A Case of Attempted Suicide in Huntington's Disease: Ethical and Moral Considerations

A 62-year-old female with Huntington's disease presented after suicide attempt. Her advance directive stated that she did not want intubation or resuscitation, which her family acknowledged and supported. In accordance with standard procedures after a suicide attempt, she was resuscitated in the Emergency Department and continued to state that she would attempt suicide again. Her suicidality in the face of a chronic and advancing illness, and her prolonged consistency in her desire to take her own life left care-providers wondering how to provide ethical, respectful care to this patient. Tension between the ethical principles of autonomy and beneficence is central in this case. The patient's narrative demonstrated that her suicide was an autonomous decision, free from coercion or disordered thinking from mental illness. Beneficence then would seem to necessitate care aligned with the patient's desire to end her life, which created ethical uneasiness for her family and care-providers. The case highlights several end-of-life ethical considerations that have received much recent attention. With ongoing discussions about legalization of aid in dying across the country, caregivers are challenged to understand what beneficence means in people with a progressively fatal disease who want a say in their death. This case also highlights the profound moral distress for families and care-providers that arises in such ethically challenging scenarios.

Author: Kristin Furfari, MD, University of Colorado, Denver, CO, USA

Co-Author: Jean T. Abbott, MD, MH, University of Colorado, Aurora, CO, USA

1029

Managing Conflicts Between Clinicians and Surrogates

Caring for the ethically complicated patient often involves conflict between clinicians and surrogate decision makers. This workshop will engage the audience in a discussion of practical approaches to preventing, mitigating, and managing these conflicts. The audience will listen to 3 brief podcasts that address these topics: 1) conflicts with surrogates related to life-sustaining treatment decisions; 2) conflicts related to surrogate requests

or demands; and 3) conflicts related to surrogate behaviors. Following each podcast, the audience will discuss the topics and their challenges, the responsibilities of the surrogate and the staff in the conflict, and specific strategies for preventing, mitigating and managing those aspects of the conflicts. We will review how consultants and staff can characterize the different types of conflicts and use appropriate resolution strategies. For each of the above topics, we will discuss how to: 1) clarify the role of the clinician and the surrogate for decision-making around life-sustaining treatments; 2) understand when it may be ethically justifiable to accommodate, decline to accommodate, or explore creative solutions to a surrogate's request or demand, and the appropriate procedures when a request will not be accommodated; and 3) appreciate how surrogate behavior that is disruptive to other patients and staff should be quickly identified, de-escalated, and limited while still promoting a positive relationship with the surrogate.

Author: Barbara L. Chanko, RN, MB, VHA National Center for Ethics in Health Care, New York, NY, USA

Co-Authors: Kenneth A. Berkowitz, MD, VHA National Center for Ethics in Health Care, New York, NY, USA

Marilyn Mitchell, RN, BSN, VHA National Center for Ethics in Health Care, New York, NY, USA Co-Authors: Steve Tokar, MA, VHA National Center for Ethics in Health Care, New York, NY, USA

1030

Ethical Considerations in the Use of the Internet to Obtain Patient Care Information

The availability of information on the Internet has transformed the delivery of health care for patients and providers. Although patients may in general use the Internet ethically as part of their care (e.g., researching medical problems, evaluating quality, etc.), the health care provider's use of the Internet to search for information about their patient is subject to specific legal, ethical, and professional considerations. This presentation will review these considerations in determining when it is ethically justified to search the Internet about a patient. Health care professional obligations include collecting relevant patient information to inform treatment planning, promoting and maintaining trust, honoring patient privacy, obtaining informed consent for specific information gathering, and maintaining the integrity of the patient-provider relationship. We will review a heuristic that can be used in ethics consultation that is based in part on best practices identified in the literature as well as relevant legal issues. The heuristic contains specific steps in determining the justifiability of using the Internet to obtain patient information, including: assessing if the information can be obtained directly from patients or surrogates without using the Internet; identifying and assessing the provider's motivation for the Internet search; the role of patient consent prior to searching; and possible justifiable exceptions to searching without patient consent.

Author: David J. Alfandre, MD, MSPH, VHA National Center for Ethics in Health Care, New York, NY, USA

Co-Authors: Kenneth A. Berkowitz, MD, FCCP, VHA National Center for Ethics in Health Care, New York, NY, USA

Cynthia Geppert, MD, PhD, DPS, New Mexico Veterans Affairs Health Care System, Albuquerque, NM, USA

Barbara L. Chanko, RN, MBA, VHA National Center for Ethics in Health Care, New York, NY, USA

1031

Brain Death: Expanding Duties to Accommodate Objections

The determination of death by neurological criteria (DDNC or "brain death") has been legally established as death in all US jurisdictions and in most other developed countries on Earth. It is supported by a "durable worldwide consensus." Moreover, the consequences of DDNC are clear. Once a patient is determined dead, clinicians typically discontinue physiological support. In short, DDNC is a "hard clinical endpoint" where technological interventions reach the limits of required or accepted medical practice. Despite this legal consensus, hospitals continue to grapple with a significant (and growing) number of conflicts. Some families do not accept DDNC as death and want clinicians to continue physiological support. While some of these disputes are due to misunderstanding or diagnostic mistrust, many are religiously based. Today, only four US states legally require hospitals to "accommodate" families with religious objections to DDNC. I argue that other states should enact similar accommodation requirements. The presenter will assess the meaning and significance of recent developments in both the Aden Hailu (Nevada Supreme Court) and Jahi McMath (Alameda Superior Court) brain death court cases.

Author: Thaddeus M Pope, JD, PhD, Mitchell Hamline School of Law, Saint Paul, MN, USA

1032

Rich in Detail, Poor in Content: Excavating the Ethical Complexities in (Presumably) Clear Clinical Language

The goals, values, and issues clinicians bring to patient care can contribute to the ethical complexities encountered, yet may be harder to identify and address in real time. To identify examples of clinician-based complexities, and illustrate the challenges they raise for patient care and the practice of ethics consultation, this presentation will explore ethical complexities hidden in the everyday clinical language of patient chart notes. Illustrated via multi-media presentation, examples include both what is omitted from (and hence overlooked) in chart notes (identifying clinician and surrogate decision-making responsibilities, naming involved parties and roles, accounts of clinical thought processes, articulation of patient goals and values, explicit mention of death) as well as what is hidden through focus and attention on the omnipresent (administrative details, technical descriptions, organ-specific medical consultations). Since these omissions and commissions highlight ethical complexities and assumptions inherent in clinicians' orientation, training, and practice as well as embedded in institutional culture, they can deeply influence patient care and the experiences of those involved in that care. Excavating the multiple complexities revealed in chart notes from a single clinical ethics consultation, the presentation will invite discussion of how ethics consultants identify and respond to such complexities for individual patients and on various institutional levels.

Author: Virginia L. Bartlett, PhD, Cedars-Sinai Medical Center, Los Angeles, CA, USA

Co-Author: Stuart Finder, PhD, Cedars-Sinai Medical Center, Los Angeles, CA, USA

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Continuous Palliative Sedation for Intractable Existential Suffering

It is frequently claimed that continuous palliative sedation (CPS), whereby sedation is used to control refractory systems in a terminally ill patient at the end of life, should not be provided as a treatment for existential suffering (1,2). Existential suffering is typically characterized as an aversive response to such factors as anxiety about one's impending death, a loss of meaningfulness or control, or deep social isolation (3-7). These sorts of factors are particularly prevalent for terminally ill patients at the

end of life, which is why existential suffering is so much more common at this stage of a patient's care.

There are at least two arguments against this practice. First, it's claimed that because existential suffering is itself not clearly characterized, we ought not resort to such extreme measures in attempting to relieve it (2,8). Next, it's claimed that the alleviation of existential suffering is outside the purview of health care, and that such symptoms are therefore not the appropriate target for any medical intervention, including palliative sedation (9). In this paper, we will present a hypothetical case presentation involving a terminally ill patient with refractory existential suffering at the end of life. Then, we will explain why neither argument against CPS for existential suffering rules out CPS in this case, and instead argue that if there is to be a prohibition on CPS for existential suffering, it must be based on the claim that one's existential suffering is not truly an intractable refractory symptom. This implies that while there is nothing in principle wrong with CPS for existential suffering, in practice the conditions for its justified use are rarely if ever met.

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Author: Elijah Weber, PhD, The University of Texas MD Anderson Cancer Center, Houston, TX, USA

Co-Authors: Alina Bennett, PhD, MA, MPH, The University of Texas MD Anderson Cancer Center, Houston, TX, USA

1034

Membership Recruitment in Health Care Ethics Committees

The growing dialogue regarding the professionalization of ethics consultations in hospitals across the USA has primarily focused on the individual, largely ignoring the forces of the complex settings in which a consultant would practice. This presentation and the research it represents intends to fill in the gap by focusing on a better understanding of HCEC recruitment and the personal attributes and training HCEC chairs value in their prospective members. This presentation presents results from an exploratory study conducted by members of the HCEC at UNC-Chapel Hill. The study surveyed members of HCECs about recruitment, appointment, and training of members. Past studies have examined HCECs, but have focused on the roles of the committees and the broad make-up of membership. Thus, our study fills an important knowledge gap in trends of membership recruitment and appointment. We will present trends in three categories of findings: training components for new and current members, appointment procedures across hospitals, and what committees reported to value during candidate identification and selection.

Author: Anya Prince, JD, UNC Chapel Hill, Chapel Hill, NC, USA

1035

Healthcare Ethicists in Canada: Who Are We and What Do We Do?

The landscape of the provision of ethics services in healthcare continues to evolve in Canada. There is no centralized body that maintains information about individuals who provide ethics services. The Empirical Working Group of the Canadian Association of Practicing Healthcare Ethicists-Association canadienne des éthiciens en soins de santé (CAPHE-ACESS) designed a survey to gather information to close this gap. The objectives of the survey are three-fold:

- 1. To describe the background, roles, and practices of individuals providing ethics services in healthcare in Canada.
- 2. To compare findings to a survey completed 20 years ago.
- 3. To gather data to inform and support the work

of CAPHE-ACESS related to practice standards, working conditions, and professional values.

The target population for the survey was all individuals currently providing ethics services in a healthcare organization in Canada. Individuals solely engaged in administration of a research ethics board or ethics teaching, research and other scholarly work in an academic setting were excluded. Individuals whose role was limited to membership on an ethics committee were also excluded. The survey was launched in September 2015 in both English and French. 88 surveys were completed. The complexity and diversity of ethical issues encountered as healthcare ethicists will be described. Relevant comparisons will also be made to findings from earlier surveys.

Author: Dianne Godkin, PhD, Trillium Health Partners, Mississauga, ON, CANADA

Co-Authors: Jennifer Bell, PhD, University Health Network, Toronto, ON, CANADA

Eoin Connolly, MHSc, Trillium Health Partners, Mississauga, ON, CANADA

Marie Edwards, PhD, University of Manitoba, Winnipeg, CANADA

Tom Foreman, DHCE, The Ottawa Hospital, Ottawa, ON, CANADA

Gary Goldsand, MA, University of Alberta, Edmonton, Alberta, CANADA

Patricia Hood MacNicol, MHSc, Trillium Health Partners, Mississauga, ON, CANADA

Jacintha Penney, PsyD, Eastern Health, St. John's, Newfoundland, CANADA

Randi Zlotnik Shaul, PhD, Hospital for Sick Children, Toronto, ON, CANADA

1036

Exploring the Impact of Values on Advance Care Planning in a Multi-Cultural and Multi-Religious Asian State

In this paper, the author proposes to explore the impact of values on advance care planning (ACP). Singapore is introducing ACP in public restructured hospitals and in long-term care settings such as hospices and nursing homes. We have adopted the Respecting Choices ACP framework. Using this framework, healthcare professionals are being trained as ACP facilitators. ACP has developed around the core values and principles of patient autonomy, informed decision-making, and truth telling. These values and principles are based on the Western bioethics philosophy of principalism, which focuses on the four moral principles of au-

tonomy, beneficence, non-maleficence and justice. Culture significantly influences how individuals perceive, experience and practice healthcare. In Singapore's multi-cultural and multi-religious society, which blends Asian values with a Western outlook, what role does culture play in ACP? What impact do values such as filial piety, family sovereignty, and truth telling have on an ACP discussion from the perspective of the ACP facilitator and the recipients of facilitation? How will these values affect the choices we make or avoid making as we near the end of our lives?

Author: Sumytra Menon, LLB, LLM, National University of Singapore, Singapore, SINGAPORE

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Certification of Healthcare Ethics Consultants: The German Model

Healthcare ethics consultation (HEC) is undergoing a process of professionalization. One way to improve its quality is to certify the consultants. As one of the first countries worldwide, Germany has introduced a national certification program in 2014. In this country, HEC has gained momentum over the last ten years due to an increasing public debate on clinical ethics issues, demand among health care professionals and requirements for hospital accreditation. The certification program primarily aims to set quality standards for healthcare ethics consultants, thus improving HEC quality across national health care and promoting professionalization, public recognition and funding of HEC. Based on a literature search and expert consensus process, the program was developed by a working group and approved by the board of the German Academy for Ethics in Medicine, comprising experts in clinical ethics from various disciplines, regions, and health care settings. The three-tier program offers certification on the levels of (1) consultant, (2) coordinator, and (3) trainer for HEC. Review criteria comprise: formal HEC and communication training and HEC experience (for level 1); education in organizational ethics (additionally for level 2); academic ethics education, didactic qualification and policy development experience (additionally for level 3). We will report an evaluation of the 93 applications during the first two years of the certification program.

Author: Ralf J. Jox, MD, PhD, University of Munich, Munich, GERMANY

Co-Authors: Nina Luisa Hoekstra, MD, German Academy for Ethics in Medicine, Göttingen, GER-MANY

Alfred Simon, PhD, German Academy for Ethics in Medicine, Göttingen, GERMANY

Georg Marckmann, MD, Institute of Ethics, History and Theory of Medicine, University of Munich, Munich, GERMANY

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Intensive Care for Organ Preservation: Ethical Considerations

[No abstract available.]

Author: Anne L. Dalle Ave, MD

Co-Author: Jack Kilcullen, MD, JD, MPH

1039

Sleepless Nights: The Ethics Consults that Continue to Haunt

Over the course of their careers, clinical ethicists often see similar types of cases, or cases with similar themes—identifying surrogate decision-makers, end-of-life decision-making, navigating withholding/withdrawing inappropriate medical treatment, etc. These cases can become somewhat routine and unmemorable. However, during a career, Ethicists generally experience a handful of cases that are different. The reasons why any particular case sticks in the mind may vary. Sometimes appropriate, well-considered ethical recommendations are ignored; ethical analysis required by a case is uniquely nuanced or novel; emotions of a patient, the family, members of the healthcare team, or even the ethicist, are particularly poignant. These cases can cause significant emotional anguish, disquiet, may prompt introspection, reflection, and, possibly, a change in consultation practice, and, even years afterwards, these cases continue to haunt clinical ethicists. This panel, comprised of clinical ethicists with a collective experience of more than a thousand consultations, will each present one case that continues to haunt him or her. By confronting, discussing, and analyzing these difficult cases, this panel will offer reflections on difficult cases and offer insights for the training of other healthcare professionals who have or will experience their own particularly troubling cases. This panel will also allow for significant question/answer time for audience discussion of additional cases.

Author: Tyler S. Gibb, JD, PhD, Western Michigan University, Kalamazoo, MI, USA

Co-Authors: James Hynds, LLB, PhD, UCLA Health System Ethics Center, Los Angeles, CA, USA Kevin M. Dirksen, MSc, MDiv, Providence Center for Health Care Ethics, Portland, OR, USA

Ryan P. Holmes, PhD(c), Santa Clara University Markkula Center for Applied Ethics, Santa Clara, CA, USA

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Hospital Ethics Consultation: Can They Provide Impartial Recommendations for a Patient and/or Surrogate, without Compromising the Organization that Employs Them?

[No abstract available.]

Author: Fernando Gutierrez, BA,

ethics4healthcare.com, Clearwater, FL, USA

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Ethical Issues Arising from Terminal Discharge of Patients

The authors will review the terminal discharge (TD) of a patient from hospital to die at home. N was diagnosed with cancer last year and treated with chemotherapy. He was diagnosed with brain metastasis on this admission. N told several nurses he wanted to stay in hospital. He did not want to burden his relatives at home because they were busy working. When the nurses asked him if he had shared his views with his relatives he said he found this difficult. His condition deteriorated rapidly over the next few days and he lost capacity to make his own healthcare decisions. N's wife told the doctors that N wished to die at home and observe Buddhist rites upon death. These rites, which include 8 hours of chanting and an 8-hour no-touch rule, would be difficult to undertake in a hospital. N's brother and wife offered to be his caregivers. The medical social worker advised that the family were not financially stable, were struggling to pay N's hospital bills and cannot afford inpatient hospice. She was also concerned about the level of care the caregivers could provide given they were employed full-time. Furthermore, the care team were concerned about the caregivers' ability to correctly administer the necessary medications and manage N's nasogastric tube. Questions:

- 1. Is TD ethically different to other forms of home discharge?
- 2. How can TD be offered using a relational framework?
- 3. What is the standard of care required of healthcare professionals when terminally discharging patients?

Author: Sumytra Menon, LLB, LLM, National University of Singapore, Singapore, SINGAPORE **Co-Authors:** Anita Ho, PhD, National University

of Singapore, Singapore, SINGAPORE Lalit Kumar Radha Krishna, MBChB, FRCP, FAMS, MA, PhD, National Cancer Centre, Singapore, SINGAPORE

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On Behalf of the Unrepresented: Does This Homeless Patient Lack Capacity?

A policy in many California hospitals allows an ethics subcommittee to act as surrogate on behalf of a patient who lacks capacity and for whom neither family nor advance directive can be located. The procedure usually works well, and the ability to promptly give consent benefits patients. However, when there is no discerning best interests may be difficult. With questionable capacity, decisions that seem counter to their best interests increase the complexity.

Mr. M, a homeless man in his mid fifties, was admitted through the Emergency Department. He was in respiratory distress, hypothermic, and suffered with bilateral severe gangrene. Within a day, Mr. M. recovered sufficiently to be extubated and transferred from the ICU. As he regained awareness, he adamantly refused to consent for bilateral above the knee amputations, He insisted he had had the condition for well over a year, had managed fine with his wheelchair. He rejected the claim his life was at stake. Initially, the consulting psychiatrist deemed Mr. M to lack capacity, due partly to his failure to accept the grim prognosis. However, as the team got to know Mr. M, and as he recovered, many argued that he did understand the options and his refusal should be honored.

The subcommittee was split; the full committee was convened. The surgeon acknowledged that the condition had been present to a varying degree for about a year. The psychiatrist stated capacity was borderline.

- What was in Mr. M's best interest?
- What legal concerns dictate minimum conditions? Who and how should capacity weigh on the decision?
- How can/should the ethics team discern critical interests of Mr. M?
- What are key factors for the committee?
- How to resolve disagreement within the Committee?

Author: Miriam Piven Cotler, PhD, CSUN/Hospitals, Redondo Beach, CA, USA

1043

Caring for the "Unrepresented Patient": Strategies to Avoid Moral Distress and Substandard Care

Unrepresented (unbefriended) patients pose one of the most under-examined and challenging issues in clinical ethics. These patients lack both decisional capacity and friends/family to represent them. Often socially isolated, some are elderly and have outlived friends and family. Others are homeless, suffer from mental illness, or are so estranged that no one is willing to act. Published studies show that 5% of the 500,000 patients who die each year in US ICUs, and an estimated 3-4% of the 1.5 million nursing home residents are unrepresented. Existing mechanisms to address decision making for these patients are scant and not uniform. Most providers muddle through on an ad hoc basis with enormous variability in practice and heightened risk to this vulnerable population. The presenters will pose three cases for small group analysis. Groups will discuss ethical dimensions and risks to patients, including under-treatment, over treatment, and delayed discharge. The panelists will then make four brief presentations:

- 1. General overview from the perspective of healthcare ethics committees.
- Current barriers and solutions developed by states.
- Evolution of collaborative effort by the ethics community in CO to examine the issue and offer recommendations.
- 4. Current legislative effort to amend CO's proxy law and develop a "best practices" document to guide providers/facilities in implementing a revised statute.

Author: Jean T. Abbott, MD, MH, Center for Bioethics and Humanities, Anschutz Medical Campus, Boulder, CO, USA

Co-Authors: Deb Bennett-Woods, EdD, Regis University, Denver, CO, USA

Jackie Glover, PhD, Center for Bioethics and Humanities, Boulder, CO, USA

Thaddeus Mason Pope, JD, PhD, Mitchell Hamline School of Law, Saint Paul, MN, USA

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Assuming Too Much, Assuming Too Little: Addictions, Clinical Ethics, and Complexity (Case Study)

[No abstract available.]

Author: Daniel Z. Buchman, PhD, RSW

1045

Death at the Beginning of Life: Can We Withdraw Life Support on a Pregnant Patient?

In 2014, two pregnant women each became the center of separate but parallel discussions about how to handle end-of-life care during pregnancy. Marlise Munoz and Robyn Benson both suffered catastrophic brain injuries, but the role of their previously expressed wishes and family input were treated very differently due to the laws regarding pregnancy in the home state of each. In some states a woman's previously stated wishes are automatically invalidated in the context of a life-threatening event during pregnancy, others require life support if the fetus could develop to viability, some allow for considerations of harm to the woman, others allow a woman's expressed preferences, and still others are silent about the issue. What are ethical implications of giving patient values more or less weight depending on the patient's location?

In this presentation, three clinical ethicists practicing in different states will consider this issue, describing their approaches to a recent consult involving a 32-year-old woman who had a pulmonary embolism and anoxic brain injury in her 22nd week of pregnancy. They will provide an overview of the differences in state statutes and the ethical challenges they present. They will discuss how their respective institutions would approach the issue, and compare that to the Munoz and Benson cases in order to give recent historical perspective. Concerns related to fetal viability, advance directives, surrogate decision making, and maternal-fetal conflict will be addressed.

Attendees will be invited to discuss how the same case would be handled at their home institutions, and what approach best serves core ethical values.

Author: Joan M. Henriksen Hellyer, PhD, Mayo Clinic, Rochester, MN, USA

Co-Authors: Leah Eisenberg, JD, University of Arkansas, Little Rock, AR, USA

Felicia Cohn, PhD, Kaiser Permanente, Anaheim, CA, USA

1046

Aging with Chronic Illness

This case study presents a set of the issues surrounding the care of seniors living alone with chronic illness for modern integrated health systems in aging societies. It draws on the case of "Mr. Lim," which concerns a middle-aged hawker's assistant with severe and progressively worsen-

ing arthritis who relies on steroids and other anti-inflammatory medications to enable him to continue to work, but is suffering from the chronic and potentially life-threatening side-effects of the long term use of these drugs. His polyclinic doctor is challenged to understand the coping strategies of her patient and how best to advocate for him. The case is taken from the Singapore Casebook project, Making Difficult Decisions with Patients and Families, funded by the Lien Foundation in Singapore, and available online at www.bioethicscasebook.sg Author: Jacqueline J.L. Chin, PhD, Centre for Biomedical Ethics, Singapore, SINGAPORE

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Evaluating the Interpersonal Skills of Clinical Ethics Consultants: Assessing Clinical Ethics Skills (ACES) Tool Launch

Interpersonal skills are vital to ethics consultation, yet assessing them systematically has been a challenge for the field. The American Society for Bioethics and Humanities (ASBH) has piloted its Quality Attestation process by evaluating portfolios of clinical ethics consultants (CECs) and is exploring next steps. One key way to assess the interpersonal skills of ethics consultants is through simulated ethics consultation cases evaluated by trained raters. To implement this approach effectively, an evaluation tool is needed. Based on the ASBH Core Competencies and the VA Integrated Ethics Tool, the authors developed the Assessing Clinical Ethics Skills (ACES) tool to evaluate a clinical ethics consultant's performance in a simulated ethics consultation. The ACES tool aims to assess the competence of the ethics consultant in 12 domains, with specific behaviors for raters to evaluate. A newly developed website (which is available for free) has been developed to train clinical ethicists on how to use the ACES tool. At the 2015 ICCEC meeting, the authors offered a workshop that demonstrated the key components of the ACES evaluation tool. This year, the authors will present the way in which the ACES tool can be accessed and utilized in one's own institution. Attendees of the workshop will receive hands-on training on how to apply the ACES tool using videotaped ethics consultations which demonstrate key elements of the tool and test the ethics consultant's performance. Additionally, preliminary data on early users of the tool and feedback will be reported. Facilitators will provide the expert raters' agreed evaluation of the CEC's performance and the strengths and limitations of the tool.

Author: Katherine Wasson, PhD, MPH, Loyola University Chicago, Maywood, IL, USA

Co-Authors: Michael McCarthy, MTS, PhD, Loyola University Chicago, Maywood, IL, USA

Kayhan Parsi, JD, PhD, Loyola University Chicago, Maywood, IL, USA

Viva Siddall, MS, Loyola University Chicago, Maywood, IL, USA

Mark Kuczewski, PhD, Loyola University Chicago, Maywood, IL, USA

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Building and Using a Tool for Ethically Complex Cases: The Moral Distress Education Project

The Moral Distress Education Project is an online tool in which core multidisciplinary experts on moral distress from across the country were interviewed in a documentary-style media project to create a self-guided web documentary. Over a dozen experts on moral distress contributed qualitative interviews for the project, and the project faculty used classic qualitative methodology code and analyze data into manageable themes, which were produced into aggregate film clips. The project utilized a professional film crew and production company; to date, this tool has been used by over 1,000 healthcare professionals, and some institutions. This session starts with a 15-minute introduction of why this tool was built, and the breadth of moral distress in healthcare institutions. It also discusses how the tool is being used globally. The remainder of the session will be interactive. Participants will be asked to view one of 12 themed aggregate clips, and then a guided discussion will elicit shared perspectives on a particular theme (20-30 minutes). Finally, in a guided discussion, participants will share how this tool can be used in the context of both clinical ethics consultation and organizational ethics activities (15-20 minutes, depending on timing for earlier discussion). By the end of this session, participants will be able to distinguish between moral distress, moral residue, and will also be able to distinguish moral courage from conscientious objection.

Author: M. Sara Rosenthal, PhD, University of Kentucky, Lexington, KY, USA

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Power of Attorney for Research: The Need for Research: The Need for a Clear Legal Mechanism The participation of decisionally incapable persons in research presents a plethora of practical

and ethical challenges. Because they are, by definition, unable to understand and appreciate the potential risks and benefits of trial participation, the incapable cannot consent on their own behalf. Excluding them from research, however, inhibits innovation that could improve their lives, or the lives of others like them, in the years to come.

We argue that the current practice of obtaining surrogate consent for research participation—generally based on hierarchies for making treatment decisions—creates as many problems as it solves. It invites conflation of therapeutic and research purposes (i.e., the therapeutic misconception), it often conflicts with regulatory guidance (including the TCPS2 which instructs researchers to seek consent from legally appointed guardians for research), and it fails to show sufficient respect for the prior capable wishes of participants because such wishes, or preferences, are rarely a topic of discussion.

To address this difficulty, we propose that a clear legal mechanism for executing a power of attorney for research participation (POA-R) ought to be established. Although there are limitations to all advance directives (and we will touch on a few) we believe that a POA-R could designate a decision-maker, provide a clear indication of an individual's research-related preferences, and/or provide prospective consent to participation in specific research projects or types of research, such as dementia research or other research involving progressive, but fairly predictable, disease courses (Pierce, 2010).

We believe that our concerns are shared far outside our jurisdiction. Indeed, a recent case study in Public Health Ethics demonstrated that researchers, as well as ethicists, are struggling with this concern in the United Kingdom as well. Our reflections on that article, and on our own experiences as research ethics board (REB) members, have convinced us that new solutions to this old problem are long overdue. In this presentation we will describe some challenges typically faced by REBs and argue for an approach that we believe is more defensible and straightforward than most of the alternatives currently on offer.

Author: Ann M. Heesters, MA, UHN, Toronto, ON, CANADA

Co-Authors: Daniel Z. Buchman, PhD, RSW, United Health Network, Toronto, ON, CANADA Kyle Anstey, PhD, United Health Network, Toronto, ON, CANADA

Jennifer A. Bell, PhD, Princess Margaret Cancer Centre, Toronto, ON, CANADA

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Barbara Russell, PhD, United Health Network, Toronto, ON, CANADA

Linda Wright, MSW, MHSc, United Health Network, Toronto, ON, CANADA

1050

Ethical Complexity of POLST Implementation: Should the POLST Be Treated Differently than Other Physicians' Orders?

Physician orders for life sustaining treatments (POLST) merges the power of a physician's order with fundamental obligations to respect patient autonomy. Despite the initial aim of the POLST to transform patient's preferences into actionable medical orders across healthcare settings, the movements to enhance the current utilization of the POLST should do so with caution. Although the POLST explicitly recommends periodic review, especially after a change in clinical status, this often occurs upon hospital admission and the medical team must decipher whether to treat the POLST as an order to follow in the hospital or revoke until confirmed. Whenever the surrogate or a clinician questions the medical applicability of the POLST to the given situation, they are frequently seen as 'violating the patient's expressed wishes' and failing to respect patient autonomy. In other healthcare decision-making contexts, physician's orders are implemented after consideration of medical appropriateness. For example, medication orders and administration are assumed to undergo an assessment of the Six Rights to ensure patient safety. Does the POLST's current format or process discourage these professional checks and balances? Who should carry the moral authority over implementation of the POLST, clinicians, PCP, or surrogates? This paper will explore these issues and propose solutions to avoid medical errors resulting from use of POLST forms.

Author: Laura B. Webster, BSN, University of Washington, Medicine Ethics Consultation Service, Seattle, WA, USA

Co-Authors: James Kirkpatrick, MD, University of Washington Medical Center, Seattle, WA, USA Denise Dudzinski, PhD, MTS, University of Washington School of Medicine, Seattle, WA, USA Sarah Shannon, PhD, RN, FAAN, University of Washington School of Nursing, Seattle, WA, USA

1051

Caring for Patients with a History of Illicit **Intravenous Drug Use: Parameters of Ethical Obligations from Beside to Boardroom**

Ethically sound care for patients who engage in potentially harmful behaviors that are illegal, perceived to be immoral, or both is a challenge for health professionals and health care organizations alike. This paper seeks to survey the parameters of ethical obligations from bedside to boardroom, highlighting the integrated nature of how to provide the best possible care with the most integrity, from a care provider standpoint as well as an institutional standpoint all the while attempting to ground those obligations in a patient-centered approach to sustaining the therapeutic relationship. This investigation began with a pattern of ethics consultations surrounding the care of patients who had a history of intravenous drug use (IVDU) and for whom prolonged IV antibiotics would need to be administered either because no oral antibiotics were indicated or because no provider thought an outpatient IV antibiotic care plan was safe enough given patients' histories with IVDU. Simultaneously, regulatory, accreditation, and reimbursement factors conspired to exacerbate the ethical tensions providers and patients encounter in these cases. So-called Central Line-Associated Bloodstream Infections (CLABSIs) became a key measure of quality, and a source of a financial penalty, as it is associated with significant morbidity and mortality risks. Patients who have an IVDU history are at a higher risk for developing a CLABSI. More specifically, providers and administrators began to ask for ethical guidance on whether or not it was ethically permissible to discharge a patient who tampers with an IV access device (often a peripherally inserted central catheter or PICC line) through which caregivers deliver antibiotic therapy. Related questions included whether to permit such patients to leave the hospitals' campuses (as they are designated non-smoking facilities by policy) so that they may smoke tobacco; concerns exist because at that time (many providers suspect) patients are accessing illicit IV drugs and may utilize their PICC lines to self-administer recreational drugs. Other questions pertain to when it is permissible to remove the PICC line even if the recommended course of antibiotic therapy has not yet been completed. To the ethicists involved, this raised a host of questions spanning a wide spectrum of issues at various levels of health care delivery. For example, should a stricter non-smoking policy be enforced, how should providers guard

against unfairly and disproportionately restricting patients with a history of IVDU versus those who do not? Should the organization rethink its policy of non-smoking campuses? Other questions include whether providers should tolerate a degree of behavior by the patient that, in the eyes of the provider, undermines the patient's own health. Author: Nicholas J. Kockler, PhD, MS, Providence Center for Health Care Ethics, Portland, OR, USA Co-Authors: John Tuohey, PhD, Providence Center for Health Care Ethics, Portland, OR, USA

Kevin Dirksen, MSc, MDiv, Providence Center for Health Care Ethics, Portland, OR, USA Peter Grover, PhD, Providence Milwaukie Hospi-

tal, Milwaukie, OR, USA

1052

Ethical Complexity: Toward a More Effective Diagnosis and Response

First, we propose a definition of ethical complexity in relationship to two, widely endorsed ethical norms: (1) shared, informed decision making and (2) patient-centeredness. The path to achieving these interrelated norms in caring for patients is littered with potential hazards and impediments, from those that are beyond anyone's control (e.g., intractable uncertainty, cultural and religious differences) to those that are within someone's control, especially the control of clinicians, hospitals and health care systems (e.g., inadequacies in the disclosure of critical information, ignorance or neglect of cultural difference, poor communication skills, uncoordinated care). The need for clinical ethics consultation arises in circumstances where these hazards and impediments are both real and multiple in number. Second, we argue that ethical complexity can be defined as a function of the number and the type of hazards or impediments encountered in the care of patients whose needs include the need for clinical ethical consultation. And finally, in light of the ethical norms of shared, informed decision making and patientcenteredness, we offer a taxonomy of the hazards and impediments that can generate degrees of ethical complexity—a taxonomy for use by clinical ethics consultants in both diagnosing and more effectively responding to ethical complexity as a frequently encountered phenomenon in ethics consultation.

Author: Frank Daniel Davis, PhD, Geisinger Health System, Danville, PA, USA

Co-Author: Joseph A. Raho, PhD, University of California, Los Angeles, Los Angeles, CA, USA

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How Neutral Should the Clinical Ethics Consultant Be?

Despite enormous efforts and achievements towards professionalization of clinical ethics consultation (CEC), there is still no universal consensus on the most appropriate methodological approach both from a practical and theoretical point of view. Empirical data show that even for the US, the practice is heterogeneous regarding whether the consultant makes normative recommendations or not—even more so internationally. This practice variation uncovers disagreement on the consultant's appropriate "role" or "authority." Irrespective of the broad rejection of an "authoritarian approach," the boundaries of the "ethics facilitation approach" are far from being sharply defined, e.g., how should the consultant handle a discrepancy between his own ethical conviction and the shared opinion of others? Both the literature and practice vary according to the question whether the consultant should be neutral. We analyze this question by disentangling four meanings of neutrality, arguing for neutrality with regard to the involved parties (impartiality), the methods (objectivity) and the outcomes (openness), but not with the regard to the values (not: indifference). Finally, we propose a coherent and practical way for consultants to manage disagreement between their own ethical insights and a discrepant consensus view of the parties involved in a case consultation. In conclusion, accepting our proposal would entail refining some of the CEC guidelines, education programs, and practices.

Author: Ralf J. Jox, MD, PhD, University of Munich, Munich, GERMANY

Co-Authors: Alessandra Gasparetto, MA, Insubria University, Varese, ITALY

Mario Picozzi, MD, PhD, Insubria University, Varese, ITALY

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Beyond Ethics Consultations (ECS): Building an Ethics Environment in a Children's Hospital

Background: There are few ethics consultations in most children's hospitals despite the abundance of ethically complex cases. We set out to understand how clinicians and ethicists in a children's hospital address these day-to-day ethics issues outside the context of formal consultations.

Objective: Determine what mechanisms, in addition to ethics consultation, exist within a children's hospital to address ethical issues.

Design/Methods: 1-year retrospective review of venues where ethics discussions were held in a large Midwestern tertiary care children's hospital.

Results: We identified nine distinct venues in which ethics issues were commonly identified: 6 were explicitly designed to address ethical issues; the other 3 had different primary purposes but ethics committee members were regular attendees and ethical issues were regularly addressed. In 2014, among the 6 venues explicitly designed to address ethical issues, there were:

- 19 ethics contacts (including 12 formal consultations) to the Hospital Ethics Committee
- 12 meetings of the Nursing Ethics Forum, designed to address nursing and interdisciplinary ethics issues, implement policy/process change, and promote ethics awareness
- 12 informal Ethics Brown Bag Workshops for any interested hospital staff to attend
- 10 PICU Ethics Forum meetings where different topics identified by PICU staff were discussed, and
- 2 hospital-wide Ethics Grand Rounds.

In the venues that were not designed explicitly to address ethical issues:

- 10 cases were reviewed in the NICU Comprehensive Care Rounds, a case-based interdisciplinary unit staff conference where patient/team goals were clarified, staff angst could be mitigated, and consensus built toward next steps;
- The Palliative Care Team had 238 new case contacts, all of whom had their goals and progress reviewed weekly—inclusive of ethical dimensions of their care, and
- There were 300 new Fetal Health Center integrated consults where together staff and families discussed what the best course of prenatal and postnatal management should be given concerning fetal diagnoses; palliative care and ethics input were regular components of these integrated consults.

Conclusions: Multiple and varied venues exist for ethics discussions in this children's hospital. Most ethics discussions take place outside of formal ethics consultation or even in those venues explicitly designed for such discussions. We suspect that similar phenomena exist in other hospitals. Measuring ethics consultation is inadequate in ascertaining the ethical environment of a hospital. Creating an ethical environment in children's

hospitals will address and promote understanding of ethics beyond consultation.

Author: Brian S. Carter, MD, Children's Mercy Hospital, Kansas City, MO, USA

1055

Addressing Racism and Discrimination in Clinical Ethics

Over the past two years, highly publicized deaths of African Americans during police encounters have led to the recognition that bias and institutional racism persists in the US. Discrimination is also burgeoning in countries around the world as acts of terrorism threaten security, tolerance and open borders. How can clinical ethicists contribute to addressing such reactions? Our skills in conflict resolution, mediation, facilitation of communication, and ethical analysis of institutional policies, could all be valuable. Additionally, promoting diversity in our field through new trainees would be useful. We could thus bring the perspectives of minority and disenfranchised populations to the table through the voices of young scholars from these communities. In this panel senior experts and teachers in the field of philosophy and clinical ethics, and a bioethics fellow will present the approaches they would suggest to address racism and other types of discrimination.

The panelists will: discuss why racism and discrimination are moral problems that clinical ethicists should address; discuss pertinent competencies of clinical ethicists for addressing discrimination; and review American Society for Bioethics and Humanities position statements on advocacy. The audience will then have an opportunity to deliberate with the panelists and consider how to best prepare the field of clinical ethics and take practical steps to address discrimination.

Author: Marion Danis, MD, National Institutes of Health, Bethesda, MD, USA

Co-Authors: Yolonda Y. Wilson, PhD, Howard University, Washington, DC, USA

Anita J. Tarzian, PhD, RN, University of Maryland, Baltimore, MD, USA

Akilah Jefferson, MD, MSc, National Institutes of Health, Bethesda, MD, USA

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ECMO and Miracles: Setting Expectations

The presenters will discuss the ethically complex case of a 20-year-old man with end-stage ARDS who is fully dependent on veno-venous ECMO support during his six-week stay in a large aca-

demic hospital. After about four weeks, when neither lung transplant nor recovery are feasible, the clinical care team recommends a shift to comfort care. However, the family opposes this shift, saying that God's ability to perform a miracle will restore the patient to health. Their faith community agrees and supports the family's decision to continue aggressive therapies. Setting expectations for families of patients who receive ECMO is challenging for clinical care teams, especially when discussing end-of-life considerations. ECMO is a unique lifesustaining intervention, as it is both time-limited and a means to either recovery or transplant: never a permanent therapy. In addition, as this case shows, initiating end-of-life discussions becomes even more challenging when families appeal to faith as a reason to continue ECMO. By discussing the complexities of this case, we hope to provide the audience with recommendations for strategically managing both organizational and consultative aspects of related cases.

- What unique ethical concerns does ECMO use entail?
- How should the ethicist assist the team in setting realistic expectations for families regarding ECMO?
- What types of questions should the ethics consultant ask to elucidate the family's religious beliefs?
- How, if at all, might ethics consultants use miracle language to help support families during the ECMO process?
- What role should ethics consultants play as members of the team working long-term ECMO patients?

Author: Ashley Stephens, MA, Baylor College of Medicine, Houston, TX, USA

Co-Authors: Trevor M. Bibler, PhD, B

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Giving In: The Capable Patient Who Defers

Although often conceived of as a right, surrogate decision-making is primarily a responsibility. This case study explores the complexities and moral uncertainties that arise when (1) a capable patient defers decision-making authority to a DPOA potentially under duress and (2) there are concerns regarding the capacity of the DPOA (and of the alternate agent). Patient S. completed an advance directive (AD) that gives "immediate" decision-making authority to her DPOA; the document also indicates a clear preference for all life-sustaining measures to be provided, in accordance with her

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religious beliefs. The patient expressed being "scared of dying but also worried about crossing" the DPOA. The DPOA attempts to dictate care by asserting that he has medical training and that he alone has exclusive power to consent to, or refuse interventions. It soon becomes apparent that the DPOA lacks the necessary insight into the severity of the patient's condition and makes decisions at variance with the patient's AD (yet, is unable to offer a clear rationale for doing so). When the patient's respiratory condition deteriorates, requiring transfer to the ICU, the DPOA continued to refuse escalation of treatment. Hospital security physically removed the DPOA and the treating team began to seek direction from the alternate agent listed on the AD. To the surprise of all involved, this alternate agent is not only questionably capable, but also defers decision-making authority to the original DPOA.

Author: Joseph A. Raho, PhD, UCLA Health System Ethics Center, Los Angeles, CA, USA

Co-Author: Frank Daniel Davis, PhD, Geisinger Health System, Danville, PA, USA

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Less Discussed Everyday Issues of End-of-Life Care Ethics

Traditionally, ethical discussions on end-of-life care focus on autonomy, truth telling, artificial nutrition and hydration. Yet, clinical ethics consultation in an oncology center in Bulgaria revealed a variety of less discussed everyday issues of end-of-life care ethics.

This panel aims to develop a diverse discussion based on real cases of everyday issues in end-of-life care. Every panelist will focus in 20 minutes on a specific issue: relatives' role (Ralf Jox), prioritization (Henk ten Have), staff's moral distress (Renzo Pegoraro). Time will be left for cases presentation and discussion with the audience.

Method: Six cases were obtained from clinical ethics consultation through adapted METAP methodology at the oncology center in Vratsa.

Discussion: First will be a case of a 76-year-old patient given futile life-prolonging treatment that caused him suffering but benefited the relatives. Second is case of a 30-year-old patient desired unnecessary hospitalization in order to protect his child from witnessing his illness. Should social status or age be taken into account in the case of 52-year-old businessman demanding priority over other patients? Where is the acceptable threshold of care demands? Should rude behavior of a dy-

ing patient toward the staff be excused? Can we withdraw from a case of futile care for a close colleague? Such issues will be discussed in an attempt to reach conclusion about the applicability of the methodology for ethics consultation.

Author: Silviya Aleksandrova-Yankulovska, MD, PhD, Medical University of Pleven, Pleven, BUL-GARIA

Co-Authors: Ralf Jox, PhD, Institute of Ethics, History and Theory of Medicine, Munich, GERMANY Henk ten Have, Professor, Duquesne University, Pittsburgh, PA, USA

Renzo Pegoraro, Professor, Pontificia Academy for Life, Rome, ITALY

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Teaching Conflict Engagement Skills in Clinical Ethics

This general session presentation will be given by three presenters: a conflict resolution practitioner, a clinical ethics educator, and a clinical ethicist. The session's focus will be on teaching conflict engagement skills, perhaps more commonly referred to as conflict management, to those involved in clinical ethics.

Our model is adapted for clinical ethics from the conflict resolution field. This model's methodology concentrates on conflict engagement through collaboration, competition, compromising, avoidance, and accommodation. This is only one of several conflict engagement models under discussion at this meeting and within the clinical ethics field more broadly. For clinical ethicists to be well trained, they should be well-versed in all available conflict engagement models. When facing conflict, there is not one process or approach that is always best.

This skills building session will teach the audience to use the model to engage around conflict in the care of ethically complex patients. First, we will offer a brief introduction of the model, situating it in the fields of bioethics and human interaction social psychology. Next, we will present a case with instructions for analysis applying the model; the audience will be broken into small groups. Finally, the audience will reconvene to discuss their small group work, including their assessment of the utility and functionality of the model

Author: Kahlia T. Kéita, MA, MedStar Washington Hospital Center, Washington, DC, USA

Co-Authors: Evan DeRenzo, PhD, MedStar Washington Hospital Center, Washington, DC, USA

Lauren Edelstein, MA, University of Maryland, Baltimore, MD, USA

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Providing Treatment of Erectile Dysfunction in Ethically Complex Cases

Treatment of erectile dysfunction (ED) is not as easy as it appears in television commercials. In the clinical setting it often presents challenges among individual patient rights, provider values, and/or public health concerns. We will describe ethics consultations requested by staff about patients seeking ED treatment (e.g., when the patient is unmarried, has a sexual transmissible infection, or perhaps most ethically challengingly, has a history of sex offense). Health care providers are duty bound to provide high quality health care by preventing and treating medical disease and the bar for denying medically indicated care is appropriately set high. However, many providers and health care staff experience considerable moral distress when confronted with the clinical situations described above, and may feel strongly about their role in preventing perceived potential harm to others. The case reviews will provide an ethical analysis of values conflicts related to decisions regarding treatment for ED and make recommendations regarding an ethical resolution of these conflicts. We will describe the ethical basis for ED treatment, ethical factors that might limit treatment, ethical standards to be met before ED treatment could be denied, including the need for transparency about the decision with the patient, mechanisms for due process for the patient, and the obligation of institutions to assist providers who experience distress with these types of concerns.

Author: David J. Alfandre, MD, MSPH, VHA National Center for Ethics in Health Care, New York, NY, USA

Co-Authors: Kenneth A. Berkowitz, MD, FCCP, VHA National Center for Ethics in Health Care, New York, NY, USA

Cynthia Geppert, MD, PhD, DPS, New Mexico Veterans Affairs Health Care System, Albuquerque, NM, USA

Barbara L. Chanko, RN, MBA, VHA National Center for Ethics in Health Care, New York, NY, USA

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Gaining Ground: The Ethical Space Between Consent and Assent

The ethically complex patient who lacks decisional capacity but is able to assent raises quandaries for bioethicists and clinicians. While there is guidance on how to assess for capacity and to guide surrogate decision-makers, there is less written on the nuances of negotiating with patients who are not fully capable but nonetheless active and critical participants in their care. What principles, theories or frameworks could clinicians draw upon to help navigate decisionmaking that respects patients while following the surrogate's decision? This panel will examine the ethical concerns that arise when trying to obtain assent from a patient who cannot give full consent. The multidisciplinary panel will use case examples and their discipline-specific expertise to explore this topic. First, a philosopher-ethicist will examine the philosophical groundings for both consent and assent, and discuss what makes them similar and dissimilar in practice. Next, a clinical psychologist/clinical ethicist will explore the social and behavioral aspects of consent versus assent and discuss the emotional impact of going against patient wishes. Finally, a lawyer-ethicist, with experience in conflict-resolution, will explore the legal differences between consent and assent. the models that exist for limited involvement in decision making and conflict resolution skills that can reduce ethical harms. The panel will be moderated by a bioethicist (PhD in Philosophy/Bioethics and a MPH) with 15 years practicing clinical ethics consultations, teaching a wide range of health professionals and students.

Author: Preya S. Tarsney, JD, RIC, Chicago, IL, USA **Co-Authors:** Debjani Mukherjee, PhD, RIC, Chicago, IL, USA

Andy Kondrat, MA, RIC, Chicago, IL, USA Katherine Wasson, PhD, MPH, Loyola University Chicago, Chicago, IL

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A Delirious or Disqualified Demand of Physician Assisted Suicide (PAS)

Mrs C. is a charming 92-year-old woman that I have been following as a cardiologist for nearly ten years, while I also was an ethicist. She first came because of a severe aortic valve stenosis that could have been easily cured surgically, what would have protected Mrs C. from the risk of an acute cardiac accident. But she firmly refused any

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kind of surgery on her heart. She had the best life she could expect, she said, her husband passed away some years ago and she didn't feel like living much longer. If she could die suddenly from her heart, it will be the best scenario for her. After in depth discussions, I let Mrs C. make her own choices. Nevertheless, she didn't suffer of any fatal cardiac event and, ten years later, she is still alive. She regularly came to see me all along the years and began to ask for PAS, even if knowing that PAS remains illegal in France. Progressively, I became confused, wondering how best to honor her trust and to respect what she expresses. I pushed her to speak with her GP who finally called me. For her, Mrs C. was delirious and psychopathological. She always has been like that. She didn't really want PAS, but more caring attention.

- What did Mrs C. ask for exactly?
- Was it beneficial towards the patient to be an ethicist in this case?
- What would have been the medical answer to this patient in countries where PAS or active euthanasia is legal?
- Was her voice disqualified in France because of the legislative context?

Author: Véronique Fournier, MD, PhD, Assistance Publique-Hôpitaux de Paris, Paris, FRANCE

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Should We Keep Louise in Hospital with Forced Treatments and Contention, or Should We Take the Risk of Her Attempting to Commit Suicide Outside the Hospital?

Louise is a 42 year old woman. Although she is very sociable and has a daughter, she is rather isolated. She presents psychotic disorders since childhood and she attempted to commit suicide several times. She is under curatorship. Until recently, she was cared for at home by a psychiatric mobile team. Because of her worsening psychotic disorders and a suicide attempt, she has been involuntary hospitalized for the past few months. She still presents many and serious episodes of agitation and aggressiveness on herself or others. Although the caregivers usually avoid coercive measures, they sometimes have to attach Louise and inject drugs without her consent. As she got better, she again attempted to commit suicide in hospital. She says she no longer wants to be coerced and that she will attempt to commit suicide again anyway. The medical team is considering transferring her to a therapeutic apartment where she would be less monitored, but fears that she will nevertheless try committing suicide again.

Discussion will be organized around the following questions:

- What is the best interest of the patient?
- How does the caregivers' professional integrity have weight in the decision? Are they more embarrassed by the coercive measures or by the suicide risk?
- What is the best way to respect the patient's autonomy? Is it a question of consent?
- Should the caregivers tell her that they are uncomfortable with her situation and the two options?

Author: Nicolas Foureur, MD, Centre d'éthique clinique, Paris, FRANCE

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Should the Medical Team Let Mr. Ali Suffer During His Agony as His Wife Demands, in Accordance with Their Cultural and Religious Values?

Mr Ali is a 69 year old man. He was diagnosed with a cholangiocarcinoma and told that no curative treatment was available. A hospice care network monitors him at home. Two months after diagnosis, he was admitted to hospital because of acute dyspnea. His state worsened rapidly and he became nearly comatose because of hepatic encephalitis. The medical team told his wife and his three adult sons that he was in the process of dying. They said he wouldn't be able to return home to die, contrary to what he and his wife, had planned. She agreed to a more elaborate medical control of his pain and agitation, but she demanded that low levels of morphine be administered to him. She was worried that morphine would provoke death, which was unacceptable with regards to their personal beliefs. She underlined that suffering, also during agony, is valued in their religion and that physicians should not interfere in this process. She refused to meet with the imam as suggested by the hospital, saying that she is well-informed of her personal religious duties. Discussion will be organized around the following questions:

- How can the patient's preferences be best elicited?
- How is the principle of beneficence/ non maleficence understood by the patient's wife? The caregivers?
- Can the patient's values and preferences be reconciled with the caregivers' professional integrity?

Author: Francois-Xavier Goudot, MD, Assistance Publique Hospitaux de Paris, Paris FRANCE Co-Authors: Negar Yahaghi, MA, Assistance Publique Hospitaux de Paris, Paris FRANCE Nicolas Foureur, MD, Assistance Publique Hospitaux de Paris, Paris FRANCE

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Smoking on Oxygen—A Double-Edged Sword

A 67-year-old man with a complicated past medical history including chronic obstructive pulmonary disease due to smoking presents to the Burn Center after sustaining a flash burn to his face. He has significant singing of his nasal passages, and soot in his oropharynx, but his vocal cords are clearly visualized. He is admitted to the intensive care unit per center protocol for monitoring of his airway, but improves to his baseline requirement of 2L nasal cannula prior to discharge. However, his insurance company refuses to provide him with more home oxygen tanks, as this is the third time he has presented to a burn center with facial burns from smoking while on home oxygen. This case study will discuss issues related to treating patients with COPD dependent on home oxygen who continue to participate in high risk behavior despite knowledge of the consequences. How should an individual patient's medical need for oxygen (to improve their quality of life) be balanced with the potential risk not only to the patient (thermal injury, coupled with inhalation injury), but also the larger population (risk of property fires threatening other lives, use of limited hospital resources, loss of provision of oxygen supplies)? Is this a decision that is solely within the bailiwick of the medical community, or do other individuals have a right to weigh in? The Audience Response System will be used to explore these and other issues surrounding this topic in an interactive fashion with participants.

Author: Laura S. Johnson, MD, MedStar Washington Hospital Center, Washington, DC, USA

Co-Author: Nneka Sederstrom, PhD, MedStar Washington Hospital Center, Washington, DC, USA

1066 Tell Me Your Story

A narrative approach to ethics consultation affirms the truth that each person comes to health care with a unique history that has a profound effect on health and well-being. The narrative approach puts the patient first, recognizes that medical analysis has meaning in light of this patient and her priorities, situates the patient within a context, and involves the patient, family and caregivers in a joint process of listening, questioning, clarifying, and ultimately partnering to achieve health and dying goals.

My aim is to discuss the importance of communication in our role as clinicians, ethicists, and those involved in spiritual care as we walk with the seriously ill and dying approaching the end of their lives.

I want to share what has informed my beliefs about the role of clinicians and ethicists. This is derived from my more than forty years of clinical practice, the death of family members, and my years as an ethics consultant. I intend to reflect on and to share what has informed my beliefs and how this informs my practice. The example of Dame Cecily Saunders and the wisdom of Viktor Frankl are central to my thoughts.

Author: Robert J. Barnet, MD, MA, Georgetown University, Falls Church, VA, USA

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Rebooting a Broken Relationship: Developing a Process for Implementing Care Agreements in a Children's Hospital

Our Ethics Consult Service (ECS) in a children's hospital is called frequently to consult on complex cases where for various reasons the relationship between the care team and patient/family has broken down. Staff often express concern about the patient's best interest, conflicts of interest, thwarted agreements, requests for care outside the standard, and decision making confusion. A tone of having "given up" signals that the relationship is broken and in need of a reboot. In an attempt to enhance clarity and transparency in rebooting the relationship with the patient/family, and to set clear expectations for both parties, the ECS drafted a template, examples and guidance for a care agreement document. We sought to keep the agreement short and balanced, avoiding excess detail that could lead to additional disagreement, and to avoid a punitive tone. Once teams gained experience using care agreements, we realized that this tool would be most effective when used proactively. In partnership with the Department of Social Work, the ECS transitioned the oversight of care agreements to the Social Work Supervisors, who are usually involved earlier in a contentious case. Care agreements can serve as one effective tool in the ethics consult service toolbox, especially when used proactively in complex cases, helping to reboot the relationship with the family,

improve communication, and establish mutually agreed upon goals of care to best serve the patient's best interest.

Author: Pamela G. Nathanson, MBE, The Children's Hospital of Philadelphia, Philadelphia, PA, USA

Co-Author: Donna McKlindon, MSN, RN, The Children's Hospital of Philadelphia, Philadelphia, PA, USA

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Countertransference and the Clinical Ethics Encounter: What, Why, and How We Feel During Consultations

One of the more draining aspects of being a clinical ethicist is dealing with the emotions of patients, family members, as well as healthcare providers. Generally, by the time a clinical ethicist is called into a case, emotions are running high, patience is low, and interpersonal communication is strained. The emotional nature of doing clinical ethics consultation has not been adequately addressed in the literature. Furthermore, the literature is almost entirely devoid of discussions of managing the emotional burden associated with doing clinical ethics consultations. Management of countertransference, the natural emotional reaction by the therapist towards the patient, is a widely discussed topic in the psychotherapeutic literature. This concept can be adapted to the clinical ethics encounter by broadening it beyond the patient-therapist relationship to refer to the ethics consultant's emotional response towards the patient, the family, or other members the healthcare team. This paper will offer suggestions on how to manage these emotional responses and their burden in the clinical ethics encounter, drawing upon techniques and strategies recommended in the psychotherapeutic literature. Using these techniques may improve consultation outcomes and reduce the emotional burden on the clinical ethicist.

Author: Tyler S. Gibb, PhD, Western Michigan University, Kalamazoo, MI, USA

Co-Authors: Michael J. Redinger, MD, MA, Western Michigan University, Kalamazoo, MI, USA

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Ongoing Evaluation of Clinical Ethics Consultations as a Form of Continuous Quality Improvement

Ongoing evaluation of the clinical ethics consultation service (ECS) allows for continuous

quality improvement, which is a process-based, data-driven approach to improving the quality of a service. Evaluations by stakeholders involved in the consultation can provide real-time feedback about what is working well and what might need to be improved. Although numerous authors have previously presented data from research studies on the effectiveness of clinical ethics consultation, few ECSs routinely send evaluations as an ongoing component of their everyday clinical activities.

This session will present eight years of ECS evaluation data from a single institution. Evaluations of the ECS show a consistently high regard for the service, with the mean overall satisfaction of the service at 4.6 on a 5-point scale. This is especially noteworthy given that ethics consultations often are called after other attempts to resolve conflicts have been unsuccessful.

The focus of this session is not on the data, however; instead the primary purpose is to equip and encourage others to engage in ongoing evaluation of their own ECS. Toward that end, the following resources will be shared: (1) the 16-item survey tool used to gather the evaluation data, (2) the procedure used to elicit and collate responses, and (3) how the resulting data is used to support continuous quality improvement and justify the continued financial support of the ECS to hospital administration.

Author: Rebecca Volpe, PhD, Penn State College of Medicine, Hershey, PA, USA

1070

A Protocol for Prioritizing Hepatitis C (HCV) Treatment: An Ethical Framework for Scarce Resource Allocations that Can Be Useful for Ethics Consultation

Recent advances in the treatment of Hepatitis C (HCV) provide vastly improved cure rates and greater tolerability over prior therapy, but pose complex resource allocation challenges. Within our large integrated health system, the financial costs (up to \$100,000/patient) and other resources (i.e., staff, space, and clinical capacity) associated with the treatment of over 180,000 patients with HCV are such that treating every patient now would overwhelm our budget and infrastructure. From an ethics perspective, the most beneficial approach to resolving resource scarcity for HCV treatment is to augment resources and treat all clinically indicated patients prior to implementing a prioritization (triage) plan. If, despite these efforts, resources remain limited, an allocation system can be ethically justified. In response to these concerns, we proactively developed a consistent, fair, and transparent ethical framework to guide resource allocation decisions for HCV treatment in our healthcare system. Features of the protocol included a clear explanation of the ethical underpinnings and goals of the protocol, clinical exclusion criteria, clinical inclusion criteria (i.e., the prioritization protocol), and appeals and oversight mechanisms. This presentation will describe our protocol, the inclusive process by which the protocol was developed by a wide range of subject matter experts and stakeholders, its system-wide implementation, and the relevance for ethics consultation.

Author: Kenneth A. Berkowitz, MD, FCCP, VHA National Center for Ethics in Health Care, New York, NY, USA

Co-Authors: Virginia Ashby Sharpe, PhD, VHA National Center for Ethics in Health Care, New York, NY, USA

Jason Dominitz, MD, MHS, VA Puget Sound Health Care System, Seattle, WA, USA

Timothy Morgan, MD, VA Long Beach Healthcare System, Long Beach, CA, USA

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Guidelines for Managing Complex Cases Involving Extracorporeal Membrane Oxygenation (ECMO)

The use of extracorporeal membrane oxygenation (ECMO) has increased 10-fold in the past 5 years. There are unique ethical and clinical considerations regarding ECMO placement and discontinuation which make ECMO cases highly complex, including: (1) identifying ideal candidates for ECMO placement, (2) agreeing on a time-limited trial, (3) managing communication and responsibilities among large care teams and surrogates/patients, and (4) "bridging-to-nowhere" when recovery or transplant are unlikely.

The presenters have been involved in 40+ ECMO cases over 3 years, and they frequently publish on the use of mechanical circulatory support. Here, the authors will present "best practices" guidelines to help manage these complex cases. The guidelines cover 3 key decision points. Our presentation will be divided sequentially:

1. 7 Minutes—Initiating ECMO. This section will focus on why ECMO initiation should be considered conceptually distinct from other types of informed consent due to the complexities of the intervention (e.g., 3 different purposes of the intervention; likelihood of shifting trajectories; the time-limited nature of ECMO and the likelihood

of negative outcomes). Practical, clinical strategies for conversations regarding ECMO initiation will be discussed.

- 2. 4 Minutes—Continuing ECMO. This section focuses on how to prepare for ECMO discontinuation, including decision-point meetings and communication models.
- 3.5 Minutes—End-of-Life. To limit bridging-tonowhere, this section outlines the ethical permissibility in using a directive communication approach with patients and families when discussing ECMO discontinuation. Roles and responsibilities among team members will be discussed.

4. 4 Minutes—Q&A.

Author: Courtenay R Bruce, JD, Baylor College of Medicine, Houston, TX, USA

Co-Authors: Trevor M. Bibler, PhD, Baylor College of Medicine, Houston, TX, USA

Ashley Stephens, MA, Baylor College of Medicine, Houston. TX. USA

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Cultural Challenges Faced by Clinical Ethics Consultation in Mexico

As complex as clinical ethics consultations are, by themselves, case studies and analysis become even more challenging when the field is utterly unknown, as is the case in Mexico. Bioethics committees are mandatory for all Mexican health establishments, but most of the people that work in them have no bioethics training, let alone, any skills in doing medical ethics counseling. The "Hospital General de México" is the largest public hospital in Mexico City, offering more than 40 high specialty services, and harboring over 1,000 beds. Two years ago, its Ethics Committee was relaunched and a great effort was made to make clinical ethics consultations available, at least in those services where it has been historically most needed: gynecology and obstetrics, transplants, oncology and pediatrics. The service is free of charge for the patients, and the bioethicists that attend the consults do so during their free time, without any economic retribution.

It has been a very difficult road to travel, starting by the introduction of the concept of clinical ethics consultation to health professionals that have done fine without it during all of their working careers, changing the patriarchal model of clinical practice to one centered on autonomous patient decisions, reconciling different points of view within the ethics committee, even explaining to the committee members how ethical decisions

are made within the field of bioethics, taking into account their lack of preparation.

Add to the above, the multicultural background of the patients treated at the hospital. A large percentage of the patients come from indigenous populations, traveling hundreds of miles from their villages to Mexico City. In many cases, these patients only speak their native languages, making clear communication with them difficult. They often live within very low poverty levels, with little or no access to medicines and the minimal elements needed for home care.

An attempt will be made to explain, through three case studies analyzed by the clinical ethics consultation service of the "Hospital General de Mexico", how all the difficulties exposed above have been addressed by the recent introduction of this field in Mexico.

Author: Yael Zonenszain, PhD(c), Hospital General de Mexico, Huixquilucan, MEXICO

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Ethical Challenges Facing Advance Care Planning in Singapore

Advance care planning was introduced in Singapore, as in other countries, recently as a means of empowering individuals to make informed decisions regarding their health and end of life care. It is a way for individuals to contemplate their own personal values and to exercise autonomy. However, there is reason to believe that the ACP may not be widely taken up and when taken up may not be applied as intended. The ethical challenges facing ACP in Singapore need careful study. This essay focuses on two problematic ethical aspects of the ACP which are:

- A strict adherence to "procedural formalism" and
- An over emphasis on "individualistic autonomy" which can lead to hindrances in its implementation.

These may explain both the low uptake as well as its ineffectiveness. ACP should not be a compliance exercise and implementers will need to think hard about when and how to implement ACP, given cultural and perceptual sensitivities. By discussing the concept of "narrativism" and "relational autonomy" we provide an avenue for solving the dilemmas faced and present a scenario which is closer to the ideal of what the ACP framework hopes to achieve. Eventually, an increased uptake of ACP will be a useful health service de-

livery indicator, but this also means developing a more morally mindful and just society in a broader sense.

Author: Shahla Siddiqui, MD, KTPH, Singapore, SINGAPORE

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Lost in the Law: Where's the Patient? Legal Impediments to Ethically Optimal Treatment

Law and ethics often converge at a patient's bedside, directly affecting outcomes. Clinical ethicists regularly navigate the ways in which legal and ethical determinants influence a patient's experience. While law and ethics often support similar goals and decisions, in some circumstances the law may unintentionally divert focus from the patient's values or best interests and inhibit pursuit of the ethically optimal course of action. This panel will feature three clinical ethicists who will each present a case to highlight the array of challenges that can arise when law and medicine intersect at the bedside. The presenters will provide a case description and evaluate the legal issues that challenged the ethics recommendation. The first panelist will discuss challenges arising from a situation in which a close friend of a patient has intimate knowledge of previously expressed preferences and values but cannot legally act as surrogate while those legally permitted to act as surrogates lack such knowledge. The second panelist will reflect on challenges in end-of-life care when a patient's values are known, but the law prevents those values from being respected. Lastly, the third panelist will examine the justice concerns that arise when the statutory definition of death by neurological criteria and religious law clash. The session will conclude with discussion on how to mitigate legal hurdles in pursuit of the ethically optimal course of action and questions from the audience.

Author: Margot M. Eves, JD, MA, Cleveland Clinic, Cleveland, OH, USA

Co-Authors: Josh Crites, PhD, Cleveland Clinic, Cleveland, OH, USA

Lauren Flicker, JD, MBE, Montefiore Medical Center, Bronx, NY, USA

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For further information regarding submission guidelines, please contact:

Christian Carrozzo, Senior Editor Journal of Hospital Ethics John J. Lynch MD Center for Ethics MedStar Washington Hospital Center christian.carrozzo@medstar.net

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education & awards

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The John J. Lynch MD Moral Courage Awards, named after the founder and Medical Director of the Center for Ethics, is a biennial program in recognition of individuals who have demonstrated courage when acting against difficult and ethically challenging circumstances. Established in 2010, this program was designed as an opportunity for hospital leaders to model through exemplification the virtues they consider central to creating and sustaining an ethically sound climate in the hospital. For more information, contact the program director, Kahlia Kéita at kahlia.t.keita@medstar.net



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