

Volume 9

Number 2

September 2023

JOURNAL OF HOSPITAL ETHICS

THE JOHN J. LYNCH, MD CENTER FOR ETHICS

Proceedings of the 17th Annual International
Conference on Clinical Ethics and Consultation



***Clinical Ethics:
Consultation and/or Education?***
Hosted by the A. Gemelli School of Medicine,
Università Cattolica del Sacro Cuore,
Rome, Italy



UNIVERSITÀ
CATTOLICA
del Sacro Cuore

JOURNAL of HOSPITAL ETHICS

THE JOHN J. LYNCH, MD CENTER FOR ETHICS

EDITORIAL GROUP

EDITOR-IN-CHIEF

Evan G. DeRenzo, PhD
Ethicist & Editor, Emeritus
John J. Lynch, MD Center for Ethics
MedStar Washington

MANAGING EDITOR

Christian Carozzo, PhD (c)
Educator & Editor
John J. Lynch, MD Center for Ethics
MedStar Washington
Department of Philosophy
University at Albany
State University of New York

MEDICAL EDITORS

Jack A. Sava, MD
Chief, Trauma
Director, Gold Surgery Team
MedStar Washington
Associate Professor of Surgery,
School of Medicine
Georgetown University Medical Center

Michael Pottash, MD
Director, Fellowship Program in Palliative Care
MedStar Washington
Associate Professor, School of Medicine
Georgetown University Medical Center

NURSING EDITOR

Lucia Wocial, PhD
Senior Clinical Ethicist
John J. Lynch, MD Center for Ethics
MedStar Washington

CONTENT EDITORS

Jory Barone, MLS
Medical Librarian
MedStar Washington

Fred King, MSLS
Medical Librarian
MedStar Washington

S. Layla Heimlich, MSLS
Medical Librarian
MedStar Washington

ADMINISTRATIVE ASSISTANT

Nikki Glover
Administrative Coordinator
John J. Lynch, MD Center for Ethics

EXECUTIVE DIRECTOR

Ben Krohmal, JD
Director, John J. Lynch, MD Center for Ethics
Associate Professor, School of Medicine,
Georgetown University Medical Center

EDITORIAL ADVISORY BOARD

Amanda Anderson, MSN, MPA, RN

Doctoral Research Assistant, University at Buffalo, School of Nursing

Amanda Bush, MA, BSN, RN

Regional Nurse Wellbeing Specialist, MedStar Health, Center for Wellbeing

Chee M. Chan, MD, MPH

Medical Director, Intermediate Care Unit, MedStar Washington

O. Mary Dwyer, JD, MA

Assistant Professor, Department of Bioethics, Case Western Reserve School of Medicine

Laura K. Guidry-Grimes, PhD

Associate Ethicist, Center for Bioethics, Cleveland Clinic

Josh Hyatt, DSH, MHL

Adjunct Professor, Massachusetts College of Pharmacy & Health Sciences

Jack Kilcullen, MD, JD, MPH

Physician, Medical Critical Care Service, INOVA

Eran Klein, MD, PhD

Assistant Professor, Department of Neurology, Oregon Health & Sciences University

Tim Lahey, MD, MMSc

Director of Medical Ethics, Infectious Disease Attending and Professor of Medicine, University of Vermont Medical Center

Jason Lesandrini, MA

Assistant Vice President of Ethics, Advanced Care Planning and Spiritual Health, WellStar Health System

Barbara M. Mitchell, MSN, RN

Senior Director, Quality and High Reliability, MedStar Washington

Stephen Peterson, MD

Physician, Department of Psychiatry, MedStar Washington

Ira Y. Rabin, MD

Vice President of Medical Operations, Deputy Chief Medical Officer, MedStar Washington

Jack Schwartz, JD

Former Chief Council for Opinions and Advice, Maryland Attorney General's Office

Stephen Selinger, MD

Chief Medical Officer, Luminis Health Anne Arundel Medical Center

Lindsay Semler, DNP, RN

Executive Director of Clinical Ethics, Brigham and Women's Hospital

Eric A. Singer, MD

Assistant Professor, Section of Urologic Cancer, Rutgers Cancer Institute of New Jersey, Robert Wood Johnson Medical School

Carol Taylor, RN, MSN, PhD

Senior Research Scholar, Kennedy Institute of Ethics and Professor, School of Nursing & Health Studies, Georgetown University

Eli Weber, PhD, MA

Bioethics Director, Kaiser Permanente, San Bernardino, California



MedStar Health

Volume 9

Number 2

September 2023

JOURNAL OF HOSPITAL ETHICS

THE JOHN J. LYNCH, MD CENTER FOR ETHICS

Proceedings of the 17th Annual International Conference on Clinical Ethics and Consultation



UNIVERSITÀ
CATTOLICA
del Sacro Cuore

Clinical Ethics: Consultation and/or Education?

Hosted by the A. Gemelli School of Medicine,
Università Cattolica del Sacro Cuore,
Rome, Italy

A Note From the Editor-in-Chief (page 5)

Abstracts and Discussion: Plenary Sessions (page 6)

Abstracts: Panel Sessions (page 13)

Abstracts: Parallel Sessions (page 15)

Posters: Poster Sessions (page 74)

All abstracts, their titles and content, as well as author names, have been published as they were provided to the Editorial Group of the Journal of Hospital Ethics by the organizers of the ICCEC Rome 2023, with minimal editing to assure publication standards (e.g., style, readability). In some cases, the abstracts of parallel sessions have been slightly abbreviated for length. Plenary sessions additionally include reports of their discussions as conducted at the conference. Posters and other visual elements are reproduced here as they were presented at the ICCEC.

The Editorial Group of the Journal of Hospital Ethics would like to thank Costanza Raimondi of the Università Cattolica del Sacro Cuore (Rome, Italy) for her invaluable assistance in producing this issue.



ICCEC Proceedings: Past, Future, and Present

Evan G. DeRenzo, PhD

Dear Readers,

Welcome to the Proceedings of the International Conference for Clinical Ethics and Consultation (ICCEC), hosted by the A. Gemelli School of Medicine, Università Cattolica del Sacro Cuore, Rome, Italy.

Before getting into it, however, I would like to spend a moment looking back to the origins of the ICCEC Proceedings. Because of Christian Carrozzo's idea to begin publishing these Proceedings, the enthusiastic response by George Agich and Stella Reiter-Theil (ICCEC's Co-Founders and continuing ICCEC leaders), and the leadership of our own MedStar Washington Hospital Center, we have now published six (6) issues devoted to the ICCEC. Beginning with the 2016 meeting sponsored by the Lynch Center for Ethics right here in Washington, DC, then the 2017 meeting in Queenstown, Singapore, to 2018 in Oxford, England, on to Vienna, Austria in 2019, Cape Town, South Africa in 2021, and finally, Rome, Italy in 2023. JoHe has gone around the world with the ICCEC.

We have published these issues because of the important function Proceedings provide. Proceedings serve as a permanent record of the combined scholarship of these important meetings. The ICCEC is the only meeting, national or international, focused solely on clinical ethics as a consultative practice. Support of this effort is also indicative of the Lynch Center's commitment to contributing to the cohesion and expansion of the global clinical ethics community.

Why is this so critically important? Perhaps the most important lesson of the COVID-19 pandemic is that if one country is affected by a disease, every other country has been or likely will be. Individuals fly around the world, carrying infectious diseases from one population to another. Moreover, diseases affecting one nation influence not only health care but have influence across global economies and political arenas. And it is important not because health care standards in one place necessarily dictate standards in another, but because the global community of clinical ethicists should be able to communicate across cultural divides, a prospect only met through cross-cultural clinical ethics education and communication. Clinical ethics practices in distant lands can be adjusted to meet cultural and economic differences in ways consistent with their own capabilities that are still grounded in sound ethical decision making. For example, health care in impoverished parts of the world, where provision of health care services cannot meet the standards of rich nations, ought to at least meet high ethical standards consistent with sound decision making within their own country's capabilities. Only if we have

a strong global clinical ethics community will it be visible as to whether such justice is achievable or not. Projects like the ICCEC envision a global clinical ethics community with a shared scholarly language and committed members capable of bringing sunlight to shine on severe inequities.

That doesn't mean that ICCEC meetings must consist of only sober and somber attention to the many global inequities in health care services, the ethical sensibilities of national leaders, or nations' varied approaches to solving these problems. Indeed, I have had the pleasure of attending many ICCEC meetings in order to take part in the frivolity and cultural beauty of the stops around the world the ICCEC has made. Which brings us to Rome and our present issue.

One would be hard pressed to find a more beautiful, culturally renowned, historically significant, and fun city than Rome. It's hard not to imagine enjoying spending a few hours in the Vatican, regardless of one's personal religious beliefs. And the joy of Italian food, shared amongst colleagues from so many corners of the world is a treat beyond words. Yet, these delights aside, the abstracts of this issue, like all ICCEC issues before, demonstrate the high level of scholarship involved in the presentations of this meeting. As will be evident, this issue represents an expanded Proceedings from those we've published in the past. We have attempted to make come alive the breadth of conversation and discussion held during plenary sessions. Thus, we present a more robust and inclusive post-ICCEC contribution as a model going forward, lighting the way for future scholarly efforts. We hope that these expansions may serve to stimulate additional global scholarship, cross-cultural communication, and expansion of the global clinical ethics community. We hope you enjoy this issue and the many more Proceedings to come as we trot around the globe together.

Sincerely,

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





Abstracts & Discussion

Plenary Sessions *(listed by order of presentation)*

Plenary Session 1: The Future of Clinical Ethics: Consultation or Education?

Speaker: *Mark P. Aulisio*

Classic bioethics cases (“Seattle God Committee,” “Quinlan,” “Baby Jane Doe,” and “Cruzan”) suggest that clinical ethics emerged in response to a practical need in clinical settings for help in the identification, analysis, and resolution of value conflict or uncertainty (often) in the presence of time-pressure, charged emotions, and high-stakes. This need was created, at least in part, by features of modern clinical settings that included developing technologies complexifying decision making, the value-laden nature of clinical practice, pluralistic societal contexts, and a growing recognition of the rights of individuals/communities to live according to their values.

If “Clinical Ethics” emerged in response to an on-the-ground/contextual need for help in addressing value conflicts or uncertainty in modern clinical settings, then the future of clinical practice and the practical needs that future creates will likely dictate the future direction of clinical ethics itself. Clinical practice in the decades ahead will be dramatically shaped by technological advances, particularly in the area of artificial intelligence, that will precipitate a major paradigm shift from the specialized knowledge and techne focused clinician-scientist to what might be termed the clinician-humanist. Procedures will be increasingly done by machines while diagnosis, prognosis, and treatment options will be a function of increasingly precise testing and vastly more refined algorithms of differential diagnosis, and evidence-based treatment options. Clinicians will need to be able to listen well, exhibit empathy and compassion, translate diagnosis and treatment options in ways that empower patients to choose and navigate the paths of care, and, in many ways, serve as companions in the medical journey. Eventually, the human side of health care will be all that remains for humans, putting care again at the center of healthcare.

What will this mean for clinical ethics? It will ultimately mean that clinical ethics education will become more central to clinician education at all levels (as will other areas like mental and behavioral health, psychiatry and psychology, and spiritual care). It will also ultimately mean that clinical ethics will become more integrated into direct patient care perhaps as a standing support for care teams, but also for the inevitable crisis cases. The future of clinical ethics: education or consultation? Yes!

Discussant: *Chris Gastmans*

The purpose of this presentation is to explore a fundamental ethical approach to healthcare and to suggest some proposals, based on this approach, for ethics education and ethics consultation. The major point is that the kind of ethics education and ethics consultation that is given reflects the view that is held of health care. Healthcare, in this presentation, is considered as the totality of skills and attitudes (caring behavior) that are applied in the context of a particular caring relationship, with the intention of providing good care (goal) to the vulnerable fellow person. Starting from this basic view, three characteristics of clinical ethics consultation are analyzed more deeply: (1) the inter-subjective character, (2) the dialogical-interpretative character, and (3) moral perception. In order to be able to provide clinical ethics consultation according to these characteristics, three sources of ethical knowledge are needed: (1) knowledge of medical/care issues, (2) knowledge of ethical values and principles, (3) knowledge of lived experiences. These knowledge sources are linked to particular attitudes that should be cultivated throughout the clinical ethics consultation process. In the last part of this presentation, concrete frameworks and tools to support ethical competence in clinical ethics consultation practices are presented: (1) skilled companionship, (2) critical companionship, (3) clinical internship, (4) interruption experience, (5) negative contrast experience, (6) controversy experience, (7) ethical reflection. We conclude that clinical ethics consultation and ethics education can strengthen each other when they are based on a shared view on healthcare as a moral practice.

Plenary Session 2: The Role of Clinical Ethics Committees and Clinical Ethics Consultation

Speaker: *Gerald Neitzke*

Clinical Ethics Committees and Ethics Consultation have become an established part of clinical medicine in many countries all over the world. Following the suggestions of the organisers of ICCEC 2023, I will reflect upon the role of such committees and services. The term “role” has different meanings and connotations: function, purpose, effect, part, significance, task, model, or impact are not synonymous, but emphasise certain aspects of different understandings of “role.” Besides, the contribution will distinguish descriptive roles, which can be analysed empirically, from normative roles, which are striving for an ideal of ethics consultation. Roles might vary regarding consultations on the ward, for the hospital, or within the healthcare system. Accordingly, the levels of ethics consultation cover case consultations, organisational ethics, and even public health ethics. Roles might also differ between the self-conception of the ethics team and the expectations of hospital staff, patients, family members, and the society at large.

Empirically, in different hospitals, in different countries, and in different health care systems both the roles and the expectations of the role of ethics consultation vary considerably. My conclusions are: “the role” of ethics consultation is therefore not singular, but has to be considered plural. The roles concerning tasks and models of ethics consultation have to be developed in a context-sensitive manner: What are the needs and resources in my hospital, in our healthcare system and in the respective society? This diversity and pluralism of roles is a chance to develop models of ethics consultation with a real and realistic impact on the ethics of clinical medicine. There is no gold standard of ethics consultation or ethics committees, unless each and every hospital, each and every healthcare system finds out which roles are adequate and suitable for the respective institutions.

Once the role is fixed explicitly, the members of the ethics team (not always and not necessarily an ethics committee) will be considered role models for clinical staff. According to the roles, different outcomes of ethics consultation might be favourable. These outcomes should be assessed and critically reflected by the ethicists. The roles should be evaluated to document the success (or failure) of the chosen model. The Clinical Ethics Committee at Hannover Medical School will serve as an example to show how the ethics team can find and continuously develop the role of ethics consultation within an institution.

Discussant: *Mario Picozzi*

In this contribution, I investigate the relationship between “The role of clinical ethics committees and clinical ethics consultation,” starting from the two aspects that define clinical ethics: a focus on the doctor-patient relationship and to improve the care of the patient.

Ethics consultation is characterized by a relationship and is therefore a practical discipline. Any relationship implies an interpretation; ethics consultation is primarily an interpretive practice. One is directly involved, with role-related expectations. The consultant's tools are not just intellectual, they are sensory. For this reason, clinical ethics consultation is an embodied experience. Besides ears, the consultant needs to use his/her eyes and hands. When at the patient's bedside, the discussion goes well beyond clinical, ethical, and psychological issues, creating the space for dialogue, for voicing the inexpressible, and grappling with the unthinkable. In this perspective, while the consultant does not decide on behalf of the designed decision makers, he/she nevertheless shares the goal to improve the quality of patient care and the responsibility for such an outcome. The consultant has to carry out the dialogue between patient and physician but without being biased; to make it possible, the consultant has to stay within the relationship, while keeping a “critical distance.”

The relationship is the prerequisite for ethics consultations to improve the care of patient. The consultant contributes to achieve this objective by creating the conditions for a shared decision. The ethics consultant should bridge the gap between who must take the ultimate decision and shared choices. Therefore, the question is: under which conditions can a patient make the ultimate decision? The ethics consultant must have the necessary skills to promote a shared choice, in which each actor (patient, doctor, nurse, siblings) ethically recognizes themselves in the decision. No actor can back down, because the identity of each person is at stake: the patient's as a patient, the doctor's as a doctor, the parent's as a parent.

In conclusion, since the relationship is essential to clinical ethics consultation, we believe that Clinical Ethics Committees are not the appropriate instrument to carry out clinical ethics consultation.

Discussant: *Keymanthri Moodley*

CECs carry the distinct advantage of diversity of expertise, gender, culture, ethnicity, and age. In healthcare settings, CECs represent the ideal consultation mechanism to resolve clinical ethical dilemmas. However, all healthcare settings are not equal and resource constraints or lack of bioethics experts may make full committees less feasible. In such settings, clinical ethics consultation may be a suitable alternative. Empirical research in sub-Saharan Africa (SSA) revealed that only 2 countries – South Africa and Kenya – have formal CECs. Most of the other countries have a limited consultation service or no such service for ethical dilemmas in the clinical setting. However, Research Eth-

ics Committees (RECs) or Institutional Review Boards (IRBs) are well established throughout the African continent by funders of medical research in resource-poor settings.

For countries in Africa that do have CECs, they play an invaluable role in assisting to resolve ethical dilemmas that range from HIV related health challenges, to withdrawal of treatment in futile situations, to termination of pregnancy. Often, the clash of indigenous African healing systems with Western allopathic medicine also creates dilemmas around refusal of treatment.

As we move into an increasingly digital era in healthcare, CECs will be challenged with new issues around health data storage, data sharing, protection of personal information, and artificial intelligence (AI). Large language models like Chat GPT and Bard will also impact healthcare and CECs. Imagine a world where AI technologies could assist in resolving clinical ethics dilemmas! All great technologies come with enormous benefits and potential or real risks. Balancing technical debt and ethical debt remain critical challenges for the future of healthcare.

Plenary Session 3: Recent Developments of Regulations About Assisted Suicide and the Role for Clinical Ethics Consultation

Speakers: *Stella Reiter-Theil and Katherine Wasson*

Discussants: *Anne Slowther, Renzo Pegoraro, Karin Bruckmueller, Kathleen Benton, and Ralf J. Jox*

The panel was initiated by Stella Reiter-Theil to address the hot topic of Assisted Suicide (AS) – not euthanasia – from a comparative perspective with a focus on providing an overview with factual information and aspects of analysis referring to certain countries. While the legal contexts are different internationally, moral arguments for and against AS are well-established in academic literature and public debate. Thus, the panel did not select moral arguments as its primary focus. The following structure was chosen:

1. **Information – Reflection:** Context and Facts; Legal, Ethical, and Social Analysis
2. **Role of Clinical Ethics Consultation (CEC):** Personal Experience with Assisted Suicide in CEC
3. **Ethical Evaluation:** Predictions and Hoped-for Visions

The summary presented here was written by the speakers using both the minutes of a preparatory online meeting before the conference (that were approved by the participants) and the notes taken during the ICCEC panel session.

Information – Reflection

The overview moves from the countries with the least liberal legal context regarding AS regulations to those with some kind of liberalization and/or tolerated AS practice.

United Kingdom: AS is illegal but there is some discretion over prosecutions. Previous Bills to liberalize AS have failed to receive approval in Parliament. The House of Commons Health and Social Care committee is currently holding an Inquiry into AS including a public consultation. In 2021, the British Medical Association changed their position from opposed to AS to “neutral.” The Royal College of Nursing and the Royal College of Physicians also now have neutral positions, but the Royal College of General Practitioners remains opposed. The British Social Attitudes survey in 2017 found 77% of respondents supported assisted dying (assisted suicide) for terminally ill patients, but support for AS for other patients is less clear. Individuals wanting AS, have tended to “travel to Switzerland” and continue to do so.

Italy: AS is illegal, but in 2019 the Constitutional Court ruled that AS may be “possible” under restrictive conditions (e.g., patient in irreversible condition, receiving life support treatments, experiencing unbearable suffering, and making a free informed choice). There is a significant amount of discussion about what kind of law might be appropriate – or whether there should be no law at all, relying rather on case-by-case decisions. Regulatory procedures and the role of ethics support remain unclear. It had been suggested that Ethics Committees could have an important role in any process, but in Italy these are mostly Research Ethics Committees, thus not familiar with clinical issues. Some major committees have declined explicitly to become involved in AS in the absence of clear legislation. Conscientious objection of staff was also discussed.

Austria: AS was totally forbidden by criminal law until 2021. One case from 2007 particularly highlighted the problematic nature of this (old) legal situation. A husband was prosecuted because he accompanied his wife (both Austrians) to Switzerland for AS. He was found not guilty, but the acquittal was based on incorrect legal arguments. However, the prosecution did not appeal. After extended parliamentary debates, public consultation and a Constitutional

Court decision, a new law was issued in 2022 permitting AS under restrictive conditions: Austrian residency, terminal illness or serious, lasting diseases, informed decision, 18 years of age, and a so called “dying order” made by the notary. Two physicians, one trained in palliative care, must inform the patient comprehensively (including alternative treatment and palliative care options), and verify the conditions are met, especially decision-making-ability and voluntariness. A moratorium of 12 weeks following the assessment is required. So far, within one year of the legislation, 130 people have registered “dying orders.” According to the Austrian Society of Palliative Care, it is estimated that 34 individuals died from AS under the law. In educational training with medical staff, it seems they are overburdened with the new law and feel uncertain in terms of how to behave and inform.

USA: In the USA, the situation is very diverse and controversial. AS (called Medical Aid in Dying; MAID) has been legalized in eleven states, beginning with the Oregon Death with Dignity Act in 1997 which gained momentum following a highly publicized case that had mobilized the media (Brittany Maynard). In other states, AS is prohibited. Family members cannot travel from a restrictive state, e.g., Georgia, with their patient to a more liberal neighbor state or abroad to obtain MAID, because residency is required for MAID. Federal funds (from Medicare or Medicaid) do not cover MAID leading to gaps and inequalities in access. The Hospice movement is not directly involved with any assisted suicide and in general is opposed. However, many programs have established policies and procedures that allow support for the family and loved ones during this choice.

Switzerland: No federal legislation prohibits AS. Rather it is explicitly permitted if the assistance is not motivated by selfish reasons. AS has been a widely accepted practice for three decades, recently becoming more and more practiced including in nursing homes, palliative care institutions, and hospitals (especially in the French-speaking part of the country). AS is conceived as a civil right and practiced with the help of right-to-die societies, such as EXIT, with only marginal involvement of physicians (capacity assessment and prescription). Four out of 26 cantons (regions) have laws regulating AS in publicly recognized health care institutions, regulated by regional oversight committees. The professional code of practice for physicians stipulates as criteria for physicians’ assistance: unbearable suffering and/or terminal illness, the patient’s free and informed will, and discussion of alternative treatment options.

There is an ongoing debate among the medical professions and right-to-die societies whether a person with mental illness or a healthy person should receive assistance or not. Equal access is an issue as the Swiss right-to-die societies charge the patient for their service which is quite expensive, both for Swiss residents and those travelling to Switzerland for AS.

Germany: Before 2015 no prohibition of AS existed in law, but little practice was established. After dubious right-to-die societies started offering AS in Germany using a “business-style” approach, parliament responded with a restrictive law prohibiting any kind of organized or professional AS. After 2015, the increasing number of citizens who wanted AS, tried in vain to get assistance from the Federal Drug Office or had to travel to Switzerland. In 2020, the Federal Constitutional Court issued a landmark judgment immediately lifting the prohibition of AS and formulating a liberal right to die and a right to use suicide assistance if offered, irrespective of suffering or any medical condition. This rule focuses on respecting individual autonomy which is consistent with the tradition of the Enlightenment informing the German constitution and jurisdiction at large.

As suggested by the court, the German parliament has discussed two bills that would regulate AS, but in July of 2023 both failed to reach majority votes, leaving the situation liberal and unregulated. It is likely that further proposals will be initiated to achieve legal regulation or, at least, for implementing reliable practice rules.

In conclusion, the overview shows that legal frameworks differ greatly among the participating countries even though they all belong to the Western healthcare tradition. This highlights the current controversial nature of AS. Moral issues and arguments mentioned by the panel included: conflict with the person’s best interests, sanctity-of-life doctrine, concern for vulnerable groups, dying with dignity, suffering – and relief of suffering – from the perspective of both patient and family, respect for autonomy including informed consent / refusal and decisional capacity, patient’s mental health status, burden on healthcare professionals, conscientious objection, and the role of palliative care.

AS appears to be an option for a minority of people only, even in Western countries, which raises the question, from the perspective of patient or human rights, why AS should be denied to those who feel they wish and need it, on behalf of others who object to it. From a health care professional perspective, the suffering of patients who were denied access to AS was described through narratives articulating how practicing clinicians may be troubled by the experience of not being able to offer AS. Practical involvement in assisted suicide may also be difficult for healthcare professionals (although medication must always be self-administered by the patient in AS per definition and regulation).

Role of Clinical Ethics Consultation (CEC): Personal Experience With Assisted Suicide in CEC*

This question is meaningful in the ICCEC context. Clearly, in countries with no liberal regulation or tolerated practice of AS, no actual involvement of Clinical Ethics Support Services can be expected. In the United Kingdom and

*Mind that clinical ethics support may include more options than case-wise consultation, e. g., guidelines, policies, training.

Italy no such involvement has been reported. However, the speakers from the UK and Italy consider the involvement of CEC (or of a specific committee for AS requests, for Italy) will be preferred, should AS become a regulated practice. In Austria, the Society of Palliative Care, in its document "Handout for dealing with desires for assisted suicide," recommends the involvement of CEC, but there is – in general – little use of clinical ethics consultation. The speaker from the USA (KBe) reported being involved as an ethics consultant in cases of requests for euthanasia frequently, but only once for AS (MAID); working in Georgia, AS is illegal (like euthanasia) and could not be offered. The situation regarding CEC in other states is not known. Practical involvement in AS in the context of CEC is described from the Swiss perspective (RJJ): This can take place at various levels, such as the regional surveillance committee or the Clinical Ethics Committee of Lausanne University Hospital Lausanne (CHUV), where a clinical ethicist is also called whenever a patient requests AS in the hospital (about 4 cases per year). As the first Swiss hospital, the CHUV has established an institutional policy on managing AS. Thus, not only individual ethics consultation is a valuable instrument of support, but also institutional ethics policies giving more general guidance.

Overall, the examples of these countries show that despite the different legal situations, Clinical Ethics Support Services and the professionals working therein, may lack preparation in dealing with upcoming challenges or uncertainties of AS requests. Experience, e.g., from Switzerland, shows that facing the topic in direct patient-healthcare professional contact is not easy and triggers many issues that should be considered in advance. The potential role and responsibilities of Clinical Ethics Support Services needs further examination, discussion, and debate to prepare for existing and future ethical issues and questions regarding AS, including how to support patients' wishes within the legal and ethical parameters of their specific setting. Existing liberal regulations of AS include the obligation of health care professionals to offer alternative treatment to the patient before proceeding with AS. This key element helps to distinguish between patients who would benefit from suicide preventive measures and those meeting the criteria for legal AS.

Ethical Evaluation: Predictions and Hoped-for Visions of the Panelists

In the United Kingdom, AS in a heavily regulated form may become legal, although unlikely in the near future. Clinical Ethics Support should be involved if this occurs.

Currently, a slippery slope is feared for Italy regarding AS. As a preference, the existing (2010) good law on Palliative Care should be applied more extensively and consistently across the country to reduce requests for AS.

In Austria, the health care personnel adjust only slowly to the new legal situation. However, they will in the future assist in more cases of AS, because the law can be expected to remain as it is for the next few years (although there are ongoing legal initiatives to lower the obstacles in practice). Therefore, more awareness-raising and resources for Clinical Ethics Support should be available for physicians and those involved. The best option would be to mention the involvement of CEC in the law.

For the USA, no large expansion can currently be expected towards AS, due to many other pressing political issues and divisions. In those states that already permit AS, broadening the scope and relieving restrictions seems probable.

In Switzerland, AS will be more and more normalized and accepted, also by medical professionals. Clinical Ethics Support should be involved with the practice of AS. In some institutions, this is already in place.

Germany remains in an unregulated situation with tension between strong liberal and conservative views at the same time. The role of Clinical Ethics Support might be put on the agenda, especially given the lack of legal and professional regulation, and this may be included in a new bill.

Plenary Session 4: Medical Humanities: It Needs to Be Entertaining

Speakers: Rouven Porz and Martha Montello

Discussants: Jan Helge Solbakk, Kurt Schmidt, Sefik Gorkey, and Guido Giarelli

For more than sixty years, teaching patient care and clinical ethics has included diverse fields of the humanities as critical components of medical education. The term "medical humanities" draws together history, literature, art, philosophy, anthropology, religious studies, and other disciplines to hone essential competencies for physicians, including professionalism, empathy, critical thinking, and an ability to cope with ambiguity and uncertainty. We think these are skills that physicians must have in order to be effective clinicians.

Each of the disciplines of the medical humanities makes its own unique contribution to an understanding of ethics, therapeutics, and the patient's experience of illness. This conference session highlighted several current, cutting-edge methods of the medical humanities. Each of the non-physician experts teaches in a major medical school in a different country: Germany, Italy, Turkey, and Norway. Each explained how he brings his discipline of the humanities into

the clinic and classroom, what kinds of resistance and encouragement he has met from colleagues and the institution, and how we might build on successes to create even stronger benefits for medical education. Here, we recapitulate some of the points of this exciting discussion by giving individual speakers the opportunity to comment again specifically on the following questions:

1. How do you bring humanities into medical education and clinical ethics in your home institution?

On this question, Sefik Gorkey refers to Italian frescoes, which he compares in his student lessons with current photographs (e.g., from war zones), in order to open up a level of emotionality for his students. Kurt Schmidt also aims for an emotional response, but uses film clips to do so. He says: “We use short film clips featuring hospitals (from movies or TV series) which portray ethical conflicts. This draws the participants into a scenario within a matter of minutes. They witness the reactions of the characters, start to like or dislike them, and then, after their initial emotional response, discuss how they might arrive at an ethically viable solution.” As with frescoes and films, the medical humanities can also work with literature. An expert in this field, Jan Helge Solbakk says: “We use literary fiction. The focus of attention is situations of moral residue in clinical practice, i.e. situations where no solution without moral error and/or failure is possible. This leaves behind a set of distressing emotions such as anguish, regret, remorse, and self-blame in the practitioners because of the perception of an unavoidable moral failure having been committed. Literary fiction is ripe with narratives of such situations, and the objective is to use this literary fiction to recraft medical case stories into narratives of moral residue.” All of these are good examples of innovative methods for teaching the medical humanities. But we must first have the opportunity to teach. How do we convince a medical school of the benefits of the humanities in educating trainees? That brings us to the second question:

2. What kinds of resistance do you/did you face?

Here the answers of our participants are divided. Some have faced strong difficulties, others have not. Jan Helge Solbakk has had rather negative experiences: “Health care professionals are taught to act, not to think, the saying goes. This represents an almost insurmountable barrier to overcome in teaching ethics. This barrier, together with the fact that medical ethics is given very little space in the curriculum of health care practitioners, makes the attempt at strengthening the art of medical education an almost Sisyphean effort.” Kurt Schmidt does not agree here, as he has much more positive experiences to report: “I have not faced any serious resistance in my inclusion of the humanities; quite the contrary, in fact: the Dean of the Medical Faculty actually explicitly supported a seminar in which medical students learn more than just the usual medical topics.” Guido Giarelli assigns the issue of resistance more to the nature of the prevailing paradigm in a medical school in general: “According to my teaching experience in a medical faculty in Italy, there are two main kinds of resistance that are closely interconnected. First, on the theoretical level, a strong persistence of a positivistic approach to medicine, grounded in the Cartesian separation of body and mind and second, on the practical level, the medical humanities are considered substantially irrelevant to clinical work, since only ‘hard sciences’ (the natural sciences) are thought to matter in dealing with disease and treatment.” So, clearly, there is ambivalence. Rather than being a purely rational choice, the decision to include medical humanities seems to depend on the country, the culture, and the openness to innovation of individuals and their superiors. The third question, then, is what does this mean for the future of the medical humanities?

3. How can we do a better job of teaching the humanistic side of medicine?

We cannot get around the need to prove that the teaching of medical humanities is useful. As Guido Giarelli thinks, we need to produce concrete results in the classroom with both theoretical and practical value: But we need to touch the students’ hearts, too, admits Jan Helge Solbakk. Kurt Schmidt concludes quite clearly: “It needs to be entertaining, so that the students have fun and feel motivated to swap their ideas.”

The exchange of ideas with the audience following the brief presentations was spirited, with participants interested in understanding others’ experiences in their home institutions. Many of the comments and questions centered around cross-cultural issues of institutional support and the need for outcome studies in an academic environment that increasingly emphasizes value-based learning.

Plenary Session 5: Clinical Ethics Consultation Services and Health Care Organizations: Towards a State of the Art

Speaker: *Georg Marckmann*

Clinical ethics consultation services (CEC-S) usually focus mainly on ethical issues in individual patient care decisions. However, CEC-S can also reflect the preconditions and routines for action on the level of health care organization (HCO) and thereby contribute to the HCO's organizational development. This field of organizational ethics becomes ever more relevant given the increasing economic pressures of most health care systems. The standard answer, strengthening ethics against economics, is not really convincing, neither conceptually nor pragmatically: on the one hand, ethics is not an antithesis to economics, and, on the other hand, ethics will remain ineffective as antagonists of economics in HCO. Rather, the consideration of ethical requirements must become an integral part of hospital management. This value management requires two consecutive steps: First, the relevant normative requirements, i.e. basic values of the HCO must be defined (e.g., patient centeredness, employee orientation, appreciative leadership, good processes and structures). Second, the realization of the normative requirements in the routine of the HCO must be assessed and managed systematically. Managing the "internal quality" of the organization must become a central leadership task on all levels of the organization. It seems plausible that this value management has the potential to be economically effective, as it results in better patient-centered care, higher staff motivation and advantages in staff recruiting which will improve the economic resilience and performance of the HCO: More ethics may pay-off financially!

Discussant: *Jürgen Waller*

Organizational ethics (OE) has been on the agenda of healthcare ethics for over twenty-five years now. Notwithstanding its noteworthy concepts, OE remains underutilized although it could contribute to healthcare ethics in various aspects. In order to develop a comprehensive OE initiative, it should address three questions: (1) the kind of actions a healthcare organization (HCO) performs (i.e., its institutional decision-making); (2) the goals an HCO pursues (i.e., its mission); (3) the sort of organization a HCO is (i.e., its corporate culture). OE has three strategies to work on each of these three questions: (1) OE may engage in developing a HCO's programs (i.e., its core services). To what extent and in which capacities is an ethics program part of the HCO's strategy? (2) OE may engage in developing a HCO's human resources (i.e., its employees). To what extent and in which capacities is ethics part of the HCO's HR competencies framework? (3) OE may engage in developing a HCO's corporate decision-making structure (i.e., its clinical and managerial processes). To what extent and in which capacities is ethical decision-making incorporated in the HCO's processes? Each of these strategies is highly complex and requires competencies that are not part of typical clinical ethics consultation (e.g., in organizational development). In addition, OE in this sense operates in a field that often is a more challenging power play than individual clinical cases. Therefore, ethicists should consider engaging in comprehensive OE only if they have a clear mandate by the HCO's leadership and the competencies to fulfill it.



Abstracts

Panel Sessions *(listed in order of presentation)*

Panel 1: The World Health Organization (WHO) Guidance on Clinical Ethics: Proposal for Structure and Content

Speakers: *Andreas Alois Reis and Ehsan Shamsi-Gooshki*

Panelists: *Dario Sacchini, George Agich, and Stella Reiter-Theil*

Clinical ethics is a practical discipline that provides a structured approach to assist health professionals in identifying, analyzing, and resolving ethical issues that arise in clinical practice. In the last decade, the area of Clinical Ethics has gained a lot of prominence within the field of health ethics from a global perspective. In particular, COVID-19 has raised many clinical ethics issues, ranging from rationing at the bedside to providing unproven therapies. So far, while WHO's ethics guidance occasionally addresses specific clinical ethics issues, there is a lack of comprehensive, general WHO guidance on clinical ethics. The need for such a document has been repeatedly expressed by various technical departments and the Global Network of WHO Collaborating Centers for Bioethics.

WHO clinical ethics guidance will be developed to support different stakeholders, mainly Member States and health policymakers, WHO technical departments, and also health care workers (HCWs) including medical professionals and non-professional health personnel, health facility administrators, international and national professional medical organizations such as medical councils, and professional associations, and health care workers syndicates, health governance, and ethics oversight agencies and committees. It will also apply to related UN agencies, medical education and biomedical research sector players, non-governmental and civil service organizations, including patients' rights advocacy organizations and civil society, private sectors players including pharmaceutical companies, medical equipment manufacturers and medical software developers, humanitarian organizations and personnel, and other related players in the field by providing general guidance on ethical issues to be observed in clinical practice.

While clinical ethics includes a wide range of issues from the general to the quite-specific, this document will be concentrated on key ethical issues of global importance in the field, especially those concerning the global south and low to middle-income countries. The first section would provide a background for clinical ethics and its evolution throughout history to give the audience a better understanding of the context and scope of clinical ethics. In addition, a glossary could be added to provide practical definitions for the main concepts used in the document. Definitions that have previously been used in other WHO publications and ethics documents could be used. The second part can address key issues of clinical ethics. In the third section, clinical ethics governance could be the main theme. Considering the situation and role of WHO in global health; while keeping in mind that clinical ethics includes an extremely wide range of bioethical issues, it is hardly possible to have one clinical ethics comprehensive document; considering the fact that there is no universal consensus on many issues in clinical ethics; considering the logic of preparing general guidance as the first step and finally considering the crucial role of governance in shaping systems for ethics implementation and the direction of recent ethics documents provided by WHO, "clinical ethics governance" can find a central place in the guidance so it could be discussed at institutional, national, and international levels. The 4th section of the guidance could be dedicated to the recommendations to be more useful for target audiences. These recommendations could be categorized according to specific audiences.

The steps which are planned to be completed for finalizing the WHO clinical ethics guidance include an initial review of published literature (mainly WHO ethics documents and other scholarly and grey literature), expert consultation on the scope, the establishment of an international expert group to develop the first version of the document, international external review, and finally, public consultation and publication.

Panel Session 2: Reorganization of Ethics Committees and the Future of Italian Clinical Ethics Consultation

Panelists: *Mario Picozzi, Laura Palazzani, and Renzo Pegoraro*

On February 7, 2023, four long-awaited decrees of the Ministry of Health on the reorganisation of Ethics Committees were published in the Official Journal. The main aim is the full implementation of Regulation (EU) No 536/2014 on clinical trials on medicinal products for human use. However, the decrees may have a relevant impact on future development of Italian clinical ethics consultations services.

The Interdisciplinary Group of Clinical Bioethics and Ethical Consultation (Gruppo Interdisciplinare di Bioetica clinica e Consulenza etica in ambito sanitario, GIBCE) is a research group affiliated to the Italian Society of Legal Medicine (Società Italiana di Medicina Legale e delle Assicurazioni e delle Scienze Forensi e Criminalistiche, SIM-LA) since 2016. Its scope is to promote the culture of clinical ethics consultation within Italian health care facilities.

With this session, the GIBCE intends to open a debate on the possible impact of the aforementioned decrees on future development of Italian clinical ethics consultations services. Specific objectives of the session will be to: illustrate the four decrees, discuss their impact on clinical ethics for Italian context, and elaborate on proposals and possible solutions. The invited speakers have been selected by the President of the GIBCE, in consultation with the scientific committee of the society.

Panel Session 3: Europe: It Is Time for Patient Participation in Ethics Interventions!

Panelists: *George Agich, Gerald Neitzke, Michael McCarthy, Bert Molewijk, Janine de Snoo-Trimpp, and Marleen Eijkholt*

A recent survey under Dutch practitioners revealed a series of reasons why patient participation (PP) in ethics interventions (EI) is uncommon in the Netherlands. PP, as an intervention in which the patient is specifically approached about the ethics issue at stake, is rejected because it would lead to a reduced ability for open provider discussions, or confusion about providers' responsibilities. According to another reason, the EI is for providers' reflective skills; the patient is superfluous.

Reasons against PP from the Dutch survey are similar to those that have been forwarded elsewhere in Europe. Some of these reasons have been connected to culture and context. Some have been connected to the perceived goals of CESS. These reasons and practice rejecting PP in Europe contrasts with the USA practice. There, PP is more or less standard where the ethics issue regards the patient. Considerations about patient rights and equality are its founding features. We question that the reasons rejecting PP could ultimately withstand scrutiny. Our idea is that PP should be an option in appropriate cases. Access to the patient or proxy to engage with the ethics issue should be an option, too.

In this panel discussion, we will address the following four questions that emerged from the Dutch survey. They seem poignant given the literature, the data and EI practices in Europe and beyond:

1. Can we really separate (controversial) medical decisions from ethical decisions to justify the exclusion of patients in conversations around these issues?
2. Can patients be represented in ethics meetings, and if so, who should do this given concerns that direct patient participation could be harmful?
3. Would 'trust building' be an important pursuit in the ethics support practice, and would this be an essential reason to desire PP?
4. Could patients be entitled to PP in ethics support services on the basis that we suggest that CESS is for education and development of moral skills of providers, so that patients should have this opportunity, too?

Panelists will scrutinize various reasons for and against PP and examine if PP is an ethical imperative in light of these questions. Speculating about our panelists' answers, we submit that those functioning in ethics support should accept the responsibility to engage in PP and actively promote it.



Abstracts

Parallel Sessions *(listed alphabetically by presenter)*

The Experience of OPBG Clinical Ethics Service in the Heart Failure Clinic for the Evaluation of Cardiac Transplantation and Mechanical Assistance in Pediatric Patients

Rachele Adorisio, Victoria D'Inzeo, Antonio Amodeo, Luigi Zucaro, and Anna Dalle Ore

Introduction: The decision around any Clinical choice rely on responsibility of the clinical case manager or clinical team. Usually, clinical team included different medical specialities and sometimes psychologists. In some case, an ethicist can contribute to the decision as a promoter among the Medical team, between doctor, patient and their caregiver in order to address the best care for the best “Quality of Life” achievable.

Methods: We organized a Multidisciplinary team which had a weekly meeting. This team included cardiac surgeons, cardiologists expert of heart failure, intensivists, interventional cardiologists, social worker, psychologist, and ethicist, in which we reviewed and analyzed in detail several cases of children and young adults. All possible clinical options have been carefully with extensive discussion. Starting from this, to delve deeper into the Beneficence for each individual case, the following questions are systematically reviewed: What, how and who decides on “Quality of Life” for a patient? Does the planning of a care pathway, for a pediatric patient or a young adult, affirm Beneficence? What significance does patient autonomy have in the decision-making process? Is ethics an added “value” that we can mention at the conclusion of a clinical choice, or can it participate in the decision-making process? Does everything that technically allows us to prolong the length of a patient’s life correspond to what is best for said patient? Are the parents the absolute custodian of their child’s will? What creates a good therapeutic alliance the empathy that the decision-making clinician conveys to the parent? The Team worked to answer properly answer to these questions in each case through the analysis of the following key points: clinical indications, patient preferences, quality of life and social and psychological aspects. According to the Principle of Beneficence, both aspects have been analysed: completeness of diagnostic pathway therapeutic pathway: transparency: traced and documented patient monitoring over time appropriateness: each patient benefits from a therapeutic pathway when the best possible benefit can be guaranteed equity: re-evaluation makes it possible to guide the therapeutic strategy. Objectivity: these criteria are shared within the multidisciplinary care team and, when the doctor sees fit, with the patient or their family

Conclusion: The analysis of all data and the systematic review allowed to the team to answer to all questions in all cases, guaranteeing completeness of clinical pathway and also equity and objective evaluation in pediatric patients for all treatment.

Transplant Ethics Encounters and Tele-Ethics Consultation: Lessons Learnt and Experiences Shared

Mahwish Ahmad, Jane Jankowski, Susannah L. Rose, and Cristie C. Horsburgh

As health care globally continues to embrace telemedicine and other patient-accessible virtual delivery platforms, technology plays an increasingly important role in how Clinical Ethics Consultations (CECs) support patients within the hospital setting. This technological transformation within health care stimulates discourse about how technology can be integrated into CEC’s expanding role and responsibilities and inspires us to innovate in the delivery of CEC. At our multi-site academic medical center, we adapted most of our outpatient scheduled transplant ethics encounters to a virtual format. This early application of virtual platforms was effectively integrated into a robust clinical ethics service before the COVID-19 pandemic began and has become a standard practice we offer for eligible transplant center patients since. This presentation will describe our experiences expanding access of CEC to more patients by integrating tele-health applications and creating connections with patients virtually for one-on-one ethics consultation via a secure platform.

Building on better practices identified in patient experience research, we triaged all scheduled transplant service pa-

tients to determine which could fit best with a virtual consultation model. We also leveraged data from virtual health research that were recently conducted, which indicates that 81.9% (344/420) of survey respondents agreed or strongly agreed that their virtual visit was as good as an in-person visit by a clinician and that telemedicine helped them access medical care.

At this forum, we aim to share data generated between mid-2019 and mid-2022, to indicate volume of virtually conducted transplant consultations, share platform details, logistic challenges, value-added features and IT support needs, as well as triage considerations used for assessing which consultations could be feasibly provided virtually. We will conclude by reflection on lessons learnt by our team during this timeframe and provide recommendations to optimize integration of digital platforms in CECs.

Between Sand and Sky: Challenging Cases for an Evolving Clinical Ethics Service at Cleveland Clinic Abu Dhabi

Mahwish Ahmad, Jeffrey Chapman, and Jamshed Khan

Ranked as the #1 hospital in United Arab Emirates for two consecutive years 2022-23, by Newsweek Global Rankings, as well as the top hospital in the entire Gulf region, Cleveland Clinic Abu Dhabi (CCAD) has been providing world class care for our patients for the past seven years. Through this time, given our facility's dedicated focus on high-risk and advanced surgical and critical care provision, many complex patients are referred to our site, sometimes choosing our clinical specialty services to seek second or even third opinions for their complex medical care, especially from neighbouring countries. Seeing a multitude of such high-stakes complex clinical scenarios leads inevitably to intricate and oftentimes unique ethical and clinical practice dilemmas within a rapidly evolving healthcare system such as the U.A.E., dilemmas which then need to be deliberated in a culturally and religiously sensitive manner given the local context and fast-changing healthcare and legal landscape in the Gulf region.

The main presenter will share details of ethical challenges encountered through the lens of such a case scenario-presented as a de-identified patient case-composite to protect patient identity, which provided no lack of delicate ethical nuances that needed to be thought through, against the backdrop of a close-knit, large, grieving family who were grappling with a medical complication happening to their family member, leading to end of life considerations being raised by the clinical team for the patient. The presenter will also share challenges our Cleveland Clinic Abu Dhabi Clinical Ethics Committee team encountered around this tough case, the synchronization process needed for ethics "second opinion" being sought from Cleveland Clinic's Main Campus due to the moral distress caused by ethics deliberations within the CCAD group, as well as lessons learnt by both groups regarding how to approach such cases in the future. Audience engagement will be prioritized so as to touch upon opportunities for improvement noted during our ethics consultation process and shared for our international attendees.

Clinical Ethics Committee team encountered around this tough case, the synchronization process needed for an ethics "second opinion" being sought from Cleveland Clinic's Main Campus due to the moral distress caused by ethics deliberations within the CCAD group, as well as lessons learnt by both groups regarding how to approach such cases in the future. Audience engagement will be prioritized so as to touch upon opportunities for improvement noted during our ethics consultation process and shared for our international attendees.

Addressing Ethical and Conceptual Issues in Gender-Affirming Medical Care Outside of the Hospital

Armand Antommaria

While clinical ethicists have important roles inside the hospital, they may also have important roles outside of it. In the United States, gender-affirming medical care has become politicized and states have sought to limit access to it. Several states have prohibited or criminalized it, Texas has characterized it as child-abuse, and Florida has withdrawn Medicaid funding for it. Clinical ethicists can address conceptual and ethical issues in legislative debates and litigation regarding gender-affirming medical care.

Prohibitions on gender-affirming medical care for minors raises conceptual and ethical issues that clinical ethicists may address. For example, legislative finds frequently characterize this care as experimental. This raises the issue of the distinction between research and clinical care. Gender-affirming medical care is not new or unproven. Such care is generally provided to promote patients' well-being and treatment is modified based on individual patient's responses. The fact that gonadotrophin releasing hormone analogs, testosterone, and estrogen are used "off-label" does not entail that they are experimental.

Some legislation also asserts that adolescents are incapable of consenting to gender-affirming medical care. This con-

fuses the role of adolescents and parents in medical decision-making in the United States. With certain exceptions, including specialized consent statutes for testing and treatment of sexually transmitted infections, parents or legal guardians are required to consent for their minor children's medical care. Parents are asked to consent to other treatments with comparable benefits, risks, and uncertainty to gender-affirming medical care. For example, the treatment of some rheumatologic disorders and hematologic conditions may also impair fertility. There is also empirical evidence that adolescents generally have sufficient medical decision-making capacity to consent to the use of puberty blockers.

Other states, specifically Texas, have characterized gender-affirming medical care as child abuse. Conceptual and ethical issues related to this characterization include whether gender-affirming medical care is medically necessary and whether it impinges on the right to procreate. Such medical care is needed to treat a disease or its symptoms and meets accepted medical standards. Gender dysphoria is a disease and clinical studies have shown that gender-affirming medical care treats its symptoms. Texas fails to distinguish interventions whose intention is sterilization and those that may result in infertility as a side-effect.

Beyond addressing these conceptual and ethical issues in the academic literature, clinical ethicists may advocate in the legislature, including testifying at legislative hearings, as well as serving as expert witnesses in litigation over this legislation and regulations.

Chain Reaction: The Organic Emergence of a National Ethics Collaborative Group

Valerie Badro, Karine Bédard, Ana Marin, and Marie-Ève Bouthillier

Background: The SARS-CoV-2 pandemic has stirred much crisis and uncertainty but also great solidarity and resilience. One successful story is the organic emergence of a national collaborative group of field ethicists (clinical and organizational ethicists) working in the different health care systems of the province (hospitals, nursing homes, home care, etc.) with a link to the national COVID-19 ethics committee. The national group of field ethicist (hereafter "The Group") came to be via the leadership of the president of the COVID-19 ethics committee, one of several provincial bodies the government put in place to respond to the crisis. While the mandate of the COVID-19 committee was to provide ethical guidance to the government on specific ethical pandemic issues (e.g., intensive care prioritization), the Group in its own way was able to contribute significantly to various efforts both at the provincial and local level on issues raised by the pandemic.

Methods: We describe 1) how a national group of field ethicists mobilized, 2) the Group's legitimacy and ties to the provincial COVID-19 ethics committee, 3) how it was structured and governed, 4) the role, tasks and activities ethicists took on to support each other and provincial efforts, and 5) how the Group's activities evolved over time.

Discussion: We will discuss (i) the elements that contributed to the creation and flourishing of this collaborative model, (ii) the role and responsibility of each contributing member, (iii) the co-experiential pathway leading to mutual knowledge and influence and (iv) and impact on provincial and local ethicists and ethics consultation services.

Conclusion: The Group met (and still meet) every week and contributed significantly to the issues raised by the pandemic. With the solidification of the group, its overall experience and expertise and lasting collaboration, it is well positioned to continue reflecting on the field of clinical and organizational ethics in the post pandemic era.

Ethicists in Training: Learning How to Do Consults

Megan Bailey

As current clinical ethics interns with the Ethics Quality Improvement Lab at William Osler Health System in Brampton, Ontario, Canada, we have opportunities to experience hands-on clinical ethics consultation training of a high caliber. The Ethics Quality Improvement Lab is devoted to quality improvement and patient-centered care within a clinical setting. The internship program has been designed to introduce prospective ethicists to a range of clinical ethics services, including consultation, education, policy writing, research, and organizational ethics. The program includes project-based activities and consultation shadowing, observation, and participation opportunities.

In this presentation, we share our experiences as clinical ethics interns in the Ethics Quality Improvement Lab and outline the various skills and techniques that we have learned during our internship as they relate to clinical ethics consultations. In particular, we share the importance of advocating for a patient-centered approach, role clarity, and using adaptive leadership and change management principles that can help ethicists to respond effectively in ethically challenging situations.

The Lab has three full-time ethicists and an internship program to train prospective ethicists and healthcare-related

professionals in clinical ethics. It provides interns with the opportunity to collaborate with multiple branches of healthcare, including allied health professionals, under the supervision of the Ethics team to provide a multi-faceted learning experience. In working with various branches of the healthcare teams, interns are able to learn from and alongside other members of the healthcare team to generate a strong theoretical and practical foundation for quality consultations.

The internship has helped us to build the capacity for quality consultations in clinical ethics. A patient-centred approach to care fosters quality consultations. This approach frames the patient as the priority in their healthcare decision-making while supporting them in their decisions. We are developing a robust skillset around conducting quality clinical ethics consultation services through an adaptive leadership model. In this adaptive leadership model, we have been able to mobilize our hands-on experience, interpersonal skills, and varying academic backgrounds to foster quality consultations. Part of this model has been centered around mitigating arising challenges within the field through our training and experience; this has been done by active skill-building activities in both theoretical and practical contexts. The program has provided us, interns, with clinical ethics experience and opportunities to engage with quality improvement in ethics from a unique theoretical and practical standpoint to improve the quality of clinical ethics consultations.

Healthcare Professionals' Experiences of Guiding Ethics Case Reflection Rounds in Pediatric Oncology

Cecilia Bartholdson and Pernilla Pergert

Background: Moral dilemmas often arise in pediatric oncology and includes different perspectives about what is best for the child. One way to handle dilemmas is through ethics case reflection rounds which is a form of clinical ethics support. A training program for healthcare professionals (nurses and physicians) to become facilitators, guiding ethics case reflection rounds, was organized by members of a Nordic working group on ethics in pediatric oncology.

Objectives/Aim: To explore facilitators' experiences of guiding ECR rounds in pediatric oncology.

Methods: Data were collected by inviting trained facilitators in focus groups and individual interviews. Totally, 22 facilitators participated in the 3 focus group interviews and in 27 individual interviews. Data analysis followed classic grounded theory methodology exploring the facilitators' main concern and how they handle it.

Results/Conclusion: When facilitators are guiding ethics case reflection rounds in pediatric oncology their main concern is to deliver a meaningful experience of ethics support. They are handling their main concern by carrying the facilitator responsibility. Facilitators expressed being responsible for defining the latent meaning of what is being expressed and the outcome, including to identify the moral dilemma followed by relevant actions, as they believe it will influence the care of the child. To be able to carry out this responsibility, the participants use different strategies. One strategy is that facilitators support each other in guiding the group and sometimes share the role as facilitators or have co-facilitator roles. Other strategies are defining their role, striving to find the neutral role, balancing guidance and standing back and keeping to a structure. Safe practicing, also emerged as a strategy, and includes further training and practicing in safe environments. Facilitators take their role very seriously and feel that they carry a great responsibility when guiding ethics case reflection rounds in pediatric oncology. This experience should be addressed during facilitator training and in facilitator networks to strive for decreasing the burden of responsibility, which could constitute a barrier for performing ethics case reflection rounds in pediatric oncology. However, when facilitators are carrying responsibility, they endeavor to improve pediatric oncology by making an effort to handle moral dilemmas.

Mapping the Clinical and Organizational Ethics Services in Quebec Healthcare Institution: A First Step for Quality Improvement

Karine Bédard

Background: Since the publication of Ellen Fox's article in 2007 reporting on clinical ethics services in health care institutions in the United States, numerous discussions at the academic and hospital levels have taken place in various countries to identify how to structure clinical ethics services and how to evaluate the quality of the services provided. In Quebec, interest in these issues is also present among ethicists working in health care institutions and directors managing these ethics services. However, before 2022, there was no current and exhaustive portrait of the clinical and organizational ethics services present in Quebec's institutions that could be used to address these questions.

Objective: The presentation will focus on the reasons that motivated the realization of this portrait, the methodology, the significant results, and the anticipated impacts on quality improvement of clinical and organizational ethics services and training of ethicists working in Quebec health care institutions.

Methodology: The constructivist approach guided the entire process with the network of ethicists working in health care institutions that was formed at the beginning of the pandemic in March 2020. A sub-committee was formed to create, collect, and analyze the data. This collaborative work resulted in a structured questionnaire that met the needs of the ethicists and directors managing the clinical and organizational ethics services. The questionnaire is divided in 7 sections that cover structure, consultation processes, numbers of consultations, issues and requestors, documentation, ethicist training and FTE, and quality improvement questions. The questionnaire was administered through the members of the subcommittee between September to October 2022.

Results: The data collection strategy resulted in a participation rate of 94% of the Quebec health care institutions. Currently, there are 65 ethics resources for a total of 19, 3 FTE in clinical and organizational ethics. The number of consultations ranges from 0 to 230 per year. Ethics consultations processes are diverse and only about half the ethicists had access to the patient record. These preliminary results show that there might be a gap in ethics services development across the health care system that need to be addressed.

Conclusion: This descriptive portrait represents the first phase in quality evaluation that is necessary before being able to reflect on standards of practice that are consistent with the mission of ethicists working in health care institutions and the context of the Quebec health care system.

Assessing Decision-Making Capacity in Persons With Aphasia: A Clinical Ethics Educational Initiative

Shelly Benjamin

Life-altering decisions often mark a patient's healthcare journey and give rise to ethical dilemmas. At the crux of such dilemmas lies an important question: does the patient have decision-making capacity? This question is rooted in the principle of respect for persons and underscores the importance of informed consent.

A formal evaluation of decision-making capacity is sometimes necessary if there is a reason to question a patient's decision-making abilities (e.g., a change in mental status). This evaluation generates a clinical understanding of whether or not a patient can autonomously make specific decisions related to their care, or signals the need for supports, including the involvement of surrogate decision-makers. Clinical ethicists can serve an important role in supporting decision-making capacity assessments by providing guidance on relevant disability ethics issues, and can also serve as evaluators of capacity.

Decision-making capacity assessments are complex when they involve a patient with a communication impairment, such as aphasia. Aphasia, a communication disorder acquired by injury to the language areas in the brain, often causes challenges in comprehension and expression that can interfere with the exchange of accurate information and mask underlying decision-making capacity, even in instances when patients retain cognitive abilities.

Research demonstrates that persons with aphasia can communicate effectively with the support of a skilled communication partner. In the context of collaborative decision-making capacity evaluations, a speech-language pathologist can partner with a clinical ethicist capacity evaluator to promote an accurate assessment. The practice of collaborative decision-making capacity evaluations, however, is not widely used due to a knowledge gap. Indeed, clinical ethicists are not formally trained on collaborating with a speech partner, and conversely, speech-language pathologists are not trained in supporting capacity evaluations.

Here, I provide an overview of a cross-disciplinary training initiative that leverages expertise in clinical ethics, speech-language pathology, and clinical education, to address this knowledge gap. The training module targets clinicians involved in capacity evaluation, including ethicists, psychologists, psychiatrists, and speech-language pathology communication partners. Through an online interactive didactic platform, it focuses on best practices for supported capacity evaluations for persons with aphasia and includes theory, best practice tips, case studies, as well as capacity evaluation demonstrations filmed with community partners who have aphasia. A dedicated training effort aimed at coordinating cross-disciplinary collaborations promotes improved outcomes in high-stakes capacity evaluations and underscores opportunities for autonomous decision-making to promote equitable outcomes for patients with communication impairments.

Ethical Reflection Groups and the Value of Training in Social Sciences and Philosophy

Brenda Bogaert

Background: this contribution will discuss a new method used by an ethical reflection group in a cancer hospital in France, namely, methods and theories from philosophy and the social sciences, to "train" ethics committees before each discussion. The group consists of ~30 representatives, including healthcare providers (doctors, nurses, nursing

assistants), social workers, and researchers working onsite, as well as outside representatives, including patients. Group members often have no formal training in ethics, nor are they offered formal training when joining the group.

The group meets 4 times a year and a theme for each session may either come from a hospital or research service onsite or by a theme identified by its members. The theme may either have direct clinical application (recommendations on how to handle a specific issue) or is part of a collegial reflection that does not necessarily lead to a decision.

Methods/Materials: we will discuss a new method that has been tried in the group for the last two sessions, namely a presentation by a member of literature from the social sciences and/or from philosophy to train group members on the topic before the discussion.

Results: given that members have an interest in, but not necessarily training in ethics, and the fact that the themes may vary considerably from one meeting to the next, the value of this methodology is to: 1) introduce alternative ways of thinking by focusing on the clinical issues from a social science/philosophical perspective; 2) give an informal training on the themes of the topic in the discussion to enhance discussion.

Discussion: the value of this methodology is that it allows members not necessarily trained in clinical ethics or the social sciences – and not necessarily specialized in the subject at hand - to establish a common basis of knowledge. This encourages a more equal distribution of speech in the discussion, as well as permits the group to have a starting point for the discussion.

Conclusion: while an informal type of “training,” the presentation of literature from the social and human sciences and philosophy during these meetings allows an alternative perspective on issues that have been experienced by members in their daily practice and permits a personalized, dynamic discussion on the theme. It also helps members have a clear understanding of the values discussed in the topic at hand prior to discussion.

Public Perspectives on Prioritisation Protocols for Access to Critical Care in Extreme Pandemic Context

Marie-Ève Bouthillier, Claudia Calderone Raminez, Karell Laporte, Louis-Martin Rousseau, Andrea Frolic, Annie Descoteaux, Clara Dallaire, Audrey L'espérance, Gina Bravo, Joseph Dahine, James Downar, Peter Tanuseputro, Nathalie Gaucher, Antoine Payot, Yanick Farmer, and Nadia Lahrichi

Background: Prioritisation protocols for access to critical care are new strategies in health, which need to be exposed to public opinion to promote their legitimacy. For reasons of urgency in their elaboration during the COVID-19 pandemic, it was not possible to count on citizen participation in their initial development. Therefore, democratic deliberations were planned to foster public transparency in relation to the key criteria and values contained in these protocols. Public participation is essential to improve these protocols and make them more ethically acceptable.

Objective: To uncover the essentials considerations and conditions that can make these protocols more acceptable to the public in Quebec and Ontario, Canada.

Methods: This was a mixed-methods study. Two online democratic deliberations were conducted simultaneously between May and June 2022, which included two pre-deliberation training sessions and pre- and post-deliberation surveys for participants. Deliberations were recorded and transcribed in Verbatim for thematic content analysis. Surveys were sent to participants to compare their perspectives on the acceptability of these strategies. A paired group analysis and t-test were performed.

Results: The online deliberations were attended by 20 participants from Quebec and 27 from Ontario. There was a diverse participation in terms of age, gender, ethnicity, origin, educational level, and occupation. We excluded people working in the healthcare system in order to get an outside perspective. Voiced considerations to optimise prioritisation protocols were: 1) Patient merit linked to healthy and safe behavior; 2) Expanding public information on alternative care for patients not prioritised in critical care; 3) Psychological support strategies for the patient's relatives or caregivers, and 4) Integration of clinical criteria to prioritise pregnant women.

Conditions to favor acceptability were: 1) Population education about prioritisation in an extreme context; 2) Legitimizing the protocol as a health strategy or policy, and 3) Prioritisation team standardization at local and regional level. Both Quebecers and Ontarians mostly valued giving priority to patients with the best survival prognosis. Survey analysis and t-test were performed.

Conclusion: Public participants expressed their support for prioritising patients with the best chance of survival. An important consideration was the inclusion of specific criteria for pregnant women. A frequently suggested condition was the importance of making these protocols legitimate in the eyes of the public.

The Value of Ethics Consultations in Cases of Moral Distress and Moral Injury

Sarah-Vaughan Brakman

Clinical ethics consultations are considered successful when they engage in original analysis of competing stakeholder value conflicts and through a dialectic of theory informing practice and the contours of the case specifying the principles, result in a resolution of the moral dilemma through practical recommendations.

Consultations that are conflict resolution mediations only, or that primarily apply laws, policy, or general ethical concepts to inform or educate those involved, typically are seen as misapplications of the ethics consult service. However, in the post-pandemic reality of healthcare for both acute care and long term care, some types of education-only case consultation requests may be ethically and practically lauded.

Data shows greater reports of moral distress and moral injury for physicians and nurses post pandemic. There is no indication in the literature or in informal discussions among clinicians and ethicists that the conditions which have lead to these increases are abating. With moral distress and moral injury identified as leading causes of burnout, the case consultation process may be the only appropriate venue through which healthcare professionals can both process moral distress and injury and also register formally that structural working conditions are detrimental to professional well-being.

It is important then to distinguish this particular deviation from the intended role of the consultation process from all others. Under certain circumstances, taking on a primarily educative role in a case consultation process does add value.

Relevant or Not? Clinical Ethics Support in Switzerland During the COVID-19 Pandemic

Caroline Brall, Rouven Porz, and Ralf J. Jox

Background: Since March 2020, the COVID-19 pandemic has posed numerous challenges to healthcare systems worldwide.

Methods: In order to get insights into which ethical challenges the COVID-19 pandemic posed to clinical ethics in Switzerland, we conducted a thematic content analysis of minutes of the Swiss COVID-19 video conferences on clinical ethics, which had been held regularly by health care professionals interested in clinical ethics since March 2020.

Results: Certain topics were discussed repeatedly during these meetings, such as the triage criteria developed by the Swiss Academy of Medical Sciences and the Swiss Society for Intensive Care Medicine, the continuing challenges in long term care facilities and nursing homes, as well as moral distress among healthcare teams.

Overall, the discussions during these video conferences placed the focus on attention to vulnerable groups and to topics that were only superficially discussed in the public discourse.

Discussion: The Covid-19 video conferences on clinical ethics therefore contributed to directing the attention to ethical topics that were relevant in practice but not yet in the focus of public debate in Switzerland. The pandemic furthermore represented an opportunity for clinical ethics to build national networks to discuss specific challenges, but also to transparently demonstrate how the discipline of ethics can provide support in hospitals, long term care facilities and nursing homes. While clinical ethics was instrumental in overcoming the immense challenges of the pandemic, it remains crucial to assess how the lessons learned can be sustainably transferred to the post-pandemic period.

Culture vs Gender: Which Identity Matters More to an Ethicist?

Leon Budrie

In the past decade, the topics of gender identity and gender-affirming care have been prominent in medicine, law and ethics. Though there are numerous ethical issues associated with gender affirming care, conversations in medical and academic circles seem to be tipped in favour of increasing access and accessibility, with many prominent professional organisations advocating for more universal provisions for minors.

A main ethical justification in support of providing gender-affirming care (including surgical care) is its necessity in improving the health and well-being of transgender and non-binary persons as it enables them to live their true identity. But are other aspects of an individual's identity, such as culture and religion, just as important?

Cultural identity has been well established as an essential aspect of one's mental health and well-being. If one's cultural identity then requires some sort of body modification, should that provide justification for a medical practition-

er's involvement? The topic of female genital cutting has been introduced by some US politicians into debates on the provision of gender-affirming care. Though the intent by some in using this comparison is questionable, there may be some validity in it. Given that clinical ethicists are becoming increasingly involved in gender-affirming care and that medicalised female genital cutting has raised numerous ethical issues in the past, the arguments for or against one or the other require a more careful examination of the issues.

In this presentation I aim to show that the arguments in favour of providing gender-affirming surgery to children and adolescents may provide justifications for some forms of medicalised female genital cutting. First, I argue that that cultural identity is as important as gender identity for health and well-being; second, that the general narrative of gender-affirming care being “good” while some minimally invasive forms of genital cutting viewed as “evil” are inconsistent; third, that the medical risks of gender-affirming surgery are significant while the risks for some forms of genital cutting are significantly less problematic for an individual.

Thus, a clinical ethicist who attempts to justify gender-affirming care versus some forms of female genital cutting may find themselves in a challenging position of defence should a parent and/or minor request such services.

Clinical Ethics Support in the Co-design of an Institutional Pediatric Sickle Cell Disease Patient Engagement Initiative: Creating Brave Spaces to Examine Issues of Equity and Power in Clinical, Research, and Advocacy Programs

Gabrielle Bujold, Yves Pastore, Evelyne Doyon-T., Jessica Darilus, and Nathalie Gaucher

Background: Several health inequalities affect patients with sickle cell disease (SCD). To address some of these disparities, youth with SCD and their families would likely benefit from a patient engagement approach in clinical and research settings. How can clinical ethics facilitate the development of a research and care improvement program for pediatric SCD that is rooted in the needs and realities of children and their families?

Objective: The primary objective of this initiative is to develop an approach to working collaboratively with youth and family partners that considers issues of inclusion, diversity, and power in recognizing and raising awareness of pediatric SCD in the different facets of families' lives, with a particular focus on their health care experiences.

Methods: Members of our clinical ethics unit (CHU Sainte-Justine, Montreal) were asked to co-design an action research study with clinicians, researchers, youth, and families. This initiative was co-constructed with a patient-partner, the mother of youth with SCD, and with input from a regional SCD patient association.

The initiative is inspired by a learning pathway proposed by the Can-SOLVE CKD Indigenous Peoples' Engagement and Research Council (IPERC), using four main aspects: (1) looking within to observe and examine racial identities, privileges, and biases, (2) listening to patients' stories and perceptions, (3) learning about the realities of patients and their families and (4) leading by taking appropriate actions in building genuine partnerships.

Focus groups will be conducted with all stakeholders, using patient and family engagement as a model of care, to explore the following themes: (1) priorities for education, recognition, and awareness of SCD, (2) how all parties envision an approach to collaborative work that considers democratic representation; (3) how to consider issues of inclusivity, diversity, and power in partnership work; (4) to explore how an institutional initiative should engage with community partners to foster patient engagement in clinical, research, and advocacy programs.

Thematic analysis will identify emerging themes and inform future focus groups from an action research perspective. Feedback from all stakeholders is planned at the end of the data collection and focus group analysis in order to enrich the reflection and develop an action plan for research and clinical partnership at the institution.

Conclusion: This initiative exemplifies how clinical ethics can lead stakeholders to engage in conversations about equity and power, while creating brave spaces and real partnerships to address these complex issues in healthcare.

What Is the Public's View of Tiebreakers in the Prioritization Protocols for Accessing Critical Care in the Extreme Pandemic Context of COVID-19?

Claudia Lucrecia Calderon Ramirez, Marie-Ève Bouthillier, Yanick Farmer, Nathalie Gaucher, Gina Bravo, Antoine Payot, Joseph Dahine, Audrey L'espérance, Annie Descoteaux, Clara Dallaire, Karell Laporte, Louis-Martin Rousseau, Vincent Dumez., Diane Poirier, Lucy Opatrny, Peter Tanuseputro, James Downar, Andrea Frolic, Naomi Singh, and Nadia Lahrichi

Background: The prioritization protocols for accessing adult critical care in the extreme context of a pandemic con-

tain tiebreaker criteria to facilitate decision making in the allocation of resources between patients with a similar survival prognosis. These criteria have been controversial, and little is known about public acceptability in this pandemic. Online democratic deliberations were held during the summer 2022, where the tiebreakers were discussed by Canadian participants from Quebec and Ontario.

Objectives: 1) To explore the perspectives of the public from Quebec and Ontario on tiebreakers, identifying the most acceptable ones, and their underlying values. 2) To analyze these results considering other public consultations held in this pandemic on these criteria.

Methods: This was a mixed-methods study, including two online democratic deliberations and surveys, between May and June 2022. Participants were recruited from both communities, excluding healthcare professionals. They were first informed about the protocols designed for both provinces, and subsequently deliberated on the acceptability of tiebreakers. The deliberations were subject to thematic content analysis. Pre- and post-deliberation surveys were sent to participants to verify the acceptability of the tiebreakers and their underlying values. Descriptive statistics were also carried out.

Results: A total of 47 citizens from Quebec (n=20) and Ontario (n=27) took part in the online deliberations. The emerging themes were: 1) Priority to young patients – the life cycle – a preferred tiebreaker; 2) Randomization value – a tiebreaker of last resort; 3) Multiplier effect of most exposed healthcare workers – a tiebreaker of moderate acceptability; and 4) Social value – a tiebreaker of low acceptability. The main argument for the life cycle was based on equity. Rapid recovery in critical care and the preservation of generations were also stated. The social value of individuals was considered an unfair tiebreaker criterion. Survey results were consistent with the insights obtained from the deliberations.

Conclusion: Life cycle was the preferred tiebreaker for participants because this criterion respects the intergenerational equity, which was relevant to them in allocating scarce resources to adult patients during an extreme pandemic. The focus on younger patients is consistent with other public consultations conducted around the world. This study may be useful to guide decision-making in the allocation of scarce resources in the chaotic environment that a pandemic can generate. More studies are needed on the public acceptability of tiebreakers.

The Jam Session Format for Retrospective Clinical Ethical Consultation: Toward a “Shared Hands-on Approach” to Professionalism Growth

Laura Campanozzi and Vittoradolfo Tambone

Background: Professionalism training for medical residents has become a topic of interest alongside the recognition that ethics is one of the essential components for realizing good medical practice. Despite evidence that educational needs are context-specific, teaching approaches of professionalism are still challenging the effort to develop learning experiences useful in supporting residents to undertake their professional accountability in facing real bioethical dilemmas. This work describes an experimental training approach for residents that has been accomplished at Campus Bio-Medico University of Rome since May 2016 to develop specific skills regarding judgment in ethical dilemmas and appropriate standards for clinical professionalism.

Methods: Drawing upon interesting suggestions from the world of music, specifically from the analysis of the jazz jam session process, we designed a training format called Jam session to emphasize the cooperation of each other's capabilities for developing a common outcome.

Results and Discussions: Based on the presentation and discussion by trainees of real cases arising ethical and professional issues in the presence of both colleagues and clinical ethics experts, the Jam sessions have been found to be useful to promote participants' willingness to establish or reframe rationally their own views, and to take an active part in identifying ethically grounded solutions.

Conclusions: The jam session format can serve as a model for a ‘shared, hands-on approach’ to identity formation as it allows the development of key professional skills in a more personal and sound way while engaging residents in an immersive and vivid learning experience.

Wearable Health-Monitoring Devices: Data Protection and Other Ethical Issues

Emma Capulli, Alessandro Silvani, Abdul Haleem Butt, Giorgio Bedogni, Francesco Palmese, Marco Domenicali, and Francesca Ingravallo

Wearable devices are defined as electronic devices designed to be worn or attached to the human body. They can take different forms and can be bio-implanted, worn by an individual as an accessory, or embedded into the user's outfit as

part of clothing. Wearable health-monitoring devices (WHMD) may be tools for more digital, individualized, and preventive medicine, but they also raise ethical problems. The most debated issues are those related to privacy and data sharing, since health data is constantly transferred over a long period of time. It is important to balance privacy limitations with possible benefits. The excessive use of WHMD may also entail cybersecurity threats, such as the use of malicious software to get personal and financial information. Other ethical issues related to the use of WHMD in clinical research and practice should also be considered if the principlism framework is adopted.

Regarding autonomy, the use of WHMD raises ethical questions related to data protection and sharing, as well as how their use may change the way people perceive themselves and their private life. WHMD can contribute to greater body awareness and positive behavior changes, but also to over-monitoring practices and technology dependency, compromising individual autonomy. Regarding beneficence, by providing real-time information about health, WHMD may provide benefits in terms of diagnosis and care, and allow some patients (e.g., frail older people) to delay institutionalization, increasing their independence and quality of life. Regarding non-maleficence, beyond risks of breach of data protection, possible over-medicalization of life should be considered. Lastly, regarding justice, the widespread use of WHMD not only raises issues of access to devices, but it may also help turn medicine into a neoliberal system that shifts care responsibility from the state to the individual. Moreover, there are questions about whether and how this data can be made available to researchers and clinicians for the advancement of technology. These issues should be shared with research participants and patients when the use of WHMD is discussed, also to promote social awareness on the topic.

Funding: NRPP Enlarged Partnership 8, project "Age-IT: A novel public-private alliance to generate socioeconomic, biomedical and technological solutions for an inclusive Italian ageing society."

The Integrated Ethical-Relational (Ethics Consultant), Psychological, Social and Spiritual Approach Improves the Clinical and Functional Outcomes of Frail Hospitalized Patients: Randomized Clinical Trials

Gennaro Cera, Grazia D'Onofrio, Leandro Cascavilla, Nicola Monopoli, and Alberto Pilotto

Introduction: The frail hospitalized patient, suffering from exacerbated chronic pathologies, presents a physical, psychological, social and existential "global suffering", which has important repercussions on their clinical and functional state and requires innovative care approaches and structured paths of humanization of treatments, according to the latest indications from the WHO and national health plans (Health Pacts). Within these pathways, the effectiveness of a personalized ethical-relational, psychological, social and spiritual approach, coordinated by an ethics consultant (case manager), on the clinical and functional status of the chronically ill and frail hospitalized patient.

Objective: To evaluate, through a randomized clinical trial, the efficacy of a therapeutic-assistance model with integrated support of an ethical-relational, psychological, social and spiritual type, coordinated by an ethical consultant (case manager), on the clinical and functional outcomes of chronically ill and frail hospitalized patients.

Materials and Methods: The study was conducted on two groups of frail patients (assignment with randomization), "experimental group" (112 patients) and "control group" (112 patients), homogeneous for sex, age and exacerbated chronic pathologies (average age = 70.4 ± 5.5 years), consecutively hospitalized at the IRCCS "Casa Sollievo della Sofferenza" in San Giovanni Rotondo. The patients of both groups, upon admission and upon discharge, underwent a Multidimensional Evaluation (VMD) of their clinical-functional status, with validated tests and evaluation scales, in relation to the following parameters: 1) functional status: Activities and instrumental of Daily Living (ADL and IADL); 2) cognitive status: Short Portable Mental Status Questionnaire (SPMSQ); 3) nutritional status: Mini Nutritional Assessment (MNA); 4) risk of pressure ulcers: Exton-Smith Scale (ESS); 5) anxiety: Hamilton scale A (HAM-A); 6) depression: Hamilton D scale (HAM-D); 7) perceived pain intensity: Numerical Rating Scale (NRS); 8) number of drugs taken; 9) stress of the caregiver: Relative's Stress Scale (RSS). During their hospitalization, the patients of the "experimental group" were subjected to: 1) standard therapeutic treatment according to the procedures of good clinical practice ("good clinical practice"); 2) integrated approach of an ethical-relational, psychological, social and spiritual type, with the execution of formal sessions, lasting an average of about 30 minutes, implemented in an integrated manner by a doctor expert in clinical ethics (acting as ethical consultant and also coordinating the team - case manager), a psychologist, a social worker, a spiritual assistant, also extended to the patients' families. The patients of the "control group" were subjected only to the standard therapeutic treatment according to the usual procedures of good clinical practice, without the multidisciplinary approach integrated and coordinated by the ethical consultant. At discharge, the patients of both groups, in addition to the Multidimensional Evaluation (output VMD), underwent, by means of validated tests and questionnaires (patient-reported outcomes) to: 1) evaluation of multidisciplinary team support and humanization of care (health professional-patient relationship, communication, information, problem solving, etc.); 2) assessment of the general satisfaction of the patient and family members with regard to the quality of assistance and the services received (through the General Satisfaction Questionnaire or GSQ).

Results: At discharge, a statistically significant difference was observed in the patients of the experimental group compared to the patients of the control group in relation to the following parameters: 1) functional status (ADL, IADL): improvement of 15% vs 0.2%, $p<0.0001$; 2) cognitive status (SPMSQ): improvement of 46% vs 5.8%, $p<0.0001$; 3) presence of anxiety (HAM-A): reduction of 77% vs 10%, $p<0.0001$; 4) presence of depression (HAM-D): reduction of 75% vs 13%, $p<0.0001$; 5) nutritional status (MNA): improvement of 7.4% vs 0.1%, $p=0.01$; 6) pain intensity (NRS): reduction of 41% vs 11%, $p<0.0001$; 7) number of drugs taken: reduction of 10.5% vs 2.4%, $p=0.02$; 8) caregiver stress (RSS): reduction of 62.4% vs 8.6%, $p<0.0001$. Furthermore, in the experimental group, a very high appreciation for the assistance, care and services received (customer satisfaction) was found compared to that of the control group [General Satisfaction Questionnaire, GSQ: very satisfied patients = 44.5% (GT) vs 19.3% (GC); satisfied = 53.2% (GT) vs 27.7% (GC); dissatisfied = 2.1% (GT) vs 33.1% (GC); very dissatisfied = 0.2% (GT) vs 9.9% (GC)].

Conclusions: An integrated therapeutic-assistance approach of an ethical-relational, psychological, social and spiritual type, coordinated by an ethical consultant (case manager), is able to improve the clinical and functional state of the frail hospitalized patient, to significantly reduce his “global suffering” and the quality of life, favoring the saving of resources (drugs, tests, shorter hospitalization) also thanks to the increase of customer satisfaction and the reduction of conflicts and legal disputes. This assistance approach can represent a valid reference for the creation of innovative paths of clinical ethics and humanization of care in the hospital setting, in the holistic and multidisciplinary dimension of assistance, as required by the most recent National Health Plans, also for the purposes of institutional accreditation and excellence of hospital structures, according to the most recent regulations.

Let's Not Forget Research: The Role of Research Ethics Consultation Services in Italy

Silvia Ceruti

Clinical Ethics Consultation Services (CECSs) have yet to become widespread in Italy, but significant efforts have recently been made to ensure their implementation in healthcare facilities in order to address ethical issues raised by clinical practice. In contrast, similar consultation services have not been introduced in the context of clinical research, despite its critical role in the advancement of modern medicine. This exclusion is largely linked to the strictly regulatory approach to clinical research traditionally used in Europe, according to which scientific and ethical requirements for conducting clinical trials are defined by a set of national and international norms and guidelines. As a consequence, the responsibility for evaluating and authorising this research is assigned to the local institutional ethics committees, whose main function is to protect the rights and well-being of research participants. This approach, however, is not always entirely effective, largely due to researchers' lack of knowledge or awareness of the ethical principles and values involved, or the rules and standards of conduct.

To address these challenges, in the United States the functions performed by institutional review boards have been complemented by the activities of Research Ethics Consultations Services (RECSs), which support researchers throughout the research process. In particular, consultations performed by RECSs are requested during study development, implementation, analysis, and reporting, and mainly concern risk-benefit assessment, study design, the informed consent process, and the dissemination of results.

Since the effectiveness of RECSs - the number of which has steadily increased over the past 20 years - is well documented, we believe that the Italian debate on the institutionalisation of CECSs should be conducted to also include and consider the ethical issues raised by clinical research, especially after the radical changes recently introduced with the full implementation of Regulation (EU) No.536/2014 on clinical trials of medicinal products for human use.

More specifically, we argue that, at this early stage of implementation, well-structured CECSs should also include research ethics consultants, who enhance the functions performed by ethics committees by providing real-time advice to a broad spectrum of stakeholders through a cooperative-collaborative approach, with the aim of improving the quality of research, which, in turn, can benefit individuals and society. Although there is no agreed-upon list of required competences, we maintain that research ethics consultants should be familiar with study design and methods, dominant ethical theories, fundamental ethical principles, rules of conduct, and standards for the protection of research participants.

Informed Consent to Clinical and Forensic Examination in the Management of Abused Patients

Federica Collini and Sarah Gino

Consent to a medical act is the patients' conscious adherence to decisions on the therapeutic treatment to be followed through exhaustive information on their health conditions and, above all, on the consequences and risks associated

with the therapy itself. It is necessary to consider the right to health of the patient, who must be correctly informed about what will be performed on his/her person: starting from the consent to the medical examination, to blood sampling, to instrumental or laboratory tests, in respect of privacy and dignity of the patient himself/herself, who has the right to refuse any treatment.

In the case of a victim of violence, the consent to the clinical and forensic examination can be read not only as a duty, but also as a therapeutic and ethical choice to restore dignity and respect. In fact, the term violence includes the concept of lack of consent to an act on one's own person. The collection of swabs, invasive blood tests, the objective examination that may require nudity could be experienced by the victim as further violence. On the contrary, it is important to communicate correctly and completely to the patient every step that is taken and its goal, motivating each gesture and obtaining their consent, with patience and empathy. This approach is also fundamental for an initial therapeutic recovery of a psychological nature which, in a moment of acuteness such as that of a violence that has just been experienced, could be of key importance in facing and reworking the violence. Obtaining consent from an adult capable of understanding is quite simple; it becomes more complex in the case of an unconscious patient, or a minor or in any other condition that compromises the ability to understand and will.

In the case of a minor who is suspected of having been abused by a parent, the situation is more difficult. Indeed, in these cases, healthcare personnel find themselves having to decide whether to provide the parents, potential abusers, with any type of medical information, which could - even indirectly - be to the detriment of the child. In these cases, therefore, parental responsibility cannot prevail over the development of the child's values and individuality, and it is in this balance between parental responsibility and protection from harm to the child that the health personnel can find an ethical justification for their choices.

Trisomy 18: A Clinical Ethics Approach to a Syndrome Considered “Incompatible With Life”

Barbara Corsano, Dario Sachinni, and Antonio G. Spagnolo

Edwards syndrome, also known as Trisomy 18, is a genetic disorder that can be characterized by multiple congenital multi-organ anomalies. It is still nowadays considered a disease “incompatible with life” and often, when its diagnosis is communicated to the pregnant mother or couple, the options offered are reduced to abortion or refusal of any treatment at birth. However, there are cases of children affected by Trisomy 18 who have lived for several years.

The Clinical Ethics Consultation Service at Fondazione Policlinico Universitario “A. Gemelli” IRCCS, Rome (IT) presents here the case of Angelica, a child affected by Trisomy 18 who is now 5 years and 8 months old. In her case, the healthcare professionals have requested clinical ethics consultations on many occasions, both in the prenatal and in the postnatal phase, in order to jointly evaluate the possible treatment options, including invasive and intensive ones. Trisomy 18 can no longer be considered a disease “incompatible with life.” During Angelica’s life, clinically and ethically appropriate and proportionate treatments were defined step by step with regards to her clinical case through interdisciplinary evaluations. A shared care plan (named “Shared Document for Healthcare Ethics Planning”), was drafted and shared within the healthcare team as well as with her parents. Ultimately, the treatments, even when invasive and intensive, are configured as implementation of palliative care, aiming at improving the quality of life of the child and at facilitating her home care management.

Clinical Ethics Support: An Opportunity in Rare Cancer Care

Chiara Crico, Virginia Sanchini, and Paolo Giovanni Casali

In oncology, clinical decision-making is often challenging due to the variety of available treatment options, each with different outcomes, side effects and costs, and to patient-specific factors. Additionally to these challenges, some clinical contexts are affected by further factors of complexity: in particular, in the care of rare cancers, the uncertainties due to limited scientific evidence has a major impact on clinical decision-making. As a result, the application of guidelines may not always be possible; the treatment plan, often discussed within multidisciplinary team (MDT) meetings, is often personalised based on the clinical characteristics of patients and their preferences and values. In this context profoundly marked by clinical uncertainty, it is even more difficult to weigh possible treatment options by giving due consideration to all the factors at play in the decision process. It is, however, critical to analyse those options also from an ethical standpoint, since potential ethical problems, dilemmas and conflicts might influence clinical choices. Yet, understanding and balancing the ethical principles involved in medical decision-making may be challenging for healthcare professionals.

Clinical ethics support services (CESS) have been proven to be of great support in dealing with ethical issues in medical-decision making, where operating a balance between ethical principles involved in that decision is particularly

complex. That is why in our opinion CESS may be of great help to multidisciplinary teams of rare cancers, in providing a punctual analysis of ethical issues arising at the patient's bedside. Although it is still scarcely studied, in the context of rare cancers, CESS may have a critical impact on two agents/group of agents: (i) the patient (or their representative): ethics support can help to make explicit the patient's subjective preferences and values, thus providing an additional factor to inform the clinicians' medical decision-making; (ii) healthcare professionals: ethical analysis in MDT meetings may add an important reflection on aspects on which MDT are not used to reasoning; it can also be a useful tool to mitigate the risk of moral distress.

Developed in the form of a case study paper, this contribution aims to: present and discuss ethical issues involved in three paradigmatic clinical cases collected during MDT meetings of two rare cancers complex units – soft tissues sarcomas and head and neck cancers – at a comprehensive cancer centre; show to what extent a structured ethical analysis of such issues can support the medical decision-making for the two above listed categories of agents. This contribution represents the preliminary step of a more structured observational study, whose primary aim is to collect and describe the most frequent ethical issues in the context of rare cancer care. The secondary objective is to describe the issues in terms of potential conflicts between ethical principles and to show how, through ethical analysis, it is possible to deconstruct the problem, thereby guiding healthcare professionals towards a more deliberate and conscious choice.

Ethics Consultation and Education in the Crucible of Exceptional Cases: Autonomy, Suffering, and Posthumous Wishes

Philip Crowell

Background: The intersection of clinical ethics consultations along with the need for clinical ethics education is a feature of complex cases. The connection is evident in exceptional cases which involve multiple teams and sub-specialists all challenged by competing priorities and significant time constraints. This presentation explores a case of a female adolescent patient diagnosed with terminal brain cancer who opts for palliative care. The turn in the narrative is when she discovers she is pregnant and wishes to prolong her life with aggressive cancer treatment in order to carry her un-born to viability.

Method: The presentation will parse the case using a quadrant method: medical indications, quality of life, contextual factors, and patient preferences assessments.

Medical Indications: In this scenario the ethics consultation is part of a larger medical discussion with the oncology and neurosurgical teams calculating how to proceed with radiation and surgery without doing harm to the fetus as well as attempting to add months to the patient's pregnancy and life expectancy.

Discussion: The ethics team in the pediatric setting gives attention to the autonomy of the patient as a mature minor according to legislation and Supreme Court precedents. A critical ethical issue emerges regarding mental capacity of the patient given the unpredictable state of a glioblastoma and the potential for brain hemorrhaging at various stages. If the patient suffers brain injury or brain death, the question becomes should life support be continued in order to protect the viability and health of the fetus?

Results: The educational/consultative role of the ethics team focused on highlighting patient autonomy, potential substitute decision makers, integrating the ethical considerations regarding suffering as well as providing research on the ethical and legal precedents relevant to this situation. The delicate ethical balancing act entails considerations of patient wishes but also an appropriate medical and ethical response in an evolving situation.

Conclusion: The duality of both quality of end of life care, and the potential for wrongful life (birth) arguments are considerations that potentially entail balancing competing goals. The scenario carries significant educational components revealing the importance of quality ethics consultations capable of identifying the specific requirements for patient capacity and engages the dynamics of narrative ethics giving voice to the patient who may not be able to speak.

The Role of the Clinical Ethicist: Consultant, Educator, or Both?

Paul Cummins, Joseph A. Raho, and Federico Nicoli

This presentation considers the role of the clinical ethics consultant as educator. Broad agreement exists that clinical ethics consultants ought to provide education in healthcare settings, and this service is often one of the values that proponents of ethics consultation services point to when justifying its costs to healthcare institutions. However, it is not clear what specific form or scope this education should take. For example, this expectation may be formalized in contracts for clinical ethics consultants in academic medical centers: teach a course; provide didactic lectures in medi-

cal or nursing curricula; lead grand rounds. On the other hand, clinical ethics consultants working in academic or non-academic settings may encounter less formal expectations for education through invitations to round with house staff or ad hoc requests for lectures. And further on the spectrum, teaching occurs informally when clinical ethicists consult on specific patient cases, participate in team and family meetings, communicate verbal and written ethics recommendations to clinical teams, join retrospective case reviews, and contribute to ethics committee meetings. This presentation examines the less formal education a clinical ethics consultant may engage in because it may not always be clear when or how to prioritize education; clinical and educational processes influence each other, and goals are not always well-defined. Given their other responsibilities – as consultants and institutional policy advisors – there are several questions that clinical ethics consultants should ask themselves about assuming the role of educator: is it a primary or secondary role? What should the aim of their educational efforts be? Should clinical ethics consultants seek to raise general ethical awareness among staff of the value-laden dimensions of healthcare or should they focus more narrowly on increasing knowledge of fundamental clinical ethics? Should it be transparent to learners that they are being educated? Finally, what is (or ought to be) the legitimate expectation that healthcare institutions can have regarding clinical ethics consultants' role as clinical educators? This presentation will offer answers to these questions and advice on navigating tensions that arise between the role of clinical ethics consultant and educator.

“Confuse not Motion With Action:” Ethics and Equity Redesigned for Antiracist Health Care

Jacob Dahlke, Ada Wilson, and Natalie Lynch

Background: In the United States there has emerged the broad discourse among the bioethics profession around its role in health care systems to address systemic racism. However, to date there have been few contributions around organizational structures and resources towards direct clinical care. This presentation seeks to describe the impetus, initial changes, and ongoing work of our midwestern academic medical center and health system's radical approach to the intersection of (1) clinical and organizational ethics and (2) equity and inclusion departments and initiatives.

Methods/Materials Part 1: We conducted an anonymous query of patient electronic medical records with terms including and related to medical “compliance” (e.g., “compliant,” “complied,” “compliance,” “non-compliant,” “did not comply,” etc.). These records were cross-referenced with the patients' (a) zip codes, (b) any demographic information related to: race or ethnicity, age, primary language spoken (English vs. non-English), sexual identity or gender identity, and citizenship, and (c) patient outcomes related to the intervention for which the patients were being considered ‘non-compliant.’ Part 2: We recruited patients from the zip codes identified as being in concentrated ‘non-compliant’ regions. We conducted qualitative interviews with participants from the relevant zip codes to capture their narratives, experiences, and/or perspectives around medical “compliance.” We analyzed the interview responses to identify and categorize overall themes aimed to guide future research.

Results: Results are anticipated to be gathered and preliminary analysis performed at the time of this conference.

Discussion: Our premises are straightforward. Societies employ structural and institutional frameworks to perpetuate asymmetrical power dynamics among citizens who ought to otherwise have balance. These dynamics, at their core, have embedded in them at best discrimination and bias, and at worst racism. Health care, as a component of the society in which it exists, employs similar frameworks. Different, specific actions must be conducted to respond to these racist frameworks. Our research aimed to identify regions within our community in which our actions within the health care system would have the most impact. There were three domains in which actions were planned: (1) institutional policies and procedures, (2) staff education, (3) and a restructuring of ethics consultation services to address individual patient situations. Conclusions will be discussed upon completion of the study analysis and will be shared at the conference.

Research, Education, Ethics Consultation: Evaluating a Bioethics Unit in an Oncological Research Hospital

Ludovica De Panfilis, Massimo Costantini, Luca Ghirotto, Giovanna Artioli, Elena Turola, and Marta Perin

Introduction: The Bioethics Unit is a research unit implemented in 2016 as a pilot project by the Scientific Directorate of the Local Health Authority AUSL-IRCCS of Reggio Emilia (Italy). It has been implemented inside the related Oncological Research Hospital to promote evidence-based ethics through research activities, ethics consultation, and training programs. Its mission is promoting a ‘bedside’ form of ethics, where the concrete experience of the healthcare relationship represents the starting point for improving the quality of care and fostering a personalized approach by enhancing the ethical competencies of healthcare professionals. Five years after its implementation, we

promoted a study aiming to quantitatively describe the activities carried out by the unit in five years (2016–2020) and to understand the perception of such activities and their perceived impact on clinical practice from healthcare professionals' perspectives. These are the final results of the study.

Methods: It is a mixed-method study that followed a quantitatively driven and explanatory design. Subsequent qualitative data build on the initial quantitative findings, offering a more in-depth understanding of the research questions through users' perceptions.

Results: From January 2016 to December 2020, the BU participated in 33 clinical and organizational research projects targeting patients, caregivers, citizens, and ethics committees. However, more than half were designed for healthcare professionals (63.6%). All the research projects had as main outcomes improving quality of care and quality of assistance and scholarly papers published in peer-review journals. The research activity was carried out in collaboration with 19 units/services. Consultation, training, and supervision activities involved 25 services/units, 22 directly involving patient care. From the qualitative part, a final sample of 18 healthcare professionals (out of 22 invited) participated in face-to-face, online, semi-structured interviews. There were two psychologists, one researcher, one biologist, one physiotherapist, one speech therapist, six nurses, and six physicians. Interviews were performed between February and March 2021 and lasted an average of 31 min (range 15–55). Framework thematic analysis identified four main themes: Ways and meanings of the BU's collaborations; Impact on the HPs' attitudes; Identifying new questions in clinical practice; Further needs.

Conclusions: According to our results, integrating research with more traditional activities provided an impetus to increase collaboration and spread an 'ethical culture' among local healthcare professionals. Such integration could be a model for other large hospitals. Further studies are needed to understand the feasibility of this model in different countries and organizations.

Training Activities Toward Health Care Professionals of a Clinical Ethics Service and Support: Advantages and Difficulties

Celia De Peuty, Nicolas Foureur, and Marta Spranzi

Since its creation, the Clinical ethics center's main mission has been to offer clinical ethics consultation for ethically difficult medical decision-making concerning a specific patient. The Center gets involved in these situations if they suppose a value conflict between a patient (or his proxies) and a doctor or caregivers. In this context, the Clinical ethics center's approach respects three pillars: patient's Voice enhancement, multidisciplinary discussion, and a rigorous case-by-case procedure. However, health care professionals (HCP) regularly ask the Clinical ethics center to help them work on ethical issues not based on its usual criteria, namely the value conflict between a patient (proxies) and HCP. To offer answers to these demands, the Center developed three different services:

Ethics support to health care teams about their own medical practices : it relates to situations where HCP ask for help in order to deal with a situation that challenges their own values. They may for example disagree, on an ethical level, about the best way to take care of a patient in their unit, or wonder about his/her best interest (e.g., "Is it in this patient's best interest to receive this chemotherapy that will save his life, while he is suffering from mental impairment so that we don't know what he would like and how he will endure this treatment ?"). HCP may also inquire about an organizational question concerning their medical/care practices (e.g., "Should we consider removing both ovaries instead of one (as we do now), for women receiving gonadotoxic treatments ?").

Methodological supervision: this service concerns other clinical ethics consultation teams who ask for help about how to approach a specific clinical ethics consultation for a given patient in their own hospital. The Clinical ethics center can help them reflect about which specific procedure would be more appropriate to deal with a particular case: what is the ethical dilemma? How should they instruct the situation? How can they best manage the ethical discussion? (e.g., "As the clinical ethics referent in my hospital, how should I answer these doctors who wonder about maintaining this 87 years old patient in intensive care unit after multiple suicide attempts ?").

Clinical ethics consultation training : every year, the Clinical ethics center offers a training course for 40 HCP, whether or not they are involved in a CESS, who want to learn about clinical ethics and get acquainted with the Clinical ethics center's methods. This training course is based on case studies and aims at getting HCP familiar with each stage of a consultation (initial call, instruction of the case, organization a multidisciplinary discussion, feed-back to stakeholders and follow up), so that they might conduct a consultation themselves. This presentation aims to describe advantages and difficulties of these three services: on the one hand they allow HCP to conduct their own ethical reflection at the patient's bedside, but on the other hand, we may wonder whether they are compatible with The Clinical ethics center's own approach, which is centered around the French patients' rights law. Do these services allow the Center to fulfill its own goals, and above all to enhance the patient's Voice? Are these services contributing to HCP's empowerment and to the defense of their own interests against patients? Or are they an occasion to support a method

that encourages the promotion of patients' rights? Are there any risks to undertake these missions? Or is it acceptable to refuse to provide them? We shall address these questions in the presentation.

Innovations in Clinical Ethics Support: Lessons Learned From Developing Ethics Support Tools

Janine de Snoo-Trimp, Margreet Stolper, and Bert Molewijk

To support healthcare professionals with their moral challenges in daily practice, new forms of Ethics support might be needed, such as tools. We have developed several tools in the last years and see the value of this for those working in practice. Yet, we also experienced challenges and encountered difficulties when working on these projects. We would like to present 1) our approach to developing ethics support tools; and 2) the lessons learned, including the value but also difficulties and potential dangers. Ethics support tools aim to provide practice-oriented guidance when dealing with specific moral challenges, and are tailored to a defined healthcare setting. Ethics support tools consist of thematic content on the specific moral issue, include aspects of existing ethics support services like moral case deliberation, and are designed for independent and easy use, and low-threshold availability.

Our approach to developing ethics support tools is based on our experience with many projects. We will briefly highlight the main features of these tools and describe the theoretical and normative aspects underlying our approach. The lessons learned during these projects of developing ethics support tools entail, firstly, that the process of development forms already a part of the (potential) impact of the resulted product. Secondly, we see the involvement of end-users as crucial in all phases of development, from defining the need at the start to having a say in the lay-out of the final product, to being asked for evaluation. A third lesson is the importance to monitor the actual usage of tools after their development, as there are several risks involved when not being able to observe and evaluate the use of ethics support tools. Lastly, we have been struggling with clearly defining underlying theoretical concepts, such as: what is a 'good' ethics support tool? And what 'should' it lead to in practice? Since these concepts do – in the end – determine how and what to evaluate, we see a need for further conceptualization and clearer definitions in the future.

Clinical Ethics Support Services in Paediatric Practice: Preliminary Results of a Mixed Studies Systematic Review on Structures, Interventions, and Outcomes

Marianna Dittborn, Bernardita Portales, and Joe Brierley

Background: Clinical ethics support services have been developing worldwide, with growing interest in evaluating their quality. Paediatric-specific CESSs (p-CESS) have received little attention to date, and evidence from adult services might not be generalisable. Evidence on specific service models and practices is crucial to inform further research and inform debate on quality evaluation and minimum standards for p-CESSs.

Aim: To systematically identify, appraise and synthesise evidence for p-CESS structures, processes, and outcomes.

Methods: We conducted a mixed-studies systematic review of empirical studies providing data on the evaluation and/or impact on any aspect of p-CESS. Seven electronic databases were searched (MEDLINE, Philosopher's Index, EMBASE, PsycINFO, LILACS, Web of Science and CINHALL). Narrative and thematic synthesis for quantitative and qualitative data was conducted, respectively, guided by Donabedian's framework of structure, process, and outcomes.

Results: After deduplication, 23,218 references were screened. 70 studies from sixteen countries, published between 1986 and 2021 (43, 61.4 % were published 2010 or after) were included. Twenty-eight studies were based on retrospective chart review, 22 on healthcare staff interviews/surveys, 4 involved interviews with patient's parents/family members, one was an ethnographic approach and 11 were descriptive reports of CESS structure and processes. Five studies reported prospective evaluations of an intervention including decision-making frameworks (2), ethics support programmes (2) and ethics educational programme (1). A total of 47 individual CESS were described in 54 studies, reporting mainly on the Clinical Case Consultation function, processes, and activity. Other CESS described roles include education, institutional policy review, moral injury staff support and research. The remaining 16 studies described CESS involvement focused on a specific paediatric field (five on gender dysphoria, one on bariatric surgery, and one on home total parenteral nutrition); the final 9 studies were multicentre surveys (5 national, 2 regional, and two clinical specialty members).

Conclusion: The studies in this systematic review were diverse in their reported domains for structures, processes, and outcomes of paediatric CESS services. The great majority of data is descriptive, based on retrospective chart reviews, with few assessing CESS stakeholders' experiences or attitudes toward CESS and there is no prospective evaluation of CESS interventions.

Increasing Patient and Family (Whanau) Participation in Clinical Ethics Consultation

Ian Dittmar

Background: The Clinical Ethics Advisory Group (CEAG) at Auckland Hospital (a major tertiary/quaternary hospital that also provides secondary care to the local population) is a group of senior clinicians, managers and other representatives who are available for clinical staff at the hospital and surrounding primary care organisations to bring clinical issues for discussion and advice. It does not deal with research ethics. About half of the issues dealt with are regarding process and system issues such as introducing innovative procedures and tests, how to deal with events that have occurred and may have been associated with clinical risk, or where that might be predicted in the future (such as limiting treatment access during CoVID surges).

Materials: The other half of cases centre around individual patients where an ethical issue is having some impact on patient care. Many of these are in end-of-life situations where there is conflict about what treatments should be offered to patients. In some of these situations the patient is not able to contribute to discussions about what might be appropriate. For many years CEAG did not have a facility for patients or family to present their views directly and relied on clinicians to do this. Clinicians generally made good efforts to ensure that they were accurately representing the patient/family views and often reported on the conflict or varied opinions within family groups with respect to treatment options. However it became increasingly apparent that this lack of an ability to present views directly was causing some degree of anxiety to some patients and family.

Results: We have gradually developed (and are continuing to develop) a formal process whereby patients and family can present their perspectives on the issues involved directly to CEAG who are represented by 2 members. We have received very positive feedback from the patients/family concerned even when our advice to clinicians has not necessarily been what they may have wanted. The majority of the clinicians involved have also found this useful noting that it has defused tensions by allowing family/patients to discuss the issue with clinicians who are not directly involved in the medical care.

Discussion: The presentation of this abstract will include description of the innovations we have made in this process and further changes that we are contemplating going forward.

Professional, Clinical, and Moral Ambivalence: Confronting the Limitations of Clinical Ethics Education

Olubukunola Dwyer

Current bioethics literature has recognized and presented a method of classifying the issue of ambivalence from the perspective of the patient. This literature however fails to address the ambivalence that arises perspective of the clinical team. Clinical ethics consults are not only beneficial to the patient and the care they receive, but they are also beneficial for clinicians involved in the consult.

When confronted with the variety of concerns that impacts a patient's willingness and/or ability to adhere to a recommended course of treatment, clinicians often are at a loss as to how to improve their patient's clinical status. These concerns are regularly caused or exacerbated by a range of factors including a patient's socioeconomic status to social determinates of health, for which clinical ethics can have a limited impact upon. When confronted with these factors, clinicians request a clinical ethics consult in order to ascertain whether ethical guidance could assist them and the patient with managing these issues. These consults are placed without the clinician having awareness of how their own ambivalence impacts the very issues they've consulted ethics to resolve. Recognition of the limited bearing clinical ethics can have on cases where ambivalence plays a key role, is often not taught or discussed amongst clinical ethicists or within clinical ethics education.

This oral presentation will define professional, clinical, and moral ambivalence from the perspective of the clinical team. Examples of clinical ethics consults where professional, clinical and/or moral ambivalence heavily influences either the ethical concern or how the concern is resolved will be presented. It will also touch upon how and why, ambivalence from the perspective of the clinical team is not often discussed within clinical ethics education. Lastly, this talk will also discuss how skills gained from completing clinical ethics consults can be expanded to create methods to actively resolve a clinician's ambivalence. Special focus will be paid to providing strategies for how to work collaboratively with patients and clinicians to resolve the ethics concerns involved in their care.

Ohtahara Syndrome: The Fine Line Between Palliative Care and Overtreatment

Alice Esposito, Martina D'Agostin, Simonetta Costa, Barbara Corsano, Antonio G. Spagnolo,

Domenica I. Battaglia, Domenica Quintiliani, Angelo Minucci, Martina Rinelli, and Giovanni Vento

Introduction: Ohtahara syndrome (OS) is a rare drug-resistant epileptic encephalopathy characterized by daily seizures associated with the specific electroencephalographic patterns of burst suppression. The prognosis is poor, and in most cases death occurs during early childhood. The management of OS is controversial, especially with regard to strategies to ensure the best interests of the young patients and their families, as they require a continuous modulation of medical interventions from intensive care while they wait for their diagnosis, to palliative care (PC) when incurable, until the possible withdrawal of overtreatment.

Case presentation: We present the case of the 38-week-old newborn M, intubated and mechanically ventilated from birth due to lack of spontaneous respiratory activity; for her, the clinical diagnosis of Ohtahara syndrome was reached at about 4 months of age. During her stay at the NICU of the Fondazione Policlinico "A. Gemelli" IRCCS, Rome (Italy), given the complexity of the clinical condition and the non-responsiveness to maximum anticonvulsant therapy, the medical team (neonatologists and child neuropsychiatrists) constantly met with the clinical ethics consultants in interdisciplinary meetings to evaluate the best healthcare assistance for the baby, from a clinical-ethics perspective. Communication with the parents was another critical issue: they were not able to accept the irreversibility of their daughter's illness and continued to ask that everything possible be done.

Discussion: In a probably irreversible clinical situation, such as OS, in which elements capable of modifying the prognosis *quoad vitam* do not emerge, it becomes difficult to identify the boundary between palliative care and overtreatment. This border and in general the discussions on the end of life must be constantly discussed, deepened, and shared with the parents, who must be guaranteed all the support, including psychological one. In the case of baby M, four clinical ethics consultations were requested during her hospitalization in the NICU to evaluate step by step the proportionality and clinical and ethical appropriateness of the treatments implemented (in particular of the mechanical ventilator) and to be implemented. In the end, the decision shared with parents was to maintain the palliative care already in place, to abstain from intensive/invasive interventions in terms of critical events, and to promote the well-being of the entire family, transferring the baby to a pediatric hospice, where death occurred when baby M was 11 months old.

Eliciting Patient Biographies in the Hospital Setting: Implications for Clinical Ethics Consultation Services

Marta Fadda, Samia Hurst-Majno, Alessandra Cristaudi, Pietro Majno-Hurst, and Martha Montello

Background: Narrative ethics emphasizes the importance of patients' lived experiences of illness and suffering and of the contextual factors shaping their moral worldview. In contrast to analytic approaches, which seek to develop solutions to ethical dilemmas through the implementation and analysis of principles and rules relevant to ethical issues, the narrative approach typically involves eliciting and integrating the patient's story, weaving different narrative threads together, and identifying the values and beliefs that guide decision-making. Narrative approaches offer a way of understanding individual patients' moral situations that can prove essential to addressing ethical challenges in clinical medicine. However, recognizing the key facilitators for this kind of inquiry and the potential contributions of specific narrative approaches to care is critical.

Methods: In a novel study, we analyzed ten autobiographies that patients wrote at the request of their surgeons before their hospitalization. We analyzed the structure of the biographies to understand how the patients communicated the complex and unique values and needs they identified as most essential for their providers to know. The initiative was promoted by the hepatobiliary and pancreatic surgery team of the Ente Ospedaliero Cantonale in Ticino, Switzerland, who believed that asking patients to write about their lives before their surgeries could help these providers give the best possible care, as well as carry other, yet unrecognized benefits.

Results: We found that patients used multiple, distinct narrative structures to describe their personal identity and to convey their need to be recognized as unique human beings. We also found that patients were grateful to use autobiographies to establish a meaningful relationship with their providers by telling them what intimately mattered to them. We also found that patients expressed trust that their providers would keep their unique identity safe during their surgeries and hospitalizations.

Conclusions: Our project showed that in order to meet patients' ethical needs, clinical ethics consultation services should elicit patients' biographies that attend to and protect patients' unique identities during their hospitalization.

Clinical Counseling in Neonatal Intensive Care Unit

Maurizio Faggioni, Francesca Bevilacqua, Francesca Monaco, and Irma Capolupo

Background: Clinical case ethics committee and clinical counselling represent two modalities traditionally deputed to assist physicians in decisions that are for some reason dilemmatic. Whereas traditional bioethics imagines addressing disembodied individuals devoid of histories, contexts, and relationships, the bioethics of care, drawing inspiration from the ethics of difference, values subjects caught in the vividness of their experiences, expectations, and relationships.

Methods: Without detracting from the usefulness of an external gaze that is supposed to be emotionally more detached, clinical counselling is a cooperative decision-making methodology in which the health care professionals themselves are the authors of the decision-making process. The purpose of this decision-making mode is to make caregivers conscious protagonists of their decisions, to sharpen the bioethical skills of health care workers, and to limit, as far as possible, the phenomenon of moral distress. This methodology has been experimented since 2014 in the Neonatal Intensive Care Unit (NICU) of the Bambino Gesù Children's Hospital in Rome. This is a pilot experience, named "Multi-voice encounter" to indicate both the dialogical structure inspired by exchange and confrontation among the operators, and the co-presence of different professionalism: physicians, nurses, psychologists and bioethicist. In the decision-making process, knowledge from various disciplines are called upon to interact with each other. Such interaction should take place through interdisciplinarity and transdisciplinarity, in the sense of a true interpenetration of knowledge. Such a method would show not only the unity of the various knowledge and their mutual inter- and trans-dependence in decision-making but would allow treating the person, both the patient (here: infant and parents) and the decision-maker in an integral and holistic way. Monthly meetings are coordinated by the ward psychologist and an ethics facilitator. Health professionals are invited to find treatment options that are as shared as possible, through a methodology of dialogue and discussion in which emotions, frustrations, clinical and ethical concerns can be voiced. After the group has reached as shared a decision as possible, the case manager meets with the parents of the child, proposing and discussing with them the outcome of the discernment.

Conclusion: The case discussion group thus conceived represents a methodology capable of containing at least in part the compulsion to do everything technically possible, fostering the conditions for genuine ethical discernment.

To What Extent It Is Necessary, and Why, to Specify the Criteria for the Clinical Ethics Consultations' Procedure

Nicolas Foureur, Marta Spranzi, and Celia de Peuty

The Clinical ethics center was founded in 2002, as an extension of a new French law on patients' rights. It offers support for ethically controversial medical decision-making, on a case-by-case basis, by practicing clinical ethics consultants (CEC). It favors 1) meeting all the stakeholders, including patients and their relatives, before the decision is made; 2) a multidisciplinary discussion with non-caregivers, including researchers in the humanities and social sciences, but also citizens and patient representatives; 3) a rigorous procedure. Other CECs exist in France, and new "clinical ethical supports" have been developed since the COVID epidemic. Five CECs in particular use the same methodology. They decided in 2022 to assert their specificity within the French ethics support landscape. They have defined procedural criteria around three main axes: the importance of the patient's voice, a multidisciplinary approach, and a case-by-case procedure.

The goal of this presentation is: To explain why it is necessary to specify the main tenets of the CEC approach. Especially in France, the ethics services use a "top-down" approach, organized around Regional Ethical Reflection Spaces (bioethics law of 2004). There are also Hospital Ethics Committees which organize local ethical reflection on "general" subjects (eg: changes in laws or use of restraint in different clinical contexts). On the contrary, clinical ethics consultations focus on particular cases and use a "bottom up" approach. To present the procedural criteria of a CEC that we have developed at this stage. Why do we think that some criteria should be respected by clinical ethics supports services in order to be called a consultation? Why should patients and/or their representatives be engaged in the ethical reflection? Why should multidisciplinary be very diversified in order to help healthcare professionals to decide? Why should some criteria be respected to ensure that the advice is an ethical one, rather than mere medical collegiality? To disclose the results of a survey we conducted about these criteria, with identified CECs in France. Many clinical ethics services and supports exist in French hospitals but nobody knows exactly where they are and what their procedural constraints are. Some CECs in France want to organize a network of all the CECs. They began this process with a survey about procedures and goals of each CEC in France. To discuss the national and international issues raised by such a movement. Many CECs use different procedures and discussions can be hard. Is it possible to develop a common approach, especially to better develop CEC and to be helped financially? Why discussions about procedures and goals would be useful, especially at a time when evaluation and certification are new stakes in the field?

CARES: A Tool for Surrogate Decision-Makers

Susan Fox

“CARES” is a tool being developed to aid surrogates during and after ethics consultations. From the surrogate’s standpoint during a hospital conversation, subjectivity, emotion, and moral dilemmas can seem overwhelming. From the ethics consultant’s perspective, attempts to introduce ethical principles can be crowded out by perceptions of institutional bias or self-interest, power imbalances, and cultural barriers. “Soft” instruction in ethics can be valuable when surrogates unfamiliar with formal language and ethical principles are catapulted into decision-making roles with “supercharged” ethical implications.

Using “ethical mnemonics” and the simple word “CARES,” the tool – in the form of a small deck of cards -- offers surrogate decision-makers a way to organize and articulate decisional elements. Each letter (C,A,R,E,S) incorporates one or more practical factors, as well as ethical considerations* discussed during the consultation. (Further development and experience will undoubtedly improve and refine vocabulary and cultural connotations presented in card decks that can be translated into different languages.) Importantly, the cards contain no prescriptive message, nor are there implicit algorithms for “correct” formulations. They are purely a device for enhancing transparency and comprehension. Ethics consultants may choose to invite a surrogate to review their use of the cards, which may frame further constructive consultations, but that choice is left to the discretion of participants.

“CARES” cards can serve as portable ethical anchors, so that principles introduced by ethics consultants remain in place with surrogates, grounding their deliberations. Often, consultations occur as a series of meetings or conversations, and “CARES” cards can be used by surrogates and families during those intervals. As “ethical souvenirs” and sequelae to real time conversations, CARES cards can travel home with the surrogate and serve as a platform for further reflection and discussion. Ideally, they offer surrogates an opportunity to examine their deliberations and elevate their awareness as they – literally – take decisions into their own hands. Will “CARES” cards actually work for their intended purposes? Will ethics consultants feel comfortable using them, or find them useful? These are open questions, and the opinions of participants in the session will be welcome. *The following list is an abbreviated version of this “ethical mnemonic:”

C = Caregiving (Vulnerability), Costs (Justice); A= Autonomy, Abilities, Attitude; R= Relationships (Relational Autonomy, Identity), Residence; E= Expertise (Beneficence – is there sufficient “expert” medical evaluation), Expectations, Experience (The patient’s narrative); S= Self (The patient’s identity, dignity and integrity); Self-interest (The surrogate’s involvement)

Final Work on Counsel vs Consultation in Ethics Consultation

Beverly Frase, Ellen Metzger, Corinne Benzinger, Ellen Case, Lisa Trost, Michael Bannon, and Kevin Whitford

Many scholars have emphasized the importance of curbside consultation in the practice of Medicine and have found curbside consultations to be vital to providing quality care to their patients. By tapping the knowledge of their colleagues in a manner that is timely and without burden to patients, providers can gain information that allows them to provide quality care to a patient without formal consultations.

Clinical Ethics has continued to struggle with determining whether ethics consultations can be done in a curbside manner. The American Society of Bioethics and Humanities, reminds us, that completing a consultation and providing recommendations with only one perspective on the case, could lead to biased and inappropriate ethics recommendations. By definition, our curbside consultations did not engage patient or family directly.

A three-year review of our ethics consults from 2019 to 2021 has shown that curbside consultations make up 29% of all consults. A retrospective review of 191 consults classified as "curbside was completed by two Ethicists who independently conducted a systematic review. The purpose was to determine if curbsides consultations were conducted in a way that did not provide any formal recommendations that influenced the plan of care. For 52% of the curbside consults, the requestor articulated a patient-specific ethics question.

However, for about 67% of the curbside consults, the Ethics Consult Service interpreted policy or provided counsel around process flow. For approximately 33% of curbside consults the guidance influenced the plan of care through assessment or interpretation of patient-specific information. We found this high percentage of curbsides that influenced the patient’s clinical course without direct engagement of patient/family worrisome, and consequently, the Ethics Consult Service implemented an improvement initiative.

The goal of this improvement initiative was to determine if the consult requests provided inappropriate or incomplete advice because patient/family were not directly engaged. Further, we developed criteria to assist in defining if a consult request is appropriate for a curbside approach or a full consultation. These criteria have helped to provide guard

rails around the practice of clinical ethics curbside consultations, which are now defined in our practice as Ethics Counsel Consultations.

Objective: Review the PI process initiated to improve accountability around approach to ethics consultation. Discuss the criteria that will assist in determining when a curbside approach is appropriate and when a full consultation approach should be initiated.

Advancing Best Clinical Practice for LGBTQ+ Cancer Patients: SOGI Data Collection and Protection

Collen Gallagher, Benjamin Schrank, Lynne Nguyen, Emma Holliday, Van Morris, Alana Newman, Kelly Meriman, Veronica Sudol, Elizabeth Chiao, and Ernest Hawk

Background: A long-standing barrier to progress against health disparities is the lack of data regarding cancer risks, prevalence, treatment, and outcomes for sexual and gender minority (SGM) patients. Sexual orientation and gender identity (SOGI) data are not routinely collected by oncologists, cancer centers, or most non-federal hospital systems in the United States. High proportions of SGM patients report discrimination in healthcare or avoid routine care due to perceived lack of acceptance in the healthcare system. Healthcare institutions must promote an inclusive environment for all patients including those self-identified from SGM groups. One strategy to achieve this aim is through the collection of SOGI data and match it with supportive training for clinicians and others.

Objectives: Standardize the collection of SOGI data for all new patients. Promote clinical staff awareness of SGM health disparities and strategies for fostering an inclusive hospital environment. Provide SGM patients and caregivers educational resources and support systems tailored to their needs.

Methods: Designed an approved Quality Improvement protocol for collecting SOGI data. Patient access specialists participated in a workshop designed specifically for SOGI data collection by our institution's Center for Community Engaged Translational Research. PAS were assigned the responsibility to collect SOGI data from newly registered patients and enter the data into the electronic health record. Clinical staff participated in training developed in collaboration with the National LGBT Cancer Network. Oncology providers completed surveys before and after training to estimate its impact on the provision of patient care.

Results: Two 1-hour interactive training sessions were offered by video conference to twenty-five Patient Access Specialists. Three 1-hour hybrid video conference and in-person sessions were offered to twenty-seven Oncology clinical staff. Of medical providers surveyed prior to training, 43% (7/16 respondents) reported low confidence using SOGI classifiers around patients, and 68% (11/16) did not use SOGI data in clinical practice. Following training, 100% felt confident using SOGI classifiers, and 100% reported SOGI data incorporation into clinical practice (13/13 respondents). A clinical pathway for SGM patients was developed to facilitate referral to our institution's SGM patient support group and distribution of patient education materials focused on sexual health.

Conclusions: Establishing standardized SOGI data collection can facilitate provision of tailored resources and care that meets the needs of patients and staff. Specialized training for staff helps foster an inclusive and welcoming environment promoting the integration, visibility, and advancement of SGM cancer care.

A New Approach to the Clinical Ethics Consultation With the “Six Thinking Hats” Technique

Francesca Gallini, Barbara Corsano, Pietro Refolo, Dario Sacchini, and Antonio G. Spagnolo

Clinical Ethics Consultation (CEC) provides an interdisciplinary comparison among several professionals who find themselves discussing complex and often very controversial issues. The different strictly clinical points of view (according to their training and background) and the different personal/moral approaches can make counseling a real challenge. The observation of the performance of some CECs by an external observer with skills in communication in the health field has allowed us to highlight different personal perspectives that make it difficult to understand each other on a technical level and to make shared decisions.

We suggest integrating in CECs the Six Thinking Hats technique as a new approach. De Bono's Six Thinking Hats is a powerful technique for looking at decision making from different perspectives. The Six Thinking Hats technique allows professionals to look at a problem in six different ways, beyond any instinctive positions, and to explore a range of perspectives. It involves six distinct types of thinking, each represented by a different hat:

(1) Blue Hat: organization and planning; (2) Green Hat: creative thinking; (3) Red Hat: feelings and instincts; (4) Yellow Hat: benefits and values; (5) Black Hat: risk assessment; (6) White Hat: information gathering.

By "wearing" each of the Six Thinking Hats, everyone in the team can gain a rich understanding of the issues and the best ways forward. It also encourages everyone to be fully involved in the decision-making process.

This new tool will be applied in a pilot study of 10 consultations in the pediatric-neonatological field at "A. Gemelli" Teaching Hospital Rome (Italy), to evaluate the degree of feasibility, reproducibility and effectiveness of this approach, before introducing it routinely in our consultations.

Should Triage Protocols for Intensive Care Resources Allocate Pediatric Resources? Results From a Democratic Deliberation During the COVID-19 Pandemic

Nathalie Gaucher, Naomi Singh, Sonny Dhanani, Marie-Ève Bouthillier, Claudia Calderon Ramirez, and Karell Laporte

During the COVID-19 pandemic, ethical consensus regarding how to allocate pediatric intensive care (PICU) resources (material, human) for adult patients was not reached. The objective of this study was to explore the public perception and values on the use of PICU resources to treat adults during the COVID-19 pandemic in Canada.

A democratic deliberation was held from May to June 2022 with adults from two Canadian provinces (n=47) (none worked in healthcare). Participants were recruited by a "call to participants" that was orchestrated by a competent survey firm from Quebec and Ontario. Participants were compensated \$200 for their two-day participation. They took part in two days of information sessions and deliberations, in English/French, on provincial triage protocols prepared by multidisciplinary teams that included clinical ethicists and clinicians. Participants were asked: how should we allocate PICU resources while protecting the interests of children in the context of the COVID-19 pandemic? Participants completed self-reflective questionnaires and were divided into six groups. Group discussions were audio-recorded and transcribed. Transcripts and answers to the questionnaire were coded independently by two researchers (NS and NG) using thematic content analysis.

Participants' answers were categorised into two themes. Theme 1: Children's resources should be protected. Participants referred to the sanctity of a child's life and to a child's right to be protected, reporting personal experiences with a child's illness, or reflecting on their role as caregiver. In this theme, children were believed to have better prognoses than adults and a long life to live; it was generally based on this premise that they were given priority to resources over adults. Theme 2: PICU resources should be included in allocation strategies when faced with a lack of resources, but only if children will continue to have access to PICU resources. In this case, participants endorsed flexible strategies that sought to maximise resource utilization and save the most lives. It was believed that PICU resources should be shared in case of a surplus or if these were not saturated.

Overall, almost all participants, believed children should receive intensive care when clinically required, and that they should not be excluded from accessing PICU resources.

This study provides insight into how non health care workers in Canada assesses the ethical tension between maximising the use of intensive care resources and protecting the interests of children. Clinical ethicists need to consider how these social values, norms and perceptions, should be considered in the preparation of value-laden protocols addressing the allocation of PICU resources.

Parents' Experiences and Recommendations for Decision-Making Regarding Lumbar Puncture and Hospitalization for Their Febrile Infant

Nathalie Gaucher, Philippe Sylvestre, Paul Aronson, and Brett Burstein

Background: Recent guidelines for the evaluation of febrile young infants recommend shared decision-making (SDM) regarding the need for lumbar puncture (LP) and hospitalization when management options exist. Little guidance exists for clinicians on how to engage with parents in these decisions.

Objective: To explore parents' experiences and recommendations regarding the decision-making process for LP and hospitalization in the context of an ED visit for their febrile infant.

Methods: This qualitative study used semi-directive focus groups with the parents of infants ≤ 60 days evaluated for fever at a pediatric ED between 05/2020-10/2021. Participants were recruited through purposive sampling. The interview guide explored decision-making processes and parents' recommendations regarding LP and hospitalization. A hypothetical scenario asked parents to choose between LP or hospitalization, both being equally safe for their infant. Interviews were conducted in English and transcribed verbatim. The qualitative analysis used thematic analysis following a constructivist approach. Interviews were completed once thematic saturation was achieved. Data was independently coded by 3 members of the research team. Codes were organised into themes and subthemes in 2 steps: (1)

inductive analysis identified parents' preferences and suggestions to engage them in the context of a high-risk febrile infant; (2) two conceptual frameworks for SDM were used to identify themes and subthemes for SDM in the context of low/intermediate-risk infants.

Results: Seven 60-minute focus groups were conducted with 17 parents (15 mothers). Participants reported that decisions regarding LP and hospitalization were taken by the medical teams and that choices should only be made available if considered safe for their child. Participants identified several ways to be engaged in their infant's care in the context of a strong medical recommendation to perform an LP: recognise parents' vulnerability and stressful experience, tailor information to different parents' preferences (use of numbers, degree of detail, use of documents), explain the procedure (indications, risks), instill trust through a supportive and coordinated approach, involve parents in the ED visit. A practical approach to tailoring information to parents' preferences and to supporting them in SDM for LP in low/intermediary risk infants includes learning about the patient, creating choice awareness, tailoring information, describing options, eliciting parental preferences and deliberation.

Conclusions: Our study provides practical tools to engage in decision-making with parents in the care of high and low/intermediary-risk febrile infants in the ED.

Re-Imagining Consultation as Education and Re-Centering the Virtue of Phronesis in Clinical Ethics Practice

MaryKatherine Gaurke and Sirin Yilmaz

The "four-quadrant method" to clinical ethical decision-making (considering medical indications, patient preferences, quality of life judgments, and contextual features) offers a helpful framework for organizing ethical dilemmas that arise in the practice of medicine, sorting out prominent issues to address in approaching a particular decision. However, similar to application of the "four principles" (respect for autonomy, beneficence, non-maleficence, and justice), over reliance on the quadrant method for ethical decision-making runs the risk of oversimplifying or altogether missing less salient features of moral dilemmas that arise in concrete clinical contexts that cannot be captured by the model. Through case study presentations, this paper demonstrates limitations of both the application of principles and the quadrants approach in clinical ethics and argues that clinical ethicists must supplement use of any model with cultivation of the intellectual virtue of phronesis. In centering the cultivation of phronesis, or practical wisdom, as key for navigating ethical decision making, this paper highlights the importance of mentorship, experience in action, and habituation to right disposition in moving the practice of clinical ethics beyond mere application of knowledge to a more enriched, intimately engaged discipline in the medical context capable of adequately addressing the particularities that arise in clinical cases. As such, the authors argue that any clinical ethics education provided through core curriculum or other designated framework must be supplemented by education through immersion in practice with guided, case-based experience and reflection. Furthermore, the authors argue that the field of clinical ethics would benefit from reimagining consultation as education, both for clinical ethicist trainees and other health care professionals engaging in clinical ethics, encouraging practicing clinical ethicists to embrace service as role models demonstrating phronetic practical reasoning in concrete clinical settings.

Training a New Generation of Clinical Ethicists: What Role Do Bioethics Doctoral Programs Play?

Anna Goff and Georgia Loutrianakis

As clinical ethics continues to gain traction as a distinct practice and discipline, a new generation of students are finding the field earlier in their academic training. Despite this, there currently exists no clear path for pursuing a career in clinical ethics. The majority of clinical ethicists currently practicing received their training in other professional fields and either completed a clinical ethics fellowship or otherwise stumbled into their work. One path is emerging, though. Bioethics doctoral programs are increasingly providing students the opportunity to gain a varying amount of experience in clinical ethics well before those students are qualified for most fellowships, which typically require the completion of a terminal degree. As a result, some doctoral students are graduating with significant exposure to and experience with clinical ethics consultation.

Methods: Critical review of clinical ethics content and opportunities in U.S. bioethics doctoral programs and clinical ethics fellowships. In-depth comparison of the clinical ethics content in two distinct U.S. bioethics doctoral programs.

Results: Several different clinical ethics exposure routes exist for bioethics doctoral students: (1) no clinical ethics exposure; (2) theoretical courses, but no practical clinical ethics exposure; (3) theoretical courses and limited observation-based clinical ethics exposure; (4) theoretical courses and substantive observation-based clinical ethics experience; and (5) theoretical courses and participatory clinical ethics experience.

Given the exposure to the clinical ethics environment and the opportunity to abridge the theory-practice gap through observation and practical clinical experience, doctoral students of routes 4 and 5 can be more prepared for professional opportunities in clinical ethics, such as fellowships and entry-level jobs, because their doctoral experience already encompasses many of the qualifications and goals established by these positions.

Discussion/Conclusion: Some doctoral students are receiving extensive, practical clinical ethics experience throughout their doctoral education, many times meeting or exceeding the qualifications of a clinical ethics fellowship. However, doctoral students with an expansive clinical ethics education and/or participatory clinical ethics experience still need complete fellowships that are intentionally designed to accommodate new graduates from a variety of academic disciplines, many of whom have minimal exposure to the practice of clinical ethics consultation. Therefore, it is not evident that a fellowship is essential for all graduates of bioethics doctoral programs.

As the field of clinical ethics continues to professionalize, it is essential to consider the training offered in doctoral programs. We represent a new generation of students who are receiving targeted clinical ethics training prior to the completion of a terminal degree. Our training ought to be factored into discussions about the continually evolving competencies and qualifications of clinical ethicists.

Is the Practice of Collusion Defensible?

Ranitha Govindasamy

Background: Collusion is the practice in Singapore where doctors withhold information on a patient's diagnosis at the request of the patient's family members. Existing literature has focused on understanding collusion – typically relying on a relational view of autonomy which gives prominence to a person's social ties. However, few papers have directly addressed whether the practice is ethically defensible and what the position on collusion ought to be. This presentation considers these questions, which have significant implications on the recommendations provided in clinical ethics consultations in cases of collusion.

Methods/Materials: I contrasted the conceptions of patient autonomy adopted in Singapore and England based on a review of leading medical law cases. I then conducted a scoping review of the existing literature on relational autonomy, which have been utilised to justify the practice of collusion. These perspectives were compared with an individual conception of autonomy. Drawing from both philosophical models of autonomy, I examined the normative justification for collusion, if any.

Results/Discussion: The concept of patient autonomy has been applied differently in Singapore and England: In England, an individual conception of autonomy is recognised as the overriding principle in bioethics. However, Singapore has been hesitant to embrace patient autonomy due to social policies and cultural values which promote family ties. In analysing collusion, a relational rather than individual model of autonomy is to be preferred, as the former recognises that the doctor's role is to enable the patient's agency to be exercised within social relationships. Relational autonomy, however, is not communitarianism, where a person is unable to reconsider their attachment to social relations and shared values because they are so constituted by them. Relational autonomy does not make blanket claims that family involvement is automatically favourable. It provides an objective framework to study relational factors that may promote or inhibit a person's ability to exercise autonomy. Ultimately, the agency and decision-making power of the patient needs to be at the foreground.

Conclusions: A relational autonomy approach only provides an understanding of collusion but not moral justifications for the practice, which inhibits a patient's access to autonomous decision-making and removes the patient as the moral subject at the centre of the consent process. The only basis on which non-disclosure or limited disclosure in collusion might be defended within clinical ethics consultations is where there is an explicit and express waiver of the right to information by the patient.

Family Refusal to Organ Donation Despite Donation Intention: A Retrospective Analysis of the Potential Role of Clinical Ethics Consultation in an Organ Procurement Organization

Alessandra Agnese Grossi, Federico Nicoli, and Mario Picozzi

Introduction: Solid organ transplantation is the gold standard treatment for end stage organ failure, and often the only life-saving option. In Italy, according to data of the Italian National Transplant Center (CNT), 3,887 people received a transplant in 2022. Yet, consistent with international figures, the supply of organs does not meet the demand. Therefore, people remain on the waiting list and sometimes die or later become too sick to benefit from transplantation. Italy has a mixed "opt-in"/"opt-out" system, requiring citizens to manifest their willingness or refusal to donate their organs after death. This choice is recorded in the national donor registry. However, in some circumstances, family

members (FMs) are against organ donation (OD) authorization regardless of the formally registered willingness of the deceased person to do so. As in earlier reports, this poses the ethical challenge of whether or not the FMs' decision should overrule the donation intention. In this study, we analyze a case reported by an organ procurement organization (OPO) in Italy, which faced the challenge of bereaved FMs from Northern Africa refusing to accept their beloved's recorded wish to be an organ donor after death. We aim to determine the contribution of Clinical Ethics Consultation (CEC) in OPOs to resolve such difficult ethical conundrums.

Methods: We used the Circle Method of CEC to analyze the case retrospectively. This Method serves to address the ethical dilemmas posed by clinical cases by answering a set of questions grouped into four areas considering: the person(s) requesting CEC, the actors involved, the reasons underlying the problem, and the ways to offer a solution.

Results: Healthcare professionals were challenged between the need to: respect the deceased person's willingness to donate organs after death, respect the FMs' refusal to OD during an emotionally overwhelming event, consider the benefits of allocating a life-saving resource to patients waiting for transplant, and respect legal regulations. FMs questioned the validity of their beloved one's donation intention, arguing that the limited language proficiency had impaired understanding of the opt-in/opt-out question. Further, FMs stressed that, within their family unit, they were all unfavorable towards OD. Yet, while they had no proof to support their argument, data derived from the CNT confirmed the high refusal rates among Northern African populations, reinforcing the FMs' position.

Discussion: When faced with such difficult ethical challenges, OPOs may benefit from CEC in its ability to improve dialogue between healthcare professionals and bereaved FMs, enable understanding of the ethical issues at stake, and offer ethically valid solutions that guarantee consideration of the different perspectives of the actors involved.

What Psychoanalysis Can Offer Clinical Ethics Consultation

Robert Guerin

Clinical ethics consultation provides guidance for complex medical ethical issues—how to balance risks and benefits, safeguard patient autonomy, promote fair distribution of scarce medical resources—yet their resolution is often delayed from, if not entirely impeded by, intense, though at times unacknowledged, emotion, affect, or passion. It is not uncommon for patients to fail to grasp their disease and its implications for treatment because there is overwhelming anxiety, depression, and despair; it is also commonplace for surrogates to fail to participate in calm, rational medical decision-making because they are overwhelmed with sadness and grief; and, all too often, we find clinicians themselves unable to sit with a patient because the clinical situation is reminiscent of personal historical trauma (death of a mother or father or brother or sister, say). In many cases, these clinical encounters lead to frustration on all sides—clinicians, patients, and families—for clinicians may rashly determine that patients lack capacity for medical decision-making or patients and families may lose trust and, at worst, terminate the therapeutic relationship.

Psychoanalysis offers a method of comprehending and working through these difficult clinical ethical encounters. It considers unconscious processes associated with behavior that impedes a working alliance in the therapeutic relationship—a common trigger for an ethics consultation. And yet, unfortunately, many clinical ethics consultants do not have any training in basic counseling, not to mention psychoanalysis, unlike so many other health professionals and despite a recent survey suggesting that clinical ethics consultants rank interpersonal skills/emotional intelligence as the second most important competency for ethics consultation, just behind knowledge in ethical theory. This presentation addresses this gap in training. It will describe fundamental unconscious processes—transference, countertransference, and defense mechanisms—to shed light on these difficult encounters. It will also provide guidance for further education and training in interpersonal skills/emotional intelligence in ethics consultation: reading suggestions, supervision, and case conferences.

Melding Clinical Ethics Consultation with Clinical Ethics Education in Hospital Settings: A Path Forward

Thomas Harter

Clinical ethics consultants (CECs) functioning within health systems risk being marginalized and, subsequently, underutilized. As noted in the conference topic, this is often for two reasons: either a) because the clinical acumen of CECs is in question or b) because the role or value of CECs toward addressing and helping resolve ethical conflict in clinical practice is unclear to medical providers. In a simplistic way, CECs are questioned because they do not provide direct patient care. When CSCs are understood in this way by medical providers, their function appears purely academic and thus of little apparent value to those who do provide direct patient care. How can CSC address this false perception and demonstrate a balance in their practice as both clinicians and as educators of medical ethics?

This presentation addresses this question by showing how CECs can and should function within health systems to demonstrate their value and engender the trust of medical providers.

I begin by briefly articulating the problem that commonly befall CECs in health systems regarding being marginalized and underutilized. While this problem can be extrapolated to non-hospitals, the presentation will primarily focus on CECs operating within hospitals. I then pivot to the fuller argument that effective CECs do not - and should not - rely merely on their clinical ethics training and how they perform clinical ethics consultations in order to demonstrate their value to medical providers. Instead - as I will argue - CECs must integrate themselves in the day-to-day functions of patient care in order to engender the trust of medical providers. Examples include consistently rounding with multidisciplinary teams, attending patient staffing meetings (often when and where medical providers discuss their most challenging patient cases), and attending other patient care meetings such as surgical morbidity and mortality meetings.

The audience will be engaged to consider other opportunities CECs might utilize to better integrate themselves in clinical care environments. I will conclude with two brief points: 1) that while this methodology for engendering trust might be ideal for CECs, it is not the only method for engendering trust by medical providers and increasing CEC utilization, and 2) the methodology presented here theoretically could be effectively modified to allow for a similar integration even when CECs are functioning off-site using telemedicine.

The Lack and Need of Ethics Support in Home-Based Care

Cecilie Hertzberg, Anna Kari Tolo Heggetsad, and Morten Magelson

This abstract is based on the findings of ethnographic fieldwork in home-based care. We wanted to investigate what ethical challenges exist in home-based care and whether staff receive ethical support in their daily work. In the future, we would like to develop ethical support for home-based care staff based on this data collection. The increasing number of older people worldwide is a challenge for health policy and service development.

In the Global North, policy makers emphasise that people should live at home as long as possible. The patient's home is not adapted for care and the patient may live with a partner or children and staff primarily work alone as "visitors" in the patient's home. To make better use of healthcare resources and improve patient outcomes, Norway and the other Nordic countries have shifted long-term care from institutions to home-based care in municipalities. The number of patients is steadily increasing, patients are discharged earlier and treatment continues at home. In general, it seems that patients who are cared for at home have more needs and are more vulnerable and sicker than before. Hence, home-based care has more responsibilities and therefore more ethical dilemmas.

This study is based on ethnographic fieldwork in home-based care in three municipalities in south-eastern Norway from September 2020 to November 2021. The main researcher conducted participant observations where she accompanied six key informants working in home-based care in their daily work, i.e. entering patients' homes, helping to care for patients, attending meetings and taking breaks. She also conducted interviews with key informants and three managers at the end of each fieldwork.

We found that those working in home-based care did not have any organised ethical support. Only one of the municipalities had a clinical ethics committee, which the key informant did not know they could contact. We found that the work environment had an impact on whether or not they had informal ethical support, i.e. whether they could talk to each other or call when needed if an ethically difficult situation arose with a patient at home. Key informants missed a place where they could discuss ethical challenges. During the interviews, several key informants stated that it was good to talk about ethics. In addition, it is more difficult to organise ethical support groups in home-based care because staff work alone, are often far away from each other and have a tight schedule.

A Casualty of Consultation? When Honoring a Decisionally Incapacitated Patient's Refusal Leads to Clinical Complications

Adira Hulkower and Francesca Thau

In his forward to the book *Cases That Haunt Us*, Dr. Albert R. Jonsen writes that there are two "ineradicable features of moral life" inherent to ethics consultation that are rarely discussed: "the embedding of the moral problem in time and the human crowd that surrounds it." Drawing on Dr. Jonsen's framing, we will present a case and reflect on how the elements of time and the human crowd impacted the outcome. Our patient, Mr. B, was a 45-year-old-man with uncontrolled type 2 diabetes and osteomyelitis who presented with a severely infected left lower extremity and was refusing the recommended below the knee amputation ("BKA"). At the time of his refusal, Mr. B lacked decisional capacity, but was firm in his objection to the procedure. Our ethics consultation team was asked to help navigate Mr.

B's refusal. Among the questions we addressed with Mr. B and with the primary team were: What is the basis for the refusal? Can Mr. B be supported to accept the intervention? Are there alternative interventions? What is Mr. B's prognosis if he does not accept the amputation? If he does? How urgent is this intervention? Though Mr. B was clear in his expressed refusal and provided consistent reasons for it, he was unable to display an appreciation for what it would mean to delay amputation and how this would impact his overall health. When asked if he would want the amputation if the only other choice was death, he was ambivalent. As our team was considering whether it would be ethically justifiable to proceed with amputation over objection, the primary team declared that Mr. B was hemodynamically stable, that discharge was appropriate, noting that discharge would have the added benefit of delaying amputation as per Mr. B's wishes. Assured by the team that Mr. B was stable for discharge and the amputation was not urgent, our team agreed that discharge was ethically permissible. Mr. B was readmitted three weeks later and, because of the delay in amputation, suffered a series of required urgent above the knee amputation and subsequent revisions.

Our talk will look focus on how our consideration of Mr. B's refusal was impacted by the elements of time and the presence (and absence) of the human crowd surrounding Mr. B. We will examine the interaction of the teams with Mr. B, the reception of the initial recommendations made by our team, and the subsequent requests for consultation that we received as Mr. B grew increasingly ill. We will ask whether, in our attempt to honor his preferences, Mr. B's health became a casualty of our consultation process.

Ethical Dilemma: If the Cure Can Become a Game

Roberto Iannone and Vinicio Busacchi

As is known, clinical bioethics is gaining more and more approval and recognition. However, many dilemmas remain open for the bioethicist, not so much as a professional figure, but in his/her relationship with other professional roles, in the characterization of the ways, possibilities and limits of the assistance he/she can offer. Is clinical bioethics part of and "limited" to the exercise of individual ethical counseling? In short, is it "only" a communicative practice? Reflection on this aspect requires a joint reflection (1) on the nature of the relationship that is established in the hospital context, (2) on the reality of the hospital space as a space of relationship, and even (3) on the reality of the hospital bed. What type of bed is the patient bed? The doctor and the "humanist" operator already come into contact with the patient near his/her bed as a "bed of social exchange," as a "bed of dialogue," as a "bed of knowledge," as a "bed of reflection." This "place" is not only used but inhabited; he/she who inhabited it exists there; he/she finds himself/herself in it, lives it, and makes it his/her environment. Because of the disease, his/her openness to the other, his/her Being there (*Dasein*) with the other, in the relationship (*mitsein*), to quote Heidegger, has a character of limit, of particularity. This relationship to the other, to the other from oneself, concerns above all the otherness of the disease as such, the lived otherness, of the illness that "presses," which is rejected or, in any case, accepted with difficulty. The ethical dilemma already arises here, and it arises in all its dramatic complexity: to accept or to refuse? Fight or give up? To respond, to retaliate by questioning its meaning?

Existentialist thought teaches that anguish and chaos are phenomena that invest and derive from the relational problem itself. According to Luigi Pirandello, chaos is a vertigo caused by a mute silence, made not of waiting but of neglect and abandonment, of indifference to the other/by the other. Now, illuminating the values at stake is here as essential as to take cure. It is what gives us back the dignity of the person and transforms the medical-patient relationship and a relationship of assistance into a human and interhuman relationship.

Speaking of game, we take a significant step forward in the proposal to rethink the assistance work of the clinical bioethicist in a creative and constructive sense as an "intervention in a theatrical space." What do we mean when we say "game"? In presenting known etymologies, we appreciate that the English *play* and the German *spielen* refer to a Saxon word *plegan* whose ancient meaning is, precisely: "to guard," "to take care." Furthermore, we know two words that derive from the Greek *pais*: *paideia*, "to educate young people," and *paidia* which means "game." Philosophically developing the significance of these etymological matrices, we could say that the "game" is what is involved in the acts of guarding, caring, educating. Where, therefore, there is a need for existential custody, personal care and education, there is a need for play. Everything the clinical bioethicist does and is comes into play: from his/her personality to his/her sensitivity, from his/her values to his/her ability to feel and identify with the other, from his/her ability to intuitively grasp and understand to his/her ability to explain and direct or advise.

The integration of the hermeneutical perspective appears useful and necessary. It allow us to formulate a perspective of understanding the work of the clinical bioethicist as an intervention not of consultancy assistance but as a path that accompanies the assisted person in an exchange that is work and game of configuration and reconfiguration of meaning, in a path of "existential relationship integrated into the care relationship" which proceeds according to the logic of interpretation and reinterpretation; and which proceeds, of course, with the aim of regaining that design perspective that is proper to man under all conditions.

The ontological foundation of the theater is the actor who plays by identifying with himself/herself in front of aware bystanders. Therefore, the possibility of generating an adequate “theatrical situation” comes into play in the skill of the bioethicist – starting with the procedural imperative given by the first hermeneutic aspect mentioned above: to understand his/her client, what he/she feels, how he/she lives what he/she attributes to it, according to which perspective he/she configures his/her own existence.

What is Theater? The various declinations, in all cultures, of the phenomenon called Theater are rooted in archaic times. The human being faced with the dead body, the totally other that also belongs to us, becomes a creature and leaves room, within himself/herself, for the “god” with whom he/she identifies; god to be ritually ingratiated. In a certain way the Theater always touches something profound and fundamental. It is not only the place of pure and simple representation, free and carefree. We could say that the Theater is the place of perpetual tension between the real and the representational, between danger and possibility, between the threat of imminent death and the possibility opened up as if by the eyes of a child. The Theater is the maximum expression of the possibility of a different, renewed, authentic life.

Communicating Conviction: A Pilot Study of Patient Perspectives on Guidance During Medical Decision Making in the United States

Celie Karel-Bart, Allyn Auslander, and Stuart Kuschner

Introduction: The COVID-19 pandemic has highlighted the difficult task physicians have of balancing the availability of misinformation with respect for patient decision making. The traditional paradigm that pits physician paternalism against patient autonomy may not adequately capture the clinical relationship. The authors hypothesized that most patients would prefer to be presented with guidance as opposed to unopinionated options in a clinical context. No population surveys exist to corroborate this in the United States.

Methods: An online survey was designed (Qualtrics, UT, USA) was distributed using Amazon Mechanical Turk (AMT) to 650 respondents. Demographic data were analyzed using descriptive statistics. Chi square (χ^2) or Fischer’s exact tests were used to analyze differences between proportions. Alpha value was set at 0.001.

Results: 499 surveys met predetermined quality criteria. Most respondents believed their doctor’s insight would be better than their own if they were injured or gravely ill, yet an equal proportion believed they would be able to make a rational, well-informed decision if sick or injured. A significantly higher proportion of respondents preferred guidance from their doctor when making medical decisions compared to being presented with unopinionated information ($p<0.001$). When presented with a mangled finger scenario, most respondents reported that they would elect observation (40.7%) or repair (47.1%) despite the surgeon advocating for amputation. 356 (71.3%) reported that they preferred when the surgeon presented the patient only with the treatment options and abstained from advocating for any one option. However, a direct, final question queried whether respondents preferred unopinionated information versus guidance from their doctor. Interestingly, the proportion of respondents indicating they wanted guidance from their doctor mirrored almost exactly the inverse of the scenario preference (69.1%). We found a consistent association between educational and economic background and affirmative responses across all questions, suggesting particular attention should be paid to patients that are disadvantaged with regard to these demographic factors.

Conclusion: This study soliciting views of nearly 500 individuals provides empirical evidence of the view that the paternalism-autonomy paradigm may not adequately capture the clinical relationship. Most patients consistently indicate that they prefer guidance over unopinionated information, though this may be mitigated by short versus long-term considerations as indicated by our case scenario. This study supports physicians communicating conviction with regard to treatment decisions. These results may help support endeavor towards shared decision making, and away from the harmful paradigm brought about by the false dichotomy of physician paternalism versus patient autonomy.

The Current State of Clinical Ethics in Turkey: “And Miles to Go Before” We Meet Healthcare Professionals’ Enormous Need for Support and Guidance

Mustafa Volkan Kavas and Fatma Özlen

Turkey has gone through structural transformation in healthcare due to marketization for more than two decades. This has brought along increased daily patient circulation, and new forms of working regimes. People’s consumption of healthcare services has multiplied, and time, labor, and money spent for therapeutic services escalated.

Parallel to excessive workload and pace, proper physician-patient communication and collaboration have become harder to sustain. Additionally, due to the emergence of competitive payment models, harmony between physicians

and other healthcare professionals seems to deteriorate. In consequence, while healthcare professionals increasingly perform medical interventions likely to result in ethical problems, they tend to obscure a morally controversial case instead of making an effort to resolve it. They also feel powerless, discontent, incompetent and/or guilty in terms of their professional right-doings. This picture gives an idea of why providing clinical ethics support (CES) to Turkish healthcare professionals is considered crucial today.

In terms of CES, however, Turkey is still at the bottom of the ladder. Although there are a few official and civil bodies supposedly to conduct various forms of CES, they are far from providing adequate services. Apart from some sporadic initiatives, professional support, consultation, guidance and/or training literally do not exist.

Methods and Results: In this study, we aim to summarize and discuss the current state of CES services (CESS) in Turkey. For this purpose, firstly, we examined 41 studies composed of review articles, case reports, and descriptive studies. According to these studies, healthcare professionals face ethical problems in clinical practice; have difficulties in the management of these problems, and need appropriate guidance. Besides, they feel lonely, helpless and/or unequipped in resolving moral conflicts and dilemmas at the workplace. Under the circumstances, we can infer that healthcare professionals either fall short of recognizing ethical dilemmas in clinics, or cannot reflect on the value content of such cases and thus choose the relevant right courses of action.

Secondly, we interviewed 6 bioethicists who have published on clinical ethics and/or provide CES at various institutions in Turkey. We determined that CESS are provided actively in a few institutions with limited resources and poor institutional backup merely in the form of ethics consultation.

Discussion and Conclusion: Based on both the literature and the interviews, we infer that healthcare professionals urgently need CESS in Turkey. We also conclude that institutional mechanisms and health policies should be developed to build and implement CESS as integrated with clinical practices.

Visitor Restrictions in Hospitals During COVID-19: Lessons From the Frontline Through the Lens of a Clinical Ethics Service

Danielle Ko and Rosalind McDougall

Background: In order to reduce the transmission of COVID-19, health care institutions around the world have implemented visitor restriction policies. Although some limitations on visitors (such as fixed visiting hours) are an accepted practice, the extent of the restrictions introduced in the pandemic was unprecedented. As waves of COVID-19 infection continue, visitor restrictions have created ongoing ethical challenges in hospitals particularly in relation to patients at end of life.

Materials: In this presentation, we share insights into the ethics of visitor restrictions, based on our experience as clinical ethicists in a large tertiary hospital in Melbourne, Australia.

Discussion: We outline the ethical challenges that visitor restrictions create for frontline staff, and the moral injury experienced particularly by palliative care teams. We argue that there are a range of ways in which a clinical ethics service can contribute to supporting all staff through policy input, education sessions, and case consultations.

Results: We describe what we have learnt as an ethics unit throughout this experience: specifically the features of an ethically justified visitor restriction policy, and the importance of providing a forum for staff to express their moral distress and increase understanding of the ethical reasoning behind visitor restriction decision-making.

Conclusion: Recognising that staff members are diverse moral agents for whom the impact and distress will be role-dependent and person-dependent is crucial in effectively supporting health professionals to provide care in the context of visitor restrictions.

Adding Value to CECS Through Anarchism

Peter Koch

Clinical ethics consultants are often tasked with navigating cases that involve legal considerations, such as in the application of advance directives or the hierarchy of surrogate decision makers. Guidance on precisely how the law ought to be involved in ethics consultations, however, remains vague. For example, the Core Competencies of American Society of Bioethics and Humanities advises that consultants operate within legal standards, yet it is unclear how this translates to practical considerations when compliance with certain legal standards might conflict with what is ethically advisable. In the following I propose that ethicists are uniquely situated to function as philosophical anarchists when it comes to weighing the law in clinical ethics cases; the mere fact that a law pertains to a case does not imply that a law per se ought to provide overriding or exclusionary reasons for a recommendation. This manner of

weighing the law, I argue, adds important value to the contribution of clinical ethicists, since ethicists represent a perspective that resists giving undue weight to the law while still recognizing potential benefits or consequences of the law. By introducing this perspective into clinical ethics cases, the ethicist can offer an important voice that differs from that of other roles, such as those of risk management or physicians.

The Challenge of Casuistic Reasoning in Moral Case Deliberation on the ICU: A Multiple Case Study

Niek Kok, Cornelia Hoedemaekers, Hans van der Hoeven, Malaika Fuchs, Marieke Zegers, and Jelle van Gurp

Moral case deliberation as a type of clinical ethics support in health care is based in dialogical ethics. Dialogical ethics presumes that moral judgment is best achieved through a dialogue of professionals with varying roles and ethical viewpoints. This dialogical process requires, among other things, that participants show a willingness to temporarily disregard personal prejudices concerning a moral case, in favor of exploring the viewpoint of others. These prejudices are regularly based on casuistic moral reasoning. Moral casuistry is a form of reasoning about a particular clinical case in terms of how it compares in morally relevant ways to analogous cases from practice. Our study aims to accurately assess the use of casuistry during moral case deliberation in adult and pediatric intensive care units (ICUs), and to consider its impact on the deliberation process.

Methods: This was a multiple case study taking place in ICUs in two Dutch hospitals. In total, 25 moral case deliberations about moral issues arising from ICU practice were observed, recorded and transcribed. Additionally, 45 semi-structured interviews were held with participants in 17 cases. Transcripts and interviews were analyzed through discourse analysis and thematic analysis respectively.

Results: In moral case deliberation, ICU professionals tend to casuistically compare present cases to 1) populations or clinical cases from the evidence-based literature (with the challenge to meaningfully combine statistics, prognostic chances, and ethical reasoning); 2) paradigmatic accounts of how a disease develops; 3) patients previously treated with similar problems; 4) hypothetical cases; 5) patient cases appearing in the public domain; 6) cases that went past in professionals' private lives. In the majority of cases, analogies played a substantial and valuable part in reaching moral judgment (the presentation will be larded with examples). However, during interviews afterwards, mostly senior ICU professionals also recounted that analogies were sometimes used strategically as a rhetorical device to effectively argue in favor of prejudices and/or pre-held positions (positions which arose from our data were: therapeutic optimism, therapeutic nihilism, and cost-benefit utilitarianism). If only used rhetorically and superficially, analogies endanger the dialogical inquiry during moral case deliberation.

Conclusions: Focusing on casuistic reasoning in practice shows that there are potential tensions between moral casuistic reasoning and the dialogical ethical underpinnings of moral case deliberation. These tensions require of both facilitators and participants an exigent attunement to casuistic reasoning and a sensitivity to explore and scrutinize analogous cases in order for the latter to be more than colorful window dressing.

On the Meta-Ethical Partiality of Moral Case Deliberation Methods: A Plea for Methodological Pluralism

J.J. Kole

Meta-ethics is the ethical discipline that concentrates on the ontology, epistemology and psychology of morality in general and moral judgement specifically. Clinical ethics is usually associated with practical ethics. It focuses on *normative*-ethical issues and the *methods* available to handle those practical issues in the context of the clinic and healthcare in general. Notwithstanding the distance between meta-ethics and clinical ethics, the former can be of critical value to the latter.

In this presentation, I will show how a meta-ethical analysis sheds light on the assumptions of one moral case deliberation method in particular. This method, briefly, called the core case deliberation method is mainly derived from the Utrecht method for case deliberation, and frequently used in case deliberation on the ward in our university medical center (Nijmegen, The Netherlands) and in our teaching to medical students.

My analysis illustrates the larger claims of this paper that, firstly, case deliberation methods (and consultation methods just as well), can never be meta-ethically neutral; Secondly, that we should critically evaluate the meta-ethical assumptions of the moral case deliberations that we use in the clinic. I argue for both claims.

Due to the *meta-ethical partiality* of case deliberation methods, they will always both articulate and silence certain

aspects of ethical deliberation and reflection. This selective articulation and silencing has both advantages and drawbacks. One consequence that we should draw from this meta-ethical partiality is that we should choose carefully which method we use, and we should embrace methodological pluralism in moral case deliberation.

Clinical Ethics Consultation in Medical Education

Mária Kolesárová

In recent years, the importance of ethics consultation services in clinical practice has become increased, as healthcare professionals are challenged by difficult ethical dilemmas in their everyday work. Counseling provided by clinical ethicists has emerged as a valuable tool for supporting medical decision-making. Future medical doctors should be aware of the possibility to ask for the service. Even if adequate ethics consultation depends on the expertise of the clinical ethicist, medical doctors should possess at least the basic competencies typically required of clinical ethics consultants. Specific skills can be developed through medical education.

This abstract focuses on the importance of medical students' education in clinical ethics consultation. I will discuss the current state of medical education in ethics counseling at the Comenius University School of Medicine in Bratislava (Slovakia). I will present three concrete examples of such training in the medical curriculum. First, students in the 4th and 5th years are offered integrated training in clinical and ethical reasoning at the Medical Education Course carried out in the medical simulation center. Second, the role-plays related to ethical dilemmas that are typically an object of clinical ethics consultation are designed within the Medical Education Course and Medical Ethics Course for the 4th year students. Third, case studies focused on the conflict mediation between the patient and the healthcare professionals are analyzed in small groups at the Medical Ethics Course for the 1st year students. The educational technique of reflective writing is used to advance students' ethical reasoning.

Furthermore, I will emphasize the need to integrate ethics education into theoretical and clinical medical subjects. Future medical doctors should receive more targeted training in medical ethics and ethics consultation. Moreover, the importance of interprofessional education in ethics consultation should be highlighted to prepare healthcare professionals for active communication in ethically complex decision-making.

In conclusion, effective clinical ethics consultation surely contributes to building a healthcare system that improves patients care. Therefore, we need comprehensive and integrated medical ethics education to promote effective clinical ethics consultation.

When Families Can't "Consent to Death:" Reimagining Clinician Responsibility

Andrew Kondrat

Over the past several decades, in a good-faith effort to back away from a medical culture rooted in paternalism, bioethicists have been instrumental in contorting (whether intentionally or not) the meaning of the principle of "respecting patient autonomy" into one synonymous with "doing what patients want." Furthermore, due to bioethics' understandable attempt to protect patients from receiving unwanted and harmful interventions, "patient autonomy" has become seen as the paramount value in medical ethics. As a result of these shifts, clinicians often request clinical ethics consultations because "the patient is dying but the family won't make them DNAR" – which is to say, when patients' loved ones won't "consent" to the reality of a dying process that is inevitable and sometimes already underway. In the process of trying to fulfill this understanding of autonomy for the patient's benefit, clinicians often ironically make matters worse.

To highlight how these bioethical understandings infiltrate and undermine the clinical setting, we provide examples of ethics consultations where clinicians experienced angst as patients began an active dying process and their surrogates demanded non-beneficial interventions (e.g., CPR or IV fluids) and/or "refused" initiation of comfort-oriented interventions (e.g., palliative medicines). In cases like this, clinicians feel they must wait until surrogates consent to the dying process before initiating end-of-life interventions, while surrogates feel pressured by the medical team to "agree to" their loved one's death.

We claim this transfer of responsibility from provider to patient/surrogates for the medical assessment of dying and formation of the ensuing plan of care (a) perpetuates the popular public myth of control over one's dying, (b) forces families to bear the burden of telling clinicians it's okay for the patient to die, and (c) contributes to clinicians' feelings of helplessness, moral distress, and burnout. Having already reimagined patient autonomy (and not for the better), the emerging question is whether bioethics can now reimagine (for the better) clinician responsibility?

Moral Challenges and the Need for Clinical Ethics Support in Tanzanian Hospitals as Perceived by Physicians, Nurses and Hospital Administrators: A Qualitative Study

Shiha Kevin Kuhumba

Moral challenges are an inseparable part of daily clinical practice in the healthcare setting. In the hospital setting, ethical challenges contribute to the complexity of decision-making for healthcare professionals while striving to fulfill both their practical obligation of treating patients and their moral obligation of caring and attending to patients. The consequences of unresolved moral conflicts have affected both patients and healthcare professionals. For patients, unresolved moral challenges may lead to a distrust of the healthcare system including the healthcare professionals. Failing to resolve a moral conflict may leave healthcare professionals with moral distress. Clinical ethics committees support healthcare professionals, patients, relatives, family members and community members by addressing moral challenges.

Despite numerous studies on moral challenges encountered in hospitals, relatively a few studies have been conducted in low-income countries. The focus of attention in this study is moral challenges encountered in government hospitals in Tanzania as perceived by physicians, nurses and hospital administrators. Hitherto relatively few studies have been conducted about the need of establishing clinical ethics committees in Tanzania. This study will employ qualitative research methods. Data will be collected from two government hospitals namely Muhimbili National Hospital and Mbeya Zonal Referral Hospital.

In-depth interview method will be used during data collection because the study is explorative in nature. The respondents will be healthcare professionals (nurses and physicians), and hospital administrators. Thematic analysis approach as proposed by Braun and Clarke will be used in analyzing data. Ethical approval from NSD (the Norwegian Centre for Research Data) has been granted, and I will seek ethical approvals from the National Health Research Ethics Committee in Tanzania (NATHREC), the Independent Review Boards of the selected hospitals, and from the University of Dar es Salaam.

What Role Can Clinical Ethics Play in Preventive Screening Programs? A Proposal for Shared Decision Making

Alexandra Larocque and Nathalie Gaucher

Systematic screening programs that target the general (asymptomatic) population have become commonplace over the past 20 years. Their effectiveness in preventing death by cancer is now well established. However, despite the many benefits of these preventive programs, many consequences can derive from them. In this presentation, we will question the role that clinical ethics can play in improving the discussion surrounding screening. To do so, we will use the case of screening mammograms for breast cancer, which are generally recommended every two years for women aged 50 and over. While the benefits are usually widely discussed, it seems that the risks of screening are much less so.

However, stats show that women are more likely to suffer consequences (false positives, unnecessary biopsies, over-diagnoses, etc.) from screening in the 25 years during which they will undergo mammograms than to be saved by it. To us, this constitutes a hermeneutical injustice, which is a type of injustice caused by the fact a person does not have the resources to understand a given situation or their own experience. Putting forward a shared decision-making approach could prevent this injustice from recurring by providing these women with the tools to make an informed decision about screening. Our goal here is not to criticize screening: rather, we want to ensure that the discussion prior to screening allows for informed consent, including on the risks and benefits, on the part of the women targeted by these programs.

To this end, we will question the effectiveness of initiatives already in place to promote a comprehensive understanding of the risks and benefits of screening. We will do so by analyzing the existing tools (internet resources, government brochures, phone lines, etc.) and their limitations. We will show that these initiatives are unfortunately not sufficient and that a shared decision-making approach could help resolve some of these issues. We will then investigate the role that clinical ethics can play in achieving a more open and informed conversation. The use of a clinical ethics approach seems to us to be an appropriate way of encompassing all the issues specific to screening, whether in terms of consent, resource allocation or shared decision making.

Public health approaches have failed in the past to consider such problems and have led to incomplete solutions. Clinical ethics, we believe, offers a more comprehensive approach.

Fostering the Quality of Clinical Ethics Committees: Didactic Method for and Results From a Reflective Dialogue Workshop

Berit Hofset Larsen, Carl Tollef Solberg, Reider Pedersen, Morten Magelssen, and Albert Christmann and Molewijk

Clinical ethics support services, such as clinical ethics committees, often deal with critical, complex ethical issues in health care. Their contribution may therefore have huge consequences. Internationally, scholars have conducted various empirical and conceptual studies investigating the quality of different ethics support services. However, there is still a lot to learn about the quality of clinical ethics committees and how to facilitate reflective dialogues about the quality of such committees among its members.

In Norway, there has been a steady growth in the number of clinical ethics committees, especially in hospitals, culminating in the first European legal requirement in 2021 of having at least one active committee in each Norwegian hospital trust. This growth and change of law sparked the need for increased attention on how to strengthen the quality of these committees. At Centre for Medical Ethics at the University of Oslo, we have a national responsibility for follow-up and competence building for the clinical ethics committees. Besides existing guidelines for Norwegian hospital committees, we developed a specific workshop format in which committee members can reflect upon the quality of their committee and how to further improve it. During a national conference for hospital ethics committees, we held a workshop with ten groups, in which we used our format to explore reflections about the quality of clinical ethics committees through the lens of its members.

In our presentation at ICCEC, we will present our workshop format and the results from analyzing written reports from the ten workshop groups. The findings suggest that committee members hold the ideals of discourse ethics within their committee work high on the agenda. Additionally, committee members have relatively high expectations of their own overall efforts to foster quality of clinical ethics support. Simultaneously, they have concerns regarding the time and resources needed to realize these ideals. Moreover, they suggested numerous specific proposed actions to increase the quality, which we believe will be helpful for the way forward in fostering the quality of clinical ethics committees in Norway and internationally. We believe that the methods used in this workshop may serve as a useful didactic tool for others when aiming to stimulate learning and reflection on the quality of ethics support services in general, and clinical ethics committees in particular.

Comparative Observation of the Practice of Ethics Representatives in Pediatrics Between Quebec and France

Fleur Le Bourgeois

Since the COVID 19 pandemic, ethics in healthcare institutions has flourished, and this led to the development of ethical support with diverse and varied modalities of form and functioning. These varieties depend on many factors, including the cultural background of the country in which the ethical support is deployed. The purpose of this work is to compare the practice of pediatric ethics representatives in two French-speaking countries, Québec in Canada, and France. This comparative observation was made by interviewing several ethics representatives practicing in France and Québec.

Ethics representatives, chosen to be interviewed, worked in a pediatric department and had training in ethics of care. The objective of the interview was to understand how ethics was practiced, promoted, and taught by respondents within their healthcare institutions. For Quebec, three people were interviewed, two were ethics consultants with initial nursing training, and one was a pediatrician in the neonatal intensive care unit. All were part of the same hospital's clinical ethics unit. In France, the three representatives interviewed were all pediatricians in intensive care units, two in neonatal and one in pediatric, they worked in three different hospitals and participated in the local ethics committee.

While in Quebec the ethics consultant position is institutionalized, in France, through the various testimonies, it remains discrete and hardly recognized. Institutionalization allows the consultant to obtain a funding for his work and assert legitimacy and recognition of his activity within the hospital. Conversely, absence of institutionalization offers the consultant freedom of action and an absence of accountability to the hospital administration but remains a major barrier to its development. In France, the dissemination of ethics is still difficult according to the representatives, indeed, it remains abstract and impressive. The trust given to the representative starts from the field, if the latter has clinical experience, then healthcare workers will listen to him. For French representants, ethics is mainly a matter of education, helping healthcare workers to recognize the situations which can be difficult because of ethical issues, for some autonomy. Each healthcare worker should have this capacity, however, the institution does not give them the tools to develop this capacity. Although both practices are different, they share a desire to develop ethics and fit the institutional culture.

Experiences of End-of-Life Consultants Under the Korean Law on End-of-Life Care Decisions Act

Ilhak Lee, Sanghee Kim, Younsuck Koh, and Claire Junga Kim

Background: The Law on End-of-Life Care Decisions Act was legislated and implemented since 2018. The law emphasizes the patient's right to self-determination by introducing measures to advance medical directives, proxy decision making and clinical ethics consultation. But there are debates over the limitations of the law and its dissemination among healthcare professionals. The knowledge about the state of end-of-life care regarding to decision making on life-sustaining treatment is necessary to establish to suggest revision of the act as well as to provide practice guidelines.

Methods: Focus group interviews of 2 groups (each group composed of 6 healthcare professionals) were performed with healthcare professionals who provide ethics services at the end-of-life care. The purposes of the interview were as follows: To identify the problems and suggestions for improvement of the current system through a description of long-term experience participating in end-of-life medical decisions. To propose the measures to protect patients' interests and right to self-determination and improvement of quality of death by verifying the concept and appropriateness of 'end-of-life process' and 'terminal patient' (Article 2 of the Life-Sustaining Treatment Act) and clarifying the decision and method of discontinuing life-sustaining treatment. Evaluate the weaknesses and deficiencies of the current end-of-life decision making system, supplement the effectiveness of the current system by adjusting to the characteristics of domestic medical settings.

Results: The experiences of healthcare professionals participating in the decision-making process on life-sustaining treatment are "1) the healthcare providers trying to establish the decision-making process on life-sustaining treatment, 2) difficulties experienced in the decision-making process on life-sustaining treatment: ambiguous legal provisions and limitations due to the scope of the law, 3) efforts to overcome difficulties in order to preserve the purpose of the process, and 4) realistic wishes to guarantee the right to self-determination to be delivered to policy makers" were identified as four themes and 17 sub-themes.

Discussion: The participants complained of the unrealistic definition of 'terminal stage' and 'dying state' of the law as a barrier to timely discussion and decision making. They suggested to simplify the official documents for efficient consultation. The digital transformation to lessen the workload related to registration was suggested. The participants also suggested more earlier discussion about end-of-life care by expanding the application of advance directive scheme. And also the transition of care is identified as crucial to improve the end-of-life decision making.

Informed Consent and Artificial Intelligence in Healthcare

Ilhak Lee, Ji Hyun Yang, Yumi Son, Ekaterina Shipova, and Minsung Kim

Background: Artificial intelligence (AI) has the potential to revolutionize healthcare with numerous applications including pattern recognition in imaging, clinical decision support systems(CDSS), counseling, and process optimization. By identifying overlooked factors, AI can lead to more precise diagnoses and treatment, ultimately improving the quality of care. However, the ethical implementation of AI remains unclear, particularly with regard to determining the standard of care for AI-enabled medical practices. Notably, the opacity of AI raises concerns regarding the potential for a paternalistic doctor-patient relationship.

Methods and Materials: To explore the considerations for the ethical implementation of AI, this study investigates the ideals and values emphasized by the doctor-patient relationship. The study applies these considerations to the requirements of informed consent in current legal regulations and relevant case law. Furthermore, in anticipation of the Korean Personal Information Protection Act introducing regulations comparable to the GDPR's right to an explanation of algorithmic decision-making, it is essential to contemplate as how to interpret informed consent through the lens of this right.

Results: The paternalistic model involves the doctor making decisions without considering the patient's preferences; the deliberative model encourages moral development and provides suggestions on both information and values. According to article 24(2) of the Korean Medical Act stipulates that medical practitioners are obligated to explain surgical procedures or anesthesia that may result in serious harm to a patient's life or body. The Supreme Court has also emphasized that this explanation should allow patients to make informed decisions regarding their medical care in accordance with the prevailing standards of medical practice.

Discussion: In cases where AI-based CDSS is employed to assess the necessity or method of surgery, or where robotic AI systems are utilized to conduct surgical procedures, patients must be provided with information. However, there is ongoing debate regarding the necessity of informed consent for AI-assisted non-invasive procedures such as imaging analysis or counseling chatbots.

Conclusions: This study identifies a basic set of criteria: first, patients must be informed when humans accept the judgment of AI as it is; second, when AI is involved in medical decision-making that poses significant risks to patients, an explanation must be given regarding its use, benefits, risks, and possible alternatives; and lastly, even when the conflicting conclusions reached by the doctor and AI do not relate to serious harm, an explanation must be provided for the basis of the judgment.

A Proposal for the Development of Global Ethics Consultation Training and Certification through ICCEC

Sana Loue and Mark Aulisio

Background: Questions continue to be raised regarding the need to professionalize the practice of and standardize the training for clinical ethics consultation. The American Society for Bioethics and Humanities (ASBH) currently offers the possibility of certification as a clinical ethics consultant following passage of an examination. ASBH certification emphasizes four core domains: assessment, analysis, process, and evaluation and quality improvement. Various institutions, including universities, now offer training programs

Methods: Web-based information relating to various clinical ethics training programs is reviewed for the goals, content, length, and emphasis of the programs.

Results: Clinical ethics training programs are of varying length and depth. Some programs focus specifically on teaching content that prepares professionals to sit for the ASBH examination. Additional training approaches include full-time fellowships and immersion experiences involving shadowing and participation on clinical ethics committees. However, there are a limited number of full-time fellowships and these are not practical mechanisms for individuals already engaged in full-time careers. Web-based programs appear to focus on content knowledge only and do not provide participants with clinical consultation experience. Some cities, including Cleveland, offer multiple clinical ethics consultation fellowship opportunities. The collaborative model adopted by Case Western Reserve University Department of Bioethics and University Hospitals Cleveland Medical Center includes opportunities for shadowing, a fellowship, a team-based approach to review of ethics consultations, and opportunities to enhance content knowledge, but does not provide certification.

Discussion: Training programs should go beyond the provision of content knowledge to include an understanding of diverse values and approaches to consultation. This is particularly critical in view of increasing patient diversity; value conflicts that may occur between healthcare teams, families, patients, and administrators; and legal, administrative, and societal constraints that may constrain potential resolutions. The absence of a more global context for the training programs may hinder consultants' awareness of diverse values and approaches and impact the quality of the consultations.

Conclusion: An international ethics consultation certification program could be developed through a partnership between the International Conference on Clinical Ethics Consultation and a variety of clinical ethics training program internationally, of which Case Western Reserve University is one example. Such a training program would provide participants, including both trainees and faculty, with a broadened understanding of values and approaches critical to effective clinical consultation, as well as enhanced opportunities for research relating to clinical ethics consultation.

Clinical Practicums Make Perfect: The New Face of Bioethics Education

Georgia Loutrianakis, Johnna Wellesley, and Jeffrey Farroni

Background: Practical experience is an important component of bioethics graduate training, especially for students who wish to pursue careers in clinical ethics consultation. Narrowing the theory–practice gap through experiences such as shadowing consultants, clinical rounding, and other patient engagement activities is imperative for a robust training program. Despite this, formal educational opportunities for extended practical experience are less common in graduate bioethics programs. We explore the value of exposure to both a theoretical and practical clinical ethics experience and why it should be required for doctoral bioethics programs.

Methods: Scoping reviews of (a) literature on bioethics and clinical ethics education and (b) literature on professional identity formation in medical education. Critical review of our program's content/structure with conceptual analysis on the value of exposure to clinical ethics practice-based environments.

Results: Our curriculum is a three-class sequence of clinical ethics education which includes one semester of clinical ethics theory and two semesters of clinical practicum. Through the curriculum at our institution, students learn essential skills in empathy, communication, and how to make difficult ethical decisions; integral skills to an ethics education, regardless of a student's career path. Exposure to the clinical environment shapes how students think and re-

spond to ethical conflicts by situating them within diverse populations and settings.

Discussion: Building a clinical ethics structure into graduate bioethics education appears to meet several aims: helping learners to 1) develop an awareness, understanding and appreciation of the complex healthcare environments in which ethical decisions are made; 2) critically assess the pragmatic, legal, social and other constraints on ethical decision-making and practice in the clinical setting; 3) engage with inter- and intra- professional roles, working relationships, objectives, and institutional mores; 4) demonstrate ability to identify and navigate ethical issues; 5) develop practical skills and self-awareness - including interacting appropriately with various health professionals and patients, effective communication, and teaching skills in clinical settings.

Conclusions: Having substantive exposure to theoretical and practical clinical experience is invaluable for the development of empathetic, problem-solving, and judgment skills necessary for clinical ethics consultants. Moreover, it can inform the career path of graduate students, as well as make them more competitive for clinical ethics fellowships. It informs professional identity formation by developing skills beyond knowledge competencies to that of communication, awareness, trustworthiness, connection, and relationship building. A required, extended clinical ethics practicum can enhance a doctoral bioethics education by integrating empathetic, decisional, and reflective skills into the repertoire of every aspiring ethicist.

Meta-Ethics: Ethical Management of Clinical Ethics Consultants' Conflicts of Interest

Janet Malek

Clinical ethicists are consultants to the primary healthcare team. As a result, we rely on members of the healthcare team to request our involvement in clinical cases. This structure can create a conflict of interest for clinical ethics consultants (CECs) who are obligated to provide ethically sound recommendations that, in some cases, the healthcare team might not like or want to follow. While clinicians can always opt to go against a CEC's recommendations, they may worry that doing so puts them in an awkward position in terms of justifying their decision to others. The discomfort clinicians may feel in such situations might make them hesitant to call for an ethics consult in future cases. As a result, CEC's have an interest in managing cases and offering recommendations in ways that healthcare teams find acceptable – an interest that may conflict with sound ethical analysis. Several examples of such conflicts will be described.

Similar tensions may occur at the administrative level when consultants are asked to participate in policy-making efforts or to help resolve organizational ethics issues. Advocating for policies that are in line with current thinking in bioethics can put a CEC on thin ice if the institutional leadership disagrees with the suggested approach. CECs may worry about being excluded from future policy-making processes if they push too strongly for their preferred position. Policy development during the COVID-19 pandemic is offered as an example.

This talk will explore the ethical issues faced by CECs in situations where their own self-interest may be at stake and offer ethical considerations that should be taken into account when working through them. The unique tension CECs navigate when offering recommendations in a context where their future engagement (and, ultimately, employment) is dependent upon the way those recommendations are received has received little attention in the literature and merits further consideration.

Clinical Ethics in Emergencies: EMR Perspectives

Ahmed Mandil

WHO/EMRO encourages clinical research in the Eastern Mediterranean Region (EMR), especially during crises and emergencies (including the recent COVID-19 pandemic), while observing ethical conduct and principles. This is based on using the expertise of current global WHO collaborating centers (WHO-CC) for bioethics-related matters (especially hosted by EMR institutions: Beirut [American University in Beirut Medical Center], Tehran [Tehran University of Medical Sciences], Karachi [Sindh Institute of Urology and Transplantation]), supporting development of a regional WHO-CC network on bioethics and supporting capacity-building activities in ethical conduct of health / clinical research (with special emphasis on introducing clinical ethics in health sciences' curricula in EMR institutions, e.g., medicine, pharmacy, dentistry, nursing, allied health sciences).

Special consideration is also given to conduct capacity-building activities to address the existing gaps in clinical ethics in medical practice and health research in the region. The presentation would expand on these concepts, from regional / national perspectives as it pertains to the EMR.

Interstices in the Male-Female Continuum: The Role of Clinical Ethics Consultation in the Health Management of Intersex Individuals

Emanuele Mangione

An intersex individual is one who was born with chromosomal, gonadal, hormonal, or genital sexual characteristics that do not fit what is typically considered male or female. Intersex, also called disorders, divergence, or differences of sex development, has been increasingly studied in medical settings, and the possibility of surgical sex reassignments for intersex adults and especially for intersex infants has been discussed. However, not much has been written about the role of clinical ethics consultation in the health management of intersex individuals. This paper aims at showing some of the specific contributes that a trained clinical ethics consultant can give to assisting intersex individuals. The main idea is that clinical ethics consultation may help focus more on the real needs of intersex individuals and address the objections that some intersex individuals made against not only the surgical assignment of sex, but also against the gender assignment per se. In order to promote a patient-centered approach that is based on care ethics, a clearer definition of “intersex” is first given, and the ethical issues that it raises are distinguished from those of transsexualism, which has been often confused with intersex. Second, some clinical case reports are analyzed, and the stories of some intersex adults are told in order to show how medical management decisions affected their lives and health. Third, some of the recommendations concerning health management of intersex individuals—especially the Opinion of the German Ethics Council, the Opinion of the Italian National Bioethics Committee, and the International Consensus Conference on Intersex—are discussed, and the role of the clinical ethics consultant in managing intersex cases is strongly considered. It is finally suggested that clinical ethics consultation should be given the due value it deserves since it can help other people, like healthcare professionals, to take ethically grounded decisions that improve the quality of life of intersex individuals and that privilege both the good of the patients and the value of difference over normalizing social expectations.

Clinical Ethics Consultation in Perinatal Hospice

Simone Masilla, Barbara Corsano, Dario Sacchini, and Antonio G. Spagnolo

A Perinatal Hospice is a place where different skills and specialties converge in order to guarantee optimal support to the family and the still unborn child, following a prenatal diagnosis with an unfortunate “quoad vitam” prognosis (i.e., end-life condition and/or life-limiting condition). However, a perinatal hospice is not just a place, but above all an approach to the patient characterized by interdisciplinarity, a shared medicine that speaks of a relational model of care and assistance, based on listening and accepting. This last characteristic makes hospices the place par excellence where the nascent life is respected in all its fragility and vulnerability. The accompaniment path are calibrated on the needs of the unborn child and the family, thus making perinatal hospices a place of hope rather than a place of death. The continuous search for the best assistance strategies opens up new care and assistance perspectives for diagnoses that were considered incompatible with extrauterine life until a few years ago.

In this context of professionals coming from different specialties, a connecting figure may be useful: a figure who could stimulate, integrate and support the reflections of each specialist, placing them at the service of the good of the assisted families. Thus, the clinical ethics consultant gains a very specific value within the multidisciplinary team. Starting from a contextual analysis, and reaching an interdisciplinary evaluation, the consultant facilitates the Perinatal Hospice team and the family in the complex work of shared treatment planning: this will occur by examining the therapeutic perspectives and the ethical principles involved in each of the possible scenarios, in order to safeguard the good of the unborn children and their families. This paper will illustrate the specific experience of the clinical ethics consultant within the multidisciplinary perinatal hospice team “Mother Teresa of Calcutta” operating within the Fondazione Policlinico Universitario “A. Gemelli” IRCCS, in Rome.

Artificial Intelligence, Shared Decision Making, and the Role of the Clinical Ethicist

Michael McCarthy

Clinical ethics consultants can serve as intermediaries for Artificial Intelligence (AI) technologies in patient care by facilitating discussions around ethical concerns that arise between patients and healthcare professions that center on privacy, trust, and intelligibility. Over the past decade, advances have continued to be made in the development and implementation of AI in healthcare with the potential to generate more precise diagnoses, personalized medicine, and predictive outcomes. These innovations create the possibility of more objective care for patients rooted in large amounts of data-driven conclusions. However, alongside these innovations have emerged ethical considerations about both the design and implementation of the technology. These ethical concerns raise questions about patient-privacy and data-security, trust between patient and healthcare professional, and the importance of ensuring the patient under-

stands how particular diagnosis or treatment options are generated. While upstream recommendations are important to ensure the ethical design of AI technologies for healthcare that work against embedding biases, it is increasingly important that ethical frameworks are in place for implementing technology designed to improve patient care should questions arise.

This presentation argues that ethics consultants are situated to facilitate a shared decision-making that enhances the informed consent process for patients and assists the medical team in articulating whether the use of AI technology presents options in the best interest of the patient. Part one of the presentation will describe innovations aimed at using AI to offer better diagnostic and personalized medicine. Part II raises ethical concerns that emerge for patients and healthcare providers about privacy, intelligibility, and responsibility in clinical decision-making. Part III focuses on the role of the clinical ethicist as a person who can identify the ethical issues raised on behalf of the patient and clinical team through a shared decision-making process that fosters the informed consent of the patient and facilitates recommendations made in the patient's best interest.

Exploring New Areas: Could Ethics Consulting Make Sense in High Performance Sports?

Ladina Meier-Ruge and Rouven Porz

In this presentation, we ask the question of whether ethics counseling can be helpful - not only in health care - but also in other areas of our lives. We focus this question on Swiss top-class sports, more precisely, on the context of the winter sport biathlon. In Swiss top-class sport, after numerous publicized cases of physical and psychological abuse, there is a call for new and binding ethical guidelines. Thus, top-level sport and ethics is currently a broad and important topic, but neither the sports federations nor the athletes themselves have a professional knowledge of ethics or the possibility of reaching out for ethical counseling (if needed).

In order to explore this new area, we chose the perspective of the top athletes themselves and conducted qualitative interviews with them about the meaning of their daily sporting life. The presenting author is among this community as she is a biathlon top athlete herself. Questions about meaning and identity then led to ethical dimensions wherein interesting implications emerge: Top-class sport is in itself a physical and psychological crossing of boundaries. Accordingly, the risk of ethical boundary transgressions is omnipresent. Thus, we methodologically and epistemologically argue for a comparison of elite sport and elite medicine to demonstrate whether and how ethical support can be best developed in either field.

Anticipatory Role of Clinical Ethics: A Feasible and Viable Proposal?

Irene Melamed

At the beginning of the pandemic and during its course, numerous professionals in the context of Clinical Ethics were specially called to offer their opinion as well as to propose recommendations for difficult decisions. Many of the situations that required them were crossed with urgency, emergency, uncertainty and also with some improvisation. Concerns about autonomy, privacy, equity, fairness, proportionality, and trust suddenly arose, as well as questions regarding: the maintenance or improvement of quality of life through relief of symptoms, pain, and suffering, avoidance of harm to the patient in the course of care and/or providing relief and support near time of death.

Another main concern - not sufficiently explicit and/or made visible partly due to the harshness of its potential realization - was related to the allocation of scarce resources. Although Bioethics has a long history in resource allocation, such as organs for transplantation, this type of prioritization is sometimes reserved for war situations. In this sense, was the recent pandemic marked by these characteristics, which made it a source of even greater pain and suffering?

The underlying question is whether the professionals belonging to the area of Clinical Ethics sufficiently qualified and trained to provide alternative solutions and responses to those difficult decisions. Perhaps somewhat irregularly and from different voices, the question that arose, not without some discomfort, was to whether adequate prior planning and the development of resilient health systems could have partly prevented Clinical Ethics from being subjected to such stress in the decision-making and, to the pressure and demand that, if present, does not always guarantee the best answers as well as the expected results.

The pandemic has undoubtedly left us with lessons learned and, among them, that Clinical Ethics must promote responsibly and through its knowledge its early incorporation into decision-making in the arena of Public Health and in that of public policies. The importance of its place at the patient's bedside is hardly subject for discussion today; however, on repeated occasions, the ethical consultation is perceived as a court that judges or audits. Reviewing the responsibility that falls to Clinical Ethics - in association with that perception - represents an essential task, as well as building capacities in the anticipatory and preventive role of Clinical Ethics. For this, it will be fruitful to dedicate

time and effort to promoting this purpose, especially focused on producing scientific evidence in the field.

An Educational Intervention With “Therapeutic” Benefits for Chairpersons of Clinical Ethics Committees in Singapore

Sumytra Menon, Chan Mei Yoke, and Kumudhini Rajasegaran

Every hospital in Singapore must establish a Clinical Ethics Committee (CEC) to encourage and promote ethical care and treatment of patients, and to review and advise on ethical problems involving care and treatment. Recent legislative changes have placed greater responsibilities on CECs, including mandatory review of certain treatments, such as in-house manufactured cell, tissue and gene therapy products used for innovative salvage therapy, and deep brain stimulation for unapproved, non-established or novel indications. This precipitated a request from the CEC chairpersons for a structured and formal educational programme in healthcare ethics and law. To meet their needs, we developed a programme exclusively for the CEC chairpersons, with the title Certificate in Healthcare Ethics & Law (CHEL). It was held synchronously over Zoom and consisted of 11 two-hour sessions, with the final session being held in-person, where we simulated a CEC meeting so the chairpersons could review a case and interview the primary clinician and patient. This presentation will highlight the development of CHEL, including topic selection and the comparative research conducted on similar educational programmes. Instead of using theoretical cases for discussion during the sessions, we asked the CEC chairpersons to present suitably anonymised past cases, and we found this injected a much needed dose of reality and relevancy. It promoted interactive discussion, and offered “therapeutic” benefits to the CEC chairpersons who developed a sense of camaraderie when empathising with each other on the challenges faced in their role. Furthermore, this platform offered the CEC chairpersons insights into the different processes adopted by each CEC when reviewing cases. This afforded an opportunity to reflect on standardisation of review processes and consistency of decision-making across the CECs in Singapore. The feedback from CHEL will inform and shape future plans for extending the programme to CEC Deputy Chairpersons.

When the Request to Die Unsettles Medicine: What Clinical Ethics Consultations Can Teach Us in France?

Valérie Mesnage and Perrine Galmiche

In France, the laws concerning end-of-life care aim to improve the conditions in which patients are cared for at the end of their life and the way end-of-life decisions are taken in a medical environment: they promote collegiality, tools to enable patients' will to be considered, and the prohibition of futility. The latest law voted in 2016 also introduces a right to continuous deep sedation until death. This has been described as a French exception because it is the first time this medical practice is considered as a patient's right as well as compulsory in situations where life-sustaining treatments are withdrawn, either on explicit patient request or on a medical decision if the patient has become unable to express his will, to avoid unreasonable obstinacy.

The risk for moral discomfort in the former situations has been pointed out abroad, notably because it creates ambiguity between “relieving and letting die” and “causing death”. In our clinical ethics consultation activity, we observe that continuous deep sedation particularly arouses ethical unease among health professionals when it is the patient who requests continuous deep sedation when they ask for a withdrawal of life-sustaining treatments which will lead to their short-term death. The porosity between continuous deep sedation and euthanasia, illegal in France, is here most unsettling because accepting this request, for a physician, blurs the line between having the intention to relieve possible symptoms at the end of life and answering a request to die. The increase in the number of continuous deep sedation in countries that have legally authorized active assistance in dying can thus be questioned and interpreted as different ways of responding to the same request to be accompanied to die. It could be a choice left to the patient or, conversely, it could reflect the influence of health professionals to favor continuous deep sedation in these situations, whether in the name of moral values or for pragmatic reasons.

Clinical ethics can help explore these questions, which persist regardless of the legislative background: what are patients' expectations of medicine at the end of their lives? What would be their criteria of choice within the different end-of-life medical practices? How do health professionals view these different practices? How does the legislative background influence the responses?

The presentation will be an opportunity to discuss a clinical ethics study's framework: which patients to see? Which professionals? In which hospital departments? In which countries?

What We Talk About When We Talk About Priority Setting at the Bedside

Ingrid Miljeteig

Background: The use of resources and the concerns for scarcity of staff and beds are increasingly a theme coming up in reflection groups, case discussions and in requests for ethics consultations in our hospital. Not providing or fearing to not be able to provide the recommended and best treatment for patients is stressful, and requests from politicians or leaders to save resources might lead to frustration and dissatisfaction among health care providers. The aim for this paper is to explore what health care providers talk about when they talk about priority setting in their clinical work.

Method: Content analysis.

Results: Three major themes were found: conceptual confusion, simplification of complex value trade-offs and the perception that it is “the other ones that need to say no, not me”. While priority setting implies denying patients or patient groups potential beneficial treatment to use the resources elsewhere, many talked about priority setting as a synonym to stop wasting resources or reducing diagnostics and treatment with no documented effect. This led to misunderstandings and disagreement with initiatives to change practice. Fair distribution of scarce resources depends on both legitimate processes and weighting of conflicting values and principles, though many talked about how priority setting dilemmas were concentrated on discussions on how to limit potential noise among stakeholders. Finally, a common response was to present the challenges of scarce resources, overtreatment, or unfair distribution as someone else’s responsibility. It could be the referral physicians referring the wrong patients, politicians not saying no to fund treatment without effect, the hospital leaders, the colleague who overtreat patients or the nurses pointing at the physicians being reluctant to say no to demanding next of kin.

Discussion: With restricted health care budgets, increasing numbers of elderly patients with complex health care needs and challenges of recruiting and keeping qualified staff in many countries, the need to set priorities in health care will increase. Health care providers are important stakeholders in these tough decisions and moral distress might increase. Our roles as clinical ethics support services should contribute to capacity building in distributional justice and fair priority setting processes among staff, facilitate discussions and analysis of value trade-offs in priority dilemmas, as well as support health care providers who must say no to treatment they would have preferred to give their patients.

Conclusion: Clinical ethics support services can contribute to ensure fair priority setting processes directly or indirectly through capacity building among health care providers and hospital leaders.

Narrative Ethics

Martha Montello

Narrative ethics provides an innovative method for conceptualizing, teaching, and practicing clinical ethics. Competence with narratives—the ability to recognize, evaluate, and resolve moral issues in stories—is fundamental to the ethical practice of medicine. Where philosophic, legal, and religious approaches use rational analysis for examining ethical issues in clinical medicine, a narrative approach to ethics uses the methodologies of the humanities, particularly literature, to examine the human, lived experience of moral problems. Privileging patients’ and providers’ individual, unique stories, this methodology emphasizes the importance of particularity, contingency, voice, context, and time to examine moral problems. Narrative ethics aims to develop skills in careful listening and critical thinking that enhance providers’ abilities to understand and resolve complex moral issues with patients, families, and colleagues.

Clinical Ethics Support at a New Women’s and Children’s Hospital in the Middle East: Challenges and Opportunities

Franco Moscuzza

Sidra Medicine is a new Women's and Children's Hospital in Doha, Qatar which opened to inpatient work in January 2018. As a practising physician at the hospital I was involved in setting up and am the current Chair of Sidra Medicine's Clinical Ethics Committee. I previously worked at a London teaching hospital and was Chair of the Hospital Clinical Ethics Committee as well as sitting on the Board of Trustees of the UK Clinical Ethics Network.

Although the guiding principles of Islamic Medical Ethics are in many respects similar to the Four Principles approach described by Beauchamp and Childress, the clinical application of ethical principles is influenced by significant religious, cultural and legal differences. This is particularly seen in clinical situations involving Best Interests decision-making, non-escalation or withdrawal of Life Sustaining Treatments and the management of Palliative Care patients.

In this talk I present a brief overview of Islamic clinical ethics and compare this to the Four Principles of biomedical ethics. Using clinical examples I examine the legal, cultural and religious influences which affect ethical decision-making at a new Women and Children's Hospital in an Islamic country.

AI and the Need for Justification to the Patient

Anantharaman Muralidharan

The norm of shared decision making in medical care presupposes that treatment decisions ought to be justifiable to the patient. Medical decisions are justifiable to the patient only if they are compatible with the patient's values and preferences and the patient is able to see that this is so. Patient-directed justifiability is threatened by Black-box AIs because the lack of rationale provided for the decision makes it difficult for patients to ascertain whether there is adequate fit between the decision and the patient's values. This paper argues that existing paradigms of Interpretable, Explainable and Value-flexible AI are inadequate in helping patients bridge the gap between their medical decisions and values. We propose a new paradigm, Justifiable AI, that aims at accomplishing just this task. Justifiability, we claim, is concerned with answering the question of "Why is this decision correct?" Justifiable AI aims at modelling normative and evaluative considerations in an explicit way so as to provide a stepping stone for patient and physician to jointly decide on a course of treatment. Given the specification of justifiability, we argue that only some post-hoc models might potentially be Justifiable AIs. Thus, we should prefer these justifiable models over alternatives if the former are available and aim to develop said models if not.

A Systematic Review of the Approach of CESSs Advising on Emergent Decisions for Patients in Healthcare

Katherine Murdoch

Background: CESSs (clinical ethics support services) have a broad and developing but loosely defined role, which may include policy input, education, and case consultation. The latter is established for when there is time for deliberation. Less appears to be known about what their role is – and should be – regarding urgent decision-making. The pandemic has heightened our awareness of difficult time-critical decision-making and the need for morally defensible decision-making in healthcare is evident at all hours of the day. This systematic review aims to gather the current evidence for the approach of CESS (phenomenon of interest) to advising on urgent decisions for patients (population) in healthcare (context).

Method: A total of 176 journal articles were initially identified by searches on PUBMED, JSTOR and PROQUEST. Grey literature was identified using internet sources, conference proceedings via SCOPUS and EMBASE. After screening and applying the eligibility criteria, 8 journal articles (5 opinion articles, 3 observational studies), 2 guidelines and 1 committee proposal were included.

Results: The favoured approach of CESS advising on urgent issues was a rapid response team (64% of records, n=6). This approach uses a smaller subgroup of a committee to respond to an urgent request albeit with a variation in time frame for response. A further two records combined the rapid response approach with other approaches, including education of the clinical team, guidelines, escalating within the team to the senior clinician and an expectation that the doctor should develop ethical reasoning skills to achieve resolution. One record discussed the doctor resolving the issue and escalating within their team for advice. Finally, another record used this approach alongside guidelines and ethics education.

Conclusion: There is currently a lack of evidence with included papers being of low evidence quality. However, the outputs which were identified indicated a majority position that the small group model is favoured. However, issues were raised about feasibility of this model, variable response time and the robustness of decision-making. In some cases, this was combined with other approaches, including education of the clinical team, guidelines, escalating within the team and that the doctor should have ethical reasoning skills to resolve the issue.

Ethics Support in Prenatal Genetic Diagnostics: From Ad Hoc Moral Case Deliberation to the Structured Development of Morisprudence

Anke J.M. Oerlemans, Ilse Feenstra, Esther Sikkels, and Jelle L.P. van Gurp

Background: Growing technical developments in prenatal testing have increased options to detect fetal health issues – through imaging, genetic testing, or both. If a fetus is diagnosed with a (possible) condition, its prospective parents

may request a pregnancy termination. Prenatal genetic diagnostics and subsequent interventions involve the collaboration of different types of healthcare professionals from two different fields: clinical genetics and obstetrics & gynecology. While some are predominantly involved in counseling and diagnostic testing, others are solely involved if the pregnancy is terminated.

At Radboud university medical center, ethics support is available for healthcare professionals facing an ethical issue. Before May 2020, professionals involved in prenatal diagnostics could request an ad-hoc moral case deliberation. In May 2020, a new ethics support structure was introduced for requests for prenatal diagnostics raising ethical questions. A fixed, multidisciplinary group of professionals, led by an ethicist, convened regularly to decide on these morally complex cases, using a structured format for case preparation and reporting. This implementation project aimed to explore the impact of this new ethics support structure on the process and contents of decision-making.

Methods/Materials: For this explorative evaluation, the following sources were used: Content analysis of reports of cases discussed before and after implementation; qualitative study among professionals involved, focusing on views and experiences regarding ethics support; field notes by ethicists facilitating the deliberations.

Results: Between May 2020-March 2023, 30 cases were discussed. Central themes in the case reports related to the genetic aberration and associated condition (e.g. age of onset, severity, treatability), the fetus (e.g. moral status, expected quality of life), and parents and their family (e.g. autonomy, resilience).

The new structure contributed to mutual understanding of each other's practices and accompanying dilemmas, resulting in thorough case discussions and improved collaboration between the two departments.

This project aimed to actively build *morisprudence* by presenting and reporting on cases in a structured manner. For each new case, a comparison was made with previous decisions in order to explore the relevant nuances of a case; this *casuistry* enhanced decision-making.

Discussion: The systematic manner of deliberating on cases of prenatal genetic diagnostics with a fixed, multidisciplinary group of professionals in this project led to a more balanced, thorough and *morisprudence*-based ethics support practice. A few open questions remain: a fixed group certainly builds expertise, but what about group bias? What should be the role of the ethicist – merely facilitating or actively engaging in discussion?

Healthcare Professionals' Experiences of Implementing Ethics Case Reflection Rounds in Childhood Cancer Care

Pernilla Pergert and Cecilia Bartholdson

Background: Ethics case reflections rounds can be offered to support the team in handling ethical dilemmas and reflecting on what should be done in treatment and care. A training program in facilitating ethics case reflections rounds has been offered to healthcare professionals in childhood cancer care by a Nordic working group on ethics. During/after the training, the trainees implemented and facilitated ethics case reflections rounds in their clinical setting. The aim of this study was to explore the trainees' experiences of implementing ethics case reflections rounds in childhood cancer care.

Methods: Healthcare professionals, who participated as trainees in the facilitator program, participated in 3 focus group interviews (n=22 from Denmark, Finland, Iceland, Norway, and Sweden) and 27 individual interviews (n=17 from all childhood cancer care centres in Sweden). Interview data were analysed concurrently with data collection following classic grounded theory methodology.

Results Positioning ethics is the core in this study, used to resolve the main concern of doing ethics. Positioning ethics is done in a context where direct patient care is prioritized. Being able to take time for activities that are not the prioritized activities, but still necessary, are considered a luxury. Positioning ethics is about establishing a position of ethics in the clinical setting. Strategies for positioning ethics include promoting ethics, scheduling ethics, inviting key stakeholders, and identifying dilemmas. These strategies can vary in intensity and be more or less successful. While positioning ethics, allying is necessary and is done with co-facilitators and key actors, including the management.

Discussion: This study highlights the need of positioning ethics in care, enabling healthcare professionals in doing ethics, and also explaining actions for doing so. Since clinical ethics support will impact the patient care, the healthcare managers need to ally with and provide support to healthcare professionals as they are positioning ethics. It is not surprising that direct patient care is prioritised in this context. However, ethics should be integrated in clinical practise as part of patient care.

Conclusions: The challenging situation in healthcare with shortage of staff and time is widely recognised, and even more so during the pandemic. However, ethical dilemmas still need to be handled for healthcare professionals to know what should be done. Strategies for positioning ethics could be used not only to implement but also to integrate

ethics in clinical practice.

Evaluating a Clinical Ethics Committee Implementation Process in an Oncological Research Hospital: Results from a Process Evaluation Study Using Normalization Process Theory

Marta Perin, Chiara Crico, Luca Ghirotto, and Ludovica De Panfilis

Introduction: The Clinical Ethics Committee of the Local Health Authority of Reggio Emilia (Italy) is an experimental, multi-professional service established in 2020 with the aim to support healthcare professionals in dealing with the ethical issues of clinical practice. To contribute to the debate on the evaluation research of ethical case interventions, we evaluated the integration of the Clinical Ethics Committee into routine practice following a 24 months period.

Methods: It is a multi-method process evaluation embedded within a mixed-method study with a retrospective quantitative analysis and a prospective qualitative evaluation. We collected quantitative data from the service's internal databases, a closed-ended survey with healthcare professionals employed at the healthcare facility, and semi-structured interviews with healthcare professionals who were differently involved with the service implementation. We analyzed quantitative data descriptively. The Normalization Process Theory's concepts (coherence, cognitive participation, collective action, and reflexive monitoring), which explain the mechanisms that shape the implementation process and its outcomes, guided the qualitative evaluation.

Results: The study is ongoing. Preliminary quantitative results showed that in 24 months the three standard functions of an ethics consultation service had been fulfilled (7 ethics consultations received, 1 ethical course provided, and 3 ethical policies developed). Notably, the volume of ethics consultation requests is in line with international standards. Between June 2022 and January 2023, 20 participants were interviewed (12 members of the service, 5 physicians who required an ethics consultation, and 3 stakeholders who formally supported the intervention). The analysis revealed that all the participants consider the service as a supportive tool for healthcare professionals and a great opportunity to 'not be left alone' in complex situations (coherence). The CEC's President, a bioethicist working at the same healthcare facility, facilitated the engagement of the participants (cognitive participation). Main barriers to the service implementation regarded external and internal factors, namely financial sustainability, lack of common education among the service's components and absence of in-person relationship (collective action). Overall, participants reported a positive experience with the service, and several recommended modifications emerged through the analysis (reflexive monitoring). We will integrate our findings with data from the closed-ended survey among healthcare professionals to understand knowledge, usage, and perception of the service. Final results will be presented during the congress.

Conclusions: Our findings can inform the development of practical strategies to enable and support the delivery of clinical ethics committees in clinical settings and the development of appropriate outcomes for their further evaluation.

Medical Assistance in Dying: Pragmatic Ethics Research on Support Structures in Canada

Catherine Perron, Marie-Ève Bouthillier, and Eric Racine

Background: Medical assistance in dying in the form of euthanasia was introduced in Quebec (Canada) in December 2015. Interdisciplinary support groups were developed with the mandate to support those involved in the administrative, clinical, legal and ethical practices of medical assistance in dying. Little research has been done on support structures for euthanasia around the world.

Aim: Our objective is to present the main results of a study in clinical ethics aiming to describe the current practices of Interdisciplinary support groups, to compare them to equivalent structures in the world, to make a critical analysis and to submit recommendations aiming at the valorisation of practices judged as promising.

Design/participants: Our methodology is based on pragmatic ethics, John Dewey's theory of inquiry. We used a mixed-methods, multi-phase research design: 1) a survey among health care practitioners involved in medical assistance in dying (N=245), 2) individual interviews with coordinators of each Interdisciplinary support group (N=59) and 3) seven focus groups with members of Interdisciplinary support groups (N=35).

Results: At the end of our analysis, 30 practices and nine sub-practices were identified as promising for Interdisciplinary support groups. These included partnership, communication and collaboration among these groups and with palliative care. Training of professionals, mentoring and networking were also identified as practices to be formalized. Communication and information to the public must be improved.

Interdisciplinary support groups stand out from other national and international support structures because of their interdisciplinarity, decentralization and proximity. However, few people involved in medical assistance in dying are aware of these groups and their support services. To date, there is no publicly available telephone line or internet site with accurate and complete information that has been validated by the regulatory authorities. This situation raises real ethical and communication issues.

Conclusion: In 2022, Quebec was the state in the world where the most medical assistance in dying per capita were administered. We argue for the relevance of studying the support offered to those who assist. We argue that the ethical analysis of Interdisciplinary support groups allows these support structures to overcome their difficulties, ensure their sustainability as well as the protection and growth of their agents.

How to Improve the Quality of Clinical Ethics Services: The Ethics Quality Improvement Approach

Angel Petropanagos, Jill Oliver, and Paula Chidwick

Over the years, our team of ethicists in the Ethics Quality Improvement Lab at William Osler Health System in Ontario Canada has supported thousands of clinical ethics consultations for physicians, staff, patients, families, and healthcare organizations. We have observed common, recurring ethical issues and identified potentially avoidable factors contributing to these challenges. We have asked: Is there a way to prevent these ethical challenges from occurring in the first place? And how do we know if our clinical ethics consultation services are helping to improve ethical decision making? In response, we have developed and incorporated into our ethics consultation services, an upstream approach, called Ethics Quality Improvement (EQI).

EQI is an innovative and effective way to address ethical challenges and improve the quality of ethics consultation services in healthcare organizations. It differs from traditional ethics consultation approaches by utilizing quality improvement tools and the principles of adaptive leadership and change management to facilitate sustainable changes to human and organizational thinking and behaviours. As an approach, EQI is about helping people to think and act differently, and in alignment with their ethical obligations.

The development and implementation of ethics quality improvement projects (EQIPs), which is an Accreditation Canada Leading Practice, is an important part of EQI. Our EQIPs prioritize person-centered care and recognize the challenges of change, by involving stakeholders in co-designing solutions to ethical challenges. For example, the Prevention of Error-based Transfers Project (PoET), the Checklist to meet Ethical and Legal Obligations (ChELO) project, and Alternate Level of Care (ALC) project, each exemplify these principles by prioritizing patient wishes, values, and beliefs, addressing stakeholder reactions and beliefs, and involving patients, families, staff, and physicians in the development process. These EQIPs include aim statements and the tracking of outcome, process, and balancing measures to evaluate the effectiveness of upstream interventions that support ethical decision-making. EQIPs help to reduce harms by preventing ethical issues and provide a framework for evaluating the effectiveness and quality of ethics consultation services and supports.

In this presentation, we introduce the concept of ethics quality improvement, share key learnings related to adaptive leadership principles, change management methodologies, and quality improvement tools. We also describe our award-winning EQIPs and show how they support upstream changes that reduce ethical errors and minimize potential harms. We maintain that the EQI approach offers an innovative and effective way to address ethical challenges and improve the quality of clinical ethics services.

Friendship Is Not the Answer for Unbefriended Patients: A New Approach to Clinical Ethics Consultation

Bryan Pilkington

Patients who need, but lack, surrogate decision makers are sometimes referred to as “unbefriended patients.” Without an advanced care directive, healthcare proxy, or another mechanism to aid in ascertaining the patient’s values, a patient may be left without someone to support the realization of those values. Unbefriended patients raise a challenge for clinical ethics consultation (CEC) precisely because their values are unknown. This challenge is not, when properly understood, ethical in nature, but rather epistemological: if the patient’s values and situation-specific wishes are known, the challenge dissipates.

To address the epistemological challenge, I argue, seemingly paradoxically, that what unbefriended patients need is not a friend, but a change within CEC practice from relation-focused to information-building decision making. “Relation-focused” describes practices which seek decision makers; that is, other agents, as determiners of what is

best for a patient who cannot speak for herself. Surrogate decision-makers are the ideal response to this challenge in terms of advocacy for this approach because they can “speak for” the patient, articulating her values and applying them to the current situation. “Information-building” describes practices which seek information about a patient in order to have an account of what is best for her, from her – that is, an articulation of her values – and aim to build a picture of that patient as a person that is sufficiently rich to allow for an application of her values to the current situation.

I argue that the information-building approach is superior because it successfully addresses the epistemological challenge in cases of unbefriended patients. I then extend this analysis, arguing that reflection on these situations offers lessons for CEC practice more broadly. Though my approach requires more of CEC consultants, it is not overly burdensome, as it only asks them to embody to a greater degree virtues they already put into practice: those of an investigator or detective.

Clinical Ethics and Speech Language Pathology: The Need for Teamwork to Support Communication and Reduce Bias

Bryan Pilkington and Kathy Nagle

The importance of communication is well supported within the clinical ethics literature, but less focused on are issues associated with what is sometimes called “accented” speech. Practices associated with the modification of a speaker’s accent to enhance communicative intelligibility in a non-primary language raise significant ethical questions about bias for communication-focused healthcare workers, such as Speech Language Pathologists (SLPs), as well as for advocates of vulnerable populations in areas with diverse linguistic practices. These questions arise due, in part, to the socio-cultural context in which SLPs, physicians, and health advocates practice and their clients live, as well as the relational nature of communication. In this presentation, we argue that clinical ethics, as a field, and clinical ethics consultants in their practices, ought to advocate for more just linguistic interactions. Although, due to the ambiguity inherent in accent modification practices, SLPs and advocates must weigh a variety of considerations before determining in what contexts and under what circumstances such services are professionally acceptable, clinical ethics need not. Clinical ethicists are thus, and often, well placed within hospitals and health systems to advocate for more just understandings and practices of communication – both between healthcare workers and patients, but also among healthcare workers themselves. Our argument is rooted in consideration of the complex nature of the ethical terrain related to communication. After surveying potentially relevant models from other healthcare professions and finding them wanting, we support our position in light of the current evidence-based assessments of the non-pathological nature of speech variation, as well as the literature on communication, in particular the lack of consensus around accounts of functionality. We conclude by offering anti-bias recommendations for clinical ethicists to consider advocating for, by encouraging greater collaboration between clinical ethicists and SLPs, and by describing the normative ethical implications of our account, which include shifting the burden from the speaker alone to a shared burden between speaker and listener.

Brain Death: Controversies, Changes, and Strategies in Canada, USA, and UK

Thaddeus Pope

Brain death (or death by neurological criteria) has been accepted as legal death in most countries on Earth for decades. The traditional rule has been that clinicians have no duty to administer treatment once an individual has been determined dead – even if requested by the family. But over just the past five years, a growing number of hospital and court cases have challenged traditional brain death rules in Canada, the United States, and the United Kingdom.

For the past two years, both quasi-governmental and professional society determination of death reform efforts have been underway in both the United States and Canada. In addition to being a prolific author and presenter on these issues, for the past several years, the author has served or is serving as a consultant to these reform efforts. And he has been a keen observer of developments in the United Kingdom. Experience over the past few years highlights that Canada, the United States, and the United Kingdom (among other jurisdictions) face similar ethical questions concerning brain death. These include: Do clinicians need family consent to administer the apnea test or other determination of death testing? May clinicians administer this testing over family objections?

At the completion of this ICCEC session, participants will be able: (1) to identify five ethical and legal problems driving legal and guideline reform. (2) They will be able to articulate ethical and professional duties when, due to religious, cultural, or other reasons, families object to either determination or declaration of death. (3) They will be able to compare strategies for diffusing conflict with families over determinations of brain death.

This highly visual presentation offers clinical ethics consultants an efficient, up-to-date primer on developments con-

cerning determination of death by neurologic criteria (brain death). First, it summarizes leading ethical and legal questions. Second, it summarizes the leading responses from recent and ongoing major reform efforts. This highly visual presentation offers clinical ethics consultants an efficient, up-to-date primer on developments concerning determination of death by neurologic criteria (brain death). First, it summarizes leading ethical and legal questions. Second, it summarizes the leading responses from recent and ongoing major reform efforts.

Top Ten Things Clinical Ethicists Need to Know About VSED

Thaddeus Pope

Across Europe, Australasia, North America, and beyond; medical aid in dying rightly gets significant attention from policymakers, academics, and advocates. But even in countries with broad eligibility for medical aid in dying and euthanasia, many interested patients cannot qualify. So, patients are increasingly turning to other end-of-life options like Voluntary Stopping Eating and Drinking (VSED). They are hastening their death from dehydration by refusing food and fluids. Clinical ethics consultants must be prepared for this growing wave of VSED cases. The presenter has conducted a comprehensive literature review on VSED, including over 100 peer-reviewed articles, over 40 webinars, and over 50 personal interviews with foremost experts in palliative medicine, law, and ethics. The presenter is co-editor and author of the most comprehensive book on VSED's clinical, legal, and ethics aspects. And the presenter has helped draft institutional policies and procedures for both hospices and hospital systems.

This presentation summarizes a vast and growing literature on VSED, so that clinical ethics consultant participants can efficiently become better equipped to handle these cases. Across Europe, North America, Japan, and beyond; more patients are using VSED and VSED advance directives. But as recently observed in the BMJ and other publications, clinicians have few or no guidelines from regulators or professional societies on whether, when, or how to honor such requests. Therefore, clinical ethics consultants must address individual cases and must develop institutional policies and procedures without such guidance. This presentation summarizes a vast literature to efficiently offer a baseline foundation of rules and principles for whether, when, and how to honor requests for VSED and requests for VSED through advance directives. More seriously ill patients are turning to VSED to hasten their death to avoid what they find intolerable circumstances like late-stage dementia. This presentation helps equip clinical ethics consultants both to develop institutional policies and to guide clinicians and patients.

Clinical Ethics Consultation Services as a Support for Treatment Limitation Decisions at End of Life

Bernardita Portales and Karen Goset

Background: Treatment limitation decisions include withdrawing or withholding certain life support treatments while reinforcing palliative care procedures and respecting the patient's values, wishes, and preferences. These are complex decisions with an impact on the patient, professionals and caregivers, because they allow but do not induce the patient's death. Clinical ethics consultations at Clínica Alemana de Santiago (Chile), established in 2008, initially sought to assist physicians at the Critical Patients Unit in their complex decisions. This service is currently available for all hospitalization units at this institution. Our goal is to describe the role of the clinical ethics consultation service for decision-making of treatment limitation at the end-of-life.

Methodology: this quantitative, non-experimental, retrospective, cross-sectional, and descriptive study included 116 clinical ethic consultation reports stored in the clinical records of 110 patients with an end-stage disease hospitalized at Clínica Alemana between January 2015 and December 2019. The variables analyzed were reasons for requesting clinical ethics consultation, recommendation of treatment limitations, death after limitations, and characteristics of the patients for whom these limitations were recommended.

Results: The main reasons for requesting clinical ethics consultation were confirming or deciding the indication of treatment limitations (40 cases, 34.5%), doubts regarding therapeutic proportionality (31 cases, 26.7%), anticipation of actions (15 cases, 12.9%), and treatment refusal (4 cases, 3.4%). Moreover, in 12 reports (10.3%), the reasons for the request were not specified, 6 requests (5.1%) were made as a follow-up measure, and 8 (6.9%) were performed for other reasons. Treatment limitation had been previously decided in 24 clinical ethics consultations and was determined as a result of consultation in 77 patients. 54 of these 77 patients' deaths occurred in a hospitalization unit a few days after the treatment limitation decision. The other 23 patients were moved to their homes or to other institutions. Clinical ethics consultation was, therefore, a positive support for these decisions. Treatment limitation was advised for male and female patients of all ages and belonging to a range of diagnostic groups: neurological (n=25), oncological (n=16), cardiopulmonary (n=15), neonatal (n=9), and other (n=12).

Discussion: clinical ethics consultation was a source of strong support for professionals and patients' families with

complex decisions regarding withholding or withdrawing disproportionate treatments for patients with an end-stage condition. This choice, based in the principle of beneficence and in the criteria of therapeutic proportionality, was pursued to maximize patients' welfare and prevent suffering.

Blind Spots Reconsidered: Expanding Feminist Approaches in Clinical Ethics

Rouvan Porz, Anna-Henrikje Seidlein, Marie-Christine Fritzsche, and Helen Kohlen

Clinical ethics has now arrived as a sub-discipline of medical ethics in many hospitals and institutions of the healthcare context in our western world. In the meantime, there is, so to speak, an established knowledge and procedure of how to 'work' in clinical ethics, also how to properly 'conduct' ethical case discussions. According to this mode of work, the current pursuit of quality development within Ethics and the goal of creating more evidence for clinical ethics support, very often, more and more facts and figures are collected to provide information about the so-called 'quality' of the clinical ethics support system within the respective institutions. However, in our perception, there are some interesting epistemological gaps here, because feminist theories are far too little represented in the established knowledge and evaluation of clinical ethics as a discipline. This becomes paradigmatically clear when ethical decision-making is usually only reduced to the four bioethical principles. We believe that this creates epistemic blind spots, e.g., concerning power structures, vulnerability, context and relations. We are convinced that expanding the knowledge of feminist approaches and consequently integrating them can lead to methods that broaden the scope of ethical case discussions. And we think that the clinical ethicist's attitude is far too little researched and analyzed. Again, self-reflective preconceptions of feminist ethics could serve as a correction here.

In this talk, we would like to show that it can be worthwhile for the discipline of clinical ethics to acquire more knowledge in the field of feminist theories, to combine these with existing theories and to develop methods from this for everyday clinical practice, e.g., to conduct ethical case discussions. Furthermore, we would like to show that feminist approaches are helpful to reflect upon the attitude of the clinical ethicist. We consider this an important connection to the topic of 'quality,' because the development of quality must not only be expressed in figures, but also in new concepts

We use an experience-based example, namely a case discussion to show the added value of feminist approaches in knowledge. Finally, we plead for a systematic examination of approaches of feminist ethics in clinical ethics consultation and their integration into existing models based on evidence from theoretical research, qualitative and quantitative studies as well as self-experiences.

The Current Scenario of Clinical Ethics in Italy

Costanza Raimondi, Antonio G. Spagnolo, and Pietro Refolo

Background: Only a few observational studies have been conducted in Italy to assess the need for ethics support perceived by healthcare professionals. All studies were limited by the restricted geographical area they were investigating, thus making it impossible to make claims about the overall situation in the country.

Aim: We sought to gain a broader and more comprehensive understanding of the need perceived by healthcare institutions and facilities by administering a questionnaire to all ALS (Local Health Authority), private IRCCS, and hospices throughout Italy.

Methods: We prepared a questionnaire, comprising both close-ended and open-ended questions. A total of 18 questions investigated the body of reference for ethical dilemmas' discussion and resolution, composition of such body, methodology and procedures used, formation initiatives offered to healthcare professionals, compliance with Law 219/2017 both in terms of organization and of training, and suggestions on how to improve, if any improvement was needed. Out of our original list of 435 facilities, 380 of them received our questionnaire and 90 of them responded (22.5%). We conducted a descriptive analysis of the data collected.

Results: Results show a great fragmentation in all the three settings investigated: for the majority of respondents, there is not one clear body of reference, and there are no standardized procedures to refer to. On the other hand, the great majority of them also declared interest and need for training initiatives and the establishment of dedicated services to face such dilemmas. End-of-life is not the only area marked by ethically challenging situations: our survey reported that a variety of areas are perceived to be ethically challenging, such as intensive care unit, oncology, pediatrics, neurology and general medicine, to name the most cited.

Conclusion: Our results confirm the need in Italy to formalize and establish services that can take care of the ethical aspects of medicine within the medical settings, from consultation to formation, in order to provide a better quality of care to patients and a better quality of work to healthcare professionals.

Consultative Hospital Ethics: How Legislation Shapes the Evolution

Kumudhini Rajasegaran, Chan Mei Yoke, and Sumytra Menon

Hospital Clinical Ethics Committees (CEC) vary in their structure, composition, governance and overall function depending on the context in which they are utilised, be it as a consultative service and/ or for education or research purposes. Using 2 cases with different outcomes and highlighting the evolution that CECs in Singapore have made, we hope to illustrate the need for consistency and continued dialogue with policy makers and other institutional ethics committees as healthcare continually advances and evolves.

Case 1: A term baby girl was born well following an uneventful pregnancy and soon after developed recurrent apnoeic episodes necessitating intubation. After investigations, the diagnosis of Congenital Central Hypoventilation Syndrome or Ondine's curse was made. This autonomic nervous system dysfunction has no definitive cure and results in cessation of breathing during sleep requiring mechanical ventilation for life, through a tracheostomy. Parents, who are doctors, requested for withdrawal of care. CEC was consulted, and the decision was that it was not ethical to agree to parents' request. Senior members of the committee met with the parents after the decision was made, to speak to the parents about the decision and the way forward.

Case 2: A 3-week-old term baby girl was noted to have multiple dysmorphic features with concerns of airway narrowing soon after birth. Diagnosis of Pfeiffer syndrome Type III was confirmed by genetic testing. She was intubated because of severe bilateral choanal stenosis typical of the syndrome. Multiple surgical procedures would be required throughout her childhood to correct her deformities and prevent increased intracranial pressure. However, guarded neurodevelopmental outcomes and shorter life expectancy due to respiratory and neurological complications, are expected. Parents requested for terminal extubation. CEC was consulted and 2 senior members met with the parents prior to the decision. The subsequent decision was that it was ethical to accede to parents' request for comfort care.

Discussion will focus on how the conduct of clinical consults by CECs in Singapore have evolved from a directive to a more consultative form. Singapore's new Healthcare Services Act 2020 has afforded CECs within local institutions the responsibility of deliberating specified cases with the outcome to be adhered to by the applicant who will be liable if a recommendation made is not followed through. This is in stark contrast to a previous advisory role.

Patient Information Journey: Patient Perspectives on Information and Education About Rectal Cancer Surgery

An Ravelingien, Luc Harlet, Simon Desnouck, Brecht Verbrugghe, and Paul Pattyn

Background: Person-centred healthcare respects patients' perspectives and expertise and invites patients and their loved ones to participate in their health care actively. Current thinking in medical ethics steers towards this participatory ideal. However, in practice, there are still many hurdles and difficulties to overcome. The paradigm requires at minimum that patients are provided with appropriate information and are able to apply that information to their own situation and needs. There remains a need for rigorous research on optimal methods and timing for patient education. This is even more so when it comes to complex and chronic care.

Methods: We conducted qualitative research with oncological patients (n = 8) who recently underwent (ultra-) low anterior resection surgery from February 2020 to May 2022. The semi-structured interviews focused on their patient information journeys. The aim was to have a deeper understanding of the patients' experiences and information needs throughout their long and complex medical journey (encompassing screening, diagnosis, oncology treatment, surgery and follow-up). We were interested in evaluating the different educational tools they had received and identifying best practices. Approval of the ethics committee of our hospital was obtained.

Results: As we know from prior empirical research, information preferences are influenced by various aspects that are unique to individuals, including their social context, (health) literacy, personality, and goals. This was also the case for our participants. Nonetheless, these interviews drew attention to the basics of communication. All interviewees emphasized the importance of personal contact with the caregivers involved, verbal explanations, and clarifications through images and the show-me method. In all, the participants appreciated the extra information, but the focus was on their personal relationships with caregivers and the extent to which they trusted them.

Conclusions: Many innovative formats are now available to ensure patients receive all appropriate information in an accessible manner. While these efforts are important and appreciated, this research complements other studies that re-emphasize the importance of some 'basics' in communication. When confronted with complex decisions, it seems that the patient provider relationship is all the more, rather than less, at the heart of effective education.

The Repertoire of Core Competencies of the Clinical Ethics Consultant in the Light of the European Qualification Framework: A Focus on Soft and Transversal Skills

Francesca Reato

Background: The process of professionalization of the Clinical Ethics Consultant, to be fully realized, requires the public recognition of the Qualification. In 2008 the European Qualifications Framework (EQF) for lifelong learning was created to allow European citizens to have their training paths and life and work experiences recognised throughout the community. The countries that have joined the EQF have had to adopt their own national system: highlighting the clear connection to the 8 reference levels indicated in the framework for each qualification; describing the learning outcomes through knowledge, skills, autonomy and responsibility for each qualification; including also the transversal and soft skills in the descriptions.

Methods/Materials: Thus, it was started of a building process of the Clinical Ethics Consultant's repertoire of competencies, focusing on transversal and soft skills. According to the criteria mentioned by the EQF (revised in 2017), the transversal and soft skills have been identified and the learning outcomes described, using the structure of the Italian National Qualifications Framework.

Results and Discussion: In the Core Competencies bibliographical sources we note "interpersonal skills," "personal characteristics," "behaviors," or "aptitude characteristics" that can be summarized as follows: the Clinical Ethics Consultant is considered a mediator, a facilitator, and a coach, who actively listens and has the responsibility to represent the opinions of stakeholders, encouraging communication and the clarification of concerns. In situations of emotional distress, the consultant offers support by showing tolerance, compassion, and empathy. Consultants lead the entire process and promote the resolution of uncertainties and moral conflicts through critical evaluation and the construction of an ethically based solution. Consultants play an active role in decision making, identifying the key decision makers and involving them in discussions, helping individuals to critically analyze the values behind decisions and possible consequences. Further, consultants act with a reflexive attitude, have knowledge of themselves, recognize their own limits and the conflicts between personal moral opinions and their role, maintaining integrity. The following transversal and soft skills were identified: 1. Leadership; 2. Communication and Interpersonal Relationship; 3. Critical Thinking 4. Problem Solving; 5. Decision Making; 6. Coping With Emotions; 7. Self Awareness.

Conclusion: The Repertoire of Core Competencies, with the clear connection to the EQF and the integration of transversal and soft skills in the educational requirements - that certainly enhance the role of the Clinical Ethics Consultant, is the unique and necessary way to allow, the competent authority, to certify the Qualification.

The Contribution of Medical Anthropology in Clinical Ethics Consultation

Pietro Refolo, Dario Sacchini, Costanza Raimondi, and Antonio G. Spagnolo

Medical Anthropology is an interdisciplinary subfield of anthropology focused on the relationship between health, illness, and culture. It emerged as a formal area of study after World War II, when anthropologists began to formalize the process of applying ethnographic methods and theories to questions of health around the world.

Medical anthropologists use anthropological theories and methods to generate unique insights into how different cultural groups around the world experience, interpret, and respond to questions, such as: How does a particular culture define health or illness? How might a diagnosis or condition be interpreted by different cultures? How are different conditions stigmatized or even celebrated in specific cultural contexts?

We argue that the analysis and resolution of ethical dilemmas in clinical contexts as well as clinical ethics consultation itself might benefit from this young discipline. In particular, Medical Anthropology can help to better understand "human nature," and to identify "good solutions" for people with different cultural backgrounds.

The Quality of Life's Relationships: A New Criterion for Ethical Counselling?

Rossana Ruggiero, Luigi Zucaro, and Stefano Kaczmarek

The model applied in contemporary medicine is based on the concept of healing, and everything that cannot combat the cause of a disease is very much relegated to the background. The experience of palliative care puts care and caring back at the very heart of medicine. Working in that context, and in particular paediatric palliative care, the authors set out an ethical pathway leading to a new concept in quality of life, driven by virtues and ethical values: a palliative approach, compassion, hope and time.

Where the incurable nature of a condition opens the door to treating without healing, the human dimension of the

person, in its fundamental relationships, can once again be seen as the most important consideration. The idea of palliative care in fact represents a desire to focus primarily not on the illness but on the patient and that individual's entire relational life, guaranteeing respect for his or her dignity. Palliative care addresses that patient's essential suffering in the last phase of life. When the end of life is near, a profound relationship is established between caregiver and patient, who together bear the suffering.

Compassion is thus no longer merely suffering 'with' the other person, but 'feeling' and recognising the other person's pain. This also applies in situations where there is a need for the relationship to go beyond the 'verbal,' as in the case of small patients or those no longer able to express themselves. This opens up the possibility of giving a new, deeper and more authentic meaning to the instrument of consent, which is no longer just a mechanism for legal precaution but more an authentic sharing of the clinical pathway, where doctor, patient, and family members navigate these issues side by side. Even the idea of hope, which is often misunderstood today, becomes clearer, providing protection from the risk of disappointments that can arise from a culture where medicine has always been viewed as having an illusory omnipotence.

There is no risk, therefore, of trespassing into a situation where treatment is abandoned, but rather a new perspective of life and time: no longer an inexorable taking-away of life (*khronos*), but instead a perfect opportunity to enhance life through relationships (*kairos*). Ultimately, the authors are proposing a redefinition of the quality-of-life criterion based on the idea of relationships: the quality of a life's relationships, as opposed to individual isolation and the consequent loneliness of the patient, guides therapeutic choices towards a holistic way of providing care for the person and not merely the illness.

What Retains Hospital Workers From Requesting Clinical Ethics Consultations? Results From an Institutional Survey and Its Impact on Clinical Ethics Consultations

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

Background. Clinical ethics consultation (CEC) facilitates value-sensitive decision-making and indicates ways of identifying and managing value conflicts in healthcare. Although CEC is more and more implemented and professionalized, it is not always accessed and utilized when its support could be helpful. Our study aims to investigate the reasons that retain some healthcare professional to request CEC support and explore the impact of this survey on the CEC activity.

Methods. From December 2021 to January 2022, a brief self-administered survey was sent to all healthcare professionals (physician, nurse, psychologist, therapists, social worker, chaplain) working in our academic hospital in Switzerland. Questions focused on the reasons retaining them to request consultations, with predefined items based on the literature. We compared the numbers of CEC requests before and after the survey and its association with participants' socio-demographic data.

Results. Among the 536 participants, 83% had never requested an CEC before. A quarter had already thought about requesting a consultation without actually doing it. The reasons most frequently expressed to not request ethics consultations were the lack of knowledge about its existence (45%), the lack of identification regarding the need of ethical support (26%), not knowing that any professional could request it (16%), the lack of time (4%), not considering CEC could actually provide support (3%) and the fear of colleagues' reprisals (2%). Although three quarters had not received any formal training in clinical ethics, 83% of them were interested in undertaking one. Compared to other categories, physicians were more likely to participate in ethical trainings or request CEC. A greater proportion of nurses considered requesting CEC but never did so. Females were significantly more receptive to receiving ethics training than males, and those in psychiatry were more receptive than those in other departments. Among the 12 months following the survey, ethics consultations increased from a mean of 15 per year to 58 in the year after the survey. Most consultations were requested by the departments of psychiatry (33%) and of medicine (14%), some departments requested CEC for the first time, such as maxillofacial surgery and penitentiary medicine.

Conclusion. A brief survey of hospital workers about access to CEC had a major impact on the number of ethics consultations, suggesting an efficient way of promoting CEC activities in a hospital. The post-pandemic era potentially facilitated the interest in clinical ethics training and offers a unique opportunity to promote CEC.

The Relevance of Standard Operating Procedures (SOPs) in Clinical Ethics Consultation (CEC): The Experience of the CEC Service at the Fondazione Policlinico Universitario "A. Gemelli" IRCCS, Rome (IT)

Dario Sacchini, Barbara Corsano, and Antonio G. Spagnolo

Clinical ethics consultation (CEC) is an expertise aimed at helping patients, their family, health professionals and managers, and other stakeholders involved, in order to solve moral doubts/conflicts that rise in the current clinical practice marked by an unprecedented complexity, and for which the experience and sensitivity of the individual medical doctor may not be enough to address the ethical concerns encountered in the exercise of the profession.

Among the technical aspects that need to be addressed, an issue is represented by the process through which CEC is carried out, i.e. Standard Operating Procedures (SOPs). In fact, the ordered sequence of the phases through which a CEC takes place is a necessary requirement for achieving an adequate CEC.

This paper deals with to contribute to the debate on this topic by illustrating the SOPs utilized by Clinical Ethics Consultation Service carried out by the Research Center for Clinical Bioethics and Medical Humanities of the Università Cattolica del Sacro Cuore for the “A. Gemelli” Teaching Hospital Foundation IRCCS (FPUG) in Rome (Italy).

Ethical Consultation and Ethics Committees: A Support to Educate the System in Times of Crisis

Leopoldo Sandonà

The crisis of resources and perspective that characterizes the entire health system does not spare the function, role, and perspectives of Ethics Committees, especially those for clinical practice, scarcely diffused in the Italian context. In reaction to this crisis, the link between ethical consultation and ethics committees can represent an important educational moment not only for clinical ethics services but for the entire social-welfare system.

If experiences of ethical consultation in Italy are mainly in the context of university structures and polyclinics, it is important to reflect on the possible role of consultation beyond university structures in reference to the territories. In addition to the advantages of this mutual integration well known in the literature, freeing the Committee from the impossibility of intervening in emergencies but at the same time fostering supervision and accompaniment of the ethical consultant who cannot have a totality of skills, some advantages can be: territorial coverage, at a time when the Ethics Committees are centralized; a training function, since the ethical consultant can intervene punctually and "educate" health professionals or ethics committees present in the territories that in subsequent cases will be able to treasure the skills acquired (think of the case of ethics committees present in some residences for the elderly); the development of adequate clinical ethics services in the field of telemedicine and using remote technologies, especially for inaccessible territories or far-from-care complexes (for example, mountain territories); a function of "sentinel" and an indication also for decision-makers with respect to the allocative-welfare needs in the territories, with a view to an ethical rationalization of resources that is not merely quantitative and linear rationing.

For these reasons, the presence of a territorial ethical consultant who can serve different places can represent an interesting networking resource for connecting a system of ethics committees, where institutionally present, as well as via experimental paths in order to arrive at an increasingly widespread presence of ethics in clinical practice. If the question from which the congress starts is "consultation and/or education?" the answer of this intervention is that there can be no consultation that is not also education.

Ethical Challenges Reported by Doctors and Nurses in Norway in the COVID-19 Period 2021 and 2022

Margrethe Schaufel, Elisabeth Schanche, Kristine Husøy Onarheim, Ingeborg Forthun, Karl Ove Hufthammer, Inger Elise Englund, and Ingrid Miljeteig

Background: Though the COVID-19 pandemic led to new and “pandemic-specific” challenges in society as well as within the healthcare system, knowledge on how health care providers respond to new demands and societal concerns can be of high value as most countries are facing an increased pressure on health care resources, aging population with complex medical needs and shortage of qualified staff. We wanted to explore what nurses and doctors in Norway reported, in their own words, as their ethical challenges in two periods of the COVID-19 pandemic: February 2021 and February 2022.

Methods: The study is a cross-sectional, hospital-based survey conducted in the Western health region of Norway (Helse Vest) where nurses and doctors were invited through their work e-mail to participate. Free-text comments about ethical challenges were analysed using Systematic Text Condensation.

Results: In 2021, 249; in 2022, 163 responded to the open-ended question. Providers outlined how many of the challenges were related to various kinds of barriers that hindered them to act as they ethically would have wanted to do. These barriers could be divided into resource barriers, regulatory barriers, system barriers and personal barriers.

They reported not being able to give adequate treatment, care and follow-up to patients primarily due to lack of time, but also lack of space, beds and equipment. Priority-setting dilemmas occurred both linked to overtreatment, transfer of resources and ranking patient needs. The barriers led to compensatory mechanisms, where the healthcare providers stretched themselves thin not to compromise on care, diagnostics, treatment or care. They experienced that the workload expanded at high personal costs and blurred work-home-balance. Some found these compensatory mechanisms unfair and unnecessary. Participants described how new roles of executing guidelines with profound negative impact on both patients and relatives challenged their professional identity.

Conclusions: In a high-income country like Norway, resource scarcity and altered professional tasks during the COVID-19 pandemic caused ethical challenges among healthcare providers. Facing limited resources ahead, there is a need to support healthcare providers to strengthen their moral resilience and develop sustainable professional identities accustomed to resources available and healthcare demands. Ensuring fair priority-setting and being able to provide “adequate” care are key for doctors and nurses, and healthcare leaders should address this in collaboration with their staff to foster resilience. Clinical ethics support can facilitate awareness, skills and knowledge related to fairness concerns, trade-offs of values and strategies to ensure legitimate processes, as well as supporting staff in tough decisions.

Clinical Ethics Sessions as Part of Pulmonologists’ Required Teaching Activities in a University Hospital in Norway

Margrethe Schaufel, Helge Solheim, Frode Lindemark, Liv Ingrid Svela, and Ingrid Miljeteig

Background: From 2017, the doctors at the Department of Thoracic Medicine at Haukeland University Hospital, Norway, invited staff from the hospital’s Section for hospital chaplaincy and ethics to facilitate regular meetings about existential, communicative and ethical challenges. The aim for this study was to explore what they find as their major learning outcomes of the meetings and which of the mandatory learning objectives in ethics and palliation they struggle with the most.

Methods: The training was implemented as part of a palliative care strategy to improve doctors’ competence supporting patients who experienced existential suffering in life-limiting pulmonary diseases, and at the same time build resilience and coping among the doctors facing their patients’ suffering. After an initial period of two years focusing mostly on existential and palliative care challenges, the sessions should then also align with the national mandatory learning objectives in medical ethics for junior doctors in Norway. To become a specialist in pulmonary medicine the doctors must document how they acquired sufficient competence in handling situations like: Treatment limitations – what drives futile treatment? Patient follow-up in case of major psychosocial suffering; The «borderless» patient/relative; Priority settings – what is fair use of time and resources? When the patient wishes to die but has longer life expectancy; When the patient/relative wants treatment that healthcare professionals do not regard appropriate/right/necessary; When the patient/relative does not want to accept the recommended treatment; Forced treatment – when the patient is not competent to consent; Moral distress and resilience.

Results: The meeting format is structured around a case study presented by one of the doctors who has experienced the case ethically, communicatively and/or existentially difficult, followed by a discussion and reflection on the topic in plenary, as well as contributions on ethical theories and models that can be useful for analysing the situation, provided by ethics consultants/members of the Clinical Ethics Committee. While the meeting is organized by the doctors themselves, the ethics consultants collaborate with the presenters of the cases before the meeting to ensure that the focus is on the ethical challenge/learning objectives, creating a safe and inclusive process and to wrap up with references to potential learning outcomes. The monthly meetings are popular with all doctors at the Department, and usually more than 20 persons are attending. Qualitative interviews and a survey are currently ongoing (March 2023), and results will be presented at the ICCEC 2023 conference.

Should Clinical Ethicists Use Direct Quotations in Chart Notes?

Olivia Schuman and Haven Romero

In April 2021, federal rules in the United States implemented the 21st Century Cures Act, enabling patients and their families immediate access to all of their medical records. Due to this, the public now has a view into the observations and reflections made by clinical ethics teams that may have hitherto remained difficult to access. This presentation will discuss some ethical issues this raises for clinical ethicists concerning best practices for documenting conversations in a patient’s medical record. In particular, the focus will be on whether it is appropriate for ethicists to directly quote patients and family members.

Clinical notes by ethicists serve several purposes, among them the opportunity to educate and teach staff about ethical

issues through explicit explanations and through role modeling appropriate attitudes and ways of referring to or talking about the patient. The question of whether and when it is appropriate to quote patients is therefore an important educational opportunity.

Although healthcare professionals often directly quote patients, some scholars argue that directly quoting patients can sometimes serve to express skepticism or derision. They argue that, because quotations seem neutral, they may actually provide a cover for expressing judgmental attitudes about patients that are inappropriate or offensive while maintaining a kind of “plausible deniability.” Some patients may feel, in seeing themselves quoted in certain ways, that they have been treated disrespectfully or had their privacy violated.

Most ethicists write notes in the patient’s chart in order to document, communicate, provide formal analyses, and make recommendations. If chart notes are written with the knowledge that patients and families may access this information immediately, should ethicists change how they write their notes? If so, educational reform may be necessary.

This presentation will offer suggestions for best practices for documentation, including when to avoid direct quotations in an effort to help improve communication, reduce conflict, and prevent potential psychosocial harms. In understanding the recent applications and implications of the 21st Century Cures Act while also assessing the risks and benefits of directly quoting patients, ethicists and clinicians can learn to apply their own conclusions to best suit themselves, their patients, and the individual jurisdiction in which they practice.

Challenges of Implementation Clinical Ethics Consultation: An Experience from Iran

Ehsan Shamsi Gooshki

Background: Clinical ethics consultation is a feature of modern health systems mainly in high-income countries where health systems enjoy an acceptable level of infrastructure. Having this service in health facilities requires various infrastructures including human and financial resources and legal/regulatory requirements. Although medical ethics in Iran has an old history from ancient times, clinical ethics consultation has not been a routine practice in Iranian hospitals until recently. In this paper we will present challenges for implementing a clinical ethics consultation service in Iran.

Method: This paper is the result of a qualitative study based on expert panel discussions among main stakeholders of the field including health care professionals, health policymakers, hospital managers and medical ethicists who work as clinical ethics consultants.

Results: The paper briefly explores the background of the Iranian health system and state of biomedical ethics discourse. Challenges are categorized into 3 main groups: The first category of challenges is related to health policymaking at the macrolevel including the financial, educational, registration, and licensing infrastructures and legal organization of the health care system. The second category of challenges are related to Institutional level (Meso-level) such as clinical relations and environment, the role of forensic medicine specialists, the attitude of admiration, the role of clinical ethics committees and other institutional departments inside hospitals. And finally, challenges which could be attributed to the professional (micro) level including the degree of proficiency of clinical ethics consultants, and the attitude of health care professionals toward clinical ethics consultation.

Discussion: Establishment of clinical ethics consultation services in low and middle-income countries has requirements that are different than those in high-income countries. Although the presence of clinical ethics consultation services in health care facilities is an essential part of providing quality health care, there are various challenges that make such implementation difficult. In this paper we will try to explore such difficulties and challenges and to provide some recommendations for improving clinical ethics consultation services in Iran and an example of middle-income country located in the Middle East region.

Conclusion: The implementation of clinical ethics consultation services in Iranian hospitals faces some challenges and barriers. Despite such challenges, this service could be implemented and enhanced using some strategies and activities.

Clinical Ethics Consultation in Complex Mental Health: Rethinking Our Approach

Linda Sheahan, Louise Campbell, Duncan George, and Edwina Light

Clinical Ethics case consultation uses a structured approach to help clinicians and patients navigate ethical complexity, and decide on the ‘best way forward’ in prospective individual clinical cases. Increasingly, the SESLHD Clinical Ethics Service is involved in case consultation relating to patients with complex mental health backgrounds, and many of the usual clinical ethics tools are found to be substantively lacking in informing best next steps. This paper

outlines how complex mental health consults differ from ‘usual’ clinical ethics case consults, delineates how and where this impacts on the clinical ethics support provided, unpacks the underlying philosophical underpinnings and explores how they influence clinical ethics support, and proposes a way forward in conceptualising how to provide effective clinical ethics case consultation in this complex group.

Should Clinical Ethics Consultations Aim at ‘Putting Themselves out of Business?’

Marta Spranzi, Nicolas Foureur, and Celia du Peuty

The role of ethics consultation in clinical care does not need to be demonstrated anymore. Even in Europe it is still developing and thriving, all the more so after the COVID-19 crisis highlighted the daily dilemmas of medical care. However, its purpose can be conceived in several ways. One common way to conceive and organize it, is to stress its pedagogical role. Clinical ethicists are ethics experts whose role can be taken over by practitioners once they have acquired enough experience and training to deal directly with such dilemmas. One can think for example of making them familiar with the principles of biomedical ethics, and with some general guidelines (e.g., always collect the patient’s and his/her relatives reasons for requesting a procedure, take time to discuss in depth difficult cases in a multi-disciplinary way, etc.). According to this view the purpose of a consultation is to “put itself out of business,” and reach the point where ethics consultants would not be necessary anymore in order to address problems in the ward. Although the consultants might have an indirect pedagogical role, we believe that the consultants as a “third party” will always play an irreplaceable role in dealing with ethics dilemmas in medical care.

Drawing on a few examples from clinical ethics consultation cases, we shall elaborate on the precious role that an impartial third party can play in the most difficult clinical cases: alleviate tensions, allow each party to better understand each other’s reasons, allow participants to distance themselves from the emotional aspects of the disagreement, provide external recognition for each party’s legitimacy, allow each party to make its own position evolve during the in-depth preliminary interviews. A consultation, however, is not a painless process: each party’s position is examined and challenged from every point of view, and what’s more, no reassuring answer is given at the end of the process, since consultants do not claim to be ethics experts. The risk is that the process will be too taxing for the concerned parties to accept the consultation process. This would indeed result in putting a consultation service out of business, but for the wrong reasons!

Back to Normal? The Value and Benefits of Online Ethics Support Services

Margreet Stolper and Janine de Snoo-Trimp

During the Covid-19 pandemic, Clinical Ethics Support Services (CESS) were forced, like many other professions, to search for alternative ways to offer their services. In the Netherlands it resulted in online sessions, especially online Moral Case Deliberation as a common yet new practice. Once the pandemic was over and restrictions were repealed many practices and professionals, as well as CESS, returned to normal routines with face-to-face sessions. ‘Back to normal,’ like it was before the pandemic; assuming that face-to-face meetings are still the best way to offer support. However, there are some advantages in online sessions, such as reduced travel-time and the idea of a low threshold to include all stakeholders involved. Some Clinical Ethics Support staff therefore decided to keep offering online consultations next to the face-to-face sessions. After all, providing online support is existing for a long time. Online therapy is well-known for many years and in the field of education, online or e-learning is a common practice as well.

Considering the fact that Moral Case Deliberation is still offered and organized via online sessions, we wondered if and how this is an acceptable new form of Clinical Ethics Support. Moral Case Deliberation is a special form of CESS, in which a group of professionals jointly reflect upon a moral issue by means of a dialogue, which can contribute to better collaboration, communication and moral learning of its participants. These outcomes are based on meetings in which the participants and facilitator are all physically present in Moral Case Deliberation. Equality, an equal say and a safe environment (to express yourself) are important pillars for dialogue and joint-learning processes. Online sessions, however, put those pillars under tension. Is it feasible to foster an online dialogue and joint reflection among participants? How do you create a safe online learning environment when everyone is physically distant yet visibly close? What are the pros and cons of online sessions of Moral Case Deliberation? Would online Moral Case Deliberation be a suitable and additional form of CESS? Those questions led the research we conducted about online CESS.

With a questionnaire distributed amongst participants and facilitators in online Moral Case Deliberation sessions, and focus group sessions with facilitators of Moral Case Deliberation, we looked into experiences with and the impact of online Moral Case Deliberation. It appeared that there are minimal differences when comparing physical and online Moral Case Deliberation meetings. We concluded that online Moral Case Deliberation can be a useful form of CESS,

yet with some important preconditions.

At the conference, we will reflect upon the theoretical foundations of Moral Case Deliberation and presuppositions of online CESS. We will also present our findings, insights, and conclusions regarding if, when and how, the online form of Moral Case Deliberation can be established as a new form of CESS.

Promoting Psychological Safety in Clinical Ethics Consultation and (or) Ethics Education

Jon Tilburt, Megan Miller, Joan Henriksen, Fred Hafferty, Kevin Whitford, and Ellen Meltzer

BACKGROUND: Psychological Safety, “a belief that one will not be punished or humiliated for speaking up with ideas, questions, concerns, or mistakes” is crucial for high functioning clinical teams, ethics consultation, and ethics education. Yet those social practices differ in their history, culture, and structures. In clinical ethics consultation, volatility, conflict, uncertainty, and complexity unfold daily. Psychological risk is inherent in that work where inter-professional power, thorny interactions, and tense dynamics converge. Psychological unsafety may manifest as silence or avoidance allowing grievances to fester.

In clinical ethics teaching, students and teachers must challenge unpopular or uncomfortable assumptions in the societal issues that arise in the thorny normative questions that arise. But avoiding conflict propagates fiction about the work of clinical ethics. Students deserve true “psychological safety” that allows all to broach differences with collegiality, humility and openness. Diverse faculty must model such risk-taking even when not everyone may “feel safe.” Ironically, to achieve clinical ethics teaching and true psychological safety, trigger avoidance cannot be a goal. Instead, learners and faculty need proactive, supportive structures and resources to navigate inevitable conflict. Learners can be pre-warned about the contentious nature of the issues discussed, but ethics teaching that is diversity-cognizant and conflict-responsive should remain open to annoyance, frustration, and even anger. Such an openness will better prepare learners for their ethically fraught clinical years and their future practice.

METHODS, RESULTS, CONCLUSIONS: In this workshop, 3-4 presenters, comprised of a physician, a hospital chaplain/clinical ethicist, and a social scientist, will devote three presentations to the nuances of applying “psychological safety” to the differing social practices of clinical ethics consultation and education, including a discussion of how simulation may be a nexus where consultation and education meet and provide learners at all levels better preparation for conflict while modeling authentic psychological safety. Then, depending on audience size, we will break into groups, with each faculty member leading a case-based discussion of how to foster the best of psychological safety in clinical ethics consultation and clinical ethics teaching. One table will also be devoted to practicing simulation skills. In brief, concluding remarks, we will bring the larger group back together to share individual group experiences and share resources for future exploration. All presentations will be in English.

Clinical Ethics Consultations in Lithuanian Hospitals: Needs Assessment

Gvidas Urbonas, Eimantas Peičius, Aušra Urbonienė, and Žydrūnė Luneckaitė

Development of ethical decision-making skills in medical education is crucial for the empowerment of medical practitioners to make decisions based on professional values and virtues. While developing Medical Ethics for more than 20 years, a new course Clinical Ethics (1 ETCS) was recently integrated into the curriculum of medical education at the Lithuanian University of Health Sciences, Lithuania. However, besides the ethics education, ethics assistance to doctors when dealing with ethical dilemmas is seen as relevant. In this context, involvement of ethics consultants in ethically complex decision-making is considered beneficial because it facilitates ethically complex decision-making while reducing the stress experienced by professionals due to uncertainty about whether they have done the right thing. In some countries of the European Union, as well as in the United States of America, personal health care professionals are assisted in making ethically complex decisions by clinical ethics specialists. However, the need for clinical ethics consultations has never been investigated in Lithuania. To fill this gap, a pilot anonymous survey was conducted to find out the need for clinical ethics consultations in Lithuania from clinicians’ (including medical doctors, nurses, and administration staff members’) perspective.

A total of 70 health professionals working in hospitals responded to our invitation to participate in an online survey. The results showed that there were no respondents who had never faced ethically challenging situations in their practice while 22.8% of respondents reported as facing such situations often or even constantly. The most relevant situations where ethical consultations would be useful were differing opinions between professional, patient, and relatives (78.6%); provision of “bad news” to the patient and his / her relatives (61.4%); revealing information about medical errors (52.8%); and end-of-life decisions (48.6%). Only 4.2% of respondents reported that they consulted with medical ethics commissions in ethically challenging situations showing that the current system of ethical assistance is not effective. Most respondents solved these issues either within the treatment team (67.1%) or during meetings at the

department (65.7%). It is important to note that the absolute majority (84.2%) of respondents held the position that it would be useful to discuss ethically challenging situations with experts in ethics.

To conclude, the development of clinical ethics consultation systems in Lithuania is in demand from the perspective of health professionals when dealing with patients and families in ethically challenging situations.

Preparation for an Absolute Scarcity Situation During COVID-19 in a Large Academic Hospital in the Netherlands

Rozemarijn van Bruchem-Visser and Suzanne van de Vathorst

In the fall of 2021, a “code black” scenario was looming over the Netherlands. In that scenario, also called “phase 3,” there is an absolute scarcity of ICU beds, thus prompting physicians to select patients who can be treated in the ICU. A direct consequence would be that during phase 3, patients who require ICU care would not be selected for an ICU bed and thus most likely would die. A national protocol was drafted, initially by ethicists, then adjusted with input from medical specialists, and was accepted by many Dutch organizations (medical society, old people association, government). The implementation, however, was left to the individual hospitals.

In the Erasmus Medical Center, the largest academic hospital in the Netherlands, a multidisciplinary group was tasked with the practical preparation for a possible phase 3 scenario. In our presentation we will elaborate on the ethical issues and challenges we encountered during this extensive preparation. These involved amongst others: setting up triage committees (who can we ask), anticipating social unrest (what will happen if people are told they are selected against) and personal threats (to triage staff).

Patient and Family Involvement in Clinical Ethics Support Services: A Dialogue About Shared Moral Reflection

Savannah van Kuppenveld, Janine de Snoo-Trimp, Margreet Stolper, and Bert Molewijk

Background: Patient and family involvement in Clinical Ethics Support services is not a standard practice. A reason could be that these supportive services, such as Moral Case Deliberation, are foremost directed at and used by healthcare professionals who struggle with a moral issue in their practice. At the same time, patient and family participation in healthcare is increasingly emphasized and established as this is considered important in providing high-quality patient-centered care. These developments call for the need to also consider patient and family involvement in Clinical Ethics Support services. Therefore, our project aims to explore why, when, and how to involve patients and family members in Clinical Ethics Support services, such as Moral Case Deliberation.

Methods: In this study we employ a Participatory Action Research approach in which we collaborate closely with two departments at our academic hospital. First, we conducted an interview study among patients, family, healthcare professionals and Clinical Ethics Support staff to explore their experiences with and views on patient and family involvement, including ideals and barriers. Subsequently, the results of the interviews were used to guide pilot sessions where patients and/or family members and healthcare professionals jointly reflect on a moral issue.

Results: We will present and elaborate on the interview findings which entails various themes, such as power dynamics, vulnerability, understanding and epistemic justice. In addition, we will share our first experiences of the pilots with new developed forms of Clinical Ethics Support where patients, family members and healthcare professionals engage in shared moral reflection.

Discussion: At the conference, we will discuss our empirical results and present some of the adjustments we made to our Clinical Ethics Support service. We will also pose questions to the audience related to normative and theoretical viewpoints on Clinical Ethics Support and patient and family involvement. We will conclude with an outlook on tools or adjustments to Clinical Ethics Support services that improve patient and family involvement as well as recommendations for ethics support staff to support them in navigating this additional level of complexity.

Ethical Consultation and Amyotrophic Lateral Sclerosis: An Urgent Matter

Marta Vassallo and Christian Lunetta

The issue of ethical consultation is evidently important in cases of neurodegenerative diseases, in which patients can lose their cognitive ability with the progression of the illness. For these reasons, the case of Amyotrophic Lateral Sclerosis (ALS), a severe adult rapidly progressive degenerative disease involving the motor neurons is especially

important. Ethical consulting in these cases is necessary for many reasons, but perhaps the most evident is linked to the changes that the illness itself, and the patients affected by it, have gone through in the last 10 years. For once, if ten years ago a patient suffering from ALS was only a neurology patient, today the awareness of the necessity of a multidisciplinary team has changed the scenario: as a matter of fact, today ALS patients are followed in their path by multiple specialists creating synergic illness management. In our contribution, we aim to bring the case of a 59-year-old female patient and the progression of her illness to show how much clinical ethics consultation is needed in cases of ALS, and what advantages it can give to the aforementioned multidisciplinary team following ALS patients. Also, an ethical consultant joining an ALS multidisciplinary team should be seen as an asset because of the dialogical nature of this job, and for this reason, he or she could enhance such a team to reach a dialogical beneficial balance for the patient.

The possibility of a clear definition of the clinical ethics consultant in Italy is an urgent matter, and cases like ours greatly enhance this urgency, because it must be an option for the patient to be given assistance also on the ethical side of his or her illness, especially if – as it is the case for ALS – they have to choose whether or not to accept invasive procedures such as a gastrostomy and/or tracheostomy.

Moral Case Deliberation as a Means to Discuss Newly Emerging Technology in the Clinic

Mira Vegter

Whether its data-driven healthcare, AI applications, or wearable technology, healthcare professionals seem to have to deal with innovation on a daily basis. Often these technologies are discussed in terms of their immediate benefit for clinical practice, making disease more predictable and manageable and making care processes more efficient. However, studies show that the use of new technologies often involves a lot more tinkering within a certain practice and often has many unexpected implicit social and ethical consequences. While bioethics, and the ethics of technology and responsible innovation, are domains concerned with the unforeseen negative consequence of newly developed technology, in terms of clinical ethics support we still have very few tools to help healthcare professionals adopt a reflective attitude towards decisions regarding new technologies in patient care. Moral Case Deliberation in a clinical setting might enable clinicians to become more reflective and responsive to innovative issues in patient care. Based on a study of the literature and experience within clinical ethics support, we suggest opportunities for moral case deliberation that takes on these challenges.

We Need More Simulation-Based Training in Clinical Ethics: Where Should We Start?

Katherine Wasson

Simulation-based education is an established evaluation method for assessing clinical skills in healthcare, yet it's seldom used to teach or evaluate ethics consultation skills. In medicine, it is a standard approach to skills acquisition from breaking bad news to surgical techniques. The desired skills are typically identified based on professional standards or educational goals and a basic competency level is determined. The learner practices these skills, is evaluated by a trained evaluator, and receives structured feedback often in real time. This presentation will address the benefits of simulation-based training for clinical ethics in different settings and countries, including identifying specific skills necessary for ethics consultation and providing a more systematic means of quality assessment. As a start, training programs and academic medical centers should develop simulation-based education for clinical ethicists. Trainees already receive instruction on conducting ethics consultation and adding simulation-based education to standardize and enhance their education could improve their skills. Academic medical centers may have simulation facilities which could be used to train their clinical ethicists and expand to others. Approaches and challenges to simulation-based education and strategies for developing it in different settings will be discussed.

Futility and Palliative Approaches in Caring for Persons with Anorexia Nervosa

Anna Westermair, Stella Reiter-Theil, and Manuel Trachsel

Background: Caring for patients with anorexia nervosa is associated with high levels of moral distress among health care professionals. The main moral conflict has been located between applying coercion to prevent serious complications, such as premature death, and accepting treatment refusals. However, empirical evidence on the ethical concerns arising in caring for persons with anorexia nervosa is scarce.

Methods: A decade of systematically structured documentations from one Clinical Ethics Support Service in Switzerland was searched for ethics consultations in the context of anorexia nervosa, yielding 19 documentations (with a

total of 130 participants) pertaining to 14 different patients. These documentations were content analyzed by coding them with a sequential deductive-inductive approach and then interpreting the code system in a case-based manner.

Results: The typical scenario was an intensely pretreated, currently extremely underweight anorexia nervosa patient endangering herself by refusing the proposed treatment, causing health professionals to wonder whether coercion should be applied. In most ethics consultations, concerns surrounding futility were voiced, i.e. unacceptably low chances of success and/or unacceptable benefit/burden ratios of further treatment aiming at weight gain. Discussed options for coping included forgoing the standard goal of weight normalization (curative intent) and instead prioritizing harm reduction and/or relief of suffering (palliative intent). However, health professionals were uncertain whether such palliative approaches might be justified and how they could be implemented.

Discussion: Health professionals' ethical reasoning on caring for severe anorexia nervosa includes concerns about standard approaches to care being futile and thus inappropriate. The ensuing dilemma of being obligated to treat in the face of probable futility may be solved by shifting to palliative approaches to care. However, currently, uncertainty around general justifiability, eligibility criteria, and concrete protocols hinders their adoption.

Conclusion: Developing explicitly palliative approaches to caring for persons with anorexia nervosa may help solve ethical dilemmas in this context.

DYAD-HEC Service Approach

Kevin Whitford, Michael Bannon, Corinne Benzinger, Ellen Case, Beverly Frase, and Ellen Meltzer

This overview of the Dyad method of Healthcare Ethics Consultation (D-HCEC) highlights the complexity of "clinical ethics consultations" and offers an account that predicts better outcomes employing two collaborative consultants compared to those mediated by one person acting as sole Healthcare Ethics Consultant (HCEC). A physician-ethicist is partnered with an allied health ethicist with experience in one of the disciplines of Social Work, Nursing, Chaplaincy, or other relevant professions. Ideally both, but at least one, will have formal graduate-level medical ethics education. Importantly, this model is not hierarchical. The strength of the model is contingent upon the absence of hierarchy and the complementary nature of the D-HCEC dynamic.

The relationship a Clinical Ethics Team has with the patient, family and care team determines how the clinical ethics team can evaluate and provide full analysis of the case. The physician component of the team offers the clinical team confidence in the clinical understanding by the Ethics Team of the complex medical components of the case that are playing a role in the ethical dilemma. The allied health ethicist offers expertise in psychosocial assessments and offers a platform for those that are perhaps more hesitant in addressing issues due to hierarchical in care team dynamic. The ability to develop this same relationship with the family and patient is also important. The Dyad team's clinical expertise and the strong interpersonal and contextual feature awareness offers the family and patient confidence in the ethics teams' ability to explore and appreciate the patient's narrative and understand the complex medical issues that have resulted in the ethical concern.

The Dyad team offers opportunities for interdisciplinary ethics education to support staff awareness and competency surrounding clinical ethics. Formally, Clinical Ethics hosts physicians, social workers, nurses, and chaplain learners in rotations to experience the process of clinical ethics consultation. Higher level grand rounds, individualized unit meetings and targeted education in the medical school allow the Clinical Ethics Physicians and Allied Staff members opportunities to share their expertise and experiences. These educational efforts have led to development of future clinical ethics consultation team members.

Objectives: Provide an overview of the Dyad Model of Ethics Consultation. Explore the relationship this type of Ethics Consultation Model has built with patient, families, and care teams. Define education opportunities an interdisciplinary Ethics team offers staff.

Normativity, Neutrality, Impartiality, or Advocacy? The Use of Systemic Consultation Concepts in Ethics Case Consultation

Katharina Woellert

Ethics case consultation (ECC) is a powerful form of intervention. The ethicist guides the conversation based on a specific attitude (normativity, neutrality, impartiality, advocacy). Various verbal and non-verbal intervention techniques are available to him/her to steer the conversation, e.g., active listening, paraphrasing, reframing, questioning, and scenario techniques. The decision for or against a form of intervention influences the further course of the con-

conversation. An intervention must always fit the case constellation, the consultation process, chosen strategy, and the essential attitude adopted. For this, it needs a theoretical and methodological foundation.

Systemics provides such a theoretical framework. Systemic consultation concepts contain a variety of intervention techniques that are well suited for implementation in ethics case consultation. Most importantly, they provide an approach for a deeper understanding of the relationship between the ethics consultant and the client (health professionals, patients, relatives, etc.). According to this conception, both find themselves in a constellation of relationships from which a mutual influence results (second-order-cybernetics). This must be taken into account when choosing the consultation approach. Even if the "right" attitude has been discussed extensively in the literature, the influence of second-order-cybernetics has not been considered yet.

I will refer to an anonymous case study from my consultation practice in my talk. I will show what effect the decision for or against an attitude can have on the consultation dynamics and the outcome of the process. Using the example, I will discuss how systemics can concretely help the ethics consultant. Significantly when, as in the case described here, strong system dynamics complicate the process. The example involves a multi-layered ethical dilemma, a complex family system, and a conflict that had already escalated over several months. Taken together, this led to a challenging consultation dynamic. Using the example, I will demonstrate the consequences of the decision for or against a certain attitude. In addition, I will discuss which intervention techniques can be used meaningfully, considering the chosen attitude.

Health Inequities in Daily Clinical Care for Migrant Patients Through the Lens of Ethics Support

Kristina M. Würth, Laura Winkler, Angelika Markaj, Ralf J. Jox, and Stella Reiter-Theil

Background: Health inequities persist despite the impressive research on this topic and efforts to eliminate them. Migration is one of the social determinants of health that can exacerbate health inequities. Yet, little is known about how individual factors that may contribute (e.g., education, income, migration history) translate into concrete outcomes in individual cases. This study aims to investigate how risk factors of health inequity manifest on the micro-level of healthcare provision for patients with a "migration background", and how these are perceived and expressed in the context of ethics support.

Methods: First, we conducted a rapid review to inform the degree to which ethically relevant issues in "migrant health" were identified and addressed in everyday clinical practice and clinical ethics support activities. Second, we systematically analyzed 42 ethics consultation reports involving migrant patients from two Swiss University Hospitals regarding social aspects relevant to the course of treatment.

Results: The rapid review revealed only scant literature addressing ethical issues regarding health equity at the micro level of health care provision for migrant patients. The analysis of the structured protocols yielded two main categories of risk factors for experiencing discrimination or inequitable care: The category "social vulnerability" includes economic and work-related aspects, educational aspects and aspects related to migration as such. The category "language and communication" includes language barriers, communication in a broader sense, and interpreters. Recognition and articulation of these issues during ethics consultation, both as relevant to health and within the context of discrimination, varied.

Discussion: Although social aspects, language and communication are known to be of high importance for health, our findings suggest that their actual relevance in the context of health inequities is not sufficiently acknowledged in clinical practice. We suppose that specific barriers, such as staff overlooking potential long-term significance, prevent these factors from being considered and their ethical relevance recognized. Here, ethical support could contribute to drawing attention to these issues and addressing related barriers.


Conclusion: To reduce health inequities, it seems important that efforts are not limited to providing knowledge about them. Risk factors need to be recognized and approached, in and outside ethics support. In this context, barriers, whether individual or structural, should also be addressed.

Posters


Poster Sessions (listed alphabetically by presenter)

Taking Cleveland Clinic's Clinical Ethics Consultation Program International: Lessons Learnt and Programming Needs Identified

Mahwish U. Ahmad and Georgina Morley



كليفلاند كلينك أبوظبي
Cleveland Clinic Abu Dhabi
A Mubadala Health Partner





Taking Cleveland Clinic's Clinical Ethics Consultation Program International- Lessons learnt and Programming Needs Identified

Mahwish U. Ahmad, MD, MPH, HEC-C^{1,2,3}, & Georgina Morley, PhD, HEC-C^{1,4}

1. Center for Bioethics, Cleveland Clinic, Cleveland, Ohio, 2. Cleveland Clinic Abu Dhabi, U.A.E. 3. Case Western School of Medicine, Department of Bioethics and 4. Nursing Institute, Cleveland Clinic, Cleveland, Ohio

Introduction	Cleveland Clinic London (CCL) Ethics Landscape	Cleveland Clinic Abu Dhabi (CCAD) Ethics Landscape
<ul style="list-style-type: none"> The Cleveland Clinic Center for Bioethics has one of the busiest clinical ethics consultation services in the United States with 750+ consults annually, rising to even higher numbers of consults post-pandemic. Shaping ethics consultation practices to respond to the ongoing expansion of the Cleveland Clinic nationally and internationally, has required diversifying our clinical ethics structures, especially internationally. To cater to evolving ethics needs, our team has added an on-site ethicist to Cleveland Clinic Abu Dhabi and established support and ethics education to Cleveland Clinic London (England) virtually. 	<p>UK's Mature Healthcare Infrastructure and Insurance network</p> <p>Medical system: NHS vs. private pay structures like CCL</p> <p>Mission: For-profit hospital site, entirely operated by CC system</p> <p>Established Bioethics services presence in the form of and Ethics Advisory Group</p> <p>Working to establish palliative care services available as needed</p> <p>State of the art facilities and procedure sites</p> <p>Mix of complex and standard risk patients in terms of case mix</p> <p>No Designated Ethicist on site</p> <p>Evolving Clinical Ethics Advisory Group (multi-disciplinary) on site</p> <p>Ethics Programming-Initiated with distance, virtual only support</p>	<p>U.A.E.'s Rapidly Developing Healthcare Infrastructure and Insurance network</p> <p>Medical system: basic healthcare SEHA centers (Abu Dhabi Health Services Co.) vs. Governmental-private collaborations like CCAD, a Mubadala Health Partner</p> <p>Mission: For-profit hospital site, only partially operated by CC system in collaboration with Mubadala Health assets</p> <p>Nascent but growing Bioethics services presence in the form of Ethics Committees but only at very large hospitals</p> <p>Relatively early presence of Ethics partners like Palliative Care hospital services in-patient and out-patient in the U.A.E.</p> <p>State of the art facilities and procedure sites, emulating Western technology and robotics use in surgical procedures</p> <p>Highly complex case mix, as CCAD is designated as a Center for Excellence in surgical procedures, critical care site and as a rising oncology care center for the region</p> <p>Designated CCF ethicist on site</p> <p>Functional Clinical Ethics Committee (multi-disciplinary) on site</p> <p>Ethics Programming-Initiated and policy/ processes review underway, on-site support</p>

Ethics Programming Aim

To strategically work towards identifying international sites' key needs, providing targeted education to ramp up local resources for new locations, and addressing needs for evolving patient populations.

Ethical Care Quandaries Shared

- Hospital site personnel awareness, especially nurses and physician, about Clinical Ethics presence on-site and support for consultations
- Minimal dedicated time for Ethics taskforce/Committee members to engage in clinical ethics consultation workflows
- Newer concept for U.A.E medical landscape although physician engagement is high due to largely Western medical training.

Ongoing Ethics Programming Efforts

Cleveland Clinic London:

- Ongoing efforts to increase physician buy-in.
- Ongoing education efforts to build awareness of clinical ethics services and appropriate consults.
- Challenging to increase awareness and education remotely.
- Ongoing efforts to promote alignment between CCL and rest of the Northeast Ohio Enterprise.
- Clinical Ethics Advisory Group members do not have designated time for ethics work.

Cleveland Clinic Abu Dhabi:

- Ongoing awareness sessions like Grand rounds are being held, discussing triggers for ethics consultations.
- Nursing empowerment for nurses as requestors, needs additional education efforts.
- Ethics service partners such as Palliative Care Medicine program is being added.

Conclusions and Next Steps

- There is a current lack of knowledge among providers regarding presence of ethics service & ethics taskforce at both Cleveland Clinic sites
- Next steps:
 - Educational initiatives are underway at both sites to increase awareness of the ethics role and the ways in which ethics services can be supportive and helpful
 - Physician and nursing awareness of institutional Opportunities to further the dialogue of ethics consultation and advanced care planning in a pre-surgical or ICU care patient population.

Training the Next Generation of Clinical Ethicists: The Need for More Practical Clinical Ethics Training Opportunities

Megan Bailey and Babitha Paulose

Training the Next Generation of Clinical Ethicists: The Need for More Practical Clinical Ethics Training Opportunities

Problem Context:

The COVID-19 pandemic has brought the importance of bioethics to the forefront of society and has increased the demand for clinical ethics consultation services. While more clinical ethics jobs are available, there is a significant gap in training opportunities for the next generation of clinical ethicists.

Driving Question:

How and where do the next generation of clinical ethicists get trained?

Clinical Ethicist Training Needs:

- Clinical ethics consultation
- Support policy development
- Coordinate organizational ethics
- Facilitate ethics education/ teaching
- Conduct research



Environmental Scan:

A preliminary environmental scan of healthcare & academic institutions in Canada and the United States was conducted to survey available opportunities within the field of clinical ethics.

Types of Training Opportunities:

- Fellowships
- Internships
- Connections with academic institutions
- Training programs within acute care settings

Findings:

- Most located within academic institutions, limited clinical experience
- Located in major cities
- 1-3 positions per program
- Most offer full-time only, few part-time options
- Program availability varies each year based on funding

Across Canada and
the United States

20

Clinical Ethics
Training
Opportunities

Conclusion and Recommendations:

Clinical ethics training programs help learners to bridge the gap between bioethics in theory and in practice. Programs often offer case-based learning and opportunities to participate in a variety of capacity-building activities that support the necessary skill development for clinical ethics consultation services. There is a need for more clinical ethics training programs in Canada and the United States to meet the growing demand for training future clinical ethicists.

By: Megan Bailey, MA, PhD Student at Carleton University & Babitha Paulose, MHA
Clinical Ethics Interns, Ethics Quality Improvement Lab – Brampton, Ontario, Canada



National Children's Hospital (Philippines) Institutional Ethics Committee: Challenges and Opportunities

Danilo A. Ballesteros



National Children's Hospital (Philippines) Institutional Ethics Committee: Challenges And Opportunities

Danilo A. Ballesteros, MD, MBAH



Background

The Institutional Ethics Committee of the National Children's Hospital (NCH) was recently revitalized and was restructured to create a multidisciplinary team representative of the hospital's staff and the community. The committee was formed to serve as a forum for interdisciplinary dialogue on ethical implications on patient care, medical research, and professionalism; develop and review hospital policies related to ethical responsibilities and promote education related to biomedical ethics. The team provides consultation and advice to staff/patients/families/other hospital committees on ethical and moral problems and issues.



Methods

The committee explored opportunities to hurdle challenges and to maximize possibilities. An Action Plan was formulated to provide focus and direction on early actions, priority areas and goals. Committee assessment and hospital staff consultation through small group discussions, surveys and feedback were conducted to respond to the shareholders' needs in a bioethical perspective.

Discussion

The committee has its strengths, namely, (1) multidisciplinary organizational structure, (2) very supportive hospital management heads and (3) commitment of most members of the committee, but the team is challenged by the lack of bioethics education and training of most committee members. Additional innovative programs aside from the current essay contests, clinicomoral conferences, grand rounds, film review, focus group discussions and Consultants' Panel have to be instituted.

With the committee's continuous capacity and quality improvement, it further needs to explore these opportunities:

(1) robust hospital cases with ethical issues, (2) accessibility of bioethics resources and opportunities for bioethics education and training, and (3) availability of local and international bioethical institutions, especially hospitals with pediatric bioethics committee and academic institutions, for collaborative activities and partnerships.

Conclusion

The committee must embark on increasing emphasis on ethics education and training, ensuring strong strategic connections and networking and creating innovative activities to strengthen health care ethics awareness.



Clinical Ethics Consultation in Developing Nations: A Rapid Review of the Literature

Leon Budrie

The most common challenges to developing CEC can be addressed by expanded education and training.

Clinical Ethics Consultation in Developing Nations: A Rapid Review of the Literature

Introduction: Clinical ethics consultation (CEC) has developed consistently in many high-income countries, but progress has been limited in low, lower and upper middle-income countries (LMIC). The goal of this review is to identify publications from these regions, describing how CEC services can be established given the specific challenges faced there.

Methods

- Ovid MEDLINE ALL and EBSCO CINAHL were searched using strategy developed in collaboration with a research librarian.
- The search sought to identify publications on clinical ethics consultation from low, lower-middle, and upper-middle income economies and limited to the past 10 years.

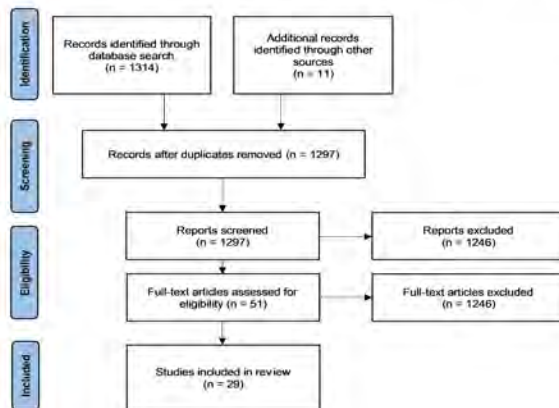


Fig. 1 Study Flow Diagram

Results

- Most reports that were excluded were due to its focus on ethics committees related to research.
- 10 papers discussed the development of CECs, 4 were on evaluation of CECs and 14 described various aspects of CECs in specific regions.

World Bank Income Classification (2021)

* Low income ** Lower-middle income *** Not classified **** Upper-middle income ***** High income



Discussion

- Despite the vast population represented, there remains a significant gap in the literature on the state of clinical ethics consultations in most LMICs.
- The most common challenge faced across geographical regions was the lack of interest or knowledge of CEC.
- In regions where awareness of CEC was high, consultations were low due to lack of confidence in benefit or effectiveness. Ongoing evaluation of CEC was thus recommended by others to show benefits.
- The limited supply of trained ethicists was the next most common challenge faced, which can be addressed by educational and training partnerships with well-resourced institutions.
- Government or accreditation requirements for CEC has been shown to drive widespread development of CEC but without appropriate training and guidelines, its functions remain limited.



Fig. 2 Number of articles and challenges faced to CEC development and/or expansion.

Limitations: This review represents the preliminary results of a current work in progress. To better understand the true state of available literature on CEC in developing nations, additional databases as well as grey literature need to be reviewed without a time limitation.



Leon Budrie, MD
Baylor College of Medicine
Houston, TX
USA

Baylor
College of
Medicine

CENTER FOR
MEDICAL ETHICS
& HEALTH POLICY

Ethical Challenges in Decision-Making in Pediatric Precision Oncology

Mei-Yoke Chan, Lisa Moses, and Jonathan Marron



CENTER FOR
BIOETHICS
HARVARD MEDICAL SCHOOL

ETHICAL CHALLENGES IN DECISION-MAKING IN PEDIATRIC PRECISION ONCOLOGY

MEI-YOKE CHAN¹, LISA MOSES², JONATHAN MARRON^{2,3}

¹KK Women's and Children's Hospital, Singapore; ²Center for Bioethics, Harvard Medical School, USA; ³Boston Children's Hospital, USA.



BACKGROUND

Precision oncology uses genomic information to improve cancer diagnosis and therapy. However, there are challenges:

1. Uncertain utility and cost-effectiveness
2. Difficulties in interpretation of results, especially unexpected and/or unrelated findings
3. Difficulties in communicating complex results to patients

AIMS

To explore the ethical challenges in decision-making, in particular the informed consent process, regarding **clinical genomic testing for diagnosis and therapy** in pediatric oncology from the perspectives of relevant stakeholders:

1. Parents
2. Pediatric oncologists
3. Support staff like nurses, psychosocial workers, genetic counsellors, pathologists and hospital lawyers

METHODS

```
graph TD; A[Literature review on informed consent in pediatric precision oncology] --> B[Potential ethical themes identified]; B --> C[Questionnaire designed]; C --> D[Stakeholders interviewed/invited :  
1. Parents 1 of 2  
2. Pediatric oncologists 1 of 2  
3. Nurses 0 of 2  
4. Psychosocial workers 2 of 2  
5. Genetic counsellors 1 of 2  
6. Pathologists 2 of 2  
7. Hospital lawyer 1 of 2]; D --> E[Virtual one-on-one interviews conducted  
N = 8 (see above for distribution)];
```

RESULTS

Common themes identified in the interviews are grouped as follows:

Information related:

- Information overload
- High complexity of information
- Implications difficult to grasp
- Too much jargon

Workflow logistics:

- Referrals to genetic counsellors sometimes missed
- Psychosocial screening not comprehensive enough
- Uncoordinated release of results
- Not all consent forms screened by lawyer

Parent factors:

- Emotional overwhelm
- Time pressured
- Did not feel engaged
- Not enough emotional support

Communication related:

- Mainly oral based, no written information given out
- Impersonal, scary, "very factual"
- Not organized, often ad-hoc, "it was sprung on us"
- Onus is on parents to follow up for the results

All interviewees acknowledged the **importance and promise** of this technology and have **no hesitation** to offer or accept the tests. The parent interviewed felt **"terrified"** (due to anxiety of what the results might uncover) but yet **hopeful** of the technology.

It was ridiculous frankly... they should have some layman's terms...or some Cliff-notey things for people in that scenario to digest.

...when the genetic counsellor is there... would be helpful to have their expertise. I also found it very helpful when social work is at these meetings... pick up on fears and uncertainties.

Things could be written.... presented graphically.... give a summary or outline.... what is the plan now. I think if there is a revisiting of the protocol and reviewing of the genetics and treatment maybe 30 days in, that would be really helpful.

Mother of boy diagnosed with brain tumor

Clinical social worker

Pediatric oncologist

DISCUSSION & CONCLUSIONS

Precision oncology is developing rapidly, and genomics is now **integrated** into cancer care in many cancers:

```
graph TD; PH[PHARMACO-GENOMICS] --> T[TREATMENT]; T --> M[MONITORING]; M --> D[DIAGNOSIS]; D --> P[PROGNOSIS]; P --> PH; PH --> PRE[PRECISION ONCOLOGY]; T --> PRE; M --> PRE; D --> PRE; P --> PRE;
```

Although precision oncology holds great potential promise, the healthcare community must be cognizant of ensuing ethical concerns, in particular whether there is true **validity of informed consent**.

A previous survey showed increased chance of cure as patients' greatest hope in precision oncology; therefore, care must be taken by healthcare professionals not to facilitate **therapeutic mis-estimation**.

LIMITATIONS

- Small number of interviewees
- Lack of nurse representative

POTENTIAL FUTURE DIRECTIONS

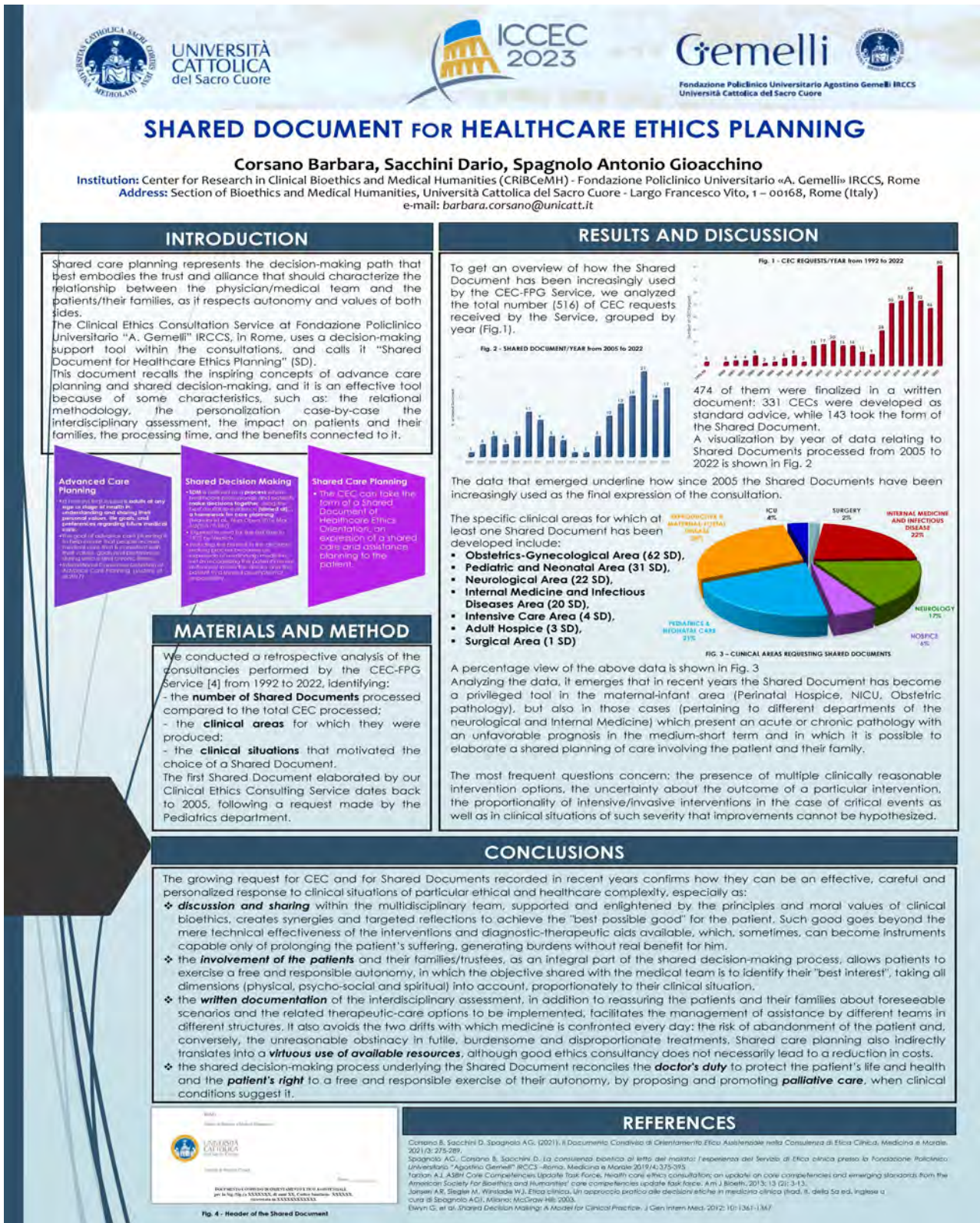
- Design information pamphlets or summary plans
- Expand project to include adolescents and other cultures or countries

REFERENCES

Use the QR code at right to view references/literature

Shared Document for Healthcare Ethics Planning

Barbara Corsano, Dario Sacchini, and Antonio G. Spagnolo



Pandemic Impact on Healthcare Priorities: Cancer Care and Ethical Decisions

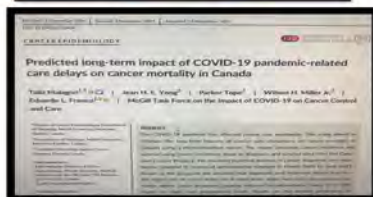
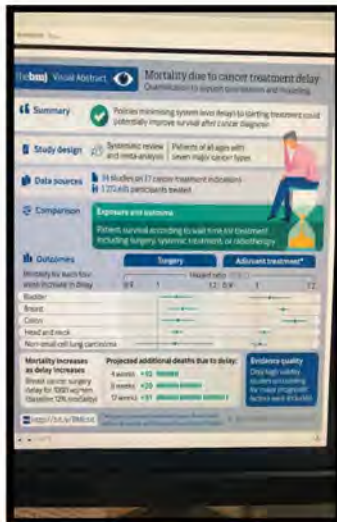
Phillip Crowell

Pandemic Impact on Healthcare Priorities: Cancer Care and Ethical Decisions

Cancer testing and treatment cancelled and delayed due to COVID-19



Mortality in Cancer Care
Increases due to screening
and treatment delays



Applying Ethics
Questions based on
the Framework
Principles & Values

To whatever extent possible, individual **autonomy**, individual liberties, and cultural safety must be respected

A society has a right to **protect itself from harm**, real or threatened...possibly impinging on the rights of individuals

Measures implemented, especially restrictive ones, should have **flexibility**, any plan must be iterative and **adapted to new knowledge**

Resources ought to be distributed such that the maximum benefits to the ***greatest number*** will achieve ***utility, and efficiency***

Those **who most need and can derive the greatest benefit** from resources ought to be offered resources **preferentially** (equity)

Pandemic Ethics Framework to guard against **discrimination** (e.g. **race, age, disability**, ethnicity, ability to pay, socioeconomic status, **pre-existing health conditions, social worth**, perceived obstacles to treatment, past use of resources).

Reciprocity: If people are asked to take increased risks, or face increased/disproportionate **burdens** they should be supported in doing so, and **the risks and burdens should be minimized as far as possible.**

At Risk	<ul style="list-style-type: none"> •Are patients in cancer care choosing to allow “increased risks” or “being put at risk” with delays ? Are the reasons for prolonged delays being made transparently clear at various stages of the pandemic ?
Flexibility	<ul style="list-style-type: none"> •Was there flexibility demonstrated in terms of the changing risk analysis especially in the light of different local COVID levels? Was it equal to the threats? Was there an appropriate measure of transparency to the public?
Burden Sharing	<ul style="list-style-type: none"> •If people are asked to take increased risks, or face increased disproportionate burdens during a pandemic influenza, then they should be supported in doing so and the risks and burdens should be minimized as far as possible. Should this apply to patients as well as providers?
Preference	<ul style="list-style-type: none"> •Was there preferential treatment for COVID vs. cancer screening and surgery? Did lack of accommodation lead patients to opt for MAiD?
Discrimination/ Social worth	<ul style="list-style-type: none"> •The challenges of addressing medical and social prejudice—that patients are not worthy because of prior conditions or other comorbidities such as smoking habits, or mental health and addiction issues

Ethical Issues in Burns Care: Impacting Professional Norms and Defining Clinical Ethicists' Scope of Practice

Jeffrey S. Farroni and Monica Gerrek

Ethical Issues in Burns Care: Impacting Professional Norms and Defining Clinical Ethicists' Scope of Practice



Bioethics & Health Humanities

Jeffrey S. Farroni¹ & Monica Gerrek²

¹ The University of Texas Medical Branch, Galveston, Texas, USA

² Case Western Reserve, Cleveland, OH, USA



Introduction

The clinical ethics consultant is a nascent discipline relative to other providers at the bedside. The discourse regarding the appropriate role of the clinical ethics consultant in the health care ecosystem continues within the clinical ethics consultant community.

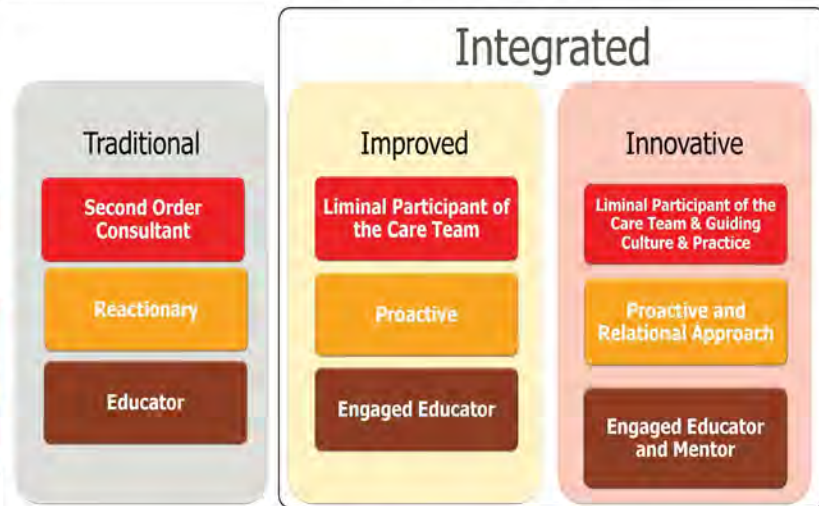
Increased Integration

	Traditional	Integrated	
		Improved	Innovative
Consult Structure	Objective, observational	Objectivity, independence but also part of the team	Also includes guidance and mentorship
Consult Type	Advisory, consultative	Also includes guidance and mentorship	Also includes guidance and mentorship
Educational Model	Provides awareness	Develops curriculum	Guidance that shapes practice

Examples of Professional Integration

- Leadership on ABA Ethics Committee
- Leading educational sessions at annual meetings, quarterly seminars, and institutions
- Development of professional codes of ethics
- Policy triggers for automatic ethics consults

Clinical Ethicists' Evolving Role

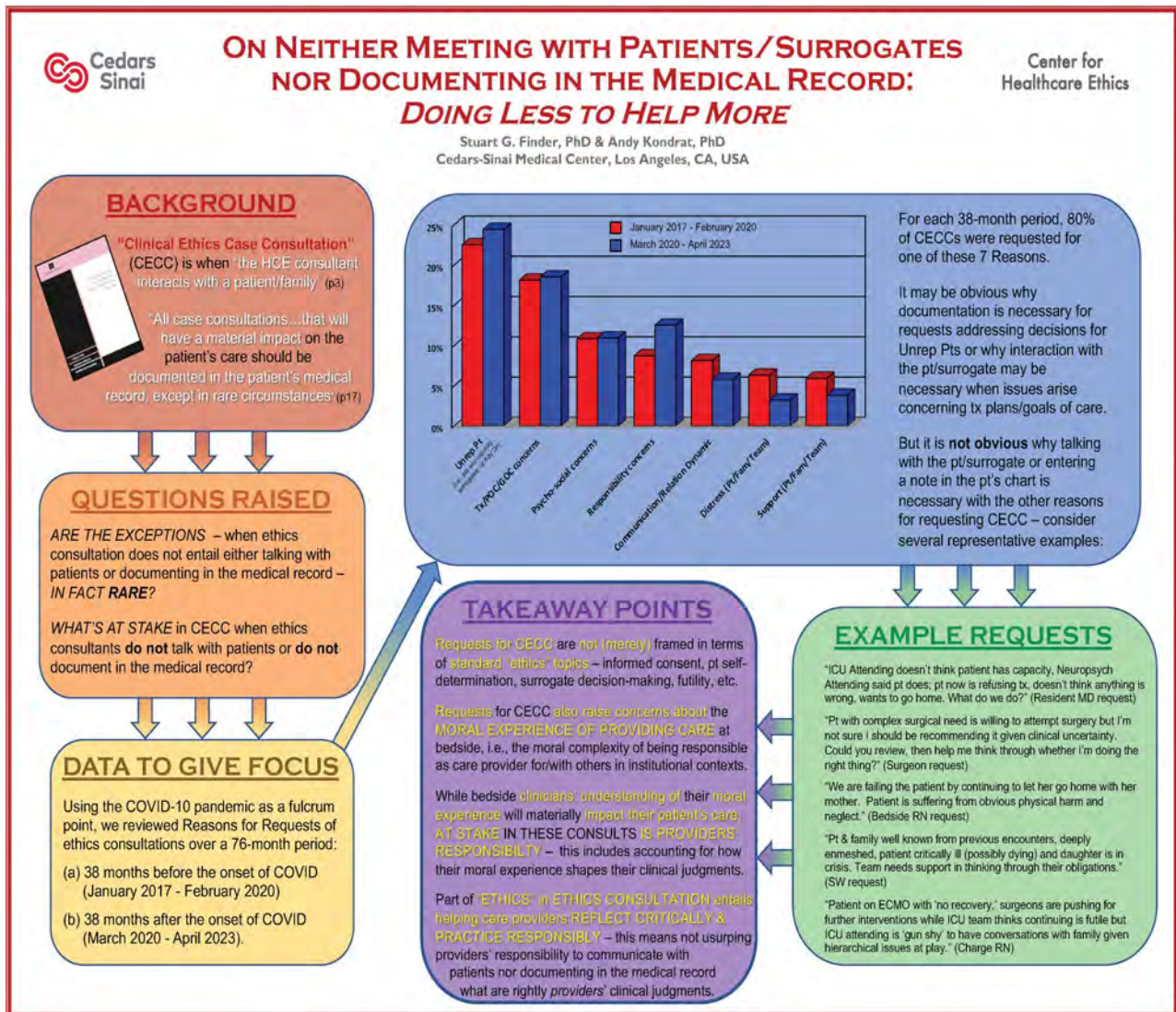


Conclusions

Clinical ethics consultants have integrated with burns care providers within their institutions by becoming permanent members of the multidisciplinary team, assumed leadership roles in research, and incorporated into patient care through proactive consultation triggers. One way to improve relationships, build ethics capacity, and encourage moral agency is by working through the prominent professional organization for burns care providers.

On Neither Meeting with Patients/Surrogates Nor Documenting in the Medical Record: Doing Less to Help More

Stuart G. Finder and Andy Kondrat



Helping Clinicians Develop Skills to Address Patients Who Endorse Medical Information About Their Cancer Care

Colleen M. Gallagher and Amitabha Palmer



Helping Clinicians Develop Skills to Address Patients Who Endorse Medical Misinformation About Their Cancer Care

Colleen M. Gallagher, PhD, LSW, FACHE, HEC-C and Amitabha Palmer, PhD, HEC-C

THE UNIVERSITY OF TEXAS
MD Anderson
Cancer Center
Making Cancer History®

Medical Misinformation about Cancer Care Harms Patients

Misinformation about cancer care causes:

1. delays or not seeking medical treatment for curable conditions;
2. Economic harm such as spending and travel on ineffective or harmful treatments;
3. harmful action such as potentially toxic effects of the suggested test/treatment
4. harmful medical interaction with standard curative treatments.

Cancer patients who chose unproven treatments administered by non-medical personnel (i.e., alternative medicine) over conventional cancer treatment increased their mortality risk by 2.5 times. (Johnson et al. 2021)

Background & Methods

Effectively caring for cancer patients who endorse medical misinformation requires better understanding the experiences, competencies, and concerns of the clinicians who treat them. We surveyed 87 clinicians at a large cancer care center about these themes.

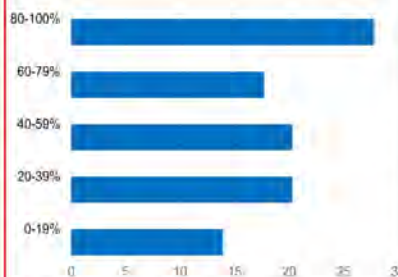
Effectiveness of Current Practice

How successful are your tools, methods, and interventions in correcting misinformation held by patients/patients' families?

- ~40% of physicians report success rates *below* 60% for correcting misinformation.
- ~70% of physicians report success rates *below* 80% for correcting misinformation.

Challenges and Barriers

I am able to dedicate sufficient time to adequately address moderately to strongly endorsed medical misinformation x% of the time:



Do you have the resources, training, and institutional support to adequately address misinformation in clinical interactions?



Policy Response: Training and Conversation Guide

To help clinicians be more effective and comfortable in correcting patients who endorse medical misinformation about cancer care we i) developed a conversation guide and ii) training to use the guide. The conversation guide and training draw on strategies, and techniques from The Serious Illness Conversation Guide for Physicians, The Covid-19 Vaccine Communication Handbook, and UNICEF's Vaccine Misinformation Management Field Guide.

Foundations of Method

Overarching Goal: The overarching goal of patient-provider interactions should be to *protect the therapeutic relationship*. Convey, when appropriate, that disagreement will not lead to abandonment. This way, if the patient doesn't initially accept recommendations, the door is still open to ask further questions or seek treatment.

General Framework:

Use an exploratory approach with empathetic listening to build trust and rapport. Fear and anxiety are common reasons for endorsing medical misinformation about care. It's important to acknowledge the emotional underpinning of such beliefs.

1. Elicit attitudes/beliefs regarding unconventional/CAM treatments. E.g.,
2. Elicit and acknowledge motivations for beliefs.
3. Provide resources and address evidence/literature.
 1. *The National Center for Complementary and Alternative Medicine* <http://nccam.nih.gov>
 2. *National Institute of Health* <https://cam.cancer.gov/>
4. Contextualize attitudes/beliefs/literature within goals of care discussion.
5. If necessary, defer to Integrative Oncology.

In the face of unyielding recalcitrance, preserve the therapeutic relationship to maintain an open door.

References

Johnson SB, Park HS, Gross CP, Yu JB. Use of Alternative Medicine for Cancer and Its Impact on Survival. *J Natl Cancer Inst.* 2018 Jan 1;110(1).
Skyler B Johnson, MD and others, Cancer Misinformation and Harmful Information on Facebook and Other Social Media: A Brief Report, *JNCI: Journal of the National Cancer Institute*, Volume 114, Issue 7, July 2022, Pages 1036–1039.

The (Unique) Nature of Emotional Distress in Clinical Ethicists

Anna D. Goff and Monica L. Gerrek

The (Unique) Nature of Emotional Distress in Clinical Ethicists

Anna D. Goff, MA, HEC-C^{1,2} and Monica L. Gerrek, PhD^{1,2}

¹ Department of Bioethics, School of Medicine, Case Western Reserve University, Cleveland, OH

² Center for Biomedical Ethics, The MetroHealth System, Cleveland, OH

Potential Sources of Distress for Clinical Ethicists

Pain and suffering	Self-doubt	Unclear or compromised scope of practice	Powerlessness	Moral ambiguity	Uncertainty	Moral compromise	Conflict between stakeholders
External constraints	Consultations involving distressed providers	Helplessness	Stakeholders having unreasonable expectations	Isolation	Consultations involving distressed patients/loved ones	Lack of authority	What would you add?

Distress Literature in Other Health Professions and its Relevance to Clinical Ethicists

Moral Distress

Definition of Moral Distress: The psychological distress of being in a situation where one is constrained from acting according to what one knows to be ethically "right" (Jameton, 1984).

Moral distress is relevant to clinical ethicists in two distinct ways:

1. Clinical ethicists are often tasked with helping health professionals navigate and mitigate moral distress.

Case A. Ethics is consulted regarding discharge planning for a homeless quadriplegic patient who is disruptive and abusive to staff. He is medically cleared for discharge, but the team reports that he is declining to go to a skilled nursing facility (SNF) where he can receive the necessary level of care for his injuries. The team is faced with a moral dilemma: It is inappropriate to allow the patient to remain in the hospital when he is no longer hospital appropriate, especially given his disruptive and abusive behavior, but the team also feels an obligation to respect the patient's autonomy, and he is insisting on remaining in the hospital. Additionally, because the patient is homeless, requires 24/7 skilled care, and SNFs generally will not accept patients against their wishes, the discharge options are extremely limited. While the clinical ethicist was consulted to help navigate moral dilemma, they must also recognize that the situation may be morally distressing to the team.

2. Clinical ethicists themselves experience moral distress.

Case B. Ethics is consulted for input on the ethical permissibility of discontinuing life-sustaining interventions for a patient that is 18 weeks pregnant following a severe traumatic brain injury. Her prognosis is extremely poor, and her family is requesting a transition to comfort care. They present an advance directive that outlines her desire not to be maintained on life support should she be permanently unconscious and insist that she "would not want to live like this." The clinical ethicist may feel that discontinuing treatment is the most ethically supportable recommendation under these circumstances and that continuing treatment against the objections of the family would be morally wrong. However, the law may constrain them from making such a recommendation given many states in the United States invalidate the advance directives of pregnant patients. This scenario has the potential to create significant distress for the clinical ethicist, who feels that they are unable to provide the full scope of ethically supportable options and/or make what they perceive to be the "right" recommendation.

Secondary Traumatic Stress (STS)/Compassion Fatigue*

Definition of STS: The stress experienced by a person who is indirectly exposed to trauma (Figley, 1995).

Definition of Compassion Fatigue: A state of reduced capacity for compassion as a consequence of exhaustion caused by contact with the suffering of others (Joinson, 1992).

STS/compassion fatigue are relevant to clinical ethicists in two distinct ways:

1. Clinical ethicists frequently work with and provide support for health care providers who are experiencing STS/compassion fatigue.

In Case A, if members of the medical team are suffering from compassion fatigue, it may impact their approach to, and tolerance of, this patient's behavior, which can ultimately change their perception of the situation. Thus, whether explicit or implicit, one element of the clinical ethics consultation may be finding ways to support the team with respect to their exhaustion.

2. Clinical ethicists themselves experience STS/compassion fatigue.

A clinical ethicist has seen a high volume of trauma-related consultations recently. They are the only clinical ethicist at their institution, so they are responsible for responding to all consultation requests. In a given month, they may only receive one to two consultations from each of their intensive care units, but this results in upwards of 10 to 15 consultations within that month. This clinical ethicist feels that an important aspect of their role is meeting with relevant stakeholders, which often includes the patient and/or their loved one(s). Over time, the burden of bearing witness to the trauma of these individuals, especially under ethically complex circumstances, may cause the clinical ethicist to experience compassion fatigue. This may impact the clinical ethicist as they navigate the consultation discussed in Case B.

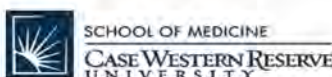
* STS and compassion fatigue are often used interchangeably.

Discussion

- The clinical ethicist's role in complicated situations like those described in Cases A and B is very different from the role of other involved health care professionals who are involved in the patient's care.
- Clinical ethicists do not provide direct patient care as part of their professional duties.
- The output of a clinical ethicist's work is most often in the form of recommendations. They are seldom, if ever, the ones making binding decisions regarding patient care.
- The clinical ethicist's proximity to patient care differs, and they often see a wider range of patients and medical issues than most health care professions given clinical ethics consultation services often span entire hospital systems.
- While moral distress and STS/compassion fatigue are helpful lenses through which we can examine the emotional impacts of clinical ethics consultation, they fail to fully capture the clinical ethicist's experience.

Conclusion

- Our current lack of understanding about the emotional impact of clinical ethics consultation on clinical ethicists may leave the field even more vulnerable to burnout than other health care professions.
- Furthermore, the lack of understanding of the clinical ethicist's experience makes it difficult to address burnout. Clinical ethicists could apply the practices that have proven effective in other medical disciplines. However, the significant differences between the clinical ethicist's role and the role of other health professionals in medical care likely requires a more nuanced and specific approach.
- As the practice of clinical ethics continues to grow, evolve, and professionalize, there exists an immediate, urgent need for further research on the emotional impact of working as a clinical ethicist.



Lost in Translation: Examining How Acts of Miscommunication Can Perpetuate Injustice in the Clinical Setting

Adira Hulkower and Ryan Marshall Felder

Lost in Translation: Examining how acts of miscommunication can perpetuate injustice in the clinical setting

Adira Hulkower, JD MS HEC-C, Montefiore Medical Center, Bronx, NY
Ryan Marshall Felder, PhD HEC-C, Stanford Center for Biomedical Ethics, Stanford, CA

Abstract

Many patient populations have been subject to generations of structural violence and racism both outside of and within the health care delivery system. These injustices are often perpetuated through small acts of miscommunication and flawed translation.

We explore a case where flawed translation perpetuated harm against the patient. Statements and actions made by the patient's family members were misunderstood, and conversations were flawed and memorialized in the chart, directly impacting patient care.

Drawing on the work of Miranda Felder on epistemic injustice¹ as well as Linda Martin Alcoff's work on "speaking for," we examine how these failures in translation can perpetuate injustice even as the reasons for them can be multifactorial: actual language barriers, the pressured nature of the clinical encounter, the presence of implicit bias, and of course, the inescapable reality that we always hear and interpret through our own lived experiences.

(part of) The Story of Nathan

BACKGROUND

- 50-year-old father, partner, and son
- Serious motorcycle accident one year prior to consult resulting in TBI, BKA
- Now with trach collar
- Multiple infections requiring repeat admissions
- Social pressure given with chronic osteomyelitis

FAMILY DECISION MAKER

- Mother, Mrs. G, is his primary medical decision-maker support along with her sister
- Family speaks Spanish
- Reason for consult (according to team)
- Family is refusing a safe discharge
- One week prior to consult, Nathan was discharged home and readmitted after 24hrs
- While home Mrs. G gave him probiotics after being instructed not to feed him, failed to pick up his medication, could not care for him
- Mrs. G cannot understand how ill he is
- Team insists Nathan must go to subacute rehab; Nathan and Mrs. G want him home

CONSULT PROCESS: Chart reviewed; Conversations held with primary team, family, Nathan, team and family meeting; Interpreter used.

Epistemic Injustice

- Epistemic injustice is a wrong to someone "in their capacity as a subject of knowledge, and thus in a capacity essential to human value"² as a transmitter and creator of knowledge in a social context.
- Miranda Felder influentially distinguishes two kinds of epistemic injustice,³ although others think about this differently⁴
 - **Testimonial injustice** occurs when someone's testimony is disbelieved because of prejudicial judgment about their credibility;^{5,6}
 - Identity-prejudice: because of certain features of identity, such as race, gender, or ability (in our case language spoken), a person is viewed implicitly and unjustly as less credible than they deserve.
 - **Hermeneutical injustice** occurs when someone is unable to interpret their experiences due to prejudicial collectively shared social images about whose interpretations matter⁷
- Many examples of epistemic injustice can be found in health care settings:
 - Testimonial injustices occur when patient testimonies about pain are ignored due to prejudices such as gender⁸
 - Testimonial and hermeneutical injustices can occur when there is a need to interpret health care information between two languages⁹
- Nathan's case was complex and involved testimonial and hermeneutical elements; the epistemic injustice was multifactorial



"Every act of communication is an act of translation."
-Gregory R. Bassa

MRS. G SAID	TRANSLATED AS	LIVED EXPERIENCE
"I want to give him broth?"	She knows that he is dysphasic and that broth can cause aspiration; she is restless	She was scared he would starve because PEG equipment delivery was delayed and manual was in English
[regarding his care] "It's simple"	Because his care is so complex, she is showing that she has little insight into the situation	Utilized Spanish phrase "es sencillo" (it's simple) to mean: the choice of caring for him is simple, she must do it.
"I will not allow him to go to a nursing home"	She doesn't understand how ill he is, nor the difference between subacute rehab and nursing home, despite telling her time again.	Nathan developed stage 4 decubitus ulcers at last residential placement due to neglect.

Interpretive misunderstandings

Epistemic injustices

TESTIMONIAL INJUSTICE	HERMENEUTICAL INJUSTICE
<ul style="list-style-type: none"> • To the team, Mrs. G's questions indicated "lack of understanding" and poor health literacy • Need for Spanish interpreter introduces second layer of interpretive complexity⁹ • Team attributes a credibility deficit to Mrs. G due to identity prejudice 	<ul style="list-style-type: none"> • Mrs. G fit the "difficult family member" archetype • This fact intersects with testimonial injustices • She was unjustly led to be unable to interpret and understand the team's bias toward her

Mitigating epistemic injustices in translation exchanges

- Standard remedies to epistemic injustice in health care include improved training in clinical interviewing,¹⁰ better awareness of problem,^{6,10} and structural changes such as more time with patients¹¹
- Remedies to epistemic injustice should be modeled on good allyship
 - Linda Martin Alcoff on speaking for others in social justice discourse: Good allies "speak with" the oppressed, speak for another in a way that is true to their experiences¹²
 - Clinical ethics can facilitate speaking-with by ensuring patient voices are heard in least distorted way
 - Can develop specific cultural competencies and learn what the individual, as a member of a unique culture and language, actually says

Consult Outcome

- Team and family meeting held where concerns were voiced; initial tone of meeting was accusatory and frustrated on both sides;
- Meeting highlighted miscommunications perpetuated in chart
- Team acknowledged that previous discharge was not set up for success; Family acknowledged a need for more training
- Decision made to set a side one full week for Nathan's mother and aunt to be trained on PEG feedings and wound care in Spanish
- One week later Nathan was discharged home
- Bioethics consult supported team in recognizing areas of "inaccurate translation" of both actions and words
- Discharge was successful

References



Acknowledgments

Montefiore Bioethics Center for Bioethics
Heidi Gorman, MD
Stanford Center for Biomedical Ethics

Clinical Bioethics Inside the Medical Curriculum: A Field for Training Communication Skills

Lenin de Janon-Queveda, Silvia Birnenbaum, Gerardo Perazzo, Laura Ventura, Lourdes Aillón, Ana Barrionuevo, and Rubén Revello



Clinical Bioethics Inside the Medical Curriculum: A Field for Training Communication Skills

Authors: Lenin de Janon-Queveda, Silvia Birnenbaum, Gerardo Perazzo, Laura Ventura, Lourdes Aillón, Ana Barrionuevo, Rubén Revello.



PONTIFICIA UNIVERSIDAD CATOLICA ARGENTINA
FACULTAD DE CIENCIAS MÉDICAS

- **BACKGROUND:** Training in communication skills (CS) is insufficiently developed during undergraduate medical education, predisposing professionals to acquire biased models after starting clinical practice. Delivering of bad news (DBN) require empathy and commitment to the patients. Learning of Clinical Bioethics (LCB) during undergrad may allow medical students (MS) to build up experiences that compromise them towards suffering of a fellow human being as a way of embodying ethical values such as harm prevention, truthfulness, compassion, and responsibility.

► **METHODS:**

	Activity: 8-hour workshop. Curriculum Subject: Bioethics at the End of Life (32 hours) Program: fifth year of the M.D. Program.		Briefing: MS (in teams of two) role-played an act of communication to standardized patients. The acts were video recorded. Immediately after simulation, each participant wrote in a logbook the sensations they perceived while communicating (S1).
	1. Train in DBN in simulated scenario. 2. Recognize sensations (emotions and feelings) while communicating death or a poor prognosis diagnosis.		Debriefing: The videos were analyzed, and sensations were described again (S2) to compare them to the first ones (S1).
	Prebriefing: A seminar covers topics of communication in Medicine and SPIKES protocol. Also, a survey (questionnaire) identified self-perception on CS among the MS.		Survey's data expressed as arithmetic mean and sensations as median.

► **RESULTS:**

General Data	
Completed surveys	129
Participants' genders	65% (84) females 35% (45) males
Average age (67%)	21 -24 years old

Compared Sensations		
	S1	S2
Most frequently reported sensation	Nervousness	Satisfaction
Other reported sensations	Frustration, fear, anxiety, stress, awkwardness, fulfilment, empathy	Surprise, awkwardness, nervousness, calm, growth

S1: written report immediately after delivering bad news.
S2: written report after the debriefing.



Figure 1. Students Trained in CS

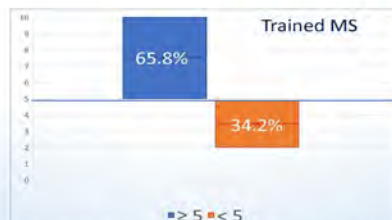


Figure 2. Self-perception of Proficiency in CS



Figure 3. Participation in DBN



Figure 4. Self-perception of MS During Communication



Figure 5. Students' Perceptions While Handling with Patients' Emotions and Feelings

► **CONCLUSIONS:**

LCB during undergraduate education makes possible training in CS and identifying moving personal sensations needed for clinical communication in a context of deep human suffering.

Bagher Larijani, Zahedi Anaraki, and Mina Mobasher

Abstract

World Health Organization (WHO) has highlighted palliative care as an urgent humanitarian need worldwide. Patients with life-threatening and incurable diseases face various medical, psychological, social, financial and even religious problems. The unique ethical challenges in palliative care make it necessary to provide specific ethical guidelines, which we intended to compile in our study. Several methods were used to carry out the study, including literature review to find relevant resources, searching related publications and guidelines worldwide and in Iran, interview with ethicists and specialists in the field of palliative care, expert opinions, poll, and a final national workshop. As the results of the current study, we finally compiled the national ethical guideline for palliative care in terminal patients which is consisted of 6 main titles of: interdisciplinary team, the responsibilities and duties of ethics advisor, general ethical guidelines for palliative care practice, specific guidelines in psychological, spiritual and religious support, and guidelines of ethical decision making in end of life care. The results of the current project, as a collection of guidelines in Farsi, is conveyed to the High Council of Medical Ethics of MOHME for further uses in policy making and clinical practice. This is an initial step to integrate palliative care into the National Health care Services.

Keywords: Palliative care, end of life care, spiritual care, Islam, Iran

<p>The term 'palliative care' was initially introduced by Balfour Mount in 1973 (1). In 1986, the World Health Organization (WHO), as the pioneer of international programs, gave its first definition of palliative care, which was updated in 2002 as:</p> <p><i>Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and management of their problems, physical, psychosocial and spiritual. Palliative care:</i></p>	<p>For compiling the ethical guideline, several methods were used to do the study including:</p> <ul style="list-style-type: none"> o Literature review to find relevant resources (using a scientific 'search strategy') o Interview with ethicists and specialists in the field of palliative care o Encompassing thesis of medical ethics PhD students o Searching related publications and guidelines in the country o A purposive poll of 32 experts in the field of ethics, palliative care and related disciplines o A national workshop to review and discuss the final draft of the guideline <p>The first draft of the guideline was prepared by main researchers and then discussed and revised through a 2-days, focus group discussion. The second draft was sent to 32 experts in the field of ethics, palliative care and related disciplines. A Workshop by participation of 47 experts was succeeded to collect various viewpoints in order to compile the final draft of the guidelines.</p>
--	--

<p>offers a support system to help patients live as actively as possible until death,</p> <p>offers a support system to help the family cope during the patients illness and their own bereavement,</p> <p>uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated, will enhance quality of life, and may also positively influence the course of illness,</p> <p>is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications" (2)</p> <p>In compiling the current guidelines, the desired target groups contain:</p> <ul style="list-style-type: none"> o Medical Ethics Professionals o Palliative medicine specialists o Specialist and sub-specialist physicians (e.g. oncologist, anesthesiologist, cardiologist, respiratory disorders sub-specialist, gastroenterologist, pediatrician, pharmacist, and other professionals involved in patient management) o General practitioners o Nursing staff o Paramedic staff and co-workers (e.g. Nutritionist, 	<p>As a part of the research, we reviewed ethical challenges in the field of palliative care in terminal patients (table 2).</p> <p>Islamic issues were also studied. Muslims believe that both living and dying provide opportunities for personal growth and self-actualization and also consider "death," "illness" and "pain" as divine gifts in which there is hidden blessing. Holy Quran says: "Every soul shall taste death. We will try you with a trial of evil and good. Then, to Us you shall be returned." (2/135)</p> <p>Perspectives of Muslim scholars on issues of palliative care was studied.</p> <p>However, as main results, "National Palliative care ethical guidelines and regulations for terminal patients" was prepared. The guideline is consisted of main sections, as follows:</p> <ol style="list-style-type: none"> 1. Interdisciplinary Team: Structure, Composition and Qualification 2. The Responsibilities and Duties of Ethics Advisor 3. General Ethical Guidelines for Palliative care Practice 4. Specific Guidelines in psychological, spiritual and religious support 5. Guidelines of Ethical Decision making in End of Life Care 	<table border="1"> <thead> <tr> <th>non-maleficence</th><th>autonomy</th><th>beneficence</th></tr> </thead> <tbody> <tr> <td> <p>Patient's dignity</p> <p>Informed consent</p> <p>Decision making capacity</p> <p>Refusal not withdraw care and comfort</p> <p>Surrogate decision-making</p> </td><td> <p>Quality of life</p> <p>Relief of pain is a core ethical principle in medicine.</p> <p>Refusal of pain pump is a legal right (NMD)</p> <p>'double effect'</p> </td><td> <p>Scarcity of health resources</p> <p>Limiting life-sustaining treatments</p> <p>social support</p> </td></tr> <tr> <td> <p>Right to know</p> <p>Truth telling</p> <p>Healthcare team honesty</p> </td><td> <p>End of life care</p> <p>The concept of a good death</p> <p>Advance care planning (advance directives)</p> <p>Unnecessary resuscitation/ do-not-resuscitate (DNR) policy</p> <p>Euthanasia</p> <p>Physician-assisted suicide</p> <p>Family</p> <p>Wishes/diathesis</p> <p>Withdrawal / withholding treatments</p> <p>withdrawing of life-sustaining therapies</p> <p>continuation of effective palliative care till the last days of life</p> </td><td> <p>provider conflict</p> <p>clinical ethics (CE) consult availability</p> <p>debatable clinical ethics (CE) consult availability</p> <p>Scientific knowledge on the subject</p> <p>Availability of PC</p> <p>effective and compassionate communications are the integral components of ethics in palliative care.</p> </td></tr> </tbody> </table>	non-maleficence	autonomy	beneficence	<p>Patient's dignity</p> <p>Informed consent</p> <p>Decision making capacity</p> <p>Refusal not withdraw care and comfort</p> <p>Surrogate decision-making</p>	<p>Quality of life</p> <p>Relief of pain is a core ethical principle in medicine.</p> <p>Refusal of pain pump is a legal right (NMD)</p> <p>'double effect'</p>	<p>Scarcity of health resources</p> <p>Limiting life-sustaining treatments</p> <p>social support</p>	<p>Right to know</p> <p>Truth telling</p> <p>Healthcare team honesty</p>	<p>End of life care</p> <p>The concept of a good death</p> <p>Advance care planning (advance directives)</p> <p>Unnecessary resuscitation/ do-not-resuscitate (DNR) policy</p> <p>Euthanasia</p> <p>Physician-assisted suicide</p> <p>Family</p> <p>Wishes/diathesis</p> <p>Withdrawal / withholding treatments</p> <p>withdrawing of life-sustaining therapies</p> <p>continuation of effective palliative care till the last days of life</p>	<p>provider conflict</p> <p>clinical ethics (CE) consult availability</p> <p>debatable clinical ethics (CE) consult availability</p> <p>Scientific knowledge on the subject</p> <p>Availability of PC</p> <p>effective and compassionate communications are the integral components of ethics in palliative care.</p>
non-maleficence	autonomy	beneficence									
<p>Patient's dignity</p> <p>Informed consent</p> <p>Decision making capacity</p> <p>Refusal not withdraw care and comfort</p> <p>Surrogate decision-making</p>	<p>Quality of life</p> <p>Relief of pain is a core ethical principle in medicine.</p> <p>Refusal of pain pump is a legal right (NMD)</p> <p>'double effect'</p>	<p>Scarcity of health resources</p> <p>Limiting life-sustaining treatments</p> <p>social support</p>									
<p>Right to know</p> <p>Truth telling</p> <p>Healthcare team honesty</p>	<p>End of life care</p> <p>The concept of a good death</p> <p>Advance care planning (advance directives)</p> <p>Unnecessary resuscitation/ do-not-resuscitate (DNR) policy</p> <p>Euthanasia</p> <p>Physician-assisted suicide</p> <p>Family</p> <p>Wishes/diathesis</p> <p>Withdrawal / withholding treatments</p> <p>withdrawing of life-sustaining therapies</p> <p>continuation of effective palliative care till the last days of life</p>	<p>provider conflict</p> <p>clinical ethics (CE) consult availability</p> <p>debatable clinical ethics (CE) consult availability</p> <p>Scientific knowledge on the subject</p> <p>Availability of PC</p> <p>effective and compassionate communications are the integral components of ethics in palliative care.</p>									

<p>o Family and relatives of terminal patients</p> <p>o Religious caregivers (chaplain)</p> <p>o Healthcare policymakers</p> <p>Life-threatening and incurable diseases are a major concern around the world. According to the national data in Iran, about 30000 people die due to cancer annually. Fortunately, Ministry of Health has established efficient programs such as National Cancer Registration and Palliative Care Clinics in recent years. As palliative care develops across the country, compiling appropriate culturally-adapted ethical guidelines was so necessary and helpful in solving ethical problems in practice.</p>	<p>of end-stage chronic diseases</p> <p>5.1.2. The Principle of Respect to Autonomy</p> <p>5.1.3. Justice in providing care and allocation of resources</p> <p>5.1.4. Beneficence in terminal patients</p> <p>5.2. Specific Guidelines of End of Life</p> <p>5.2.1. Ethical Decision making in terminal patients</p> <p>5.2.2. Do not Resuscitate (DNR) order</p> <p>5.2.3. Futility of Treatments</p> <p>5.2.4. Terminal Patients-Physician Relationship</p> <p>5.1. Ethical Decision making in terminal patients</p> <p>5.2. Do not Resuscitate (DNR) order</p> <p>5.3. Futility of Treatments</p> <p>5.4. Terminal Patients-Physician Relationship</p> <p>It is recommended that the compiled guidelines be revised after one pilot run; so, the guidelines will be reviewed after 5 years by a panel of palliative care experts and medical ethics professionals.</p>	<h3>Discussion & Conclusions</h3> <p>Specific national guidelines for palliative care in terminal patients have not been compiled by the medical ethics department of the IMIR of Tehran University of Medical Sciences due to the ever-increasing attention to palliative care in the country. This was supported by a grant from the WHO office in the MOHME. The results of the project were submitted to the High Council of Medical Ethics of MOHME and after approval (February 2019) was conveyed to the medical sciences universities for being implemented in clinical practice.</p> <p>Compiling the necessary clinical protocols and adaptation of related laws will be highly effective to pave the way for successful implementation of the guidelines of ethical decision making in end of life care in the country.</p> <p>The guideline is specific for adults who have chronic diseases or are in the late stages of life, and does not include palliative care in children. Meanwhile, this guideline may not provide adequate coverage of ethical matters in home care and out-patient services.</p>
---	---	---

Quality of life	Alleviation of pain and discomfort	The Office of World Health Organization (WHO) in the Ministry of Health and Medical Education (MOHME) of Islamic Republic of IRAN supported the research. [APW Contract Report of PO Number 201754808]
Human feelings and normal emotions	Provide psychological and spiritual care to support the	We acknowledge Fateneh sadat Bathaie, MD, MPH, PhD; Eghbal Taheri, PharmD, MSc.; Marziyeh Madani, MD, PhD; Saeed SaediTehrani, MD, PhD; Hamideh Moosapour, MD, PhD; Rasha Atlas, MSc, PhD; Nasrin Nejadnasarviri, MD, PhD; Mahshad Noroozi, MD, PhD; and all participants in workshops for their sincere cooperation.

Affiliations: [Some References](#)

<p>Medical Sciences, Tehran, Iran</p> <p>1. Department of Medical Ethics and History of Medicine, Faculty of Western Traditional Medicine, Kermanshah University of Medical Sciences, Kermanshah, Iran</p> <p>Email: farahzad134@gmail.com</p> <p>fahrad@kermu.ac.ir</p> <p>[FL, Director of Medical Ethics Research Group, of ENORI]</p>	<p>1. The Indian ethical adaptation for Hospice and Palliative Care (BAMC): The IAMP: <i>Journal of Palliative Care</i>, 31st Edition, 2015.</p> <p>2. The Westminster Hospice Palliative Care Alliance (WHPCA) Building Trust: <i>Journal of Palliative Care Programs and Services</i>, 2017.</p> <p>3. The National Cancer Institute's Project to Quality Palliative Care (NCPL): <i>Journal of Palliative Care</i>, 2017.</p> <p>4. The National Institute for Health and Care Excellence (NICE), UK: Improving supportive and palliative care for adults with cancer.</p> <p>5. American college of Surgeons, USA: The Standards of Principles of Palliative Care.</p> <p>6. Swiss Academy of Medical Sciences, Switzerland: Medical ethics guidelines and recommendations.</p> <p>7. Paragopal A, Shrivastava R, Murthy M, et al. Zaretsky G, Lurie M. The second strategic plan of medical research national priority. <i>J Med Ethics Hist Med</i>. 2019;14.</p>
--	---

Clinical Ethics Consultation, Telehealth, and Covid Pandemic

Bagher Larijani and Zahedi Anaraki



Clinical ethics consultation, Telehealth and Covid Pandemic

Bagher Larijani, MD, FACEP^{1,2},
Zahedi Anaraki, MD, MSc.²





17th Annual International Conference on Clinical Ethics: From Conscience to Compliance
October 12-14, 2020 | Rome, Italy

Introduction

Telemedicine attracted a lot of interests around the world in outbreak of covid-19. There has been an increasing attention to online consultation during and after the pandemic. Considering this matter, the use of telemedicine in clinical ethics consultation needs special attention to related ethical challenges. Review of ethical issues and the approaches was the purpose of current study.

In Iran, Primary Health Care (PHC) program has been an important step in order to achieve justice in health care after Islamic revolution. Also, special attention to electronic services has emphasized through 4th, 5th and 6th national programs of development in the country. In recent years, electronic prescriptions has replaced the paper ones. Covid pandemics played a specific role to accelerate the trend.

According to data of 31,918 patients of two outpatient Diabetes Clinics affiliated to Tehran University of Medical Sciences, Tehran, Iran, there has been about 50 % reduction in diabetes visits during corona pandemic (Fig. 1). The study shows that public lockdown during the covid-19 pandemic resulted in metabolic improvement in patients. Obviously, many patients have no face-to-face visits with their doctors, but may have virtual consultation in some situations. The pandemics emphasized the necessity of tele-health services. While tele-consulting with health care providers were not firstly available in many countries, corona outbreak paved the way to more attention to digital treatments. This is so important, especially in chronic non-communicable diseases such as diabetes mellitus.



Fig. 1 Diabetes Clinic visits before and during covid-19 pandemic.

Methods and Materials

Current study was a scoping review on the the ethical challenges which are certain to arise due to the use of telemedicine in clinical ethics consultation during covid-19 pandemic. Literature review was performed on PubMed (using the MeSH terms of: telemedicine, covid, ethics, without time limitation), and also by the use of some other references cited by authors in the area.

Results

The first search on the PubMed consisted of 32 papers. We also gave some through on the references cited in these papers.

Various aspects of issues such as professionalism and good communication are important in this field. Privacy, confidentiality and security of data, informed consent, and quality of services are some important challenges. Equality in access to online consultation services and justice in telemedicine is also another issue which needs attention. Main ethical issues discussed by authors are depicted in [Table 1](#).

Table 2. Main Ethical Challenges in Telehealth and covid pandemic.

Main subjects	Examples
Autonomy	<ul style="list-style-type: none"> Informed consent Data protection and cyber security Lack of attention to personal characteristics such as culture and social context (depersonalization) Patient safety
Issue of relationships	<ul style="list-style-type: none"> Patient-healthcare provider relationships Patient/family/the public/ healthcare provider communications Shared decision making Clinical consultation issues Health co-workers relationships Privacy and confidentiality Depersonalization Technology as a facilitator or barrier? Patient's responsibility Healthcare provider's accountability Financial issues Reimbursement/ insurance coverage Cultural sensitivity
Quality of care	<ul style="list-style-type: none"> Standards of care Access to care Patients records availability Nonmaleficence and beneficence (minimize harm) Prioritizing health economics over care (conflicts of interests) Emergencies Issues of treatment delivery Governance, and methods of evaluation Risk of malpractice Specific training? (license)
Justice	<ul style="list-style-type: none"> Health equity and accessibility Vulnerable groups (elderly, disabled, lack of competence, etc.) Health insurance accountability Policies and regulations

Discussion

Telehealth or telemedicine may have some definitions, however, according to WHO: "telemedicine is the delivery of healthcare services, where distance is a critical factor, by all healthcare professionals using information and communication technologies for the exchange of valid information for the diagnosis, treatment, and prevention of disease and injuries, research and evaluation, and for continuing education of healthcare providers, all in the interest of advancing the health of individuals and their communities". It is clear that telemedicine have great benefits by spreading online consultation; however, compliance with ethical principles is necessary. So, ethical codes and guidelines is necessary for utilizing telemedicine in clinical ethics consultation.

As a scoping review, our investigating reviewed limited papers which were mainly studies that only described ethical challenges of telehealth. However, the papers were not concentrate on solutions and did not evaluate the related outcomes in various countries. Expanding telehealth needs complementary research on the issue, in order to help successful implementation of telemedicine in every day practice.

Conclusions

Covid pandemics illuminated ethical concerns of tele-health, especially in clinical consultation. Bioethicists and ethics committees around the world can learn from this experience and evidence, in order to recognize related values, to provide necessary policy and standards, and to recommend ethical guidelines and codes of conduct.

Keywords: clinical ethics, ethics consultation, telemedicine, tele-health, ethical guideline, covid-19

Affiliations

1. Medical Ethics and History of Medicine Research Center, Tehran University of Medical Sciences, Tehran, Iran
2. Endocrinology and Metabolism Research Center, Endocrinology and Metabolism Clinical Sciences Institute (EMRI), Tehran University of Medical Sciences, Tehran, Iran

Email: larijani@tums.ac.ir
zahedi@tums.ac.ir
(PI, Director of Medical Ethics Research Group of EMRI)

Some References

1. Bhandari N, Qorbani A, Aslani, P, Larijani, B, et al. Changes in clinic visits and diabetes and metabolic control in patients with type 2 diabetes during COVID-19 pandemic: A real world evidence. *Primary Care Diabetes* 2023; 37(3): 238-241.
2. Tabrizi JS, et al. Status of Iran's Primary Health Care System in Terms of Health Systems Control Knobs: A Review Article. *Iran J Public Health*. 2017 Sep;66(9):1156-1166.
3. Raghimi Lankarani K, et al (2013). Health in the Islamic Republic of Iran: challenges and progress. *Med J Islam Repub Iran*; 27:42-49.
4. Sanjari, et al. Telehealth for fighting the novel coronavirus: review of activities on Diabetes and Osteoporosis management in outbreak. *J Diabetes Metab Disord* 19, 2023-24.
5. Menezes CG, et al. Telemedicine, ethics, and law in times of COVID-19: A look towards the future. *Revista Clínica Española* (English Edition). 2021 Aug; 322(17):408-10.
6. Kaplan B. Resolving Health Information Technology (Ethical, Legal, and Social Issues and Evaluation) Telehealth/Telemedicine and Covid-19. *Int J Med Inform*. 2020; 143:104239.
7. Solimani R, et al. Ethical and Legal Challenges of Telemedicine in the Era of the COVID-19 Pandemic. *Medicina (Kaunas)*. 2021 Nov 30;57(12):1314.
8. Parsapour A, Shamsi Goushi L, Malekafzali H, Zahedi F, Larijani B. The second strategic plan of medical ethics: a national report. *J Med Ethics Hist Med*. 2021;14.
9. WHO Global Observatory for eHealth - Telemedicine: Opportunities and Developments in Member States. *Report on the Second Global Survey on eHealth*. Geneva: World Health Organization; (2020).

Ethics as Framework for Organizational Reflection on the Pandemic Experience: Example of the CISSS de Chaudière-Appalaches

Ana Marin, Pierre-Maurice Ferland, Andréanne Talbot, and Francis Berthelot



ETHICS AS FRAMEWORK FOR ORGANIZATIONAL REFLECTION ON THE PANDEMIC EXPERIENCE. EXAMPLE OF THE CISSS DE CHAUDIÈRE-APPALACHES

Ana Marin, Pierre-Maurice Ferland, Andréanne Talbot, Francis Berthelot

Introduction

After one year of the pandemic, in June 2021, the Clinical and Organizational Ethics Committee and the CISSS-CA's Senior Management (our health and social services organization situated in the Chaudière-Appalaches region in the province of Quebec) decided to conduct an organizational reflection on the pandemic experience through different perspectives. The goal was to answer the following questions - what did we learn about ourselves and the organization and how do we plan for the future? The collected data lead to recommendations and an action plan for this our organization. This experience provided some lessons about organizational ethics (competence, culture, leadership).

Context

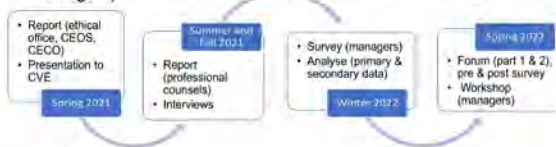
- ❖ More than one year of pandemic experience (March 2020 – June 2021)
- ❖ Moral distress among the employees and managers (Ethical report June 2021)
- ❖ Ethics at CISSS de Chaudière-Appalaches



Methods

Ethical reflections on the pandemic experience in the organization (2021-2022). Various sources of data:

- Primary: Interviews (19 participants); Forum (60 participants); Workshop (400 managers)
- Secondary (reports from professional advisory, survey with managers)



Results

Report (Summer 2022):

- Observations : for the users, the health care workers and the organization
- Actions for the future of the organization

Ethical advice (Fall 2022):

- Analysis (observation, ethical risks, ethical issues)
- Recommendations

Action plan (Winter 2023):

- Responses from the organization to the recommendations, supported by the Bureau of Ethics

Conclusion

This kind of reflection on an organizational level :

- Gives a good visibility to ethics
- Has an impact on the development of the ethical competence and ethical culture in the organization

The leadership of managers is a favourable factor.

It's important to find way to perpetuate the ethical reflection in the organization.



References & Acknowledgement

- CISSS de Chaudière-Appalaches, 2022, *Bilan de la démarche éthique de réflexion organisationnelle sur la pandémie (ETH-O-SSS Pandémie)*;
- CEOS du CISSS de Chaudière-Appalaches, 2022 (MAJ 2023), *Avis éthique sur la pandémie*.






Thanks to all the participants of ETH-O-SSS Pandémie for their implication and to the managers (Direction of Ethics & Senior Management) for the support

Ana Marin, PhD, Consultante en éthique, Responsable du Bureau de l'éthique clinique et organisationnelle, Centre de recherche en éthique, CISSS de Chaudière-Appalaches, Téléphone : 418 386-7568 (ou au poste 43564), Courriel: MAR-AN@cihss.ca, pferland@cihss.ca, atalbot@cihss.ca, fberthelot@cihss.ca

Clinical Ethics Teaching of Challenging Cases: A New Pedagogy

Bryan Pilkington, Nancy Innella, Alicia John, Jenna Mustafa, and Sereen Abu Hawa

 SETON HALL UNIVERSITY 1855		Clinical Ethics Teaching of Challenging Cases: A New Pedagogy Bryan Pilkington, PhD ^{1,2} , Nancy Innella, PhD, RN, CNE ³ , Alicia John ⁴ , Jenna Mustafa ⁴ , Sereen Abu Hawa ⁴ ¹ Seton Hall University, ² Hackensack Meridian School of Medicine		 SETON HALL UNIVERSITY 1855	
Abstract <p>Teaching students about the sensitive or challenging topics that can arise in clinical ethics education can present pedagogical obstacles due to the important aims of sharing rich ethical concepts, engendering empathetic interactions, and doing so with limited time and resources. We believe that clinical ethics trainers ought to embrace new pedagogical approaches, borrowing from other healthcare professions. In particular, we were interested in the role that debate might play in a clinical ethics training session, as opposed to (only) the standard sharing of clinical ethics information via a case discussion or the common "acting out" of roles within a clinical ethics consultation. To begin to explore the potential of debate pedagogy, we focused on one of the most challenging, and ethically fraught, situations for healthcare staff and clinical ethicists: pediatric end-of-life (EOL) cases. We hypothesized that employing debate as a pedagogical model to teach relevant clinical ethics concepts (including dignity, autonomy, and respect) around that arise in discussions of end-of-life care that involve children is both a viable and valuable option. This poster highlights findings from a new research study on pediatric end-of-life care educational interventions in undergraduate students interested in entering a variety of health professions (including nursing, medicine, ethics, or other allied health professions), which led to a significant increase in self-efficacy. Though further research is needed, the results of this study support our contention that trainers and teachers of clinical ethics should consider this model for university-based clinical ethics teaching and (potentially) for hospital-based teaching, as well.</p>		Methods <p>This research study evaluated the impact on healthcare students' self efficacy following an educational intervention on pediatric EOL care had in a pre- and post- test design methodology. The educational session was developed during the summer of 2022 and recorded in the fall of 2022. Data collection began in late fall of 2022 with a total of 64 undergraduate student participants.</p> <p>During a variety of courses that engaged topics in healthcare, students were given a letter of solicitation and, if they agreed, they were provided with a link to the consent form and a pretest survey on self efficacy related to pediatric EOL ethical concepts. The students who agreed to participate, during class time, watched a 17-minute video and then completed the survey again.</p>		Implications <p>Undergraduate students in the health professions (or interested in health professions careers) report the need for additional education on the topic of ethical issues in pediatric (EOL) care. The results of this study demonstrated that students reported more confidence and self efficacy in caring for pediatric EOL patients after an educational session that utilized debates. Additionally, exploring ethical concepts related to dignity and autonomy were highlighted in student responses, with dignity especially noted as increasing health professions students' confidence related to caring for pediatric EOL patients.</p>	
				Findings <p>64 health professions (or interested) students, with the following designated majors: communications, psychology, nursing, and biology (including BS/MD) comprised the participant class.</p> <p>As a result of the educational session and debate, there was significant ($p < 0.05$) changes in self efficacy related to: defining pediatric EOL, defining dignity related to pediatric EOL, and respecting and reflecting on dignity as related to pediatric EOL care.</p>	
				Future Research <p>Future research is needed to address limitations, including a study to contrast students who receive the debate intervention and those who engage the topic in a more traditional way.</p> <p>Study funded by Seton Hall University-Opportunity Meets Innovation Challenge Grant-008. Presentation supported by The Office of the Provost, Seton Hall University.</p>	
Contact Bryan Pilkington, PhD Seton Hall University bryan.pilkington@shu.edu @bcpethic		References <ol style="list-style-type: none"> 1. Beauchamp, T. L., & Childress, J. F. (2013). <i>Principles of Biomedical Ethics</i> (7th ed.). Oxford University Press. 2. Carman, M. J., Siano, K., Mello, W., Vint, E., & Phillips, B. (2018). Implementation of a learning bundle to promote end-of-life education for pre-licensure nursing students. <i>Journal of Hospice and Palliative Nursing</i>, 30(4), 356-363. 3. Greenberg, S., Innella, N., Pilkington, B. (2021). Teaching End-of-Life Decision Making to Undergraduate Nursing Students. <i>Innovation in Aging</i>, Volume 3, Issue Supplement 1, Page 126. 4. Innella, N., Pilkington, B. & Greenberg, S. (2022). Undergraduate nursing students' responses to an end-of-life educational session. <i>Gerontology and Geriatrics Education</i>. DOI:10.1080/02701960.2022.2085981. 5. Heron, L., & deLente-Bertkau, J. (2020). Ethical dilemmas at the beginning and end of life: A needs-based, experiential-informed, small-group, case-based curriculum for pediatric residents. <i>MedEdPORTAL</i>, 16(10285). 6. Pilkington, Bryan C. (2022). "Ethics Education in the Health Professions." In <i>Applied Philosophy for Health Professions Education</i>, edited by Megan E. L. Brown, Marco Veer, and Gabrielle Maria Finn, 219-32. Springer Nature Singapore. 7. Pilkington, B. (2016). "Dignity, Health, and Membership: Who Counts as One of Us?" <i>Journal of Medicine and Philosophy</i> 41, 123, 115-39. https://doi.org/10.1080/03616274.2016.1156001. 			

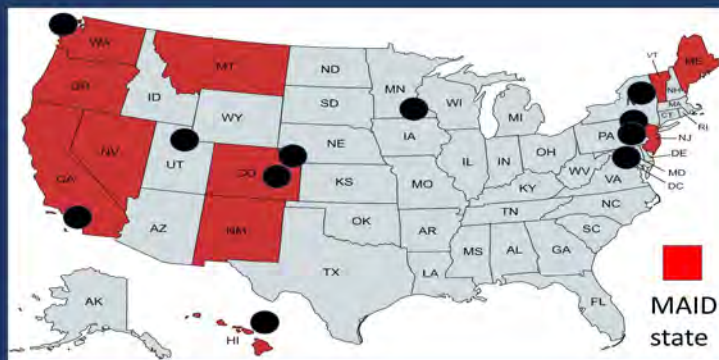
Medical Aid in Dying Ethics Consultation

MAID ethics

Since 2021, the professional society for U.S. medical aid in dying clinicians, ACAMAID, has offered an ethics consult service for eligibility, administration, and other ethics questions concerning MAID.

11 CEC

from 9 states
& 5 disciplines
(MD, JD, RN,
PhD, MPA)



6 cases

Summaries



- Losing hospice eligibility
- VSED as bridge to qualify
- Anorexia as terminal illness
- Consulting physician conflict

Publications



Hospice Nurse Ethics and Institutional Policies Toward Medical Aid in Dying
How can nurses fulfill their duty to patient and family?

ICCEC (Rome)
June 2023



Thaddeus Mason Pope, JD, PhD, HEC-C
Mitchell Hamline School of Law (USA)
www.thaddeuspope.com

Integration of Clinical Ethics Consultation Service in a Private Hospital in Chile

María Bernardita Portales Velasco, Juan Pablo Beca Infante, and Karen Goset Poblete



INTEGRATION OF A CLINICAL ETHICS CONSULTATION SERVICE IN A PRIVATE HOSPITAL IN CHILE

MARÍA BERNARDITA PORTALES VELASCO^{1,2,3}
JUAN PABLO BECA INFANTE^{1,2}
KAREN GOSSET POBLETE¹

¹ Clinical ethics consultant, Clínica Alemana de Santiago, Chile
² Professor, Bioethics Center, Faculty of Medicine Clínica Alemana Universidad del Desarrollo, Santiago, Chile
³ PhD student, Bioethics Faculty, Anahuac University, Mexico City, Mexico

INTRODUCTION

Clínica Alemana de Santiago (Chile) has had a Clinical Ethics Committee since 1999 and a Clinical Ethics Consultation Service since 2008 with complementary roles.

This Clinical Ethics Consultation Service is available all through the working week and is staffed by 3 clinicians.

Clínica Alemana de Santiago is a non-profit, private teaching hospital. It has all medical specialties and a capacity of 410 beds:

- 67 adult intensive and intermediate care
- 25 neonatal intensive and intermediate care
- 12 pediatric intensive care
- 278 general medicine and surgical
- 28 temporary hospitalization (1)



OBJECTIVE

To describe how the clinical ethics consultation system is integrated within clinical care of hospitalized patients in Clínica Alemana de Santiago.

METHODOLOGY

A quantitative, retrospective, cross-sectional, and descriptive analysis.

The database included 156 clinical ethics consultation reports saved in the records of 143 patients hospitalized at Clínica Alemana from January 2015 to December 2019.

RESULTS

- 142 of the 156 (91.0%) consultations - were requested by physicians, 1 by a nurse, and 4 by patients' relatives or surrogates. One report did not specify who made the request and 8 consults correspond to patients follow up for whom there was no formal interconsultation request.
- 128 (82.0%) were requested in adults units; and 26 (16.7%) neonatal and pediatric inpatient units. Only 1 for the high obstetric risk unit, and 1 for the adult emergency unit.

CONCLUSIONS

1.- Clinical Ethics Consultation Service was generally requested by physicians, for adult patients aged over 60 years with an unrecoverable prognosis, or in a terminal condition.

2.- These findings corroborate the necessity of training clinical personnel to expand the integration of clinical ethics consultation services within patient's care.

3.- Clinical staff need to know the purposes of ethical consultation and learn when and how to request it.

4.- It would be appropriate to promote and ease access to clinical ethics service in Clínica Alemana de Santiago to patients and their relatives.

ANALYSIS

Patient's characteristics	N°	%
Total of patients	143	100
Gender		
Male	90	62.9
Female	53	37.1
Age	64 (0-89)	
0-11 months	26	18.2
1-14 years	4	2.8
15-24 years	3	2.1
25-34 years	11	7.7
35-44 years	17	12.0
45-54 years	17	12.0
55-64 years	17	12.0
65-74 years	17	12.0
75-84 years	17	12.0
85-94 years	17	12.0
95-104 years	17	12.0
Diagnosis		
Neurological	39	27.2
Cardiopulmonary	27	18.9
Oncological	23	16.1
Neonatal	16	11.2
Other	16	11.2
Prognosis		
Unrecoverable	14	9.8
Recoverable	19	13.3
Unrecoverable	80	55.9
Terminal	70	49.0
Capacity at first consultation		
Yes	37	25.9
No	106	74.1
Doubtful	1	0.7
Not registered	4	2.8

Table 1. Characteristics of hospitalized patients with clinical ethics consultation between 2015 and 2019.

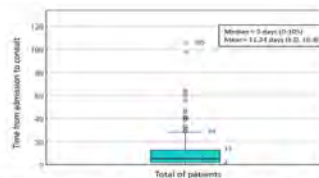


Figure 1. Time elapsed between the admission of the patient to the hospitalization service requesting bioethics consultation and the day on which clinical ethics consulting is carried out in the total number of patients in the sample.

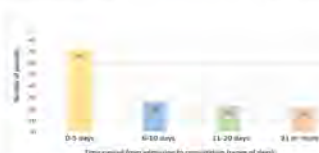


Figure 2. Range of days elapsed between the admission of the patient to the hospitalization service requesting bioethics consultation and the day on which clinical ethics consulting is carried out in the total number of patients in the sample.

REFERENCES

- 1) Clínica Alemana de Santiago. Guías de Ética Clínica (2015). Disponible en: <https://www.clinicaalemana.cl/etiqueta/etica-clinica>. Fecha de consulta: junio 8, 2020.



Bedside Bioethics Consultation: The Experience of the Clinical Ethics Consultation Service at the Fondazione Policlinico Universitario "A. Gemelli" IRCCS in Rome

Antonio G. Spagnolo, Barbara Corsano, and Dario Sacchini



Spagnolo Antonio Gioacchino, Corsano Barbara, Sacchini Dario

Institution: Center for Research in Clinical Bioethics and Medical Humanities (CRIBCeMH) - Fondazione Policlinico Universitario "A. Gemelli" IRCCS, Rome
Address: Section of Bioethics and Medical Humanities, Università Cattolica del Sacro Cuore - Largo Francesco Vito, 1 – 00168, Rome (Italy)
e-mail: barbara.corsano@unicatt.it

INTRODUCTION

In the last few decades, Clinical Ethics Consultation (CEC) has been introduced in the clinical practice of some Italian hospital facilities. It has proved itself to be a precious and efficient tool: it helps healthcare professionals, as well as patients and guardians/trustees, to identify the ethical and value dimensions within those complex and problematic clinical cases where ethics dilemmas or conflicts arise with regards to decisions to be taken.

The overall objective of CEC is to serve the good of the whole person, through the optimization of the quality of care and by fostering a better climate within the hospital setting.

OBJECTIVE

We wish to reflect on the experience of the Clinical Ethics Consultation Service (CEC Service) of the Institute of Bioethics and Medical Humanities at the Università Cattolica del Sacro Cuore for Fondazione Policlinico Universitario "A. Gemelli" IRCCS (FPG), in Rome.

MATERIALS AND METHOD

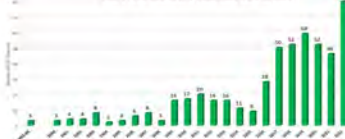
We conducted a retrospective analysis of the consultations performed by the CEC-FPG Service identifying the consultations requested and performed from the beginning of the service (1992) to 2022.

In particular, the trimestral data coming from the last 3 years (2020-2022) were gathered and analyzed, critically discussing:

- number of CEC requested,
- number of CEC performed,
- clinical areas that requested CECs,
- type of consultation (standard CEC or shared document),
- questions that emerged, both ethical and non-ethical.

RESULTS AND DISCUSSION

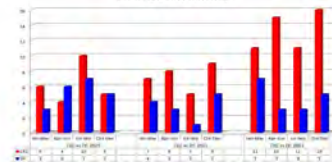
FIG. 1 - CEC REQUESTS/YEAR from 1992 to 2022



To get a sense of how the Clinical Ethics Consulting Service has evolved in the departments of the "A. Gemelli", the total number of CEC requests received by the CEC-FPG Service was first acquired (516) and subsequently grouped by year (Fig. 1).

The general upward trend in CEC requests over the years is evident, despite the decline that may have occurred in one single year. In particular, this trend has clearly grown since the Clinical Ethics Consulting Service was officially included in the Information System of the University Hospital, facilitating the clinicians in their request for CEC.

FIG. 6 - CEC vs SD 2020-2022



In Fig. 6, the number of standard CECs and Shared Documents performed in the last 3 years are compared.

In most cases, the question for which the CEC was requested was of a purely ethical nature: proportionality of the treatments (invasive, such as tracheostomy and PEG; resuscitators, in case of critical events; dialysis; pain management; antibiotic therapy), pain management and palliative care up to continuous/intermittent deep palliative sedation, ethics of life-saving interventions in the case of ectopic pregnancies (ectopic pregnancies, scar pregnancy), shared care planning, evaluation of the care setting.

FIG. 2 - TRIMESTRAL CEC REQUESTS 2020-2022

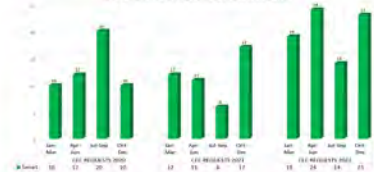


FIG. 3 - TRIMESTRAL PERFORMED CEC 2020-2022

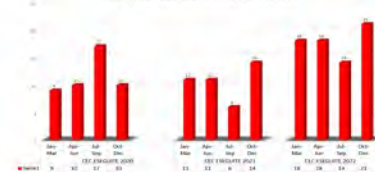


Fig. 4 shows the data relating to the origin of the CEC requests from 1992 to 2022, identifying the departments and classifying them in specific clinical areas: Obstetrics-Gynecological Area, Pediatric and Neonatal Area, Internal Medicine and Infectious Diseases Area, Neurology, Intensive Care Area, Surgical Area, Adult Hospice.

In Fig. 4, the requesting areas of the last three years are shown. It is evident that, even if the percentages have slightly changed over time, the areas that continue to require the most CEC are those related to women's and children's health (> 50%) as well as those involving neurodegenerative diseases.

FIG. 4 - CLINICAL AREAS REQUIRING CEC (1992-2022)

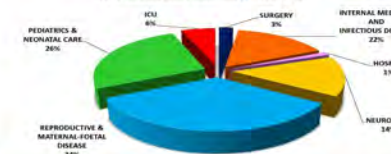
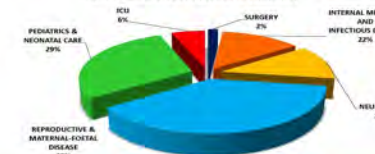


FIG. 5 - CLINICAL AREAS REQUIRING CEC (2020-2022)



CONCLUSIONS

The retrospective analysis of the reported data shows that, since the CEC-FPG Service was established, it has had an ever-increasing trend, especially in the last three years due to various factors: increased awareness and training of healthcare professionals, its more visibility into the organizational information system, a team of 3 consultants and the elaboration of SOPs and PCAs which codify the CEC Service. The changed socio-cultural and legislative conditions (Law 38/2010 and Law 219/2017) also played a role, placing end-of-life ethical issues to the attention of the public debate, without hiding the weight associated with liability issues professional and clinical risk management.

The data presented also highlight how the major ethical issues emerge in the beginning of life and the end of life areas.

REFERENCES

1. Spagnolo AG, Corsano B, Sacchini D. La consulenza bioetica di letto del malato: l'esperienza del Servizio di Etica clinica presso la Fondazione Policlinico Universitario "Agostino Gemelli" IRCCS - Roma. *Medicina e Morale* 2019;4: 375-395.
2. Corsano B, Sacchini D, Spagnolo AG. (2021). «Documento Condiviso di Orientamento Etico-Assistenziale nella Consulenza di Etica Clinica». *Medicina e Morale*, 2021;73: 275-289.
3. Society for Health And Human Values – Society For Bioethics Consultation, Task Force On Standards for Bioethics Consultation, Core competencies for health care ethics consultation. The report of the American Society for Bioethics and Humanities, Glenview, American Society for Bioethics and Humanities;2011.
4. Sacchini D, Corsano B, Spagnolo AG. Le procedure operative nella consulenza di etica clinica: l'esperienza del Servizio di Bioetica clinica presso la Fondazione Policlinico Universitario "A. Gemelli" IRCCS-Università Cattolica del Sacro Cuore. *Roma (IT), MEDIC* 2019; 27 (1): 33-39.

Female Genital Mutilation: High Prevalence, Few Convictions

Rachele Turrini, Francesco Baldisser, Francesco Ausania, Stefania Turrina, and Domenico De Leo

«17th Annual International Conference on Clinical Ethics and - Consultation»
7-10 June 2023, Rome

Female Genital Mutilation: high prevalence, few convictions

Rachele Turrini¹, Francesco Baldisser¹, Francesco Ausania¹, Stefania Turrina¹, Domenico De Leo¹

¹. Department of Diagnostics and Public Health - Unit of Forensic Medicine, University of Verona, Italy

BACKGROUND

As defined by the World Health Organization, female genital mutilation is a practice that involves the partial or total removal of the external female genitalia for non-medical reasons¹ and is recognized internationally as a violation of the women's human rights. Despite being illegal in Italy (*Codice Penale, Art. 583-bis*), this practice remains prevalent, particularly among immigrant communities, and represents a widespread and current problem.

The aim of this study is to evaluate the correlation between the scale of this phenomenon and its juridic outcomes.

MATERIALS AND METHODS

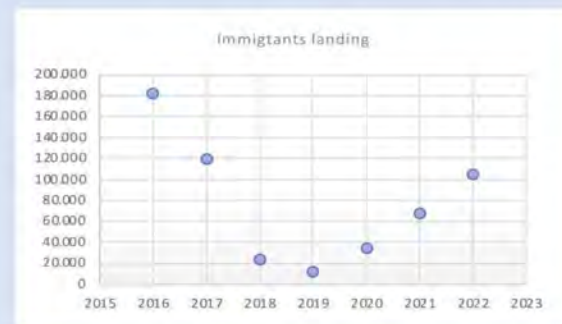
We reviewed the scientific literature, integrating it with immigrants landing data collected by Italian Ministry of Interior. We also examined data by European Institute for Gender Equality about the number of women affected by female genital mutilation in Italy, as well as those at risk of undergoing this procedure. These data were compared with the number of existing criminal prosecutions.

RESULTS

In 2016, women affected by female genital mutilation were estimated to be approximately 70.469²; in 2018, their number was almost 87.600³.

In 2016, according to the European Institute for Gender Equality, 15-24% of girls aged 0-18 from female genital mutilation-practicing countries were at risk of being subjected to the procedure⁴.

Despite these data, the number of criminal proceedings carried out from 2015 to 2019 for the crime of female genital mutilation is extremely low, with, at most, 5 cases per year.



DISCUSSION

In consideration of the recent increase in migratory flows, it is reasonable to assume that the number of women affected by female genital mutilation and those at risk of being subjected to the same procedure has increased further.

The inconsistency between the cases and the number of criminal proceedings indicates that the phenomenon of female genital mutilation is not properly recognized and reported.

Given the complexity of the admissibility criteria for this offence, it is necessary to consult with specific figures such as a forensic scientist.

Years	Preliminary investigations		Trial section	
	Entered in the criminal prosecution register	Defined	Entered in the criminal prosecution register	Defined
2015	1	1	1	1
2016	0	0	1	1
2017	4	1	0	0
2018	3	5	3	1
2019	4	4	4	2

Table 1. Italian Senate of the Republic, Document n° XXII- bis n.6, "Commissione parlamentare di inchiesta sul femminicidio nonché ogni forma di violenza di genere".

CONCLUSIONS

It is advisable to train and make healthcare professionals aware of the clinical presentation of these procedures; furthermore, is necessary to involve a medical legal expertise to help the decision-making process of reporting to the judicial authority, when necessary.

REFERENCES

1. <https://www.who.int/news-room/fact-sheets/detail/female-genital-mutilation>
2. Ortensi LE, Farina P, Leye E. Female genital mutilation/cutting in Italy: an enhanced estimation for first generation migrant women based on 2016 survey data. BMC Public Health. 2018 Jan 12;18(1):129. doi: 10.1186/s12889-017-5000-6. PMID: 29329573; PMCID: PMC5767052.
3. Italian Senate of the Republic, document n° XXII- bis n.6, "Commissione parlamentare di inchiesta sul femminicidio nonché ogni forma di violenza di genere".
4. European Institute for Gender Equality, "Female genital mutilation how many girls are at risk in Italy?", Doi: 10.2839/730929

AIMS & SCOPE

The Journal of Hospital Ethics (JoHE) is designed to enhance interdisciplinary discourse in bioethics, and to assist in the development of the practical reasoning and clinical skills required for recognizing, understanding, and managing moral uncertainties and ethical complexities within hospital systems and hospital practice.

EDITORIAL POLICY

The Journal of Hospital Ethics (JoHE) adheres to the editorial standards and authorship criteria recommended by the International Committee of Medical Journal Editors (ICMJE). We welcome submissions of completed manuscripts as well as abstract paper proposals by authors with academic or professional expertise in relevant fields. Whereas book reviews are solicited by the Editorial Group, all other submissions to the journal will be reviewed for publication with the understanding that they are not under consideration, accepted, or published elsewhere. Authors of all material accepted for publication will be required to assign copyright to the publisher. Please limit manuscript submissions (whether intended as a feature or case analysis) to a range of 4000-6000 words, and abstract paper proposals to 250 words. All manuscripts should be anonymized for review, include an abstract of no more than 250 words (a specific abstract structure is intentionally not provided given the interdisciplinary nature of the journal's content). JoHE adheres to the American Medical Association Manual of Style (11th Edition).

PEER REVIEW PROCESS

Manuscript submissions are subject to two double-blind peer reviews by individuals chosen for their expertise in relation to the content of the manuscript. Should these two reviews result in inconsistent recommendations as to the general acceptance of the manuscript, a third individual will be selected for an additional double-blind peer review in order to determine the submission's suitability for publication. Reviewers follow a guided peer review process for the determination of a manuscript's acceptance, need for revision, as well as rejection, in addition to being provided the opportunity to return qualitative feedback to submitting authors (for additional information regarding this process, please contact the Managing Editor). Editors are not involved in decisions regarding papers they have authored or co-authored. Should any member of JoHE's Editorial Group or Editorial Advisory Board submit internally a manuscript for consideration, that manuscript will undergo the same double-blind peer review process and be held to the same publication standards as any other submission. In addition, accepted manuscripts will undergo a scholarship review by the medical librarians listed in the Editorial Group (Content Editors) as part of the production process.

DISCLAIMER

The opinions and perspectives offered in JoHE reflect only the views of the authors and editors, and do not represent the views of others within the MedStar Health system or other institution or organization with which any of the members of the JoHE Editorial Advisory Board are affiliated. Clinical case analyses are entirely fictional. No part of this journal may be reproduced by any process or technique without explicit written permission from the Editorial Group.

For complete information regarding JoHE's publishing policies and best practices, or to subscribe, please visit: www.medstarwashington.org. Click on About MedStar Washington, The John J. Lynch, MD Center for Ethics, then Journal of Hospital Ethics.

SUBSCRIPTIONS

The *Journal of Hospital Ethics* is produced and published by the John J. Lynch, MD Center for Ethics. Subscriptions are by volume; each volume consists of 3 issues.

INSTITUTIONAL*.....\$100.00

Institutional subscriptions include full network institutional access to all back and current issues via IP validation. Two print copies of each issue are also mailed to your library/institution.

INDIVIDUAL.....\$50.00

Individual subscriptions include one print and one e-copy of each issue, mailed directly to the individual subscriber.

INDIVIDUAL BACK ISSUES.....\$25.00

Includes an e-copy of a single back issue for non-institutional subscribers.

***INSTITUTIONAL ACCESS**

Institutional subscribers are able to access the full run of JoHE volumes directly from their network: Log-in from your home institution and go to www.medstarwashington.org, click on About *MedStar Washington, The John J. Lynch, MD Center for Ethics*, then *Journal of Hospital Ethics* to download an e-copy of any issue. Please send all subscription inquiries to: JOHE@MedStar.net

The Journal of Hospital Ethics is the official proceedings publication for the International Conference on Clinical Ethics and Consultation (ICCEC) and a partner journal of the American Society for Bioethics and Humanities (ASBH). Members of the ASBH will receive a 30% discount from their subscription to JoHE. All presenters of the ICCEC receive a complementary copy of their respective conference's proceedings.





MedStar Health

John J. Lynch, MD Center for Ethics
MedStar Washington Hospital Center
110 Irving Street, NW
EB 3108
Washington, DC 20010

Non-Profit
Organization

U.S. Postage
PAID

Washington Hospital
Center