I. Plenary Sessions

Plenary 1
Jocelyn Downie
Dalhousie University
Lindy Willmott
Australian Centre for Health Law Research, Queensland University of Technology
Katrine Del Villar
Australian Centre for Health Law Research, Queensland University of Technology
Comparative International Review: Legal Status of Assisted Dying around the World

Assisted dying has been lawful in some countries for many years including in Belgium, the Netherlands, and some states within the U.S. But the past five to ten years have seen unprecedented and, sometimes, unexpected developments in legalizing assisted dying in many countries around the world. This session briefly reviews the law in countries where assisted dying has been lawful for an extended time. Then the focus turns to describing the major recent developments internationally in the regulation of assisted dying. Explanations of what the legal status has become and how the changes came about are offered through illustrative examples including Canada, Australia, and Portugal. The audience is invited to reflect on the substantive and procedural differences between the jurisdictions and to continue engaging in the process of learning from others and paying it forward that characterizes the field of the study of end-of-life law, ethics, and policy. Dr. Downie will cover both the USA and Canada but will focus on Canada. Dr. Willmott will cover both Australia and NZ but will focus on Australia. Dr. Del Villar will cover all Europe but will focus on Spain and Portugal.

Plenary 2
Ben White
Australian Centre for Health Law Research
Eliana Close
Australian Centre for Health Law Research, Queensland University of Technology
Madeleine Archer
Australian Centre for Health Law Research, Queensland University of Technology
Kenneth Chambaere
End-of-Life Care Research Group, Ghent University
How Best to Regulate Assisted Dying? Reflections from a Comparative Study of Assisted Dying Regulation in Australia, Canada, and Belgium

While much attention has focused on whether assisted dying should be lawful, and if so, who should have access to it, less consideration has been given to how best to regulate assisted dying. This 4-year project analyzed how assisted dying is regulated in three countries with different assisted dying systems, in which assisted dying has been lawful for different periods of time. Australia has arguably the most conservative and highly regulated model of assisted dying in the world and its first law (in the state of Victoria) has been operational for only 4 years. Canada has more experience of assisted dying (legalization was prompted by a court decision in 2015) and has wider eligibility criteria, the scope of which are being actively deliberated upon by government inquiries. Finally, Belgium also has broad eligibility criteria but has over two decades of experience with assisted dying. This session presents project findings from across these three

countries drawing on two main bodies of work. First, we undertook a comprehensive mapping exercise of the sources of regulation that govern assisted dying, including law, policy, training, and system design. Second, we conducted semi-structured interviews across the three countries with over 250 key participants in the assisted dying system: patients, family caregivers, doctors, nurses, pharmacists, hospital administrators, aged care facility managers, oversight body members, health departments, advocacy organizations, health and medical organizations, and others. After reflecting on the experience of regulating assisted dying in each of the three countries, comparative observations are made about what we learn about regulating assisted dying. Opportunities for improving this regulation both locally and globally are considered.

Plenary 3
Bregje D. Onwuteaka-Philipsen
Amsterdam University Medical Center
Agnes van der Heide
Erasmus University Medical Center Rotterdam
How Best to Regulate Assisted Dying? Reflections from the Netherlands

In May 2023, the fourth evaluation report on The Dutch Termination of Life on Request and Assisted Suicide Act was published. This report covers the period 2017 - 2022. What lessons does this assessment offer for the optimal regulation of assisted dying?

Plenary 4
Constance MacIntosh, MA, LLB
Schulich School of Law , Dalhousie University
Hot Topics in Assisted Dying

This fast-paced question-and-answer moderated session dives into tension points and controversies in various jurisdictions concerning assisted dying practices and their future. From debates arising from disabled/vulnerable communities to 'completed life' requests, mental illness, and advanced directives, this session highlights where, how, and by whom legal, ethical and clinical boundaries are being drawn and pushed.

Plenary 5
James Downar
University of Ottawa
Luc Deliens
End-of-life Care Research Group, Vrije Universiteit Brussel (VUB) & Ghent University
Christian Ntizimira
African Center for Research on End of Life Care
Palliative Care: Global Challenges and Opportunities

Palliative Care as a health service model has become an important part of healthcare, as many fields of medicine have come to appreciate how a palliative approach can improve quality of life and can be given alongside curative or life prolonging therapies. Although Cicely Saunders at the start of palliative care in the UK had envisaged total and holistic care, including mental, social,

and spiritual care, the service models of palliative care that have been implemented ever since have become highly medicalized, missing out on reality that dying is a social experience with a medical component, not a medical experience with a social component. Even in the most developed countries, access to palliative care is limited. In the UK, the hospice movement has been described as 'too good to be true and too small to be useful'. Furthermore, as the demand for palliative care expands and people come to expect palliative care as the standard of care, particularly approaching the end-of-life, the challenge of meeting this demand has exposed the limitation of our medically focused model of palliative care. There are not enough palliative care clinicians to have a palliative care specialist next to the bedside of all dying patients, but this is not needed. People prefer to die at home and not in hospitals and palliative care should be re-integrated into the community, just like it was 50 years ago when dying took place within family homes surrounded by loved once. Given the fact that 80% of needs and problems of patients and their families are social and psychological problems, the main challenge of palliative care policy is how to redesign palliative care as an intrinsic part and value of our societies. What can be done by people, family, neighbors, friends, volunteers, colleagues, etc within their own communities to support people with serious illness, to support people that are confronted with loss? And what needs to be done by specialized services for these people? Expanding palliative care into society has huge implications for policy and practice. Next to service development, some of the new challenges are community engagement, community development, empowering of local communities, social networks and creating social capital. Other challenges are also emerging, including the limitations of advance directives and advance care planning, (un)healthy aging, the legalization of Medical Assistance in Dying, the problems associated with protocolization of end-of-life care in Europe, for-profit hospices in the US, etc. In this session, the speakers will outline these challenges and how they affect palliative care and describe novel approaches or opportunities to overcome these challenges in order to facilitate the provision of palliative care to those who currently do not receive it.

II. Abstracts of submitted presentations in alphabetical order by first (submitting) author's family name

Indra Albrecht
Ghent University
Oral Presentation
What are indicators to evaluate the quality of palliative sedation? A scoping review
#94

Introduction. Palliative sedation entails the use of sedating drugs to induce a state of decreased consciousness until death and is frequently used in end-of-life care. Initiatives to evaluate and improve the quality of palliative sedation (PS) are still missing a comprehensive set of core indicators for evaluating the quality of PS.

Research question. What are outcome- and process indicators, as reported in academic and grey literature, for evaluating the quality of palliative sedation?

Methods. In this scoping review, we searched academic databases (MEDLINE, EMBASE, CENTRAL, CINAHL, PsychINFO), alongside non-academic databases (MEDNAR, Web of Science) between February and April 2023. Articles with primary data published after 2009, not restricted to any specific population and/or study design, were included in the review.

Results. Fifty-five articles were included (academic 45, grey 10). In total, 146 unique indicators could be identified. These were organized into 19 outcome domains and further categorized into four categories: process indicators of decision-making (indication, proximity to death, patient involvement, patient support, family involvement, artificial nutrition, and hydration), process indicators of performance (level of sedation, medication, monitoring, duration, care continuation, family support), outcome indicators (patient comfort, family wellbeing, family satisfaction, HCP wellbeing, HCP satisfaction), and interprofessional collaboration (HCP team, documentation).

Conclusions & recommendations. Our review underlines the complexity inherent to PS practice, presenting an extensive list of indicators for quality of palliative sedation. It also suggests that an evaluation solely focused on clinical parameters may be insufficient; equal emphasis placed on appropriate decision-making, care coordination, and satisfaction and well-being among bereaved family members and healthcare professionals could contribute to its quality. These findings demonstrate the need for a comprehensible instrument to evaluate the practice and can serve as the basis for a Core Outcome Set to evaluate palliative sedation."

Madeleine Archer
Australian Centre for Health Law Research, Queensland University of Technology
Oral Presentation
Key challenges in providing assisted dying in Belgium: a qualitative study of health professionals' perspectives
#40

Background: Belgium has one of the longest standing assisted dying or 'euthanasia' systems in the world. The period since legalisation is characterised by a significant volume of empirical research,

reports produced by the federal oversight body, and several legislative and judicial developments in euthanasia law and practice. While evidence suggests that this system is working well, the law has not yet been formally evaluated. There is a need to obtain providers' perspectives on persisting or novel challenges experienced in providing euthanasia and navigating this system. This need is emphasised considering recent research highlighting the complex regulatory framework which governs euthanasia in Belgium. As such, we sought to identify the key challenges that health professionals experience providing euthanasia in Belgium.
Methods: Semi-structured, online interviews were conducted with 20 physicians and nurses who had recent experience providing euthanasia. Interview transcripts were thematically analysed using a reflexive approach, which generated several semantic themes.

Results: While participants globally endorsed the system, several challenges were identified. These include the emotional and professional challenges of providing euthanasia; managing patients' and families' expectations in relation to the accessibility and appropriateness of an assisted death; difficulty applying the law with confidence in some clinical situations, for example, when assessing non-terminally ill patients for euthanasia, or when an advance directive on euthanasia is invoked; issues impacting patient access; and limited opportunities to reflect on the system in an objective and productive way.

Discussion: The findings of this study suggest that more support is needed for euthanasia providers, and that a formal evaluation of the law is needed. These findings demonstrate the value of ongoing scrutiny of assisted dying systems, and routine legislative reviews, even in well-established systems. This research provides opportunities for policymakers in Belgium (and internationally) to develop strategies to mitigate or avoid some of the identified challenges.

Margaret Battin
University of Utah
Rebecca Brown
Panel
What do we really want in a medical aid in dying law?
#34

Beginning with a brief discussion of the rationale for medical aid in dying, this session explores current and potential features of MAID laws, both in the U.S. and internationally, in order to consider what provisions are medically, legally, and/or morally essential to the safe and helpful provision of such services. The format of this session will invite direct audience participation, with the moderators shaping the conversation, to explore three general areas:

1) What provisions need a MAID law have in order to be politically acceptable?
2) What provisions need a MAID law have in order to be morally acceptable?
3) What combinations of provisions of both sorts would serve to make a most nearly ideal MAID law, if there could be such a thing?

Issues for discussion might include qualifying conditions (e.g., requirements for prognoses, terminal illness, mental health) waiting times, residency requirements, adaptations for disability needs, drug administration requirements (including oral and other gastrointestinal routes, IV, inhalation, etc.), exceptions for medical challenges, conscience clauses, licensure of providers, reporting to health authorities, safeguards, and of course much much more. There's no

stipulated agenda; any or all of these can be on the table.

In avoiding pre-prepared lectures and stressing interactive audience participation, this session is intended to stress creative thinking about MAID regulation—not just what it is, but what it could be.

Nancy Berlinger
The Hastings Center
Anna Elsner
University of St. Gallen (Switzerland)
Emily Largent
Perelman School of Medicine, University of Pennsylvania
Panel
When persons facing dementia choose to hasten death: America's ethical, legal, medical & social landscape
#81

This panel will share and explore a new special report from The Hastings Center centered on a landscape review of current ethical, legal, medical, and social considerations concerning hastening death in the context of a primary diagnosis of dementia. Panelists, who include the lead editor of the report and a co-editor who is the first author of the landscape review, will discuss the goals of this special report and potential applications of the landscape review to structure clinical and legal practitioner discussion and policy development concerning evolving questions not fully covered by existing medical decision-making provisions and largely outside the scope of MAID provisions in the US. Panelists will also explain the process of developing this open-access report, its attention to selected topics beyond the landscape review, and the consolidated recommendations of report authors for clinical and legal practitioners, policymakers, and research funders, relevant to equity in dementia care and improved lives for people facing dementia.

Solenne Blanc
Palliative and Supportive Care Service, Lausanne University Hospital (CHUV), Lausanne, Switzerland
Oral Presentation
Professional facilitators' practices of advance care planning in Switzerland: a qualitative study
#67

Introduction: In Switzerland, the Federal Office of Public Health (FOPH) has recently published a roadmap for the implementation of Advance Care Planning (ACP). This document promotes and strengthens its implementation by suggesting homogenized guidelines and has become a document of reference for Swiss health care institutions. Since there is no federal mandate for ACP implementation, it remains a process conducted at a cantonal or private institution level where local adaptations are made. Hence, multiple approaches have emerged, and health care professionals are not using a common procedure.

Aim: Our aim is to explore how ACP is conducted by trained and non-trained facilitators in practice and understand their experiences with ACP.

Methods: Starting in September 2023, data will be collected through a qualitative and exploratory design. ACP facilitators working in palliative care in the three different linguistic regions of Switzerland (Zurich, Lausanne, Lugano) will be invited to describe their perspective and assessment about ACP in semi-structured interviews. Qualitative analysis will focus on patterns in facilitators' experiences and examine challenges they face.

Results: Findings from preliminary analysis of the interviews will be presented. We will identify issues underlying the implementation of ACP with patients, such as the low engagement rate and patient dropout during the ACP process. We expect cultural differences to be strong factors influencing the practices of facilitators. By clarifying the context in which they act, we want to determine what challenges facilitators face, to which extent they rely on the different existent official documents (roadmap, advances directives of the Swiss Medical Association FMH, etc.) and how they adapt ACP discussions according to patient profiles, expectations and ACP needs.

Conclusion: Analyzing facilitator experiences will provide critical reflection for suggestions to improve ACP implementation in Switzerland as well as in other countries."

Solenne Blanc
Palliative and Supportive Care Service, Lausanne University Hospital (CHUV), Lausanne, Switzerland
Oral Presentation
"I don't want to be a burden": A qualitative study about patient choices about assisted suicide
#83

Introduction: As more countries establish laws to allow assisted dying, more people have greater access to this option. In Switzerland, this process is referred to as assisted suicide. Research shows that many patients who undergo assisted suicide often justify this decision via different motivations, such as the fear of unbearable suffering or self-perceptions of becoming a burden to their families. Patient desires to alleviate this self-perceived burden can be considered as an altruistic gesture, in the sense that patients may intentionally take into account the well-being of family members by wanting to relieve them of challenges related to their cares. More research is needed to explore the relationship between patients' self-perceptions and motivations to undergo assisted suicide. Furthermore, families' experiences of loved ones' burden perceptions in this process have not received adequate research attention.

Aim: The aim of the study is to describe and understand patients' experiences in relation to their self-perceptions of being a burden to their families, unbearable patient and family suffering, and assisted suicide choices. We will also investigate family experiences and resources when a seriously ill family member expresses feeling like a burden and wishes assisted suicide.

Methods: We will conduct 48 qualitative, semi-structured interviews with patients and their relatives throughout Switzerland. Data will be analyzed with thematic analysis. An inductive approach will allow us to account for unexpected findings that may emerge from participants' narratives and discourses.

Results: We will present preliminary results from interviews, during which we will ask participants about resources (financial, social, health system), family involvement, perceptions of burden, and

alleviating suffering. We will also discuss methodological approaches for exploring such an intimate and sensitive topic.

Conclusions: Results will provide important insights to inform clinician practices for diverse sociopolitical contexts in countries where assisted dying procedures are legal."

Fenne Bosma
Department of Public Health, Erasmus MC, University Medical Center Rotterdam
Oral Presentation
The frequency of self-directed dying in the Netherlands: a research protocol
#50

In the Netherlands, assisting in suicide is allowed for physicians, and regulated by the Termination of Life on Request and Assisted Suicide (Review Procedures) Act. However, some people decide to end their lives without a physician's help. Two ways of such self-directed dying are Voluntary Stopping Eating and Drinking (VSED) and Independently taking Lethal Medication attended by a Confidant (ILMC). The frequency of people who die each year by one of these methods was last examined in 2007. Since then, there have been some major developments, such as the issue of a guideline by the Royal Dutch Medical Association (RDMA) on VSED, the endorsement by various political parties of a proposal for a new law on assistance in dying, and the societal debate surrounding self-chosen death. These developments may have had an influence on the frequency of self-directed dying.

The primary objective of this study is to estimate how many people die each year in the Netherlands by VSED or ILMC. Secondary objectives include studying whether this number has changed since 2007; exploring possible explanations for changes in frequencies; and providing insight in the quality of dying of people who choose self-directed dying.

In 2024, we will conduct a cross-sectional questionnaire study with additional qualitative interviews. An online questionnaire will be sent out to a randomly drawn sample ($n \approx 37.500$) from a large representative panel of the Dutch adult population. A two-stage screening procedure will be used to check whether the experiences of the respondents represent a death by VSED or ILMC. Data will be analyzed using quantitative software SPSS. Interviews (20 from VSED, 20 from ILMC) will be audio recorded and thematically analyzed using qualitative software N-Vivo.

Results will be published in a scientific journal within one year after the completion date of the study.

Fenne Bosma
Department of Public Health, Erasmus MC, University Medical Center Rotterdam
Oral Presentation
The Dutch practice of euthanasia and assisted suicide in patients with psychiatric disorders (between 2017-2022)
#111

The Netherlands are still one of the few countries in the world that legally allow euthanasia or assisted suicide (EAS) in patients who suffer from a psychiatric disorder (PD). Each performance

of EAS must be reported to the Regional Euthanasia Review Committees (RTEs), which subsequently assess whether the physician acted in accordance with the six statutory criteria of due care. Assessment of EAS in PD cases is widely acknowledged as complex, and the practice is continuously evolving. With our study we aim to provide more insight into the (review) practice of EAS in patients with a PD.

In a retrospective study we identified characteristics of summarized and anonymized PD cases published on the RTEs' website between 2017 and 2022 (N=72). Furthermore, we explored the RTEs' review of PD cases that were assessed as 'not in accordance with the due care criteria' (NIA) (N=11) and considerations behind this assessment.

Patients suffering from a PD who died by EAS were mostly female (67%), older than 30 years (89%), and suffering from two or more conditions, both psychiatric and somatic (74%). In almost all published cases (99%) two or more independent physicians were consulted for evaluation of the patient's EAS request. In 63% of the cases, EAS was performed by a physician associated with the Euthanasia Expertise Centre (EE). When a case was assessed as NIA, it mostly concerned the due care criterion of consulting an independent physician (N=8). The other cases concerned the criterion of the unbearable suffering with no prospect of improvement (N=2), and the voluntary and well considered request (N=1).

In assessing PD cases, the RTEs give more specific content to some of the broadly defined statutory criteria of due care. They seem to attach great importance to the role of the consulted independent physician, which should be a psychiatrist.

Lowrey Brown
Final Exit Network
Poster
Ethical decision-making when choosing to die: Connecting how people choose with what they choose
#24

New research examining the religious beliefs, source of moral authority, and perceived locus of control of individuals wishing to end their lives in the face of intractable suffering from a medical condition provides empirical support for Ronald Dworkin's framework for ethical decision-making when facing the question of ending life. The study population comprised applicants to Final Exit Network, some of whom choose to use medical aid in dying. They had a combination of a high level of education, a high sense of internal locus of control, a non-theist or no spiritual identification, a high inner sense of authority in moral decision-making, and lack of belief in an afterlife. These factors inevitably influence their personal and moral choices throughout their lives, including their choice to end their lives.

In his 1993 book, Life's Dominion, Dworkin argues that conservative and liberal disagreements about choosing to end life are founded in the same conviction: that human life is a creative investment and has inherent value. Where people's viewpoints diverge is in how they value different contributions to that creative investment. From one viewpoint, people find human life sacred based upon the "natural" or divine creative investment in that life. From the other, people find human life sacred based upon the "human" creative investment in that life. Dworkin argues that how individuals approach the question of ending life depends on which viewpoint they

operate from. The more value one places on the divine investment, the more value one places on the existence of life itself. The more value one places on the human investment, the more value one places on the quality of the life in question and the lives that are connected to it.

Clinicians and others may find Dworkin's framework useful in understanding and supporting individuals choosing to end their lives."

Lowrey Brown
Final Exit Network
Oral Presentation
Choice in dying outside the medical model: Serving those without access to MAID or VSED
#46

Final Exit Network is a nonprofit right to die organization serving competent adults faced with intractable suffering from a medical condition. For those meeting FEN's criteria, the Exit Guide Program provides education on a reliable, comfortable method of ending one's own life with publicly available equipment; support in planning a responsible self-deliverance; and a compassionate presence at the time of chosen death. This presentation will cover the criteria to qualify for guide support, an outline of the guide process, and an introduction to the use of inert gas for self-deliverance.

Access to choice in dying has been slowly expanding in the US, but options within the medical system, such as medical aid in dying (MAID) and voluntarily stopping eating and drinking (VSED), do not meet the needs of many who wish to conclude their lives before a future they consider unacceptable. The criteria for MAID are quite restrictive and exclude those facing dementia, while VSED is arduous and requires a support team, which many cannot assemble or afford, even if they are content with a drawn-out VSED death.

FEN's Exit Guide Program does not require applicants to have a terminal illness or be within six months of death, and serves individuals with early-stage dementia and those suffering from debility in advanced old age who feel their lives are complete. Exit guide support is provided free of charge, but, due to laws prohibiting assistance, clients must purchase their own equipment.

While MAID and VSED have received considerable attention among right to die organizations, academics, and the media, choice in dying outside the medical model remains far less known and often misunderstood. Final Exit Network's service is an option for meeting the needs of patients who wish to hasten their deaths but for whom medical options are not available or feasible.

Ian Brownhill
39 Essex Chambers
Oral Presentation
Protestor or patient: Is the law able to differentiate in VSED cases?
#77

The law of England and Wales has two competing and long-standing principles: the first and most fundamental is the principle of the sanctity of human life (as per Lord Goff of Chieveley in Bland). In a medical context, that means, there is a very strong presumption in favour of taking

all steps which will prolong life, and save in exceptional circumstances, or where the patient is dying, the best interests of the patient will normally require such steps to be taken. In cases of doubt that doubt falls to be resolved in favour of the preservation of life (as per Munby J in Burke).

The second principle is the protection of autonomy. In a medical context, the English and Welsh law recognizes that even when his or her own life depends on receiving medical treatment, an adult of sound mind is entitled to refuse it. In respect of voluntary stopping eating and drinking, the law of England and Wales appears clear: if a patient has the capacity to make decisions as to whether to take food and drink, he is entitled to starve himself to death if he so chooses (as per Baker J in the Dr A case).

This oral presentation will focus on three tensions between these principles:

(1) How can the law differentiate between a patient on hunger strike due to a political belief or one experiencing a delusional disorder?

(2) What does the law do when a patient refuses, or is unable, to explain their reason for stopping eating and drinking?

(3) All patients will, at some stage, lose the mental capacity to make decisions as to their hydration and nutrition before their death. Does the Mental Capacity Act 2005 sufficiently protect the patient's entitlement to starve themselves?

Julie Campbell
DePaul University College of Law
Oral Presentation
Beneficial care only: Reframing medical orders limiting the use of CPR at the end-of-life
#22

Despite the numerous medical advances that have occurred over the past century, the efficacy of cardiopulmonary resuscitation ("CPR") remains relatively low in patients at the end of their lives. Despite this fact, family members or surrogates routinely request ineffective therapies such as CPR be provided to terminal patients in hospital intensive care units ("ICUs"). The ethical guideline of beneficence requires physicians to avoid harmful interventions with a low likelihood of success. This places the physician and the family at odds when it comes to whether CPR should be administered to terminal patients amid the dying process.

This study investigates whether reframing the language used for orders limiting the use of CPR in end-of-life situations will result in greater patient acceptance of the physician-advised plan of care. Prior studies have examined whether "Allow Natural Death" orders would result in greater patient acceptance. Unfortunately, results from these studies are varied with the consensus in the United States being no significant change absent comprehensive conversations detailing the potential harms of CPR. We speculate these results are due to the patient/family's perception that such an order grants the medical team permission to discontinue all effective medical therapies.

This study attempts to overcome this misconception with the use of "Beneficial Care Only" in place of the traditional "Do Not Resuscitate" or the more recent "Allow Natural Death." The hypothesis is there will be increased patient acceptance of the plan of care if the order were

renamed using descriptive and affirmative terminology, which communicates to the patient and family the positive right to beneficial care, rather than the fallacious right to harmful CPR, or the misconception that other medically beneficial interventions will be discontinued.

Hannah Carpenter
University of Texas Medical Branch, Galveston
Georgia Loutrianakis
University of Texas Medical Branch, Galveston
Oral Presentation
Loss of end-of-life autonomy for pregnant persons post-Dobbs
#32

All individuals, regardless of their pregnancy status, should be able to direct their end-of-life care. However, over half of the states in the US endorse pregnancy clauses within their advanced directive regulations, invalidating the end-of-life decision-making of pregnant persons. Whilst pregnancy exclusion laws already impose several ethical implications on pregnant persons, anti-abortion legislation will place further constraints on autonomy, injustice, and dignity of pregnant or potentially pregnant persons. Dobbs v. Jackson Women's Health Organization carries further implications for pregnant persons and physicians in states where abortion is now criminalized. This legislation has exacerbated the need for advanced directives for pregnant persons following a growth in pregnancies, which has resulted in increased pregnancy mortality rates, unsafe pregnancies, and a lack of access to safe abortions.

Dobbs may result in further states adopting similar pregnancy exclusion laws, making it even harder for pregnant persons and their families to challenge restrictive advanced directive statutes. Pregnant persons have become increasingly more vulnerable because they experience an increased risk of mortality, health complications, and reduced access to needed care. These provide a need for end-of-life planning. To protect this vulnerable population, we suggest: (1) increasing awareness of exclusion laws; (2) encouraging persons to discuss their end-of-life preferences and complete advanced directives; (3) increasing research on how pregnant persons are affected by exclusions clauses; and (4) supporting legislation that allows pregnant persons' advanced directives to remain legitimate, regardless of their pregnancy status. In the shadow of Dobbs, we need to protect pregnant persons' autonomy wherever possible.

CM Cassady
Wayne State University
Oral Presentation
"Number one is patient choice": Complicating the recommendation for clinical attendants in United States MAiD
#95

The United States is in the minority among MAiD-legalizing countries in that clinician administration (euthanasia) is illegal, and no state statute requires the presence of another while ingesting the medicine. Those seeking to complete MAiD are required to be able to self-ingest life-ending medications. This mandate has created situations where refusing a clinical attendant, or completing MAiD where one cannot be present, is a possibility. Although no statute requires

it, the American Clinicians Academy on Medical Aid in Dying "strongly advises" that the dying person not take medications alone. Best practices recently published in UpToDate note that a clinical attendant at bedside can provide education, consultation, and instrumental assistance in mixing the medicine. Using the results of recent ethnographic work, this paper examines a spectrum of views on the role of clinical attendants and practice experiences regarding physician presence or absence on the day of their patients' planned deaths. Data are derived from a recent national MAiD conference and thirty-eight in-depth interviews with twenty United States physicians participating as MAiD providers. Themes from this analysis include: concerns about patient privacy and choice, medication safety, family emotional wellbeing, timing, and boundaries for clinical attendant wellbeing. Findings reveal important logistical and ethical questions about clinician attendants and decision-making in MAiD. This paper contributes to a discussion of ethical issues in MAiD surrounding who attends planned deaths, their role, and what should happen if a clinical attendant cannot be present or is refused.

Aulina Chowdhury
Boston Children's Hospital
Madeleine Carroll
Program in Global Surgery and Social Change - Harvard Medical School
Leslie McNolty
University of Missouri - Kansas City
Kiana Winslow
Program in Global Surgery and Social Change - Harvard Medical School
Panel
Balancing duties to the sick and dying in resource-limited settings
#121

The provision of healthcare services in resource-limited settings with high demand necessarily creates resource allocation challenges. Traditionally, a utilitarian framework that aims to distribute resources in a manner that generates the most substantial benefit possible for the greatest number of people has been favored to resolve these dilemmas. However, this approach leaves many patients with unmet needs. Recently, to address these gaps, focus has shifted to expanding access to perioperative, post-operative and specialty care. Advocates for increasing access to surgical care in LMICs argue that, contrary to purely utilitarian ethical calculations, there is a duty to improve individual patients' quality of life and the overall health status of communities by reducing long-term chronic manifestations of untreated surgical disease. The higher initial cost of investment in surgical care, ultimately improves not only the health status of individuals and populations, but also benefits these countries' economies. Availability of curative surgical options earlier on in a disease process, minimizes negative impact on patients' productivity and financial contributions, thereby reducing the economic burden of untreated surgical disease.

In this presentation, we will argue that there is a similar duty to provide access to care for patients at the end of life. Palliative care services are essential to reduce suffering and preserve dignity at the end of life for many patients. Unfortunately, meeting the needs of these two groups (surgical patients and end-of-life patients) may increase competition for scarce resources; pain management and sedation medications are essential to both palliative care and perioperative care. How do we allocate from the same resource pool to sufficiently meet both needs? We will contend that the duty to care for the individual patient applies equally to the sick who may

recover and the dying who will not. Thus, it is imperative to create strategies to maximize resource utilization to meet the needs of both groups of patients."

Jordana Clayton
University of Utah
Oral Presentation
Healthy older adults' perceptions of the wish to hasten death in future hypothetical disease scenarios
#101

Several studies have examined perspectives on the wish to hasten death (WTHD) within patient populations. However, to our knowledge, no studies have examined the values and preferences of older adults regarding WTHD within the context of hypothetical future disease scenarios. In previous work (Dassel et al., 2016, 2017), we found that controlling the timing of one's death is a desirable care preference within the context of future hypothetical disease scenarios (pancreatic cancer, congestive heart failure, and Alzheimer's disease) and is influenced by the value of autonomy. In the current study, we expanded upon these findings by analyzing qualitative responses to examine participants' values and preferences regarding WTHD in future hypothetical disease scenarios. A subset (n=135) of a national sample of 517 healthy older adults (age 55+) described values and preferences for controlling the timing of one's death in response to the question, "What other things not identified in this study would you consider when thinking about your end-of-life wishes?" Using thematic analysis methods, codes and themes for participant responses were generated using a deductive and latent approach. The analysis revealed five themes: 1) A Good Death, 2) Relationship with Family, 3) Burden to Others, 4) Ambivalence, and 5) Legal Restrictions and Consequences. The most common preferences for controlling the timing of one's death were a desire to hasten death (accelerating death in a non-specific manner, n=25), for a natural death (n=7), for medical aid in dying (MAiD, n=15), for rational suicide (n=10), for either MAiD or rational suicide (n=11), for refusal of life-sustaining treatment (n=20), and ambivalent responses (n=27). This formative work elucidates healthy older adults' perceptions of the option to control the timing of one's death in future potential disease states. The insight gained from this data can inform end-of-life conversations, documentation, and policy for those with terminal illnesses.

Eliana Close
Australian Centre for Health Law Research, Queensland University of Technology
Jocelyn Downie
Dalhousie University
Ben P White
Australian Centre for Health Law Research
Oral Presentation
Regulating medical assistance in dying (MAiD) in Canada: a qualitative study of key stakeholders
#82

Background: Modern regulatory theory suggests regulation is often polycentric, involving a complex web of interdependent actors which guide behaviour beyond just the state. Medical assistance in dying (MAiD) in Canada is an example of such a decentred system. While the federal and provincial/territorial governments have established law and other regulation to

govern MAiD delivery, a range of other actors play a key role in shaping and steering practice including Colleges, professional organizations, and healthcare institutions. This raises the issue of how best to regulate and coordinate this complex clinical practice. This paper examines what key stakeholders think of MAiD regulation and compares the views of organizational decision-makers (i.e. the bodies seeking to guide practice) to those of MAiD assessors and providers (i.e. the objects of regulation).

Methods: Semi-structured interviews were conducted with 40 organizational decision-makers (key stakeholders in government bodies, provincial regulators, and institutions, federally and in three target provinces) and 32 MAiD assessors and providers (n = 25 doctors, 7 nurse practitioners). Data was thematically analysed to identify participants' views on how to guide MAiD practice most effectively.

Results: Preliminary results indicate strengths and gaps in MAiD regulation, with some provincial variation. MAiD assessors and providers valued strong peer networks and care coordination services over top-down regulation yet sought more top-down guidance in some areas. Regulators emphasised a need for more national coordination, which was slowly improving over time.

Implications: This research highlights strengths and challenges of Canada's complex model of MAiD regulation and provides insights for countries which are considering passing MAiD laws. The polycentric nature of MAiD regulation in Canada is inevitable, given it is a diverse country of 10 provinces and 3 territories. However, this study highlights that governments and medical and nursing regulators should play strong leadership roles to promote a robust and sustainable MAiD system.

Thomas Cunningham
Kaiser Permanente Southern California Bioethics Program
Oral Presentation
Mr. JR: Decisional capacity, prolonged grief, and an inpatient request for physician-aid-in-dying
#75

JR is a 76-year-old artist working in the entertainment industry who recently cared for and lost his wife of 42 years, from metastatic ovarian cancer. He recently experienced a lengthy hospitalization to treat a heart attack, acute kidney injury, hospital acquired delirium, and other problems. During his hospitalization, JR told multiple clinicians he was tired of living, he wanted to stop hemodialysis, and he desired physician-aid-in-dying (PAID). This talk describes the ethical issues that presented in JR's case and their resolution. An ethicist met with JR regularly to solicit his values and explored the meaning of JR's statements with the team and his loved ones. Multiple case features complicated the ethicist's analysis and recommendations. First, although legal in California, whether PAID it is permitted for admitted hospital patients is unclear; so, even if JR's requests were authentic, they probably could not be acted upon during his admission. Second, although a psychiatrist deemed JR incapacitated, the validity of this assessment was uncertain: JR could sometimes demonstrate understanding, awareness, and reasoning about his diagnosis, prognosis, and treatment options. And the capacity evaluation was not specific to PAID decision-making. Third, JR's appointed agent was disengaged from treatment decision making, making a reliable description of JR's prior baseline and values difficult to establish. Fourth, over time JR revealed that his desire to receive PAID waned as his cognition improved

and he was able to recall the vivid, meaningful, and personal memories of his wife and their cherished moments together. Ultimately, through ethics facilitation, JR came to believe that he wanted to continue living, even with greater medical burdens than before his hospitalization, so that he could continue to produce art and to enjoy the memories of his wife. His health improved and he was discharged to an acute rehabilitation facility.

Dena Davis
Lehigh University (emerita)
Oral Presentation
End-of-life preferences in the face of dementia: A survey of older Americans
#51

We know little about how currently competent people value their continued lives should they become demented. The goal of the study is to understand the opinions of people over 50 with regard to 1- how long they would hope for their lives to go before experiencing a fatal event; 2- if and when they would refuse life-sustaining medical care should they become demented.

The survey presents a series of vignettes that outline the stages of Alzheimer as told via the story of a fictional patient. Qualtrix was used to complete a survey of 1,000 participants.
56% of participants responded that they would wish to experience a fatal heart attack in the very first stage of Alzheimer; 20% chose the second stage, still living at home but unable to drive and exhibiting increasing erratic behavior. 20% would wish their families to refuse antibiotics if they got pneumonia while in the first stage, and 35% at stage two.

This result calls into question the current focus on refusing feeding tubes and handfeeding in dementia, as most people would not wish to get anywhere this final stage. Further, it problematizes certain medical decisions, e.g. whether to give cholinesterase inhibitors to people with Alzheimer, as it addresses some symptoms but decreases risk of heart attack; whether to vaccinate people with dementia against Covid; and whether and when to enroll people with dementia in cancer trials. How would practice and policies change if we could acknowledge and respect this diversity of opinion with respect to lifespan after a diagnosis of impending dementia?

Michael Deml
Palliative and Supportive Care Service Lausanne University Hospital (CHUV), Lausanne, Switzerland
Oral Presentation
What issues do LGBTQ+ individuals face at the end-of-life in Switzerland? An exploratory, narrative review
#36

Background: Often overlooked in high-income countries' ageing populations is that our societies are pluralistic, with diverse needs. Specifically, healthcare offered to LGBTQ+ (lesbian, gay, bisexual, transgender, queer, +) patients and beloved ones in palliative care contexts and end-of-life phases can be characterized by inequities and barriers. Despite being a high-income country with universal health insurance coverage, Switzerland's research on these groups consistently shows disparities in terms of mental health, discrimination and violence, substance use, sexual

health, and physical health. Less attention has been paid to these individuals' life-course trajectories and issues related to ageing and end-of-life issues over time.

Methods: We conducted a narrative, exploratory literature (scientific, grey, policy) review on the issues LGBTQ+ individuals face at the end-of-life in Switzerland. In addition to peer-reviewed original research articles and LGBT-related health policy, we have drawn upon the Swiss LGTIQ+ Panel reports1 and Swiss Federal Council commissioned reports2 on LGBT Health in Switzerland from 2022. Since there is little explicit mention of ageing and end-of-life issues for these populations, our search strategy was flexible and inclusive to maximize the corpus of texts available for review. The exploratory narrative review approach provides a descriptive account of the state of the literature on end-of-life issues for LGBTQ+ populations in Switzerland.

Results: Preliminary results show a glaring gap on end-of-life issues for LGBTQ+ individuals in the context of ageing populations in Switzerland. In effect, scientific research conducted on these populations tends to focus on other health-specific outcomes (i.e. mental health, sexual health, physical health, substance use) and does not consider long-term demographic trends related to ageing or end-of-life.

Conclusions: The research gap and lack of systematic health policy for this sub-population's specific needs represent an opportunity for future research efforts designed to systematically and empirically investigate LGBTQ+ ageing and end-of-life needs.

Dan Diaz
TheBrittanyFund.org
Oral Presentation
Advocacy for MAID legislation – Brittany Maynard
#14

"Experiencing a good death is merely the extension of having lived a good life. I won't let this brain tumor take that from me." These are the words my wife, Brittany Maynard, said to me as we made plans to leave our home in California and move to Oregon in May 2014.
Brittany died on November 1, 2014. She was only 29 years old. Her story captivated the nation and received media coverage around the globe. During the remaining few weeks of her life, Brittany spoke up to help inform the general public about medical aid in dying, and to insist that legislators pass these laws in more states. When she died there were only 4 States with this option. There are now 11.

The advocacy required to get MAID legislation passed is a monumental task. It includes connecting with individuals and groups from the disciplines of medicine, nursing, law, philosophy, bioethics, and religion.

I promised Brittany I'd help pass legislation in more states so that no one else would ever have to leave their home like we did. That promise has taken me to 18 State capitals across the country to meet with Governors, Senators, Assemblymembers; Palliative care conferences to educate physicians, nurses, caregivers, as well as assisted living facilities, universities, and high schools to reach the elderly, faculty, students, and clergy.

My advocacy focuses on patient autonomy, legal protections, religious interference, and battling the growing misinformation campaign and fear tactics used by opposition groups. I simply share Brittany's view that end of life care should not be so obsessed with prolonging life, instead, it should simply nourish it. The rest is up to the patient. My presentation will include the topics of legislative advocacy, MAID vs palliative sedation from the patient's perspective, and the limits of modern medicine.

Pia Dittke
University of Muenster, Germany
Oral Presentation
Beyond assisted suicide – a rights-based approach to sedation at the end of life
#79

In Germany, everyone talks and writes about assisted suicide. Meanwhile, no one in the legal field addresses issues regarding sedation at the end of life. Why should we?

The German constitutional court decided in 2020 that the German constitution contains an (unwritten) right to die. Some reactions celebrated it as manifestation of autonomy at the end of one's own life, others framed it as a catastrophe expressing that "assisted suicide was now even allowed for teens after their first heartbreak" (Frankfurter Allgemeine Zeitung, February 26, 2020). The right does not only protect the right to end one's own life but also the right to receive help from others. The court explicitly denied a limitation in regard to health conditions or death proximity. On the contrary, it ruled that everyone is entitled to this right "in every phase of human existence" (GCC, February 26, 2020 – 2 BvR 2347/15 et al).
Now, what does this have to do with sedation? The court did not tell. Palliative sedation as an option of last resort in the last hours or days of life is well accepted, whereas expanding the practice of sedation strikes dismissal. Many questions remain in legal disguise, leaving professionals with uncertainty and patients without adequate treatment. One remaining question is the question of obligation: Can a patient who decides to end her life by voluntarily stopping eating and drinking demand sedation to unconsciousness? What about a patient who decides to end treatment, but only under the condition to be sedated preemptively? Can he even oblige the doctor to agree to sedation beforehand, because if not, he would be stripped of his right to die? How far does this "new" right to die in the German constitution reach? What could this mean for countries where assisted suicide is not a legal option?"

Laure Dombrecht
End-of-Life Care Research Group - VUB and Ghent University
Oral Presentation
Neonatal end-of-life decisions: A comprehensive overview of estimates, views and experiences based on three studies
#65

Deaths of neonates are often preceded by a possibly life-shortening end-of-life decision (ELD). We aimed to shed light on population prevalence rates, daily practice and personal experiences of neonatal ELDs to provide recommendations and guidelines.

We conducted a 1) population mortality follow-back survey of all deaths under one year over a period of 16 months to examine prevalence rates of ELDs preceding death; 2) a survey sent to all neonatologists and nurses working in a NICU to examine attitudes toward neonatal ELDs and psychological support offered to healthcare providers; and 3) a semi-structured interview study in 15 neonatologists, 15 nurses and 23 bereaved parents to shed light on experiences with ELDs in neonates. All studies were performed in Flanders, Belgium between 2016 and 2019.

Results: 1) Response rate of the population survey was 83% (229/276). In 61% of all deceased infants, an ELD preceded death. Non-treatment decisions (NTDs) are most prevalent (37%). In 24% of cases, drugs are administered including a possible (14%) or explicit life-shortening intention (10%). 2) The survey had a response rate of 50% (302/610) and indicated considerable support for NTDs (90-100%) and administering medication with explicit intention to hasten death (60-74%), despite not being legally tolerated in Belgium. Psychological support provided by the ward is considered insufficient by 59% of respondents. Only 45% of nurses indicated being heard by the treating physician when ELDs are considered. 3) Interviews revealed several barriers and facilitators towards neonatal ELD decision-making such as uncertainty of diagnosis, cultural differences, lack of privacy, and complex legislation.

ELDs are an important part of daily clinical practice when caring for neonates with severe conditions. Despite their commonality, deciding on an ELD in cases of severe suffering of the infant brings forth significant barriers and stress for all involved, which are not always adequately addressed. Findings were used to formulate readily implementable recommendations to aid future infants, parents and healthcare providers.

Laure Dombrecht
End-of-Life Care Research Group - VUB and Ghent University
Oral Presentation
A post-mortem survey on continuous deep sedation until death in neonates and infants in Flanders
#66

Background: Though terminology varies, the administration and use of analgesics and sedatives to alleviate discomfort and pain is common practice in end-of-life care for neonates. However, the prevalence of using these types of medication with the specific aim of bringing the infant in a state of continuous deep sedation is currently unknown.

Aims: To examine the prevalence and associated clinical characteristics of continuous deep sedation until death in neonates and infants who died under the age of one.

Methods: A nationwide mortality follow-back survey was performed based on all deaths under the age of one over a period of 16 months in Flanders, Belgium. Treating physicians were asked whether continuous deep sedation preceded death, and which clinical characteristics associated with the sedation (including type of drugs used, the duration of sedation, whether or not artificial nutrition and hydration were provided, intent to hasten death). Questionnaire data were linked to demographic and clinical information from death certificates.

Results: Response rate was 83% (229/276). Death was preceded by continuous deep sedation in 39% of all deceased neonates. Most often, a combination of morphine and benzodiazepines

(53%) or morphine alone (45%) was used in order to continuously and deeply sedate the infant. Artificial nutrition and hydration were administered until death in 92% of cases, and in 89% of cases the infant died within one week after sedation was started. In 49% of continuous deep sedation cases there was no intention by the physician to hasten death, and in 40% the possibility of hastening was taken into account.

Discussion: Continuous deep sedation precedes about 2 in 5 neonatal and infant deaths. Guidelines for continuous deep sedation in this age group are nonexistent and it is unclear whether the same recommendations as in the adult population apply and can be considered as good practice.

Laure Dombrecht
End-of-Life Care Research Group - VUB and Ghent University
Poster
Palliative sedation practice and opinions in pediatrics
#68

Background: Because infant mortality is low and children do not often need palliative sedation, only few physicians or specialist nurses are able to build clinical experience to confidently provide such care and to rely on previous experience to develop their own best practice. Hence, physicians have to rely on single-center consensus and expert opinion for pediatric palliative care. Data about palliative sedation in pediatric patients is limited. Guidelines for sedative choice, dosage and titration in children are nonexistent in Belgium, and scarce internationally.

Aims: We aim to:

1. analyse opinions and practice of palliative sedation of physicians responsible for caring for terminally ill paediatric patients between 0 and 18 years old,
2. evaluate the intention to start palliative sedation, the intended doses and medications to be used, and reasons for starting palliative sedation based on three paediatric vignette cases.

Methods: We are currently performing an online survey to gain insight into opinions and practices of Belgian Pediatric healthcare professionals regarding palliative sedation using LimeSurvey. Data will be available for presentation at the ICEL conference. We developed a new questionnaire based on existing international surveys on palliative sedation in adults and neonates consisting of four parts: sociodemographic information, questions regarding current medical practices (experience of participants), questions on opinions and attitudes regarding palliative sedation (what is considered as acceptable medical practice), and a detailed vignette case in which participants are able to indicate their envisioned medical decision-making process. The vignette cases consider either a child with an acute and serious illness, a child with cancer or a neonatal case.

Conclusion: Being able to support medical decisions on reliable data, which are currently non-existent in Belgium, can help pediatricians and general physicians in this ethical and clinical-pharmacological challenging decision and help future pediatric patients who are suffering from refractory symptoms at the end of life and could possibly benefit from palliative sedation preceding death."

Laure Dombrecht
End-of-Life Care Research Group - VUB and Ghent University
Poster
Prenatal end-of-life decisions at viable stage: an overview of prevalence estimates and healthcare professionals' attitudes
#69

In case of a prenatal diagnosis of congenital malformations, termination of pregnancy (TOP) may be an option, sometimes at a gestational age when the fetus is already viable (late TOP). No adequate registration of incidence of late termination of pregnancy (TOP) or abortion for medical reasons exists in Flanders; and attitudes of involved healthcare providers towards these decisions are unknown.

We conducted a: 1) population mortality follow-back survey of all stillbirths from 22 weeks gestation onward in Flanders. Questions measured whether late TOP preceded stillbirth, and which clinical and sociodemographic characteristics were indicated. 2) mail survey among all physicians and paramedical professionals involved in late TOP decision-making in all eight centers with a Neonatal Intensive Care Unit in Flanders. The questionnaire contained general and case-based attitude items concerning late TOP at viable stage.

Results: 1) Response rate was 56% (203/366). 38% of stillbirths (77/203) concerned late TOP. In 88.3% of late TOPs, physicians classified congenital anomalies of the foetus as serious or very serious (incompatibility with life outside the womb or severe neurological or physical impairment). 2) Response rate was 79% (92/117). Late TOP was highly accepted in both lethal fetal conditions (100%) and serious (but not lethal) fetal conditions (95.6%). Where the fetus is healthy, 19.8% of respondents agreed with late TOP for maternal psychological problems and fewer respondents (13.2%) agreed with late TOP in the case of maternal socio-economic problems (P = .002). Physicians more often preferred feticide over neonatal palliative care in case of non-lethal fetal conditions compared with paramedical professionals (68.1% vs 53.2%, P = .013). 2/5 stillbirths were preceded by late TOP, indicating severe under-reporting by existing registrations and a dire need for adequate registration methods.

Healthcare professionals practicing late TOP in Flanders, Belgium have a high degree of tolerance towards late TOP, and are demanding legislative change regarding active life-ending in the fetal and neonatal periods.

James Downar
University of Ottawa
Oral Presentation
What drives requests for medical assistance in dying, and what are lessons for palliative care?
#33

There has long been a fear that if Medical Assistance in Dying (MAID) were available for people with terminal illness, requests for MAID would be driven by socioeconomic deprivation or poor service availability (e.g. Palliative Care). In this session, we will review the available data, which

consistently indicates the opposite- that MAID is most common among those with high socioeconomic status, high involvement of palliative care, and low support needs. Moreover, we will also review the data regarding the modest effect and duration of palliative care and psychosocial interventions. Based on this data, increasing the availability of palliative and psychotherapeutic interventions should be an international priority, but this is unlikely to substantially affect the incidence of requests for MAID. In reviewing this data, we will explore some of the implications for MAID and palliative care practice. Whether our aim is to reduce the use of MAID or simply reduce suffering among the dying, we need to adopt an evidence-informed understanding of the complex factors that drive patient choices at the end of life.

James Downar
University of Ottawa
Marie-Eve Bouthillier
University of Ottowa
Andrea Frolic
Centre intégré de santé et de services sociaux de Laval
Jennifer Gibson
Joint Centre for Bioethics, University of Toronto
Panel
Critical care triage protocol development in Quebec and Ontario, Canada: Lessons learned
#84

The COVID-19 pandemic produced an unprecedented demand for critical care in many jurisdictions around the world, at times exceeding conventional capacity limits. Triage frameworks were developed to guide the rationing of limited critical care resources in such a scenario. In Ontario and Quebec, Canada, a similar framework was rapidly developed but never used. The process of development and engagement with key stakeholders and decision-makers was different, leading to important differences in preparedness and institutional support.

In this presentation, speakers from both Quebec and Ontario will review their experience developing the triage framework and preparing to implement it, while simultaneously engaging stakeholders and updating the framework. Key challenges arose in trying to balance competing principles and achieve consensus about how best to operationalize justice and fairness while trying to save as many lives as possible. Additional challenges arose when preparing hospitals and regions to implement the framework, including logistical and technological challenges. Political challenges also arose, owing to a widespread hesitation to take responsibility for initiating a triage process, and a consequent effort to shift responsibility to others, or to shift resources and hyper-prioritize critical care to avoid having to triage anyone.

Public and stakeholder engagement was challenging in this environment but ultimately did take place, revealing strong support for the framework but a need to simplify and prepare better in advance of a crisis, and support members of the public and healthcare professionals alike. A process of democratic deliberation, taking place during the pandemic itself, highlighted important priorities for stakeholders and suggestions for approaches that would improve public understanding and acceptance of any triage framework.

Julia Duffy
Queensland University of Technology
Oral Presentation
Cognitive disability and surrogate decision-making – a new understanding of human dignity and human rights
#44

In Western philosophy and law, autonomy is taken to be the foundation of personhood, so if we fail to recognize someone's autonomy and legal capacity, we also fail to recognize their personhood. This is the view of many disability advocates, practitioners and lawyers, and the premise underpinning the UN Disability Committee's stance, that all adults with cognitive disabilities must have their legal capacity recognized, as a foundational human right. Concomitant with that stance is that surrogate decision-making is always a breach of human rights. I argue against that widely held position.

I consider the case of Sesha, as described in the literature by her loving philosopher mother, Eva Kittay. Sesha cannot read, and Kittay says she cannot 'engage in moral practical reasoning' or participate in political life. It is hard to know what Sesha's cognitive capacities are because she cannot speak. Yet Sesha experiences many joys in life, chief among them listening to classical music. If Sesha were to become ill and asked to choose whether or not to have medical treatment which would save her life but destroy her hearing, we have no way of knowing what her answer would be. In real terms, a surrogate would have to take responsibility for that very grave decision.

I discuss this hypothetical scenario to illustrate how an innovative formulation of 'five-dimensional dignity' can serve as a more inclusive basis of personhood than autonomy. Recognising dignity as the basis for personhood allows for surrogate decision-making when, as a matter of concrete fact, a person lacks decision-making autonomy. Five-dimensional dignity recognizes: our equal worth or value; the autonomy of those capable of autonomy; the interdependent and social nature of being human; the embodied nature of personhood, and the interdependence and indivisibility of human rights.

Jason Eberl
Albert Gnaegi Center for Health Care Ethics at Saint Louis University
Oral Presentation
The Catholic debate on brain death
#98

Debate persists regarding the revision of the Uniform Determination of Death Act, and cases like that of Jahi McMath continue to fuel both scholarly and public controversy regarding the validity of neurological criteria for determining the death of a human being. Such debate within the wider public arena is mirrored within Catholic health care. As approximately 1 in 7 hospitals beds are located within Catholic health care systems, it is salient to understand the intra-Catholic debate and where it intersects or departs from the broader secular controversy. Since the mid-1980s, advisory bodies to the Vatican and official papal pronouncements have affirmed and reaffirmed that neurological criteria may be appropriately utilized to determine human death. Nevertheless, several prominent Catholic scholars, including emeritus UCLA pediatric neurologist D. Alan Shewmon, have continually challenged the moral validity of using neurological criteria since the late 1990s. This presentation will elucidate the history of the intra-Catholic debate, canvass the

various arguments offered in critique or defense of the use of neurological criteria, and outline key points of disagreement yet to be resolved. The last includes whether the use of neurological criteria coheres with accepted Catholic philosophical anthropology, grounded in the thought of Thomas Aquinas; whether "integrative unity" is a sufficient rationale for defining human death and whether the irreversible cessation of whole-brain function constitutes the loss of such organismal unity; and whether, due to the evidence and arguments that have been put forth against the use of neurological criteria, there is sufficient "moral certitude" than a whole-brain dead human being is truly dead. In closing, a brief argument will be given, on Catholic grounds, in support of continued affirmation of neurological criteria as sufficient for establishing that a human being has died.

Jason Eberl
Albert Gnaegi Center for Health Care Ethics at Saint Louis University
Oral Presentation
Reasonable conscientious refusal to participate in medical aid-in-dying and euthanasia
#99

Conscientious refusals to provide legal medical services that fall under the accepted standard of care, when autonomously requested by patients, is a significant topic of debate among health care professionals, bioethicists, and policy makers. One issue around which this debate circles is the provision of medical aid-in-dying (MAiD) and euthanasia. Unlike other contested services, such as elective abortion and sterilization, MAiD and euthanasia have not yet been widely accepted as part of the standard of end-of-life care, as seen in the current edition of the American Medical Association's 'Code of Medical Ethics.' Yet, as more countries and U.S. states legalize MAiD and sometimes also euthanasia, either or both may soon become recognized as constitutive of standard end-of-life care. Regardless, conscientious refusals on the part of physicians and other health care professionals who refuse to assist or directly cause a patient's death will surely persist. Are such refusals reasonable? This presentation will explore this question utilizing a previously developed framework for acknowledging and validating certain types of conscientious refusals when specific reasonability criteria have been met. Such criteria include the refusal being defensible (if defeasible) according to the standards of "public reason." Such standards include not relying on purely faith-based religious premises, being internally coherent, and also cohering with well-founded scientific understanding. Furthermore, while this presentation will argue that a reasonable conscientious refusal to participate in MAiD or euthanasia are ethically justifiable and should be legally protected, there are limits to such protection, including that refusing professionals should still present MAiD/euthanasia (where legal) as an option to their patients and provide referrals to other providers.

Angela Wentz Faulconer
Department of Philosophy, Brigham Young University
Oral Presentation
Scarce resources and reallocation: ECMO, personal ventilators, and maintenance drugs
#123

I will look at how allocation and reallocation differ in contexts of scarcity, arguing that it is a mistake to generalize from the end-of-life scenarios where the equivalence thesis was first

formulated—where a patient consents to ending treatment and is ready for her life to end—to scarce resource scenarios where a patient does not consent to ending treatment but desires to continue treatment and hopes to recover. I will turn to Philippa Foot's argument that the duty to avoid inflicting injury is higher than the duty to bring aid and consider the implications for withdrawing ECMO and reallocating personal ventilators. I will then consider the analogy between personal ventilators and maintenance drugs and consider whether the arguments against reallocation still hold—even when this means more lives will be lost.

Allocation in contexts of scarcity is best understood as a bringing-of-aid, where reallocation can be an inflicting-of-injury. Reallocation decisions therefore carry an additional moral weight. Even though it may mean fewer lives saved or less suffering averted, there are some scarce medical resources that should not be subject to reallocation and some circumstances in which reallocation is morally unacceptable. I will conclude that reallocating scarce resources like maintenance drugs is a morally serious act, one that has received too little attention.

Some have argued that under crisis standards of care in a pandemic or other emergency, a physician's fiduciary duties toward their patients are suspended as the personal fiduciary focus properly shifts to a public health focus. However, I will follow Sulmasy and Maldonado in arguing that ethical exceptionalism is a risk, because our ethical touchstones are most important when we are under duress.

RachelFeeney
Queensland University of Technology
Oral Presentation
Online modules to improve health professionals' end-of-life law knowledge and confidence: A pre-post survey study
#56

Health professionals and medical students have knowledge gaps about the law that governs end-of-life decision-making in clinical practice. There is a lack of dedicated training on end-of-life law and corresponding research on the impact of such training.

End of Life Law for Clinicians (ELLC) is a training program for medical practitioners and students, nurses and allied health professionals that focuses on Australian laws on end of life decision-making. We examined the impact of ELLC online training modules on health professionals' knowledge of end-of-life law and their self-reported confidence in applying the law in practice. Training participants completed optional pre- and post-training surveys. Surveys directly assessed legal knowledge and measured self-reported confidence in applying the law in clinical practice, before and after training. Feedback on the training was also analysed.

The final sample for analysis (n=136) included nurses, doctors, allied health professionals, medical students and a small number of non-health professionals. Following completion of the online training modules legal knowledge scores significantly increased overall and across each domain of end-of-life law (pre-training mean 5.65 out of 10, SD 1.89, post-training mean 7.92, SD 1.32). Participants also reported increased confidence in applying this law in practice after training (post-training median = 3.0, confident; pre-training median = 2.0, not confident). Participants provided consistently positive feedback on the training.

Following completion of the ELLC online training modules, health professionals demonstrated significantly better legal knowledge and reported enhanced confidence in applying the law. Participants demonstrated some remaining knowledge gaps after training, suggesting that the training, while effective, should be undertaken as part of ongoing education on end-of-life law. Recommendations for training improvements are being implemented in response to participant feedback.

Lauren Flicker
Einstein Montefiore Center for Bioethics
Oral Presentation
Out of Options: How America has Failed its Elders
#118

There is a vast chasm between the dying who can act on their right to refuse medical intervention, and those who have no treatment to refuse. The ability to refuse treatment at the end of life is one of the most profound legal and ethical rights held by capacitated adults. This right is so significant that we have created health care proxies and advanced directives to ensure that one's desire to stop medical intervention can be preserved even after one has lost capacity or the ability to communicate. The natural consequence of the right to refuse treatment is the right to determine when one's life is completed and to die with comfort and dignity. Yet the legal system denies this right to our most vulnerable persons. The old-old and oldest-old nearing the end of life, experiencing frailty and diminishing independence, but who are not dependent on medical intervention to prolong life are often left with no options but to suffer or to take matters into their own hands. It is not surprising then, that according to the CDC, older adults have among the highest suicide rates in the United States, with older adult men over the age of 75 having the single highest rate. When suicide is not successful, these adults are further harmed when their suicide attempt is seen as proof of lack of capacity, and they are stripped of their right to refuse treatment. This paper will consider how we have failed our elders who are ready to die, but have no treatment to refuse, and how we might take steps to promote their autonomy at the end of life.

Perrine Galmiche
Centre d'éthique clinique de l'AP-HP / Université Paris-Saclay
Oral Presentation
Assisted dying and medical responsibility: lessons from the French debate and abroad
#42

In September 2022, France reopened the debate on assisted dying (AD) with an official position from the National Ethics Council followed by a Citizens' convention on end-of-life. Both concluded in favor of AD, for two reasons similar to those of countries that authorize it: the recognition of situations of unbearable suffering despite the development of palliative care, and the increase in the importance given to patients' autonomy in decisions that concern them. However, both undermined the extent of these arguments in the name of the unyielding opposition of physicians against AD, by noting that euthanasia should stay prohibited or be an exception for this sole reason. In the opinion columns against AD that we studied by content analysis, they defend that AD should not fall under their responsibility: they argue that it conflicts

with their professional values; they consider it too violent for them, too risky for the doctor/patient relationship, and do not envision it as "care".

Based on a comparison with other AD laws and the end-of-life law in France on the right to terminal sedation, we wish to argue in response that giving too much weight to the opposition of physicians, thus restricting their role in the AD process or determining restrictive criteria, will lead to a practice that will fall short of the expected demand. Indeed, clinical experience shows that the law on terminal sedation, resulting from a compromise to content physicians against AD, ends up preventing access to it more than facilitating it and weakens end of life care.

This presentation is in line with the topic of "legal, ethical, clinical issues with MAID". It will be an opportunity to clarify the latest developments in the French law on end-of-life; as well as to discuss how choosing to restrain medical responsibility when considering assisted dying affects legislative choices, future practices, and ultimately diminish patients' rights.

Perrine Galmiche
Centre d'éthique clinique de l'AP-HP / Université Paris-Saclay
Poster
When a patient requests to die with the help of medicine: main ethical conflicts
#43

The ethical issues on a societal level concerning the authorization of AD are well studied in literature; however, they are not necessarily the same in case-by-case situations, in which more personal and contextual concerns are at stake. The singular, repeated discussions between the individual and their doctor is then often favored to address them. When they cannot be resolved or they cause conflict between the patient and their doctor, a third party can help reflect on the situation.

The Clinical ethics center of the Greater Parisian Hospitals, which opened in 2002 following the law on patients' rights, is asked regularly to consult on cases of requests to die with the help of medicine. The qualitative content analysis of these situations – about 30 to date since 2016 and the enforcement of the latest law on end of life in France, which created a right to access continuous deep sedation until death – reveals different ethical issues on the individual level:

- Regarding respect for autonomy, questions arise about ambivalence more than about capacity.
- Regarding beneficence/non-maleficence, questions arise about the right moment for providing the help more than about uncertainty of the prognosis or the nature of suffering.
- Regarding medical responsibility, questions arise about their own conception of medicine's goals depending on the case rather than about a general conception of what physicians should do.

Further analysis of these situations will allow for more conclusions, and differentiations between pathologies.

It stands out that these questions relate to the health professionals' point of view and ethical reasoning. This presentation will then also be an opportunity to present how we are trying to

approach the patient's perspective on these issues to help professionals navigate these requests, through a clinical ethics research protocol. Are these issues according to them? What do they expect from medicine when they make a request to die?

Daphne Gilbert
University of Ottawa, Faculty of Law
Oral Presentation
Litigating institutional religious obstructions to MAiD
#131

In Canada, several provinces have faith-influenced hospitals that deliver publicly-funded health care. These institutions claim a right to freedom of religion and refuse to allow MAiD to be performed on-site. This is a claim that has never been tested in court and one that I argue is unlikely to succeed. I am part of a legal team that will launch litigation in Fall 2023 to challenge the practice of Institutional Religious Obstructions (IROs) to MAiD. Together with Professor Jocelyn Downie, and the law firm Arvay Finlay (which brought the Carter case that decriminalized MAiD in Canada in 2015), we argue that IROs violate the constitutional rights of patients, their families and MAiD providers. Our litigation will proceed against the province of British Columbia which has a MAiD policy that allows faith-influenced hospitals to "opt out" of providing MAiD. Other named parties will include the faith-influenced health authority. A high-profile case in St. Paul's Hospital in Vancouver, BC saw a 34-year-old cancer patient forcibly transferred to another institution to receive MAiD. She never regained consciousness after the transfer and her family lost the opportunity for a meaningful goodbye. Her family and others impacted by IROs will be plaintiffs, as well as MAiD providers and Dying with Dignity Canada as a public interest litigant. In this session, I will outline our litigation strategy and frame the constitutional arguments. I will also offer my thoughts on why there is no institutional right to freedom of religion. Religious interference in health care is an issue in many countries, including in particular the United States and Australia. I hope to engage in a conversation about the limits of freedom of religion claims as balanced against the rights of patients and health care providers to determine the best end-of-life outcome for those who are experiencing intolerable suffering.

Kristin Good
Ministry of Health New Zealand
Oral Presentation
Assisted dying from implementation to delivery within the New Zealand prison system
#53

The End of Life Choice Act (2019) came in to force in New Zealand on 7 November 2021 following a twelve-month implementation period. Corrections were identified as a key stakeholder and we sought engagement early on. The journey from implementation to the delivery of the first assisted death within the prison system has encountered many barriers. These include a lack of understanding of the legislation, acceptance of prisoner rights to apply, appreciating the need for being prepared, privacy issues, barriers to access, where the medication would be administered, alignment of prisoner rights under this Act where tensions exist with other legislation, managing conscientious objection and prisoner safety, practitioner selection and

the support required. This presentation will outline the journey, how we overcame the barriers, and include recommendations for other jurisdictions encountering this issue.

Aaron Gray
Georgetown University
Oral Presentation
Advance directives, stopping eating and drinking, and the continuous personhood of patients with dementia
#27

Contemporary shifts in end-of-life care policy and practice raise ethical questions around dementia-specific advance directives and voluntarily stopping eating and drinking (VSED). Drawing on Ronald Dworkin's account of precedent autonomy, Norman Cantor has argued that an advance directive that clinicians withhold food and drink at a specified point of disease progression ought to be followed. This view is challenged by Rebecca Dresser, who argues that advance directives made by a competent patient at an earlier point in time do not bind in a progressed state of dementia owing to discontinuity of the patients' personhood.

I argue that the progression of dementia indicates an incrementally changing yet continuous personhood, such that Dresser's arguments fail. Setting out my position referencing Dworkin's framework, I argue that this continuity of personal identity is explained by the continuity of a patient's experiential and critical interests, even into advanced stages of dementia. Drawing on narrative accounts of dementia, I argue that while some of the critical interests invoked in favor of the bindingness of advance directives wane in their expression – interests in directing one's life, influencing how one's life narrative ends, or shaping how we are remembered – other critical interests continue to be expressed, however clumsily. If this is correct, advance directives will often not be decisive in determining treatment despite their significance. In part this is because it is unclear on Dworkin's view why critical interests that are no longer capable of expression outweigh those continually expressed. I further argue that experiential interests in food, drink, (and nutrition generally) are necessary conditions for the possession and expression of all other critical and experiential interests. I conclude that advance directives to facilitate a patients' stopping eating and drinking will generally be outweighed by the continued expression of morally significant interests, at least until the latest stages of disease progression.

Stefanie Green
CAMAP
Oral Presentation
The truth about assisted dying
#106

Assisted dying, in some form, has been legal in at least one jurisdiction within western societies since 1918 (Switzerland), more prominently discussed and available since 1997 (Oregon), and available throughout the Benelux countries since 2002. It is currently legally permitted in 14 countries worldwide and in multiple jurisdictions within both the U.S.A. and Australia, yet assisted dying remains poorly understood, often misrepresented by opponents, and grossly unfamiliar to the majority of the population. Despite increasing access, increasing acceptance, and

increasing interest, the vast majority of people are unaware of what assisted dying is, and a tremendous amount of fear and misinformation persists.

Dr. Stefanie Green has been a practitioner of assisted dying in Canada since it first became permitted in June 2016. In January 2023, she was given the opportunity to give a TEDx talk to a global audience, and she used this platform to create an opening for a shift in thinking about death and dying as a whole, end of life options in general, and assisted dying in particular. Through powerful storytelling, she demonstrates how assisted dying can be an empowering, compassionate, humane form of health care, and she brings her audience to her own conclusion that assisted dying, in her experience, is in fact less about death than it is about how we wish to live.

Mona Gupta
Département de Psychiatrie et d'Addictologie, l'Université de Montréal
Jocelyn Downie
Dalhousie University
Sisco Van Veen
Amsterdam University Medical Center - Departments of Medical Humanities and Psychiatry
Panel
Interdisciplinary perspectives on irremediability in the context of assisted dying for persons with mental disorders
#64

In most countries where assisted dying is legally permissible, one of the eligibility requirements is that a person have a medical condition and that this condition is known to be permanent. Assisted dying for persons with mental disorders is a controversial precisely because of doubts about whether such disorders are permanent or at least, whether they can be known to be permanent. As a result, there is a vigorous debate about the permissibility of this practice in Canada where it is planned to begin in March 2024. Active debate also persists in the Netherlands where assisted dying for persons with mental disorders has been allowed for over 20 years.

This first part of this panel will set the scene with three short presentations exploring this eligibility requirement for assisted dying in both the Netherlands and Canada from legal, ethical, and clinical perspectives. The first presentation will explore the legal understandings of the Dutch eligibility criteria 'no reasonable alternative to the person's situation', and 'irremediable suffering' as well as the Canadian eligibility criteria 'incurable illness, disease or disability' and 'advanced state of irreversible decline.' The second presentation will discuss the clinical and ethical approaches in the Netherlands to establishing whether these legal criteria are fulfilled. The third presentation will consider the concerns raised in the Canadian context about these criteria for applicants with mental disorders and the extent to which Dutch approaches do and do not respond to these concerns. The second part of the panel will consist of a moderated discussion with the audience.

Mona Gupta

Département de Psychiatrie et d'Addictologie, l'Université de Montréal
Leila Rached-D'Astous
Département de Psychiatrie et d'Addictologie, l'Université de Montréal
Oral Presentation
Exploring suffering in the context of MAID requests in Canada
#113

This presentation reports the findings of a qualitative study of the experiences of physicians assessing requests for an assisted death in the early years of Canada's MAID regime when requesters were required to be at the end of life or their natural deaths reasonably foreseeable. In this study 19 English and French speaking physicians in two Canadian cities participated in individual semi-structured interviews in which they discussed their approaches to assessing suffering. We had the interviews transcribed by an independent professional transcriptionist. The French language transcriptions were also professionally translated and reviewed for use by non-French speaking research team members. We undertook an initial deductive analysis based on guiding questions derived from existing theory about suffering (namely the work of Cassell, Frank, Kleinman, Norwood, and Ricoeur). We then engaged in further inductive analysis in which we identified the concept of coherence as central to physicians' MAID assessments. Furthermore, we found that participants' assessment of suffering was not dissociable from their assessments of the request as a whole.

In their dialogue with the person about their request for an assisted death, physicians seek various types of coherence (relational and epistemic coherence which contribute to normative coherence). If these forms of coherence are not apparent, physicians work to find them because coherence supports the physician's decision about eligibility. However, a lack of coherence does not render a person ineligible for MAiD. If physicians believe the legal criteria are fulfilled, they will approve the request even they do not perceive coherence. Amongst our participants, this situation generates discomfort in the physician or distance between the physician and the requester. Finally, in a small number of cases, participants found a request to be normatively coherent and approved it even though they were uncertain about whether a legal criterion was fulfilled.

Lyn Hagan
Newcastle University
Poster
Ex-humans and pre-persons
#54

In 2011, I wrote to and then began visiting a man on Death Row in San Quentin State Prison. This friendship began a journey of moral consideration of the right to take life and led me to a position of righteous indignation, until I realized that the drugs used in lethal injection were the same as those used in the second trimester abortion, I had signed papers for once.
Twinning the aborted fetus and death row prisoner as subjects in extremis, this article attempts to reconcile my own experiences and place them within a broader ethical framework. I argue that there is substantial moral ambiguity in whom we choose to privilege for survival or destroy that undermines a definitive pro-life or pro-choice position, as those concepts are commonly understood. It is not so much Thou Shalt Not Kill, as Thou Shalt Not Kill unless.

This philosophical reflection is about those exceptions and adopts a poetic style to encourage empathic connection with maternal, fetal, and condemned subject. By concentrating on the affective relationships that are possible with such subjects through images and words, mediated by technology, my sole aim is to widen the debate to become more nuanced and flexible in its moral positioning.

Finally, I argue that technological intervention is troubling the concepts of what constitutes 'living' and 'dying'. Technologies that keep the moribund infant alive are creating a liminal space where subjects hang in between life and death so that our concept of both may need to be redefined to include 'a living death', akin to a life spent on Death Row.

Casey Haining
Australian Centre for Health Law Research, Queensland University of Technology
Poster
Regulating VAD at the clinical coal face
#87

Introduction: Regulation of assisted dying practices is front of mind of many jurisdictions globally, as an increasing number of jurisdictions seek to introduce assisted dying laws or revise their current regime. To date, much of this focus on regulation is at a macro level and considers the impact of law, policy and system design on assisted dying practices. However, in practice, much of the control of assisted dying occurs at the clinical level, yet this has comparatively received less attention. The aim of this presentation will be to shed light on this micro-level form of regulation and consider how assisted dying is regulated at the coalface.

Methods: Semi-structured interviews with Victorian regulators (individuals who are involved in steering and guiding behaviour in relation to Voluntary Assisted Dying [VAD], including State and non-State actors) were conducted between September 2022 and July 2023 with 37 participants and analysed thematically.

Results: Preliminary analysis reveals that much of the regulation of VAD occurs at the level of the coalface, and several clinical decisions need to be made by a variety of personnel. While some forms of this type of regulation appeared to apply globally, others are heavily contingent on context and informed by local processes and approaches. In some cases, clinical decisions pertaining to VAD were perceived to be an extension of other areas of clinical practice relating to end-of-life care, whereas other clinical decisions required a more specialised approach.
Conclusion: While assisted dying regimes are typically designed and implemented at the level of the State, much of the control of VAD and regulation of access occurs at the level of the coalface. A greater understanding of this micro-level form of regulation can help inform future assisted dying regimes and may inform current practices in jurisdictions where assisted dying is lawful.

Brandon Heidinger
Ottawa Hospital Research Institute
Oral Presentation

International comparison of underlying illnesses among recipients of medical assistance in dying (MAID)
#35

Introduction: MAID availability is increasing worldwide, although eligibility criteria (e.g. intolerable suffering, short prognosis, or both) vary by jurisdiction. Despite this variability, published reports show many sociodemographic similarities among MAID recipients, particularly in terms of the underlying illness (i.e. mostly cancer and amyotrophic lateral sclerosis (ALS)). To explore this further, we collected publicly available data about underlying diseases in MAID deaths, and compared these to overall mortality from these diseases in different jurisdictions over time.

Methods: We recorded the number of MAID recipients and all other decedents with an underlying diagnosis of cancer, neurological, respiratory, and cardiovascular disease across 17 jurisdictions with publicly available data. We calculated the proportion of decedents in each illness group that received MAID. We then calculated the relative risk of receiving MAID for each disease by dividing the MAID rate for each disease by the MAID rate for all cancer diagnoses.

Results: In 115,016 MAID deaths across jurisdictions and time, people with ALS were significantly more likely to receive MAID than those with cancer (RR 7.07 95% CI [5.64, 8.86]), while people with neurological (RR 0.54 95% CI [0.44, 0.65]), respiratory (RR 0.19 95% CI [0.16, 0.23]), and cardiovascular (RR 0.07 95% CI [0.06-0.08]) disease were less likely. The magnitudes of these RRs compared to cancer remained relatively similar between jurisdictions and over time.

Conclusion: Relative differences in MAID rates by disease are large in magnitude and relatively preserved across jurisdictions and over time. While safeguards or cultural and structural factors may influence the overall incidence of MAID, our findings suggest that the main factors driving MAID relate to the disease and MAID recipient. Future studies should explore why the underlying illness is so strongly associated with MAID rates.

Mahoganie Hines
Hamilton Health Sciences
Teresa Donaldson
Community Living Dufferin
Bob Parke
Self-employed Community Bioethics ConsultantUniversity of Toronto
Panel
End of life care: Getting it right for people with IDD is right for all
#133

We have been working on a project to improve end of life care for people with intellectual and developmental disabilities (IDD). We are a dedicated group of people from diverse healthcare and developmental service backgrounds who have come together from a wide range of perspectives, supporting those with lived experience. Our collaborative focus is from the point of diagnosis through to the end of life.

This session will make space for the stories of people with IDD from first-hand experience that illustrate how our approach improves end of life care. By involving people with IDD in every aspect of their care planning in a way that they can understand and appreciate. We will highlight how laws ought to be applied and tools used to improve informed consent and participation in decision making. We will illustrate how ethical values including dignity, trust, truth telling and respect for autonomy are realized throughout our work. We will also address policy and practice implications that contribute to making a positive difference. It is the responsibility of all disciplines across every sector to play an integral role in the discussion and delivery of inclusive services.

Through participating in the conference, we will demonstrate how getting end of life care "right with this population, (people with IDD), is getting it right for ALL."

Asmat Islam
Jagannath University, North South University
Oral Presentation
Buddhism and Catholicism on the moral permissibility of palliative sedation: A blurred demarcation line
#97

Although Theravada Buddhism and Roman Catholicism agree on the moral justification for palliative sedation, they differ on the premises underlying the justification. While Catholicism justifies palliative sedation on the ground of the Principle of Double Effect, Buddhism does so on the basis of the Third Noble Truth. Despite their theological differences, Buddhism and Catholicism both value the moral significance of the physician's intent to reduce suffering and both respect the sanctity of life. This blurs the demarcation line between Buddhism and Catholicism regarding the moral justification of palliative sedation.

Asmat Islam
Jagannath University, North South University
Oral Presentation
Seeking inclusivity: A bioethical hurdle in justifying passive euthanasia in Bangladesh
#119

The diverse interactions of law, religion, and culture in Bangladesh complicate justifying a standard for end-of-life care. Even with the efforts of lawyers and physicians, the issue is substantially more complex in the context of Bangladesh. Often, the moral justification of passive euthanasia is exclusively grounded on the principle of autonomy. Critics of the idea that passive euthanasia could be justified by the principle of autonomy worry about the equal applicability of individual autonomy in societies that are composed of diverse cultures. I argue, through counterexamples, that the more we understand the bioethical hurdles to applying the principle of autonomy in multicultural societies, the more we can compare the principle's relevance in realizing and implementing the moral justification of passive euthanasia, especially in the context of global health. To support this argument, I explore how there has been no multidisciplinary effort to develop bioethics in Bangladesh because the current educational practices lack an appropriate understanding of the value of the medical humanities. Drawing on the premises of critical medical humanities, I argue for the value of interdisciplinary collaborative relationships

and ethics for healthcare in Bangladesh. First, I identify the moral dynamic between religious fatalism, dukkha, and negative attitudes towards death and poverty that shape South Asian understandings of dignity in dying. Next, I examine the relationship between the lack of multidisciplinary institutional ethics and the lack of understanding surrounding the values of the medical humanities. Finally, having identified the problem that end-of-life care is understood in a non-inclusive sense in Bangladesh, I conclude that the main worry about the principle of autonomy needs more scrutiny so that the principle captures the shared decision-making in end-of-life care in Bangladesh. My argument is crucial not only for developing and furthering bioethics in Bangladesh and South Asia but also for understanding elderly care planning in multicultural societies so to enhance inclusivity in bioethics.

Ruthie Jeanneret
Queensland University of Technology
Oral Presentation
How actions by Canadian patients and caregivers to overcome MAiD access barriers influence regulation
#74

Medical assistance in dying (MAiD) was legalised federally in Canada in 2016, after the Supreme Court decision in Carter v Canada (Attorney General) [2015] 1 SCR 331. The federal legislative framework for MAiD was then established via Bill C-14. Patients and caregivers were central to MAiD legalisation, through Carter litigation and broader advocacy. Litigation and advocacy by patients and caregivers also resulted in Bill C-7 amendments to the Criminal Code in 2021. This study investigates regulatory barriers and facilitators to MAiD access in Canada since 2016, and how patients' and caregivers' actions to overcome barriers have influenced MAiD regulation in Canada.

We conducted 32 semi-structured, qualitative interviews with 34 participants (1 patient, 33 caregivers) about 33 patient experiences. Our preliminary findings are that key facilitators of MAiD access included dedicated and supportive individuals: clinicians, representatives from advocacy and peer support organisations, and caregivers. Participants also reported barriers to MAiD access including prohibitive legal requirements (e.g., witnessing and final consent in all MAiD cases requirements), and other regulatory barriers (e.g., religious and philosophical objections by individuals and institutions to MAiD). Participants undertook various actions aimed at overcoming access barriers, including advocacy, complaints, and law reform efforts. Patients and caregivers influenced law reform and the operation of MAiD in practice through their actions to overcome access barriers, and consequently improved MAiD regulation.

We argue that other regulatory actors (e.g., governments and organisational decision-makers) should be receptive to action by patients and caregivers to overcome barriers to accessing MAiD. Recognising the potential burdens on patients and caregivers of undertaking this action, they should seek to reduce this burden on patients and caregivers where possible. MAiD systems should also ensure appropriate support for key facilitators of MAiD access, such as clinicians and caregivers, to ensure sustainability of MAiD as an end-of-life choice in Canada."

Jeanne Kerwin
Health Care Ethics Consultant for American Clinicians Academy on Medical Aid in Dying

Patricia Westmoreland
ACUTE Center for Eating Disorders and Severe Malnutrition
Panel
Medical aid in dying for severe and enduring anorexia nervosa: Legal and ethical analysis
#31

Eating disorders, and primarily anorexia nervosa, have the second highest mortality of psychiatric disorders and the end-of-life options for those for whom weight restoration or even harm reduction has not been successful raise complex ethical and legal questions.

We will present the following case: A 36-year-old female with anorexia nervosa requested aid in dying from her palliative care physician. The patient had a history of severe and enduring anorexia without any sustained recovery despite multiple attempts at treatment. The patient never attained the "gold standard" of full body weight restoration. Despite being underweight and with questionable decisional capacity due to a starved brain, she was deemed by her treating physician to have decision-making capacity. The patient was currently enrolled in hospice, refusing further treatments and living with her family, who supported her request for medical aid in dying. She lived in a jurisdiction where medical aid in dying was legal. We will analyze the following ethical and legal questions:

1. Is there a role for medical aid in dying for those with severe and enduring anorexia nervosa?
2. Is there a defined "end stage" or "terminal stage" of anorexia nervosa that would meet the legal criteria for accessing medical aid in dying?
3. What are the barriers for an individual with severe and enduring anorexia nervosa in obtaining medical aid in dying?
4. Is a psychiatric illness ever considered "terminal" and "irreversible"?

Exploration of the diversity of professional opinions on these ethical and legal questions will be reviewed and discussed, along with the pros and cons of end-of-life options available to those with severe and enduring anorexia nervosa, including palliative care, hospice care, and voluntary stopping of eating and drinking (VSED), as well as medical aid in dying.

Erika Landau
Columbia University Medical Center Religion and End of Life Care
Poster
Religion and end-of-life care
#89

Background: Patients' religious beliefs challenge clinicians when providing competent end-of-life care. In areas with a high concentration of ethnic and religious minority groups, not knowing or understanding such issues can lead to conflict. The patients' and their families' beliefs in the religious sanctity of life may be against what health professionals consider "futile medicine".

Purpose: The purpose of this study is twofold, to provide health practitioners with knowledge about several main religions' views on end-of-life care and offer a communication plan.

Understanding socio-cultural and religious traditions will enhance the patients' and families' experience and avoid conflict.

Material and method: A thorough literature search was performed through PubMed, JStor, journals, and personal experience. A medical/ethical case of conflict between a physician and the patient's religious beliefs is presented. The stand on the sanctity of life, physician-assisted suicide, organ donation, feeding, hydration, and care withdrawal is discussed within the major religions.

Results: Studies show that health professionals do not possess enough knowledge about sensitive socio-cultural issues and religious beliefs. Conflicts between them and the already stressed patients and family members may arise. There is a need for more education for health professionals.
Conclusion: Barriers to preparing the families for the death of a loved one include family crises, caregivers' hostility or lack of understanding, denial, the clinicians' lack of time and training, lack of interest or confidence in managing the situation, and avoidance. The clinicians need to determine which portion of the encounter may be most challenging, confront their own weaknesses, and be prepared for the emotional challenge of these conversations. Knowledge of socio-cultural issues and religious beliefs addressed with understanding and compassion will enhance this difficult time for the patients and their families.

Garson Leder
Medical College of Wisconsin
Arthur Derse
Medical College of Wisconsin
Oral Presentation
ECMO, 'inappropriate treatment', and conscience: Grounding and justifying a policy on 'futile' treatment.
#105

Attempts to establish a consensus definition of 'medical futility' have been unsuccessful. Given this, healthcare institutions in the US have been left to establish their own 'futility' or 'inappropriate treatment' policies or guidelines (often with significant variations). This talk will examine one large Mid-Western Level 1 Trauma Center's recent transition from a minimally value-laden futility policy (i.e., a physiological futility-based policy) to a more expansively value-laden policy (i.e., based on expected survivability to discharge). This transition was primarily made in response to advances in the development and utilization of life-sustaining technology (including ECMO) that have led to a significant increase in so-called 'bridge to nowhere' patients whose lives may be sustained for prolonged periods in the ICU setting, but who are unlikely to be able to survive their hospitalization. We critically analyze and defend the motivations and theoretical rationales for this change as well as the practical applications of this policy (with a specific focus on ECMO). We present and defend three rationales for this more expansive futility policy (distributive justice, the purpose of medicine, and conscientious objection) and argue that, when applicable, claims of 'futility' or 'inappropriateness' are most often best justified when they appeal to the autonomy and conscience of the providers being asked to perform these treatments (rather than appealing to concepts such as 'best interests', 'benefits vs burdens', or 'standards of care'). We then conclude by addressing practical issues related to the utilization of the revised policy in the case of ECMO-dependent individuals. Specifically, we address the justifications for non-escalation of treatment vs. withdrawal of treatment, the importance of the psychological

differences between withholding and withdrawing treatments, and the application of the revised policy in cases of conscious and capacitated patients.

Meredith Levine
The Weinberg Center for Elder Justice
Mercedes Bern-Klug
University of Iowa School of Social Work
Oral Presentation
Nursing home staff perspectives on challenges in implementing dementia ddvance directives related to stopping feeding
#17

Purpose: Solicit comments from nursing home staff about possible implications of attempting to follow dementia-specific advance directives which request no feeding, when the person can no longer self-feed.

Relevance: Dementia-specific advance directives with the option to request no feeding are online and available to the public. The literature contains perspectives regarding not feeding a person with dementia by medical professionals, attorneys, and philosophers. This study contributes the perspective of nursing home direct care staff who would be interacting with residents and families in the event a resident has such a directive.
Design: Cross-sectional

Participants: 12 nursing home staff (nurses, social workers, nursing assistants, dietitians, physician)

Method: Qualitative descriptive

Results: Direct care staff identified concrete challenges to attempting to honor a resident's dementia-specific advance directive requesting that the resident not be fed once he/she is no longer able to self-feed. Logistical challenges (language ambiguity, the fluctuating nature of dementia, honoring then-self or now-self determination) as well as moral challenges related to potential harm to residents, staff, family and the nursing home were discussed.

Conclusions: Unless nursing homes have clear policies and protocols for accepting residents with this type of advance directive, attempting to implement the directives, in their current form, would likely be problematic for staff and potentially for family members and could lead to care confusion and moral distress.

Laura Ley Greaves
Australian Centre for Health Law Research, Queensland University of Technology, Australia
Oral Presentation
Experiences of Australian practitioners with in-principle support of voluntary assisted dying prior to commencing operation.

#18

Objective: To understand the perspectives and expected experiences of medical practitioners during the implementation phase, prior to the commencement of voluntary assisted dying in Queensland, Australia.

Design: Semi structured interviews of 31 medical practitioners who had no in-principle objection to voluntary assisted dying, during the implementation phase of the Voluntary Assisted Dying Act 2021 in Queensland, Australia. Interviews conducted March 2022 – January 2023.

Results: 31 interviews, 5 face-to-face and 26 conducted via Zoom. 14 General Practitioners and 17 specialists including 3 Palliative Care and 4 Oncologists. 21 participants had signed up or were planning on becoming authorised voluntary assisted dying practitioners. Five general themes were identified: (1) A new practice with many unknowns including where, how and to whom voluntary assisted dying would be provided. (2) Medical practitioner choice versus patient choice for decisions on administration and pressure on medical practitioners to participate. (3) Voluntary assisted dying as a valid end of life option. (4) Personal and professional implications including a high emotional load, lack of remuneration, significant time requirement and associated stigma of participating. (5) Practicalities of the Act including eligibility assessments, the process of implementation, and available support and information.

Conclusion: Participation in voluntary assisted dying by medical practitioners is facilitated by in-principle support, however the practicalities of a new practice and how it may influence current practice pose barriers to participation. Attention is needed to address how best to support those medical practitioners looking to participate and how voluntary assisted dying is implemented in practice.

Serena Isenberg
Bruyère Research Institute
Jaya Rastogi
Bruyère Research Institute
Taylor Shorting
Bruyère Research Institute
Poster
Developing a jurisdiction-level actionable resource allocation framework for the use of triage and triage-avoidant strategies
#109

Amidst the COVID-19 pandemic, healthcare systems struggled to meet demands for critical care. Most jurisdictions implemented triage-avoidant strategies (e.g., cancelling non-emergent surgery, rerouting patients to other regions). These strategies led to unintended, and not yet fully understood, consequences for patients, families, staff, healthcare organizations, and particularly marginalized individuals within these groups. While some frameworks included principles of non-discrimination, equity, and autonomy, more research is required to understand how to better incorporate these into an actionable framework. We aim to develop an evidence-informed, ethically justified jurisdiction-level resource allocation framework to assist decision-makers in optimizing outcomes and mitigating the disproportionate effects of future surges in demand

upon marginalized populations, particularly within intensive care units (ICUs) and acute care. This research is comprised of two qualitative phases. In phase one, focus groups (n=20) were organized thematically (i.e., disease-based, racialized individuals, persons with disabilities, healthcare organizations, government). Participants were asked to share the impact of triage-avoidant strategies on their community and ideas on how to best allocate limited ICU resources. Using grounded theory, we are analyzing the transcripts to develop a framework to guide the use of triage and triage-avoidant strategies during overwhelming demand for critical care. In phase two, we will share the updated framework with phase one participants to refine the framework. While focus groups are underway, preliminary themes include: the importance of consulting marginalized groups when developing and implementing frameworks; the disproportionate negative health impacts of relocating patients and cancelling or postponing specialist treatment, non-emergent surgery, and ICU recovery-requiring surgery; and the importance of having a triage protocol available if triage-avoidant strategies are insufficient and/or lead to unintended consequences. Participants also discussed how histories of systemic oppression and mistrust of the healthcare system shaped their healthcare experiences during the pandemic; several felt that triage avoidant strategies reinforced these structural barriers.

Genevieve Mann
Gonzaga School of Law
Oral Presentation
A good death: End-of-life lawyering through a relational autonomy lens
#80

Death is difficult. Even for lawyers who counsel clients on end-of-life planning. The predominant approach to counseling clients about death relies too heavily on traditional notions of personal autonomy and a nearly impenetrable right to be free from interference by others. Rooted in these notions, contracts called "advance directives" emerged as the primary tool for choosing one's final destiny. Nevertheless, advance directives are underutilized and ineffective because many people are mired in death anxiety, indecision, and the weight of planning for a hypothetical illness. In the end, many do not get the death they choose: to trust in others and share the arduous decision-making responsibility with loved ones.

This article proposes that lawyers shift away from a rights-based paradigm that insists clients make decisions alone, unobstructed by family and friends. Instead, it offers an alternative counseling model that draws on relational autonomy and values the inherent interplay between client independence and interdependence. Grounded in feminism, relational autonomy reimagines individualistic conceptions of self and identity to embrace our essential social and connected nature. Lawyers can enhance end-of-life decision-making to be in alignment with client goals by refocusing it from a solitary experience to one inclusive of the interests and participation of loved ones. While death is inevitable, we no longer need to insist it is done alone.

Radboud Marijnissen
University Medical Center Groningen
Oral Presentation
MAID and the assessment of decisional capacity in dementia: the Dutch perspective

#28

The Netherlands allows Medical Assistance in Dying (MAID) based on a diagnosis of dementia under strict legal conditions. The number of dementia MAID cases gradually increase every year up to 288 cases in 2022; 282 were decisionally competent and 6 were decisionally incompetent. In decisionally incompetent patients MAID has been granted based on a written advance directive.

To assess decisional competence the Dutch euthanasia review committees refer to criteria of Appelbaum and Grisso. To examine which factors, and how, influence the judgment of decisional competence for MAID requests of patients with dementia a qualitative analysis was performed of 60 dementia MAID case summaries as published online by the Dutch euthanasie review committees between 2012 and 2021: 20 cases had an advance directive and were decisionally-compromised at time of MAID, 40 patients were decisionally-competent at time of MAID, of which 20 also had an advance directive (purposive sampling). Two researchers independently coded all text related to decisional competence. A theoretical framework about the assessment of decisional competence was developed. The four cognitive criteria of Appelbaum and Grisso were dimensional and cut-off points were influenced by six factors that also directly impacted on competence assessment, i.e. level of communication, psychiatric comorbidity, personality, presence of an advance directive, consistency of the request, and the patient-physician relationship.

In this presentation an overview will be given of epidemiology, legal regulation, clinical guidelines and societal debate regarding MAID in dementia from the Netherlands. Furthermore the multidimensionality and subjectivity of decisional competence assessment may pose ethical and legal challenges. As the ethical dilemmas and controversial aspects are discussed, countries with or preparing new legislation could learn lessons of 20 years of development and experience on euthanasia in patients with dementia.

Stevie Martin
University of Cambridge
Oral Presentation
Living through dying: why bans on assisted dying are incompatible with the right to life
#60

Long before the recent judgment of the European Court of Human Rights (ECtHR) in Mortier v Belgium, the UK Supreme Court (UKSC) in Nicklinson and Smith J (British Colombia Supreme Court) in Carter recognised that blanket prohibitions on assisted suicide caused some people to take their lives prematurely, while they were still physically able to do so unassisted. This, those courts held, raised issues with respect to the state's obligation to protect life under the rights instruments in those jurisdictions. Fast forward to the ECtHR's 2022 judgment in Mortier. While a majority of the Court held that assisted dying regimes could be compatible with the state's obligation under Article 2 of the European Convention on Human Rights to protect life, Judge Serghides in dissent held that no legalised system of assisted dying could ever be compatible with the right to life (and the state's obligation to protect it). This is an oft-cited argument in the debates in the UK (and elsewhere) regarding legalisation of assisted dying. But it ignores the realities recognised by the UKSC in Nicklinson and Smith J in Carter, and recognised by inquiries in other jurisdictions which have subsequently introduced assisted dying regimes. Namely, that

blanket prohibitions on assisted suicide violate the right to life of a not insignificant number of people who are compelled to take their lives prematurely for fear that they will be unable to do so unassisted at a point in the future. This paper demonstrates, by reference to anecdotal evidence from the UK and evidence cited in courts and by inquiries in other jurisdictions, that far from being incompatible with the right to life, assisted dying regimes protect life: they enable people to live longer, secure in the knowledge that if their suffering becomes intolerable, they will be able to access assistance to die.

Clément Meier
University of Lausanne
Oral Presentation
How can I choose? Personal end-of-life health literacy; a key factor for advance care planning
#57

Background: Individuals' attitudes toward advance care planning (ACP) can be influenced by their end-of-life health literacy. Personal end-of-life health literacy skills can empower individuals to make decisions in the face of death, potentially resulting in the decision to engage in ACP. This study investigates the associations between individuals' end-of-life health literacy and their knowledge and attitudes toward end-of-life healthcare planning among a population-based sample of adults aged 58+ in Switzerland.

Method: We used data from 1,319 respondents from Wave 8 (2019/2020) of the Survey on Health, Ageing, and Retirement in Europe. The Subjective End-of-life Health Literacy scale measured individuals' competencies in understanding medical interventions, finding information, communicating, and making decisions about end-of-life healthcare options. End-of-life knowledge was assessed using 11 questions on diverse medical situations. Engagement in end-of-life healthcare planning was measured by whether respondents have discussed their end-of-life wishes, completed advance directives (AD), and appointed a surrogate for medical decisions. Associations were estimated using separate ordinary least squares and probit regressions, controlling for social, health, and regional characteristics.
Results: We found that respondents with higher end-of-life health literacy tended to have higher end-of-life knowledge and were more likely to discuss their end-of-life wishes, to have completed AD, and to have appointed a surrogate for medical decisions. In addition, when regressing on the end-of-life health literacy scale's dimensions, interactive end-of-life health literacy was positively associated with knowledge and the three attitudes toward end-of-life healthcare planning, while critical end-of-life health literacy was positively associated with having AD and appointed a surrogate for medical decisions.

Conclusions: Our findings suggest that end-of-life health literacy may play a significant role in individuals' level of knowledge and attitudes toward end-of-life healthcare planning. Thus, one effective approach to enhance individuals' engagement in the ACP process might be developing public health policies aimed at strengthening their end-of-life health literacy skills.

Clément Meier
University of Lausanne
Oral Presentation

Learning by experience: Does caregiving for loved ones boost personal end-of-life health literacy?
#58

Background: Low health literacy was shown to be associated with fewer palliative care visits, reduced engagement in advance care planning and fewer advance directive completion. Despite its importance for terminally ill patients, their caregivers, and individuals wishing to engage in advance care planning, limited research exists on the determinants of end-of-life health literacy. This study investigates the association between individuals' experiences with end-of-life care support to loved ones and end-of-life health literacy among a population-based sample of adults aged 58+ in Switzerland.

Method: We used data from 1,548 respondents from Wave 8 (2019/2020) of the Survey on Health, Ageing, and Retirement in Europe in Switzerland. The Subjective End-of-Life Health Literacy Scale measured respondents' ability to understand medical jargon, find information, communicate, and make decisions about end-of-life care options. Experiences with end-of-life care support was measured by asking respondents whether they had previously made medical decisions as a healthcare proxy, accompanied, or cared for a loved one at the end of life. Associations between the provision of end-of-life care support and the end-of-life health literacy score were estimated using ordinary least squares regressions, controlling for socio-demographic, health, and regional characteristics.

Results: Preliminary results suggested that respondents who experienced being a healthcare proxy ($p<0.001$), who accompanied ($p<0.001$), or who cared for a dying relative or close friend ($p<0.001$) tended to have higher levels of end-of-life health literacy. These results remained statistically significant when the three variables assessing respondents' experiences with end-of-life care support were simultaneously included in the multivariable model ($p<0.001$, $p<0.001$ and $p<0.05$, respectively).

Conclusions: Our findings suggest that providing end-of-life support to loved ones is associated with higher end-of-life health literacy. Thus, as caregivers gain experience caring for others, targeted interventions could leverage their skills and encourage them to also think of engaging in end-of-life planning for themselves.

Paul T. Menzel
Pacific Lutheran University (emeritus)
Peter Reagan
Family Medical Practice, Portland, OR (retired)
Hope Wechkin
Medical Director, EvergreenHealth Hospice
Panel
Voluntarily stopping eating and drinking: Issues in devising and implementing clinical guidelines
#13

Until recently, few if any readily available clinical guidelines existed for Voluntarily Stopping Eating and Drinking (VSED) despite VSED's status as a compassionate, legal, and feasible option in end-of-life care. To fill this void, an inter-professional group representing medicine, nursing, ethics, theology, spiritual care, and the law, and including a death doula, gathered to

formulate practical counsel for patients considering VSED and the clinicians and institutions able to support them. The group published its guidelines in the Journal of Pain & Symptom Management in June, 2023. All the presenters on this panel participated in that process.

After briefly summarizing the guidelines, the presenters highlight and pursue some of the especially difficult issues encountered in formulating them – questions and dilemmas about initiation, location, timing, the involvement of caregivers, symptom management, and phases of the typical 7-14 day VSED process. Particular attention will be devoted to ethical aspects of VSED encountered by clinicians, including: (1) the diagnoses and circumstances important to discuss prior to agreeing to support VSED, (2) informing all parties involved beforehand of not only the nature of VSED but the difficulties that may arise, (3) managing the ambivalence that may occur after the decision to proceed with VSED, and (4) how aggressively to palliate symptoms of distress.

The presenters also discuss other contentious issues likely to be encountered in implementing such guidelines, including: (1) hospice eligibility, (2) how to respond to a patient who requests resumption of eating and drinking after losing decision-making capacity late in the process, and (3) how to address and manage conflict with providers and facilities and among family members and caregivers.

Presenters will describe the process by which they achieved consensus on these issues.

Paul T. Menzel
Pacific Lutheran University (emeritus)
Thaddeus M. Pope
Mitchell Hamline School of Law
Hope Wechkin
Medical Director, EvergreenHealth Home Care Services
Panel
VSED by advance directive: A legal, ethical, and clinically supportable option for hastening death?
#47

This presentation addresses legal, ethical, and clinical dimensions of using advance directives to withhold oral food and drink.

VSED is a legally and ethically permissible option for hastening death. With its legal status grounded in common law, it does not have the usual restrictions regarding prognosis, residency, etc. that accompany laws governing MAiD. This makes it attractive for those with decision making capacity (DMC) who live where MAiD is not legal, not accessible, or for which they are not medically eligible due to an extended prognosis.

VSED by AD, unlike VSED, does not require a person to have DMC at the time it is undertaken. In this case, ADs allow a person to plan to live until – but not beyond – the point that quality of life is no longer acceptable, even if DMC is then absent. The determination of what constitutes acceptable quality of life is made in advance by the individual. But VSED by AD presents ethical, legal, and clinical challenges that VSED by those with DMC does not. Ethical

and legal arguments for such ADs will be offered, and the difficulties encountered by the actual implementation will be pursued, including:

(1) Whether what is to be withheld should be strictly limited to manually assisted eating and drinking.
(2) How to describe the conditions that trigger withholding.
(3) What to do when the person expresses a desire to eat or drink.
(4) How intensive palliative measures to address discomfort may be (e.g., sedation).
(5) What to do when facilities where the patient resides will not support implementation.
(6) Degree of discretion the patient's appointed healthcare agent should have.

Presenters: From three different disciplines, they include co-authors (TMP and PTM) of a recently devised, soon to be published Sample AD for VSED. Another, a clinician (HW), is co-author of recently published clinical guidelines for VSED.

Darcy Metcalfe
University of Findlay
Oral Presentation
Ethics of using chemical restraint with self-harming advanced Alzheimer's patients in hospice
#70

This presentation is an ethical argument for using chemical restraint with advanced Alzheimer's patients who are in hospice and/or at the end-of-life and are at increased risk for falls and self-harm. Within the US, the legalities for using chemical restraint in such situations varies drastically according to state statutes and preferences of individual care facilities. This presentation reviews a sampling of differing state statues as well as key federal legislation and explains why these legal inconsistencies complicate patient care in these particular circumstances.

I agree with many ethicists who argue that chemical restraint has been used too often in long-term care facilities in unethical and abusive ways. The federal Nursing Homes Bill of Rights of 1987 was created to, in part, address and prevent these abuses. However, the legal and ethical implications of such legislation have led to complexities in using chemical restraint in certain cases in which it would be beneficial for the patient. One example of possible benefit is the use of chemical restraint as a resource of palliative care in end-of-life Alzheimer's patients who inflict considerable harm to themselves through falls and/or other self-harming behaviors.

I argue that patient autonomy becomes a secondary ethical concern when care providers are presented with this specific end-of-life care scenario. The primary ethical concerns in such cases should be non-maleficence and benevolence—ethical principles which are strongly informed and guided by an ethic of compassion. State statutes and facility preferences should not prevent families from providing the best end-of-life care for their loved ones in these particular circumstances.

Sarah Mroz
End-of-life Care Research Group, Vrije Universiteit Brussel (VUB) & Ghent University
Luc Deliens

End-of-life Care Research Group, Vrije Universiteit Brussel (VUB) & Ghent University
Ben White
Australian Centre for Health Law Research, Faculty of Business and Law
Lindy Willmott
Australian Centre for Health Law Research, Queensland University of Technology
James Downar
University of Ottawa
Panel
Physicians' preferences for MAID and other end-of-life decisions, and how those preferences impact clinical practice
#108

Physicians play a key role in end-of-life decisions (ELDs), which are increasingly important as the global aging population expands and death is often preceded by an ELD (including withholding and withdrawing treatment, palliative sedation, or assisted dying, among others). Research suggests a connection between physicians' personal preferences regarding ELDs and their clinical practice, but little is known about physicians' preferences at the end of life. There is also a gap in knowledge regarding the factors that influence physicians' preferences (eg. personal background, legal context concerning assisted dying), and to what extent physicians feel there is a connection between their personal preferences and their clinical practice.

The international PROPEL consortium, including researchers from Belgium, Italy, Canada, the USA, and Australia, has examined the ELD preferences of physicians, the connection to clinical practice, and to what extent physicians' ELD preferences differ from their preferred treatments for patients. Since the implementation of assisted dying legislation can have a substantial impact on the role of physicians, medical practice, and end-of-life culture, we intentionally selected jurisdictions which have diverse cultural environments and varied levels of experience with assisted dying legislation. The survey study includes responses from 1157 physicians in eight jurisdictions in Europe (Belgium, Italy), North America (Canada, Wisconsin, Georgia and Oregon) and Australia (Queensland and Victoria). In this panel session, we will present and discuss the findings of this mixed methods cross-sectional PROPEL study.

Penny Neller
Australian Centre for Health Law Research, Queensland University of Technology, Brisbane, Australia
Oral Presentation
Aboriginal and Torres Strait Islander Peoples and end-of-life decision-making
#55

For Australia's First Peoples - Aboriginal and Torres Strait Islander Peoples – health and wellbeing are intrinsically linked to cultural values, spiritual beliefs, and knowledges; and connection to family, community, and Country (the land or waters the person considers belonging to). These factors can profoundly influence approaches to death, dying and end-of-life decision-making. Also relevant are historical, socio-economic, and health experiences, including the legacy of Australia's colonisation, past and continuing discrimination and trauma, and challenges accessing end-of-life care.

There has been limited examination of the interaction between law and end-of-life medical treatment decision-making with Aboriginal and Torres Strait Islander Peoples. Here we describe the development of a new online training module exploring these issues, launched in September 2022. The module is part of End of Life Law for Clinicians (ELLC), a training program for health professionals on Australian end-of-life decision-making laws.
To inform the module, ELLC analysed Australian law and literature, and consulted with Aboriginal and Torres Strait Islander stakeholders to identify the key cultural and legal considerations that may arise when caring for Australia's First Peoples at the end-of-life.

Two key themes emerged from this work:

1. The importance of clear, honest and culturally safe and respectful communication with Aboriginal and Torres Strait Islander Peoples. This is critical to obtaining consent, informed decision-making, and effective communication between individuals, families, and health professionals.

2. The role of collective decision-making. Depending on the person, decision-making may occur individually, or collectively with family and community.

These findings, and the training it informed, can support health professionals to deliver Culturally Safe and Responsive end-of-life and palliative care for Aboriginal and Torres Strait Islander Communities. There are also important learnings for Australian legal professionals, policy makers, health departments, and health professional bodies to consider, to embed cultural values into mainstream practices.

Bernadette Nunley
National Director of Policy, Compassion and Choices
Oral Presentation
Measuring legislative impacts on inequities at the end of life in the United States
#114

In the United States, persistent structural inequities exist at the end of life. By the time a person from a historically underserved community has reached their end-of-life journey, they have likely experienced a lifetime of unequal access to healthcare. The end of life is a unique time and opportunity to change that experience, but only if healthcare providers, systems, and policy leaders can engage with their community. From completion of advance directives to hospice utilization to utilization of end-of-life options like medical aid in dying (MAID), there are many opportunities to support planning and care that align with an individual's wishes and values.

This presentation will cover trends in legislation focused on end-of-life care throughout the United States and their impacts on healthcare disparities at the end of life.

This presentation will begin with trends in MAID legislation, mapped through methods of legal epidemiology. In the United States, MAID refers to the process by which a terminally ill adult with six months or less to live, who is capable of making medical decisions, can request medication they can self-ingest to peacefully bring death. Since the practice was first authorized in Oregon, some jurisdictions have amended their laws or passed new laws that remove barriers to

access. Legal epidemiology demonstrates these trends over time and examines rates of use of MAID in these jurisdictions, exploring whether the changes in legislation led to increased access.

Additionally, this presentation will cover other areas of end-of-life planning and care where similar tracking will be completed in time to understand national trends and structural inequities created and solved by legislation. Such areas include variations in advance directive laws and completion rates of advance directives and laws related to religious and conscience-based refusals in healthcare and their impact on patient-directed care.

Michaela Okninski
University of Adelaide, Adelaide Law School
Neera Bhatia
Deakin Law School, Deakin University
Oral Presentation
Challenging the status quo – Should Australia permit voluntary assisted dying for 'Gillick' competent minors?
#23

In 2017, Victoria, became the first Australian state to legalise voluntary assisted dying (VAD) by passing the Voluntary Assisted Dying Act 2017 (Vic). Since then, every Australian State has enacted laws permitting eligible persons to request an assisted death. Consequently, Australia now joins a small cohort of international jurisdictions to permit this practice. While Australia has taken the first critical step by permitting VAD in certain circumstances, we contend that it is necessary to consider the eligibility criteria and other related aspects of the legislation as it pertains to access to VAD for persons under the age of 18 years.

Whether minors who, for the purposes of this discussion are those that would be deemed to be "Gillick" competent should be permitted to access VAD is a controversial topic that has perhaps not been given in-depth consideration from an Australian perspective. It has largely been overlooked in academic literature and has only recently been highlighted in the media. The aim of this presentation is to critically explore this issue and consider whether the current prohibition on minors accessing VAD is defensible.

We focus on the legislative framework adopted under the Voluntary Assisted Dying Act 2017 (Vic), paying particular attention to the parliamentary reports that preceded the introduction of the legislation. This will be followed by a critical examination of the Australian common law cases discussing 'Gillick' competence, noting that there has been an incremental shift towards children having greater authority over treatment decisions if they can demonstrate sufficient maturity and understanding. We contend that if all eligibility criteria are satisfied – with added emphasis placed on ensuring that decision-making capacity is stringently assessed – then age should not pose a barrier to access, and this should be recognised in the Victorian VAD framework.

Bregje Onwuteaka-Philipsen
Amsterdam University Medical Center
Oral Presentation
Trends on older adults' opinions on euthanasia and a suicide-pill: the longitudinal LASA study 2001-2018

#102

Background and aim: In the Netherlands, in the last decades there has been debate on older people wishing to die due to completed life in the absence of (a serious) illness. In this study we want to inform this debate by studying trends in the opinions of older people on imagining ever requesting euthanasia or ever wanting to have access to a suicide pill.

Methods: The Longitudinal Aging Study Amsterdam (LASA) consists of older people of 55 years and older. There is a measurement cycle every three years. From 2001 until 2018 (n=1279) it included the following questions: 'can you imagine that you would ever ask your physician to end your life? (yes/no)'; 'can you imagine that you ever would want to have a suicide pill at your disposal (yes/no)'. General Estimated Equations (GEE) were done to assess the influence of birth cohort, age and year on trends.

Results: The proportion of respondents that could imagine ever wanting to have a suicide pill increased from 31% in 2001 to 43% in 2018; corresponding proportions for ever asking a physician to end life were 54% and 71%. GEE analyses showed that the age of respondents and the year of measurement were not and birth cohort was related to respondents imagining ever wanting to have a suicide pill. Similar results were found for imagining ever asking a physician to end life.

Discussion: Our study shows that the increase in the proportion of older people who can imagine ever wanting to have a suicide pill or ever asking a physician to end life is due to the proportion of older people from younger birth cohorts is increasing and not because older people themselves change their views over the years when ageing or due to society changing.

Richard Oude Voshaar
University of Groningen
Oral Presentation
The downside of progressive euthanasia legislation for patient and clinician – a case-report
#63

The Netherlands was the first jurisdiction that has legalized euthanasia and physician-assisted dying by adopting the Termination of Life on Request and Assisted Suicide Act in 2002. Internationally, the Dutch legislation is still progressive by permitting performance of euthanasia and assisted suicide (EAS) for unbearable suffering due to psychiatric disorders judged to be untreatable. Even though a tenfold increase in the past decade, only 1.3% (n=115) of all euthanasia cases in 2022 in the Netherlands was based on a psychiatric disorder. Nonetheless, growing awareness among psychiatric patients about the possibilities of a self-chosen end-of-life may be pressing clinical practice. Public opinion is more liberal towards euthanasia for psychiatric disorders than psychiatrists. This difference in viewpoint as well as the fact that most psychiatrists are not familiar with euthanasia trajectories poses clinical challenges.

Within this context, a clinical case is presented from a man in his 60s who unbearably suffered due to a bipolar disorder and requested for euthanasia. Two responsible psychiatrists confirmed that the patient met the due care criteria set by law for receiving euthanasia and initially expressed their support to start a euthanasia trajectory. Due to their inner struggle regarding their own

attitude towards euthanasia and lack of experience, they did not act accordingly. The unclear signals they gave led to the patient committing suicide in the presence of his son and daughter-in-law. Feeling let down by the medical profession, the family considered this the most human way to end life of dying. We conclude that knowledge on euthanasia trajectories and transparency about one's own attitude and experience is key to provide adequate care. This becomes increasingly important as it has been estimated that on average Dutch psychiatrists faces every two years a patient requesting euthanasia and even yearly a patient requesting for euthanasia in due course.

Iris Parra Jounou
Universitat Autònoma de Barcelona
Poster
Beyond the "in favor/against" dichotomy in conscientious objection to MAID: A qualitative study
#93

Conscientious objection (CO) to Medical Assistance in Dying (MAID) is usually understood as an "in favor/against" matter. Nevertheless, empirical data show that not all professionals who are against MAID would declare themself conscientious objectors and not all conscientious objectors would be against the existence of a law regulating MAID.

To understand the motivations lying behind CO we conducted a qualitative research study through semi-structured interviews to 25 healthcare professionals (physicians and nurses) with different professional backgrounds (primary care, palliative care, hospital care) in three different regions of Spain (Madrid, Catalonia and Andalusia) between March and May 2023.

We found 4 analytical types of discourses among professionals: Full Support, Conditioned Support, Conditioned Rejection and Full Rejection. "Full Support" and "Full Rejection" profiles include the typical in favor/against positions in MAID and their active participation or non-participation in the practice. In between these two opposite sides, there is a group of ambivalent profiles whose discourses can overlap. The "Conditioned Support" profile includes professionals in favor of MAID who wouldn't do it in all cases; instead, their decisions would depend on the particular context of each patient and they might even declare themselves conscientious objectors. The "Conditioned Rejection" profile includes professionals that identify themselves as religious and are against MAID but who recognize the relevance of the autonomy of the patient. They usually accompany them during the whole process, except for the final injection of a lethal drug. Some of them declare themselves conscientious objectors but others do not.

Our results show that there is a spectrum of gray in professionals' decisions that can easily fall on one side or the other depending on every case and context. This has to be considered when analyzing motivations in CO that are not included in the traditional definition used in the theoretical framework. Therefore, empirical data can move forward the classical and dichotomous discussion on CO.

Roeline Pasman

Department of Public and Occupational Health, Amsterdam Public Health Research Institute, Expertise Center for Palliative Care, Amsterdam UMC - Location VU University Medical Center, Amsterdam, The Netherlands
Oral Presentation
Trends in SCEN consultations in case of euthanasia: 17 years of monitoring in the Netherlands
#129

Introduction and aim: In the Netherlands, consulting an independent physician is one of the due care criteria for euthanasia and physician-assisted suicide. Since 2004 physicians throughout the Netherlands can turn to the SCEN organization (Support and Consultation on Euthanasia in the Netherlands) for consultation by a specifically trained and independent consultant. We aim to get insight in trends in number and characteristics of consultations between 2004 and 2021.

Methods: Every year all SCEN physicians are asked to fill in a questionnaire on their consultations of the past year. In 2021, 359 of 635 SCEN-physicians (57%) filled out this questionnaire

Results: The estimated total number of consultations in the Netherlands per year increased over the years: from 2350 in 2004 to 9600 in 2021. The average number of consultations per SCEN-physician per year increased from 5 in 2004 to 15 in 2021. There is much variation between SCEN-physicians; in 2021 the number of consultations per year ranged between 2 and 42. The proportion of consultations for patients with cancer decreased over the years: from 84% in 2007 to 70% in 2020. The proportion of consultations for which the SCEN-physician came to the conclusion that the due care criteria were met increased over the years: from 78% in 2004 to 93% in 2021.

Discussion: There has been an increase in consultations over the years which resulted in an increased workload for SCEN-physicians. It can be debated what the optimal number of consultations for a SCEN-physician is per year. That SCEN-physician more often conclude that the due care criteria are met might be related to physicians being increasingly knowledgeable about the due care criteria, but it can also be related to broader interpretation of the criteria over the years.

Roeline Pasman
Department of Public and Occupational Health, Amsterdam Public Health Research Institute, Expertise Center for Palliative Care, Amsterdam UMC - Location VU University Medical Center, Amsterdam, The Netherlands
Eva Bolt
Amsterdam UMC
Poster
How do patients come to voluntary stopping of eating and drinking? A qualitative interview study
#48

Purpose: Voluntary stopping eating and drinking (VSED) is increasingly recognized as a potential humane method to hasten death. Little is known about why and how people come to VSED and studies involving patients are lacking. We aimed to explore patients' motives, how patients decide on VSED, the way patients prepare for VSED and involve others.

Methods: A qualitative interview study in The Netherlands with 29 cases, 24 started VSED and 19 died. Thirteen cases were included before/during VSED and 16 afterwards. Participants were 17 patients, 18 informal and 10 professional caregivers. Data was analysed by inductive ideal-type analysis to describe typologies.

Results: Based on their motives, decision-making process, preparations and involvement of others, three patient groups emerged. The first were older people who felt live was completed, for whom control was important. They prepared VSED well, but could overlook the need for help and the emotional burden placed on relatives. The second group were older care-dependent patients with a poor quality of life. They closely involved others in decision-making. While they relied heavily on (informal) caregivers for the preparation and execution of their plan, they could be in a hurry to initiate VSED. The third group were psychiatric patients with a long-lasting but fluctuating death wish, mostly younger. They often prepared VSED in secrecy or started VSED unprepared.

Conclusions: Patients embarking on a trajectory towards VSED are a diverse group, with different support needs. Patients in the first group should be advised to timely involve close ones. In the second group, informal caregivers need professional support to arrange VSED well. In the third group, a wish for VSED can be a sign of despair, which needs to be heard to prevent avoidable or unprepared attempts at VSED. Guidelines or guidances for VSED need to be applicable to all three groups.

Marta Perin
Azienda USL-IRCCS Di Reggio Emilia
Oral Presentation
How to implement a clinical ethics committee? Results from a process evaluation study by Normalization Process Theory
#107

Introduction: The Clinical Ethics Committee (CEC) of Reggio Emilia (Italy) Local Health Authority (LHA) is an experimental, multi-disciplinary service established in 2020 with the aim of supporting healthcare professionals in dealing with ethical issues in clinical practice. We evaluated the new CEC and its implementation 24 months after its entry into force.

Methods: The CEC was evaluated through a multi-method process, within a mixed-method study (still ongoing). We collected quantitative data from the CEC internal databases, from a closed-ended survey to all LHA healthcare professionals, and conducted semi-structured interviews with professionals involved with the service implementation and activities. Quantitative data were analysed descriptively, while we used the Normalization Process Theory's concepts (coherence, cognitive participation, collective action, and reflexive monitoring) to guide the qualitative evaluation.

Results: Preliminary quantitative results showed that the CEC is fulfilling the three standard functions of a Clinical Ethics Support Service (7 ethics consultations performed, 1 training in ethics provided, and 3 ethical policies developed). 20 participants were interviewed (12 CEC members, 5 physicians who required an ethics consultation, 3 stakeholders formally supporting

CEC implementation). All participants consider the service as a supportive tool for healthcare professionals and a great opportunity in complex situations (coherence). The CEC's President, a bioethicist from the LHA, facilitated participant's engagement (cognitive participation). We found external and internal barriers to the service implementation: e.g. financial sustainability, lack of common training among the CEC components, online activities and absence of in-personal relationship (collective action). Overall, participants reported a positive experience with the service, though several recommendations emerged (reflexive monitoring).

These findings will be integrated with data from the closed-ended surveys to understand knowledge, usage, and perception of the CEC.

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

Marta Perin
Azienda USL-IRCCS Di Reggio Emilia
Poster
Developing ethical competencies in mental health: A pilot mixed-method study
#110

Caring for persons with mental health (MH) illness exposes healthcare professionals (HPs) to complex ethical issues and dilemmas. To improve the comprehensive care for their patients, HPs in MH have to develop ethical competencies.

We propose the implementation and evaluation of Ethics in Mental Health (EiMH), a theoretical-experiential training program in medical ethics dedicated to HPs working in two MH Centers of a research hospital in Northern Italy. EiMH consisted of 2 theoretical classes; 1 theoretical-empirical session; and an on-demand ethical case discussion within participants' daily activities.

This is a pilot study, with mixed-method before (T0)-after (T1) evaluation following Moore's model. An ethical-competencies portfolio has been developed for the quantitative evaluation and self-administer by each participant. Focus Groups (FG) with representatives of the two centers were conducted for the qualitative evaluation.

EiMH lasted from October 2022 to February 2023. A total of 63 HPs participated (15 male and 43 female; 17 psychiatrists, 2 psychologists, 23 nurses, 2 social workers, 1 psychiatric rehabilitation therapist (PRT), 7 social educators, 1 health worker; 8 residents). A total of 58 portfolios have been completed. A general and common increase in the self-evaluation was noted among the majority of participants, who passed from a low perception ("not at all" or "little competent") of their ethical skills at T0 to an intermedium level at T2 ("fairly or very much"). 4 FG were performed (2 at T0 and 2 at T1) involving 20 HPs (5 male and 15 female; 6 psychiatrists, 7 nurses, 2 social workers, 2 social educators, 2 psychologists, 1 PRT). The analysis is still ongoing.

We expect that qualitative data will enrich our preliminary findings, especially as regards the perceived impact and benefit in HPs' clinical practice, and its weakness. The final results will be presented at the Congress.

Rosalie Pronk
Amsterdam UMC
Radboud Marijnissen
UMCG
Oral Presentation
Are you ready? ThaNet: Helping mental health professionals prepare for MAID requests from patients with mental illness
#29

MAID for patients with mental illness is, although controversial, allowed in the Netherlands under strict legal criteria. The number of patients with mental illness who wish for MAID are rising. However, psychiatrists who receive these requests are reluctant and struggle with them, due to complexity of the requests but also a lack of knowledge and experience. The patients are often referred to Expertisecentre Euthanasia (EE), an organization specialized in evaluating complex MAID requests (like on psychiatric basis) and to perform euthanasia if the due care criteria are met. However the waiting list EE is currently over 3 years.

From patients and their relatives perspective it is preferable that death wishes and MAID requests are discussed and evaluated by the psychiatrist and other professionals in psychiatry themselves. For this aspect, in combination with the long waiting list for EE, ThaNet was established in 2023 and funded by the Ministry of Health. ThaNet is a national network for persisting wishes to die and MAID requests on psychiatric basis. Our aim is to develop and spread both knowledge and experience about the subject among professionals working in psychiatry. ThaNet facilitates a network where mental healthcare professionals can come together, get acquainted with the subject matter, receive practical guidance (for example with regard to the mandatory second-opinion) and learn how to deal with MAID requests from patients with mental illness. We want to help mental healthcare workers prepare to discuss persistent death wishes with their patient and to evaluate the complex MAID requests on due care criteria. In the presentation an overview will be given about the first activities, experiences and challenges in ThaNet

The perspective and experience might be relevant for countries where MAID for mental illness is already allowed and also for countries where this is debated.

Sophie Renckens
Amsterdam UMC, Department of Public and Occupational Health
Oral Presentation
Preferences for euthanasia or physician-assisted suicide among physicians in the Netherlands
#59

In the Netherlands, two legal methods for ending a patient's life on request exist: euthanasia, where a physician administers lethal medication, and physician-assisted suicide, where the patient self-administers medication provided by a physician. Our study explored physicians' preferences for euthanasia or physician-assisted suicide considering different medical conditions, and reasons behind their preferences. In a mixed-methods study, 746 physicians (33% response rate) completed a questionnaire, and 15 were interviewed in 2022. The questionnaire included statements on preference for euthanasia or physician-assisted suicide in general and for different conditions in particular. In subsequent interviews, we explored reasons for these preferences using thematic analysis. Within the preceding 12 months, 34% of physicians had performed euthanasia and 4% had performed physician-assisted suicide. Overall, 55% preferred euthanasia because they feel more confident it will go well, whereas 12% preferred physician-assisted suicide because that gives more assurance that the patient really wants it. Preferences varied depending on medical conditions. For patients with life-threatening conditions, 65% preferred euthanasia, 29% had no preference and 6% preferred physician-assisted suicide. Physician-assisted suicide was preferred most for psychiatric conditions (30%), followed by accumulation of age-related health problems (29%), 'tired of living' (28%), and dementia (18%). Interviews revealed that physicians preferred euthanasia due to limited experience with physician-assisted suicide, patient's preference, more certainty about the performance, and more predictable dying process. Conversely, physician-assisted suicide was preferred due to more certainty that the patient wants it (especially for complex cases, such as dementia and psychiatric conditions), lower emotional burden, and more 'elegant' dying process.

To conclude, generally euthanasia seems the preferred method, however there are physicians that prefer physician-assisted suicide especially in complex cases. Control seems to be an important factor in preferring either euthanasia or physician-assisted suicide. On the one hand control regarding the performance and on the other hand control regarding the request being voluntary and well-considered.

Sophie Renckens
Amsterdam UMC, Department of Public and Occupational Health
Oral Presentation
Euthanasia in people with an accumulation of age-related health problems: cross-sectional questionnaire among Dutch physicians
#76

The ongoing debate about euthanasia or physician-assisted suicide (EAS) for older adults without life-threatening conditions has intensified as older adults who suffer from an accumulation of age-related health problems increasingly request EAS. We know that 55% of physicians in the Netherlands consider granting such a request conceivable. This study explores characteristics of older adults with an accumulation of age-related health problems who request EAS, and identifies patient characteristics associated with granting EAS in these cases. We conducted a cross-sectional questionnaire study among 2,255 physicians (response n=746, 33%). Of these, 123 physicians reported on characteristics of an EAS request of a patient with an accumulation of age-related health problems. Associations between granting a request and patient characteristics were analysed using multivariable logistic regression. Our results show that the majority of people with an accumulation of age-related health problems who requested EAS were >80 years old (84.0%), female (69.6%), widow/widower (74.8%), (partially) care-dependent (72.9%), and had a

life expectancy of >12 months (67.2%). The most prevalent age-related health problems were osteoarthritis (71.6%) and impaired vision and hearing (54.5% and 43.1%). Reasons for the request were mostly physical deterioration (69.2%), dependence (60.9%), general weakness/fatigue (56.5%) and loss of control (50.0%). Of these 123 EAS requests, 44.7% were granted. Granting a request was positively associated with dependence, impaired vision, osteoporosis, loss of control over one's own life, hopeless suffering, a life expectancy of <12 months and a treatment relationship with the physician of >12 months. To conclude, the reasons for euthanasia requests among older adults with an accumulation of age-related health problems and positively associated factors with granting a request all seem to be related to dependency and loss of control. Enhanced understanding of older adults requesting EAS due to an accumulation of age-related health problems can contribute to the ongoing debate on the permissibility of EAS in older adults without life-threatening conditions.

Sean Riley
The Ohio State University
Oral Presentation
Epistemic humility in the age of assisted dying
#12

Medical Assistance in Dying (MAiD) stands at the intersection of profound ethical and empirical debates. Yet, this discourse often overlooks the limitations of empirical data and the influence cognitive biases exert in interpreting evidence and formulating arguments. This paper examines the evidentiary foundations of the MAiD debates and advocates for epistemic humility, embracing that our understanding of MAiD practice is fallible and incomplete. Research into MAiD suffers from unique ethical and clinical challenges. Most MAiD research is observational and descriptive, inhibiting both causal inference and external validity. Defining and studying certain concepts, such as what constitutes a clinical complication or what qualifies as an autonomous decision, muddies research. Privacy considerations further limit research scope. State-reported data, predominantly self-reported, lacks appropriate validation and does not provide sufficient methodological transparency. This opacity hampers the assessment of the accuracy and comprehensiveness of the collected information. Furthermore, political influences coupled with the prevalence of underreported or unrecorded cases undermine the reliability and completeness of these datasets. Additionally, cognitive biases, such as confirmation bias and anchoring bias, lead stakeholders to cherry-pick or misinterpret evidence to reinforce existing viewpoints. These challenges cast doubts over the quality of data shaping public opinion, policy-making, and the broader MAiD discourse. This paper next addresses the "is-ought" distinction and the "naturalistic fallacy", asserting that these philosophical tenets underscore the need for epistemic humility, reminding us that empirical data alone cannot dictate ethical arguments or policy choices. To achieve a well-balanced MAiD policy, we must pursue a delicate and nuanced interplay of data and ethics. Recommendations for achieving this include devising more rigorous and innovative research methods, building more comprehensive data collection systems, enhancing bias education, and advocating for a continuous commitment to epistemic humility.

John Robinson
South Metropolitan Health Service
Oral Presentation

Integrating palliative care into standard care in a motor neurone disease outpatient clinic
#104

Background: Motor neurone disease (MND) is a relentlessly progressive, incurable and ultimately fatal disorder of, primarily, the motor neurones of the brain and spinal cord. It is associated with significant social and economic burden for patients, their families and the wider community. Palliative care intervention has been shown to improve quality of life for people with MND and their carers

Objective: To incorporate palliative care into standard care for patients with MND. Best practice guidelines around the world indicate that a multidisciplinary approach, that incorporates palliative care, improves the quality-of-life and prognosis for patients and their families with MND.

Method: A palliative care clinical nurse consultant (CNC) was invited to participate in a specialist MND outpatients clinic to support the multidisciplinary team with symptom management and to liaise with the community palliative care services.

Results: The palliative care CNC has been instrumental in the integration of palliative care in this setting and in enhancing the care for patients and their families living with MND.

David Rodriguez-Arias
Departamento de Filosofía 1, FiloLab-UGR, Universidad de Granada, Spain
Oral Presentation
What leads patients to request MAiD? A qualitative study
#115

Many groups (healthcare professionals, lawyers, philosophers, non-governmental organisations, bioethics committees, journalists, religious groups, etc.) participate in the bioethical debate about medical assistance in dying (MAiD). While some voices (e.g. healthcare professionals) have been widely considered in empirical studies, the voice of people who request MAiD has been neglected. Understanding the personal and medical circumstances that lead to MAiD can only be achieved by listening to the discourse of those involved. This study aims to provide knowledge from the testimonies and experiences of patients who have initiated a MAiD request. We believe this type of research can inform and improve end-of-life public policies, and the health care of individuals who request a MAiD.

This study involves phenomenological qualitative research through semi-structured interviews of >10 people in the process of requesting MAiD, as outlined in the 3/2021 Spanish Law on the Regulation of Euthanasia. The study is conducted nationally using a convenience/availability sampling. For the purposes of analysis, the interviews have been transcribed verbatim and pseudonymised afterwards. Data analysis is conducted at the same time as data collection. Categories of analysis include: motivation for requesting MAiD, experiences, values and emotions, nature of suffering, biopsychosocial profiles, and proposals for improvement of the procedure to request MAiD. The proposed study has received a favourable report from the Coordinating Committee on Biomedical Research Ethics of Andalusia (CCEIBA). A group of eight researchers is conducting the study. More information about this research can in the PDF document.

David Rodriguez-Arias
Departamento de Filosofía 1, FiloLab-UGR, Universidad de Granada, Spain
Poster
Does MAiD legalization causally precede, or instead result from societal moral approval?
#116

The transition toward legalizing MAiD across numerous countries has been accompanied by growing public support for euthanasia and medically assisted suicide. In this work, we ask whether these legislative shifts causally precede, or instead result from, moral attitude change– by combining a cross-national review of laws on assisted dying, experimental survey evidence, and four decades of time-series data. The eligibility restrictions that most euthanasia laws place on the patient's age (e.g. >18yo) and competence (e.g. competent patients), the nature of their ailment (e.g. unbearable suffering/pain), and their prognosis (e.g. irreversibility, terminality) also shape people's moral approval of a physician's provision of aid in dying–both in countries where euthanasia is legal (e.g. Spain) and illegal (e.g. United Kingdom). A broader look at MAiD attitudes over time uncovered anticipatory increases in moral approval leading up to a country's legalization of euthanasia– but no accelerated growth post-legalization. Collectively, our evidence suggests that legal provisions on MAiD crystallize prevailing moral considerations.

David Rodriguez-Arias
Departamento de Filosofía 1, FiloLab-UGR, Universidad de Granada, Spain
Oral Presentation
Organ donation euthanasia: Ethical tensions between optimal end-of-life care and organ retrieval
#117

Organ donation euthanasia (ODE) allows patients who request MAiD to donate their organs following lethal injection as soon as their circulation is considered permanent. This deceased donation modality is possible in countries that combine legal provisions for MAiD with protocols for controlled donation after circulatory death (cDCD), including Belgium, the Netherlads, Canada and Spain. In Spain ODE is increasingly practiced, with 42 Spanish patients undergoing such procedure in 2022 and more than 100 being expected by the end of 2023. ODE raises a number of ethical issues related to possible interference of organ donation with optimal end-of-life care, undue pressure to candidates for MAiD who consider postmortem donation, ambiguity of health professionals' duties, and observance of the dead donor rule (DDR) which forbids causing death by organ retrieval or in order to facilitate organ procurement. ODE is different from other modalities of deceased donation in that donors are typically conscious while organ preservation interventions start, which makes them more vulnerable to harm, undue influence and pressure. However, this circumstance enables improved information and consent processes. In this presentation, I identify the typical circumstances where organ donation may compromise the interest of patients who are candidates for ODE, and will suggest mechanisms to address that risk.

Barbra Rothschild
Columbia University

Liz Blackler
Memorial Sloan Kettering Cancer Center
Oral Presentation
Race, class and medical aid in dying (MAID): An issue for the 1%?
#71

Much has been discussed in the bioethics literature concerning the ethics of Medical Aid in Dying (MAID), including the potentially paradoxical role of the healthcare provider, risk of the 'slippery slope' phenomenon and access for those with limited resources. In the United States (US), extensive lobbying efforts have resulted in at least one in five Americans having varying forms of access to legalized MAID. Compassion & Choices - one example of a pro-MAID lobbying organization - has annual revenue of more than $23 million. Yet, despite the tremendous dollars, time, and effort, MAID is rarely used in states where it is legal. When it is, the patients are primarily White, educated, and insured. For example, according to 2021 California data, deaths using 'aid-in-dying' represented 0.17% of all mortalities (excluding COVID deaths). Regarding educational status, 55.2% of California's MAiD participants had a bachelor's degree or higher, compared with 35.3% of the state's general population. Racially, MAID patients were disproportionally White (85.6%) with limited Hispanic (5.1%) and Black (.8%) representation, compared to US Census data reporting California's racial make-up as White 34.7%, Hispanic 40.3%, and Black 6.5%.

The US preoccupation with MAID shows no signs of abating. However, ironically, quality end-of-life care in the US ranks 43 of 81 countries in a recent study. Individuals who are treated at primarily minority serving hospitals are 33% less likely to receive palliative care. We suggest that there is gross inequity in the amount of time and emphasis placed on empiric research, discussion and policy development devoted to a method of dying that is primarily utilized by an already empowered population. Resources and efforts should focus on improving the quality and quantity of accessible and comprehensive end-of-life care, including palliative and hospice care for all Americans. In the current healthcare climate, attention on MAID legislation is misaligned, misdirected, and most certainly not 'for the people.'

Ben Sarbey
Duke University
Oral Presentation
The vulnerable populations objection to medical aid in dying
#30

One of the most prominent criticisms of medical aid in dying (MAiD) is that it could allow for cases of patients being pressured or coerced into hastening death. The concern is that if MAiD were legalized or expanded then certain individuals would choose death as a result of factors that ideally should not come into consideration. The "disability objection" to MAiD focuses on disability as one such factor that should not play a role in deciding to end life. This objection has historically played a large role in the debate over the ethics of MAiD. As I will argue, this objection can be broadened to include individuals who face discrimination for an aspect of their identity (e.g., race or sexual orientation), or who are financially or socially disadvantaged, older, or lack adequate access to medical services. There are many possible ways to be at disproportionate risk from MAiD relative to the general population. As I will argue, the ways in which the

disability objection to MAiD has been lodged can be extended to vulnerable populations more generally. In this way there is a broader, more coherent "vulnerable populations" objection to MAiD. I will explore the contours of such an objection and identify shared features of arguments relying on particular aspects of patient identity. As I claim, various instances of the vulnerable populations objection are united by a speculation-based analysis of possible harms to individuals of certain groups arising from MAiD programs. This shared feature also provides a means for evaluating arguments under this heading: possible harms to certain individuals must be clearly specified and supported via analysis of MAiD data and case studies otherwise critical claims become overly speculative.

Jessica Shaw
University of Calgary
Oral Presentation
Understanding the global context, standards of practice, and ethical considerations of assisted dying for prisoners
#132

In jurisdictions where assisted dying is legal, Canada is the only place that has specific guidelines about how it is implemented for prisoners. This has led to there being more assisted deaths of prisoners in Canada, than in the rest of the world combined. To align with global human rights norms on health care standards for prisoners, policymakers need to determine how – not whether – assisted dying is available to prisoners. This session will provide a brief overview of the global context, the Canadian guidelines, and some of the ethical considerations that are specific to assisted dying for prisoners.

Fiona Slater
Canadian Blood Services
Kim Wiebe
Manitoba Shared Health
Oral Presentation
Deceased organ and tissue donation after medical assistance in dying: 2023 updated guidance for policy
#52

Driven by patient requests (like those of Dr. Shelly Sarwal in the film, Her Last Project), Canadian Blood Services assembled a group of experts to examine the 2021, updated Canadian legislation for medical assistance in dying (MAiD) and its impact on organ and tissue donation. The outcome of this work provides an update to the 2019 guidance for policy for clinicians, organ donation organizations, end-of-life care experts, MAiD providers, and policymakers for donation following MAiD in Canada.

Methods: CBS assembled a diverse panel of experts from critical care, organ and tissue donation, healthcare administration, MAiD, bioethics, law, and research. Two patients who had been approved for MAiD and two family members of patients who donated organs after MAiD also participated. In a series of three online meetings, participants addressed a variety of donation and MAiD related topics in small and large groups. Recommendations were generated using a modified version of nominal group technique.

Results: Forum participants informed the development of 8 new and 2 updated recommendations for donation after MAiD in Canada. Three themes emerged from the forums as priority considerations in the updated guidelines: 1. Strong support for upholding first person consent for MAiD and organ donation for Track 1 patients who have completed a waiver of final consent. 2. Track 2 patients may be approached for formal consent for organ donation during the mandatory 90-day assessment period if already deemed eligible for MAiD. 3. Organ donation organizations should develop policy regarding directed donation after MAiD.

Conclusion: This updated guidance supports the development of policies and practices for donation after MAiD in Canada following the introduction of MAiD legislation in 2016 and an update to legislation in 2021. The recommendations serve as a framework for clinicians to navigate the medical, legal, and ethical challenges that arise when supporting patients requesting donation after MAiD.

Erica Srinivasan
Associate Professor of Psychology, University of Wisconsin-La Crosse
Oral Presentation
Physicians' moral experience with medical aid-in-dying
#86

Healthcare practitioners (HCP) who willingly participate in clinician-administered or self-administered medical aid-in-dying, in places where these practices are legal, still report feeling moral tension with these practices. (Pesut et al., 2020; Elmore et al., 2018). For example, in one study, nurses who participated in medical aid-in-dying in Canada reported feeling the tension between belonging to a culture that emphasizes "do no harm," and participating in something that gave the feeling of killing someone, or being the cause of death (Pesut et al., 2020).

Controversy within medical communities also informs the moral understanding of medical aid-in-dying. For example, historically, U.S. medical associations have opposed aid-in-dying. More recently, support is mixed (Buchbinder, 2021). While some medical societies offer approval, others remain opposed, hold a neutral stance, or acknowledge moral tension—disputes over "right" action—without endorsing a specific value (American Medical Association, 2023). These varying perspectives may influence medical students' understanding of this topic as well as the experience of those who do offer these services.

It's important to understand how physicians make sense of moral experiences with medical aid-in-dying, both patient-administered and clinician-administered, as it could have implications for medical students who may be making decisions on what services they would like to offer, as well as for physicians who work with patients who are either considering or receiving these services. Despite the importance of understanding physicians' moral experiences with these services, little research has been done.

In this session, I will present qualitative data from 17 semi-structured interviews with physicians on their moral experiences with medical aid-in-dying. Themes include the experience of and ways to cope with moral tension and ambiguity. Discussion will explore how the findings can be used to inform medical training, practice and professional values around end-of-life care."

Gianna Strand
The Completed Life Initiative
Poster
The impact of legal mandates on hospice aid-in-dying policy availability and transparency
#10

Terminally ill patients seeking to access MAiD face difficulties in navigating this legal process particularly due to the lack of support by many hospice facilities and policy disinformation which inhibits patients from making fully informed decisions on where to receive end of life care. We report on the current state of MAiD policy transparency and availability nationally. California and Washington have enacted legal mandates which require facilities to post aid-in-dying policy. An in-depth research review of aid-in-dying policies is undertaken specific to facilities in California after their mandate took effect and in Washington where the availability and content of MAiD policies were tracked both before and after their mandate took effect in Summer 2023. We report on the sustained lack of compliance with these posting requirements, the variability of clarity in posted policies, and evaluate whether such legal mandates are necessary or sufficient at improving patient care in the hospice landscape.

Gianna Strand
The Completed Life Initiative
David Hoffman
The Completed Life Initiative
Oral Presentation
Novel approaches to remove feelings of moral culpability in prescribing MAiD
#15

The Food, Drug and Cosmetics Act of 1932 was created by the US Congress to protect the public from harmful chemical formulation by establishing an authority and obligation for physicians to limit access to certain medicinal chemical compounds. If it is in fact morally objectionable to some physicians to be involved in prescribing MAID, then the solution ought not be to prohibit MAID, but rather to remove those physicians from that process. This can be accomplished in two ways.

> (1) Take the process out of the hands of physicians and pharmacists entirely. Some jurisdictions already permit advanced practice nurses to evaluate patients and prescribe MAID. This can be further expanded by creating a new professional license or new professional status: interventional clinical ethicist. Such an individual would need the training embodied in a graduate bioethics degree combined with the training of an advanced emergency medical technician in medication management and administration.
>
> (2) Create a mechanism for physicians to certify that a patient's circumstance no longer requires FD&C Act gatekeeping. The responsibility for dispensing medications through the physician gatekeeper function can be eliminated by a simple legal and ethical acknowledgment that the purposes of the FD&C Act are no longer relevant to the individual's circumstance. Physicians would not have to write a prescription. That

individual would simply be afforded the opportunity to purchase that medication "without prescription." Though this is merely an operation of the mind because some clinician would have to provide the acknowledgement, they are relieved of the moral culpability.

These are radical notions – creating an opt-out of FD&C Act and establishing alternative prescriber options – that may not assuage all concerns around MAID. Their discussion and debate will allow for critical examination of the underlying legal and ethical barriers we have created, which we have the power to remove.

Yvette Vieira
ACAMAID Ethics Consultation Service
Jean Abbot
Center for Bioethics and Humanities, CU Anschutz Medical Campus
Charles Miller
Medical oncologist, Director of Kaiser Hawaii Aid-in-Dying Program
Thaddeus M. Pope
Mitchell Hamline School of Law
Panel
Ethical issues encountered in the practice of aid-in-dying: A survey of healthcare professionals
#78

In June 2021 the American Clinicians Academy on Medical Aid in Dying developed a tertiary Ethics Consultation Service to explore the ethical issues for those professionals providing aid-in-dying services. The ethics service is comprised of eleven members from diverse professions across the United States with both expertise in medical ethics and knowledge about aid in dying.

Objectives: To determine the nature of ethical issues encountered by health care professionals caring for patients pursuing aid in dying.

Methods: Between February and April 2023, the ethics service distributed a digital survey to the physician and non-physician aid-in-dying professionals subscribing to the ACAMAID listserv. Respondents submitted 183 completed surveys. The survey included information on professional role, practice setting, jurisdiction and importance of 18 possible ethical issues, with a Likert scale for level of importance.

Results: Survey results indicated that both physicians and non-physicians had important ethical concerns. The largest percentage (37%) of respondents were physicians. This presentation focuses on the experiences of these active attending and consulting physicians providing aid-in-dying services. They identified five top ethical concerns:

1. Establishing a patient's decision-making capacity, especially as impacted by mental illness, and addressing the patient's diminished capacity after aid-in-dying medications are dispensed.
2. Addressing a patient's physical ability to self-ingest and identifying legal means to provide physical assistance with ingestion.
3. Dealing with patients experiencing conflicts/institutional restrictions regarding aid in dying with their post-acute facility.

4. Responding to patients desiring expedited aid in dying process for access to aid-in-dying medications.
5. Resolving conflicts/disagreement about eligibility between providers.

Conclusion: Ethical concerns for practitioners who care for patients pursuing aid in dying are common. To support those involved with these patients requires acknowledging and understanding these concerns from an ethical perspective. The medical and ethics community need to continue engaging with providers in response to their ethical issues and assessing the challenges that this aspect of their medical practice entails.

Stijn Vissers
End-of-Life Care Research Group, Vrije Universiteit Brussel, Brussels, Belgium
Panel
What constitutes a high-quality medical aid in dying trajectory? Insights from 4 years of research
#92

In recent years, medical aid in dying (MAID) practices have been increasingly implemented worldwide, resulting in about 300 million people residing in permissive jurisdictions, which accounts for about 4% of the total world population. Additionally, the number of individuals accessing MAID is increasing annually in most permissive countries. This trend is expected to persist, emphasizing the (growing) importance of MAID practice. However, there remains limited consensus and comprehensive understanding about what defines a high-quality MAID trajectory. This is in part reflected in the suboptimal and negative experiences that patients, relatives and health professionals may encounter in MAID practice. Therefore, in this plenary session, we will reflect upon the question of what constitutes a high-quality MAID trajectory. In other words, we will explore in-depth the prerequisites that ensure a positive MAID experience for patients, relatives and health professionals by:

1) Sharing insights from Flanders, Belgium, a permissive jurisdiction having over 20 years of MAID legislation. More specifically, we will discuss the research findings of three recent studies conducted in Flanders between 2019 and 2022 that examined the lived experiences of patients, relatives and health professionals via three complementary presentations (total duration: 45 minutes):

- Presentation 1: 'What are the support needs of patients requesting MAID and their relatives?: A qualitative study using qualitative interviews and written narratives'. Presenter: Sigrid Dierickx (15 minutes).
- Presentation 2: 'Why do adults with psychiatric conditions request MAID and how do they experience the MAID assessment procedure?: A qualitative interview study'. Presenter: Kenneth Chambaere (15 minutes).
- Presentation 3: 'What good practices do health professionals deploy in their MAID practices?: A qualitative study among health professionals.' Presenter: Stijn Vissers (15 minutes).

2) Sharing insights and experiences from other permissive jurisdictions through a panel discussion (30 minutes), with moderator Luc Deliens (Director of the End-of-Life Care Research

Group) and the following panel members with extensive expertise in MAID practice and research:

- The Netherlands: Bregje Onwuteaka-Philipsen (TBC) or
- Canada: Ellen Wiebe (TBC) or James Downar (TBC)
- Belgium: Kenneth Chambaere
- The United States: Timothy Edward Quill (TBC) or Peggy Battin (TBC)
- Switzerland: Claudia Gamondi (TBC)
- Australia: Ben White or Lindy Willmott (TBC)

Examples of questions that can be asked in the panel discussion include:

- To what extent do you believe the findings from the studies in Flanders are also applicable in your jurisdictions?
- What good practices and/or support needs do you think were not discussed in the presentations but are also crucial for ensuring high-quality MAID trajectories for patients and their relatives?
- According to your experience as an expert, what elements determine a high-quality MAID trajectory?
- To what extent is palliative care suitable for addressing the support needs of patients requesting MAiD and their relatives?

Ben White
Australian Centre for Health Law Research
Oral Presentation
Effective approaches to regulating voluntary assisted dying: a qualitative study of doctors and regulators
#45

Introduction: The safe operation of voluntary assisted dying systems depends on effective regulation. Australian voluntary assisted dying systems draw on a range of regulatory tools to ensure compliance including law, policy, training and system design. A key part of this regulation is directed at doctors. Yet little is known about the most effective ways for regulation to influence doctors' medical practice.

Methods: Semi-structured interviews were conducted with doctors who provide voluntary assisted dying and regulators (those whose role involves "altering behaviour" in this field, including non-State actors such as professional and advocacy groups). Interviews were conducted in both Victoria and Western Australia, the two first Australian states to have voluntary assisted dying. Participants were asked about the best way to regulate voluntary assisted dying, including how to most effectively guide participating doctors to follow the processes set out in the law. Thematic analysis was undertaken.

Results: The interview sample included 39 doctors and 54 regulators. Participants identified a range of ways in which voluntary assisted dying can be effectively regulated and reflected on strengths and weaknesses of different forms of current regulation. Preliminary findings include that peer opinion and professional consensus were powerful forms of regulation, and that law has a role to play but has limitations in guiding clinical practice.

Conclusion: Regulation design should be guided by the perspectives of the intended target of that regulation. Existing voluntary assisted dying regulation can be enhanced through utilising those forms of guidance which are most influential for doctors.

Ellen Wiebe
University of BC
Oral Presentation
Interpreting irremediable, incurable, and irreversible in the context of Medical Assistance in Dying (MAiD)
#124

Background: Some MAiD assessors have expressed challenges interpreting the legal terms "irremediable", "incurable", and "irreversible" when assessing people for MAiD in Canada and there has been controversy in the media about cases deemed incurable. The aim of this study was to identify how MAiD assessors interpret and use these terms. In March 2023, Health Canada published a Model Practice Standard for MAiD that defined these terms and it is important to know how useful these definitions are to MAiD assessors.

Methods: This was an online questionnaire sent to members of the Canadian Association of MAiD Assessors and Providers (CAMAP) who identified as MAiD assessors. It asked how they defined and used the terms "irremediable," "incurable" or "irreversible" in practice and gave two hypothetical cases. The data were analyzed descriptively.

Results: We received completed questionnaires from 76 physicians and 12 nurse practitioners from across Canada with collective experience of thousands of assessments and hundreds of MAiD provisions. There was a high level of agreement with the definition of "incurable" in the new Model Practice Standard (44/47, 93.6%). There was considerable disagreement on whether the two hypothetical cases were eligible for MAiD (52.7% and 44.3%). More experienced clinicians were more likely to be willing to assess people whose natural death was not reasonable where the assessments of "irremediable," "incurable", and "irreversible" were anticipated to be more difficult (76.9% vs 49.0%).

Discussion: There was a high level of agreement on the definitions used in the Model Practice Standard published by Health Canada. This agreement on definitions did not translate into agreement on whether the two hypothetical cases were eligible for MAiD.
Implications: The wording of the new Model Practice Standard is clear and useable in practice by assessors. There is still a great variation on how these assessors use these definitions to find people eligible or ineligible for MAiD.

Ellen Wiebe
University of BC
Oral Presentation
Clinician-researchers' and patients' experience of requests for assisted death for psychiatric conditions in Canada
#126

Background: We expect the law in Canada to change in 2024 to allow people with mental illness as the sole underlying medical condition to be eligible for medical assistance in dying (MAiD). We interviewed people who requested MAiD for mental illness and, as our team of clinician researchers were reviewing the interview transcripts of people requesting, we found ourselves sharing our own feelings. This became such an important part of our meetings, that we chose to do add a metacognitive analysis. Our goal is improved ability to plan for necessary supports after the law changes to allow MAiD for mental illness as the sole underlying medical condition.

Methods: We conducted semi-structured interviews, audio-recorded and transcribed these and we wrote notes as we read and reread each transcript. We then dedicated team meetings to discussing themes arising as well as our own and each other's reactions. We met again to discuss themes arising from both analyses and we used member checking until we reached consensus.

Findings: The most important theme from the patients was the immense amount of suffering and lack of response to many treatments. The most important theme from the clinician researchers was the powerful emotional reaction they had to conducting the interviews and reading the transcripts. The clinician researchers also had great difficulty separating their roles as researchers from treating clinicians and or MAiD assessors.

Conclusions: Since even reading and analysing research transcripts caused strong emotional reactions to the suffering expressed by people requesting MAiD for mental illness, we can predict that assessing and providing MAiD for people with mental conditions will be difficult and those involved will need support to do this work.

Implications for MAiD practice: We must plan for necessary supports for MAiD team members after the law changes to allow MAiD for mental illness as the sole underlying medical condition.

Lindy Willmott
Australian Centre for Health Law Research, Queensland University of Technology
Stefanie Green
Founding President Canadian Association of MAiD Assessors and Providers
Katherine Waller
Australian Centre for Health Law Research, Faculty of Business and Law, Queensland University of Technology
Ben White
Australian Centre for Health Law Research, Faculty of Business and Law
Panel
Training for health professionals participating in MAiD and VAD: omparing Canadian and Australian programs
#41

The practice of Medical Aid in Dying (MAiD) has been lawful across Canada since 2016, with Quebec's provincial MAiD legislation coming into force in 2015. In Australia, all six Australian states now have voluntary assisted dying (VAD) legislation. Victoria was the first Australian state to commence operation in 2019, and New South Wales the last state to commence in November 2023. While the six legislative models in Australia vary across the states, there is broadly one model.

Both Australia and Canada have programs in place to train health professionals who have chosen to participate in assisted dying, yet the journey to establishing those programs and the nature of the programs are different in each country.

This Panel Session will provide a deep dive into the training programs for health professionals participating in MAiD in Canada and VAD in Australia from the creators of those programs. The Session will commence with two brief presentations that provide an overview of the training program in both Canada and Australia. These presentations will be followed by a moderated Panel Session that will explore in more detail similarities and differences between the programs including:

· drivers for the development of the training programs
· timing of the development of the training programs relative to the commencement of lawful assisted dying practice
· whether the training programs are mandatory
· content of the training programs
· uptake and evaluation of the training programs

The audience will be invited to reflect on the relative merits of the different approaches to training of health professionals, and encouraged to participate by providing their own insights into training programs whether in Australia, Canada or elsewhere.

MeganWright
Penn State Law
Oral Presentation
Assisted dying, decisional capacity, and supported decision making
#72

Individuals must demonstrate contemporaneous decisional capacity in order to receive medical aid in dying in the United States. This eligibility requirement excludes many individuals, such as those with moderate dementia, from accessing this end-of-life option. Some scholars have thus argued for use of advance directives for assisted dying, but advance directives risk locking someone into prior preferences that conflict with their current interests. This presentation explores another option for individuals with impaired decisional capacity to access medical aid in dying. Specifically, this presentation explores the potential for supported decision making to enable individuals with cognitive impairments to choose medical aid in dying. This presentation will discuss the intersection of supported decision-making laws and medical aid-in-dying laws in the United States and will also briefly discuss decisional capacity requirements in other countries with assisted dying.

MeganWright
Penn State Law
Cindy Cain
University of Alabama at Birmingham
Oral Presentation
Mediating autonomy: Organizational mediation of the California End of Life Option Act

#73

Law and society research demonstrates that law in practice is often different than law on the books and that organizational policy matters for the construction of law. This study examines how healthcare organizations' policies mediate laws designed to promote patient autonomy. Specifically, this study focuses on healthcare organizations' policies regarding medical aid in dying (MAiD) in California, which legalized MAiD in 2015 to increase patients' end-of-life options. Beginning in 2022, California MAiD law requires healthcare organizations to post their MAiD policy on their public website, and we collect and analyze these policies for whether organizations opt in or out of participating in MAiD and whether organizations add restrictions to or conditions of participation for healthcare providers or patients that are not contained in the text of the law. We find that 1) many organizations are not yet compliant with the mandate to publicly post their MAiD policy and 2) organizational policies vary in how they restrict patient and provider participation in MAiD, including: adopting no policy, using the text of the law as policy, restricting provider participation only, restricting patient participation only, or adding conditions to participation for both providers and patients. We conclude that organizational policy limits patient autonomy that California's MAiD law was meant to increase, but that the limits to patient autonomy will primarily be experienced by rural patients, low-income patients, and patients with low health literacy.

Ming Cheng Yap
Yale-NUS
Poster
Tripping on equity: Assessing the ethics of equity interventions to improve psychedelic therapy access
#39

In the pursuit of new solutions for hard-to-treat mental conditions, government legislation and clinical trials have begun to explore the viability of psychedelic-assisted psychotherapy as treatment. Despite its potential, the high costs associated with psychedelic therapy pose significant barriers to access and give rise to issues of equity. This paper explores the ethical implications of two interventions in equity: making firsthand experience of psychedelic treatments a soft requirement in training programs and considering the administration of psychedelics in group therapy settings. Drawing upon secondary literature on ethics and clinical trials of psychedelic-assisted group psychotherapy (PAGP), the paper identifies the ethical tensions of each intervention, and identifies areas that subsequent clinical trials can explore to reconcile those tensions. The paper finds the former intervention ethically sound, in view of the available alternatives to psychedelic consumption by trainees and potentially unknown side effects of psychedelics on trainees with existing medical contraindications. For the latter intervention, a review of existing clinical data suggests that PAGP is viable and possibly beneficial to treatment outcomes, though further clinical data on larger group settings is lacking and required. As psychedelic clinical trials move towards their critical phases, they present an invaluable opportunity to substantiate the suggestions presented in this paper as financially and ethically viable steps toward safe and equitable access to psychedelic therapy.

Jessica Young
Victoria University of Wellington

Jeanne Snelling
University of Otago
Oral Presentation
Prohibition, institutional objection, and funding: Health professionals' views on the End of Life Choice Act
#90

In November 2021, assisted dying (AD) became lawful in Aotearoa New Zealand. A terminally ill person may now request, and receive, pharmacological assistance (self-administered or provided by a medical practitioner/nurse practitioner) to end their life, subject to specific legal criteria and processes. The researchers sought to identify the experiences, both positive and negative, of health care practitioners involved with the early implementation of AD in New Zealand.

A mixed-methods survey of health professionals was undertaken five months after legalization. One hundred and nineteen respondents completed the survey and most rated themselves as having a moderate to good understanding of the Act. Twenty-six interviews were also conducted with 7 AD providers and 19 non-providers. Thematic analysis of interview data and open-ended survey questions was undertaken.

This presentation focuses on three of the unique aspects of AD in New Zealand: the legal prohibition on health professionals raising AD in the Act, the practice of institutional objection, and the Ministry of Health funding model.

The prohibition on raising AD was experienced differently, including feeling professionally censored; reassured by; or in some instances misunderstanding the prohibition. Some participants considered it limited patient choice. Although the notion that institutions possess a "conscience" is contested, the concept received support in New Zealand's High Court. Many organisations were still establishing their policies and may have been ambivalent or under-resourced instead of objecting on the grounds of conscience. Remuneration for providers supported equitable access for patients, though the limited funding model for palliative care was frequently referenced as inconsistent with AD funding.

Exploring the experiences of health providers in the initial stage of the implementing AD legislation is vital to inform the ongoing development of safe and effective AD practice, operationalizable policy and accessible laws.

Jessica Young
Victoria University of Wellington
Oral Presentation
Anticipating the date of death: The experiences of patients, family, and assisted dying providers
#91

The New Zealand End of Life Choice Act (2019) has provided new choices for people with terminal illnesses since November 2021. It has also created challenges for patients, families, and assisted dying providers. In this talk, I will briefly describe the Act and the application process, notably the unique procedural aspect of selecting a date and time for death. I will share findings from the first New Zealand study on the experiences of people applying for assisted dying, their

family and their attending medical practitioners focusing on their anticipated and unanticipated experiences.

Six patients seeking assisted dying, eight family members, and six providers were interviewed over time, resulting in 30 interviews representing nine deaths. Participants were recruited through the media, social media, the End of Life Choice Society, and through assisted dying providers. Patients did not anticipate, despite seeking an assisted death, how difficult it would be to choose a date and time for their death. Waiting for the day to arrive was an opportunity to prepare themselves, family, and friends for death, as well as feeling like an unwelcome countdown.

The grief for family members was both lessened by having a date for the assisted death because any suffering ended, and complicated because there were few established rituals for an anticipated death. Families were surprised that there was no support provided after the day of death.

There was some variation in how providers managed the time and date procedure. They described a steep learning curve in their early experiences including eligibility assessments, procedural requirements, managing availability, and etiquette on the day.

This research suggests that where a date and time must be selected for death, patients, families, and providers need specific support to prepare for the anticipated and unanticipated aspects of assisted dying timing as well as other aspects.

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57 How can I choose? Personal end-of-life health literacy; a key factor for advance care planning.

67 Professional facilitators' practices of advance care planning in Switzerland: a qualitative study

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28 MAID and the assessment of decisional capacity in dementia: the Dutch perspective!

29 Are you ready? ThaNet: helping mental health professionals prepare for MAID requests from patients with mental illness

30 The Vulnerable Populations Objection to Medical Aid in Dying

31 Medical Aid in Dying for Severe and Enduring Anorexia Nervosa: Legal and Ethical Analysis

33 What drives requests for Medical Assistance in Dying, and what are lessons for Palliative Care?

34 What do we really want in a Medical Aid in Dying law?

40 Key challenges in providing assisted dying in Belgium: a qualitative study of health professionals' perspectives

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60 Living through dying: why bans on assisted dying are incompatible with the right to life

63 The downside of progressive euthanasia legislation for patient and clinician – a case-report.

64 Interdisciplinary perspectives on irremediability in the context of assisted dying for persons with mental disorders

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74 How actions by Canadian patients and caregivers to overcome MAiD access barriers influence regulation

75 Mr. JR: Decisional Capacity, Prolonged Grief, and An Inpatient Request for Physician-Aid-In-Dying

78 Ethical Issues Encountered in the Practice of Aid-in-Dying: A Survey of Healthcare Professionals

81 When persons facing dementia choose to hasten death: America's ethical, legal, medical & social landscape

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92 What constitutes a high-quality medical aid in dying trajectory? Insights from 4 years of research

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86 Physicians' moral experience with medical aid-in-dying

93 Beyond the "in favor/against" dichotomy in Conscientious Objection to MAID. A Qualitative Study

95 "Number one is patient choice": Complicating the Recommendation for Clinical Attendants in United States MAiD

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115 What leads patients to request MAiD? A qualitative study

116 Does MAiD legalization causally precede, or instead result from societal moral approval?

129 Trends in SCEN consultations in case of euthanasia: 17 years of monitoring in the Netherlands

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68 Palliative sedation practice and opinions in pediatrics

70 "Ethics for Using Chemical Restraint with Self-Harming Advanced Alzheimer's Patients in Hospice"

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94 What are indicators to evaluate the quality of palliative sedation? A scoping review

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48 How do patients come to voluntary stopping of eating and drinking? A qualitative interview study

50 The frequency of self-directed dying in the Netherlands: a research protocol.

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44 Cognitive disability and surrogate decision-making – a new understanding of human dignity and human rights

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34 Margaret Battin, Rebecca Brown: What do we really want in a Medical Aid in Dying law?

41 Lindy Willmott, Stephanie Green, Katherine Waller, Ben White: Training for health professionals participating in MAiD and VAD: comparing Canadian and Australian programs

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78 Yvette Vieria, Charles Miller, Jean Abbot, Thaddeus M. Pope: Ethical Issues Encountered in the Practice of Aid-in-Dying: A Survey of Healthcare Professionals

81 Nancy Berlinger, Anna Elsner, Emily Largent: When persons facing dementia choose to hasten death: America's ethical, legal, medical & social landscape

84 James Downar, Marie-Eve Bouthillier, Andrea Frolic, Jennifer Gibson: Critical Care Triage Protocol development in Quebec and Ontario, Canada: Lessons learned

92 Stijn Vissers: What constitutes a high-quality medical aid in dying trajectory? Insights from 4 years of research

108 Sarah Mroz, Luc Deliens, Ben White, Lindy Willmott: Physicians' preferences for MAID and other end-of-life decisions, and how those preferences impact clinical practice

121 Aulina Chowdhury, Madeleine Carroll, Leslie McNolty, Kiana Winslow: Balancing Duties to the Sick and Dying in Resource-Limited Settings

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50 Fenne Bosma: The frequency of self-directed dying in the Netherlands: a research protocol

51 Dena Davis: End-of-Life Preferences in the Face of Dementia: A Survey of Older Americans

52 Fiona Slater, Kim Wiebe: Deceased organ and tissue donation after medical assistance in dying: 2023 updated guidance for policy

53 Kristin Good: Assisted Dying from implementation to delivery within the New Zealand prison system

55 Penny Neller Aboriginal and Torres Strait Islander Peoples and end-of-life decision-making

56 Rachel Feeney: Online modules to improve health professionals' end-of-life law knowledge and confidence: A pre-post survey study

57 Clément Meier: How can I choose? Personal end-of-life health literacy; a key factor for advance care planning

58 Clément Meier: Learning by Experience: Does caregiving for loved ones boost personal end-of-life health literacy?

59 Sophie Renckens: Preferences for euthanasia or physician-assisted suicide among physicians in the Netherlands

60 Stevie Martin: Living through dying: why bans on assisted dying are incompatible with the right to life

63 Richard Oude Voshaar: The downside of progressive euthanasia legislation for patient and clinician – a case-report

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66 Laure Dombrecht: A post-mortem survey on continuous deep sedation until death in neonates and infants in Flanders

67 Solenne Blanc: Professional facilitators' practices of advance care planning in Switzerland: a qualitative study

70 Darcy Metcalfe: "Ethics for Using Chemical Restraint with Self-Harming Advanced Alzheimer's Patients in Hospice"

71 Barbra Rothschild, Liz Blackler: Race, Class and Medical Aid in Dying (MAID): an issue for the 1%?

72 Megan Wright: Assisted Dying, Decisional Capacity, and Supported Decision Making

73 Megan Wright, Cindy Cain: Mediating Autonomy: Organizational Mediation of the California End of Life Option Act

74 Ruthie Jeanneret: How actions by Canadian patients and caregivers to overcome MAiD access barriers influence regulation

75 Thomas Cunningham: Mr. JR: Decisional Capacity, Prolonged Grief, and An Inpatient Request for Physician-Aid-In-Dying

76 Sophie Renckens: Euthanasia in people with an accumulation of age-related health problems: cross-sectional questionnaire among Dutch physicians

77 Ian Brownhill: Protestor or Patient: Is the law able to differentiate in VSED cases?

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83 Solenne Blanc: "I don't want to be a burden": A qualitative study about patient choices about assisted suicide

86 Erica Srinivasan: Physicians' moral experience with medical aid-in-dying

90 Jessica Young, Jeanne Snelling: Prohibition, institutional objection, and funding: Health professionals' views on the End of Life Choice Act

91 Jessica Young: Anticipating the date of death: The experiences of patients, family, and assisted dying providers

94 Indra Albrecht: What are indicators to evaluate the quality of palliative sedation? A scoping review

123 Angela Wentz Faulconer: Scarce Resources and Reallocation: ECMO, Personal Ventilators, and Maintenance Drugs

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126 Ellen Wiebe: Clinician-researchers' and patients' experience of requests for assisted death for psychiatric conditions in Canada

129 Roeline Pasman: Trends in SCEN consultations in case of euthanasia: 17 years of monitoring in the Netherlands

131 Daphne Gilbert: Litigating Institutional Religious Obstructions to MAiD

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109 Serena Isenberg, Jaya Rastogi, Taylor Shorting: Developing a jurisdiction-level actionable resource allocation framework for the use of triage and triage-avoidant strategies