

**Eighth Annual Western Michigan University Medical Humanities Conference
Conference Abstracts**

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Ethics After Error: Malpractice, Mistrust, and the Limits of Medical Moral Repair

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Abstract: One limitation of medical ethics modelled on ideal moral theory is its relative silence on the aftermath of medical error – that is, not just on the recognition and avoidance of injustice, wrongdoing, or other such failures of medical ethics, but how to respond *given* medical injustice or wrongdoing. Ideally, we would never do each other wrong; but given that inevitably we do, as fallible and imperfect agents we require non-ideal ethical guidance. For such non-ideal moral contexts, I suggest, Margaret Walker’s account of moral repair and reparative justice presents powerful hermeneutical and practical tools toward understanding and enacting what is needed to restore moral relationships and moral standing in the aftermath of injustice or wrongdoing, tools that might be usefully extended to medical ethics and error specifically. Where retributive justice aims to make injured parties whole and retributive justice aims to mete out punishment, reparative justice “involves the restoration or reconstruction of confidence, trust, and hope in the reality of shared moral standards and of our reliability in meeting and enforcing them.” Medical moral repair is not without its challenges, however, in both theory and practice: standard ways of holding medical professionals and institutions responsible for medical error and malpractice function retributively and/or restitutively, either giving benign inattention to patient-practitioner relational repair or impeding it. To that end, this presentation offers a preliminary argument for the value of moral repair after medical error, while considering some theoretical and practical difficulties of taking Walker’s approach in this direction.

Putting Science in its Place: Neuroscience and Neuroethics

Stephanie Bird, PhD

Editor-in-Chief, *Science and Engineering Ethics*

Abstract: The roots of the fundamental ethical principles of research ethics lie in the observation that science is a part of society, not apart from it. The ethical standards and professional responsibility of researchers reflect both the expectations of peers, colleagues and students, and also the expectations of society, whether informed and reasonable or not. To some degree, these expectations need to be recognized, acknowledged and addressed. Among the professional responsibilities of researchers is participation in an explicit, recurring discussion of the contributions and impacts of their work on society. The array of issues that compose the field of neuroethics illustrates the way that ethical concerns are interwoven into the practice of neuroscience and the application of neuroscience research findings. Researchers need to be proactive in opposing the misuse and abuse of their science, in disseminating solid and established findings, and in resisting the premature promotion of encouraging but nascent research results.

Taking *Pulse: voices from the heart of medicine* into the Classroom

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Abstract: *Pulse: voices from the heart of medicine* (<http://pulsevoices.org/>) is an online journal which states this mission on the masthead: “publishing personal accounts of illness and healing, fostering the humanistic practice of medicine, encouraging health care advocacy.” The journal, edited by Paul Gross, MD, publishes creative work, including stories, poems, images and haiku, by patients and healthcare providers. I have found this journal to be an excellent classroom resource for teaching empathy and compassion. In his book, *Why Read?*, Mark Edmundson, professor of English, and literary and cultural critic, argues that studying literature does not make one more humane or empathetic, unless, that is, it includes deliberate and thoughtful identification with the characters. Too often, he says, students in literature courses are pushed to engage in abstract analysis without being allowed to insert themselves into the narrative. Within a healthcare curriculum, literary analysis, like diagnosis, can quite easily be engaged in without personal involvement with the material.

In this workshop, I will provide a demonstration of how I use this resource with students as a way to develop a sense of empathy for patients. Participants will discuss a selection of images, stories, and poems from this resource and then will engage in a series of writing and/or drawing exercises responding to the work.

Racial and Reproductive Medicine in the Nazi SS

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Abstract: The Schutzstaffel, more commonly known as the SS, was founded in 1925 with a simple purpose: to serve as a loyal bodyguard for Adolf Hitler. Over the next two decades, the responsibilities, and likewise the ambitions, of the SS grew. One of the most important aspirations of many high-ranking SS leaders was to transform their organization from a body of men dedicated to serving Hitler in the present to an elite racial aristocracy that could perpetually serve as the vanguard of the Third Reich. SS leaders imagined this aristocracy as a family community that encompassed not just SS men, but their wives and children too. They created an entire regulatory process to guide SS men as they got married and established families. This process was not entirely based on their romanticized whims; rather, it was grounded in the tenets of a then-valid science: eugenics. SS leaders selectively employed the eugenic ideals that best suited their needs. Their decision to regulate family decisions based on scientific ideals was the largest and most-sustained endeavor to apply positive eugenics within a single community.

SS doctors were an integral part of this process. They served as the arbiters between scientific rhetoric and medical practice. They vetted men, women, and children and determined their worthiness to belong to the SS family community. Physicians likewise promoted the establishment of child-rich, hereditarily healthy families. And to assist couples who could not conceive, SS physicians conducted medical research on infertility. Through these contributions, they ensured that all members of the SS had the opportunity to advance the organization's population goals. The purpose of this presentation is to highlight this medical work and to show how medicine as practiced by SS physicians contributed to the development of the SS family community as well as the history of reproductive medicine.

**Descartes and Death: The Historical Impact of Cartesian Thought on the Western Attitude Toward
Death and Contemporary Physician-Aided-Dying Policies**

Rachel Cicoria

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Abstract: While the notion of physician aid-in-dying (PAD) may be uniquely contemporary, the conceptual framework that allows for both the possibility and intelligibility of a death with dignity is inherently historical in nature. Therefore, to decontextualize PAD and the current regard for death that supports it is to render the issue fundamentally incomplete. A historical approach to understanding the death with dignity debate provides the opportunity to critically examine the origins of the movement and to see PAD as a response to the situation from which it emerges. If death with dignity policies are to be successful, it is not enough to simply identify the historical presuppositions that PAD seeks to challenge. It is also necessary to determine whether such assumptions are operating within PAD legislation, and if so, whether such policies are therefore undermining the aims of the death with dignity movement.

In this presentation, I historically assess the impact of Rene Descartes, the so-called “father of modern philosophy,” to better understand the contemporary attitude toward death, the development of biomedicine, and the emerging desire to die with dignity. I also examine PAD policies as they relate to and have been informed by Descartes’ conceptions of Reason, mind-body dualism, and free will. Ultimately, I argue that the policies, understood as a response to the troubling nature of a medicalized death, are in fact informed by the same set of problematic Cartesian assumptions from which the death with dignity movement seeks liberation.

Competing Stories Surrounding Concierge Medicine

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Abstract: In the labyrinth of U.S. healthcare system, there are no straightforward solutions in providing equal and consistent medical care across such a diverse patient base. One aspect that has caught the attention of Congress, ethicists, patients, and physicians, is the rising business model of concierge medicine. Contrary to standard primary care, concierge medicine provides personalized care within the patient-physician relationship, in return for annual fees. These annual payments differ from traditional 'fee-for-service' plan in standard primary care model. Many have suggested that concierge medicine has the potential to create a two-tiered health care system. In this presentation, I intend to investigate the competing stories surrounding concierge medicine, ultimately, arguing concierge medicine has the potential to exacerbate the existing gap between the vulnerable patient population and wealthy.

Despite the lack of clinical studies surrounding this model of care, advocates for concierge medicine have raised valid points. Concierge medicine provides patients with access to near 24-hours of care, allowing providers the opportunity to focus on preventative medicine. Supporters argue that concierge medicine allows physicians to truly undertake the ethical responsibility of the patient's welfare above anything else. However, many of these perks come with a cost for socioeconomic-disadvantaged patients. It is estimated that when a physician transitions to a concierge practice, they drop their patient base by 1,500. The switch to charging for retainer fees in a concierge practice ultimately shifts the allocations of resources in a community. Regular primary care physicians would be responsible for the patient population left behind, not to mention that there is already a national shortage of these physicians. It has been found that teaching hospitals too have taken initiatives to improve their competitive financial edge by developing luxury primary care clinics. It is vital that physicians who do intend to switch models of treatment, provide their patients with the right tools to finding care, as suggested by the American Medical Association.

Moreover, concierge medicine presents as a serious barrier to access. It is critical that any form of primary care must actively avoid discrimination and favoritism. One primary care physician recently contested that concierge medicine allows doctors to "cherry pick" and only invite the most healthy to join their practice. It has been proven that people of color and those of lower socioeconomic status tend to remain in traditional primary care practices more, rather than concierge care. Even though the concierge model is a market innovation, physicians still have their ethical obligations. Physicians must remain committed to serve all patients from all backgrounds.

In whole, more attention needs to be placed on the social, health, and financial implications of the concierge model. There is a pressing need for peer reviewed research evaluating the clinical effectiveness of the concierge model. As of now, the medical community must be wary of concierge model format, as it has the potential to intensify the socioeconomic disparities in health care.

Imagine Wanting to Witness This: The Ethics of Looking in Graphic Medicine

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Abstract: Graphic narratives have been recognized as a particularly effective tool for expanding empathy, as they allow caregivers, health practitioners, and any interested other to understand what it is like to experience illness or disability. The hybrid nature of the graphic format allows for a representation of experience not only across time, but also across space, as the reader toggles back and forth between reading about and witnessing another's experience. The time-based, and text-based aspect of reading graphic narrative pushes the reader along before witnessing becomes staring, and, at the same time, the spatial aspects involved in seeing images (a) allows for otherwise invisible illnesses or disabilities to be rendered visible, and (b) resists a total absorption in the narrative, preventing us from forgetting ourselves completely in the other.

Even as they may disrupt the "medical gaze" that turns persons to bodies, graphic autopathographies also present some ethical risks involved in witnessing another's illness. There is, for example, the possibility of gawking—that is, a risk of slipping into an appalled fascination with atypical bodies. Additionally, since graphic medicine depends upon the repetition of images across space and time, this repeated exposure may desensitize the viewer to images of illness, suffering or death.

Focusing on Kristen Radtke's recent graphic memoir, *Imagine Wanting Only This* (2017), this presentation explores the ethical ambiguity of *looking* in graphic narratives about death and illness. Radtke's memoir documents her grief over her uncle's death, her anxiety about the possibility that she inherited the dilated cardiomyopathy that killed him, and her restless travels and fascination with architectural ruins. The conceit of the ruin binds these threads together as Radtke imagines her own heart turned to rubble. But the text also leads her to an ethically problematic fascination with and eventual appropriation of decay and loss beyond her own.

Ultimately, the text asks whether we can ethically grieve over those we don't know. What does it mean to read graphic autopathographies ethically? How might we find meaning in another's loss or illness without appropriating it as, somehow, also belonging to us?

Role Modeling Virtue in Family Caregiving

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School of Nursing & Health Professions

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Abstract: Family caregiving plays an increasingly central and necessary role in our contemporary healthcare environment and economy. Yet it is a phenomenon little studied within the literature of bioethics. While there is no controversy regarding whether providing care for a fatally or chronically ill family member is in itself moral, or likely whether it provides overall utility, more nuanced questions may exist about the specific moral demands and foundation of the caregiving phenomenon. Given this lack of question regarding the overall morality, a fitting lens through which to investigate the phenomenon is virtue ethics. What virtues make a good family caregiver? How does one overcome pre-existing vices to become a good family caregiver? Is providing care for an ill family member a heroic act or merely a minimally decent act? Role modelling is a technique for addressing questions such as these from within the framework of virtue theory that traces back to the work of Aristotle. In order to learn to become a good person, we must look to other good people (role models) for inspiration and direction. Additionally, we can learn from the moral faults of those who are generally good but not morally perfect. In order to begin addressing some of these questions I have chosen a collection of fictional and non-fictional role models in order to analyze their actions, motives, etc. to attain a deeper understanding of what makes a virtuous family caregiver. The role models a plan to examine include the following:

- Michaela Odone, as played by Susan Sarandon in the 1991 film *Lorenzo's Oil* (George Miller).
- John Bayley, British author and literary critic who famously cared for his wife, philosopher and novelist, Iris Murdoch as she declined due to the ravages of Alzheimer's disease.
- Barry Petersen, American journalist who documented caring for his wife, Jan Petersen after she developed early onset Alzheimer's disease, in his memoir *Jan's Story*.
- Michael Schiavo, who found himself the center of a nationwide controversy when he decided that after years in a persistent vegetative state, his wife, Terri Schiavo, should be removed from artificial nutrition and hydration.

Each of these cases brings unique situations and backgrounds. Each role model expresses their own combination of values, virtues, and vices in their actions. Some may seem moral ideals from the outset, but a closer look may reveal important shortcomings to learn from or unexpected virtues behind what may at first seem objectionable behavior. Whatever we may find will be a move forward in our limited moral understanding of the phenomenon of family caregiving.

Attention Deficit Hyperactive Disorder, the Myth?

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Denis Keimakh, Department of Medical Biophysics, University of Toronto

Abstract: Decades of medical research have confirmed the validity of Attention Deficit Hyperactive Disorder (ADHD) as a neurobiological disorder of the central nervous system. Due to complexities in both diagnosis and treatment, the legitimacy of ADHD as a medical disorder has come into question by the media and in popular culture.

More recently, ADHD has been challenged indirectly by having its importance trivialized. We argue that ADHD has been trivialized in three key ways: in claims that ADHD is seriously over-diagnosed, that its pharmaceutical treatment options are harmful stimulants equivalent to street drugs, and that what people see as ADHD are just the effects of new cultural and technological developments. Similarly dismissive is the myth that ADHD is a condition that affects everyone in the population in some capacity (Aren't we all just a little ADHD?).

In this presentation, we challenge the trivialization of ADHD in the twenty-first century on three grounds:

Firstly, we introduce the neurobiological basis of ADHD, detailing the dysregulation of neurotransmitter systems involved in the disorder. This section will discuss ADHD from a molecular biology standpoint, focusing on dopamine neurotransmitters, drug targets, and neuroanatomy. The purpose of the section is to demonstrate that the disorder is a heritable condition, not just one that appears in temperamental individuals. With heritability estimates of around 0.7, ADHD is one of the most heritable psychiatric conditions. Current research efforts have focused on the underlying genetics in dopaminergic transmission. The literature details a significant genetic component to the disorder, reducing free dopamine levels. Dopamine deficiencies have been observed in children with the disorder, which thereby negatively influences mood, impulsivity and concentration.

Secondly, we demonstrate how the popular myths and ways ADHD is represented in the media, do not match the results of the literature. Certain tropes have gained prominence recently and include ideas that ADHD is a social construct, the product of bad parenting, or the result of living in the modern world. While strides are being made in the field by leading industry professionals, there remains a public stigma surrounding ADHD.

This leads into the third and final point we want to make: the recent trivialization of ADHD can have tragic consequences for those with the disorder: namely, they create stigma and are a form of epistemic injustice. We draw on lived experience accounts from ADHD patients to show how the myths of ADHD lead to harmful consequences for those with the disorder. We will demonstrate that recognition of the reality of ADHD patients as unique is a necessary prerequisite to promote the well-being of those with ADHD. Through bridging humanities and sciences in this way, we hope to present a holistic view regarding the state of ADHD in 2018.

**When Discipline Fails: The Place of Humanities in Medical Education as a Remedy for
Provider Fraud and Abuse in the 1960s and 1970s**

Brian Dolan, PhD

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Abstract: When the US's largest national health insurance program was established in 1965 with the passage of Medicare and Medicaid, health care providers assumed responsibility for ensuring proper utilization and accounting for the services charged to the government. As health care costs immediately grew out of control, and treatment plans became demographically inconsistent, concerned patients and congressional representatives learned that approximately 10% of the entire federal health care fund was wasted on practitioner fraud and abuse. In light of mounting evidence and prosecutions, even the AMA, normally a fierce defender of medical autonomy and self-regulation, acknowledged a problem. Albeit saying it was confined to a small group of "bad apples," the AMA proposed enhancing physician training in ethics and codes of conduct, in part by requiring Continuing Medical Education. This opened the door to ethicists, philosophers, and medical education deans to discuss the role of humanities in medical education as a way to inculcate morally sound business practices.

The emerging advocacy for the study of the history and philosophy of medicine was in part a way of ameliorating the public's sense of betrayal of trust by organized medicine. But far from being an esoteric idea about the lofty status of a liberal education, the humanities were seen—in specific contexts—as a practical answer to a visible public relations crisis.

This talk will provide a brief overview of the rising awareness of the problem of provider fraud and abuse, and will illustrate how it gained momentum, leading (for instance) to the Clinton Administration's "Operation Restore Trust" in 1995. More specifically, the talk will examine the debates about the extent to which the problem of fraud and abuse is a result of poor physician education. It will examine the ideas on this topic by well-known sociologists and philosopher, such as Eliot Freidson (author of *Profession of Medicine*, 1970) and Edmund Pellegrino. My hope is to show that medical humanities was thought to have a place in physician education not only because it offered a holistic view of patient care, but because it provided a practical approach to explaining moral and ethical business conduct.

Including Disability in 21st Century Health Care Education: Promise, Progress, and Pitfalls

Kathleen Eggleston, PhD, Department of Medicine, Indiana University School of Medicine – South Bend

R. Daniel Lodge-Rigal, MD, Clinical Pathology & Laboratory Medicine,

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Abstract: This presentation will examine current efforts to integrate the subject matter of disability into the education of physicians and other health professionals, with case snapshots at three levels of organization: an individual course, an institutional curriculum, and a national grassroots movement that is currently gaining traction. The classroom-level snapshot will exhibit a set of disability-related learning experiences delivered to medical students during one week of a 'Foundations of Clinical Practice' course during their first year of study. Selected components of a pre-class online module will be displayed, and excerpts of a creatively formatted small group discussion will be shared, along with description of a documentary film-based, open-to-the-public event. The institutional-level snapshot will feature Indiana University School of Medicine, which dramatically reformed its curriculum beginning with the 2016-2017 academic year. In December 2017, IU School of Medicine formally recognized Disability as one of six Curricular Threads spanning all four years of its undergraduate program, across diverse courses of study and learning modalities. At the national level, the Alliance for Disability in Health Care Education organization will be highlighted, with particular attention to its consensus document 'Core Competencies on Disability for Health Education' and the quest to persuade accreditation and licensure boards to include disability-related competencies in educational standards for the health professions. While the three case snapshots exemplify progress toward full inclusion of disability in health care education at the present moment, anticipatory consideration of the near future's promise and pitfalls will also be offered.

**Maladies of the Great War: An Examination of the Intersections of
Conflict and Medical Science through the First World War**

Madeline Embrey

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Abstract: War has had, throughout recorded history, a way of permeating all facets of human society. The field of medicine represents one of the institutions most profoundly affected by war, as the combination of scarcity, necessity, and crisis drives members of the medical community to examine causes, treatments, and preventative measures for diseases and injuries caused or exacerbated by wartime conditions.

This presentation asserts that the First World War provides an especially rich case study in this area of research for several reasons, and it examines these topics primarily with regards to the American and British geopolitical landscapes. First, given its eruption in the decades following the popularization of germ theory and corresponding public health measures, the war can be studied in terms of its impact on nascent fields such as bacteriology and virology, as well as the ways in which it strained the still-developing methodologies of infectious disease control. The ancient disease of tuberculosis provides an excellent vehicle for the study of the field of public health at the cusp of the war and serves as an example of the accelerated study and debate within the medical community as a direct result of the war. In addition, the war represents a landmark era in the study of psychological disease in the form of “shell shock”; in fact, the war is strongly and directly connected to the evolution of the study of psychological and neurological disease. This presentation demonstrates that “shell shock,” first specifically named and described in the First World War and later termed posttraumatic stress disorder, expedited the study of myriad neuropsychological disorders and furthered debate over the very nature of the brain’s illnesses. Finally, the Great War’s ties to Spanish influenza crisis of 1918 are examined; although the pandemic erupted very near the close of the war, the conflict was integral to the disease’s scope and the ways in which the disease was received by the populace. The war provided the H1N1 virus with already-overflowing hospitals, the movement of soldiers and displaced populations, and a citizenry exhausted by chaos. As a result, the flu added just one more element of confusion and hysteria to the world landscape, while puzzling researchers and inducing further debate and discovery in the field of virology.

The First World War represented great shifts in the world’s political and diplomatic dynamic. However, as this presentation demonstrates, the nature of the relationship between this war and the landscape of medical research is worth equal consideration.

The Concept of Health: African Perspective

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"...the loss of moral values due to a ruthless pursuit of scientific progress 'would make its most dazzling triumphs not worth having.'" (Hans Jonas, 1955-1976)

Abstract: A central theme in recent discourse on bioethics involves a discussion of the relationship between culture and bioethics. The discussion is raised by concerns about the globalization of Western bioethics. It is believed that bioethics, in its orthodox form, is dominated by and globalizes Western ethical principles, norms, and issues. The norms adopted from Western bioethical theories are assumed to be universally valid and binding. This raises questions about the extent to which the norms which currently define bioethical discourse and practices reflect and accommodate non-Western values, beliefs and particularities. So far, many of the literature on African bioethics follows Western form of medicine to focus discourse on bioethics on ethical issues arising from biomedical science.

The theme of African bioethics has to be broadened to also address non-biomedical ethical questions generated by African traditional health practices. Bioethics should be conceived broadly to consist of that branch of applied ethics concerned with all aspects of *bios*, life. This conception of bioethics takes a broader framework than the standard idea of bioethics which is often conceived scientifically in biomedical and biotechnological clinical terms. A restrictive focus on biomedically-related bioethics is problematic in the African context in at least two fundamental ways. First, it neglects indigenous African holistic conception of health and health care, and second, it marginalizes a crucial aspect of bioethical issues distinctive and dominant in African cultures: bioethical issues raised by African traditional system of health and health care, broadly construed. This presentation adds a new voice to calls for bioethics in Africa to be conceived and done in African ways by focusing on cultural bioethics, distinguished from the mainstream biomedically-centered bioethics. I argue that African bioethics must be distinctively African in at least two fundamental ways. First, it must be conceived in terms of indigenous African conception of health, disease, illness, and healing. This conception is, as I discuss in this presentation, rooted in indigenous African cosmological worldview, including African conception of personhood. Second, for it to be genuinely African, the ethical norms and values of African bioethics must come from indigenous African moral system. These ethical norms and values are, as I argue, grounded in the communitarian (i.e. community-centered) character of African culture (constituted by their beliefs and practices. This contrasts with Western ethical norms and values defined by Western individualistic culture. Regarding the first, I discuss philosophical puzzles raised by African mystical system of beliefs and practices in which African traditional medicine is fundamentally rooted. About the second, I use a case study from traditional healthcare practices of the Yoruba ethnic group in Nigeria (viz. consultation of healer-diviner) to examine bioethical implications of the widespread caregiver roles that family members play in traditional African communitarian system of health care.

Lifestyle Diseases, Personal Responsibility, and Moral Standing

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Abstract: Socioeconomic status is a strong predictor of one's risk of developing certain lifestyle diseases, such as heart disease, type 2 diabetes, and diseases brought about by using cigarettes and alcohol. According to Andersen and Nielsen 2016, leading theories of responsibility cannot explain why those who were influenced by environmental or socioeconomic factors to engage in riskier lifestyle behaviors seem less personally responsible for their lifestyle diseases than those who were not. One might think that an advocate of a reasons-responsiveness view of responsibility, for example, must claim that all individuals are equally responsible for their lifestyle diseases provided their risky behaviors were the result of a reasons-responsive mechanism. Because this is counterintuitive, however, and because outside factors causally influence our behaviors and choices, they argue that it is more plausible to hold that no one is responsible for anything, including their lifestyle diseases.

I argue that Andersen and Nielsen are mistaken. A reasons-responsiveness view of responsibility has the resources to account for degrees of responsibility. These resources can be used in a novel way to explain how individuals who adopted risky lifestyle behaviors in part due to socioeconomic pressures are less responsible for their resulting lifestyle diseases. Reasons-responsiveness is a function of how *reactive* one's mechanism is to reasons as well as how *receptive* it is to reasons. The external pressures of socioeconomic status and upbringing can affect how easily one's reasons-responsive mechanism reacts to certain reasons, as well as what sorts of reasons one's mechanism recognizes. Even if one's mechanism is moderately reasons-responsive, such that one crosses the threshold of responsibility, how reactive or receptive to reasons one's mechanism is past this point can mitigate the degree to which one is responsible. For instance, the fact that less healthy, processed foods are more affordable, accessible, and promoted than fresh, healthy foods in the US can explain why someone on a tighter budget would find it harder to react to reasons to purchase healthier foods. Similarly, socioeconomic status can affect how receptive one's mechanism is to certain reasons: someone without many resources will see price as a very weighty reason not to buy some food, even though it is healthy.

Importantly, this does not entail that we are justified in prioritizing those with congenital diseases over those with lifestyle diseases. Even if individuals are responsible for their lifestyle diseases, US society has fostered the social inequalities that lead to unhealthy behaviors and has encouraged such behaviors in advertising and policy. This complicity undermines the moral standing, or authority, to hold individuals responsible for their lifestyle diseases.

Error and Determinations of Decision-making Competence in Mentally Ill Patients

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Department of Philosophy

University of Maryland

Abstract: Medical error is characteristically thought of in terms of mistakes made during procedures or in prescribing and dispensing medications. However, there is an earlier point in the medical process where equally impactful and morally troubling errors may be made: during determinations of a patient's competence to give informed consent, particularly in cases of psychological illness. Psychological illness doesn't necessarily preclude a patient from possessing the requisite capacities to give genuine informed consent, but it sometimes may do so. It is imperative that we do our best to make accurate determinations of patient competence, especially regarding life and death decisions, but psychological illness may produce situations ripe for error. Here I consider as a paradigm case Julian Savulescu's (2013) example of an anorexic who wishes to opt for voluntary palliated starvation (VPS). I will argue that an anorexic might judge a world in which she must eat—given the pain of her illness and little to no prospect of a cure in her specific case—as worse than death, and thus rationally opt for VPS as a means to death. This would be importantly different from opting for VPS as a means to persist in a state of starving herself, with death as a mere side-effect. However, even if competence could be determined based on such a distinction, there would be a significant chance of error in determining the intentions of any particular anorexic. And this uncertainty alone might provide reason to judge anorexics generally incompetent to make such a choice.

Confidentiality and Professional Self-Defense

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Abstract: Confidentiality is a fundamental building block of the doctor-patient relationship. Physicians quite rightly have a legal and ethical obligation to safeguard the highly private and sensitive information patients reveal during a clinical encounter. In fact, medical personnel are held to one of the highest standards of confidentiality of any civil profession- able only to break confidentiality when a patient is an imminent danger to himself or to others. While patients have always retained the option to share their medical information publicly, the world of social media has fundamentally changed the communication landscape. Patients and their families can now broadcast their personal stories and their praise or scorn for the medical professionals involved in their care for all to easily see without any accountability. This information may be disconcerting to the public and to other patients facing similar circumstances, and with current restrictions, only the patient's or family member's side of the story is told. Such a one-sided account can color the perceptions of future patients and create a persistent distrust of the medical profession that is unfortunate for both patients and physicians. Here, I consider the cases of Charlie Gard and Allie Evans—two British children whose families pursued highly public litigation against the medical personnel caring for their children. These families did not simply disagree with the medical opinions of their doctors but also impugned the doctors' motivations. Nearly continuous, one-sided coverage inflamed the public and resulted in threats against caregivers and permanent professional damage. So, what should happen when patients decide to reveal the intimate details of their lives and to accuse their physicians publicly of maleficence?

In this presentation, I argue that it is time to consider a new exception to confidentiality in the doctor-patient relationship- that of professional self-defense. This narrow exception would cover only those instances where patients or their family members make the first public move and willingly decide to share their stories. It would also be limited to those cases where families allege ill-intent and would not cover more mundane cases of medical error or malpractice. A decision to pursue a lawsuit would not be sufficient grounds for disclosure if the patient and family does not involve the press. Physicians would only be able to provide the minimum information necessary to refute public claims of maleficence and would not be able to reveal medical information that was not specifically needed to mount a defense. In this way, I believe we can strike a balance between the obviously important obligation of confidentiality and the need to allow professionals to defend themselves against public allegations. Allowing a defense builds the credibility of the medical profession and allows future patients to make better informed choices rather than deciding based upon a biased media firestorm.

Over-Testing, Racial Distrust, and Medical Error

Luke Golemon

Department of Philosophy

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Abstract: The phenomenon of medical over-testing in general and specifically in the emergency room is well-known. In order to avoid medical malpractice lawsuits, doctors feel incredible pressure to perform every test they can think of to avoid liability. Furthermore, the problem is very resistant to solutions because it rests on three fundamental parts of American life: an individualistic society, the limitations of our court of law, and healthcare's construal and practice as a business. While I give some possible solutions to the problem in my exposition of these fundamental pieces that lead to over-testing, I will mostly focus on how this system might actually be best for racial and ethnic minorities.

Considering that medical malpractice and error are much more common when the patients are in a racial or ethnic minority, it is no surprise that the mortality rate is similarly much higher in proportion to white patients. This has been highlighted recently in regard to the black maternal mortality rate, among other statistics. I argue that in these populations, an environment that emphasizes medical over-testing may well be the desirable medical environment until care evens out among races and ethnicities. This argument can be extended to other minorities that suffer error or malpractice at greater rates than the general population, like transgender or other LGBT folks.

I also address whether over-testing additionally burdens racial and ethnic minorities. While I admit that the effects of medical over-testing are increased, so are their positive effects. Furthermore, medical over-testing may help to assuage racial distrust. Because the medical community has a long and terrible history with oppressed groups (see Tuskegee, race-science, pathologization of LGBT community, etc.), an environment that is more sensitive than it need be can help ease fears and make it harder for bias of any kind to manifest. I conclude that our system of medical over-testing is not the best possible system, but it is not nearly as bad as some make it out to be. An environment of medical over-testing can help overcome bias in the clinic and assuage distrust between oppressed groups and the medical community.

“World”-Travelling as a Means to Applying Epistemic Humility in Chronic Pain Management

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Ethics and Public Affairs Unit

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Abstract: In their 2017 article, “Investigating Trust, Expertise, and Epistemic Injustice in Chronic Pain,” Buchman, Ho, and Goldberg suggest that health care practitioners (HCPs) should employ “epistemic humility” towards patients under their care in order to achieve epistemic justice. In this presentation, I suggest a tool, Maria Lugones’ *“world”-travelling*, that can help HCPs engage in epistemic humility, and thereby strive towards epistemic justice. Acknowledging that it is not uncommon for pain sufferers to have their experiences with pain be epistemically downgraded, the authors argue that the experiences of pain sufferers ought to be in epistemic equilibrium (epistemic justice) with the expertise of HCPs. Epistemic humility is a contributor to epistemic justice because it calls on outsiders (HCPs) to acknowledge the value of the insiders’ (pain sufferers’) perspectives, and as Uma Narayan states, carry out their possible criticism of the insiders’ perceptions in a way that does not attempt to dismiss the validity of insiders’ point of view. Based on Sandra Harding’s point that, “One has to either live as a member of an oppressed group, or do the necessary work to gain a rich and nuanced understanding of what such life worlds are like, in order to think within that group’s standpoint,” I will explain how Lugones’ conception of *“World”-travelling* can help HCPs better understand the perspectives of chronic pain patients. Lugones describes *“world”* as a construction of and within a society, and *“travelling”* as the shifting from being one person to being a different person. When combined, *“World”-travelling* can be understood as the flexibility one shows in shifting from different constructions of life (i.e. going back and forth between different roles/crossing insider-outsider boundaries with respect to pain management). *“World”-travelling* can mostly support one’s ability to engage in epistemic humility by allowing them to let go of strict/rigid constructions and stereotypes.

Impact of EHR Usability on Provider Efficiency and Patient Safety

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Abstract: Healthcare organizations may reap substantial benefits when transitioning to electronic health records (EHRs), such as decreased healthcare costs and better care. However, severe unintended consequences from the implementation and design of these systems have emerged. Poorly implemented EHR systems may endanger the integrity of clinical or administrative data. That, in turn, can lead to errors that may jeopardize patient safety or decrease quality of care. Adding poor design quality of EHRs can significantly increase the mental workload of clinicians, thereby increasing frustration, reducing user satisfaction, and causing unproductive workarounds. A literature review from over 300 sources identified how EHR implementation and design can impact the workload of healthcare providers, patient-provider relationships, and health outcomes. Additional research of EHR impact on patient safety, quality of care, and care coordination was conducted to assess contributing factors to these outcomes. From this literature review, we constructed a tailored survey and set of interview questions that adds to the effort on evaluating the impact of EHR usability on patient-provider relationships and health outcomes. The survey and interviews are intended for EHR users, specifically healthcare professionals working in physician offices.

Reducing Medical Errors Through Simulation: An Ethical Alternative for Training Medical Practitioners

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Abstract: The ethics of medical training are complex, balancing the need to provide trainees with experience while minimizing the potential harm to patients from their lack of skill. The traditional method—a graduated relaxation of direct supervision and assumption of personal responsibility over time—accepts a certain risk of harm to patients. Our current tolerance for preventable medical errors is appropriately low, yet our human nature makes the elimination of all error impossible. Advances in medical simulation over the last ten years have provided new ways of training medical practitioners that reduce the exposure of patients to less skilled caregivers. In health care, simulation provides a unique opportunity to allow trainees to learn specific psychomotor skills, work through complicated patient-care scenarios, improve their teamwork, and learn from mistakes without affecting direct patient care. Properly designed and implemented simulation scenarios have been shown to impact both individual and team performance. Skills training improves efficiency, saves time, increases confidence, and lessens errors. Team training improves communication, increases efficiency, and improves outcomes. Working with standardized patients improves skill in history-taking, physical examination, communication, and professionalism. In this presentation, we examine available simulation modalities such as low-fidelity skill trainers, virtual reality trainers, high fidelity manikins, and standardized patients that can be employed to provide medical education in an ethical manner. We review current literature on the efficacy of simulation in training practitioners and reducing medical errors, and provide recommendations for future research.

Off the Chart: Taking Your Healthcare Story from the Page to the Stage

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Amanda Page, MFA, Mount Carmel College of Nursing

Abstract: Oral storytelling has been made popular through radio shows such as *This American Life*, *The Moth*, and a variety of independently produced local events across the nation. It has become an important tool and popular method of delivery to engage audiences in learning more about themselves and the experiences of others. Here, we will explore the many facets of the healthcare world; those who hold a stake in healthcare careers, healthcare costs, the overall health of their human bodies, and the current state of the larger healthcare system. Not all stories are built the same, though, and presentation often provides the real impact, sometimes more than the content itself. Participants in this workshop will learn effective literary devices, structures and formulas, timing techniques, and delivery tips for telling the best story possible in three to five minutes. By writing down a brief first version of a story, participants will have a foundation from which to improvise. Special attention will be paid to methods for de-identifying Protected Health Information (PHI) to avoid Health Insurance Portability and Accountability Act (HIPAA) violations. Ways to incorporate storytelling into healthcare practices, organizations, and careers will also be discussed, along with lesson plans to help teach healthcare stories. The workshop will culminate in performances, which will be followed by reflections on the storytelling experience and the value of storytelling in medical humanities.

The Medical Humanities: A Life

Lawrence Hultgren, PhD
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Virginia Wesleyan University

Abstract. In his famous Sanger lecture in 1970, Dr. Edmund Pellegrino (1920 – 2013), one of the founding fathers of bioethics as a formal academic pursuit, observed that “Medicine is the most scientific of the humanities, the most empiric of the arts, and the most humane of the sciences.” A world-renowned innovator in the medical humanities, Dr. Pellegrino spent his career championing the need for the humanities in medical education and practice and arguing that a liberal arts education is good for medicine. As H. Tristram Engelhardt, Jr. said of him: “Bioethics and the medical humanities, especially their emergence in the latter part of the twentieth century, cannot be understood apart from Edmund D. Pellegrino.”

Dr. Pellegrino logged almost 70 years in medicine as a clinician, teacher, bioethicist, research-scholar, and administrator, serving as departmental chairman, dean, vice chancellor, and president. Author of over 600 articles and 23 books, as well as the founding editor of *The Journal of Medicine and Philosophy*, Dr. Pellegrino served nationally as Chairman of the President’s Council of Bioethics in Washington, DC, from 2005-2009.

However, it is in his life, and not just in his academic writings or research, that Dr. Pellegrino made, perhaps, the strongest case that the humanities and medicine should not be separated from one another. This presentation will explore how the medical humanities are exemplified in life—in the life of Dr. Edmund Pellegrino.

Medical Errors and Medical Conspiracy Theories

Mark R. Huston, PhD
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Schoolcraft College

Abstract: In this presentation, I will first provide a brief conceptual analysis of medical error. Specifically, I will examine the difference between individual medical errors (e.g. a doctor misdiagnosing a patient) and group medical errors. Group medical errors will also need to be further analyzed. For example, an institution such as an individual hospital may count as a group, but so may the Public Health Service and the Tuskegee Institute (the responsible parties for the infamous Tuskegee Syphilis study).

To more fully complete this task, I will discuss epistemological and ethical medical errors by using the work of virtue epistemologists such as Miranda Fricker and Jennifer Lackey. In particular, I will look at many of the essays in Lackey's edited book *Essays in Collective Epistemology*.

Once that conceptual apparatus is in place, I will provide a definition of medical conspiracy theories that pulls from an abundance of academic literature that has been produced over the last fifteen years on conspiracy theories. This is important because it establishes the other side of the medical error coin, namely error on the part of the patient (such as the belief that the MMR vaccine causes autism).

Additionally, I will show how both types of errors, group and patient, work to reinforce each other via the example of medical conspiracy theories. Finally, I will argue for possible solutions based upon more general work in the realm of political and philosophical disagreement, with a particular focus on the work of the scholar Cass Sunstein.

Respecting Patient Autonomy in Radiation Oncology

Megan A. Hyun, PhD, University of Nebraska Medical Center

Alexander B. Hyun, PhD, Keck Graduate Institute

Abstract: In contemporary biomedical ethics, it is widely accepted that medical practitioners have a strong *prima facie* duty to respect the autonomy of patients. The first goal of our presentation is to demonstrate that this *prima facie* duty to respect autonomy entails that there is something morally problematic about the way in which cancer patients are presently informed about risks of medical error in the context of radiation oncology. In particular, we defend the following claims: (i) The *prima facie* duty to respect autonomy entails that medical practitioners are morally obligated to evaluate cancer patients' ability to understand information about medical errors, and to tailor the amount of such information that they provide accordingly; and (ii) Presently, medical practitioners fail to engage in this sort of tailoring.

The second goal of our presentation is to offer a practical proposal for addressing this moral problem. Specifically, we argue that cancer patients should always be provided with the opportunity to have a consultation with a medical physicist during which the relevant risks of medical error are explained. The level of sophistication of this explanation will be appropriate for the individual patient's ability to understand the relevant medical issues. We highlight two attractive features of this proposal. First, clinical medical physicists have extensive experience explaining technical aspects of radiation oncology to non-experts, so they have the communication skills needed to be effective consultants. Second, our proposal is in line with the current movement in the medical physics community to re-define the role of physicists in the clinic given recent evolutions in healthcare.

My Body, My Choice? The Moral Dimensions of Assisting Patients with BIID

Llona Kavege
Barry University

Abstract: Bodily Identity Integrity Disorder (BIID) or Apotemnophilia is a rare condition where there exist a conflict between a person's actual physical body and their idea of how their body should be—usually it involves an able bodied person who believes that they should be disabled. The causes of BIID are still unknown and scientists still disagree on whether to classify it as a neurological, psychological or psychotic disorder. Sufferers from BIID are known to develop obsessive behavior and discomfort about a certain body part and often seek help from medical professionals to undergo procedures as extreme as amputations.

In modern medicine surgery is used as a last resort intervention when alternative methods have failed to bring fruitful results and ameliorations to the patient's condition. In cases of amputations this becomes even trickier because of the potential severe complications such procedures can engender.

In this presentation I will use the precautionary principle to analyze the moral dimensions involved in assisting patients suffering from BIID and how medical practitioners should respond to the requests of the sufferers of this condition.

First, I will explore the principle of autonomy, a foundation of medical ethics, and assess whether the concept of freewill can be exercised by some or all sufferers of BIID to justify their wish to seek help to disable themselves.

Second, I will use the doctrine of the double effect to evaluate the potential harm that could stem from performing an irreversible operation on a patient with BIID compared to the benefits that such procedure could have on the patient's life and wellbeing.

Third, I will evaluate the sociocultural implications of BIID to investigate the roots and reasons this condition develops and how it can affect the common good.

In the end I will conclude that as it stands with the current understanding of the nature of BIID it is morally impermissible for medical practitioners to assist patients with BIID in disabling themselves. Furthermore, I will offer advice to physicians about ways to deal with patients with BIID.

Gendered Conceptions of Abuse and Borderline Personality Disorder

Rachel Keith

Department of Philosophy

Virginia Tech

Abstract: *The Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* (DSM-5) cites a shockingly large gender difference in diagnoses of Borderline Personality Disorder (BPD). Such a large gender difference calls for an explanation. According to multiple studies at the community, legal, and clinical level, the gender difference in diagnoses does not match up with the prevalence of BPD in reality. Something must explain the difference between prevalence of BPD and diagnoses of BPD. I first acknowledge potential problems in the diagnostic criteria for BPD but proceed under the assumption that the criteria in and of itself is unproblematic. I then explain why more apparent explanations for the incongruence do not seem accurate or sufficient. Given the relationship between BPD and intimate partner violence (IPV), I argue that gendered conceptions of abuse and violence are likely to at least partially account for this discrepancy. I do not wish to claim that all individuals with BPD are abusive, nor do I want to say that all perpetrators of abuse suffer from some sort of mental illness. I do acknowledge that certain features of BPD—such as poor impulse control and efforts to avoid real or imagined abandonment—may make a person more likely to commit IPV. Instead, I argue that society largely views men as abusers and women as the abused, causing abusive women to wrongly be diagnosed with BPD and men with BPD—who may exhibit abusive tendencies—to go undiagnosed. I argue that abusive men are viewed as common place, but abusive women—given the caregiving roles assigned to them—are more likely to be seen as abnormal or defective. This has social, clinical, and legal implications. Most notably, misdiagnosing abusive women as mentally ill is likely to disproportionately affect homosexual victims of abuse, who are unlikely to see their partners as abusive given gendered stereotypes about abuse and may be unwilling to call out their partners for abusive behavior because of their mental illness.

Medicine and a Virtuous Death: An Aristotelian Perspective

Michaeleen Kelly, PhD
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Aquinas College

Abstract: Medical professionals should be involved in enabling a dying patient in severe pain with medical assistance to hasten his death. A good death will be interpreted here as one in which loved ones are present and one is spared excruciating pain so that one can communicate rationally one's final messages to this group. Hospice and palliative care protocols are in place already in American medicine and these are known to enable patients to live out their final days with less pain and more peace of mind regarding the physical stages of dying they are experiencing. But Western medicine generally regards death as a failure of medicine's mission to cure or heal and dying as the final stage inseparable from death itself.

Dying should be distinguished from death as a liminal stage during which certain conditions can be provided by medical professionals as an opportunity for spiritual growth, as well as for the expression of other virtues. Aristotle described a well-lived life as a virtuous engagement in a variety of different projects, goals and competencies. Included are capacities for cognitive, emotional, spiritual, productive, creative and affective growth. An intentional death provides the patient with a liminal space and time in which these capabilities can be exercised, similar to how they were experienced in life, rather than shut down due to fear and severe pain. Medical professionals can provide the experience and training essential to maximizing the value of this profound event. Despair, anxiety, fear, anger, uncertainty and other negative emotional states can be diminished when they can ameliorate pain and uncertainty about the predictable bodily changes. This liminal state is known to provide dying persons with the opportunity to experience spiritual enlightenment, peace of mind and transcendence, especially when in the presence of loved ones and spiritual mentors.

Non-Western cultures have provided cultural rituals and spirit guides to accompany dying members of their communities with emotional and spiritual support during this liminal, transitional state. Physician-assisted death can provide similar opportunities for experiencing the following virtues:

- wisdom regarding the one's most significant values and life experiences, made possible in a unique liminal space and time of peace and emotional support;
- integrity as completeness when the patient can determine rationally and peacefully to his survivors the meaning of a well-lived life and a valuable transition to death;
- hope regarding the value of their lives for survivors, many of whom may be present;
- creativity (an intellectual virtue) regarding the possibilities for transcendence and enhanced spiritual development in the liminal stage.

Given the possibilities for experiencing a virtuous death when medical professionals and loved ones are present, physician-assisted death should be part of Western medicine's protocol to deal with society's most vulnerable group, the extremely sick and dying persons, given they are in our trust in their profoundly spiritual last stages of a well-lived life.

**Gangrene, Guardians and a side of Ethics: A Case Report Highlighting the
Multidisciplinary Approach to Clinical Questions**

Tania Kohal, MD

Internal Medicine Residency Program

Henry Ford Hospital

Abstract: For many people who chose medicine as a career, *primum non nocere* is a credo that is not only a motivator to join healthcare as a career, but also an ethos by which one practices. Here a case is presented from a large tertiary care facility where beneficence, autonomy, and justice intersected, reminding us that there are times when we must take pause and reflect on patient-centered values, personal values and interpersonal conflict when evaluating patient cases, and to approach such cases with a multidisciplinary approach.

DC was a middle aged man who had a history marked by homelessness, remote drug abuse and poor health literacy who presented for evaluation of bilateral below the knee amputations for frostbite leading to dry gangrene. The patient had a poor understanding of his own health condition and had refused any surgical intervention. Given that he had refused a bilateral below the knee amputation at the outside hospital, he was appointed a guardian because he was deemed to lack capacity. He was then transferred to our facility after his guardian had consented for surgery as the surgeon at the originating facility refused to operate on a man who refused the procedure. Upon discussion with our surgery team regarding the patient's gangrenous feet, he was boarded for surgery though he continued to refuse the operation despite the medical team's pause to evaluate his case further and an ethics committee evaluation. His evaluation considered his social situation, psychological well-being and prognosis amongst many other factors in making a decision. This assessment was informed by discussion with the surgery team, rehabilitation team, and our case manager principally amongst others. Ultimately a decision was made that was thought to take into account these factors and the best method to uphold beneficence, justice, and autonomy.

This case reminded us that patients are complex and decisions we make as healthcare providers for the best interest of patients are not always easy to elucidate. Guardianship, consultants and system-wide policies can offer perspective that help us understand ways to decipher a path where we uphold bioethical values that define our practice, but when determining the most ethical course, there oftentimes is no clear-cut definition. I hope to share this case as an example of how a multidisciplinary team came together to advocate for a patient in a case where his options yielded drastically different results.

Gender and Pain Management: An Exploratory Study

Sara Kolmes, Department of Philosophy, Georgetown University

Kyle Boerstler, Department of Philosophy, Florida State University

Abstract: Many medical interventions are indicated primarily by patient pain, which leaves doctors relying on patient reports of pain intensity and type to know how to prescribe pain management methods. While looking at objective signs such as imaging or physical exam results from a patient may suggest several possible courses of treatment, patient reports of pain may be one of the major factors in deciding what course of treatment to take.

There are documented differences in the treatment of pain-related conditions between men and women, which are moderated by race. In some chronic pain conditions, women have a lower chance of positive outcomes of treatment defined as self-reports of manageable pain levels or a decrease in disability, particularly women of color. In a controlled study in which physicians were presented with identical symptoms in men and women, physicians were four times more likely to recommend a knee replacement for pain in male patients than for female patients. Studies on interventions for which pain is a primary indication show that women are less likely to receive these interventions than men, and further that women receive them only after more serious pain and physical disability, and some show that this effect is stronger for women of color.

Some philosophers have pointed out that people may be less likely to advocate for themselves in situations in which their desires go against the dominant cultural narrative within which they were raised, for fear of social retribution for abandoning cultural norms or because it simply feels wrong to do so. In particular, women are socialized to be less aggressive and less likely to confront stereotypically male authority figures like doctors. It has also been argued that members of marginalized groups who are less likely to be taken seriously may stop reporting their experiences. Difficulty expressing 'feelings' (as opposed to measurable facts) in medical situations may make these effects especially strong in cases in which relevant medical details are related to pain.

A combination of these phenomena may result in women self-advocating less aggressively when doctors undertreat their pain, and thus may explain some portion of the disparity in pain treatment offered to men and women.

Women's attitudes towards advocating for themselves in medical decisions relating to pain are empirically testable. An investigation into the feelings of efficacy regarding self-advocacy relating to the treatment of pain in women may provide a framework within which to address the problem of women's untreated pain. We have designed and are currently running an exploratory study to investigate this issue.

This exploratory study will provide subjects with a vignette describing a situation in which their pain is not being treated adequately and ask them questions about their attitudes towards self-advocacy and the strategies they would likely use. We will then determine if subjects' responses are affected by their gender, race, or conformity to gender norms.

Photography and the Pediatric Patient

Alex Kritzmacher

Jonides Cognitive Neuroimaging Lab

University of Michigan

Abstract: Although photography is an often underutilized medium in the realm of arts in medicine, it can generate tangible benefits for patients as well as instructors. The act of image-making can be incredibly therapeutic, as it allows for non-verbal expression of a patient's pain and fears. Dr. John Moses of Duke University has been teaching an undergraduate photography course for the last 20 years, where students work alongside pediatric patients to create a gallery installation. The patients whose lives are deeply intertwined with the hospital can often feel isolated and overwhelmed by the medical procedures they must receive on a regular basis. When the chronically ill child is provided with a camera and told to tell their story, they gain autonomy and a platform where their feelings and experiences can be heard. This workshop will guide participants through significant images in the genre of medical art, and examine photographs created by patients, in order to gain insight into the perspectives of each artist. We will also investigate ways of encouraging creativity and "buy-in" for the reluctant patient, as well as existing research regarding the benefits of art therapy programs.

**When Medical Errors Occur before Implantation: An Ethical Inquiry into the Accidental
Loss of Cryopreserved Embryos and Gametes**

Rashmi Kudesia, MD, CCRM Houston

Robert Rebar, MD, Western Michigan University Homer Stryker MD School of Medicine

Abstract: The responsible provision of assisted reproductive technologies, including *in vitro fertilization*, requires detailed coordination between medical, scientific and administrative staff to maintain highly-specialized equipment and technology, to assist patients in not only treating current conditions but also preserving future fertility, and to remain vigilant in managing ethical and legal dilemmas as they arise. Recently, in two high-profile instances, technical failures and lapses in team communication and execution led to the irretrievable loss of thousands of vitrified oocytes and embryos. Such events impact innumerable individuals or couples, whose family-building ability may be drastically altered or rendered altogether impossible as a result. Indeed, one unique aspect of reproductive medicine is that the untoward effects can harm not only the current, but also future generations, giving rise to complex claims such as the wrongful loss of potential life. As such, these cases can be utilized to examine larger issues in this field: the ethical responsibility of medical and laboratory staff to counsel patients regarding the likelihood of such a failure and to prevent mistakes impacting the viability of gametes and embryos; whether the loss of such biological material, legally construed as property, is ethically equivalent to human morbidity or mortality; an ethical framework for communicating such a catastrophic error; and a justice-based assessment of the appropriate reparation for such a costly mistake.

“Food,” Disease, and Behavior Change: Looking Beyond the Individual to Find Solutions

Paige Kyle, MPH, RDN

Community Health, Equity & Inclusion

Bronson Healthcare Group

Abstract: Since the 1950's, the United States has seen the rates of lifestyle-related diseases rise to epidemic proportions. Around 50% of deaths & disease in the United States are caused by individual lifestyle decisions and human behavior- the prevailing one being, dietary decisions. The conventional approach to this challenge has existed in the belief that if our very own behaviors are the reason why we are getting sick, then the solution has to reside within self-control and free will. Herein lies the reason for a concomitant rise in a very narrow, profit driven wellness industry focused on individual behavior change: eat less, eat better, exercise more.

Yet this push to change behavior is happening in an environment where cheap highly processed food is everywhere, cooking in our kitchens and cafeterias have become things of the past, fast food and soda prey particularly on youth and communities of color, and monocropping subsidized soy, corn, and wheat have flooded America's heartland and grocery store aisles. Meanwhile, the wellness industry continues to profit off the individual's failed attempts to change. This is the trap. We are the wellness industry's perfect consumers.

With as much logic there is behind changing individual behavior, if we begin to look at the political, social, and environmental forces at play, we can begin to understand why this approach hasn't been effective. So the question isn't whether prevention is important, it's how we approach it. I would propose we have to take the blame off individual behavior and rethink our assumptions about what truly drives health behavior in a population.

Thus, this presentation will investigate the historical context and present-day significance of 3 fundamental root causes of poor dietary choices:

1. Consumerism: the power of marketing and advertising
2. Accessibility: the ubiquity of food-like substances
3. Convenience: the disappearance of growers and chefs

Whispered Words: Destigmatizing Abortion Using Comics

Kathryn Lafferty

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University of Louisville

Abstract: Abortion is a contentious topic in American culture and public discourse, often leading to politicized discussion and an ethical or legal evaluation of “rights” for pregnant people. Lost in these discussions are the lived experiences of the individuals who choose to go through an abortion, reflecting the stigma surrounding abortion that often dehumanizes the patient, removing them from the experience almost entirely or prompting false narratives of the “type” of patient who undergoes an abortion procedure. Medical humanities can be used as a framework to aid in discussing abortion in a way that highlights the individual and simultaneously works to dismantle stereotypes and stigmas that are related to the procedure. Graphic novels and medical narratives provide a useful format to present complex ethical and medical issues visually and textually, appealing to a wide variety of audiences. Leah Hayes’ *Not Funny Haha: A Handbook for Something Hard*, a 2015 graphic novel about abortion, provides the reader with two narratives about women who receive different types of abortions in a way that normalizes and destigmatizes the procedure. Both visually and textually, this book focuses on the individual lived experience of going through an abortion, removing the political and ethical conversations that often obscure the discussion. *Comics for Choice*, an anthology of comics about abortion, also highlights the individual lived experience and works to reduce the stigma of abortion. While abortion stigma decentralizes the individual body, these comics reposition the body at the center and focuses on the visual representation of an emotional and often difficult decision.

This presentation discusses *Not Funny Haha* and *Comics for Choice* to show the importance of medical humanities in reducing the stigma and shame that pervades popular abortion discourse. Using graphic medicine and Charon’s theory of narrative medicine, I will demonstrate how comics are useful in providing specific knowledge of lived experiences of abortion and how these comics can aid in our public understanding of abortion. Furthermore, I argue that these graphic novels seek to not only normalize abortion but also to lessen feelings of isolation that are often associated with abortion procedures by creating a sense of community and shared understanding.

Double-Blind Trials and Tribulations

Muriel Lederman, PhD, Medical Humanities, Case Western Reserve School of Medicine

David Bleich, PhD, Department of English, University of Rochester

Abstract: Currently, the process for gaining approval in the United States for drug treatment is elaborate and arduous, to assure the safety and efficacy of the treatment. Double blind trials are considered the gold standard to test the efficacy of new investigational drugs and protocols. First, one of us will relate his experience as the relative of a patient enrolled in such a clinical trial. Then, we will consider ethical aspects of these trials and promote the use of historical control trials as a widespread alternative, which may be feasible with the availability of computerized medical records. In this case, rather than enroll persons in the group that receives a placebo or the standard of care, persons who, in previous clinical trials have been in such a group, would fill this category. We will also discuss the possibility of avoiding clinical trials altogether, by determining, for an individual, the three-dimensional structure of her mutated, disease-causing protein, and finding an interactive agent whose structure overcomes the mutation.

Medical Overtreatment and its Relation to Disease

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Abstract: When treatment is excessive and unnecessary with respect to care that is judged to be appropriate, or 'just right,' in response to particular health needs, it is thought to constitute overtreatment. Contemporary medicine, we believe, should be able to identify a treatment course that is 'just right' in addressing a particular case of disease or illness given a specific patient profile. However, it is not uncommon for a patient, seeking a 'second opinion,' to be recommended two courses of therapy differing in kind and scope, one more involved and rigorous than the other, by two equally competent physicians. One person's overtreatment seems to be another person's appropriate care.

I will argue that evaluations of appropriate care, and by extension dependent judgments of overtreatment, are inherently uncertain, tentative, and unstable as all treatment decisions hinge on prior determinations of disease. However, what counts as disease is controversial, and various disease understandings are at play in healthcare. Moreover, the dominant disease paradigm in Western medicine is purportedly scientific, objective, and value-free, yet, on closer inspection, disease understandings are, fundamentally, shaped by value judgments. Consequently, assessments of appropriate care and overtreatment must also be evaluative, thus, inherently variable according to personal and/or social values and norms that infuse individual cases of care. This results in inconsistent overtreatment judgments with negative consequences for the justification of medical interventions as necessary and appropriate treatments, and the optimal practice of medicine. This presentation's goal is to analyze the overtreatment-disease connection underlying this problem, thereby elucidating a hidden aspect of medical overtreatment.

This discussion has three parts. The first part explicates three socio-medical contexts—medicalization, nosology, and overdiagnosis—where ascriptions of disease status of certain somatic/mental states is contested. These contexts are useful in stressing the evaluative nature of disease concepts and their implications for overtreatment. The second part critically investigates descriptive, bio-medical conceptions of disease and their claim to being value neutral. Specifically, Christopher Boorse's 'biostatistical' theory of disease (BST), based on a special notion of function, competes with Peter Hucklenbroich's view of 'disease entity', which is claimed to be the disease concept actually used in medicine, without a functionalist basis that resembles that of the BST. My inspection shows that (a) the BST cannot defend the value-neutrality of disease, and (b) the disease entity view also relies on a function concept similar to the BST's, thus, it is open to similar criticisms. The third part examines evaluative accounts of disease, illness, and sickness from a 'strong' and a 'weak' normativist perspective. Strong normativism leads to a relativist indeterminacy of disease and treatment and cannot contribute to an understanding of overtreatment. On the other hand, George Agich's weak normativist position known as the 'pragmatic theory' of disease, is able to account for the evaluative ambiguities of care while integrating descriptive understandings of disease and treatment. It thus explains the inconsistencies in overtreatment judgments in terms of evaluative notions of disease.

The Racialized Medical Gaze: Racial Disparities as Medical Error

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Department of Philosophy

San José State University

Abstract: In the United States, there are significant racial disparities between nonwhites, especially Blacks and Hispanics, and Whites in health care. To date, much of the research on these disparities have examined the impact of various social, economic and environmental factors in maintaining these disparities. Beyond these social determinants of health, it is worth examining the relationship between perceived discrimination, racial bias and stereotypes, and racial disparities. For instance, how do medical stereotypes about the greater pain resilience of Blacks and Hispanics or about the potential biological basis of higher rates of chronic diseases such as cancer and type-2 diabetes influence care and maintain racial disparities? In other words, what is the relationship between racial disparities and medical error? This presentation will examine the notion of racial disparities as medical errors. To this end, I will utilize Michel Foucault's notion of a medical gaze. In *The Birth of the Clinic*, Foucault argues that physicians exert a disciplinary force upon patients rendering them docile to their expert judgment. However, if this gaze is skewed by social or medical stereotypes about racial and ethnic groups, then it may itself produce and maintain racial disparities. To examine this relationship, this presentation will be divided into five sections: the first will briefly outline the current state of racial disparities in healthcare; the second will outline Foucault's notion of a medical gaze. Next, the third section will argue that medical stereotypes combine with the medical gaze to perpetuate racial disparities through medical errors—errors that have the appearance of 'truth' and medical expertise. The fourth section will offer some potential solutions or forms of address to this problem. Finally, the fifth section will offer a few concluding remarks.

Hunger Strike versus Protest Psychosis: Discourses of Anorexia and Schizophrenia

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Abstract: The story of anorexia's embodiment and the story of schizophrenia's embodiment follow radically different trajectories. Anorexia, particularly in early feminist work seeking to raise awareness of eating disorders, is talked of in evocative, lyrical, and romanticized terms: to be anorexic, or so the story goes, is to be *too good* at all the things culture values, exposing a point of slippage in the fabric of culture where the attainment of a goal exposes its very incommensurability. Anorexia, then, is the body as metaphor: performativity of hunger strike rather than fault in neurochemistry. Schizophrenia, in contrast, is understood as breakdown rather than breakthrough. When spoken of in terms of metaphor, schizophrenia serves as a marker for the chaos and incoherence of modern life. To be schizophrenia is not to expose the incoherence of a culture's values: rather, it is to be the victim of a broken brain, over which one has little agency or control.

However, these narratives are fairly recent points of departure. Until the 1980s, anorexia was rarely talked of in the clinical literature, and when it was it was understood in radically different terms. In a similar vein, the discourse on psychosis evidences a striking shift at the start of the civil rights era from an illness that primarily afflicted (docile) white bodies to one lodged primarily in (violent) black men. Along the way, the cultural uptake of both illnesses changed drastically: anorexia changed from an illness of (inexplicable) nervous loss of appetite to a silent protest that demanded acknowledgment and uptake, a striking indictment of the damage inflicted on white, female bodies (and minds) by patriarchal beauty norms. At the same time, schizophrenia became conceptualized as a protest, one that needed to be controlled effectively in order not to pose a threat to the established order of society. Simultaneously, the understanding of embodiment of both disorders changed: anorexia became understood as expression of distress enacted primarily *through* the body, whereas schizophrenia became the object of a truth discourse lodged primarily in defective neurology. Thus, in one case the embodiment of an illness was valorized, whereas in the other it was almost completely elided.

This presentation will argue that this difference in understanding of embodiment, both in terms of its valorization and elision, was fundamental to the vast divergence in the truth discourses of anorexia and schizophrenia. Using the work of Rebeca Lester, it will point to the ways in which valorization of certain illness categories as metaphors reifies, rather than escapes, mind-body dualism. In particular, it will argue that the understanding of some illnesses as metaphorical expressions of distress and others as neurologically-based illnesses relates back to the understanding of embodiment in both anorexia nervosa and schizophrenia. In particular, the bodies inherent to discourses of anorexia and schizophrenia, and whether they are read as transgressive or emblematic, impact which illnesses are read as a performativity and which are read as indicative of inescapable flaws in neurochemistry.

Medical Error and Information Flow: Lessons from Pediatric Medical Ethics

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Abstract: Discussions of the ethics of medical error operate from the presumptions of priority of the principle of autonomy and the physician-patient relationship. Considerations of beneficence are often only employed when there are other conflicting circumstances. This model presumes that beneficent considerations are filtered through the patient's autonomy—beneficent treatment must be the patient's decision and the disclosure of medical error is essential for this when it arises. However, in pediatric medical ethics, this is reversed. In pediatric medical ethics, beneficence has general priority over autonomy. As children are not able to give autonomous informed consent and parental/guardian decisions can put children at risk, all parties must focus on the child's best interests. Here the model is more dynamic in it takes the medical evidence, medical information, and values from the child, parent(s)/guardian(s), and health care professionals attempting to converge them on the protection of the basic interests and welfare of the child. Communication of medical error plays a different role and one where disclosure to the patient is not primary. This pediatric model, it will be argued, provides important lessons for a revision of the model for adult medicine. Specifically, the pediatric model and the coordination of medical information coming from medical evidence, clinical diagnosis, patient narrative, and the role of the health care professionals shows when, on grounds of beneficence, the information of medical error is required and where, when, and to whom it should be disclosed all the while respecting the patient's or decision-maker's autonomy.

**ADHD, Opioid Addiction, and Schizophrenia:
Reflections on Mental Health Stigma, Narrative, and Lived Experience**

Andrew Molas, Department of Philosophy, York University
Kaliopi Dimitrakoudis, Department of Philosophy, York University

Abstract: Our panel explores stigma surrounding mental illness through critical explorations of ADHD, opioid addiction, and schizophrenia. The first part of our panel discussion explores the topic of stigma by challenging the trivialization of ADHD depictions in popular media. We argue that the myths created through popular culture reinforce harmful stereotypes for persons living with ADHD by delegitimizing their condition and their unique experience of being in the world. In the second part of our panel, we discuss the politics of stigma surrounding intravenous opioid use. Working within the harm reduction framework, we explore how stigma is manifested in the context of opioid addiction. To address this issue, we argue for the ways communities can help reduce stigma surrounding IV-substance use, including promoting safe injection sites and providing naloxone kits for treating overdoses. The final part of this panel addresses the stigma surrounding schizophrenia. In particular, we examine the personal narratives to underscore the impact that stigma has on their lives. We argue that overcoming stigma requires cultivating empathy and fostering intersubjective relationships based on respect and care. The overall theme of our panel focuses on the public's role in promoting both mental health awareness and mental illness prevention by emphasizing the importance of interpersonal interaction between persons living with mental health challenges and their systems of social support. These support systems include their primary healthcare providers, nurses, therapists, social workers, and their communities at large. Shifting the negative and harmful impact of stigma surrounding mental illness, and changing the public's perception of mental health challenges in a more positive manner, requires a collective effort to raise awareness about the realities of living with these diagnoses. To that end, our panel aims to explore these interconnected issues by emphasizing the importance of acknowledging and respecting the lived experience and testimony of persons living with ADHD, opioid addiction, and schizophrenia, respectively. We argue that it is crucial to attentively listen to these narratives as they provide us with better understandings of how to support people diagnosed with these conditions. By engaging directly with the lived experience of mental illness, and by engaging with the narratives which underscore the damaging impact that stigma has, the public can begin developing more accepting views of mental illness and begin to support those who need it the most.

Between the Earth and the Sky: Intergenerational Interactions of Visibility

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University of Michigan

Abstract: *Between the Earth and the Sky: Intergenerational Interactions of Visibility* is a community-based art program designed to bring together youth and people living with memory loss to build mutual respect and greater compassion. Led by professional artists, Anne Mondro and Charlie Michaels, in partnership with Corner Health Center's Youth Leadership Council in Ypsilanti, MI, and the Memory Support Center of Brecon Village in Saline, MI, *Between the Earth and the Sky* uses art to sustain wellbeing and foster community.

Encouraging social interaction, expression, and wonder, the program's art activities engaged the youth and older adults in the creation of two large-scale collaborative artworks. Revolving around the winter and summer solstice, the artworks—an installation of hand-made lanterns and a garden installation created from hand-made concrete planters filled with herbs to form a geometric pattern – physically and symbolically encompass the themes of “light” and “growth.”

Using *Between the Earth and the Sky* as a model, the presentation will focus on the design and implementation of an intergenerational art program for people living with dementia. Recognizing that the youth participating in the program represent the next generation of professionals and community leaders, the presentation will highlight the program's design to increase the youths' sensitivity towards and understanding of persons living with dementia. The presentation will also discuss the role of art to provide adults living with dementia opportunities to serve as mentors to youth and as creators of public art. This opportunity to contribute to the community in both of these ways actively seeks to help people living with memory loss maintain their rights as citizens—rights that are often ignored due to their dementia.

**Life-Altering Decisions: The Role of the Physician, Parents, and Disease
Communities in Childhood Medical Decisions**

Tabitha E. Moses

Wayne State University School of Medicine

Abstract: The physician's role is changing. There is no longer a place for the paternalistic physician who tells his patient what to do without explanation. Patients have access to more information than ever and want to play an active role in their healthcare decisions. The medical profession has adjusted accordingly; physicians provide patients with the information to make decisions for themselves. Nonetheless, there are still areas in which the physician's and patient's goals may not align. This issue is most prominent when discussing chronic disorders—in particular, those whose very definition is based on a subjective view of normal (e.g. Autism Spectrum Disorders (ASDs) and the concept of neurodiversity). This is not a concern when discussing treatment of adults; however, many of these disorders manifest in childhood and their treatments are usually initiated early. Lamentably, there are many instances wherein the treatments advocated for by physicians and parents are directly opposed to the desires expressed by adults in that disease community.

This issue arose with introduction of cochlear implants to Deaf children. Today this problem is more frequent. This is seen prominently in the treatment of children with ASD. Physicians and parents laud the use of Applied Behavioral Analysis (ABA) as an effective intervention, but many adults with ASD compare ABA to torture and are actively opposed to its use. This leads to fundamental question about whose interests are being valued when treating children. We trust parents and physicians to make the best choice for their children. Nevertheless, there are increasing numbers of advocacy groups that state the way they were treated as children is not what they would have wanted. Those with Differences in Sexual Development (DSD) have echoed this cry. Until very recently, children born with DSD underwent surgery to “normalize” their genitalia as early as possible. Advocacy groups of adults with DSD have gone to great lengths to change this practice, arguing there was no medical reason for it—that they would have preferred to make that choice later in life.

These situations are becoming more commonplace, which elucidates a fundamental problem: physicians are recommending treatments that do not align with what adults with the disorder would have wanted. Parents made those choices due to physician recommendations or personal preference. DSD is a prime example. Even today, some physicians cite the need for this surgery because of the psychosocial stress on the *parents* of not being able to tell relatives their child's binary gender. This attitude is inherently problematic; the treatment of children should focus solely on the long-term wellbeing of the child. As such, we must consider how we approach treatment of certain disorders. If the parents' desires clash with the outspoken beliefs of those with the disorder, it is possible they are not making the best choice for their child. In conjunction with the current changing paradigm of healthcare that places more focus on patient narratives, we must also look to disease communities to guide our treatment of those too young to advocate for themselves.

Error, Inductive Risk, and The Biomedical Model of Medicine

Dane Muckler

Department of Philosophy

Saint Louis University

Abstract: One of the most frequently criticized assumptions of the biomedical model is the identity of typical bodies with healthy bodies. It has been lamented that this assumption enables discrimination against marginalized persons and is therefore unwarranted. I contend that the issue can be better understood in the context of what Douglas calls inductive risk. Inductive risk is the idea that scientists should adjust the level of evidence they require to accept a hypothesis to be proportional to the risk of harm that may result if the hypothesis is accepted erroneously. I argue that the assumption that typical bodies are healthy bodies would have posed much less inductive risk in the context of pre-20th century medicine than it does today. Furthermore, the assumption of an identity between typicality and health enabled the acquisition of morally important medical knowledge that would not have been accessible otherwise. For example, the assumption of typicality and health permitted the discipline of physiology to proceed through the study of cadavers and live human models. In the current epistemic environment, the assumption of an identity between typicality and health may no longer be justified. Nevertheless, understanding why such an assumption was once warranted helps explain why the assumption retains its influence on medical thought.

Against Pediatric Assent: Children's Capacity for Preferences Grounds their Decision-Making Authority

Mark Navin, PhD, Department of Philosophy, Oakland University

Jason Adam Wasserman, PhD, Oakland University William Beaumont School of Medicine

Abstract: Since 1995, the American Academy of Pediatrics (AAP) has promoted 'pediatric assent' as a mechanism for involving children in decisions about their health care. Pediatric assent is analogous to informed consent, since it is an extended process of (relatively) informed participation in health care decision making. However, pediatric assent is usually understood to require less understanding, rationality, etc. than informed consent requires. Furthermore, children who are unable to participate in pediatric assent are usually understood not to have moral rights to participate in their health care decision making.

We argue that 'pediatric assent' should be abandoned because it occupies an untenable middle ground between autonomous and non-autonomous decision making. If children are capable of informed consent, then pediatric assent does not apply, since their moral rights to participate in health care decision making are as weighty as are those of adults who possess decision making capacity. However, if children are incapable of informed consent, then the mere fact that they have preferences about potential interventions or treatments—and not whether they are capable of participating in the pediatric assent process—provides moral reasons for involving them in health care decision making. In this presentation, we argue that the concept of what we call *Capacity for Preferences* provides a stronger moral basis for children's participation in health care than do the AAP's arguments on behalf of pediatric assent.

'Unstoppable Machines' and 'Unrelenting Thoughts': Cultural Conceptions of Insomnia in the U.S.

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Abstract: Insomnia is a prevalent and significant health concern in the United States. Epidemiological studies suggest that 20-35% of the general population regularly report symptoms of insomnia, and 10-20% have a clinically significant insomnia syndrome. Although Americans tend to valorize sleep deficits due to demanding work schedules, the impact on sufferers' health and well-being can be substantial. Individuals suffering from acute and chronic insomnia report poorer overall health, and greater work absenteeism and use of medical services. Insomnia is associated with impaired glucose metabolism, increased rates of type 2 diabetes, and cardiovascular disease. Although insomnia has been the subject of substantial research in the health sciences, there has been relatively little research on insomnia in the social sciences and humanities.

This presentation will report on a study that examined cultural conceptions of insomnia in adults in the U.S. with the goal of understanding how these conceptions give shape to subjective experience and sufferers' response to their health problem. Twenty-seven individuals (70% female) between 22 and 58 years of age ($M = 38.0$, $SD = 11.6$) reporting moderately severe insomnia over the past six months were interviewed and completed surveys. Analysis of the illness narratives found a pair of commonly used metaphors that were used to explain the origin and cause of their problems with sleep: (a) the brain as an "unstoppable machine" and (b) a cognitive style characterized by a compulsion to ruminate, usually about inconsequential issues. Conceptions of insomnia built around these metaphors appears to lead to a form of medical fatalism in which insomnia might be managed but cannot be fully resolved because the origin is thought to be basic to the individual's personality and cognitive style. This fatalistic approach to insomnia has a range of impacts on their management of the condition. Study participants were reluctant to discuss the condition with family, friends and their physicians and many reported a profound sense of isolation. They also tended to avoid long-term solutions, such as adopting basic "sleep hygiene" measures and cognitive behavioral therapy, preferring instead to manage their insomnia using numerous and diverse short-term treatments, including over-the-counter sleep aids, prescription medications, alcohol and illegal drugs, dietary supplements and vitamins, and complementary and alternative (CAM) treatments. For most of the study participants this approach has provided only limited relief with some high social and financial costs, side effects, and even legal risks.

Folk Medicine Among the Igbo People of South-Eastern Nigeria: Past and Present

John Mark Chinaemerem Ogu

School of Liberal Arts

Duquesne University

Abstract: The practice of folk medicine is as old as the Igbo people in Nigeria. Many other tribes and races in the world still follow the same ancient beliefs. Folk medicine was and continues to be an integral part of life in many tribes and races in the world today; despite the advent of orthodox medicine. It is not out of place to say that orthodox medicine developed out of folk medicine, because medical practice in the past had its birth using herbs and divinations. Folk medicine was and still continues to play a large part in the medical practices that people of old and even the present use to contain diseases and illnesses. This belief in folk medicine is still prominent in the Igbo society today; as some diseases and illnesses are being treated using folk medicine. There is still the preference for folk medicine over orthodox medicine among some Igbo people.

The practice of folk medicine varies among people of different locations and tribes. The practice of folk medicine among the Igbo tribe is unique and different from other tribes, because religion, culture and medicine are interconnected and interrelated. It is very difficult to separate religion, culture and folk medicine among the Igbo. The Igbo people believe strongly in the interconnectedness and the interrelatedness between the spiritual and physical life and one's well-being. This Igbo philosophy of interconnectedness and interrelatedness of the spiritual and the physical life is the bedrock of Igbo tradition (*omenala*). Tradition (*omenala*) is a way of life of the Igbo people, and the compendium of religious and medical practice; no wonder folk medicine is called *Ogwu Igbo*—traditional medicine among the Igbo people. Physical well-being and bad health are given spiritual interpretation. Good health, plentiful harvest, poor harvest and bad health are all given divine interpretations, because of their strong belief in God (Chi).

Therefore, this presentation will focus on the following issues about folk medicine among the Igbo tribe:

1. The important and resilience of folk medicine among the Igbo tribe
2. The preference of folk medicine over orthodox medicine by some Igbo people today
3. The relationship between folk medicine, religion and culture –tradition (*omenala*) among the Igbo tribe
4. The ethical and unethical issues in Igbo folk medical practice

The Paradox of Clinical Outcomes

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Texas State University

Abstract: There is now a growing body of evidence that a significant portion of published research is reporting empirically insignificant relations or false positives. Some argue that the situation is particularly worse in medicine and pharmacology where gradually increasing precision of experimental methodology leads to clinical trial designs that are hypersensitive to minute differences in effect sizes that might not translate into better outcomes. Compounding the problem is that there are serious questions about the reproducibility of foundational studies and preclinical trials. And still worse, the quality of evidence in the “gold standard” randomized clinical trials might be getting lower over time due to increased experimental bias resulting from escalating financial conflicts of interest.

Against this backdrop of declining reliability, there is a startling but undeniable fact: that patient outcomes in virtually all areas of clinical medicine are improving. For instance, breast cancer mortality in the US declined 34% between 1975 and present, whereas the decline cannot be written off to earlier detection. This presents an empirical puzzle, which I will call “The Paradox of Clinical Outcomes”: If evidence in medicine is getting worse, why are patients getting better? In this presentation, I explore two solutions to the paradox, and discuss the challenges they face as well as the epistemic and ethical implications they have.

One solution is to declare the concerns stated above alarmist. Although this would easily explain the improving patient outcomes, it is in tension with basic statistics and well-documented facts such as the immense increase in research retraction. Another solution is based on reevaluation of the clinical mind: contrary to what medical researchers and philosophers of science believe, in the eyes of the average medical practitioner randomized clinical trials might not be the “gold standard.” If most physicians who prescribe treatment base their decisions largely on anecdotal reports or their own personal experience with patients, they would be late at adopting cutting edge treatments and interventions, and perhaps inadvertently serve as a filter against problematic research findings. Adopting this latter solution, however, would require us to reform our notions about methodology of medical practice and the role of the ordinary physician. In this reformed version of philosophy of medicine, there is no strict separation between researcher and practitioner, and the practitioner is in fact an integral part of the self-corrective character of science.

Hospice, DNR Orders, and Suicide Attempts

Christopher Pynes, PhD

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Western Illinois University

Abstract: There are three general principles that conflict and create a dilemma for doctors, nurses, and staff who work in hospice environments. I name them:

Hospice: Hospice care neither prolongs life nor hastens death.

DNR: A legal order to prevent cardiac resuscitation or advanced cardiac life support.

Suicide: The taking of one's own life.

As it stands, these three principles conflict in an important way in the hospice environment. Given that hospice policies do not condone suicide, but they also do not promote the unnecessary extension of life, one can quickly realize that doctors, nurses and staff who are on call in hospice environments face a dilemma. If there is a suicide attempt of a hospice patient with a valid DNR, what should occur?

Typically, a doctors and staff try to revive the patient. But in the case of hospice care, this would be to prolong life, especially where there is a DNR order on the patient. When this occurs, and it does happen, there is a conflict between the mission of hospice, the patient's clear wishes to not be resuscitated and die, and the doctors code to do no harm.

This presentation aims to achieve three goals: (a) defend a view that a suicide attempt in a hospice environment isn't a sufficient reason to revoke a valid DNR order; (b) that these decisions can't be made on the spot by doctors and that hospitals and hospices need to have policies for how to handle these cases, and (c) that the U.S. needs to reconsider how it handles end of life situations, particularly the prohibition of euthanasia.

Medical Students' First Real-Life Ethical Dilemmas: What Do They Learn from Them and What Can We Learn from Their Narratives?

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Department of Biomedical Sciences

University of Montréal and University of Montréal Medical School

Abstract: As it is now common to include in a medical ethics curriculum, our medical school recently developed narrative ethics workshops for third year medical students. The goal of these workshops is, in collaboration with patient partners, to discuss and write about ethically complex situations encountered during clerkship that raise questions, discomfort or distress. This project included 394 vignettes from two student cohorts. These were coded to identify the main ethical dilemmas reported by the students. Narrative aspects of these vignettes were then analyzed in a comprehensive fashion. The themes most commonly reported by students are consent, autonomy and communication. Authority and hierarchy are also often addressed. Emotions identified throughout the vignettes almost always related to the self-perceived helplessness and powerlessness of the medical student. This in turn resulted in students describing emotional reactions ranging from discomfort to true moral distress secondary to doing things that went against personal values and beliefs. Students adopted a critical posture in 70% of the vignettes, and solutions to the ethical dilemmas were frequently and spontaneously identified by the students themselves. Despite recent advances and research in the field of teaching clinical ethics, the challenges experienced by medical students remain numerous and complex. Clerkship is a pivotal period in students' development as future physicians; ethical dilemmas experienced by clerks and the way these are solved contribute to shaping their morality and professional values. Student's experience has been of interest for many years now and should continue to be, as those findings allow for continuous critical discussion on medical education. Moreover, the findings should be used to enhance training, and to rethink educational and clinical habitus within our training environments.

**Awakening the Disembodied Soul: Complementary Therapies:
A Whole Person Approach to Oncologic Healing**

Albert T Quiery, Jr., MD University of Michigan Rogel Cancer Center
Claire J. Casselman, LMSW University of Michigan Rogel Cancer Center
Bob Huffman, MT-BC University of Michigan Rogel Cancer Center
Peter Carpenter, MT-BC University of Michigan Rogel Cancer Center
Melinda Hallenbeck-Kostecky, MS, ATR-BC University of Michigan Rogel Cancer Center

Abstract: A diagnosis of cancer disrupts our biography; a biography that we have created for ourselves in the context of health. Our lived human experience, one of a unified mind and body, dichotomizes, with the body becoming the captor of the soul. Cancer and cancer treatment are often associated with pain, suffering, and disfigurement. This experience amends the way we view our bodies and disrupts our relatedness to self, family, colleagues, and the greater society. The human impact of cancer is far more than a biologic process. The associated stigmatization leads to social isolation, feelings of loneliness and hopelessness, and a loss of creativity. Contrary to popular culture that increasingly values integrative approaches to care; oncologic care in the United States has never been more focused on biologically targeted modalities. The language of cancer treatment is that of surgery, chemotherapy, immunotherapy, radiation, clinical trials, and outcomes; leaving little room for the healing of a disembodied soul.

The Rogel Cancer Center at the University of Michigan has incorporated complementary methods to the care of patients with cancer. These approaches include psychoncology, meditation, guided imagery, music therapy, art therapy, spiritual care, legacy work, and other integrative medicine services. This participatory workshop will demonstrate the application of three such approaches to a patient experience of cancer care: guided imagery, art therapy and music therapy. Charmaz described four problems that the body has with illness: loss of control, altered self-image, disruption of social engagement, and loss of desire. This session will demonstrate how the application of the humanities to cancer care can add valuable resources to a patient's tool-kit that move cancer care beyond the mere treatment of disease to a whole person approach to healing.

Rehabilitating Blame

Samuel Reis-Dennis, PhD
Berman Institute of Bioethics
Johns Hopkins University

Abstract: Much of the recent work on medical error is forward looking, focusing on reducing the risk of future mistakes and making the hospital a safer place for future patients. This presentation has a different focus: I ask what kinds of attitudes doctors, patients, and families should have toward errors that have already occurred, and what kinds of emotional exchanges we should encourage between these parties in the wake of harmful mistakes. I argue that to adequately face and respond to medical error, we must make space for blame. In vindicating blame as a response to medical error, I do not advocate a return to a “bad apple” blame culture in which unlucky practitioners are unfairly scapegoated. I do, however, defend the targeted feeling and expression of angry and even resentful blaming attitudes toward healthcare providers who make at least certain kinds of mistakes. I make the case that feelings of angry blame reflect a conception of oneself as a person worthy of consideration, and that expressing fitting feelings of blame allows victims to fight for their dignity and self-respect. Along the way, I distinguish between shame and blame, explaining that blame, unlike shame, characteristically aims to draw offenders into a moral dialogue. As a result, blame can provide a logic within which providers who make costly errors may seek forgiveness, reconciliation, and healing.

Why is That Parsley on My Plate?

Richard R. Roach, MD, Western Michigan University Homer Stryker MD School of Medicine

Tracey L. Mersfelder, PharmD, College of Pharmacy, Ferris State University

William H. Nichols Jr., DO, Bronson Methodist Hospital

Abstract: Nowadays, spices are typically added to our food to make it more pleasurable to eat. When these ingredients were originally used, however, it was not to enhance flavor but rather for their perceived therapeutic effects. Our objective here is to review the historic use of a few common spices—including their intended medicinal value—and to relate our present knowledge of their chemistry and therapeutic benefits. In this presentation, we offer a review of the literature focused on the historic medical benefit of certain spices and report on our current knowledge of their true pharmaceutical properties.

Early European cooking was quite basic. Meat was a staple and was cooked simply, typically either boiled or roasted. By the 5th century, ingredients such as nutmeg, cinnamon, anise, oregano, mustard, and parsley were commonly added. This was done with the intention of treating such ailments as indigestion or poor circulation, or to ward off poisons; only later did they come to be used purely to enhance the food's flavor. These spices have now been studied with contemporary methods and found to truly have beneficial pharmacologic properties.

So the next time you are at a restaurant, you should eat the parsley on your plate if you think your food may have been poisoned.

Another Fundamental Moral Relation

Wade L. Robison, PhD

Department of Philosophy

Rochester Institute of Technology

Abstract: Wesley Hohfeld said of legal cases, 'One of the greatest hindrances to the clear understanding, the incisive statement, and the true solution of legal problems frequently arises from the express or tacit assumption that all relations may be reduced to "rights" and "duties," and that these latter categories are therefore adequate for the purpose of analyzing even the most complex legal issues.' Assimilating all legal relations to the right/duty relation prevents us from fully understanding and properly resolving a case.

The same is true in ethics. All ethical relations are assimilated to the right/duty relation, but that relation does not capture the ethical relation we are in when we empower physicians to care for us, for instance. We make ourselves liable to the decisions our physicians makes about our care, giving them discretion, among other things, and the kinds of ethical problems that can arise regarding discretion are different from those that arise regarding rights and duties.

All this will no doubt seem puzzling to those used to thinking of ethics only in terms of rights and duties. Kant and Mill would certainly be puzzled. Both recognize only the right/duty relation, and yet we can readily find examples that defy understanding and resolution if they are not seen in light of the power/liability relation. We will look at several medical cases to illustrate and explain this point.

**Homelessness and Mental Illness in the U.S.: Ethical Ramifications of a Gap in how the
U.S. Healthcare System Deals with Mental Illness for the Homelessness**

James E. Roper, PhD, Department of Philosophy, Michigan State University

Daniel Roper, MD, Department of Emergency Medicine, Mercy St. Mary's Hospital, Grand Rapids, MI

Abstract: Recent changes in U.S. healthcare law provide those with health insurance better mental health, but many homeless individuals remain without healthcare coverage and go to hospital emergency departments, which are ill prepared to handle them. Providing suitable support for these individuals would reduce homelessness in the United States because the mentally ill are often unemployable, which denies them access to traditional sources of health insurance. Moreover, such individuals are generally not welcomed into the households of even their closest relatives. Most families cannot accommodate the special medical needs of a person living with mental illness. (Some of these individuals are dangerous and should not be living in unsupervised environments—especially with children.) Helping these individuals deal with their mental illnesses would enable many of them to hold jobs or live with family.

Healthcare is arguably a right, and mental illness should be dealt with in the same way physical illnesses are. Using an appropriate characterization of distributive justice, we argue that the mentally ill should have access to appropriate treatment. This argument will depend on establishing (1) that healthcare is a right and (2) that mental illness should be regarded as bona fide illness which must be treated by medical professionals. We next argue that dealing with the problems of those who go to hospital emergency departments in hope of finding treatment for their mental illness is an ethical imperative in a society as wealthy as the U.S.—even if doing so requires redistributing wealth.

Some claim that dealing with the mentally ill in the same way that we deal with the physically ill is too costly. In a 2013 article in the *New York Times*, Julie Creswell shows that E.R. costs for mentally ill individuals are soaring—far in excess of other medical costs, which actually appear to be declining. We explain this argument and show how it establishes that, even for someone whose sole criterion for moral correctness is the general utility of society, dealing with the crisis in mental health care for those whose sole recourse is a hospital emergency department will actually increase the utility of society because it will be less costly than the current situation.

Some will contest our conclusions by arguing that health care is a privilege that must be paid for by the individuals who seek it. It is “their responsibility.” Those who so argue do not understand the concept of responsibility—that it requires knowledge and ability. I will show how this deficit leads them to specious conclusions.

Finally, having established a moral basis for our conclusions, we argue for specific policy changes to address the problems. These policy recommendations will be informed by the experience of coauthor Dr. Daniel Roper, MD and by discussions with David Zin (Chief Economist, Michigan Senate Fiscal Agency).

Journeys End, Journeys Begin

Shapir Rosenberg, MD, Psychiatry Residency Program, University of Maryland Medical Center

Alison Hartman, Licensed Acupuncturist, Westminster, MD

Abstract: In this performance debut, a mother and her son's physician tell stories within a story, in many voices, of a young man's life—his smile and vitality, his homelessness and drug use—and of his death. Told in monologue and dialogue, through words and images, via hospital records, police reports, and poetry, it is a moving tale of love, loss, caregiving, and healing. With compassion and vulnerability, humor and creativity, mother and doctor grieve and transcend, together.

Victoria Sweet's Premodern Philosophy of Medicine

Eve Salisbury, PhD

Department of English

Western Michigan University

Abstract: Victoria Sweet is a practicing physician at the University of California, San Francisco who also holds a PhD in history and social medicine. Her dissertation (now a book) on Hildegard of Bingen, the twelfth-century polymath, distinguishes her from other physician/writers by acknowledging the efficacy of premodern medicine in a modern setting and by bringing to our attention her philosophy of medical practice as articulated in memoirs written for the general public. Sweet tells of how she enfolded Hildegard's ideas into her practice at Laguna Honda Hospital and Rehabilitation Center in San Francisco, a state-of-the-art facility that was once an almshouse for the poor and indigent. Like Hildegard, Sweet considers medicine to be an art as well as a craft and a science with the patient at its center. In what she calls "slow medicine," Sweet advocates for additional time spent in observing and examining patients, talking with them, attending to their needs, practicing in a way often considered by others in her field to be inefficient and outmoded, antithetical to "fast" medicine driven by the need for efficiency, dependent upon computer screens and impersonal data analysis. By shifting the working metaphor for medical practice from the body as a machine to the body as a garden, that is, a living thing, Sweet's philosophy of medicine may be understood as holistic and humanistic, natural, organic, and attentive to minuscule details. That much of her way of thinking comes from a twelfth-century nun is itself no small matter. This presentation addresses the principal features of Hildegard's medical treatises (*Causae et Curae* and *Physica*) and Sweet's integration of those ideas.

Personalized Medicine: Education and Competency Rich in Genomics and Ethics is a Necessity for Healthcare Professionals in the Era of Genomics and Personalized Medicine

Evangel Sarwar

Center for Healthcare Ethics

Duquesne University

Abstract: Genomics is a powerful tool for understanding the totality of the factors that contribute to health and disease—how human and pathogen genomic factors and their interactions—contribute to individual differences in immunologic responses to vaccines, infections and drug therapies. Advances in genomic technologies are transforming medical practice, necessitating the expertise of genomically-literate physicians and other healthcare professionals. Healthcare based on genomics will not only require understanding of the knowledge of genomics, and how to utilize personalized medicine, but also the ethical, legal and social implications (ELSI) that are associated with it. To keep up with the changes, the various actors within the health system must be trained in a completely different manner, focusing on the ability to work as part of a multidisciplinary team that includes medical doctors, nurses, engineers in medical imaging, and others who collect information from patients, and translate them using the advances made by genomics. Genetic counseling offered today is not going to be enough for future healthcare deliveries. Studies demonstrate that healthcare professionals are not properly trained and lack the confidence in providing genomic based treatments. In spite of the importance of the need for education geared towards the emergence and success of personalized medicine in our societies, there are challenges of implementing new training methods, and curriculum that incorporates greater knowledge of genomics, and process of translation and delivery.

Trends in genetics curricula in US and Canadian medical schools suggest that even though most schools have already incorporated genomics materials into their curriculum, it is not adequate to prepare physicians and other healthcare professionals to deliver confidently in the era of personalized medicine. In this presentation, I examine existing educational standards, competencies, and practice resources to support the different actors in the healthcare sector, and outline the specific needs and challenges associated with advances of genomics and personalized medicine. I also propose potential solutions for educators to keep pace with this rapid advancement. With the rapid progress of genomics, it is likely to be incorporated into mainstream health care sooner than later, affecting the delivery of health care at all levels. Healthcare professionals need to be trained and competent in understanding, analyzing, utilizing and delivering personalized, genomic based healthcare services that are also sensitive to significance of ELSIs, by applying ethical principles.

Embodiment, Health, and Instruments Measuring Spiritual Experience

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Abstract: Research increasingly demonstrates that religious and spiritual orientations impact physical health. One of the largest issues facing researchers is how to adequately measure the subjective spiritual experiences of research participants. Various scales and inventories have been developed to give researchers a window into subjective spiritual orientations of research participants. Referred to as “instruments” in the literature, these scales attempt to account for multiple dimensions of spirituality, from cultural background to personal beliefs. Researchers administer these instruments to participants by asking them to rate their spiritual experiences in response to a variety of questions. The responses of participants are then analyzed to gain insight into the subjective spiritual world of each participant. While these instruments are useful for many applications—for instance, in delivering culturally competent healthcare—there are aspects of spiritual experience that are underrepresented. I argue that one of the largest underrepresented aspects in current instruments is embodied experience. Researchers in the social sciences and humanities utilize the concept of embodiment to assess the relationship between subjectivity, culture, and human physiology. I argue that scholarship on embodiment can contribute to the design of instruments by bridging the gap between culture, spiritual experience, and the body. The incorporation of embodied categories into instruments allows researchers to further comprehend and articulate connections between spirituality/religiosity and health.

Nothing and Everything is Possible:

On Constraint in Medical Education Curriculum Revision

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Kyle Rosenberger, Office of Instructional Innovation, Ohio University

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Abstract: Curriculum construction is a paradox. On the one hand, the rethinking and restructuring of a curriculum is billed as a tabula rasa, an open space in which possibility and innovation can drive a process characterized by creativity. A new curriculum is, in a sense, an open sea, an opportunity to reset processes, fix problems, advance new modes of learning, and re-envision an educational institution's aims. On the other, a new curriculum is characterized by constraint arising from stakeholder interests and attempts to appease multiple constituents, accreditation and licensing requirements, entrenched norms and a tendency to default to institutional and procedural conservatism. As a result, many of the ideas that exist at the outset of a curricular revision, especially those that address the humanistic, historical, social scientific, policy, and cultural aspects of medicine, come up against constraints, perceived or real, that short-circuit some of the creativity that gave rise to the process in the first place.

This presentation explores the idea of curricular constraint by mapping its contours in medical education. First, we catalog the various quarters from where constraint arises. Second, we evaluate the nature of each of these forms of constraint to understand the forces that sustain them. Third, looking at the question from an inverse perspective, we advance an argument about the scope of possibility in curricular construction. We ask the following: what is actually possible in curricular construction when one engages in a radical critique of constraint? And what are the consequences for the medical humanities when such a critique is undertaken? Furthermore, how might this critical eye be helpful moving forward as medical education seeks to shed itself of traditional curricular pathways and train medical professionals that possess the robust skill sets and competencies that an evolving, 21st century, health care landscape requires?

In the Mind's Eye: Human Vision and Artist Chuck Close

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Western Michigan University

Abstract: The life and work of artist Chuck Close provides much to fascinate anyone interested in ways that art and medicine intersect. In particular, Chuck Close's artwork sheds light on how we perceive sight itself. In his career as a painter we can view how he responded to disabilities he suffered with from childhood, including prosopagnosia and dyslexia. When Close was 48 years old and already a famous artist, he suffered the collapse of a spinal artery in his neck and became a quadriplegic. This disability precipitated changes in how he worked from that time forward.

Close's work prompts questions about the nature of human vision, and conversation about the prospect of artificial vision and facial recognition systems. From his beginnings as a super-realist painter, Chuck Close used photography as a tool. Gradually however, he began making photographs for their own sake. "I think of the camera as a way of seeing," Close said in an interview. It is a better way of seeing than using my naked eye. My naked eye is more subjective and fallible. I don't believe what I see because it is an illusion. . . I use the mediation of the camera to capture the basis of an image."

In this presentation I'll discuss and illustrate the methodologies Chuck Close developed to explore the nature of human vision. Close has said he was influenced by watching his grandmother crochet. "She would make small squares or stars — individual shapes formed over and over again. But she would sew them together so that these simple integers grew into something larger and more complicated." This is not unlike how our brain pieces together the world. Our eyes are constantly moving. Our brain's complex visual system assembles images. What we see is processed imagery impacted by many factors.

We live in a time when our language has become increasingly based on images. Stories are told visually on social media. Emoticons have become part of everyday lexicons. We are overwhelmed with images. In his work we can discern the roles that past and present technologies play in the creation of images. Close created pixelated paintings before 'pixel' was a word. "I'm pre-pixel," says Close. "They got it from me."

I'll also address recent allegations that Close harassed women he asked to pose nude for him.

**‘we are war and peace in a single bed’ – An Exploration of Identities Related to AIDS
and Sexuality in *Borrowed Time* (1988) and *Love Alone* (1989) by Paul Monette**

Christine Stadler

Faculty of Humanities

Chemnitz University of Technology

Abstract: After the Stonewall Riots (1969), gay men increasingly rejected the formerly used designation “homosexual” so as to claim a distinct identity. No longer content with restraining themselves to furtive sexual encounters with male prostitutes, or internalizing pathologizing views of their desires, gay men were increasingly keen to adopt a sense of pride and separateness from their straight counterparts. This budding identity formation was accompanied by distinct sexual behaviors and infrastructures. Rejecting monogamy for a multitude of sexual partners was constructed as a gay lifestyle to aspire to, as was frequenting bathhouses. However, societal stigmatization and even demonization of gay men continued. In Dade County (Miami) an ordinance that forbade discrimination on the grounds of sexual orientation was repealed via public vote, following a campaign which stressed the sinfulness of “homosexuality” and claimed that an acceptance of gay men as teachers would lead to them “recruiting” children. Therefore, gay men needed to negotiate their own views of themselves with these external views of them. No matter how they reacted to these external views, their identity formation generally was accompanied by a sense of shame.

As gay men had created a community, or gay communities, and had found sources of pride, first reports of gay men dying of a previously unknown cause soon became a veritable epidemic. The new disease was AIDS and AIDS added another range of potential identities. At the very least they had to position themselves vis-à-vis the threat and determine, how they would continue to live their sexuality in a climate of fear and demonization. However, many of them were persons with AIDS, or spouses or caregivers of a sick person. This also constituted a further requirement regarding identity formation. Studying how they took their “sick role” (Parsons), how they reacted to crossing over into the kingdom of the sick (Sontag), or how they lived with a loved one who was sick is relevant to illuminating both how individuals deal with the precariousness of life and how this occurs against the backdrop of sexual stigmatization. The shaming of gay men for this disease and the disregard for their suffering was reflected by its initial labeling as Gay-Related Immune Deficiency (GRID).

These cultural and societal phenomena are incorporated into autobiographical texts by Paul Monette. In his memoir *Borrowed Time* and the elegies for his deceased lover Roger, *Love Alone*, he expresses a range of identities that are relevant to his being a gay man with AIDS, and also as first caregiver, then widower of a spouse with AIDS. I want to explore how the identities he claims intersect with discourses on AIDS and sexuality, how he positions himself against these identities, and additionally how he portrays himself as an individual. My intention is to show the autobiographical subject negotiating a plethora of identities. What happens when a subject finds himself in a precarious situation that requires a response to uphold his integrity?

Visualizing Chronic Illness in Medicine and the Arts

Devan Stahl, PhD, Center for Ethics and Humanities in the Life Sciences, College of Human Medicine,
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Darian Goldin Stahl, MFA, Centre for Interdisciplinary Studies in Society and Culture, Vanier Scholar,
Concordia University

Abstract: The history of medicine can be understood by its images: from the drawn, engraved, or etched representations of the body created and bound into tomes by collaborating physicians and printmakers, to the extraordinary scans produced from penetrating waves of magnetic resonance. These bodily visualizations teach us not only about disease, but how cultures through time have answered the question, “Who is the ideal patient?” Viewing the ossified scans produced by the MRI machine, the ideal patient is one who is still, willing, and transparent. The ubiquitous images of contemporary biomedical scanning technologies, in their quest for objectivity, have transformed the visual culture of medicine in ways that ultimately deny the messiness, ambiguities, identity, and even the flesh of the patient. In their co-keynote address, Dr. Devan Stahl and printmaker Darian Goldin Stahl present their collaborative and interdisciplinary project based on their recently published book, *Imaging and Imagining Illness*. The presenters aim to expand the culture of medicine to include subjective and identity-affirming narratives, philosophy, and artworks. Integrating MRI scans and printmaking, the Stahl sisters release a voice from within the scanner and redress the patient’s flesh.

The presenters will explore how interdisciplinary work in the humanities can shed light on the meaning of illness. Dr. Devan Stahl will narrate her experience of being diagnosed with MS through the use of MRIs and how those images came to shape her understanding of illness. From her perspective as a medical ethicist, chaplain, and patient, these medical imagines cannot capture the lived experience of illness within individual bodies or within the cultural context. Dr. Stahl will place that pathography into typologies commonly used in literature and medical humanities to reveal the types of illness narratives that are frequently underrepresented. The second presenter, Darian Goldin Stahl, MFA, will describe how she uses those same MRIs and other medical ephemera from the scanning process to create prints, installations, and Artists’ books that are more reflective of living with chronic illness on a daily basis. By merging her own body with that of the ill patient, the presenters explore how they reconstructs ill-identity in mutuality. Together the Stahls explore what is significant about this patient-printmaker collaboration, including how it challenges power-ontology of biomedicine and what possibilities emerge as a result of allowing for a multidisciplinary perspective on illness.

What Makes a Monster?

Nina Stoyan-Rosenzweig, PhD
Libraries and Medical Humanities
University of Florida College of Medicine

Abstract: This workshop explores questions about monsters—why we care about them in the first place, and what our monsters tell us about ourselves, our fears, and our ethical dilemmas. Certainly, our monsters can vary widely, including such various individuals as Godzilla, a serial killer, a child born with a deformity. Although they seem widely disparate, these individuals do have one thing in common: at one time they were labeled “monsters.” And perhaps they thus illustrate how society’s monsters may change over time, in response to new or old fears. Sometimes, however, there is a degree of continuity in our fascination with a particular monster, and in this case, giving rise to a monster industry that continues to grow even 200 years after the monster appeared on the world stage. In 1818, Frankenstein entered our consciousness and remains there as the quintessential monster- whether one considers that monster to be the made creature or the doctor. The questions Frankenstein raises—about the ethics of creating monsters, and indeed, what behavior is monstrous, keep the book alive and the material relevant. We have asked the same questions more recently when in the film *The Shape of Water* viewers wondered whether the creature or the promoter was the monster. Thus we often wonder whether a true monster is the fantastic and grotesque creature of the imagination—or for children the bogeyman in the closet—or the human being who behaves inhumanely. The latter human monster has come to societal attention, with the rise of the MeToo movement. Since that time, society has labeled such individuals monstrous, and engaged in a discussion about such behavior and what it might mean to support or follow the artistic output of an accused abuser. Americans, however, consistently respond to stress and anxiety by scapegoating and naming monsters. In this presentation, we will examine and discuss the nature of monsters. We also will discuss what a library exhibit on medical monsters, undergraduate-taught class, speaker series, art contest, museum exhibit, graphic novel contest, and conference have in common, describing a project focusing the attention of UF undergraduates- and the broader local community—on the process of creating monsters. By understanding the process, project participants will discuss how monsters shape our world, and perhaps why they fear the monster in the closet This workshop will show how the project came to life and how it will promote discussion and understanding of our fears- whether we fear ourselves or others. Participants in the workshop will discuss and describe their own vision of monsters, and also will have the opportunity to create their own monsters via a graphic medicine jam session and finally through their choice of artistic media.

**Helping Children Hurt Themselves: Why Pediatricians Ought to Support
Adolescent Football Players in Their Athletic Goals**

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Hillsborough Community College

Abstract: It's no secret that participation in sports such as football puts players at high risk of injury. Helmets cannot protect players from the possibility of traumatic brain injury, and repeated concussive injuries can lead to chronic traumatic encephalopathy later in life. In light of such facts, the morally appropriate role of physicians who treat patient athletes comes into question.

For the purpose of this presentation, I will focus on adolescent athletes in particular, considering the role of pediatricians whose patients participate in full contact sports such as football. In response to growing awareness of the severe long-term damage players have incurred, all 50 states have now passed some form of return-to-play law for minor athletes. This puts doctors in the position of gatekeepers, with the power to stand as a road block preventing injured athletes from returning to the field. While mandating a medical all-clear is a good step toward protecting athletes, there are questions as to the damage such a system can have on the physician-patient relationship. Unlike a broken nose or shattered knee cap, concussion is not always detectable by a player who chooses not to report his symptoms. Failure to report, and thus failure to obtain treatment, will result in worse health outcomes for the players, so physicians interested in maximizing health outcomes for their minor patient-athletes will find more success if they can persuade their patients to be honest with them about their injuries.

To this end, I argue that such physicians ought to be committed to a high level of shared decision making, whereby their goal, rather than being that of providing the medically best advice (which, let's be honest, would be to not play football at all), would be that of providing the medically best advice in light of the patient's honestly professed plans and goals. What this means is, a physician who knows her patient is hell-bent on playing out the season no matter what, will need to make that her goal as well – and to convince her patient that this is the case. If the patient athlete sees his doctor as an ally, who wants him on the field as much as he wants to be there, he will be more likely to trust her to help him realize his goals even if he reports an injury. This can also make the student-athlete more committed to implementing recommended precautions the physician might recommend, that could help avoid such injuries in the first place. While this approach could feel like a medical betrayal, in that the physician could feel complicit in helping a patient to continue engaging in high risk behavior, I argue that the medical outcomes will actually be better than if a patient athlete sees his physician as an obstruction to his athletic goals.

Addiction Prevention and Recovery: Ordinary Spiritual Experiences as a Stress Buffer

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Abstract: Addiction and substance abuse are currently serious problems. We should continue to try to eliminate the societal, personal, biological and interpersonal problems and stressors that exacerbate these, but this is not easy. Meanwhile, are there ways to mitigate the effects of these stressors and pressures? Ordinary daily experiences of awe, compassionate love, mercy, being blessed, being uplifted by beauty, and a sense of transcendent strength and comfort, can help promote resiliency and recovery. This has been shown in a number of studies using the Daily Spiritual Experience Scale (DSES www.dsesc.org). This scale of 16 questions works for those from most religions, as well as for those not comfortable with religion, and has been translated into 40 languages including Hindi, Mandarin Chinese, Spanish, Indonesian and Arabic, and has been used in over 300 published studies. More frequent spiritual experiences are also correlated with less addictions in adolescents and adults from many countries, cultures, and religions. There are ways to enhance the frequency of these experiences, and studies have shown that various kinds of interventions can increase scores on the DSES. This can provide an adjunct to other approaches to addiction.

These experiences have been shown in 65 studies to prevent burnout, enhance resiliency and post traumatic growth, improve relationships and pro-social behaviors, and prevent and treat addictions. Many other studies have shown positive effects on various mental health outcomes. The effects on these various outcomes add to the support for the usefulness of these experiences for addiction prevention and treatment. These effects also show how these ordinary spiritual experiences can be helpful for many kinds of difficult life experiences such as chronic disease, trauma, mental illness, and disability.

The questions are also being used in health care, hospice, and social service agencies, as a way to communicate with people of different beliefs about spiritual issues, and identify possible resources for them to draw on.

Like Life and Medical Humanities

Elisabeth L. Vines, PhD

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Abstract: *Like Life: Sculpture, Color, and the Body*, the exhibit at the Metropolitan Museum of Art in New York city from March 21- July 22, 2018, covers seven centuries of sculpture. The exhibit focuses on the challenge artists have faced in replicating the human body. Organized according to themes (presumption of white, likeness, desire for life, proxy figures, layered realities, figuring flesh, between life and art), this show illustrates the human urge to replicate the human body for purposes of worship, motives of desire, and statements of immortality. The show is arranged thematically and not chronologically, but in the various themes the concern for the mortality of the human condition resonates.

One evidence of the show's interest in technology and science is the emphasis placed on the use of new and unusual (unusual to the standardized canon) materials; artists such as Gibson applied a thin layer of tinted wax to make a sculpture's skin seem flesh-like (*Tinted Venus* of 1862). Of interest in this presentation, however, is the development of the attitude about advancements in medical science through the centuries.

Susini's *Anatomical Venus*, 1780, is an example of the awakening interest in human anatomy that took place in the eighteenth century. Termed "peepshow science" by some, these sculptures nonetheless prove that some were aware of the inner workings of the body (however lascivious some of the posed statues might seem). The *Auto Icon of Jeremy Bentham*, created by Thomas Southwood Smith in 1832 per Bentham's will, seems merely a lifelike depiction of the eponymous figure until the viewer realizes that within the somewhat stuffy-looking figure are Bentham's actual bones. Bentham, an English philosopher who was a proponent of utilitarianism, had wanted his mummified head to be displayed on the body as well but the mummification process left something to be desired and the head on display is of wax. Damien Hirst's 2005 *Virgin (Exposed)* reveals quite different understanding of art (and medicine) than that of Degas's *Little Fourteen-Year-Old Dancer* from 1881—although the pose mirrors the earlier statue, which had shocked some viewers at the time for being such a common subject created with unconventional materials – beeswax and found objects. The little dancer nevertheless reveals a commitment to the unidealized world, foreshadowing, perhaps, Hirst's anatomical *Virgin*.

This presentation will link some of the works from the Met exhibit to the growing acceptance and awareness of medical discoveries, demonstrating that depictions of the human body reflect these changes.

The Right to Medical Privacy: The Unexpected Aftermath of Toxic Shock Syndrome

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Purdue University

Abstract: In 1980, the media alerted women to a new and frightening illness associated with menstrual periods and tampon use: toxic shock syndrome (TSS). The illness raised grave concerns because it struck healthy individuals, and 75% of women used tampons. In addition, the early symptoms deceptively resembled the flu, which quickly deteriorated into septic shock and death. The Centers for Disease Control (CDC) conducted epidemiological studies and worked in conjunction with state and local public health agencies to track outbreaks and identify co-factors of the illness. While the studies determined that all super-absorbent tampons carried risk, the Rely tampon manufactured by Procter & Gamble demonstrated the highest rate of all. The company bore the brunt of the bad publicity and voluntarily withdrew Rely tampons from stores, sparing itself from an official Food & Drug Administration (FDA) recall due to the tampon's deadly association with TSS.

While Procter & Gamble publicly received accolades for taking responsibility for its product and alerting women to the dangers of Rely, behind-the-scenes it fought for access to data. This presentation examines the aftermath of the recall, and the ways in which Procter & Gamble pressured, challenged, and sued the CDC for the right to identify informants and access their medical records. It utilizes archival documents and oral histories to trace arguments amongst FDA, CDC, and corporate lawyers concerning the nature of a patient's right to privacy, and why this matters to contemporary medical standards and treatment.

Procter & Gamble exerted strong commercial interests in seeking to retrieve the data that the CDC collected because it led to the demise of its newly developed Rely tampons. As such, it requested all the names and addresses of informants—many of whom contracted TSS—from the formal epidemiological studies conducted by the CDC. Having put full faith in its corporate scientists, Procter & Gamble sought to home in on the presumed errors upon which the policy decision was based. According to Gene Matthews, the chief legal advisor to the CDC from 1979- 2004, the agency tried to work with Procter & Gamble by redacting names and then sharing data, and even sending a letter out to the informants, asking if they would be willing to talk with Procter & Gamble. These efforts were inadequate for the company, and Procter & Gamble proceeded to subpoena records, which the CDC contested. At stake was the very system of trust which patients and informants voluntarily gave, and the CDC depended upon, for quality data.

As the AIDS crisis loomed on the horizon, the policy efforts to affirm and legally guarantee patients' rights to privacy have served as an important pillar of ethics in a system constantly challenged by commercial and outside interests that do not necessarily hold individuals' rights as a core value. This historical research exemplifies the dynamic relationship between medicine, society, and law, and the importance of looking at women's health, including menstrual hygiene management, as significant areas of research to yield deeper understandings of medical humanities.

**“I Don’t Even Know Who I am Anymore”:
Radically Reimagining the “Humanities” Through Health Humanities**

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Abstract: The health humanities are in a period of intense self-reflection as participants from a wide variety of professions and disciplines seek to re/define the fields’ parameters, purposes, and methodologies. Many of these conversations explore how the health humanities can be critically employed to reimagine medical training, the practice of medicine, and broader conceptions of “health.”

Seldom, however, is this reflective, critical gaze similarly turned on humanities disciplines and practices themselves. Indeed, in many conversations about humanities’ participation in the health humanities, humanities disciplines and their ways of knowing are implicitly taken as givens. We see this in discussions about the proper relationship of the humanities to medicine, real world applications of the humanities, the expansion of the content and reach of humanities disciplines, saving the humanities, and most models of interdisciplinary collaboration. Too rarely, however, are the parameters, purposes, and methodologies of the humanities opened up for truly radical interrogation. Almost never are paradigms and concepts from medicine and health studies used as tools in such interrogations.

This lack seems both a fascinating epistemological blind spot and an important missed opportunity. Many of the theories and methodologies identified with the medical and health humanities are based on a belief in the mutual transformation of entities brought into contact—whether those entities are human beings, ideas, art forms, disciplines, professions, or cultures. It seems, then, a significant omission that the humanities would so often be treated as stable entities in this moment of interdisciplinary investigation. This presentation considers possible sources of this blind spot and invites participants to consider the ways in which the humanities are being and could be radically transformed by their participation in the medical and health humanities.

Understanding Death from an Interdisciplinary Perspective

Leslie Whetstone, PhD, Division of Humanities (Philosophy), Walsh University

Katherine Brown, PhD, Division of Fine and Performing Arts (Museum Studies and Art History), Walsh University

Rachel Constance, PhD, Division of Humanities (History), Walsh University

Bradley Beach, PhD, Division of Humanities (Philosophy), Walsh University

Abstract: Most of us regard death as something so obvious and self-evident that it must be impervious to debate. The old trope that “you’re dead when your doctor says so” has a comforting appeal because it forecloses the possibility that there can be any ambiguity in the matter. The boundaries between dying and being dead are hazy, however, and require an analysis of what it means to be a person within society and within of a particular culture. The criteria used to determine that death has occurred are surely clinical in nature, though the concept of when we are dead and why, requires an evaluation that can be conducted through the scope of medical humanities.

This panel will investigate the concept of death through the disciplines of history, art, and philosophy. We will begin with a treatment of how epidemics had a profound impact upon communities and how contagious disease transmitted pathogens along with blame, stigma and social instability. Epidemics also had the effect of causing mass casualties, which increased the risk of premature burial. The terror of hasty interment permeated art and literature and catalyzed public distrust of the medical community, leading to novel—if not in some cases gruesome— methods to avoid such a fate.

Epidemics, in particular the bubonic plague, led to vivid iconography. Such death imagery influenced morality, politics, and culture in early modern Europe, as artifacts depicting the macabre were visceral and often traumatic and reflected the somber reality of a world in crisis.

Finally, our panel will consider how technological advancements in the latter part of the 20th century, including the advent of life support systems, cardio pulmonary resuscitation, and Intensive Care Units, have challenged our epistemic certainty of death. Now that vital signs can now be maintained almost indefinitely, even as the brain liquefies, we are left to ask when is a person dead, and why?

Reporting Potential Errors: How Honest Should a Medical Professional Be?

Andy Wible, PhD

Department of Arts and Humanities

Muskegon Community College

Abstract: Hospital medical errors are the third leading cause of death in the United States. This presentation will examine how honest and informative medical professionals should be about the potential for those errors. How much information should be given to patients to ensure full informed consent?

The presentation will start by looking at common errors clinical and research settings. Second, a conceptual analysis of medical errors will take place. Some questions that will be examined are: Are all bad outcomes errors? Are all errors unexpected? How substantial must a mistake be to be considered an error?

Third, the heart of the presentation will look into how much information is sufficient for informed consent. Should an informed consent document simply give a list of possible bad outcomes or should more precise percentages be given? Should surgeons give statistical data only? Should they provide data on personal outcomes as well? Should the information on potential for error be relativized to the patient's condition? Should medical professionals help patients understand the probabilities? Given the physician has an obligation act in the best interests of the patient, if another physician or hospital has lower rates of medical error, should that information be given to the patient? Do patients have an obligation to do their own research?

The presentation will conclude with some general moral guidelines for medical professional to follow that allows for honesty, transparency, and sufficient informed consent.

The Ethics of Nudging: A Case Study

Sarah Wieten, PhD

Center for Biomedical Ethics

Stanford University School of Medicine

Abstract: In 1999, Nadine Montgomery, a diabetic short-statured Scottish woman, was pregnant. While these characteristics make her at high risk for shoulder dystocia, her obstetrician Dr. McLellan did not raise this risk with Mrs. Montgomery, advocating for vaginal delivery. Dr. McLellan explained her decision to not raise these issues with her patient, saying, “if you were to mention shoulder dystocia to every [diabetic] patient, if you were to mention to any mother who faces labour that there is a very small risk of the baby dying in labour, then everyone would ask for a caesarean section, and it’s not in the maternal interests for women to have caesarean sections.”

Mrs. Montgomery’s child suffered shoulder dystocia during vaginal birth, and as a result, her child suffers from cerebral palsy, a condition which could have been avoided through caesarian section. In 2013, the Supreme Court of the United Kingdom ruled that Dr. McLellan should have informed Mrs. Montgomery of these risks.

In this presentation, I argue that the Montgomery ruling has implications for the bioethical principle of nudging—that is, this ruling disallows a particular kind of nudging. First, I discuss the facts of the case and the content of the ruling, as well as comparisons of this ruling with others including Bolam and Sidaway. I then provide an account of what I call, “nudging through ignorance,” which I claim is the kind of behavior which was condemned by the Montgomery ruling. Finally, I attempt to show the difference between nudging via ignorance and straight paternalism, a distinction which needs to be made in order to show that the Montgomery ruling involves a new prohibition, rather than simply a reinforcement of previously discussed prohibitions. While it is focused on a ruling in British law, this work advances the field of practical and professional ethics by providing a case study which reveals more about the structure of nudging (an important bioethical concept globally), and the ethical and legal limits of nudging.

Bodily Rights and the Problem of Organ Conscription

Alexander Zambrano, PhD

Department of Philosophy and Religion

Coe College

Abstract: The institution of postmortem organ transplantation continues to face the problem of organ scarcity: every year, the demand for donor organs consistently exceeds supply, resulting in the tragic deaths of thousands of patients on transplantation waiting lists. What should be done about this perennial tragedy? This presentation considers the ethical merits of an Organ Conscription policy, an often discussed but almost universally rejected solution to the scarcity problem. Organ Conscription is a procurement policy according to which the State takes usable organs automatically from the bodies of the dead, regardless of whether the person consented to donation, had a clear and strong preference against donation, or was at all inclined to have her organs removed for transplantation. While an Organ Conscription policy is widely thought to be ethically untenable, there is a powerful and as-of-yet unrefuted argument in its favor. This argument—which I call the Greater Needs Argument—claims that patients who need organ transplants have a great interest in continuing to live and improving the quality of their lives. Furthermore, whatever interests people may have in what happens to their organs after they die is plausibly outweighed by the interests of patients who require new organs to continue living. Since we ought to act in a way that fulfills the more important interests, it follows that we should remove a person's organs after their deaths.

One reason that the Greater Needs Argument appears so persuasive is that it is standardly thought that the dead do not have interests that can be thwarted. And if that's the case, then there doesn't seem to be any strong moral reason to act in accordance with what the deceased wanted when we could save the lives of living people in need. However, recently some philosophers and bioethicists have argued quite convincingly that the interests of living persons can be thwarted after they die. And if these interests are sufficiently important so as to protect them with a right, then it may turn out to be impermissible to conscript organs since doing so violates people's rights regarding what can be done to their bodies. Call this the Rights-Based Argument against organ conscription.

While I think that there is something right about the Rights-Based Argument, I argue that it fails, on its own, to refute the Greater Needs Argument. For even if it's true that a person's bodily right would be posthumously violated by a Conscription Policy, it does not follow that this right outweighs the interests of needy patients who require new organs. Indeed, it might turn out to be all-things-considered permissible to violate the person's right in order to aid living patients in need.

To remedy this shortcoming of the Rights-Based Argument, I present and analyze an argument for the conclusion that the interests that would be thwarted by a Conscription Policy are of sufficient importance to be protected by a right *and* that this right outweighs the interests of living patients in need of organs. Roughly, the argument begins by considering our judgments about cases of *serious unfelt harm*, i.e. cases in which a person's important interests are thwarted, but unbeknownst to them. I argue that the interests thwarted in cases of serious unfelt bodily harm are significant enough to generate a right against such harm, and one that outweighs the relevant interests of living people. I use these cases to draw an analogy to organ conscription, by suggesting that posthumously conscripting organs from people who have refused organ removal constitutes a case of serious unfelt bodily harm, and should thereby be protected by a right that outweighs the relevant interests of living patients.

Incurables: What *The Faerie Queene* has to offer Sexaholics Anonymous

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Abstract: This presentation introduces medical humanists to the challenging and rewarding early modern English epic poem *The Faerie Queene* (1590), by Edmund Spenser, and uses it to illustrate and discuss more modern critiques of medicinal cures for addictions, especially lust or sexaholism. It focuses on a side-by-side close-reading of the Sexaholics Anonymous (SA) manual or “White Book” and Spenser’s “Legend of Chastity.” The arch of Spenser’s narrative anticipates SA’s idea that one does not fight sex-and-love-addictions with over-the-counter drugs, one-time treatments, or fix-it operations but by acknowledging incurability as a reality and by pursuing sobriety nonetheless, cyclically and endlessly. Lust – both Spenser and the White Book warn us – is a moral, spiritual, and paradoxical phenomenon, one predicated on a desire for instant gratification and for which one is most prone to seek (and least prone to find) instant solutions. But Spenser goes one step further, perhaps, than SA by juxtaposing his most lustful characters with the most therapeutically ambitious, revealing an uncanny kinship between the relentless healer and the relentless addict.