



## Online Abstract Book



TIMPE [KEYNOTE]

**Systems That Harm: The Ethics of Scaffolding for Support**

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Humans are fundamentally interdependent and social beings; we depend not only on other individuals in our communities, but also on the social systems that structure them. Drawing on work in disability studies, I first show a number of ways social systems can harm through unjust treatment. Especially worrisome are those systems where their failures cannot be accounted for by unjust actions of individuals within those systems. I then argue that we have a social obligation to collectively build systems that will provide minimal conditions of justice for everyone in our communities.

AICH

**Beyond the Pledge: Navigating the Narratives of Societal Barriers to Deceased Organ  
Donation in India**

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Organ failure is rising globally due to increasing non-communicable diseases, aging populations, and related risk factors. In India, this trend has intensified the burden on healthcare systems. While organ transplantation offers a vital solution, a significant gap persists between organ demand and availability. Despite awareness efforts encouraging pledging, actual donations after brain death remain limited. This study explores the gap between intention and deceased organ donation in Eastern India, using interrelated objectives and the socio-ecological model as a guiding framework. The empirical component of the study explores how individual, interpersonal, institutional, and societal factors shape decisions around organ donation. To better understand these influences in a culturally and socially embedded context, the study uses qualitative methods.

Data were collected through in-depth interviews and FGDs with donor families and healthcare professionals from the National Organ and Tissue Transplant Organization of India (NOTTO) approved hospitals. These qualitative methods offered rich insights into the interaction between personal experiences and systemic structures. Additionally, a detailed literature review situated the primary findings within broader national and international contexts of organ donation and transplantation. The findings of this study indicate that decisions surrounding deceased organ donation are embedded within a broader socio-cultural and relational context. Social norms, familial dynamics, and belief systems significantly shape these decisions, often overriding the explicit intent of the deceased, even when a formal pledge to donate exists. In India's opt-in legal framework, where family consent remains legally and ethically necessary, this socio-cultural entanglement contributes to the persistent gap between willingness and actual donation.

This complexity underscores the need for policies that reflect pluralism and cultural specificity rather than relying on universalized public health messaging or infrastructural solutions alone. This study highlights that, Organ donation as a public health issue, requires sensitivity to the moral, emotional, and spiritual dimensions that communities associate with death and the human body. The 'Narrative' plays an important transformative tool. Sharing lived experiences of organ donors and recipients, discussions on death and the human body in school curricula through storytelling, media, and public campaigns can humanize the process and generate empathy. Religious belief and cultural meanings surrounding the body and death emerge as influencing factors of decision making in this study. Such affective narratives enable a re-framing of organ donation from a clinical procedure to a shared social and ethical act. This shift can contribute to destigmatizing the act of donation and re-situating it within the moral fabric of everyday life. It argues that policies and interventions can move beyond a singular biomedical focus and instead reflect the complex, lived realities of individuals and families making these profound decisions. And in foregrounding these dimensions, the study contributes to the growing body of work in medical humanities that seeks to bridge the clinical and the cultural, the systemic and the personal. To acknowledge the pluralities of belief and experience that exist within the social structures in India.

ANAPARTHY

## **The Effect Creative Writing Knowledge Has On Improved Medical Practice and The Future of Surgery**

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The STEM and humanities fields are two separately designed specializations that target their own niche audiences and typically face minimal overlap. However, having a background in both of these studies will allow for a deeper understanding of necessary skills such as problem-solving, critical thinking, and tough decision-making. By utilizing both sides of the brain, the left for logical reasoning and the right for creative thinking, one has the ability to become proficient in their field in non-traditional ways. Particularly in the medical field, education in narrative medicine allows for improved stress management and decreased physician burnout by using writing as a coping mechanism. Maintaining a creative outlet amidst encountering difficult and stressful situations, such as a rotation in the ER or attempting to solve a difficult diagnosis, allows physicians to continue work in this taxing profession while preventing exhaustion and disinterest in their jobs. Additionally, gaining an understanding of creative writing leads to improved doctor-patient relationships and patient care, especially due to the problem-solving and deductive thinking that authors need in order to complete their story's plot line and character development. This study employs a narrative analysis methodology to examine written reflections, personal essays, and published narratives by physicians with creative writing backgrounds. This data was analyzed to recognize patterns within the responses on how creative writing knowledge and integration to the medical field shapes empathetic interactions with patients, listening-oriented communication, and adequate decision-making abilities. Analyzing reoccurring themes in these narrative pieces allows a quantitative ability to analyze data and provide the frequency of certain trends as justification while a qualitative approach also allows a deeper social and experiential approach to recognizing these trends. The implicit thinking required to produce a character's internal feelings is similar to the thought process required to empathize with a patient during their most difficult time and derive aspects of the patient's history that they may not be eager to disclose. All in all, creative writing is important in the psychological aspect of medicine but can also be used in the tactile aspects of it, such as improved surgical techniques.



BAKER

**Nature as Necessity: A Medical Humanities Approach to Disability-Inclusive Play**

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Barriers to connecting children with safe and engaging play in nature are a growing concern among pediatricians, parents, caregivers, and educators. These spaces represent more than physical barriers, reflecting the broader systemic exclusion of disabled children in society, particularly from environments that directly contribute to well-being, agency, and connection. Informed by the intersections of disability studies, public health, and medical humanities, this presentation aims to explore these barriers while promoting access to nature for children of all abilities, as a matter of narrative justice, as supported by the American Academy of Pediatrics.

The existing literature has established the benefits of play in nature, noting the stimulation of cognition, enhancement of emotional regulation, and promotion of feelings of belonging; however, these benefits are not equitable among all children. Children of differing abilities, particularly those with mobility limitations, sensory processing differences, or complex medical needs, frequently face obstacles to equitably experiencing nature due to barriers like inaccessible trails, socially or sensory challenging designs of nature play, safety concerns with a lack of paraprofessionals, and scarcity of inclusive programming.

Exploring the documented literature and conveying lived experience from the community, this presentation seeks to reframe access to nature beyond a recreational issue. We propose that this is both a public health and a narrative concern with implications on whose stories get to be told in natural spaces and who may be deemed as not belonging in these spaces. We will share findings from a local needs assessment in Austin, Texas, conducted in collaboration with families, caregivers, and disability advocates. This work uplifts and partners with the voices of those most affected and highlights the need for inclusive, community-centered solutions that affirm the right of all children to live, learn, and play in nature.

We examine how ableism is embedded in the design and stewardship of outdoor environments. In response, we offer a set of community-sourced strategies and resources: sensory and mobility-adapted nature spaces, promotion of safety in case of medical emergency, and local partnerships that embed disability inclusion into public health and planning.

Framing our discussion through the lens of the medical humanities, we argue that inclusive nature play demands a shift in narrative: from viewing nature as an optional luxury to recognizing it as a space of healing, identity formation, and cultivation of a necessary human experience as a fundamental right of all children.

This interactive session will invite attendees to reflect on the following question: How do we reimagine public nature spaces through the lived realities of children with differing abilities? Participants will leave with concrete tools, community-driven frameworks, and inspiration to advocate for environmental justice that is considerate and accommodating of the unique and diverse ways in which some children may engage with play in nature.

In aligning the pursuit of accessible nature with the core tenets of medical humanities: narrative inclusion, structural awareness, and embodied ethics, we call for a commitment to ensuring that all children, regardless of ability, have the opportunity to connect meaningfully with nature.

BEATTY

## **Translating Interoception: Towards Desirable Futures in Autism Care**

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Autism spectrum disorder (ASD) or “autism” is a neurodevelopmental disability characterized by social interaction and communication impairments, restricted and repetitive patterns of behavior or interests, altered sensory processing, and a multitude of commonly co-occurring psychological, developmental and medical conditions. Approximately 5.5M adults and about 1 in 36 children in the United States have been diagnosed with ASD. Unfortunately, there is a dearth of available treatments, as existing therapeutic interventions, which include applied behavioral analysis (ABA), speech, occupational, and pharmacological therapies, have a contentious history and are often described by autistic adults with lived childhood experience as traumatic and dehumanizing. Desperate and therefore vulnerable parents are subject to aggressive marketing for alternative therapies and direct-to-consumer (DTC) technologies, such as biofeedback and noninvasive neurostimulation, which lack proven efficacy, are unregulated by the FDA, and inflict false hope and financial harms. Current bottom-up research priorities gathered from the autism community include investigating pseudoscientific treatments, improving understanding of sensory systems, developing and tailoring interventions that address mental health, and clarifying public understanding of autism in order to reduce stigma and increase social and self-acceptance. Clearly, a better understanding of pathology, co-occurring conditions, and, most importantly, a sensitivity to the needs of the autistic community is needed to develop new and improved interventions.

An emerging area of neuroscience research in ASD involves interoception; referred to as the “6th sense”, interoception is the internal sensory system of the body and plays an integral role in emotion, motivation and self-regulation. A characteristic of ASD is altered interoceptive function, making it a potential therapeutic target. While scientists are developing a mechanistic understanding of interoception’s role in pathology, engineers, designers and inventors are starting to implement findings into novel neurotechnologies and reimagined systems of existing technologies and interventions. These emerging translational outcomes of interoception research hold great promise, but have not been studied fully, especially related to potential harmful outcomes when applied to autistic individuals – a population plagued by historic harms.

Following a prospective neuroethics framework, this work explores how various ethical, regulatory, and social models intersect with interoception research and innovation. Particular focus is placed on DTC neurotechnology oversight, social versus medical models of disability, critical disability and the neurodiversity movement. Early ethics-by-design guidelines are proposed as an open, in-process suggestion in order to stimulate multidisciplinary, multisector exchange and to scaffold recommendations amenable to a broad scope of research and practice. Ongoing interdisciplinary development and public outreach can address possible consequences before they become problematic and encourage early course corrections in order to 1) avoid harms; 2) promote appropriate regulation; 3) ensure that innovations will be relevant, usable and value-aligned with the autism community; and 4) increase the likelihood translational efforts can be successfully implemented.

BECKMAN

## **Epistemic Skepticism and the Patient Responsibility Problem**

Elizabeth Beckman

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Can we consider patients responsible for “voluntary, health-risky conduct” (Brudney, 2007, p. 41)? And if we do, how should that responsibility factor into decisions about their care, through triage, transplant list priority, and so on? One familiar response is that patients who have freely chosen to engage in risky behavior such as excessive drinking should be lower on a transplant list, for example. The general idea being that we should take into account a patient’s past choices and behavior in deciding their moral claim to care.

This sort of response has been resisted on the grounds that social determinants of health sufficiently limit an agent’s freedom in what might, from the outside, look like good old-fashioned voluntary conduct (Brown, 2013). Neil Levy (2019) specifically emphasizes that such social determinants directly limit an agent’s reasons-responsiveness, which we might think importantly determines responsibility. In order to properly assess responsibility for one’s condition, and corresponding claim to care, we would have to conduct extensive neuropsychological testing and history-taking. Citing concerns about cost and efficiency, Levy suggests that policy is left agnostic about whether patients are responsible for their condition – in the end the people who actually meet our threshold for responsibility will be quite small, he argues.

In this paper, I argue for a similar conclusion, but I will go a step further. No type or amount of current neuropsychological testing or patient history-taking could possibly fill in the gaps of what we know about patient responsibility, or responsibility more generally.

I approach this familiar question from what I call an epistemically skeptic position. In particular, I argue the following: we are not in a position to know whether conditions of moral responsibility, on compatibilist approaches such as reasons-responsiveness accounts, are ever met. This holds true in the case of transplant and generally in the allocation of scarce resources. The epistemic demands of these theories are too high for us to meet, particularly given the stakes. We cannot meet an appropriate level of confidence on attributions of responsibility and should therefore withhold judgments of responsibility, and its corresponding effects on policy.



BLOOMER

**Picturing Care: Medical Photography, Embodied Knowledge, and the Social Life of Diagnosis  
(1840-1910)**

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This paper examines how nineteenth-century medical photographs helped construct what counted as legitimate medical knowledge and who counted as a medical subject. Drawing on daguerreotypes, stereoscopic images, lantern slides, and early X-rays from the Stanley B. Burns, M.D., Historic Medical Photography Collection at Yale's Medical Historical Library (1840-1910), the author traces the emergence of a new "medical gaze" forged at the intersection of technology, clinical ritual, and cultural expectations about the body.

Guided by Gilbert Simondon's notion of individuation and Martin Heidegger's concept of Gestell (technological enframing), I read these photographs as ontological objects that actively configure what illness, normalcy, and care could mean within their social contexts. The painstaking studio-like setups, patients posed, physicians gesturing, plates sensitized, reveal a choreography of authority and vulnerability that shaped both diagnostic practice and patient identity. Walter Benjamin's idea of "aura" clarifies how the tactile surfaces of early photographs generated a ritual intimacy between observer and image, reinforcing medical authority even as they circulated in teaching collections, public exhibitions, and popular journals.

The paper reframes medical photography as a mediating practice that linked hospital wards, lecture halls, and broader public debates about hygiene, disability, and social reform. It shows, for instance, how stereoscopic views of orthopedic cases doubled as advertisements for new surgical techniques, or how lantern-slide lectures transformed private suffering into civic lessons on public health.

Positioned within the conference's concern for the social, historical, and cultural dimensions of medicine, this work contributes to:

- History of Medicine: revealing how photographic technologies reconfigured diagnostic authority in the late nineteenth century.
- Medicine and Art/Literature: demonstrating photography's role as both clinical tool and cultural text.
- Bioethics and Medical Anthropology: exposing early visual negotiations of consent, stigma, and bodily display.

Ultimately, the talk argues that today's debates over medical images and patient agency have deep roots in these early photographic encounters, reminding us that every diagnostic picture carries a social life beyond the clinic.

BRAUSCH [PANEL]

**Narrating Illness, Reimagining Identity: Disability and Vulnerability Across Genre**

Cassandra Brausch

Emily Alexander

Muiz Adewola

Cynthia Klestinec, PhD

Miami University, Department of English

Narratives of illness and disability are central to how we understand identity, embodiment, and care—especially when told from perspectives that challenge dominant cultural expectations of health and normalcy. Building on the work of scholars such as Arthur Frank, and Kathryn Allan, this panel brings together three presentations that examine how disability and illness are represented across distinct genres: speculative fiction, graphic memoir, and Black autopathographical writing, respectively. Each paper explores how genre shapes the stories we tell about the body, and how those stories resist reductive narratives of cure, decline, or endurance. Whether through imagined futures where disability is refigured as a source of connection, visual memoirs that depict memory loss, or life writing that reframes Black masculinity through vulnerability, these presentations explore how illness and disability are not just medical experiences but also narrative acts that engage with race, kinship, identity, and genre.

Our first paper examines how speculative fiction reimagines disability and chronic illness not as conditions to be cured, but as meaningful modes of being that shape alternative futures and social configurations. It considers how speculative genres offer space to imagine non-normative embodiments as generative rather than tragic, challenging dominant cultural narratives of medical normalization.

Our second paper explores how graphic memoirs about dementia narrate and preserve memory. This paper asks why graphic storytelling has become a dominant genre for rendering stories of memory loss, and how the visual form contributes to both the representation and transmission of identity in the face of cognitive decline.

Our third and final paper investigates how Black male life writing performs vulnerability in the context of chronic illness or disability, especially through the conventions of autopathography. By analyzing autobiographical narratives that foreground both physical and emotional vulnerability, this paper explores how Black masculinity is redefined through the lens of illness, moving beyond traditionally reductive representations of Black male suffering.

Together, these papers consider the intersection of illness and identity through the lenses of genre, embodiment, race, and relationality. While each takes a distinct approach, the panel as a whole asks: How do different narrative forms reshape cultural expectations of the ill or disabled body? What new possibilities for care, kinship, and identity emerge when illness is not only experienced, but narrated? And how do these stories help us rethink the boundaries between health and illness, vulnerability and agency, memory and identity? Each presentation will be approximately twelve to fifteen minutes in length, allowing time for questions and discussion.

BYSTRA

**Schimberg's "A Different Man": Interrogating Notions of Cure, Medical Science and Technologies, and Bodily Variance**

Tiffany Bystra

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In Schimberg's 2024 film, "A Different Man", a fictional story is told of Edward, an aspiring actor with neurofibromatosis. Edward's condition has manifested through multiple facial tumors and asymmetries that partially occludes his vision and necessitates compensatory techniques for tasks like eating. Edward's bodily variance has left him subject to public taunting which creates the backdrop for further discussion when he's offered participation in a clinical trial with the potential to "heal" his condition. Edward consents to participation in the trial, to which the film stokes insight into Edward's concerns, questions, and lived experience through the course of his trial engagement and clinical encounters. Schimberg's film brings into conversation significant themes relevant to the medical humanities and disability justice arenas including public and systemic interfacing with bodily variances, inquiry into the telos of medical science and technologies, and broader understandings of cure and healing. This presentation would service to illuminate disability and medical humanities themes inherent to the film, including its portrayal of the clinical and research encounter, using methodologies of deep textual reading, reflection, and thematic synthesis positioned alongside other works including Bharat Venkat's "At the Limits of Cure". Questions of disability visibility, narratives of healing that idealize the normate phenotype, and the role of social influences on meaning-making will be raised.

CARTER

**“I Just Knew She Wasn’t Dead”: Jahi McMath’s Queer Silence**

Reece Carter

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University of North Carolina School of Medicine, Center for Bioethics

Physicians have long misunderstood disability as a fate worse than death. In 1968, this belief led a group of Harvard physicians to declare that patients who were dependent on mechanical ventilators to live were not alive at all but were “brain dead.” Since their groundbreaking paper defining “brain death syndrome,” the diagnosis has evolved but remains fraught as these patients often have independently beating hearts, warm skin, and do not meet the typical cardiopulmonary criteria of death. Brain death represents an overreach of biomedical epistemologies of the body that has led to legal conflicts between physicians and patient families. One such case is that of Jahi McMath who was declared brain dead in 2013 but was not believed by her family to be dead until 2018. In the intervening years, Jahi was cared for by her mother in a quiet, sparsely furnished New Jersey apartment. Jahi’s mother understood something that the physicians did not—that disability is not a death sentence. While Jahi remained silent in those final five years of her life, I argue that this was a “queer silence” that her mother, situated outside of biomedical rhetorics and epistemologies, was able to hear. J. Logan Smilges argues that silence is not a marker of rhetorical absence and incapacity; rather, it is the space from which all rhetoric emerges. This amounts to a queering of rhetoric’s emphasis on the verbal and allows us to consider how Jahi might be rhetorical and agentic in ways for which Western biomedical epistemologies cannot account. For Jahi, queer silence was a way of continuing to live in her disabled body against the ableist forces of medicine that sought to declare her dead. In this talk, I will briefly outline the tendentious origins of brain death before discussing the ways in which Jahi McMath’s silence was queer and how this queer silence provides a crip alternative to biomedical understandings of death and disability.

CAUGHEY

**Revisiting “Operation Tat-Type”: How a Cold War Blood-Typing Program Informs Health Debate Today**

Grainne Caughey

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Vaccines, raw milk, fluoride. In recent years, national media has been flooded with debate on wellness, bodily autonomy, and the scope of public health intervention. Today’s rising medical mistrust juxtaposes with the implementation of a U.S. government-backed initiative in the 1950s called Operation Tat-Type (1950–1952), a civil defense pilot program aimed at creating “walking blood banks” amid fears of mass-casualty events. Albeit short-lived, Operation Tat-Type was well-received, successfully blood-typing hundreds of thousands of Americans through community blood-typing events, including in schools, where both adult and child participants received either a dog tag or a tattoo indicating their blood type and Rh factor. Blood-typing events were held in several locations across the Midwest, as well as two counties in rural Utah.

This project utilized a mixed-methods qualitative approach, including historical and archival research, online public comments and feedback, and personal narratives of participants and family members, to examine Operation Tat-Type and its echoes in contemporary wellness discourse. We report on the fascinating but little-known legacy of Operation Tat-Type, the project’s collaboration with a dominant religious denomination in Utah (the Church of Jesus Christ of the Latter-day Saints), dramatic changes in blood banking technologies at the time, and jingoistic propaganda motivated by the Red Scare.

We highlight the historical echoes of perennial subjects of health debate—bodily self-determination, governmental coercion, public health priorities impacting personal autonomy—and examine how they relate to cultural attitudes toward medical intervention today.

CHEN

## **Pet Euthanasia and Human Euthanasia**

Jason Chen, PhD

The Ohio State University, College of Pharmacy

A common criticism of assisted suicide and euthanasia, which I will refer to together as assisted death, is that it violates the moral prohibition against intentionally killing innocent people. This prohibition often stems from the belief that death necessarily harms the person who dies, which is an idea found in numerous contexts, including discussions about the intrinsic goodness of life as well as the Hippocratic Oath that commands doctors to give no deadly drug and do no harm. While the prohibition is appealing to many, it only makes sense if we assume that death is necessarily harmful to the person who dies, for if death were in someone's best interest, then that prohibition would state that it would be wrong to do something beneficial, which is implausible. Thus, if it is true that death can be in someone's best interest, then invoking a prohibition against intentionally killing innocents would not constitute a strong objection to assisted death.

There has been significant work by deprivationists and Epicureans on the prudential effect of death on the deceased. Deprivationists argue that death can be good or bad for you, while Epicureans argue that it cannot. Though relevant, I will not directly engage in that debate in this paper; rather, what I will do is approach this topic via the analogy of pet euthanasia. Specifically, I argue that the fact that we possess a rational nature is insufficient to preclude the possibility of death being in our best interest in the same way it can be for our pets. To support this argument, I provide a number of basic propositions that, together, support our belief that death can be good for our pets. Then, I show that the same basic propositions also apply to human beings despite our capacity to transcend our suffering. The upshot is that there is reason to think that death can be in our best interest in the same way it can be for our pets.

In the last section of the paper, I respond to the objection that states that a prohibition is still justified because of our ignorance of the future. Since humans may transcend their suffering, we cannot know if a particular person's future will be overall negative; thus, we should act according to a precautionary principle that amounts to a prohibition. I argue that this objection is not convincing because we are also ignorant of our pets' futures, and yet, that does not justify banning pet euthanasia.

COLACO

**Recreational and Therapeutic Dance for Children with Autism: Class Structure, Facilitation, and Supportive Outcomes**

Abigail Colaco

Amaavi Miriyagalla

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Dance-based activities are increasingly recognized for their potential to support children with autism spectrum disorder (ASD) through social, emotional, sensory, and motor engagement. Dance and movement classes allow children with ASD to build upon skills through a strengths-based approach that leverages their creativity, individual capabilities and sensory attunement. Importantly, dance provides a nonverbal mode of communication, a medium through which children with autism can express thoughts and feelings that may be otherwise difficult. Children on the autism spectrum may also experience challenges with social interaction, and dance offers an accessible and affirming way to engage with others and the world around them.

While Dance Movement Therapy (DMT) has garnered significant attention for its therapeutic benefits in supporting children with ASD, recreational dance also offers valuable opportunities for engagement that are not rooted in medicalized frameworks. Additionally, technological advancements, such as robotic-assisted systems and digital interfaces, are diversifying the modes through which dance can be delivered. This evolving landscape underscores the need for a scoping review like this one, which aims to map the existing literature of dance-based intervention and recreational activity for children with ASD, helping us better understand the range, structure, and impact of these classes. Specifically, it explores the types of dance activities used, the structure and facilitation of the classes, and the various outcomes reported by way of developmental and psychosocial support. We conducted a structured literature search across three databases: PubMed, Embase, and Web of Science.

In addition to examining class structure and facilitation modes, we conducted an in-depth thematic analysis on how dance interventions supported children with ASD. We uncovered five themes in the process: (1) social and cognitive growth, (2) motor and physical skill development, (3) enjoyment and safe spaces, (4) interpersonal relationship-building, and (5) insight into the child's lived experience from the perspective of peers, family members, and other caregivers.

Ultimately, by synthesizing how class structure, facilitation methods, and contextual factors influence outcomes for children with ASD, this work offers a number of valuable insights. First, practitioners, educators, therapists and researchers are better able to design inclusive and effective dance movement-based programs for these children. This research is not just about children with ASD; it is for them. Additionally, these findings can provide guidance for family members and loved ones striving to foster greater understanding and connection with their child within the broader disability community.

COTTONE

**Rethinking Chronic Pain and Disability: Meaning and Embodiment in the Medical Humanities**

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In recent years, the medical humanities have increasingly engaged with the question of chronic pain by attending to non-dualist perspectives, narrative, and explorations of subjectivity. Additionally, attention has been given to questions about pain's impact on selfhood and the human condition, addressing the meaning and significance of pain in ways that inform and extend beyond clinical contexts. However, the discussions have given comparatively less attention to pain in the context of disability from a medical humanist perspective. To fill this gap, we draw on critical disability studies and affect theory to develop a new understanding of chronic pain that, from a medical humanities perspective, challenges dominant biomedical understandings—while also mindfully addressing certain limitations in how chronic pain is conceptualized within disability studies.

We begin by situating our discussion of pain within feminist disability studies (FDS), critically engaging with perspectives that position the body-in-pain as the source of disablement—treating the body itself as the problem. This view emerged as a response to early views of the social model of disability, which feminist disability studies challenged for overlooking experiences like chronic pain, particularly as they affect women (e.g., fibromyalgia, ME/CFS). While we challenge the idea that the in-pain body is itself the source of disablement, we nonetheless take seriously these critiques by focusing on the phenomenological experience of chronic pain—exploring how it can come to be lived and felt as the body itself being the problem. We offer a phenomenological characterization of chronic pain experiences, which we describe as enclosed surfacing—highlighting how the body can feel like an enclosure that holds and circulates pain inwardly, rather than a site of mediated contact with the external world. This approach complements and extends medical humanities perspectives that emphasize the embodied and socially mediated nature of pain.

Central to our argument is that the experience of chronic pain is socially mediated through circulating meanings and affect, which actively shape how pain is perceived and interpreted. Drawing on affect theory and medical humanities scholarship, we show how these experiences acquire specific meanings that reflect common but hegemonic assumptions: that the body is itself the problem, pain is inherently bad, disability necessarily involves pain, and that a disabled and painful life is not worth living. These meanings are not abstract; they are rooted in histories of violence against disabled people, where fear of pain has been used to justify unjust medical interventions and assisted death (e.g., 'assisted death' in the case of Terri Schiavo). This historical and ongoing mediation helps explain why some strands within disability studies tend to conceptualize chronic pain primarily in terms of impairment—a view we critically engage with in our analysis.

By integrating phenomenology, affect theory, and medical humanities perspectives, our analysis reconceptualizes pain as a socially and affectively mediated experience. This reframing is essential for rethinking the relationship between chronic pain and disability, contributing to ongoing conversations within both medical humanities and disability studies, and offering a more nuanced understanding of their complex interplay.



DALRYMPLE-FRASER

**Disabling Grief and Resistance in Rix Road**

C Dalrymple-Fraser, PhD

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The first season of *Andor* (2022) culminates in a funerary procession that erupts into an anti-imperial riot. This presentation analyzes this “riot of Rix Road” through the lens of disability studies, arguing that the imperial response to grief reveals a biopolitical logic in which mourning is medicalized, pathologized, and targeted for elimination. Textual and paratextual sources portray Ferrix’s mourning rituals as multiply disabled: framed as social dysfunction to be corrected, as threats to the health of imperial rule, and as justifications for disabling violence against populations. At the same time, the disruptive potential of Ferrix’s communal mourning reveals possibilities for resistance, including the physical resistance that erupts. By situating the riot within frameworks of crip time, critiques of grief disorders, and histories of resistant mourning, I argue that *Andor* offers a counternarrative to normative scripts of health, recovery, and cure. I conclude by positioning *Andor* against trends in contemporary grief media, suggesting that it offers further resources for examining the potentials of resistant grief.

DELLA CROCE

**Equality at the End-of-Life: The Case for a Procedural Approach to Assisted Dying**

Yoann Della Croce, PhD

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The literature about the ethics of assisted dying is rife with diverse conceptions of equality and quandaries about how best to achieve it. This paper proposes a drastic shift in how equality should be approached in the context of assisted dying and argues that instead of focusing on the results of policies, more attention should be drawn to how such policies are designed, particularly concerning the ideal of inclusion. I defend the view that what should matter for the egalitarian in the context of assisted dying are the procedures that design and implement policies rather than the outcomes of such policies. I contend that such a democratic approach is the most promising way to achieve true equality in assisted dying. Doing so allows for a proper engagement with the idea of structural injustice and vulnerability that guarantees the empowerment and inclusion of those deemed vulnerable in assisted dying.

DUE

**Access to Services ≠ Access to Care: The Case of Pharmaceutical-Telehealth Partnerships**

Austin Due, PhD

East Tennessee State University, Department of Philosophy & Religious Studies

Modern telehealth or telemedicine has been around in some form for decades. However, its use has drastically increased since the COVID-19 pandemic. Recently, some private pharmaceutical companies like Pfizer and Eli Lilly have started directly partnering with direct-to-consumer telehealth companies. When clicking on an online advertisement for a drug, a potential customer is directed to resources including telehealth services where they can inquire about and be prescribed the advertised drug. These pharmaceutical-telehealth partnerships (PTPs) potentially violate anti-kickback laws and significantly increase the risks of conflicts of interest negatively affecting care. PTPs also reify existing concerns with telehealth including over-prescription, misdiagnosis, and poor follow-up care. Given the rise of these PTPs, I offer two arguments. The first argument I call the ‘weak’ argument: PTPs risk instantiating low-quality healthcare. This is based on some of the aforementioned points, e.g., risks of misdiagnosis and how conflicts of interest negatively influence the decision-making process. Through examining various decision models including shared decision-making and informed decision-making, I show how PTP marketing and practices yield low-quality or flawed healthcare decisions. I call this the ‘weak’ argument since it depends in part on empirical data about prescribing patterns resulting from PTPs. For example, if it were to be shown someday that prescribing practices from PTPs were roughly equivalent to in-person care, the ‘weak’ argument would lose its teeth – at least, assuming that the in-person care being compared to was good quality care. The second argument I offer I will call the ‘strong’ argument since it rests on a conceptual distinction moreso than on empirical data. The ‘strong’ argument is that PTPs risk instantiating something that is not healthcare at all in the first place. This comes from considerations of how framing patients as consumers affects medical practice and considering the overarching aims of medicine. I appeal to recent arguments on what constitute the proper aims of medicine to show that the promotion of autonomy is core to what makes the practice of medicine such. And though PTPs foreseeably promote autonomy through providing access to services, I will argue that this conception of autonomy, related to what I call ‘libertarian’ autonomy, is not the sort of autonomy that constitutes the aims of medicine. In short, by using the case study of PTPs I will argue that the consumer’s access to services is categorically different from the patient’s access to care.

DUNKLE

## **Over What Do the Social and Medical Models of Disability Disagree?**

Ian Dunkle, PhD

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Philosophers of disability commonly criticize the so-called medical model of disability in favor of a proposed social model of disability. What each respective model refers to, however, shifts across these works, and so the utility of characterizing debate this way is questionable. For this reason, Barnes (2023: 130-9) proposes to recast debate over the social and medical models as a disagreement over whether being disabled always makes one less healthy than the non-disabled. On one side of this disagreement, she identifies views of health, like Boorse's famous biostatistical theory of health (BST), that endorse what she calls the "spectrum view," according to which disability belongs on a spectrum from full to minimal health (see Boorse 2014, 1997, 1977). While I do not aim to vindicate the BST as a theory of health overall, I aim to show that philosophers and activists concerned with disability rights are mistaken to focus their critical attention on the BST, the spectrum view, or similar positions.

In recasting the debate over the social and medical models this way, Barnes specifically aims to show that (i) the debate is meaningful even though both sides are mistaken; that (ii) in particular, the prevalent spectrum view of disability is importantly mistaken; and that (iii) adherence to the spectrum view is among the reasons for rejecting the BST. Her argument for (ii) involves marking a distinction between the view that "[d]isability always involves a loss of health," and that persons with disability are always less healthy than non-disabled persons (132). While Barnes grants the plausibility of the former, she correctly rejects latter. She argues, though, that the spectrum view and the BST entail that persons with disability are always less healthy than the non-disabled. I show that neither the spectrum view nor the BST entail such and, therefore, that Barnes' case for (i-iii) is unfounded.

I then draw on Barnes' other arguments regarding disability and the BST to consider possible, alternative defenses of (i). For instance, might the dispute be over whether disabilities (always or usually) involve intrinsic decrements health? I raise doubts on this and other possibilities. In doing so, I raise a number of criticisms of Barnes' objections to the BST. My conclusion is that, if there is a meaningful debate between the social and medical models of disability, it is not plausibly tied to criticisms of the BST or the spectrum view. Rather it likely concerns a normative, rather than descriptive, view about how disabilities are to be treated in a clinical context.

EGGLESON

**The Secret Guardian: Insights from a Medical Educator Abiding in Multiple Disability Roles**

Kathleen Eggleston, PhD

Indiana University School of Medicine, Department of Medicine

Indiana University School of Medicine-South Bend, Ethics, Equity, & Justice Scholarly Concentration

This presentation will invite conversation and share lessons learned from the presenter's years of experience working on disability in the context of medical education and as a parent and legal guardian of an adult child with disabilities.

The presenter's leadership roles at the intersection of disability and health have included the Indiana University School of Medicine Disability Curricular Thread, the Disability Accommodations Committee, and co-leading the Disability Task Force. She served as the lead designer of clinical courses' disability curricula intended for first-year medical students and co-lead designer for second-year medical students. She has also delivered internal and external presentations on disability and medical education, including at the Eighth Annual WMU Medical Humanities Conference.

Advocacy is inherent to academic work on disability and health. People with disabilities are more likely to experience unmet healthcare needs and represent a population with health disparities. Training the next generation of physicians as patient advocates and allies includes imbuing them with empathetic awareness about lived disability experiences and imparting the skills necessary to engage individuals, families, and systems. Physicians should be prepared to facilitate the flourishing of their patients with disabilities, including avoidance of common pitfalls such as diagnostic overshadowing and timely completion of vital documents behind the scenes.

Disability is integral to DEI, both within and beyond academic medicine. Disability identity is underrepresented among physicians and many trainees are reluctant to disclose their conditions, even sacrificing accommodations that would benefit them and their work. With recent changes to broader sociocultural context in the United States, medicine's professionals, trainees, and patients with disabilities are experiencing impacts in real time.

Taken together, all personal and professional experiences with disability have inspired reflection and yielded insights. Some cross-cutting themes and their meaning will come as no surprise to attendees (bias, pity, unjust disparities) but there are others that only could have been gleaned from lived experience. These insights will frame the presentation, which will open an interactive space to allow attendees to engage a professional with a range of experiences around disability and health, including legal guardianship of an adult child with multiple types of disability.

ERDMAN

**Using Improvisation to Explore the Role of Everyday Objects in Patient-Clinician  
Communication**

Lisa Erdman, DA

Elizabethtown College, Department of Art & Design

It is widely acknowledged that effective communication is critical for establishing a therapeutic relationship between the patient and clinician. However, in medical education research, there has been relatively little emphasis on non-verbal aspects of communication in the clinical setting, even though it has been shown that non-verbal communication (body gestures, positioning in the room), impacts how the patient perceives their relationship with their provider.

Building on communications research with standardized patients, this study in this presentation considers everyday objects (i.e door, chair, computer) as an integral component of non-verbal clinical communication. For example, the door is a way to enter the room, but it also has meaning beyond its operative function, depending on how the clinician knocks on and opens the door before entering the room. The primary goal was to explore how medical students' awareness of everyday objects in the clinical setting can affect outpatient communication between clinician and patient.

Data for this qualitative small-scale study was collected through an arts-based intervention with 4th-year medical students enrolled in an elective course on medical improvisation at Penn State College of Medicine. The intervention staged a mock clinical encounter where emphasis was placed on interactions between the student, a patient, and two physical objects: the exam room door and chairs. Additionally, students engaged in self-reflective writing exercises about their relationship to specific exam room objects. From this study several themes emerged, including the hierarchical power dynamics between patient and clinician, as well as the impact of furniture layout on communication in medical consultations. In this way, the research has implications for the design of equitable healthcare spaces that support ethical clinical interactions.

This presentation is intended for healthcare practitioners and health professions students. From this presentation, the audience will be able to: 1) explore the impact of object usage in clinical communication within the outpatient setting, 2) reflect on the significance of non-verbal communication in establishing trust and communication between patient and clinician, and 3) describe the value of arts-based methods in enhancing clinical communication skills.

ESCHWEILER

**From Shortage to Solution: The Ethical Allocation of IV Fluids in Healthcare**

Eilis Eschweiler

Western Michigan University, Homer Stryker M.D. School of Medicine

In this presentation we argue IV fluids should be classified as “essential infrastructure” and propose a two-tier lottery framework that mitigates health disparities during shortages. Over 200 million liters of intravenous (IV) fluids are used annually in the United States, with approximately 90% of patients receiving IV fluids during hospitalization. IV fluids are essential to the treatment of several diseases—including sickle cell anemia pain crisis effecting predominantly affects Black populations, as well as diabetic ketoacidosis and sepsis which have worse outcomes for those with lower socioeconomic status. Hurricane Helene caused a nationwide fluid shortage, raising uncomfortable questions regarding the ethical allocation of essential IV fluids and the impact of scarcity on worsening health disparities. Drawing on published allocation frameworks, we explore several ethical approaches used for the allocation of other scarce medical resources—including utilitarianism, prioritarianism, instrumental value, and reciprocity—to argue that IV fluids should be officially deemed “essential infrastructure”. This designation triggers federal oversight and requirements of strategic reserves and redundancy across the supply chain.

Until such safeguards exist, scarce-supply allocation must be governed by an ethically defensible, equity-sensitive schema. Owing to the importance of IV fluids, we propose a new allocation schema consisting of a tiered lottery system that incorporates the moral principles of the complete life system to allocate IV fluids ethically. Tier 1 includes acute care needs, where IV fluids are prioritized for resuscitative boluses for trauma patients, burns, emergent surgery, pediatric patients, and critical illness. Tier 1 includes prioritizing those whose mainstay of treatment is IVF, such as those with sickle cell anemia pain crisis, diabetic ketoacidosis in under-resourced areas, and sepsis in patients with limited healthcare access. This scheme prioritizes patients facing a disproportionate burden of health disparities to prevent the widening of existing gaps, while ensuring the most in need have access to life-saving fluids. We recommend the use of evidence-based discontinuation criteria to ensure that excess IV fluids are not administered during times of shortage. In Tier 2, IV fluids should be distributed across as many patients as possible, even if no patient receives a standard dose, provided the dosage is beneficial. If shortages remain, a lottery system should be implemented to allocate the remaining fluids. We conclude by examining how our tiered allocation system can help reduce existing health disparities and contribute to health equity.

FAUSONE

**Putting Quality of Life and Flourishing at the Center of Healthcare for Patients with Disabilities**

Molly Fausone, MD, MA

Kristi Kirschner, MD

Dorothy Clare Tessman, DNP, APRN, PMHMP-BC

University of Illinois Chicago, University of Illinois Medical School

Molly Fausone reflects on the purpose of healthcare, proposing that healthcare exists to promote human flourishing. This includes the promotion of wellbeing broadly defined, not just physical health, but also psychological, social, cultural, and spiritual dimensions of people's lives and how they interact with the world. This should compel us to look at the patient in front of us and ask not, 'how might this person die and how can we prevent that?' but, 'how might this person live and how can we facilitate that?'. If this is what we owe our patients, then the responsibilities that follow from this commitment extend beyond diagnosis and management of disease. Our responsibilities include an interest in our patients' lives outside the healthcare setting, robust wrap-around services, and attention to the ways in which needing healthcare may sometimes act as an impediment to rather than a facilitator of living a full life. People with disabilities face a number of barriers to function and participation that we must partner with our patients to address in order to facilitate their flourishing. This is the model of care that we aim to build at the Lifespan Disability Clinic at UIC.

Kristi Kirschner examines the importance of centering Quality of Life considerations in the care of patients with disabilities. Her presentation will review the general approaches to measuring quality of life (e.g., provider-centric vs. patient-centric; health-related vs. global) and how the methodology can lead to very different conclusions which often do not reflect what people with disabilities tell us matters. Data on provider explicit and implicit disability bias, and how misperceptions of quality of life have unintended consequences and harm will also be explored. She will define the concept of the disability paradox and use various case examples to illustrate how this might show up in clinical practice. Her talk will conclude with a discussion of how the Golden Rule shows up in medical decision-making around disability issues.

Dorothy Clare Tessman will discuss how provider burnout is a disruptive factor in healthcare delivery. Moral injury and overwhelming workloads contribute and are encountered disproportionately in providing for underserved populations such as people with complex disabilities and behavioral health needs. The prioritization of fiscal demands over care needs, such as improved medications that are made inaccessible due to costs, are a particular struggle when providers are constrained from taking actions they know represent better care. A workplace culture with mission-driven values and quality relationships among providers is protective, as is an institutional priority of providing good continuity of care. Clare will describe how the Lifespan Disability Clinic is designed to provide excellent continuity of care with a team of like-minded professionals, and the impact this can have on preventing burnout.



## **Dignity and Disability**

Robert Fudge, PhD

Weber State University, Department of Political Science and Philosophy

Despite concerns that it is an inherently vague and, ultimately, unhelpful concept, dignity continues to play a central role in discussions of medical ethics and bioethics. Mentions of dignity appear, for example, in debates concerning end of life care, physician-assisted suicide, human gene editing, and abortion, among other issues. And those who struggle with disabilities are continually reminded how fragile dignity is and the myriad ways in which it can be violated. It behooves us, then, as humanities scholars to gain as clear an understanding of dignity as possible, not only so we can recognize what sort of actions and conditions violate it, but also so we can develop practices to uphold and preserve it.

In this paper, I begin by presenting my own conception of dignity that I develop at length in a book manuscript under preparation. As typically conceived, dignity refers to the inherent value of the individual. From a philosophical standpoint, this assertion raises any number of questions. What underlies this value? Are we to assume that the vilest fiend possesses dignity to the same degree as a moral saint? Why think that only humans possess this special sort of value? And, ultimately, what practical principles follow from this assertion? Given these challenges, I argue that dignity is better understood as the state or condition of being free from degradation. One of the advantages of defining dignity in this way is that it points to three kinds of degradation—moral, social, and natural—to which we are all subject and all of which threaten to undermine our dignity to various degrees. Social and natural degradation are especially pertinent when addressing issues surrounding disability.

In the second part of the paper, I turn to more practical issues concerning what it means to both protect and advance the dignity of disabled people. In sum, if dignity is the opposite of degradation, we need to be attentive to actions and social practices and conditions that serve to degrade. Further, gaining a clearer appreciation of what dignity is also suggests ways to improve our behaviors and social structures to promote the dignity of the disabled and able-bodied alike.

GOLDBERG

**"IS IT YOUR TIME OF THE MONTH?": Journalism as a Women's Health Intervention**

Alyssa Goldberg, MS

USA Today

Gender bias in the biomedical sciences is detrimentally impacting the quality and delivery of personalized care for women, particularly in the context of reproductive health care and among those experiencing chronic pain. Gender medicine, specifically women's health, is nearly forgotten in medical schools' curricula. In a 2016 study, 70% of postgraduate physicians undergoing training indicated that gender issues and concepts are rarely or never discussed. This lack of gender medicine training, along with weight bias, menstrual stigma and the normalization of menstrual pain, hinders the timely diagnosis of common reproductive health conditions. Women are constantly experiencing pain in routine healthcare—from suffering from ongoing symptoms of polycystic ovarian syndrome (PCOS) and pelvic disorders to extreme medical negligence during fertility treatment—that is belittled or blatantly ignored by medical professionals, academics, researchers, and societal discourse. As feminist magazines like *Bitch* shut down and independent youth media companies are acquired and dissolved by larger media conglomerates, integrating journalism that offers a patient perspective on women's health issues into mainstream media with substantial readership—such as *The New York Times*, *The Washington Post*, *USA TODAY*, and *The New Yorker*—can positively shape public discourse and encourage broader discussions of patient neglect and the ongoing disregard of women's pain. Uplifting existing and emerging women's health magazines that present alternative approaches and perspectives to the normative is also imperative to the advancement of conversations and research on gender medicine. Journalism can serve as a platform for justice and change, and as the starting point for advancing women's health. This novel intervention proposes a completed, three-story reported features series that investigates patient neglect in three distinct reproductive healthcare settings, focusing on hormonal disorders, such as PCOS, pelvic disorders, and in-vitro fertilization (IVF).



GRAVES

## **Mapping Core Competencies on Disability for Health Care Education: An Institutional Snapshot**

Kylie Graves

Yovia Xu, PhD, MSW

University of Illinois Chicago, University of Illinois College of Medicine

Despite nearly 28% of the U.S population living with disabilities, many individuals with disabilities face bias and discrimination in healthcare. Concurrently, many physicians report feeling ill-prepared to care for this patient population. With the NIH reclassifying individuals with disabilities as a population with health disparities, understanding how disability topics are embedded in medical education is both timely and critical. The Core Competencies on Disability for Health Care Education, created in 2019, outline essential content for training future healthcare providers, yet few studies have systematically mapped undergraduate medical curricula to these competencies.

This study aims to assess how comprehensively the competencies are covered in the University of Illinois College of Medicine (UICOM) required curriculum during the 2024-2025 academic year, with the goal of identifying areas of strength and opportunities for development.

Our review focused exclusively on the required pre-clinical coursework in Years 1 and 2. The coding process occurred in two phases. 1) The presenting authors reviewed the curriculum to identify all courses with disability-related content. 2) The team then independently reviewed these materials and coded each of the 49 sub-competencies as “met” or “unmet”. The team met to resolve discrepancies through discussion and consensus. The frequency of coverage was then calculated to highlight content gaps and strengths.

UICOM met 45 out of 49 sub-competencies, with coverage across all six core competencies. Strengths included clear coverage of social and cultural models of disability, structural ableism, health disparities, respectful communication, and lived-experience-informed content through standardized patients and community panels. Overall coverage was strongest in Core Competency 1, Contextual and Conceptual Frameworks of Disability, with Sub-Competency coverage most extensive in 2.1, mitigating one’s own bias related to disability. Gaps emerged in adapting physical exam and history skills, encouraging healthy lifestyle modifications to patients with disabilities, and provider recognition of the need to accommodate functional limitations in a healthcare setting. During coding, the research team was able to identify areas where guidelines were not included but were represented in our curriculum. Four unmet sub-competencies highlight opportunities for further development of the curriculum to better prepare students to meet the needs of all patients.

This work is especially significant given UICOM’s national leadership in disability-inclusive education. Faculty leaders, along with collaborations with the Disability Cultural Center and independent living centers, enrich educational experiences through community-informed teaching. Future directions may include revisiting the existing Core Competencies and evaluating whether any competencies can be shortened, new competencies should be added, and how these Core Competencies may be better integrated into the foundational competencies of undergrad medical education. This project further offers a replicable model for other institutions aiming to embed disability justice into medical education and advance health equity for people with disabilities.

GRAY

**Advance Directives, Stopping Eating and Drinking, and the Continuous Personhood of People with Dementia**

Aaron Gray, MLitt, MSc (OT)

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Work by Ronald Dworkin and Rebecca Dresser has long been invoked in arguments for and against, respectively, the bindingness of advance directives. Meanwhile, recent trends in end-of-life care have led to increased legislative support both for dementia-specific advance directives, and for voluntarily stopping eating and drinking (VSED). The convergence of these two trends has raised stark new concerns about the possible justification of withholding food and drink from patients. In short, legislation has provided for people to specify, in advance directives, points of disease progression at which clinicians can be directed to withhold food and drink. Through reflection on this issue, I argue that the dominant philosophical frameworks that have structured debate in this area are inadequate, implausibly flattening a complex moral landscape. In doing so, I develop and defend an account, drawing on insights from Dworkin, L.A. Paul, and Hilde Lindemann, of the continuous personhood of patients with dementia. I argue it can be shown to obtain in most patients with dementia once we recognise the degree of continuity of what Dworkin terms experiential and critical interests even into advanced stages of dementia. After highlighting the ways in which this account makes clear the moral complexity of caring for patients with dementia, I conclude by arguing that while the critical interests of patients who make advance directives to stop eating and drinking remain of moral significance, they will in general be outweighed by the continual expression of both experiential interests and other, continually expressed critical interests.

GRUBBS

**Beyond Words: Addressing Ethical Issues in Clinical Documentation Through Medical Education**

Lindsey Grubbs, PhD

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Danielle Wilfand

Case Western Reserve University School of Medicine

Medical charts are complex documents with many audiences and roles, but perhaps the most overlooked function of medical charting is constructing and legitimizing illness experiences and transmitting medical narratives within the healthcare system. Medical charts have the ability to alienate patients from the healthcare system through the use of negative language in medical documentation, including expressions of doubt and racial or class-based stereotypes. Research has emphasized that negative language within the medical charts of patients of marginalized identities also plays a crucial role in compounding, amplifying, and propagating biases and healthcare inequities. While there are many contributing factors and thus diverse possible interventions for addressing the use of biased language in the EHR, we propose that one powerful and overlooked avenue for change is within undergraduate medical education. Since the USMLE Step 2 Clinical Skills exam was phased out in 2020, no standardized evaluation assesses the quality of undergraduate medical students' clinical skills, including documentation, resulting in little consistency in instruction on this topic between medical schools. The American Medical Association has raised concerns regarding medical students' lack of proficiency in clinical documentation and utilization of the EHR, resulting in the release of a policy calling for the adoption of medical note writing and documentation curriculum, both regarding ethical documentation and the technical skills involved with navigating the EHR. We argue that medical education curricula should incorporate didactic and discussion-based learning on the implications of biased and negative language in medical documentation, with a particular focus on justice and inequity. This curriculum should prompt students not just to make more neutral linguistic choices but to interrogate (1) their role as narrators of patient stories, (2) patient-provider power dynamics, and (3) structural inequalities within healthcare as they prepare to enter the clinic. Offering pre-clinical students explicit education on the ethics and politics of medical language provides a critical lens they can deploy as they develop their professional habits and identities and deepen introspection on their power as medical professionals to compound or combat inequities.

HALL

**The Proper Subject and the Case Study: A Genealogy of Medical Knowledge**

Melinda Hall, PhD

University of Central Florida, School of Interdisciplinary Studies

Hannah Markley, PhD

Stetson University, Department of English

Case studies appear indispensable to the practice of medicine. From the distribution of CME credits to the discharging of legal responsibilities, the case study is both an active and passive practice of modern medicine. And yet, the case study, which seems to be everywhere a grounding for best medical practices, remains itself undertheorized as a genre with a history and a set of possibilities, limits, and assumptions.

In this paper, we explore the case study in its historical contingency and common structures; we wonder who are the subjects and authors of case studies, and what content and which speakers are taken as authoritative. Using the relationship between disability and bioethics as a point of departure, we suggest that case studies imply a proper subject both institutionally and discursively because they introduce a “problem” subject.” In other words, case studies are always invoked to deal with a problem or challenge to existing medical knowledge and practice. Further, in articulating the subject of a case study, authors assume and produce a range of concrete conditions. This has the effect of naturalizing contingent conditions by attempting to resolve tension between idealized, “proper subjects”, and problem subjects - head cases.

In suggesting that case studies are therefore functional, we call into view certain historical moments and examples that both serve as our own case studies and allow us to theorize explicitly about how power operates in these contingent constructions. We consider Locke’s anxiety (a theorist of mind), Rousseau’s nervous disorder (a theorist of sensibility), and Freud’s Dora (a theorist of neuroses). Each of our historical examples deals with problems of embodiment and mindedness; in particular, they wonder how can minds have bodies? What is the standing of this mind in relation to body, and to what extent do case studies always imply mind-body relationships? In a contemporary context, Morbidity and Mortality Conferences attempt a campaign of continuous improvement for the medical profession, at the same time concealing the inheritances of their genre, a complex entanglement of uncertainty activated by the case study as a genre.

We go on to consider the objection that data is necessary for knowledge, and anecdote must be adequately transformed into data for certainty to reign. In reply, we note that a reliance on data obfuscates the nature of the case study as an inadequate attempt to close uncertainty. Indeed, data conceals its own case studies. As co-authors, we may reach different ends, and want to explicitly play with the tension between our perspectives in an experimental conclusion. Tensions may be irresolvable, mimicking the case study itself in its irreducibility.

HANKES

## **Standards and Values for Assessing Patient Competence**

Borb Hankes

Duquesne University, Philosophy Department

Whether a patient is competent to decide, direct, or consent to their healthcare is a difficult evaluation that healthcare providers must make every day. There are certainly clear cases of incompetence, but there are many cases in which the proper path is unclear. When patients refuse treatment, demand procedures that are contraindicated for their health and the health of others, or go against the wishes of their appointed guardians, healthcare professionals must make the weighty decision of whether the patient is in their right mind. Rather than approaching this problematic as a discussion of autonomy or beneficence, I will assess standards for patient competence and suggest my own using epistemic and logical values such as coherence, understanding of cause and effect, and the ability to articulate even vaguely principles and their consequences. I will suggest a principle of competence and informed consent that relies on establishing rationality without forcing the doctor to evaluate the patient's moral beliefs. This standard would be much stricter than current definitions of competence, but would therefore be a much more confident measurement.



HARDY

## **Moral Sensitivity Training for Healthcare Ethics Consultants**

Carter Hardy, PhD

Worcester State University, Philosophy Department

The Healthcare Ethics Consultant Certification (HEC-C) is an attempt to formalize and professionalize the process of medical ethics consultation. For this certification, potential healthcare ethics consultants (HECs) receive training and certification that focuses more on principlism than the humanities. Principlism is the ethical approach most often used in medical ethics as indicated by the common four principles of bioethics. This approach focuses on following specific core principles such as respecting patient autonomy and working for the best interest of the patient. These principles are very useful in addressing a range of problems, but they only serve to address one dimension of our moral psychology. Focusing exclusively on principles is useful for compliance, but fails to train decision-makers as full moral persons.

Recent work in moral psychology shows that principles and rational arguments only do part of the work for our moral decision-making. They are often secondary to our emotional responses and motivations. When we find our drives in conflict with our principles, we tend to tweak our principles to justify our drives. This presents a clear conflict for principlism and any moral approach that prioritizes it. As such, a principlist approach to ethics consultation not only fails to train full moral agents, it also risks the well-being of patients.

My presentation will address this problematic gap in the ethics training of HECs, but in such a way that still offers concrete recommendations that can be incorporated into the certification process. I will argue that the health humanities are essential to healthcare ethics because they refine our moral identity and moral sensitivity beyond mere rule-following. Especially in a time characterized by the rise of AI use, moral sensitivity is an area where humans still far outpace AI. It is a valuable skill that should be fostered, especially in a field that will likely turn increasingly toward AI for applying ethical principles.

My presentation will be divided into three parts. First, I will address the importance and need for a HEC-C. Without it, we leave medical professionals and hospital ethics committees without a significant resource, or at least without any way of knowing who to trust to be that resource. While medical professionals do need to make many moral decisions on their own, there will be many decisions that require specialists who are more familiar with medical law, ethical theory, and the cases that have established current protocols. Second, I will explain the importance of developing moral identity, part of which consists of our moral principles. However, other important aspects of our moral identity need to be fleshed out through the study of moral psychology, including our character, values, and community.

Finally, I will focus on something entirely unaddressed by principlism—our moral sensitivity. This is our ability to recognize and care about moral issues and those impacted by them. It is our lived experience of morality and our emotional engagement with a morally defined world. This dimension of our moral lives is especially enhanced by an engagement with the health humanities.

HIGBEA

**Medical Humanities, Disabilities, and the Electronic Health Record**

Raymond Higbea, PhD

Larry Warkoczeski, JD

Grand Valley State University, School of Community Leadership & Development

Guenter Tusch, PhD

Grand Valley State University, College of Computing

The combination of medical humanities and disability studies is a phenomenon that seeks to view and provide care to those who are disabled from a holistic lens that embraces the patient experience over the medicalization of the physical needs. The electronic health record (EHR) is a necessary resource in providing holistic care for those who are disabled while avoiding the phenomenon of ableism. A holistic care approach aligns with complex care coordination, addressing social determinants of health (the nonmedical factors affecting a person's health), and value-based care which, based upon our research, can only be accomplished through the use of an EHR. Examples of EHR necessity include the use of an accommodations tab in the EHR. The accommodation tab is a patient-facing questionnaire that provides the information necessary for providers and staff to provide accommodations in a barrier-free environment and allows for the redesign of the care provided to meet the needs of those with disabilities. Another example is the existence of accountable care organization (ACO) which are provider led organizations that focus on coordinating the care of special populations of individuals with a goal of positive patient outcomes. ACOs assume risk for these outcomes and in exchange are rewarded with enhanced payment that, despite of the enhanced payment, reduce the overall cost of care. Finally, from an ethical lens when those who are disabled are treated holistically, practitioners are acknowledging the individual's autonomy and treating them in a manner that is respectful of them as an individual. We will demonstrate in this session why the EHR is a necessary tool in providing a holistic care experience for disabled individuals.

HILL-GRANT

**Community Voice and Collective Impact: Addressing Racism as a Public Health Crisis in Practice**

Lydia Hill-Grant, PhD  
Adler University

This presentation builds upon my doctoral dissertation, *Moving Social Determinants of Health from Theory to Practice: Addressing Racism as a Public Health Crisis from the Inside Out* (Adler University, 2025), which applied Industrial and Organizational Psychology to public health inequities. The current project advances that research by embedding its findings into an ongoing community-based initiative in Lorain County, Ohio, where racism has been declared a public health crisis. Drawing from principles in the medical humanities, including narrative ethics, lived experience, and structural critique, this work integrates community voices into systemic analysis and healing practices.

Using ethnographic methods, community listening sessions, and participatory workshops, the project surfaces how residents and stakeholders experience racism through the five social determinants of health (SDoH): Economic Stability, Education Access, Health Care Access, Neighborhood Environment, and Social/Community Context. Findings underscore urgent needs in affordable housing (91.7%), mental health access (83.3%), and workforce development, while also revealing strengths such as family ties, local businesses, and cultural heritage.

Workshops grounded in critical race theory, intersectionality, and youth-centered engagement equipped participants to unpack issues like redlining, institutional bias, and systemic poverty. A medical humanities lens allows these experiences to be processed not just as data points but as human stories that carry ethical weight and demand collective action. Stakeholders co-constructed policy recommendations and strategies for embedding racial equity into infrastructure, health systems, and education.

By translating dissertation research into community praxis, the project models how academic inquiry can inform public action and how humanities-based approaches can restore voice, dignity, and cultural meaning to health equity work. This session will appeal to interdisciplinary scholars, public health leaders, and practitioner-educators seeking to bridge research and real-world change through culturally responsive, community-rooted frameworks.

HINZMANN

**Neurophilosophy and Neurodiversity: A Complicated Relationship**

Jeff Hinzmann

University of South Florida, Department of Philosophy

In this paper, I look at and analyze the relationship between reductionist neurophilosophy and activist neurodiversity. Though there is a *prima facie* similarity between the positions, they also actively seem to avoid interacting with each other. I explore the reasons for this, which are rooted in the activist goals of neurodiversity, which are much closer to other forms of disability advocacy. I then speculate about whether neurophilosophy can help adjudicate or even support the activist claims of neurodiversity.

HOAGLUND

**"The Remissionaries:" Literary Community and Narcopolitical Resistance in post-Soviet  
Russia**

Ryan Hoaglund

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The present paper explores *The Remissionaries* (2002), an anthology of literary texts produced by people who use(d) drugs in post-Soviet Russia. It asks why drug users—a medicalized, criminalized, and stigmatized population in Russia since the collapse of the USSR—were drawn to literature as a means of resistance to sociocultural subordination. Ultimately, it argues that literature provided a medium for the construction of a culturally and politically agentive “counterpublic,” a space in which alternative discourses and representations could freely circulate. Influenced by the technologies of the late Soviet Underground, the early Russian internet (Runet), and the emerging literary trend of “new sincerity,” these writers compiled a unique set of artistic challenges to hegemonic (socialist, neoliberal capitalist, nationalist) notions of citizenship. In their place, they imagined novel modes of belonging based on a unique combination of shared material practices and ideological dissensus. In this way, their project aimed at a sustained engagement with what Jacques Rancière calls the “redistribution of the sensible,” a vision of “politics” without “police.”

HUNTER

**Disability, Folk Medicine, and the Social Body in “The Withered Arm” and “The Handless Maiden”**

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This paper examines the treatment of disability in two stories, “The Withered Arm” (1888) by Thomas Hardy and “The Handless Maiden” (1889), a folktale as told by Clarissa Pinkola Estés. Hands play an important role in the formation of the social body, and in the two pieces of literature I have selected for analysis, the authors use disabled hands as a metaphor for social illness. Increasing research is being done even in western medicine about how trauma, energy, and the social body all impact the biological body. In this paper, I focus specifically on aspects of the social body, such as class and gender, as factors contributing to the heroines’ unique disabilities and healing journeys.

“The Withered Arm” is a ghost story that features an illness that is supernatural in origin, while symbolically representing the broken social order in which the patriarch abandons the mother of his child in favor of marrying a new young bride. While the illness may serve as a symbol for social illnesses, it also points to Hardy’s interest in the changing boundaries between western medicine and folk medicine. Scholars have demonstrated that the story clearly illustrates Hardy’s disdain for superstition, witchcraft, and folk remedies. While he may represent folk remedies in a questioning voice, I argue that his portrayal of the heroine’s desperate attempts to solve her mysterious illness captures an even more important element of understanding medicine beyond the biological body.

In “The Handless Maiden,” the heroine’s father chops off her hands in the service of the devil in consequence of his own greed for wealth. Instead of remaining in a life of ease and wealth with her father, she chooses instead the more difficult journey of setting out on her own in the woods. Her process of individuation and inner growth is eventually rewarded with the external regrowth of her hands. The story rewards character and virtue, and thus offers a complicated reflection on how disability is caused and, perhaps more problematically, how it might be healed.

In comparing the two stories, I’m able to formulate some conclusions about how hand disabilities are perceived in western cultures. I consider the role of the social body and the class structures that contribute to the conflicts surrounding the disability, as well as the ensuing commentary on social production and capital embedded in the specific disability of the hands / arms. I also consider how the healing journey is portrayed in these stories, with value and reward being placed more highly on internal reflection rather than external obsession, with complicated commentaries on virtue and character. Finally, I consider the moving boundary between western medicine and folk medicine as captured in these two stories, positing instead how these stories offer an integrated view on the relationship between the biological body and the social body.

HUNZIKER

**From Philosophical Insights to Practical Implications: A Phenomenological and Interdisciplinary Approach to Understanding 'Stimmigkeitserleben'**

Iris Hunziker

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We all seek to lead meaningful, fulfilling lives, a pursuit closely connected to purpose, well-being and human flourishing. Yet this pursuit often confronts us with struggles, uncertainties, and ambivalences that cognitive reasoning alone cannot resolve. In such moments, the experience of *Stimmigkeit* can serve as a guide, helping us navigate challenges and connect with meaning.

For now, I choose not to translate the terms *Stimmigkeit*, *Stimmigkeitserleben*, or *stimmig* into English. Renderings such as “inner coherence” or “being in tune” capture certain aspects but fail to convey the terms’ multifaceted nature and risk oversimplifying their meaning. Any adequate English equivalent would require thorough conceptual refinement—something that, if achievable at all, may only become possible at the end of the research, not at its outset.

*Stimmigkeitserleben* is a key element in hypnosystemic psychotherapeutic practice, developed by Gunther Schmidt (2013, 2022). It builds on the hypnotherapeutic concepts of Milton H. Erickson (Rossi, 2015) and the systemic-constructivist principles of the Heidelberg School, as shaped by Helm Stierlin (2001) and his colleagues. It emphasises the activation of inner resources and fosters solution-focused coping strategies in the face of personal challenges. It invites meaningful engagement with symptoms and encourages a mindful, appreciative stance towards oneself and others. In Schmidt’s work, *Stimmigkeitserleben* refers to a form of intuitive, bodily-felt knowledge. In this context, he touches on Eugene Gendlin’s (2003) felt sense.

Despite its relevance, *Stimmigkeitserleben* has received little attention in both philosophical and empirical research. My PhD project addresses this gap by exploring how people experience and articulate it, and by examining how it differs meaningfully from related phenomena such as moods, emotions, feelings, resonance, and intuition. A central aim is to develop a conceptual framework of *Stimmigkeitserleben* that includes an experience-based model reflecting its phenomenological structure, enabling its theoretical articulation across disciplines.

My research adopts an interdisciplinary approach, integrating philosophy, phenomenology, and psychotherapy with social science methodologies. It follows a spiral process in which empirical investigations and philosophical inquiry continuously inform one another, creating a hermeneutic cycle of understanding. This contributes to the growing field of Medical Humanities by offering a conceptual and empirically grounded account of *Stimmigkeitserleben*.

At the conference, I will present a daily self-observation format that I am currently developing for use in clinical settings. Data collection with this tool is scheduled to begin in January 2026. The format is designed to invite clients to reflect on moments of *Stimmigkeitserleben* during their stay, providing a longitudinal, experience-near perspective. In doing so, it aims to support both empirical investigation and client-centred reflection in therapy, thereby bridging philosophical inquiry with medical and therapeutic practice.

KARIDAKIS

**Dismantling Barriers: a Collaborative Model for First Nations Health Communication**

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Effective health communication is compromised for First Nations Peoples, where the ongoing impacts of historical trauma and systemic barriers create a deep chasm in healthcare engagement (Sherwood, 2013). This abstract presents a thematic analysis of practitioner interviews across complex conditions, revealing the urgent need to move beyond conventional paradigms. It argues that addressing these persistent health inequities requires a shift towards culturally safe models of care that privilege a new language of healing, that is empathetic, culturally grounded, and confronts the weight of history (Dudgeon, Milroy, & Walker, 2014).

Our analysis identifies four interconnected themes. Firstly, ‘the complex clinical landscape’ reveals unique disease profiles, such as the early onset of Type 2 diabetes in children linked to high familial prevalence. This intergenerational burden is compounded by the invisibility of conditions like renal disease and their often multifaceted nature.

Secondly, ‘the weight of history: fear, stigma, and shame’, highlights ongoing emotional barriers. For instance, justified mistrust, rooted in the experiences of the Stolen Generation, creates “instant hyper vigilance” and a fear of institutionalisation. This, combined with shame surrounding diagnoses, makes psychological safety an absolute prerequisite for any therapeutic dialogue.

Thirdly, ‘the communication chasm’ details practical obstacles where conventional health education fails. Widespread illiteracy renders text-based resources futile, while clinical jargon causes disengagement. The complexity of treatments can lead to dangerous misunderstandings, necessitating a shift towards direct, visual communication.

Finally, ‘forging a new language: a culturally grounded toolkit for healing’, points to the path forward. Practitioners are developing creative strategies, including reframing the clinical encounter from “what’s wrong” to “what happened”, using holistic frameworks. Critically, it involves the integration of First Nations languages, facilitated by interpreters, to ensure communication is not merely translated, but truly understood within its cultural context. This is combined with culturally resonant metaphors and visual aids—like an animation of a “sick emu” to reduce shame. These narrative, linguistic, and metaphorical tools, co-designed with community members, build trust and empower individuals far beyond simple information delivery.

To break intergenerational cycles of poor health, the medical humanities must champion such approaches rooted in cultural humility and narrative medicine. The toolkit emerging from the collaboration between research and clinical partners offers a powerful blueprint for dismantling historical inequities, demonstrating that the most effective medicine is often a new way of listening, seeing, and speaking.



KITTS

**Anything but Endo: Diagnostic Buck-Passing in Endometriosis Care**

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Endometriosis is a chronic condition of the female reproductive system where tissue similar to the lining of the uterus grows elsewhere in the body leading to pain, cysts, and potential infertility. It affects approximately 10% (190 million) women and people born with female reproductive organs. Despite the prevalence of endometriosis, little is known about potential risk factors or its etiology, leading to prolonged and arduous diagnostic journeys for those seeking explanations for their symptoms.

In this presentation, we introduce the concept of “diagnostic buck-passing” as one dimension across which diagnostic journey is problematized for those with endometriosis. Diagnostic buck-passing occurs when potential causes of and clinical responsibility over symptoms of endometriosis are shifted to other conditions within different specialties before they are seen as possibly being endometriosis. Not only does diagnostic buck-passing prolong care and lead to harmful delays in diagnosis and treatment, but it is also a product of epistemic injustices against persons with endometriosis.

We argue that these diagnostic delays are a result of systematic ‘willful ignorance’ present in biomedical research and clinical care for endometriosis that stems from consistent underinvestment in women’s health generally, joining those who have suggested the endometriosis is marked by undone science (Hudson, 2022). Drawing on an on-going qualitative study, we will present several vignettes of people living with endometriosis to explore their diagnostic trajectory. We demonstrate this process empirically using three cases taken from the study on lived experience with endometriosis.

Finally, we imagine what conditions would be required for a future of just care in endometriosis diagnosis. To do so, structural changes are requisite. Such changes require social action both within biomedicine and broader society. We consider the potential impact of changes such as reimagining the seriousness of patient’s pain reports, pressures against deferring to different clinical specialties, and increased clinical education on endometriosis.

LABABIDI

**Medical Students' Understanding and Attitudes Towards Ethical Considerations in  
Pharmaceutical Ingredients: A Cross-Sectional Survey**

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Patients frequently prefer to avoid certain ingredients in their food and medications, whether due to religious values or dietary preferences. For example, Muslims, Jews, vegetarians, and vegans represent portions of the patient population seeking to mitigate the use of particular animal-derived ingredients. Healthcare providers, especially physicians, have an ethical obligation to develop the competence and humility to cater to these preferences and be transparent about the contents of prescribed medications. Yet, most physicians receive little to no instruction on medication ingredients in their training. Data shows that 70% of physicians are entirely unaware of the presence of animal-derived ingredients in medications despite a strong majority of medications containing ingredients commonly sourced from animal components. It is important for physicians to not only be adequately aware of this issue, but also to develop the skills needed to proactively address it.

Medical students at Central Michigan University College of Medicine attended a pharmacist-led session on pharmacotherapy ethics as part of their Medicine and Society course. This session was composed of a 15-minute pre-recorded lecture followed by in-person instruction. Upon conclusion of the session, students were administered a voluntary survey assessing the impact of the session on their perceived knowledge and competence in medication ingredient ethics. The survey was composed of identical pre- and post-session questions, with 16 questions in each category. Responses were collected on Likert scales ranging from 1 to 5, and higher scores indicated higher perceived knowledge or competence of the content. The Wilcoxon signed-rank test was used to compare pre- vs post-session results. IRB approval for the survey was waived.

The session delivered instruction on common controversial medication ingredients, drug information resources to assess for medication ingredients, and a standardized algorithm to safely alter pharmacotherapy in accommodating patient values pertaining to medication ingredients. 59 subjects chose to take part in the survey. The mean pre-session total score was 34.66 with a standard deviation of 11.9, and the mean post-session total score was 66.31 with a standard deviation of 8.0 ( $p < 0.001$ ).

Physicians' knowledge gap in the ethics of medication ingredients is due, in part, to the lack of standardized instruction in the subject matter within medical curricula. This study demonstrated that instruction in medication ingredient ethics relating to objectionable ingredients, drug information sources, and strategies for safe treatment modification significantly improves perceived medical student knowledge and competence of this content. This extraordinary improvement showed that previous instruction in this topic was lacking. Given the increasing prevalence of patient vaccine hesitancy and overall mistrust in the healthcare system, medical schools are encouraged to incorporate medication ingredient ethics into their curricula, as physicians with enhanced knowledge and competence in this important area would be better equipped to build patient trust in healthcare providers.

LAFOLLETTE

**Medical Museums and Archives in/as Medical Humanities**

Kristin LaFollette, PhD  
University of Southern Indiana

This presentation explores medical museums and archives through the lens of medical humanities by acknowledging the inherent humanity of these institutions and advocating for people of the past. Historically, human remains in medical museums and archives have been presented as objects of scientific curiosity, which reduces the individuals they represent to their basic anatomy or pathologies (Gruenthal-Rankin & Somogyi, 2025). Using this notion as a springboard, this presentation shares the results of an original qualitative study that involved visiting several medical museums and archives in the United States (i.e., Monroe Moosnick Medical and Science Museum, Warren Anatomical Museum collection, Cushing Center, and Indiana Medical History Museum) and analyzing the displays to determine what was being communicated about human remains in their collections. In addition, I use the Anatomical Museum within the Indiana Medical History Museum as a model and concepts from Molloy (2015) and Winderman and Landau (2020) as theoretical frameworks to propose a heuristic for rehumanizing displays so as to better convey the humanity of the people represented by human remains in medical museums and archives. Further, I make the case for integrating conversations about medical museums and archives into medical humanities courses to introduce students to important historical events and the associated power dynamics (that still impact the contemporary study and practice of medicine) and highlight the importance of emphasizing the humanity of people in every aspect of medicine.

LOH

**Insights from The Farewell for Healthcare Professionals: Chinese Cultural Perspectives  
Toward Truth-Telling and End-of-Life Care**

Angelyn A. Loh

Stony Brook University, Renaissance School of Medicine

This project explores how Chinese cultural values influence truth-telling at the end of life. By analyzing insights from the film *The Farewell* and relevant scholarly literature, the goal is to equip healthcare professionals with the cultural sensitivity and ethical understanding needed to effectively navigate cross-cultural care.

The 2019 film *The Farewell* follows a Chinese family's decision to conceal a terminal cancer diagnosis from their grandmother, believing it spares her unnecessary suffering. Billi, a Chinese American woman, travels to China to gather with her extended family under the guise of a fake wedding to say goodbye. With her U.S. upbringing, Billi struggles with the family's decision not to tell her grandmother the truth, highlighting the cultural tensions and ethics underlying truth-telling and autonomy. In many East Asian cultures, discussing death is considered taboo, rooted in the belief that speaking something aloud will bring it into existence.

Following PRISMA-ScR guidelines, the databases PubMed, Web of Science, and China National Knowledge Infrastructure were searched for papers related to Chinese culture, truth-telling, and end-of-life care. 88 studies were identified initially, and 21 duplicates were removed. Two reviewers independently performed title/abstract screening and full text screening. A total of 30 studies were included for the scoping review.

I identified three themes from *The Farewell* for healthcare professionals, including (1) truth-telling and disclosure, (2) family-centered decision making, and (3) cultural definitions of a "good death." Some studies found that truth-telling could worsen psychological outcomes for patients, while others found a growing preference for transparency, indicating mixed perspectives even within the same culture. Studies also found that family members are highly involved in decision making because illness is seen as a shared burden, not just something that impacts the individual. Lastly, the literature explains that talking openly about death is often avoided, shaped by philosophies like Taoism, Confucianism, and Buddhism, which discourage fixation on the afterlife or dying process. A "good death" in Chinese culture often centers on maintaining emotional harmony, minimizing burden, and dying at peace with family around, not necessarily on disclosure or control. Overall, these findings highlight that cultural values deeply influence how truth-telling, autonomy, and compassion are perceived. Instead of "do unto others as you wish them to do to you," a cross-cultural Golden Rule urges healthcare professionals to "do unto others as a kind person in that culture would do unto you."

This work contributes to broader conversations about fostering cultural humility in medicine. Compassion in medicine is not one-size-fits-all. By exploring different cultural understandings of compassionate care and a "good death," healthcare professionals can adopt more nuanced and respectful approaches, help reduce disparities, and build trust within diverse patient populations, especially when navigating difficult conversations about end-of-life care.

LOVELAND SWANSTROM

**Disability, Medicine, and Sin: Thou Shall Not Blame God or Moral Failings for Disabilities**

Julie Loveland Swanstrom, PhD

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One persistent explanation of disability ties disabilities to some moral failing or disobedience of the divine; while the medicine points elsewhere, it is worthwhile discussing how the religion also typically pointed elsewhere (other than sin) to explain a patient's specific disabilities. Neither Christian nor Muslim religious practice, historically, entails that a patient's disabilities are from the divine. The development of the idea that someone's specific disability is caused (or allowed) by the divine takes a twisted path in Europe involving witches, Satan, and personal responsibility. Christian thinkers such as Augustine and Aquinas focus more on the initial human disobedience of God to explain how disability became possible in general, but they do not blame individuals for their own disabilities. They each discuss both the origins of disability and the permanence of it, considering whether individuals will retain their disabilities at the end of time. Muslim thinkers Ibn Sina and Al-Ghazali address the limits of the human condition, but, again, they do not blame the development of specific disabilities on the individuals who have them. The movement from such key thinkers in Christianity and Islam rejecting the notion that individuals have disabilities or become disabled due to moral failing(s) reflects the social, religious, economic, and environmental instability in Europe during the latter medieval period. In Europe, especially with the rise of Christian articulations of Satan and Satan's power from the 1200s CE forward, Satan's corrupting influence—which eventually gets connected to a person's (or that person's parents') moral failings—becomes an explanation for why certain people have certain disabilities. People with disabilities were shunned, cast out, or harmed by community members in the name of moral purity at times, all in an attempt to rebuke Satan's power. Satan's power could be seen at work in those who are not virtuous, and thus Satan's power and influence began to be equated with both moral failings and physical or mental disabilities. In the early modern period, references to Satan become startlingly more frequent—most witch trials occur in the early modern period, for example—and then infrequent, though the connection between moral failing and physical/mental disability remained. The thought that some moral failing explains why someone has a disability has been pervasive to the point of influencing medical treatments, recommendations for approaches to disabilities, and public medical policy. Because ideas connecting disabilities to moral failing(s) have been so persistent in America, awareness of the origins of this idea—including the awareness of how far removed from religious practice this idea was in general—can help people spot and debunk variations of the idea. Awareness that the majority of Christians and Muslims do not necessarily hold such a view of disability can support medical practitioners as they engage with patients.

LOWELL

**Reframing Identity: Stroke Survivors' Agency in Navigating Disability and Recovery**

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Loneliness and social disconnection disproportionately affect individuals with disabilities. Stroke survivors—individuals who experience a non-lethal stroke—experience significantly higher rates of loneliness and social isolation. Previous work shows that stroke survivors experience identity changes concerning their physical capabilities, social role, and relationships after having a stroke, often as they face new physical disabilities and dependence on others. Although much scholarship examines psychological distress, caregiver burden, and social isolation that follow stroke, comparatively little work centers on stroke survivors' agency in reshaping their identity as both individuals and community members as they navigate stroke symptoms and potential disabilities.

I argue that core to understanding changes to identity after a major health event is examining personal agency, including capabilities, perceptions of connectivity, and possibilities of reshaping one's identity. By centering stroke survivors' agency during the recovery process, I pull from philosophies of disability ethics and body aesthetics; I suggest that stroke survivors' disabilities and post-stroke symptoms may be understood as opportunities for reframing identity and creating new forms of self-expression and movement adapted to stroke survivors' needs and changing physical capabilities. On this view, stroke survivors should be recognized as the agents of reforming their identity as individuals capable and worthy of engaging with others and with the world around them.

Furthermore, I argue that centering stroke survivors' agency in reshaping their identity and managing their stroke symptoms is integral to improving recovery. An agency perspective advocates for forming support groups for stroke survivors that aim at enhancing social connection and promoting the exchange of ideas, experiences, and novel approaches to managing stroke symptoms and disability among stroke survivors themselves.

Such groups may enhance survivors' resources for navigating the effects of their stroke while affirming their sense of agency in forming new ways of expressing themselves and interacting with others, such as communication methods with community members and strangers unused to speech patterns affected by stroke. Notably, providing stroke survivors the opportunity to engage with others who identify with their experience in a dedicated support group has been demonstrated to reduce loneliness. By connecting with others navigating identity changes, stroke survivors may generate new understandings of agency. This often-unseen aspect of recovery is essential to consider since healthcare settings are known to foster "othering" of identities, especially among patients with disabilities.

Finally, I argue that healthcare centers should provide the social infrastructure, i.e., physical space, labor, specialists, and funding, to support this crucial aspect of recovery that centers stroke survivors' agency in guiding identity change. The opportunity to develop new language regarding their stroke, obtain new information, and build new relationships should enrich survivors' worlds and more fully integrate them into a world in which they belong.



LUNT

## **Evaluating Future Selves in Clinical Decision-Making: A Pragmatist Perspective**

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When patients are asked to make medical decisions, that decision is often framed as a question about the patient's current values and preferences: "Based on your present values and life goals, how would you assess medical options A, B and C?" The implicit assumption is often that the patient should inform the care team (and perhaps their families) about their present values and goals, to guide and explain the decisions they make about healthcare.

The privileging of the patient's current values and goals is practically and morally supportable in most cases. The patient obviously does not have access to the values and goals they will have next year, or five years from now. Also, a concern for autonomy should lead physicians, nurses, and other clinicians to elicit the values and goals that patient actually has. If we make treatment decisions about the values and goals that a patient "should" have or "will" have, we risk of making paternalistic decisions that ignore the actual priorities a patient believes in.

However, some ethicists argue that a patient's future values and goals should also be considered when making certain treatment decisions. For instance, evidence shows that patients who receive early diagnoses of medical conditions that will lead to dementia often have catastrophic views of their future condition—when, in fact, dementia may allow for a greater quality of life, and a longer enjoyment of that quality of life, than the patient is currently able to imagine. The patient may not be able to anticipate how their own values and goals may shift, as dementia changes their capacities.

Similar tensions between our current and future selves show up in medical decisions about amputations, chronic pain management and genomic testing. The patient obviously does not know the values and goals that their future self will have, but some ethicists argue that we need to reframe the questions we ask patients: e.g., "Do you imagine your values and goals changing, as your dementia becomes more pronounced? How could we constructively explore what a 'good life' would look like, with dementia?" Creutzfeldt and Holloway conclude, "Because most patients adapt and find meaning in new health states, ensuring respect for the patient's future autonomy would require that clinicians describe not just possible future outcomes, but also the ability for most individuals to adjust to a new normal."

My proposal is to bring this bioethics debate about "future selves" into conversation with pragmatist ethics, which emphasizes the role of openness, experimentation and meliorism in our moral lives. American pragmatism has classically argued for an ethics that prioritizes inquiry: the ongoing evolution of our moral beliefs, where experience is allowed to constructively enter into our evaluation of our values and goals. Recent American pragmatists like Philip Kitcher and Robert Brandom may provide a fecund perspective on how clinicians should prompt patients to consider the values and goals of "future selves," and help us distinguish between paternalistic and non-paternalistic approaches to medical decision-making about dementia, amputations and certain genomic diagnoses.



MAGLIO

**Metaethics at the Margin: Disability in the Debate Between Aristotelians and Kantians**

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The standard operating principle in metaethics is to take as primary moral data cases that are the clearest, most common, or most certain. This principle operates in the metaethical theorizing of neo-Aristotelian Naturalists by generating species norms through biological observations that become the basis for evaluating behavior and functioning of individual organisms. This, in turn, is the logic that explains moral normativity in terms of the normativity of the human will. The claim is that there is an irreducibly biological mode of observation which is intrinsically normative, yielding norms about the organism's proper functioning, which in the human case includes facts about our sociality, rationality, and so forth. While Aristotelian Naturalists hold that generating 'natural-historical judgments' for evaluating species are neither statistical generalizations nor merely empirical judgments, it is unclear in certain cases what adjudicates among competing judgments.

In response to skepticism about life forms that might arise due to these epistemic concerns about difficult cases, Aristotelian Naturalists might reaffirm the irreducibility of life form judgments and their decisiveness in some cases. For example, the fact that we can have some life form knowledge, such as "Tigers have four legs" and "The purpose of the heart is to pump blood," is not negated by the fact that we might not know how to classify difficult cases about individual organisms that display atypical traits for their species (maybe even raising the question of species membership). As a result, my goal in this presentation is to argue for the importance of thinking about disability within this metaethical debate, both to highlight the ways in which marginalized groups have been epistemically disadvantaged in this conversation and to refresh our thinking about metaethical debates. I will argue that cases of disability represent a challenge to the evaluative norms of Aristotelian Naturalism and their supposed epistemic basis in biological observation. Some Aristotelians have responded by emphasizing the fact that Aristotelian Naturalism offers an empirically informed procedure for metaethics without entailing substantive claims about the human good that would exclude those with disabilities from flourishing. They have revised traditional Aristotelianism to accommodate human variation. I will argue that, while this revision offers one possible response, it still does not fully address the epistemic concerns with life form knowledge that questions about disability raise and make pressing. I will, in turn, consider whether a Kantian ethic might better diagnose these epistemic concerns and offer a more compelling story about the basis of normativity that avoids these worries. Thus, I will argue that a Kantian metaethic is better suited to explain a variation of human goods and forms than Aristotelianism. If successful, I will suggest a few implications for understanding how variation of bodies and abilities can importantly inform the content of a Kantian ethic and inform our duties to persons. I will address the remaining concern that the Kantian understanding of personhood as rational being excludes persons with intellectual disabilities from moral consideration.

MCBRIDE

## **Does Honoring Assent Really Respect Participant Preferences and Values?**

Mary McBride

The Ohio State University, School of Health and Rehabilitation Sciences

Processes of representative consent and individual assent for those with intellectual and developmental disorders (IDD) in the research context are intended to protect such individuals from the inherent power imbalance existing between participants and researchers. However, despite their protective aims, these processes often lead to exclusionary practices by researchers, limiting opportunities for individuals with IDD to reap the same benefits from research as other, less vulnerable populations. With reduced access to research participation, the development of knowledge and medical interventions for those with IDD may be restricted, thereby perpetuating existing disparities faced by people with disabilities.

Current conversations in research ethics heavily emphasize relying on participant assent as the solution to such exclusionary research practices. Assent is often regarded as the most respectful means of honoring one's preferences and values, and many bioethicists view the process as a compassionate way to maintain participant dignity. Yet, while such arguments are well-intended, we propose that the extent to which assent serves as a remedy to the exclusion of those with IDD in research is unclear.

We argue that individuals who lack the capacity to provide consent often do so because they struggle to make decisions which align best with their preferences and values. This misalignment is especially relevant when considering situations in which short-term and long-term desires are weighed, as some individuals with IDD may struggle to consider the rippling effects of their decisions. There may also be an inability to relate present decisions with deeper beliefs and values. We explore this phenomenon through multiple case examples.

Since children and individuals with IDD share similar protection protocols, we call upon pediatric research examples to examine how assent applies in populations unable to provide their own informed consent. Additionally, we utilize research-based examples involving individuals with mild to moderate IDD to ensure our ideas remain consistent in the relevant context. These cases are meant to show that assent does not always reflect a participant with IDD's true preferences or values. It follows that assent is likely not well suited to serve as the primary solution to exclusionary research practices.

The aim of this piece is not to argue that assent is unimportant. We are not advocating for individuals with IDD to be forcibly involved in research despite their lack of agreement. Rather, we are attempting to highlight the complex and potentially misunderstood relationship between assent and a participant's genuine preferences and values. By doing so, we hope to encourage a more nuanced and inclusive approach to research ethics involving individuals with IDD.

## **Medicine and the Capitalist Contract**

Jonathan McCabe, MBE  
University of Michigan Medical School

Within the history of medicine, there have been unique shifts in the conceptualization and norms of patient-doctor relationships. In the modern context, however, this relationship has become strained. This paper argues that the degradation and modern tension of the patient-doctor relationship is due to the replacement of a social contract between doctor and patient with a metaphorical capitalistic contract. This shift represents a move from a relationship grounded in professional obligation and respect for others to one that fixates on buyer-seller dynamics.

Discussion around contractualism within medicine is not new, as it has been a major medical ethics theory. However, the substance and expectations of these contracts have changed in modern times. This transformation has arisen due to two main developments: first, the diffuse integration of capitalism into medicine; and second, the conflation of consumer empowerment with increasing patient autonomy.

Capitalistic practices have been intertwined with medicine for millennia, but the industrialization of health and its subsequent effects have created an economic environment of hyper-commodification and depersonalization. As capitalist practices have become institutionalized through corporate healthcare systems, insurance markets, and efficiency metrics, the doctor-patient relationship has been reframed by economic incentives rather than ethical obligations.

In parallel, the rise in patient empowerment as a consumer of health has also contributed to this new form of contractual relationship. The emphasis on patient empowerment is not without justification, as historical injustices, perpetrated by the research and medical industries, have underscored the need for individuals to make informed and fair decisions. However, beginning with Beauchamp and Childress, a distinctive shift occurred in the conceptualization of respect and autonomy. The Belmont Report originally demanded respect for persons, but Beauchamp and Childress reframed this as respect for autonomy. As a result, the focal point of respect that was central to healing from these injustices was altered. This focus on autonomy was absorbed into the logic of the capitalist space and a concentration on choice as a patient-consumer was placed at the forefront. This reorientation of autonomy, when combined with the industrialization of healthcare, contributed to the rise of consumerism in medicine and now a capitalistic contract between doctor and patient.

These two aforementioned points have contributed to a contractual shift in the patient-doctor relationship. Moving from a social contract to a capitalistic contract marks another phase in medical ethics, one in which the clinical encounter is dictated not by moral duties, but by transactional services. This change in definition of the clinical relationship has implications on who is defined as a patient and what our duties are as healthcare providers.

MCCOOG

**Shared Wisdom: Documenting and Preserving the Oral History of Retired and Retiring  
Healthcare Practitioners**

Ian McCoog, Ed.D.

Jenna O'Donnell

Jordan Salvato

Geisinger Commonwealth School of Medicine

What do you do with the questions you want to ask after a person is gone? The authors of this study experienced this conundrum firsthand and decided to document the stories of retired and retiring healthcare practitioners in order to document their experience and share their expertise with future generations. In addition to archiving interviews, the researchers are analyzing transcripts to identify themes that express commonalities in practitioners at the end of their careers.

This is a qualitative research study that involves interviewing retired and retiring healthcare practitioners and identifying themes that develop through the coding of data. The team also hopes to archive records of the interviews for future medical students, families, and friends of those interviewed. The study has progressed from the identification of storytelling's role in medical humanities, through the development of the initial 20 questions for participants to choose from, to interviewing 20 participants, and to the analysis of nearly 40 hours of recordings and transcripts.

The study emphasizes the significance of narrative in medicine, fostering empathy, compassion, and understanding. This research highlights the value of oral history in healthcare, emphasizing the role of narrative in facilitating conversations and preserving collective wisdom. The outcomes of this study contribute to medical education by adding to the body of literature on narrative-based medicine and fostering patient-centered practice in medical students in addition to ensuring the transmission of valuable knowledge.

### **Addiction as Social Pathology**

James Mollison, PhD

Purdue University, College of Liberal Arts

I suggest addiction can be understood as a social pathology. My discussion has four sections. Each section receives a paragraph below.

On the moral model of addiction, (1) substance use is a choice (2) meriting moral condemnation. Empirical studies suggest (1) is false: psycho-sociological factors make some more disposed to addiction than others and some addicts struggle with physical dependence. The disease model of addiction denies (1), analyzing substance use as a neurobiological compulsion. But this approach belies cases of recovery and denies addicts' standing as rational, responsible agents. In response to this apparent dilemma, recent work on addiction pursues some middle ground between the moral and disease models.

Consider Pickard's influential account, on which individuals might continue substance use – not due to moral failure or biological compulsion, but – because identifying as addicts secures social benefits – e.g., community, pride regarding functional use, social cachet from violating norms, and so on. Pickard is especially interested in people who lack a sense of self apart from identifying as 'addicts.' For such individuals, adorning the label 'addict' might be "a barrier protecting against the experience of looking inwards and finding, not a stable, core sense of self as positive and morally good, but only a dark and empty void where that self should be" (Pickard 2020: 751). As recovery poses an "existential threat" to such individuals, Pickard recommends that (i) 'addiction' be replaced by 'persons with substance use disorders,' (ii) psilocybin-therapy to uncover alternate senses of self, and (iii) addicts cultivate imagined selves worth pursuing (752-54). In contrast with the moral and disease models, such an approach purportedly addresses how addiction benefits people in harmful social circumstances without "getting [the rest of] us off the hook" (754).

Despite its attractions, Pickard's view replicates the moral model she otherwise seeks to avoid. In particular, the 'authentic self' which she seeks to cultivate among addicts is arguably nothing other than the internalization of socially enforced, moral norms – which presuppose a 'true' self to make moral accountability possible (Nietzsche D 109; GS 354; GM I:13; TI 'Errors'). From this vantage, Pickard's concluding recommendation that "we should not let ourselves off the hook" (2020: 754) amounts to a moral condemnation of society for failing to inculcate a 'deeper' or 'authentic' sense of self within so-called addicts. Pickard's analysis, in other words, does not avoid the moral model of addiction as much as it expands the moral model to society generally.

Instead of extending the moral model to demonstrate society's moral failing, I propose that addiction be understood as a social disorder. Disorders, unlike diseases, require contingent background conditions. (Cancer is a disease in most proximate, possible worlds; color-blindness and dyslexia aren't.) In particular, extant models of addiction presuppose that individuals are substrata with libertarian freedom. Abandoning this presupposition generates a social account of addiction. This, in turn, suggests unique approaches to recovery and rehabilitation – where (i) grammatical conventions, (ii) psychedelic-use, and (iii) imaginative aspirations can be used to resist the substantial self-assumed by the moral model.

MUCKIAN

**Bereavement As a Social Determinant of Health and Physicians' Role in Addressing It**

Claire Muckian

Nyla Hart

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Losing a loved one—a social property—affects a person's health. But bereavement and grief have been overlooked in medicine as social determinants of health. Recently, some have proposed that bereavement be considered a social determinant of health, due to the wide array of long-term physical health, mental health, and social consequences it has on the bereaved. However, the body of work on physicians' responsibilities to address bereavement in the care of their patients is limited. Historically, bereavement care is provided only insofar as it is connected to the care of the dying patient. After the patient's death, the family is abandoned by the healthcare system and is expected to complete the grieving process on their own and return to society. With knowledge of the long-term effects of bereavement, physicians should instead approach bereavement as they do with financial instability, food deserts, discrimination, unsafe environments, and low educational attainment. That is to say, with an eye toward the developmental effects and diseases they are at risk for, taking care to implement risk-reducing and early-diagnosis measures. We propose that bereavement screening should be implemented in both outpatient and inpatient settings as a means of triggering clinicians' awareness of other conditions for which the bereaved are at risk. For example, a positive history of bereavement may trigger conversations related to depression, addiction, heart disease, and more. Additionally, this may prompt connection to community resources that can address the social risk factors that exist beyond the scope of medicine. Earlier investigation, recognition, and management of these adverse consequences can reduce the public health burden created by bereavement.

MUNTEAN

**Retain or Relinquish the Disunity of Psychiatry? Values, Facts in AI, Datafication, and Precision Medicine**

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How do disruptive technologies drive general progress, especially in its scientific and social dimensions? Two recent, disruptive technologies with an impact on science and society are AI and datafication (e.g., Big Data). Psychiatry and psychopathology can be examined as scientific disciplines and as institutions with significant social, political, and legal power over society (Knox, Murphy). However, psychiatry is both an evidence-based and value-laden science, characterized by a diversity of theories, models, evidence, and goals. Interpretations of unity and disunity of psychiatry range from eliminative/reductive stances to varieties of 'pluralisms' (Popa, Mitchell, Van Bouwel, Radden). The debate is normative as it is about what psychiatry "should be," rather than what "it is". The question is how pluralistic one should be about pluralism (Feyerabend, Dupre, Cartwright) and how much disunity is too much and how much unity is needed?

This paper presents a conceptual framework that situates these technologies (AI and datafication) on a 'unity vs. disunity' map of psychiatry and psychopathology. There are areas of psychiatry where both technologies promise a significant transformation, including "digital phenotyping," "precision mental health," and "optogenetics," among others.

Insel thinks that some models in psychopathology are "brainless", and others are "mindless", while Rust argues that the psychopathology should ask about the proper target of treatment: the gene? The brain? The mind? Nothing but the social environment? Or all of the above? One can see that models in psychopathology (functional, organic, social, etc.) are divergent and contradictory.

We argue that the implementation of AI and datafication in psychopathology has the potential to contribute to the progress of psychiatry in a 'corrective' manner: to center pluralism within the right range of value and evidence pluralism, without discounting or overemphasizing the fact/values conflict. Implementing AI in psychopathology and mental diagnosis necessitates a reconsideration of the roles of values and evidence, which should be assessed against a background of core human identities situated in medical humanities, philosophy of science, and bioethics.

Therefore, a rectification of this imbalance between plurality and unity, based on AI and datafication in psychodiagnostics through "digital phenotyping" and "precision mental health," is foreseeable. As an epistemic feature of science, consistency in a fragmented field is desirable, without altering the plurality of models, explanations, and predictions. To rectify the fault lines in psychiatry and gain more trust in the discipline itself cannot be done by two technologies alone, without a deeper analysis of the values, methods, and evidential support needed for a diagnosis.





OZTURK

**Misgendering, Linguistic Difference, and Epistemic Injustice: A Perspective on  
Neurodiversity and Moral Blame**

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An influential strand in contemporary academic discourse treats misgendering as an indicator of bias, hostility, or rejection of the gendered person's self-identification. While some label these mistakes as instances of epistemic injustice or even acts of violence toward trans people, I argue that rigid interpretations of linguistic error without contextual sensitivity risk becoming a different kind of harm. This is not epistemic injustice in the Frickerian sense but rather a case of moral misrecognition rooted in cognitive essentialism. While the framing in question is undoubtedly well-intentioned, it conceptually and empirically overreaches and overlooks the role of cognitive and linguistic diversity in linguistic performance.

This presentation uses the author's experience as a fluent but non-native speaker of English who learned the language as an adult as a steppingstone for a reframing of the issue that generalizes to other related contexts. Despite persistently trying to use others' preferred pronouns in conversation for years, he still frequently misuses gendered pronouns in speech, including when referring to his unambiguously cisgender wife and biological children. Given their generality, these errors are unlikely to be caused by bias, hostility, or unconscious disbelief toward trans people and their identities. A more plausible explanation of such systematic errors locates the causation in the structural influence of the author's native language (Turkish), which lacks grammatical gender. Turkish uses a single, ungendered pronoun ("o"), does not mark nouns for gender, and does not draw a pronominal distinction between people and objects. These features shape how native speakers of Turkish and similar languages (e.g., Japanese, Hungarian, and Finnish) involuntarily process and retrieve referential linguistic representations of gendered beings. Yet they are rarely recognized or factored within English-dominant cultural, professional, and academic settings, especially when the non-native speaker is otherwise fluent.

Similarly, and more generally, in contexts involving disability, neurodiversity, age, trauma, or non-native speech, pronoun errors should be interpreted with care. Treating all instances of persistent misgendering as suspected moral wrongs ignores how the individual idiosyncrasies of memory, attention, and linguistic architecture shape involuntary linguistic behavior, hence, risking the moralization of neuro-linguistic noise.

Therefore, there is a need and room for a contextualized approach to the moral evaluation of gendered language. Such an approach is already broadly supported by available empirical evidence from cognitive neuroscience on language learning and use, and it is situated within broader concerns in medical humanities, especially around the ethical treatment of cognitive and communicative differences in clinical and interpersonal settings.

Recognizing that misgendering can arise from linguistic or cognitive differences does not excuse disrespect or other forms of mistreatment. Rather, it allows us to identify the relevant harms more precisely and address them with greater moral and clinical clarity.

PARK

**“Lives Unworthy of Life”: Medical Power, Disability, and Historical similarities between Nazi Germany and America**

Jina Park

Philadelphia College of Osteopathic Medicine

During the Holocaust, over 300,000 disabled individuals—both children and adults—were systematically murdered or sterilized under the Nazi regime’s so-called “euthanasia” initiative known as Aktion T4. Far from being ethical acts of violence, these killings were orchestrated and legitimized by physicians who employed scientific and medical rhetoric to classify disabled lives as “unworthy” and “harmful” to society. This abstract examines the complicity of medical professionals in these atrocities, drawing from works such as Suzanne Evan’s *Forgotten Crimes: The Holocaust and People with Disabilities* (2004) and Emmeline Burdett’s *Disability, Nazi euthanasia, and the Legacy of the Nuremberg Medical Trial* (2023).

These books pursue two primary aims. First, it investigates how the medicalization of disability facilitated mass violence in Nazi Germany. Second, it explores how similar ideologies echoed across the world through late 19th-century to early 20th-century American eugenics. Notably, U.S. physicians and lawmakers created forced sterilization laws—such as those upheld in *Buck v. Bell* (1927). This law directly influenced Nazi legal policies. These parallels reveal a disturbing time in the devaluation of disabled lives through the lens of medical authority.

Grounded in historical analysis, survivor testimony, and contemporary disability scholarship, the literature challenges prevailing narratives around medicine’s role in shaping societal values. It critically examines the ongoing legacy of the “medical model” of disability, which tends to view disabled individuals as deficits that need to be corrected. In contrast, there are highlights such as the development of the social model of disability, the emergence of disability justice movements, and key legal milestones such as the Americans with Disabilities Act (ADA) established in 1990. Together, these frameworks highlight both progress made and the challenges that persist in combating ableism within healthcare.

These topics hold particular significance for medical students, clinicians, and educators. It underscores the importance of understanding historical contexts that have shaped modern medical ethics and reinforces the need for culturally adept and inclusive care. By reflecting on this history, future healthcare professionals are better equipped to recognize and dismantle harmful narratives—especially those masked in medical jargon—that continue to influence medical practice today.

PETERSON

**Rethinking Disability Technologies: How Invisible Disabilities Reveal the Limits of Narrative Identity**

Mack Peterson

Division of Bioethics, Department of Biomedical Education and Anatomy, College of Medicine, The Ohio State University

Curative technology is often criticized for treating disability as something to be fixed, which many argue is morally inappropriate. This view holds that disability is not a defect, and efforts to cure it create a new person, essentially killing the original person. These concerns highlight the importance of distinguishing curative from assistive technology.

Stramondo critiques traditional distinctions between assistive and curative technologies—such as restoring “normal” function or being physically incorporated into the body—as insufficient. Instead, he proposes that the difference lies in the narrative identity a technology confers. Assistive technologies (e.g., wheelchairs, prosthetics, or closed captions) enhance function while affirming the user’s identity as a disabled person. In contrast, curative technologies (e.g., LASIK, antibiotics) aim to eliminate or “fix” the disability, thereby erasing the disability identity and severing ties to associated communities and cultures.

However, Stramondo’s work does not fully bridge the gap in current literature by addressing how these identity-related dynamics affect individuals with invisible or less visible disabilities. AirPods can be seen on a person and are not automatically assumed to be an assistive technology. AirPods can serve as an audio enhancer and as a way for a person to block out sounds. The same goes for sunglasses. It can be used for a person with autism when the sun is overstimulating, or for someone who is just sitting outside and doesn’t want to strain their eyes. A complete definition of disability technologies cannot solely lie in the narrative identity the technology confers because not all technologies can do that. Invisible disabilities are still disabilities, and while they do not imply disability on a person, they are still a part of this person’s identity.

PINILLA-BAQUERO

**Practicing Medicine at a Different Speed: Embracing Slow Processing, ADHD, and  
Neurodiverse Identity**

Alejandro Pinilla-Baquero  
Martha Garcia-Osorio, MD, MSc  
Universidad Central Del Caribe

In the fast-paced culture of medical training, where there's barely time to find your footing, a clinician's value is often measured by recall speed, multitasking, and rapid decision-making. These aren't just expectations, they're ideals. For students like me, diagnosed with Attention-Deficit/Hyperactivity Disorder, Inattentive Presentation, this framework doesn't just challenge us, it can create shame. It often erases the lived experience of learning with a cognitive disability. A recent neuropsychological evaluation placed my processing speed in the 18th percentile, revealing impairments in attention, working memory, and sustained focus. But that wasn't a failure. It was an explanation. What changed wasn't my brain, it was the permission to understand it differently.

Drawing from the philosophy of mind, I began to reflect on how my identity in medicine had been shaped by internalized mental models, what I thought thinking "should" look like. My neuropsychological diagnosis became more than a clinical label. It became an epistemic permission—a philosophical and personal shift that allowed me to accept and legitimize my cognitive rhythm. Once I saw slow processing as valid, my reality changed. I stopped resisting how my mind worked and began working with it.

This presentation explores what it's like to navigate medical school with slow processing, and how I came to view disability not as deficit, but as a different cognitive rhythm. One of the most transformative supports was mentorship. Meeting regularly with someone outside the noise and pressure of medical school gave me space to reframe my reality. My mentor didn't just offer study tips, they taught from the ground up, used storytelling, explained concepts step by step, and offered genuine encouragement.

I'll share how this mentorship restructured my learning. How storytelling, written instructions, and tailored strategies helped me study more efficiently and with less burnout. But more than academic success, this experience deepened my empathy—for patients who struggle to communicate or feel left behind, and for peers who face their own invisible barriers. I stopped forcing myself to match the system's pace and started listening to my own. I discovered a kind of attention rooted in patience, clarity, and depth.

Invisible disabilities remain widely overlooked in medical education. Recognizing neurodiversity requires more than accommodations, it calls for cultural change. We need a more inclusive vision of training, one that respects different ways of learning and thinking, and that finally lets go of the myth that speed equals competence.

Through personal stories, from both student and mentor, philosophical reflection, and lessons learned so far in medical school, this presentation invites us to rethink how we define ability. It's a call to embrace difference and, in doing so, build a more compassionate approach to care.

PRIJATELJ

**Telling Lives Differently: Disability and Narrative Identity**

Erika Prijatelj, PhD

Hellenic College, Psychology & Human Development Program  
University of Ljubljana

This presentation examines the construction of narrative identity in the context of disability, drawing on the theoretical framework and empirical contributions of Jonathan M. Adler. Narrative identity refers to the evolving internalized story individuals construct to make sense of their lives, linking past experiences with present meaning and future possibilities. Within disability discourse, however, these stories often develop in tension with dominant cultural narratives that valorize independence, productivity, and linear development.

Adler's work highlights the psychological importance of narrative coherence and agency—but also urges a rethinking of these constructs through the lens of lived difference. For many individuals with disabilities, identity is not shaped in isolation, but through relational interdependence, adaptive meaning-making, and resistance to stigmatizing master narratives. In this light, psychological well-being may be more accurately supported not by promoting autonomy alone, but by affirming interconnection, community, and multiple forms of agency.

By centering disability within narrative psychological research, this presentation challenges reductive models of development and mental health, and invites new possibilities for therapeutic practice, educational engagement, and inclusive identity formation. It asks: what happens when we tell lives differently—and listen accordingly?



RESPESS

## **Embodied Social AI: Personal Robots for Aging at Home**

Shaun Respass, PhD

NC State, Department of Philosophy and Religious Studies

Carebots – robots with social intelligence that respond to the needs of their users – are a promising technology for assisting elderly persons with everyday tasks, medication/schedule reminders, and emergencies. Several studies claim that carebots might be socially and psychologically beneficial for elderly persons and would extend the time that they can safely remain in their homes. However, research into the use of social robotics in the context of cognitive conditions such as mild cognitive impairment (MCI), which impacts memory and decision-making, is inadequate. Furthermore, prior work has not systematically examined the unique perspectives of this population and their (formal or informal) caregivers. In this project, we developed interactive social protocols for a humanoid Pepper robot and acquired pilot qualitative data on user perceptions. Participants from these groups engaged in simple and expanded conversations with the robot in order to gauge its efficacy, social skills, and adaptive responses before then completing semi-structured interviews. These interviews were then examined for thematic relations prior to coding. In this presentation, I outline our process for robotics development and participant interactions, including the use of innovative technologies like large language models (LLMs), as well as communicate the initial findings of the research. The data from this study first demonstrates the wide range of acceptance, apprehension, curiosity, and cooperative behaviors of participants, identifying the need for embodied AI systems to adapt their behavior according to a user's social needs and proficiencies. Second, it confirms the desire for greater physical capabilities for common use, as many describe it as an enhanced version of an AI virtual assistant. Third, the study informs the need for a pluralistic, computational ethics design that accounts for real-time moral intuitions in order to balance respectfulness and practical goals. Improvements in social robotics could radically change the prospects of caring for a rapidly rising population.

RICH

### **Bricks and Brakes: Masculine Metaphors of Abortion**

Leigh Rich, PhD

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In 1988, presidential candidate George H.W. Bush called for “a kinder and gentler nation” — encouraging Americans to take up “public service,” “celebrate[] the individual” without being “self-centered,” and serve others through “reliable love” — despite it being “soft and insufficiently tough to care about these things.” This more “feminine” approach to politics, however, also coincided with the Gulf War, an increase in neoliberal policies, and the appointment of Clarence Thomas to the Supreme Court, which in 1992 eroded the constitutional right to abortion established in *Roe v. Wade*. For the first time in two decades, states could regulate abortion at any point in pregnancy, and conservatives began promoting laws creating obstacles for patients and providers. Like the Roman god Janus, the 1990s appear two-faced: gazing in a “kinder” direction with third wave feminism and Judith Butler’s *Gender Trouble*, while eyeing the return of patriarchal orthodoxy through the Federalist Society and the GOP’s Contract with America. In this double-vision, an interesting trend in music emerged: a peak in abortion-related songs, particularly by male musicians. These songs simultaneously present emotional, inward-looking explorations while using metaphors that, on certain readings, objectify women as emasculating drags. For example, Ben Folds Five’s “Brick” and Del Amitri’s “Driving with the Brakes On” might depict the powerlessness of men “drowning slowly” under the weight of a woman’s reproductive decision and no longer in the driver’s seat. Through the lens of Butler’s philosophy, however, the songs offer a poetic exaggeration akin to drag: male protagonists engaged in heterosexual reproduction performing in a “feminine” way — expressing passivity, uncertainty, prioritizing the needs of others, and “standing by your (wo)man.” Like drag, these metaphors produce ambivalent “spaces in which those annihilating norms, those killing ideals of gender and race, are mimed, reworked, resignified” and open up new possibilities of the “terms by which subjectivation proceeds — and fails to proceed.” But as Butler notes, “parodying the dominant norms” may not be “enough to displace them,” and “the denaturalization of gender [may] be the very vehicle for a reconsolidation of hegemonic norms” — as demonstrated in the 2022 Dobbs decision and recent anti-LGBTQI+ policies. With abortion (and gender), however, even speaking the subject is a political act, and such songs engaged a subversive repetition allowing men to be “kinder and gentler” with their partners and themselves and slow down for occasions that, per Carol Gilligan, challenge “reconcil[ing] the disparity between hurt and care.” Nineties abortion songs, like Anita Hill’s testimony in Thomas’s confirmation, initiated movements holding patriarchy to account that are under new assault today.



ROBINSON

**The Fiduciary Argument Against Conscientious Refusal in Health Care**

Michael Robinson, PhD

Chapman University, Philosophy Department

Sometimes health care practitioners are asked to participate in providing medical interventions that conflict with their religious or moral convictions. Prominent examples of this include physicians with conscientious objections to participating in physician-assisted suicide, nurses who object to facilitating abortions, and pharmacists opposed to filling prescriptions for emergency contraception. There are also many less well-known instances, such as obstetrics nurses who oppose participating in infant male circumcision (on the grounds that it is a medically unnecessary violation of the patient's bodily integrity), fertility specialists with moral qualms about providing in vitro fertilization to lesbian couples, Muslim physicians who refuse to conduct intimate examinations of opposite-sex patients, and clinicians with objections to providing any number of gender-affirming medical procedures to transgender patients (such as hysterectomies, hormone therapy, and top surgery). The question of when, if ever, practitioners' conscientious objections should be accommodated by permitting them to refuse to provide medical care to which they morally object is a heated issue that has received significant attention in the medical ethics literature in recent years. While the longstanding official policy of most medical professional organizations has been that such objections should be accommodated in a broad range of cases, a vocal and growing minority has been fervently arguing that the medical profession should cease accommodating conscientious objections and should rarely, if ever, permit clinicians to refrain from providing medical care on the grounds that it conflicts with their consciences. One of the most popular arguments offered by non-accommodationists focuses on the claim that conscientious refusal is incompatible with health care practitioners' fiduciary duty to put patients' interests ahead of their own. My aim in this paper is to show that, despite its initial plausibility, this argument is unable to withstand scrutiny. The fiduciary argument against conscientious refusal appears to face a dilemma. There is no fiduciary duty that is obviously incompatible with conscientious refusal that it is plausible to think health care practitioners actually have. There is a certain kind of fiduciary duty that it is plausible to think clinicians have—one that is similar to the fiduciary duties that lawyers, financial advisors, and other professionals in special positions of trust have toward their clients. But this kind of fiduciary duty is compatible with conscientious refusal. There are other, stricter or more encompassing, kinds of fiduciary duty that would obviously preclude conscientious refusal, but it is implausible to think that health care professionals actually (currently) have duties of this sort.

ROSEN

**Dreaming Vessels: Countering Acquisitive Medicine in the Novels of Louise Erdrich and Cherie Dimaline**

Rebecca Rosen, PhD

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In this paper, I will discuss how three works of Indigenous medical science fiction—Louise Erdrich’s (Ojibwe/Turtle Mountain Chippewa) *Future Home of the Living God* (2017) and Cherie Dimaline’s (Métis/First Nations) YA novels *The Marrow Thieves* (2017) and *Hunting By Stars* (2021)—explore issues of embodied BIPOC sovereignty through the lenses of reproductive rights and genetic engineering. In *Future Home*, Cedar Songmaker/Mary Potts is an Indigenous woman operating at the nexus of three realities that threaten her bodily sovereignty: the reversion and mutation of global species in the wake of climate change; her compromised self-knowledge, brought about by an obscured story of adoption and lineage that only emerges in her adulthood; and by the attempts of an emerging, dictatorial church-state to hijack her body for several purposes. This church, loosely governed but represented by a figure who calls herself “Mother,” wants to monitor her gestating fetus; take the child that fetus will become; and to enlist Cedar/Mary as a “Womb Volunteer,” an unwilling gestational surrogate for embryos fertilized either before the great genetic reversion.

Although at first glance the peril that Cherie Dimaline’s Frenchie faces is quite different from Cedar’s—he lives in a world where First Nations people are being hunted by the settler population for their ability to dream—he is, like Cedar/Mary, an Indigenous subject who is perceived by settler scientists as impervious to genetic and biologically expressed mutation. In Dimaline’s novels, Indigenous bone marrow extraction and implantation is thought to rewire non-Indigenous subjects such that they can resume dreaming—an ability they have lost, leading to mental illness. I argue that both authors use medical science fiction frameworks to depict the evolving methods of settler institutions—rather than conversion and infection, these institutions covet and frame Indigenous bodies themselves as resources essential to the futurity of settler colonial society. As such, these novels not only identify but grapple with the ways Indigenous actors can resist bodily encroachment while searching for and creating new worlds, goals Cedar/Mary, Frenchie, and their communities achieve through organized medical and narrative resistance.

SARNECKI

**Everything, Everywhere, All at Once: Vaccine Distribution in the COVID-19 Pandemic**

John Sarnecki, PhD

University of Toledo, Department of Philosophy and Religious Studies

The development and early distribution of the COVID-19 vaccine was both a singular achievement and missed opportunity. In this paper, I argue that the consensus regarding the goals of an effective and morally responsible vaccine distribution program were often eschewed in favor of a reversion to the problematic pre-pandemic healthcare distribution practices. I examine the goals of vaccine planning in terms of the public health, economic and social impacts of a distribution plan against the “first come, first served” strategies that were ultimately employed. I maintain that the failure to implement a coherent top-down vaccine policy resulted in a proliferation of vaccine distribution programs that undermined efforts to combat the virus while also increasing pre-existing inequities in the healthcare system. The distribution of the vaccine according to a phased rollout strategy for individual groups often limited access to the vaccine for those most likely to suffer the worst outcomes of the disease. Future pandemic planning must learn from these outcomes and employ new technologies to limit the contagion and target at-risk groups most effectively.



SHA

## **Behind The Mask: Reimagining Pediatric Preoperative Care and Anxiety Through Gameplay**

Nidha Sha, M.S.

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Perioperative anxiety affects up to 60% of children, often leading to heightened pain, prolonged recovery times, and behavioral disturbances such as nightmares, separation anxiety, and aggression (Liu et al., 2022). Digital tools, such as video games and animated content, can offer non-pharmacological anxiety relief and have shown promise in easing children's distress (Oktaviani et al., 2024). Drawing on insights from child psychology, anesthesiology, and human-centered design, this project introduces a developmentally tailored, play-based video game for children aged 4-10, the age range most vulnerable to preoperative stress and most responsive to media interventions (Cheng et al., 2022; Chicas et al., 2023; Hou et al., 2023).

Informed by a human-centered co-design process, this game was iteratively developed in close collaboration with child life specialists, pediatric anesthesiologists, caregivers, and children themselves to ensure developmental appropriateness, engagement, and ease of use. Complementing the gameplay, an original soundscape composed by an inpatient music therapist enhances relaxation through rhythmic, child-friendly melodies and interactive audio cues, reinforcing breathing exercises and rewarding progress within the game.

The gameplay unfolds in two sequential phases that mirror the child's perioperative journey. In Phase 1 (Pre-op and Transport), the player guides a scuba diver avatar to pop floating bubbles and collect colorful fish, encouraging calm focus as the gurney moves through hospital corridors. In Phase 2 (Anesthesia Induction), the diver dons an anesthesia mask and the child is prompted to take deep, rainbow-colored breaths, each exhalation filling a virtual pot of gold—reinforcing slow, focused breathing. By offering playful, goal-directed challenges, combining guided breathing with instant rewards, the game cultivates mastery and calm in young patients.

Optimized for both the preoperative holding area and transport to the operating room, it seamlessly integrates into perioperative routines to guide children through interactive tasks from arrival through induction. Its flexible structure accommodates varying surgical workflows and time constraints, ensuring seamless integration into standard perioperative routines. For patient transport, a portable projector casts the game onto the ceiling above the gurney or onto a bedsheet stretched out in front of the child, enabling uninterrupted play even as they're wheeled through the corridors.

By integrating principles from child life, media studies, and clinical care, this project advocates for media interventions that meet children where they are: through play. It supports the role of interactive storytelling in pediatric care, highlighting how media can offer agency, familiarity, and calm in moments of fear.

SIDZIŃSKA

**Biological Individuality in Pregnancy: An Argument from Biomedical Practice**

Maja Sidzińska, PhD

University of Pennsylvania, Department of Philosophy

Pregnant mammals, including pregnant human beings, are unique biological individuals that instantiate a transient level of biological organization which falls between the organismal and population levels. I offer a pragmatic argument for this thesis: the argument from biomedical practice. In my view, the pregnant mammal, understood as inclusive of the maternal and fetal entities, is a single biological individual because certain clinical interventions into either the maternal or the fetal entity generally directly affect the other. And successful interventions reveal the boundaries of biological individuals. I demonstrate this point by briefly explaining James Woodward's interventionism (2003), and by providing a detailed discussion of successful treatments for gestational diabetes mellitus (GDM). GDM is treated with insulin injections into the maternal entity, yet these injections treat macrosomia and prevents neonatal hypoglycemia in the fetus. The treatment of macrosomia and the prevention of neonatal hypoglycemia in the fetus could not occur—or could not occur as efficiently—were it not for the biological individuality of the pregnant mammal.

In my paper, I first clarify what is at issue, discuss other approaches to the question of biological individuality in pregnancy, and explain the interventionist thesis (Section II). Next, I make the argument from biomedical practice, with a focus on gestational diabetes mellitus (Section III). I contextualize my argument by showing its fit within the framework of promiscuous individualism advocated by John Dupré (2012)(Section IV). Finally, I conclude by suggesting what's at stake in the question (Section V). A prominent normative issue at this intersection of metaphysics, philosophy of biology, and philosophy of medicine is the theoretical neglect of pregnant bodies. My argument resolves a problem in debates about how many organisms there are where there is a pregnant mammal (Smith and Brogaard 2003; Kingma 2020; Grose 2020; Meincke 2021; Geddes 2023), and it has implications for how we understand the agency, autonomy, and consent in the context of maternity care.

SMITH

## **Death as a Process: Some Lessons for Medical Ethics from Process Ontology**

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Questions still swirl around transplantation technology. The whole brain death definition of death, although widely encoded in law and policy, remains deeply controversial, morally and medically, and the creation of new methods, like thoracoabdominal-normothermic regional perfusion (TA-NRP), are also met with moral and medical challenges. Given this whirlpool, a new way of approaching might help to alleviate the problems. The goal of this paper is to show how process ontology might provide avenues for responding to these challenges.

First, process biology sees the world as made up of stable but dynamic processes rather than static objects. Organisms are interconnected processes that are essential to maintain homeostasis. Organisms must maintain themselves, and to do so, they take in nutrients from the environment, turn those nutrients into both energy and material building blocks through metabolism, use that energy and material to maintain itself while expelling waste back out into their environment. All of this must be done in a way that allows the organism to maintain a steady state lest the organism succumb to entropy.

This turn to process should help us to solve one of the standard problems for Whole Brain Death—the fact that biological processes, like metabolism, continue after the loss of whole brain functioning. In the most striking example, a pregnant woman properly diagnosed as brain dead was able to successfully maintain the pregnancy with the help of life support. Such continued biological functioning appears to be at odds with the notion that the whole brain is required for integrated biological functioning, as the definition requires.

Seeing human beings as processes allows us to respond to this problem. Biological processes are distributed throughout the body. Such processes can continue after the loss of whole brain functioning, yet they fail to play their role within the organism—the overall activity of the human being. As such these processes are no longer integrated into the functioning of the organism. So, some process might linger on, but integrated functioning is lost because the brain, the organ that integrates and controls these functions, has ceased functioning.

In addition, this argument might help clarify ethical controversies surrounding TA-NRP. For TA-NRP, patients are declared dead after they have been removed from artificial means of support and cardiopulmonary function ceases for the five-minute “hands-off” period. Critics maintain that TA-NRP patients fail to satisfy criteria for death—blood flow has returned with the use of ECMO and patients retain some potential brain function. Thus, removing vital organs violates the Dead Donor Rule (DDR).

TA-NRP patients were shown to lack integrated functioning through the hands-off period, given the lack of spontaneous restart of the heart. Starting ECMO does not reverse these lost processes and return integrated functioning to the body. The occlusion that occurs should not be seen as blocking the reversal of functioning to parts of the body, but as allowing the cessation of functioning consistent with death to continue while ECMO helps to maintain the viability of vital organs for transplant.

STOYAN-ROSENZWEIG

**What do Health Professions Students Want to Read—and What Written Works do they Value?**

Nina Stoyan-Rosenzweig  
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Physicians and patients alike have long championed the importance of literature (and the humanities in general, of course) as a means of retaining empathy, developing wellness practices, and enhancing reflective, compassionate practice. For instance, Sir William Osler had a list of books that he believed all medical students should keep by the bedside to read daily[i]. Dr. Thomas Maren, faculty member and first chair of Pharmacology at the UF College of Medicine, funded the creation of a Reading Room where medical students would be able to enjoy music, poetry, classic novels, art-but they were not to study in this location. Dr. Maren had a background in comparative literature and believed that reading literature would help students become well rounded practitioners. By extension, access to leisure reading materials can benefit students in all the health professions, and academic health libraries are well positioned to provide materials in a central, neutral setting.

To learn more about student leisure reading practices and by extension, how libraries could support humanistic reading practices for students across the health professions, a team at the UF Health Science Center Library conducted a leisure reading survey of its users. These users include students from the six colleges in the Health Science Center, residents, post-doctoral students, and faculty. Participants were asked to discuss their leisure reading preferences, including books they found particularly significant in shaping their world view. This presentation includes discussion of the student responses and suggestions.



TAK

**Material Agency and Relational Ethics: Posthuman Encounters in Rebecca Solnit's *The Faraway Nearby***

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This paper examines how Rebecca Solnit's *The Faraway Nearby* (2013) transforms the understanding of caregiving relationships through posthuman ethics, in the process offering important insights for the medical humanities and clinical practice. Analyzing Solnit's experience of caring for a mother with dementia—a progressive cognitive disability—while confronting her own potential cancer diagnosis, the study explores how material objects—specifically apricots from her mother's tree—become active participants in healing and reconciliation processes that extend beyond conventional therapeutic frameworks.

The memoir paints a complex portrait of intergenerational trauma and medical vulnerability that challenges traditional models of patient-caregiver relationships. Solnit's mother, who failed to recognize her daughter's autonomy and treated caregiving as a natural obligation rather than an ethical choice, exemplifies how power dynamics within family care can perpetuate harm. Drawing on Emmanuel Levinas's concept of alterity and infinite responsibility, the paper argues that ethical caregiving fundamentally requires the recognition of the unknowability of others, including of patients experiencing cognitive decline who may resist attempts at understanding or control.

Solnit's narrative demonstrates how her own medical vulnerability—awaiting biopsy results and undergoing the isolation of physical pain—becomes a catalyst for developing genuine empathy toward her mother's condition. This embodied encounter with illness reveals the shared fragility that connects a caregiver and care recipient, disrupting hierarchical assumptions about who provides and receives care. Through Hannah Arendt's concept of forgiveness being essential for human renewal, the analysis shows how healing emerges not through resolution but through accepting the irreversibility of past wounds while shaping future relationships.

Central to this transformation are some apricots that arrive unexpectedly from her mother's former home. These apricots function as more than literary metaphor—they serve as material agents with their own temporality of ripening and decay that demands a response. Drawing on Jane Bennett's "vibrant matter" theory, the paper demonstrates how non-human entities actively shape caregiving relationships through their physical presence and material demands. The apricots' arrival, preservation, and eventual gifting create what Bennett terms an "assemblage" through which human emotions and material processes become mutually constitutive.

This analysis contributes to the medical humanities by proposing a relational ethics that extends beyond anthropocentric models of care. Solnit's memoir reveals how healing emerges along complex networks involving human actors, material objects, memories, and embodied experiences. This framework offers practical guidance for healthcare providers and family caregivers navigating ethical complexities, particularly in which traditional communication fails, particularly in dementia care where patients' agency and personhood are often questioned due to cognitive impairment.

The study's implications extend to clinical environments where acknowledging the agency of both human and non-human elements—from medical technologies to personal items that carry emotional significance—can foster more compassionate therapeutic relationships. By recognizing how material environments actively take part in care processes, healthcare providers can create more holistic approaches that honor patients' full humanity while supporting family caregivers in their own processes of ethical transformation. This posthuman framework ultimately challenges medical practice to embrace interdependence and vulnerability as components of the foundation for healing.



THOMPSON

**"Is It Enough?": Claiming Autism and Performing Abjection**

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Many high-masking autistic folks (those who may “pass” as neurotypical) struggle against both implicit and explicit accusations that they are not “autistic enough.” Neurodiversity scholars have pointed out that autism is often still abject in the public imagination, a condition that begets disturbing disorder rather than differences (Murry 2010; Limburg 2016; Yergeau 2016). Autistic folks are often expected not simply to be disabled, but to be disabled in an especially unappealing, degrading, or debasing way. In the absence of stirring details about fixations and fecal smearing, for example, the autist cannot be perceived as “autistic enough” and thereby cannot be perceived as disabled. Through aut(ie)ethnographic methods, I will explore the rhetorical limitations and social pressures that these expectations may place on the high-masking autist. When faced with pressure to expose oneself as abject, many autists enact a performance of “the rhetorical freak show,” or the performance of oneself as freakishly disabled, to have their autism legitimized by the authority of others (Vidali 2007). This presentation will interrogate the psychological effects that such performances have on high-masking or “passing” autistic folks.

TUNTIYA

**Health Literacy in International Perspective: Considerations for Medical Humanities  
Instruction**

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As a key factor underlying patient decision-making and illness behavior, health literacy deserves much closer attention from medical sociologists and healthcare practitioners than it currently receives. Previous research has indicated that patients often form their own illness explanations based on a variety of unscientific sources, which might conflict with medical providers' advice or treatment plans. Patient views determine treatment compliance, preferences for specific therapeutic or pharmaceutical interventions, and trust toward individual physicians or the healthcare system in general. The wide availability of medical information coupled with an active role patients can now play in the more egalitarian model of care in the United States, puts patient health literacy at the forefront of factors that influence doctor-patient relationships and, potentially, treatment outcomes.

The existing research on health literacy tends to focus on patient educational attainment, reading competence, and the influence of incorrect or fraudulent information on patient attitudes. Without discounting these important considerations, the present paper utilizes OECD country reports to compare information seeking patterns across countries and to illustrate the complex interplay of cultural attitudes, social contexts, and individual information seeking behaviors in diverse international contexts. This approach allows to expand the discussion of literacy in health-related courses beyond the topic of patient agency and information competence, to emphasize how varying patterns of technology use and specific socio-cultural conditions impact health literacy across different countries.

VARTY

**Pulling Stories from the Shadows: Narrative Medicine Tunes into Stories of Disability and Caregiving/Receiving**

Nicole Varty, PhD

Wayne State University, Department of English

Because successful healthcare is dependent on patients' abilities to accurately and clearly relay their stories of illness, and practitioners' abilities to listen to, empathize with and act on those stories (Charon, 2001; Campbell and Miller, 2023), storytelling is a powerful tool to help understand the nature of the healthcare community. The field of Narrative Medicine is designed to support healthcare providers through close reading and creative writing, in order to develop empathy, reflection and trust in the caregiving relationship (Charon, 2001; Baruch, 2013). While much pedagogical design taking up narrative medicine as a frame emphasizes the student-practitioner/caregiver as reader/writer in order to cultivate what Rita Charon calls "narrative competence" for the practitioner, there are few models for community engaged pedagogy that utilize these tools. In community writing courses, students can be guided to theorize, enact, and write, not merely about community members, but with and for them as well (Adler-Kassner, 2000). As Campbell and Miller assert, putting diverse fields in conversation leads to overall gains and can deepen all fields' understanding of empathetic practice (2023). A convergence of the fields of rhetoric, community writing, and narrative medicine can explore the possibilities for a pedagogy of rhetorical empathy-in-action that brings care-receivers and care-givers into the conversation together, increasing narrative competence by engaging with theories of narrative medicine, rhetorical listening, empathy, and embodiment (Charon, 2021; Ratcliffe, 1999; Olszewski et al. 2021; Taussig, 2020). Through the community storytelling project described in this session, students theorize using narrative medicine and rhetorical listening frameworks, enact empathy through community engaged research methods, and write the stories of caregiving and receiving to represent community members as they express themselves.

In this conference presentation, the facilitator will walk participants through the Community Storytelling project and demonstrate how students worked with and for community partners to co-create their projects, which range in scope from adaptive technology start-up content creation, to interviews with patients marginalized due to language barriers, to teenagers living with chronic illness. This project and others like it can shape a community writing course that enhances a narrative medicine pedagogy to support rhetorical empathy-in-action in healthcare contexts of all kinds, from elder-care, to occupational therapy, to public health.

VASUDEVAN

**The Power Dynamics in Institutional Spaces: The Schizophrenic Body as an Object of Medical Subjugation**

Arunima Vasudevan, PhD

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Schizophrenia as an embodied experience overshadows the intricacies of the internal world of the individual, often manifested through positive symptoms of the illness. The inability to subjugate their inner chaos culminates in restricting their bodies. Deprived of bodily autonomy and agency, a schizophrenic body proves to be a medical object that needs to be tamed so as not to disturb the rational world. This paper attempts to look at how individuals with schizophrenia navigate institutional spaces with their bodies pinned as objects. The constant surveillance and the segregation of themselves into different spaces or rooms based on their behavior strip them of their human essence. Restraints and force become the last resort to control them and to compensate for the unruliness of their minds. The paper will look into the interaction of their bodies with the medical system, especially medicines that further complicate the situation with their side effects. I propose that in this scenario, individuals with schizophrenia attempt to manipulate the medical power structures through their behavior and their symptoms, like hallucinations and delusions, which also interact with this atmosphere, influencing their struggles. Therefore, I look at how the body mediates the lost autonomy and agency of the individual despite the limitations set by the system. In light of Agamben's concept, 'homo sacer', I would examine how the medical institutions mediate the biopower of the state to maintain the status quo in the U.S. compared to the U.K. In addition, the paper will address the role of infrastructural elements like walls, doors, and windows in a medical institution in exercising power. It will also analyze how beds transform into a symbol of oppression from a symbol of care and comfort. Hence, the paper aims to evaluate the power dynamics between the patient and the institution with their bodies as the primary site of control, as demonstrated in the texts, *The Center Cannot Hold: My Journey Through Madness* by Elyn Saks and *The Day the Voices Stopped: A Memoir of Hope* by Kennethe Steele. Both memoirs are peculiar in their ways and illustrate the injustices and irrational measures of the institutional authority amid the suffering of the illness. Thus, I contend that the objectification of their bodies reduces them to a medical toy, and this indicates the incompetence of the medical practices in dealing with the illness. This incompetence is imposed on the patients in the hospital to emphasize that they are a threat to the state and social equilibrium. Therefore, I argue that the medical force is in effect the state's tool rather than a place of solace for the patients. Consequently, this will delay recovery and become counterproductive, worsening their condition. Moreover, the paper will study the narratives of the authors who respond to such treatments and voice their opinions about the medical setup. It will also analyze how they have narrativized the image of their bodies as perceived by the hospital staff and themselves, differentiating both, highlighting the idiosyncrasies, and restoring meaning and autonomy to their identity.

WAGNER

**Development of a Health Humanities Elective Within a Doctor of Physical Therapy Program**

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Disability in physical therapy has been viewed through a medical model (focusing on impairments and pathology), a social model, and hybrid models, including use of the International Classification of Function, Disability, and Health (ICF). Physical Therapy is a field that requires observational skills, narrative reasoning (awareness of and appreciation for a patient's story), empathy, and knowledge of a variety of pathologies and how they affect the human movement system. A health humanities course was developed to enhance the teaching of these topics. Use of health humanities, taught through the theoretical lens of disability studies, may help bridge the gap between clinical knowledge and the lived experience of the patient or client, and may improve observational skills, professional identity formation, narrative reasoning, empathy, and communication.

This presentation will discuss the current application of the use of the humanities in an entry-level health humanities elective within a Doctor of Physical Therapy program, incorporating principles of disability studies. These principles include the social model of disability, the affirmative model of disability, inclusion, and an emphasis on the relationship with the built environment. Perspective taking and understanding multiple points of view is a key concept of the course. The use of imagination is critical to building empathy. Works explored in this paper will include:

- Comics, graphic novels to promote empathy, narrative reasoning, understanding of the patient's "story."
- Poetry analysis and interpretation and application to patient care.
- Literature-the short novella "The Metamorphosis" by Franz Kafka is read and discussed in a small group. The purpose of this activity is to deepen empathy for people involved within patient and caregiver roles. The novella is viewed through a lens of critical disability theory.
- Film - a short film is used to help students explore the lived experience of people who use wheelchairs, thus enhancing empathy for that population.
- Visual Arts- Visual arts, including paintings, are used to help students develop observation skills through visual thinking strategies.
- Ethical reasoning through "graphic medicine" cases to interpret multiple perspectives in a patient scenario.

Exemplars of teaching using synchronous and asynchronous methods will be described. Course planning, teaching, and assessment methods will be discussed with practical examples for application.

WALKER

**Eugenics and the State: American Legal Discourse, Selective Abortion Bans, & Jeremy  
Hersch's *The Surrogate* (2020)**

Alexis Walker, PhD

Columbia University, Department of Medical Humanities and Ethics

In the years leading up to the US Supreme Court decision *Dobbs v. Jackson Women's Health Organization*, a series of states passed laws that prohibit doctors from performing an abortion if they know that a patient is seeking it because of the predicted gender, race, and/or disability status of the fetus. These selective abortion laws have divided disability rights circles; some have lauded the work these bans do in valuing and protecting disabled Americans, while others have argued that conservative limitations on reproductive autonomy are not the best means to teach people that the lives of people with disability are as valuable and precious as those without. Proponents of the bans have called them "anti-eugenics laws," but legal scholars have argued in response that selective abortion cannot be seen as a form of eugenics because it is not a state-sponsored effort (for example, Sital Kalantry in the *Cornell Law Review*, Carole Petersen in the *University of Detroit Law Review*, Tori Gooder in the *University of Cincinnati Law Review*). The proposed paper presentation reads these debates regarding selective abortion law against the 2020 American independent film *The Surrogate*, arguing that together they provide insight into the relationship between the ethics of law and the ethics of social practice, and the operation of power in the realm of disability and reproduction today.



WOMACK

## **Hunger, Food Noise, and Bodily Authority in the GLP-1 Drug Experience**

Catherine Womack, PhD

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The new GLP-1 and GLP-1/GIP medications (e.g. Wegovy, Ozempic, Zepbound, Mounjaro) are touted as miracle drugs, solutions to the intractable problem of long-term weight loss and management. According to a recent Kaiser Family Foundation poll, 12% of Americans reported having taken a GLP-1, and 6% say they are currently taking one.

These drugs work mainly by reducing appetite and increasing satiety, resulting in weight loss. However, many patients also report drastic reductions in what is now called “food noise”—a persistent and anxious preoccupation with food. Anecdotal reports include marked changes in food preferences (say, kale over brownies) and even taste profiles (kale yum, brownies meh).

We’ll examine the notion of food noise and its relation to hunger and eating, as two researchers and one patient on Zepbound. We argue that a better understanding of the constraints that food noise imposes on individuals addresses worries that these medications interfere with what philosopher Kate Manne calls ‘bodily authority’. She argues that we have something like a moral duty to ourselves to satisfy our hunger, rather than trying either to ignore it or silence it.

Citing both recent research and experiential accounts, we suggest and explain how reduction of food noise can in fact increase bodily authority. By turning the volume down on food noise and the accompanying anxiety of managing daily food selection, preparation and consumption, patients can attain greater choice and freedom around eating behaviors (e.g., increased individually prepared foods, decreased impulsive or binge eating, decreased eating isolation, increased incentives to eat with others). All of these shifts in behavior contribute, we argue, to greater satisfaction in and authority over one’s relationship with food.

YADAV

**Rethinking Health: Disability, Ageing, and Ecology in Medical Humanities**

Adarsh Yadav

Department of English, University of Exeter

This paper contributes to the growing field of medical humanities in India by bringing theoretical and political perspectives on ageing, illness, and disability into conversation. Through a close reading of selected contemporary Indian English texts, it explores how ableism shapes the embodied experiences of ageing and illness. Drawing on scholars such as Alison Kafer, Margrit Shildrick, and Janet Price, who frame disability as political and relational to "pluralize the ways we understand bodily instability" (Kafer 7), this paper uses disability as a conceptual entry point to examine gendered, caste-based, and colonial constructions of health.

The discussion is anchored in two case studies. The first focuses on ageing through a novel called the Tomb of Sand by Geetanjali Shree (translated by Daisy Rockwell), which follows the transformative journey of an older woman across borders, bodies, and histories. The second examines disability, debility, ecology, and industrial disaster through Indra Sinha's novel *Animal's People*, narrated by Animal, a disabled man living in Khaufpur, which is a fictional town modelled on the aftermath of the Bhopal Gas Tragedy.

By reading these texts together, this paper argues that disability studies can disrupt normative conceptions of health, illness, cure, and care by interrogating their dominant epistemological and ontological foundations. It calls for a more expansive and generative understanding of 'health' that moves beyond biomedical frameworks. In addition, the paper examines the genre and form of these texts, exploring how the narrative structures of these novels challenge normative assumptions about the body. Through Kafer's intervention, disability studies emerge as a method of reading where kinship, queer community formations, connections between health, ecology, and borders can be traced and rethought.