

# PBJ | PENN BIOETHICS JOURNAL

Fall 2024 Volume XX, Issue ii

[bioethicsjournal.com](http://bioethicsjournal.com)



## Bioethics as a Guide

*How can bioethics help us navigate an increasingly complex world, as we strive to create a better tomorrow?*

# Penn Bioethics Journal

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Embracing the interdisciplinarity of bioethics, PBJ reviews and publishes original work addressing debates in medicine, technology, philosophy, public policy, law, theology, and ethics, among other disciplines. The biannual issue also features news briefs summarizing current issues and interviews with eminent figures in the field.

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Philadelphia, PA. ISSN: 2150-5462



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# Letter from the Editors

Dear Readers,

It is our honor to present to you Volume XX, issue ii of the *Penn Bioethics Journal*, entitled “Bioethics as a Guide.” As the field of bioethics confronts cutting-edge technologies and the societal impact of changes in medical decision-making, so does our journal. We might even look into the future to consider the ethical implications of yet unimagined possibilities. In this issue, we explore a variety of topics, once again demonstrating the versatility of bioethics as a mode of analysis and a rights-based approach to health care provision.

The first article, “Navigating the Neural Divide: Ethical Considerations in Sex Differences Research in Neuroscience,” discusses the importance of acknowledging neurological differences between sexes, especially as they relate to the conduct and organization of research on the brain. Author Eshika Kudaravalli of the University of Alabama at Birmingham identifies several issues at the intersection of biological sex, societal perceptions of gender, and neurology, arguing for stronger guidelines to overcome these hurdles, both in research and beyond.

The second article, “The Ethics of Weight-Loss Drugs: Patient Autonomy vs. Societal Beneficence,” delves into the recent development and approval of weight-loss drugs such as Ozempic, often touted as game-changers for the treatment of diabetes type II, obesity, and other related health conditions. Author Kaitlin Ross of the University of Alabama at Birmingham highlights various ethical concerns, including problems of access, beneficence, and more, supporting her argument that the prescription and use of weight-loss drugs requires greater care and consideration.

The third article, “Brain-to-Brain Communication: Hyper-Empathy and Identity,” considers a future where it is possible to communicate via thoughts alone, drawing parallels to other forms of communication while simultaneously recognizing the divergence of this method of interpersonal transmission. Author Yuliya Liberman of Temple University outlines the potential ethical dilemmas and necessary safeguards that would accompany this new neurotechnology.

The fourth article, “Using Autonomy Thresholds to Assign Medical Decision-Making Models for Adults with Autism,” examines existing medical decision-making models used to support adults with autism through a proposed framework to assess levels of autonomy on the basis of impairment to rational capacities. Author Adarsh Mavathaveedu of the University of Rochester suggests a lack of clear guidelines for the implementation of medical decision-making models leads to paternalism, identifying specific thresholds of autonomy that strengthen the right to self-governance for adults with autism.

The fifth article, “The Moral Vulnerability of the Physician and a Novel Approach to Conscientious Objection,” explores the conflict between physician autonomy and patient rights in the context of conscientious objection. Author Joshua Park of Case Western Reserve University argues inadequate ethical education leaves physicians morally vulnerable and unprepared to address moral-professional disjuncture, recommending improved bioethical training in order to protect patient welfare.

Our Bioethics-in-Brief section provides news style coverage of current issues related to the field of bioethics. In her brief, Caitlyn Chen underscores the critical divide between the costs, benefits, and accessibility of Assisted Reproductive Technology (ART). Chen cautions us from embracing ART as the singular solution to declining global birth rates, instead urging policy makers to strive for a more just future where ART is readily available to all on an international scale.

This issue includes an interview with Dr. Rebecca Puhl, Deputy Director for the Rudd Center for Food Policy & Health and Professor in the Department of Human Development and Family Sciences at the University of Connecticut, whose research is broadly concerned with weight-based bullying, bias, and discrimination. Jacob Kim and Navneeth Murali ask Dr. Puhl about the prevalence of weight bias in medical spaces and the societal impact of widely available weight-loss treatments.

# Letter from the Editors

We would like to thank our publisher, Claire Jun, and amazing team of editors, without which this issue would not have been possible. Also, a special thanks to our faculty advisor, Dr. Harald Schmidt, for his support throughout the editing and publication process. We hope you enjoy this issue of the *Penn Bioethics Journal* and it inspires you to engage further with the field of bioethics. Please contact us with any questions, comments, or ideas for collaboration at [pbjeditorinchief@gmail.com](mailto:pbjeditorinchief@gmail.com).

As we end our term as Co-Editors-in-Chief and welcome our successors, Sophie Kudler and Iman Dorman, we would like to personally thank all of our readers, contributors, and staff for making our time with the *Penn Bioethics Journal* so special. It has been a privilege to explore the field of bioethics through the eyes of our editors and authors. We look forward to witnessing this publication continue to grow into the future.

Avalon Hinchman and Ashrit Challa  
Co-Editors-in-Chief  
University of Pennsylvania



# Article

## Navigating the Neural Divide: Ethical Considerations in Sex Differences Research in Neuroscience

Eshika Kudaravalli\*

### INTRODUCTION

Biologic sex is important in neuroscience. Multiple studies have demonstrated the brain to be a sex-type organ with clear differences in the anatomy and respective physiological functions in neural structures (Goldman 2017). Biological sex accounts for variabilities in antidepressant efficacy (Sramek, Murphy, and Cutler 2016), differences in autistic traits (Sohn 2019), and an increased risk for Alzheimer's disease among women compared to men (Sauer 2019). Yet despite compelling evidence, much of neuroscience research has not considered biological sex as an experimental variable. Often favoring the use of male subjects over females in experiments or omitting the biological sex of the research subject entirely, neuroscientists have failed to depict a representative population in research (Mamlouk et al. 2020). The consequence of this bias and omission of biological sex manifests themselves in real-world health-care disparities between men and women. For example, the inadequate consideration of biological sex differences in the metabolization of neurological medications has led to devastating results, including the equal dose prescription of zolpidem—an action that caused an adverse health outcome in women, with twice the number of women hospitalized in the emergency room than men (Armstrong 2018).

As this issue was brought to light, the National Institutes of Health (NIH) convened in 2016 to discuss the long-term omission of women and the over-representation of male subjects in research (Garcia-Sifuentes and Maney 2021). The meeting concluded by creating the requirement of considering sex as an experimental variable in the design, analysis, and reporting of all NIH-funded preclinical research. This policy, created in hopes of mitigating health inequities between biological sex while also improving rigor and reproducibility in research, was proved successful as numerous novel discoveries about sex differences in neuroscience followed along with other research fields.

While the policy increased the use of both biological sexes in research, it did not provide training on how to do so appropriately. As a result, a surge of misinformative or misrepresentative studies investigating sex differences were disseminated to the public. With most of these studies existing within the neuroscience field, the important question



By Gérard DuBois, *Stanford Medicine Magazine*, 2017

arises: Given the harms, do neuroscientific studies investigating biological sex differences do more harm than good? This paper seeks to answer this question by exploring the prominent and controversial topics embedded in the ethics of biological sex differences in neuroscience research.

### SEX DIFFERENCES RESEARCH IN NEUROSCIENCE

Sex differences research in neuroscience investigates the impact of biological sex on brain structure, function, and behavior, focusing on how hormonal, genetic, and developmental factors contribute to variations in cognition, emotion, and behavior, with the aim of enhancing personalized medical treatments and understanding sex-specific neurological processes (Cahill 2006). This research enables scientists to elucidate sex-specific vulnerabilities in

\*Eshika Kudaravalli studies neuroscience at the University of Alabama at Birmingham. Eshika can be reached at [eshika0707@gmail.com](mailto:eshika0707@gmail.com)

the brain to enhance the understanding of psychiatric and neurological disorders that manifest differently in men and women (Stanford Medicine 2024). This is seen in a study with balanced sex representation using brain imaging to examine 98 individuals with autism spectrum disorder (ASD) and 98 controls. This research reaffirmed previous findings on sex-based cortical thickness variability and discovered that many female ASD subjects had cortical profiles akin to those of typical non-ASD males. This highlights that a male-like brain structure—regardless of one's sex—constitutes a significant risk factor for ASD, potentially explaining its four- to fivefold higher prevalence in males (Spector 2017). Moreover, advancements were seen in the understanding of carotid atherosclerotic disease, where the morphological and compositional characteristics of plaques isolated from women have notable differences from those in men. This finding would not have been uncovered if it was not for neuroscientific research in sex differences (Gasbarrino, Di Iorio, and Daskalopoulou 2021).

Novel findings like this continue to underscore the importance of conducting sex differences research. Stroke, pain management, Alzheimer's disease, and Parkinson's disease are just a few of the neurologic conditions that present distinct manifestations and differential prevalence rates between sexes and would benefit most from research being conducted based on sex differences. This oversight causes this gap in knowledge of differential presentation, outcomes, and treatment responses between men and women and creates an urgent call to action for sex differences in neurological research in neuroscience to tailor diagnostic and therapeutic strategies that accommodate sex differences. This persistent negligence of such research highlights an ethical imperative to advance sex-specific scientific inquiry, thereby ensuring equitable and precision-based approaches in diagnostics and therapeutics that address the nuanced and differential needs of all individuals.

## NEUROSEXISM

In and of itself, neuroscientific studies of sex differences are not the primary focus of bioethical debate. Critics agree that areas in the brain do exist where their respective functions and structures differ between females and males, and those differences need to be studied. However, the extrapolation of such research from biological differences in the brain to behavioral differences is contested. "Neurosexism" refers to the belief that the differences between female and male brains "explain women's inferiority or unsuitability for certain roles" (Rippon 2016). This controversial view is perhaps the largest ethical quandary in sex difference-based neuroscientific studies as it could strengthen already existing sexism and discrimination against women.

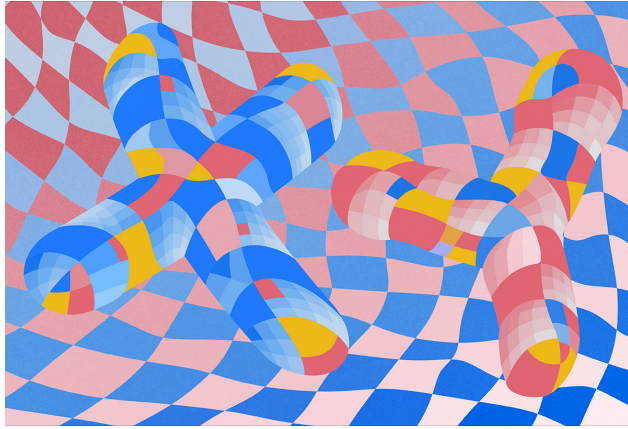
Much research on sexual differentiation in the brain has faced scrutiny due to many making confident claims of

sex differences despite interpretive bias and methodological weakness. This is exactly what happened in Ingallhalikar et al.'s (2013) study of applying Diffusion Tensor Imaging, a brain imaging technique, to model the neural connectivity of 949 young people's brains. The study revealed that females had greater connectivity across hemispheres, while males had greater neural connectivity within each brain hemisphere. These findings apparently proved that the brain was dichotomous due to gender. Yet what was not included in the scope of the study was that there was no difference in the majority of neural connections between the adolescent participants, nor were the variables of puberty-related maturation or brain size controlled for—variables which would have reduced male-female difference (Eliot 2019). Furthermore, though there was no behavioral data directly reported in the Ingallhalikar et al. 2013 paper, the finding of sex differences in connectivity was hailed by the authors of the paper as "scientific proof" for women being more emotional due to their greater inter-hemispheric connectivity while men compartmentalize their emotions from their rational thought due their hemispheres being more structurally independent (O'Connor and Joffe 2014). Articles used in Ingallhalikar et al. paper to justify stereotype content (e.g., women having better parenting skills, men being more logical and focused, women being more caring and emotional).

This study is one of many that despite having methodological flaws used the credibility of science to defend gender stereotypes as socially, factually, and biologically true. In fact, Garcia-Sifuentes and Maney's (2021) analysis of 147 articles in the field of neuroscience found 71% of articles reporting significance found for one sex but not the other as a statistically significant sex-based difference when that is untrue. Therefore, the prevalence of errors in such studies bears significant concern due to the dangers they pose in legitimizing societal gender roles.

## SEX ESSENTIALISM

Closely related to the issue of neurosexism, sex essentialism, the view that an individual's genetic makeup can explain the individual's behaviors and characteristics (Dar-Nimrod & Heine 2011), exists as another key ethical stipulation. This idea is grounded on the beliefs that (1) female and male 'essence' is partly formed from the differences between dimorphic brains (male brain vs. female brain) and (2) the structures and functions within the dimorphic brains are fixed and innate (Rippon 2020). However, new evidence proposes that significant overlap in both sexes' functional connectivity networks (Joel et al., 2015), suggesting that the brain should not be strictly classified as either female or male but instead be recognized as a mosaic. This finding contradicts previous assumptions as it highlights the continuity present in the brain's neural structures, regardless of sex. Thus, the principle beliefs of sex essentialism fall short; brain regions



By Saiman Chow, *The Transmitter*, 2024

are not dimorphic. Furthermore, when investigating the sex differences in the function and anatomy of the brain, it was found that there were a few somewhat strong differences; however, there were multiple moderate and weak differences (Jäncke 2018). This finding is further extended by how a lack of difference was found in the brain's structure and connectivity patterns between sexes (Kong et al. 2018). These similarities found between the brains of males and females challenge the previous assumption of the existence of dimorphic brains (Lippa 2010).

Simultaneously, advancements in brain imaging techniques have provided unprecedented insights into neural activity, exposing the brain's plasticity and its responsiveness to a myriad of experiences, including those shaped by gender (May 2011). This underscores the inadequacy of a purely biological determinist perspective, which fails to account for socio-economic, educational, and cultural variables that influence brain characteristics. Questions begin to arise on how much these mechanisms of the brain have been oversimplified as the lack of strong evidence showing sexual dimorphism in the brain, highlighting the need to adopt a more inclusive approach to classifying the brain in neuroscience research, so that it recognizes the complexity of genders and its implications for neuroscience research.

### REVERSE INFERENCE

Reverse inference is the practice of inferring the engagement of specific cognitive functions based on observed activation in particular brain regions (Poldrack 2006). Traditionally, neuroimaging studies operate under a more straightforward deductive framework, where the inference proceeds from the premise that if cognitive process X is engaged, then brain area Z is expected to be active. However, a troubling trend has emerged in which researchers engage in a form of reasoning that draws conclusions in the opposite direction: from the presence of brain activation to the assertion of cognitive engagement. For example, one might encounter statements in functional magnetic resonance

imaging literature that indicate, "In the present study, the brain area anterior cingulate cortex was active during the experience of envy."

Researchers may then refer to prior studies linking brain area of the anterior cingulate cortex with cognitive process of conflict or social pain processing, leading to the inference that the observed activation signifies the engagement of process cognitive conflict or social pain processing during experience of envy. This reasoning is fundamentally flawed and exemplifies the logical fallacy known as affirming the consequent.

Unfortunately, the fallacy of reference inference does not erase the belief from research as it continues to infect neuroscientific studies about sex differences. The prevalence of reverse inference in neuroscience research is highlighted in Fine's (2012) review of 39 studies, where 27 (69%) utilized reverse inference to hypothesize differences in response to stimuli between males and females or differences in cognitive processing. However, in 11 of these studies, behavioral data contradicted or were inconsistent with the reverse inferences made. For example, one study concluded that men were more conditioned for sexual arousal due to greater neural responses in regions such as the occipital cortex and amygdala compared to women. Nonetheless, the behavioral data showed that while men rated erotic pictures as more arousing, women rated them similarly in terms of valence and arousal, despite lower initial arousal levels. Thus, the behavioral evidence suggested that women might be more readily conditioned to find stimuli sexually arousing, contrary to the reverse inference drawn (Fine 2012).

Therefore, these interpretations made by researchers are dangerous. Instead of basing conclusions on relevant data collected, researchers begin to falsely correlate sex differences in the brain as the sole reason for behavior differences between genders. They often overlook contradictory behavioral data and rely on assumptions about expected gender differences, rather than empirical evidence. This not only misrepresents the intricacies of human cognition but also reinforces societal stereotypes regarding gender and cognitive abilities. When researchers overlook contradictory behavioral evidence in favor of anticipated conclusions, they contribute to a body of scientific literature that may misinform public understanding and policy.

### CONCLUSION

When asked the question of whether neuroscientific studies investigating biological sex differences do more harm than good, the current analysis concludes with a stance of a cautious approach. The evidence clearly demonstrates that biological sex influences neurological function, disease susceptibility, and therapeutic responses. However, the historical tendency to prioritize male subjects in research has led to significant gaps in understanding the



unique needs of diverse populations, resulting in real-world health disparities. The National Institutes of Health's (NIH) recent policy initiatives of creating the requirement of considering sex as an experimental variable in the design, analysis, and reporting of all NIH-funded preclinical research mark a pivotal step toward rectifying this oversight, yet they have inadvertently paved the way for an influx of studies that may misinterpret or misrepresent the complexities of sex differences. The ethical dilemmas surrounding neurosexism and sex essentialism further complicate this landscape. The risk of reinforcing harmful stereotypes through flawed interpretations of neuroscientific data is not merely an academic concern; it has far-reaching implications for societal perceptions of gender roles and individual capabilities. Misguided conclusions can perpetuate discrimination, thereby exacerbating existing inequities in healthcare and professional opportunities. Furthermore, the prevalence of reverse inference in the literature exacerbates these issues, leading researchers to draw unwarranted conclusions from neuroimaging data that fail to align with behavioral evidence. This not only misrepresents cognitive processes but also fosters a misleading narrative regarding innate differences between genders. Thus, there are too many harms associated with sex differences studies that outweigh the possible benefits and can not fully be appreciated if aspects such as false assumptions, reverse inferences, and neurosexism cannot be mitigated. Therefore, such research in the field of neuroscience should be continued cautiously in order to maximize advancement in scientific knowledge and societal benefit while minimizing the production of false knowledge. In order to achieve this, more stringent guidelines could be instilled into sex difference neuroscience research that could allow for such research to continue so society can reap its benefits without suffering harm. Recommendations put forth by Rippon et al. (2014) advocate for methodological enhancements, such as implementing in-principle acceptance in peer review processes and urging researchers to include conditions examining the reversibility of gendered brain differences through environmental interventions. Additionally, mandating replication of findings in separate samples and maintaining databases of gender similarities rather than differences are proposed strategies to mitigate biases and enhance the integrity of research outcomes.

Ultimately, addressing the issues of neuroscientific studies on sex/gender differences requires a set of rigid guidelines that prevent researchers from pushing false conclusions based on faulty methods or previous assumptions. While the exact guidelines that should be placed still remain unknown, recognizing the harms that come with such studies serves as an important first step in creating a more equitable and scientifically rigorous research landscape.

## ACKNOWLEDGMENTS

I would like to acknowledge Dr. Gregory Pence for his mentorship and guidance throughout the writing process of this paper. His expert insights and support were invaluable in shaping the research and enhancing the overall quality of the work.

## BIBLIOGRAPHY

- Armstrong, Elisabeth. 2018. "The Gender Gap in Pharmaceutical Research." *Voices in Bioethics* 4 (September). <https://doi.org/10.7916/vib.v4i.6008>.
- Cahill, Larry. 2006. "Why Sex Matters for Neuroscience." *Nature Reviews Neuroscience* 7 (6): 477–84. <https://doi.org/10.1038/nrn1909>.
- Dar-Nimrod, Ilan, and Steven J. Heine. 2011. "Genetic Essentialism: On the Deceptive Determinism of DNA." *Psychological Bulletin* 137 (5): 800–818. <https://doi.org/10.1037/a0021860>.
- Eliot, Lise. 2019. "Neurosexism: The Myth That Men and Women Have Different Brains." *Nature* 566 (7745): 453–54. <https://doi.org/10.1038/d41586-019-00677-x>.
- Fine, Cordelia. 2012. "Is There Neurosexism in Functional Neuroimaging Investigations of Sex Differences?" *Neuroethics* 6 (2): 369–409. <https://doi.org/10.1007/s12152-012-9169-1>.
- Garcia-Sifuentes, Yesenia, and Donna L Maney. 2021. "Reporting and Misreporting of Sex Differences in the Biological Sciences." *eLife. eLife Sciences Publications, Ltd.* November 2, 2021. <https://elifesciences.org/articles/70817#bib24>.
- Gasbarrino, Karina, Diana Di Iorio, and Stella S Daskalopoulou. 2021. "Importance of Sex and Gender in Ischaemic Stroke and Carotid Atherosclerotic Disease." *European Heart Journal* 43 (6): 460–73. <https://doi.org/10.1093/eurheartj/ehab756>.
- Goldman, Bruce. 2017. "How Men's and Women's Brains Are Different." *Stanford Medicine Magazine*. May 22, 2017. <https://stanmed.stanford.edu/how-mens-and-womens-brains-are-different/>.
- Ingalhalikar, M., A. Smith, D. Parker, T. D. Satterthwaite, M. A. Elliott, K. Ruparel, H. Hakonarson, R. E. Gur, R. C. Gur, and R. Verma. 2013. "Sex Differences in the Structural Connectome of the Human Brain." *Proceedings of the National Academy of Sciences* 111 (2): 823–28. <https://doi.org/10.1073/pnas.1316909110>.
- Jäncke, Lutz. 2018. "Sex/Gender Differences in Cognition, Neurophysiology, and Neuroanatomy." *F1000Research* 7 (June): 805. <https://doi.org/10.12688/f1000research.13917.1>.
- Joel, Daphna, Zohar Berman, Ido Tavor, Nadav Wexler, Olga Gaber, Yaniv Stein, Nisan Shefi, et al. 2015. "Sex

- beyond the Genitalia: The Human Brain Mosaic.” *Proceedings of the National Academy of Sciences* 112 (50): 15468–73. <https://doi.org/10.1073/pnas.1509654112>.
- Kong, Ru, Jingwei Li, Csaba Orban, Mert R Sabuncu, Hesheng Liu, Alexander Schaefer, Nanbo Sun, et al. 2018. “Spatial Topography of Individual-Specific Cortical Networks Predicts Human Cognition, Personality, and Emotion.” *Cerebral Cortex* 29 (6): 2533–51. <https://doi.org/10.1093/cercor/bhy123>.
- Lippa, Richard A. 2010. “Gender Differences in Personality and Interests: When, Where, and Why?” *Social and Personality Psychology Compass* 4 (11): 1098–1110. <https://doi.org/10.1111/j.1751-9004.2010.00320.x>.
- Mamlouk, Gabriella M., David M. Dorris, Lily R. Barrett, and John Meitzen. 2020. “Sex Bias and Omission in Neuroscience Research Is Influenced by Research Model and Journal, but Not Reported NIH Funding.” *Frontiers in Neuroendocrinology* 57 (April): 100835. <https://doi.org/10.1016/j.yfrne.2020.100835>.
- May, Arne. 2011. “Experience-Dependent Structural Plasticity in the Adult Human Brain.” *Trends in Cognitive Sciences* 15 (10): 475–82. <https://doi.org/10.1016/j.tics.2011.08.002>.
- O’Connor, Cliodhna, and Helene Joffe. 2014. “Gender on the Brain: A Case Study of Science Communication in the New Media Environment.” Edited by Thomas Boraud. *PLoS ONE* 9 (10): e110830. <https://doi.org/10.1371/journal.pone.0110830>.
- Poldrack, R. 2006. “Can Cognitive Processes Be Inferred from Neuroimaging Data?” *Trends in Cognitive Sciences* 10 (2): 59–63. <https://doi.org/10.1016/j.tics.2005.12.004>.
- Poldrack, Russell A. 2011. “Inferring Mental States from Neuroimaging Data: From Reverse Inference to Large-Scale Decoding.” *Neuron* 72 (5): 692–97. <https://doi.org/10.1016/j.neuron.2011.11.001>.
- Rippon, Gina. 2016. “How ‘Neurosexism’ Is Holding Back Gender Equality – and Science Itself?” *The Conversation*. October 27, 2016. <https://theconversation.com/how-neurosexism-is-holding-back-gender-equality-and-science-itself-67597>.
- Rippon, Gina. 2020. *THE GENDERED BRAIN : The New Neuroscience That Shatters the Myth of the Female Brain*. S.L.: Vintage.
- Rippon, Gina, Rebecca Jordan-Young, Anelis Kaiser, and Cordelia Fine. 2014. “Recommendations for Sex/Gender Neuroimaging Research: Key Principles and Implications for Research Design, Analysis, and Interpretation.” *Frontiers in Human Neuroscience* 8 (August). <https://doi.org/10.3389/fnhum.2014.00650>.
- Sauer, Alissa. 2019. “Why Is Alzheimer’s More Likely in Women?” *Alzheimers.net*. September 5, 2019. <https://www.alzheimers.net/8-12-15-why-is-alzheimers-more-likely-in-women>.
- Sohn, Emily. 2019. “Righting the Gender Imbalance in Autism Studies.” *The Transmitter: Neuroscience News and Perspectives*. March 13, 2019. <https://www.thetransmitter.org/spectrum/righting-gender-imbalance-autism-studies/?fspec=1>.
- Spector, Rosanne. 2017. “How Men’s and Women’s Brains Are Different.” *Stanford Medicine Magazine*. May 22, 2017. <https://stanmed.stanford.edu/how-mens-and-womens-brains-are-different/#:~:text=Adjust ed%20for%20total%20brain%20size>.
- Sramek, John J., Michael F. Murphy, and Neal R. Cutler. 2016. “Sex Differences in the Psychopharmacological Treatment of Depression.” *Dialogues in Clinical Neuroscience* 18 (4): 447–57. <https://pubmed.ncbi.nlm.nih.gov/28179816/>.
- Stanford Medicine. 2024. “Stanford Medicine Study Identifies Distinct Brain Organization Patterns in Women and Men.” *News Center*. February 1, 2024. <https://med.stanford.edu/news/all-news/2024/02/men-women-brain-organization-patterns.html>.

# Article

## The Ethics of Weight–Loss Drugs: Patient Autonomy vs. Societal Beneficence

Kaitlin Ross\*

### I. INTRODUCTION

For centuries, dieting has been a social norm, and weight loss has been the determining measure of success and self-worth. In the 18th century, society idealized slim bodies, and the most celebrated and romanticized public figures were all thin, with many going to great lengths to maintain their slim waists. Diets have drastically changed from decade to decade, with the 1820s featuring the first low-carb diet, the early 1900s focusing on chewing food up to one hundred times to liquefy it, and the 2000s ushering in digitized weight-loss platforms (“The History of Dieting | Skyterra Wellness,” n.d.; “2000s,” n.d.). A large majority of the United States population is clinically obese, which also means these individuals are at risk of developing type 2 diabetes, hypertension, cardiovascular disease, cancer, and a number of other health problems.

In 1947, the FDA approved the first prescription obesity drug, desoxyephedrine (or methamphetamine). Over the following decades, appetite suppressants were introduced, but their use was restricted to only a few weeks. In 1995, the FDA reconvened to discuss the implementation of new weight-loss drugs, emphasizing the need for long-term efficacy. The shift toward drugs such as Ozempic or Wegovy was catalyzed in 2007 when a study revealed that weight-loss drugs could also treat type 2 diabetes and vice versa (“Circulation | AHA/ASA Journals,” n.d.).

Ozempic resembles a hormone called GLP-1, which acts as an appetite suppressant, and gained popularity through social media in 2021 after being featured on several famous television shows and endorsed by many celebrities (Sommi 2022d). After Ozempic was rebranded as Wegovy and restructured to a higher dosage, the drug quickly rose to prominence and sent the weight-loss world into upheaval. Platforms such as Noom and Weight Watchers began to shift their messaging from “anyone can do it” to recommending different diet plans and advising consulting physicians who could prescribe the new drugs. Currently, controversy surrounds the accessibility, competition, and classification of weight-loss drugs. This controversy regards accessibility, classification, and varying perspectives on the necessity of the drug. This paper explores the progression of societal views on dieting and their connection with weight-loss drugs, highlighting the ethical issues over public health

and personal autonomy.

### II. THE CASES OF YOLANDA HAMILTON AND ARTEMIS BAYANDOR

Yolanda Hamilton, a nurse from South Holland, Illinois, presented with an elevated Body Mass Index (BMI), high blood pressure, and elevated blood sugar when her physician prescribed her Wegovy. She responded well to the drug, experiencing improved energy, curbed sugar cravings, and a reduced appetite, which led to her losing 60 lbs (Etienne 2023). Originally, Yolanda was on Aetna insurance, but after getting a new job, she switched to Blue Cross and Blue Shield insurance. She was denied coverage and was forced to either stop the drug or pay \$1,400 out of pocket per month. Her job involves a relatively sedentary lifestyle, including sitting at a desk and registering patients, so she naturally gained approximately 20 lbs back after stopping the drug. She said, “I’m very frustrated about the weight coming back in such a short time.” She anticipates needing additional medications in the future, not for weight loss, but to address other health problems related to her previous overweight condition (Aubrey 2023). Hamilton viewed these weight-loss drugs as a medical need to improve her health and well-being, yet with recent restrictive policy and insurance implementations her patient autonomy could not be fully exercised. In many cases besides Hamilton’s patients were denied coverage to weight-loss drugs as they were not



By Getty Images, Public Sourcing

\*Kaitlin Ross studies Cancer Biology at the University of Alabama at Birmingham. Kaitlin can be reached at kaitlin.ross01@gmail.com.

deemed “medically necessary”, which has led to nationwide controversy over the necessity of weight-loss drugs and patient rights.

### III. ETHICAL ISSUES RAISED BY WEIGHT-LOSS DRUGS

#### i. Ethics of Access

To gain access to weight-loss drugs such as Wegovy, individuals must meet certain basic requirements. These requirements can vary, but the standard typically includes being over twelve years of age, having a BMI over 30 kg/m<sup>2</sup>, or having a BMI over 27 kg/m<sup>2</sup> with associated weight-related medical problems, in addition to having attempted a diet and exercise routine (Diet 2024). Weight-related medical problems can range from hypertension to Type 2 diabetes, which broadens access to the drug, as 54.5% of adults aged 45-59 alone are considered hypertensive (“Products - Data Briefs - Number 364 - April 2020,” n.d.). Another somewhat ambiguous requirement is having previously tried a diet and exercise routine, which most people have done at some point, whether through the latest Facebook Keto diet or a new gym membership as part of a New Year's resolution. Therefore, it is reasonable to assume that most people have “tried a diet and exercise routine.” Wegovy and other weight-loss drugs are recommended and advertised to individuals who are “prediabetic,” but nearly every citizen could be considered to some extent “prediabetic,” with statistics showing that over 1 in 3 U.S. citizens are currently prediabetic (“Prediabetes - Your Chance to Prevent Type 2 Diabetes” 2021). Overall, qualifying for weight-loss drugs under the current standards is relatively easy, and growing access to physicians who can prescribe these drugs, such as through Noom, has made them more available.

However, even if individuals qualify for the drugs, they may not necessarily be able to use them. The typical cost of using weight-loss drugs for one month is approximately \$1,400, which is higher than the monthly minimum wage (Indeed Editorial Team 2024), making it an unrealistic cost for many people. Some insurance plans, such as Blue Cross Blue Shield, Aetna, and Cigna, cover the cost of the drugs, while others do not (Medicare has recently begun covering them) (Woloshin, Woloshin, and SingleCare 2024). With insurance, costs can be reduced to as little as \$25, making them more affordable. Because the drugs are not affordable for everyone, they have largely become accessible only to the wealthy.

Issues related to the high cost of these drugs have already arisen, as seen in North Carolina in January 2024, when the state government cut coverage for anti-obesity medications for public employees. After North Carolina spent \$100 million on these drugs in 2023, with a projected \$1.5 billion loss by 2030, state officials deemed the costs un-

sustainable (“North Carolina Drops Coverage for Wegovy and Ozempic, With Implications for Anti-obesity Drug Market Projected to Hit \$100B by 2030” 2024).

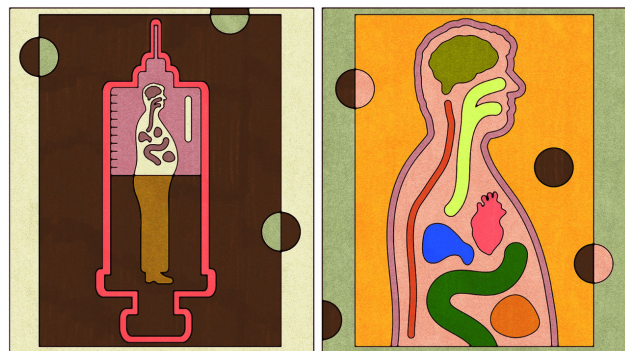
In August 2024, North Carolina began covering obesity medications under Medicaid to provide for some of the state's poorest residents. This decision was a dramatic turnaround for many of the state's workers, who had lost coverage about six months prior, leading to the cessation of treatment for nearly 25,000 people. North Carolina has generated significant controversy by now providing access to drugs for its poorest residents, while some middle-class workers cannot afford them (Sanger-Katz 2024). The state is now at the center of the debate, with citizens claiming denial of necessary healthcare despite the evident benefits and prevention potential of these drugs for numerous chronic health issues.

There are various opinions on what BMI qualifies someone for weight-loss drugs. Some physicians argue that a BMI exceeding 30 is required, while others believe that a BMI over 27 would make a person eligible. Over 130 million adults in the United States have a BMI greater than 30, and if you include other qualifying factors such as hypertension, diabetes, or a BMI over 27, an additional 50-70 million adults could be eligible (Centers for Disease Control and Prevention 2023). With such a large number of people qualifying, some insurance plans have begun to cover the cost, and many individuals have started treatment. However, this widespread use has led to issues, such as people using the drugs for purposes other than weight loss, which has created difficulties for those who need them for medical reasons.

#### ii. Patient Autonomy: Life-Saving vs. Life-Enhancing

Ozempic was originally known for its use as a weekly injection to help lower blood sugar by assisting the pancreas in secreting insulin. As a result, Ozempic's users were primarily people with Type 2 diabetes, and one of its side effects was weight loss. Although Ozempic is not officially approved for weight-loss purposes, physicians are prescribing it to patients for this use (UC Davis Health 2023). However, issues quickly arose when there was limited stock of Ozempic, and a new market of consumers began purchasing the drug. Many people with Type 2 diabetes struggled to find the medication and were repeatedly told that it was on “backorder,” creating problems for both patients and physicians. Physicians are now being forced to find alternative treatments for their patients (“Diabetes Patients Struggle to Find Ozempic Due to Its Popularity as Weight Loss Drug” 2023). Controversy has emerged over whether non-diabetics should be allowed to purchase drugs originally intended for treating diabetes, raising ethical issues about patient autonomy and whether the drug is life-enhancing or life-saving.





By Allie Sullberg, *The Economist*, 2024

One of the most important ethical standards in medical practice is patient autonomy, which refers to a patient's ability to make decisions for themselves and have input into their treatment. One aspect of patient autonomy that appears to be jeopardized is when physicians "take the easy way out" by using a "one-size-fits-all" approach to weight loss. This has led to physicians focusing on achieving weight loss as the ultimate goal for their patients to address associated health factors, often without considering the patients' preferences or desires. This approach can be seen as medically paternalistic (Team 2024). The ethics of medical paternalism versus patient autonomy have come to the forefront during the "fat-buster era." While both concepts should hold value in society, they may not both be appropriate in every physician-patient conversation regarding a patient's health.

### iii. Ethical Problems of Preventing Abuse

Another ethical debate is emerging regarding the new implementation and use of weight-loss drugs: how should these drugs be regulated to prevent abuse? How can we define a clear boundary between using the drugs to reduce weight from 400 lbs to 250 lbs versus using them to go from 175 lbs to 140 lbs?

The "Biggest Loser" problem highlights the difficulty of drawing a definitive line to prevent abuse of these drugs. This issue arises because individuals will vary significantly in their response to the drugs: some might lose significant amounts of weight, some might maintain their weight, and some might even gain weight. Contestants from the show *The Biggest Loser* have reported weight gain and permanently damaged metabolisms (Mazziotta 2021). This risk is even greater for individuals like Yolanda Hamilton and Artemis Bayandor, who might be forced to stop taking the drug and then end up gaining weight instead of losing it. Regaining weight could become a more frequent issue if physicians prescribe drugs haphazardly, leading patients to forgo healthy habits such as dieting or exercising. Once the drug is discontinued, patients may revert to old habits and quickly regain the weight.

Building on earlier points, since these drugs must be taken for life and come with associated side effects, they should not be the first option recommended by physicians. To prevent overuse and avoid the slippery slope of using the drugs for vanity purposes, physicians should ensure that the long-term benefits of taking the drug outweigh the associated costs and risks.

### iv. Life-Extending Aspects of Anti-Obesity Drugs

Could weight-loss drugs provide such significant health benefits that they could arguably be considered health beneficiaries? As already established these drugs help manage blood sugar control, bring cardiovascular benefits, improve lipid levels and many other benefits giving a person an overall improved quality of life. Heart disease is the leading cause of death in the United States with about 1 in 5 people dying from heart disease in 2022. High blood pressure and high cholesterol are contributing factors to heart disease (Centers for Disease Control and Prevention 2024) and studies have shown the increased benefits weight-loss drugs have brought to reduce the impact of these factors. These results also showed that the health benefits added were independent of how much weight was lost overall, indicating even if individuals did not lose the weight they set out to lose they could still have overall health improvements regardless (British Heart Foundation 2024).

The maker of Ozempic and Wegovy began to shed light earlier this year on some long-term effects of taking these drugs. Some results from the study concluded the majority of people were able to keep the weight off long-term while staying on the drug and only 17% of patients had to stop treatment from negative side effects (Kindelan 2024). However, various drugs have shown various long-term associated side effects such as kidney, gastrointestinal or thyroid problems as only a few. Long-term effects are still being closely evaluated and not fully understood. Many trials for the approval of these drugs only lasted 1-2 years yet they are intended to be taken for many decades.

## IV. BIOETHICISTS PERSPECTIVES

Bioethicist Immanuel Kant's principle of universalizability is centered around acting in accordance with rules that are applicable to everyone. This principle is highly relevant to the ethics of weight-loss drug implementation because, currently, access to these drugs is not universal but instead limited to those who can afford them and those whose physicians deem them eligible. Kant would support weight-loss drugs if they could be universally recommended. A Kantian framework would emphasize ethical principles that ensure patient autonomy during treatment and benefit both individuals and the public, aiming to prevent the exploitation of vulnerable people. Kant values patient

autonomy and would emphasize patients understanding the full effects—both good and bad and then being allowed to make a personal decision to take them or not. Kant's beliefs, which emphasize patient dignity, would support a patient-physician relationship where a patient is given full autonomy over their decision to use weight-loss drugs or not. Kant would also emphasize people should not be treated as mere means to an end but ends in themselves. If all humans are pressured into looking a certain way by societal beauty standards rather than respecting individuality then it is inherently unethical. If the drugs are offered in a way that respects autonomy and is universal without enforcing societal pressures or manipulation then they would be seen as morally acceptable by Kant.

## V. CONCLUSION AND FUTURE REMARKS

Throughout this paper, I have illustrated that the intricate nature of prescribing and implementing weight-loss drugs in society will exacerbate existing controversies and lay the groundwork for future debates, while reinforcing that infringement on patients' right to bodily autonomy is inherently unethical. In circumstances where patients and physicians have carefully assessed and explored alternative options, patients should be able to access treatments that could improve their current health and quality of life. However, drugs should not be the immediate solution for all patients, and physicians should establish stronger limitations on their use to prevent abuse for vanity purposes rather than addressing health needs.

If these drugs are to be applied in society, patients should be entitled to their affordability, especially if physicians are prescribing or recommending them. Looking towards future ethical issues surrounding weight-loss drugs, further research will be needed on individuals' metabolism, long-term efficacy of the drugs, and the impact upon diverse patient populations. Addressing these issues are crucial to navigating the new implications of weight management in society by prioritizing patient well-being and ethical healthcare practices.

## ACKNOWLEDGMENTS

This paper was consulted upon by my mentor, bioethicist Dr. Gregory Pence, and influenced by my fellow students in my bioethics seminar class at the University of Alabama at Birmingham.

## BIBLIOGRAPHY

- "About Heart Disease." Centers for Disease Control and Prevention, *Centers for Disease Control and Prevention*, 15 May 2024, <https://www.cdc.gov/heart-disease/about/index.html>
- Anthropologist or Ethicist: Paul Farmer, MD 1959-2022 | Center for Bioethics. 16 May 2022, <https://bioethics.umn.edu/news/anthropologist-or-ethicist-paul-farmer-md-1959-2022>
- Aubrey, Allison. 2023. "Wegovy Works. But Here's What Happens if You Can't Afford to Keep Taking the Drug." *NPR*, January 30, 2023. <https://www.npr.org/sections/health-shots/2023/01/30/1152039799/ozempic-wegovy-weight-loss-drugs>.
- British Heart Foundation. 2024. "Weight Loss Drugs Could Have Cardiovascular Benefits, New Research Shows." *BHF*. Accessed September 8, 2024. <https://www.bhf.org.uk/what-we-do/news-from-the-bhf/news-archive/2024/may/weight-loss-drugs-could-have-cardiovascular-benefits-new-research-shows>
- Cantwell, Margaret. 2023. "Wegovy: From Rebound Weight to That Black Box Warning." *Easy Health Options*°. June 21, 2023. <https://easyhealthoptions.com/wegovy-from-rebound-weight-to-that-black-box-warning/>.
- Centers for Disease Control and Prevention. (2023, March 23). Adult obesity facts. *Centers for Disease Control and Prevention*. <https://www.cdc.gov/obesity/adult-obesity-facts/index.html>
- "Circulation | AHA/ASA Journals." *American Heart Association Journal*. <https://www.ahajournals.org/journal/circ.2022d>.
- "How Ozempic Became a Celebrity Weight Loss Sensation." *diaTribe*, November 7, 2022. <https://diatriber.org/how-ozempic-became-celebrity-weight-loss-sensation>.
- "Diabetes Patients Struggle to Find Ozempic Due to Its Popularity as Weight Loss Drug." 2023. *ABC7 Chicago*. November 10, 2023. <https://abc7chicago.com/ozempic-weight-loss-drug-miracle-wonder/14037871/>.
- "Diet Culture Timeline." *Diet Culture Timeline*. <https://dietculturetimeline.com/2000s/>.
- Diet, Mayo Clinic. 2024. "Who Qualifies for Semaglutide Injections?" *Mayo Clinic Diet* (blog). January 9, 2024. <https://diet.mayoclinic.org/us/blog/2024/who-qualifies-for-semaglutide-injections/>.
- Etienne, Vanessa. 2023. "Ozempic Rebound Is Real: Doctor Says Weight Gain Can Be 'Devastating' After Stopping." *Peoplemag*, January 30, 2023. <https://people.com/health/ozempic-rebound-is-real-doctor-says-weight-gain-can-be-devastating-after-stopping/>.
- Indeed Editorial Team. 2024. "How Much Does a Minimum Wage Job Pay a Year?" *Indeed*. 2024. <https://www.indeed.com/career-advice/pay-salary/how>

- [much-does-a-minimum-wage-job-pay-a-year.](#)
- Jack W. 2024. "Wegovy Made Available in the UK for Weight Loss in People With Prediabetes and Type 2 Diabetes." *Diabetes UK*, January 5, 2024. <https://www.diabetes.org.uk/about-us/news-and-views/wegovy-key-facts-know-about-weight-loss-drug>.
- Katie Kindelan, "New Study Focuses on How to Stay on Weight-Loss Drug Wegovy," *ABC News*, April 27, 2023, <https://abcnews.go.com/GMA/Wellness/new-study-focuses-stay-weight-loss-drug-wegovy/story?id=110401021>.
- Mazziotta, Julie. 2021. "Jillian Michaels Has Problems With 'the Biggest Loser' : 'the Producers Gamified Weight Loss'" *Peoplemag*, December 15, 2021. <https://people.com/health/jillian-michaels-has-problems-with-the-biggest-loser-the-producers-gamified-weight-loss/>
- "North Carolina Drops Coverage for Wegovy and Ozempic, With Implications for Anti-obesity Drug Market Projected to Hit \$100B by 2030." 2024. *Fortune*. January 27, 2024. <https://fortune.com/2024/01/27/north-carolina-drops-coverage-for-wegovy-and-ozempic-weight-loss-drugs/>.
- "Prediabetes - Your Chance to Prevent Type 2 Diabetes." 2021. *Centers for Disease Control and Prevention*. December 21, 2021. <https://www.cdc.gov/diabetes/prevention-type-2/prediabetes-prevent-type-2.html#cdc-generic-section-5-prevent-type-2-diabetes>
- "Products - Data Briefs - Number 364 - April 2020." *Centers for Disease Control and Prevention*. <https://www.cdc.gov/nchs/products/databriefs/db364.htm>.
- Steinberg, Brooke. 2024. "We Stopped Taking Ozempic and Wegovy — and Regained More Weight Than We Lost." *New York Post*, January 3, 2024. <https://nypost.com/2024/01/03/lifestyle/we-stopped-taking-ozempic-wegovy-and-regained-more-weight/>.
- Team, Author Mjhl | Rdsm. 2024. "The Ozempic 'Epidemic' and Its Dangerous Consequences." *McGill Journal of Law and Health*. March 13, 2024. <https://mjhl.mcgill.ca/2024/03/12/the-ozempic-epidemic-and-its-dangerous-consequences/>.
- "The History of Dieting" *Skyterra Wellness*. <https://skyterrawellness.com/history-of-dieting/#:~:text=The%20first%20actual%20diet%20book,and%2014%20ounces%20of%20wine.>
- Tomiyaama, A. J., Ahlström, B. H., & Mann, T. (2013). Long-term effects of dieting: Is weight loss related to health? *Social and Personality Psychology Compass*, 7(12), 861–877. <https://doi.org/10.1111/spc3.12076>
- UC Davis Health. 2023. "Ozempic for Weight Loss: Does It Work, and What Do Experts Recommend?" *Cultivating Health*. July 19, 2023. <https://health.ucdavis.edu/blog/cultivating-health/ozempic-for-weight-loss-does-it-work-and-what-do-experts-recommend/2023/07>
- Woloshin, Nadine, Nadine Woloshin, and SingleCare. 2024. "How to Get Wegovy Covered by Insurance." *The Checkup*. March 21, 2024. <https://www.singlecare.com/blog/how-to-get-wegovy-covered-by-insurance/>

# Article

## Brain-to-Brain Communication: Hyper-Empathy and Identity

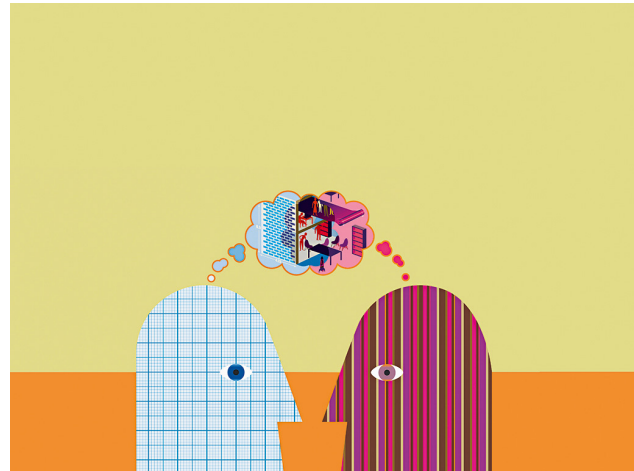
Yuliya Liberman\*

### INTRODUCTION

Telepathy has long been a staple of science fiction and a token superhero power. However, according to the current trajectory of technology companies such as Neuralink, Meta, etc., a real-life version of telepathy can be possible for the general public. Neurotechnology that links two or more brains and allows for communication between them, also known as brain-to-brain communication, is a rapidly developing sector of research and advancement. It is worth considering what could be lost through brain-to-brain communication when it has the potential to replace the current forms of mediated and unmediated communication.

Brain-to-brain communication is possible today and is a likely trajectory for neurotechnology to expand into. Studies have shown that two or more brains can communicate with each other, most notably by Jiang et al. (Jiang et al. 2019). Additionally, with the progress of the latest neurotechnology companies, it seems clear that communication is a high-priority function that aims to be realized. Projects like BrainNet have demonstrated non-invasive interfaces that allow multiple individuals to collaborate using direct brain-to-brain communication. This system employs EEG to decode brain signals and TMS to transmit information between brains (Hildt 2019). Researchers are exploring methods to enhance the complexity of information shared, such as using fMRI alongside TMS for better semantic content transfer. While this technology may seem far-fetched or only probable in the distant future, the reality is that with continued research and with these notable accomplishments and suggested goals, brain-to-brain interpersonal communication will likely emerge much sooner than expected and be a crucial part of all neurotechnology released for personal use.

In this paper, I offer a scenario depicting the near future in which individuals primarily communicate through brain-to-brain interface technology and suggest that this would be a dystopia where communication, relationships, and even people's identities are fundamentally altered in an undesirable way. This is followed by an overview of current forms of mediated interpersonal communication (MIC) and their advantages and ethical challenges in comparison to brain-interface mediated interpersonal communication (BIMIC). I analyze a novel concern, which only pertains to BIMIC, of the need for two distinct interlocutors, which BIMIC threatens to merge into one. If two interlocutors



From *The New Economy*, Public Sourcing

share their memories, thoughts, and feelings with each other for a long period of time, then there could be a point at which they would develop a type of hyper-empathy. While an argument can be made that BIMIC would remove the distinction of two or more interlocutors and their respective identities, I suggest that a necessary distinction can still be retained. Since individuals have agency, and this capacity would remain even if two people had completely identical experiences and memories, individuals could never truly merge identities. Additionally, in BIMIC, precautions could be put in place, such as identifying markers on each transmission which would allow for a receiver of transmissions to differentiate between their own thoughts and the sender's transmissions. However, there is a further consideration of the nature of BIMIC which may not relay valuable aspects of communication. When interlocutors partake in face-to-face communication there is a certain recognition that occurs which leads to respect for each individual as a fellow human and an individual with moral worth. I suggest that this phenomenon may not be translatable in BIMIC and interlocutors could suffer the loss of these aspects. I argue that while BIMIC allows for an unprecedented ability of hyper-empathy, there is a line that can be retained where two interlocutors will still remain unique individuals and agents. Additionally, the use of BIMIC could lead to the loss of necessary conditions of communication, namely respect and recognition. Within this understanding, I suggest that the hypothetical dystopia as a result of BIMIC remains a potential negative outcome rather than an impediment to

\*Yuliya Liberman studies Philosophy and Neuroscience at Temple University. Yuliya can be reached at [yuliya.liberman@temple.edu](mailto:yuliya.liberman@temple.edu).



progress in this field of inquiry.

### A POTENTIAL DYSTOPIAN FUTURE

Two individuals, James and Jessica, are sitting across from each other at a coffee shop, each with a wearable device that has the ability to interpret commands that they send to it through their thoughts. They do not speak to each other, and in fact, the entire coffee shop is completely void of conversation. The majority of people have obtained these devices and solely communicate through them. In this world, auditory communication is too arduous and inefficient. Public places are still used, despite the ability to communicate from anywhere without even moving a finger. People in this society still realize the value of meeting places, and they believe that talking is not necessary for the human need to be around others to be met.

James thinks the command: “Hey Roger, (this is the signal phrase that alerts the device that a command is next), send message to Jessica that this coffee is good”. This command takes place in a millisecond at the speed of brain activity and between passing thoughts that are simultaneously occurring for James. In the same millisecond, Jessica receives a mental transmission, much like telepathy as the device sends a thought to Jessica’s consciousness, “Hey Jessica, James wants you to know that his coffee is good, he is very happy about being here”. In a split second the message has been transmitted with an addition of implied tone to fully convey what James meant. Both James and Jessica continue to exchange remarks about the coffee shop and update each other about their lives using brain-to-brain communication without looking up from their computers or breaking from their work.

A bit later, James decides he wants to check in on his mother who is on vacation. His device sends a message to his mom’s wearable device to receive permission to transmit what she is seeing. James can now see in his mind where his mom is and what she is experiencing. This appears to him much like a memory does, though clearer, yet still only in his mind.

Simultaneously, Jessica is still sitting in front of him working on her computer though she is receiving mental transmissions from her boss who is telling her that she is getting a promotion. She commands her device, “Hey Roger, tell my boss I say thank you but in a more formal way” and her wearable device transmits a professional message with much gratitude and appreciation to her boss. However, the boss’s own wearable device retranslated this message as “Jessica said she is very thankful.” This was to allow for greater efficiency as opposed to reading the whole message as it was sent.

Both James and Jessica continue drinking their coffee and working on their computers, and they are happy to have these interactions, not through spoken language, not at the tips of their fingers, but integrated into their consciousness. It seems to them that this is the most organic and efficient way to communicate. A spontaneous thought can instantly

be transmitted, saved, cataloged, and then revisited. Tone can be easily conveyed as the device also interprets brain signals that correspond to the emotion the individual is feeling. To people in this society, brain-to-brain communication is an advancement that promotes honesty, efficiency, and greater possibilities of empathy, much like the concept of telepathy once promised, though with a respect of personal privacy. To them it is the ultimate advancement which allows all to live more connected, yet individual lives.

### MEDIATED INTERPERSONAL COMMUNICATION

While interpersonal communication is the term that describes face-to-face communication, typically with two interlocutors, mediated interpersonal communication (MIC) describes the phenomenon during which this interpersonal communication is somehow mediated, or cultivated, by something other than the two interlocutors’ ability to communicate. Computer mediated communication (CMC) describes interactions between people on the internet, though this is likely an outdated term as far more than just computers are used as tools for interaction, such as essentially every technology that has an internet connection from phones, tablets, smart watches, gaming systems, virtual reality headsets, and more. In this paper, CMC will be used as an umbrella term to describe mediated interpersonal communication using any technological device.

MIC occurs today through many devices and many variations, some with only text, and others with a function of video as well. Each is able to answer the question: “is true connection possible?”, differently. With the emergence of online chat groups almost simultaneously with the adoption of computers for personal use, online communication has increased access to anyone in the world at any time and the possibility of collaboration despite distance. Some forms of MIC such as texting promote a greater degree of inauthenticity or the possibility of miscommunication, while phone calls allow for the recognition of tone therefore allowing for a lesser degree of potential information lost. Video calls, even more so than phone calls, allow for conversation and communication that is almost indistinguishable from face-to-face communication. With the ability to FaceTime, Zoom call, or Skype anyone in the world at any time it would seem that surely this alternative is better than the limitations that in-person communication possesses.

A heavily researched area of MIC has been social media, especially Facebook, through which many individuals can form communities and even discover life-long friendships and relationships. Some findings argue that true connection is possible through this virtual medium and that people are able to build trust, and understanding, and have authentic conversation despite the fact that on the surface they are interacting with an avatar and online profile (Candrasari 2020).

A novel version of MIC is brain-interface mediated interpersonal communication (BIMIC). This form of MIC

has been proposed through the use of brain-to-brain interfaces (BBIs). This technique involves brain-computer interface (BCI) technology and a computer-brain interface (CBI). A BCI is a device that involves connecting neural circuits to external support systems (Jangwan et al. 2022) and a CBI uses computer commands to deliver information to a brain (Hildt 2019). This method would connect two brains and allow for the transmission of information between them.

Brain-to-brain communication is currently not only conceivable but has been successfully demonstrated. A study showed that not only is brain-to-brain communication possible, but it is also possible to connect more than two brains with BBI technology. This study involved three individuals using a non-invasive BBI called BrainNet to communicate with each other and complete a Tetris-like game (Jiang et al. 2019). Two individuals in this study communicated using brain-to-brain communication and one individual was the receiver of transmissions. The two individuals transmitted simple messages guiding the decision-making process of the third participant who physically manifested their suggestions by playing the game. It is likely that in the near future, a “large network of individuals connected via BBIs and a cloud-based server” could lead to the advancement of inputs and outputs from multiple devices and perhaps even a new form of social networking or professional collaboration (Hildt 2019). However, various components of BIMIC such as the ability to use this device outside of a lab environment are still motivating research.

### A NEW FRONTIER OF MIC

BIMIC aims to provide a more efficient alternative to other forms of communication. BIMIC offers the possibility

of not having to reach for a phone, type in a message, then wait for a response. Instead, one could simply send a signal directly to another person, at the speed of thought, without any physical action. There is less chance that the recipient would miss this transmission as it is a directly connected piece of technology. This mode of communication would be faster, require less effort, and be arguably more reliable than other forms of MIC. It follows that since communication is more efficient, faster, and easier, there can be more communication. In a similar way that CMC has allowed for a connection between people who are not physically in the same place at the same time, BIMIC has the potential to form a similar connection and further it by increasing the amount of communication possible.

Finally, there is a great potential for new possibilities of increasing empathy with BIMIC than was ever possible with CMC and even face-to-face communication. BIMIC could allow for the transmission of not only text, or the voice of the sender, or an AI generated image of them speaking the message, but a direct transmission of emotion and sensation. If BBIs are able to advance, it could be possible that even memories are transmitted directly into the mind of the recipient. It can be possible to transmit a feeling of anger or joy not only through tone, but through a mental sensation that would be conveyed alongside the received message. Sensations such as adrenaline, pain, and fear could likewise be transmitted. Undoubtedly, this opens an array of ethical questions such as to what extent such transmissions should be realistic, would the recipient have to consent to being subjected to this direct form of empathy, and whether a line could be drawn between malicious intent and innocent sharing of emotion.

Other ethical concerns, similar to those encountered by CMC, such as inauthenticity, privacy, safety, accessibility, cyber-security, regulation, and longevity create another layer of challenges that this technology would have to overcome (Chandler et al. 2022, Candarsari 2020).

### THE DYSTOPIA OF BIMIC

#### Hyper-empathy

In the described hypothetical scenario, James and Jessica were utilizing their BBI devices to transmit their feelings and thoughts to each other and James was able to even view an experience of his mom as if he was retrieving a memory of his own. Consider the possibility of James and Jessica continuously exchanging their thoughts with each other for years and on a daily basis. A potential repercussion of this unfolds: can James and Jessica then differentiate between their own thoughts and the thoughts of the other? Years later, could Jessica confuse James’ thought of his coffee being good with her own thoughts about her coffee? Furthermore, if James receives a transmission of a memory that Jessica has, would James be able to differentiate this memory from his own? If two individuals are transmitting their thoughts to each other frequently and for a long



From *Medium*, Public Sourcing

period, it could be true that after a certain time, most of their thoughts, memories, feelings, and impressions will be shared.

This is a somewhat opposite concern of typical MIC discourse. Oftentimes, we are concerned with whether MIC will lead to a loss of connection or a misunderstanding that will result in diminished empathy. In social media, for example, communication can be more accessible and frequent, however, there is a distance that exists between two individuals through this mediated mode of communicating. In contrast, BIMIC decreases the distance that exists even with in-person communication. Here, BIMIC threatens to allow us to share so much of ourselves that two people or more can become almost one. This is a level of unreachable empathy and connection with rudimentary in-person communication. BIMIC would allow people to almost merge into one, and raises the contrary concern about MIC of whether two interlocutors can be retained with BIMIC as the primary mode of communication.

The problem of BIMIC appears to be the difference of communication inside one's mind rather than between minds (Riva and Galjimberty 1997). All other modes of MIC exist between two or more interlocutors, or minds. One interlocutor has a certain level of separation from both the conversation at hand and the recipient of the communication and this distinction forms the basis of communication itself. It is in a way a defining factor of communication. In BIMIC, when transmissions of messages are sent and received within one's mind, it seems that communication loses this crucial condition of a separation between interlocutors. In this way, the hyper-empathy problem grows into a problem of whether communication can even exist without two distinct interlocutors.

### Agency

However, perhaps while a greater portion of thoughts and experiences may be shared between two or more individuals, there can be certain factors such as the design of the device itself or aspects of identity that ensure the separation of one interlocutor from the other. If the threat to identity is confusing who's thoughts belong to who, then the identification of messages, even when stored and retrieved from one's memory, can prevent this. On the other hand, if the issue is the actual act of communicating within one's mind, and if this can even be called a conversation, then perhaps the agency of individuals involved in BIMIC can be considered and whether this is enough to both draw a distinction between interlocutors and prevent a merging of identity.

The practical solution seems possible, at least hypothetically. Developers, granted that this concern will be considered in the design process, could implement labels, frames, or other identifiers that would distinguish external transmissions. Despite there not being a solution now, it is entirely possible that a practical solution to distinguish and recall transmissions will be found. In that case, the confusion of the receiving interlocutor's thoughts would be

avoided.

However, this would only literally prevent one's thoughts and memories from becoming another's. If it is true that BIMIC would increase communication generally, and people would be able to share messages more effortlessly and frequently, perhaps interlocutors would come to know too much about another person. By sharing memories, desires, feelings, and experiences, which can be said to influence actions and thoughts and decisions in the future, would two individuals start to completely become identical in those aspects over time? The question then appears to be whether there will be sufficient other characteristics that an interlocutor possesses to retain their unique individuality. If it is true that memories influence thoughts and actions in the present, and memories can be argued to make up our identity and self-perception, then two interlocutors would be giving up their identity and individuality and become merged.

Yet, this concern presupposes a view on identity. Many philosophers have argued that identity is in fact not dependent on memories and thoughts, as is assumed in this reasoning. Joseph Butler believed that there must be an underlying identity that consciousness reveals, but does not create (Butler 1736). Thomas Reid affirmed that humans persist as the same person over time and that memory is evidence for personal identity rather than constitutive of it (Reid 2002). David Hume rejected the idea of an underlying substance or essence that constitutes personal identity, instead believing that identity emerges from the relations between our perceptions and ideas (Hume 2007). While John Locke posited that identity is made up of our memories and consciousness, this view has been considered circular and said to presuppose identity in a narrow definition (Locke 1979). If Locke's view on identity is accepted, then BIMIC would undoubtedly be expected to cause a merged identity. However, the overwhelming majority of theories do not accept identity as being solely determined by memories and thoughts. Identity could be a constant or self-evident characteristic of humans that does not rely on past experiences, or an ever-changing illusion based on mental phenomena. Regardless, it seems true that identity is more complex than thoughts, memories, or experiences.

Assuming this view, the ethical concern of merging identities is mitigated. Instead, an aspect of identity may be considered one's agency to act in the world. Agency, as the capacity for action, remains ultimately undisturbed even during BIMIC. Regardless of common past experiences, agency would allow an individual to act and think autonomously. If identity is constant, and we have agency, then our identity would not be impacted by BIMIC, and our agency would be the differentiating factor that sets us apart from an interlocutor even if we share all thoughts, memories, and experiences.

While hyper-empathy to the point of becoming one and the same with an interlocutor through BIMIC appears novel and may infringe upon a certain level of individuality that is currently the normal, it is not likely that users of BIMIC



will unintentionally be subjected to a complete loss of individual distinction. There seems to be a line that can not be crossed by BIMIC which is defined by one's capacity for agency. While one can become totally empathetic towards an interlocutor over extended use of BIMIC, one's agency can not be revoked and therefore BIMIC will not cause two interlocutors to merge into one.

Further evidence that identity may not be entirely infringed upon through the use of BIMIC can be found in the current neuropsychological understanding of identity. Memory is a crucial component of identity, but it is not the only factor considered in neuropsychology. Identity is multifaceted, involving personal, relational, collective, and public components. These components encompass goals, values, beliefs, social roles, and group affiliations. Additionally, identity development involves distinctiveness, coherence, and continuity. Recognition and identification processes also contribute to identity by linking sensory information with semantic knowledge about individuals. Thus, identity is shaped by a combination of memory and various cognitive and social elements (Meca et al. 2015). This insight further exemplifies the fact that while BIMIC threatens to influence identity significantly by affecting an individual's memory, identity is likely determined by multiple factors which can remain untouched by BIMIC and unique.

### Respect and Recognition

Yet there is still another concern, unique to BIMIC, which deserves consideration. As Robert Sparrow writes in his paper on robots in aged care (2016), technology threatens to subvert respect and recognition. He argues that if an elderly care facility were to implement all robot assistants, who would hypothetically provide a better standard of care objectively, the robots would ultimately fail to provide the essential respect and recognition that people require. In this view, respect is the content, and recognition is "a matter of the form of social relations". Respect is a necessary condition of understanding one's personhood. Recognition is the knowledge that an interlocutor is a particular and "valued member of a community". The absence of respect would therefore lead to a failure to acknowledge one's moral worth. Without recognition, one can not be part of a community, undoubtedly threatening their subjective well-being.

In BIMIC, this same respect and recognition may be impossible to achieve. A user of BIMIC would, presumably, communicate with the BBI assistant, which would transmit the message, which would also be translated through a corresponding BBI assistant. In this way, BIMIC endangers the recognition of an interlocutor in communication. While there is a similar lack of recognition in other forms of mediated communication, BIMIC requires an individual to communicate with an assistant, and receive messages from an assistant. As Sparrow outlines, communication with AI or robotic systems uniquely lacks a recognition aspect which is present in even other forms of MIC, and is similarly present in BIMIC. Without this recognition, mutual respect be-

tween two individuals may be impossible. Respect can only come about through the realization of recognition, and play the role of establishing a connection between two people through communication. If this aspect of communication is lost, it is arguably true that the well-being of individuals will likewise suffer. Additionally, this concern appears to showcase an aspect of BIMIC which does not directly have a solution. It seems as if due to the nature of BIMIC, respect and recognition may always be unattainable with this technology.

Respect and recognition as conditions of well-being are speculative, and may not be sufficient to overshadow the benefits BIMIC offers. However, this line of reasoning supports the idea that through BIMIC, a vital value of interaction between two interlocutors is lost. It isn't certain that this aspect is a necessary condition of communication or that BIMIC should not be researched and developed. However, the future implementation of this technology should acknowledge such a possibility as a loss of respect and recognition, and move forward with caution.

### CONCLUSION

While BIMIC may garner ethical concerns and require adequate regulation, BIMIC would provide increased globalization, efficiency, and increased empathy among users beyond that which is possible with any other form of MIC today. Whether the risks, both known and unknown, are enough to halt this research is yet to be determined. Many of these concerns have also been prevalent in the use of CMC. Since users and developers of CMC have been able to resolve these mutual ethical issues or at least prevent significant negative outcomes, it would likewise follow that as such instances occur with BIMIC, the response would mirror that of CMC and some harm can be avoided.

The hypothetical dystopia that may come about with the use of BIMIC categorized by hyper-empathy and a loss of respect and recognition in communication, for now, remains solely hypothetical. It is entirely plausible that with thoughtful development, these serious problems can be avoided. With the understanding of these concerns, developers of this technology should strive to create built-in solutions such as clear identifiers of other user's transmissions and continue conducting research on how these transmissions will be stored and recalled in the receiver's brain. If a user's memory could clearly distinguish between their own thoughts and memories and external transmissions of thoughts and memories, the concern of merged identity can be mitigated at least on a surface, functional level. While an unprecedented ability for hyper-empathy and loss of individuality may occur with BIMIC use, agency seems to be the key for the identity of interlocutors to be retained. Since one's identity seems majorly influenced by their capacity for agency, and BIMIC can not threaten agency, the identity of user's seems to be threatened by prolonged BIMIC use, though not at risk of complete erasure or significant merging with others. Since the outlined ethical issues cen-



ter around prolonged and regular use of this technology, if BIMIC was designed in such a way that it could not be used in such pervasive ways, some of these challenges can be avoided. As in the debate of AI ethics, it is worthwhile to consider potential “friction” in user’s interactions with this technology. For example, BIMIC technology could be made intentionally less convenient so as to prevent the replacement of communication by this tool such as through additional steps in the process of transmitting a message, or limiting the quality of transmitted messages. By accepting that this technology is on the verge of a breakthrough, it is necessary to continue discussion rather than suggest arguments to prevent its creation. Though BIMIC would certainly bring about a drastically new mode of communication, and lead humans into uncharted territory, even seemingly the worst consequence of BIMIC could be just a consideration rather than reason to not progress research.

## BIBLIOGRAPHY

- Butler, Joseph. 1736. *The Analogy of Religion, Natural and Revealed, to the Constitution and Course of Nature*. 2nd corrected edition. London: J. and P. Knapton.
- Candrasari, Yuni. 2020. "Mediated Interpersonal Communication: A New Way of Social Interaction in the Digital Age."
- Chandler, Jennifer A., Karin I. van der Loos, Sebastian Boehnke, Jeanette S. Beaudry, Daniela Z. Buchman, and Judy Illes. 2022. "Brain Computer Interfaces and Communication Disabilities: Ethical, Legal, and Social Aspects of Decoding Speech From the Brain." *Frontiers in Human Neuroscience* 16. <https://doi.org/10.3389/fnhum.2022.841035>.
- Hildt, Elisabeth. 2019. "Multi-Person Brain-To-Brain Interfaces: Ethical Issues." *Frontiers in Neuroscience* 13. <https://doi.org/10.3389/fnins.2019.01177>.
- Hume, David. 2007. *A Treatise of Human Nature*. Oxford: Clarendon Press. (Original work published in 1739-40.)
- Jangwan, N. S., G. M. Ashraf, V. Ram, V. Singh, B. S. Alghamdi, A. M. Abuzenadah, and M. F. Singh. 2022. "Brain Augmentation and Neuroscience Technologies: Current Applications, Challenges, Ethics and Future Prospects." In *Frontiers in Systems Neuroscience* 16. Frontiers Media S.A. <https://doi.org/10.3389/fnsys.2022.1000495>.
- Jiang, Linxing, Andrea Stocco, Shihao Ye, Jingying Zhu, and Rajesh P. N. Rao. 2019. "BrainNet: A Multi-Person Brain-to-Brain Interface for Direct Collaboration Between Brains." *Scientific Reports* 9 (1): 6115. <https://doi.org/10.1038/s41598-019-41895-7>.
- Locke, John. 1979. *An Essay Concerning Human Understanding*. Oxford: Clarendon Press. (Original work published in 1700.)
- Meca, Alan et al. "Identity Centrality and Psychosocial Functioning: A Person-Centered Approach." *Emerging adulthood* (Print) vol. 3,5 (2015): 327-339. doi:10.1177/2167696815593183
- Reid, Thomas. 2002. *Essays on the Intellectual Powers of Man—A Critical Edition*. Edited by Derek R. Brookes. Edinburgh, UK: Edinburgh University Press. (Original work published in 1785.)
- Riva, Giuseppe, and Carlo Galjmberti. 1997. "The Psychology of Cyberspace: A Socio-Cognitive Framework to Computer-Mediated Communication." *New Ideas in Psychology* 15 (2).
- Sparrow, Robert. 2016. "Robots in Aged Care: A Dystopian Future?" *AI & Society* 31 (4): 445-454. <https://doi.org/10.1007/s00146-015-0625-4>.

# Article

## Using Autonomy Thresholds to Assign Medical Decision-Making Models for Adults with Autism

Adarsh Mavathaveedu\*

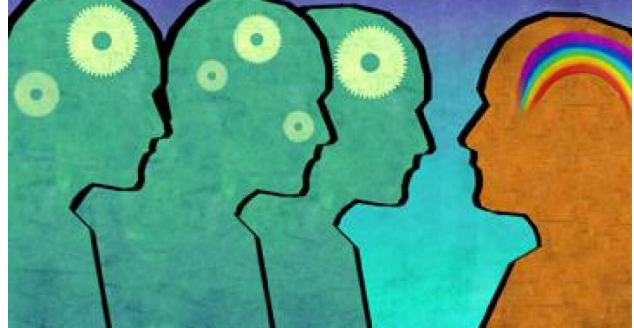
### INTRODUCTION

The right to patient autonomy, or generally the ability to make one's medical decisions, is a guiding principle throughout healthcare (Ubel, Scherr, and Fagerlin 2018). However, questions arise for patients with autism regarding their levels of autonomy both in principle and in practice.

To date, discussions on autonomy, in both non-autistic and autistic adults, have often conflated issues between competence and capacity for decision-making. Competence is a legal term and refers to individuals having sufficient ability, as recognized by a judge, to partake in legally recognized activities such as making medical decisions (Leo 1999). Specifically, the Convention on the Rights of Persons with Disabilities (CRPD) has served as an international agreement to protect this legal right for vulnerable populations (United Nations 2006). As part of these efforts, members of the United Nations (UN) have strongly advocated for supported decision-making models in which the final medical decision is made by the individual with autism but is informed by a trusted team of family, friends, and/or clinicians (United Nations 2014; ASAN n.d.). Interestingly, the United States has not yet ratified the CRPD, partly on the grounds that current autonomy legislation is already robust (Barsky 2018). However, such a claim is cast in doubt by the existence of conflicting state laws – while some states support the UN's suggestion, others advocate for guardianship models in which a surrogate decision-maker acts on behalf of the autistic individual (ASAN n.d.).

The conflicting legal views of competence may be a consequence of the varying views of capacity among those with autism. Capacity for patient autonomy, which shall be the focus of the remainder of the paper, refers to the ability to make a medical decision within a given situation (Leo 1999). To determine capacity, the physician evaluates the patient's ability to comprehend, manipulate and utilize information when forming medical decisions (Leo 1999). Historically, biases from the clinician's perspective have perpetuated myths that those with autism do not deserve autonomy, consequently leading to unnecessary external influence and limitations in their treatment choices (Späth and Jongsma 2020; McVey et al. 2023).

Given the high heterogeneity across individuals with autism, it is impractical to describe what autonomy looks like for all individuals with the diagnosis. Such an at-



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tempt is further complicated by how autonomy itself exists on a spectrum of varying degrees that fluctuate over time (Varelius 2006). Instead, a more feasible goal would be to develop an ethical framework for determining which decision-making model would be most appropriate for such patients based on whether they meet a certain level of autonomy. The idea of using thresholds of autonomy to determine capacity has been previously proposed by several authors (Varelius 2006; Hirsch 2023). However, there remains limited discussion of what exactly these thresholds are. In other words, what are the internal capacities that individuals must possess (or lack) before their decisions are either accepted (or overridden)? Identifying such clear thresholds can hopefully prevent the unjustified restriction of autonomy for people with autism, and rather allow them to exercise their remaining capacity as much as they wish.

This paper will be divided into three main parts. First, a basic understanding of patient autonomy, including its definitions and value, will be developed. Secondly, three separate case studies will be utilized to identify both the thresholds of autonomy and the rational capacities required for each decision-making model, including independent decision-making, supported decision-making, and guardianship. Finally, directions for future work will be described to both develop this framework further and enable its implementation. Notably, this discussion will be limited to only adults to avoid conflating concerns about developing autonomy among autistic children, although other papers have discussed such cases more fully (McVey 2023).

### PATIENT AUTONOMY & ITS VALUE

To date, definitions of autonomy have largely been

\*Adarsh Mavathaveedu studied Neuroscience at the University of Rochester. Adarsh can be reached at amavath33@gmail.com.

split between individualistic and relational conceptions. In the traditional, “individualistic” view, autonomy is seen as the patient’s capacity to self-govern one’s healthcare by freely choosing treatment options (i.e., positive liberty) with limited external influence (i.e., negative liberty) (Späth and Jongsma 2020). However, others have argued for more “relational” views, which emphasizes, and sometimes even requires, the role of social relationships such as clinicians, family, and friends (Dove et al. 2017). While there are several arguments for both, it is important to note that these two views can co-exist; with the “causal” view, it can be acknowledged that while autonomy is generally enabled by social conditions, it largely depends on one’s internal capacities during specific, provider-patient interactions (Dove et al. 2017). Such an approach is particularly useful because it not only recognizes that autistic adults’ rational capacities ultimately determine their decision-making model, but also appreciates the social relationships needed for such models to occur practically and meaningfully.

When considering the value of autonomy in healthcare, authors have explored both its instrumental and intrinsic components. The instrumental value of autonomy is the most generally accepted (Hirsch 2023; Lee and Lin 2010; Alonso-Sardón et al. 2019). On the other hand, the intrinsic value of patient autonomy, or whether autonomy has any value irrespective of its beneficial outcomes, remains highly debated (Wall 1998; Hirsch 2023; Varelius 2006). Regardless of its value, patient autonomy is not a principle that should be maximized across all cases. Attempts to universally increase the involvement of autistic adults in decision-making, including those with severe impairments (or a simple preference to defer their autonomy), could lead to unnecessary, uninformed, and adverse health outcomes. Instead, balancing the principles of autonomy (by promoting freedom of choice and minimizing external influence) and beneficence (by promoting well-being and minimizing harm) would be most helpful in assigning medical decision-making models (Graber 2017).

To summarize, patient autonomy, which depends on individual capacities and social conditions, is of great value for both non-autistic and autistic adults. In the latter group, the intrinsic value of autonomy is of particular interest because it justifies their participation in medical decision-making whenever possible (Hirsch 2023). This participation, however, may be limited in cases where the physician’s obligations to other moral principles, such as beneficence, take precedence.

#### **ASSIGNING MEDICAL DECISION-MAKING MODELS BASED ON PATIENT AUTONOMY**

Now that a foundation of autonomy and its value in healthcare have been established, its role in adults with autism can be explored. As mentioned, the term “autism” refers to a broad category of disorders that affects a highly

heterogeneous population, resulting in varying rational capacities. This phenotypic range makes it impractical to outline what autonomous healthcare may look like for everyone diagnosed. Similarly, the recent neurodivergence movement has called for the reclassification of autism from a disability to just another variant on the wide spectrum of human minds (Ripamonti 2016). While the classification of autism as a disability is outside the scope of this paper, most would agree that a diagnosis of autism in itself is not sufficient to impose restrictions on patients. Rather, the focus should be placed on its secondary impairments to individuals’ rational capacities that question their autonomy. This line of thinking both prevents the overgeneralization of principles across those with autism and enables this framework to be used for adults with other intellectual disabilities.

Currently, the three available decision-making models include independent decision-making, supported decision-making, and guardianship (ASAN n.d.). In the following sections, various case studies of adults with autism will be utilized to assess the thresholds of autonomy and intact rational capacities needed for each model.

#### **INDEPENDENT DECISION-MAKING**

Case 1: Alan is a 21-year-old, undergraduate student diagnosed with autism. He is approached by a research team to enroll in an experimental asthma medication. Due to his prior coursework, he is able to understand the protocol, recognize the potentially lethal risks associated with his participation, and ask clarifying questions to the research team. However, to recall the details of the study, he asks the research team to write down their answers in a collaborative notebook.

Independent decision-making, or the ability to make healthcare decisions with complete privacy, grants the full range of self-governance typically given to non-autistic adults. This type of decision-making should be reserved for autistic individuals who possess enough autonomy to choose their medical decisions, according to their own wishes and values, without the required dependence on other rational agents. To meet this threshold, autistic adults would present very limited cognitive, rational, or social impairments relative to non-autistic individuals. Specifically, if Alan experiences no significant reductions in the rational capacities (e.g., the ability to reason, plan, or value) needed to make healthcare decisions or the social capacities needed to communicate his decisions, he should be afforded the opportunity to participate in the research study, regardless of his diagnosis.

Alan and other similar individuals may exhibit a greater reliance on accommodations or cognitive prostheses which do not necessarily exclude them from independence and privacy (Peterson, Karlawish, and Largent 2021). Rather, accommodations can be seen as a restoration of their autonomy to the threshold needed for independent decision-

making (Peterson, Karlawish, and Largent 2021). Therefore, if Alan and the research team were to use a collaborative notebook to convey details of the intervention, the notebook should be seen as a tool to restore his autonomy, rather than a threat to his positive and negative liberties.

It is important to note that autistic adults in this category of decision-making should not have their autonomy questioned based on the quality of their healthcare decisions. This rationale stems from how individuals without autism are almost always given the opportunity to pursue risky surgeries or decline life-saving treatments for various reasons (religion, quality of life, etc.). As McVey et al. describes, there is “dignity in risk-taking” as it is innately part of the human experience (McVey et al. 2023). Similarly, if Alan is deemed to have levels of capacity similar to non-autistic adults, he should also be able to exercise this dignity by participating in the experimental intervention, regardless of the lethal risk.

### SUPPORTED DECISION-MAKING

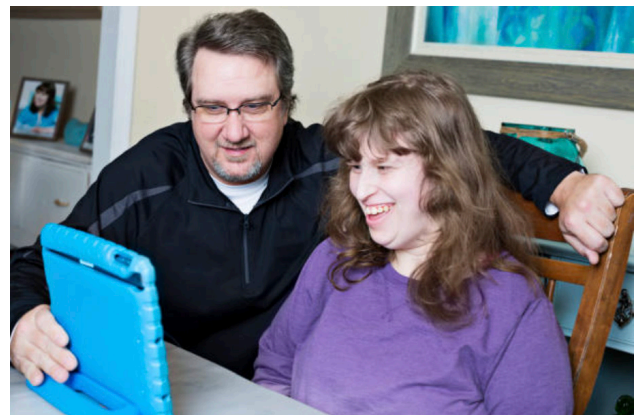
Case 2: Grace is an 18-year-old high school student who has been diagnosed with autism and requires learning accommodations at school. She and her parents are approached by the same research team as described in Case 1. Grace expresses she is interested in the study but is unable to weigh the potential benefits and risks of her participation. Consequently, she asks her parents to make a list of the pros/cons and to present it to her. Similarly, she asks her primary care provider to simplify the medical jargon so that she can better understand how the drug works.

In supported decision-making, the autistic adult retains the right to make the final decision but requires the assistance of clinicians, family, and other support members throughout the process (ASAN n.d.). This model should be reserved for autistic adults who do not possess the patient autonomy needed for independent-decision making. Such a hierarchy is supported by findings that adults (with mild cognitive impairments) may lack the capacity needed to make their own medical decisions but still retain the capacity needed to appoint a decision-making surrogate (Kim et al. 2011). As an extension, autistic adults who lack the capacity for independent decision-making may still have sufficient autonomy to determine who may assist them. Patients in this category have impairments to their rational capacities that are significant enough to require the assistance of other rational agents around them. For example, if accommodations are no longer sufficient to restore Grace’s self-governance, and she relies on her parents to weigh the study’s benefits and risks, she would benefit greatly from the supported decision-making model. It is important to recognize that within this model, Grace’s parents cannot directly force or prohibit her participation in the study; rather, they can work with the clinician, research staff, and other mem-

bers of the support team to either encourage or discourage her involvement.

Some may counter that using a supporter to offload mental processes is identical to using accommodations. In other words, there is no difference between Alan using a notebook to remember/communicate the details of the protocol and Grace utilizing her parents for a similar function. However, this is an inaccurate analogy for two reasons. Primarily, as other authors have mentioned, there is a difference between using an inert object to supplement autonomy compared to another rational agent who has their own capacities, desires, and needs, all of which are likely to influence the healthcare decision (Peterson, Karlawish, and Largent 2021). Secondly, depending on inert tools seems less of a deficit and more of an adaptation, as exemplified by how fully autonomous adults also utilize cognitive prostheses to assist with their decision-making (e.g. a doctor using a notebook to remember his patients). However, the required dependency on others’ rational capacities is unique to impaired adults and calls for a supported decision-making model.

The lower threshold for supported decision-making is that individuals must retain enough autonomy to recruit and utilize the supporters needed to help them self-govern their healthcare. Prior to recruiting this team, autistic individuals need to first identify the type of support they need from the agents around them. Therefore, this threshold of autonomy is highly dependent on the rational capacity to recognize one’s impairments and limitations. As Berlin describes, the autonomous individual wishes “to be a subject and not an object” and, as such, is self-aware of their strengths and shortcomings (Berlin 1969). Awareness of the latter is particularly relevant for supported decision-making models. For example, Grace is able to recognize the complexity of clinical research jargon as an obstacle and to recruit someone from the medical field into her support team to better translate and appreciate such information. Therefore, her informed decision to either participate or refuse the study should be seen as an appropriate exercise of



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her capacity of autonomy.

Regarding positive and negative liberties, there may be a loss of both during supported decision-making if only the range of total possible choices is considered. Supporters often restrict the number of healthcare choices by heavily encouraging highly therapeutic treatments over others. On the contrary, they may intervene to discourage dangerous treatment options. However, when considering the range of meaningful choices, which is arguably of greater relevance, supported decision-making may, in fact, be protecting both these liberties. Grace's parents may aid her positive liberty by helping her choose the treatments that best align with her values, interests, and desires. Similarly, they may also enable her negative liberty by not allowing misinformation/ambiguity to exclude other treatments of potential interest.

## GUARDIANSHIP

Case 3: David is a 20-year-old who has been diagnosed with autism and requires full-time assistance for most activities of daily life. He and his guardians are approached by the same research team as described in Cases 1 & 2. Although David is largely non-verbal, he loves science and expresses joy when he hears the word "research" from the study team.

While supported decision-making models offer a more nuanced option for patients, it may not be appropriate for autistic adults at the lower range of autonomy who are unable to build a support team or even to utilize one effectively if such a team is appointed for them. Rather, guardianship should be reserved as a last resort for such patients (Peterson, Karlawish, and Largent 2021). With highly impaired rational capacities, these individuals are unable to recognize their limitations in decision-making and therefore are highly vulnerable to its consequences. From the clinician's and/or supporter's perspective, the duty of beneficence to these patients outweighs any duty to respect their autonomy. In other words, if David lacks the rational capacity to recognize his impairments (and consequently, the autonomy to recruit and to utilize a support team), then his request to participate in research can be overridden by his guardians for his protection.

Additional questions arise regarding the existence of autonomy in patients with such drastic impairments due to the complete (or close to complete) lack of self-governance. While most discussions on autonomy focus on rational capacities exclusively, other authors have pointed to the role of emotional capacities, or "carings," as pre-forms of autonomy that still ought to be recognized (Hirsch 2023). In this example, even if David could not participate in the decision-making, his eagerness and joy to participate in research is still worth recognizing and implementing whenever possible. However, these carings, which fail to reflect David's understanding of the risks, do not seem sufficient

to allow his participation in potentially lethal interventions. Additionally, those with autism may not always display the anticipated emotions when making healthcare decisions, which can further skew their autonomy determinations (Satkoske, Migyanka, and Kappel 2020). Therefore, even if emotional capacities are retained, David's guardianship still seems morally required because his rational capacities are impaired.

While guardianship inevitably includes overriding any positive and negative liberties of the autistic adult, this model does not prevent their interests from being considered in the decision. Different frameworks have been proposed for how to best respect these interests, including substituted judgment ("What choice would this individual make and would align with their preferences?") and best interests ("What choice would be in the best interests for this individual?") (Peterson, Karlawish, and Largent 2021). For autistic adults, the latter seems preferred for healthcare decisions. Substituted judgment is more applicable for dynamic impairments where autonomy fluctuates over time (Peterson, Karlawish, and Largent 2021), but in relatively stable conditions such as autism, there may not be an original baseline for full autonomy. In other words, the choice David would make if he were able to might be a poor standard of comparison if he was never able to make meaningful choices to begin with. Instead, the "best interests" framework would be able to more consistently provide the healthcare decisions needed for him and other autistic individuals requiring the guardianship model.

## OPEN QUESTIONS AND FUTURE WORK

Overall, patient autonomy in adults with autism is a complex discussion that requires assessing each individual's level of autonomy and impairment to their rational capacities. As suggested in other patient populations, these thresholds may change depending on the risk posed to the individual (Kim et al. 2011). For example, if David was approached for a nasal swab study with minimal risks, his "caring" may be sufficient to justify his participation. Despite these shortcomings, this framework still remains useful in providing relative measures of autonomy across adults on the autism spectrum while preventing the overgeneralization of bioethical principles or healthcare models.

Future work should identify the relationship between specific rational capacities and their relative contributions to overall patient autonomy. Further discussion is also warranted on how to best support patients with autonomy levels that are highly depleted or exist at the boundaries between decision-making models where any general categorization may fail. Ultimately, the findings from such investigations on capacity can better inform state, national, and even international legislation regarding the competence among adults with autism and other intellectual disabilities.

In a recent large-scale study, autistic individuals reported lower quality healthcare across 50 out of 51 items compared to non-autistic adults, including poorer communication and increased anxiety during the medical process (Mazurek et al. 2023). Given this disparity, it is urgent that providers, nurses, and advocates work together to ensure autistic adults can not only access medical care, but also that their interests and wishes are prioritized in the process. A tangible first step is to recognize, to appreciate, and to support the existing levels of autonomy among autistic patients and re-center their healthcare experience around them whenever possible.

#### ACKNOWLEDGEMENTS

I thank Dr. William FitzPatrick for his guidance and support during the revision of this paper. I have had the pleasure of attending many of his lectures on various topics in bioethics, which have highlighted the need for careful consideration of moral principles in everyday health care situations.

#### BIBLIOGRAPHY

- Alonso-Sardón, M., et al. 2019. Do health and social support and personal autonomy have an influence on the health-related quality of life of individuals with intellectual disability?. *BMC Health Services Research*, 19(1): 63.
- Autistic Self Advocacy Network (ASAN). "The right to make choices: International laws and decision-making by people with disabilities." *Autistic Advocacy*, accessed September 16.
- Berlin, I. 1969. *Four essays on liberty*. Oxford, England: Oxford University Press.
- Barsky, B.L. "How American cities and states comply with international disability law: a snapshot of a Cutler Fellow's research." *2018 Global Affairs Review*, June 28.
- Dove, E. S., et al. 2017. Beyond individualism: Is there a place for relational autonomy in clinical practice and research?. *Clinical Ethics*, 12(3): 150–165.
- Graber, A. 2017. Autism, intellectual disability, and a challenge to our understanding of proxy consent. *Medicine, Health care, and Philosophy*, 20(2): 229–236.
- Hirsch A. 2023. Why we have duties of autonomy towards marginal agents. *Theoretical Medicine and Bioethics*, 44(5): 453–475.
- Kim, S. Y., et al. 2011. Preservation of the capacity to appoint a proxy decision maker: implications for dementia research. *Archives of General Psychiatry*, 68(2): 214–220.
- Lee, Y. Y., and J. L. Lin. 2010. Do patient autonomy preferences matter? Linking patient-centered care to patient-physician relationships and health outcomes. *Social Science & Medicine*, 71(10): 1811–1818.
- Leo, R. J. 1999. Competency and the capacity to make treatment decisions: A primer for primary care physicians. *Primary Care Companion to the Journal of Clinical Psychiatry*, 1(5): 131–141
- Mazurek, M. O., et al. 2023. Health care needs, experiences, and perspectives of autistic adults. *Autism in Adulthood: Challenges and Management*, 5(1): 51–62.
- McVey, A. J., et al. 2023. The ethical imperative to honor autistic clients' autonomy in mental health treatment. *Frontiers in Psychiatry*, 14.
- Peterson, A., J. Karlawish, and E. Largent. 2021. Supported decision making with people at the margins of autonomy. *The American Journal of Bioethics*, 21(11): 4–18.
- Ripamonti, L. 2016. Disability, diversity, and autism: Philosophical perspectives on health. *The New Bioethics: A Multidisciplinary Journal of Biotechnology and the Body*, 22(1), 56–70.
- Satkoske, V., J. M. Migyanka, and D. Kappel. 2020. Autism and advance directives: Determining capability and the use of health-care tools to aid in effective communication and decision-making. *The American Journal of Hospice & Palliative Care*, 37(5): 354–363.
- Späth, E. M. A., and K. R. Jongsma. 2020. Autism, autonomy, and authenticity. *Medicine, Health care, and Philosophy*, 23(1): 73–80.
- Ubel, P. A., K. A. Scherr, and A. Fagerlin. 2018. Autonomy: What's shared decision making have to do with it?. *The American Journal of Bioethics*, 18(2): W11–W12.
- United Nations. "Convention on the Rights of Persons with Disabilities" *United Nations*, December 12.
- United Nations. "General Comment No.1 on CRPD - Article 12: Equal Recognition Before the Law." *United Nations*, May 19.
- Varelius, J. 2006. The value of autonomy in medical ethics. *Medicine, Health care, and Philosophy*, 9(3): 377–388.
- Wall, S. 1998. *Liberalism, perfectionism and restraint*. Cambridge, UK: Cambridge University Press.

# Article

## The Moral Vulnerability of the Physician and a Novel Approach to Conscientious Objection

Joshua Park\*

### INTRODUCTION

The 1973 Church Amendment granted legal protection to physicians and institutions that morally objected to abortions. This, in turn, led to significant implementation of medical “conscience bills,” which allow modern physicians to enjoy an unprecedented right to object to certain treatments. CO (conscientious objection) is generally defined as the “refusal to provide a legal, professionally accepted, and clinically appropriate practice within the clinician’s scope of competence because it is contrary to the clinician’s moral beliefs (Wicclair 2014).” However, from its inception, there has been considerable controversy over CO. The importance of discussing medical CO is largely two-fold. For one, medical CO challenges the revered duty of medical professionals to advance the well-being of the treated. A physician has been generally regarded as a reliable healer that the sick can turn to in the time of need. There are legitimate concerns that CO can threaten the all-important trust that patients and society generally hold towards physicians. Secondly, medical CO is practically concerning from a patient’s perspective in terms of access to care. This anxiety is readily apparent in inflammatory headlines intermittently published by major news outlets, such as the headline by NBC News in July 2022 that “More than 1 in 8 LGBTQ people live in states where doctors can refuse to treat them” (NBC 2022). These concerns have also been supported in recent research, with two independently conducted systematic reviews by Autorino et al., 2020 and Londras et al., 2023 both finding that CO hampers abortion access, resulting in greater mental and financial burdens. It’s also important to consider that CO conflicts are magnified in settings of low socioeconomic status, where there is already a lack of sufficient access to medical care (Autorino et al., 2020; Londras et al., 2023).

### KEY POSITIONS OF MEDICAL CONSCIENTIOUS OBJECTION

There are generally two major arguments in favor of CO: physician autonomy and moral integrity. The first argument favoring CO invokes an underappreciated conception in contemporary bioethics: the physician’s autonomy. While principles such as beneficence and patient autonomy



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occupies a central position in modern medical-decision making, physician autonomy is less emphasized (Pellegrino 1994). The physician’s autonomy stems from the simple fact that being human, the physician, too, enjoys the basic right to autonomy. While there are disagreements about how powerful physician autonomy is relative to patient autonomy, we can nevertheless suppose it is a variable that, at the very least, holds some weight in medical decision-making. However, the salience of the physician autonomy argument is undermined by the magnitude of patient autonomy. Still, some argue that “as it is wrong to ignore the patient’s right to autonomy by expecting him to conform to the physician’s perspective, in the same way, it would be unfair to treat physicians with a different standard” (Rouse 2012). This argument overlooks the inherent power imbalance in the patient-physician relationship. Treating both patient and physician autonomy with the same standard could gravely jeopardize patient well-being, as it fails to account for the physician’s position of authority as the provider of care.

A stronger argument for CO derives from the moral integrity of the physician. One of the primary proponents of the moral integrity argument is Mark Wicclair. In his conception, one must refrain from performing actions against one’s conscience to maintain moral integrity (Wicclair 2014). He further argues that moral integrity is valuable because it is an essential component of a person’s conception of a meaningful life, and breaking it can lead to devastating consequences like strong feelings of guilt, remorse, shame, loss of self-respect, and an assault on self-identity (Wicclair 2014). Practicing CO helps protect against these consequences by preserving such integrity in the face of profes-

\*Joshua Park studies Biochemistry at Case Western Reserve University. Joshua can be reached at [jjp214@case.edu](mailto:jjp214@case.edu).

sional obligation.

Those opposing CO primarily base their arguments on principles of justice and professional obligations in health-care. Justice concerns arise because CO disproportionately impacts patients of lower socioeconomic status (SES) and under-resourced hospitals. While hospitals in more affluent areas can find replacement physicians for conscientious objectors, lower-resource hospitals will have much more difficulty finding substitutes (Jones-Nosacek 2021). This, in turn, detrimentally affects patients of lower SES who cannot live in affluent areas with high-resource hospitals. While proponents of medical CO argue that advance directives by conscientious objector physicians can address this problem, it would be naive to think that this can fully address justice concerns. When medical care is sparse, even advance notice of the provider's care preferences will be a barrier for patients living in such environments, requiring financial and temporal expenditure to find care elsewhere. A further implication is when the CO is circumstance-based and not principle-based, introducing variability and unpredictability (Wicclair 2014). For example, a physician who opposes all abortions is more straightforward to accommodate than one who refuses to perform an abortion procedure only under more specific circumstances, such as when the mother's health is not at significant risk.

Opponents of medical CO most prominently argue that the practice compromises professional obligations and, ultimately, the patient-physician relationship. In the incompatibility thesis, professional commitments and moral integrity are incompatible with each other. The physician's professional obligation requires them to wholly care for the patient and act with the patient's best interests in mind (Wicclair 2008). Practicing CO subverts this by putting the physician's needs before the patient's, causing a potential loss of trust in the relationship. The resulting lack of trust individually and systematically threatens the patient-physician relationship (Wicclair 2008). The importance of the patient-physician relationship cannot be overstated, as it is frequently cited as the cornerstone of modern medicine. The physician's unique authority to provide or withhold medical interventions creates an inherent power imbalance in the doctor-patient relationship. When patients lose trust in their physician's commitment to act in their best interest, they become particularly vulnerable to this power imbalance. Although comprehensive statistical data on this phenomenon remains limited, compelling personal accounts from both healthcare providers and patients highlight these concerns. One general practitioner, reflecting on a patient's experience with rejection due to CO, emphasized that 'this is something that is harmful for the physician-patient relationship' (Nordberg et al., 2014). These narratives demonstrate how CO can conflict with the professional obligations of physicians from the patients' perspective, lending credibility to the incompatibility thesis.

## MORAL VULNERABILITY FRAMEWORK

CO centers on finding an equilibrium between the physician's moral integrity and professional responsibilities. No-exemption believers argue that professional responsibilities always trump the moral integrity of the physician, conscientious absolutism proponents hold moral integrity in higher regard, and others aim to balance these two principles by introducing middle-ground approaches. A crucial but underappreciated mediating variable is the moral vulnerability of the physician.

Moral vulnerability refers to the physician's lack of proper understanding of the moral implications of the professional vow due to a lack of appropriate ethics training. A morally vulnerable physician is naive to the sort and magnitude of ethical challenges that follow their professional obligations. While the moral vulnerability of the physician has been well-documented in the literature, there has not been a true recognition of its importance in the CO debate. Formalized bioethical education first began to be incorporated into medical school curricula in the 1980s. Although all US medical schools require ethics training now, evidence suggests that the bioethics curriculum in many institutions is insufficient (DuBois & Burkemper 2002). Notably, many papers report a lack of education on medical professionalism and a physician's professional obligations. Instead of holistic instruction and demonstration of these concepts, medical institutions do not define professionalism and the oath well (Mintz 2022). The lack of sufficient training is reflected in physicians today. For example, a study found that only 1 in 4 physicians acknowledged the importance of the oath, and many cannot remember the principles they swore to by being a physician (Antiel 2011). More specifically, explicit instruction on possible moral-professional clashes and their implications is also lacking, and thus, the authors claim that clearer guidance for medical students about the issue of CO at medical school is necessary (Strickland 2012). Altogether, this suggests that many physicians are unaware and vulnerable to the possible implications of the moral-professional tension they may encounter.

Moral vulnerability disrupts the balance between moral integrity and professional obligation. It enhances the case for CO by intensifying threats to a physician's moral integrity. For those facing such vulnerability, predicting moral-professional conflicts is challenging, hindering their ability to develop preemptive mental or practical defenses against potential harms. Moreover, the physician's moral vulnerability can counter the incompatibility thesis. Proponents of the incompatibility thesis may commonly claim that "If you are unable to carry out the professional obligations of a physician due to moral inconsistencies, you should not become a physician in the first place" (Savulescu 2006). However, it is crucial to consider that inadequate ethical education may render these moral-professional clashes elusive to physicians, making them unforeseeable before en-





By Jeffrey Decoster, *NY Magazine*, 2008

tering the profession. It is primarily the responsibility of the institution to protect the physicians and adequately prepare them for this challenge. Hence, the incompatibility thesis unfairly victimizes physicians when inadequate instruction in medical education contributes significantly. Even if these issues are foreseen, their detriment might not have been expressed enough in ethics training. As such, physicians may be somewhat acquitted in their decision to exercise CO due to moral vulnerability. This acquittal of responsibility is coherent with the general ethical consensus that externally derived vulnerability and ignorance can serve to alleviate responsibility. For instance, we legally and ethically contrast a child's shoplifting with a 30-year-old's shoplifting. The child's decisions were not wholly their fault but also their naivety and lack of proper ethical instruction. Although the analogy isn't fully compatible, it suggests that a physician's CO might similarly stem from a lack of proper knowledge.

In contrast to the acquittal of responsibility given moral vulnerability, the scenario shifts when this vulnerability is no longer a factor. Once physicians receive adequate training and are no longer considered morally vulnerable, professional obligations take precedence over the moral integrity argument. This is because the potential for harm to moral integrity is reduced when such conflicts are anticipated. A primary example is choosing a specialty in which moral-professional conflicts are very unlikely. For instance, a Catholic physician may opt against specializing in OB-GYN, where they might frequently encounter responsibilities like performing abortions, and instead select a specialty less morally contentious, such as orthopedics. However, there is a pertinent possibility of unexpected cases of CO arising, even in less morally contentious specialties. A plastic surgeon may encounter a patient wishing to undergo gender-affirming surgery when they have a strong moral objection to the procedure. In such scenarios, anticipation and prophylactic planning allow the physician to develop coping responses to minimize harm. Physicians might

adopt emotion-focused coping strategies, such as self-care and self-validation, or engage in problem-focused coping, where they actively reduce threats to their self-identity. Both strategies are well-established and effective techniques within psychological science. Many studies establish emotional-focused and problem-focused coping as adequate buffers against psychological stress, even in high-stress situations like pandemics (Badon et al., 2022; Chankasingh et al., 2022; Main et al., 2011). Given these capabilities, physicians who have received comprehensive ethical training should be held to a higher standard in prioritizing professional responsibilities over personal moral objections. However, it is important to recognize that not all situations can be anticipated, especially with the continuous emergence of new medical practices and procedures.

### FUTURE POLICY PROPOSAL

In sum, moral vulnerability acts as a crucial mediating factor that favors moral integrity, and in its absence, the balance shifts in favor of prioritizing professional obligations. While not central to the paper's argument, a cursory policy proposition recognizing moral vulnerability demonstrates its efficacy. This position has three central tenets. First, currently practicing physicians have the right to CO but must adopt a reasonable accommodation approach detailed by *Wicclair*. Second, ethical instruction in medical schools and general practice should be rectified to better acknowledge moral-practical conflicts and their implications. Third, physicians benefitting from this enhanced ethical training should be encouraged to adopt a no-exemption approach. This position advocates for a combination of the reasonable accommodation thesis and the no-exemption standard.

Currently practicing physicians should have the right to CO due to their moral vulnerability. However, they must practice CO under the reasonable accommodation approach detailed by *Wicclair* to minimize possible detriments to patient well-being. The reasonable accommodation approach proposed by *Wicclair* has four essential guidelines: "(1) Whenever feasible and apt, clinicians should provide advance notification to patients/surrogates, administrators, and employers, (2) accommodation should not impede a patient's/surrogates' timely access to information, counseling, and referral, (3) accommodation should not impede a patient's timely access to health care services, and (4) accommodation should not impose excessive burdens on other clinicians, administrators, or organizations (*Wicclair* 2014)." The middle-ground approach, which combines the requirement of advance notice and reasonable lack of burden to patient access, will help protect patient well-being and a physician's moral integrity to some extent.

As allowing CO threatens the profession's integrity by undermining the importance of professional obligations, reasonable accommodation is an unsuitable long-term policy choice. CO should be tolerated as an exception, but it

becomes dangerous as a norm by undermining the importance of the physician's professional obligations. To address the sustainability issues with the reasonable accommodation model, ethical instruction in medical schools must expand education on CO both in the classroom and clinical setting. The proposed approach offers practical advantages. It shields currently practicing physicians from abrupt policy shifts, enhancing their compliance and safeguarding against potential backlash or even cessation of practice among these professionals. However, implementing the no-exemption strategy for upcoming physicians may be concerning in terms of a possible decline in the general number of physicians, especially those entering morally contentious professions. While this concern must be empirically demonstrated, the aforementioned techniques, avoidance, and coping, can help alleviate this concern. Additionally, further research into medical students' views on entering professions without exemptions could provide crucial insights. Although it's important to acknowledge that this proposal has its limitations, it serves as a valuable example of how recognizing moral vulnerability can make existing CO policy frameworks more robust.

## CONCLUSION

A previously overlooked variable, moral vulnerability, plays a vital role in the future of conscientious objection by lending to a model that protects the patient and physician. The proposed approach, which includes reasonable accommodation and a standard for exemptions, effectively addresses this tension. Despite potential flaws in a rapidly evolving medical landscape, this balanced approach will help prevent the perversion of professionalism while also preventing serious harm to one's moral integrity.

## BIBLIOGRAPHY

- Antiel, Ryan M. "The Impact of Medical School Oaths and Other Professional Codes of Ethics: Results of a National Physician Survey." *Archives of Internal Medicine* 171, no. 5 (2011): 469. <https://doi.org/10.1001/archinternmed.2011.47>.
- Autorino, Tommaso, Francesco Mattioli, and Letizia Mencarini. "The Impact of Gynecologists' Conscientious Objection on Abortion Access." *Social Science Research* 87 (2020, January): 102403. <https://doi.org/10.1016/j.ssresearch.2020.102403>.
- Badon, Sylvia E., Lisa A. Croen, Assiamira Ferrara, Jennifer L. Ames, Monique M. Hedderson, Kelly C. Young-Wolff, Yeyi Zhu, and Lyndsay A. Avalos. "Coping Strategies for COVID-19 Pandemic-Related Stress and Mental Health during Pregnancy." *Journal of Affective Disorders* 309 (2022, July): 309–13. <https://doi.org/10.1016/j.jad.2022.04.146>.
- Chankasingh, Kyle, Amy Booth, Arianne Albert, Angela Kaida, Laurie W. Smith, C. Sarai Racey, Anna Gottschlich, et al. "Coping during the COVID-19 Pandemic: A Mixed Methods Approach to Understand How Social Factors Influence Coping Ability." *Heliyon* 8, no. 10 (2022): e10880. <https://doi.org/10.1016/j.heliyon.2022.e10880>.
- DuBois, James M., and Jill Burkemper. "Ethics Education in U.S. Medical Schools." *Academic Medicine* 77, no. 5 (2002): 432–37. <https://doi.org/10.1097/00001888-200205000-00019>.
- Jones-Nosacek, Cynthia. "Conscientious Objection, Not Refusal: The Power of a Word." *The Linacre Quarterly* 88, no. 3 (2021): 242–46. <https://doi.org/10.1177/00243639211008271>.
- Londras, Fiona de, Amanda Cleeve, Maria I. Rodriguez, Alana Farrell, Magdalena Furgalska, and Antonella F. Lavelanet. "The Impact of 'Conscientious Objection' on Abortion-Related Outcomes: A Synthesis of Legal and Health Evidence." *Health Policy* 129 (2023, March): 104716. <https://doi.org/10.1016/j.healthpol.2023.104716>.
- Main, Alexandra, Qing Zhou, Yue Ma, Linda J. Luecken, and Xin Liu. "Relations of SARS-Related Stressors and Coping to Chinese College Students' Psychological Adjustment during the 2003 Beijing SARS Epidemic." *Journal of Counseling Psychology* 58, no. 3 (2011): 410–23. <https://doi.org/10.1037/a0023632>.
- Mintz, Rachel, Leah Pierson, and David Gibbes Miller. "Rethinking Professionalism Assessments in Medical Education." *Annals of Internal Medicine* (2022, May). <https://doi.org/10.7326/m22-0488>.
- Nordberg, Eva M. Kibsgaard, et al. "Conscientious Objection to Referrals for Abortion: Pragmatic Solution or Threat to Women's Rights?" *BMC Medical Ethics* 15 (2014, February 26): 15. <https://doi.org/10.1186/1472-6939-15-15>.
- Pellegrino, Edmund. "Patient and Physician Autonomy: Conflicting Rights and Obligations in the Physician-Patient Relationship." *Journal of Contemporary Health Law and Policy* 10 (1994).
- Rouse, Susan T. "Professional Autonomy in Medicine: Defending the Right of Conscience in Health Care beyond the Right to Religious Freedom." *The Linacre Quarterly* 79, no. 2 (2012): 155–68. <https://doi.org/10.1179/002436312803571393>.
- Savulescu, Julian. "Conscientious Objection in Medicine." *BMJ* 332, no. 7536 (2006): 294–97. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1360408/>.
- Wicclair, Mark R. *Conscientious Objection*. Oxford: Oxford University Press (2014). <https://doi.org/10.1093/oxfordhb/9780199974412.013.8>.
- Wicclair, Mark R. "Is Conscientious Objection Incompatible with a Physician's Professional Obligations?" *Theoretical Medicine and Bioethics* 29, no. 3 (2008): 171–85. <https://doi.org/10.1007/s11017-008-9075-z>.
- Yurcaba, Jo. "More than 1 in 8 LGBTQ People Live in States Where Doctors Can Refuse to Treat Them." *NBC News* (2022, July 28). <https://www.nbcnews.com/nbc-out/out-health-and-wellness/1-8-lgbtq-people-live-states-doctors-can-refus-e-treat-rcna39161>.

# Bioethics-in-Brief

## Expanding Access to Fertility Treatments Through Medical Insurance

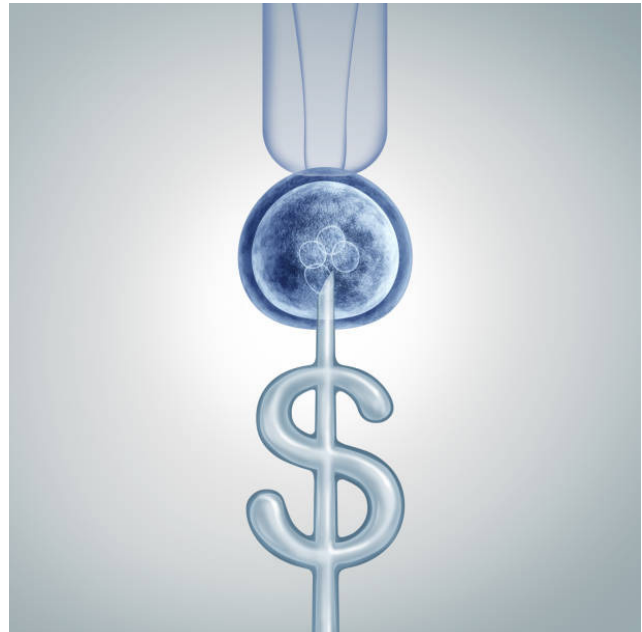
Caitlyn Chen

Globally, birth rates are plummeting, raising concerns about population sustainability and economic growth. A significant contributing factor is the rising prevalence of infertility, exacerbated by trends such as delayed childbearing and declining male reproductive health. In countries like China, fertility rates have dropped sharply from 1.75 (births per woman) in 2016 to a projected 1.3 in 2050, well below the replacement level.<sup>1</sup> Lifestyle changes and advanced maternal age play critical roles in the decline of birth rates. According to the World Health Organization (WHO), infertility, defined as the inability to conceive after 12 months of unprotected intercourse, affects 17.5% of reproductive-aged individuals globally.<sup>2</sup>

Assisted Reproductive Technology (ART) offers a potential solution, encompassing techniques such as in vitro fertilization (IVF) and intracytoplasmic sperm injection (ICSI). However, the high costs of ART—averaging \$15,000 to \$20,000 per cycle in the United States—prevent many couples from accessing treatment.<sup>3</sup> As birth rates decline, medical insurance coverage of ART is increasingly viewed as a practical strategy to alleviate the burden of infertility and promote population growth.

In the United States, insurance coverage for ART is fragmented, largely dictated by state-level mandates. Currently, 21 U.S. states require some degree of infertility treatment coverage, with only a small subset mandating comprehensive ART coverage.<sup>3</sup> States with these mandates see a 277% higher utilization of IVF compared to those without.<sup>4</sup> However, these policies often limit coverage to employer-sponsored insurance plans, leaving many uninsured couples without affordable options. Efforts to integrate ART into broader healthcare frameworks are hindered by the high per-cycle costs and varying definitions of medical necessity. Advocates emphasize that infertility is a medical condition recognized by the World Health Organization, and thus deserving of comprehensive insurance coverage.<sup>2</sup> Denying coverage, they argue, discriminates against individuals and couples struggling to conceive, particularly as reproduction is viewed as a fundamental human right. Equitable access to ART is essential for reducing disparities, ensuring all socio-economic groups can pursue family-building options.

Critics, however, raise concerns about the allocation of finite healthcare resources. They argue that prioritizing ART could divert funding from life-saving treatments; fertility treatments are often perceived as elective rather than essential, challenging the justification for insurance coverage when contrasted with urgent medical needs. Furthermore, ethical questions arise about age-based access



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to ART, with considerations of maternal age and previous childbirth.<sup>5</sup> Critics warn against the potential overmedicalization and commodification of reproduction and question whether societal pressures to conceive may lead to unnecessary medical intervention.

Globally, more than 80% of European and Oceanian countries partially or fully reimburse ART costs, showcasing varied, yet consistently more progressive approaches. Scandinavian countries lead the way with extensive subsidies: Norway, Sweden, and Denmark cover three or more IVF cycles through public healthcare systems.<sup>6</sup> France, similarly, funds up to four cycles for women under 43.7 In China, where infertility affects up to 12.5% of couples, ART remains largely self-funded.<sup>8</sup> Out-of-pocket costs exclude over 60% of infertile couples from accessing treatment. However, with the government's 2021 three-child policy aimed at reversing population decline, ART's inclusion in medical insurance is gaining traction. A recent feasibility study estimated that incorporating ART would cost 72-207 billion yuan (\$10-28 billion USD) annually, representing 2-6% of China's medical insurance fund.<sup>8</sup> This is projected to result in 3.3-9.6 million new live births annually, with a cumulative population growth of 37-65 million by 2050. The financial input-output ratio, denoting the ratio of costs to benefits, for ART coverage is estimated at 13.02, reflecting a highly favorable return on investment. On the societal level, ART coverage can mitigate the psychological and



social stresses of infertility, reducing incidences of anxiety, depression, and even divorce. By lowering financial barriers, ART inclusion can prevent socioeconomic disparities in access to reproductive healthcare.

However, the implementation of ART as covered by medical insurance faces significant challenges. Expanding ART services requires substantial investment in medical infrastructure and workforce development. Many countries, particularly in developing regions, face a shortage of specialized reproductive medicine clinics, skilled professionals, and advanced laboratory facilities. Even in nations with existing ART capacity, a surge in demand following inclusion in medical insurance may overwhelm current systems, leading to longer wait times and reduced quality of care. Scaling up infrastructure and training new professionals will require long term investment to meet increased demand without compromising service delivery.

Implementing ART coverage also demands a stringent regulatory framework to ensure cost containment and prevent misuse. Policymakers must establish transparent pricing models and treatment guidelines while fostering collaborations between public and private sectors to maintain affordability. Regulations limiting the number of reimbursable cycles or encouraging single-embryo transfers, can prevent complications like multiple births, which are associated with higher healthcare costs. Equity is a significant concern, as ART accessibility may disproportionately benefit higher-income groups even with medical insurance coverage. For instance, indirect costs such as transportation, childcare, and lost wages during treatment cycles can still pose barriers for low-income families. Addressing these disparities requires supplementary measures, such as targeted subsidies for economically disadvantaged groups or the integration of ART within broader social welfare programs. Ensuring geographic equity, particularly in rural or underserved areas, is another critical aspect that demands attention.

The inclusion of ART in medical insurance represents a transformative opportunity to address declining birth rates and improve access to infertility treatments. Despite existing challenges, the potential demographic and societal benefits make this approach compelling. By addressing inequities, investing in infrastructure, and implementing robust regulatory frameworks, nations can create accessible, cost-effective systems that support family-building aspirations for all citizens.

## REFERENCES

1. Luo, Y., Su, B., & Zheng, X. (2021). Preplanned Studies: Trends and Challenges for Population and Health During Population Aging - China, 2015-2050. *China CDC Weekly*. 3(28), 593-598.
2. World Health Organization. (2023). 1 in 6 people globally affected by infertility. Retrieved from: <https://www.who.int/news/item/04-04-2023-1-in-6-people-globally-affected-by-infertility>
3. U.S. Department of Health and Human Services. (2024). Fact Sheet: In Vitro Fertilization (IVF) Use Across the United States. Retrieved from: <https://www.hhs.gov/about/news/2024/03/13/fact-sheet-in-vitro-fertilization-ivf-use-across-united-states.html>
4. Peipert, B.J., Montoya, M.N., Bedrick, B.S., Seifer, D.B., & Jain, T. (2022). Impact of in vitro fertilization state mandates for third party insurance coverage in the United States: a review and critical assessment. *Reproductive Biology and Endocrinology*. 20, 111.
5. Harrison, B.J., Hilton, T.N., Riviere, R.N., Ferraro, Z.M., Deonandan, R., & Walker, M.C. (2017). Advanced maternal age: ethical and medical considerations for assisted reproductive technology. *International Journal of Women's Health*. 9, 561-570.
6. Nordic Health & Welfare Statistics. (2024). Fertility. Retrieved from: <https://nhwstat.org/populations/fertility>
7. Institut National D'Etudes Demographiques. (2021). Success rate of in vitro fertilization (IVF) in France. Retrieved from: <https://www.ined.fr/en/everything-about-population/demographic-facts-sheets/focus-on/success-rate-of-in-vitro-fertilization-ivf-in-france/>
8. Huang, R., Yu, J., He, W., & Liu, R. (2024). Feasibility analysis of China's medical insurance coverage of assisted reproductive technology. *Scientific Reports*. 14, 7998.



# Interview

## Food Access Around the World: Examining a Health Policy Problem from a Bioethical Lens

### An Interview with Dr. Rebecca Puhl



Rebecca Puhl, PhD is a professor in the Department of Human Development & Family Sciences at the University of Connecticut. There, she is also a researcher at the Rudd Center for Food Policy and Health, where her work has earned her a spot on the World's Highly Cited Research List. Her work broadly addresses weight-based bullying, bias, and discrimination experienced by children and adults. Her work has documented the prevalence and origins of weight bias and discrimination, assessed the pervasiveness and impact of weight stigma in the media, examined the effects of weight bias on emotional and physical health, assessed experiences and health consequences of weight-bullying in youth, tested intervention strategies to reduce weight bias, and studied potential policy and legal remedies to reduce weight discrimination and bullying. She is also on the editorial board for numerous journals dealing with obesity and weight stigma, and has won numerous awards for her work including the Bias Buster Award.

This interview was conducted by Jacob Kim and Navneeth Murali.

#### **What initially drew you to research on weight stigma? What do you see as the main goals of your research?**

When I set out to complete my PhD in clinical psychology, weight stigma was not on my radar. This was not something that I planned to do for a career. I attended Yale's PhD program in clinical psych and my plan at that point was to do research on prevention of eating disorders. But when I was a graduate student, I was offered an opportunity by my research mentor, Kelly Brownell, to do some research on the topic of weight stigma. I didn't really know very much about it. This was back in the year 2000. There was really not very much published in this area. It was very scattered and so I kind of jumped into that. At the same time that I was doing that, I was in a clinical psych program, so I was starting to be trained treating patients with different psychological conditions. I was working with people with eating disorders and struggling with weight and one of the things that I saw consistently in the patients I was treating is how much stigma they were facing because of their body size and how much that was contributing to their poor mental well-being. It was interfering with their treatment and their progress and it was really reducing their quality of life. So I had this clinical experience and this research experience happening at the same time and both of those experiences really changed the direction of my work. It was at a time where I was able to see that there's a real problem here that really isn't getting very much research attention, that it's really ripe for research investigation. And so my career took that direction, and I've been doing it ever since.

I look at my work as kind of multi-purpose. I'm very multidisciplinary in the research that I do and where I pub-

lish because I've come to recognize how resistant this form of stigma is to societal change. And we really need multidisciplinary efforts in order to effectively address this problem. So my research has, first of all, had the objective of trying to document the prevalence and nature and extent of weight stigma and discrimination that both children and adults face to really try to put that on the map. We've also done a lot of research to try to understand its impact on people, on their health, on their well-being, on their relationships, on their health care. And then another angle of my work has really tried to investigate different strategies that can be implemented to prohibit and reduce weight discrimination in our society. Some of that involves policy, for example, right now in the United States, it's illegal almost everywhere to discriminate against a person because of their body size. And so I've been pretty involved in policy work, both in terms of policy research, but also doing things like testifying at state legal hearings about the evidence that we have on weight discrimination and why weight should be added as a protected category, like other aspects of identity in discrimination legislation. I also do research to look at how we can address weight stigma in different settings and one of those settings is health care. We've done a lot of research to look at who are the most common sources of weight stigma, and doctors are often close to the top of that list. And so we've done a lot of work to create educational resources for health care professionals, for medical students and training to really try to help them understand what weight stigma is, how it harms their patients, and what they can do to improve patient care.

**How does weight stigma and bias affect patients at an in-**

**dividual level, especially when it comes to seeking weight loss treatment?**

Well, so let me kind of answer that in two parts. So the first question is kind of how does weight stigma impact people at an individual level? And that's where we have a lot of evidence. What we know is that when people are shamed or stigmatized or discriminated against because of their weight, that this has a range of consequences, both for their psychological well-being and also for their physical health. So for example, we know that when people experience weight stigma, this contributes to higher levels of depressive symptoms, anxiety, low self-esteem, poor body image, even substance use and suicidality. But we also see that it affects people's physical health behaviors and some of the most common findings are that people who are stigmatized about their weight tend to have higher levels of maladaptive and disordered eating. Oftentimes, people may turn to food as an unhealthy coping mechanism to deal with the distress of being stigmatized. We also see lower levels of physical activity. And one of the reasons for that is that people feel very vulnerable to shame and stigma about their body size in physical activity settings. We also see higher levels of physiological stress when people experience weight stigma, primarily elevated cortisol level. And we also see over time that weight stigma actually predicts increased weight gain and obesity, kind of because of what I've just talked about, about unhealthy eating patterns, lack of physical activity, elevated cortisol. And so in some ways that creates this cycle where weight stigma predicts increased weight gain, which predicts more stigma, right? Because it makes a person more vulnerable to being stigmatized. So there are certainly a lot of negative impacts at the individual level.

Your second question, we don't know the answer to that yet. You know, with weight loss treatment with medications and weight loss medications, does stigma motivate people to turn to these medications or potentially demotivate them to want to use those medications? We don't know the answer to that. Certainly, if we step back and look at how thinness is valued in our culture, this is something that has been valued for decades. And it's really come to symbolize important values in Western culture. It symbolizes desirability and success and ambition and desire. And if a person is not thin, they are assumed to be lacking in those qualities. So as long as those values of thinness remain prevalent, people are going to be motivated to seek weight loss for aesthetic reasons, even when potentially health is not part of that reason. So it's a complicated question to answer. We do know that sometimes people will seek weight loss in order to escape the stigma that they've experienced, that they feel that losing weight will kind of eliminate this stigmatized identity that they have. At the same time, we sometimes find that people report experiencing residual stigma after they've lost weight. One of the things that can

be really psychologically challenging, if you are treated one way in society when you have a larger body and then you're treated a different way when you change your body, even though you're the same person, that residual stigma can also be complicated to deal with.

**What are the ethical implications of individuals using weight loss treatments, as a result of societal stigma versus for health reasons? Do you think there's a disproportionate number of doctors recommending weight loss just for the sake of their patients losing weight? Or are doctors actually looking out for their patients?**

Well, those kinds of questions and motivations behind prescribing patterns are hard to know. And it's not something that I study. But what I will say is that we certainly don't want people to be taking things like GLP-1s for aesthetic reasons. That's not their intended purpose. Health should be the focus. And so for people who meet criteria for medications, who have legitimate health reasons, it may also be that part of their motivation to take those drugs or to engage in weight loss is because they hope to achieve weight loss to alter their physical appearance. I will say that I think it's important for any kind of counseling from health care providers to really emphasize and keep the focus on health and health changes, rather than on how many pounds are lost or how a person looks after losing weight. We really want to make sure that it's being used for the right reasons. Now, in terms of the societal impact of these medications and weight loss treatment, we don't really know yet. I think time will tell whether anti-obesity or weight loss medications affect societal stigma of people with higher weight. Because on the one hand, these new medications could increase attention to the complexity of obesity, to the chronic nature of obesity, and that could potentially reduce societal blame that is often attributed to people who have a higher body weight. But on the other hand, weight stigma could persist or perhaps increase if medication is viewed as taking the easy way out. And that's something that we've seen to some degree with metabolic and bariatric surgery, where there can be a stigma of the surgery itself. So I think that's pretty telling of our society where we're at, that it's really unfortunate we live in a society where people are stigmatized for having a higher body weight, and then they're stigmatized again if they seek medical treatment to lose weight. That's an additive stigma that just leads to more societal blame, and I think can lead to more internalized shame and harm for individuals as well. So we can see it going in either or both of those directions, and we're still too early in this to know what the ultimate and long-term impact is going to be.

**How do you think weight bias manifests in medical spaces, and do you think it has a meaningful impact on how**

### providers treat their patients?

Yes, this is a great question, and there's a lot of pieces to this. First of all, we know from several decades of research that weight bias and stigma and stereotypes are documented and expressed by health care professionals towards patients with higher weight, and this includes stereotypes that patients who have obesity are lazy or lacking motivation or have poor self-control or are non-compliant with treatment and are essentially to blame for their weight. And those attitudes have been reported and documented in research studies by a range of different healthcare professionals, so that includes doctors, nurses, medical students. There's also research evidence that was done now over 10 years ago that shows that the level of implicit and explicit weight bias among doctors is actually at similar levels that we see in the general population. So I think it's important to recognize that medical professionals aren't immune to societal weight bias, and that's kind of the first piece of this. The second piece is that we see from the perspective of patients that they're very aware of these biases, and we've done a number of studies with adults with higher body weight with obesity or type 2 diabetes. There's also work with adults who are undergoing bariatric surgery, and we see very high percentages of patients reporting that they have experienced weight stigma from a health care professional. In some cases, weight stigma is being reported by as many as two-thirds of study samples, and this plays out in different ways.

So when we look at the side of the provider and the health care professional, studies have documented that compared to providing care to lower body weight or thinner patients, when it comes to patients with higher body weight, providers are spending less time in their appointments. They're engaging in less discussion with patients. They admit that they aren't intervening as much as they probably should, and they also report having less respect for patients as their BMI increases. Then when we look at the patient side of this, we see that patients report feeling blamed and judged by health care professionals because of their weight, and in turn, that leads to things like lower trust in their health care provider. They're more reluctant to talk about their weight. They perceive a lack of empathy. They feel like they won't be taken seriously because of their weight, and they report that often their weight is blamed for unrelated medical problems. And when it comes to what this means for seeking care, we see that people are more likely to switch doctors if they've experienced weight stigma, and they're also more likely to avoid health care, and that's particularly true for women with higher body weight. We conducted a multinational study a few years ago with over 13,000 adults, mostly women, across six different countries, and what we found is that weight stigma was consistently associated with health care avoidance across these different countries, especially when adults, again, primarily women,

were internalizing weight stigma and blaming themselves for the stigma that they experienced. We found that they were more likely to avoid health care. They obtained less frequent routine checkups. They felt negatively judged about their weight, and they overall perceived the quality of their health care to be lower. So there's considerable evidence that this is a problem that is present that needs to be addressed, and one of the issues here is that this is a topic that doesn't get a whole lot of coverage in things like medical training and medical education. We know, for example, that obesity and nutrition only get a little bit of time, let alone weight stigma and bias. There's a real need to integrate this topic into training much earlier so that we're not waiting to educate professionals who are already in practice, and that it needs to become a more systemic wide aspect of training that we just aren't seeing.

### What do you think the ideal weight stigma training would look like for healthcare providers, and how do you think we can better address the issue of weight stigma in medicine?

Yeah, so like any form of bias, a small amount of training at one time period is probably not going to have a long-term significant impact. This is something that needs to be integrated repeatedly if we're going to really shift practices and attitudes. What I will say is that when it comes to weight bias and education and stigma reduction, several pieces are necessary. One is providing education on the complex etiology of obesity to really challenge stereotypes that this is a simple issue of willpower or calories in, calories out. We know from a lot of research that when people are aware of the more complex etiology of body weight regulation and obesity that this reduces weight bias, whereas when people focus on personal responsibility or behavioral aspects of weight, weight bias can increase. So that's one piece of it, but it's also about communication with patients and patient-centered approaches and thinking about how we talk about body weight. We've recently developed a number of educational resources for healthcare professionals on this topic ([supportiveobesitycare.org](http://supportiveobesitycare.org)). We have a number of different strategies that we talk about for improving patient care and clinical practice and reducing weight bias. And a lot of it comes down to communication and how providers talk to their patients about body weight. This also means not only focusing on body weight, but focusing on health and other indices of health, not just the number on the scale. So there are a lot of pieces to this that really involve not only knowledge, but communication style and using patient-centered approaches and seeing patients more holistically rather than the number on the scale or a BMI.

I think also distangling obesity from body size, which gets conflated all the time, but obesity is much more complicated. There was a piece in the Lancet that came out [date].

It's a big deal from the commission on clinical obesity, talking about new definitions for obesity that go beyond BMI. It's getting a lot of press right now. That kind of thing could potentially reduce stigma because it's really mandating that we approach diagnosis of obesity in a much more nuanced way. We're really looking at aspects of health and disease that you can't see by looking at someone's body size. So those kinds of things I think could help reduce weight stigma. But these are things that need to be integrated into training in different ways. So in medical school, for example, there are different places where this could go. It could certainly be part of training on obesity and nutrition and body weight regulation, but it could also go into diversity focused training and education that students receive in other areas related to race and ethnicity or sex orientation, etc. I think the more exposure that we can get on these topics in either of those areas would be very beneficial.

**So how does your research translate to policy implementation?**

For a long time, I've been doing research to really assess how much public support there is in our country for different kinds of policies and laws that could be implemented to prohibit weight discrimination. I started this back in 2007 or so, which is when I was starting to be asked to testify in legal hearings about weight discrimination. I was interacting with policymakers and I said, "What kind of research would be informative or helpful for you as you tackle these problems?" And they said, "Well, we need to understand if the public are even behind this, would they support laws, would they support policies?" And as a researcher, that's a pretty straightforward question to answer. And so we started conducting studies with national samples and essentially looking at their degree of support for different types of policies. Some of those policies would be things like adding body weight as a protected category to existing civil rights laws that already exist in every state. Other policies would be creating new legislation that focus specifically on things like weight discrimination and employment. That evidence was very helpful because then when I went back to provide expert testimony in these hearings, I presented that evidence, which was very helpful and influential. And so I think the more that researchers can interact with policymakers and really find out what are the research questions that need to be addressed to help inform policy and how can we engage in those? That's been an important part of my work.

And the same has been true for children. We know that weight-based bullying is one of the most prevalent reasons that kids are teased and bullied. But this really isn't being adequately addressed at the policy level in schools either. Most schools now are required to have an anti-bullying policy in place, but the comprehensiveness of those policies really varies a lot. What we are finding is that parents really

want to see those policies strengthened to better protect kids from weight-based bullying. And that can be achieved in a very straightforward way by the language in these policies, making sure that body weight is included, because a lot of the time it's just not even on the radar. So there are tangible ways for researchers, especially social scientists like myself, to be doing research that can directly inform policy dialogue and hopefully also policy implementation.

**Could you talk a little bit about your most recent work?**

In the past few years, my work has started to extend to stigma related to Type II diabetes in addition to obesity. And part of the reason for that is that we see a lot of overlap in perceptions when it comes to obesity and Type II diabetes in terms of their stereotypes. We see that both are viewed to be conditions that people are personally responsible for. They're attributed as stereotypes of being lazy, things like that. And we also know that the comorbidity of those two conditions is very high. So many people who have diabetes also have obesity. We started to look at this in terms of bias as well and we carried out one of the first studies to look at how physician biases manifest when we're talking about both Type II diabetes and obesity. And what we found is that both of those biases are present. It seems like the weight stigma is a little bit stronger, but they're both present. That really has implications for patients, certainly with Type II diabetes or obesity, but it also has implications for where we need to direct training and stigma reduction, that it's not just obesity, but it's also Type II diabetes. So this is an area that has started to receive more attention. There was a recent international consensus statement on diabetes stigma. This is a newer topic area for research, but it's really gaining traction and I think we'll see a lot more coming out of that area as well. We've also done some research with patients who have Type II diabetes, and we see that they're experiencing both weight stigma and diabetes stigma, and that has implications for things like diabetes-related distress and eating behaviors and diabetes care and management. So we need to really be focusing more on how we can intervene with education and training with medical professionals who are treating these two different issues and make sure that it's not harming patients' health.

The only other kind of recent area that I've been focusing on is actually looking at weight stigma from parents towards kids. And this is an area that we're doing more research in because our studies are finding that, especially in adolescents, parents are a very common source of weight stigma, unfortunately, and that this has really a long-term impact on their health and well-being. We're looking at how parents are talking about weight with their kids, how kids want to talk about these issues, how it's impacting their health, and what kinds of education and resources can we be giving parents on this topic to make sure that they're creating a supportive family environment at home.



**As college students, how might stigma manifest in our living spaces and communities?**

I think we're all, but especially young people, living in a culture that is saturated with messages about body weight. I mean, you put on any social media and you're going to see content related to body weight. And so when it comes to social media in particular, we've got kind of two sides here with respect to weight stigma. We've got the body positivity movement, which is emerging more strongly on social media now, which is really trying to challenge weight stigma and promote messages of body diversity and body acceptance. And at the same time, we've got a lot of really harmful messages on social media related to weight loss and eating disorders and stigma and fat shaming. That's a lot to deal with and I think that it does impact the way we think about body weight. We know that the media has a profound influence on societal attitudes and public attitudes, and body weight is a very emotionally charged topic that most people have a feeling or opinion about. I think it's really about being more critical and mindful of the content that we are exposed to and thinking about, "Is this something that is reinforcing or promoting stigma or is it something that is trying to reduce stigma and create more respect and diversity and sensitivity to people of all body sizes?" And I think there are things we can do in our daily lives, in any setting that we're in, to really ensure that we are treating people of all body sizes with respect and dignity. And fundamentally, that's really what this is about.

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