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Conflict from Culture: Bioethics in the Community

How religious and cultural perspectives influence public acceptance of scientific advances

Penn Bioethics Journal

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Letter from the Editors

Dear Readers,

It is our pleasure to present you with Volume XVIII, Issue i of the Penn Bioethics Journal, entitled "Conflict from Culture: Bioethics in the Community." The two articles in this issue explore how religious and cultural perspectives influence public acceptance of scientific advances.

The first article, "A Cross-Cultural Perspective on Neuroethics," examines how contemporary neuroscience and neuroethics face challenges stemming from cultural and community values. Author Chinmayi Balusu of Columbia University utilizes examples from Western and non-Western nations to examine the variation in responses to issues such as organ donation and neurodegenerative diseases.

The second article, "What's in a Microchip? Using Biopower to Examine COVID-19 Anti-Vaccination and Anti-Mask Movements," utilizes biopower, defined as the use of biological and medical data to manage populations, to analyze variations in response to the COVID-19 pandemic. Author Neha Tallapragada of Rice University finds that medical mistrust and cultural community sentiments have driven groups to rebel due to fear of increased surveillance and anti-establishment sentiments.

Our Bioethics-in-Brief section covers current issues in the field of bioethics. In our first brief, Kim explores the perspectives of locked-in syndrome patients, who are cognitively aware and consciously alert but unable to move or speak due to damage to a section of the brainstem. With issues ranging from patient autonomy and quality of life to the cost of care and resulting financial burden, the discussion surrounding locked-in syndrome patients is complex and one that will certainly be further explored by bioethicists. In our second brief, Proano examines the concern regarding adverse reactions to COVID-19 vaccines. Amidst the misinformation surrounding COVID-19 online, patients who experienced severe adverse reactions often found their voices inadvertently silenced, prompting discussion about the balance between ensuring that individual's concerns are heard and preventing mass panic.

PBJ also had the privilege of interviewing Dr. Jonathan D. Moreno, Professor of History and Sociology of Science, Medical Ethics and Health Policy, and Philosophy at the University of Pennsylvania. In addition to teaching, Moreno is a prolific author. He co-authored one of his most recent books, *Everybody Wants to Go to Heaven but Nobody Wants to Die: Bioethics and the Transformation of Healthcare in America*, with current United States Ambassador to Germany and former University of Pennsylvania President Amy Gutmann. During our discussion, Moreno offered insight on how different communities engage with bioethics on hot topics such as vaccination and abortion. Moreno also highlights the importance of bioethics in regards to more "quirky" topics, such as gene editing technologies and neuroethics, and the invaluable role of different perspectives when discussing such topics.

We would like to thank our faculty advisor, Dr. Harald Schmidt, for his support during the editing and publication process. Additionally, we would like to thank our publisher and amazing team of editors, without which this issue would not have been possible. These past couple of years have been filled with unprecedented changes, and we are so proud of our PBJ community for rising to the challenge.

We hope you enjoy this latest issue of the Penn Bioethics Journal and that it inspires you to engage with the field of bioethics. Please contact us with any questions, comments, or ideas for collaboration at pbjeditorinchief@gmail.com.

Ella Atsavapranee and Amy Chen
Editors-in-Chief
University of Pennsylvania C'23

Article

A Cross-Cultural Perspective on Neuroethics

Chinmayi Balusu*

The boundaries of contemporary neuroscience are rapidly expanding due to cutting-edge technological innovation, including deep brain stimulation brain-computer interfaces, as well as increased understanding of neurological conditions such as Alzheimer's Disease and epilepsy. In response, neuroethics has emerged as a discipline studying the "implications of neuroscience for human self-understanding, ethics, and policy" (International Neuroethics Society).

Neuroethics brings a myriad of individuals into the conversation, including physicians, researchers, entrepreneurs, lawyers, and philosophers.[1] The field's overarching aim is to ensure neuroscience advances human well-being while protecting humans' physical, psychological, and emotional safety during participation in any research or clinical activities (Greely et al. 2018). However, one issue that limits effective and impactful application of neuroethics is the gap in cultural understanding. Situations in which patients are diagnosed with neurological conditions, receive medical treatment, participate in research trials, and beyond vary based on cultural, spiritual, social, historical, political, and economic lenses.

To explore how a cross-cultural neuroethics perspective can come to life, this paper will focus on two real-world examples of neuroethics from Japan and Canada that demonstrate interactions with social stigma, spiritual traditions, autonomy, confidentiality, and barriers for subject participation, among other factors that complicate our understanding of the discipline and present room for further growth.

Background

Currently, there are only seven neuroethics governing boards worldwide (located in the United States, Canada, European Union, Japan, China, Korea, and Australia). These governing boards focus on accountability but face discrepancies in international "bureaucratic hurdles." For instance, Institutional Review Boards (IRBs) differ in their leeway for research approval from institute to institute and nation to nation (Rommelfanger et al. 2018).[2] The attempt to standardize neuroethics frameworks on an accountability basis is making steady progress, yet the focus on understanding how cultural values contribute is lagging behind. For example, in Mexico, the "mix of western and pre-Hispanic philosophies has been an important factor in leading many patients to consider going to a priest or a Chamán before consulting a psychologist or a psychiatrist" (Salles et al. 2018). Current neuroethics frameworks fail to consider how cultural and spiritual traditions, as well as social stigma, interact to influence community members' health decisions at the local level. This has led many neuroscience scholars to call for building a "wider and more inclusive neuroethics" discipline, whether it is framed as "cross-cultural," "global," or "international" neuroethics" (Salles et al. 2018). Analyzing disparities in neuroethics through a cross-cultural lens enables increased understanding of how we can bridge complex ground-level experiences with national-level frameworks, promoting the greater well-being of communities.

The Brain's Role in Defining Our Sense of "Self"

In 2012, researchers from the Kumamoto University Graduate School of Medical Science in Japan conducted a study on public perception of brain death and donation before and after the Japanese Organ Transplant Law revision. Prior to the revision, declaring a patient as brain dead was considered only for the purposes of organ donation; once the revised law was passed, brain death could now be considered equivalent to a patient's legal death. This was a revision to earlier guidelines that only used lack of cardiac activity to define a patient's death without regard to brain death (Asai et al. 2012). Organ donation from patients who are recently deceased can provide life-saving treatment for other patients who are in crisis at the time. Specific to the brain, donating one's entire brain after death is also incredibly valuable for research purposes. However, Japan has the lowest proportion of organ donors compared to other developed countries. Part of this cultural phenomenon stems from

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[1] Within the United States, these conversations engaging multiple stakeholders are typically hosted by university academic centers (e.g. University of Pennsylvania's Center for Neuroscience & Society), professional membership societies (e.g. International Neuroethics Society), and independent not-for-profit organizations (e.g. NeuroTechX). Additionally, government-sponsored programs such as the NIH's Brain Research Through Advancing Innovative Neurotechnologies (BRAIN) Initiative strive to promote neuroethics discussion at a federal policy level.

[2] While these governing boards were primarily formed for the purpose of establishing regulations and safeguards regarding neurotechnological developments, the boards have also come to be regarded as the premier source of adjudicating what is "right" and "wrong" in broader neuroethics.

*Chinmayi Balusu is studying Medical Humanities at Columbia University. She can be reached at chinmayi.balusu@columbia.edu.

many community members' complex relationship with the brain's role in defining identity and sense of "self."

In neuroethics, "brain exceptionalism" is the idea that the brain is unique compared to other bodily organs because it is "foundational to human identity," functioning as the "locus of fundamental human elements such as personality, desires, hopes, fears, memories and free will" (Rommelfanger et al. 2018). Compared to a bodily organ such as the kidney, the brain is more directly associated with the intimate identity and personality of an individual — defining what makes them the human being that they are. As a result, Japanese community members often believe that a patient does not have the same personality after undergoing a brain transplant, considering the brain's human identity is now detached from the physical body (Asai et al. 2012). Especially since brain-dead patients still have a pulse and may look as though they are simply asleep, family members may consider organ transplantation unacceptable since it is as though organs are "being taken from living human beings" (Asai et al. 2012). Grieving family members may understand that medically speaking, it is very unlikely for their brain-dead family member to recover, but it can be extremely difficult to decide to take the large decision to approve organ donation.

In Japanese culture, separating the brain and body during the transplant process means detaching one's sense of identity after death, which can be a difficult concept to grasp in purely legal interpretations of brain death. Especially since Japan and other East Asian countries are experiencing a shortage of brain specimens and organs for both clinical and research purposes, this can be a difficult situation for healthcare professionals. There is a conflict between trying to donate the organs toward a good cause while respectfully keeping the family's wishes in mind (Raposo 2018). If scholars in the field are not able to unite these two stances and address the greater public perception of the brain's role in identity, there will be a great loss scientifically and medically.

Individual Versus Familial Autonomy

Neurological disorders can have debilitating effects on a patient's health and autonomy. These disorders are also associated with "impaired, fluctuating, or diminished decision-making capacities" due to symptoms such as memory loss, personality shifts, changes in consciousness, and impaired language skills, depending on the illness severity (Greely et al. 2018). For example, a patient with Alzheimer's Disease, a neurodegenerative disorder that can cause loss of memory, judgment, and motor skills, may not be able to make decisions to the best of their abilities. This means that family members may need to function as substitute decision-makers, which can cause conflicting circumstances where individual autonomy is lost.

An example of this tug-and-pull between the individual and family's wishes can be witnessed in a real-life example from Canada. From 1998 to 2009, nine members of a First Nations kindred community were assessed at the University of British Columbia Hospital Clinic for Alzheimer Disease and Related Disorders (UBCH-CARD). Researchers were concerned about the health of these individuals, as they had a strong familial history of early-onset Alzheimer's Disease, which affects individuals in mid-life. UBCH-CARD researchers identified a specific, novel gene mutation that contributed to the kindred members' development of the disease and later identified over 100 family relatives to be at risk of inheriting the condition as well (Butler et al. 2010).

Individuals with a case of early-onset familial Alzheimer's Disease often require extensive long-term care that cannot be provided at home. For members of the First Nations kindred, this meant that patients would be forced to leave the traditional territory and travel to a more urban, clinical facility to receive that dedicated care. In this situation, the family must make a difficult decision on behalf of the individual, which can be a disorienting experience, as the "family feels it has abrogated its duty of care to their loved one, and the community experiences the transfer as a death" (Butler et al. 2010).

On the other hand, familial autonomy overpowering individual autonomy (in a more forceful manner) can also be seen following an individual's brain death. Between 1997 and 2007 in Japan, 1,133 individuals consented to serve as organ donors following their death. Of this group, there were 103 individuals who were later identified as clinically brain-dead by a physician. For almost one-third of these brain-dead patients, however, their families did not consent to the determination of brain death, and the patients were left on life support without the possibility of organ donation (Asai et al. 2012). In the end, the patients' surviving relatives carried full autonomy in determining life support and organ donation, even if it directly opposed the patients' wishes from when they were still alive. Considering how familial autonomy can dominate the patient's individual autonomy regarding brain donation after death is another aspect of neuroethics that is important to consider. There is no legal violation in the family's decision to overturn the formerly living individual's decision regarding brain death in Japan – the revised organ transplant law allows this veto power to the family. This conflicts with the typical western perspective of the individual patient's wishes standing after death as well. A cross-cultural neuroethics lens would encourage developing frameworks that consider these individual-familial autonomy dynamics across various communities, allowing for equal negotiation between both the individual's and the family's wishes on a social, cultural, and legal level.

Informed Consent and the Relationship with the Researcher/Physician

Informed consent, whether on an individual or a familial level, is essential to ensure people know the purpose behind their participation in a study or medical action and the long-term impact of their decision. Researchers should understand that when working with patients with impaired neurological function such as in Alzheimer's Disease, it is important to conduct routine assessments to determine if the patient is processing the conveyed information properly (Greely et al. 2018). This applies to cross-cultural neuroethics as well, especially when researchers are engaging with marginalized populations, as medical mistrust is an obstacle for many communities.

The process of informed consent relies on the effective rapport between the individual and the professional researcher or physician. Whether we consider the case of how the Canadian government has unethically mistreated Indigenous populations or the case of the controversial Wada transplant in Japan,[3] patients and their families may worry that they are being taken advantage of by physicians and researchers. For instance, many Japanese individuals believe that if brain death is defined as a person's legal death, it will reduce their autonomy and give physicians the power to stop medical treatment in order to harvest organs (Asai et al. 2012). Keeping this history in mind, informed consent should not simply be the researcher telling the participants what to expect; instead, it should focus on a two-way relationship emphasizing active listening. For example, scholars have expressed how "much of the research to date [about Indigenous peoples' health] has been 'on' or 'about' Indigenous people with dementia, rather than research 'with' Indigenous peoples and communities" (Hulko et al. 2010).

A hallmark of the UBCH-CARD study was the researchers' dedicated efforts to build rapport by engaging Elders from the kindred. Their relationship was strengthened, as community members understood that UBCH-CARD staff was not using them to discover a cure for the disease, but instead were invested in improving their long-term medical care. Additionally, the researchers crafted easily understandable education materials and distributed them at "Health Fair" awareness events under the guidance of Elder leaders. This ensured that First Nations members were able to receive crucial information in their own native language and be a central part of the conversation instead of perpetuating an "outsider-insider" dynamic that causes the First Nations members' health status to be taken advantage of (Butler et al. 2010).

Confidentiality of Health Information and Social Implications

Among the First Nations kindred, there were several concerns about how information regarding the risk of Alzheimer's mutation could be gathered and how information could be disseminated without affecting patient privacy. One issue that the Canadian researchers ran into was determining precise biological relationships among the First Nations kindred members to build an effective pedigree framework for assessing genetic risk. Relationships were "complicated by half- and step-siblings, informal adoptions, non-paternity, consanguinity and the recurring use of names in different generations or branches of the family" (Butler et al. 2010). Various individuals who were surveyed had differing methods of describing relationships. Additionally, researchers could not ask clarifying questions about certain individuals outside of immediate families, as it would break confidentiality. This meant that researchers were navigating complex familial relationships that they were personally unfamiliar with, illustrating how prior knowledge of social dynamics within First Nations kindred would be a valuable aid from a neuroethics standpoint and reduce the researchers' personal biases.

In close-knit rural communities, relationships also have "greater overlap between health care providers, residents, family members and business people in their social networks," which poses additional obstacles to confidentiality (Butler et al. 2010). The researchers described one such complicated case of revealing the risk for passing on disease:

> "The complicated nature of maintaining confidentiality in this particular kindred is poignantly illustrated by the concerns of one family member who wished to disclose her carrier status to her children who are at 50% risk to inherit [early-onset familial Alzheimer's Disease]

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[3] Dr. Juro (Jerry) Wada was a surgeon at Sapporo Medical University in Japan who performed the country's first cardiac transplantation in 1968 amidst great controversy. As this was prior to the implementation of laws that clearly defined clinical brain death, Dr. Wada was charged with murdering the patient who served as the organ donor. He was exonerated several years later (Cooley 2011).

> EOFAD. She hesitated to do so based on her fear that her children could not be relied on to maintain her privacy within the community, given their tendency to alcoholism and binge-drinking episodes."

In such cases, an individual who is at risk and willing to disclose can feel pressured to remain silent because of social stigma within the community. If other community members knew of her status as a disease carrier, she could be shunned because of cultural attitudes toward the disease, which is further detailed in the next section.

From a practical standpoint, researchers were often unable to follow up with kindred members over the telephone since they pursued hunting excursions for extended periods of time. If other kindred members answered the certain individual's telephone calls in the meantime, the researchers were not able to share a follow-up message because of concerns about patient confidentiality (Butler et al. 2010). This meant that participants often missed time-sensitive follow-up steps, delaying crucial medical recommendations because of cultural misunderstandings.

Spiritual and Cultural Misconceptions

Compared to other physical ailments such as a leg fracture or kidney stones, neurological conditions typically carry greater weight in regard to social stigma and misconceptions, which can catalyze cultural tensions. For instance, during the Japanese study surrounding the Organ Transplant Law revision, researchers found that Japanese views towards life and death were based on Shinto practices[4] with influences from Buddhism and Confucianism (Asai et al. 2012). Specific to organ transplantation, brain death departs from a Japanese custom known as "Mogari," where the corpse of the deceased must lay undisturbed in a coffin for a certain amount of time. Therefore, organ transplantation, which counts as a "ritual of separation," cannot be performed in order to preserve the physical body. Brain death is seen as an "unnatural" and "unseen death" because the body remains there, but Mogari cannot occur since life is still present (Asai et al. 2012).

Additionally, among the First Nations kindred in Canada, there are differing views about memory loss, contrasting the traditional "going through the full circle of life" (where an individual is not affected by dementia) with the "shémá [white] way" (where an individual is diagnosed with dementia such as Alzheimer's Disease). The term "dementia" is not traditionally used among First Nation communities, as individuals tend to associate dementia with being a "western diagnostic category […] for sickness, tiredness, or childlike behavior." Some First Nations members shared the belief that their Alzheimer's Disease diagnosis came from "the effect of eating non-traditional foods, industrial activities on their territory, and alcohol and drug misuse" – overall, connecting symptoms of Alzheimer's Disease with "disconnection from the land and traditions" (Hulko et al. 2010). The stigma surrounding Alzheimer's Disease can be isolating for individuals with the disease, as their communities question how they have strayed from the traditional way of living, aligning themselves with the negatively perceived "White Man" (Butler et al. 2010).

Financial and Geographic Barriers

Financial and geographic limitations are hidden barriers in neuroethics approaches. For the First Nations kindred, traveling to the UBCH-CARD location meant taking a 25-hour car trip or an eight-hour flight (which cost approximately $1,200). Traveling to the clinical site was especially difficult during the severe winter conditions. Individuals would also lose out on pay from employment and be required to arrange for childcare. The kindred implemented a fixed quarterly budget for medical expenses on behalf of all members, but since the budget could only account for limited resources, the genetic testing and associated travel costs were not feasible. This decreased members' willingness to participate in the UBCH-CARD study, even if it meant ignoring preventative measures. Furthermore, kindred members experienced stress during the process of traveling outside of their traditional community to an unfamiliar clinical setting (Butler et al. 2010). Japanese community members may also face similar struggles considering the wide gap between urban and rural access to care. Rural populations may have limited access to organ donation compared to urban residents, as well as less access to information about the positive impact of organ donation. As a result, community members residing outside of urban regions may be less inclined to consent to their deceased family members' brains being donated.

Conclusions

Overall, it is essential that professionals involved in neuroethics engage with "underlying values and ethical concerns that drive brain research [as well as clinical care and community perceptions] across cultures and continents" to build multifaceted frameworks (Rommelfanger et al. 2018). Exploring cultural perspectives may seem like a separate vision from advancing research, but these perspectives are essential in understanding how research and innovation will be adopted in society, from the national policy level of the seven primary governing boards to local health clinics

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[4] Shinto is an ancient Japanese faith system based on "devotion to invisible spiritual beings and powers called 'kami,' to shrines, and to various rituals" (BBC 2011).

such as UBCH-CARD.

Furthermore, while embracing cross-cultural neuroethics will be incredibly beneficial for neuroscience professionals, it is equally important to consider the "risks reinforcing ill-informed stereotypes" (Rommelfanger et al. 2018). For instance, we cannot generalize the findings from a neuroethics study focusing on connections within one First Nations community to all other Indigenous communities. These studies are meant to serve as a launching pad for discussion but cannot encompass the diversity of thought, practices, and customs present among different identity groups. For example, despite many other East Asian countries containing similarly large Buddhist and Confucian populations, the Japanese view on brain death and Mogari should not be broadly extended, as there are nuanced differences in cultural beliefs. This should not, however, be viewed negatively, but rather as an essential reminder that neuroscience and neuroethics trickle down to local communities in a myriad of ways. When interrelated issues of autonomy, patient-physician mistrust, confidentiality, financial barriers, and beyond are considered together, neuroethics scholars can ensure that both healthcare professionals and community members feel empowered in brain-related health discourse.

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Article

What's in a Microchip? Using Biopower to Examine COVID-19 Anti-Vaccination and Anti-Mask Movements

Neha Tallapragada*

As COVID-19 has swept across the U.S., a deep division has emerged on how to approach the pandemic. Public health measures that may have seemed innocuous at the outset have proven to be flashpoints of cultural debate. One lens that provides insight into the widespread backlash against COVID-19 measures is Foucault's theory of biopower. Biopower helps to articulate the perspective that we are seeing resistance to measures like vaccination and mask-wearing in part because of a fundamental distrust of institutional authority. Of course, there are individuals who do trust higher levels of government like the Trump administration, but distrust state governance at Trump's behest. However, I will focus on the group of people who express consistent distrust in government "elites" and feel uncomfortable with state mandates and surveillance measures. Keeping in mind the goal of successful COVID-19 prevention, it may be more feasible and effective to meaningfully engage with this group's specific concerns. Biopower explains the phenomenon of surveillance, and historical context enables us to see how similarly-motivated backlash has been observed during past epidemics. I will argue that this distrust of bureaucratic systems can be linked to perceived abuses of institutional power, specifically regarding scientific racism and the increased surveillance of individuals. I will also indicate the importance of viewing these movements using a biocultural perspective, as well as evaluate the success of biopower as a biocultural approach.

The definition of biopower was devised by Michel Foucault, and has come to take on greater significance as more examples of biopower are shown on a greater scale. Biopower refers to the use of biological and medical data to manage populations (Hanna and Kleinman 2014). Biopower is the aspect of governmentality relevant to life–governmentality itself relates to the "counting and controlling [of] the health and social welfare of populations" (Hanna and Kleinman 2014: 27). Examples abound in the U.S.: mandated vaccinations for children in public schools, tracking a state's obesity rate, observing a country's birth and death rates. Biopower and governmentality are both related to the idea of rational-legal authority, wherein people "feel pressure to obey rules and conventions that have become dissociated from human agents and are instead imbued with coercive power because they have been legitimated and institutionalized" (Hanna and Kleinman 2014: 19). Orders like stay-at-home mandates that are enforced by monetary or carceral consequences become depersonalized, perceived to be founded not upon values of mutual benefit and altruism, but on a desire for control over the population. Additionally, biopower can be seen in past epidemic responses. During plague outbreaks as old as the Bubonic Plague's terror, or as recent as the emergences of Ebola and SARS, an infrastructure of quarantine and surveillance of quarantined bodies was created to manage disease response. This system of surveillance continued well after the epidemics themselves had faded (Roberts 2019: 96). These historical patterns lay the groundwork for the fear that governmental contact tracing systems, for instance, may also become part of daily life well after the COVID-19 pandemic subsides. In addition, the perception that methods of surveillance associated with biopower are increasing has been compounded by the longstanding trend of American institutions abusing power to harm marginalized populations. If trust in an institutionalized, bureaucratic authority is damaged, it follows that it would become difficult to employ a productive biopower to successfully regulate population health. This destroyed trust contributes to Americans' resistance to COVID-19 safety measures.

The United States' medical institutions have committed multiple atrocities in the name of science against historically marginalized populations, which has caused trust in such institutions to be very low. Only a "quarter of Black respondents and 37 percent of Hispanic respondents in [an] AP-NORC poll [say] they would commit to getting the [COVID-19] vaccine" (Watley and Shodiya 2020). The authors assert that a distrust of vaccines in marginalized communities arises from trends of scientific racism in the U.S. One example is involuntary sterilization by eugenics movements in the late nineteenth and early twentieth centuries, which targeted mentally ill and Black, Indigenous, and Latina women. Another well-known example is the Tuskegee syphilis study, when Black men with syphilis were offered free healthcare in return for participating in a U.S. Public Health Service study. However, even after a treatment was created, it was not offered to the men in the study, as researchers wanted to observe the progression of syphilis (Watley and Shodiya 2020). This recurrence of

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*Neha Tallapragada is studying Cell Biology and Genetics and Medical Humanities at Rice University. She can be reached at nt19@rice.edu.

violations of bodily autonomy contextualizes current fears about the COVID-19 vaccine. To illustrate, with respect to the idea that the vaccines will contain a microchip that the government will use to track vaccine recipients, it is "not so far-fetched to believe rumors that scientists will take people's most private information without permission while administering care when, in 1951, while Henrietta Lacks was receiving cancer treatment at Johns Hopkins Hospital, a tissue sample was taken without her knowledge" (Watley and Shodiya 2020). COVID-19 conspiracy theories circulating in these communities are backed by the trend of scientific racism in the U.S., which has culminated in fears of further institutionally-sanctioned abuse against community members. To add to the U.S. government's documented misuse of authority, the phenomenon of surveillance creep has contributed to a mistrust of the governmental institutions responsible for enforcing COVID-19 safety measures and vaccine distribution.

As explained above, central to concepts of governmentality and biopower is the surveillance of individuals, with the purpose of disciplining and managing the biological processes of said populations. Living under constant and heightened surveillance has significant psychological consequences. Autonomy, or the "sense of having volition and choice in your actions" (Calvo et. al 2020: 3), fulfills a basic psychological need necessary for societies and individuals to flourish. Surveillance damages this need by creating a sense that one is being controlled, which naturally leads to backlash against further surveillance methods (Calvo et. al 2020). Current resistance to public health measures follows the pattern that Calvo et. al delineate of an aversion to perceived threats to autonomy, as well as underscoring the fear that, like in the past, these surveillance systems will continue beyond pandemic response. This wariness of augmented surveillance is not baseless. Enhanced surveillance of populations has taken many shapes during the pandemic. For instance, governments are "implementing new measures such as geofencing and artificial intelligence (AI)–based facial recognition to facilitate the enforcement of social distancing" (Sylvia 2020). Additionally, location data from cell phones are being sold to third-party companies and collected by government-run health organizations like the CDC without the knowledge of the individuals from whom the data originates (Sylvia 2020). This is the phenomenon of surveillance creep, which is when surveillance "developed for a limited purpose, such as fighting a pandemic or filming traffic violations, becomes used in ever more pervasive and permanent ways" (Calvo et. al 2020: 3). As indicated earlier, Hanna and Kleinman (2014) substantiated this forecast with their analysis of surveillance under plague epidemics continuing even after the outbreaks had subsided. One particularly modern example of surveillance creep is the use of drone technology to monitor COVID-19 cases in the U.S. and China. Both countries have used drones to enforce social distancing protocols by blaring loud music. In Connecticut, drones monitored individuals' heart rate, temperature, and breathing (Sylvia 2020). The ability for various countries to gather information about an individual down to distinct biometrics in a matter of seconds is unique to this pandemic, and raises concerns that these methods may be here to stay. The U.S. and China may share this specific method of surveillance, but larger scale governmental strategies for pandemic response vary greatly overall between countries, which also affects the nature of citizen responses. These differences can be analyzed using a biocultural approach, which biopower incorporates to varying degrees.

Taking a biocultural view of the pandemic into the understanding of American pandemic response has several benefits. A biocultural perspective provides a fuller picture of the rationales behind health-associated behaviors that consequently affect the biological and physiological realities of pandemic life. For example, comprehending Italy's COVID-19 fatality rate can come from looking at the country's wider sociopolitical landscape. Italians' high rates of vaccine skepticism can be connected to contemporary state-society relationships In Italy. These "include suggested correlative links between rises in populism and vaccine scepticism" (Friedler 2020: 6). An inclusion of cultural analysis connects the larger political landscape, where there are growing movements based in populism, to vaccine skepticism. Similarly, this biocultural viewpoint can be applied to a historical example of anti-mask movements in past pandemics. The 1918 influenza pandemic in San Francisco led to authorities establishing a mask ordinance punishable by fine or arrest; when they decided to reinstate it following a spike in cases, they faced much backlash from the public (Dolan 2020). One of the most vocal groups, the Anti-Mask League, "campaigned in opposition to medical tests for children in schools, saying that "'it was an interference of the rights of parents and an invasion of the home'" (Dolan 2020: 19). This historical parallel can be more completely understood by examining an analogous trend in increasing management of the American populations' health through current mandates for children's vaccination in public schools. Overall, connecting the health-related phenomena themselves (anti-mask movements, anti-vaccination movements, etcetera) to both contemporary power structures and the wider sociocultural context in which said phenomena operate can create a more thorough understanding of why these trends are observed. It remains to be seen whether or not biopower is a sufficient example of a biocultural perspective. For instance, mechanisms of biopower function in every country, but adding an independent biocultural approach helps one see why or how different social and cultural groups respond differently.

Contrasting models of "COVID-19 population prevention have relied upon the "operation of pandemic authority as disciplinary biopower. [South Korea] has utilized mass biological surveillance through voluntary and compulsory surrender of personal privacy to undertake comprehensive diagnostic testing and contact tracing enabling targeted quarantines...South Korea used extensive surveillance technologies including closed-circuit television and GPS smartphone data to track the movements of the infected" (Porter 2020: 6). South Korea's plan demonstrates that intensified surveillance measures have been taken in other regions that Americans have not experienced. Yet, it is far right movements in the U.S., and not in countries in South Korea, who are credited with creating theories such as the idea that the epidemic was created to help Bill Gates' political prospects (Porter 2020). A potential biopower-related explanation for this difference in citizen response is that the U.S. has had to use the most visibly coercive COVID-19 measures, while South Korea has not. Specifically, the U.S. is one of the countries to have states enact the most drastic measures in an attempt to slow the spread of COVID-19, such as the sovereign land quarantine in California that was backed by armed forces (Porter 2020). By contrast, in a "small number of democratic states, disciplinary biopower through surveillance to facilitate targeted quarantine limited the necessity for the exercise of sovereign pandemic authoritarian power through mass land quarantines" (Porter 2020: 7). South Korea did not need to institute a comprehensive land quarantine for an extended period of time, as they utilized biological surveillance earlier and as opposed to more authoritarian approaches that are more visible measures of coercion. But even though biological surveillance measures were used, South Koreans widely supported these measures (Porter 2020). For that reason, an explicitly biocultural perspective would be valuable to incorporate in tandem with biopower to explore why or how responses to biopower vary between countries that prioritize collective health versus countries that prioritize individual autonomy. Ultimately, though, the above comparison corroborates the biopower-related determination that anti-vaccination and anti-mask movements are a response to surveillance and coercive measures that are specific to the U.S. These movements are amplified by the construction of insular, stratified social groups.

Vaccine refusal in the U.S. is a product of several intertwined factors: rising populism, fear of aforementioned surveillance practices, and the creation of social groups founded on the principle of freedom, which all converge to create a strong anti-establishment sentiment. Firstly, vaccine refusal is characterized not by negation, but by an affinity with a certain group. Refusers "reaffirm in-group framings and, thereby, in-group ties" (Sobo 2016: 343). One specific environment observed by Sobo was the majority-white, affluent community that comprised the Waldorf School. Parents justified their refusals to vaccinate their children for a variety of reasons, but these reasons were fundamentally social (for instance, talking with peers about the vaccination status of a child) and bonded the in-group together in the process (Sobo 2016). This perspective highlights the fundamentally affiliative nature of vaccine resistance as a declaration of belonging to a certain group, as well as being a way to signal one's values. Anti-vaxxers are necessarily "anti-vaccination and anti-authority, but they also take affiliative positions like being pro-self-determination and pro-freedom (McAteer et. al 2020: 704). These broad foundational principles are diametrically opposed to the idea of the "establishment," a rebuttal to the institutional authority that also imposes surveillance systems on the public.

Thus, this value system may explain the overlap between growing anti-vaccine and anti-mask movements and the rise of populism around the world; ideas of biopower link together sociopolitical movements like populism and specific anti-hygiene movements as responses to a backlash against surveillance controlled by the "establishment." What distinguishes populism is the role of the "'(established) elite' as polemically positioned in opposition to 'the people'. Nationalism discursively includes the elite in the notion of the national people" (Vieten 2020: 5). Similar to vaccine hesitancy, aligning with populism is also an affiliative act in support of an in-group–supporting the "people" as opposed to the "elites" of the government. Vieten (2020) describes "anti-hygiene" protests observed across western Europe as responses to the powers supposedly enacted in emergency situations that institutions later seek to normalize and legitimize through biopower. These protests connect to the "propaganda exercises of far-right activists" (Porter 2020: 6) in the United States. Similarly, anti-mask movements are founded upon opposition to the reach of governmentality in imposing mask mandates. Consider French anti-maskers, who were "attracted by libertarian beliefs...and to conspiracy theories. These included government connivance with the pharmaceutical industry to conceal vaccine harm" (Rayner 2020). The French protests support Vieten's earlier assertion that the perceived failures of the government are producing anti-establishment, extremist belief systems, fueled by online polarization. As articulated previously, this distrust is a direct response to perceived institutional overreach, which the lens of biopower has helped depict.

Firsthand perspectives from the U.S. can contextualize the above analyses in order to tie together the concepts of biopower, heightened surveillance, institutional distrust, and the subsequent cultural and political rise of the alt-right. In an interview with Vox at an anti-mask protest, most people insisted that they did not believe that the coronavirus was made up, but also "expressed doubts about the growing body of scientific knowledge around the virus, opting for cherry-picked and unverified sources of information found on social media…[those interviewed] acknowledged they leaned right" (Stewart 2020). This evidence further links the rise of alt-right, populist movements to resistance of government-regulated ordinances such as mask mandates. One interviewee cites "the 14th Amendment of the US Constitution. 'No states are allowed to make laws that take our freedoms and liberties away'" (Stewart 2020). This recurring fear of a loss of independence calls back the point from Calvo et. al about the threat of such a loss in the face of increased surveillance of one's body. This line of thought was carried through by another respondent, who believes "masks are a step in 'getting people into compliance so that they can make vaccines mandatory as well…Soon it will be, 'take the vaccine,' or you can't travel, shop, etc.' Or worse, he [says], digital IDs or 'health care passports'" (Stewart 2020). This participant fears the forfeiture of his autonomy from increasingly intrusive methods of managing the biological and medical data collection of Americans; in other words, he fears the exact situation of surveillance creep. Overall, examining this primary source proves the central thesis that a suspicion based in fears about surveillance creep has intersected with far-right agendas and created a smorgasbord of anti-vaccination and anti-mask movements, which concepts of biopower have helped reveal. On the other hand, perhaps there are alternative frameworks to biopower that may better characterize these developments.

Rayner puts forth two main critiques of using biopower to explain the anti-COVID-19-measures movements: it is not current enough, and it is not cultural enough. First, Foucault's concept of biopower is decades old; it neglects the transformation of surveillance systems from market and governmental institutions to forms of surveillance capitalism through companies such as Facebook (Rayner 2020). Second, Rayner posits that Foucault's ideas surrounding biopower do not adequately take into account the influence of culture. This is significant, as it was asserted earlier that a biocultural perspective is critical to understanding the movements discussed. Rayner introduces the question of whether biopower has limitations as a biocultural approach in and of itself. Placing "greater emphasis on mutuality and social norms, produced from 'below' rather than 'above', might suggest that the Covid-19 experience is not just solely that of biopower, but also engages culture and mechanisms of collective responsibility" (Rayner 2020). It is true that biopower is a very specific theory. This was observed when looking at the differences between the U.S. and South Korea; biopower could only offer one reason why the responses in each country were different, and it did not fully incorporate the uniquely cultural underpinnings of how South Koreans view their enhanced surveillance compared to Americans. At the same time, the idea of biopower enables one to make the connection between two phenomena. The first is populism–a recurring political and deeply sociocultural phenomenon. The second is backlash to governmentality, as a main facet of populism is an opposition to institutional authority. Biopower makes one aware of the surveillance systems in place and how they connect to the larger structural landscape. Therefore, while biopower may not account for all cultural influences on pandemic response, it certainly possesses cultural aspects. As the analysis of South Korea's pandemic response versus the U.S. demonstrated, perhaps considering biopower concurrently with independent cultural explanations can create a more three-dimensional perspective of the current moment. All in all, a concerted effort to consider modern-day and historical cultural contributions to pandemic response that a lens of biopower alone may not take into account can supplement the perspective that this social theory offers.

To conclude, observing the U.S.'s COVID-19 pandemic response alongside Foucault's theories of biopower has exposed a connection between vaccine and mask resistance and a fear of autonomy loss due to enhanced surveillance. Unlike other countries that employed significant surveillance measures at the beginning of the pandemic, the U.S.'s resort to highly visible examples of coercion, such as land quarantines enforceable by armed forces, has affected the collective consciousness of those who are already concerned about institutional abuse. Right-wing populists in particular have this concern. On the other side of the coin, marginalized communities who have historically been abused by these same institutions are also suspicious of pandemic response measures, specifically about future vaccine distribution. The reveal of how governmental institutions have been utilizing biopower to coerce, manage, and discipline the American population has generated a significant backlash from a variety of different communities. Thus, while biopower may overlook certain cultural influences, it is still intimately tied to an understanding of the cultural and political rationales behind pandemic response. It is critical for U.S. public health institutions to understand the concerns that individuals have about their autonomy and surveillance, so that they can incorporate these sensitivities into COVID-19 safety measures and perhaps generate a positive biopower that mitigates the effect of this devastating disease.

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Interview

A Conversation with Dr. Jonathan D. Moreno

Jonathan D. Moreno, PhD is the David and Lyn Silfen University Professor at the University of Pennsylvania where he is a Penn Integrates Knowledge (PIK) professor. At Penn he is also Professor of Medical Ethics and Health Policy, of History and Sociology of Science, and of Philosophy. Moreno is an elected member of the National Academy of Medicine. In addition to teaching, Moreno is a prolific author. He co-authored one of his most recent books, Everybody Wants to Go to Heaven but Nobody Wants to Die: Bioethics and the Transformation of Healthcare in America, with current United States Ambassador to Germany and former University of Pennsylvania President Amy Gutmann.

This interview was conducted by Ayotzin Bravo and Avalon Hinchman.

Can you tell us a bit about yourself and your role at Penn?

I got to Penn in 2007. I'm in the Medical Ethics and Health Policy [department] in the medical school and History and Sociology of Science [department] in the School of Arts and Sciences. I'm a philosopher by training. I also have a courtesy appointment in philosophy, but I don't consider myself a technical philosopher.

What does bioethics mean to you? And what drew you to the field?

I define bioethics as the study of moral values in medicine and the life sciences. When I got to GW, which is where I started in 1979, what drew me formally was a new "experimental" course in bioethics. I was asked if I would participate and then I really got hooked. Informally, like many people in healthcare, not only bioethics, I had some family experiences that resonated and I started really focusing on bioethics. And I had friends who were already in bioethics, so I had a nodding acquaintance with the field. At the time, I didn't think I would be a "bioethicist," but that's just how life turns out.

How do we decide what is ethical? Who do you think has the power to decide what practices are ethical and how to enforce them in the best way possible?

I should first say that I define bioethics as a departure from traditional medical ethics which was mainly doctor oriented, with expectations about the conduct of physicians. By the late 1960s, you have this sort of gradual emergence of bioethics. To me, the big difference is that the patient's voice gets incorporated into bioethics. This changes the whole chemistry of the physician-patient relationship and modifies the power relation between doctors and patients and families.

Part of the problem here is that there are so many senses in which bioethics operates, in so many different sectors. I tend to take a historical approach. I think of the emergence of research ethics committees, which we now call institutional review boards (IRBs). Gradually, bioethics found its way into required lectures, if not whole courses in medical education, in nursing education, and in other healthcare related fields. And by the early 90s, consensus was seen as the way that entities within bioethics operated. In particular, in hospital ethics committees, which don't have a well defined role. IRBs do. They're a creature of federal law, but hospital ethics committees really define their role in whatever institution they happen to be in. So already there's moral consensus in these small groups.

At the time, we did not look sufficiently, I'll certainly include myself in this, in the background structures of society. The power structures that were recapitulated, whether we like it or not in the hospital setting. I think we're much more aware of that now. The field has changed. Take, for example, the role of immigration officers in the hospital. This was a worry a few years ago that hospital emergency departments will become sites for the identification of undocumented immigrants. I think that is a bioethics issue. That's not an issue that would have been obvious to us, although it should have been in the 1990s.

So now with the evident departure of Roe v. Wade, we're facing a whole other set of challenges for the field. Bioethics has really presupposed access to abortion in a way that enabled people in bioethics to avoid the sort of the core moral issue about abortion and access and focus instead on high tech issues around in vitro fertilization, surrogate motherhood, and the moral status of human embryos. That is very likely to change now, and people in bioethics will have to be much more involved in questions about access because it looks as though a right based on constitutional interpretation is going to be lost, at least at the federal level. There's no doubt that, as an institution, bioethics has had to become more aware of institutional structures.

In the relevant paper, they propose a shift towards the community leaders and a detachment from academia of the bioethics field as a whole. How do you think community leaders are currently involved in bioethics? What's the current role in bioethics as it is now?

One way in which community input is included in IRBs and hospital ethics committees, is that these entities, particularly IRBs, as a matter of law, are supposed to have community representatives, people who can represent the values of the community. The problem in many cases, is that the community member is themselves from a specific situation. The spouse of a doctor in the hospital, for example. This does get to the more general question that troubled me back in the early 90s about whose values are represented in bioethics. Even if the values are identical, whose voice helps to frame the way those values are articulated?

There are some other areas in which attempts are made to satisfy that goal, such as democratic deliberation. You know, it's a labor intensive and time intensive and, frankly, capital intensive process to do this. So, unfortunately, often it comes down to whose ox is being gored, as the old saying goes. Who's going to pay for this? Who's going to take time to do this? Who benefits from this process? Also, how do you identify the participants in a process? For example, if you're doing a study that involves randomization in the emergency department in a hospital, you're supposed to do what's called community consultation. Now, what is that? You go to churches and civic organizations and you could make a special announcement to say we want you to know that this study is going on for [this certain community]. But, there's room for a great deal of disagreement about how you find the people who are really representative of the community. And what even is the community?

We are now a society that is deeply divided. So who decides? Which community? In the early 1960s during the beginning of kidney dialysis, there were not enough dialysis machines to go around. At Swedish Hospital in Seattle, a group of people from the community in Seattle were brought together to decide basically who lives and who dies. They would go into the hospital conference room, and there'd be a pile of folders with materials about individuals who had end stage kidney disease and they had to decide who got on the machine. And what they found was that people who met certain middle class standards, the vice president of the bank with three kids, got on the machine. You can well imagine the person with no fixed address, who showed up in the ER repeatedly and was hostile to the caregivers and so forth didn't. So they kind of imploded around this because they realized that their values were leading them to certain kinds of allocation decisions. This is a hard problem. And it is something that people have tried to address, but it's tough.

The footnote to that. Before Roe v. Wade, in places like California, different hospitals had abortion selection committees, which made decisions about who got abortions and who didn't. You could have hospitals within a few miles of each other making very different decisions. We are at risk of falling back into that situation. Maybe as many as 26 states in which abortion is essentially illegal, which doesn't mean it won't happen. But even within those states, there will be district attorneys who will decide to follow up on allegations of abortion, and some that will not. Each state will be a patchwork very much like the pre-Roe v. Wade situation. And again, those are community values. The Catholic hospital in a community in California takes one position and the non-religiously affiliated hospital a few miles away, takes another position.

Would you agree that the inclusion of community members beliefs and their opinions can at times end up hindering the medical process?

I don't know if I'd say it hinders it. Medical students are taught to be culturally sensitive. I'm not an authority on how well that works. I was really involved in clinical ethics, when I worked at a hospital in Brooklyn, in the 90s. I used to do a monthly case conference with people in family medicine and people in family medicine have to be aware of the cultural setting of their patients. Otherwise, they're just not effective. My old friend Jay Katz, who died 12 years ago, was a psychiatrist at Yale Law School. He wrote a book called The Silent World of Doctor and Patient in which he said, historically, there's been guerrilla warfare between doctors and patients. Patients want to be fixed. The doctors tell them to do this, and then patients maybe do it and maybe they don't. In Brooklyn, you had people who would go to their traditional healer in the morning and their scientific doctor in the afternoon. The doctor in the afternoon needed to know what their traditional healer had prescribed them because there could be medication interaction. So, there are some areas of medicine that are probably more accustomed to this than others. Frankly, for surgeons, it's not so much of an issue, but for people in primary care, it is very much an issue.

Do you think relocating bioethics in the community could help to address medical mistrust?

Yeah, I mean, we've just come out of this period in which the inequities in health care have been so pronounced. Such as allocation issues in hospitals during the beginning of the pandemic before people understood what the problems were in the respiratory system and how to use ventilators and how to avoid using ventilators. A problem has been the mistrust of the medical establishment, largely the white medical establishment, by minority communities. This is something that I've experienced for decades and as an old white guy, I have limited credibility to address this, but here I am. What happened the last two years is that, I think in some cases very effectively, clergy have been involved in trying to break this down and encourage people to be vaccinated. It's very interesting that if you look at the data on the anti vaccination movement and on people who are vaccine hesitant, it tends to be from higher SES zip codes. This is true in the US, it's also true in the UK. So, you know, why people reach certain conclusions about what they don't trust in medical systems can vary a lot and that means that the solutions have to vary in the case of communities of color. It appears to me, although I'm not a social scientist, that there has been some progress. A problem in the beginning of the pandemic was that access to vaccination was also perceived to be a problem in terms of where the sites were located. So, I think there's more sensitivity to that as well. But as I said, the medical system is not immune to the unfairness of the larger society. The scandalous lack of access to health care, in general, is a reflection of that.

In the relevant article, the author writes that the abundance of injustices permitted by bioethics means the field at times operates "as not social reform but social stagnation or even regression." Do you agree with this statement?

No, I think bioethics essentially started as a social reform movement in which the patient's voice was a matter of advocacy and I don't think people really realized that at the time. And then, the first federal government commission in bioethics was the National Commission in the 70s. There is no doubt though that, like any other social movement including academic movements, bioethics has become a kind of establishment.

I think one area in which bioethics has failed is the environmental movement. The word bioethics was actually coined by a University of Wisconsin scientist named Van Rensselaer Potter in the late 60s to refer to what we would today call environmental ethics. In the larger sense, and I wrote about this after Katrina, when, again, inequalities were so gross, were so obvious in the people who were left behind in New Orleans, we have failed to appreciate the larger structures of inequality.

There has been a tendency in bioethics to focus on pretty wonky topics like embryonic stem cell biology, which doesn't affect very many people, and I will include myself in that criticism. But I do think coming out of the pandemic, the economic consequences, and I would say the loss of Roe v. Wade is going to shake up the field. I also think the war is shaking up the field, or should, because bioethics is a product of an international rules-based order, starting with the Nuremberg Code, that has been presupposed. If that international rules-based order goes, then the field is in a new situation, it's bioethics 2.0. So, again, how do you actually implement a kind of bioethics in which the community has voices that are systematically engaged? That is, in a way, an organizational issue that the field has not faced, and again, sadly, we're in a world in which we have to look at what the rewards will be for doing that. Whose ox will be gored one way or the other.

Is there merit to focusing on these "quirky" topics when we have yet to answer some of the more fundamental questions in bioethics?

I think quirky, elite, esoteric topics like neuroethics and the implications of CRISPR and related technologies are still important questions. In the late 60s, early 70s, the implications of the new genetic technologies that people could see just over the horizon, that was an agenda item. One question for the field is whether the emphasis on the lead committees and institutions, and I will add, governmental federal advisory commissions, has to be shifted in ways that involve more grassroots democratic deliberation. But, I will say that the simple invocation of the notion of community is not necessarily going to do the job because you're still faced with the problem of who is the community and who represents the community? For example, in the early 90s, I sat on an ethics committee for the medical society in New York and there was a meeting that involved what's called harm reduction. The notion of harm reduction, which was pioneered, to a great extent by people at Montefiore Medical Center in the Bronx, was that people who are sharing needles, and this is the HIV era, need to be given needles because they're gonna die from sharing dirty needles. A couple of white men from Montefiore who came to that meeting explained this concept of harm reduction and two senior Black physicians from Harlem, both men, were not comfortable with this idea. Why? Because from their point of view, and this will sound really antique, any indication to their community that drug use was acceptable would send a bad message. So you see what I'm getting at? You don't always get the response from the community that you may expect. Now, did these physicians represent West Harlem? Well, I don't know. I'm not a Black man. And I'm not a Black man who's practicing medicine around 125th Street in West Harlem. It's so hard to know, as well intended as you might be, what counts as the community and you may get answers that you don't like, or that you certainly don't expect.

Do you think academics can address these problems? What problems do academics face when trying to solve them?

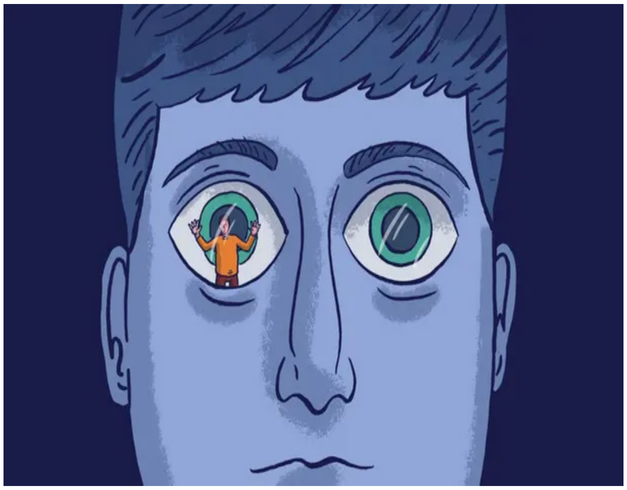
My experience with people in bioethics, first of all, there are more people of color in bioethics than there were 20 years ago. As a matter of fact, a graduate student who just finished his PhD, is working on race theory and ethics in neuroscience.

It's a small world, maybe too small, but this is part of the problem. By and large people in bioethics are very well intended people and they will listen. They will read papers like the one in PBJ and they'll say this author has a good point. So by and large, I would say, people in the field will listen and people in the field by and large will agree it's an elite business. Just think about having the opportunity to study bioethics at Penn. You're already in an elite group like it or not. So you go back to the communities and figure out what your connection is to those communities, and how to bring those folks in.

Bioethics-in-Brief

A Look into the Perspective of Locked-In Syndrome Patients

Natalie Nari Kim



Locked-in syndrome is a rare condition in which affected patients are cognitively aware and consciously alert but unable to move or speak due to damage to the pons, an area of the brainstem responsible for delivery of information to other cerebral areas through nerve fibers (NORD 2018). As a result, patients are unable to perform any movements besides those related to the eyes, including those vital to carrying out life functions—such as breathing and swallowing (NORD 2018). Due to this, questions have been posed and debates risen from ethical concerns regarding the quality of life these patients may face. These include prominent ethical issues that arise from the decision regarding the administration of life-sustaining treatment as well as surrogate decision-making where the physicians are advised to respect decisions made by family members or guardians on behalf of the patient (Abbott and Peck 2016).

Much of the focus and interest surrounding locked-in syndrome patients is due to concerns regarding the patients' quality of life that result in questions regarding the continued extension and prolongation of their lives for those in severe cases. However, in contrast to popular belief, the miraculous recovery of a woman who recently recovered from locked in syndrome can shed light on this issue and show others the importance of perseverance, trust, and belief. This area can be further explored by taking a deeper look into the perspective of the woman as she discusses her long journey to recovery, a rare feat that can not be easily accomplished and should not be easily overlooked (Curran 2021). By delving into the story of the woman on her arduous road to recovery, a new perspective is provided into the mindset and complex emotions expressed by locked-in syndrome patients to better serve as another form of insight for physicians and others to assist with difficult decisions or when dealing with ethical concerns.

While some argue that there are many patients that are able to overcome the posed obstacles and go on to live satisfactory and meaningful lives even with this condition such as the aforementioned case, others argue that patients and close family members face a significant burden along with possible financial hardships from continuous treatment. One such treatment includes the implementation of brain-computer interfaces (BCI) integrated with an alphabet system that have served as a form of communication between patients and health care professionals or loved ones (Abbott and Peck 2016). Unfortunately, it is often argued that it is the right of the patient to choose whether to continue to receive the BCI and communicate with others, or not, if deemed to be able to make medical decisions independently. Those among locked-in syndrome patients with complete paralysis of muscles are more likely to rely on BCI to communicate unlike others with limited amounts of voluntary muscle control, but this is not something that can be enforced by others as a patient can choose not to continue with the BCI treatment. Regardless of the belief of the physicians or close family/guardians of the patient that have deemed them unlikely to make the call, physicians should respect the wishes of the patient.

BCI has been used as a form of communication and served as an intermediary between a locked-in syndrome patient and surrounding loved ones through electrodes implanted in the individuals that allow the conversion of the neural signals into messages. Unfortunately, ethical issues are raised over the initiation of BCI research in locked-in syndrome patients as some have argued that it may not be morally right to "conduct communication research with individuals who are locked in or may become locked in" (Klein, et. al 2018). This poses ethical concerns as it is relying on the presumption that those with locked-in syndrome are all living a poor quality of life although there may be some that are not and those that believe they are making the best of their situation and are trying to find ways to live rewarding lives. Not only this, but the implementation of BCI in patients have weakened the principle and exercise of autonomy as patients should be able to decide whether to have it, as well as may result in a violation of basic human rights (Klein, et. al 2018). This is because there are patients that may not wish to have the BCI but may be unable to communicate their wish for not having one or may be having it forced on to them against their will by surrogates or guardians making decisions who believe them to be acting on behalf of their best interests.

Expanding upon this idea of patient autonomy, physicians are obligated to comply with the wishes of patients, even if they wish to no longer prolong their life and request practices to terminate their life early such as euthanasia. According to the American Academy of Neurology, physicians should honor the wishes of their patients and "they should be allowed to die if they are competent, are fully informed of their prognosis, [and] have not been coerced" (Abbott and Peck 2016). Regardless of the wishes of loved ones, or decision-making of surrogates, or even the beliefs of the physicians, the desires of the patient should be valued and prioritized above all. As long as the patient has been deemed to be psychologically stable and cognitively able to make independent decisions, the patient deserves to have their opinions heard and respected.

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A Growing Concern: Adverse Reactions Related to COVID-19 Vaccinations

Michael Proano

Going back to November of 2020, AstraZeneca's clinical trials of the COVID-19 vaccine were in full swing. After Brianne Dresson, one of the participants in the trials, received her dose of the vaccine, she began feeling a tingling sensation in her arm, followed by fever and chills. As time went on, Dresson lost most sensation in her arm, in addition to becoming very sensitive to light and sound. Once she reached the emergency room, the numbness had taken over her entire lower body, essentially paralyzing her. In her recovery process, Dresson sought out relief from doctors, who she claims to have neglected her experience, denying any possible ties to the vaccine. Dresson's story, though rare, is representative of a body of individuals who feel distraught and ignored by the medical community, unable to get recognition for what appear to be very extreme adverse side effects related to the COVID-19 vaccine (Broader 2022).

Most commonly, those who report adverse reactions to the vaccine experience either myopericarditis, a condition resulting in inflammation of the heart muscle, or neurological symptoms, both of which are said to be the result of a hyper-active immune response to the vaccine. However, these conditions are also observed with roughly the same frequency in those that are infected with the COVID-19 virus itself. A meta-analysis conducted by The Lancet Respiratory Medicine suggests that heart inflammation rates are equivalent between the COVID-19 vaccine and other vaccines. "Our research suggests that the overall risk of myopericarditis appears to be no different for this newly approved group of vaccines against other diseases," said Dr. Kollengode Ramanthan, cardiologist at the National University of Singapore. Moreover, the researchers found that the rates of myopericarditis had not increased from before the pandemic to after the rollout of the vaccines (Shukla 2022). Typically, myopericarditis resolves itself in a short period of time. There are few cases, however, where the condition is fatal. The researchers also determined that the incidence of myopericarditis was three times higher in mRNA vaccines as opposed to non-mRNA vaccines. Dr. Margaret Ryan of the University of California San Diego commented on the findings, saying, "Analyses of the pathology and immunological mechanisms behind these demographic-dependent adverse events following vaccination are likely to advance our understanding of cardiology and immunology. These advances could spur the development of safer vaccines or precision vaccination practices" (Shukla 2022).

Some individuals experiencing complications after receiving the COVID-19 vaccine state that doctors are hesitant to address any mentions of "adverse effects" to prevent the spread of misinformation. The vaccine itself has become highly politicized since its rollout, leading many to fear bringing attention to these graphic circumstances. For one, Facebook has flagged any group discussions of extreme vaccine side-effects as misinformation, frustrating individuals such as Dresson, who says, "From top down, we are not allowed to be heard in any way, shape or form… Our lives are not misinformation" (Broader 2022).

At the beginning of May, the FDA placed heavy restrictions on the Johnson & Johnson vaccine, limiting its use to those who otherwise would not get vaccinated or for whom other vaccines are unavailable. The reason for this change is a significant risk of developing thrombosis with thrombocytopenia syndrome (TTS), a blood clotting condition, which has been linked with the J&J vaccine. According to the FDA, 60 cases of TTS associated with the vaccine have been confirmed so far, with about 15% of these cases being fatal. "Today's action demonstrates the robustness of our safety surveillance systems and our commitment to ensuring that science and data guide our actions," said Dr. Peter Marks, director of the FDA's Center for Biologics Evaluation and Research, in a statement. To date, there have been roughly 19 million doses of the J&J vaccine administered in the US. The firm has addressed publicly the concerns surrounding these adverse effects, saying, "We are aware of an extremely rare disorder involving people with blood clots in combination with low platelets in a small number of individuals who have received our COVID-19 vaccine…We have been working closely with medical experts and health authorities, and we strongly support the open communication of this information to healthcare professionals and the public" (Dillinger 2022).

The FDA also reported that the COVID-19 vaccine developed by Johnson & Johnson has a slight chance of causing Guillain-Barre syndrome (GBS), a disorder wherein the immune system attacks nerves surrounding the brain and spinal cord, causing paralysis. As of March this year, over 40,000 reports of neurological symptoms developed after receiving the COVID-19 vaccine had been logged in the Vaccine Adverse Events Reporting System (VAERS). Although the system, controlled by the CDC and FDA, is a passive reporting database and contains some unverified entries, these are still worthwhile cases to consider. Still, according to scientific authors in the U.K., the neurological effects of COVID-19 are said to be equally if not more prevalent than those associated with the vaccine. The authors found that cases of GBS, along with other debilitating and inflammatory disorders, were more common on average in cases of COVID-19 infection when compared to vaccinations (Broader 2022).

The questions and concerns surrounding the adverse reactions highlight the underlying ethics of the vaccine rollout and mandate. During the initial distribution of the vaccines in 2021, Dr. Aaron Kheriaty sued the UC Board of Regents for a violation of the equal protection clause of the 14th Amendment. Kheriaty, director of the medical ethics program at UC Irvine, claimed that his COVID-19 infection in July granted him better immunity than the vaccines, advocating for the same exemptions for other individuals with previous infections. Kheriaty claims that the "one-size-fits-all coercive policies that attempt to override informed consent for competent adults" pose a danger for individuals susceptible to severe side effects of the vaccine. Kheriaty says he went to court for this issue not only for his personal defiance, but also for those "who were not in a position to stand up and assert their rights," including those who "don't have the credibility that comes with being a physician or a directorship title at the hospital" (Grant 2021). Regardless of how these concerns are handled at a public level, there remains decades of research ahead to evaluate the true effects of both the vaccines and COVID-19 itself, both of which came upon the world in a very unprecedented manner, forcing individuals and powerful agencies to make decisions that may very well have repercussions lasting a lifetime.

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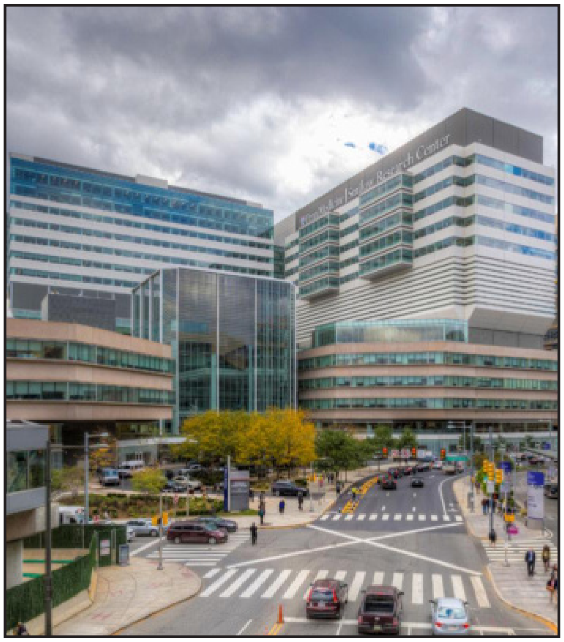

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