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Information and Ignorance

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Content

Letter from the Editors

Dear Readers,

It is our pleasure to present Volume XVII, Issue i of the Penn Bioethics Journal, titled "Information and Ignorance." It is one of our broadest issues yet, but also one of the most reflective—the articles and news briefs echo each other, creating an incisive conversation that carves out some of the defining topics across the modern bioethical spectrum. They survey the consequences of new information to old research guidelines and clinical models, as well as the impact of ignorance on an individual, familial, and public level.

We begin with a series of four news briefs that cut across the technological, clinical, and social dimensions of bioethics and lay the groundwork for what is to come in the rest of the issue. Proano's article explores brain-computer interfaces (BCIs), including the corporate hype distilled in Elon Musk's Neuralink and the bioethicists that caution against its promises. Proano lifts the sensationalist curtain and focuses on the patients that stand to benefit from targeted BCIs—those with movement disorders and brain injuries that impair their ability to interact with the world. Kim's article takes a closer look at the hopes and fears surrounding BCI development for one such disorder, locked-in syndrome (LIS), in which patients are awake and conscious but unable to make voluntary movements. Bravo's article zooms out to examine how bioethics and health policy can protect the rights of transgender people and maximize their access to healthcare. Lastly, Chenna evaluates the emerging topic of vaccine passports through the bioethical arguments both for and against their use.

Our first article titled "Brain-Computer Interfaces for Communication in Locked-In Patients" by Justin Chu maps onto the overview of BCIs by Proano and Kim, and provides a more in-depth summary of BCI development for LIS. Chu investigates the ethical concerns that arise within this endeavor including long-term effects, issues of identity and agency, and stigma.

The second article titled "Ethical Considerations in The Role of Psychologists in the Pursual of Sex Reassignment Surgery" by Drewcila Noble is an answer to Bravo's incitement. Noble challenges the established psychological standards that must be met for a transgender person to pursue sex reassignment surgery (SRS), arguing that this "psychologists as gatekeepers" model creates barriers to care access that are based on dated and discriminatory evidence.

Finally, Juliana Qin's article, titled "Defending a Limited Right to Genetic Ignorance," outlines the specific conditions that should be met for genetic ignorance, or the right to deny genetic information about oneself, to be ethically permissible. Qin then translates these circumstances into a decision-making framework for patients to exercise this right to genetic ignorance. While genetic ignorance may appear a stand-alone topic, its implications for families with heritable disorders evokes the same conflict between an individual's rights over their own health information and the welfare of others playing out in Chenna's brief.

We would like to extend our thanks to authors and editors for their ideas, engagement, and dedication, and to the readers of the Penn Bioethics Journal for their continued support. Please contact us with any questions, comments, or ideas for collaboration at pbjeditorinchief@gmail.com.

Millie Huang and Jordan Liu
Editors-in-Chief

Bioethics-in-Brief

Brain-Machine Interfaces: A Vital Cure or Pandora's Box?

Michael Proano

The emerging field of neurotechnology promises unforseen solutions to widespread disorders such as Parkinson's, locked-in syndrome, and even blindness. Neurotechnologies such as brain-machine interfaces (BMIs) have the potential to grant immediate connection with devices for consumers of neurotech in the future. But for most, the anticipation of such a breakthrough technology brings as much fear as it does wonder. As such, ethicists from all sides of the topic have something to say about BMIs, and more specifically about Neuralink: the most prominent neurotechnology company developing BMIs, co-founded by Elon Musk.

Much of the public perceives brain-machine interfaces as futuristic devices used to interconnect people with their smartphones or other technology. In actuality, BMIs are already used in medical practice to treat disorders such as Parkinson's Disease, a disorder of the central nervous system causing tremors and diminished motor function. Wearable BMIs are also being developed for patients with locked-in syndrome, a disease characterized by the complete paralysis of voluntary muscles, which can avert much of the difficulties posed by invasive surgery. Recently, researchers at Columbia University have managed to control the intended movements of mice after recording neural activity from mice performing the action. Other studies have shown it possible to transmit learned tasks and memories between rodents (Gil).

Many of the barriers to advancing neurotechnology at the moment are born out of ethical and medical concerns. In order to build functional BMIs, scientists first need a proper understanding of how action potentials and electrical impulses are sent across the nervous system, and to do so requires immense intrusion into an individual's brain. Several attempts have been made at researching this neural language, including the BRAIN Initiative in the US along with the Human Brain Project in the EU. However, programs like these are ultimately constrained by principles of autonomy and informed consent, and invasive brain surgeries used to conduct them pose incredible risk for brain damage (Humphries). Taking a look at the tools used to investigate brain activity, namely electrodes or fiber optics, one can see how invasive these methods are. That is why most research in the past and present has been performed on animal subjects such as mice or zebrafish. However, despite the ethical and medical concerns of invasive experimentation and testing, there are currently no cemented regulations for neurotechnology, partly due to its novelty and unpredictability as a frontier in enterprise (Gil).

Elon Musk's Neuralink hopes to record live neural activity through patients that already require substantial medical intervention, including those suffering from paralysis. At first, their goal is to implement BMIs for patients suffering from loss of motor function. They even plan on using their BMIs to alleviate other more widespread disorders including addiction and depression along with other sensory depriments like blindness. However, Neuralink is also looking to "create BMIs that are sufficiently safe and powerful that healthy individuals would want to have them" (Humphries). Very soon, policymakers will have to grapple with letting researchers probe the brain for technological advancement or preserving the organ entirely.

Recently, Neuralink reported that a monkey being tested for BMIs, named Pager, was able to play the game Pong using only its mind to control the panels (Bergan). While innovators have already figured out how to control technology with one's voice, using one's thoughts to dictate messages and interfaces opens the door to a whole new frontier for both patients with locked-in syndrome and general consumers alike. Yet, such an outcome is not all so foreseeable with today's progress; according to Penn professor of medical ethics and health policy, Anna Wexler: "I doubt we will have accurate, mind-reading consumer devices in the near future. Neuroscience is far from understanding how the mind works, much less having the ability to decode it" (Wexler). Neurotechnology also poses the potential of even more harmful instances of hacking, which could completely reverse the intended good BMIs can

provide. Nonetheless, Neuralink continues to advance the development of its technology without much hesitation. Human trials for the microchip implant are planned to take place at the end of 2021, primarily concerning patients with spinal impairments.

What Wexler is most concerned about are the "potentially false claims" coming from Neuralink. She says that "the company's co-founder is fond of making grandiose and bombastic claims about the potential to cure all diseases and allow humans to merge with AI" (Wexler). Cognitive psychologist and philosopher Susan Schneider writes, "Without proper regulations, your innermost thoughts and biometric data could be sold to the highest bidder. People may feel compelled to use brain chips to stay employed in a future in which AI outmodes us in the workplace" (Cao). Even then, such a circumstance poses questions about personal privacy and unconscious thoughts, especially when one's neurodata can be revealed to employers or criminals. Before giving firms such as Neuralink free range to proliferate BMIs, these considerations should be addressed sooner rather than later. Two years prior to her comments, Schneider predicted that Musk's vision would amount to "suicide for the human mind" (Cao). Although BMIs could very well be the solution to debilitating diseases, they are likely to bring about a singularity in human technological progress if not handled properly.

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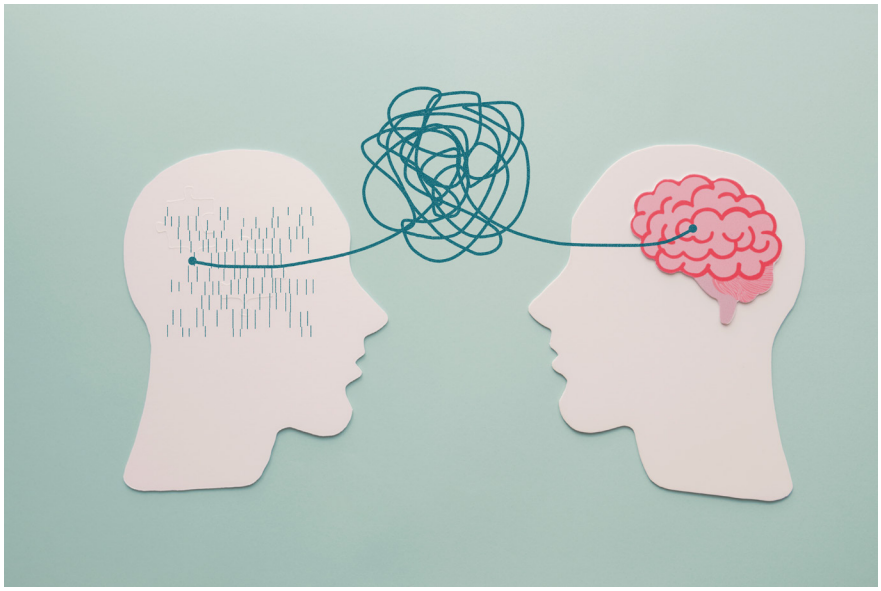
A Look Into the Perspective of Locked-In Syndrome Patients

Nari Natalie 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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Bioethics And Policymaking: Providing Transgender People with the Care they Need

Ayotzin Bravo

Transgender individuals have long faced discrimination. Even in our present-day they must overcome many barriers, not only as it relates to health care, but beyond in their everyday lives. This has been an especially prominent issue in the last decade and has sparked reformation in the US government. However, this change has not always been in the best interests of transgender people and sometimes even policies that appear to superficially benefit them are actually detrimental. On one hand, there is a grave need for regulations to be put in place to protect transgender individuals and prevent further discrimination from taking place, yet there also appears to be a need for the transgender community to be protected from the regulations themselves.

There have been large improvements with regards to the protection of transgender individuals in the workplace but particularly, in health care, they are still facing a lot of obstacles ("What You Should Know: The EEOC and Protections for LGBT Workers."). Bioethics and public policy are two fields that have been a vital part of the transgender discourse which exert great influence over each other ("Public Policy and Bioethics"). A big part of bioethics deals with the ethical obligations that healthcare professionals have to their patients. In contrast, public policy focuses on broader laws that impact society as a whole usually set in place by a government-like entity (Coleman). As seen above, the transgender discourse is an intersection of both of these fields; as we move forward, it is important to prioritize transgender people both as individuals and in the context of society.

Until now, some of the policies put in place have only served to further alienate the transgender community. One such example of this alienation happening outside of health care would be the 71 "'bathroom bills' introduced in various states and localities" whose aim was to restrict bathroom access for transgender people and to criminalize gender nonconforming embodiment (Murib). These bills appear to invalidate the identity of transgender people. Part of this problem stems from the newness of the field of transgender studies, but more importantly the uncertainty found within the medical field with regards to understanding transgender people. However, this problem is inherently tied to health care and bioethics due to the nature of its classification. Being transgender was originally categorized as a mental disorder—among psychologists, there is still uncertainty as to how to classify it. This can be seen from the way that the listing of trangender classification has changed in the Diagnostic and Statistical Manual of Mental Disorders (which psychologists use to diagnose patients) across recent years (Stroumsa). Notwithstanding our lack of medical understanding of transgender people, we have elected to classify them under the umbrella of mental disorder which itself holds connotations to being ill or not healthy. This pathologization, while it does provide diagnostic coding for care, goes on to serve as an excuse for policies such as the bill above, or current regulations with regards to gender-confirming surgery—often referred to as sex reassignment surgery (SRS) (Stroumsa). Even worse, recent research shows that these policies disproportionately affect the medical care of transgender people of color (Goldenberg).

Transgender people have a need for medical care just like anyone else, nevertheless, it is necessary to understand that their needs may be different from that of the majority of the population. It is necessary to develop proper jargon to describe their situation, however, given the lack of knowledge available to physicians, whom policymakers depend on to help guide their policies, it is a lot harder for policies to be correct the first time around. Considering these limitations, it is best to steer away from making further regulations with respect to trasngender individuals and to modify the current ones so that they emphasize flexibility and delegate more decision-making to the physician that knows each patient better. Although we have made some progress in the last few decades towards the acceptance of transgender people, we are still far off from creating ethical policies that serve to protect the rights of transgender individuals and it is of upmost importance that we strive to minimize stigmatization and maximimize the access to health care offered to transgender individuals. While we wait for medicine to gain a better understanding of transgender individuals, the responsibility falls beyond physicians and into the rest of society to destigmatize the transgender community. This will create more inclusive public places that are more welcoming to transgender people, allowing them to seek the medical care they need.

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Enforcing Vaccine Passports in the Era of COVID-19

Srish Chenna

As we cross the one billion mark for vaccines administered worldwide, lawmakers are now thinking about implementing vaccine passports. By definition, vaccine passports certify the number of vaccine doses received, validating the bearer's protection against COVID-19 and allowing participation in otherwise restricted activity (Immunity Passports 2020).

Multiple countries, like the UK and the United States, have been considering their use, with countries like Israel and Australia putting them in effect already (Brown et al. 2021; Hall and Studdert 2021). Israel's green pass, for example, allows less restricted entry into public facilities like gyms. However, there is constant bioethical debate surrounding enforcing their use.

Some scholars argue against the use of vaccination passports due to concerns about widening current health inequalities,
the danger of infringing upon personal autonomy, and the lack of scientific research supporting long-term immunity.

On socioeconomic lines, more than 75% of vaccines so far have been sold to the world's richest countries (Community 2021). On racial lines in the United States, the percent of White people who have received at least one dose (38%) is approximately 1.5 times higher than the percent of Black people (24%) and percent of Hispanic people (25%) (Pham et al. 2021).

Mandating a vaccine passport reinforces health disparities by providing greater freedom to vaccinated persons, which tend to be richer and, more likely, White. Unless vaccines become equally accessible to everyone, mandating the use of vaccine passports puts the unvaccinated at a medical disadvantage, compromising the bioethical principle of justice.

Another compelling bioethical argument incorporates the principle of personal autonomy. Using vaccine passports can easily threaten the personal liberties of the unvaccinated by limiting movement and travel.

One of bioethics' core arguments lies in the subject's will to participate in an activity and make informed decisions; the principle of least infringement warns against establishing policies that violate these civic rights (Voo et al. 2021).

Lastly, a more objective case against vaccine passports is the lack of scientific re-

search studying the longevity of immunity (Memish et al. 2021). Intensive studies are also needed to analyze how effectively the vaccines protect against rising variants. The rapid emergence of future strains could undermine the vaccine's protection, which takes away from the purpose of having a vaccine passport and proving one's immunity to others (Siqueira et al. 2021).

However, even though studies have not carefully assessed how long vaccine immunity lasts, there is sufficient evidence to prove that the risk of severe disease is significantly lower, so vaccine passports could still be useful (Doremalen et al. 2020; Gao et al. 2020).

Scholars further use the bioethical principles of nonmaleficence and justice to argue for the use of vaccine passports. They also cite economic advantages and the eventual emergence of some type of immunity passports in private-public sectors to complement their claims.

The principle of nonmaleficence requires that we don't pose an unintentional threat to others (McCormick 2018). Knowing that there are chances of virus transmission to an unvaccinated person, a vaccinated subject can avoid any interaction and not put them at risk. Thus, establishing vaccine passports demonstrates that accidental harm can be prevented.

On a similar note, the principle of justice supports vaccine passport use for vaccinated citizens. It is unethical to cage persons who are protected and restrict them from their daily lives when they pose minimal to no health risks to others (Brown et al. 2021).

An economic reason behind the use of vaccine passports is the rehabilitation of the struggling tourism economies. Global leisure tourism spending halved in 2020, while business tourism spending dropped by 60% (Statista 2021). As vaccinations jump every day, enforcing vaccine passports could allow the economy to improve as traveling restrictions will ease for the vaccinated. It will also allow the vaccinated to travel with less associated social stigma (Memish et al. 2021).

Lastly, academics believe that the rising number of vaccinations will eventually bring about some sort of immunity passports in the private-public field, such as travel, that will then spread to other recreational sectors like sports (Hall and Studdert 2021). Hence, it's to the government's advantage to take the reins now, agree on standards of establishing immunity and implement just policies for all sectors before different standards come about.

Another crucial argument either for or against the use of vaccine passports is that mandating passports for certain leisure activities would mandate vaccination. On the one hand, it could incentivize getting vaccinated, but some may perceive the requirement as an attack on their autonomy. This topic warrants further discussion on its own.

The motivation behind a vaccine passport is to strike a balance between participating in socially valuable activities and health safety. In the end, there must be a compromise. If there's anything that 2020 has taught us, it's the importance of rapid adaptability and working together.

Establishing vaccine passports might be a controversial topic, but the goal is the same: returning to a sense of normalcy. The only hurdle is to do so with breaching the least number of interests possible.

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Article

A Voice for the Voiceless: Brain-Computer Interfaces for Communication in Locked-In Patients

Justin Chu*

Brain-computer interfaces (BCIs) are a class of technologies that acquire brain signals and translate them into commands for devices that interact with the environment. One prominent medical research area has been the use of BCIs to restore an avenue for communication in patients with locked in syndrome (LIS), an advanced disease condition that describes a loss of voluntary motor function. Although promising research has been conducted in this area, the unique situation of LIS patients and the novel nature of BCI technology require special ethical guidelines to be established concerning the physical, existential, and social domains of the human research subjects in BCI studies. Noted areas of concern in BCI research include the uncertain response of the brain to long-term electrode implantation, the barriers to obtaining informed consent from patients with limited communication, issues of identity and agency with human thought-action circuits being mediated by a computer, and concerns about the stigma that patients using BCIs might face. In surveying the state of BCI research, BCIs possess a clear potential for improving the quality of life and autonomy of LIS patients. Researchers, however, must remain cognizant of the specific ethical challenges posed by BCIs in achieving the goal of communication for LIS patients.

Introduction

In August 2020, Elon Musk made headlines when his company, Neuralink, unveiled a functional computer implant in the brain of a pig (The Economist 2020). While this revelation placed brain-computer interfaces (BCIs) in the public eye, research and development of such implantable technologies have been going on for decades (Kübler 2020; Shih, Krusienski, and Wolpaw 2012). BCIs have a wide range of potential applications, but much medically based research has focused on the restoration of communication for patients with locked-in syndrome (LIS), a condition involving paralysis of skeletal muscles with retained cognitive function (M Das, Anosike, and Asuncion 2020). This paper will examine how researchers can ethically develop and study BCIs for communication for LIS patients.

Although ethical principles and boundaries in research became well established in the aftermath of World War II, the condition of patients with LIS and the novelty of the technology used in BCIs present unique ethical challenges in the development of such devices. Patients with very advanced stages of LIS, labeled total or complete locked-in syndrome (CLIS), cannot even control the movement of their eyes. This means that obtaining informed consent from subjects eligible for BCI research presents a special challenge, even apart from the development of the BCI technology itself (Abbott and Peck 2017). While current ethical guidelines are useful in the development of new technologies, the unique challenges of BCI research, especially for patients with LIS, require special ethical consideration. Failing to examine the distinct ethical hurdles of BCI technology risks a dual challenge to BCI development. The first is the halting of BCI research because of unclear ethical guidelines. The second, more likely challenge is the proceeding of BCI research without proper regard for the ethical concerns specific to the BCI research subject.

The unique situation of LIS patients and the novel nature of BCI technology warrant special ethical consideration of LIS patients as human subjects in BCI research. LIS patients lack the ease of communication by which to express their wishes despite having full cognitive function, while BCIs are integrated into the patient's thought-action processing in a way undescribed by any other machine. Additionally, the existing understanding of patient/subject culpability appears insufficient to handle the interaction of machine and cognition happening in BCIs. Thus, special ethical considerations specific to the development of BCIs should occur in three domains: the patient's physical, existential, and social domains. The special considerations highlighted here are not intended to define the entire scope and methods of BCI research. Rather these reflections are intended to guide researchers through some of the major ethical areas of particular significance to the research and development of BCI applications for LIS patients.

Overview of Brain Computer Interface Systems

A basic understanding of BCIs, their potential applications, and the current state of BCI research is necessary to the development of ethical research guidelines. BCIs, also known as brain-machine interfaces (BMIs), can be defined to include a large category of technologies. Shih et al. define a BCI as a "computer-based system that acquires brain signals, analyzes them, and translates them into commands that are relayed to an output device to carry out a desired action" (Shih, Krusienski, and Wolpaw 2012). This definition has two aspects of note. First, it limits BCIs to devices that use signals from the central nervous system, rather than alternative signals such as only eye movement. Second, there is a required output function of the BCI that acts on the subject's environment.

Shih et al. describe the four general components of a

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BCI system to be (1) signal acquisition, (2) feature extraction, (3) feature translation, and (4) device output (Shih, Krusienski, and Wolpaw 2012). Electrodes placed on the scalp, on the brain (subdurally or epidurally), or in the brain (intracortically) acquire electrical signals from the brain. The signals are then digitized, and the computer processes and extracts relevant signals from irrelevant background "noise." The signals are translated into commands for an output device, which also provides feedback to the subject, allowing for adjustment of the brain signals (Shih, Krusienski, and Wolpaw 2012).

Potential Applications of Brain Computer Interface Systems

As a novel research area, BCIs command a broad field of potential application. Much of the research has gravitated towards the potential medical applications of BCIs, including stroke rehabilitation; the restoration of limb function in tetraplegics or limb amputees; and the restoration of communication, senses, and cognitive function (Slutzky 2019). In addition to medical treatments, BCIs may be employed in the prevention or early detection of disease conditions (Mudgal et al. 2020). Researchers have also recognized the impact that BCIs could have on advancing the scientific understanding of neurological function. Such scientific investigation could include neurological signal stability, neural control of movement, motor learning, and the effects of BCIs on an individual's motor system (Slutzky 2019).

More broadly, applications for BCIs have been describe for use in smart environments, entertainment and games, and the military (Kotchetkov et al. 2010; Mudgal et al. 2020). The research arm of the United States Department of Defense, DARPA, has heavily invested in projects that use BCIs to allow for speechless communication ("Silent Talk") , control of heavy machinery and vehicles, visual interfaces with an enhanced field of vision, and remote interaction with an environment (telepresence) (Kotchetkov et al. 2010). A full ethical assessment of all these applications is beyond the scope of this paper. However, the nature of many military (and nonmilitary) applications of BCIs as arguable enhancements of human function, rather than treatments of dysfunction, engenders some serious ethical concern.

Among the potential applications of BCI research, particularly promising is the potential to restore communication in patients with LIS. Locked-in syndrome (LIS) describes a loss of voluntary motor function with the retention of consciousness and awareness (M Das, Anosike, and Asuncion 2020). LIS is differentiated from unresponsive wakefulness syndrome (UWS, also known as persistent vegetative state, or PVS) because EEG signals can show consciousness in LIS patients, whereas patients with UWS are not aware or conscious (Abbott and Peck 2017). LIS is categorized as classical, incomplete, or complete (M Das, Anosike, and Asuncion 2020). Patients with classical LIS retain some eye movements despite being totally immobile, and patients with incomplete LIS retain minor voluntary control of motor function. Patients with complete LIS are totally immobile and have lost voluntary control of eye movements, despite being aware and conscious. This paper will focus on patients with classical LIS (denoted LIS) and complete LIS (CLIS). LIS will be used generally to include patients with LIS and CLIS. CLIS will be used to indicate special consideration for patients with complete locked-in syndrome.

Some commonly cited causes of LIS include traumatic brain injury, ischemic stroke, and nerve demyelination (M Das, Anosike, and Asuncion 2020). Within the last category, amyotrophic lateral sclerosis (ALS) is frequently cited in the literature on LIS and BCIs (Klein, Peters, and Higger 2018). ALS, also known as Lou Gehrig's disease, is a progressive neuropathy involving the axon degeneration of motor neurons, leading to paralysis and death (Brotman et al. 2020). There is no cure for ALS. A major promise for BCI research in LIS patients is to restore an avenue of communication for those who have little to no ability to communicate with others despite being fully aware and conscious (Klein, Peters, and Higger 2018; Slutzky 2019). Providing such an opportunity for communication could help to promote the autonomy and quality of life of patients with LIS (Abbott and Peck 2017; Klein, Peters, and Higger 2018).

Current State of Brain Computer Interface Research

Although the literature has recorded rapid advances in BCI technology over the past few decades, additional challenges for clinical applications remain (Choi et al. 2018; Miller, Hermes, and Staff 2020; Rashid et al. 2020). Much of the development in BCI devices is based on the method of signal acquisition. The three most prominently utilized signal acquisition modalities are EEG, electrocorticography (ECoG), and intracortical electrodes (Miller, Hermes, and Staff 2020). These three types of signal acquisition systems differ in their invasiveness to the subject. While EEGs are placed on the scalp as noninvasive collectors of brain signals, ECoG electrodes are placed on the brain, either subdurally or epidurally, and intracortical electrodes are placed within the brain tissue itself (Shih, Krusienski, and Wolpaw 2012).

EEGs have been extensively utilized in BCIs because they are noninvasive (Choi et al. 2018).

Nevertheless, the inferior signal quality of EEGs compared to ECoGs and intracortical electrodes has driven an increased interest in more invasive technology. The Utah Array, for example, is an intracortical BCI that has been FDA-approved for clinical research (Choi et al. 2018). Furthermore, Choi et al. highlight ECoG-based BCIs as holding increased potential in clinical applications because they balance the benefits of an intracortical electrode's quality signal without causing as much damage to the cortical tissue (Choi et al. 2018). As much of the technology used in ECoG BCIs has already been utilized in patients with epilepsy, researchers incorporating this technology into their studies also have the benefit of prior information about procedural risks and side effects of the technology (M. Vansteensel, Pels, and Bleichner 2016). Overall, one can already identify many studies researching both novel and refocused systems in healthy and affected animals and humans (see, e.g., Miller, Hermes, and Staff 2020). Research specifically involving patients with LIS and CLIS, however, remains a largely exploratory field (Kübler 2020).

Physical Concerns for the Human Subject

Although BCI research continues to advance, there are numerous ethical concerns regarding the unique physical challenges to the human subjects of this research. Physical concerns include general risks of surgery and implanted technology. Implanted technology can cause infections or damage to the surrounding tissue (Burwell, Sample, and Racine 2017; Klein 2016). Electrodes can corrode and lose their function over time. There is also evidence that stimulation from BCIs can cause the brain to rewire itself and disrupt local neurophysiology (Klein 2016). As Choi et al. note, ECoGs and other emerging technology for minimally invasive neurological signal acquisition can reduce some of these risks, but their development must be balanced with the need to maintain a high-quality signal for the BCI (Choi et al. 2018). Implanted technology, especially if wired to an external device, may cause discomfort to the user. Furthermore, the training needed to use a BCI device effectively can be wearisome to the subject, and researchers often report subject fatigue as a central physical concern for researchers involved in BCI technology (McCullagh et al. 2014).

Concerns for the physical integrity of BCI research subjects center around the ethical principles of beneficence and nonmaleficence. In seeking to maintain the physical integrity of the person's body, researchers will want to attend to the invasiveness of their procedures. As noted previously, EEGs are noninvasive but provide a lower quality signal than ECoG or intracortical electrode systems (Chaudhary, Mrachacz-Kersting, and Birbaumer 2020). Researchers should seek to utilize the minimum necessary invasive technology to achieve the required quality of signal detection. ECoG technology seems promising in this area, as it gathers high-quality signals without requiring direct implantation into the cortical tissue (Choi et al. 2018). Wireless systems have been suggested to increase comfort and decrease infection risk (Choi et al. 2018). However, this comfort must be weighed against the increased security risks of potential unauthorized access to the BCI system. In the case of patients with LIS, movement is already limited, so researchers can identify a means of wire placement that can easily remain in a comfortable location for the patient.

In a case study that demonstrates proper care for an LIS patient, Vansteensel et al. describe the placement of an ECoG BCI system in which fMRI technology was first used to create a 3D rendering of the patient's brain (M. Vansteensel, Pels, and Bleichner 2016). This mapping allowed them to place the electrodes precisely at predetermined locations in the brain. The ECoG system used in this case was already approved for use in patients with epilepsy, thus the research team had pertinent information on infection risk from such equipment. The patient underwent extensive pre-operation assessment, and the researchers provided for the necessary post-operation care. (M. J. Vansteensel et al. 2016)

With regard to user fatigue, researchers ought to provide sufficient training to subjects and caregivers in utilizing and maintaining the technology. The BCI training and usage should foster rest periods for the user (McCullagh et al. 2014). The BCI should also be designed with ease of maintenance in mind, as caregivers will likely have to clean the equipment and maintain the patient's hygiene to prevent infection. In the case study from Vansteensel et al., the patient underwent extensive post-operation training with the BCI to ensure proper usage (M. J. Vansteensel et al. 2016). Vansteensel et al. illustrate a research methodology for utilizing a BCI system while making the wellbeing of the subject central to their investigation. Other researchers should likewise regard the patient's health as paramount in these risky and invasive procedures.

Existential Concerns for the Human Subject

Existential concerns—those relating to the nonphysical aspects of the individual—remain a point of intrigue and challenge in the development of BCIs. The issue of informed consent figures prominently in the mitigation of such concerns. BCIs are deployed with the intention of restoring some degree of autonomy to patients with LIS (Klein, Peters, and Higger 2018). However, an immediate challenge to this goal is the inability of patients with LIS to communicate their wishes, readily and reliably, without technological assistance. If informed consent is not properly obtained, patients with LIS may have their values undermined through participation in BCI research studies (Burwell, Sample, and Racine 2017). A key aspect of obtaining legitimate informed consent is that the subject agrees voluntarily with cognitive capacity and in possession of all pertinent information. Thus, the difficulties involved in determining capacity, understanding, and voluntariness in a patient with LIS are immense (Klein 2015).

The concerns about informed consent likewise impact discussions surrounding managing research subjects' expectations when engaging in BCI research. Patients may accept the risks of research out of desperation from their condition (Burwell, Sample, and Racine 2017). They may also misunderstand the continuing exploratory nature of BCI research and expect greater improvement of their condition than available (Klein 2016). Misunderstandings about the efficacy of experimental technology, which seem also to be

influenced by exaggerated media coverage and expectations of greater-than-available benefits, could inhibit researchers' ability to obtain properly informed consent.

Informed consent is a concern not only at the study outset but also throughout the study. Abbott and Peck raise the issue of a patient wishing to withdraw from a BCI study (Abbott and Peck 2017). In such a case, because the patient is presumably unable to communicate without the BCI, how should researchers ensure continued respect for the patient's autonomy? Abbott and Peck recommend reestablishing communication at regular intervals or if consent is needed for a medical procedure. Additionally, Klein notes the possibility of research subjects becoming cognitively impaired and losing decision-making capacity during the study (Klein 2016). Not only does this pose challenges for informed consent, but BCIs that function based on neurological input (either to assess an individual's cognition or to operate an external device) may fail to operate properly in the case of abnormal neurological function. Solutions aside, these questions further highlight the unique circumstances involved in BCI research that need to be considered in the respect of the patient's autonomy.

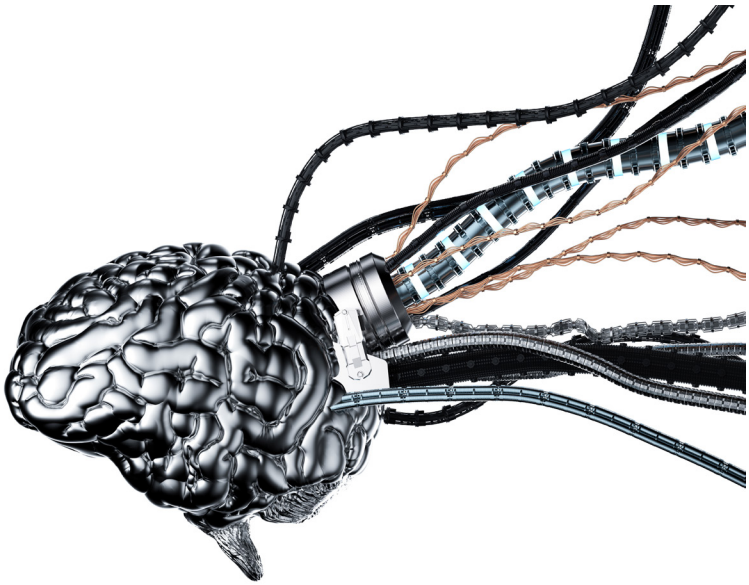
Another existential concern is the potential threat to the subject's sense of identity. If a computer is involved in the output processes of a person's cognition, it is easy to imagine how that person may have a crisis of identity and locus of control (Burwell, Sample, and Racine 2017; Klein 2016). Gilbert et al. reported on the qualitative experience of six participants in a study of BCI warning devices for epilepsy patients (Gilbert et al. 2019). Although some participants felt an increased sense of control from the BCIs, others felt a loss of control and depression from the constant reminders of their ill state. Participants also described the feeling that the BCI became integrated into their sense of self (Gilbert et al. 2019).

The study by Gilbert et al. is limited in its results and addresses a patient population different from LIS patients. However, it provides support for the identity concerns in BCI research described by Burwell et al. and Klein, among others (Klein 2016; Burwell, Sample, and Racine 2017). With identity already impacted by life-altering illness, BCIs, in connecting one's brain directly to a machine, could readily affect a patient's sense of self. With a BCI's effects on brain plasticity, one's character or personality might be impacted (Burwell, Sample, and Racine 2017). Patients' narrative identities, or their overarching sense of self, may also be at risk of alteration. Neurological data collected by the BCI may elucidate aspects of patients' personality (e.g. unconscious biases) that are at odds with their personal conception of themselves (Klein 2016). Despite the possible negative effects, BCIs also have the potential to positively impact identity by restoring communication as an avenue of interpersonal connection (Burwell, Sample, and Racine 2017). Thus, concerns about identity should not prima facie bar BCI research. To be sure, researchers must thoroughly explain the risks to identity as part of the informed consent process, and further research regarding actual patient feelings of identity must run parallel to logistical BCI research. Yet, in carefully attending to these risks and gathering more data while minding the research subjects' identity and sense of self, BCI research can proceed ethically and uphold respect for the subject.

A final existential concern is the issue of data privacy and security. BCI improvement requires rigorous data collection that includes personal and private information. Particularly in wireless BCI systems, Klein notes the potential for hackers to compromise the availability, integrity, and confidentiality of a BCI system (Klein 2016). As wireless technology may provide less discomfort than a wired BCI at the cost of increased security risks, use of such technology requires a strategic balance between comfort and security. Mechanisms should be enacted to transmit and store subjects' neurological data securely and reliably. Even with a wired connection, research data contains sensitive neurological information that researchers should protect (Klein 2016).

Responses to existential concerns in BCI research are derived from the principle of respect for persons. Researchers must be vigilant to maintain the respect of the human subjects involved, protecting them from the potential of identity crises and loss of autonomy that the very nature of the implanted technology threatens. Researchers must remain true to the primary mission of BCIs in restoring communication to those who cannot communicate, thus upholding patient autonomy and quality of life (Klein, Peters, and Higger 2018; Miller, Hermes, and Staff 2020). Above all, in BCI research, researchers must provide continued opportunities for surrogates and the patient to reaffirm consent or to withdraw from research at any time. The vulnerable nature of patients with LIS provides an easy path to exploitation, as these individuals rely on a BCI or other technology to express their wishes, and they lack a standard of care for communication (Klein, Peters, and Higger 2018). Researchers must recall their fiduciary obligations to the research subject and promote the patient's best interests in starting, continuing, or ending research (Klein, Peters, and Higger 2018). As Abbott and Peck mention, there may be wisdom in determining situations to reestablish BCI communication with patients choosing to withdraw from studies, such as for changing medical conditions or determining if the patient would like to re-enroll in a BCI study (Abbott and Peck 2017).

Obtaining informed consent at the outset of a research study requires identifying the patient's decision-making capacity. Determining consent from patients who cannot easily communicate poses risks to their autonomy and engenders concerns about the validity of their consent. Nevertheless, consenting LIS patients should not be ruled out as subjects for research participation, as BCIs are, in part, a tool for restoring a degree of autonomy to such patients (Klein, Peters, and Higger 2018). Surrogates may be consulted about informed consent for patients without a current means of communication (Abbott and Peck 2017). For instance, in the gradual onset of LIS in ALS, researchers could use physicians as a point of contact to obtain consent at the time of diagnosis. This would not eliminate all hurdles, as the research and consent may change over the course of the illness. However, it could open early avenues for conversations with patients and their surrogates in the interest of upholding patient autonomy .



Vansteensel et al. detail a rigorous informed consent procedure involving the research participant, participant's relative , researcher, and independent observer who had experience working with patients with LIS (M. Vansteensel, Pels, and Bleichner 2016). Because the participant could utilize eye blinks to communicate, the researchers determined the reliability of the eye blinks, and then explained the entire research project to all the above parties. They then questioned the participant on her understanding of the procedure and asked the participant three times for consent to participate in the study. Finally, all the parties signed the consent form once consent was given. Although tedious, such a procedure seems more than justified given the difficulty of communication and risks of the procedure. While the exact informed consent procedure may vary between studies, researchers should account for the complexities of consent given by patients with LIS.

In the process of securing informed consent, another significant guideline should be to emphasize the exploratory nature of BCI research. There are no guarantees that the BCI can successfully restore reliable avenues of communication, and a patient's declining cognitive function (with an associated loss of ability to provide consent) may require cessation of research (Klein 2016). Researchers hope that managing expectations early on in research may help mitigate social pressures for patients engaging in BCI research and uphold researcher integrity and honesty in the research process.

Social Concerns for the Human Subject

In addition to physical and existential concerns, there are also social concerns related to the unique nature of BCI in human interaction that give rise to ethical issues. The social concerns fall into two main areas: agency and stigma. For agency, the issue of whether or not responsibility for actions (particularly those that harm others) should rest on the BCI or the individual equipped with the BCI remains an unanswered question. Current structures are insufficient to accommodate the ethical challenges surrounding human actions mediated by a computer. Because human cognition is not observable, misattributions can easily be made for actions regulated by the BCI (Burwell, Sample, and Racine 2017). Klein offers the example of a wheelchair stopping when it senses danger, but the user assuming it was their intention to stop that caused the wheelchair to do so (Klein 2016). Such misunderstandings may impact the user's sense of autonomy, but it also places the individual's responsibility in a gray area with respect to the rest of society. Legally, it is not clear if BCI users are completely responsible for their actions. Imagine, for example, an accident associated with a BCI user who, if not for the BCI, would never have been in the position to cause the accident. People inevitably entertain thoughts that they have no intention or ability to carry out, but it is unclear how BCIs would differentiate relevant thoughts or how a legal system would consider such a situation. Fortunately, BCIs used only for communication may avoid the dangers of a BCI used to, say, drive a car. However, the agency of a BCI user in daily living remains unclear.

Social concerns, especially institutional ones, are difficult to approach. Researchers cannot hope to single-handedly affect the social issues facing the vulnerability of patients with LIS. However, the demands of justice require these concerns be given due consideration. Concerning legal and moral culpability for BCI users, increasing public policy advocacy and awareness could be a proper first step towards resolving these currently unanswerable questions regarding the responsibility of a BCI user. Accurate public education on the nature of BCIs in human beings must accompany such advocacy. However, this is something that no researcher can at present fully explain. As such, progress in research must move forward alongside a developing philosophy of agency in BCI users.

A second social hurdle in BCI development is the issue of stigma. Patients facing stigma from their condition may be compelled to seek out participation in BCI studies to remove such stigma (Burwell, Sample, and Racine 2017; Klein 2016). While this is an issue of informed consent, researchers themselves must be careful not to contribute to the stigma by taking advantage of individuals who have inappropriate expectations regarding the possibility for restoration through BCIs. On the flip side, individuals using BCIs may be stigmatized for their use of such technology, creating a barrier to the development of BCIs and their availability to people who could benefit from them (Burwell, Sample, and Racine 2017). An opportunity to mitigate the effects of stigma could come in the form of rigorous review and guidance by institutional review boards (IRBs). Research protocols that do not provide a clear understanding of the purpose of the study fail ethically to uphold the rights of study participants

(Sullivan and Illes 2016). IRBs should account for the stigma and vulnerability of patients with LIS by requiring clearly established research objectives and justifications for a study. In doing so, the IRB can uphold justice and respect for persons by ensuring that studies mitigate factors that could enable researchers to exploit the condition of patients with LIS.

Conclusion

BCIs have the promise to provide an avenue of communication for patients suffering from LIS. Although large strides have been made in the development of BCI technology, further research is still necessary before such devices can be made available for widespread clinical use. Specific concerns regarding the physical, existential, and social nature of LIS and use of BCIs need to be considered when designing and conducting research studies involving LIS patients as human subjects. Ethical issues of informed consent, identity, agency, and stigma present prominently as unique challenges to BCI research, development, and integration into society. While these concerns do not pose an inherent obstacle to the development of BCIs, ethical boundaries must be employed in BCI research to protect LIS patients as research subjects with unique vulnerabilities. When utilized with conscious respect for the person, BCIs possess the potential to do tremendous good in advancing the quality of life and autonomy of patients with LIS.

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Article

Ethical Considerations in the Role of Psychologists in the Pursual of Sex Reassignment Surgery

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For transgender individuals, sex reassignment surgery (SRS) is often requested to be performed as it validates and affirms their identity. The current standards of care for transgender individuals require that two letters of reference be provided by different psychologists that inform the physician the patient is ready and able to consent to surgery. These standards were constructed for a variety of reasons, including the irreversibility of the procedure, the potential of post-operative regret, and the existing evidence that transgender people often have comorbid mental disorders. However, transgender people, and current researchers in bioethics, are challenging the basis for the creation of these standards of care. They claim that these standards are no longer based on current research and have preconceived notions of transgender people that are false and harmful. They also provide evidence that the nature of psychologists as gatekeepers to SRS is discriminatory on several levels of the process, including comparisons to similar surgeries, creating barriers to care, and impeding on transgender autonomy.

A transgender individual is an individual whose biological sex does not align with their psychological sex/gender (Toivonen and Dobson 2017). Many individuals who are transgender wish to seek out hormonal therapy, facial surgery, or sex reassignment surgery (SRS) to affirm their gender identity (World Professional Association for Transgender Health 2011). To receive SRS, transgender people are required to fulfill multiple requirements that require services from a psychologist, including two letters of recommendations (from separate psychologists), a complete psychological assessment, participation in psychotherapy if warranted, and twelve months of continuous hormonal therapy (which also requires psychological assessment; Hale 2007).

Defenders of the current psychological "gatekeeping" role argue that it is necessary to prevent and minimize the possibility of post-surgical regret, by ensuring that participants of the surgery have the capacity to consent, are psychologically prepared, and are qualified for the procedure (Budge and Dickey 2017). Additionally, requiring psychological services such as counseling would be beneficial to a transitioning person as they are an at-risk group for mental disorders and suicide, and therapy could facilitate a more successful transition with surgery (Dhejne et al. 2011; Murphy 2016). Opponents of the current protocols argue that the gatekeeping for SRS done by psychologists violates basic autonomy, creates a discriminatory double standard based on misinformation about gender, wrongfully pathologizes transgenderism, creates and enforces barriers and stigmatizations for transgender individuals, and facilitates distrust and dishonesty between psychologists and transgender individuals (Ashley 2019; Inch 2016; MacKinnon et al. 2020). In this paper, I will discuss and evaluate evidence from both defenders and challengers of the current Standards of Care (SOC) for SRS and generate suggestions for moving forward in this debate.

EVIDENCE SUPPORTING CURRENT PROTOCOLS

Ensuring the Eligibility of a Patient

The first reason for requiring psychological reference letters for SRS is to ensure that the patient is certain that they wish to go forward with the permanent procedure, and that the patient can provide consent (Toivonen and Dobson 2017). Because SRS is virtually irreversible, the assessment and letter of reference ensure that the individual is not making a decision without knowing the possible consequences (Hale 2007). Additionally, psychologists can assess the readiness of the patient and determine if the patient has fulfilled the other requirements before surgery, such as continuous hormone therapy (McIntosh 2015). The objective of this assessment is to minimize post-operative regret and prevent exposing patients to the possible risks of surgery (Budge and Dickey 2017). Rates for postoperative regrets are generally very low because the current SOC successfully excludes specific populations of people from receiving the surgery (Danker et al. 2018)

Another concern is that individuals may have comorbid disorders which can incapacitate their ability to consent to such procedures (Budge and Dickey 2017). One example of this was researched in a study containing children and adolescents with gender-identity disorders (GID) (Vries et al. 2010). Researchers found that adolescents and children with GID had a ten times higher chance of having Autism Spectrum Disorders than the general population (Vries et al. 2010). While researchers did not comment on the clinical implication for SRS, it is possible to use this data to infer that it is important to assess individuals pursuing SRS, as they are at a higher risk of a disorder that may impact their ability to consent. It would be necessary for a psychologist to determine if there are intellectual disabilities present, and then assess if those will impact the capacity to consent (Toivonen and Dobson 2017).

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Ensuring Medical Necessity

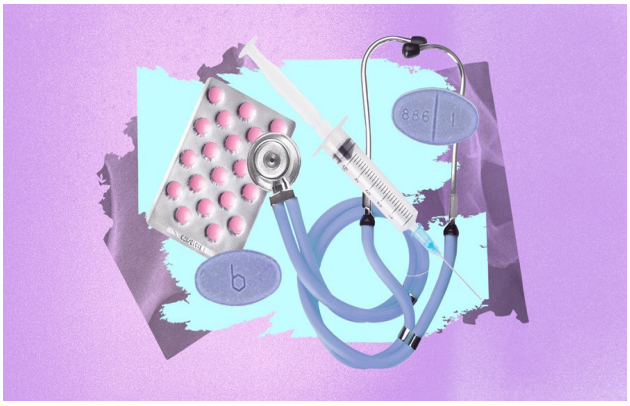
A crucial aspect of the psychological assessment for SRS is the diagnosis of gender dysphoria (GD), distress about the incongruence between one's physical and mental sex, or GID (MacKinnon et al. 2020; Ashley 2019). This diagnosis changes SRS from being a cosmetic surgery to one that is medically necessary (World Professional Association for Transgender Health 2011). The official Standards of Care state that to justify the removal of healthy tissue (which is an ethical concern), the patient must be experiencing gender dysphoria, which outweighs the risks of surgery (World Professional Association for Transgender Health 2011). The diagnosis allows SRS to be insured (which would increase accessibility to treatment) and it is also likely that most surgeons will refuse patients without it (Budge and Dickey 2017).

Another reason for the diagnosis is having a standardized way of ensuring that patients are transgender (Inch 2016). The DSM-V task force reason that giving a GD diagnosis is important in maintaining access to care (Zucker 2015). However, the DSM-V does not have any evidence for the validity of GID/GD disorders. (Dewey and Gesbeck 2017). Therefore, the diagnosis of GID/GD may be beneficial to a society that believes GID/GD are valid disorders, although this may not be the case. Currently, the diagnosis of GD is considered valid by society, and because of that, the diagnosis is necessary for procedures such as SRS, dictates whether or not individuals receive coverage by their insurance, and distinguishes transgender individuals from other people (Dewey and Gesbeck 2017). These are important considerations when exploring SRS, and a GD diagnosis helps navigate these considerations.

Benefit of Counselling

The last argument that I will discuss is one of maximizing benefit, which states that the requirement of being consulted, being assessed, and then receiving treatment for comorbid disorders are significantly helpful to transgender people, and therefore should be seen as beneficial (Murphy 2016). Connolly et al. states that transgender individuals are at a higher risk of suicide, mental disorders and self-harm, so this group would benefit greatly from psychological services. Murphy (2016) states in a case report analysis that these services benefit transgender patients because they help the patient set goals, create realistic expectations, deal with comorbid problems and flesh out their reasons for seeking out SRS, thereby leading to a smoother and more successful transition. Studies show that even after SRS, transgender people are at a higher risk for mental disorders and suicide, so counselling and assessment prior to SRS may help mitigate that risk (Dhejne et al. 2011). A doctor-psychologist team could ensure that patients have all the right tools in order to treat the gender dysphoria, pre-surgery suicide and psychiatric disorders and mitigate the risk of post-surgery suicide and other psychiatric disorders, by having a psychologist conduct interventions for those individuals prior to surgery (Murphy 2016).

From the challengers, it can also be argued that this stance does not focus on the main criticisms of requiring psychological services for SRS, such as impeding autonomy or discriminating against transgender individuals, and is vague on why the benefits of psychotherapy and assessment constitute being required for SRS. More specifically, proponents of this stance maintain the view that no one is disputing that psychological services are beneficial to transitioning individuals, yet it is still being used as a reason to justify why these services should be obligatory.



EVIDENCE AGAINST CURRENT PROTOCOLS

Wrongful Pathologizing

Proponents for changing the SOC for transgender patients seeking SRS propose that the requirement of a GD/GID diagnosis be abolished, as well as the existence of the disorder (Inch 2016). The reason for this stems from the stance that the classification of transgender individuals as mentally disordered invalidates their identity, creates harmful misconceptions about gender identity (Inch 2016; Benestad 2010) and excludes people who do not experience gender dysphoria, but other gender expressions (Ashley 2019; Dewey and Gesbeck 2017).

First, by classifying transgender people as mentally disordered, it creates a harmful perception in which it is implied that there is something wrong with the individual (Dewey and Gesbeck 2017). Recent gender conceptions understand that transgenderism is a normal variant of a gender/sex spectrum that is separate from any psychiatric illnesses an individual may have (Inch 2016). The classification of different expressions of gender as pathological also creates a negative sense of belonging to society and implies a sense of permanent shame in transgender individuals (Benestad 2010). While defenders of current protocol claim that this nomenclature and standardization of GD/GID help distinguish real transgender people from other mental health disorders, researchers found that individuals will simply lie about their symptoms to fulfill a GD/GID

diagnosis (MacKinnon et al. 2020). This means that the current diagnostic standards for transgender people are not congruent with real transgender experiences.

According to a transgender author, gender dysphoria is not the only reason to seek out SRS (Ashley 2019). The individual may also experience gender euphoria (extreme enjoyment from opposite sex features) or creative transfiguration (using/modifying the body as a form of artistic expression/expression of personal aesthetic (Ashley 2019). Gender euphoria is a positive way of creating a sense of belonging and inclusivity to the gender spectrum, and changes the conversation about the shame of dysphoria into the fulfillment of gender (Benestad 2010). Individuals may be gender non-conforming or gender fluid, but still wish to seek out SRS to affirm their identity (Dewey and Gesbeck 2017). But because the diagnoses of GID focus heavily on identifying as the opposite gender, these patients may be denied if they do not appear to identify strongly enough with the opposite sex or experience enough dysphoria from being their current sex (Dewey and Gesbeck 2017). This creates a space of discrimination, as not everyone can "pass" as being the gender they are, and some people will not fit into this binary anyways, such is the case for agender, genderfluid, and other gender nonconforming individuals (Benestad 2010). A person who identifies as a woman may be just fine with wearing "masculine" clothes, but still want to have SRS to affirm their identity and fulfill their gender euphoria. Most cisgender people do not have to be hyperfeminine/masculine to be identified with their preferred gender, so why should transgender people?

If SRS would bring benefit/euphoria to these individuals and affirm their gender identity, why is it not seen as valid as gender dysphoria? The GID/GD diagnosis is harmful to the transgender community and does not correspond with recent understandings of the gender spectrum (Inch 2016). Other medical procedures do not need a pathological diagnosis, such as childbirth/pregnancy (Budge and Dickey 2017), so it is unnecessary to pathologize transgender individuals and excludes the variation of gender experience (Ashley 2019). An updated SOC which excludes a formal diagnosis of GID/GD, or an updated diagnosis that is parallel to a diagnosis of pregnancy and does not carry negative stigma, would alleviate these concerns (Dewey and Gesbeck 2017).

Discrimination Against Transgender Individuals

Possibly the strongest and most extensive argument against the use of psychologists as gatekeepers for SRS is the discriminatory nature of the qualifying requirements. These restrictions allow for discrimination based on perspectives about transgender individuals (Budge and Dickey 2017), deny individuals autonomy over their body, and implicate a distrust for trans' identities, creating a double standard from other types of surgery (Hale 2007).

The autonomy of the individual is severely restricted in a transgender person pursuing SRS, as the individual is not allowed to decide for themselves if they are ready and want to proceed with the surgery (Hale 2007). Instead, patients need to get assessed by two psychologists and do therapy if required by the psychologist, which they may not want to do (Dewey and Gesbeck 2017). Some may defend this by proposing that these requirements are necessary because it is a medical procedure in which healthy tissue is permanently altered, and reproductive rights are removed (Toivonen and Dobson 2017). However, in other procedures that also permanently alter tissue, such as a vasectomy, patients are never required to undergo a psychological assessment to determine if they are psychologically "ready" for the procedure. This shows obvious discrimination towards transgender people (Hale 2007).

For almost all other procedures, physicians proceed with informed consent; this means that if the patient is aware of the process and the possible risks, consequences, and benefits, the doctor can administer the procedure (Cavanaugh, Hopwood and Lambert 2016). Because of this, transgender people feel as though society views them as a group of people who are not capable of making their own decisions or having self-determination, which perpetuates discrimination against them (Ashley 2019). Furthermore, it allows discrimination from health care psychologists who evaluate patients based on how much "effort" they put into looking feminine/masculine (Dewey and Gesbeck 2017). This devalues their identity, their bodies, and their lives (Ashley 2019). It does not allow these individuals to present themselves in a way they feel comfortable with, which also denies their autonomy in a different, however, important way.

Additionally, there is no evidence (based on research) that supports the idea that postoperative regret is enough of a significant issue to require multiple psychological assessments (Toivonen and Dobson 2017). Like previously stated, research suggests the opposite, but this could be because the samples are not appropriate to test if the SOC actually prevents regret (Danker et al. 2018). However, an additional study that examined why patients have postoperative regret found that the reasons mostly stem from a dissatisfaction of the results and medical complications, rather than a change in gender identity (Lawrence 2003). The implications of this study reveal that regret is less dependent on traits of the individual (such as mental health or not being "authentically" transgender), but rather more dependent on the success of the actual surgery (Lawrence 2003). In this way, SOC that require assessment based on postoperative regret are not based on evidence, but wrongful perceptions of transgender people (Budge and Dickey 2017).

Creating More Barriers for a Marginalized Group

Lastly, the SOC for accepting a patient to have SRS provides systematic barriers that are harmful to the transgender community, as the SOC disadvantage transgender individuals and prevent them from getting a needed treatment (MacKinnon et al. 2020; Toivonen and Dobson 2017).

Transgender individuals are less likely to access medical care when there are more barriers and discrimination (Grant et al. 2010).

When accessing health care, transgender individuals are already at a disadvantage due to the discrimination and in some cases, cost of healthcare (Grant et al. 2010). In a survey conducted for transgender individuals, a significant amount reported being refused care for being transgender, experiencing harassment and violence in medical environments and having to teach their medical providers about transgender care (Grant et al. 2010). With this, it is no surprise that many individuals postpone medical care when sick because of the discrimination (Grant et al. 2010).These are the barriers that transgender individuals face when accessing general healthcare, which shows that they are already a marginalized group in this setting.

Requiring two letters of reference from psychologists before surgery puts a heavy burden on transgender individuals. The severe scarcity of clinicians that offer these services subjects individuals to extreme wait times of up to three years and can be particularly dangerous for transgender people who are a high-risk group for suicide (Toivonen and Dobson 2017). Additionally, the time spent into therapy and assessments could mean lost time for employment, an area where transgender people are already disadvantaged (Toivonen and Dobson 2017). These factors can force transgender people to pursue dangerous alternatives, such as SRS in different countries or underground treatment (Toivonen and Dobson 2017). Some transgender people may not pursue SRS because of the required effort, time and money, and suffer from declined psychological health, suicide, and discrimination/violence from peers because they have not fully transitioned (Hale 2007).

While requiring psychological services was argued to be beneficial because it provided mental health resources to an at-risk group, studies show that it actually prevents transgender individuals from benefiting from psychological treatment (MacKinnon et al. 2020). Because transgender people need to downplay mental health symptoms to get recommended for SRS, they end up not being honest with their psychologist, and therefore, cannot receive treatment for issues they have and need treatment for (MacKinnon et al. 2020). On top of hiding their mental health issues, transgender people may also distrust psychologists from the discrimination they receive, which negates any long-term benefit of therapy, as a client-therapist relationship is crucial (MacKinnon et al. 2020).

Conclusion

There are serious considerations that need to be made when designing the next edition of the SOC. Many of the current protocols are based on outdated perspectives of transgender people rather than evidence-based research and findings (Budge and Dickey 2017; Toivonen and Dobson 2017). As a result, the requirements expected of transgender people impede on their right to self-determination and show discrimination when comparing to similar procedures for cisgender people (Hale 2007). This SOC is unacceptable for individuals pursuing SRS. I propose that the best way to move forward is to eliminate the role of psychologists as gatekeepers and transform their role into supporters. Instead of letters of reference, the physician would talk with the patient, deciding if this is the right treatment for them, as they would any other procedure such as vasectomies or hysterectomies. They would also spend time thoroughly informing the patient of the irreversibility, consequences, and benefits of the procedure. The informed consent model gives patients autonomy while fulfilling responsibilities to "do no harm" and maximize benefits to the patient (Cavanaugh, Hopwood and Lambert 2016). In this way, transgender people do not have to be shamed with a diagnosis of a disorder, discriminated against by misconceptions about gender expression and gender binary, and they do not have to face the barriers of time, money, and psychological effort in order to get "permission" to receive SRS. This allows for honest patient-doctor communication and gender fulfillment with a positive sense of belonging for transgender people (Benestad 2010).

To successfully remove psychologists as gatekeepers for SRS, we must also abolish the diagnosis of GID/GD. This removes the necessity of the psychologist in determining readiness for SRS. I propose this removal of diagnosis not only as part of removing psychologists as gatekeepers, but also in its own right. A gender dysphoria diagnosis has proven to carry shame for transgender individuals, which fosters a negative sense of belonging in society (Ashley 2019; Benestad 2010). In addition, people who require SRS but do not fit into the binary or do not experience enough dysphoria are forced to lie about their experiences in order to affirm their gender through SRS (MacKinnon et al. 2020). This creates a break in the patient-doctor/psychologist trust, and goes against the very basis of scientific method, as the diagnosis no longer fits with the actual people who are the targets of this diagnosis. It is outdated, based on misconceptions about gender, and is not inclusive to the gender spectrum (Ashley 2019; Benestad 2010; Inch 2016).

An alternative diagnosis that focuses on the condition of requiring gender fulfillment and gender euphoria, instead of treating gender dysphoria, should be put into place. In that way, it is not a stigmatized disorder, but a condition that can be celebrated and joyful for those individuals who seek out and experience SRS for gender affirmation.

The outcome in these two suggestions for moving forward is more than just creating a fair, just, and unstigmatized process for transgender individuals seeking out SRS, but can also have other positive consequences such as having better psychologist/patient relationships. As studies have shown, psychologists can be helpful in the transitioning process, as well as helpful for the common comorbidities seen in transgender people (Murphy 2016). With a better relationship, transgender individuals can feel safe to express themselves without worrying about having to fit within an outdated diagnosis, and get help from psychologists, if needed (MacKinnon et al. 2020). Furthermore, psychologists and society can learn a lot more about the real experiences of transgender people if they are allowed a space to be honest.

In conclusion, the defenders of the current protocols claim that requiring psychologist referrals safeguards against uninformed decision making (Budge and Dickey 2017), false transgenderism (MacKinnon et al. 2020), and incapacity to consent (Toivonen and Dobson 2017), and provides beneficial psychological resources (Murphy 2016). However, challengers of the current protocol argue that having psychologists as gatekeepers invalidates transgender patients' autonomy and existence (Hale 2007), is not inclusive of different gender expressions (Ashley 2019), creates systematic barriers for transgender people (Toivonen and Dobson 2017), wrongfully pathologizes transgender people (Inch 2016), and is based on harmful stereotypes of transgender people (Budge and Dickey 2017). I propose that we move from a psychological diagnostic approach to an informed consent model and abolish the pathologization of transgender individuals in order to maximize benefit to the patient and remove barriers and discrimination against them.

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Article

Defending a Limited Right to Genetic Ignorance

Juliana S. Qin*

Recent scientific advances have made personal genetic information more readily accessible, but knowledge of this information is not always preferable to ignorance. Using W. D. Ross's principle-based moral theory, this paper argues that genetic ignorance, the right not to know one's own genetic information, can be morally defensible. It then develops a decision-making process that identifies the circumstances under which it can be appropriate for patients to exercise a right to genetic ignorance. This process depends on the patient's family structure and the genetic disorder's inheritability, fatality, time of onset, and treatment options. Generally, genetic ignorance cannot be defensible if (a) the disorder is fatal in childhood and treatable or (b) the patient has living biological relatives and the disorder is both inherited and fatal. Ultimately, this discussion of genetic ignorance provides patients guidance regarding their medical care and suggests a role for health care providers during their patients' decision-making process. Furthermore, it informs the larger discussion of what can be considered appropriate use of medical information.

Introduction

While improvements in predictive genetics research have helped individuals make more informed medical decisions, they have also introduced new ethical concerns regarding the appropriate applications of genetic testing. Generally, giving patients accurate and detailed information is an essential component of quality medical care. Protecting patients' rights to this type of information has led to a legal and potentially moral "right to know" (Wilson 2005). However, knowledge of genetic test results can also cause serious mental harm that diminishes one's overall well-being. For example, a study published by Almqvist et al. (1999) suggested a link between Huntington's disease diagnosis and subsequent occurrence of catastrophic events like suicide, suicide attempt, and psychiatric hospitalization. Thus, others argue that having knowledge of genetic test results is not always preferable and instead defend genetic ignorance, or a so-called "right not to know" one's own genetic test results (Wilson 2005). As scientists elucidate the underlying genetic factors for common and deadly human disorders, genetic tests will become more accurate and available. We are at a crucial point in the advancement of medical science: it is now necessary to determine whether individuals have a right to be voluntarily ignorant of their genetic test results. To this end, we must identify the salient factors and a suitable moral framework for decision-making. In this paper, I use W. D. Ross's principle-based moral theory to argue that the permissibility of genetic ignorance depends on the patient's family structure and the genetic disorder's inheritability, fatality, time of onset, and treatment options.

I. The Rossian Framework

Principle-based ethics has become widely used to resolve contemporary issues in health care (Knapp and Vandecreek 2007). The well-known bioethical principles of beneficence, non-maleficence, respect for autonomy, and justice were proposed by Beauchamp and Childress (1994) and greatly influenced by the work of W. D. Ross (2002). Though the Rossian framework is more complicated than the principles developed by Beauchamp and Childress, it provides more comprehensive guidance to resolve moral conflicts.

Ross develops a pluralistic deontological framework consisting of seven prima facie duties to answer what makes right acts right (2002). A prima facie duty or obligation "must be fulfilled unless it conflicts on a particular occasion with an equal or stronger obligation" (Beauchamp and Childress 1994, 33). This flexibility makes the Rossian framework applicable to dynamic medical situations like those involving genetic testing and genetic ignorance.

Ross presents seven prima facie duties, including fidelity, reparation, gratitude, justice, beneficence, self-improvement, and non-maleficence. First, there are duties that rest on one's own previous acts. These include the duty of fidelity, which rests on implicit or explicit promises made, and the duty of reparation, which rests on previous wrongful acts. The next duty is gratitude, which rests on services done for one by others. The fourth duty is justice, which involves the distribution of pleasure or happiness in accordance with merit. The duty of beneficence moves one to make others' conditions better with respect to the intrinsic goods of virtue, intelligence, or pleasure. Similarly, the duty of self-improvement moves one to improve one's own conditions with respect to virtue, intelligence, and potentially pleasure. Lastly, there is the duty of non-maleficence, to not harm others, which is separate from the duty of beneficence.

Respect for autonomy is notably absent, but Ross states that if individuals with good motives balance the prima facie rightness and wrongness of their options, their decisions should be respected even if they appear to make mistakes in judgment. One cannot be compelled to do the right act, as this would detract from the moral value of the act (Ross 2002, 26). Instead, Ross states that individuals

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have a duty to promote virtue in others, which is "not different in kind from our duty to improve our own characters" (Ross 2002, 26).

Using Ross's principle-based moral theory, I will now develop a framework that informs decision-making regarding genetic ignorance by considering the distinctions among different genetic disorders and family structures.

II. Genetic Disorder Distinctions

Genetic testing can be used to identify and evaluate future health risks, confirm suspected diagnoses, and inform reproductive decision-making (Burke 2002). As such, it can have consequences related to future health such as changes in family planning, lifestyle, and evaluations of quality of life. Additionally, there can be psychological consequences related to becoming a patient or caring for a patient. The consequences of knowing genetic test results largely depend on the type of disorder being tested.

A genetic disorder can be understood as any disorder caused by an abnormality in an individual's DNA sequence, including unexpected chromosome numbers, mutations caused spontaneously by errors in biological processes, and mutations induced by environmental factors ("Genetic Disorders" n.d.). Though all genetic disorders stem from abnormalities in DNA, not all of them can be inherited. For example, disorders caused by abnormal chromosome number, including Down syndrome, are not passed onto future generations, thus making them non-inherited genetic disorders. This distinction in inheritability is important when considering who in particular would be affected by a patient's genetic test results.

Perhaps the most significant distinction within genetic disorders is whether the disorder is classified as fatal or non-fatal since death is generally viewed as the most undesirable outcome. While the severity of symptoms can vary, fatal disorders almost certainly result in death. Fatality is a particularly salient factor for prospective parents, as "the emotional trauma of delivering a baby who would suffer and eventually die" (Gawron et al. 2013, 113) may be so great that they would rather choose to terminate the pregnancy.

Genetic disorders can be further distinguished by time of onset. An individual positive for Huntington's disease gene markers may live several decades in good health before succumbing to the disease ("Huntington's Disease" n.d.). When a genetic disorder allows the patient to live for many years in good health, the argument that terminating the pregnancies of fetuses with positive diagnoses can prevent harm (Blakeley et al. 2019; Gawron et al. 2013) becomes less relevant.

Some disorders that develop gradually after birth have treatments available in childhood. For example, individuals with spina bifida can undergo surgical correction ("Health Issues & Treatments for Spina Bifida" n.d.) while individuals with Down syndrome can begin specialized education ("Facts about Down Syndrome" n.d.). Early intervention and preparation are necessary to ensure the highest quality of life possible, so many individuals get tested for treatable disorders. But on the other hand, genetic tests can also reveal that individuals have a genetic predisposition for an untreatable disorder. For some, knowing these results can lead to significant psychological burdens on the patient and their family, a feeling of futility, and no apparent medical benefits (Beskow et al. 2010).

Since genetic disorders differ significantly in their inheritability, fatality, time of onset, and treatment options, the distinct ethical implications of testing for each type of disorder should be considered. The Rossian framework offers individualized moral guidance regarding the permissibility of genetic ignorance to acknowledge the ethical challenges associated with each type of disorder.

III. Ethical Dimensions

While each type of genetic disorder carries its own set of ethical challenges, the general challenges of defining respect for autonomy, non-maleficence, and beneficence are shared. First, the moral framework for genetic testing and genetic ignorance must define what it means to respect autonomy, which is understood broadly as the right for rational individuals to make their own decisions (Beauchamp and Childress 1994, 38). Respect for autonomy has become prioritized in medical practice as the model of informed consent has emerged in favor of medical paternalism (Gillon 2003; Hallowell et al. 2003). However, autonomous patients may not always make morally good decisions. Still, it is generally agreed upon by the medical community that it is wrong to force patients to choose what is believed to be the medically superior option (Davies 2020; Lantos, Matlock, and Wendler 2011). Thus, the framework must address what constitutes respect for autonomy and whether providers can act against the will of the patient.

The framework must also address concerns about non-maleficence and beneficence. The principle of non-maleficence declares an obligation not to intentionally inflict harm upon others while the principle of beneficence declares an obligation to provide benefits (Beauchamp and Childress 1994, 38). In health care, determining which actions best align with these principles can be challenging. For instance, health care providers tend to administer more aggressive chemotherapy treatment to consenting young adult patients near the ends of their lives even though it would harm the patients (Laryionava et al. 2018).

These general issues become more difficult to resolve when applied to genetic testing and genetic ignorance because there are several potential stakeholders involved.

IV. Identifying Stakeholders

A patient's decision to remain ignorant of potentially displeasing genetic knowledge should be taken seriously, especially if it is an autonomous decision. However, determining the permissibility of genetic ignorance is challenging

since patients are unavoidably connected to others through shared genetic material.

Given that the disorder is inherited through one or multiple genes, we can justify the inclusion of biological relatives as stakeholders by referring to the duties of gratitude, beneficence, non-maleficence, and fidelity. In the context of genetic testing, individuals should express their gratitude for the biological relatives who have cared for them by sharing relevant genetic test results. Next, the duty of beneficence should drive individuals to gain knowledge that would make them better situated to act on the behalf of their biological relatives, while the duty of non-maleficence should drive individuals to avoid refusing their biological relatives the opportunity to quickly begin intervention or lifestyle changes. Additionally, there can be implicit promises to care for relatives by communicating relevant health information that should be honored according to the duty of fidelity. Furthermore, the inclusion of biological relatives is supported by the view that underlying genetic connections make it impossible to make morally permissible decisions about genetic testing without considering the interests of biological relatives (Hallowell et al. 2003; Knoppers and Chadwick 2005).

Next, the interests of life partners should be considered because they would likely be expected to carry the potential burden of caring for the sick patient. The relationship between partners generally involves trust and a feeling of oneness, so we cannot think of the patient as an isolated moral agent. The justifications referring to gratitude, beneficence, non-maleficence, and fidelity that were applied to biological relatives can also be applied to life partners.

In the context of prenatal genetic screening, another party that could be considered is the unborn fetus. Consideration of a fetus's interest could be justified in the same way a child's interest is in the existing recommendations for adult-onset disorders that cannot be treated in childhood. These state that genetic testing should not be performed on children unless ignorance poses a significant burden to the family (Committee on Bioethics, American College of Medical Genetics 2013). Instead, children's autonomy should be protected by letting them decide whether they want to get tested after they reach adulthood. Of course, whether fetuses have personhood is debated, and a discussion of their eventual autonomy may not be appropriate if they do not have personhood.

Biological relatives, life partners, and fetuses are the primary parties that could be affected by a patient's genetic test results, but this does not preclude others from being involved in the decision to exercise a right to genetic ignorance. The interests of providers are also important because providers are autonomous moral agents. Ross's theory supports that providers have a duty to push back on their patients to promote their patients' virtue, but neither party should feel compelled to action. Thus, it is acceptable for providers to decline treating patients if doing so would be a significant moral challenge. Although Ross's theory resolves the issue of whether personal moral beliefs should be kept separate from professional duties, this issue continues to be debated (Lantos, Matlock, and Wendler 2011).

After considering the diversity of genetic disorders and the various stakeholders involved in the care of individuals with genetic disorders, it should be clear that there needs to be a nuanced response to the discussion about the existence of a right to genetic ignorance. A general "yes" or "no" response that does not consider the implications of these distinctions is not appropriate.

V. Applications to Genetic Testing

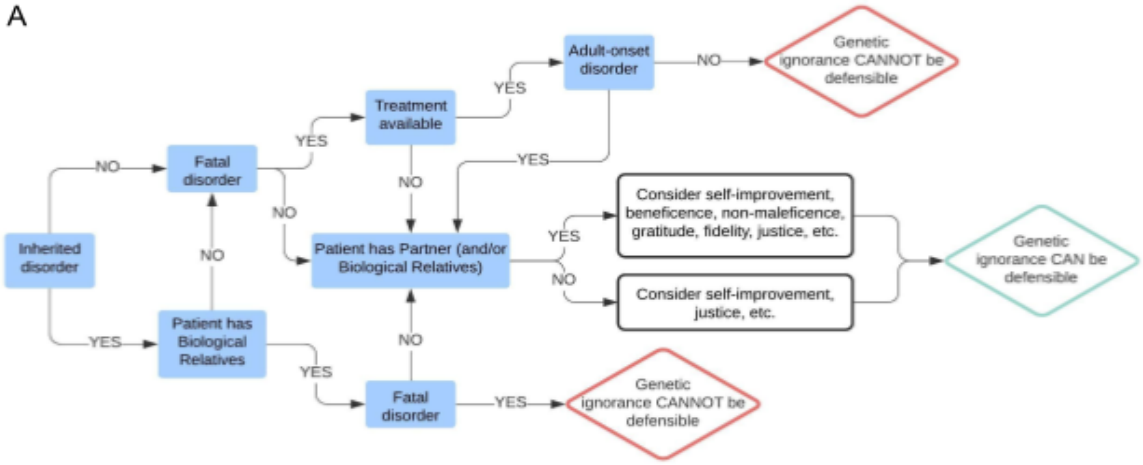
To determine whether genetic ignorance is defensible, the patient's family structure and the genetic disorder's inheritability, fatality, time of onset, and treatment options must be carefully considered. First, I will consider two circumstances under which a right to genetic ignorance cannot be morally defensible. However, there still may be unique personal factors that lead patients to insist on exercising a right to genetic ignorance under these circumstances. I will give two examples of such factors, accessibility of existing preventive treatments and estrangement from biological relatives, to describe how they fit into the framework. Next, I will consider circumstances under which there can be a morally defensible right to genetic ignorance.

The recommended decision-making process for determining whether genetic ignorance is permissible is presented graphically (Fig. 1A). This process identifies nine categories of circumstances that differ according to genetic disorder distinctions and family structures (Fig. 1B). For Categories 1-4, consideration of biological relatives is not applicable because the genetic disorders are non-inheritable. Category 1 refers to genetic disorders that are non-inheritable, fatal in childhood, and treatable. Category 2 refers to genetic disorders that are non-inheritable, fatal in adulthood, and treatable. Category 3 refers to genetic disorders that are non-inheritable, fatal, and untreatable. Category 4 refers to genetic disorders that are non-inheritable and non-fatal. The remaining five categories refer to inheritable genetic disorders, so biological relatives must be considered. If patients do not have living biological relatives who could be affected by the inheritable genetic disorder being tested, then the decision-making process remains the same as that for disorders that are non-inheritable. Therefore, Categories 5-8 are practically equivalent to Categories 1-4, respectively. Lastly, Category 9 refers to cases in which patients have living biological relatives and are testing for inheritable and fatal genetic disorders.

When Genetic Ignorance Cannot be Defensible

The first circumstance under which ignorance of genetic testing results is not typically morally defensible includes Categories 1 and 5, which refer to disorders that are fatal in childhood and treatable. Choosing genetic ignorance when knowledge would almost certainly impede the development of a fatal disorder would not be in the best

A



B

Category	Inherited disorder	Patient has Biological Relatives	Fatal disorder	Treatment Available	Adult-on set disorder	Ignorance Defensible	Examples
1	NO	--	YES	YES	NO	NO	(if a treatment for Edwards syndrome becomes available)
2	NO	--	YES	YES	YES	YES	(if Huntington's disease were not inherited)
3	NO	--	YES	NO	--	YES	Edwards syndrome (trisomy 18)
4	NO	--	NO	--	--	YES	Down syndrome (trisomy 21)
5	YES	NO	YES	YES	NO	NO	Phenylketonuria
6	YES	NO	YES	YES	YES	YES	(if a treatment for Huntington's disease becomes available)
7	YES	NO	YES	NO	--	YES	Tay-Sachs disease, Huntington's disease
8	YES	YES or NO	NO	--	--	YES	Cystic fibrosis
9	YES	YES	YES	--	--	NO	Tay-Sachs disease, Huntington's disease, phenylketonuria

Figure 1. Circumstances under which genetic ignorance can and cannot be defensible
(A) Decision-making flowchart for patients considering genetic ignorance. (B) Descriptions and examples of the nine categories of circumstances resulting from the recommended decision-making process.

interest of the individual being tested (Knoppers 2012).

However, the existence of treatments does not necessarily guarantee their accessibility. First, the mental and emotional investment that individuals may need to care for themselves or a loved one can be overwhelming. Additionally, temporal, geographical, and financial obstacles can impede access to health care that is recommended or morally desirable. Financial obstacles are especially challenging, as treatments like speech therapy, special education, surgical correction, or treatments for secondary conditions can be long-term expenses. Furthermore, concerns about genetic discrimination, discrimination on the basis of genetic information produced by genetic testing, may discourage individuals from getting tested (Wauters and Van Hoyweghen 2021). Though there are laws protecting against genetic discrimination (Joly et al. 2017), there are also potential loopholes for employers and health insurance companies to use patients' genetic information as justification for denying employment or coverage (Rothstein 2008).

My recommendations assume that these issues of accessibility can be avoided, but individuals may not be able to overcome the obstacles to treatment access. In these cases, if there are no biological relatives and the patient has thoughtfully balanced their prima facie duties, then the disorder can be considered untreatable and genetic ignorance can be defensible.

The second circumstance under which genetic ignorance cannot be morally defensible involves inheritable fatal disorders and patients with living biological relatives (Category 9). If there are living biological relatives who could be affected by the inheritable genetic disorder being tested, then several prima facie duties would call for the patient to become informed. Some patients may hesitate to accept this recommendation because of estrangement from biological relatives, understood as "the physical distancing and loss of affection… often due to intense conflict or ongoing disagreement" (Agilias 2011, 108). However, the unresolved tensions associated with estrangement may give hope of reparation and reconciliation, especially when individuals are faced with issues of health, life, and death (Agilias 2011; Laabs 2008). Thus, even if individuals do not have special obligations to biological relatives by nature of their genetic connections, their relatives would still factor into the prima facie duties (reparation, among the others mentioned previ-

ously).

In arguing that genetic ignorance cannot be justifiable if the disorder is fatal and the patient has living biological relatives, I diverge from the consensus. Many argue that since adult-onset disorders are not immediately threatening, children should not be tested for them to preserve their autonomy and prevent unnecessary distribution of clinically irrelevant information (Ross and Clayton, 2019, 2). Ideally, children would not be tested for adult-onset disorders to preserve their autonomy. However, the potential benefits to biological relatives resulting from testing a child bear weight because of the potential direct benefits to the child being tested. A positive diagnosis of the child could motivate many relatives to get tested themselves and prepare them to care for the child. Thus, patient age and time of disorder onset do not justify a decision to remain genetically ignorant when the disorder is fatal and the patient has living biological relatives.

When Genetic Ignorance Can be Defensible

I will now consider three circumstances under which genetic ignorance can be defensible for non-inherited genetic disorders. First, if the disorder is fatal in adulthood but there is a preventive treatment available (Category 2), there is no immediate threat to health. This factor of immediacy is particularly relevant in the context of prenatal testing or testing of minors. If the threat of death is not immediate, it would be best for surrogate decision-makers to wait until the affected fetus or minor can make an autonomous decision. Of course, this must occur before it is too late for the treatment to be effective. Second, if the non-inherited disorder is fatal and there is no treatment available (Category 3), having knowledge of a positive diagnosis would not reveal options to overcome the diagnosis or produce similarly significant benefits. Instead, the inevitable early death could make an individual's remaining years in good health seem futile. As ignorance can help one avoid this sense of futility without causing great harm to biological relatives, it can be defensible. Third, genetic ignorance can be defensible if the non-inherited disorder is non-fatal (Category 4). Testing for such disorders could give individuals clarity on their own health (and in the context of prenatal testing, it could give prospective parents clarity on the health of their fetuses), but there is no sense of immediacy that would motivate a recommendation against genetic ignorance.

Next, there are three circumstances under which genetic ignorance can be defensible for inherited disorders. The first refers to those that are not necessarily fatal (Category 8). The justification for this type is like the previous one for non-fatal disorders that are non-inherited (Category 4). However, after considering the prima facie duties and interests of relevant parties, it is possible that genetic ignorance would be less preferable because of the inheritance pattern. For example, cystic fibrosis is not immediately fatal anymore because of available treatments, but the issue of treatment accessibility may be relevant to biological relatives of the patient being tested. Thus, individuals may forgo their right to genetic ignorance if they determine that their duty is to maximize knowledge that could help others. Second, there are circumstances under which the individual being tested does not have biological relatives and the inherited disorder is fatal and untreatable (Category 7). The reasoning for why genetic ignorance can be defensible is the same as when the disorder is non-inherited, fatal, and untreatable (Category 3). Lastly, if the patient does not have biological relatives and the inherited disorder is fatal in adulthood but treatable (Category 6), genetic ignorance can be defensible. The justification is the same as that for disorders that are non-inherited, fatal in adulthood, and treatable (Category 2).

In summary, there is a right to genetic ignorance, but there are three circumstances under which genetic ignorance cannot be defensible. For Categories 1 and 5, it cannot be defensible because there are ways to intervene with the progression of the fatal disorder. For Category 9, it cannot be defensible because there are living biological relatives who could be affected by the genetic test results. There are exceptions, but these recommendations offer some clarity on the considerations that should drive an individual's decision regarding genetic ignorance.

VI. A Role for Health Care Providers

Deciding to be genetically ignorant or not is always a matter of patient preference, so how can health care providers promote or even enforce the pursuit of morally defensible acts? One option could be to expand the power that they have in their patients' decision-making processes. However, suggesting that providers should have a right to override the decisions of autonomous patients would shift back toward the medical paternalism model of health care. Instead, increasing the moral obligations of providers to the biological relatives and partners of patients could expand the power of providers without introducing medical paternalism. This alternative has been suggested (Wilcke 1998; Parker 2015), but it is difficult to do in practice because of privacy concerns and respect for patient autonomy.

Ultimately, the nature of the patient-provider relationship must be clarified. The current balance of power allows autonomous patients great liberties in their medical care to protect against medical paternalism. However, there is likely an intermediate between the current relationship and a paternalistic relationship that is more conducive to the pursuit of morally defensible actions. Once this relationship is better understood, health care providers will be better equipped to implement a moral framework that helps patients make morally defensible decisions about genetic testing and genetic ignorance.

Conclusion

In this paper, I have argued that there can be a morally defensible right to genetic ignorance. Using W. D. Ross's

moral theory, I developed a decision-making process that can resolve some of the controversy surrounding genetic ignorance. This process depends on the patient's family structure and the genetic disorder's inheritability, fatality, time of onset, and treatment options. While this discussion of genetic ignorance is focused on the individual level, it also informs the broader discussion about the consequences of biomedical information becoming more readily accessible. Emerging concerns about genetic discrimination confirm that more information, even genetic information that could prevent future deaths, does not always benefit the beholder more than it harms them. Thus, just as there are circumstances under which genetic ignorance may be the best option for an individual, there may be circumstances under which limiting aspects of biomedical research may be the best option for the general population. As biomedical research continues to expand our knowledge base and push the boundaries of what is humanly possible, we must remember to critically evaluate scientific advancements before adopting them in practice.

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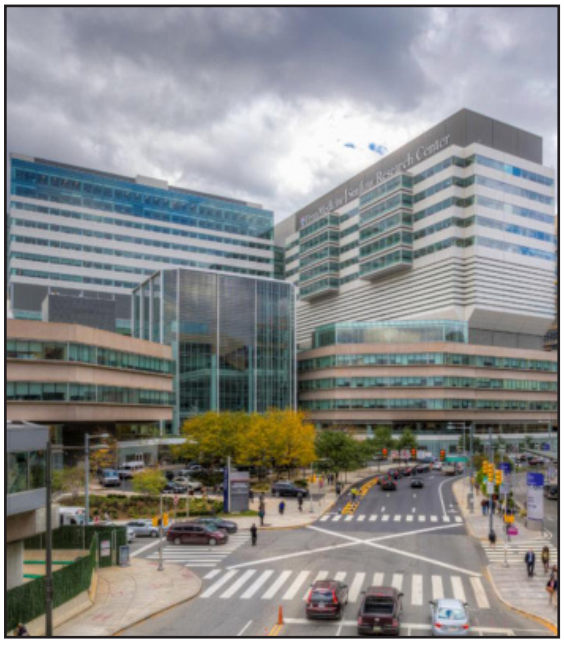

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