

# THE RUTGERS JOURNAL OF BIOETHICS

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*The Rutgers Journal of Bioethics* is an undergraduate journal exploring the intersection of ethics, biology, society, and public policy. It has been published each year since 2009. While the Journal solicits articles from all persons wishing to participate in the open discussion on bioethics, it is managed by students at Rutgers, the State University of New Jersey. The Journal is published by Premier Graphics (165 First Avenue, Unit C, Atlantic Highlands, NJ 07716) and funded through generous contributions from the Rutgers University Student Assembly Allocations Board. The Journal welcomes all unsolicited original essays, book reviews, editorials, and art. To submit, please e-mail a copy of your paper or a high-resolution image of your work of art to <rubioethics.journ@gmail.com>.

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to art or essays belong to their respective authors. All other copyrights belong to *The Rutgers Journal of Bioethics*. Please send all questions and comments to the aforementioned email address. Our sister organization, the Bioethics Society of Rutgers University, meets every other Wednesday during the academic year at 9:00 PM in Scott Hall on the College Ave. Campus at Rutgers-New Brunswick (43 College Avenue, New Brunswick, NJ 08901). All are welcome to attend. Sometimes we have pizza. Meeting details are available at <<https://www.facebook.com/bioethics.ru>>. We would like to thank Dr. Budolfson of the Center for Population - Level Bioethics (CPLB) and Department of Environmental and Occupational Health for his advice and support.

# Letter from the Editor

In many ways, 2022 has marked a whirlwind of change within our society as we begin our entry into a post-COVID world. We have witnessed first hand how individuals, populations, and governments re-adjusted to these changes, all with a newfound emphasis on public health. However, this is contrasted with themes of healthcare autonomy, forcing us to reevaluate the way in which we see the world.

At *the Rutgers Journal of Bioethics*, we strive to publish unique pieces at the forefront of bioethics whether it be biology, society, public health, or public policy. Thus, I am proud to introduce to you the 13th issue of *the Rutgers Journal of Bioethics*.

This year's theme for our Journal is "Healthcare Autonomy in a Post-Covid World", where our authors touch upon a wide-range of bioethical concerns such as COVID-19 vaccine distribution, advance care planning, and contraception ethics. It is amazing to note the variety of domains our authors hail from, including undergraduate researchers, medical students, a doctor, and an attorney. I am beyond excited to present both an editorial and an article written by two of our Journal's talented associate editors. Anjana Ramesh opens this volume with an analysis of psychedelic drug policies in both the U.S. and Portugal, while Nikhil Ramavenkat critically examines the moral dilemma of nootropics, a class of substances that can improve cognitive function.

Ranjitha Vasa, a medical student pursuing a career in Obstetrics/Gynecology, leads with our second editorial, advocating for yearly comprehensive contraception education. Adele Jasperse, an appellate advocacy attorney, argues that phenomenal value is the only sound moral framework we should use when determining the bioethical implications of part-human chimera research. Given the COVID-19 pandemic's devastating impact on people's lives, Sydney Goldberg and Dr. Brian Cummings recommend using social networking sites as a method to motivate young people to participate in their own advance care planning. Juliana Kim and Jennifer Geller, both medical students, explore the bioethical implications of global COVID-19 vaccine distribution between wealthier and poorer countries. Lastly, Xudong Ma examines how to best preserve the bioethical integrity of patients with impaired competence, ultimately recommending the usage of a legal guardianship system. It is truly impressive how all these pieces add to the body of bioethical literature in various fields, disciplines, and schools of thought.

I want to thank this year's authors for their incredible contributions and insights, and to my Journal staff for their never-ending dedication and vision to furthering the ideas of our authors. A special thanks to our Managing Editor Siddhant Kumarapuram for all his advice and Senior Design Editor Nicole Au for her acuity and creativity. Like my colleagues at the Rutgers Bioethics Society, I encourage you to reflect upon and develop your own perspective on the ideas shared by the authors. I hope that you find this issue as engrossing and thought-provoking as we at the Journal have.

Lily Chang

Editor-in-Chief, *The Rutgers Journal of Bioethics*

# *Letter from the Society*

The Bioethics Society at Rutgers University fosters an open forum to express discussion and evaluation of complex and controversial topics in bioethics. We support undergraduates in developing the relevant communication and reflection skills that will help them as they partake in the workforce. Over the course of the past year, we have tapped into grave, moral dilemmas, including physician assisted suicide, as well as bioethical implications of the everchanging landscape of modern biotechnology, including xenotransplantation.

As we strive to support the next generation of healthcare leaders, ethical considerations must remain of paramount importance. From clinical considerations, such as the procedures involved in triage to vast industry level changes, including the advent of genomics in modern medicine, bioethics looks at how scientific progress is changing at a microscopic scale to induce macro-level impacts. Our discussions give members the opportunity to explore diverse angles and viewpoints from which to answer these essential questions. In doing so, we are creating not only more compassionate healthcare providers and scientists, but critical thinkers well equipped to handle the challenges of technology and medicine.

One of the biggest modern challenges that faced the biomedical field was the COVID-19 pandemic. Our club adapted to the changes in modern day discussion in medicine, including the importance of establishing patient trust for modern research while improving communication and outreach. These discussions were in line with our outlook of a post-pandemic world that will value new areas of research and medical care that may not have been considered prior to COVID-19. Despite adapting our purview to meet the changes observed in our world, the Bioethics Society stays connected to the roots of bioethics, specifically the four pillars of beneficence, non-maleficence, justice, and autonomy.

As the fields of biotechnology and medicine progress, we integrate these considerations in order to reveal their applications in modern biomedical industries. Furthermore, we revealed to our members the relevance of these conversations by inviting Dr. Eric Singer, the Associate Chief of Urology Urologic Oncology at the Rutgers Cancer Institute of New Jersey along with the Director of the Distinction in Bioethics Program at Rutgers Robert Wood Johnson Medical School. Via clinical case studies, Dr. Singer revealed the implications of ethical decision making at the junction between patient and biotechnology.

We express our gratitude to our dedicated executive board and members, who work to support the integration and promotion of bioethics amongst our undergraduate population, many of which will go on to shape the future of biomedical progress. Finally, we want to thank the Journal executive board for their hard work in putting together Volume XIII of The Rutgers Journal of Bioethics. We encourage you to reflect upon the ideas shared by the authors to build your own perspective on their bioethical implications.

Julia Zheng & Maxim Yacun  
Presidents, Bioethics Society of Rutgers University



# *the* Rutgers Journal of Bioethics

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**Cover:** USGS. (2020). *Meandering wadis combine to form dense, branching networks across the stark, arid landscape of southeastern Jordan. The Arabic word “wadi” means a gully or streambed that typically remains dry except after drenching, seasonal rains.* Photograph. Retrieved from <https://unsplash.com/photos/AQ9-jKmebjM>.

## A New War on Drugs: Significance of Psychedelic Legalization

by Anjana Ramesh†

The negative impact that drug penalties have had on psychedelic users throughout recent decades shares a disproportionate relationship with their lack of efficacy, as the war on drugs has given rise to a large discourse surrounding the legalization of these substances [9]. As various types of these hallucinogens have been shown to have positive effects on individuals for its therapeutic use in the alleviation of mental disorders and improvements in cognitive flexibility and social connectedness, legalization could allow for more opportunities for users to obtain better health benefits [11]. Legalization has also been promoted under the idea that there would be less governmental regulation, which would suppress biopower, a term frequently used in discussions of political regulation, and which is defined as the state's ability to discipline the public to become subjects of the states. Yet, full legalization also has its complications, as the complete removal of sanctions represents a hypothetical extreme

for the movement, as lack of any regulation could lead to impure drugs being sold on the market and increased rates of psychedelic abuse. Therefore, an investigation surrounding the benefits and consequences of the legalization of psychedelics offers a potential framework for drug regulation in the United States. This paper aims to encourage the implementation of a considerate system where the goal is not to govern the drug but to be willing to educate and regulate in a way in which the individual's relationship with these drugs will be cultivated into a healthy one, therefore leading to a nuanced sensitivity of psychedelics' legality.

### *Biopower and Biopolitics*

The foundation of modern drug policies mainly arises from the "war on drugs" that began in the 1960s, and its motives can be seen through Michel Foucault's analysis on biopower and biopolitics. Foucault, an influential 20th century political philosopher, coined the concept

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† **Anjana Ramesh** is a third-year undergraduate student at Rutgers University majoring in Cell Biology/ Neuroscience and Philosophy. She believes that intersectionality in ethics and medicine allows for a crucial reflection upon human autonomy, dignity, and freedom, and that it is important to have productive discussions in bioethics in order to develop this empathy. Specifically, she is interested in addiction medicine, drug recovery, and its biological, social, and political impacts.

of biopower: “an explosion of numerous and diverse techniques for achieving the subjugation of bodies and the control of populations” [7]. This use of biopower mirrors the attitude of the government during the 1960s: as the counterculture movement was born alongside its peaceful protests against the cultural norms on literature, art, and political ideas, its proponents were at odds with the government regulation surrounding it. To emphasize their rationality, the government sensationalized psychedelic incidents in April 1966 to enforce stricter regulations on LSD (lysergic acid diethylamide) use: in one, a 5-year old girl had convulsions after taking a sugar-cube laced with LSD put in the refrigerator by her uncle; in the other, a student living with mental illness unknowingly stabbed his mother-in-law to death after stating, “man, I’ve been flying for three days on LSD. Did I rape somebody? Did I kill my wife?” [1]. These stories along with reports detailing the negative consequences of LSD, citing evidence of patients in the ER with bad reactions because of it, provide a valid justification for the government’s illegalization of psychedelics, as it seems as though psychedelics were harming the physical and mental health of individuals. However, in the case of the murder, it was revealed that the patient had actually taken “one and a half grains of phenobarbital” (an anti-epilepsy drug) and “three quarts of lab alcohol”, and this coupling triggered his amnesia and stupor [2]. Similarly, individuals who had adverse reactions normally took a high amount of street acid that “usually contained 100 to 200 micrograms...since 1972, the bulk of

it seems to contain no more than 25 to 50 micrograms...and is not enough... to lead to adverse reactions [1]. There has been no evidence that acid leads to brain or genetic damage. Evidently, the government overlooked evidence that LSD was not the primary cause of these events and instead sensationalized them in the media. Their propaganda allowed them to enforce the political rationality that acid was linked to this counterculture, nonconformist movement, thus maintaining resistance against the movement and keeping their political structures intact. These events created a social stigma of the inherent “evil” concerning psychedelics today. Their ability to subjugate the public meant that they were not confronting a public health preventative discourse of drug use but were instead demonizing psychedelic users as individuals who could not function in society, subjugating their autonomy.



Ott, C. (2021). *Brain medicine*. Photograph. Retrieved from <https://unsplash.com/photos/nywp3wRLIMw>.

Further, the government exerted its authority by concentrating it within laws that limited the potential for legalization through the correlation that psychedelics were harmful to overall society. The government held two Senate subcommittees in 1966 that illegalized hallucinogenic drugs, even though they heard from various eminent individuals such as psychologist Timothy Leary and Senator Robert Kennedy who claimed that “perhaps to some extent we have lost sight of the fact that it can be very, very helpful in our society if used properly” [16]. Instead, the subcommittee concluded that LSD caused individuals to “withdraw not only from society but also from meaningful family ties” and thus developed “the loss of all cultural values and are lost to society” [14]. Rather than centering the effects of psychedelic use to autonomous choices made by drug users, the subcommittee correlated responsibility of psychedelic users to institutionalized traditions such as family values. This relationship reduced psychedelic users to subjects of the state, as compliance was emphasized through displacing virtue on cultural and political norms rooted in maintenance of power. Psychedelic users’ sense of self were subjugated, as the government expanded its power to suppress autonomy. Evidently, they were afraid of the disarray that the widespread use of psychedelics could cause in the stability of their functionalist society [12]. If psychedelics were legalized, it would allow individuals enhanced levels of perception and cognition, thus turning nonconformist and opposed to the government’s societal and political structures. As Foucault

explains, “the ‘right’ to rediscover what one is and all that one can be, which the classical juridical system was utterly incapable of comprehending, was the political response to all these new procedures of power which did not derive, from the traditional right of sovereignty” [8]. Since a government’s structure is inherently dependent on a hierarchy of power, they perceive individuals as political subjects and use individuality as a tool to exert disciplinary power. As psychedelics promote an “unconstrained style of thinking,” it undermines the very hierarchy and individuality that the government tries to suppress with its judicial power [11]. Thus, the government’s techniques of linking psychedelics to the anti-war, counterculture, and liberation movement allowed the continuation of their traditional disciplinary mindset and perpetuated the stigma surrounding psychedelics. The framework in psychedelic legalization should begin by being attentive to the influence of governmental control in maintaining biopower and furthering hegemonic tendencies.

### *Portugal’s Case Study: Drug Decriminalization*

To foster a more equitable drug policy that is independent of these government motives, Portugal may provide insight into a newfound perspective on drug decriminalization. Since 2001, Portugal has decriminalized a variety of drugs, including psychedelics such as cannabis and psilocybin. Decriminalization is defined as “the removal of sanctions under the criminal law, with optional use of administrative sanctions,” as opposed to legalization which completely

removes all penalties [10]. Even though the drug itself is prohibited, the use and possession of up to ten days' supply are enabled, and numerous social services are provided to educate communities more affected by addiction such as high schools, underprivileged neighborhoods, and brothels. This freedom coupled with education has resulted in lower HIV and Hepatitis infection rates. Indeed, "a decreasing trend in the total number of notifications of human immunodeficiency virus (HIV) infection cases has continued to be registered since the early 2000s in Portugal" with only 12% testing positive in 2015 [13]. While the expected drug tourism industry did not materialize, the teenage hard drug use remained stagnant, and excessive use of psychedelics like MDMA by adults decreased from 7.6 to 6.8 per 1000 people [3]. As of 2015, Portugal has the lowest drug-induced death rate in Western Europe. These positive effects from decriminalization demonstrate how it can decrease negative consequences of psychedelic use such as disease rates due to injection and psychological addiction. By legalizing small amounts, Portugal demonstrates positive results of legalization.

However, there are a few limitations to Portugal's model, as there are also negative effects. Even though drug rates stabilized after a few years, "the Lisbon government still has no control over drug purity or dosage, and...organized crime still controls Portugal's supply and distribution" [3]. If the government cannot regulate the drugs, more opportunities arise for corrupt businesses to sell drugs, as manufacturing impure drugs

are cost-reductive and easier. In fact, many markets "adulterate their LSD with a variety of substances, including amphetamines and even strychnine... [and contain] a variety of related substances whose effects are little known" [4]. These corrupt organizations can result in a dangerous market for the substance. It also allows the opportunity for pharmaceutical companies to profit from the selling of psychedelics, as they can market the drug in manipulative ways, reducing competition in the market and ultimately creating monopolies in which they then have sole control over the drug. Legalization would increase the freedom of the manufacturer to effectively increase their profit by selling impure substances to the consumer at a higher price. It becomes ironic, as power is now manifested in these companies who would have control over society as opposed to the government. A cost-benefit analysis may be useful in this case to analyze the individual risk probability of purchasing from independent companies, of which can be futile, against governmental control, oftentimes resulting in incarceration.

Additionally, as decriminalization still prohibits psychedelic/drug purchase, contraband drug shipments and illicit markets necessarily exist to purchase them as a result. This creates a paradox, as illicit markets would occur in both cases of decriminalization as well as illegalization, and so can only be reduced if psychedelics were legalized completely; yet, full legalization still prevents the government from controlling the purity and efficacy of the substance. Therefore, even though decriminaliza-

tion would not completely prevent illicit markets from occurring, at least some regulation would provide a minimum level of drug safety for the consumer even as the illicit markets keep existing.

In encouraging a framework for psychedelic regulation, another significant limitation of Portugal's case must be described: the cultural disparities present between the U.S. and Portugal. Many arguments claim that the benefits of Portugal's decriminalization are attributed to the increase of education and treatment social services in addition to legalization. Indeed, once Portugal decriminalized psychedelics, they subsequently created Centros de Atendimento a Toxicodependentes, or CATs, which are drug prevention centers that provide people with a substance use disorder

with psychiatric help and methadone, a narcotic to help prevent withdrawal symptoms and addiction. They also have administrative programs like Project Vida, created by the prime minister that "promote a series of state initiatives by local authorities and private bodies... that makes them more effective in coordinating treatment of drug addicts" [5]. These initiatives implemented both on the state and federal level promote safe drug use and decreases addiction rates through readily available rehabilitation and education centers, as seen in 2017 when more than 16,000 clients went to CAT's to receive successful therapy [17]. These enforcements would have ceased to occur unless a major cultural shift concerning more tolerance on drug use, increased scientific research on the ben-



Czerwinski, P. (2019). Photograph. Retrieved from <https://unsplash.com/photos/Q5oCIFL2xKc>.

efits of psychedelics, and local and federal activists pressing for federal legislation happened. Unfortunately, the “war on drugs” was built on the demonization of drugs, making the public believe that the conflict lied in the drug itself and not in the individual’s relationship with them. For these reasons, Portugal’s model might not be viable for the United States, where “the White House has remained reluctant to address what drug policy reform advocates have termed an ‘addiction to punishment’” [6]. In the United States, the war on drugs and subsequent legislation aimed to eradicate the drugs entirely instead of understanding the need for individuals to develop healthy relationships with them. However, Portugal’s model should not be disregarded entirely, as it demonstrates how additional implementations surrounding the balance of legislation by the state and federal aid promotes safer care and less stigma surrounding psychedelics.

## CONCLUSION

The benefits of psychedelics in helping with mental health problems and therapeutic treatment have long been established, and they ultimately provide others with the capacity to understand and reflect upon the human experience; to gain the maximum advantages of them, the public and the government must become aware of both their own biases and how the latter’s war on drugs has created stigma on psychedelics and addiction. It is important to encourage a cultural shift with more education on the cause and effects of these drugs and promote harm reduction so that psy-

chedelic users can better understand their relationship to these drugs, receive treatment for substance use disorder, and help dissolve the inherent stigma surrounding them. Perhaps in the future, a more sensitive psychedelic drug policy can be implemented to not only stop the war on drugs but to prioritize public health concerns and safety for psychedelic and other drug users.

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## Commencement of Contraception Education

by Ranjitha Vasa<sup>†</sup>

Commencement of contraception education is a tricky subject to address as we are concerned about the content of contraception education, but most importantly at what age is it appropriate to introduce children to this subject. Traditionally, contraception education is implemented in health curricula beginning at the high school levels (9-12 grades with students aged 14-18) across the United States, and many parents rely on schools to provide this education. However, there are many sexual education programs across the United States that vouch for abstinence as the only form of contraception and do not go into detail about ways to prevent pregnancy. According to the National Survey of Family Growth conducted between 2015-2017, 21% of females included in the analysis said they had sexual intercourse by age 15, 53% by age 17, and by age 20 the number increased to 70%. Among the males surveyed, 20% had sexual intercourse by age 15, by age 17 the number jumped to 48% and by

age 20 it was 77% [1]. Though pregnancy rates have been dropping, there has been a steady rise of sexually transmitted infections in the United States, and teenage pregnancy is higher than in any other developed country [3-5]. Opinions on contraception methods are heavily influenced by experiences of both family and friends, which shape an individual's opinion and knowledge about contraception methods. In this paper, we aim to identify the ideal age range to commence contraception education.

### *History of Contraception Education in the United States*

The main goal of sexual education is to promote sexual health, and the World Health Organization's 1975 definition of sexual health is as follows: "sexual health is the integration of the somatic, emotional, intellectual, and social aspects of sexual being, in ways that are positively enriching and that enhance personality, communication, and love." Fundamental to this concept is the right to sexual in-

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formation and the right to pleasure [7]. The history of sexual education in the United States has varied throughout the years. Up until the 1960s and 1970s, sexual education was focused on social hygiene and moral purity [7].

Starting in the 1980s, sexual education in the United States became more comprehensive as focus shifted to providing information about contraception and abstinence only programs [8]. From here on out, sexual education was divided between the aforementioned categories. Why certain schools chose one program over the other was between two beliefs: the former was based on the idea that providing detailed information to students would help them make informed decisions regarding their contraception, and schools that chose abstinence-only programs thought that if students had detailed information about contraception, this would provide an incentive for them to be more sexually active [9]. Thus, the National Campaign to Prevent Teen and Unplanned Pregnancy published *Emerging Answers* in November 2007, where 115 programs, which focused on the role of sexual health outcomes for adolescents who were exposed to comprehensive sexual education, were evaluated. Students belonging to 48 of these programs exhibited a delay in age of first intercourse, had fewer sexual partners and frequency of sexual intercourse, along with an increase in condom and other contraceptive use. [11,12]. Furthermore, when Kirby (2008) evaluated the impact of abstinence-only versus comprehensive sex, HIV/AIDS, and STD education curricula, he found the former programs did

not delay primary sexual intercourse, while,  $\frac{2}{3}$  of the latter showed a delay in initiation of sex and increased use of condom and contraceptive use [10]. In fact, programs that offer a comprehensive approach to sexual education (encompassing both abstinence and use of contraceptives) have a positive impact on young people [11,12].

Programs that focus solely on abstinence have been on the rise from 1992-2005, with an increasing number of adolescents having absolutely no formal instruction about birth control [13]. The CDC notes that more than 95% of adolescents (ages 15-19) across the United States have received some sort of "formal" sexual education from schools, community centers, or churches before the age of 18 [14]. However, when the same age range of adolescents were analyzed by both topic and gender from the National Survey of Family Growth, there was a significant decline in their retention of the formal sex education from 2006-2013, specifically in the populations away from metropolitan areas. There was a significant decline in female retention of birth control information (70%-60%), methods of denying sex (89%-82%), sexually transmitted disease (94%-90%), and HIV/AIDS (89%-86%) [14]. There was also a significant decline in male retention of information regarding birth control (61%-55%). Interestingly, 21% of females and 35% of males do not report receiving any birth control information from their parents [15].

Only about half of girls and a third of boys receive some information about birth control before their first intercourse



Reproductive Health Supplies Coalition (2019). *A range of contraceptive methods: contraceptive pills, emergency contraception, condom, IUD, vaginal ring, implant.* Photograph. Retrieved from <https://unsplash.com/photos/YR44OXwMA4>.

experience [16]. Yet another study has found that about 40% teenagers from 18-19 years old know very little to nothing about condoms, and roughly 75 percent know very little or nothing about the pill [17]. What is so interesting is that many American parents do support sexual education that is comprehensive to their children encompassing contraception (84%), abortion (79%), , sexual orientation (76%), the consequences of becoming sexually active (94%), and risks of becoming sexually active (94%), along with the emotional sides of sexual relations [18]. Most recently, it was shown that 90% of parents believe that sexual education programs that begin in middle school should cover the topics listed above, and a majority of these parents do not support abstinence-only programs [19]. Unfortunately, many parents do not talk about these topics with their children.

Interestingly, 41% of parents have admitted to discussing how to say “no” to sexual intercourse with their teens, while only 27% of their teens said they had this discussion. This discrepancy continues as 50% of parents said they’ve discussed both healthy and unhealthy relationships with their teens, but only 32% of teens said they’ve discussed this with their parents. Furthermore, 29% of parents said they have discussed birth control methods with their teens, while only 24% of teens said they have discussed this many times with their parents [19]. This is important as there remains a consistent disparity between what parents report discussing with their children versus what actually has taken place when it comes to discussing sexual health and relationship wellness.

#### *Biological basis of Contraception*

Contraception gives both women and

men control of their reproductive health. Education on contraceptive methods for adolescents should include addressing the different types of contraception that exist, since it is an exhaustive list. Contraception devices range from LARCs (Long Acting Reversible Contraception) such as intrauterine devices (IUDs), oral contraceptive pills (OCPs), and condoms among others. Given the wide variety of tools to choose from, it is important for the youth to be aware of what options exist to make an informed decision that is adequate for their lifestyle. In 2015-2017, 78% of young females and 89% of young males aged 15-24 who had sexual intercourse before age 20 used a method of contraception the first time they had sexual intercourse [1]. Further, the contraception tools of choice include the condom, withdrawal, and the OCP. There was an increase in the use of emergency contraception and LARC in the past three decades [1].

### *Right to Contraception Information for All Adolescents*

Contraception education commencement needs to be standardized throughout the United States as it gives adolescents the right to making informed decisions when it comes to their sexual health. It has been shown that adolescents who are sexually active and have faced barriers with respect to their sexual and reproductive health, inadvertently impact their overall well-being in a negative manner [20]. Furthermore, adolescents are not taken seriously because of their age and many providers do not provide information about contraception to these patients for fear

of encouraging further sexual activity, amongst other reasons [20]. As a result, these patients are at a greater risk for unintended pregnancy and infection. If adolescents are not given proper contraception education, then they fall at risk for choosing contraception that does not match their lifestyle/preferences [21]. Contraception education needs to begin before the commencement of sexual activity in adolescents, and it must provide them with sufficient education to make informed decisions based on their preferences. The American Association of Pediatrics recommends beginning conversations starting at the age of 11, by encouraging parents to openly talk about contraception, sexuality, and even internet use/social media aligning with the family and child's beliefs, values [22]. By introducing sufficient education-that is, being aware of how differing methods of contraception work, the time frame for follow-up appointments, potential side-effects, and being aware of which providers close to them will be able to offer such services. There is substantial evidence that shows that individuals who receive contraception according to their needs are more satisfied and actually adhere to the regulations of their contraceptive method [23].

### *Effective Dissemination of Contraception Information*

How contraception information is relayed to adolescents plays a crucial role in their retention and needs to be appropriately tailored for their age group. For those in prime reproductive ages, how the education is received is what decides how effective the retention capacity of

this valuable information is. In a project that examined how women retain information about LARC, providers showed women information from most to least effective contraception. In the paper, the authors demonstrate that when information was presented by focusing on the effectiveness of the method, rather than discussing how the method can fit into the patient's lives, then the information was not retained as well. Therefore, counseling for contraception should take into account the individual's personal preferences and lifestyle, and in this case tailoring the education based on maturity and grade level of the children, which will not only strengthen patient autonomy but also promote better sexual health [24].

#### *Inclusivity of the Male Gender when Discussing Contraception Information*

There exists many rationales why contraception education is limiting for certain populations, especially the male gender. Ever since contraceptive services were "medicalized" for women (ex. IUDs, OCPs), contraception education has been focused towards females and centers around providing female contraception. As a result, it seems that the male gender is left behind when it comes to understanding the full scope of contraceptive education. It is fair to say that information on contraception education is geared towards women, from the educators to information pamphlets, even at family planning clinics. It would be fruitful for family planning clinics to have more male staff, and encourage male healthcare professionals to conduct contraception education in schools so

as to destigmatize the feminine culture around contraception, and emphasize the shared responsibility between males and females when it comes to sexual intercourse [25]. In rural areas of the United States such as Tulare County, California there is not only a lack of providers able to disseminate information and physically provide contraception, but also, there are prevalent local standards that encourage abstinence above providing comprehensive contraception education [26]. As an upholding of social justice, both female and male genders who are sexually active should have access to contraception education because it can protect these individuals from STIs and other adverse outcomes of sexual intercourse.

#### **CONCLUSION**

Initiation of contraception education should begin at the age of 11, according to the American Association of Pediatricians. At age 11, it is recommended to begin having those conversations and gauge exactly where the child is in terms of sexual maturity. Specific education in schools should begin when children are between ages 13-14 years old. The quality of the education should be a mix of specific contraception education and abstinence. As of October 1, 2020, 30 states and the District of Columbia require public schools to teach sex education, of which 28 require both sex education and HIV education, and 22 states require that if sex and/or HIV education is provided it needs to be medically, factually or technically accurate [27]. Definitions of 'medically accurate' can change which can be monitored by eval-

uating the health curriculums annually to make sure it is based on information from “published authorities” that medical professionals rely on. Essentially, not only is the commencement of contraception education crucial in the young lives of adolescents, but also the content delivered is encouraged to be comprehensive.

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# Ethical Implications Of Research On Part-Human Chimeras: The Need For A More Rigorous Moral Status

by Adelaida Jasperse<sup>†</sup>

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*Research on part-human chimeras, creatures possessing animal and human cells, raises the ethical concern of whether this technology changes chimera's moral status such that to render this research morally impermissible. This paper argues that the current conception of moral status for these beings should not be rooted in uniquely human qualities but, rather, in properties that are morally significant in their own right. In this context, moral status should be conceived in terms of what is valuable in diverse kinds of conscious experience, otherwise designated as phenomenal value. Chimera research primarily entails inserting human embryonic stem cells "hES cell" into animal embryos. Another pertinent stem cell type, human-induced pluripotent stem cells ("iPS") of which capacity for division allows them to transform into any type of the adult body cells including brain cells, are used to create structures called brain organoids. Apart from stem cell technology, chimera application involves grafting human somatic cells or tissues into animals that have been rendered immune-deficient. The current prevalent arguments offer varied views about the moral status of chimeras and their corresponding interests. Differing views lead to confusion about the treatment of chimeras and bring into question the views' epistemic merits. More significantly, their one commonality; namely, that they ground the chimera moral status in uniquely human qualities such as intelligence, memory, self-awareness, communication or numeracy, is vulnerable to moral scrutiny. Instead, phenomenal value—which connotes the value found within different conscious experiences including but not limited to smell, taste, motor activities, mental states and processes unique to that being—is epistemically and morally sounder. This is so because phenomenal value does not favor emphasizing intellectual features or disregarding other shared qualities and experiences. It also provides consistency and avoids the moral risk inherent in the present moral judgments and practices. Our moral obligation to such*

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*a being would hinge on the types and the degree of phenomenal value. This type of phenomenal value that is not uniquely human should deserve sufficient moral weight for safeguarding against inflicting pain and killing. Guided by this moral status framework, we should implement regulations that ban this unethical form of research.*

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## **WHAT IS CHIMERA RESEARCH AND WHY DOES IT MATTER TO RESEARCH ETHICS?**

**R**esearch on part-human chimeras, creatures possessing animal and human cells, has increasingly gained prominence in biomedical research. Alongside its prominence significant concerns whether chimera experimentation, especially neural chimera research, is justifiable have risen [1]. Of particular saliency is the question – might this technology change neural chimera’s moral status such that to render this research morally impermissible?

Chimera research, primarily, entails inserting human embryonic stem cells “hES cell” into animal embryos. Stem cells are cells that renew themselves and give rise to more specialized kinds of cells. Another pertinent stem cell type, human-induced pluripotent stem cells (“iPS”) of which capacity for division allows them to transform into any type of the adult body cells including brain cells, are used to create structures called brain organoids. These entities are tiny collections of neurons which self-organize into structures that resemble parts of the human brain producing specific architecture like neural progenitor zones and rudimentary cortical layers. They are of particular scientific interest as well as ethical concern when transplanted to animals where they grow quicker and survive longer. Apart from stem cell technology, chimera application involves grafting human somatic cells or tissues into animals that have been rendered immune-deficient [2].

Generally, the degree of chimerism depends on the type and number of stem cells transplanted, the host species, their stage of development, and the location of transplantation of stem cells. Of special scientific interest and ethical concern is the type of chimerism that invades a great portion of the nonhuman animal including their central nervous system. In this realm, most discussions have focused around two sorts of chimeras resulting from: (1) transferring human pluripotent stem cells into early-stage gestating animal embryos; and (2) grafting a large number of human pluripotent stem cells into the central nervous system (“CNS”) of living animal hosts [3].

Chimera technology has flourished in the past several decades because of various scientific advantages. They include studying human tissue of scientific interest during the incipient stages of translational research without experimentation on living human subjects; understanding how human stem cells react, beyond the confines of a culture dish, in a

non-human living organism; or how they integrate into intricate systems [4]. A non-inclusive list of specific goals encompasses generating human tissues and organs inside human-animal chimeras, understanding and treating a variety of cancers and gaining insight into human brain development and neurological disorders, such as autism or schizophrenia.

Despite its broad ranging scientific value and skepticism on the likelihood of the current upgrade potential of this technology on the animal hosts, concerns about the probability of enhancement that would be relevant to moral status persist. Recent experimentation with human-mouse brain chimeras finding that chimeric mice developed enhanced capacity for learning and memory further highlight this point [5].

Of course enhancement is not inherently morally objectionable and could even be beneficial. The importance of the ethical implications of this research, however, involve the concern that humanlike capacities would augment the propensity for suffering [6], especially on research chimeras that are prevented from exercising any autonomous expression, most notably, farm mammals and neural human nonhuman primate chimeras (“H-NHP”), the primary focus of this paper.

## **WHAT IS THE REGULATORY LANDSCAPE OF CHIMERA RESEARCH?**

In the United States (“U.S.”) no federal law specific to chimera research exists. Generally, animal research in the U.S. is governed by the Animal Welfare Act (AWA) [7] and the Public Health Service (“PHS”) Policy on Humane Care and Use of Laboratory Animals [8]. This legal framework requires that research facilities appoint Institutional Animal Care and Use Committees (“IACUC”), local working groups, to oversee animal research. AWA and its supporting regulations contain certain requirements that procedures “will avoid or minimize discomfort, distress, and pain to the animals” and that “animals’ living conditions will be appropriate for their species . . . and contribute to their health and comfort” [9]. In essence, these legal documents mandate that animals are used for legitimate purposes, not subjected to pain if possible and if pain is unavoidable to minimize its severity. Further, they require that the proposed animal experimentations have scientific merit and that the lowest statistically significant number of animals be used.

The other regulatory component pertinent to chimeric research, is that concerning stem cell research, which is subject to a patchwork of guidelines. The National Academy of Sciences’ (“NAS”) guidelines, the most instructive in this space, make the following recommendations. That the introduction of hES cells into nonhuman animals, at any stage of embryonic, fetal, or postnatal development, be reviewed by stem cell research oversight committees (“SCRO Committee”) Special emphasis should be

dedicated “to the probable pattern and effects of differentiation and integration of the human cells into the nonhuman animal tissues” [10]. Impermissible at this time should be the introduction of hES cells into nonhuman primate blastocysts or in which any non-human embryonic stem cells are introduced into human blastocysts. Finally, no animal with hES cells introduced at any stage of development should be permitted to procreate.

The International Society of Stem Cell Research (“ISSCR”), a non-profit organization with a mission to promote excellence in stem cell science and applications to human health, recommends that the transfer of human stem cells or their direct derivatives into postnatal animals be reviewed by animal research committees [11]. ISSCR’s guidelines exclude chimera research involving great and lesser ape species hosts such as chimpanzees, gorillas, orangutans, bonobos, gibbons, and siamangs [12].

The regulations adopted by the National Institutes of Health (“NHI”) in 2009 for human embryonic stem cell research are less restrictive than the NAS guidelines [13]. They do not require SCRO review for hES cells placed into non-human animals. In the U.S. experimentation on a wide range of animals, including monkeys and the great apes, is not prohibited [14].

## **DO PART-HUMAN CHIMERAS HAVE MORAL STATUS?**

Determining the moral status of part-human chimera, composed of animal and human cells, and particularly chimeras whose brains partially or entirely consist of human neurons, is salient because to have moral status means to deserve at least some protection afforded by moral norms. It imposes an obligation on other agents to uphold the interests that flow from the entity’s moral status, which matter for the entity’s own sake. For example, an entity that possesses full moral status has a moral interest that stringently obliges others to not arbitrarily kill or interfere with its bodily integrity, treated it in a way that respects not only its interest to not be harmed but also its interests in being treated fairly and have its welfare furthered. An entity with a lesser degree of moral status might also possess these interests but they might be overruled by other competing interests. Yet, it might still be entitled to that degree of moral standing conferring the most basic interests of not being killed or experimented on [15].

We implicitly ascribe moral status to living things in various degrees. And we accept as axiomatic that humans have full moral status or sufficient moral status so that, at minimum, killing or inflicting serious injury on them without proper justification is considered a heightened moral wrong. Generally, moral status is, by and large, found on our cognitive abilities such as rationality and self awareness. In the case of neural H-NHP chimeras, it is not inconceivable that they might develop capacities that might further augment their moral status.

The creation of part-human chimeras has sparked a debate about the

degree to which they might acquire moral status. Some are against their creation, others permit it with some restrictions, and another view is fully supportive. The prohibitionist camp argues that research involving the transplantation of human stem cells and their derivatives into early fetal or embryonic nonhuman animals might lead to their humanization. They might acquire human-like abilities relevant to moral status. This in turn, might confer upon them near or full human moral status. The resultant ethical concerns would then warrant restricting this research until empirical and ethical uncertainties about the degree of chimeric status enhancement are better understood [16]. Another view in this camp, prohibits chimera research on grounds that elevating human-nonhuman chimeras to equal or near the level of human status would be morally repugnant, an affront to human dignity and a denigration of our values [17].

Yet another perspective on the moral implications of this research posits that such experimentation would diminish human dignity because a chimera cannot fully exercise a cluster of psychological and cognitive capacities that are intrinsically human and associated with human dignity. Their focus is chimeric experiments involving transfers of human brain or retinal stem cells into early nonhuman embryos. They therefore delineate conditions under which this research is permissible as follows: 1) the number of cells transferred should be restricted to the smallest number necessary to reach the research goal; (2) the host animal chosen for the transfer should not be morphologically or functionally similar to humans; and (3) only dissociated human stem cells rather than post-anatomical tissue transplants should be utilized in the development of early and later prenatal chimeras to guard against any possibility that features of human patterns associated with human dignity would emerge [18].

A similarly permissive approach with caveats opines that features of mental status include mental capacities, language, and rationality. A creature that achieves these capacities has moral standing. With a focus on the H-NHP grafting technology, this view proposes that research committees



Hays, D. (2017). *Scientist with a Petri dish*. Photograph. Retrieved from <https://unsplash.com/photos/tGYrlchfObE>.

consider six factors in determining the permissibility of H-NHP: They are: 1) the proportions of engrafted human cells (a higher proportion would increase the probability of humanness neural function); 2) neural development (the earlier stages of development will increase function of engrafted cells); 3) the species of non-human primate (the closer physiologically with humans the greater similarities with brain structure); 4) brain size (the closer to human scale the higher the capacity to allow structural complexity); 5) the site of integration (certain areas of the brain, such as cerebrum, are more conducive to higher brain function); and, 6) brain pathology. This framework suggests that the most ethically concerning experiments are those where human neural stem cells are engrafted in the developing brain of great apes and comprise a substantial portion of the engrafted brain [19].

Another argument grounds moral status solely on one feature: self-consciousness, designated as Factor X. This factor is an agent's cognitive capacity to recognize itself as having mental experiences or an ability that entails "thinking about thinking" also described as recursive thinking. This view admits that non-human primates are "sentient, highly intelligent and capable of simple self-discernment" but yet devoid of moral status because they cannot think of themselves as themselves. Cognitive differences between animals and humans are differences in kind therefore for human chimeras to gain moral status a transformation is required. Consequently, this view recommends that the focus of chimera research remain, as it is, within the framework of animal welfare.

## **HOW CAN WE CREATE A MORE CONSISTENT AND RIGOROUS FRAMEWORK REGARDING THE MORAL STATUS OF PART-HUMAN CHIMERA?**

These prevalent arguments offer varied views about the moral status of chimeras and their corresponding interests. Differing views lead to confusion about the treatment of chimeras and bring into question the views' epistemic merits. More significantly, their one commonality; namely, that they ground the chimera moral status in uniquely human qualities such as intelligence, memory, self-awareness, communication, or numeracy, is vulnerable to moral scrutiny.

One approach, with which I agree, argues that our conception of morality for other species should not be rooted in uniquely human qualities but, rather, in properties that are morally significant in their own right [20]. The current human yardstick with which we evaluate animal moral status, in general, and that of part-human chimeras, in particular, is designed to measure uniquely human capacities. As such, it is biased, logically flawed and inconclusive.

It is biased because it solely advances the interest of humans without regard to the degree of the moral status of other animals and their cor-

responding interests. It effectively creates a species membership that non-human animals cannot enter. As it is fashioned to measure unique human capacities, it is inevitable that it will fail for other species. According to this species prejudice framework, only humans can enjoy moral status because they are the only ones who have uniquely human characteristics. This logic is also flawed and circuitous because it holds that non-human species cannot have moral status because they are not humans.

Moreover, this approach is inconclusive because it is empirically non-measurable given that our understanding of other animals is insufficient and still evolving. Although the scientific community now recognizes that many animals are sentient, in the past this feature was attributed solely to humans. Discoveries of animal tool usage continue to demonstrate



Anirudh. (2021). *DNA*. Photograph. Retrieved from <https://unsplash.com/photos/YQYacL-W8o2U>.

our limited understanding and tendency to underestimate their abilities [21]. Regarding the latter, recent research on chimpanzees, for example, shows that they excel at face recognition. But this discovery connotes a departure from the previously held understanding that their facial recognition was inferior because they were tested on human faces based on an erroneous assumption that human faces are more distinguishable to them, and hence easier to recognize [22]. Indeed, epistemological questions about what we know and do not know about the conscious lives of animals are not settled.

In rejecting the uniquely human qualities approach, the question becomes what cluster of moral properties are significant for their own sake, therefore germane to part-human chimeras? Sentience, a capacity to feel pain and pleasure and to suffer, is present in many animals and certainly in H-NHP whose suffering resembles ours because of our physical, emotional and cognitive similarities. Pain is perceived as evil and pleasure as good. Intentionally causing pain to an entity means harming it. It is fundamental to morality that pain causing actions are prohibited unless there are justifying moral reasons.

Sentience therefore has intrinsic moral value, and it is a sufficient condition for conferring moral status to sentient beings. A sentient being is a conscious being, in that it is capable of having some kind of subjective experience. Sentience and consciousness are intrinsic properties that provide a being with intrinsic value. They are intrinsically valuable properties of moral status. Moral status can be conceived in terms of what is

valuable in diverse kinds of conscious experience, otherwise designated as phenomenal value. The latter connotes the value found within different conscious experiences including but not limited to smell, taste, motor activities, mental states, and processes unique to that being [23]. A being's moral status would spring from its phenomenal value that is derived from its conscious and sentient experience. Our moral obligation to such a being would hinge on the types and the degree of phenomenal value. Many animals have experiences that are unique to their species, nonetheless, they are enjoyable, engaging, and even spectacular. Some of these experiences are shared with humans like great apes' and monkeys' social complexities and mammalians' caring interactions [24]. And some are beyond our capacities, such as soaring eagles, dashing cheetahs, and sonar-generating dolphins.

Many of the characteristics that make human life imbued with high moral status and deserving of protection, such as pain and pleasure and social interactions, are shared to some degree with many other animals. Salient features of phenomenal value do not require the presence of sophisticated cognitive capacities. This type of phenomenal value that is not uniquely human should deserve sufficient moral weight for safeguarding against inflicting pain and killing. In the context of farm mammals or a neural H-NHP chimera, such as a pig or a monkey, having a brain infused with human neurons, might have phenomenal value unique to its animal species, its human aspects, or its own unique chimeric nature.

It is true that the framework proposed here does not yet offer a methodology for determining the strength of the phenomenal value in a wide variety of species. It is, however, epistemically and morally sounder than the anthropocentric approach because it does not favor emphasizing intellectual features or disregarding other shared qualities and experiences. It also provides consistency and avoids the moral risk inherent in the present moral judgments and practices.

## **WHAT SHOULD WE DO NEXT?**

The creation of the chimera technology could prove beneficial for the study of serious diseases, therapeutic drug development, and generating tissues and organs for transplant. The phenomenal value framework is a better approach for addressing the important ethical concerns about certain animals' moral standing and, especially, part-human chimeras' moral status. We should exercise epistemic humility about the lives of the beings not like us who have a significant degree of moral status. And, currently, at minimum, we should draw the line on banning farm mammals and H-NHP neural chimera research. The analysis and empirical knowledge suggest they have a sufficient level of moral status precluding us from subjecting them to significant pain or death. Guided by this moral status framework,

we should implement regulations that ban this unethical form of research. This would be the first step toward balancing two key goals: facilitating ethical research involving part-human chimeras and preventing unethical research on chimeras that have a substantial degree of moral standing.

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## Young Adults and Advance Care Planning: A Promising Path Forward with Social Networking Sites

by Sydney L. Goldberg<sup>†</sup> and Brian M. Cummings<sup>††</sup>

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*Advance care planning (ACP) is an essential part of health management for patients and caregivers, with the COVID-19 pandemic illuminating the crucial role of understanding patients' preferences when hospitalized and seriously ill. Although ACP awareness was increasing pre-pandemic, current collaborative efforts to improve patient's knowledge and documentation of their preferences has not engaged young adults. The cause of serious illness and death for young adults is frequently unintentional or unexpected, leaving limited opportunity for exploration of medical care desires when ill. Proactive engagement is crucial and social networking sites (SNS) can serve a potential role. Young adults spend time on, and their identities and communities can be shaped by their SNS involvement. Evidence from pilots in organ donation and smoking cessation reveal SNS can motivate behavior in stigmatized health-related topics. Given the existing gaps and the availability of SNS, the time is right to operationalize ACP into SNS.*

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**K**aren Ann Quinlan and Nancy Cruzan were two healthy young women whose lives were suddenly upended. Their families and providers were unexpectedly forced to consider invasive medical care, with little understanding of what Karen or Nancy themselves would have wanted. The result was emotional distress for the families and providers, prolonged conflict, confusion, and ultimately the courts. Karen and Nancy's legal cases were sentinel events, highlighting the emerging need for advanced directives and health care proxies [1]. A more recent term, advanced care planning (ACP), has evolved to encompass the comprehensive process that can include documentation like instructional living wills and healthcare proxy forms, but also emphasizes the need to have continued dialogue with healthcare proxies about values, goals, and preferences [2].

Since these legal landmarks, participation and programming to encourage ACP has increased. The 1990 Patient Self Determination Act requires hospitals that receive Medicare or Medicaid payments to provide information to patients about advance directives [3]. Given many providers and patients remain largely unengaged or avoid end-of-life conversations, multiple outreach and collaborative efforts were initiated in the United States for ACP over the past decade. Organizations, such as The Conversation Project (<https://theconversationproject.org/>) and Advance Care Planning Decision, now provide programs to encourage people to talk to their loved ones about ACP [4, 5].

The recent COVID-19 pandemic has further emphasized the importance of engaging ACP with increasing numbers of patients arriving to hospitals incapacitated, unable to have visitors, and without designated healthcare preferences or proxies. This has provoked healthcare providers and organizations to actively encourage people to fill out advanced directives and healthcare proxy forms [6,7]. For many who were not alive or could not comprehend the relevance of the cases of Quinlan and Cruzan, the COVID-19 pandemic emphasizes the impact of sudden death and invasive medical care. Pervasive throughout all forms of news and media, COVID-19 creates an opportunity to reach the population on end-of-life decisions and invasive medical care. In summation, the COVID-19 pandemic has reaffirmed the importance of engaging in advanced care planning to improve the concordance between care preference and actual care delivered to the patient [8]. Despite landmark cases involving previously healthy young adults, the existing organizational programming, the COVID-19 pandemic, and the benefits of advanced care planning, young adults have largely remained unengaged with ACP [9]. Current organizations promoting ACP focus on older adults or adults with chronic illness, without a targeted outreach of healthy young adults. Concentration on the elderly as opposed to young adults makes intuitive sense, as young adults are not perceived to be closer to the end of life. Yet despite the perceived time distance between

young adults and death, ACP is a relevant public health issue for this population. For young adults, death is often sudden and caused by an unexpected trauma, whereas older adults die more frequently from chronic illnesses [10]. The suddenness of potential death or serious injury is a primary reason why ACP is particularly important for the population of young adults. There is often an inability to have ongoing conversations over a long period of time that older adults can be afforded as one adjusts to a chronic illness, the effects of old age, or a terminal progressive condition. The inability to have continued conversations as a result of the unintentional accidents highlights one of the important reasons why engaging in ACP with young adults is essential. This can ensure that prior to these accidents, health care proxies are named, the patient's wishes are known, and the patient's autonomy can be respected.

With this epidemiological need, research demonstrates that young adults want to have these conversations, but the best approach for this population is unknown [9, 11-14]. The challenge remains in how ACP programs can reach healthy young adults, who typically have end-of-life care far removed from their immediate consciousness. For this, a population wide approach appears necessary to engage as many healthy young adults in ACP as possible. Given the amount of usage by young adults, social networking sites (SNS) can serve as one potential method to increase engagement with ACP.

## **ROLE OF SNS**

Social networking sites (SNS) are defined as web-based services that allow individuals to (1) construct a public or semi-public profile within a bounded system, (2) articulate a list of other users with whom they share a connection, and (3) view and traverse their list of connections and those made by others within the system [15]. Over 90% of young adults are internet users and the majority of time that young adults spend on the internet is spent on social networking sites, such as Facebook, Instagram, and other forms of entertainment [16, 17]. Young adults spend more time on SNS than any other activity, consuming over 3 hours of SNS a day [16, 17]. Aside from the quantity of time spent, SNS can shape young adults' sense of identity and inform their belief systems as they advance into adulthood. Young adults often use SNS as a means to seek out and develop other aspects of their identities including gender, sexuality, political affiliation, and religious beliefs [16]. Recently, young adults led the Black Lives Matter Movement on social media with Instagram stories, Facebook posts, and Tik Tok videos. Young adults advocate for change by utilizing the pervasiveness of SNS among their generation to reach larger audiences [18, 19]. As a result of the immense amount of time that young adults spend on SNS and the influence that it has on shaping their identities, SNS provide a potential platform to bring awareness to and educate this population on the importance of ACP.

In addition to SNS consuming time, shaping identities, and promoting advocacy in young adults, SNS have demonstrated some utility in public health-related campaigns for organ donation and smoking cessation [20, 21]. In 2012, researchers at Johns Hopkins University partnered with Facebook to increase the number of registered organ donors and available organs in the United States [20]. Facebook users were allowed to share their organ donation status with their friends, which is similar to the display of their education and marital status on their personal profiles. When Facebook users elected to share their organ donation status on their Timelines, their Facebook friends were sent notification messages about their donation status with a prompt for the friends to register their donation status.

On the first day of the campaign, over 50,000 Facebook user profiles shared their organ donation status and >12,000 additional people registered as organ donors. At the end of the 13-day study, there were 39,818 newly registered organ donors, significantly exceeding the teams' pre-study estimate [20]. Termed "The Facebook Effect," this campaign successfully moved a public health issue previously delegated to the Motor Vehicle Administration onto a SNS space. The campaign motivated large amounts of people to individual action, registering themselves as donors.

The "Tweet2Quit" campaign was conducted by researchers at the University of California, Irvine, and the campaign's goal was to motivate smoking cessation by providing a social support system to enhance tobacco quit rates [21]. The intervention arm enrolled participants into 100-day Twitter



Grubnyak, A. (2018). Photograph. Retrieved from <https://unsplash.com/photos/R84Oy-89aNKs>.

groups for Twitter discussions and daily motivational texts on healthy behaviors. Twitter “quit buddies” were established with the goal to use these new friendships to promote smoking cessation. The comparison control group received standard of care which included nicotine patches and referrals to [smokefree.gov](http://smokefree.gov) without specific Twitter engagement. Surveys were administered at 7, 30, and 60 days following an individual’s intended quit date to assess the time they remained tobacco-free. The results were impressive. Participants enrolled in the Twitter groups were more than twice as likely to abstain from tobacco use 60-days following their quit date than those in the control group.

These campaigns highlight SNS potential effectiveness. First, these campaigns demonstrated SNS’ ability to generate conversations about health-related topics with large numbers of engagement in target populations. Whether it was via messaging or status sharing, each campaign highlights the ability of SNS to spark discussions and engage individuals with difficult topics. This engagement gives hope that a similar SNS campaign for ACP could create meaningful conversation in the target population. Second, not only was there engagement and conversation, but action- motivating behavioral changes such as registering as an organ donor or quitting smoking were fostered. Advanced care planning can benefit from this dual framework. ACP differs in this concrete need of behavioral change from these campaigns because one of the major components of ACP is simply ongoing conversations themselves; the specific action of advance care planning is, and should be, flexible. Therefore, any ACP conversation by the population of healthy young adults would be a success!

## **KEYS TO SUCCESS**

A SNS ACP campaign must ensure delivery of accurate and inclusive information to successfully engage young adults in this process. Introduction to the topic, including links to outside websites to guide further depth and self- discovery into the practice of ACP can be a successful way of distributing information. Links with resources for legal documents such as health care proxies and living wills is essential. One could measure both traffic to links, as well as the completion of legal actions. These links to additional ACP resources may encourage those that feel ill-prepared to participate in ACP after seeing or hearing of the campaign to seek outside resources and education prior to having additional conversations with their loved ones about preferences and values. Trusted organizations such as the Centers for Disease Control and Prevention already advertise some of these key materials on their webpages [22].

Repetition and reminders have been used in prior public health SNS campaigns, and this tactic could be incorporated. The Tweet2Quit campaign

provided daily messaging and direct outreach to the participants in the campaign. In doing so, people were continuously reminded about the harms of smoking and reminded to remain tobacco-free. This tactic could be incorporated into an ACP campaign by creating reminders to reevaluate their wishes and preferences of care at specific time frames. One could imagine check-ins to re-visit one's stated preferences at various life stages- marriage, childbirth, birthdays, or age milestones. One current challenge in ACP is that life experiences, along with shifting beliefs and inputs, may change the prioritization of care when seriously ill. An updated system that provides reminders through SNS could mitigate this issue. For example, the campaign could auto-generate a message to participants every 3-6 months to ensure that the information that was previously provided still accurately reflects the person's values. This can result in a more informed, timely and accurate ACP documentation than exists today!

There are additional practical considerations for a successful SNS ACP campaign. The first is which SNS would be the most effective in reaching this population. A key component of SNS that makes this such an appealing platform for young adults is that much of the content and outreach on SNS is user-generated [15, 23]. Most media on social networking sites is user-generated: when one person chooses to share information to their site, all of their SNS friends also have access to it. This sharing and messaging system fosters identity among social networking peers. An ACP campaign could allow friends to share the campaign to their Facebook timelines, Twitter, or Instagram feeds and would allow people to be informed and hopefully persuaded by their friends' decisions. A second important practical consideration is that due to this user-generated material, most distribution costs could be free. Social networking campaigns are relatively cheap because of these low distribution costs associated with user-generated content [24]. Although the creation of a campaign will require initial financial support because there are limited distribution costs for a campaign on SNS, this type of outreach strategy could be a cost-effective method.

## **PITFALLS**

Of course, SNS are not a panacea and there are downsides to their use, particularly in considering a complex topic such as ACP. ACP, where discussions of life and death are the focus, the role of invasive or costly medical therapies, and life sustaining versus shortening treatment, requires reflection, nuance, and persistence. Therefore, one must acknowledge potential limitations, including disinformation and the unknown sustainability of SNS efforts for ACP.

Critics may raise the concern of the potential for misinformation on SNS and how this misinformation could hinder the influence of an ACP SNS

campaign or even contribute to worsening fears of engagement in ACP [25] SNS have been implicated in the spread of false information from topics like vaccine-effectiveness, recently highlighted in the COVID-19 vaccine campaign, or in other charged issues such as the legitimacy of the 2021 election [26, 27]. This misinformation perception could hinder the influence of an ACP SNS campaign. Even worse, it could contribute to worsening fears of engaging in ACP and thus have a detrimental effect if ACP misinformation included false information about the benefits of ACP or an inaccurate portrayal of the importance of autonomy as it relates to healthcare decisions. As a critical public health topic that could utilize the potential positive effects of SNS, the concern for misinformation could be met with additional mon-



Meyer, M. (2018). Photograph. Retrieved from <https://unsplash.com/photos/SYTO3xs-06fU>.

itoring of the conversations surrounding ACP throughout SNS and active clarifications to enhance messaging effectiveness. Just as public health officials must address the current misconceptions on Covid-19 vaccinations, the threat of misinformation is not a reason to not proceed, but a challenge to be managed.

Perhaps a bigger concern is long-term effectiveness and sustainability. Misinformation and attacks will happen and one can hopefully address them. But we have yet to dedicate a SNS public health effort for more than a brief period of time. Although a SNS campaign may initially attract many users, it is reasonable to worry about the sustainability of a SNS ACP campaign. The Facebook organ donation campaign and the Twitter smoking cessation campaign were limited pilots and discontinued. Although extremely influential,

the Facebook organ donation saw an immediate spike in registered organ donors, but after only a few dates of the campaign, the rate of registrations began to decline. Since the campaign only lasted 2 weeks, it is unknown what could be done given a longer timeframe to establish sustainability. Thus, it will be important to establish systems to ensure the campaign continues to attract SNS users. One strategy could be an automatic reposting schedule. On a weekly or bi-weekly basis, the campaign could be reshared to all social networking site platforms to ensure ongoing participation remains high and continues to attract new individuals.

## **MOVING FORWARD**

ACP is more relevant today than ever before. Before the recent pandemic, the inciting legal cases and the role of unexpected and unintentional injury on young adults made it highly relevant. The recent increase in health care worries and hospitalization among younger patients with COVID-19, including invasive ICU care and the potential shortage of life sustaining equipment worldwide, only amplifies the gap in the ability to provide technological care and the knowledge of individual preferences in a hospital. ACP is a critical component of healthcare because it allows healthcare providers to respect patient autonomy and improves the concordance between desired and received care for patients. Despite the current lack of participation by healthy young adults in ACP, it is vital that young adults participate in this process due to the fact that the majority of young adult deaths are a result of unintentional accidents that leave young adults unable to have future conversations about care. It is time to try something different and move ACP away from doctor's visits. All of healthcare has been disrupted with the pandemic, with virtual care and telemedicine becoming a new normal. The time seems right to move ACP away from something only done in a doctor's visit or focused on seniors with chronic illness, to something readily found in a person's everyday life. As young adults spend large amounts of time on SNS, and prior health related SNS campaigns raise signals of success, the opportunity is there.

Prior public health campaigns can form promising frameworks for a new public health ACP SNS campaign. Large organizations such as The Conversation Project that already work to promote ACP and researchers in the field should engage more fully with their SNS to actively target and effectively engage the population of healthy young adults in ACP. Given the public health need and this early evidence of engagement in other topics, the time is right to operationalize ACP into SNS.

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# COVID-19 Vaccine Distribution: A Current Ethical Assessment

by Juliana E. Kim<sup>†</sup> and Jennifer E. Geller<sup>††</sup>

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*With the declaration of COVID-19 as a global pandemic on March 11, 2020, difficult discussions concerning the ethical allocation of limited resources such as ventilators began. With the approval of vaccines worldwide, the conversation has pivoted to how to ethically and efficiently distribute vaccines worldwide to achieve global herd immunity. As vaccine distribution progresses in countries such as the United States, and stalls in others such as India, the strategy of vaccine allocation must be revisited. In doing the greatest good for the greatest number of people, efforts must target those who are vulnerable and from poorer countries to not only distribute the vaccine but establish a vaccine administration program. In addition to being a moral quandary concerning human rights, the breakdown of proper primary prevention poses the potential development of perpetual variants that can further destroy the world economy as a result. This review piece seeks to describe the present status of vaccine distribution to assess where wealthier nations need to go from here in protecting the world stage.*

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**W**hen the World Health Organization declared COVID-19 a global pandemic on March 11, 2020, it soon became clear that no country was prepared to handle such a crisis [1]. Causing over 50 million cases and over 800,000 deaths worldwide to date, it has become a defining moment in history that few expected to be as catastrophic as it has been [2]. The COVID-19 pandemic has changed the scope of how people view the state of different elements of healthcare — access to such being of one of utmost importance.

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Ethics have become inextricably intertwined with this novel public health crisis as hospitals, states, and countries have struggled to allocate the limited resources needed to maximize the lives that can be saved. From personal protective equipment for the frontline workers to the ventilators for afflicted patients, deciding how to distribute these vital assets amidst an overwhelming surge of patients proved to be a confounding task.

Vaccines against COVID-19 are arguably the most important resources to date because they are the primary preventative measure against the virus and help mitigate the severity of the disease and the length of the pandemic [3]. According to Yale Medicine in a November 19, 2021 the Pfizer-BioNTech vaccine has a 91.3% efficacy against the virus with a 100% efficacy of preventing severe disease per the CDC. They also say that the Moderna vaccine has a 96.3% efficacy in preventing symptomatic infection and that Janssen's vaccine has a 72% overall efficacy with a 86% efficacy against moderate to severe disease [4]. On the other hand, wearing masks were 79% effective in preventing transmission thus making vaccines of increased importance [5]. The aim of this review is to discuss the present state of vaccine distribution and the ethical considerations of investing national resources into ensuring international access to vaccines as distribution progresses.

## **VACCINE DISTRIBUTION INITIATIVES THUS FAR**

In the quest to lower COVID-19 transmission and disease, a vaccine is critical, and international organizations have put initiatives in place targeted at ensuring global vaccine distribution. While these initiatives alone are not enough to get vaccines into the arms of every single person who needs them around the world, the efforts they are putting forward are steps in the correct direction. The cooperation of all countries (especially wealthier ones) is necessary to build upon this foundation and accomplish the shared goal of eradicating the pandemic entirely.

### **COVAX**

The COVAX initiative is a global effort to increase access to tests, treatments, and vaccinations against COVID-19 [6]. Led by CEPI, Gavi and WHO alongside UNICEF (and PAHO in the Americas), the initiative is based in the understanding that for the world to gain immunity against COVID-19, there must be equitable access to effective primary prevention.

This program was meant to prevent a repeat of the H1N1 pandemic of 2009 when richer countries bought up a large proportion of the vaccine supply, leaving poorer and more vulnerable areas without access [6]. We are seeing history repeat itself; wealthier countries utilized their capital to gain access to COVID-19 vaccines first [7]. COVAX aims to send vaccines countries where the government and citizens cannot personally afford the vac-

cine, aiming to get all of these countries to 20% vaccination [6]. A regulatory framework that was lacking in 2009 will be essential to ensuring the success of the COVAX initiative, and accountability needs to exist so that wealthier countries put international populations at the forefront of future vaccination efforts. Otherwise, the COVAX initiative will fail to complete its stated goals.

### *Operation Warp Speed*

Operation Warp Speed is a United States-initiative to financially support many of the companies that were creating COVID-19 vaccines [8]. The United States provided \$18 billion in funding to aid the development of vaccines specifically for its own population. Various vaccines were assessed via the traditional approval pathway, but with some modifications to accelerate the timeline [9].

The FDA subsequently issued guidelines that allowed for accelerated development. After simultaneously running Phase I and II studies together in summer of 2020, the Pfizer and Moderna vaccine were proved safe and effective, both with around 95% efficacy [4]. This granted them both EUA in December of 2020 when mass production began. OWS then invested money into vaccine distribution to deliver those doses to the American public beginning in late 2020 and headed into 2021 [9]. At this time, there is a surplus of vaccines [10]. Therefore, the vaccines made under OWS should be allocated to countries who need them but cannot afford such technological innovations on their own.

## **WHERE ARE WE NOW IN VACCINE DISTRIBUTION?**

Per Our World In Data, the vaccination rates among country populations vary greatly across the world, and that is truly at the heart of why present initiatives are not enough to satisfy the needs of the world's populations. Understanding the present state of vaccination sheds light on where distribution efforts need to go from here.

Their reports represent the percentage of the total population that has received at least one dose of a COVID-19 vaccine and specifies the companies that produced the doses [11]. 54.2% of the world's population has received at least one dose of the vaccine with 7.94 billion doses administered globally as of November 29, 2021. However, only 5.8% of people in low-income countries have received at least one dose as of that same date.

To better illustrate the dichotomy that exists given the data from Our World in Data, as of November 28, 2021, 79.69% of Canada, 74.66% of the United Kingdom, and 68.59% of Israel has received at least one dose. 56.31% of India, 58.81% of Mexico, and 50.13% of Indonesia have received at least one dose of a COVID-19 vaccine [Figure 1]. Except for Morocco with 65.6%, Tunisia with 50.79%, Rwanda with 43.27% and Botswana with 36.84% of

residents receiving at least one dose, the rest of the African countries has less than 10% of its population vaccinated. And of note as well given the recent surge of the delta variant stemming from here, only 31.47% of the Indian population has been fully vaccinated against COVID-19 as of November 29, 2021 [11].

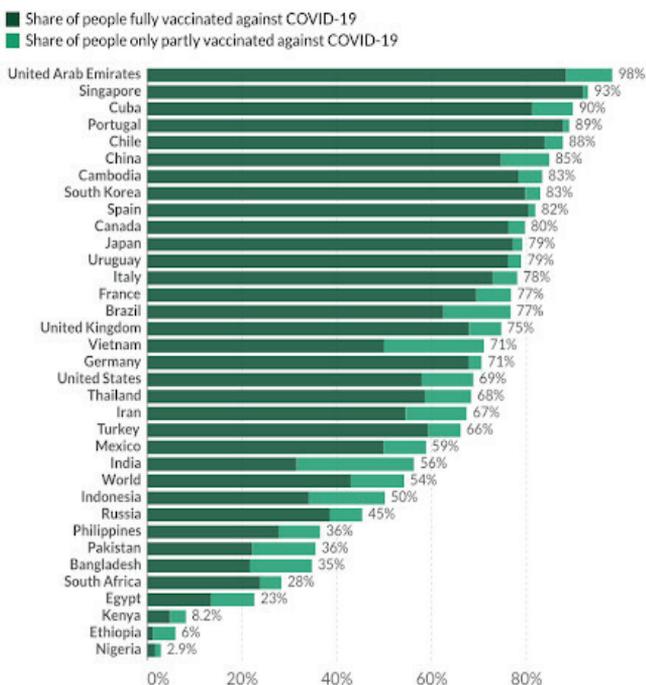
These startling numbers are the basis from which we will now analyze global vaccination barriers with the purpose of advocating for better efforts going forward.

The BBC reported in June that the Biden administration pledged to donate 500 million doses of the Pfizer-BioNTech vaccine through COVAX. Japan has pledged a donation of \$1 billion dollars for the vaccination effort, the European Union has pledged 500 million euros (\$590,635,000), other European countries have pledged more than 1 billion euros (\$1,181,250,000), the UK has promised more than 25 million doses before the end of 2021, and Germany, France, Italy, and Sweden gave promised at least 100 million doses [12].

Share of people vaccinated against COVID-19, Nov 28, 2021



Alternative definitions of a full vaccination, e.g. having been infected with SARS-CoV-2 and having 1 dose of a 2-dose protocol, are ignored to maximize comparability between countries.



Our World in Data. 2021. *The percentage of people who are vaccinated against COVID-19 in different countries as of November 28, 2021.* Retrieved from <https://ourworldindata.org/covid-vaccinations>. [11]

## BARRIERS TO DISTRIBUTING VACCINES GLOBALLY

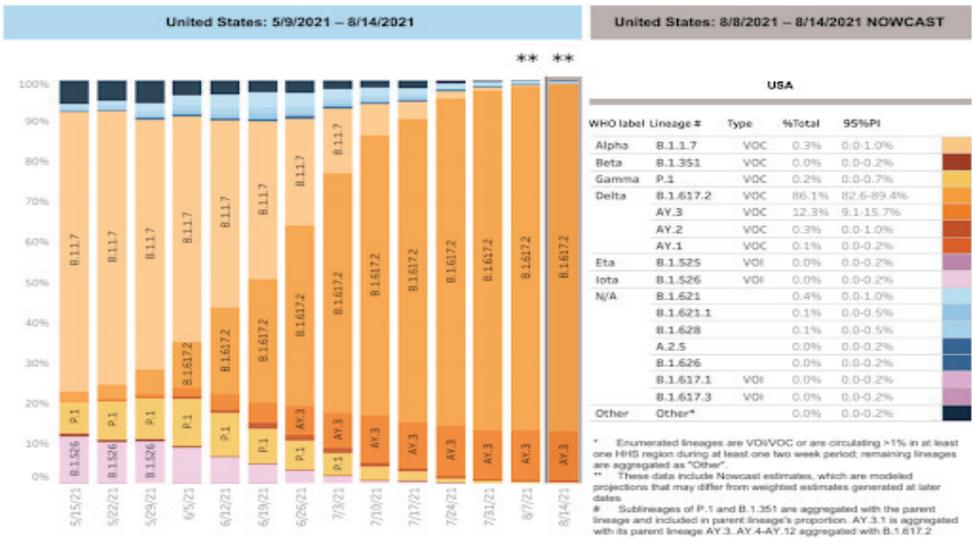
Although there appears to be a universal consensus that global immunity must be achieved to end the pandemic, there are several factors obstructing this goal. Most notably, the concept of vaccine nationalism halts equitable distribution of vaccines. Vaccine nationalism is the prioritization of a country's needs at the expense of other nations and is a difficult obstacle to

overcome in terms of achieving global immunity. As described previously in this review, the US and many other wealthy nations have privately financed vaccine trials and manufacturing in exchange for vaccines. Before clinical trials even came a close, countries such as US, UK, Japan, and much of the rest of Europe had already secured most of the global supply of the efficacious vaccines. Ferguson et al. argues that vaccine nationalism in a limited form is valuable and not inherently immoral. Protecting one's own carries its own weight of moral commitments and is therefore not inherently unethical [13]. It has also been compared to putting on your own oxygen mask on an airplane before helping others. However, it is also important to consider that due to the global nature of today's economy, it is impossible to isolate oneself from the rest of the world. It does not affect one person if someone else on the plane does not or cannot put on their own oxygen mask. However, failing to aid in the distribution of vaccines globally will harm the US. Regardless of what is just, the World Health Organization chief Tedros Adhanom Ghebreyesus commented that vaccine nationalism could prolong the pandemic if not addressed [14]. Given that the point of initiatives like OWS was to shorten the pandemic it is important for wealthy countries to understand that their work may be null if they do not provide vaccines for those who are unable to finance them themselves.

Aside from international allocation of vaccines, localized challenges to distributing vaccines are just as present and difficult to address. Mills et al. noted that there are three things that need to be in place for efficient vaccine distribution: vaccine supplies such as cold storage space and syringes, people to administer, monitor, and document them, and people to be vaccinated [15]. Coordinating these three entities are essential for productive vaccine efforts. However, as of 2018, only 120 of 194 WHO member states had an adult vaccination program, with less than 11% of countries in Africa and South Asia possessing any such program [16]. A robust vaccination program is especially important in the context of COVID-19 vaccines. Due to the fragile nature of mRNA vaccines (Pfizer-BioNTech and Moderna), cold storage chains are essential to preserving efficacy. Initial distribution of the Pfizer vaccine was challenged due to its extremely low storage temperature of  $-70^{\circ}\text{C}$ , which is well below the  $-20^{\circ}\text{C}$  threshold of most freezers. Pfizer and BioNTech did announce on February 19 that their vaccine could now be kept stable from  $-25$  to  $-15^{\circ}\text{C}$ . The Moderna vaccine must be stored at  $-20^{\circ}\text{C}$ , and has a shelf life of 8 hours post thawing [17]. Thus, the vaccination capacity of any country will be limited by adequate refrigeration.

This issue is not just relevant to lower income countries. Sah et al. commented that as of April 2021, the current pace of vaccine rollout in the United States was insufficient in preventing additional waves of COVID-19 due to more lethal variants. Without timely vaccination administration, we run the

risk of exacerbating the pandemic and experiencing surges in COVID-19 hospitalizations and deaths [18]. The United Kingdom is currently experiencing this, with a surge of the delta variant, aka B.1.617.2. The UK saw its first case of SARS-CoV-2 delta in mid-April, and has now initiated a third wave of hospitalizations and deaths, forcing the nation to halt the steps it was taking to reopen the nation [19]. The US has begun to see cases from the Delta variant and it is now the dominant strain [20]. As seen in Figure 2, it is responsible for over 85% of all COVID-19 cases in August in the US, despite the CDC only recording its first cases in May. The original alpha strain accounted for only 0.3% of cases. As of November 29, the Delta variant accounts for 99.9% of the cases in the US (CDC).



Centers of Disease Control (CDC). 2021. *The percentage of cases caused by various COVID-19 strains as of mid-August, 2021.* Retrieved from <https://covid.cdc.gov/covid-data-tracker/#-variant-proportions>. [20]

However, a large issue within the United States is vaccine hesitancy. From a high of administering 3.38 million doses on April 13, 2021, to less than 2 million doses per day in May, the US has experienced a significant decrease in vaccine administration [21]. Yet, at 50.14% of the US population having received one dose of the vaccine, we are nowhere close to the necessary 80% to achieve a semblance of herd immunity. Despite this necessity, states and local governments are struggling to vaccinate their constituents. Many mass vaccination sites are shutting down due to lack of demand and pharmacies are reducing slots [22]. Local institutions have begun even offering incentives such as a \$100 saving bonds in West Virginia, free beer in New Jersey, and even offering a lottery with a \$5 million prize in New York [21]. There have been many discussions as to how to overcome this vaccine hesitancy, such as whether to mandate vaccination like a flu vaccine, or

reach out to communities to educate them [21]. Regardless of the method, until the US feels that it has internally achieved herd immunity, it will be hesitant to relinquish its vaccine stores. It is a strange ethical quandary when state governments must bribe their citizens to receive a vaccine that billions worldwide are waiting to receive. However, it is undeniable that vaccine hesitancy, regardless of the presence of other countries, is prolonging the pandemic within the US.

## **ETHICAL CONSIDERATIONS OF GLOBAL VACCINE DISTRIBUTION**

Ensuring global access to vaccines will be ultimately mutually beneficial in ensuring the end of the pandemic. More virulent and lethal strains like the Delta variant were initially traced to a COVID-19 resurgence in Nepal and Southeast Asia, most notably India, where vaccine efforts have been limited due to the inability of the nations to secure vaccines [23]. The strains can then spread to other nations — even those with ample access to vaccines due to the connected nature of our global economy. The global economy refers to how each nation's economic activity impacts other countries. Globalization — the integration of regional, national, cultural, and societal immigration —, international trade, international finance and money transfer, and global investments all tie these nations together. The economies of the top countries influence other countries through, for example, the trade of goods and services. If there is restrictions on imports and exports, then there is a hindrance on the economic stability of the party selling the goods and parties receiving the goods [24]. If leaders of higher income countries solely focus on local vaccinations without consideration of efforts towards global immunity, it increases the probability of virus proliferation. We have already begun seeing this occurring with the recent virulent spread of the more deadly Delta variant. Current vaccines are moderately effective against these strains. A single dose of the Pfizer or AstraZeneca vaccine reduced a person's risk of developing COVID-19 symptoms caused by the delta variant by only 33%, as compared to 50% for the alpha variant [25]. One can therefore predict that with each new subsequent strain, current vaccines will be less and less effective. Thus, investing in universal vaccination will ultimately limit the length of this pandemic.

Vaccine nationalism is ultimately a short-sighted goal when securing global immunity. The tendency of wealthier countries to purchase and hoard vaccines could extend the pandemic in the long term. Experts reference the 2009 H1N1 influenza outbreak, when several wealthy countries secured most of the vaccine supplies. Although the 2009 pandemic was far less severe, the hoarding of vaccines created more barriers for people who needed them. Since then, equitable access to all influenza vaccines have become a popular topic of discussion, with no real amendments in policies [26]. If a similar

misallocation occurs with COVID-19, more deaths are predicted due to the inaccessibility of the vaccines [7]. Additionally, with the new Delta variant, because it is more infectious, it is a simple fact that the proportion of people who need to be vaccinated to ensure herd immunity has increased [27].

Increasing global distribution does not have to strictly mean sending physical vaccines to countries. As noted previously in this review, an organized vaccination program is necessary for effective vaccine distribution. Establishing vaccination programs in lacking countries should be a global priority even before the procurement of any vaccines. European countries began rolling out vaccines in December 2020; Africa's COVID-19 vaccination program began in March 2021 [28]. Weintraub et al. advocated for leaders to invest in delivery programs as early as November 2020, before the US experienced its peak infection wave, citing past pandemics and vaccine campaigns [29]. Investing in these programs in continents such as Africa, where the vaccination rate is as low as 5% in most countries, will be vital in ending the pandemic [23]. Closing the gap in these public health disparities between wealthy and poor countries will be essential handling COVID-19. This will ensure that when there are enough vaccines to distribute either via the COVAX initiative or through individual country agreements, these vaccines can be administered.

This is a difficult thing to advocate, as contributing to international vaccine programs will cost US taxpayers money. However, it is important for taxpayers and government leaders to recognize that the US does not exist in a bubble. If we do not invest in international vaccination programs now, we are acting against our own interests due to the nature of our global economy. It is estimated that the economic costs of premature deaths from COVID-19 in the US will be around \$4.4 trillion [30]. Not only will it harm US investments abroad, but it will hurt internal revenue. Recessions exist as a positive feedback loop that feeds itself. Workers that cannot work due to illness have less expendable income, which impacts downstream businesses. The Congressional Budget project a loss of up to \$7.6 trillion over the next decade [30]. Variants from other countries will spread to the US which ultimately harms the US further both in terms of the economy, but also in terms of individual lives. Both of which go against the ethical principle of doing no harm.

## **CONCLUSIONS AND FUTURE DIRECTIONS**

Equity, of course, plays a role in discussions regarding COVID-19 vaccine distribution, because there are vulnerable human lives at stake for those who may not have access to vaccines. Regardless of the actual benefit from the US and other wealthier countries, aiding in the prevention of deaths globally should be a universal priority from a humanitarian perspective. Equity

and humanitarianism are at the heart of providing justice and beneficence to individuals and helping others should not have to have an economic benefit to wealthier countries to be a priority. However, these countries have shown to need monetary incentives to get involved with the vaccination effort. The COVID-19 pandemic has quite clearly ravaged the world and disrupted the global economy, and for many wealthy countries, this is an understanding that can ultimately get countries to invest more in international vaccine programs.

The purchasing power afforded to the US by its economic status has allowed it and other similarly powerful nations to hold onto their vaccine shares for their citizens. However, at what point will the US release their stores if their citizens refuse to receive the vaccine? It is an interesting question that we believe must be answered due to the rapid decline in vaccination rates despite the US not achieving herd immunity. It appears as if the US is attempting to drag citizens kicking and screaming into vaccine clinics while other nations are attempting to get in.

It is quite natural to feel the instinctive urge to protect one's own first. However, nations have become undeniably inextricably linked through trade and commerce and if vaccination efforts solely remain local without a thought to how other countries will be impacted, it will ultimately drag the entire global economy down and cause more deaths. Global investment in not just the procurement of vaccines, but also vaccination programs will be essential to seeing the end of this pandemic before experiencing more loss of life.

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# Building Better Brains: Exploring the Societal Effects Of Nootropics

by Nikhil Ramavenkat<sup>†</sup>

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*A nootropic is any synthetic or natural substance that has the potential to enhance an individual's cognitive capacities. While the scope of their effects is currently limited to mild boosts in memory and performance, as pharmacological research continues their use may become more mainstream. The promise of nootropics, however, also paves the way for several moral conundrums, such as their impact on educational and occupational disparities as well as the long-term effects they may wreak on human biology. These questions highlight the need for a continued discussion on the ethicality of cognitive performance enhancers as they relate to societal standards of fairness and equality. The goal of this paper is to examine and explore the social consequences of nootropics through the lens of the four pillars of bioethics: autonomy, beneficence, nonmaleficence, and social justice. By framing a discussion about nootropics around the ideas of social coercion, competition, and the brain itself, we can better assess the effect they might have on our society and the questions we must continue to ask ourselves about their use.*

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**T**he brain is regarded as one of the most complex objects in the universe. It is composed of hundreds of billions of neurons and hundreds of trillions of unique connections. While a single one of these neurons can do nothing more than conduct electrical impulses and secrete chemical messages, put together, their emergent properties have led to everything from Ulysses to space flight to the atomic bomb. Our ability to observe, ponder, and create has defined us as a species, leading

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us to populate every continent on the planet and shape it with our emerging technology. For much of our existence, it was nature's will that *Homo sapiens* develop one of the most advanced computational engines on Earth, allowing us to adapt to our changing surroundings in the wild. However, as the fields of neurotechnology and neuropharmacology continue to develop in the modern era, mankind has seen the possibility of hijacking evolution and augmenting the brain in ways that could change what it means to be human.

Jean Piaget, a Swiss psychologist who studied child development and pioneered the field of cognitive psychology, said, "Intelligence is what you use when you don't know what to do" [1]. In our modern world, intelligence is a concept that is easy to describe but difficult to quantify and define; its true meaning lies muddled between words like "creativity," "adaptability," "productivity," and "acuity." Cognitive power is an important asset for living and working in society, but little is known about its genetic or environmental onset, nor about how one increases this valuable personal attribute. Much of our effort and research regarding theories describing the connection between human cognition and neuroanatomy have culminated in only more questions and uncertainty - an uncertainty further complicated by the development of nootropics agents.

Originating from the Greek roots "noos," meaning mind, and "tropos," meaning towards, nootropics are a class of drug compounds that are purported to increase and improve memory, attention, and cognitive function. First synthesized in 1964 by Corneliu E. Giurgea, the inventor of Piracetam (a drug used to treat dementia), nootropics and their use revolve around the concept of a healthy person taking a mind-enhancing drug meant to provide functional assistance to those who may have a cognitive disorder [2-3]. One example is Ritalin, which is meant to treat attention-deficit/hyperactivity disorder (ADHD) but can induce nootropic effects in those without the disorder, such as increased focus [4]. While the pharmacological development of nootropics is a relatively new field with many current products only offering mild boosts to cognitive capacity, emerging research has illuminated the possibility of more effective nootropics becoming commonplace.

As technology continues to progress and the ability to alter our biology increases, we arrive at novel situations shrouded in moral dilemmas. This paper aims to bring to light the issue of nootropics and present various arguments as to how this new class of drug will be perceived under the four pillars of bioethics: autonomy, justice, beneficence, and non-maleficence. Above all else, it aims to discuss and discern what our shared future with these treatments and enhancement may look like. When Thomas Edison's successful prototype of the light bulb swept the world, human productivity

increased by orders of magnitude, with people now able to work in safer conditions as well as in the dark [5]. With the possibility of artificially illuminating cognitive pathways now on the horizon, how will nootropics accelerate our society and warp our conceptualization of the human mind?

## MECHANICS

In order to grasp the sociological and future effects of nootropics, it is first important to understand how these agents may act on the molecular level and to distinguish between synthetic nootropics and natural, household substances that exert similar effects. One popular example of a natural nootropic is Asian Ginseng, a well-known herb found in herbal teas and traditional Chinese therapeutics. The active components in Asian Ginseng, also known as *Panax ginseng*, are ginsenosides, steroid glycoside compounds that have been shown through EEG and peripheral blood glucose concentration studies to modulate and enhance cognitive function [6-8]. One specific compound referred to as G115 has been shown to improve working memory, accelerate attention-related processes, and even augment mental arithmetic abilities following 12 weeks of administration of standardized ginseng extract [9]. Studies in the neuropharmacology of these compounds have pointed to their nootropic effects, specifically their ability to prevent microglia activation - an inflammatory process that, while a part of a regular immune response, can also lead to cell apoptosis and oxidative stress within the brain [6,10].

While Ginseng's benefits are seen on a much more acute basis, *Bacopa monnieri*, known as Brahmi, displays more chronic effects on the brain. For this reason, it is a key component of Ayurvedic medicine, having been used for centuries by scholars in India to memorize scriptures and hymns such as the Vedas [11]. *B. monnieri*'s key constituent is Bacoside A, a chemical belonging to a class of compounds called triterpenoid saponins. These compounds serve as the plant's defense against pathogens and microbes [8,12]. In humans, they can exert antioxidative effects and reduce protein carbonyls, lipid peroxidation, and DNA damage - processes which contribute to aging and various diseases [13,14]. Studies have shown that bacoside compounds can even inhibit acetylcholinesterase, an enzyme that breaks down the neurotransmitter acetylcholine. Lack of this neurotransmitter can result in progressive loss of neurons and neurodegeneration, leading to a variety of disorders like Alzheimer's disease and epilepsy [15].

Natural nootropics have been used by humanity for centuries and their effects are well-documented amongst the scientific community. While ginseng and Brahmi operate by preventing inflammation and oxidation, synthetic nootropics directly augment neurotransmitters in the brain, which can present with deleterious side effects. One example is Adderall, a

well-known drug that is a combination of dextroamphetamine and amphetamine. It is typically prescribed to those who have ADHD or a wakefulness disorder like narcolepsy and is one of the most abused drugs on college campuses [16]. Amphetamines work by inhibiting the enzyme vesicular monoamine transporter 2 (VMAT2) which transports monoamine neurotransmitters, like norepinephrine, dopamine, and serotonin, into vesicles. This inhibition leads to higher levels of these specific neurotransmitters within the cell body. While the exact mechanism behind this is still



(2014). Photograph. Retrieved from <https://pixabay.com/vectors/science-neuron-synapse-biology-305773/>.

unclear, amphetamines are also capable of reversing the effects of VMAT2, causing monoamines to be dumped into the synaptic cleft where they can be absorbed in massive quantities by the adjacent neurons [17]. This effect is compounded by the inhibition of monoamine oxidase, which metabolizes neurotransmitters (thus reducing their quantities), and the inhibition of reuptake, a process by which a neuron recycles any neurotransmitters not absorbed by the post-synaptic neuron. By commandeering control of dopamine, the brain's hedonic

currency, amphetamines make its users highly susceptible to addiction. This in turn can lead to severe withdrawal symptoms like fatigue, sluggishness, and the characteristic "Adderall crash," which has led to mixed opinions among researchers about whether this drug is a true nootropic or simply a high-consequence performance enhancer [18].

Another popular synthetic nootropic is methylphenidate, more commonly known by its brand name Ritalin. Like Adderall, methylphenidate is also a high target for abuse on college campuses, with one study at a liberal arts college showing that over a sixth of the student population used methylphenidate recreationally and 12.7% even administered the drug improperly through nasal inhalation [19]. The mechanism of action is quite similar to dextroamphetamine in that they both prevent the reuptake of norepinephrine and dopamine and can both be used as a treatment for ADHD and narcolepsy. However, methylphenidate has also been shown to accelerate the firing rate of neurons by acting specifically upon dopamine neurons, which allows for greater processing of incoming information and greater

detail in outgoing messages between neurons [20-22].

## **SOCIAL COERCION AND COMPETITION**

The gravity and ubiquity of competitive culture in our society need no introduction. It has dominated every aspect and situation of our life from education to the workplace, illustrated by the fact that as time goes on, it has become harder for high school students to get into high-ranking colleges and harder for college graduates to get a well-paying job in their career [24]. Nootropics are capable of creating a much higher playing field within these spheres, rewarding and normalizing those who choose to use them and ostracizing those who do not. This calls into question whether the use of nootropics and the subsequent widening of the achievement gap conflict with the bioethical principle of autonomy. Dr. Thomas McCormick, a pioneer in medical ethics from the University of Washington, writes in his “Principles of Bioethics” that autonomy seeks to emphasize the patient as the arbiter of their own healthcare and ensure that their decision is made free of any external controlling interest [24]. If nootropics increase the productive capacities of the user, it makes economic sense to hire and admit these individuals more often because their “return on investment” is far higher and more consistent than individuals who may not subscribe to nootropic agents. Students already use high-yield learning methods such as spaced repetition, mnemonic devices, and active recall to improve their retention of the material they learn in class. They often come at the cost of time, requiring weeks or even months to truly facilitate long-term potentiation. The use of methylphenidate has the potential to negate this temporal barrier or even make these techniques obsolete in the future, as studies have shown that it can create significant improvements in working memory, episodic memory, and a wide array of other cognitive abilities [25]. Could the possibility of being left behind in their careers and education influence people’s decision to utilize nootropics? While this may appear like employment of the slippery slope fallacy, a future in which our natural productivity is amplified through the use of nootropic agents is not far away. Stimulants like modafinil, sold under the name Provigil, are already being used by military aircrews in the United States to maintain their cognitive function during extended day-night air missions [26]. A study observing the effects of modafinil usage during simulator exercises conducted within the US Air Force shows that not only are these pilots able to stay awake for longer but their ability to maintain flight accuracy is preserved too. Those who completed the flight simulation without modafinil experienced a decline in accuracy from sixty to a hundred percent, while the group that used modafinil during the exercise saw a decline of only fifteen to thirty percent [27]. While this increased standard may seem like an absolute ben-

efit, it is important to realize that the presence of nootropics will provide little incentive for the private and public sector to employ those who do not partake in these substances and can even force current objectors out of the workforce. One such example is the story of the Tarnak Farm incident. In 2006, Air Force Majors Umbach and Schmidt were court-martialed for a friendly fire accident over Kandahar, Afghanistan where twelve members of the Canadian military were killed. Investigations into the cause of the incident revealed that the men were using “go pills” filled with the amphetamine Dexedrine during the mission. While the Air Force claims that the use of these pills is strictly voluntary as per the behest of the pilot, Charles Gittins, a former marine pilot, and lawyer for Major Schmidt, denied this claim and stated, “All you have to do is read the quote-unquote informed consent, and it basically says, if you don't take them, you'll be grounded” [28, 29]. Keeping in mind Dr. McCormick's definition of autonomy as previously iterated, pressuring someone to take a medication in order to keep their job is highly unethical, and sets a dangerous precedent across the private and public sectors. The need to maintain a competitive edge can drive employers to cut corners at the expense of their employees' welfare and coerce them into making decisions that negatively impact their own health and livelihood. While substances like modafinil and amphetamines are currently not allowed for use during commercial flights as per the Federal Aviation Administration, this policy is likely to change as demand for more productive pilots increases. These effects could plausibly translate into other lines of work as well, with surgeons being more susceptible to malpractice suits if it were revealed they did not choose to take modafinil during a particularly long operation, or investment bankers using prescription nootropics to meet their sensitive deadlines. Such practices raise the question of whether it is more important to ensure a fair mental playing field or to pursue optimization and success in the face of potential health consequences.

## **PERFORMANCE ENHANCEMENT AND EQUITY**

The term “cosmetic neurology” was coined by neurologist Anjan Chatterjee to describe drugs that act specifically upon the nervous system with the purpose of enhancing the human body beyond the simple purposes of general medicine [30]. With such disruptive technology at our disposal, it becomes necessary to understand the socioeconomics of acquiring such a drug and evaluate what constitutes its fair use in the context of justice. In bioethical discussions, justice is the preservation of equity and fairness as well as the principle that all people deserve equal treatment regardless of their identity. Considering the fact that nootropics are primarily used by those who can afford them, comparisons can be drawn between nootropics and other

classist mechanisms of merit determination that already exist in our society, such as preparatory courses for college admissions tests and the need for expensive textbooks and technology to keep up with a school's curriculum. Indeed, the acquisition and use of illicit nootropics are already more likely to be observed in Caucasian students and are strongly associated with being male or a member of a Greek organization or fraternity [31]. This highlights the present-day inequity of cognitive enhancers which is only furthered by predatory practices and price gouging of the pharmaceutical industry. In 2005, Adderall cost nearly \$1,356 per year and costs have continued to rise, with the price jumping 9.4% in 2021 alone [32]. This especially impacts those diagnosed with ADHD who are advised to take Adderall daily for non-nootropic purposes [33].

The notion of "academic doping" through nootropic usage, which in one study was practiced by roughly 17% of the undergraduate student population within UK universities, raises the question of how these drugs fit into social norms [34]. Bodily augmentation exists in a certain moral gray area, and its morality tends to be determined on a case-by-case basis. This highlights the need for the use of nootropic agents to be characterized according to their own moral and social consequences. For example, it is considered acceptable for a celebrity to receive cosmetic surgery in order to improve their brand and image but anabolic steroids and performance-enhancing drug (PED) use among athletes is seen as unfair [35]. A study conducted by the Norwegian School of Sports Sciences in Oslo surveyed the opinions of 234 Norwegian athletes regarding various performance enhancement methods ranging from simple vitamins all the way to PEDs and doping. A large majority of the surveyees were in favor of techniques like the hypoxic chamber but the same cannot be said when the athletes were asked about the use of erythropoietin (EPO), a hormone banned by the World Anti-Doping Agency that stimulates the production of red blood cells [36]. Olympic speed skating champion Adne Sondral even states, "Doping is a high treason against the nation", alluding to the legal consequences and widespread shame that can follow an athlete should they be involved in a doping scandal [37]. Despite hypoxic chambers and EPO both being used to achieve a similar function, increasing the number of red blood cells within one's body, potential health consequences and optics have led one method to be approved for use in sports and one to be designated unethical. Athletes would have the most to gain from PED and EPO use, yet it is clear that they are not just competitors, but role models as well. Hypoxic chambers possess very few side effects but pale in comparison to the risk of heart attacks and thrombosis that can result from EPO use. Compromising one's health for the sake of a win is not an inspiring achievement but a Pyrrhic victory and violates several qualities of the "spirit of sport" as declared by the World Anti-Doping Agency, including fairness

and [minimizing] the risk of harm [38]. Even though many nootropics are still understudied, keeping the above approach in mind and analyzing their potential health implications allows us to discern the fair use of a drug by weighing its benefits against its costs. Caffeine and creatine, two of the most highly studied nootropic substances, present with very few side effects and are thus normalized for personal use within society [39, 40]. On the other hand, dopamine-acting stimulants like methylphenidate, amphetamines, and modafinil all activate the brain's reward pathway and can make the users highly susceptible to addiction. Academic or personal achievements should not occur at the expense of permanently altering a person's brain or having to suffer through a neurological disorder, but it is clear the social norms surrounding nootropics will have a greater effect on their popularity than their potential health risks.

## **BRIGHT FUTURES AND BLEAK OUTCOMES**

The power of the human brain lies in its ability to change. As our ancestors spread across the continents and encountered novel environments, our brains were able to learn and augment themselves accordingly through plasticity, the process by which our nervous system rearranges, repairs, and grows in response to various stimuli. Plasticity can be observed through our evolutionary history in the development of our exceptionally sized cerebral cortex in relation to our ancestors, but it is also a process that occurs regularly whenever we challenge our brains or try to learn a new skill [41, 42]. This can be observed in studies that show learning a second language or attempting to play an instrument can actually change the architecture of the brain, resulting in grooves and folds that are not visible in a person who does not possess either of these skills [43, 44]. Simply put, the brain, like a muscle in the body, can be trained to suit the difficulty of the challenges presented to it. This concept is important to understand in regard to nootropics because these drugs can only improve upon the baseline cognition present within a person. As previously discussed, the use of nootropics could potentially render intensive learning methods that occur over time, like active recall and spaced repetition, far less difficult or even obsolete. If the stimuli to which we expose ourselves are no longer considered challenging, could this lead to our brains slowing down as time goes on? While this may seem hyperbolic, the brain is a highly parsimonious organ, being both effective at managing its resources and minimizing the energy it spends. This can be seen in our brains' preference for high-calorie foods, which may have been important for our evolutionary ancestors, whose next meal was often insecure, but has actually become the basis of an addiction in the modern world due to the dopaminergic response these foods can exert in the brain [45]. One of the central principles of biology is that structure serves function; introducing

nootropics as a crutch for our brain would create little incentive for it to develop in the face of challenge and could lead to future humans being less capable than those who never exercised the use of nootropics. Ultimately, discussion about the future sociological effects of nootropics is muddled in uncertainty, as many of these compounds lack longitudinal studies that could prove what side effects these substances can collect over time. Evaluating their effects in the short term can be done through the lens of the last two bioethical pillars: beneficence and nonmaleficence. These two values together combine a patient's right to be free from harm with the idea that all patients deserve the most optimal medical treatment (“optimal” refer-



Zhyvchik, E. (2020). Photograph. Retrieved from <https://unsplash.com/photos/xJY-7gt-C38o>.

ring to effectiveness and low financial burden). Keeping this in mind, it is important to understand that these compounds are still prescription drugs and controlled substances, meaning they have the potential for dose-dependent toxicity, long-term substance abuse, and even neurological abnormalities as a result of their continuous effect on the brain. One study attempted to distinguish the effects of methylphenidate, a treatment used for ADHD and a popular illicit nootropic drug on college campuses, in both juvenile and adult age groups. The researchers found that early-age usage can disrupt the sleep-wake cycle, lead to chronic anxiety, and even interrupt the natural maturation of the hippocampus and prefrontal cortex [46, 47]. This last effect is significant, as the prefrontal cortex is responsible for higher cognitive functions such as working memory, personality, and logical reasoning; these abilities arise from its high level of plasticity. This plasticity - the immense

potential of the brain to change its structure to suit its current purpose - is especially potent in the adolescent age because the brain is hypersensitive to its own neurotransmitters during this time frame. Augmenting the endogenously-generated levels of these signals does result in long-term potentiation (and thus enhanced memory), but studies indicate that it also represses several of the chemical subunits involved in working memory and behavioral flexibility [48]. This means that one could potentially be trading an increase in memory for retention of future subjects, social adaptability, and interpersonal skills [49]. It falls upon us to assess whether the risk of manipulating our own evolution behooves humanity in the long run. Do we trust the course of nature to determine the bounds of our cognitive capacity or do we undertake the evolutionary task ourselves?

## CONCLUSION

Are neurologists the new plastic surgeons? The field of medicine is constantly evolving to suit the needs and wants of its population, and as doctors and researchers continue to innovate, the bioethical responsibility of each of their fields morphs accordingly. Nootropic agents are just one of the many controversial technologies to emerge in the past few years and while they hold great promise, they hide even more dire consequences. While the idea of a smarter populace may seem like a tremendous gain, could nootropics be nothing more than fools gold? The promise of a more productive society is certainly enticing and holds great benefit to both organizations and individuals, but the exclusion of non-nootropic users must also be weighed in this decision. Are we as a society ready for the crushing competitive standards that will follow the implementation of nootropics? Their ability to increase our cognitive capability and quality of life is certainly to be noted, as is the possible revolutionization of the education system as we know it. But is this worth endangering socioeconomic equity through the widening of the achievement gap and the reinforcement of academic disparities? Most of all, nootropics have illuminated the possibility of better brains. If the three-pound organ residing in all of our heads has thus far led to the world as we know it, who knows what we might be capable of as a species with the aid of nootropics? Are we truly capable of improving a system nature has perfected over millions of years or will we find ourselves disrupting the very processes that have enabled us to make so much progress? As research and development continue to progress, it is imperative that we closely examine the effects of nootropics and their ramifications through the lens of bioethics in order to truly determine the changes they may render on our shared future.

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## Autonomy and Depression: Preserving Bioethical Integrity For Patients with Impaired Competence

by Xudong Ma<sup>†</sup>

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*In bioethics, the principle of autonomy stipulates that patients' rights to make their own medical decisions should be preserved as much as possible. In some complicated cases, especially cases of mental disorders, patients might lose the competence of making rational medical decisions. For example, some mental disorders impair a patient's cognitive capacity and deprive their ability to think rationally. For these cases, MacCAT-T is an assessment tool often used to determine if it is appropriate to preserve rights of autonomy for a certain patient with a mental disorder. However, this paper indicates that MacCAT-T does not work for some prevalent mental disorders, such as depression. This is because these mental disorders do not impair one's cognitive capacity such as memory, reasoning, and perception, but rather negatively affect the patient's psychological tendency of making any rational medical decisions, and this is what the MacCAT-T is not capable of detecting. Moreover, as this paper indicates, since the pathological cause of depression is still unclear, the ethical dilemma of preserving the rights of autonomy for patients with depression has further complications. Thus, an expedient for the current situation that would not rely on the invalid assessment tool is needed. This paper proposes that a legal guardianship system would fulfill this need, as it not only avoids the questionability of allowing patients with depression to make medical decisions that are possibly irrational, but also preserves the maximal rights of autonomy for these patients indirectly.*

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In areas of bioethics, debates on the conflict between the principle of autonomy and mental disorders are noticeable. Such a conflict is highlighted by a recent event that raised enormous outcries in China. In a Weibo article published in 2016, a psychiatric clinic run by a doctor named Yongxing Yang in Shandong was accused of inappropriate uses of medical therapy in which they applied shock therapy on teenage patients with internet addiction disorders and asserted that it was a method of cure [1]. This method was implemented with a machine called DX-II electric convulsion therapy instrument, which was later indicated to be appropriate for only adult patients with serious mental disorders [2]. In the article that brought this event into public awareness, the author, Lei Silin, describes Yongxing Yang's behaviors as follows: "Electric shock is used without body examination. It starts soon after kids come to his camp and it does not stop until kids finally obey him." [1] One common mental disorder around which arises questions of cognitive competence is depression. Abraham Rudnick, a current professor at the Dalhousie University, states: "while major depression may not impair the four abilities generally considered necessary for competence, it may 'disrupt' coherence of personal preferences by changing them." [3] This statement indicates that the key factor that should be seriously considered during medication for patients with depression is, impaired competence in making decisions. Normally, patients with a variety of disorders can have their autonomy fully preserved and make medical decisions for themselves, but there are also other patients who are assessed to be unable to make rational medical decisions. Here, complex problems arise. How should we determine which group of patients have their decision-making capacity impaired? How much autonomy should we preserve for them? How can we ensure that the existing stipulations and acts have represented their best interests? These questions get even more complicated when they encounter the case of depression.

This paper aims to answer the question: How should the rights stipulated by the bioethical principle of autonomy be preserved for patients of depression whose competence of making decisions is not impaired but yet affected by the disorder? In answering this question, there are two secondary inquiries. The first one is: How effective is the major method of evaluating patients' competence in the case of depression? To further analyze this topic, more specified concepts will be provided. The MacCAT-T method illustrated by Gerben Meynen, a current professor at Utrecht University, will be introduced. It is a popularly used tool for estimating if a patient with a mental disorder has their decision-making competence impaired. Afterward, the effectiveness and potential bioethical controversies of this method will be analyzed in this paper. Then, the second question arises: How should the bioethical principle of autonomy be preserved for patients

whose medical decisions may be negatively influenced by their mental illness? This question will be answered based on the analysis of the MacCAT-T method. Furthermore, the key principles of the Mental Capacity Act, which is a stipulation illustrated by Nicholson et al. to empower and protect vulnerable patients who are not able to make their own medical decisions that are prevalently applied in the UK, will also be introduced and applied for an additional ethical evaluation of the classification of diseases of depression. These inquiries altogether will lead to the final argument of this paper: though the pathological causation for depression is still unclear, rights of autonomy should not be entirely, directly preserved for patients with depression, since the conceivable impacts of preserving these rights are critical. The adult guardianship system can be a method of indirectly preserving autonomy for the patients to ensure the provision of proper cures.

This paper is separated into three main sections. In the first section, the critical lens and conceptual frame will be illustrated with more details. The context of the research topic will be introduced and different opinions from different sides of the academic debate will be provided and analyzed. In the second section, one of the prevalent methods used to examine patients' competence will be introduced, that is, the MacCAT-T method. Then, analysis on this method will be done in the case of depression, and the invalidity of this method will be highlighted. In the third part, an ethical examination of depression itself as a mental disorder will be done. This analysis starts with an introduction of the key principles of the Mental Incapacity Act. Then, a sub-analysis of the prevalent theory of "chemical imbalance" will be done, which is a controversial theory that attempts to explain the cause of depression. Afterward, the introduction and examination of the International Classification of Diseases will be done to introduce a possible solution for the bioethical dilemma of depression. Finally, a proposal for an alternative method, the adult guardianship system, will be introduced.

## **THE DILEMMA OF BIOETHICS AND DEPRESSION IN THE 21<sup>ST</sup> CENTURY**

After WWII, modern medication underwent standardization. A series of related codes and rules were established, and the four bioethical principles underlie all of them. Specifically, these four principles are:

1. Autonomy, which focuses on the patient's independence or liberty.
2. Beneficence, which states that a physician must act in the best interest of the patient.
3. Nonmaleficence, which states that a physician must not harm the patient through carelessness, malice, vengeance, or dislike.
4. Justice, which refers to fairness with respect to the distribution of

medical resources.

Among these four bioethical principles, the principle of autonomy is the most concerned with the patient's individual cognitive competence during treatment. Genevra Richardson, the current vice-president of the British Academy, provides a helpful description of autonomy. She states: "autonomy relates to the capacity of individuals to pursue their right to self-determination and is said to require three essential elements: agency, independence, and rationality" [4]. The element of independence mentioned here establishes another important component in contemporary medical ethics: that doctors are required to obtain informed consent from patients prior to medical treatment. Such a requirement is typically met in normal medical circumstances, but some mental disorders impair a patient's general decision-making capacity. In such situations, a patient might not be able to make rational medical decisions. For example, dementia causes deterioration in a patient's overall

cognitive function and makes the patient unable to process thoughts that they previously could have. Consequently, the patient does not have the capacity to make medical decisions. In such cases, the normal medical procedure that requires



Hodge, K. (2019). *Loss - A sculpture by Jane Mortimer*. Photograph. Retrieved from <https://unsplash.com/photos/IqSaG9zv2e0>.

informed consent from the patient becomes impracticable, so additional methods and rules are established and applied to help make assessments. When certain mental disorders render patients' decision-making competence questionable, physicians adopt these mental assessment tools to determine if their patients still possess sufficient decision-making abilities.

However, these tools and methods do not address all problems. Doctors are still met with unique difficulties during the treatment for some kinds of mental disorders, an important one of which is depression. According to the American Psychiatric Association, unlike other mental disorders, depression would cause further difficulties because it "negatively affects how you feel, the way you think and how you act." [5] In other words, even though it

changes patients' medical decision preferences, it does not impair a patient's cognitive functions. Thus, bioethicists are faced with the question of whether the medical decisions made by people living with depression should be equally respected even if those decisions may harm the patients themselves. For this difficulty, Dr. A. Rudnick at Tel Aviv University has a good description: "question is raised whether such individuals are competent to refuse psychiatric treatment. The standard notion of competence to consent to treatment, which refers to the expression of choice, understanding of medical information, appreciation of the personal relevance of this information, and logical reasoning, may be insufficient to address this question. This is so because major depression may not impair these four abilities, while it may disrupt the coherence of personal preferences by changing them" [3].

Moreover, patients with depression tend to have a negative attitude to their situation and make decisions that are harmful to their own health. According to the American Psychiatric Association, symptoms of depression include:

1. Feeling sad or having a depressed mood
2. Loss of interest or pleasure in activities once enjoyed
3. Changes in appetite — weight loss or gain unrelated to dieting
4. Trouble sleeping or sleeping too much
5. Loss of energy or increased fatigue
6. Increase in purposeless physical activity (e.g., inability to sit still, pacing, hand-wringing) or slowed movements or speech (these actions must be severe enough to be observable by others)
7. Feeling worthless or guilty
8. Difficulty thinking, concentrating, or making decisions
9. Thoughts of death or suicide [5]

Thus, a serious defect of the modern medical system has presented itself. On one side, patients with depression display essential differences from patients with other mental disorders, as they preserve their decision-making ability. On the other side, these patients with depression, if given intact autonomy according to the existing system, might make medical decisions that are harmful to themselves. Depression is estimated to be the most prevalent mental disorder worldwide; about 5% of adults suffer from depression according to data from the World Health Organization (WHO) [6]. Evidently, the negative impact of such a dilemma has become non-neglectable. A resolution is needed.

Debates aiming to provide a solution are ongoing, and two ideas have emerged as the most popular. The first idea suggests that patients' rights to autonomy should be preserved since patients with depression still have complete cognitive capacity. Additionally, some methods of treatment can be provided before patients make their decisions. Professor G. Meynen at

Utrecht University supports this; he claims that “providing environmental cues may be one way of enhancing the decision-making capacities of these patients.” [7] This suggests that if certain conditions are given, such as appropriate environmental cues, patients with depression might be able to present medical decisions that are as rational and reliable as decisions made by normal people.

The second idea suggests that the principle of autonomy should not be preserved, since people with depression might make harmful medical decisions. For example, they might refuse to take any medical treatments even if the treatments are apparently positive for them in order to do harm to themselves. Moreover, since existing rules and methods do not address this difficulty well, scholars advocating for this idea suggest that new rules should be introduced and provide a variety of proposals. Dr. A. Rudnick supports this point of view, explaining that “when past treatment preferences of the patient from periods without depression can be established, it is suggested that they should override current treatment preferences of the patient” [3]. This proposal serves as a strong alternative, as it finds a way to represent patients’ own medical decision preferences while accounting for their current lack of autonomy.

Above all, the dilemma of depression and autonomy is not a black-and-white problem but rather an extremely complex issue of modern bioethics. To see if such an ethical dilemma is resolvable, a thorough analysis of the disorder itself is necessary. This will be done in the third section and lead this paper to incline to the second idea - that is, to suggest that the rights of autonomy for patients with depression should not be preserved. Before that, however, it is also necessary to examine the ineffectiveness of the current tools that assess the capacities of decision-making capacities of patients with depression, which would help provide a closer revelation of the problem itself.

## **EXAMINING AN EXISTING METHOD THAT DEALS WITH PATIENTS WHO HAVE IMPAIRED COMPETENCES OF DECISION-MAKING**

Unlike depression, there are other mental disorders that impair patients’ cognitive capacities and thus impair their decision-making abilities. Some types of mental disorders make patients unable to present decisions with integrated rationality; other types make patients unable to make any decisions at all. As mentioned above, dementia is a typical example. Thus, methods and tools used to determine whether the patient has sufficient decision-making competence and whether their rights of autonomy should be preserved have been developed. These methods and tools are effectively and prevalently used. However, depression changes patients’ decision-making preferences

without impairing patients' cognitive capacity, and so it is questionable if these tools and methods can remain effective when applied to patients with depression. A detailed analysis must be done. In this section, MacCAT-T, a popular mental assessment tool will be introduced. Then, an analysis will be done to examine if this tool is effective while applied to patients with depression.

MacCAT-T stands for the MacArthur Competence Assessment Tool for Treatment. It was proposed by Grisso et al. from the University of Massachusetts Chan Medical School and is the product of an 8-year study of patients' capacities to make medical treatment decisions. Basically, MacCAT-T is a semi-structured interview that assists clinicians in assessing a patient's competence to consent to treatment [8]. Grisso et al. tested the feasibility and validity of the MacCAT-T method and suggested that the benefits of the MacCAT-T are mainly its thorough coverage of the patient's decision-making abilities and the convenience it provides for physicians. However, these benefits were not identified in regards to depression, and thus are not inherently applicable. Hence, it is necessary to complete a more specific analysis. According to Meynen's description, the MacCAT-T method is based on the assessment of four abilities:

1. the ability to express a choice;
2. the ability to understand the relevant information;
3. the ability to appreciate one's situation and the consequences of the options;
4. the ability to reason about treatment choices. [7]

Subsequently, the analysis will be separated into four parts, and each part will examine if each ability required for competent decision-making is intact for patients with depression. As suggested above, patients with depression may have self-harming tendencies and thus make harmful medical decisions. Thus, if all four abilities covered in the range of the MacCAT-T test are intact for a patient with depression, then it necessarily leads to the conclusion that the MacCAT-T test would fail to detect such a patient's inability to maintain their rational medical decision preferences.

First is the ability to express a choice. This ability requires the patient to have a basic language-using ability, which in itself requires the patient to be physically able to communicate, and the basic rationality that helps them present meaningful expressions. The major symptoms of depression, according to WHO, are "depressed mood, loss of interest and enjoyment, and reduced energy leading to diminished activity for at least two weeks." [6] Based on this summary, the patient's cognitive capacities related to choice making (memory, reasoning, perception, etc) are not affected and a patient with depression has the ability to express a choice.

Second is the ability to understand relevant information. This ability re-

quires the patient to have the basic capacity of perceiving the outside world and thinking rationally about received information. As listed in the previous section, according to WHO, a patient with depression normally has a depressed mood or feels sad. Thus, depression affects a patient's emotions and psychological tendencies but does not impair a patient's perception. Moreover, a negative psychological tendency caused by depression might make the patient think in negative ways - for example, they might feel guilty or pessimistic - but the patient's ability to reason is well preserved. Thus, a patient with depression usually has the ability to understand relevant information.

Third is the ability to appreciate one's situation and the consequences of the options. This ability requires the patient to have a normal capacity for memorizing things, organizing information, and imagining. These are all inherent abilities of the brain, and, as mentioned above, depression does not affect any basic mental or physical ability. Although a patient with depression normally loses their interest or pleasure in activities once enjoyed, they might also be unwilling to have a social connection with others and incapable of dealing with any social affairs, thus weakening their ability to interpret the surrounding social situation. But, as long as the patient still owns sufficient cerebral capacities, they are not considered incompetent or incapable of appreciating their situation and the consequences of the options.

Finally is the ability to reason about treatment choice. This ability also requires a patient to have basic analytical skills, i.e., the ability to apply logic and reason to information they receive from outside. As listed previously, one relevant symptom of depression is that it can make thinking, concentrating, or making decisions difficult. However, the patient usually still has sufficient cognitive capacity to reason about and analyze things. Another possible situation is that, while a patient with depression is capable of analyzing treatment choices, he or she might make an apparent worse choice due to the self-harming tendency caused by depression. However, technically, as the patient still possessed the required cerebral capacities, they are not considered to be incompetent in regards to reasoning about treatment choice.

As the analysis reveals, there are some symptoms of depression that might affect the four abilities of competent decision-making but they are far from impairing them. However, as the fourth analysis mentions, though the patient with depression still has an intact cognitive capacity, they might still make an unreasonable medical decision due to potential self-harming tendency. Thus, if the result of applying the MacCAT-T method on patients with depression is deemed valid and their autonomy is preserved, the consequence would be unacceptable. Overall, it is necessary to conclude that the prevalent MacCAT-T method is invalid for patients with depression, and

new medical rules and assessment tools must be introduced.

## **AN ETHICAL EXAMINATION AND A PROPOSAL BASED ON IT**

One potential controversy of depression is that it is sometimes difficult to differentiate depression from normal negative emotional reactions. In an article written by Nicholson et al., five key principles of the UK Mental Capacity Act are described. One of them says that a patient is entitled to make unwise decisions even if they harm the patient themselves [9]. Thus, it is essential to examine if depression can be definitively classified as a disease from pathological perspectives. If a solid reason for differentiating depression from normal negative emotional reactions cannot be found, then, according to the existing principle, unreasonable treatment decisions made by patients with depression should be permitted. Above all, an ethical examination of depression itself is essentially an examination of the existing classification of diseases.

Harvard Medical School professor Joseph Loscalzo describes the contemporary method of classification of human disease in his article “Human Disease Classification in Postgenomic Era.” He states, “Contemporary classification of human disease derives from observational correlation between pathological analysis and clinical syndromes” [10]. However, reality is not always ideal. A major difficulty in nosology (the study of disease classification) is that diseases often cannot be defined and classified clearly, especially when cause or pathogenesis is unknown. Thus, diagnostic terms often reflect only a symptom or set of symptoms. This difficulty is revealed in the classification of depression. A clear pathological causation of depression has not been declared as yet. According to WHO’s definition, “depression results from a complex interaction of social, psychological and biological factors” [6]. But exactly which factor causes depression is not clear.

There is a prevalent theory that depression is caused by a chemical imbalance. Ryan P. Robinson at the University of Akron and his fellow scholars performed an experiment to examine if this theory can be supported. Their conclusion is that “chemical imbalance hypothesis of depression causation have been quite useful in many ways (e.g., by stimulating research and influencing the development of new antidepressants). However, at present such hypotheses remain unproven and, at least as presented in many television ads, are likely overly simplistic and oversold” [11].

The International Classification of Diseases (ICD) is the most widespread and renowned classification system used by medical institutions and organizations. It is developed and regularly updated by the WHO, and the latest version is ICD-11. ICD-11 is a large taxonomy consisting of tens of thousands of entities that can be anything relevant to healthcare. It usually describes a disease or a pathogen, but it can also be an isolated symptom or

anomaly of the human body. The description of depression in ICD-11 is as follows: “Depressive disorders are characterized by depressive mood (e.g., sad, irritable, empty) or loss of pleasure accompanied by other cognitive, behavioral, or neurovegetative symptoms that significantly affect the individual’s ability to function.” [12] (Note that by “cognitive symptoms”, it refers to indetermination of attention and memory, which does not contradict the conclusion regarding cognitive capacity above). As presented, the classification of ICD-11 is based only on syndromes and not an analysis of pathological causation.

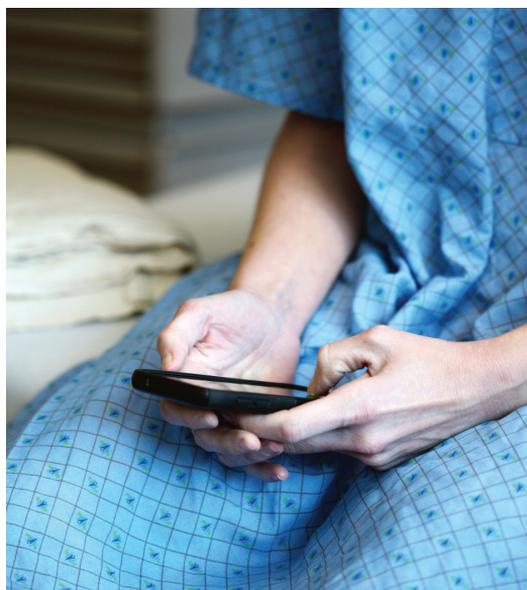
Such a situation implies a possibility that might lead to further difficulty, as hypothesized above. At present, scholars have not found the causation of depression, so it is logically possible that there is simply no way to differentiate depression from normal negative emotional reactions, and depression might be nothing more than a severe kind of that. As the principle of the Mental Capacity Act says that people are entitled to have upset moments and also entitled to make unwise decisions based on their emotions and take responsibility for these decisions, it is possible that those who are deemed patients with depression are actually normal from a pathological perspective. Thus, their rights of autonomy should not be interrupted.

Regardless of the above theorizing, the social problems caused by depression such as high suicide rates are real and must be addressed. According to data from the U.S. Department of Health & Human Services, about 2 percent of people ever treated for depression in an outpatient setting will die by suicide [13]. This occurs not only due to issues of the disorder itself, but also the existing codes and rules of the medical system. Currently, a number of scholars are striving to identify the main factors that lead to depression. For example, H. M. Van Praag at the Albert Einstein College of Medicine has endeavored to investigate the relationship between stress and depression [14]. The chance that researchers will uncover the secrets to depression is overall optimistic. Thus, as opening up the rights of making treatment decisions to patients of depression may be harmful to patients themselves, the rights stipulated by the bioethical principle of autonomy should not be preserved for patients of depression, and alternative methods to ensure patients’ best interests are needed. However, if physicians do not grant patients themselves the rights of autonomy, who could serve as a qualified decision-maker and advocate for the best interests of the patients? There has been some legislation that addresses this question through the institution of guardianship.

Guardianship is a legal procedure that orders a legal guardian for another person. A legal guardian is a person who has the legal authority to care for the personal and property interests of another person. According to the definition of California Court Web, the guardian of a person has the same lawful responsibilities to care for the person just as their parents would [15]. As it

implies, guardianship is normally applied to protect the interest of minors, but there is also a history of applying guardianship for incapacitated seniors and other people who suffer from mental disorders. The Japanese Ministry of Justice site provides an illustration of guardianship for adults: “This system protects and supports those who constantly lack mental capacity due to mental disorders (dementia, intellectual disorders, mental disorders, etc.)” (Ministry of Justice, 1). Though patients with depression are not deemed to lack mental capacity, the adult guardianship system should still be applied to them.

Nicholson et al.’s introduction of the five key principles of the Mental Capacity Act mentioned above that another principle is that “decisions (and actions) made for people lacking capacity must be in their best interests.” [9] The adult guardianship system is an appropriate way of preserving the best interests of incompetent people, as the guardian has parental responsibilities supervised by the court. The case of Yongxin Yang discussed previously is relevant here. That case indicates a common problem of the guardianship system, namely that even though guardians normally strive for the best interest for their children, they sometimes act irresponsibly. Thus, with respect to medical decisions, there should be more conditions imposed on the guardianship rules to prevent similar tragedies. Since guardianship is one of the only lawful ways to let another person represent one’s best interest, and as long as the conditions for such preventions are specified through further research, guardianship is still the best solution to the current decision-making quandaries of depression. Furthermore, though rights of autonomy are not preserved directly for patients, the existence of adult guardians ensures that these rights are partially preserved for them in an indirect way. According to the Japanese Ministry of Justice, “Family courts appoint adult guardians according to the circumstances such as what kind of protection or support is necessary for the individual. In addition to a relative of the individual in question, a legal/welfare expert or other third parties, or a welfare-related public interest corporation or other corporation



McCutcheon, S. (2020). *Patient with phone before surgery*. Photograph. Retrieved from <https://unsplash.com/photos/BrECcnO7hsg>.

may be chosen. It is also possible to select multiple adult guardians” [16]. This specification expands the range of electing guardians for a patient. Not only can the parents of a child be guardians, but so can a legal expert or a third party (for instance, welfare-related groups). Such an expansion of guardianship enables the system to be applied not only to children, but also to adults since a lawful election for guardians can be open to anyone that has such needs. Thus, the use of the guardianship system could exceed the traditional range that is limited to children and their parents, creating the possibility to solve further difficulties. Most importantly, rather than leaving the treatment decision to an evaluation tool, this method ensures that patients’ interests and perspectives are sufficiently considered. Overall, as the analysis shows, patients with depression cannot be deemed to be incompetent with existing methods. Yet, they might make harmful medical decisions if intact, direct rights of autonomy are opened to them. Thus, to preserve the maximum rights of autonomy for patients of depression, it is reasonable to consider some indirect ways to do so, and the adult guardianship system is an appropriate method for this purpose.

## CONCLUSION

Though the classification of depression still does not include a pathological cause for the disorder, as the conceivable impacts led by opening rights of autonomy to patients of depression are critical, these rights should not be preserved for patients in any direct ways. The adult guardianship system can be a method of indirectly preserving autonomy for the patients to ensure the provision of proper cures. The bioethical dilemma caused by depression is highlighted by the invalidity of the MacCAT-T method. While depression does not impair patients’ cognitive capacity, it changes the patients’ preferences for making treatment decisions. This way, as patients with depression are not considered to have their competence impaired according to the MacCAT-T method, the tendency of harming themselves raised by the depression while making medical decisions can lead to serious problems. This is from which the debate about whether we should preserve rights of autonomy with its entirety for patients with depression arises. On the other hand, though the formal classification of human disease is derived from the correlation between clinical syndromes and pathological analysis, difficulty occurs in the case of depression. ICD-11, the latest version of disease classification published by WHO, cannot indicate the causation of depression yet. As the analysis of the ethical value of the classification of depression is yet an ongoing project, it is urgent for people to have an alternative method to cope with the dilemma.

After exploring the modern clinical conclusion for the pathological cause of depression and evaluating the ethical conflict within the situation,

this paper has suggested that the rights of autonomy should not be preserved directly for patients with depression. This conclusion is built upon the analysis that the MacCAT-T method is invalid towards cases of depression and the fact that if rights to autonomy are fully preserved for patients with depression, then the patients' psychological tendency of doing harm to themselves caused by the disorder would lead them to make unwise medical decisions and cause further negative consequences. Moreover, in addition to depression, there are other mental illnesses such as anxiety and mania that similarly do not impair one's cognitive functions but negatively influence the patient's psychological tendency while making medical decisions. Thus, the analysis and conclusion made in this paper could be impactful for patients with these disorders, and as the above has suggested, the rights of autonomy should not be preserved directly for patients who have mental illness of this kind. Instead, a mature legal system that utilizes guardianship for bioethical purposes should be built to solve the dilemma. This way, not only is the principle of autonomy preserved for patients with these disorders, but their best interests are also maximally represented in an indirect way.

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