We encourage you to use this publication as a starting point to increase awareness and promote discussion of these exceedingly important bioethical topics. The issues addressed in the following pages demand action. After all, bioethics is an activity that encourages shared, reflective examination of ethical issues in healthcare, science, and related policy, the key word being "shared." We do not live our lives in isolation; health is a collective effort. It requires us to challenge assumptions about the way we approach community, national, and global issues. And most essentially, it requires us to participate and engage.

— Letter from the Editor

The Rutgers Journal of Bioethics Vol. IX, Spring 2018

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THE RUTGERS JOURNAL OF BIOETHICS

VOLUME IX, SPRING 2018

ABOUT

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 by students at Rutgers, the State University of New Jersey. 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>. The Journal is published by Premier Graphics (500 Central Avenue, Atlantic Highlands, NJ 07716) and funded through generous contributions from the Rutgers University Student Assembly Allocations Board.

Letter from the Editor

This publication was made possible with the help of our sister organization, the Rutgers Bioethics Society, which has worked tirelessly to organize its symposium, during which this publication will be launched. We thank our publishers, our editors, and our design team for their hard work in creating a diverse and insightful publication. We urge you, our readers, to consider the multiple perspectives on the issues discussed in this publication.

During the past two years *The Rutgers Journal of Bioethics* shifted focus, highlighting health disparities in the way patients access and receive treatment, a topic which is more salient than ever. Furthermore, our emphasis on public health comes at a time when the field encompasses more than disease and injury surveillance. The reach of public health is increasingly inclusive, expanding its breadth to address issues of social disparities and the intersection of a variety of determinants including policy, urban planning, discrimination, life-style, socioeconomic status, etc. that have a profound impact on our health.

To this end, the Journal presents an article dissecting mental health conditions in American Indian and Alaskan Native populations, as well as a discussion describing the impact of mass incarceration on the health of individuals and communities. Additionally, two of our authors explore the impact of making incorrect assumptions in the medical field-- one considers disabled patients, while the other examines the role of adolescents in clinical research. We also include a socio-ethical analysis of Rebecca Skloot's *The Immortal Life of Henrietta Lacks*.

We encourage you to use this publication as a starting point to increase awareness and promote discussion of these exceedingly important bioethical topics. The issues addressed in the following pages demand action. After all, bioethics is an activity that encourages shared, reflective examination of ethical issues in healthcare, science, and related policy, the key word being "shared." We do not live our lives in isolation; health is a collective effort. It requires us to challenge assumptions about the way we approach community, national, and global issues. And most essentially, it requires us to participate and engage.

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

Letter from the Society

The Rutgers Bioethics Society is an organization that brings students together to discuss ethical dilemmas in the fields of healthcare and biomedical research, among others. Our biweekly meetings involve group discussions in which students analyze issues in bioethics and discuss potential solutions. The subjects of our discussions this year have included the ethical implications of savior siblings, pre-implantation genetic diagnosis, euthanasia, and more. It is important to discuss these matters since the "correct" answer in many cases in biology and related fields is not always clear.

This year, Dr. Eric Singer, a urologic oncologist at the Rutgers Cancer Institute of New Jersey and a member of the Robert Wood Johnson University Hospital Ethics Committee, spoke at one of our events during the fall semester, "Bioethics with Dr. Singer." He discussed the various ethical issues involved in clinical research trials and development of treatments for diseases. Additionally, we hosted an event called "The Principles of Ethics" with the Rutgers Association of Undergraduate Geneticists. Dr. Karen Schindler, a member of the Rutgers Genetics faculty, led a discussion that focused on how the pillars of ethics apply to several case studies in the field of genetics. Both of these events were great successes and offered real world examples of the importance of bioethics.

Dr. Francis Barchi will be the keynote speaker for this year's seventh annual Rutgers Bioethics symposium. The symposium aims to bring awareness to current and pressing issues in health and medicine. Our theme this year is focused on global health ethics since Rutgers is taking new initiatives to advance global health awareness. It is essential to understand the need for thought-provoking discussion when addressing global health initiatives. Consequently, we hope the symposium will inspire young minds to examine global health and its moral and ethical implications.

We would like to express our gratitude to the members of the Rutgers Bioethics Society. The dedication and commitment of our members is admirable and is the main reason for the success of this organization. As they progress in life, we hope that they carry forth the principles and ideals discussed at our meetings and events. We would also like to thank the executive boards of the Society and the Journal for helping with the programs throughout the year. Their devotion to the organization and passion for bioethics is what makes our meetings and events possible. The publication of Volume IX of *The Rutgers Journal of Bioethics* is a prime example of the hard work of the Journal executive board, and we hope that you benefit from reading this edition.

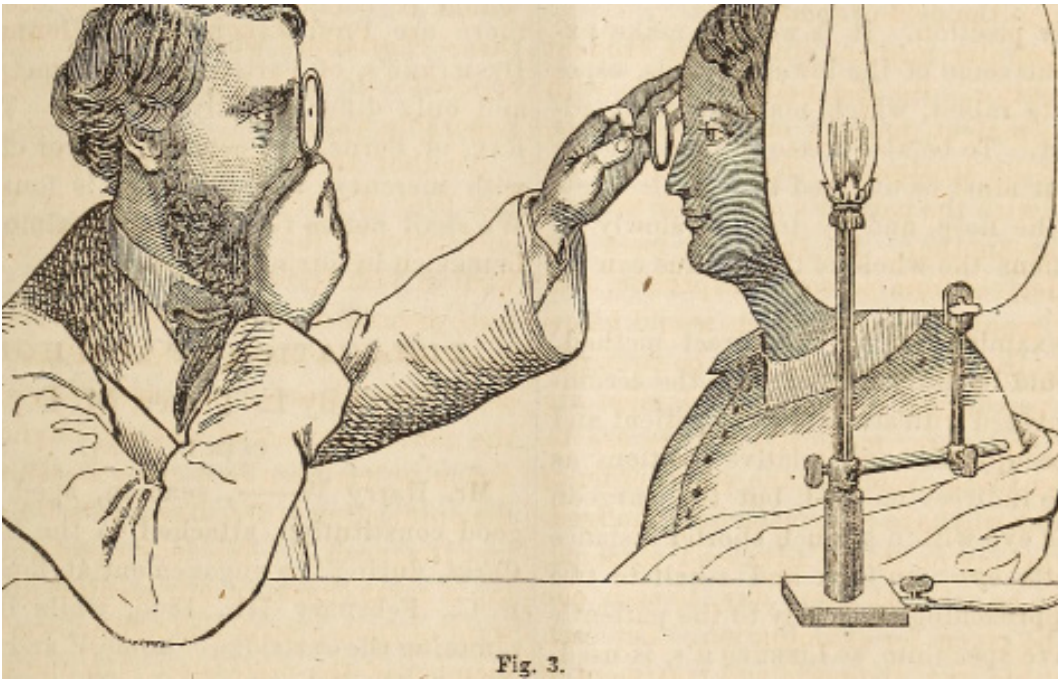
Aditya Brahmbhatt & Muhammed Rahim,
Presidents, Bioethics Society of Rutgers University

the Rutgers Journal of Bioethics

Volume IX, Spring 2018

Editorial

Articles & Essays



Above: Turnbull, L., M.D. (1863). *The Opthalmoscope–Directions as to its Employment*. In S. W. Butler, M.D. (Ed.), *The Medical and Surgical Reporter* (Vol. 10, p. 345). Philadelphia, PA: King & Baird Printers.
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Articles & Essays

Editorial

The Ethical and Legal Implications of Human Germline Editing and Cytoplasmic Transfer as Assisted Reproductive Technologies

by Divya Thonur †

Germ-line editing is a type of genetic modification process, whereby the genomes of gametes (egg and sperm cells) or early embryos are selectively and intentionally modified for the removal of undesirable traits or the implementation of certain desirable features ("About Human Germline Gene Editing," 2015). With respect to human germline modification, it aims to repair or eliminate a threatening mutation that could cause devastating disease (Lanphier et al., 2015) and has huge ethical and legal implications for society and for future generations on a global scale. Unlike cytoplasmic transfer, germline gene editing has far-reaching effects as it aims to modify the nuclear DNA in sex cells, not the mitochondrial DNA.

The aforementioned cytoplasmic transfer is a procedure where a donor egg's cytoplasm is integrated into another individual's defected egg to promote fertility and reproductive success. This procedure provides couples with a viable way to conceive by circumventing any complications in the egg's mitochondrial DNA, which can cause birth defects. The major difference between germline editing and cytoplasmic transfer is that germline editing does not preserve the original mother's genetic information in the developing child, whereas with cytoplasmic transfer the mother's genetic DNA is retained in the developing child while the mitochondrial DNA comes from the donor egg. As per several studies, it is not known whether cytoplasmic transfer has a profound effect on the developing child's physiology (Barritt, Willadsen, Brenner, & Cohen, 2001). Although both germ-line editing and cytoplasmic transfer procedures differ in the genetic information retained in the resulting child and the long-term health consequences involved, both methods involve genetic modification. That is, the removal of negative traits and/or the addition of positive, desirable traits. This raises the question of which method is safer, and what are the associated ethical and legal implications of each.

The most prominent ethical and legal implications of these types of genetic

† **Divya Thonur** is a Rutgers University graduate with a bachelor's degree in biological sciences. Her hobbies include creative writing, poetry, photography, ceramics projects, playing the piano, composing original music, debating, working with children, and traveling the world to explore different cultures. She hopes her writing encourages open and positive educational discussions about these pressing bioethical issues among fellow students and university faculty.

engineering and assisted reproductive technologies stem from the possibility that this technology may unknowingly cause mutations that have a lasting, deleterious impact on future generations. For instance, the issue of using germline editing on humans is a highly controversial ethical issue because it could irreparably change the human species through permanent mutations. This is a problem, from a legal standpoint, because people could accuse and possibly sue others for genetically modifying their genomes and sex cells, as well as for any damage or burden they incurred from using these technologies. It puts people in a vulnerable legal situation because these technologies are still relatively new and we do not have much clarity about the long-term health consequences. From an ethical standpoint, Darnovsky's commentary sheds light on how germline modification is ethically and morally questionable because it lacks proof of safety (Darnovsky, 2013). She believes that mitochondrial replacement is the same as germline modification and that mitochondrial DNA is a significant part of the human genome and can influence a person's whole identity, contrary to supporters of this technology (Darnovsky, 2013).

This portrays cytoplasmic transfer as a questionable practice because the donor's cytoplasm could cause unpredicted mutations in the resulting embryo, if not genetically compatible with the original mother's egg. By applying germline editing and cytoplasmic transfer to humans, there is a chance that the resulting children produced could suffer from deleterious mutations, which could propagate and negatively impact future generations. Using these types of technologies also opens the door for increased legal liability among physicians and specialists that prescribe these treatment methods to their patients for infertility. If germline editing procedures were approved for human use, then doctors who prescribe this treatment for couples at high risk of conceiving a diseased child could be susceptible to lawsuits or losing their licenses if the procedure fails or causes permanent mutations in the child during the early or late stages of human development. With this in mind, it is imperative for physicians to understand the overarching ethical and legal consequences of prescribing these treatment options to patients for infertility.

Furthermore, I think that the future ethical and legal implications of germline editing and cytoplasmic transfer ten to twenty years from now would be vast because it could further peoples' interests in designer babies and genetic engineering for enhancement purposes. In my opinion, I think that both germline editing and cytoplasmic transfer technologies will become much more tangible in the future, especially with the astonishing rise of CRISPR/Cas9 genetic engineering technology. Perhaps there could be a new way of transferring the donor's cytoplasm to the mother's egg cell without inducing any negative mutations in the resulting child. With the rise in genetic engineering research development, our understanding of the ethicality of genetic modification could completely transform a few years from now. If these technologies are accepted in the U.S. for use on humans, I think

that more people will show an interest in creating designer babies and practicing genetic engineering because of the widespread availability of these tools.

With respect to the legal implications of this shift in genetic engineering technologies, I think that new societal laws would need to be created and continuously amended in order to promote the safe use of these technologies. For instance, it would be advisable to look into the intentions of people using these technologies and explicitly state the consequences for misusing them for destructive purposes. This would definitely affect the current legal system because we would need to apply more stringent criteria for the use of these technologies when considering malpractice and other legal cases where people may have suffered from genetic engineering procedures. These major changes in the legal system and high surveillance on those using assisted reproductive technologies would certainly affect our society because we may see less people making use of ARTs, as a result of increased regulation. They may even only use it in emergency situations and not for enhancement purposes, if it is highly regulated. Personally, I agree with Darnovsky's commentary and feel that both assisted reproductive technologies pose challenging short and long-term consequences for the public and should be cautiously evaluated through detailed clinical trials and long-term studies before approving them. Although the rise in the development of these technologies is remarkable, especially in locations outside of the U.S., I think that policy-makers and legislators should take a closer look at the who, why, and how before making use of germline editing and cytoplasmic transfer in the future.

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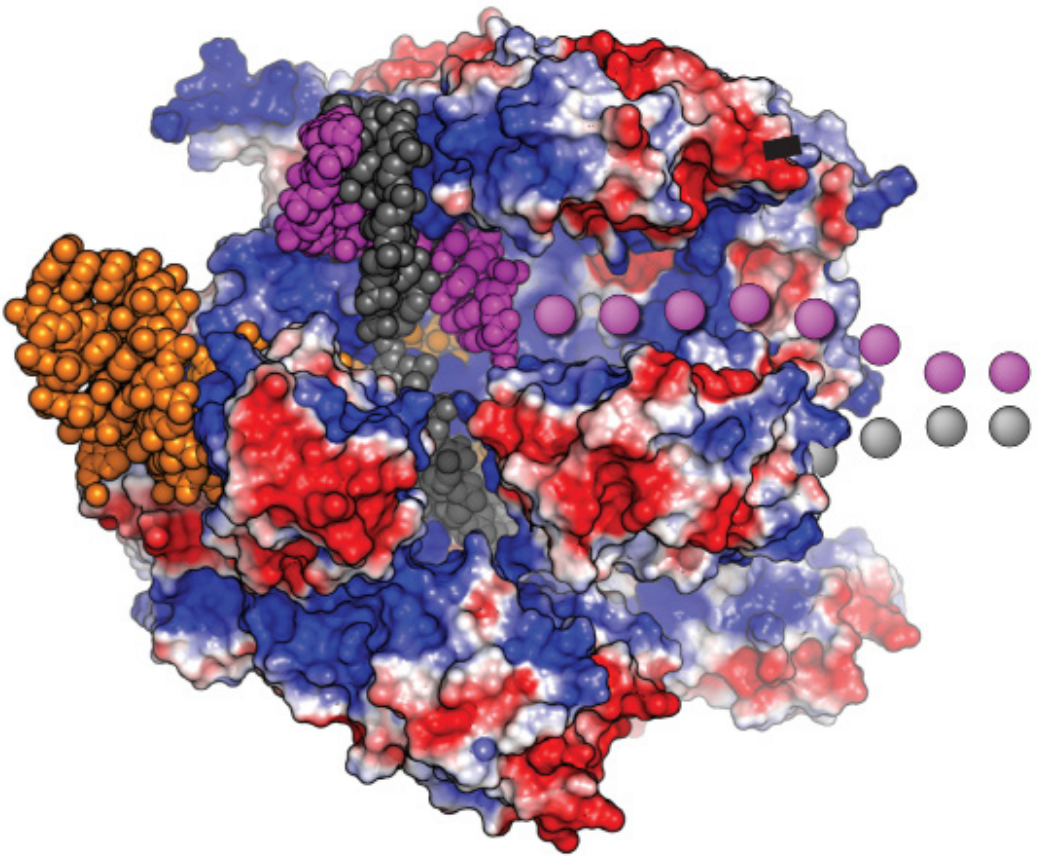

Christopher Richardson, UC Berkeley, 2016, *Cas9 Protein*. CRISPR-Cas9 technology is one of many techniques being researched for its applications in genome editing. In the model above, the Cas9 protein is represented by red and blue spheres while double-stranded DNA is represented by purple and grey spheres.

Article

Ethically-mandated Responses to the High Prevalence of Mental Health Conditions in American Indian/Alaska Native Women

by Sajya Singh†

American Indian/Alaska Native (AI/AN) women access fewer mental healthcare resources than White women despite a higher prevalence of mental health conditions in this population. Factors in the psychosocial environment of AI/AN women may contribute to the elevated proportion of individuals in this group affected by higher levels of violence, poverty, and historical trauma. The most prominent mental health conditions for AI/AN women are post-traumatic stress disorder, alcohol abuse, and major depression. These findings mandate a response to alleviate the burden of mental health concerns in AI/AN women. In particular, greater persecution of perpetrators of sexual assault, an increase in research analyzing mental health and resource use in the AI/AN community, and retribution for historical trauma caused by the systematic oppression of AI/AN women are recommended. Each of these efforts should be done in a way that empowers AI/AN women to lead the proposed changes and that respects the cultural traditions of the AI/AN community.

† **Sajya Singh** is a senior at the University of Minnesota-Twin Cities majoring in Genetics, Cell Biology, and Development (B.S.) and minoring in French Studies. After graduation, she will pursue a career in medicine, through which she would like to work with patients who have genetic conditions. Her interest in this field has heightened through her experience as a Research Associate at the Minneapolis Heart Institute's Genetic Arrhythmia Center. She has also developed a passion for bioethics, particularly regarding women's health and advances in genetic engineering.

The United States Surgeon General's report on mental health and race/ethnicity states, "Racial and ethnic minorities have less access to mental health services than do whites, are less likely to receive needed care

and are more likely to receive poor quality care when treated" (Office of the Surgeon General, 2001). This far-reaching statement implies the millions of Americans across the country who belong to one or more racial group are more affected by the devastating impacts of mental illnesses due to inadequate care. Because of the large diversity of populations that live within the United States, unique within-group characteristics and culture, historical context, and overall socioeconomic status influences how the consequences of this finding are felt by members of each group. Furthermore, the intersectionality of gender and race plays a role in the mental health status of an individual and in obtaining adequate care (World Health Organization). Therefore, it is important for health inequity policies to consider the unique problems faced by each population regarding access to and use of mental health services.

Here, national data on the prevalence of mental health conditions and the use of mental health services by the American Indian/Alaska Native (AI/AN) population of the United States, both male and female, will be considered. Next, this article lists the psychosocial conditions that may induce and exacerbate mental health illnesses within this community along with how these particularly affect AI/AN women. It explores mental health conditions that are most common in the AI/AN female population and the potential reasons for which these occur. Finally, this work presents an ethical analysis of and call for responses to a few of the significant issues faced by AI/AN women.

BACKGROUND

AI/AN individuals experience a higher prevalence of poor mental health than any other racial/ethnic population in the United States. The percentage of the AI/AN population over 18 affected by a mental health condition is 28.3% compared to 19.3% of non-Hispanic White adults, 18.6% of non-Hispanic Black adults, 16.3% of Hispanic adults, and 13.9% of Asian adults (SAMHSA, 2015).

The "Racial/Ethnic Differences in Mental Health Service Use among Adults" report from the U.S. Substance Abuse and Mental Health Services Administration (SAMHSA) details the prevalence of mental illnesses in the United States as well as the use of mental health services across the demographic categories of race, gender, poverty level, and age. Interestingly, the majority of the report focuses on reporting differences between three racial categories: White, Black, and Hispanic. Although the AI/AN population constitutes a small percentage of the population—0.9% AI/AN alone and 1.7% AI/AN alone or in combination with other races (National Congress of American Indians)—the significance of mental illness in this population calls into question the lack of reported data for this demographic. Moreover, the report acknowledges the difficulty in reporting data for the AI/AN people due to the small number of nationally representative studies aimed at examining use of

mental health services in this population (SAMHSA, 2015).

The SAMHSA data illustrates several significant trends to consider related to the AI/AN population. First, the use of any mental health service by AI/AN individuals between 2008 and 2012 was nearly as high as for White individuals, 15.6% compared to 16.6% respectively, and quite higher than for Black or Hispanic populations, 8.6% and 7.3% respectively. Yet the AI/AN population is the only race/ethnicity in which men utilize these services more than women— AI/AN males used mental health care more than White, Black, Asian, or Hispanic men. In contrast, the use of mental health services by AI/AN females is lower than that of their White counterparts, 15.1% versus 21.5% (SAMHSA, 2015). Therefore, while the White and AI/AN populations are using an overall similar amount of services, AI/AN women are not accessing care as often as this statistic would indicate.

Although the SAMHSA report documents that the AI/AN population is among the races/ethnicities estimated to use more mental health services, this result must be considered in the context of the increased prevalence of mental health issues in this population. Simply reporting the use of mental health services gives no indication regarding the quality of care received. The report also discloses that AI/AN adults were less likely to report structural barriers as obstacles in accessing mental health services (SAMHSA, 2015). Although this is encouraging in the fight against healthcare inequity, it begs the question why a higher prevalence of mental health conditions continues to be observed in this population when there are fewer perceived barriers to resources. The answer to this question must be found outside the context of mental health office visits, and instead in the psychosocial environment which influences the lives of AI/AN women.

Psychosocial Context

Trauma and violence are prevalent for many AI/AN individuals, regardless of age or gender. For women in particular, the well-documented exposure to violence is significantly high. In a study by the U.S. Department of Justice (2000), 39% of AI/AN women reported victimization by violence from intimate partners, a higher percentage than for any other racial/ethnicity demographic. The rate of physical assault against AI/AN women is estimated to be 50% higher than the next most victimized demographic (Perry, 2004).

In addition to domestic violence, sexual assault and abuse are unfortunately widespread. AI/AN women are greater than 2.5 times more likely to be raped or sexually assaulted compared to women of other races. Furthermore, 78% of the rape incidents described in one report were committed by White perpetrators (Perry, 2004). The combination of domestic violence by family members with sexual assault committed by strangers leads to the intense prevalence of violence in some of the lives of these women.

The high poverty rate present in the AI/AN population is one of the factors most relevant to the mental health status of individuals. Lower socioeconomic status incurred by an elevated prevalence of poverty is associated with traumatic or stressful life events (Office of the Surgeon General, 2001). AI/AN women are disproportionately affected by poverty compared to the national average. In 2015, the National Women's Law Center reported the poverty rate for AI/AN women was 22.7% compared to a national average of 13.4%. This rate was only lower than for African American women (23.1%) and much higher than that for White or Asian women, 9.6% and 11.7% respectively (National Women's Law Center, 2015).

The AI/AN community is recognized for having an overlying shadow of historical trauma, the intergenerational experience resulting from persecution due to their group identity (Ehlers et al., 2013). Much of the harm done to this population was by the U.S. government through actions including genocide, removal from tribal lands, and placement of AI/AN children in boarding schools, at which they experienced abuse and removal of their culture among other mistreatments (Ehlers et al., 2013). The loss of land, including the plants and animals that inhabit it, represents an additional loss as these hold sacred value to the AI/AN community (Brave Heart and DeBruyn, 1998). The importance of considering historical trauma is emphasized in the words of one Native American female researcher: "Historical trauma provides a context for current trauma, grief, and loss across the lifespan by rooting them in the collective psychosocial suffering across generations" (Heart et al., 2016).

Mental health conditions that affect AI/AN women

In order, the three most prominent mental illnesses that affect AI/AN women are post-traumatic stress disorder, alcohol dependence, and major depression. Post-traumatic stress disorder (PTSD) is a particular threat to AI/AN women, hypothesized to be the result of a high exposure to violence (Basset et al., 2014). The prevalence of this condition in AI/AN women is estimated to be between two and three times the national rate (Office of the Surgeon General, 2001). Unfortunately, there is a dearth of research regarding the clinical course and the treatment of PTSD in this population (Basset et al., 2014).

Alcohol is the most common substance that is overused within the AI/AN population, and alcohol abuse leads AI/AN women to have a 20.3% death rate due to this condition as compared to 3.5% for other racial demographics (Walters and Simoni, 2002). AI/AN women acknowledged in one study the abuse of substances as "a means of coping with a variety of painful life experiences and circumstances" (Peterson et al., 2002).

A high prevalence of depression is also noted to be one of the most

prominent conditions affecting the AI/AN population (American Psychiatric Association, 2010). Like with PTSD, it has been found that depression is significantly correlated with intimate partner violence, which occurs at a higher rate to AI/AN women than to women of other racial/ethnic groups. In one study, 50.8% of abused women were suffering from depression compared to 6.1% those who were not (Prosman et al., 2011).

Mental health conditions do not occur in isolation from one another. Alcohol abuse is correlated with depression as 30 to 40% of individuals with a diagnosed alcohol dependence have also been diagnosed with at least one major depressive episode (Tann et al., 2007). Further, AI/AN women experiencing severe intimate partner violence were five times more likely to have PTSD than their counterparts (Duran et al., 2009).

ETHICAL ANALYSIS AND CRITIQUE

The disheartening statement made by the Surgeon General's 2001 report regarding the state of access to and quality of mental health resources for racial and ethnic minorities is ethically unacceptable, in particular for AI/AN women. The unique problems faced by AI/AN women include a high prevalence of mental illness, low use of mental health services, stranger sexual assault, domestic violence by intimates, a high poverty rate, and the implications of historical trauma. Though these challenges are all threatening to the quality of life of AI/AN women, this critique will focus on three ethically-mandated responses to combat the high prevalence of mental health conditions found in this community.

Justice for crimes of sexual assault

For survivors of sexual assault and/or domestic violence, obtaining justice for the committed crime often does not occur or when it does, and is hard-won after months of legal struggle. In 2015, only 32% of rape and sexual assaults were reported to the police in the United States (Bureau of Justice Statistics, 2016). This percentage is not broken down by race or ethnicity, which does not take into account the lack of trust in law enforcement for some populations in this country. For example, only one in at least fifteen Black women (~7%) will report a sexual assault or rape, a significant difference from the overall reporting percent (Houlemade, 2013).

Though the reporting percentage for sexual assault is not available for AI/AN women, the Women of Color Network's 2006 document on sexual violence states these women may report less due to a lack of trust in and the historical oppression by White agencies/healthcare providers. Furthermore, women may fear ostracization by their family and tribe (Women of Color Network, 2006). These statements indicate that like for other women of color, the actual rate of reporting sexual violence crimes to law enforcement by

AI/AN women might be lower than the national average. They also demonstrate the need to more accurately collect data regarding reporting in minority populations and to act upon the findings in an attempt to increase reporting rates by women of color.

Reporting a sexual assault does not guarantee justice. Nationally, only 31% of reported sexual assaults result in an arrest, 9% result in a prosecution, and 0.7% lead to a felony conviction (RAINN, 2016). The situation is even worse for AI/AN women wishing to move forward with a prosecution. Unlike sexual assault as a whole, where 78% of rape and sexual assault victimizations between 2005 to 2010 were committed by a "non-stranger", AI/AN women are primarily targeted by individuals who are not from their community (Planty et al., 2013; Perry, 2004). This occurrence may be the result of jurisdictional issues, where crimes committed on Indian reservations are under the purview of tribal courts, which cannot prosecute non-Indians (Planty et al., 2013; Futures without Violence). The result of this complex legislative system is that, "non-Indians who commit acts of domestic violence that are misdemeanors on Indian reservations are virtually immune from prosecution in most areas of the country" (Futures without Violence).

Sexual assault/rape can be a highly traumatizing experience for survivors. AI/AN women bear the additional burden of an increased prevalence of these crimes within their community, often without the possibility of reporting the crime due to distrust and without the possibility of seeking justice due to a loophole in the law. This can be countered by allowing tribal courts to prosecute any crimes occurring with their jurisdiction regardless of the race of the offender, thereby overturning the Supreme Court decision of Oliphant v. Suquamish (Rizzo, 2015). Tribal sovereignty in law enforcement must be preserved but not while allowing the exploitation of AI/AN women.

Increase in AI/AN women's mental health research

Reporting data for the AI/AN population is difficult due to a dearth of comprehensive investigations on mental health service use in this group (SAMHSA, 2015). Though the available data regarding violence against AI/AN women are alarming, these come from only a few studies. Nationwide data about these crimes is not forthcoming because there is no organization— federal or tribal— systematically collecting it. Furthermore, tribal judicial systems and federal authorities can under-report crimes that occur on reservations (Rizzo, 2015).

Lack of mental health research has significant implications on attempts to address the issues faced by AI/AN women. For example, while 30% of AI/AN women experience sexual assault, there is a lack of awareness and resources within tribal jurisdictions to properly combat this issue (Planty et al., 2013). Stigma can also result from lack of understanding regarding the causes for

certain mental health conditions. In the case of alcohol abuse, there are stereotypes regarding drinking habits within the AI/AN community, yet little actual research has actually analyzed this trend (Herman-Stahl and Chong, 2002).

Research as a whole needs to engage in a culturally-sensitive manner with the mental health problems facing AI/AN women. When possible, AI/AN women should be empowered to become involved in this work (Brave Heart et al., 2016). One prominent example of a AI/AN female researcher is Maria Yellow Horse Brave Heart, who has written extensively about and developed a model of historical trauma in AI/AN communities. She has also described the importance of community-engaged research to develop interventions that address the particular challenges faced by this group of women, including the reestablishment of traditional gender roles (Brave Heart et al., 2016).

Both the heterogeneity among tribes throughout the nation as well as the relatively small size of the AI/AN population create complications for research; however, the necessity of an informed and culturally-sensitive response to the state of mental health and to the quality of mental health care in this community demands efforts be made to overcome them (American Psychiatric Association, 2010). An example of such a movement is the University of Colorado-Denver's Centers for American Indian and Alaska Native Health and the associated National Center for American Indian and Alaska Native Mental Health Research. Further investments at the federal level are necessary to increase both awareness and understanding of the mental health plight of the AI/AN population as a whole and of the particular issues facing AI/AN women.

Retribution for historical trauma

Historical trauma is an intergenerational experience caused by a complex trauma that originated in the past but that is not benign in the present (Brave Heart, 2013). The trauma experienced by the AI/AN community occurred over a long period of time and continues today as a result of violence toward women, substance abuse, and suicide (Ehlers et al, 2013). In particular, AI/AN women suffered a loss from being unable to enact traditional gender roles of parenting and of protecting the family, a sacred and special position within the community, as a result of the boarding school requirements set upon their children (Brave Heart, 2013).

Historical trauma with respect to a group of people linked across time by a particular identity to a current population can have a substantial presence with the members of that population (Whitbeck et al., 2009). In one study, a sample of over 400 AI/AN adolescents aged 11 to 13 reported that over 20% of respondents thought daily or more about losses related to land, language, traditional spirituality, culture, alcoholism, early death, and respect for elders

(Whitbeck et al., 2009). Documented gender differences in responding to historical trauma have been shown through a study of historical trauma intervention on 45 Lakota men and women. Women experience greater pain when remembering historically traumatic events and feel more responsible for undoing the pain caused by these events (Brave Heart, 1999).

Historical trauma has been linked to mental health conditions and adverse health behaviors in the current AI/AN population. One study analyzed respondents' answers based on a Historical Loss Associated Symptoms Scale (HLASS), aimed at understanding how frequently losses were thought about. They demonstrated that PTSD was significantly correlated with higher scores on the HLASS (Ehlers et al., 2013). A study on AI youth from California found that historical trauma was a risk factor for cigarette smoking (Soto et al., 2015).

The mental health of many members of the AI/AN community has been significantly impacted by historical trauma. There is no way to undo the harms done to this population. Therefore, retribution is due in the form of federal aid for the AI/AN people to provide resources that contend with their historical grief as well as mental health services to treat the associated conditions. Both the use of traditional methods (storytelling, involvement of elders, or communal grief rituals) and clinical care can be effectively used (Schultz et al., 2016; Brave Heart and DeBruyn, 1998).

CONCLUSION

The shocking prevalence of psychological and physiological distress in AI/AN women manifests itself in ways that continue to perpetrate the trauma experienced by these people for hundreds of years. For many women, historical trauma may compound with current issues of violence, poverty, and suicide, leading to clinical conditions including PTSD, substance abuse, and depression. Healthcare policy must address the disproportionate burden of individual mental health illnesses borne by AI/AN women and the resulting impact on the community. In particular, both federal and state-level agencies should contend with the high prevalence of sexual assault of AI/AN women, increase nationally-representative research on mental health conditions and service use by this population, and provide acknowledgement and retribution for the effects of historical trauma. Moreover, these actions must be done in a way that aims to return the cultural losses accrued by AI/AN women. This includes empowering women to lead or participate in interventional research and incorporating traditional practices in the process of treating mental health. Without culturally-driven and urgent attempts to mediate the problems faced by AI/AN women, the cycle of trauma across generations will continue.

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Article

Intent versus Impact: Ableist Assumptions are Dangerous to Disabled Patients

by Hannah Kent†

There is an undeniable culture of unequal treatment between patients with and without disabilities. This work will address the moral conflict between well-meaning healthcare workers, their duties to provide compassionate care, and the actual expression of these duties as experienced by patients with disabilities. I will introduce first-hand accounts of these experiences, outline the biases and assumptions that underlie the culture that allows them, and provide evidence that those assumptions are incorrect. I then identify that the ableist conflation is a significant factor in promoting ableist bias in health care, and that the surrogate decision making technique of the Best Interest Standard allow them to persist.

To begin, some caveats: I am not addressing theories of disability. I will not define disability, as the term is global and applies to an extremely heterogeneous population. I also rely heavily on first person accounts of experiences by those who live with disabilities. Many disability advocates use the slogan, "nothing about us, without us," which demands involvement of the disability community in all efforts that involve them. Presenting first-hand accounts of these experiences is useful insight; the themes they present are supported by research and the fears they express are valid. I do not assume that these suggestions represent all persons with disabilities, nor all health care workers. I also acknowledge that, regardless of intent or efforts to remain unbiased, my interpretation of the experiences of people with disabilities is limited and likely influenced by bias.

BACKGROUND: ABLEISM

Ableism is discrimination against people with disabilities in the same way

† **Hannah Kent** is in her final year of a dual-degree program in cognitive science and bioethics at Case Western Reserve University. She is passionate about including diverse viewpoints to address issues of inequality and health inequity. She will be pursuing public health and health policy.

that racism and sexism is discrimination of people based on race and sex. In the medical setting, implicit bias leads to ableist assumptions; the duties of the health care workers may then translate to ableist interactions. Biases such as out-group homogeneity bias (when one thinks members of other groups lack inner group diversity), group attribution error (when one assumes characteristics of one individual represent the whole population of that group), fundamental attribution error (when one assumes that what people can do determines their worth and identity), and confirmation bias (once one determines expectations, they tend to pay attention only to experiences that support those expectations) make up just a fraction of the complex interactions between disabled patients and care providers and contribute to ableist interactions. First-hand experiences of ableism in the medical setting are widely available in disabilities rights activist groups as well as in academic literature.

Dr. William Peace published his experience under the title, "Comfort Care as Denial of Personhood" [1]. After developing a stage four wound, he expresses awareness of the difficulties ahead, processing the necessary steps for healing, and then states:

> "What transpired after the nurse exited the room has haunted me… The hospitalist asked me if I understood the gravity of my condition. Yes, I said, I am well aware of the implications. He grimly told me I would be bed bound for at least six months and most likely a year or more… I would never be able to work again. Not close to done, he told me I was looking at a life of complete and utter dependence. My medical expenses would be staggering. Bankruptcy was not just possible but likely. Insurance would stop covering wound care well before I was healed. Most people with the type of wound I had ended up in a nursing home.
>
> This litany of disaster is all too familiar to me and others with a disability. The scenario laid out happens with shocking regularity to paralyzed people… His next words were unforgettable. The choice to receive antibiotics was my decision and mine alone. He informed me I had the right to forego any medication, including the lifesaving antibiotics. If I chose not to continue with the current therapy, I could be made very comfortable. I would feel no pain or discomfort at all. Although not explicitly stated, the message was loud and clear. I can help you die peacefully. Clearly death was preferable to nursing home care, unemployment, bankruptcy, and a lifetime in bed. I am not sure exactly what I said or how I said it, but I was emphatic—I wanted to continue treatment, including the antibiotics. I wanted to live."

Further, Disability Rights group Not Dead Yet presented the story of Terrie Lincoln. Terrie was 19 when she was in a car accident. She explains the persistent offerings of termination of life support through the NDY report titled "Disability Perspectives on Advance Care Planning." She says, "They'd work

at my parents…Then they'd work on me. Saying stuff like: 'Are you sure this is something you can live with? Do you want to spend the rest of your life on a ventilator?' These are all the things we heard every day even though my health was improving." Not Dead Yet notes that, "Experiences like Terrie's, pressure to forego life-sustaining treatment, are all too common in the disability community" [2].

Patients with disabilities often experience encounters that imply that their lives are worth less than the lives of patients without disabilities. Curt Decker, Executive Director of the National Disabilities Rights Network (NDRN), expresses this insight, "These conversations happen because the persons being considered are viewed as having little value as they are. They are considered not as fully human…solely because they were born with a disability" [3]. The NDRN produced a report titled "Devaluing People with Disabilities" and identifies that the medical model of disability often purports that patients with disabilities cannot be a fully active member of society, and that they are "defective and in need of fixing." Personal accounts that express the ramifications of these assumptions include the general themes of the need for respect, autonomy, and communication. For example, Heidi expressed,"They think because you have a disability that you are not so important." Thelma added,"[They think] you don't have a mind of your own." John reported, "Very few doctors have positive examples when they explain diagnoses to new parents. Many of them are not even aware of the lives people with disabilities – even severe disabilities – are living" [3]. Returning to Dr. Peace's experience:

> "... the underlying emotion I felt during my long and arduous recovery was fear. My fear was based on the knowledge that my existence as a person with a disability was not valued. Many people—the physician I met that fateful night included—assume disability is a fate worse than death. Paralysis does not merely prevent someone from walking but robs a person of his or her dignity. In a visceral and potentially lethal way, that night made me realize I was not a human being but rather a tragic figure. Out of the kindness of the physician's heart, I was being given a chance to end my life."

These interactions may seem shocking, but realistically, they are the manifestation of a long history of controversial treatment towards those with disabilities. For instance, the Ashley treatment, a host of procedures for a six-year-old girl with static encephalopathy, is an extremely contentious topic. The family of the young girl proposed that she have interventions including breast bud removal, hysterectomy, and growth plate fusion, to make her more comfortable and ease burden on her caretakers. While some people, almost entirely outside of the disabilities rights groups, claim it was a necessary and appropriate approach, others express that the procedures violated

Ashley's body in drastic and unnecessary ways, solely due to her disability.

Another historic account of prejudice against people with disabilities was the case of *Buck v. Bell* (1927), the involuntary sterilization of a young woman deemed to be 'feeble minded.' Referring to Carrie Buck, her mother Emma, and her daughter Vivian, Justice Oliver Wendell Holmes infamously reported, "Three generations of imbeciles are enough" [4]. Consequently, the ruling set a federal precedent for the legitimacy of compulsory sterilization to keep the "manifestly unfit from continuing their kind." This led to sterilization legislation in 30 states and an estimated 65,000 citizens deemed to be 'feeble minded' were sterilized [5]. This case is particularly interesting, because Carrie Buck was neither epileptic nor developmentally delayed, and, in fact, had been institutionalized largely due to being raped and carrying a child out of wedlock [6]. Ableism was so prevalent that it allowed the eugenics movement to flourish both in America and abroad, and even to this day, *Buck v. Bell* has not been overturned [7].

The Truth about Happiness and Well-Being

The intent behind these ableist interactions is based in the belief that patients with disabilities are suffering or lead worse lives than their peers. People without disabilities tend to view the possibility of living with a disability as far less enjoyable than people with disabilities actually report of their wellbeing [8]. The failure to accurately interpret happiness in a life lived with a disability even extends to professionals who work with people with disabilities. These assumptions perpetuate the view that disability is a pitiful tragedy, which leads to social stigma [8].

One study found no significant difference between the self-reported quality of life between "severely mobility-impaired" and control subjects without physical disabilities, as well as no significant difference between congenital or acquired and progressive or permanent disability. This effect is likely due to personal adjustment, societal and medical compensation, and positive features of the disability [9]. Additionally, after an initial transition period, people who acquire disabilities tend to stay at the same level of enjoyment in their lives [8]. Therefore, sentiments that disability is chronically harmful to all are largely false. As Professor Elizabeth Barns has expressed, "It's consistent to think both that disability is not in general something bad and that disability is bad for some people or in some circumstances" [11].

In Action: The Impact of Bias on Health Outcomes

People with disabilities are less likely to have adequate medical care. In a 2004 study from North Carolina, adults with self-reported physical disabilities and adults with developmental disabilities report worse health than adults without disabilities, including having more chronic health conditions

and a higher risk of chronic pain [12]. Additionally, the same study found that almost one in ten women with developmental disabilities had never visited a gynecologist, and slightly over one in four women with developmental disabilities over 40 years old had never had a mammogram. Patients with disabilities were also significantly less likely to have the same extent of oral health care than the non-disabilities group. Research indicates that implicit bias in the health field may contribute to these disparities.

Implicit bias forms in childhood from repeated reinforcement of social stereotypes [13]. These biases, generally occurring through a negative evaluation of one of these categories, affect judgements as well as nonverbal behavior. One systematic review of the literature explored implicit bias in health care professionals and revealed that almost all of the 42 studies included found some evidence to support that implicit bias exists among physicians and nurses [14], to the same extent that it exists in the general population, although with more implicit than explicit bias [15]. Implicit bias, an unconscious, largely unintentional pattern of assumptions, differs from explicit bias in that it cannot be easily regulated: those who have it are not aware of it. While there is a lack of evidence for a causal negative influence of these biases on health outcomes, there is clear evidence that bias negatively impacts clinical interactions [13, 14]. Two 'paths' that implicit bias could contribute to health disparities include that bias may affect medical judgements themselves which leads to downstream disparities in health, and that bias may deter health professionals' communication and interaction with patients, causing patients' negative perceptions, judgements, and trust with health care workers [15]. These paths may interact and compound the effects on patient health. This is more likely to affect care between parties without an established relationship, in decisions with limited time and information, and instances without guidelines [15]. Additionally, health training emphasizes efficiency, and exposes trainees to minorities in unfavorable circumstances, which all could contribute to stereotype reinforcement [13].

The Ableist Conflation

Recently, Reynolds has identified the "ableist conflation," a viewpoint informed by how people without disabilities understand pain and suffering. He explains that one interprets the meaning of 'disability' through the subjective experience of pain; this limits the ability to have a nuanced conception of a positive life with disabilities. Reynolds highlights the medical model of disability and its conceptualization of disability as 'misfortune' and identifies the ideas of 'disease,' 'death,' and 'disability' are often grouped together in the same contexts; notably in reports about health from government organizations such as the Centers for Disease Control and the World Health Organization [16]. The minimal understanding of the ableist conflation in-

cludes four tenants: that disability is conceptualized as a deprivation of a natural good; that deprivation of natural goods is considered a harm; that harm is a form of pain and suffering; and that, given these stipulations, disability is coextensive or causes pain and suffering [16].

Justification for ending the lives of people with disabilities includes adding one assumption: that the goal is to maximize flourishing and reduce pain. This implies that people who act to end suffering are justified in doing so, even if the basis of their assessment of suffering is inaccurate. The logical flaw here is glaring: not everyone who lives with a disability is suffering. Our conceptualization of disability, which is based in limited perspective and biased assumptions, is inept at projecting an accurate reality, and "flattens communication about disability to communication about pain, suffering, hardship, disadvantage, morbidity, and mortality." [16]. This bias also perverts narratives of people with disabilities who are in fact flourishing. As Professor Elizabeth Barnes expresses:

"We stereotype disabled people as being unfortunate, as being long-suffering, as being brave, as being tragic overcomers. When a disabled person says that they are happy-not happy in spite of being disabled, just happy-it doesn't match our view of what disabled lives are like. Likewise, when a disabled person says that they value being disabled, or that being disabled can be just as good as being non-disabled, it doesn't match our view of disability as misfortune. And so we reinterpret what disabled people are saying...In short, we don't take them at their word, because of our stereotypes of what disability and disabled people are like" [11].

Barnes calls this 'testimonial injustice.' Some lived experiences and real phrases that people with disabilities often hear from well-meaning others include Harriet McBryde Johnson's accounts in her New York Times article titled,"Unspeakable Conversations" such as, "I admire you for being out; most people would give up. / God bless you! I'll pray for you. / If I had to live like you, I think I'd kill myself." [17]. Understanding these expressions are much easier when seen in light of the ableist conflation; the "countervailing logics of pity and inspiration" are due not to the lives of those living with disabilities, but of our projection of those lives, and the missteps one come across when narratives conflict with those projections [16].

Cumulative Effects: Assumed Diminished Capacity

How does this affect medical decision making? These assumptions may drive health care workers to unconsciously impede their interactions with patients with disabilities by assuming their autonomy is compromised. Stereotypes about vulnerable populations, especially patients with disabilities, are persistent enough to limit our conceptions of those patients' decision-making capacities. As one participant in the NDRN expert panel expressed, people with

disabilities have difficulties with others' perceptions in their development, as Thomas expresses, "When you have a disability, you have to fight for the right to grow up. It isn't given to you" [3]. Research supports this theory, as a 2012 study explored stereotypes and biases' affect on decision-making processes in clinical interactions and found that, "…people with either mental or physical disabilities are stereotyped as high on warmth but low on competence." Researchers express,"These groups are viewed as low status but well meaning in their own ineffectual way…paternalistic emotions, such as pity, feel subjectively benign but disrespect their target" [18]. These findings suggest that, in their interactions, health care professionals could take up paternalistic roles and utilize surrogate decision positions, even though their patients with physical disabilities are adults with capacity. The deficits in the Best Interest Standard of surrogate decision-making explain the obstacles that patients with disabilities come across in their clinical interactions.

Surrogate Decision Making: The Best Interest Standard

The Best Interest Standard (BIS), outlined and formulated by Kopelman, is a form of surrogate decision-making that aims to protect the interests of the person under the surrogate's decisions, independently of the surrogate's views. It states that decision makers should use what persons of "good will" in similar situations would consider acceptable and reasonable, given the circumstances. Surrogates should make choices in line with their wards' values, with the best available information about long-term interests, and focus on the option that maximizes benefits and minimizes harm. However, decisions must be made on at least a minimum threshold of accepted care, and what is considered a "good enough" level of care is derived from what a "reasonable person" would do, or what most people would regard as acceptable in those circumstances [19].

Kopelman presents complications to the BIS, including (1) that "balancing harms and benefits can be prone to misinformation, conflicts of interest, bias, or prejudice"; (2) "there may be disagreements about what choices are acceptable in the first"; and (3) "there may be disputes over the nature, interpretation, or ranking of people's rights and duties" [19, emphasis added]. There are obvious parallels here to the difficulties patients with disabilities face. Dr. Peace's provider calculated the risks and benefits of treatment, but was affected by bias that lead to an unintentional, yet unacceptable proposal; they thought the difficulties of treatment would outweigh the benefits of healing process, and proposed their calculations to Dr. Peace without being aware of their bias or including the value he places in his life.

DISCUSSION

In addition to disabilities ethics, this discussion could enrich the current leg-

islative atmosphere around assisted dying. Assisted dying laws in Oregon and other states allow physicians to prescribe lethal medication through a process that requires multiple voluntary and uncoerced requests for assistance, a waiting period between requests, a terminal diagnosis, and for the patient to administer the medication themselves. Disability rights groups such as Not Dead Yet vehemently oppose this phenomenon based in the fear that patients with disabilities will be disproportionately targeted to end their lives with the medication due to the reasons explored in this work, including bias, paternalism, and ableist tendencies. They additionally call into question futility judgements in cases where patients with disabilities have been diagnosed as terminal. They posit that, when providers determine that a treatment is not beneficial, this decision is often based on unreliable medical predictions and biased quality of life judgements [20]. As Not Dead Yet's CEO, Diane Coleman, expresses, "Enough disabled people have survived predictions that they would die that our community can't help but be skeptical about terminal labels." [21]. They call for a balanced approach that addresses both overtreatment of dying individuals and undertreatment of people who may not really be terminal [22]. As assisted dying is currently being progressively legalizing across states, these sentiments should be incorporated into the dialogue.

CONCLUSION

Bias in the healthcare field exists, persists, and contributes to health disparities in patients with disabilities. This bias influences clinical interactions, and may be explained by the ableist conflation and the deficits of the Best Interest Standard. These factors manifest in the ethical conflict between the compassion of health workers in attempts to end suffering and the danger patients with disabilities face when confronted with choices that do not value their lives. Ableist assumptions derive from prevalent bias, which is reinforced when health professionals only see patients in times of poor health and experience disability only in the context of pain and suffering. The consequences of these should reevaluate the consequences of these understandings on other dialogues surrounding disability ethics, such as with prenatal genetic testing, allocation of health resources and accessible medical technology, and assisted dying.

In the current environment, it is crucial to identify that these factors are contributing to the discrepancy in health between those with disabilities and those without. The term 'disability' is extremely heterogeneous and complex; it cannot be generalized from one experience to describe the lives of all people with disabilities. The medical field must re-conceptualize its understanding of disability, actively combat influences of implicit bias, and retain open communication between health providers and their patients to address them and end discrimination of patients with disabilities.

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Article

Teens and Children in Clinical Research: An Ethical Discussion

by Anastasia Matano†

Thousands of children and adolescents in the United States, from ages 0-18, are afflicted with diseases that have no known cure or treatment. While medical journals boast the discovery of new treatments spawned from innovative clinical trials, many fail to recognize that a majority of these clinical trials only focus on the adult demographic and fail to properly cater to adolescents who are afflicted with the same or a similar disorder. This major misconception in the medical community has prevailed for decades: that adolescents are "small adults." This idea stems from the scientific hypothesis that adult dosages of clinically tested medications can simply be modified for children depending on factors like height, weight, age, etc. The unfortunate truth, however, is that children cannot rely on dosages established by adult clinical trials. There remains an urgent need to include adolescents from ages 0-18 in clinical trials that study deadly diseases and disorders, for if this does not occur, the field of medical research will have failed the adolescent population in its promise of fair participant selection.

There is a lack of adolescents in clinical trials for myriad reasons, including the many protective regulations set upon children, a lack of willing participants, and the lack of funding for research concerning rare conditions. These reasons are coupled with the three major ethical issues concerning adolescent involvement in clinical research, as well as the three major components of this discussion: consent, confidentiality, and the protection of adolescents from harm. These reasons have served as legal and biological barriers for medical researchers who attempt to discover cures for fatal diseases and disorders. However, instead of avoiding pediatric research due to its challenges, it is cru-

† **Anastasia Matano** is currently a junior at Fort Lee High School and an active member of Fort Lee High School's Science Research Program. During a 2017 summer internship at NYU's High School Bioethics Program, she wrote a module on the implications of using adolescents in clinical research. This module has been published on NYU's High School Bioethics website, where modules of other scientific caliber are available.

cial to support such research in order to advance pediatric research. Without such support, adolescents are at great risk.

Consent, confidentiality, and protection from harm are three major pillars to which all medical practitioners must adhere, the most vital of which is consent. Commonly cited issues with consent involve articulating clear criteria to obtain truly informed consent, establishing an age at which a person is able to consent to research participation, and knowing to what extent parents and guardians should be involved. Because the risks of involving children in research studies may be high, children are not considered competent enough to consent to participation in medical research under the law. Consent thus becomes an issue of convincing parents of the safety and efficacy of a particular medical treatment or trial, as it is not yet clear at what age children are capable of providing consent. Indeed, voluntary consent is a hallmark of ethical research conduct. This begs the question: How can a medical practitioner determine the level at which an adolescent can comprehend the information required to provide consent? Moreover, what should the adolescent patient be aware of compared to what their parent or guardian must be aware of? These questions are crucial towards the ultimate goal of fairly including adolescents in in medical research, as well as the questions that will be explored in this review using key examples such as epilepsy and oncology research. Oncology research, or cancer research, has been an extremely prevalent field for decades now, and is a field that a majority of the population has at least some knowledge of. Oncology research is thus a more familiar topic and can be easily understood when explaining the ethical challenges surrounding adolescents in clinical research. In contrast, epilepsy research is used to explain how newer, but less known types of disorders, also face many ethical barriers in adolescent clinical research.

ADOLESCENTS IN ONCOLOGY RESEARCH

Oncology research, or cancer research, is a field of research that has garnered much attention for being both controversial and ethically hazardous. This is due to the fact that cancer therapy itself is usually characterized by its toxicity and its many harmful adverse effects (Berg, 2017). Since such toxic therapy is currently the standard of care, oncology researchers testing new therapies hope that the safety and efficacy of these new treatments could potentially reduce the harmful effects of a variety of medicines that are currently in use. According to Dr. Archie Bleyer, Clinical Research Professor at Oregon Health and Science University and the Knight Cancer Institute, "Cancer in children, adolescents, and young adults are so different that each age group needs its own research effort." He says that "adolescents and young adults have had low clinical trial participation levels in the past, but that's changing."

This claim has proven to be true. In recent years, there has been a dou-

bling, even tripling, in the number of adolescents participating in clinical trials for cancer, which provides a beacon of hope for the thousands of patients suffering from different cancers. In 2017 alone, it is estimated that 10,270 children younger than 15 and about 5,000 adolescents between the ages 15 and 19 will be diagnosed with cancer in the United States. An estimated 1,190 deaths will occur for children under 15 and an additional 600 for those between the ages of 15 and 19. As of 2017, there are 4,574 clinical trials being conducted in the U.S. for children with cancer of ages 0-17. 511 of these trials are active, meaning that they are no longer recruiting and have begun to collect data.

It is important to remember that adult cancer treatments given to children at lower doses are not optimal therapeutic options, chiefly because there are so many types and subtypes of pediatric cancers and because the immune system of a child is not strong enough to withstand the intense adverse effects of adult cancer treatment. Many available therapeutic options, particularly radiation, actually do more harm than good. Children will experience severe adverse effects, such as hair loss, nausea, weight loss, weakened immune system, etc., and there is still no guarantee that the cancer will completely disappear despite the immense stress that treatments such as radiation put on the cancer.

The ethics of oncology research has three specific challenges: the challenge of obtaining informed consent and assent from children/parents, the therapeutic misconception, and challenges related to unknown safety and efficacy of these new, experimental treatments.

Clinical trial researchers often question the quality of consent they are provided because adolescent patients may not fully comprehend the risks, benefits, and potential outcomes of the study in which they are being asked to participate. The ethical issues of using parental consent and patient assent, however, is the question of whether or not there should be "limits to parents' ability to give permission for a child to participate" in clinical, nontherapeutic research. Adolescents have a right to their bodies and minds as all other human beings do; medical research is, however, one of the many places such a statement becomes complicated. It is difficult to determine whether or not a parent of an adolescent knows what is truly best for the adolescent. And if the adolescent does provide assent, it is unclear as to "how this affirmative agreement can be measured, how seriously dissent should be taken, and at what developmental stage the child's wishes should take precedence over all else" (Berg, 2017). This means that each case is unique, for the medical researcher would have to determine, based on his/her perception of the adolescent, whether or not the patient can handle and process the information necessary to provide assent. There is no standard method of obtaining consent, which makes it particularly difficult when one asks whose opinion

takes precedence over the other: the adolescent or the parent?

After consent/assent is provided, there comes the issue of dealing with the risks that accompany each study phase: I, II, III and IV (though most oncology trials focus on discussing phase I, II, and III). Each phase focuses on a different scientific question, with the ultimate goal of having the medication or treatment being tested to be approved and adopted for use amongst the general population. Phase I assesses the safety of a drug or device, including how it is absorbed, metabolized, and excreted. Phase II studies the efficacy of a drug or device, and this can last from any time between several months to two years, depending on the study itself. Phase III involves randomized and blind testing in several hundred to several thousand patients; this can last several years. Phase IV, often dubbed "Post Marketing Surveillance Trials," is conducted after the drug/service has been approved for consumer sale, the goal generally being to monitor any long term effects of the drug and determine its cost-effectiveness.

In the end, risk assessment is a question of how much risk the doctor is willing to place the patient in for the sake of research. Since few are willing to put their daughter or son's life on the line for the sake of research, this concept raises concern.

An additional struggle concerning study phases is a phenomenon known as "therapeutic misconception." Many people consent to research participation because they believe that they will personally receive a benefit, most often in the form of improved health. However, individual benefit for individual participants is not the goal of clinical research, but rather to gather knowledge from a representative participant population in order to benefit the medical community as a whole. The therapeutic misconception illustrates a tension between the stated goal of the researchers and the motive of the patient for participating in research, particularly a study with the potential to offer a benefit. The ethical issues here lies in the interference of the consent process. Because the patient seeks immediate relief or aid from the experiment as opposed to participating for the purpose of gathering generalizable knowledge, the therapeutic misconception can often interfere with the consent process, especially for adolescents. Parents do not wish to cede their children for the purpose of "experimentation." Thus, parents and adolescents alike are often more likely to retract consent if the immediate purpose of the agent is not to "cure" the patient.

The last ethical challenge relates to establishing the safety and efficacy of the new treatment. Next to consent, this is likely the most prominent ethical concern pediatric oncologists face. Let's consider the example of a more recent technological breakthrough: molecularly targeted therapy.

Molecularly targeted therapy is designed to "specifically target a critical pathway within cancer cells" in order for doctors to tailor treatment to a par-

ticular type of tumor (Berg, 2017). This removes the issue of excessive tests and screenings to determine the most effective form of treatment, whether it be chemotherapy or clinically tested pharmaceutical drugs. However, it does present an ethical concern for adolescents. At some point, this technology could be developed to target pediatric tumors without an analogous target in adult tumors, meaning that anticancer drugs and treatments could be developed to first be used in children instead of adults. While it is true that one cannot use treatment meant for adults on children, the fact that the safety and efficacy of a certain treatment was first tested on adults and thus found to be effective has provided some reassurance to doctors and parents for many years. Removing the safety barrier of first conducting research on adults to confirm safety and efficacy makes doctors, parents, and adolescent patients extremely hesitant to approach such new technologies like molecularly targeted therapy.

The development of molecularly targeted agents also includes assessments of the drugs on the target. "This brings into sharp focus the problem of more than minimal risk, non-therapeutic components included in therapeutic trials, such as tumor biopsies" (Berg, 2017). This again raises the question of consent versus assent, consent meaning a voluntary agreement to participate in research and assent meaning a willingness to participate in research by persons who are too young to give informed consent. An adult, of course, can consent to trials that pose more than minimal risk, but is it acceptable for a parent to provide consent for an adolescent to take part in such a trial?

The case of Grimes v. Kennedy-Krieger in the state of Maryland provides insight into this question. This 2001 court case questioned the level of risk in pediatric research studies after an accusation of negligence was brought against the Kennedy Krieger Institute (KKI) for lead related health injuries contracted by children in a KKI research study. In the end of this 2001 case, the court held that, "a parent...cannot consent to the participation of a child or other person under legal disability (this includes vulnerable subjects) in nontherapeutic research or studies in which there is any risk of injury or damage to the health of the subject" (Mastroianni, 2002). Any risk was later defined as "greater than minimal risk."

There is a questionable balance between the positive and negative aspects of adolescent involvement in oncology research. Though their participation is necessary, it can also be life threatening, and the implications surrounding the ethical challenges of oncology research should be first on the agenda of doctors and researchers to deal with before any further advancements are made.

ADOLESCENTS IN EPILEPSY RESEARCH

Another prominent field of research where ethical challenges are a major concern is epilepsy research. While cancers are widespread throughout the body, epilepsy deals with, arguably, the most crucial organ of the body: the brain. The brain is the basis for the development of a human being as a person; something like epilepsy, where excessive electrical activity can harm crucial areas of the brain, impairs this development in varying degrees. Extremely severe forms, such as Lennox-Gastaut Syndrome or Dravet Syndrome, can slow neurodevelopment by years, preventing children from reading, writing, speaking, and carrying out basic functions without the assistance of a caretaker until well past adulthood. Childhood epilepsies are most common among epilepsy diagnosis, thus placing childhood-onset epilepsy in the spotlight of clinical research.

Unfortunately, many childhood-onset epilepsies are refractory epilepsies, meaning that they do not respond to conventional antiepileptic drugs. This means that extremely severe epilepsies can wreak a path of destruction in an adolescent's brain because doctors do not have an effective way to drastically reduce or eradicate the seizures. Thus, there is an urgent need to find alternative methods to essentially "cure" refractory epilepsy, as the rate of sudden unexpected death is "6 per 1,000 patients with epilepsy per year, and the lifetime incidence is 7% to 35% with the greater end of this range applying to childhood-onset refractory epilepsy" (Laxer, 2014).

There are four key ethical challenges surrounding epilepsy research: diagnostic challenges, communication of the diagnosis, the decision of starting a treatment after the first seizure, and the use of new drugs in children. These challenges have much more to do with the physical developments of the adolescent rather than federal regulations. The brain is a delicate organ, so childhood epilepsies present a broad range of treatment challenges that are particular to adolescents. This is due to the wide range of causes of epileptic syndromes, many of which doctors have yet to pin down.

Diagnostic challenges arise from a myriad of reasons and tie in directly with communication of the diagnosis. When an adolescent has a seizure, it must be recorded using an electroencephalogram, or an EEG, which detects electrical activity in the brain through the use of small, flat metal discs (electrodes) that attach to the patient's scalp. The results appear as spiked lines either on paper or on a computer, and any abnormally large spikes will indicate the appearance of a seizure. Seizures and epilepsy are not synonymous; one does not have to have epilepsy in order to have seizures. This is why "diagnostic challenges" is one of the ethical issues in the childhood epilepsy community, because treatment is dependent on the correct diagnoses and the child suffers for it if the doctor fails to properly diagnose. The doctor must be able to determine if the patient suffers from something like tonic-clonic seizures,

whereby the entire body convulses and the patient may lose consciousness, or something less severe, like absence seizures, whereby the patient simply stares off into space without any physical indication of a seizure. These often require additional diagnostic tests, the danger of which lies in their injection of unnecessary drugs into an adolescent's system in order to confirm diagnostic suspicions. Both patient and guardian must also provide the informed consent and assent to undergo these additional diagnostic tests. Explaining its implications is crucial not only for the guardian, but also for the patient; an adolescent, regardless of his/her age status, must still have a certain level of awareness of what diagnostic tests they must undergo.

Once the type of epilepsy is determined, treatment options are the next biggest hurdle. Does the patient wish to use antiepileptic drugs? If the condition is very severe, does the patient wish to opt for surgery, or a drastic change in diet? These are the types of questions that must be addressed. The problem is: who answers them?

The answer may seem very obvious, but if one has a five-year-old patient with extremely severe seizures and a parent who is seemingly oblivious about the disorder, the situation becomes very complicated. The doctor must address the patient's guardian, who must make the decision about whether or not he/she should implement changes into the patient's life, sometimes ones that are very drastic, such as invasive neurosurgery. While necessary, these changes are not ones that can always be assented to by the oblivious five-year-old child with refractory epilepsy, who must undergo treatment with very little understanding of what that treatment actually entails. If the child feels uncomfortable and does not want the treatment, is it ethical, human even, to ignore that protest and tell the child that this treatment is for his/her own good? Or should both doctor and guardian comply with the patient, who is not even old enough to be considered legally competent? This type of situation is what puts doctors in a bind when it comes to staying within ethical limits of a medical practitioner's job while also ensuring the patient receives the best standard of care possible.

There are, of course, individual risks that come with taking standard antiepileptic drugs, of which both guardian and patient must be aware of and consent to. There must also be discussion of "potential risks of recurrent seizures, on and off medication," and other details about changes that treatments either entail or cannot control. As stated before, seizures are not synonymous with epilepsy, so "whether to treat a single unprovoked epileptic seizure becomes an individual decision for each patient, dependent from the possible detrimental effect of AEDs (antiepileptic drugs) on one hand and the risks and consequences of a second seizure on the other" (Barba, 2017). If the seizures are not detrimental enough to cause significant change in the patient's life, or extremely sporadic and very unlikely to occur again, the question of

taking AEDs and risking its side-effects as opposed to depending on the chance of a second seizure not occurring is something the patient must determine. These implications are also something that the doctor must discuss, even if the patient cannot fully comprehend it.

The use of new drugs is a common ethical challenge in any field of medicine, especially in those where it is common for adolescents to be unresponsive to standard treatment options. For adolescents who do not respond well or at all to standard AEDs, the "clinical goal is to find an optimal balance between the benefits and side effects of any medical treatment" (Barba, 2017). The two main concerns when dealing with new drugs are: are they safe enough to be tested and when should they be administered? Utilizing adolescents in clinical trials to test the safety and tolerability of a new drug is already accompanied by layers of regulations and safety concerns. Should a medication be approved even after a trial has been completed, the question of when it should be publicly administered hangs in the balance. Doctors and researchers must still keep track of the participants of the trial that allowed the new drug to be approved, for if any long term collateral effects occur, the safety and efficacy of the drug would automatically be compromised. However, financially, the faster the new drug arrives on the market, the faster revenue will flow in, pitting patient safety against financial concerns.

These are the most prevalent dangers in epilepsy research, but they should not stand in the way of adolescents participating in clinical trials. The most recent breakthrough in support of this claim is the near-approval of Epidiolex, a pure cannabidiol (CBD) plant extract developed by the British company GW Pharmaceuticals. In layman's terms, this is liquid medical marijuana. Under the supervision of GW Pharma, and in conjunction with Dr. Orrin Devinsky, director of the Comprehensive Epilepsy Center at NYU Langone Health in New York City, Epidiolex has advanced to Phase III trials in order to treat the severe, early-onset, treatment-resistant epilepsies of Dravet syndrome, Lennox-Gastaut Syndrome (LGS), Tuberous Sclerosis Complex (TSC), and Infantile Spasms (IS). For both Phase 3 trials in LGS and Dravet Syndrome, the researchers at GW Pharma noted a "significantly greater reductions in specific seizure types for patients taking Epidiolex compared to those taking placebo" (GW Pharmaceuticals, 2017). This trial included patients under the age of 18 and has provided a beacon of hope for the thousands afflicted with the treatment-resistant epilepsy.

CONCLUSION

The positive results from these types of trials should prompt the continuous participation of adolescents in clinical trials, as this kind of participation is what advances the field of science and allows for new, alternative treatment options to become a reality. In future, the same degree of knowledge

provided to the guardians of an adolescent should be provided to the adolescent him/herself. When there is a larger degree of understanding and trust between, adolescent, guardian, and medical practitioner, it is easier for such consent/assent to be provided. Pediatric research should become a field based on the education of the adolescents involved, and in the future, proper guidelines should be established in order to determine at what age and mental capacity adolescents must be at in order to provide informed consent. Such guidelines must include: under what conditions adolescents under the age of eighteen may be the sole provider of informed consent, how to determine whether an adolescent is mentally and emotionally sound enough to provide said consent, and several other aspects discussed throughout this paper. It would be wise for non-invasive tests to be conducted in the future whereby child psychologists and medical researchers determine at what age adolescents under the age of eighteen can suitably provide informed consent and fully comprehend their medical situations, as well as the consequences their consent could result in. It must, of course, be acknowledged that each medical situation is unique to the adolescent and the case, but if there was a stronger, more trustworthy foundation upon which medical practitioners could rely on to determine whether or not adolescents can provide informed consent, there will be incredible benefits. When these guidelines are properly established, a more progressive field of medical research will arise that suitably caters to adolescents in medical need, and will not only educate medical researchers, but the adolescent demographic as well.

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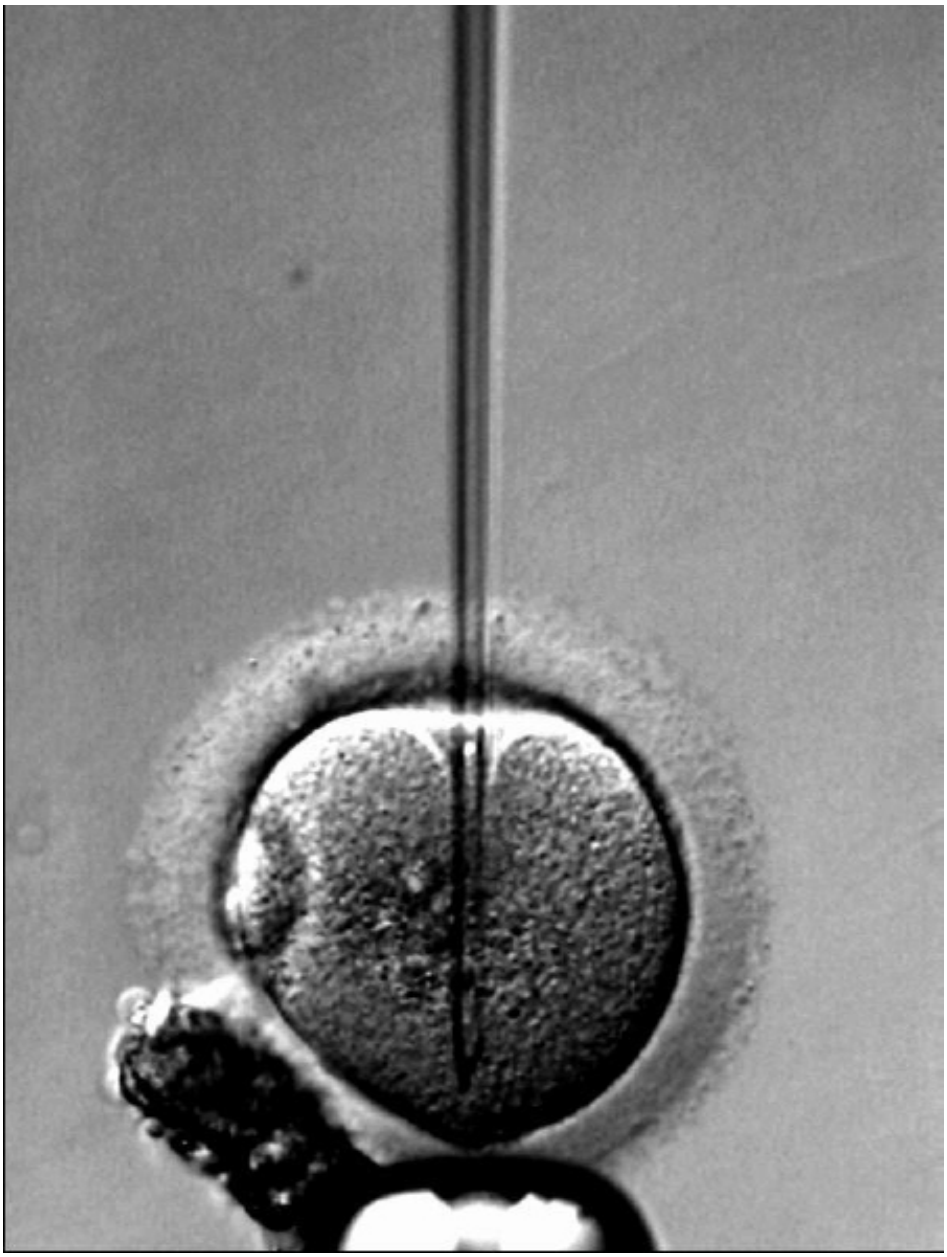

RWJMS IVF Laboratory, 2005, *ICSI sperm injection into oocyte*. In vitro fertilization (IVF) is an assisted reproductive technology used for infertility treatment.

Article

Psychological Effects of Post-IVF Options

by Caroline Kratka†

The research discussed in this paper covers the psychological adjustment of patients following their decisions after an unsuccessful IVF treatment. The decisions investigated include: adoption, assisted reproductive treatments such as donor egg, donor sperm, or surrogacy, or forgoing all treatment and attempts to have a child. The psychological effects of these options will be considered in turn, with the information coming from a review of productive infertility studies. Overall, there was no option that appeared to be the "ultimate" choice in regards to long-term mental health. Rather, the majority of patients were able to find happiness in life regardless of the decision they made. The goal of this paper is to provide IVF patients with a basis for understanding the mental health effects associated with the options available to them, and in doing so help them to consider the optimal option for their family.

Since its first clinical use in 1978 ("Assisted Reproductive Technology Surveillance," n.d.), assisted reproductive technologies have revolutionized the way infertile couples can conceive. One of the most widely used options is in-vitro fertilization (IVF), in which an oocyte is fertilized artificially outside of the body. The resulting embryo is then transferred back into the uterus of the female patient. When national data was last collected in 2014, the Society for Assisted Reproductive Technology reported that 190,394 IVF cycles were performed that year in the United States ("National Summary Report," n.d.).

As long as a female patient does not have a significant infertility factor or a genetic risk for disease, she will typically choose to use her own eggs in the process. The same concept applies to males and the use of their own sperm, assuming that the couple is heterosexual. (Same sex couples must use egg or

† **Caroline Kratka** is a sophomore in the School of Arts and Sciences at Rutgers University. She is majoring in Genetics and would like to pursue a career in medicine. Caroline has shadowed both embryologists and reproductive endocrinologists to see in vitro fertilization first hand.

sperm donations.) Using the eggs and sperm of the couple who will ultimately raise the child ensures that the child will be genetically related to the parents; this biological connection is important to many men and women. However, 42.9% of IVF cycles are unsuccessful in women under 35 years of age who use their own eggs. This percentage increases with age, until the IVF failure rate reaches 93.5% in women 42 years or older ("National Summary Report," n.d.). It is not surprising that an unsuccessful IVF cycle can be devastating to a couple, but the psychological impacts of the experience can also be severe. The psychological stress continues when couples are forced to make a decision about their next steps in the process. For couples recovering from failed cycles, options include choosing not to pursue further treatment, adoption, using a surrogate mother, donor egg or donor sperm.

CHOOSING NOT TO PURSUE FURTHER TREATMENT

The option of forgoing further treatment altogether, coupled with an inability or lack of desire to adopt, leaves a couple childless. Some couples are able to naturally conceive at some point in the future, but this is clearly not the case for all infertile couples. In order to thoroughly understand the psychological effects of childlessness following failed IVF treatment, research that addresses both short-term and long-term impact will be discussed.

Short Term Impact

In a study by Daniluk (2001), phenomenological methods were used to investigate the relatively short-term psychological adjustment of women three years following their last failed cycle. 37 couples were asked to describe their experiences of childlessness every 10 months, which allowed the researchers to analyze how couples "make sense" of their past and to find common themes amongst participants. Daniluk (2001) was able to distinguish four central themes related to the couples' mental progression over the three-year period. She calls the first theme, "Hitting the Wall," in which couples expressed intense relief that they would no longer be subjected to the destructive nature of hope-despair cycles that typically characterize IVF treatment. However, it was common for couples to feel isolated from their fertile counterparts, intense grief over the loss of the parenthood they had envisioned, and apprehension over the future which now did not encompass the identity the individuals had predicted for themselves (Daniluk, 2001).

Daniluk's (2001) second theme is called, "Reworking the Past," in which couples move towards an angry emotional state. They demonstrate anger towards medical professionals that gave them false hope, towards couples who take their children for granted and/or abuse their privilege as parents, and towards themselves as they consider the mistakes they made in prolonging ineffective treatment rather than investigating other options. A second com-

ponent of this theme is questioning the meanings of concepts such as marriage and family, and attempting to rediscover their purpose as individuals (Daniluk, 2001).

The third theme, "Turning Towards the Future," takes a more positive direction in which couples begin to explore the opportunities available to them as childless men and women. The subjects were able to pursue intrinsically motivating activities, and pay more attention to relationship development with their partner. Some subset of participants, however, still faced significant levels of stress as a result of their inability to accept their infertility; this was especially present in couples who did not share an opinion on how to proceed after the failed cycle (Daniluk, 2001).

The last theme that Daniluk (2001) found in short-term reconciliation is, "Renewal and Regeneration." Throughout this stage, couples began to appreciate the strength they had exhibited throughout IVF treatment, which gave them a sense of pride and confidence that they could overcome future challenges. Many found that their marital relationships were now backed by a greater sense of mutual trust. Further, couples appeared to consider their infertility as part of the past, which allowed them to move forward from a child-centered life. IVF is a cyclical process that can require daily visits to the clinic, as well as constant attention to hormonal levels, and the menstrual cycle. Many participants felt that freedom from IVF treatment allowed them to pursue life paths that they would not have been able to have as parents (Daniluk, 2001).

Long Term Impact

The emotional experiences that occur in the relatively short time span following the cutoff of treatment and the adoption search are valuable information for couples concerned with the psychological effects of their choice. However, of utmost importance is the long-term impact of childlessness, as the decades following the end of treatment encompass a much greater portion of life overall. The study by Wirtberg et al. (2006) investigates the psychological health of women twenty years after IVF failure. Similarly to the Daniluk et al. (2001) study, Wirtberg et al. (2006) interviewed women in order to extract shared themes from their experiences and search for their psychological significance.

The first common situation the researchers identified was that women struggled significantly once again with their infertility at the onset of the "grandparent phase." Negative states of emotion strikingly similar to that of twenty years before caused women to resent their peers with grandchildren. Additionally, women began to reflect again on the fact that they had no offspring to care for them in the future, as they approached old age. Over the twenty-year period since their last IVF failure, they had transitioned from

worrying about their inability to be a parent to anxiety about the fact that they had not left behind their own children (Wirtberg et al., 2006).

A second similarity amongst the subjects was their account of how infertility affected their sexuality and marital satisfaction. The majority of those interviewed expressed that they lost their desire to engage in sexual activity. Referring back to Daniluk's (2001) study, she explains that once sex had become a forced activity timed exactly with optimal conception conditions—and once it had become associated with an ultimate failure to conceive naturally- couples found it difficult to regain the pleasure they once had from sex. IVF treatment can also be invasive and often draws away from the intimacy that sex provides. Further, 50% of the subjects in the Wirtberg et al. (2006) study had separated from their partner or gotten divorced since their unsuccessful cycle. With the exception of one participant, all of the divorced/separated women said that infertility contributed to the separation (Wirtberg et al., 2006).

The most prevalent pattern found in the Wirtberg et al. (2006) study was that women found joy and consolation in investing interest in other children. These children may be any young ones the woman is close to in some way: nieces or nephews, the children of close friends, etc. Whereas many women found themselves avoiding interaction with children or with peers that had children immediately following failed cycles, they grew to enjoy forming attachments with children later on. These types of relationships were also found amongst the women and their pets or their elderly relatives. Overall, finding another human or animal to care for in motherly ways allowed many of the participants to cope with the infertility that had once dominated their life (Wirtberg et al., 2006).

Besides devoting time to others, a significant number of participants focused extensively on their career or on other life dreams such as travelling or exploring various hobbies. The connection between the short-term and long-term impact of fertility is clear in this case: the women studied in Daniluk's (2001) study had begun to pursue other aspirations at the end of three years, and the subjects of Wirtberg et al.'s (2006) study demonstrated that long-term satisfaction could be found in the exploration of their ambitions. However, although the majority of the women studied were able to find happiness in lives regardless of their infertility, three of the subjects were never quite able to find satisfaction in a life without children. What the interviews with these women all had in common was that their accounts focused on their misfortunes or mistakes throughout their attempts to conceive, rather than on the joy they found in the childless lifestyle they chose post-IVF. One coped by consuming alcohol or prescription drugs, while another never felt at ease even after developing a close relationship with her niece, and the third found she could simply never relate to her family members that had

children. It is important to note that only a minority of the women studied were never able to find a fulfilling lifestyle due to their infertility, and that couples should not expect to feel the same way in the extended future if they choose to or involuntarily remain childless after unsuccessful IVF treatments. The mental health history of the subjects was not considered in the sampling process, so it is possible that some women had previous psychological disorders that affected their ability to cope with their infertility over time (Wirtberg et al., 2006).

ADOPTION

Following unsuccessful IVF cycles, many patients choose to adopt children as opposed to continuing treatment or remaining childless. The popularity of this choice may be due to the psychological benefits that adoption generates, as several recent studies have shown. For example, through interviews with women who had unsuccessfully undergone IVF, Peddie, Van Teijlingen, & Bhattacharya (2005) concluded that women who chose to adopt tended to view their future more positively than women who remained childless. Those who adopted felt less of the societal pressure that comes from the expectation to bear and raise children at the appropriate adult age (as defined by culture, socioeconomic status, etc.) Additionally, adoptive mothers who had the company of a child to call their own no longer felt "childless," despite the fact that they were not genetically related to the child (Peddie et al., 2005).

Similarly, Bryson, Sykes, & Traub (2000) distributed surveys to women between four and nine years after their failed IVF cycle to analyze how they have adjusted psychologically since. It was determined that women who stopped IVF treatment, but were able to conceive naturally later on or adopt, maintained a higher self-esteem and level of life satisfaction than women who could not. Further, women who remained childless were significantly more depressed and more stressed than women in the conceived/adopted group (Bryson et al., 2000). The authors make a point that women who were unable to adopt significantly influenced the results pertaining to childless women. This suggests that the lack of freedom to have a child, through any means, can significantly harm the psychological well-being of the mother. The inability to adopt may be a foreign concept to some, yet it is a prevalent challenge for couples who cannot conceive naturally. One subject in the same study explained that not only were she and her partner "too old" to adopt (as based on societal standards), but they feared that they could not sufficiently care for a child that may have psychological issues from time spent in an orphanage or from conditions he or she is genetically predisposed to. In interviews conducted by Wirtberg, Moller, Hogstrom, Tronstad, and Lalos (2006), women also expressed the difficulties they faced in adoption.

These included both financial limitations and an inability to be in assent with their partner. Wirtberg et al. (2006) subjects also conveyed that they feared the child, if adopted from a culture underrepresented where they live, would experience racism and be discontent throughout childhood.

ALTERNATE ASSISTED REPRODUCTIVE TREATMENTS

If IVF is unsuccessful with the use of the couple's own gametes, some couples opt to undergo fertility treatment with the gametes of another man or woman. One such option, known as "Donor Egg," uses the sperm from the intended father and eggs donated from another woman to form the zygote. The opposite process, "Donor Sperm," fertilizes the intended mother's egg with donated sperm. The method chosen depends on whether the fertility issue preventing natural conception originates from the female or the male. A second option is to use a surrogate, who will use her own eggs and the intended father's sperm, carry the baby throughout the entire pregnancy, and then give the newborn to the intended parents. This choice is most common when the conditions of the intended mother's uterus are not optimal for supporting the growth and development of an embryo.

A study by Golombok, Murray, Jadva, Lycett, MacCallum, and Rust (2006) thoroughly discusses the effects of these three processes on the psychological health of both parents, and on parent-child interactions. Parents were assessed using the Golombok Rust Inventory of Marital State, the Trait Anxiety Inventory, the Edinburgh Depression Scale, and the Parenting Stress Index in order to gain a comprehensive understanding of the mental health status of both parents. The results showed that there was no significant difference in psychological well-being between parents who had conceived naturally (the control group) and those who had conceived using a surrogate, donor egg, or donor sperm (variable groups). The test scores of each variable group were found to be within standard population ranges. Furthermore, each mother was interviewed to measure: how warmly she regarded her child in conversation ("expressed warmth"); how protective she was of the child, and to what extent her life centered upon him or her ("emotional over-involvement"); the level of interaction between the mother and the child ("mother-child interaction"); and how well she responded to the needs of the child ("sensitive responding"). The statistical analysis demonstrated that women who used ART to conceive showed higher levels of "expressed warmth" than women who naturally conceived. Similarly, mothers from the variable groups had significantly higher "mother-child interaction" scores than mothers from the control group. More specifically, women who were not related genetically to the child (due to the use of donor egg or a surrogate) exhibited higher levels of mother-child interaction than women who used donor sperm (Golombok et al., 2006).

These results suggest that families should not fear using ART based on

the preconceived notions that they will be psychologically damaged, and/or inadvertently parent at a lower quality than the norm. Not only do the findings indicate that parents who conceived with ART are just as psychologically healthy as parents who did not, but mothers who use ART seem to express higher levels of certain positive parenting traits (Golombok et al., 2006). Overall, there is no evidence from this study that should deter couples from donor egg, donor sperm, or surrogate use, at least on a psychological basis.

LIMITATIONS OF FEATURED STUDIES

Compared to other medical techniques, in-vitro fertilization is a very new technology. Most research conducted on IVF is focused on the effectiveness and safety of the treatment, as well as on its potential improvements. For this reason, the number of psychological investigations conducted on couples in any stage of IVF treatment is somewhat secondary. As the number of years since the inception of IVF increases, information about the psychological health of IVF patients should become more prevalent.

In general, the papers used studied only small samples of women, all from the same geographic region. None of the papers accounted for factors such as economic status, ethnicity, type of relationship between partners (heterosexual or homosexual), etc. in their studies, which are all potential confounding variables. (Some studies recorded such factors about their participants, but did not incorporate them into the statistical analysis of the results.) In addition, the studies chose their participants by voluntary response sampling, which means that only women or couples willing to share their experiences or health information were studied. It is likely that the results of these papers are lacking input from a subset of people unable to reflect upon their infertility in a structured setting/share their personal experiences with strangers.

CONCLUSION

The purpose of this paper is to provide information about the psychological effects of various choices that single women or couples can pursue following unsuccessful IVF treatment. Based on the results of past studies, it is evident that there is no optimal option for people to choose if psychological health is a major concern. Regardless of the choice (or in some cases, the involuntary outcome), a significant number of participants were able to find positive aspects of the life that resulted. From the data presented, it seems as though adoption or other ART such as donor egg, donor sperm, or surrogacy are the most favorable choices when considering mental health. This is a very reasonable finding, as patients who wanted a child enough to undergo IVF treatment would likely be extremely happy to have a child to call their own. However, these options are not possible for some women or couples due to financial limitations, cultural or societal pressures, or partner discordance. If patients

choose to conclude their attempts to have a child -whether voluntarily due to the stresses of IVF cycles or involuntarily due to their personal infertility restraints- they are likely to benefit psychologically from coping methods such as dedicating more time to their personal ambitions or to another child present in their life. To conclude, more intensive research is needed to develop an understanding of how patients develop psychologically following their post-IVF choices. However, there is no evidence that couples should expect to be indefinitely depressed if they are unable to have a child genetically related to both parents, or if they are unable to have a child at all. It was in no way an easy transition from IVF to other choices, as couples were essentially "giving up" their opportunity to have a child with a complete genetic link to themselves. Nonetheless, it was possible for most patients to find life satisfaction no matter what the outcome of their choice.

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Essay

Why Medical Students, Doctors, and Other Healthcare Professionals Should Care About Mass Incarceration

by Ikenna Achebe[†]

Today, mass incarceration is an epidemic in the United States and demands the attention of medical students, doctors, and health professionals. With well over 2 million people in jails and prisons, there are more prisoners in the United States than any other country in the world, and it has been well documented that the United States has only 5 percent of the world's population, but 25 percent of the world's prisoners. The number of people incarcerated in this country has grown more than six-fold since the 1970s. The current rate of incarceration, 693 people confined per 100,000 residents, is 5 to 10 times larger than European countries with comparable crime rates and is higher than the incarceration rates of countries with much higher rates of violent crime (The Sentencing Project, 2015). In fact, the United States houses more inmates than the top 35 European nations combined (The Pew Charitable Trusts, 2010). The incarceration problem facing this country is a full-fledged epidemic. It calls for the attention of healthcare providers because it has deleterious effects on the health of those incarcerated, both before and after their release. It drives health inequities that destroys families and communities, and it costs the country billions of dollars annually that could otherwise provide healthcare coverage to those that cannot afford it.

INCARCERATION LEADS TO POOR HEALTH OUTCOMES

According to a report from the Vera Institute of Justice, the millions of people that are currently incarcerated experience chronic health conditions,

† **Ikenna Achebe** is a graduate student in the Masters of Arts program in Urban Bioethics at the Temple University Lewis Katz School of Medicine. His major areas of interest include health equity and social justice, violence prevention programs, substance use disorders, HIV prevention, the justice system, and working with underserved and vulnerable populations.

infectious diseases, substance use, and mental illness at dramatically higher rates than the general population. The report states that the conditions of confinement inside jails and prisons, such as overcrowding, violence, sexual victimization, use of solitary confinement, and lower standards of medical care are harmful to the physical and mental health of individuals (Cloud, 2014).

According to the national vital statistics reports, chronic diseases such as cardiovascular disease and diabetes are among the primary causes of death and disability in the United States. When it comes to chronic diseases within the incarcerated population, a recent study found that there are disproportionately higher rates of hypertension, asthma, arthritis, cancer, and cervical cancer among correctional populations compared to the general population, even after controlling for a range of socioeconomic factors (Binswanger, Krueger, and Steiner, 2009). Infectious diseases are also more prevalent among people in correctional facilities than the general population. The Hepatitis C virus (HCV) occurs at rates between 8 to 21 times higher, and rates of tuberculosis (TB) are 29.4 cases per 100,000 prisoners compared to 6.7 cases per 100,000 people in the general population. HIV/AIDS as well as common sexually transmitted diseases, such as chlamydia and gonorrhea, are much more prevalent in correctional environments than in all other populations (CDC, 2011).

Furthermore, imprisonment negatively affects the mental health of incarcerated individuals more than the general population. Today, about 14.5 percent of men and 31 percent of women in jails have a serious mental illness, such as schizophrenia, major depression, or bipolar disorder, compared to 3.2 and 4.9 percent respectively in the general population (Prins, 2014). Additionally, most incarcerated individuals that suffer from serious mental illnesses are also diagnosed with histories of substance use disorders. An estimated 72 percent of people in jails with a serious mental illness also have a substance use disorder. Nearly 68 percent of people in jail overall and more than 50 percent of those in state prisons have a diagnosable substance use disorder, compared to 9 percent of the general population. To compound matters, less than 15 percent of people who are incarcerated receive appropriate treatment for their disorders (Belenko, 2008). An example of this is that even though most medical research shows that methadone and buprenorphine effectively treat opioid addictions, the majority of correctional facilities do not offer these pharmacological treatments. This subjects incarcerated individuals to withdrawals while they are in custody and a higher risk of overdose when released back into the community (Gordon et al., 2008, Magura et al., 2009, and Nunn et al., 2009).

For many incarcerated individuals, these health problems do not end once they have been released. In fact, for many of them, it only gets worse. Once released from prison, the mortality rate of a formerly reduced individual skyrockets in comparison to the general population. During the first two weeks

after release, former inmates have a 12.7 times higher risk of death than the general population and a 129 times higher risk of drug overdose. One explanation of this phenomenon is that released individuals are often forced to return to the same exact environment in which they were arrested in the first place, which exposes them to an excess risk of homicide and drug overdose. Recently released prisoners that suffer from mental illnesses often have an excess risk of suicide due to the fact that that they go from from an environment where they receive some form of healthcare services, mental support services, and constant supervision to an environment where those services are no longer provided or guaranteed.

One of the biggest reasons why the issues of high mortality and poor health persist amongst this population is that a prison record or prior conviction drastically reduces the ability of formerly incarcerated individuals to find employment, especially employment that provides suitable health care coverage. It also eliminates the individual's eligibility for public assistance such as food stamps, public housing, and student loans (Dument et al., 2012). Even if a recently released individual was receiving Medicaid coverage prior to imprisonment, 90 percent of states have policies that terminate Medicaid enrollment upon incarceration, which leaves most members of this medically vulnerable population uninsured during the months following release back into society (Wakemen et al., 2009).

INCARCERATION LEADS TO POORER HEALTH OUTCOMES OF THE CHILDREN OF INCARCERATED INDIVIDUALS AND ON ENTIRE COMMUNITIES

Incarceration is a destructive force on children, families as a whole, and entire communities. 2.7 million children have a parent behind bars. This means that 1 in every 28 children has a parent incarcerated, which is up from 1 in 125 just 25 years ago. At the very tip of the problem, it simply forces many parents to raise children without the support of a partner. According to data from the Pew Research Center, more than two-thirds of incarcerated men had been employed prior to serving their sentence and nearly half of incarcerated men had lived with their children before going to prison.

In addition to these numbers, more than half of parents that are incarcerated were the principal earners in their household prior to imprisonment. Once a wage-earning parent is removed from a household, the burden then falls on the remaining parent to financially support the children alone, leaving many families at an economic disadvantage. This often even continues after the absent parent is released from confinement because incarceration reduces earning power, which compounds the financial challenges that affected families often face. Children with an incarcerated parent are more likely to end up in poverty and are more likely to become incarcerated as

adults (The Pew Charitable Trusts, 2010).

In addition to the economic ramifications, parental incarceration negatively effects cognitive development and performance in school. Specifically, children whose fathers have been incarcerated are more likely than other children to be expelled or suspended from school, at an astounding rate of 23 percent compared to 4 percent (Johnson, 2009). Similarly, they are more likely to misbehave in school, develop learning disabilities such as attention deficit hyperactivity disorder (ADHD), and experience declines in grade point average. Even though one would think that such outcomes are consistent with disadvantaged children, regardless of parental incarceration, the aforementioned studies have accounted for these factors. The studies show that the children of incarcerated individuals still have worse cognitive and non-cognitive outcomes when compared to children with similar socioeconomic and demographic characteristics whose parents have not experienced incarceration (Foster and Hagan 2009, Aaron and Dallaire 2010, Nichols and Loper 2012).

Due to the fact that children with an incarcerated parent are more likely to grow up in poverty, drop out of school, be poor as adults, and become incarcerated themselves, they suffer from migraines, asthma, high cholesterol, depression, anxiety, post-traumatic stress disorder, and homelessness at much higher rates than their counterparts without an incarcerated parent. All of these conditions present an additional burden on academic performance.

A 2015 study titled, "The Collateral Damage of Mass Incarceration: Risk of Psychiatric Morbidity Among Non-incarcerated Residents of High-Incarceration Neighborhoods" found that people living in neighborhoods with high incarceration rates are more likely to meet the criteria for major depressive disorders and generalized anxiety disorder than individuals that live in neighborhoods with lower incarceration rates (Hatzenbuehler et al, 2015). This shows that incarceration not only has an effect on the health of the individuals incarcerated and their children, but that it also has an effect on entire communities. Mass incarceration actually affects the entire population because the operation of federal, state, and local correctional facilities costs taxpayers over $80 billion per year (Bureau of Justice, 2015). According to a recent study conducted by researchers at Washington University in St. Louis, the true cost of mass incarceration on society is over $1 trillion per year. The study indicates that more than half of those costs are ultimately levied upon families, children, and community members who have not committed any crimes at all (McLaughlin et al, 2016).

CONCLUSION

It is imperative that medical students, physicians, and healthcare profession-

als care about mass incarceration. Incarceration often leads to the development of the same chronic diseases, infectious diseases, and mental illnesses in which it is their job to treat and prevent. Understanding this issue as a result of our society's over-reliance on imprisonment and helping to address it through research and informing policy is, at its core, a form of practicing preventive medicine. Some of the policy changes that we must make are to pass comprehensive bail reform and abolish cash bails, make the conditions of probation easier to meet, establish true speedy trial laws to avoid unnecessary pre-trial detentions, and consider the use of community restitution as an alternative to imprisonment.

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Essay

Socio-Ethical Analysis: *The Immortal Life of Henrietta Lacks*

by Eun Young (Isabel) Park†

In this paper, I take a sociological perspective to analyze Rebecca Skloot's best-selling "The Immortal Life of Henrietta Lacks" and highlight some of the ways in which it fails to adequately raise important aspects of the bioethical issues that are central to Henrietta Lacks' story. By using empirical studies that examine the effects of Skloot's book on bioethical debates as a starting point, I suggest that social factors — racial and class hierarchies, to be specific — which had inevitably crucial effects on the way Lacks' life played out could have been better addressed in order to more raise a more fully aware and developed discussion of bioethics in practice.

In *The Immortal Life of Henrietta Lacks*, Rebecca Skloot tells the heart-breaking story of a woman whose cells set an unparalleled precedent in what could be considered the most intimate convergence of science and humanity at the time. Referred to first and foremost as a piece of science writing, Skloot's book undoubtedly brings attention to key issues in bioethics such as informed consent, the patenting of biological property, and vulnerable populations in medical research. The crux of Henrietta Lacks' narrative, and arguably what makes her legacy so compelling, hinges on details of her life that complicate these bioethical principles in unique ways. Not only were she and her family unaware of the fact that doctors had taken her cells for research, but they were subsequently prevented from claiming any ownership to property or profit that they were entitled to. Although Henrietta's cells paved the way for what has since become a multibillion-dollar industry, her family members and closest friends remained ghettoized by a vicious cycle of poverty. How did this happen?

† **Eun Young (Isabel) Park** is a senior studying Sociology, with a minor in Philosophy at the University of Michigan in Ann Arbor. She is the Editor in Chief of the Journal of Bioethics at UofM, and her bioethical interests mainly lie in how bioethics is shaped by the legal system and the notion of value.

Perhaps one of the biggest shortcomings of this novel is its lack of a sociological framework through which it investigates notions of power, agency, and identity. Despite the fact that Henrietta Lacks' cells (HeLa) are a trailblazing example of the medical field's growing research capabilities, the bioethical issues brought into public discussion cannot be fully understood without considering the racial and class hierarchies that were at play in constructing Henrietta's life. In this paper, I aim to refract these social issues through a sociological lens and utilize a critical bioethics approach — one that "incorporates social science research into philosophical thinking" — in analyzing the themes of injustice and informed consent presented by Skloot's novel (Hedgecoe, 2004, p. 123).

BACKGROUND

A study done by Dimaano and Spigner (2017)[1] revealed that students in an intervention group that read Skloot's novel, as opposed to those who did not, underwent more significant changes in their perception of health disparities as affected by race and social factors. Compared to the control group, students in the intervention group were able to discuss these base-line issues with more nuance and concreteness. However, the fact that Skloot's book could serve as a starting point for interesting sociological and bioethical discussions does not necessarily mean that it adequately addresses relevant issues. While these findings are significant, data from other studies provide nuanced insights into the effects that *The Immortal Life of Henrietta Lacks* has had on the broader public. In an empirical study conducted to examine the media impacts of *The Immortal Life of Henrietta Lacks* on what they call the "biobank debate," Nisbet and Fahy (2013) analyzed themes in articles and reviews about Skloot's novel. They found that informed consent and donor compensation were prominent topics of discussion while control/access and accountability/oversight dichotomies, along with education and poverty were only secondarily discussed. Along this thread, Vanessa Gamble (2014) takes a more critical view of Skloot's work in a Hastings Center Report when she states that the book portrays a "stereotypically dysfunctional black family" by foregrounding abuse, mental illness, and incarceration without making it clear as to how these factors contributed to the story (p. 1).

John Lantos (2016) also echoes this critical sentiment in an article titled "Thirteen Ways of Looking at Henrietta Lacks," in which he questions the mindfulness behind Skloot's reasons for divulging such personal details about the Lacks family — concerning Henrietta's siblings' personal lives such as

[1] In Dimaano and Spigner's study (2017), these intervention group students attended a book-based seminar course, whereas the control group did not. They (1) "[engaged] in weekly reading assignments based on a chapter-by chapter analysis of the Henrietta Lacks book," (2) [responded] to an online discussion board of questions posed for each other and with the instructor," and (3) wrote a paper on the book (pp. 262).

Zakariyya's incarceration, Deborah's abusive childhood and marriage, and even "the amount on her Social Security check" (229). While their situation of poverty certainly contributed to the outcome of Henrietta's uncredited and uncompensated contribution to science, the inclusion of these personal details precariously verge on invading the family's privacy, rather than providing a meaningful backdrop that better informs the reader of the primary narrative.

The "single-minded focus on scientific discovery" and consequently the urgency to arrive at some conclusion about the difficult moral and ethical questions that the life of Henrietta Lacks brought forward has ultimately shifted public discussion away from the intersectionality that played such a crucial factor in the way her story unfolded (Parker, 2012, p. 162). As De Vries, Dingwall, and Orfali (2009) note, social and cultural context "shape the content and boundaries of bioethical work" and thus affect its authority and domain of jurisdiction (p. 556). What results from contextualizing these ethical qualms are two relatively straightforward conclusions: (1) there is no such thing as a "universally justifiable, ahistorically valid, secular morality or bioethics; therefore, (2) the ethical person must simply "follow the well-known and explicit rules of his own situation," as dictated by the "particular, socio-historically conditioned community" that he lives in (Engelhardt, 2012, p. 98).

This calls for a sociologically motivated attempt to understand "the social determinants of health as a sequence of socially defined events, termed as one's 'life course'" (Dimaano and Spigner, 2017, p. 260). At some point in Skloot's book, Henrietta's son Lawrence rightfully inquires, "[Henrietta's] the most important person in the world and her family living in poverty. If our mother so important to science, why can't we get health insurance?" (Skloot, 2010, p. 168). In junction with Skloot's passing comment about how Henrietta's treatment and life might have differed if she were white, Parker's piece on feminist themes raises interesting points for investigation on how intersectionality contributed to the extremity of injustice that Henrietta faced as a poorer woman of color (Skloot, 2010, p. 64). De Vries puts the issue in direct perspective when he reiterates the necessity of looking beyond the scope of the moral or ethical problem, taking into consideration "the conditions that generate moral problems" to begin with (De Vries, 2011, p. 419). As a black female, her story is not confined to ethical ambiguities of justice and informed consent, but bleeds into broader humanitarian qualms such as agency and the most fundamental right to health.

Parker notes that terms like "disenfranchised" and "oppressed" are crucial in addressing the real, material consequences that Henrietta faced as a result of her black, female identity (Parker, p. 161). The empirical truth is that social relationships permeate disciplines that might seem speciously

apolitical or objective, including bioethics and the medical field. In an article that discusses legal consciousness in the form of disparities within which individuals decide to mobilize the law in community contexts, Sally Engle Merry (1990) explains that the language used to address conflicts is one of social relationships as opposed to law (p. 37).

ANALYSIS

"A doctor put Henrietta's feet in stirrups once again, to take a few more cells from her cervix at the request of George Gey" (Skloot, 2010, p. 65). This image of Henrietta restricted from free movement occurs twice within the first sixty pages of the novel. Even in this simple depiction, the complexity of power dynamics at play is evident — realized through the doctor-patient relationship, patriarchal hierarchies, and structural racism that all work simultaneously to suppress Henrietta's agency over her life and health. Contextualizing Henrietta's identity as a poor woman of color in post-slavery Baltimore introduces an elevated sense of awareness with which to exercise a sociological imagination. Mills describes this sense of awareness as a tool for understanding one's contributing role in "shaping of this society and to the course of its history, even as he is made by society and by its historical push and shove" (Mills, 1959, p. 2). Framing Henrietta's experiences as a cancer patient and research subject within the aforementioned power dynamics makes it evident that she was ultimately robbed of her selfhood — the ability to use her sociological imagination to fully realize who she was, not only as an individual but also in terms of her "social and historical meaning of [herself] in the society and in the period in which she has her quality and her being" (Mills, 1959, p. 3).

Arguably, Henrietta's debilitated sense of agency becomes most easily perceptible through Skloot's decision to bring up the John Moore and Ted Slavin cases that happened contemporary to the HeLa controversy. Despite the fact that these stories all occurred around the same time period, their outcomes were starkly different. Ted Slavin's case was the most notably divergent from Henrietta's in that his doctor explicitly told him that his body was producing very valuable antibodies (Skloot, 2010). To discuss the nuances of these cases with concepts such as 'benevolent deception' or 'informed consent' — either partially or in full — suggest an element of abstraction and moral quandary. The better way to frame this juxtaposition would be in terms of education and agency. For Ted Slavin, the simple piece of information educated, and thus empowered him to exercise agency over what happened to his antibodies.

On the other hand, John Moore's case was not quite as successful, but only in the sense that his obtainment of the knowledge that his doctor was deceiving him was delayed. Through a series of court appearances, the law

eventually ruled in Moore's favor and resulted in the implementation of a statute which required "research on humans respect the 'right of individuals to determine what is done to their bodies'" (Skloot, 2010, p. 205). One could argue that the subsequent overruling which stated that an individual loses any right to ownership of tissues removed from the body, with or without consent, ultimately made the Moore case a failure, much like that of Henrietta's.

Henrietta Lacks' case is different because she never received the information that was due to her. The HeLa case is certainly one that shows the intricacy of issues such as informed consent and ownership of biological property; however, they were further complicated by underlying sociological aspects of Henrietta Lacks' life such as poverty, institutional racism, and lack of education. As Parker (2012) states in her article on feminist themes in *The Immortal Life of Henrietta Lacks*, Henrietta and her family "lacked basic health and scientific information to be able to discern anything out of the ordinary." Even before she entered the health system, she was at an inherent disadvantage by her illiteracy and impoverishment, both of which indicate underlying issues of larger structural forces such as racial oppression.

By examining the effects of Henrietta's health decline and legacy on her daughter Deborah, the added complexity of female identity emerges. Throughout the novel, it is clear that Deborah is the most affected by the death of her mother and what happened to Henrietta — even far into adulthood. When Henrietta's husband, Day, called to let her know that Johns Hopkins wanted to take their blood to check if any of Henrietta's children had cancer, "Deborah panicked. She knew her mother had gotten sick at thirty, so she'd long feared her own thirtieth birthday, figuring that whatever happened to her mother at that age would happen to her too" (Skloot, 2010, p. 185).

The problem was aggravated by the fact that Deborah was not equipped with the proper knowledge or education to seek out help. As Skloot writes, at the time "it was understood that black people didn't question white people's professional judgment. Many black people were just glad to be getting treatment, since discrimination in hospitals was widespread" (Skloot, 2010, p. 63-64). In this case, the entire Lacks family was continually facing personal troubles but were deprived of the knowledge that "public issues of social structure (Mills, 1959, p. 4)" were also at play in creating their state of affairs. It is clear that the existence of race and class disparities serve a basic premise from which the Lacks family's relationship with the health system and the broader society around them was constructed in a skewed, unjust manner.

CONCLUSION

Clearly, there are multiple layers of sociological considerations that are

missing from Skloot's novel. By virtue of the fact that Henrietta Lacks was a woman of color living in poverty, there is more to her narrative than issues of informed consent or the hierarchical nature of doctor-patient relationships. Despite the inspiring mission statement proffered by large corporations — "the company believes that research conducted on human cell lines is crucial to helping scientists develop better and safer treatments for intractable diseases, which ultimately help drive down the cost of healthcare for everyone" — it makes little sense that certain vials of HeLa cells sell for over $10,000 while the Lacks family continues to live in poverty and deprivation of healthcare (Kroll, 2013). A meaningful understanding of Henrietta's life and legacy requires a thorough investigation of structural, supra-individual forces by use of what Mills calls the sociological imagination.

As for policy implications, the most productive starting point for reform would be basic education — both in general and in regard to health. If the courts rule that the right to ownership is forfeited once biological property leaves an individual's body, everything that can be done to enable people to protect what happens to their bodies and retain the authority and dignity that they are entitled to is of utmost importance. Individuals should be equipped with a comprehensive sense of where they exist in the broader social world so that they can exercise autonomy and agency in the form of making informed decisions. No individual should have to nod and say yes in the face of confusion, as Day did with the doctors at Johns Hopkins. The bureaucratic, legalistic jargon should be stripped away to refocus bioethical issues to their root sources: society's shortcoming in allowing every individual to exercise an unrestricted sociological imagination, which is "the most fruitful form of self-consciousness (Mills, 1959, 3)."

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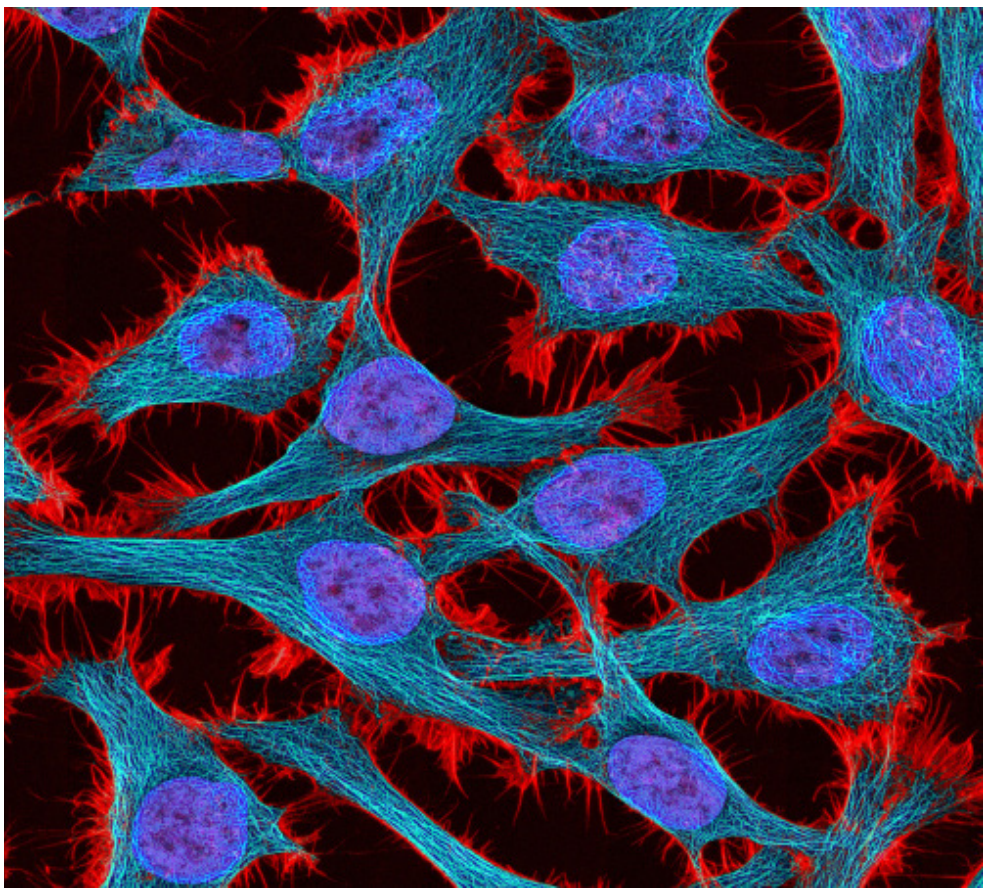

Tom Deernick, National Institutes of Health, 2013, *HeLa Cells*. Multiphoton fluorescence image of HeLa cells stained with the actin binding toxin phalloidin (red), microtubules (cyan), and cell nuclei (blue).

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