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Individual Autonomy

In the modern day, a confluence of factors influences our daily decisions, some of which we are consciously aware of and others we are blind to.

Penn Bioethics Journal

The Penn Bioethics Journal (PBJ) is the premier peer-reviewed undergraduate bioethics journal. Established in 2004, the Journal provides a venue for undergraduates to make contributions to the field of bioethics.

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

Authors and the editorial staff alike have a unique opportunity to experience the peer-review process through the collaborative, rigorous review and preparation of the Journal. With an audience ranging from undergraduates to scholars in the field to the broader public seeking unbiased information, the Penn Bioethics Journal occupies a unique niche in the field of bioethics.

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Content

Letter from the Editor

Dear Readers,

It is my great honor to present you with Volume XIX, Issue ii of the Penn Bioethics Journal, entitled "Individual Autonomy." In the modern day, a confluence of factors influences our daily decisions, some of which we are consciously aware of and others we are blind to. Such a distinction has led to the perpetuation of some of the most distressing ethical transgressions of modern times without the affected population not understanding the full scope of the situation and it has enabled others to take matters into their own hands.

The first article, "The Disastrous Separation of Informed Consent and Medical Care in the United States Public Health Service Syphilis Study," discusses the injustices of the well-known USPHS Syphilis Study which eventually led to the National Research Act. Author Mychaela Mathews of Northwestern tactfully explains the long-lasting impacts of this study on minority populations despite all that has been done to learn from it.

The second article, "The Urgency for Harmonized Global Cross-Border Reproductive Care," digs into the pressing nature of providing necessary resources for those impacted by the shifting regulations surrounding reproductive care. Author Claire Jun of the University of Pennsylvania explains that there exists potential even for international regulation and posits that if such reform is not rapidly instituted, countries will find it less important to prioritize their citizens' health.

The third article, "Should We Lie to Terminally Ill Pediatric Patients?," scrutinizes one of the most hotly debated topics in bioethics using Kantian frameworks. Author Emily Bach of Georgetown examines a specific case to sift out the nuances of the dynamics between pediatric patients and their providers, investigating how both the patient and their autonomy can be protected.

The fourth article, "Motherhood As A Vector For Sexism in Treatment Refusal Controversies," highlights several court cases that underscore the role that gender plays in differences in patient treatment. Author Samuel Streicher of the University of Rochester interestingly observes that cases outside of the scope of medicine in which women have their autonomy limited lead to a precedent that is often translated into other cases regarding their women's health.

As always, our Bioethics-in-Brief section covers current issues in the field of bioethics, with one focused on telemedicine and the other focused on private equity firms. This edition's interview is with Dr. Steven Joffe, a pediatric oncologist and bioethicist who is the Chair of the Department of Medical Ethics & Health Policy at the University of Pennsylvania.

I would like to thank our publisher and amazing team of editors, without which this issue would not have been possible. Also, a special thanks to faculty advisor, Dr. Harald Schmidt, for his support during the editing and publication process.

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

On a more personal note, as I end my term as Editor-in-Chief of Penn Bioethics Journal for the calendar year 2023, I would like to thank all of our readers, contributors, and staff for making the journey over the past three and a half years so special. Since joining the Journal as an Associate Editor in my freshman year of college online during the pandemic, I have learned so much and grown - I hope this publication has been able to provide that to you all as well. I am so excited to see the Journal continue to grow in the coming years.

Srish Chenna
Editor-in-Chief
University of Pennsylvania

Article

The Disastrous Separation of Informed Consent and Medical Care in the United States Public Health Service Syphilis Study

Mychaela Mathews*

ABSTRACT

The United States Public Health Service (USPHS) Syphilis Study (1932-1972) has been classified as a historical trauma due to the emotional and physical harms endured by the 600 Black men from Macon County, AL who participated. USPHS researchers failed to obtain implicit or explicit consent from participants who were recruited based on their race and low socio-economic status, and coercive recruitment strategies were used, such as promised incentives like free medical care and hot meals. While labeling this event as historical trauma helps researchers better examine the ethics of research methods and the importance of consent, I argue that the USPHS should be classified as a disaster due to the degree of social disruption the study created, not only for the men participating in the study and their families, but for Black Americans as a group. Additionally, I will explain why the USPHS study has not been previously declared a disaster and how a formal declaration of this event as a disaster can positively reshape how historic racially traumatizing events are transmitted between generations. Through the coding of newspaper articles and scholarly literature, I analyze the case of the USPHS Syphilis Study by examining inequalities in disaster preparation, response, and recovery along lines of gender, race, and socioeconomic status to argue that framing this event as non-disastrous contributed to this government-facilitated trauma continued for 40 years without interruption, leading to lasting consequences.

INTRODUCTION

Often, the connection of consent and medical treatment commences with an explicit statement of "I agree". Other times, patients use implicit or nonverbal gestures to indicate approval and understanding of medical treatment in the intimate partnership between patient and physician (Cornell Law School n.d.). From 1932 to 1972 in Macon County, AL, the United States Public Health Service (USPHS) breached the trust in the patient-physician relationship during their now infamous Syphilis Study by omitting crucial details about medical treatment and experimentation on 600 Black men: 399 men with syphilis and 201 without syphilis in the study's "control group" (Frazier 2020; Lucas 1970). Though they were promised free medical care in return for their participation, these men were not informed whether they had syphilis, nor were they provided the known treatment for syphilis, penicillin, leading to over one hundred estimated deaths (Frazier 2020; Tobin 2022).

The USPHS Syphilis Study was initiated to observe the natural progression of syphilis and determine the physiological differences between Black and White patients with untreated syphilis through "race medicine", which attempted to prove that the pathology of diseases differed between races (Brawley 1998). The experiment was conducted in

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Macon County, AL due to the economic and social characteristics, such as local sharecropping arrangements, that made Black men in this community an ideal target by the USPHS. Further, limited financial resources exacerbated by the Great Depression ensured that most Black people never visited a physician for the treatment of syphilis or any other ailment (Brawley 1998). The combination of systematic racism—the implementation of intentional barriers to prosperity based on race that are "deeply embedded in society and reinforced by state power and market systems"—and extensive poverty facilitated the medical coercion of Black, low-

*Mychaela Mathews studies Neuroscience and Science in Human Culture at Northwestern University. She can be reached at mychaelamathews2025@u.northwestern.edu

income men in Macon County (Pellow 2016).

While considerable research documents the harms of this racially biased and exploitative medical experiment, few consider the similarities the event has with environmentally disastrous events. Charles Fritz (1961) defines disasters as "actual or threatened accidental or uncontrollable *events that are concentrated in time and space, in which a society,* or a relatively self-sufficient subdivision of a society *undergoes severe danger, and incurs such losses to its members and physical appurtenances that the social structure is disrupted* and the fulfillment of all or some of the essential functions of society, or its subdivision, is prevented" [emphasis added]. The USPHS Syphilis Study occurred in a concentrated time (not including the intergenerational effects or collective memory of the study), from 1932 to 1972, and in a concentrated space: Macon County, AL (Fritz 1961). Therefore, the USPHS Study should be considered a disaster with a slow onset and chronic consequences that resulted in disruptions to daily life, such as through signs of untreated syphilis and the loss of life (Fischer 2008; White 2000).

The USPHS Syphilis Study has not been previously regarded as a disaster by scholars or declared a disaster by government actors because the entity responsible for providing aid—the U.S. government—was also the perpetrator of violence and injustice. Systems of power influence how events are viewed and historicized by determining which events are disasters when they can utilize the aid, privilege, and attention of the majority in a society. The USPHS Syphilis Study has never been declared a disaster because the systematic racism that encouraged the initiation of the study also masked the exigence of declaring this event as such. Archival newspaper data demonstrates how Black research participants were recruited and retained as part of the study, showing how inequalities across time map onto the stages of disaster: preparation, response, and recovery (Fischer, 2008). This analysis of newspaper articles, government documents, and secondary literature reveals how structural, racial, and gender inequalities undermined governmental mandates to protect disaster survivors in the past to better inform disaster declarations and associated relief efforts in the future.

METHODS

The media is a primary source utilized by people living in disasters and reflects how they respond to them (Greenberg and Scanlon 2016). To analyze different media frames of this event, I focused on a local news source that would be accessible to the victims of this disaster: *The Tuskegee News*. I searched the archives of this paper for any articles referencing syphilis during the study itself (1932 to 1972). This resulted in 29 news articles. I engaged in open coding and inductive research by reading each article twice and marking evidence that confirmed why Black men were targeted for this study and why the USPHS study has not been declared a disaster. In this article, I draw upon the trends identified across all 29 articles and provide qualitative evidence from nine pieces from that period to demonstrate how racism influence media outlets to present information. The tenth article was from the *Associated Press*, which was the first newspaper article to expose the injustices occurring in Tuskegee. I specifically chose articles from the *Tuskegee News* to understand how information regarding syphilis and the USPHS study were strategically disseminated in the community where the study was taking place. Additionally, I coded four government publications in this period (1932-1972) and five academic sources to analyze how leaders in medicine and science framed the study at this time.

RESULTS

The targeting of Black men for the Tuskegee Syphilis Study was a deliberate choice to exploit the gendered positioning of men as "providers" in the traditional family and inhibit proper disaster preparation and response. One news article, "Syphilis Control Program Mapped by Co. Health Board" (*Tuskegee News* 1937) warns readers that syphilis will "reduce the earning capacity" of 25% of the Black residents of Macon County and warns the audience of the negative effects of syphilis, such as total blindness and paralysis, that would prevent men from working and financially providing for their families. By describing syphilis as a life-altering disease that threatens one's ability to contribute to their family, Black men in Macon County were confronted with a potential barrier to their ability to fulfill their role as a provider within their households. In "Alabama Declares War on Syphilis: Macon County Attacks!!," syphilis is described as "the greatest threat to the success of our armed forces…and of industry", which underscores the role syphilis had on the ability to contribute to both one's family, country, or community (Local State and Health Departments 1944). The fear of contracting a disease that compromised one's ability to provide deceived men into thinking that they were being treated by the USPHS for a fictitious disease called "bad blood" (Brawley 1998). Incentives, such as free medical care and hot meals, reduced the financial burden on the participants' families and bolstered the feeling of being providers despite the horrific impacts that participating in the study unknowingly catalyzed (Brawley 1998; Laurie 1970). In "Macon Ranks Low in Percentage of Syphilis Cases" (*Tuskegee News* 1944a), material goods cloaked in medical coercion were used to deceive participants and retain their investment in the study to exploit their lack of awareness regarding the ineffective medical treatment they received. Essentially, the perpetrators of violence in this disaster leveraged the

By Department of Health, Education, and Welfare. Public Health Service. Health Services and Mental Health Administration. Center for Disease Control. Venereal Disease Branch (1970 - 1973), Public Domain

gendered idea of men as providers to ensure investment and longevity in the USPHS study, which stifled adequate preparation and response to this disaster.

Inequalities in socioeconomic status also allowed the United States Public Health Service to choose a target population for the study and exacerbated disaster response inequalities. "Macon County Blood Testing Stations" (*Tuskegee News* 1949) describes how blood testing stations were set up by the recommendation of local health officials, judges, law enforcement, and the superintendent of education to screen all people from the ages of 14 to 50 for syphilis in Macon County. As low-income Black men became the desired participants in the study, these blood testing/screening stations were relocated from churches and schools to Depression-era work projects where women and children were not typically present (Gray 1998). These work sites were removed from the public and allowed scientists to "observe" the untreated impacts of syphilis, incentivize men without the general public's interference, and avoid wasting screening material on women and children (Gray 1998). The participants in the study were low-income sharecroppers and tenant farmers with no experience navigating any medical environment (Brandt 1978). Low income and low literacy rates compounded the effects of the study by preventing the participants from having a broad understanding of the healthcare system and encouraging them to remain involved in the study, an example of delayed disaster response, due to the financial benefits it provided (Schroeter 1970).

The role of race in the USPHS Syphilis Study highlights the inequalities in disaster response that repressed the circulation of information about this event around the world for forty years. The media is a key means for people to find out about disasters, but it was not immediately employed in this case (Greenberg and Scanlon 2016). The USPHS utilized several methods to suppress responses and outcry over the study. For example, in "Negro Nurse Given Health Work Award" (*Tuskegee News* 1958), a Black nurse, Eunice Rivers Laurie, was used to recruit participants in the study and to assuage suspicions regarding the USPHS's intentions. The nurse was later applauded in the local newspaper for being a beacon of trust in the community despite her role as a key organizer and perpetrator of the study, such as when she drafted and disseminated the autopsy protocol for deceased participants in the study (Laurie 1970). When reporting syphilis positivity rates, "Macon Ranks Low In Percentage of Syphilis Cases" (*Tuskegee News* 1944b), the authors state that "white persons showed only 0.0082 percent while the percentage for Negroes was 10.14", which depicts syphilis as a disease that Black people were more prone to contracting due to the vast difference in positivity rates. Publishing statistics like this in a public newspaper may encourage readers to associate race-related stigmas with positivity status (Smith 1937). In "Important Health Measures" by Dr. Murray Smith (1936), he warns the audience to be cautious of "cooks, maids, nurses, laundry women, and waiters" as harboring "disease-producing bacteria", which demonstrates how race and socioeconomic status were leveraged in this disaster to villainize Black and low-income people as being carriers of the disease. Surveying results may have been misleading due to selection bias (Brawley 1998). Essentially, the coordinators of the USPHS Study utilized the previously existing social division of people by race and class to subdue resistance, or disaster response, to the experiment from both White and Black citizens.

Media blackout makes it difficult for the public and victims of a disaster to know and stop the event (Greenberg and Scanlon 2016). However, even without media, many scientists, physicians, and public health officials were aware of the study, which is confirmed by the14 articles with experimental data that were published during the USPHS Syphilis Study (White 2000). The peer-review process did not spotlight the racism that riddled these articles (White 2000). In a letter to the Chief of Venereal Disease Branch, Dr. James B. Lucas, Assistant Chief of Venereal Disease Branch, wrote that "any findings of special interest or importance might then be published in appropriate journals as has been done in the past", which confirmed awareness of the study in the medical, scientific, and governmental arenas (Lucas 1970). Systematic racism and racial bias prevented prestigious medical organizations, such as the American Medical Association, from acknowledging and reprimanding the USPHS for unethical medical treatment and experimentation (White 2000). Interestingly, the USPHS Study did not end until a reporter from the *Associated Press* released an article that bolstered condemnation of the study around the globe (Heller 1972). The biased articles from the *Tuskegee News* attempted to remove the public from the study while Heller's article informed readers on the truth about the study (Brawley 1998; Heller 1972). Heller's article was a tool to ensure accountability while the *Tuskegee News*' articles were a tool for deception. Systematic racism negatively impacted the ability and willingness of the participants and scientists to

respond to this event in a timely and effective manner.

Inequalities in recovery are evident in the collective memory of the USPHS Study that remains in the Black community. Frazier defines collective memory as a socially constructed framework or story that places an individual within a group and often links people to one another through a culture that carries memories of the past (Frazier 2020). The reporting of the USPHS Study in historically Black magazines, such as *Ebony* and *Jet*, and other forms of media have encouraged central themes about the USPHS Syphilis Study to emerge in the collective memories of Black and African American people in the U.S., such as exploitation of uneducated victims, genocide, and medical mistrust (Frazier 2020). The recovery of Tuskegee has not been isolated to the geographic location of Macon County, AL but has reached the collective memory of many Black-identifying people throughout the U.S. who question medical intentions and scientific authority today. For example, the legacy of the USPHS Study caused many Black Americans to question the efficacy of the COVID-19 vaccine and consider the risks of receiving the vaccine (Okorodudu et al. 2021). Undoubtedly, the COVID-19 pandemic is conceptualized as a disaster due to the degree of social disruption and physical harm that virtually all people, no matter their social class, experienced. Although the USPHS Study prompted similar emotional, physical, and social consequences as the COVID-19 pandemic, its significance as a disaster is minimized because of the marginalization of the group it impacted. Comparing the USPHS Study to the COVID-19 pandemic highlights how disasters are only perceived as such when they affect people with the privilege to receive aid and attention due to their status in a population.

DISCUSSION

The aforementioned actions underscore why the USPHS Study has not been deemed a disaster in U.S. History: the perpetrators of the violence refused to reprimand themselves. Most disasters are only declared disasters if the United States government perceives them as such. The declaration of a disaster by the government allows disaster sites to receive aid from outside entities to help in the recovery process. However, the United States Public Health Services did not declare the USPHS Syphilis Study as a disaster because they were responsible for initiating the disaster. The backlash from the Tuskegee community was prevented through the biased presentation of syphilis in the popular media and the lack of accurate reporting on the experiment, both to the general public and scientific circles. The Tuskegee Study reveals that disasters may not be declared as such if they do not affect people that are a part of the majority of society.

Inequalities in disaster preparedness, response, and recovery are underscored in the coercion the USPHS committed against study participants by not requesting patient consent for medical experimentation (Gray 1998). With no experience navigating a medical system plagued by white supremacy, systematic racism thwarted any preparation participants could have employed to grapple with an undiagnosed illness. Survivors of the USPHS Study were unable to adequately respond to the disaster because they were unaware of their positivity status, the horrific effects that syphilis would have on their bodies, and the degree of social disruption the study would encourage (Brawley 1998; Hill 1970). Inequalities in recovery are evident in the collective memory that the Tuskegee Syphilis Study has cultivated in the Black community today through popular media sources, which has bolstered medical mistrust (Frazier 2020). Essentially, the analysis of media demonstrates how coercion intersected with race, gender, and socioeconomic status to allow the perpetrators of the USPHS Syphilis Study—the United States government—to conceal the scale and scope of this disaster while leveraging social stratification to accomplish an intentionally caused human disaster.

Furthermore, a proper response to the Tuskegee Syphilis Study was stifled by structural racism in the healthcare system and scientific circles. Structural racism manifests in laws, rules, and practices in governments, cultures, and economic systems that accommodate prejudice in a society (Bailey et al. 2021). Low-income Black men were targeted for this study because "most southern Negroes, being poor, had never seen a physician for any reason", which highlights the limited interactions with physicians that participants had before the experiment and prevented participants from being advocates for their health (Brawley 1998). This connects to the sociological theory of unequal exposure to risk because, structural racism reinforces a social where some people are more vulnerable to a disaster due to previously existing social factors (Cannon, 1994). This is also an example of the human culpability theory in which certain societal factors culminated in a disaster rather than a 'natural' or "physical agent" (Dynes 1993). A lack of accessible and affordable healthcare, health literacy, or awareness of informed consent in the physician-patient relationship prevented participants from detecting the injustice that was inflicted on them amidst the study; this is similar to what environmental sociologist Sherry Cable and colleagues found among nuclear weapons workers at the federal Oak Ridge Nuclear Reservation (2008). An additional example of inequality influencing disaster preparation and response can be seen when emergency alerts are only disbursed in English, which solidifies barriers to well-being and safety based on what language someone speaks (Guevarra et al. 2023). Without the necessary tools and awareness, certain groups are unequally positioned to properly prepare for and respond to disasters.

CONCLUSION

Ultimately, the intersection of gender, race, and socioeconomic status made Black men in Macon County, AL the desired target of the USPHS Study, which lead to inequalities in disaster preparedness, response, and recovery. Inequalities in disaster preparedness and response are evident in the structural racism that prevented study participants from having experience navigating a medical system haunted by systemic racism and paralleled Cannon's sociological theory in which social systems facilitate unequal exposure to risk (Cannon 1994; Brawley 1998). Additionally, structural racism prevented scientists from identifying unethical and biased research methods when analyzing data from the USPHS Study (White 2000). The role of socioeconomic status in this disaster illustrates the human culpability theory of disaster because social factors, such as low income and race, were vulnerabilities that the USPHS targeted to deceive participants with incentives (Dynes 1993; Brawley 1998). Finally, inequalities in disaster recovery are evident in the collective memory that Black and African American people in the U.S. have experienced when confronting medical mistrust (Frazier 2020). At the close of the study, all survivors, and eventually their spouses and children, received medical care from the Tuskegee Health Benefit program. In 1974, a $10 million out-of-court settlement was reached on behalf of study participants and their families. In 1997, President Bill Clinton issued a presidential apology for the USPHS study (Office of Science 2022). These efforts are attempts to pacify criticisms that the U.S. government received for breaching their morality in exchange for "scientific progress". The 600 men of the USPHS Study have been overlooked as survivors of a disaster because these inequalities have allowed the majority group in society to trivialize this event to merely be designated as a historical trauma rather than a government-facilitated disaster.

Although this disaster occurred over 50 years ago, the blemishes of mistrust still linger in Black and African American communities (Frazier 2020). For example, a study performed at the University of Chicago revealed that while 16% of White individuals stated they would not get the COVID-19 vaccine, 40% of Black people made the same statement (Okorodudu et al. 2021). By not designating the USPHS Study as a disaster, the scale and scope of the study have been minimized in White history because this group of people was virtually unaffected. Moreover, the Black community has been grappling with the painful history and memory of this study since its commencement in 1932 (Gray 1998). Other disasters since 1932 have been obscured or concealed due to racial and economic inequalities and discrimination. In the Flint Michigan Water Crisis, corrosion controls were not implemented during the switch of water supplies, which resulted in discolored and odorous water, the proliferation of toxic chemicals, and the outbreak of disease (Craft-Blacksheare et al. 2021; Mohai 2018). Amidst the Flint Michigan Water Crisis, the intersection of race and gender highlighted how inequalities in disaster response, which included "denial and inaction" from the state government, motivated Black mothers to ensure clean drinking water for their children (Craft-Blacksheare et al. 2021; Mohai 2018). Similar to the delayed governmental response to the USPHS Syphilis Study, the Flint Michigan Water crisis demonstrates how disasters are not deemed as such when they do not directly affect groups of people in positions of social power, whether through race, class, gender, etc. Another example of a disaster that underscores the importance of power and authority is the Baltimore Paint Study in which blood lead levels in children were measured after researchers tried different lead paint abatement treatments in homes (Buchanan and Miller 2006). Although unethical infringements regarding informed consent in the study were identified and recognized in a court case regarding this experiment, the case was later dismissed, which demonstrates how the label of disaster is held in the hands of those who have the power and authority to place it on an event (Buchanan and Miller 2006).

This research should be used to help compensate people who went through disasters, set the precedence for how events should be classified, and highlight how racially motivated events are disasters and should be framed this way. An actionable next step is the classification of the USPHS study as a disaster. Without characterizing the USPHS study as a disaster, the historical significance of this horrendous study may wither over time. The USPHS deserves to be classified as a disaster to ensure that future generations will never attempt to see the silver linings to such atrocities, which is evident in the reframing of slavery in Florida public school education (Álvarez 2023). Recognizing racial bias can improve governmental responses to disasters and facilitate the initiation of disaster recovery. The USPHS Study is a historic example of how systematic and structural racism can stall the response and recovery phases of a disaster—and how social difference is exploited and concealed through the naming and framing of disaster by determining who has the power to say what is classified as a disaster. Power and inequality produce disaster, but these differences also emerge amidst disaster. As a policy recommendation, governments should declare disasters by the social impact they have on a population rather than who the disaster impacts or by limiting the scope of what is deemed a disaster by only its environmental consequences. Additionally, governments must consider the vulnerabilities and marginalization of minority groups to understand the magnitude of social disruption from a traumatic event and ensure that the proper measures are taken to aid recovery. In the future, we must analyze vulnerability in disaster preparedness, response, and recovery to ensure that these vulnerabilities are not exploited and that the connection of consent and medical treatment will never separate.

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Article

The Urgency for Harmonized Global Cross-Border Reproductive Care

Claire Jun*

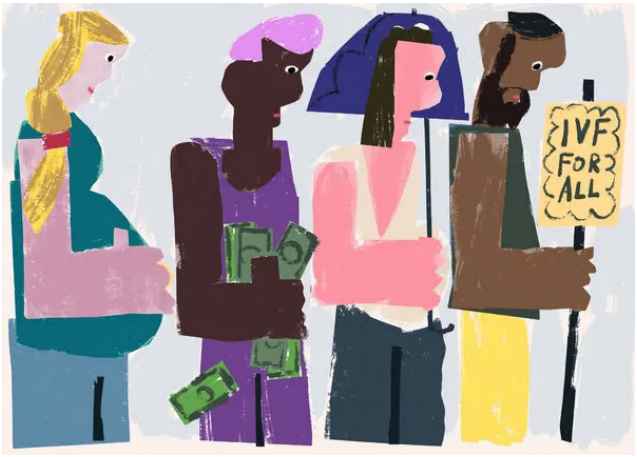
ABSTRACT

When patients are restricted by economic and political constraints to care, they may feel obligated to seek healthcare in countries with lax regulations or none at all. Scholars have named this global movement as cross-border reproductive care (CBRC). A common service prompting CBRC is in-vitro fertilization (IVF), a form of assisted reproductive technology (ART) that has allowed more people to become parents, but is yet to be universally accessible. Various factors such as cost, time, and legal restrictions limit its usage and with *Roe v. Wade* being overturned, standards of IVF practice have become blurry. Consequently, genetic testing on embryos, also known as preimplantation genetic diagnosis (PGD) that accompanies IVF faces additional regulations on a country by country basis. In this paper, I describe the regulations of PGD in the UK and US and delineate their impact on the largely unregulated phenomenon of global CBRC. Overall, I focus on how differential regulatory regimes across the globe drive CBRC which in turn creates medical and legal harms for patients. Using examples of CBRC originating from various countries, I primarily focus on the US and UK because they are emblematic of a laissez-faire, unregulated system versus one that is universal and highly regulated. The US and UK therefore serve as frameworks that represent the markedly different ways that nations regulate ARTs. Such regulations are critical for situating ART within different economic, social, and legal contexts across the globe. Drawing upon scholarly literature on CBRC, I center my investigation from the late 2000s to present day and focus on the push and pull factors that drive global CBRC by providing examples from various countries. Ultimately, I argue that the lack of harmonized CBRC regulation on a global scale ultimately imposes health and legal risks for consumers. I conclude by discussing current recommendations that governments and regulatory agencies are considering to protect the health of their citizens.

INTRODUCTION

A form of assisted reproductive technology (ART), IVF has made it possible for more people to become parents since its invention in 1978, but it's not accessible to everyone. The procedure is often costly, time consuming, and clouded by complex regulations. Such factors create additional burdens for low-income individuals and the LGBTQ+ community in the United States where regulations around reproductive technologies vary tremendously across insurance plans and state lines. Additionally, the Supreme Court's recent ruling overturning *Roe v. Wade* puts fertility treatments at risk due to its proximity to the debate around the rights of 'unborn human beings.' With all jurisdiction given to states, many states have begun to ban abortions completely and are attempting to pass legislation that would grant personhood rights to embryos and fertilized eggs (Polo, 2022). Such laws that blur the standards of IVF practice and pose a threat to the procedure for patients living in states where the ban is present may also deem routine genetic testing on embryos illegal.

An example of genetic testing on embryos is preimplantation genetic diagnosis (PGD), which is a voluntary



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test that examines an embryo's genes before deciding to transfer the embryo to the uterus. Performed in conjunction with IVF, PGD is primarily used to detect serious heritable disorders, such as Tay-Sachs or cystic fibrosis. It can also be used for more controversial purposes, such as selecting for a child who can serve as a tissue donor for a sick sibling, selecting for a child with a certain condition, such as deafness, and selecting for a child of a particular sex. In nearly

*Claire Jun studies Health and Societies with a concentration in Health Policy & Law at the University of Pennsylvania. She can be reached at clajun@sas.upenn.edu.

all countries with advanced fertility clinics carrying out the technique, PGD is a medical technology that is situated and restricted by legal, material, and economic constraints (Löwy, 2020) which sometimes lead to a phenomenon called cross-border reproductive care (CBRC) that poses various risks for patients and their offspring (Ethics Committee of the American Society for Reproductive Medicine, 2022).

In this paper, I describe the regulations of PGD in the UK and US and delineate their impact on global cross-border reproductive care (CBRC), a largely unregulated phenomenon where patients are forced to travel abroad to access healthcare due to lack of it at home. Overall, I focus on how differential regulatory regimes across the globe drive CBRC which in turn creates medical and legal harms for patients. I chose these two countries because they are emblematic of a laissez-faire, unregulated system versus a universal, regulated one. The UK and US therefore serve as frameworks that represent the markedly different ways that nations regulate ARTs. Such regulations are critical for situating ART within different economic, social, and legal contexts across the globe. Drawing upon scholarly literature on CBRC, I center my investigation from the late 2000s to present day and focus on the push and pull factors that drive global CBRC by providing examples from various countries. Ultimately, I argue that the lack of harmonized CBRC regulation on a global scale ultimately imposes health and legal risks for consumers. I conclude by proposing recommendations that governments and regulatory agencies should implement to protect the health of their citizens.

FRAMEWORKS FOR PGD REGULATIONS

The United Kingdom: Universal Healthcare

In the UK, residents are served by a universal healthcare system funded by the National Health Service (NHS) based on clinical need, not ability to pay. Access to publicly-funded care means that services often have varying eligibility criteria across the country. A statutory body called the Human Fertilization and Embryology Authority (HFEA) regulates how ARTs may be offered. The HFEA received its authority from the 1990 and 2008 Human Fertilization and Embryology Acts, which allows PGD only for medical purposes, including blood or bone marrow matching (HLA matching). The HFEA also maintains a detailed list of disorders for which PGD is permitted (HFEA PGT-M Conditions, 2023), and license committees determine whether new conditions qualify as appropriate after reviewing an application submitted by a fertility clinic on behalf of a patient. Licenses may be given when there is a significant risk that an embryo will have "a. a serious physical or mental disability; b. a serious illness; or c. any other serious medical condition" (Human Fertilization and Embryology Act, 1990). For lower penetrance (genetic conditions in which the person has a variant but do not develop the features of the condition) and later onset conditions, the HFEA has conducted wider policy reviews that involved public consultation.

As such, the UK regulates exactly which conditions PGD can be used for and has concluded that PGD can be used to select against serious medical conditions. The specific ethical usage of PGD is beyond the scope of this paper and will not be discussed. On the regulatory landscape of PGD, a study surveying UK clinics found that the majority of clinics believe the current model is inappropriate with four out of five clinics stating that PGD should be an autonomous and private decision between physician and patient, while one clinic stated that current regulations help give clarity to staff and clinics (Zika et al., 2007).

The United States: the Wild West

In the USA, there is no analogous agency to the HFEA, and there are no state or federal laws specifying the acceptable uses of PGD. At the highest level, the Clinical Laboratory Improvement Amendments regulates labs that perform diagnostic testing on human specimens, but this does not apply to tests performed in the context of IVF such as PGD. Similarly, the Food and Drug Administration (FDA) regulates the safety and efficacy of test kits for genetic testing, but as most labs use assays that they develop themselves, the FDA has a limited role in the regulation of PGD. Although they can ensure that such tests are clinically valid, the context in which the tests are applied is left to the discretion of clinicians, who are influenced – to an extent – by recommendations made by professional organizations (Reproduction and Responsibility: The Regulation of New Biotechnologies, 2004).

However, professional guidance relevant to the use of PGD is scant and insufficient. Society guidelines are not legally binding, and many guidelines state that they are educational resources, not requirements (Bayefsky and Jennings, 2015). For example, the American Society for Reproductive Medicine (ASRM) has published several ethics committee guidelines for clinicians who coordinate PGD, but ASRM has not been explicit in establishing appropriate indications or uses. Many committee opinions come to the same conclusions that PGD is a matter of reproductive liberty and that patients should be "thoroughly counseled to weigh the risks"(Ethics Committee of the ASRM, 2018; Practice Committee of the Society for Assisted Reproductive Technology and Practice Committee of ASRM, 2008; Judith D et al., 2017). Furthermore, an ASRM Ethics Committee opinion on sex selection states that "there are reasoned differences of opinion about the permissibility" of non-medical sex selection, and therefore practitioners "are

under no ethical obligation to provide or refuse to provide non-medically indicated methods of sex selection" (Ethics Committee of the ASRM, 2015). Thus, while ASRM addresses some uses of PGD, their guidelines do not draw a clear line between acceptable and unacceptable uses.

In contrast, the American Congress of Obstetricians and Gynecologists (ACOG) draws a clearer line regarding the use of ART for sex selection, recommending against elective sex selection for any reason (ACOG Committee Opintion, 2008). However, their guidelines are not binding and sex selection is performed nonetheless. ACOG does not directly address other uses of PGD. Similarly, the American Medical Association's Code of Medical Ethics explicitly states that it is "unethical to engage in selection on the basis of non-disease related characteristics or traits" (AMA Code of Medical Ethics, 2023) while the American College of Medical Genetics suggests that for adult-onset disorders and those with lower penetrance, parental autonomy must prevail (Grody et al., 2013). As none of these opinions have more than hortatory power, it is again left to the patient whether they want to use PGD.

As such, this type of self-regulation effectively allows individual clinicians to practice an essentially limitless use of PGD. As PGD is offered for increasingly controversial conditions such as sex selection, scholars have proposed attempts to regulate the practice at the state or federal level. However, due to proximity of PGD to the abortion debate, they recognize that increased regulation would most likely provoke controversy and could even result in outright bans of PGD (Bayefsky, 2018).

The UK and US as frameworks represent contrasting approaches to regulating PGD and provide a glimpse into how people access reproductive care. Yet, national guidelines only have so much influence, and the sheer variation between nations has consequences for how people access care. In the following sections, I discuss healthcare-related economic features of the US in comparison to the UK that bear on the current regulatory landscape for PGD. Ultimately, the lack of regulation in the US and similarly regulated nations affects patients worldwide because it makes such countries destinations for reproductive tourism for patients from countries with more restrictive laws.

MATTERS OF AFFORDABILITY PROMPT TRAVEL

Like many other countries in Europe, the UK's healthcare system operates on universal coverage and is largely funded by the government. Since the government plays a major role in financing healthcare, government officials must consider the applications of medical treatments in order to determine what to cover. In the UK, the NHS funds up to three cycles of IVF for women and coverage is not restricted to heterosexuals or couples (HFEA: Costs and Funding, 2023; Heath, 2022) Though, in practice, coverage for IVF depends in part on the funding available in a given NHS locality. Thus, depending on one's postcode, the number of cycles for which someone may receive coverage by the NHS varies.

By contrast, in the US, most people access health insurance through employer-based plans or governmental programs for senior citizens, low-income individuals, and Veterans. Coverage of IVF and PGD, and the governmental plans do not cover advanced fertility treatments (Weigel and Ranji, 2020). Therefore, because the government does not directly fund ART, they are not financially invested in assessing the appropriateness of different reproductive technologies, including PGD. Currently, twenty states in the US have insurance mandates that require some coverage of fertility treatment by private insurers, but coverage requirements and eligibility criteria vary widely across borders and plans, and several of the mandates specifically do not require coverage for IVF (The National Infertility Association, 2022). In states that do require coverage, diagnosis of heritable genetic disorders may be covered, but fertility treatment following such diagnosis is often excluded (Leonhardt, 2019). Additionally, many individuals at high risk of having offspring affected by genetic conditions are not medically infertile, which is often a prerequisite for health insurance plans in the United States that do cover costly IVF treatments (Drazba et al., 2013). Similar to the UK, there is no law that explicitly bars single women and LGBTQ+ couples from undergoing fertility treatment. However, while ART is available to everyone by law, only those with the financial means can access them in reality.

As such, one of the biggest barriers to accessing IVF – in both the US and the UK – is its high price tag. As IVF does not always succeed on the first attempt, the lack of insurance coverage and high cost of treatment creates financial burdens for many patients in the US. The average cost of a single cycle of IVF (including ovarian stimulation, egg retrieval, and egg transfer) in the United States ranges from $15,000 to $30,000 depending on patient need and clinic location (Forbes, 2023). Treatments for PGD can account for an extra $5000 to an already hefty price tag (FertilityIQ, 2023). While treatments cost much less in the UK than in the US, patients still find the cost of IVF burdensome at £4,000 to £6,000 per cycle (excluding medications) with PGD alone adding about £1,600 - £3,000 to the package (Fertility Road, 2023). Other barriers to IVF in the UK include long waiting lists up to two years and a shortage of gamete donors due to the cessation of donor anonymity in 2005 (Laurance, 2010). Therefore, in addition to challenges in affordability, many patients face social and legal issues that may drive them to seek other markets.

As such, many patients look internationally for high-quality, affordable, and accessible treatments based on their needs. For example, after getting a quote of $40,000 for their IVF treatment in the US, an American couple went to Bar-

bados where their entire treatment only cost them $5750 (Montgomery, 2011). Employing a longer embryo culture period, the Barbados Fertility Centre (BFC) claims higher success rates (67%) as compared to the US (47%) and UK (32%) (Barbados Fertility Centre; Centers for Disease Control and Prevention, 2022; NHS, 2021). Clinics like BFC make the burden of traveling attractive as patients can get high quality and affordable treatments while enjoying a relaxing vacation all in one package. In the recent decade, scholars have begun to document trends in traveling to obtain care that is unattainable in one's home country. They call such a phenomenon cross-border reproductive care (CBRC), a form of 'global gynecology' or 'reproductive tourism,' in which travelers – for diverse reasons – exercise their reproductive autonomy to seek ART abroad (Inhorn and Patrizio, 2012).

EMERGENCE OF GLOBAL CBRC

CBRC is a rather recent, yet common phenomenon, accounting for 5% of all European fertility care and 4% of US fertility treatment (Ethics Committee of the ASRM, 2022). Scholars state that the need to travel to another country for health care "arises from limitations to the rights granted in the country of residence, but it can also be considered a safety valve" for those who would have campaigned vigorously for reform in their home countries if they were prohibited from traveling (Ferraretti et al., 2010). Currently, there is limited data on CBRC, and the lack of a global registry to track the movement of patients across borders makes developing an international harmonization system for fertility treatments challenging. Nonetheless, such systems are vital and necessary in reducing the health and legal risks associated with the phenomenon. Despite the absence of a regulatory system, scholars have presumed that such deficiency may reduce domestic moral conflicts and promote peaceful coexistence of different ethical and religious views (Ferraretti et al., 2010). As a result, some governments are encouraged to enforce their current restrictions.

THE LACK OF GLOBAL CBRC REGULATION

Due to the current information gap surrounding CBRC, the phenomenon currently comprises a patchwork of 'restrictive' and 'permissive' countries (Inhorn and Patrizio, 2012) shaped by various regulatory and social landscapes as exemplified by the US vs. the UK. In Europe, patients from restrictive countries (i.e. the UK) will travel to more permissive countries such as Denmark or the Czech Republic for more affordable treatments (Fertility Road, 2022). In North America, Canadians will travel to the US for surrogacy. Within the US, the lack of federal regulation on topics of assisted reproduction has given more power to states to decide which treatments are legal. As a result, some residents in a restrictive state will travel across state lines to access surrogacy services in a more permissive state. However, clinics are not obligated to record patient migration histories and some may not publicize their data due to a fear of litigation (Bayefsky, 2016).

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As global CBRC increases, a transparent reporting system is essential to diminishing the current information gap (Salama, M et al., 2018). For this reason, the European Society of Human Reproduction and Embryology (ESHRE) formed a CBRC task force to collect quantitative and qualitative information on the trend (Ferraretti et al., 2010). North American-based societies have attempted to compile CBRC data such as a 2016 study aimed at developing a prospective data collection system for CBRC in the United States and Canada, but almost all clinics expressed disinterest in collecting data on patients' country of origin and reason for travel (Ethics Committee of the ASRM, 2022). Furthermore, the time-consuming nature of compiling such data poses another challenge for the dearth of CBRC regulation today (Inhorn and Patrizio, 2009).

REASONS FOR CBRC

Perhaps the largest challenge in organizing CBRC data is that its reasons are unpredictable, and its travelers come from all over the world. Scholars postulate that people have more than one reason for pursuing reproductive care abroad, and "these reasons do not simply line up with the country of origin" (Hertz et al., 2016). In other words, CRBC does not manifest in a linear direction – just because another country is more affordable, it does not mean that ART services are available to everyone. In this case, patients are required to shop around based on personal need, which creates a stratification of global medical care. In this stratified market, sociologist Heather Jacobson posits that only those who are economically privileged are able to choose "a particular type of CBRC experience, signaling that the process itself, not the 'end product' alone, is something that is purchased" with certain ART markets "catering to clients able to afford and willing to spend on the full range of services, concierge style, while other markets provide more limited services and may be bound by time and legal constraints" (Jacobson, 2020).

Thus far, I have focused on the UK and US as emblematic frameworks for ART regulation, but as I describe be-

low, the factors that motivate patients to travel abroad for fertility care are varied, complex, and often interrelated. I narrow my discussion to two main categories: legal and economic.

Legal Challenges

Law evasion is a primary reason for CBRC (Inhorn and Patrizio, 2012) and the regulations that motivate the use of CBRC can fall into 2 broad categories: restrictions on who can access fertility care and restrictions on what fertility care can be accessed (Ethics Committee of the ASRM, 2022). Restrictions on patient age, marital status, and sexual orientation send older, single, and LGBTQ+ patients across national borders. An example of this was noted in the ESHRE CBRC Task Force study where only couples in Sweden, whether heterosexual or homosexual, have access to ARTs. Therefore, a higher proportion of single women were seen to travel abroad for care (Shenfield et al., 2010). While there has not yet been a follow-up study by ESHRE, it can be reasonably assumed that countries that restricted ART access to single women at the time of the study but have now recently expanded ART access to such demographics, including France (BBC News, 2021) and the UK (Heath, 2022), would see a decrease in travel. However, in Italy, same-sex couples, single women, and those of older age are still denied access to ARTs (Ethics Committee of the ASRM, 2022).

However, legal restrictions do little to discourage patients from searching for these services wherever available. As described before with the end of donor anonymity in the UK and Italy (Shenfield et al., 2010), many individuals have been seen to travel to Spain where the law protects the lifelong anonymity of all medical donors (Hertz et al., 2016). Furthermore, PGD is outright banned in some countries such as Italy (Shenfield et al, 2010), and sex-selection PGD is considered ethically unacceptable in most European countries. In other countries, PGD is also not allowed for any indication, providing yet another reason for patient mobility. As such, a 2008 PGD Consortium Report revealed that a single center in Jordan carried out more sex-selection procedures for couples traveling from all continents than those performed in all of Europe (Ferraretti et al., 2010).

Another type of genetic testing is mitochondrial replacement therapy (MRT), which is currently halted in the US, but is permitted in the UK under the regulation of the HFEA (Castro, 2016). Those who desire the procedure may travel to the UK without fully understanding the unintended consequences which include complications surrounding parentage and consent regarding children born outside the UK. Furthermore, limited clinical follow-up of children born through MRT when couples return home pose health risks.

Overlapping with legal restrictions, social reasons for CBRC due to religion pose additional challenges. For example, in Middle Eastern countries, only opposite-sex, married couples have access to reproductive care, with the exception of Israel (Inhorn et al., 2017). In predominantly Muslim countries, Sunni religious authorities have banned all forms of third-party gamete donation and surrogacy, leading some Muslim patients to seek care in less restrictive Shia-dominant countries (Inhorn and Patrizio, 2012). To a more extreme level, Turkey enacted the world's first legislation banning CBRC in 2010, which prohibits Turkish citizens from using donors and surrogates and from going abroad for reproductive treatment. Though, the extent to which such restrictions are enforced is unknown. According to ASRM, "there is little or no support for punishing patients who evade the law in pursuit of biologic parenthood; nor is there widespread advocacy for penalizing the physicians who assist patients in their quest to access CBRC" (Ethics Committee of the ASRM, 2022).

Economic Challenges

Cross-border reproductive care travel usually refers to patients who wish to avoid law evasion, but this is not the only motivation. As discussed previously, financial reasons for travel are prevalent because in reality, a large part of infertility treatments are performed in for-profit, private clinics, and the costs of treatments differ tremendously among countries (Ferraretti et al., 2010). As seen by the US couple who sought high-quality yet cheaper treatment in Barbados, it is possible to obtain treatments abroad that otherwise could never be affordable. Another such example are British and German patients who travel to the Czech Republic and Spain (Shenfield et al., 2010; Culley et al., 2011) for more affordable IVF where the costs range from €2,100 to €3,500 (Fertility Road, 2022). Furthermore, media reports indicate that India has been a popular destination country for accessing gestational surrogacy services because of its significantly lower compensation amounts (Ethics Committee of the ASRM, 2022).

The phenomenon of CBRC is complex and multifaceted, and its existence is a consequence of the regulatory, social, religious, and economic factors influencing accessibility to assisted reproduction worldwide. As briefly touched upon when discussing MRT in the UK, the unregulated nature of global CBRC may lead to unintended consequences. From an ethical standpoint, scholars state that the need to even travel for adequate care is considered a limitation of one's reproductive autonomy (Ferraretti et al., 2010). Additionally, CBRC promotes the inequity of access as a result of economically based discrimination because only patients with adequate financial resources can afford treatments abroad. Therefore, while CBRC may appear to be a practical solution for patients seeking fertility treatments forbidden in their home countries, it is only available to patients of suf-

ficient means and is associated with significant health and legal risks.

CONSEQUENCES OF CBRC

Health Risks

While CBRC can be viewed as a useful option for patients seeking access to treatments prohibited at home, the practice also poses a number of health risks to patients and the resulting offspring. In addition to the challenge of identifying high-quality, foreign clinics, patients may have a hard time in evaluating the quality and safety of the centers, and deal with unsatisfactory counseling due to language differences (Ferraretti et al., 2010). Additionally, patients may feel pressured to transfer multiple embryos at once, which exposes both the patient and offspring to the greater morbidity risks associated with multiple pregnancy (Bayefsky, 2016). Moreover, some providers at home may be reluctant to treat returning patients due to potential persecution. This makes it difficult to follow-up on patients after IVF and/or PGD to ensure a healthy pregnancy (Zika et al., 2007). The lack of local care with relevant records is especially concerning after a potential complication from a procedure abroad due to the inability to access their medical records. Patients may also not be entirely truthful about fertility care abroad because of insurance coverage concerns. Such unique situations may present unanticipated medical and ethical challenges for both the patient and provider (Ethics Committee of the ASRM, 2022).

Legal Risks and Effects on Legislation

Because CBRC often involves law evasion and possible legal consequences for patients and practitioners, it is often carried out in an atmosphere of secrecy (Inhorn and Patrizio, 2012). Additional harms to patients include the possibility of dealing with legal risks in their home country. For example, countries may refuse to recognize the legal parental status of those who have crossed borders to illegally have a child (Storrow, 2011). Furthermore, patients may be left in frustration due to the lack of psychological or legal assistance in the case of malpractice. Another important question for CBRC is what the effect will be on legislation. At its core, the movement of patients to other countries may symbolize a form of protest in which patients' decisions insinuate a need to change the existing legislation. However, as echoed by CBRC scholars, the phenomenon may have the opposite effect. Governments may simply accept such movement as a safety valve, decreasing the pressure for internal law reform (Pennings et al, 2008). As such, restrictive legislation will continue in place, and more patients will continue to seek care abroad at their own health and legal risks.

CURRENT DISCUSSIONS TO REGULATE CBRC

Given these health and legal risks as a result of unregulated CBRC, scholars have proposed solutions to mitigate the compulsory need to travel abroad include establishing an international system to harmonize assisted reproduction by tracking patients to ensure their safety overseas and/or instituting strong policies to guarantee public funding for universal coverage of ART treatments (Ferraretti et al., 2010). However, this is much easier said than done as there may be serious health and legal consequences with going to a foreign country to optimize one's reproductive needs. As discussed earlier, health risks include multiple-order pregnancies that result in transferring more than one embryo as well as the inability to ensure proper follow-up upon returning to one's home country. The latter is of particular concern as home countries may reprimand returning patients who have traveled to obtain an illegal procedure. Their legal parental status may not be recognized in their home country, and may find difficulties accessing legal assistance in the case of overseas malpractice. Without an international system to coordinate patient care, nations with more strict laws may decide to maintain their current restrictions and permit their citizens to keep traveling. Decreasing the pressure for internal reform, these countries inadvertently opt out of taking responsibility for the health and legal security of their citizens.

More feasibly, scholars have recommended instituting an international certification system to guarantee that all patients get safe and effective treatment wherever they go. This system should include both the logistics of travel and standard of care aspects in addition to compliance with ethical standards and psychological counseling (Pennings et al., 2008). However, in its Ethics Committee Opinion on CBRC, ASRM states that departure-country providers have an ethical duty to accurately share their knowledge on CBRC options including addressing their own gaps in knowledge about the issue. However, they are not duty-bound to offer the possibility of CBRC as a treatment option, and a physician who wishes "to terminate an existing relationship with a patient returning after receiving cross-border care may refer the patient to a willing provider" (Ethics Committee of the ASRM, 2022). As for destination-country providers, ASRM states that they have "no duty to act as a patient's legal advisor, and in fact doing so carries a risk of engaging in the illegal practice of law" (Ethics Committee of the ASRM, 2022). Ultimately, ASRM maintains their 'neutral' and 'autonomy-first' position for CBRC as they did for PGD regulation, which emphasizes the ethically murky field of reproductive care in the US. Such a position also clouds the extent to which US providers deliver care and whether patients are guaranteed security in their decision to travel abroad.

CONCLUSION

Cross-border reproductive care is a growing phenomenon in the world of reproductive technologies. Different legal landscapes around the world dictate how ARTs are accessed, which consequently compel patients to travel for essential care. While economic reasons are substantial drivers of CBRC, they are not the only reason. Scholars have posited that law evasion is the primary driver, and patients take this risk due to their home country's religion, bans on certain ART-related treatments such as PGD, or restrictions based on their personal identities. There may also be a recent increase in CBRC due to the overturn of *Roe v. Wade* in the United States that restricts the practice of reproductive care across the nation. This ruling goes to show the impact of a country's unique laws in driving patients to seek care elsewhere.

There is a clear inequity in accessing ARTs globally and although cross-border movements serve to increase the autonomy of patients, it is generally only available to those with the financial means of traveling. Ultimately, when creating regulations for the use of ARTs, governments and professional organizations around the world should not only consider the need for laws to reflect the desires and access for their citizens, but also the impact of policies that drive many patients to seek alternative – but highly risky – care in another country.

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Article

Should We Lie to Terminally Ill Pediatric Patients?

Emily Bach*

ABSTRACT

This paper addresses the duty of truthfulness in Kant's moral philosophy and whether it applies in the case of a terminally ill pediatric patient. Although lying to an adult patient about a terminal prognosis is a clear violation of Kant's categorical imperative, lying to a pediatric patient is a more complicated case. Based on Tamar Schapiro's Kantian conception of childhood, our special obligations to children make certain paternalistic actions morally permissible. Even so, lying to a pediatric patient about a terminal prognosis "for her own good" does not qualify as acceptable paternalism. Medical providers have a duty to not lie to their patient even if that patient is a terminally ill child.

We lie to children constantly. We tell them that a magic fairy comes in the middle of the night to replace their baby teeth with gifts, that broccoli wards off vampires, that the penicillin they need to cure their strep tastes like chocolate milk. Nevertheless, we tell them lying is morally wrong and raise them to refrain from lying. Although many regard lying to other adults as a moral misstep, lying to children seems to warrant less blame. We often tell white lies to children with "good" intentions in mind–to protect them, keep them happy, or refrain from explaining a concept that goes beyond the limits of their understanding. While it may be normalized to lie to children for paternalistic reasons like these, the moral permissibility of such lies should not be taken for granted. In this paper, I narrow my focus to lies told to children "for their own good" in a medical context. More specifically, I explore whether medical practitioners have a duty to terminally ill pediatric patients to tell them their true prognosis.

To accomplish this aim, I first detail a case in which a pediatric oncologist, Dr. Patty Paternalist, must decide whether to lie to her terminally ill patient, Robbie. After explaining this example, I provide the relevant background on medical truth-telling and why Kantianism might suggest that Dr. Paternalist has a duty to her patient to not lie to him. Once this philosophical framework is established, I examine whether the pertinent Kantian duty to not lie to patients applies only to adults or to both adults and children. I draw on Tamar Schapiro's "What Is a Child?" and explain how children are distinct from adults. I elaborate on the special duties Schapiro thinks children are owed and use them to determine when paternalistic behavior toward children is morally appropriate. I ultimately appeal to my views on paternalism to argue that Dr. Paternalist has a duty to Robbie to not tell a paternalistic lie about his prognosis. Finally, I consider an objection that distinguishes between paternalism toward children and paternalism toward terminally ill children. After responding to this objection in defense of my position, I restate my main premises and conclude the paper.

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To start, I will clarify the case I have in mind. Suppose Dr. Patty Paternalist is a pediatric oncologist who has been treating her cancer patient, a 10-year-old male named Robbie, for a year. In this time, Dr. Paternalist has developed a close relationship with her patient as well as his family. Robbie and his parents fully trust Dr. Paternalist and her medical judgment. Recently, Robbie got a routine scan as a part of his ongoing cancer treatment. Although Robbie's symptoms have remained the same, the scan indicates that his cancer has progressed to a later stage. Without treatment, Robbie would have one week to live; with continued treatment, Robbie would have one month to live. The parents and Dr. Paternalist have discussed the situation at length and have decided to continue with Robbie's treatment, which will resemble the treatment he received regularly prior to the scan. Robbie's parents have made it clear that they think Robbie might be better off not knowing his prognosis. They are seriously considering lying to Robbie, telling him that there is still hope, and not revealing that his illness is now terminal. However, the parents are asking Dr. Paternalist whether they should lie to Robbie about the matter. They are seeking

*Emily Bach studied Philosophy at Georgetown University. She can be reached at emilybach@me.com.

Dr. Paternalist's advice both because they acknowledge that Dr. Paternalist would also have to lie to Robbie and because they are genuinely unsure about the moral permissibility of lying to Robbie. Dr. Paternalist concedes that Robbie might be better off not knowing his prognosis but is unsure whether lying is the best course of action. In the remainder of this paper, I explore whether Dr. Paternalist (or any medical provider) owes Robbie (or any terminally ill pediatric patient) the truth.

Before getting to the nuances of this case, I will address why lying to a patient who is a competent *adult* would be impermissible. From the Kantian perspective, the morality of any action is contingent on whether that action sufficiently appreciates or respects human dignity. Kant believes that every person has dignity, an intrinsic value that is absolute, incommensurable, and indefeasible. We have this dignity by virtue of our capacity to reason. Since we have rational wills and are capable of reflecting on the proper principles to hold and making choices that align with those principles, we have dignity as opposed to price (the value of an object).

Kant specifies a binding moral principle to ensure that this dignity can be realized in each person: the categorical imperative. The humanity formulation of the categorical imperative requires us to act in ways that "*use humanity, whether in your own person or in the person of another, always at the same time as an end, never merely as a means*" (Kant 1996, 4: 429). The first requirement, to treat humanity always as an end, mandates that we treat ourselves and other people as end-setters, rational agents, or dignity-possessors. Our positive duties–duties to perform actions that promote human dignity–stem from this first requirement. The second requirement, to treat humanity never as a mere means, mandates us to not destroy or compromise a person's (ours or another's) rational capacity. Our negative duties–duties to refrain from performing actions that violate human dignity–stem from this second requirement. Negative duties are perfect, exceptionless duties that take precedence over our positive, imperfect duties.

When a physician such as Dr. Paternalist faces a choice between telling a patient a paternalistic lie and telling that patient the tragic truth, the physician is essentially deciding whether to abide by a negative duty to not lie to others. Although Kant alludes to three different duties to not lie to others (a duty to self, a duty to others, and a duty to humanity as such), for the purposes of this paper I focus only on our duty to others to not lie to others (e.g., a physician's duty to her patient to not lie to that patient). Suppose I lie to my friend Gabe to achieve some end *X*. I am giving Gabe false information, but that information still has the power to inform Gabe's rational decision-making since I purport it to be true. I am impairing Gabe's ability to properly act based on reasons and am therefore treating him as an object I can use to help me achieve end *X* and not as a person or end-setter. Thus, I am violating the second requirement of the humanity formulation and treating Gabe as a mere means. Even if I think I am helping Gabe or fulfilling the first requirement of the categorical imperative because end *X* somehow promotes human dignity, I cannot lie to Gabe. My perfect, negative duty to not lie to Gabe takes precedence over any positive duty I may or may not be fulfilling.

In *Bioethics: Principles, Issues, and Cases*, Vaughn echoes my points on why lying to another person is treating that person as a mere means. However, Vaughn frames the discussion in terms of the physician-patient relationship: "When physicians deceive a patient, they fail to respect his autonomy by constraining his ability to make informed choices. They compel him to make important decisions in a fog of distorted or missing information" (Vaughn 2019, 172). Thus, if Dr. Paternalist's patients were competent adults (i.e., fully-fledged rational agents) and not children, it would be morally impermissible for Dr. Paternalist to lie to one of those patients. Regardless of what benefits Dr. Paternalist thinks her patient would accrue from the lie, lying is treating the patient as a mere means and violates the categorical imperative. A patient who thinks he will survive has different reasons for action than a patient who thinks he will soon die, so lying about a prognosis would disrespect that patient's dignity. Returning to the case in question, if Dr. Paternalist has the same duties to Robbie that she would have to a competent, adult patient, then Dr. Paternalist would have a duty to Robbie to not lie to Robbie. Thus, the next section of this paper discusses whether our duties to children differ from our duties to adults.

In "What is a Child?" Tamar Schapiro addresses the distinction between adults and children through a Kantian lens. Schapiro recognizes that children are not yet full-fledged rational agents and develop principles to act on as they mature. An adult "is one who is in a position to speak in her own voice, the voice of one who stands in a determinate, authoritative relation to the various motivational forces within her" (Schapiro 1999, 729). In contrast, a child acts on "something like a principle" because she is a "reflective agent" (Schapiro 1999, 729). However, a child "cannot adjudicate [conflicting motivational claims] in a truly authoritative way for lack of an established constitution, that is, a principled perspective which would count as the law of her will" (Schapiro 1999, 729). Essentially, there is a sense in which a child is an agent, but a child has more work set out for her than an adult when it comes to cultivating a rational will. Schapiro characterizes childhood as a predicament whereby children take on provisional selves, "play" to try out different roles and principles for action, and are "characteristically 'in search of themselves'" (Schapiro 1999, 732-733).

Although Schapiro refers to children as a collective category, she leaves room for some distinctions between older and younger children. Schapiro accounts for the progression of childhood by introducing the concept of "domains

of discretion" (Schapiro 1999, 733). The idea is that, as children gain life experience, they become more capable of self-governance. An older child might have already had enough exposure to a particular domain, i.e. a certain situational context or subcategory of rational life, to develop principles for rational decision-making in that domain. More mature children thus "have adult status with respect to some domains of discretion, but not others" (Schapiro 1999, 734). Consequently, "children at different stages of development differ from one another in the extent of their hegemony over themselves" (Schapiro 1999, 734). Although any agent still in the predicament of childhood cannot be said to possess a rational will in a strict sense, some children are more capable of exercising their capacity to reason than others. Those who are more practiced at reasoning in a particular domain might be accorded the adult status of an end-setter within the confines of that domain. Such a child might not have a complete "voice" or "will" yet but should still be treated as having a voice or rational will within the context of the pertinent domain.

Now that I have shed some light on Schapiro's conception of childhood and the distinction between adults and children, I will address the special obligations or duties that come with this view. Schapiro mentions three such duties–one duty children owe to themselves and two duties adults owe to children. The duty that children have is to "pull themselves together," i.e. to work their way out of childhood and act in ways that bring about their eventual rational will (Schapiro 1999, 734). The two duties that adults owe to children stem from children's special duty–an adult's treatment toward a child can either promote or prevent that child from realizing his end to pull himself together. Thus, the first special duty adults owe to children is a positive duty to "help children work their way out of childhood" (Schapiro 1999, 735). In other words, adults have a positive duty to help children become end-setters, to fully develop and exercise their rational wills. One way of fulfilling this duty is to encourage children to self-govern in their domains of discretion and allow children "the opportunity to make decisions in limited ways wherever possible" (Schapiro 1999, 736). In contrast, the second special duty adults owe to children is a negative duty "not to treat children as if they belonged to a distinct and permanent underclass" (Schapiro 1999, 735). The way to fulfill this duty is effectively to not treat children as mere means. Schapiro notes:

> [W]e are not to treat them as anything other than practical agents, creatures who share with us the human problem of finding reasons for action. We are not to treat them as if they were mere objects to be possessed, manipulated, and exploited; nor may we treat them as if they were wild animals, creatures of instinct who have no potential for reason. (Schapiro 1999, 735)

From my perspective, this passage suggests that a child has dignity despite lacking a rational will. Her reflective nature and partial, developing will still accord her an incommensurable, absolute, intrinsic worth despite her lack of *complete* rational agency. Thus, the predicament of childhood lends itself to three special duties, all derived from the notion that children are on their way to becoming agents with rational wills.

With this framework for the nature of childhood and the special duties associated with childhood, I will explore what conditions make paternalism toward children permissible and whether certain paternalistic lies can satisfy these conditions. I will address the issue of paternalism in general, then turn to paternalism toward children and when it is appropriate, and finally examine whether telling a terminally ill pediatric patient a paternalistic lie is an appropriate instance of paternalism.

Paternalistic actions are ones that manipulate a person's undertakings, choices, or reasons for acting under the assumption that doing so is in that person's best interests. If a competent adult or agent with a rational will is the subject of paternalism, then her dignity is not being properly appreciated. If I think I know what is best for person *Z* and manipulate her behavior to bring about that "best" consequence, then I am not treating person *Z* as an end-setter. I am treating her as a mere means, as an object incapable of using her own reasoning to determine the best ends to set and act in ways that help bring about those ends. Nevertheless, the moral duty to not act paternalistically might not apply when the subject of paternalism is a child. As Schapiro notes, "paternalism with respect to children might be excusable on the grounds that children do not really have wills of their own" (Schapiro 1999, 734). Children frequently must rely on the authority of adults to determine a principled course of action; they do not yet have rational wills to determine what is right on their own all the time. Thus, paternalism toward children is permissible at least some of the time, and I hope to clarify when such paternalism is morally appropriate.

In my view, we should limit paternalism whenever possible in order to properly fulfill our duty to help children pull themselves together and become fellow end-setters. Before acting paternalistically, we should give a child the opportunity to make rational decisions on her own. If she fails to do so, then that child has not yet fully developed her rational agency when it comes to the relevant domain of discretion, and we can be paternalistic. If we can reasonably assume that a child has adult status in a certain domain of discretion, then we should not act paternalistically until that child has exhibited a lack of rational agency in that domain. This way, we can avoid treating children as mere means. If we exercised paternalism before first leaving open the possibility that a child can act as a rational agent and not need any paternalistic influence, then we would be treating children as though they belong to a distinct, permanent underclass. Our moral duties prohibit us from subjecting adults to pa-

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ternalism, so subjecting children to paternalism simply because they are children (and not because they have demonstrated a need for principled guidance from a rational agent in a particular circumstance) would be failing in our duty to help raise children into adults.

To illustrate this principle for acceptable paternalism toward children, suppose 11-year-old Sophia is at the pediatrician for her annual checkup. Sophia's doctor communicates to both Sophia and her parents that Sophia is due for her next tetanus injection. The doctor explains that Sophia needs the tetanus booster to ensure her protection against tetanus, which can be fatal without treatment or a prior vaccination. After the doctor's comments, Sophia's father adds that Sophia needs the booster in order to return to school in the fall. The doctor then says, "Ok, Sophia. If you are ready for your shot, you can head to the vaccination room across from this exam room." So far, the doctor and Sophia's parents have not engaged in any paternalistic behavior. They have invited Sophia to exhibit her rational agency by providing her potential reasons to get her vaccine and telling her that she can go to the vaccination room rather than coercing or forcing her into the room. The adults are allowing Sophia to use her reflective skills, act based on the reasons given to get the vaccine, and go to the next room.

However, suppose that Sophia does not want to go to the vaccination room after listening to what the doctor and her father have to say. She cries, "I will not get a shot! Shots hurt, and I hate them!" and hides under the exam table in the hope that she can avoid the vaccination room. Clearly, Sophia has demonstrated that she is not yet capable of using her rational agency when it comes to the domain of vaccination. She must rely on the rational will of a parent to guide her toward the best course of action: entering the vaccination room and getting the tetanus injection. Thus, Sophia's father carries Sophia from under the exam table into the vaccination room and holds her in his lap so she stays still for the vaccine. These actions are paternalistic, as they go against Sophia's judgments in order to guide her actions in accordance with what is "best" for her. Even so, the father's choice to do so and the doctor's lack of intervention are morally permissible since both individuals first allowed Sophia the opportunity to exercise her adult status in the domain of vaccination. The adults are acting paternalistically only because Sophia has clearly demonstrated that she *lacks* adult status in the domain of vaccination.

This understanding of paternalism and its limits seems to prohibit Dr. Paternalist from lying to Robbie about his prognosis. To appropriately use paternalism, it should be a last resort. A child should be given the opportunity to exercise rational agency and be treated paternalistically only if she has first failed to exercise rational agency in the relevant domain. Lying to Robbie and telling him that he can live is bypassing Robbie's potential to demonstrate his reasoning capabilities. Paternalism is not appropriate in this situation because the only way to tell a paternalistic lie of this sort would be to assume from the outset that Robbie is not capable of reason-guided action in the relevant domain of discretion (coming to terms with a terminal prognosis). Even though it could arguably be the case that Robbie lacks adult status with respect to this domain, it is logically impossible to both lie to Robbie about his prognosis and test Robbie's potential adult status in the domain of living with a terminal prognosis. Thus, paternalism is impermissible, and Dr. Paternalist does have a duty to her patient to tell him the truth even though he is a pediatric patient.

One might object to my conclusion and argue that paternalism toward a terminally ill child is distinct from paternalism toward any other child. The requirement that paternalism be preceded by an invitation for a child to exercise his rationality comes from our special duty to help children pull themselves together. However, the underlying assumption behind this special duty is that a child has the ability to pull himself together. A terminally ill child with only one month to live will never fully pull himself together. He will die before realizing his adult status and his full-fledged rational agency, so he is unlike other children in that he is part of a distinct and permanent underclass. The conditions for paternalism to be permissible therefore do not apply to him, and we can tell him paternalistic lies about his prognosis.

In response to this objection, I counter that we cannot treat a child as a mere means simply because that child is likely going to die without fully cultivating his rational will. Just as an adult has dignity by virtue of his rational will, a child has dignity by virtue of his partial rational will. A child who has an undeveloped will and lacks an authoritative "voice" is still a reflective agent capable of acting based on reasons in certain circumstances. Therefore, that child has dignity, a value that a mere object could never have. Moreover, a child is reflective and capable of *some* reason-guided action regardless of whether that child is perfectly healthy or terminally ill with a condition like Robbie's. The child has dignity regardless, and that dignity is incommensurable, so a healthy child is not more valuable than

a terminally ill child. We cannot consider terminally ill children an underclass of healthy children or any other rational agents because doing so disrespects their dignity. We can excuse paternalism toward children provided it is last-resort paternalism, the kind that avoids treating children as mere means to the highest extent possible, but we cannot excuse treating some children as objects and others as future rational agents. A child with a terminal illness still has a duty to pull himself together in his last month of life, and an awareness of his prognosis might even make him pull himself together faster than a non-terminally ill child would, all else being equal. Since he is still increasing his rational capabilities in this last month of life, he should be afforded the same dignity as any other human and be treated the same way any other child would. (We need not consider the case where a terminally ill child has lost his reflective capabilities completely, as I have structured the case around the assumption that Robbie has enough cognitive functioning intact to at least partially understand his prognosis. Otherwise, Dr. Paternalist and Robbie's parents would not fret over what to tell Robbie.)

Overall, I have attempted to show that physicians have a negative duty to terminally ill pediatric patients to not lie to those patients about their prognoses. Lying to a competent adult patient about his prognosis is a clear violation of the categorical imperative, as it treats that competent adult as a mere means. However, lying to a pediatric patient for paternalistic reasons is a more complicated action because childhood is a predicament that makes paternalism toward children sometimes permissible. We have a special duty to help children pull themselves together, i.e. cultivate their rational wills, so we must refrain from practicing paternalism and allow children to practice their rational decision-making whenever possible. Nevertheless, if we have allowed a child this opportunity and the child has demonstrated a need for the authoritative voice of an adult in that particular context, then an adult can exercise paternalism. By acting according to this principle and saving paternalism as a last resort, we avoid treating children as mere means. Even so, the case where a physician has the opportunity to lie to a pediatric patient about his terminal prognosis "for his own good" does not fall into the realm of morally acceptable paternalism. A white lie of this sort involves using paternalism without first allowing the child the opportunity to exercise his adult status. Terminally ill pediatric patients will never fully cultivate their rational wills, but we must still respect their dignity and treat them as having the same value as any other human. We cannot treat them as mere means, so we owe them the same duties we owe to any other child. The standards for permissible paternalism toward a child do not change simply because that child is terminally ill.

According to an estimate from 2015, the "the point prevalence of pediatric patients living with life-threatening conditions on any given day [in the United States is] about 45,000" (Feudtner et al. 2015, 546). Given this staggeringly high figure, a myriad of medical practitioners and parents ought to think critically about how to best respect these patients' dignity and acknowledge their developing autonomy. In my view, communicating truthfully with pediatric patients about their terminal prognoses–provided those patients are capable of understanding those prognoses to some extent–offers a palpable way to do so.

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[1] The page numbers here correspond to the pagination of the translation. However, the page numbers in my in-text citation corresponds to the Prussian Academy pagination.

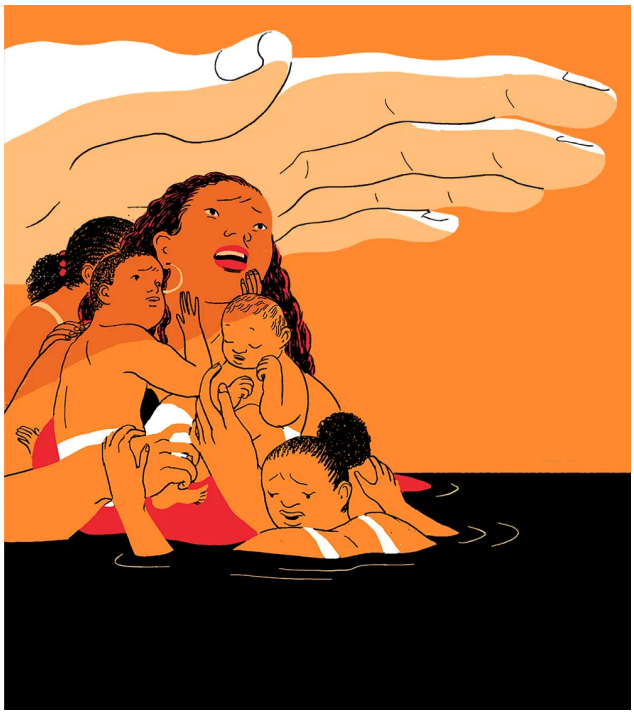
Article

Motherhood As A Vector For Sexism in Treatment Refusal Controversies

Samuel Streicher* and Dr. Marjorie Shaw

ABSTRACT

Although capacitated patients have the right to refuse treatment, courts may weigh this right against state interests. By comparing maternal and paternal refusals of treatment, we identify motherhood as a historical vector for sexism in medicolegal settings. Motherhood appears to impede judicial recognition of decisional authority, while fatherhood does not appear to impose this same limitation, even when mothers and fathers cite the same arguments for refusal. Although we dissect past American judicial decisions, we position the recent *Dobbs v. Jackson Women's Health Organization* controversy as an extension of our identified pattern. Based on our findings, if cisgender fathers were capable of pregnancy, we argue they would benefit from the greater social autonomy afforded to paternal roles, and abortion would be, accordingly, more accessible. We, therefore, emphasize the importance of labeling abortion as a gendered issue.



By Eleanor Davis on Mother Jones (2022), Public Domain

PART I: INTRODUCTION

Patients can legally refuse life-saving interventions when they possess capacity to make medical decisions (Quill et al. 1997, p. 2100; Kamisar 1996, pp. 129-30). However, courts often weigh this patient right against state interests (Coleman 2020, pp. 171-182; *Fosmire v. Nicoleau* 1989; *IAN SHINE, Administrator vs. JOSE VEGA & Another* 1999; Dangelantonio 1992, pp. 351-354; Leeman 1999, pp. 112-115; *Cruzan v. Director, Missouri Dep't of Health* 1990; *Vacco v. Quill* 1997; *Washington v. Glucksberg* 1997; *State of Ga. v. McAfee 1989; Bourke* 1990, p. 77), especially when treatment refusal imposes potential harms upon the health of the public or a third party (*Jacobson v. Massachusetts* 1905; *Commonwealth v. Pugh* 2012; In Re A.C 1990).

By comparing cases involving a mother's refusal of life-saving or life-sustaining treatment with cases involving a father's refusal of life-saving or life-sustaining treatment, we identified a troubling differential: a patient's role as a mother appears to impede judicial recognition of her decisional authority in treatment refusal controversies, whereas a patient's role as a father does not appear to impose this same limitation. In this way, motherhood appears to serve as a vector for sexism in medicolegal settings.

Although many of our studied legal disputes reflect past decisions, our findings position the recent *Dobbs v. Jackson Women's Health Organization* within a pre-existing pattern of gendered judicial decision-making - one that legislatively restricts women's autonomy. Indeed, based on the differential treatment towards mothers and fathers in our case analyses, we hypothesize that, if cisgender fathers were capable of pregnancy, they would benefit from the greater social autonomy afforded to their paternal roles, and abortion would be, accordingly, more accessible.

PART II: METHODS

The sexist patterns highlighted below were originally noted when researching the state interest in preserving life and its disparate applications among disabled and non-disabled patients (Streicher and Shaw 2023). When analyzing the role of ableism in refusal cases, it seemed female patients were also frequently challenged when they requested to refuse treatment, prompting an investigation to separately and specifically analyze the role of sexism in refusal controversies (Streicher and Shaw 2023). The first cases se-

*Samuel Streicher studied Bioethics at the University of Rochester. He can be reached at samuelloganstreicher@gmail.com.

lected were inspired by the controversies highlighted in the ableism-focused discussion by Streicher and Shaw. From this initial ableism-focused discussion, we collected over fifty-four controversies for preliminary analysis. We excluded from further review controversies that did not address treatment refusal but instead assessed other distinct legal principles. Cases that involved patients in persistent vegetative states (PVS) or that featured patients with unclear end-of-life wishes were also excluded from review, given that this piece aims to analyze the role of sexism in patients that actively and competently refuse treatment.

Though not exclusively, the comparisons below largely focus on religiously-motivated treatment refusals, and some readers might perceive these types of decisions to be niche or less than generalizable. However, tailoring our analysis to this form of treatment refusal provides for fair comparison among mothers and fathers, given that both cite similar justifications for their decision yet experience different judicial outcomes. Consequently, we more confidently argue that gender - particularly motherhood - serves as the primary mechanism for differential treatment, rather than changing judicial sympathy towards variable patient rationales.

We do not claim to capture all possible cases in the field, nor do we mean to suggest that the patterns described above hold in every instance. In fact, we intentionally sought to uncover cases that demonstrate bias. By purposefully collecting explicit and subtle examples of bias, we hope to underscore the value of a feminist lens in medical and legal analysis, even in cases that are not mentioned in this work.

PART III: MARY E. SCHLOENDORFF V. THE SOCIETY OF THE NEW YORK HOSPITAL & TREATMENT REFUSAL

The twentieth-century controversy of *Mary E. Schloendorff v. The Society of the New York Hospital* is frequently held as a prominent legal foundation for informed consent and the patient's right to refuse treatment (Lombardo 2005, p. 791). Despite its reputation, a deeper analysis of the case reveals that disrespect towards the decisional authority of women is sewn into the history of patient rights.

Mrs. Schloendorff arrived at the Society of the New York Hospital in January 1908 due to stomach concerns (*Schloendorff v. New York Hospital* 1914). After staying at the hospital for multiple weeks, house physician Dr. Bartlett diagnosed Mrs. Schloendorff with a fibroid tumor, and visiting surgeon Dr. Stimson suggested surgery. According to Mrs. Schloendorff, her physicians told her an ether examination was necessary to examine the "character" of the tumor (*Schloendorff v. New York Hospital* 1914). Although Mrs. Schloendorff consented to the ether examination, she claimed she informed Dr. Bartlett that she did not consent to surgery.

While Mrs. Schloendorff was under examination and unconscious, her tumor was surgically removed. Post-operation, Mrs. Schloendorff's left arm became gangrenous, requiring the amputation of numerous fingers. Mrs. Schloendorff brought the issue to court, arguing the hospital was liable for trespass and its subsequent medical consequences. The trial court ruled in favor of the hospital (*Schloendorff v. New York Hospital* 1914; "Law School Case Brief: Schloendorff v. Soc'y of N.Y. Hosp." 2022). Mrs. Schloendorff appealed the decision, to no avail (*Schloendorff v. New York Hospital* 1914). Notwithstanding that the plaintiff allegedly communicated her rejection of surgery to nurses and assistants, Justice Cardozo believed it was "clearly true" that the hospital provided its tools unaware of the harm they would corroborate (*Schloendorff v. New York Hospital* 1914). Relying on a masculine sense of valor, Justice Cardozo suggested that no rational individual would have thought such esteemed men of medicine could so blatantly disregard their patient's wishes. He proceeded by writing that the surgeons were lauded men, "men of tested merit" (*Schloendorff v. New York Hospital* 1914).

Post-operation, Mrs. Schloendorff claimed she was relocated to the basement so that others would not hear her suffering (Lombardo 2005, p. 796). Mrs. Schloendorff alleged that her doctor chuckled at her pain, calling her "imaginative" (796). According to Mrs. Schloendorff, Dr. Stimson would hit her in the abdomen and ask, "How are you, how do you feel old girl?" (796).

Exploring the transcript of the case rather than relying exclusively on Justice Cardozo's written opinion, scholar Dr. Lombardo provides further insight into Mrs. Schloendorff's suffering. Notably, the fibroid tumor in question was located in Mrs. Schloendorff's uterus, and the non-consensual surgery performed was a hysterectomy (Lombardo 2005, p. 795). As well, it was not the case that Mrs. Schloendorff merely accepted a fate of mistreatment. Mrs. Schloendorff reportedly attempted to leave prior to surgery, but her effort was thwarted by a doctor who had allegedly "pushed [her] back and put the mouthpiece to [her] mouth" (796).

Dr. George Schoeps, who had treated Mrs. Schloendorff between 1909 and 1911, served as a witness in the case, testifying that Mrs. Schloendorff had suffered an embolism post-operation, possibly leading to the gangrenous complications of her hand (796-797). Dr. Schoeps also noted that surgery was not the only treatment available for fibroid tumors and that tumor examinations did not require ether,

[1] The judgment's disregard for Ms. Schloendorff's refusal cannot merely be ascribed to the protocol of the era. Dr. Lombardo notes that, even at the time of Mrs. Schloendorff's operation, consent was generally necessary prior to treatment (Lombardo 2005, p. 798). Indeed, Justice Cardozo himself cited two precedents regarding the importance of patient consent, with one of these precedents, *Pratt v. Davis*, similarly involving a non-consensual hysterectomy (798).

despite Mrs. Schloendorff's experience (797).[1]

PART IV: COMPARING MOTHERS AND FATHERS IN TREATMENT REFUSALS

Part IVa: Mothers Refusing Treatment

As one of the focal points in this section, *Public Health Trust of Dade County v. Wons* demonstrates how sexism manifests itself in treatment refusal controversies. Firstly, the initial authorization of forced treatment was seemingly in itself sexist, at least when compared to the authority granted to fathers who refuse treatment, a subject discussed later in this manuscript. Secondly, sexism unexpectedly emerges in both the dissenting and concurring opinions of the Supreme Court of Florida when affirming the decision to overturn the original blood transfusion order.

In 1986 (*Wons v. Public Health Trust of Dade County* 1989), Mrs. Wons presented to Jackson Memorial Hospital, a medical facility operated by the Public Health Trust of Dade County, with dysfunctional uterine bleeding (*Public Health Trust of Dade County v. Wons* 1989). Physicians informed Mrs. Wons that her condition would likely be fatal absent a blood transfusion. As a Jehovah's Witness, Mrs. Wons refused blood transfusions, and Mrs. Wons was found to be "conscious and able to reach an informed decision" (*Public Health Trust of Dade County v. Wons* 1989).

Despite this finding, the Public Health Trust of Dade County sought court authorization to transfuse Mrs. Wons against her objections. At the hearing, the husband of Mrs. Wons supported his wife's decision and stated that he would care for their minor children alongside the aid of Mrs. Wons's mother and brothers if necessary. Nevertheless, the court authorized the administration of the blood transfusion and found that the right of the children to be raised by two parents overpowered Mrs. Wons's rights to privacy and religious practice. Consequently, Mrs. Wons received a blood transfusion while unconscious.

Mrs. Wons later appealed the decision, and the blood transfusion authorization was reversed, with the district court finding that Mrs. Wons's constitutional rights to privacy and religious practice should not have fallen secondary to the state's interests.

The majority opinion of the Supreme Court of Florida affirmed Mrs. Wons's right to refuse treatment. Although this affirmation may seem to empower Mrs. Wons's legal agency, certain concurring and dissenting opinions demonstrate bias. To understand the bias involved, it is necessary to dissect the precedents involved in the Supreme Court of Florida's majority decision.

The Supreme Court of Florida majority references *Satz v. Perlmutter* to introduce the four criteria involved in overpowering a patient's right to refuse treatment: preserving life, protecting third parties, preventing suicide, and maintaining medical professionalism and ethical integrity. The Public Health Trust of Dade County claimed that the right of Mrs. Wons's children to be raised by two parents invokes the state interest in protecting third parties. Although the Supreme Court of Florida majority was somewhat sympathetic to this perspective, it did not find this interest strong enough to "override fundamental constitutional rights" (*Public Health Trust of Dade County v. Wons* 1989). Indeed, the Supreme Court majority references the district court opinion, noting that the practice of religion is one of the deepest manifestations of privacy.

Although Judge Ehrlich offers a concurring opinion for the Supreme Court of Florida majority, his arguments veer into the realm of subtly offensive when he suggests that the protection of third parties stands as this controversy's central state interest, seemingly disregarding the prominence of the state interest in preserving Mrs. Wons's life for its own sake. In fact, Ehrlich notes that the "petitioner conceded below that the other interests enumerated in Perlmutter are not implicated in this case," implying that the Public Health Trust is less concerned with the preservation of Mrs. Wons's life and more so focused on her obligations as a mother (*Public Health Trust of Dade County v. Wons* 1989).

Further, Ehrlich alleviates the state interest in preventing child abandonment by noting the presence of a caring father and other supportive family members. In this way, a portion of Ehrlich's concurring opinion seems to rest less on balancing the mother's rights and more so on the fact that other figures can assume the mother's role.

Justice Overton demonstrates a more overtly biased attitude in his dissent against the Supreme Court of Florida majority, writing that the state interest in preserving life and preventing child abandonment should have justified the forced blood transfusions.

One of Overton's argumentative strategies is to critique the majority's reference to *St. Mary's Hosp. v. Ramsey* - a case in which a father was permitted to refuse life-saving blood transfusions. According to Overton, *St. Mary's Hosp. v. Ramsey* cannot corroborate Mrs. Wons's right to refusal because the precedent differs from Mrs. Wons's case; Overton explains that, in *St. Mary's Hosp. v. Ramsey*, the father was not heavily involved in the child's life, whereas Mrs. Wons is involved in her childrens' lives. With this logic, Overton seems to endorse the perspective that the state may not intervene when a less-than-invested parent - or at least a father - removes himself from a child's life, yet an invested mother ought to be legally barred from putting her life or maternal responsibilities at risk.

Instead of relying on *St. Mary's Hosp. v. Ramsey*, Overton suggests that the court ought to defer to Application of the President and Directors of Georgetown College, Inc., whereby the court authorized life-saving blood transfusions over the objection of a Jehovah's witness who was also a mother to a minor child (*Public Health Trust of Dade County v. Wons* 1989). Overton explains that this cited ex-

ample displays the state's justified efforts to prevent child abandonment and preserve the mother's "responsibility to the community to care for her infant" (*Application of the President and Directors of Georgetown College, Inc. 1964 qtd. in Public Health Trust of Dade County v. Wons* 1989).

Curiously and concerningly, however, Overton fails to consider two major flaws regarding his deference to *Application of the President and Directors of Georgetown College, Inc.* Firstly, *Application of the President and Directors of Georgetown College, Inc.* does not represent "an action by the Circuit Court of Appeals itself" and was instead an instance in which only one federal judge authorized the order (*Public Health Trust of Dade County v. Wons* 1989). Secondly, and perhaps more critically, *Application of the President and Directors of Georgetown College, Inc.* pertained to a mother who lacked competency at the time of treatment decision-making, markedly changing the medical context and legally permissible level of state intervention (*Public Health Trust of Dade County v. Wons* 1989; *Application of the President and Directors of Georgetown College, Inc.* 1964).

Despite the fact that unclear competency drastically changes the nature of the issue, Judge Overton is not the only authority to defer to the Georgetown College controversy, even when faced with competent patients.

In the 1985 controversy *Matter of Winthrop Univ. Hosp. v Hess*, Judge John Lockman also references the Georgetown College case to support the authorization of blood transfusions over the religious objections of a patient who was a mother to a young child.

In the case before Judge Lockman, Winthrop University Hospital sought a court order to authorize the administration of blood derivatives or transfusions for Ms. Susan Hess if the attending physician or surgeon deemed such interventions necessary to save her life. This request was made in advance of Ms. Hess's surgery. The surgeon refused to proceed with the kidney stone removal operation absent the authorization, even though transfusions are rarely needed for this procedure.

Though she would not allow for blood transfusions, Ms. Hess did not refuse surgery. Moreover, court proceedings acknowledged Ms. Hess's competency. A hearing was held, with Ms. Hess and her husband both in attendance. Ms. Hess was noted as the mother of "two young children, one being only one month old" (*Matter of Winthrop Univ. v. Hess* 1985).

Lockman, on behalf of the Nassau County Supreme Court, references *Mary E. Schloendorff v. The Society of the New York Hospital*, the foundational yet sexist case precedent supporting the right to refuse medical treatment. However, Lockman qualifies this right by noting that, in 1985, the state had not yet decided the specific question of whether compulsory medical interventions can be ordered to "save the life of the mother of infants" (*Matter of Winthrop Univ. v. Hess* 1985). Lockman, similar to Overton, relies on the language within *Application of the President and Directors of Georgetown College, Inc.*:

> The state, as *parens patriae*, will not allow a parent to abandon a child, and so it should not allow this most ultimate of voluntary abandonments. The patient had a responsibility to the community to care for her infant. Thus the people had an interest in preserving the life of this mother (*Application of the President and Directors of Georgetown College, Inc.* 1964).

Consequently, Lockman granted the hospital's application for the requested order. The logic employed in the quoted argument is significant: specifically *because* "the patient had a responsibility to the community to care for her infant," the community correspondingly had "an interest in preserving the life of this mother" (*Application of the President and Directors of Georgetown College, Inc.* 1964). This argument necessitates governmental authority over the bodies and lives of women when motherhood is implicated.

Moreover, it is especially difficult to understand a mother's religious refusal of treatment as "the most ultimate of voluntary abandonments" when courts seem to view a father's refusal of treatment in a different light, as discussed later in this work (*Application of the President and Directors of Georgetown College, Inc* 1964.).

Occurring shortly after *Matter of Winthrop Univ. Hosp. v Hess, Fosmire v. Nicoleau* stands as another incident featuring a mother's refusal of treatment and a curious response from the judicial system.

Jehovah's Witness Denise Nicoleau refused blood transfusions after undergoing a cesarean section. Mrs. Nicoleau's consent form - which had been completed one month before the operation - documented her specific refusal of blood transfusions. Post-operation, Mrs. Nicoleau suffered uterine blood loss and a notable drop in hemoglobin, prompting Brookhaven Memorial Hospital to request authorization from the Supreme Court in Suffolk county to administer transfusions against patient wishes. The physician filing the affidavit specified that a transfusion would likely be necessary to keep Mrs. Nicoleau alive (*Matter of Fosmire v. Nicoleau* 1990), and the court's subsequent ex parte order permitted the intervention. Neither Mrs. Nicoleau nor her family was informed of the order application until after it had been signed (*Fosmire v. Nicoleau* 1989).

Although the order was eventually vacated, Mrs. Nicoleau had already received two transfusions. Only after she appealed the ex parte order did the courts acknowledge that it was erroneous to authorize transfusion without providing Mrs. Nicoleau or her family the opportunity to be involved in the legal decision before its rendering. This error was exacerbated by the failure to inform Mrs. Nicoleau or her family that the order had been authorized, limiting Mrs.

Nicoleau's ability to challenge the decision prior to the administration of the transfusions (*Fosmire v. Nicoleau* 1989).

Particularly relevant to this discussion are the hospital's arguments in favor of the order. These arguments were heavily emphasized when the hospital proceeded to appeal the appellate division's judgment to vacate the ex parte order (*Matter of Fosmire v. Nicoleau* 1990). In their follow-up appeal, the hospital claimed that the right to refuse life-saving treatment should be restricted to patients with "terminal or degenerative disease[s]" (*Matter of Fosmire v. Nicoleau* 1990). The hospital also argued that the state interest in preserving the life of an individual is heightened when the patient is a parent to a minor child; the hospital explained that it is always preferable for a child to be reared by two parents. The hospital further suggested that Mrs. Nicoleau's refusal would constitute intentional abandonment of her child, problematically referencing the Georgetown College controversy yet again (*Application of the President and Directors of Georgetown College, Inc.* 1964; *Matter of Fosmire v. Nicoleau* 1990).

Properly, the court of appeals found that such a perception of abandonment stretched the term to an unjustified scope (*Matter of Fosmire v. Nicoleau* 1990). The court noted that the state does not interfere with every matter that may affect the family, nor does the state forbid parents from engaging in precarious activities simply to ensure that they will not leave their children parentless. Yet, unsurprisingly, even within Judge Simons's concurring opinion that supported the majority's decision to vacate the authorization of the transfusions, the interest in preserving the life of a parent for the sake of children was emphasized (*Matter of Fosmire v. Nicoleau* 1990). Although this interest seems rational, it is differentially applied to fathers, as explored below.

Part IVb: Fathers Refusing Treatment

Unlike maternal treatment refusal, when a father refuses treatment on religious grounds, his decision is more likely to be respected, at least in the examples below. Consider the case of *St. Mary's Hospital v. Ramsey.* In this case, the Florida District Court of Appeals affirmed a circuit judge's decision to authorize a father's refusal of a potentially life-saving blood transfusion (*St. Mary's Hosp. v. Ramsey* 1985; *Herr et al.* 1992). Judge Letts acknowledged that the kidney disease patient at hand, age twenty-seven, was alert and competent, and in need of regular renal dialysis (*St. Mary's Hosp. v. Ramsey* 1985). Moreover, Letts noted that the patient, Mr. Ramsey, was not expected to die in the near future if he were to accept the transfusion. Mr. Ramsey, however, refused blood transfusions due to his religious beliefs as a Jehovah's Witness.

Mr. Ramsey was the father to a minor daughter, though this child lived in Michigan with her mother. Mr. Ramsey was required to pay fifty dollars weekly to support this child.

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Curiously, Mr. Ramsey's status as a father was not cited in the hospital's reasoning for appealing the trial court's decision, a decision that allowed Mr. Ramsey to refuse treatment. Instead, the appellate court noted that the hospital cited the following concerns in its appeal: firstly, the case raised potential criminal issues for the state; secondly, the case imposed potential legal consequences for the physician and hospital caring for Mr. Ramsey if they were to accept his refusal; thirdly, the physician and hospital caring for Mr. Ramsey were concerned for his well being.

The appellate court noted that, during trial court proceedings, "the state and petitioners [did] not [demonstrate] sufficient compelling interests to outweigh Mr. Ramsey's constitutional entitlement to privacy and to make this decision without governmental interference" (*St. Mary's Hosp. v. Ramsey* 1985). It is also relevant that, according to the appellate court, the trial judge not only found Mr. Ramsey to be competent, but also "intelligent, rational and lucid" (*St. Mary's Hosp. v. Ramsey* 1985). In this way, Mr. Ramsey's decisional authority was bolstered by the judicial system, yet no mother was characterized in this almost empowering manner in the previously described controversies.

The notable gender-based difference in judicial response continues when Judge Letts references *Satz v. Perlmutter* to identify four interests that can be weight against the patient right to refuse treatment: preservation of life, third-party protection, prevention of suicide, and medical ethics. With respect to the state interest in preserving life, Letts noted that the interest is not absolute. Letts also strengthened the legitimacy of Mr. Ramsey's refusal of treatment by acknowledging the risks of blood transfusion and the desire to avoid "impure blood," adding to the court's characterization of Mr. Ramsey as "intelligent, rational and lucid" (*St. Mary's Hosp. v. Ramsey* 1985). In fact, Letts considered Mr. Ramsey's refusal "even more compelling" because it was motivated by religious faith (*St. Mary's Hosp. v. Ramsey* 1985).

While Letts did acknowledge that the protection of

third-party children is the most pressing interest in the present controversy, Letts nevertheless argued that "it is difficult to categorize the refusal of treatment here as an abandonment" (*St. Mary's Hosp. v. Ramsey* 1985), relying on three arguments: firstly, the child predominantly resided with her mother in a different state and the father did not often see the child; secondly, there was reason to believe in this instance that other supportive family members would assist in child-rearing; thirdly, Mr. Ramsey had named his child as the beneficiary of an annuity. Notice that these arguments, particularly the first and the third argument, can be analyzed to reveal the prominence of traditional gender expectations, with the mother as the caregiver and the father as the financial provider. Under this framework, the father may be permitted to refuse life-saving treatment so long as there remains a maternal presence as well as a source of income to support the child.

Although Judge Anstead concurred in conclusion only, both Judge Anstead and Judge Dell concurred with Judge Letts, rendering the conclusion unanimous.

A similar decision was rendered for a father refusing life-saving blood transfusions in *In Re Osborne*, where the trial court and court of appeals affirmed Mr. Osborne's ability to exercise his right of treatment refusal. At age 34, a tree fell on Mr. Charles Osborne, and he presented to the hospital with related injuries and internal bleeding. In response to the need for blood transfusions, Mr. Osborne, as well as his wife, refused the intervention, citing their religious faith as Jehovah's Witnesses.

In response to capacity questions, hospital counsel informed the trial judge - Judge Bacon - that Mr. Osborne was conscious and comprehended his medical situation as well as the likely consequences resulting from his refusal. In response to Mr. Osborne's status as a father to "two young children," Judge Bacon did not require state intervention given "the maturity of this lucid patient, his long-standing beliefs and those of his family" (*In Re Osborne* 1972). Additionally, the proceedings soothe the state interest in protecting third parties by again appealing to traditional gender roles, with maternal care and paternal financial support. As noted in the legal proceedings, when Mr. Osborne's wife was asked about the future family dynamic, she answered, "my husband has a business and it will be turned over to me (*In Re Osborne* 1972). And his brothers work for him, so it will be carried on," explaining further that "if anything ever happens, I have a big enough family and the family is prepared to care for the children" (*In Re Osborne* 1972).

It is also important to note that a bedside hearing was conducted to prevent the use of hearsay statements, allowing Mr. Osborne to directly voice his concerns. Recall that this opportunity was absent in *Fosmire v. Nicoleau*; there, the majority noted the erroneous authorization of blood transfusions for Mrs. Nicoleau without first providing her or her family the opportunity to partake in the court decision-making process (*Fosmire v. Nicoleau* 1989). However, Mr. Osborne, a father, indeed had the ability to state expressly that he "wish[ed] to live, but with no blood transfusions," directing the court to "get that straight" (*In Re Osborne* 1972).

Associate Judge Yeagley concurred with the decision of the court of appeals, which affirmed Judge Bacon's findings. Yeagley added that Mr. Ramsey's right to refuse treatment was not merely based in religious freedom but also in "the broader based freedom of choice whether founded on religious beliefs or otherwise" (*In Re Osborne* 1972). As noted in future sections, the glorification of the freedom to choose will be questioned when those who wish to exercise it are women, particularly women seeking an abortion.

Part IVc: Motherhood & Young Children

The cases we analyze do not encompass all disputes in this area of medical law. For instance, we recognize *Matter of Melideo* and *In re Requena* as examples of proceedings whereby a woman's refusal of treatment was respected without the need for appellate trial intervention. However, in these selected cases - cases which are relatively similar to the controversies discussed above - the women involved are not mothers or are not mothers to young children. In other words, it is possible that societal expectations of mothers shift with time, weakening motherhood as a vector for sexism as children age. In fact, *Public Health Trust of Dade County v. Wons* explicitly noted that courts may regard the death of a parent as less "grave" when the affected children have met the age of majority (*Public Health Trust of Dade County v. Wons* 1989).[2]

Concerning the 1976 case of *Matter of Melideo,* at the age of twenty-three, Kathleen Melideo, who was neither a mother nor pregnant, suffered a uterine hemorrhage following dilatation and curettage. As a Jehovah's Witness, Melideo refused blood transfusions. The hospital attorney acknowledged Melideo's competence, yet Brunswick Hospital Center still sought a court order to authorize the intervention.

Judge Leon Lazer relies on *Application of President Directors of Georgetown College, Inc.* to argue that "the State's interest, as *parens patriae*, in the welfare of children may justify compulsory medical care where necessary to save the life of the mother of young children" (quote from *Matter of Melideo* 1976 when discussing *Application of President Directors of Georgetown College* 1964). Because Kathleen Melideo was "not pregnant, and [had] no children," her deci-

[2] *Matter of Erickson v. Dilgard* also demonstrates judicial recognition of transfusion refusal authority among fathers to adult children. However, an assessment of fathers to adult children is less relevant because, as we noted above, even fathers to *young* children - where the interest in preserving a paternal role would appear to be higher - are allowed to exercise refusal rights. It seems that societal expectations of fathers are consistently less stringent. It seems that only societal expectations of *mothers* are subject to change in weight according to the age of affected children.

sion to refuse treatment was respected (*Matter of Melideo* 1976).

In re Requena raises similar issues. From April 1985 until the time of the case, September 1986, Beverly Requena received care at St. Clare's/Riverside Medical Center related to amyotrophic lateral sclerosis (ALS). Mrs. Requena was married and was a mother to adult children. Mrs. Requena was also a grandparent. At the time of the proceeding, Mrs. Requena was noted as competent. Mrs. Requena informed the Medical Center that she would refuse artificial nutrition when she lost the ability to swallow.

Although the Medical Center acknowledged Mrs. Requena's right to refuse artificial nutrition, the Medical Center held an institutional policy that prohibited its involvement in the withholding of nutrition and hydration. The Medical Center offered to aid in Mrs. Requena's transfer to an alternative facility, including St. Barnabas Hospital, which would have allegedly accepted Mrs. Requena as a patient as well as her refusal. The Medical Center brought the case to the court, however, when Mrs. Requena refused to leave.

The case proceedings noted that Mrs. Requena trusted the providers at St. Clare's/Riverside Medical Center and developed a comforting sense of familiarity there - a transfer of care would have been emotionally challenging for her. Judge Stanton held that Mrs. Requena could not be removed from the Medical Center absent consent. Stanton argued as well that Mrs. Requena's choice to refuse artificial nutrition must be respected.

Although such a decision may appear to have empowered a woman's right to exercise her decisional authority, the written opinion raises multiple concerns. Firstly, Judge Stanton utilizes overtly ableist language, characterizing Mrs. Requena's body as "useless" and that, with her condition, "she has nothing much to look forward to in this life" (*In Re Requena* 1986).

Exacerbating the above concerns, Judge Stanton frequently referred to a potential "'pro-life' versus 'anti-life' issue" (*In Re Requena* 1986). Judge Stanton noted that Mrs. Requena's choice to refuse life-saving treatment "is not anti-life" (*In Re Requena* 1986). Judge Stanton then explicitly referred to the issue of abortion, calling it "a terrible evil" (*In Re Requena* 1986). Further injecting personal values into his decision, Judge Stanton suggested that, as the Medical Center staff care for Mrs. Requena, they ought to remember "the beautiful words of Jesus: 'Come to me, all you who are weary and find life burdensome, and I will refresh you' (Matthew 11:28)" (*In Re Requena* 1986).

We acknowledge that the cases presented above may be less than modern. However, these historical patterns of bias towards women, specifically mothers, uniquely illustrate the gendered context underlying the *Dobbs v. Jackson Women's Health Organization* decision.

Part V: Relevant Clarifications & Acknowledgements

Prior to exploring the *Dobbs* controversy, we wish to provide certain clarifications. Firstly, the discussion above highlights the historical tendency of courts to strive to protect maternal life by limiting the decisional authority of mothers. However, we also recognize that, in other instances, sexism may intersect with additional biases to skew proceedings in potentially different ways. For example, as noted in a separate work, ableist reductions of a disabled patient's life value may result in quick judicial *authorization* of one's refusal of life-saving treatment (Streicher and Shaw 2023). For instance, *In re Farrell* concerns the request of an amyotrophic lateral sclerosis patient, who is also a mother to minor children, to withdraw her life-sustaining respirator. In this controversy, the mother was allowed to exercise her refusal rights, potentially due to an ableism-motivated sympathy that soothed what would have otherwise been a more stringent expectation of motherhood. In its decision, the court highlights the way in which disability strips a mother's societal value, writing:

> While the State does have an interest in preserving life, here the quality of the life in question is so poor, so minimal and wracked with pain, that it would be unfair and unjust to force its continuance against the person's wish. Mrs. Farrell's mind, soul and spirit are really imprisoned in a dead body, and to force her to continue to live in this fashion would constitute cruel and unreasonable punishment. Mrs. Farrell's husband and sons are willing to respect her wish and do not oppose her application to terminate the respirator. Because of her total immobility, she is unable to contribute anything to enrich their lives, and the rights of third parties are thus not really involved (*In Re Farrell* 1986).

Secondly, disregarding a mother's decisional capability is not isolated to circumstances in which mothers refuse treatment for themselves; even in cases where mothers serve as surrogates for their children, medical professionals have in the past leapfrogged over legitimate female authority, as seen in *John F. Kennedy Memorial Hospital v. Heston*. At age 22, Delores Heston required an operation alongside blood transfusions due to a ruptured spleen that resulted from an automobile accident . However, Ms. Heston identified as a Jehovah's Witness. Uncomfortable with Ms. Heston's transfusion refusal and her mother's support, healthcare providers described Ms. Heston as "incoherent," disregarded both her mother's advocacy and signature on "a release of liability for the hospital and medical personnel," and commenced guardianship proceedings (*John F. Kennedy Memorial Hospital v. Heston* 1971). A guardian assigned by the Superior court provided consent for the transfusions, and surgeons in the hospital performed the

surgery, administering blood transfusions over the objections of the patient and her mother.

Thirdly, we acknowledge that the comparisons assessed above largely exclude the specific experiences of marginalized women. This exclusion is not intentional but is an artifact of the limited number of cases in this field. Future research should dissect compounded biases relating to sexism, motherhood, racism, transphobia, and discrimination toward Indigenous peoples. Indeed, it has been noted that the social burdens of the *Dobbs* decision, discussed in the forthcoming section, are expected to fall most heavily on marginalized women and those of low socioeconomic status ("The Disproportionate Harm of Abortion Bans" 2021).

Lastly, we argue that motherhood acts as an *additional* - but not an exclusive - vector for sexism within medical law. For instance, the struggles faced by Mary Schloendorff - although indeed a mother to an adult son, Mr. Evan Gamble (Lombardo 2005, p. 796) - seem to reflect a sociohistorical disregard for female authority rather than bias specifically precipitated by motherhood. *IAN SHINE, administrator vs. JOSE VEGA & another* serves as a more recent example of the same idea: the mistreatment of Ms. Catherine Shine - a female patient subject to forced intubation, a trauma that would fatally deter her from seeking care in future emergencies - illustrates that even childless women suffer the consequences of potential sexism when seeking to exercise treatment refusal rights.[3]

Ultimately, sexism can hinder a woman's right to refuse treatment, even when motherhood is not at stake. Recognizing this reality, in our previous sections, we argue that motherhood acts as an *additional* mechanism by which sexism bleeds into judicial proceedings. It is this additional mechanism that provides helpful insight into the *Dobbs v. Jackson Women's Health Organization* decision.

Part VI: Dobbs v. Jackson Women's Health Organization & Abortion

We suggest that *Dobbs* ought to be viewed as an extension of a historical tendency to disrespect the authority of women, specifically mothers, in medical settings. The cases in Section IV illustrate that the right to refuse treatment is questioned when the authoritative patient is a mother, and this hesitancy seemingly stems from societal values and expectations related to motherhood. We view abortion in a similar light. When fathers refuse treatment, their choices are recognized as legitimate, and we argue that similarly greater authority would be afforded to those assigned male at birth seeking an abortion if they had the capacity for pregnancy.

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When *Dobbs v. Jackson Women's Health Organization* first percolated through the judicial system, lower courts recognized legal precedent protecting the right to pre-viability abortion (Oyez, LII Supreme Court Resources 2023).

The *Dobbs* controversy began with the 2018 Mississippi law known as the "Gestational Age Act," banning abortions after 15 weeks of gestation, with limited exceptions (Oyez, LII Supreme Court Resources 2023). Jackson Women's Health organization, as well as an affiliated physician, filed suit against the law, seeking an emergency temporary restraining order (TRO) to prevent its enactment. Aligning with the previously authoritative legal precedent - precedent specifying that states were not authorized to

[3] It should be noted that *IAN SHINE, administrator vs. JOSE VEGA & another* is also discussed in a related ableism discussion by Streicher and Shaw (2023). A lifelong asthmatic, Catherine Shine sought care at Massachusetts General Hospital (MGH) for a serious asthma attack in 1990 but only consented to oxygen administration (*IAN SHINE, Administrator vs. JOSE VEGA & Another* 1999). Despite Catherine's specifications and the related promise made to her sister Anna, MGH administered medication alongside oxygen therapy via nebulizer. To strengthen the confidence of MGH providers in Catherine's medical decision-making ability, Anna contacted their father, who was himself a physician. Well-versed in his daughter's asthmatic condition, Dr. Shine pressed an MGH physician to accept Catherine's wishes and to gain her consent prior to any intervention. Shortly thereafter, when Catherine had improved slightly in her condition, she and her sister sought to leave MGH through an emergency exit. Dr. Vega, an emergency physician, ordered that Catherine be restrained, forcibly intubated, and separated from her sister. Dr. Vega testified that he purposely did not inform Catherine of her father's opposition to intubation, that he did not inform Catherine of intubation benefits and risks, that he did not seek the consent of Dr. Shine or Catherine's sister, and that he did not read Catherine's updated and available blood gas test results - which had shown improvement in Catherine's condition - prior to intubation. Catherine was allegedly traumatized by this incident and "repeatedly 'swore' she would never go to a hospital again" (*IAN SHINE, Administrator vs. JOSE VEGA & Another* 1999). When Catherine experienced another serious asthma attack in 1992, she refused to seek hospital care and died. Even when Dr. Ian Shine brought a wrongful death case against Dr. Vega and MGH, Dr. Vega held that Catherine's consent was not necessary for intubation. Similar to the Schloendorff controversy almost eighty years prior, Dr. Vega characterized Catherine as "combative" (*IAN SHINE, Administrator vs. JOSE VEGA & Another* 1999), argued that Catherine was too confused to provide assent, and suggested that Catherine did not appreciate the degree of her condition. Dr. Shine's parties, however, provided strong evidence of Catherine's ability to provide consent and noted that family members were available for consultation even if it were true that Catherine had lost this ability to provide consent. Experts supporting Dr. Shine also testified that intubation constituted inappropriate treatment for Catherine.

prohibit abortions prior to viability - the TRO was enforced by the district court. The district court also granted summary judgment for Jackson Women's Health Organization and enjoined the enforcement of the Gestational Age Act, arguing that Mississippi had not shown fetal viability at 15 weeks. This decision was affirmed by the US Court of Appeals for the Fifth Circuit.

In stark contrast to the findings of these lower courts, the Supreme Court delivered a contested 4 to 3 decision overruling landmark precedents *Roe v. Wade and Planned Parenthood of Southeastern Pa. v. Casey*, finding that the Constitution does not guarantee a right to abortion. The majority opinion argued that the right to abortion is not a critical element of "ordered liberty" (*Dobbs v. Jackson Women's Health Organization* 2022), and the right is not firmly entrenched in national US history (Oyez, LII Supreme Court Resources 2023).

We do not intend to dissect the troublesome arguments used to support the outcome of the *Dobbs* controversy. Numerous scholars have already critiqued the rationales and consequences of the Supreme Court decision, noting, for instance, the majority opinion's curious interpretation of the Constitution (Nichols 2022; Cruickshank 2022) and their peculiar disregard for abortion's place in American medical history ("Abortion in U.S. History" 2023; Bernick 2022, pp. 227-257). Notwithstanding the value of these academic analyses, we instead seek to contribute to the literature by offering a new lens with which to study the *Dobbs* decision. Specifically, we suggest that the *Dobbs* case is an extension of a historical pattern of disrespect towards the decisional authority of mothers - a pattern highlighted by the above comparison of mothers and fathers refusing treatment. We, therefore, emphasize the importance of recognizing abortion as, most prominently, a women's issue.

To label something explicitly as *a women's issue* does not erase the involvement of other ethical questions - including the moral value of the life of a fetus. Instead, the title recognizes historical gender injustices: women have endured medical sexism, heightened paternalism, and erasure of rights in a way that men have not experienced. Our comparison of treatment refusal among mothers and fathers illustrates the medicolegal tendency to afford varying levels of decision-making authority based on gender. Reflecting upon this analysis of sociohistorical gender dynamics in medicine, we suspect that if the experience of pregnancy fell upon those assigned male at birth, a higher level of legal authority would be granted to those seeking an abortion. This is not to say that fathers are completely unaffected by abortion-related decisions. Instead, we argue that if abortion were to be squarely considered a *father's or men's issue*, or at least a genderless issue, the legal landscape of abortion would differ drastically from our current reality. Because abortion laws appear to be subject to gender-variable recognitions of autonomy, abortion ought to be emphasized explicitly as a gendered issue - namely, a women's issue.

We recognize that refusal of treatment is not precisely analogous to abortion, with the primary difference being that, in the above examples, the decision to refuse life-saving treatment directly affected only one individual - the female patient. In contrast, a decision to forgo continued pregnancy or seek an abortion affects the life of another potential being, the fetus. In this sense, some readers rightfully argue that an abortion holds a closer similarity to a mother's refusal of treatment during pregnancy when this refusal endangers the health of the fetus. While these circumstances are indeed more clearly analogous, there are a few points to consider.

The analysis of treatment refusal as a non-pregnant adult is relevant in that any individual can make this choice, regardless of gender. However, those assigned male at birth do not have the capacity for child-bearing, and in this sense, it would not have been possible to compare the experiences of mothers and fathers refusing treatment during pregnancy. Importantly, it is this comparison of genders that is most revealing in illustrating differential recognition of authority. Moreover, it is especially helpful that the cases explored above - regardless of gender - invoke the same religious rationales, removing a confounding variable and underscoring gender as the primary motivation for differential treatment.

Even within the context of fetus-endangering refusal of treatment during pregnancy, there exists a strong - though not uncontroversial (*Raleigh Fitkin-Paul Morgan Mem. Hosp. v. Anderson* 1964; *In Re A.C* 1990; *Matter of Jamaica Hosp* 1985; *Crouse-Irving Hosp. v. Paddock* 1985) - historical precedent supporting the mother's ability to exercise autonomy (*In Re Brown* 1997; *In Re A.C* 1990), especially prior to fetal viability. The majority opinion of *In re A.C.*, for instance, noted that "courts do not compel one person to permit a significant intrusion upon his or her bodily integrity for the benefit of another person's health" (*In Re A.C* 1990). The American College of Obstetricians and Gynecologists adds that ethical dilemmas involving maternal and fetal risks are especially complex, given that fetal interventions "must be undertaken *through* the pregnant woman's body" (American College of Obstetricians and Gynecologists' Committee 2016, emphasis added). In this way, the potential for coercion and bodily intrusion is significant. When pregnant women are forced to undergo unwanted treatment, this coercion is frequently exerted upon women of color and those of low socioeconomic status (American College of Obstetricians and Gynecologists' Committee 2016; Kolder et al. 1987, p. 1192; Paltrow and Flavin 2013, pp. 300-301). These considerations again underscore that social power dynamics underlie this sensitive area of medical law.

If our intention in naming abortion as a women's issue is to highlight the vulnerable parties affected, many readers will argue that we should instead refer to abortion as an *issue of unborn human life*. In response to this idea,

some individuals will note that the lack of social support for children after birth suggests a more pronounced focus on *child delivery* rather than the life of unborn or newly-born human beings (Casper 2023), redirecting the issue again to the values imposed upon those capable of giving birth. We add to this latter perspective. We recognize that abortion indeed involves legitimate questions surrounding the moral value of a fetus. However, because medical decision-making authority is heavily contingent upon the gender of the patient, the issue of abortion should be correspondingly underscored as gendered. If we are correct in suggesting that men would be afforded greater respect in their pursuit of abortions, relative to women seeking the same care, abortion becomes less so about the life of a fetus and more so about the gendered social position of the decision-maker.

Although we emphasize the importance of labeling abortion as a women's issue, we recognize that not all individuals capable of pregnancy identify as women. Our use of the term "women" is not intended to exclude non-cisgender individuals. Instead, the term "women" is utilized to consistently reflect the language and gender dynamics present within the above comparison of mothers and fathers refusing treatment.

Part VII: Conclusion

Tracing history with a feminist lens, from Mary Schloendorff, through a comparison of mothers and fathers refusing treatment as a result of their belonging to the Jehovah's Witness faith, we suggest a specific historical pattern of disrespect towards the decisional authority of mothers.

It appears that *Dobbs* is an extension of this tendency, with constraints on maternal autonomy seemingly motivated by societal expectations thrust upon women and the role of motherhood. If fathers were comparatively freer to exercise their religiously-motivated treatment refusal rights, we suggest that, if those assigned male at birth had the capacity for pregnancy, they would similarly enjoy greater judicial recognition of authority in the context of abortion. In other words, if a cisgender father were in a position to obtain an abortion, we argue he would benefit from the greater social autonomy afforded to paternal roles. In this sense, we emphasize the importance of recognizing abortion as a women's issue.

The title of *women's issue* is not powerless. In order to detangle controversial legal dilemmas, it is important to identify biases that bleed into our judicial system. By recognizing abortion as a gendered issue, legal authorities may be more inclined to question their own gender biases and render more equitable, just decisions.

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Bioethics-in-Brief

Twentyeight Health: The Transformative Impact of Reproductive Telemedicine

Caitlyn Chen & Charlotte Devlin

By Twentyeight Health, Public Domain

The Fund For Health is a collaboration between Penn Medicine and the Environmental, Social, and Governance (ESG) Initiative of the Wharton School, aiming to invest in early-stage companies to improve healthcare accessibility in Philadelphia. This year, the Fund for Health began its partnership with Twentyeight Health, an online telemedicine platform advocating for disadvantaged women's access to reproductive care (Otto 2023).

Since its founding in 2021, the Fund for Health has invested nearly $1.7 million in seven different early-stage companies (Boltman 2023). The Fund for Health most recently invested in Twentyeight Health, following successful previous investments in six different healthcare companies ("Penn Medicine and Wharton" 2023). Twentyeight Health was launched in 2018 by Amy Fan, who was featured in the 2021 Forbes Next 1000, and Bruno Van Tuykom, who serves as the current CEO of the company (Shacknai 2022). The company aims to provide women with affordable contraceptive options, such as birth control pills, morning after pills, STI treatment, and even prenatal vitamins (Epker 2023). Twentyeight Health provides women seeking contraception virtual telemedicine visits with U.S. physicians, who can prescribe medications, which are then shipped to the patient.

Both the accessibility and women's right to contraceptives has been a highly discussed topic, especially following the Supreme Court's overturning of *Roe v. Wade* in 2022 (Totenberg and McCammon 2022). Following this controversial decision, many are left wondering if women's right to contraception, as provided by *Griswold v. Connecticut*, is next to be overturned. Following the Court's decision on *Roe*, many abortion clinics have shut down, especially in states with strict regulations on abortion. As of 2023, 13 abortion clinics have permanently closed in Texas, with 9 remaining to provide alternate services. Additionally, Tennessee and Louisiana experienced closures of 3 abortion clinics (McCann and Schoenfeld-Walker 2023). With the rise of abortion clinic shutdowns, inaccessibility to many other forms of contraception arises.

Yet, Twentyeight Health is breaking barriers in the field of contraception, providing birth control and other reproductive health treatment at mere fractions of the cost of traditional clinics. Rajith Sebastian, the co-founder of the Fund for Health, said in a press release following the major investment: "The student investment team in the Fund for Health recognized Twentyeight Health's innovations and how they position the company to address challenges in women's health, especially for underserved communities here in Philadelphia. It's the right fit for what we're hoping to do with our investments" (Otto 2023). Twentyeight Health supports the accessibility of reproductive care by donating 2% of their revenues to the National Institute for

Reproductive Health and Bedside. The mission of Twentyeight Health evidently aligns with the core purpose of the Fund for Health, to provide innovative healthcare for both women in Philadelphia as well as women all across the United States.

As online telemedicine gains prominence in mainstream use, concerns arise about the security of sensitive personal health information collected by these platforms. According to Twentyeight Health's privacy policy, patient information may be de-identified and accessible to advertisers and affiliated businesses. Complete anonymity is difficult to achieve, as aggregated data and use patterns may still contain sensitive information that can be combined with other publicly available records for re-identification. Geographic details, for instance, can be used to narrow in on particular groups. Further, unique data points threaten to identify specific individuals. Reproductive healthcare is often stigmatized, and individuals may face social ostracization if their health status is revealed and may make the individual less likely to seek out help in the future (Glicksman 2022). Vulnerabilities in health databases may also be a target for malicious activity, such as medical identity theft, which may have a profound impact on health systems and result in more restrictive access to contraception and related health services, contradicting the mission of virtual health companies (Ollove 2014). Targeted advertising could also potentially be exploited for commercial gain, compromising quality of care and breaching patient trust. It is critical that Twentyeight Health and other virtual health platforms be routinely and carefully assessed for compliance with the privacy standards of the Health Insurance Portability and Accountability Act (HIPAA). Toward users, transparency of the data collection and use processes is necessary to ensure that patients are aware and in control

of their personal health information.

Access to affordable contraception is essential to maintaining reproductive autonomy for women in the United States. The missions of the Affordable Care Act of 2010 and Title X are centered in providing accessible reproductive care for low-income citizens (Bailey 2023). Despite these mandates, health insurance companies frequently do not cover contraception, limiting women's ability to obtain treatment, and effectively disrupting reproductive autonomy. Thus, costly forms of contraception bring about several bioethical implications. While a woman may reserve the right to contraceptives, their inaccessibility essentially violates a women's reproductive autonomy. Companies such as Twentyeight Health break financial burdens by providing low-cost, virtual reproductive care, moving towards comprehensive reproductive autonomy in the U.S.

However, online telemedicine requires an even more stringent definition of informed consent than in conventional healthcare. Virtual health visits limit thorough assessments of patients' health status: the absence of physical examination may compromise the accuracy of diagnoses and adequacy of prescriptions. It is increasingly critical that healthcare providers present information to patients in a clear manner, especially given limited access to health education in underserved communities. The personal trust between the provider and the patient remains a critical part of all interactions in healthcare, particularly in telemedicine. In a survey by Kennedy *et al.*, trust is a significant qualitative theme in bidirectional understanding of beliefs and values between providers and patients, which in turn may improve clinical outcomes due to stronger adherence to treatment plans (Kennedy 2017). However, telemedicine prevents the exchange of nonverbal cues and produces a disconnect due to technological issues, thereby hindering the development of empathic relationships. This is further exacerbated in the intimate contexts of reproductive care. In a survey by Rao *et al.*, healthcare providers reported challenges in discussing sensitive topics critical to providing personalized quality care, such as sexually transmitted infections and sexual assault (Rao 2022). It is therefore crucial that telemedicine platforms provide a comfortable environment for patients to openly share their concerns and preferences with licensed professionals.

The integration of technology into reproductive care holds immense potential to enhance accessibility and quality of health services, particularly for underserved communities. However, the ethical considerations surrounding this technological advancement must be a priority in ensuring the autonomy and informed consent of individuals seeking reproductive care. Many challenges lie ahead in navigating this ethical landscape, and a collaborative effort among providers, legislators, and the broader community is necessary to fully realize the transformative power of virtual reproductive care.

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Bioethics-in-Brief

The Impact of Private Equity on the Future of Healthcare Practices

Akhila Guttikonda & Pragat Patel

The future of independent private medical practices is not as promising as it once was. To remain operational, smaller healthcare facilities are faced with the decision to either join larger health systems or seek new funding sources through partnerships with private equity.

The distinction between private equity buyouts and those of hospital systems lies in who is investing and the use of cash versus debt. Not all private equity investors are necessarily knowledgeable in healthcare, as they may simply view it as a new market opportunity for profit. Typically, when private equity takes control of a healthcare practice, the firms secure loans in the pursuit of profit, using the facilities and the physical practice as collateral. Furthermore, since private equity is inherently designed to generate revenue through management and performance fees, increased financial pressure can become a burden on the hospital, potentially leading to a focus on profit over patient care. This solution has its own pros and cons, as it becomes challenging to balance quality of care, cost, access to care, and innovation.

Over the past decade, private equity firms have invested billions of dollars in various types of medical practices. This new form of funding has given smaller entities more market power, improved access to technology, and fostered innovation in the biomedical space. Physicians who have chosen this path have reported that partnering with private equity has helped alleviate administrative burdens while simultaneously accelerating growth for individual practices.[1] These practitioners believe they can still prioritize building relationships with their patients and providing quality care.

By Getty Images (2020), Public Domain

While this may be true for some practices, recent studies have shown that hospitals see a decline in quality of care once acquired by private equity. One measurement that is indicative of this is the likelihood of nosocomial, or hospital-originating, complications. According to a study conducted at Harvard Medical School, researchers saw a 25% increase in complications directly resulting from hospital care for Medicare patients at a hospital bought out by private equity. More alarmingly, a 38% increase in bloodstream infections directly attributed to central lines used in the hospital for easy intravenous access.[2] These brand new findings have led industry leaders to call for policy action to increase transparency for how private equity truly impacts patient outcomes.

In addition, a study conducted by the UC Berkeley School of Public Health examined the surge in private equity investment in the healthcare sector. The study found that private equity's focus on short-term revenue generation and consolidation undermines a stable, competitive healthcare industry.[3] Two recent National Bureau of Economic Research studies of the nursing home and dialysis markets found that private equity ownership is correlated with worse health outcomes and higher prices. These findings underscore the complex and often controversial role of private equity in the healthcare sector, prompting further calls for increased transparency and regulation.[4] This new player in the healthcare industry is significantly altering the landscape of the field and its future. It is crucial to continue monitoring these impacts to ensure the best possible patient outcomes.

While there are concerns about its focus on short-term revenue generation and potential negative impacts on patient care, it's important to highlight the positive influences as well. For instance, Dr. Matthew Zimm, a Pennsylvania ophthalmologist, found that private equity partnership alleviated administrative burdens and accelerated growth for his practice.[5] This echoes the experiences of many physicians who have reported improved access to technology, expanded facilities, and increased market power as a result of private equity investment. Over the past decade, billions of dollars have been invested by private equity firms in various types of medical practices, fostering innovation in the biomedical space. Despite the challenges and controversies, these instances highlight the potential benefits of private equity in healthcare.

Overall, this new player in the healthcare industry is making a noticeable change in the landscape of the field and its future.

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Interview

An Interview with Dr. Steven Joffe

Dr. Steven Joffe is the Chair of the Department of Medical Ethics & Health Policy, Art and Ilene Penn Professor of Medical Ethics & Health Policy, a Professor of Pediatrics at Penn, Director of Penn Postdoctoral Training Program in the Ethical, Legal and Social Implications (ELSI) of Genetics and Genomics, and Co-director of the Cancer Control Program in the Abramson Cancer Center. Dr. Joffe is a pediatric oncologist and bioethicist, and he researches ethical challenges regarding conduct of clinical and translational investigation and ethical challenges in genomic medicine and science. Among other topics, Dr. Joffe has researched children's capacity to be involved in research decisions.

This interview was conducted by Hannah Cho, Sophie Kudler, Lillian Lama, & Avi Loren

What inspired you to study medical ethics and health policy?

I got really interested in medical ethics when I was in medical school because, as a third and fourth year medical student doing my rotations, I realized that a lot of the things I found really interesting about the patient care stories or patient care situations were the ethical sides of them, so that planted a seed. When I got to my pediatric oncology fellowship, so many of the challenging, interesting issues that we were dealing with were ethical issues related to decision-making for kids, kids participating in clinical trials, or other research or end-of-life issues, so that was when the seed started to germinate, I guess you could say.

In a field as dynamic as bioethics, where social implications of certain treatments and our understandings of the influence of race, economic class, etc. constantly are evolving, how do you handle this, ensuring that your scholarship and research can withstand these changes?

Many of you are familiar with one approach to bioethics that invokes a group of principles like the autonomy of patients or research participants. Autonomy is one important value, beneficence doing good or net good is another really important value, but the third principle I think has historically gotten less attention but is getting more attention now, is justice – that has a number of different dimensions to it. One is making sure the benefits and the burdens of healthcare are fairly distributed. One example is people having access to healthcare in the first place. Even if we just talk about the United States, lots of people have not had access to healthcare, for example lack of health insurance or health insurance that does not give them full access. Things got a lot better with passage of the Affordable Care Act and Obamacare, although still not perfect and still varies a lot depending on which state you're in, for example. But really attending to the question of who has access or who has power, who's beendisadvantaged or who is living in the context of past injustice, present injustice, structural injustice, that sort of thing, you can't really think about bioethics without taking into account all of those structural and societal issues, so for any question you face in bioethics, that is an angle or lens you have to take to it. I think in today's bioethics, when we are a lot more attuned than many of us have historically been to these kinds of issue, it is really integral to the work that we do and fits nicely under the principle of justice, which again historically has not gotten nearly the attention it deserved, but I think today it really does.

In your pieces, "Quality of informed consent: a new measure of understanding among research subjects" and "Quality of informed consent in cancer clinical trials: a cross-sectional survey," you used a Quality of Informed Consent (QuIC) questionnaire to measure the outcome of informed consent. This was published over 20 years ago, do you still believe this is a valid survey? If you could change it, how would you update it to better reflect today's ethical and medical practices?

I do still think it is a valid survey, and in fact, I am amazed that several times a year, I get requests from someplace in the world, asking to use it or to translate it into the language of their country. It has been translated into four, five, or six languages that I'm aware of – that's pretty cool and exciting and fulfilling. There is a paper that I wrote with a colleague six or seven years ago that took a somewhat different approach, it's gotten less attention and hasn't been cited nearly as much, to try to understand informed consent or what people understand when they take part in medical research. Instead of just giving people a paper survey that they could fill out on a computer or on paper, it involved asking people questions about their study and making some assessments about whether their answers to the questions were rich and complete and show complete, partial, or not much understanding at all. I have come to believe that is a better way of assessing understanding because it allows you to fit the measure to the details of whatever the study that someone is participating in – it is more flexible. I still think the approach we use in the quality of

informed consent series of papers is valid and is certainly one way of doing it and in some sense the easiest way of doing it, but if I were doing another study, I would probably use our newer approach, which is a lot more work but I think gets you a better answer.

Because a paper we are publishing in this edition of PBJ mainly focuses on pediatric cancer patients, how does the child having cancer, as opposed to another illness, as their terminal illness affect the bioethical implications of whether you should lie to the child about their illness/prognosis? How does cancer being potentially fatal, commonly discussed, and prevalent in today's society affect the decision?

I don't think the answer is that different than other conditions that have similar prognosis or implications. For example, a lot of literature on truth-telling to kids came out of pediatric HIV, which today is actually very treatable – with combination therapy people can live a very long time, in fact, they can live a pretty normal lifespan with HIV. If you think back 25 years ago or so, that wasn't the case, and HIV was more of a fatal diagnosis. A lot of the literature and thinking grows out of that condition, which is an interesting situation because it is so stigmatized and is something many people are reluctant to admit to or think they may be discriminated against if they have it. I think with cancer, it's a fear-inducing condition to be told you have cancer. Our general understanding of cancer is that it's this devastating and life-threatening disease, and unfortunately, for many people, it still is. It's really that fear that cancer induces that leads people to say, "I can't really tell my kid," or "I don't want you, the doctor, to tell my kid that they have cancer." It is complicated when someone is walking into a clinic that has cancer over the door. You walk into the Dana Farber Cancer Institute or the pediatric cancer clinic at CHOP, and if somebody is 8 or 10 or 13 years old, they probably will understand what that means. I certainly have, not commonly, had parents even of kids in their early teenage years saying, "we really don't want you to tell our kid what their diagnosis is," and it has been a very difficult situation to navigate. On the one hand, the parents love them and know their kids best, and who am I to force that diagnosis on that family or a kid when the parents' judgment is that it would not be in that kid's interest? And on the other hand, it's really hard to lie to somebody. The approach I have always taken is to say, "I won't lie, I don't have to volunteer it, I don't have to say the word, but if anybody ever asks me, I won't lie to them." That's the deal I've been willing to strike with parents. Fortunately, it has happened to me very infrequently.

There are a lot of cultural differences in how people approach cancer. I wouldn't be surprised if there are places in the world or cultures where sharing that information with a kid would be contrary to cultural values, and that is another thing you want to be respectful of – not just where is this family coming from, what do the parents judge, but also what's culturally appropriate. I think there are a lot of things to take into account in making that decision: most of it doesn't have to do with the diagnosis that is cancer itself, but how you respect the judgment parents make for their kids. How do you think about respecting culture while on the other hand staying true to your own values?

In your paper, "Establishing a global regulatory floor for children's decisions about participation in clinical research," you analyze ICH guidelines regarding enrolling children in clinical trials. With your extensive experience as an oncologist and bioethics researcher, how do you recommend physicians offer clinical trials to pediatric patients, particularly those whose potential last option for treatment is a clinical trial?

First of all, if a trial is an appropriate or reasonable option for a kid, the kid is eligible, it is accessible, and they don't have to travel halfway across the country or something like that, it's almost an obligation of us to offer the trial because it would be very inappropriate for me, as a doctor, to make a unilateral judgment that I shouldn't offer it. I think the offer is always appropriate if you think that it's an okay option for a kid, and if the kid is eligible and all of that. Second thing is, if we are talking about very young kids, we are just talking about parents; if we're talking about kids in middle school or high school, I think about offering it to the family – the parents and kid. Then the question is: how do they go about deciding? I think the ideal way, and probably what happens most of the time, is that it ends up becoming a family decision. Sometimes, the two parents disagree, or sometimes there will be disagreement with the kid, but most of the time, it's a family decision – they get together, and they decide collectively, "this is right for us," or "this is not right for us," and whatever it is, that is fine.

One thing I would say regarding if there aren't many other options, it is really important in that situation where there is no other proven treatment, to also put palliative care, or symptom care, out there as an option because it is always an option, particularly as you get close to the end of life, so it is always important that that be on the table as an appropriate and reasonable option that people ought to consider.

On the issue of disagreement, disagreement can cut a couple of ways. Let's say it is a teenager who really wants to be on the trial but the parents for whatever reason don't want their child to be on the trial. The fact of the matter is, legally you can't enroll a kid in the trial if their parents aren't willing to give permission. I might be bummed out about that, I might feel like ethically I want to be able to enroll them, but you just can't legally. The flip side is, if the parents want the kid to be in a trial and the kid doesn't want to be in the trial, I think that is the most difficult situation. There are rules and regulations saying if the patient is capable of

giving assent, the child must be asked to give assent, which means they must agree, unless in a rare case – if, say, the clinical trial is so clearly the right answer, so clearly better than any alternative then you can waive that. In practice, I actually think we often don't live up to that standard. We will enroll kids in trials even if it is clear they are reluctant or don't want to, and I think we actually could be a lot better about saying, "Look, if you, the kid, really don't want to be in the trial, tell us, and even if your parents want you to be, we are not going to enroll you in the trial." I also have seen situations where it is clear the patient does not want to be in the trial, the parents nudge or cajole the kid to reluctantly say yes. My sense is, maybe more often we need to just read between the lines, and if you the kid doesn't want to be in the trial, and their reasons make sense, then that should be the end of it.

Although the paper we are publishing argues that lying to a terminally ill patient and treating them paternalistically is fundamentally distinct from subjecting a healthy child to the same treatment, the author of the piece offers that a child should not be treated as a "means simply because that child is likely going to die without fully cultivating his rational will," arguing that children still can act rationally and maturely. What are your thoughts on the logic of allowing the child to show maturity/understanding? Is that logic valid here? How have you arrived at your current strategy of not lying to the child but not necessarily offering the full scope of the diagnosis up front?

I certainly would offer the full scope of the diagnosis up front unless I hear very clearly something different from the parents, and then we have a kind of negotiation about what we can and what we can't say. The fact that a child is terminally ill doesn't change our obligations to engage with them at their level of understanding and maturity. Let's assume the illness hasn't affected their cognitive capabilities or their ability to engage in conversation, decision-making, that sort of thing. I don't think the fact that they are terminally ill changes anything. I think we should be able to engage kids to the extent they want and aligned with their capabilities, like for children who are younger or less mature it's going to be a different conversation than an older teenager who's more mature, and if some kid really doesn't want to be part of the conversations, we want to respect that, too. I think there is a concept of developing autonomy in kids, and they may not have some of the full capabilities that somebody who's an adult or in college or out of college might have, but they are along that pathway, and we should engage kids at the level that they want and their level of development allows because kids know when you are excluding them from conversation and when they don't want that, and they kind of know when you are lying to them. Sometimes they are playing along because they are trying to protect their parents, but a kid is going to feel very isolated and abandoned if they want conversations to happen with them in the room and that doesn't happen. It's bad enough to be dealing with a really serious illness, and I think it's even worse when people are talking behind your back, or talking behind closed doors, or not talking to you in the way that you want to be included.

The doctor-parent relationship exists in addition to the doctor-patient relationship – a doctor has responsibility to the patient, but parents also have an important and legal role in medical decision making. What should the relationship be between doctor, parents, and patients? What role should the parents play while the child is a minor? Should the doctor listen to the parents' wishes? Can the doctor make an educated decision about what to tell the patient? How does health policy play into these issues?

In an ideal world, when the relationship and the situation is going really well, I tend to think that parents have the responsibility to look out for their kids' best interests and to make decisions in the best interests of their kids, and the doctor is there to advise and to help the parents do that, and to give the parents the information or the options they need to do that on the kid's behalf. But at the same time, there are limits to that and boundaries on what is okay for a parent to do, or not do, on behalf of their kid. I think a pediatrician or a doctor taking care of a kid is also there to look out for those boundaries and to make sure that, for example, parents are not making decisions that are really contrary to their kid's best interest. It's kind of a twofold thing: one is you're helping and advising the parents and letting them be the primary decision-makers because they love their kid and have to live with their kid, and that's their parental responsibility, but you're also making sure that things stay within societally acceptable boundaries. How wide or narrow those boundaries are is pretty interesting and complicated, and people don't agree on some options that are "gray-zone options" that some people feel comfortable with and others don't. I think as a pediatrician, you are operating on these two tracks: help and advise the parents, put them in first place as far as decision-makers, but then make sure things stay within what is socially acceptable. By socially acceptable, I mean decisions that are reasonable or permissible to make on behalf of kids.

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