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Medical Technology's Breakdown of Personhood: The Power and Politics of Modern Medicine

by Erin Gannon

The Argument

Humans have always revered medicine as a godlike entity for its healing power and extending life. With this wonder-like enchantment towards medicine, specifically modern medicine, humans have given deference to the use of technology in our medical treatments and the diagnostic decisions it can make for us. However, using such medical technology often requires separating parts of the human body from the whole, creating a missing mass. This missing mass creates a disconnect between the person and the medical treatment due to a lack of complete understanding of medical decision-making. This disconnect and lack of understanding increase medicines wonder. This cycle continues in a loop, which promotes the ongoing advancement of medical technology in our society without any current signs of slowing down.

Throughout history, human beings have attempted to control our bodies and lives. Medicine is at the center of this desire for control. Since the introduction of modern medicine, its scope of control over human bodies has expanded to touch almost every aspect of healthcare. Through this expansion, there is an opportunity for those in power to control the concept of

personhood. In the United States, the private sector and the government use this power to control individuals' legal rights.

Medical Technology's Missing Mass

It is no surprise that medicine has a hold over humans as it has allowed humans to heal wounds, cure illnesses, and extend lives. Throughout medical history, humans have used technology to aid in treatments and expand their knowledge and understanding of the human body. However, before modern medicine, healthcare focused largely on addressing and fixing symptoms of illnesses or immediate problems, such as open wounds or broken bones.¹ The introduction of medical technology shifted the focus of health towards addressing long-term problems, like extending human life and reducing widespread disease.² The ability to identify and address previously unknown and even microscopic health problems shifted humans' approach to medicine.³ Physicians focused more on understanding the inside of the human body to gain more control over our bodies.⁴ As with many other technologies, human beings began to rely on their use in everyday life, beginning with the advent of modern medicine.⁵

¹ Douglas James Guthrie, *history of medicine*, Britannica, <https://www.britannica.com/science/history-of-medicine>

² National Research Council (US) Committee to Update Science, Medicine, and Animals. *Science, medicine, and Animals: A Theory of Germs*, National Academies Press; (2004) <https://www.ncbi.nlm.nih.gov/books/NBK24649/>

³ *Id.*

⁴ Douglas James Guthrie, *history of medicine*, Britannica, <https://www.britannica.com/science/history-of-medicine>

⁵ *Id.*

In the paper "*The Sorcerer's Broom: Medicine's Rampant Technology*," Eric J. Cassell proposes that scientific technology has a hold on humans, creating a 'wonder' around the use of this technology.⁶ Medical technology is no exception, even developing a power of its own.⁷ According to Cassell, this originates from five places:

- (1) wonder and wonderment;
- (2) the lure of the immediate;
- (3) unambiguous values;
- (4) the avoidance of uncertainty; and
- (5) human desires for power.⁸

This power may lead physicians and scientists, the 'users of medical technology,' to over-rely on it in medicine.⁹ Wonder and wonderment are humans' energy and excitement surrounding new and seemingly miraculous objects and ideas.¹⁰ The ability to control illness and death, some of the least controllable aspects of life, bring enormous excitement. Cassell argues that the lure of the immediate is that it is a thing in and of itself, "unmediated by our own reasoning."¹¹ Technology grants us this information

⁶ Eric J. Cassell, *The Sorcerer's Broom Medicine's Rampant Technology*, The Hastings Center Report, Nov.-Dec.. 1993, Vol 23, No. 6, 32-39 (Nov. -Dec. 1993).

⁷ *Id.*

⁸ *Id.*

⁹ *Id.* at 33

¹⁰ *Id.*

¹¹ *Id.* at 32-39

without needing prolonged questioning or expectant waiting. Further, this immediately accessible information is also unambiguous and specific. The information, which frequently takes the form of exact values like negative and positive, creates answers about the human body, which is inherently ambiguous.¹² Finally, humans' desire for power is twofold. Those who opt to become doctors often do so based on a desire for an influential societal role. Additionally, medical technology gives humans power through control over their bodies.

In medicine, "users of medical technology" frequently must separate 'parts of the body' from the individual or the 'whole body' to utilize medical technology's power. An example of the separation of the "part of the body" from the "whole body" is in blood testing. When a patient goes to the doctor, and the doctor recommends the patient go to get a blood test, the patient goes to a phlebotomist to take their blood. The phlebotomist then sends this blood sample to a lab, which breaks down the blood into elemental parts to analyze. Those results are analyzed, and the data from the 'part of the body' is sent to the original doctor. Only then does the doctor decide on the patient's health. Here, the whole turns into a part that breaks down into many parts and even more into data points. The human body becomes data, and the doctor becomes an engineer of facts about that body. The original intention of the blood test is to find out something

¹² *Id.* at 34-36

about the body and help the doctor and patient address it. What it does instead and in addition is break down the body, reveal multiple points of information to the doctor that may not be necessary to the diagnosis, and give more information to people whose role is not the diagnosis. Taking blood is simply one example of when and where medicine creates missing masses. A few other examples are the use of x-rays, the creation of new cell lines from other people, and the transplanting of organs from one human to another human.

During this, the connection between the person treated and the 'parts of the body' used spreads further apart as more body parts detach from the whole person. In this separation, the connection between the 'whole body' receiving treatment and the 'parts of the body' used to treat spreads and eventually creates a clear distinction between the two. Somewhere in this distinction lies a missing mass. Latour says a missing mass may occur "when techniques allow both to ignore the delegated act and walk away without even feeling their presence."¹³ It is not surprising that human use of medical technology has created a missing mass. A missing mass occurs when there is a missing moral or social law explaining why humans act in one way when it does not necessarily seem like the most obvious way to act.¹⁴

¹³ Bruno Latour, 'Where are the missing masses? The sociology of a few mundane artifacts', in Bijker, W. E. and Law, J. (eds) *Shaping Technology/Building Society: Studies in Sociotechnical Change*, Cambridge, MA, MIT Press, pp. 225-58, 249 Latour (1992).

¹⁴ *Id.* at 252

Medical technology is so ingrained in medicine "that [physicians] have come to accept these technologies and their output as the equivalent of the thing being tested."¹⁵

Unfortunately, during medical treatment, when technology splits the 'parts of the body' from the 'whole body,' neither the patient nor the physician is aware of the missing mass, as medicine and technology have become so intertwined throughout history that there cannot be one without the other. This separation of a 'part' from a 'whole' and the creation of an unknown element, something not quite human and not quite technology, pervades modern medicine. As Latour says, "students of technology are never faced with people on the one hand and things on the other; they are faced with programs of action, sections of which are endowed to *parts* of humans, while other sections are entrusted to parts of nonhumans."¹⁶

The Breakdown of Personhood

Human's attempt to control our lives and existence has brought questions about what it truly means to be a person. The attempt to answer these questions is the philosophical concept of personhood.¹⁷ While there are multiple philosophical theories

¹⁵ Eric J. Cassell, *The Sorcerer's Broom Medicine's Rampant Technology*, The Hastings Center Report, Nov.-Dec.. 1993, Vol 23, No. 6, 32-39, 34 (Nov. -Dec. 1993).

¹⁶ Bruno Latour, 'Where are the missing masses? The sociology of a few mundane artifacts', in Bijker, W. E. and Law, J. (eds) *Shaping Technology/Building Society: Studies in Sociotechnical Change*, Cambridge, MA, MIT Press, pp. 225-58, 254 Latour (1992).

¹⁷ Center for Health Ethics, *Concept of Personhood*, <https://medicine.missouri.edu/centers-institutes-labs/health->

around personhood, a core principle of this theory is the relationship between the person and the body.¹⁸ For example, those that believe in materialist personhood believe that all it means to be a person is to be a physical body.¹⁹ Additionally, there is a legal definition of personhood whose purpose is to expand legal rights beyond human beings.²⁰ While initially intended to give rights to corporations, this legal concept has recently been used in other legal issues, such as the debate over abortion rights.²¹

The discussion of personhood concerning abortion rights has created flexibility in the legal definition of personhood that can extend to other areas of human life, such as the integration between medical technology and human beings. One of the most prominent definitions of personhood used in legal debates is that of Mary Anne Warren.²² Warren's theory of personhood is based on creating moral standards to consider when deciding whether or not a fetus is a legal person; however, it can apply to other aspects of the law.²³ According to Warren, to be a legal

[ethics/faq/personhood#:~:text=Moral%20personhood,acts%20are%20blameworthy%20or%20praiseworthy.](#)

¹⁸ *Id.*

¹⁹ *Id.*

²⁰ Legal Information Institute, *legal person*, https://www.law.cornell.edu/wex/legal_person

²¹ Warren, M. A. (1973). ON THE MORAL AND LEGAL STATUS OF ABORTION. *The Monist*, 57(1), 43–61.

²² *Id.*

²³ *Id.*

person, one must have "1. Consciousness, 2. Reasoning, 3. Self-motivated activity, 4. Capacity to communicate, and 5. Presence of self-awareness."²⁴ In this theory, only a 'whole body' and not a 'part of the body' would be considered a person.

With the use of medical technology on persons, the separation of "parts of the body" from the 'whole body' shifts our view of that individual's personhood. All living humans qualify as a person, whether under Mary Anne Warren's definition or another. However, 'parts of the body' would never qualify as a person. For example, blood samples would not qualify as a person as they do not have conscious reasoning, self-motivated activity, communication capacity, or self-awareness.²⁵ Even if one were to apply one of the broadest theories of personhood, such as materialism, the 'parts of the body' is not equivalent to the entire physical body.²⁶ When medical technology separates these "parts of the body" from the 'whole body,' it takes something that is not a person out of something that is a person. Therefore, users of medical technology are making healthcare decisions about a person based on information acquired from something separate from the person on a meaningful level. This distinction, especially in the legal distinction between a person

²⁴ *Id.*

²⁵ *Id.*

²⁶ Some personhood theorists argue that removing the brain from the whole body could be considered a person's removal from the physical body. See M. Rowlands, *The Mind-Body Problem*, Encyclopedia of Consciousness, 2009, <https://www.sciencedirect.com/topics/neuroscience/mind-body-problem>.

and a non-person, may change a medical decision that could affect the patient's entire life.

Medicine sustains those living with chronic illnesses, replaces limbs for those missing them, and even brings people back from the brink of death. When a significant actor in those medical decisions, the 'parts of the body,' do not have the same moral or legal value as 'a whole body,' it may weaken the moral and legal value of the actual human being treatment. The missing mass created by medical technology and its breakdown of personhood leave individuals within the healthcare system vulnerable to being taken advantage of and discriminated against in a system that utilizes power.

The Power and Politics of Medical Technology

The American healthcare system relies heavily on technology to operate throughout all aspects of itself. The use of technology in medicine has become both a tool for power and power in and of itself. Medical technology has power in its 'wonder' as it "promise[s] to alleviate human flaws and undesirable traits at the same time is a mechanism by which power is consolidated within a technocratic class that exercises an administrative hegemony and is immensely privileged over biomedicine's consumers."²⁷

²⁷ J L Finkelstein, *Biomedicine and technocratic power*, Hastings Cent Rep. Vol. 20No. 4, 13-16, 14 (Jul-Aug. 1990).

Nearly every aspect of medicine, such as diagnostics, treatment, and long-term care, rely on technological tools like x-rays, ventilators, and even robotic surgical instruments. Even the healthcare system itself relies on advanced medical technology. For example, the rise of telehealth that accompanied the COVID-19 pandemic, the use of rating systems for doctors, and the computerization of medical files all intertwine the practice of medicine with medical technology in a symbiotic way. With this reliance on technology, society has become entrenched in medical technology. In the United States, citizens must have some version of health insurance, school systems require vaccines, and if a person is found injured on the street, someone will likely call an ambulance. Modern medicine has prolonged life expectancy, cured diseases, and helped those with chronic illnesses in a way that it could not if it were not for medical technology. Simply, it is challenging, if not impossible, for a citizen of the United States to live outside the bounds of the medical system.

In the article "*Do Artifacts Have Politics?*" Winner explains how artifacts have politics in two ways. First, "specific features in the design or arrangement of a device or system could provide a convenient means of establishing patterns of power and authority in a given setting."²⁸ Second, "some intractable properties of certain kinds of technology are strongly, perhaps

²⁸ Langdon Winner, *Do Artifacts Have Politics?*, Daedalus, Vol. 109, No. 1, Modern Technology: Problem or Opportunity? 121-136, 134 (Winter, 1980)

unavoidably, linked to particular institutionalized patterns of power and authority."²⁹ Medical technology as an artifact within a healthcare system has politics. Winner purports "that to understand which technologies and contexts are essential to us, we must study the specific technical systems as well as their grasp of concepts and controversies of political theory."³⁰ In order to understand how medical technology has politics, one needs to understand its power within the healthcare system.

Technology, or artifacts, that have power do not exist separate from the rest of society. It would be naive to think that the medical technology industry, or even the United States healthcare system, is outside politics. This power may be attributed to the conditions in which an "immediate democratic administration" can have powers.³¹ The healthcare system is the primary user of medical technology and subtly uses the power it has attained from using medical devices over individuals. Systems have "immediate democratic administration" power under the following conditions:

"First, the organization must be local or otherwise limited in the number of members; second: the social position of the members must not differ greatly from each other; third: the administrative function must be relatively simple and stable; fourth: however,

²⁹ *Id.* at 135

³⁰ *Id.* at 132

³¹ Max Weber, on Law in Economy and Society, Clarion Book, 330 (1967)

there must be a certain minimum development of training in objectively determining ways and means.”³²

While the healthcare system, at first glance, does not seem simple, the actual interaction between physicians and patients is. Returning to the blood sample example, the hierarchical relationship between those in power and those not in power in medicine becomes clear. The physician, the phlebotomist, and the data analyst all have some *ability to access and understand "part of the body"* that the patient does not. The function is simple: to be treated, a person must rely on those actors within the healthcare network. However, as Weber points out, this kind of power is not stable and is quickly taken advantage of by those in power, which may be the case in the healthcare system.³³ A capitalized system requires the input and export of some capital. In the case of the healthcare system, bodies and information about those bodies are used to make money. As Foucault describes, “if the development of the great instruments of the state, as institutions of power, ensured the maintenance of production relations, the rudiments of anatomy- and biopolitics, created in the eighteenth century as techniques of power present at every level of the social body and utilized by very diverse institutions, operated in the sphere of economic

³² *Id.* at 331

³³ *Id.*

processes, their development and the forces working to sustain them.”³⁴

Those capable of being defined as legal persons benefit from legal rights. When the “parts of the body” are used to research, make a profit or serve a political agenda without the consent or awareness of the person from which the “parts of the body” are derived, the body is politicized. This politicization is an example of biopower, which is described by Foucault as “the ‘right’ to life, to one’s body, to health, to happiness, to the satisfaction of needs, and beyond all the oppression or ‘alienations,’ the ‘right’ to rediscover what one is, and all that one can be.”³⁵ It could be that the breakdown of “whole bodies” into “parts of the bodies” is the justification for this capitalization.

This breakdown of personhood shifts the legal right of ownership from the “whole-bodied” person to some other entity, as seen in the case of *Schmerber v. California*. In this case, Schmerber, receiving treatment for injuries in a hospital, was arrested for drunk driving.³⁶ During this treatment, the hospital had taken a sample of his blood for treatment; however, the police officers demanded access to the results of the blood test and took the blood sample against Schmerber’s wishes.³⁷ One of the issues brought in by Schmerber was whether or not taking

³⁴ Michel Foucault, *Power Knowledge: Biopower*, Random House, 263 (1988)

³⁵ Michel Foucault, *Power Knowledge: Biopower*, Random House, 263 (1988)

³⁶ *Schmerber v. Cal.*, 86 S. Ct. 1826, 1829 (June 1966)

³⁷ *Id.*

the blood sample violated his Fourth Amendment right to privacy.³⁸ As shown by the court, the Fourth Amendment provides that [t]he right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures, shall not be violated.”³⁹

Here, the court had to decide whether or not a part of the body, like a blood sample, has the same legal right as a person, which according to the court, would be the first time they ruled on the right of a body with regards to the Fourth Amendment.⁴⁰ Immediately the Court points out that they will assume the privilege against self-incrimination does not bar forced intrusion into the body and that they will only be looking at instructions that “are not justified in the circumstances.”⁴¹ In doing this, the court indicates that taking part from the ‘whole body’ is justified when it is required to fulfill some necessary legal duty.⁴² The court justifies the taking of Schmerber's blood for two main reasons: (1) if they had waited for any local, his blood alcohol level may have gone down; and (2) it would be unnecessary to require a new blood sample to be drawn once under arrest.⁴³ Finally, the court noted that this was a “minor intrusion into an

³⁸ *Id.* at 1834

³⁹ *Id.*

⁴⁰ *Id.*

⁴¹ *Id.*

⁴² *Id.*

⁴³ *Id.* at 1835

individual's body under stringently limited conditions” and emphasized that they still value the integrity of an individual's person.”⁴⁴

In the case, *Moore v. Regents of the University of California*, Moore's cells were extracted during treatment and then used for medical research.⁴⁵ These cells were eventually patented and used for commercial purposes, all without the knowledge or permission of Moore himself.⁴⁶ Among Moore's complaints in the case, his argument for the right of the conversation relates the most to personhood.⁴⁷ Moore argued that he “continued to own his cells following their removal from his body” and that he should have a proprietary interest in them.⁴⁸ Rather than acknowledging that his cells come from his own body, the court discusses how this would negatively affect the medical community and “impose a tort duty” onto the scientific researchers.⁴⁹ The court seemingly decides that “socially important medical research” triumphs over the rights of an individual to have autonomy over their parts of the body.⁵⁰

For this argument, the court relies on a law that treats “such things as human tissues, transplantable organs, blood” as

⁴⁴ *Id.* at 1836

⁴⁵ *Moore v. Regents of the University of California*, 51 Cal. 3d 120, 126 (July 1990).

⁴⁶ *Id.*

⁴⁷ *Id.* at 134

⁴⁸ *Id.*

⁴⁹ *Id.*

⁵⁰ *Id.*

objects sui generis.⁵¹ Stating that the courts regulate objects sui generis as if removed from the human body entirely, with the primary goal of regulation to be about policy goals rather than personal goals.⁵² At what put does a body part become an *object sui generis*? Is it when it serves the public interest, or is there a hard line? Based on the examples given by the court, many of these *objects dui sui* are those 'parts of the body' that may be removed from the body and potentially have a *profitable* element.⁵³ For example, transplantable organs may be sold, tissues can be studied, and blood can be patented. Separating the part from the whole allows for the capitalization of the part legally in a way that could not exist for the whole. The separation of 'parts of the body' from the 'whole body' allows the court to justify the regulation and capitalization of the 'whole body.'

In the recent case of *Dobbs v. Jackson Women's Health Organization*, the Supreme Court made a historical decision to overturn the right to abortion.⁵⁴ In their dissent, Justice Breyer, and Sotomayor and Kagan, discuss the use of personhood in *Planned Parenthood v. Casey*, citing the court's choice to grant the right of abortion based on the protection from government intrusion on family matters, child rearing, intimate relationships, and procreation.⁵⁵ Quoting *Casey*, the court describes these

⁵¹ *Id.* at 137

⁵² *Id.*

⁵³ *Id.*

⁵⁴ *Dobbs v. Jackson Women's Health Org.*, 142 S. Ct. 2228 (June 2022)

choices as "the most intimate and personal" a person can make - reflect fundamental aspects of personal identity; they define the very 'attributes of personhood,' and they inevitably shape the nature and future course of a person's life."⁵⁶ In *Casey*, the court ruled that those personal choices belong to an individual, not the government, but *Dobbs* overturned this decision.⁵⁷ This shift in the Supreme Court's opinion that the right to privacy over choices over one's body is no longer the right of the individual may reflect the increased politicization of bodies.

Schmerber and *Moore* demonstrate instances of the revocation of a right from a person based on removing "parts of the body." The court justifies this revocation based on the *individual's consent* to separate the "parts of the body." However, the option to participate in the healthcare system in the United States is not there. There is a minimal choice in whether or not a person's blood sample will be taken or if a failing organ should be removed. The *power* of medicine over individuals reduces the freedom of choice. When a system of law disregards that influence of power, perhaps because it is another missing mass, it further entrenches individuals into the system. Revoking rights based on the theory of personal choice when the individual does not have a choice demonstrated the domination

⁵⁵ *Id.* at 2328; *Planned Parenthood v. Casey*, 505 U. S., at 856, 112 S. Ct. 2791, 120 L. Ed. 2d 674.

⁵⁶ *Id.*; *Id.*

⁵⁷ *Id.*; *Id.*

power of the medical system.⁵⁸ The *Dobbs* decision of the Supreme Court affirms this notion.⁵⁹ It shows that a person has no legal right to have privacy, or control, over their own body. Overturning *Casey* reflects a belief that the government can, and potentially should assert its power over individuals' bodies.⁶⁰

Foucault states that the emergence of modern medicine has brought with it biopower that brings technologies and techniques for "achieving the subjugation of bodies and the control of the population."⁶¹ As stripping away of an individual's rights over their body increases, so does the likelihood of this becoming a "legal norm."⁶² With the symbiotic relationship between the American healthcare system and citizens, this legal norm of stripping away an individual's rights could become a conventional understanding that individuals should not or do not have rights over their bodies.⁶³ A convention is "characterized by the very absence of any coercive apparatus."⁶⁴ This convention could mean that entities outside the scope of standard 'power,' like physicians and hospitals, feel empowered

⁵⁸ Max Weber, *On Law in Economy and Society*, Clarion Book, 322-336 (1967)

⁵⁹ *Dobbs v. Jackson Women's Health Org.*, 142 S. Ct. 2228, 2328 (June 2022)

⁶⁰ *Planned Parenthood v. Casey*, *Casey*, 505 U. S., at 856, 112 S. Ct. 2791, 120 L. Ed. 2d 674.

⁶¹ Michel Foucault, *Power Knowledge: Biopower*, Random House, 263 (1988)

⁶² Max Weber, *On Law in Economy and Society*, Clarion Book, 15-16 (1967)

⁶³ Max Weber, *on Law in Economy and Society*, Clarion Book, 20 (1967)

⁶⁴ *Id.* at 15-15.

to take from bodies what they wish as they gain more access to medical technology.⁶⁵

In the United States, there are specific groups of individuals that this use of body has particularly harmed. The exploitation of bodies affects groups commonly marginalized from our society, including people of color, women, prisoners, and those in psychiatric institutions. There is an entire history of discrimination that led to the United States government justifying the use of bodies for experimentation; it demonstrates the use and abuse of human bodies for the supposed "benefit" of the public good.⁶⁶ Just like in the cases of individuals in *Schmerber* and *Moore*, the United States government prioritizes public policy over private persons' rights.⁶⁷ It seems that the power medical technology gives its users over the human body allows them to justify exploiting bodies to further the "public

⁶⁵ This convention could already occur when considering selling healthcare data or the organ transplant black market.

⁶⁶ For example, in 1932, the United States Public Health Service began an experiment with the goal of "observ[ing]the natural history of untreated syphilis" and chose the subjects of this experiment to be Black males. Over forty years, the experiment infected these young men with syphilis, and, through various means, the researchers from USPHS did not treat the infection. In 1952, an estimated 30% of the participants had received penicillin treatment, yet the researchers still attempted to block the participants from gaining treatment. This experiment did not end until 1972, when the New York Times published information about the experiment. See, Ada McVean B. Sc. *40 Years of Human Experimentation in America: The Tuskegee Study*, McGill (January 2019), <https://www.mcgill.ca/oss/article/history/40-years-human-experimentation-america-tuskegee-study>.

⁶⁷ Ada McVean B. Sc. *40 Years of Human Experimentation in America: The Tuskegee Study*, McGill (January 2019), <https://www.mcgill.ca/oss/article/history/40-years-human-experimentation-america-tuskegee-study>

interest." The missing mass created in the separation of 'parts of the body' from the 'whole body' may have created a cognitive dissonance in the use of human bodies.

In conclusion, there exists a cycle created by medical technology that breaks down our concept of personhood, giving medical technology power over the human body. With human's adoration of medicine as a 'wonder' in the world, we have consented to the separation of 'parts of our body' from our 'whole body' based medicine's promise of health and longevity. However, this separation breaks down our understanding of personhood with regards to these body parts, leaving the 'parts of our body' vulnerable to exploitation. This cycle gives power to medical technology, which is used by the powerful healthcare system to assert dominance over the human body. Rather than intervening in this domination, the United States government has begun to exploit this breakdown of personhood through the revocation of the rights of individuals. These systems of authority in healthcare then take those rights and use them to assert dominance over the human body further. Moving forward, the relationship between the breakdown of personhood and the politicization of the bodies of specific kinds of persons needs further exploring and a deeper understanding of the historical context of these exploitations.



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The Right to Thrive: Championing Healthcare Accessibility for a Stronger Generation

by Vedaant Mutha and Sanjay Alagappan

Abstract: Despite significant advancements, healthcare accessibility remains a critical issue in the United States, with disparities that persist across socioeconomic, demographic, and geographic lines. My study delves into the experiences of individuals who are facing barriers to healthcare access while identifying potential solutions for enhancing equity in the healthcare system, drawing inspiration from the works of prominent researchers like Dr. Camara Phyllis Jones and Dr. David Satcher, who have dedicated their careers to understanding and addressing health inequities. Utilizing the Amazon Mechanical Turk Platform, a 17-question survey was conducted sampling 198 adults across the United States. The study explores the perceived barriers to care and the impact that socioeconomic factors and gender play in healthcare access. Findings reveal that transportation, affordability, and lack of insurance emerged as the most prevalent barriers, with lower-income individuals disproportionately affected by transportation limitations. In addition, women viewed health disparities and prioritized affordability as a barrier, while men

highlighted the lack of public health insurance programs. These findings highlight the need for a versatile approach that addresses the gap in access to health care. Policy interventions should focus on expanding access to affordable health care, improving public transportation systems, and implementing gender-sensitive strategies to address the unique challenges of women and men alike. By addressing these disparities through multilateral policy interventions, the United States can strive to provide equitable and accessible health care for all its citizens, regardless of what they cannot control. This study provides valuable insights for policymakers and healthcare providers to work towards a more inclusive and equitable healthcare system for all.

Introduction

Achieving health equity requires that all individuals have timely access to needed medical services (WHO Commission, 2008; Jones, 2000). Yet in the United States, millions of working-age adults remain uninsured or underinsured, and face diverse obstacles in reaching care (Collins & Gupta, 2024; Kaiser Family Foundation, 2024). Recent national surveys found that 26 million Americans (~8%) lacked health insurance in 2023 (Collins & Gupta, 2024). Uninsured persons are much less likely to seek preventive care and far more likely to delay or forgo treatment because of cost (Kaiser Family Foundation, 2024). In

addition to coverage gaps, nonfinancial factors—such as geographic access and transportation—critically hinder care. For example, over one-fifth of U.S. adults without reliable vehicle or transit access reported skipping needed care due to transportation barriers (Smith et al., 2023). These barriers fall hardest on low-income, rural, and minority communities, whose health outcomes already lag behind national averages (Wolfe et al., 2020; Smith et al., 2023).

Seminal work on social determinants of health emphasizes that poverty, racism, and other structural factors can “push” people off the cliff of good health (Jones, 2000). In this context, policymakers and scholars have called for an integrated approach: expanding insurance coverage (e.g. via Medicaid or subsidized plans) while also addressing non-medical determinants (like transit access and affordability). The present study builds on this framework to examine which barriers U.S. adults perceive as most significant, and how those perceptions vary by income and gender. Drawing inspiration from leaders in health equity (e.g. Jones and Satcher), we aimed to characterize the lived experiences of diverse Americans in accessing care. Specifically, we hypothesized that (1) transportation, cost, and insurance problems would predominate among reported barriers, and (2) lower-income and female respondents would report different primary barriers than higher-income and male

respondents. Understanding these patterns can inform targeted interventions to close access gaps.

The model in Figure 1 illustrates how upstream social determinants such as socioeconomic status, structural inequities, and policy context contribute to intermediate access barriers like transportation limitations, insurance gaps, and cost. These barriers influence individual healthcare-seeking behaviors and ultimately shape broader population-level disparities in health outcomes and equity. The framework reflects a continuum from systemic factors to lived experiences, emphasizing the need for holistic, multilevel interventions.

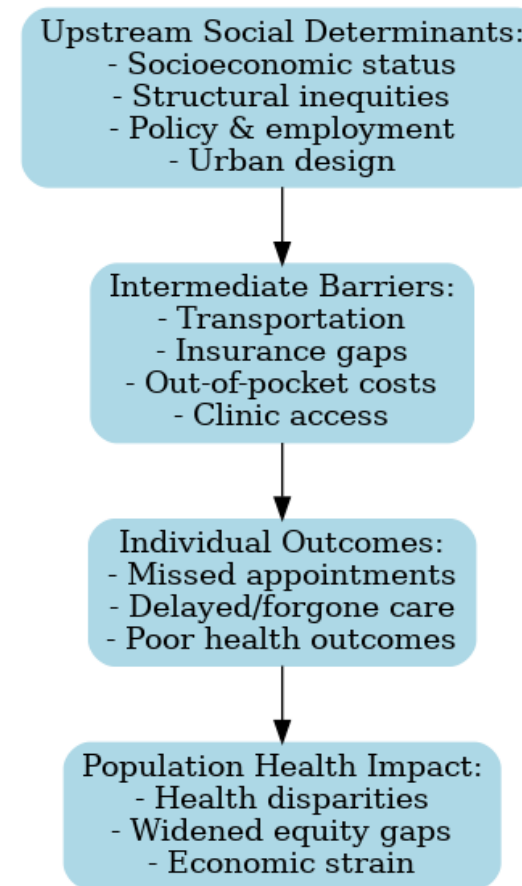


Figure 1: Conceptual Model of Healthcare Access Barriers

Methods

We conducted a cross-sectional survey of U.S. adults (age ≥ 18) in March–April 2025. Participants (N=198) were recruited online (via Amazon’s MTurk platform) and provided informed consent. The questionnaire (17 items) collected demographic data (age, gender, income, etc.) and asked respondents to select the single

greatest barrier they experienced in obtaining healthcare (options included: transportation difficulties, cost/affordability, lack of insurance, difficulty finding providers, etc.). The survey instrument was developed de novo for this project but was informed by prior studies of access barriers. No personal identifiers were collected and the protocol was approved by the Florida Atlantic University IRB.

Survey data were analyzed using descriptive statistics. We categorized respondents into three income groups (lower-, middle-, higher-income) and by gender (male, female; no respondents identified outside this binary). We computed the proportion of each group endorsing each barrier. Associations between income or gender and barrier selection were tested with chi-square tests ($\alpha=0.05$). When multiple barriers were endorsed, respondents were asked to indicate the single most significant one; analysis focused on these top barriers. All analyses were performed in SPSS.c

Results

Transportation emerged as the single most common barrier to care overall, followed closely by cost-related issues and lack of insurance. Approximately 34% of respondents identified transportation barriers as their primary obstacle, 27% cited cost or affordability concerns, and 24% cited lack of insurance

coverage. Lower-income respondents overwhelmingly prioritized transportation: 91.5% of those in the lowest income bracket reported transportation as the biggest problem in accessing care. In contrast, among middle-income respondents, 50.5% cited lack of insurance as their primary barrier, making it the leading concern for that group. By comparison, 87% of higher-income respondents indicated no major barrier, suggesting relative ease of access for the wealthiest. A chi-square analysis confirmed a highly significant association between income group and reported barrier ($\chi^2(4)=251.55$, $p<0.01$).

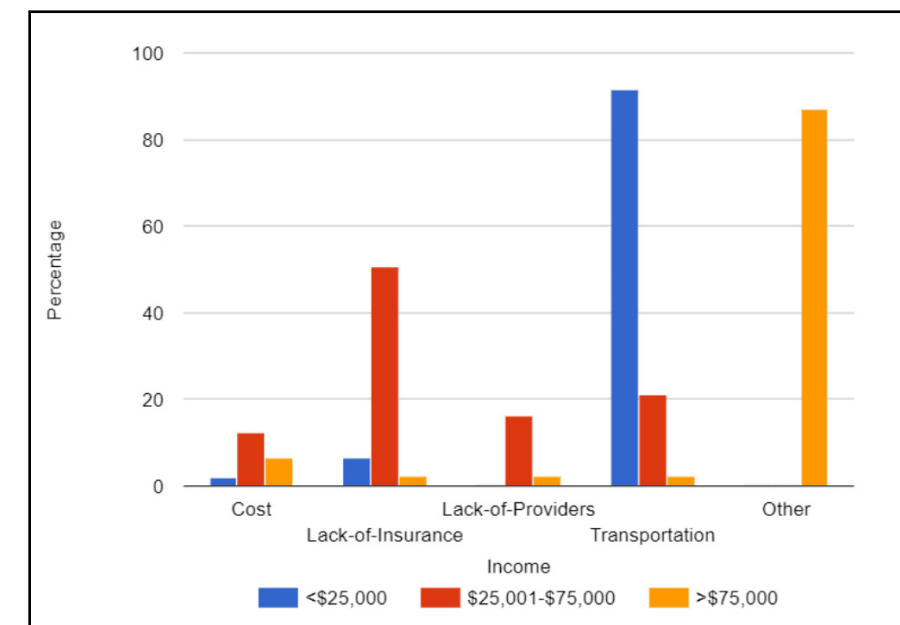


Figure 2: Biggest Barrier to Access by Income

By gender, different patterns emerged (Figure 3). Among male respondents, the top barriers were lack of public or private insurance (19.3%) and transportation (29.5%). Among female respondents, 38.0% identified transportation as their greatest obstacle, followed by cost/affordability (19.3%). Only 8.6% of women and 14.8% of men reported no significant barrier. The gender difference in barrier prioritization was statistically significant ($\chi^2(4)=54.37$, $p<0.01$). These results suggest that women in our sample experienced more cost-related barriers, whereas men were more likely to perceive insurance gaps as critical.

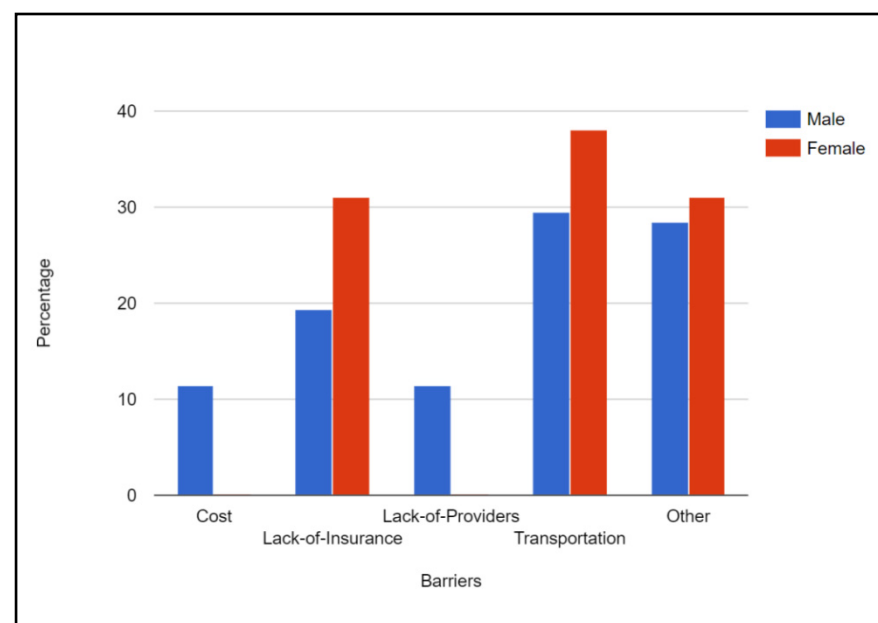


Figure 3: Biggest Barrier to Access by Gender

Discussion

This survey illuminates the distribution of self-reported healthcare access barriers among American adults and highlights key disparities by income and gender. Consistent with prior evidence, transportation, affordability, and insurance emerged as the predominant obstacles (Starbird et al., 2019; Kaiser Family Foundation, 2024). Our finding that lower-income individuals overwhelmingly reported transportation issues aligns with national trends: transportation barriers have long been documented as a major impediment for poor and disabled patients (Syed et al., 2013; Starbird et al., 2019). Indeed, Wolfe et al. (2020) found that the poorest and Medicaid-insured Americans have over 50% greater odds of missing care due to transport problems. Similarly, the Robert Wood Johnson Foundation (Smith et al., 2023) reports that 14% of low-income adults forwent needed care because they lacked reliable transit. Our data reinforce that transportation is not merely a rural issue but a social determinant of health affecting urban and inner-city poor as well.

The prominence of cost and insurance barriers in our results also mirrors existing literature. Many Americans still forgo care because of cost, even when insured, and a lack of adequate coverage independently hinders access (Kaiser Family Foundation, 2024; DeVoe et al., 2007). Our middle-income

group's emphasis on insurance gaps is striking and suggests that even moderate-income adults struggle without robust coverage. DeVoe et al. (2007) similarly found that low-income families "made a clear distinction between insurance and access," with uninsured parents reporting vastly higher problems obtaining coverage. In our sample, uninsured men in particular were more likely to cite lack of insurance as their main barrier, whereas uninsured women were more likely to mention cost. This pattern reflects the complexity of cost-related barriers: many insured families still face high deductibles and copays that effectively block care (Kaiser Family Foundation, 2024).

Gender differences in our findings echo other studies of health-seeking behavior. Women typically have stronger ties to the healthcare system (higher rates of check-ups, reproductive care, etc.) but also shoulder disproportionate cost burdens (Daher et al., 2021; Kaiser Family Foundation, 2024). National surveys have shown that women more often experience medical bill problems and delay care due to cost (Daher et al., 2021; Kaiser Family Foundation, 2024). Consistent with this, our female respondents prioritized affordability and transportation, while reporting insurance coverage issues less frequently. By contrast, men in the U.S. remain slightly more likely to be uninsured and to lack a usual source of care (Daher et al., 2021). The CDC's BRFSS data likewise demonstrated that women were less likely

than men to report being uninsured (OR=0.71) but were more likely to report delaying care due to cost (Daher et al., 2021). Our results fit this pattern: men in our study often highlighted insurance as the top barrier, suggesting that expanding enrollment (especially among working-age men) could yield substantial gains in access.

Given these insights, policy interventions must be multifaceted. Transportation barriers can be mitigated through expanded transit and specialized programs: for example, Medicaid's non-emergency medical transportation (NEMT) benefit has been shown to improve appointment attendance and chronic care management (Syed et al., 2013). Innovative community health initiatives, such as providing bus vouchers or ride-share credits, have improved screening and follow-up in high-risk populations (Starbird et al., 2019). On the insurance front, maintaining and extending affordable coverage pathways is critical. Studies link Medicaid expansion to improved health outcomes (lower mortality from cancer, heart disease, etc.) and greater access (Kaiser Family Foundation, 2024). Consistent with this, nearly all reductions in the uninsured rate since 2019 have come in expansion states, and non-expansion regions now shoulder a disproportionate burden of uncovered poor adults (Kaiser Family Foundation, 2024; Collins & Gupta, 2024). Policies that preserve expanded Medicaid eligibility and enhance marketplace

subsidies will help keep the uninsured at historic lows (Kaiser Family Foundation, 2024; Collins & Gupta, 2024).

Finally, we note that social determinants of health—including poverty, education, and structural inequities underpin these access issues (Jones, 2000; WHO Commission, 2008). Approaches that address root causes (improving job security, housing, and transportation infrastructure) alongside health-specific reforms are needed. For instance, workplace policies mandating employer-sponsored insurance or improving sick leave could reduce access gaps among working adults. Similarly, gender-responsive interventions (such as community clinics with flexible hours and childcare) can ease care-seeking for women and families. In sum, no single solution will suffice. Our findings reinforce a growing consensus: equitable access requires synchronized action on multiple fronts, reflecting the “continuum” of barriers identified in health services models (WHO Commission, 2008).

Conclusion

This study highlights the modern reality that healthcare access in America is unjustifiably uneven and stratified. Despite our uninsurance rates reaching historical lows in the last 5 years (CDC, 2024), other systemic obstacles remain: about one in five low-income adults still skip care due to transportation

constraints, and many middle-income and male adults forgo medical care for lack of coverage (Smith et al., 2023; Kaiser Family Foundation, 2024). Closing these gaps is a matter of public health and social justice policies. Policymakers and health systems should prioritize strategies that reduce both financial and non-financial barriers: expanding Medicaid and other affordable coverage options, investing in expanded systems of reliable public transit and NEMT services, and creating inclusive, community-based care models. By instilling a right to thrive, not just to survive, we can forge a stronger, healthier generation to succeed us.



Vedaant Mutha



Sanjay Alagappan

Vedaant Mutha is entering his senior year as an undergraduate student at the University of Florida pursuing a double major in Biology and Economics on the pre-medical track. His academic focus centers on the intersection of healthcare, economics, and business, with a particular commitment to advancing health accessibility and equity. Through the Business and Economics Polling Initiative at Florida Atlantic University, Vedaant conducted this survey research to examine socioeconomic determinants of healthcare access. He currently serves as a research intern at the University of Miami

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Sanjay Alagappan is a biology major at the University of Florida with a strong interest in the fields of medicine, ethics, and social equity. He has gained hands-on experience in clinical and research settings through his time as a medical assistant playing a major role in surgical procedures and contributing to investigations in the field of healthcare. Sanjay is also deeply involved in the field of emergency medicine and hospital-centric volunteering through his role on a fully volunteer based EMS squad providing free critical care to those requesting aid from 911. These experiences have shaped his understanding of patient care and its diverse nature. Sanjay is involved in cultural organizations on campus, most notably his bollywood fusion dance team - Gator Udaya, which reflect his commitment to inclusivity. In addition to his academic and medical pursuits, He is particularly drawn to examining how structural and cultural forces influence health outcomes with the long-term goal of advancing accessible care.

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Revisiting the Bioethical Challenges of Normothermic Regional Perfusion (NRP) and its implications for Personhood and Prospective donors

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Synopsis

Normothermic Regional Perfusion (NRP) is an innovative medical technique involving the perfusion of organs in a person's body after declaration of death and before organ procurement. After the declaration of death, a prospective organ donor is reperfused to re-establish blood circulation, although the circulation is limited to a specific area of the body. Despite its acclaim, NRP for the procurement of the human heart in Donation after Circulatory death (DCD) presents important bioethical challenges for medical practitioners, the public, prospective donors and families of donor patients. While several studies have highlighted the benefits and ethical challenges of NRP, this proposal revisits three crucial ethical challenges vis-a-vis the contemporary understanding of life and death. It argues that, for NRPs in DCD to become ethically acceptable, it's procedure must be reviewed, with an overhaul of existing oversights/regulatory frameworks. Furthermore, full disclosure of NRP as an organ procurement procedure must be transparent

to the public and should only be done after the informed consent of prospective donors and/or families as needed.

Key words: Normothermic Regional Perfusion (NRP), Donation after Circulatory Death (DCD), Bioethics, Personhood, Prospective Donors, Informed Consent

Background: Defining and Discussing Normothermic Regional Perfusion (NRP)

Advancements in medical science have transformed legal, religious, and cultural understanding of humanity, life, and death in unimagined ways. Normothermic Regional Perfusion (NRP) is an innovative medical technique that involves using a machine to pass oxygenated blood through organs in a person's body following declaration of death and prior to organ procurement. NRP has been known to significantly improve the "assessment, quality, and utilization of organs for transplantation."⁶⁸ This method gained prominence a couple of years ago and became recognized by proponents as a timely and less expensive alternative, compared to Machine perfusion and standard methods for meeting the growing demands of high-quality organs for transplantation. However, the peculiarities of NRP, especially for procuring the human heart, following circulatory death (DCD) presents unique challenges. Donation after

⁶⁸ Wall, A, and Testa, G. 2024. "The ethics surrounding normothermic regional perfusion in donors following circulatory death." *Clinical liver disease* vol. 23,1 e0193. doi:10.1097/CLD.0000000000000193

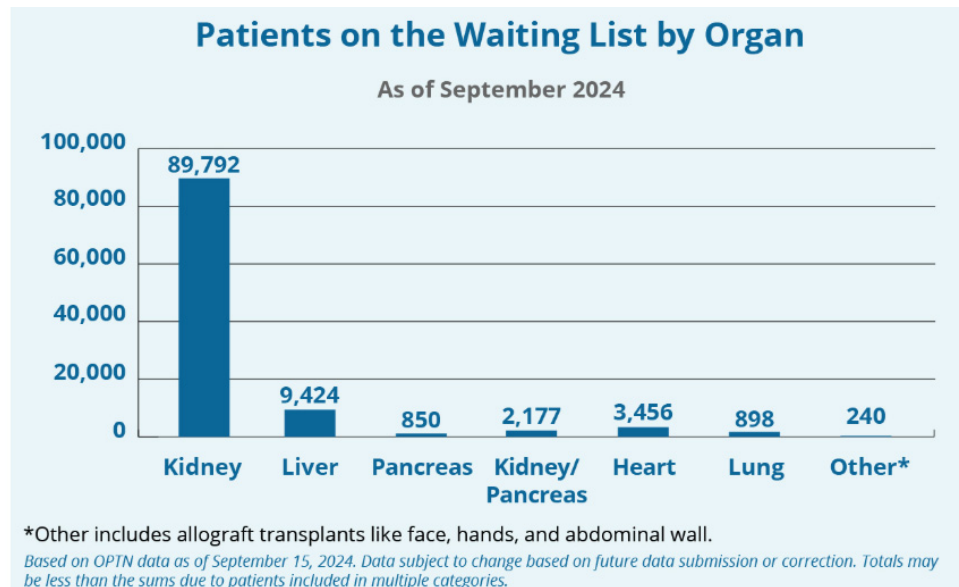
circulatory death (DCD) has been the largest driver of growth in deceased organ donation in the United States over the past 5 years.

The benefits of NRP procedures includes the fact that the procedure quickly "reconditions organs using oxygenated blood and allows for an in-situ assessment of organ function", to assess its viability which would have otherwise been impossible.⁶⁹ The quick reconditioning of organs through reperfusion also stops the damage that will have started with agonal time and resets the clock on the damage that would have occurred from the state of preservation to implantation in recipients. After the declaration of death, a 5-minute "hands off" is observed before the surgical organ removal process is initiated. However, instead of removal, in NRP the dead patients are reintubated to restore oxygenated blood to the organs, to observe the organ's functionality and reduce ischemic injury prior to surgical removal process. According to experts, this process helps to "minimize the warm ischemic time to all the organs and safely initiate circulatory support" thereby producing much more viable organs for transplant.⁷⁰ Research data reveals that there is a crisis of shortage of organ donation in the US and globally.

⁶⁹ Hessheimer AJ, Cárdenas A, García-Valdecasas JC, Fondevila C. 2016. "Can we prevent ischemic-type biliary lesions in donation after circulatory determination of death?" *Liver Transplantation*. Vol 22:pp 1025–1033.

⁷⁰ Shah, A. 2022. Normothermic regional perfusion in donor heart recovery: Establishing a new normal" *The Journal of Thoracic and Cardiovascular Surgery*, Vol 164: 1, 142 – 146.

According to the US Health Resource and Service Administration, about seventeen people die each day waiting for an organ transplant while a new person is added to the waiting list every nine minutes.⁷¹



Source: [https://www.organdonor.gov/learn/organ-](https://www.organdonor.gov/learn/organ-donation-statistics)

[donation-statistics](https://www.organdonor.gov/learn/organ-donation-statistics) Health Resource and Service Administration.

Two types of NRP

NRP is one of the procedures that can significantly increase organ procurement as well as the viability of organs procured, although not without significant ethical challenges. NRP is applicable to two surgical protocols. The first is Abdominal-NRP

⁷¹ Fleck, A. 2022. "Organ Shortage Crises in the US". *Statista Research*. Accessed 8/7/2025.

(A-NRP), where perfusion is restored to only the abdominal organs – the liver, kidneys, pancreas, and bowel. In abdominal normothermic regional perfusion, only the abdominal cavity is perfused which involves "inserting an arterial ECMO cannula into the abdominal aorta...a venous drainage cannula into the inferior vena cava or common iliac vein to provide oxygenated blood to the abdominal organs."⁷² The proximal clamp is placed on the supraceliac aorta (either in the abdomen or the chest), and the distal clamps are placed on the external iliac arteries.⁷³

The second is Thoracoabdominal-NRP (TA-NRP) where oxygenated blood is perfused through all the organs, most especially the heart and lungs, with the exclusion of the brain. In TA-NRP, both the abdominal and thoracic cavities are perfused with oxygenated blood. Here, oxygenated blood is prevented from flowing to the brain, and this is done by clamping or cutting the cerebral arch vessels to forestall the reemergence of consciousness or pain when cardiac and circulatory function is resumed. This implies that active measures are taken to "restrict blood flow to the brain to avoid resumption of brain function".⁷⁴ With this, the heart of the erstwhile dead donor regains functionality and begins beating again to observe the viability of

⁷² Kirschen MP, Lewis A. et al. 2024. "Beyond the Final Heartbeat: Neurological Perspectives on Normothermic Regional Perfusion for Organ Donation after Circulatory Death." *Annals of Neurology*. Vol 95: 6. Pp1035-1039.

⁷³ Wall and Testa. 2024. Pp 1

⁷⁴ Kirschen et al. 2024.

the organ for either several minutes or hours, depending. Organ procurement then occurs, if acceptable. TA-NRP is usually focused on the recovery of a viable heart for heart transplant patients and it has been praised as a technique that increases the overall supply and quality of organs for transplant.⁷⁵

Ethical Challenges raised with NRP

Several ethical challenges have been raised with NRP, especially when it comes to TA-NRP which involves the reperfusion of the heart in patients who were declared dead by circulatory cessation, i.e. DCD. The first and the most notable is that it violates the Dead Donor Rule of the Uniform Declaration of Death Act where a donor must be dead before organs are procured. According to the rule, donors cannot be killed or made dead for organ procurement purposes and organ procurement cannot cause death.⁷⁶

As such, it becomes precarious when, in the process of NRP in DCD cases, cardiac functionality is restored to the dead patient, who was declared dead because of a loss of cardiac and circulatory function to begin with. This presents a logical inconsistency, in that, circulatory cessation was declared to be

⁷⁵ Truog RD, Flescher A, Ladin K. 2023. "Normothermic Regional Perfusion—The Next Frontier in Organ Transplants? *Journal of American Medical Association*. Vol 329:24. pp 2123–2124. doi:10.1001/jama.2023.9294

⁷⁶ Dalle Ave AL, Sulmasy DP, Bernat JL. 2020. "The ethical obligation of the *dead donor rule*" *Medical Health Care and Philosophy*. Vol 23(1): pp43-50. doi: 10.1007/s11019-019-09904-8. PMID: 31087205.

the primal cause of death, only for circulation to in fact be restored again to the body, and most notable to the heart in TA-NRP, and not for the purpose of life sustenance but for organ procurement.⁷⁷ If the dead Donor Rule states that the donor must be dead, and if the donor was dead by circulatory cessation, is restoration of cardiac and circulatory functions bringing the person back to life? Proponents and enthusiasts of NRP have said no, because while the heart is beating again, the brain cells are not directly perfused in order "to respect the basic premise of death" which is by circulatory criteria.⁷⁸

Which brings us to the second ethical challenge with NRP – the distinction between the primal and proximate cause of death. Because the primal cause of death in DCD is the cessation of circulatory and cardiac functions, when the organs are re-perfused (especially in TA-NRP), the cerebral/arch vessels are clamped or cut off to ensure that blood flow to the brain and the reemergence of consciousness or pain when cardiac function is resumed is prevented, for many this becomes the proximate cause of death, i.e. brain death. Neurology experts have argued that overall blood circulation can hypothetically carry oxygenated blood to the brain through the anterior spinal and

⁷⁷ Magnus, D. 2024. "Resuscitating the Dead: NRP and Language" *The American Journal of Bioethics*, Vol 24:6, pp1-3, DOI: 10.1080/15265161.2024.2350873

⁷⁸ Shah, A. 2022. pp143

subclavian arteries, although it is unclear whether that flow is sufficient to support cellular or clinical brain function.⁷⁹

The American College of Physicians (ACP) in a 2021 statement on NRP in DCD comments on the deliberate occlusion of cerebral circulation, that while “perfusion is deemed regional, primarily because circulation to the brain has been actively excluded...Brain death has been caused...” as a result of cutting or clamping of cerebral vessels, thus brain death becomes the proximate cause of death.⁸⁰ This claim presents astute challenges to the understanding of life and death, in that “NRP-cDCD requires a deliberate act intended to prevent the potential for recovery of brain function after reperfusion and the reversal of circulatory determination of death.”⁸¹

What happens if the brain vessels are not clamped or ligated? Is there an understated fear or concern for the possibility of autoresuscitation and/or restoration of consciousness during the reperfusion process? It becomes necessary to ascertain that oxygenated blood flow to the arch vessels will not cause the DCD donor to regain consciousness or brain function, following NRP without brain vessels ligation, and that brain death is not

⁷⁹ Kirschen et al. 2024. pp1036-1037

⁸⁰ American College of Physicians Statement. 2021. Ethics, determination of death, and organ transplantation in Normothermic Regional Perfusion (NRP) with controlled donation after Circulatory Determination of Death (cDCD): *American College of Physicians Statement of Concern*. Published April 17, 2021.

⁸¹ Ibid.

consequentially caused by the litigation or clamping. While the ACP is not against the quest to increase viable organ supply, it believes there are other alternatives that are less ethically disturbing, such as using machines for ex situ (outside the body) perfusion of organs to assess its viability without restarting the donor’s circulatory functions or deliberately causing brain death. Another major challenge is the irregularity in acceptability, techniques, and practice across diverse medical providers, institutions and countries. While many are enthusiastic about the promise and innovation in NRP, others are wary and cautious of its techniques. NRP is faced with several ethical issues that prevent it from becoming a standard practice, acceptable in advanced countries and medical practices. For example, NRP for procuring abdominal organs is acceptable in several countries in Europe, including Spain and the United Kingdom, but even in these countries, there are challenges to exploring NRP for TA-NRP organ donations.⁸²

Recommendations on respecting Personhood of Involved Patients and Prospective Donors

According to ACP, “the ethical obligation to respect persons, including the dying and the dead, limit what can and should be done in organ retrieval.”⁸³ However, medical practice concerning

⁸² Wall and Testa. 2024. pp2

⁸³ ACP. 2021. *ibid.*

the dying and the dead has been largely unregulated. All existing laws regarding the treatment of patients in medical settings or even human subjects in research exclude the dying or the dead. Although not the intention, the current regulatory landscape subliminally infers that ‘anything goes’ once a person has been declared dead. While some form of limited regulation is provided by the Uniform Anatomical Gift Act, it does not directly address the concerns raised with modern medical practice and innovation.

Although NRP has been in practice in some medical establishments for some years, there is still a lack of transparency and full disclosure of patients/families and the public/prospective donors. Some have argued that it is unnecessary to bother grieving families with the intricacies and technicalities of the process of NRP which justifies lack of transparency; “the technique details of standard deceased organ recovery are not shared with families. Whether families want to know, or need to know, specific NRP techniques, is not known.”⁸⁴ As such, there is inadequate informed consent with regards to the process, and many families are unaware of the technicalities involved in the procedure. An important consideration is to aggregate public opinion about NRP. If NRP were to become a generally acceptable procedure in medical practices, will the

⁸⁴ Parent, B., A. Caplan, N. Moazami, and R. A. Montgomery. 2022. “Regarding normothermic regional perfusion: Arguing by insistence is not a strong argument.” *American Journal of Transplantation* vol 22 (6): pp1729–30.

knowledge of such procedure change the mind of people who sign up to be organ donors?

It will indeed make for informed decision making and respect for personhood of both the living and the dead, if organ donors were to be pre-informed of such practices as NRP, especially in organ procurements that involve TA-NRP procedures in DCD cases prior to the procedure being done. As recommended by the *American Medical Association Code of Medical Ethics’ Opinions on Organ Transplantation*, the organ procurement team should be separated from the donor’s care team or the recipient’s care team to minimize conflict of interest and that “full discussion of the proposed procedure with the donor and the recipient or their responsible relatives or representatives is mandatory.”⁸⁵ This ensures that the donor is treated with respect, even after death, and that the procurement process is ethically conducted with consent of the families involved. As noted by Stanford Professor of Bioethics, David Magnus, if the success of a procedure of technique involves obscuring information with misleading language, it is a “pretty good indication that you are on the wrong track;” best practices in bioethics should always involve informed consent, respect for patient personhood, and transparency.⁸⁶

⁸⁵ American Medical Association (AMA) *Code of Medical Ethics’ Opinions on Organ Transplantation* 2012;14(3):204-214. doi: 10.1001/virtualmentor.2012.14.3.coet1-1203. AMA Council on Ethical and Judicial Affairs, accessed 8/11/2015.

⁸⁶ Magnus. 2024. pp3



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Ethical Implications of Hospital Consolidation: A LCMC-Tulane Acquisition Case Review

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Abstract

This paper will explore the systemic and ethical implications of hospital mergers and acquisitions (M &A) by focusing on the recent LCMC-HCA acquisition in New Orleans. It will provide a broad overview of ethical motives, clinical integration, market effects, and the regulatory landscape of mergers and their impact on healthcare infrastructure. In revealing this general background, it will give context to analyze the ethical implications of reduced competition in healthcare and potential impact on access to equitable, affordable, and quality patient care, as well as impact on healthcare workers.

Introduction

In a rapidly evolving hospital system, the usage of mergers and acquisitions to advance the hospital landscape is on the rise all across the United States. Following the slowdown in M&A activity due to the COVID-19 pandemic, the ongoing recovery has led to a steady increase in M&A deals (Oh, 2019). Over the past decade, the reliance on M&As has come from the strategies to

diversify and grow access to care to aid and resolve financial burdens on the hospital systems (Burmeister, 2023). But the direct impact of recent mergers, whether rural or urban deals, has had different lasting outcomes. In this paper, the context of why hospital mergers and acquisitions occur, alongside the current growing trends, will help explain and outline the importance of the broader context of the LCMC-HCA merger in New Orleans. In doing so, analyzing broader ethical implications of reduced competition in healthcare, and how this may impact patient care, access, and equity, and general systemic impacts of hospital M&As.

To fully understand the difference between an acquisition and a merger in healthcare, it must first be defined. A hospital merger or acquisition is defined by Hayford as “the consolidation of two facilities into a single legal entity. The license-relinquishing facility becomes a satellite campus of the license-retaining facility, and hospital boards and physician and nursing staff are unified” (Hayford, 2011). Whereas an acquisition differs from a merger as it usually concerns “when one company acquires a portion or all of another company's shares” (Corporate Finance Institute, n.d.). In the context of healthcare, this does not create a new entity like mergers; rather, it involves adding to the acquirer's assets, usually to expand their services, technology, or reach.

Healthcare institutions across the United States use M&A to allow for growth and a larger patient population to care for. But how can this broader patient population lead to positive and negative impacts? In order to understand the potential for widespread impact of hospital M&A's, Burmeister highlights that “many organizations have deployed tactics like expanding healthcare insurance products, collaborating with commercial insurance companies, and increasing service differentiation by improving customer service, brand identity, and reputation” (Burmeister, 2023). By implementing these on a large scale, it has the potential to expand opportunity, all while allowing for cost efficiency. For instance, creating differentiation between hospitals may include providing specialized treatment plans or specializations, attracting different target patient populations, adapting to changing patient needs, or even avoiding competition solely based on pricing with specialized or unique services. This differentiation can be boosted with an M&A or reduced depending on the goals of the healthcare system. The assumption of using differentiation and M&As is that there will be a tangible impact on improvements to technology, quality care, and improved financial margins, but the variability from hospital to hospital has great variance.

Literature Review

Hospital merger and acquisition activity has slowed during the COVID-19 pandemic, but has since been back on the rise, allowing for an ever-changing hospital landscape (Oh, 2019). According to a study from 2010 to 2019 by Hyesung Oh, there has been a steady increase over the past decade of hospital M&As that affect hospital market competition within regions (Oh, 2019). The general continuous trend of mergers before COVID and after COVID shows that this may further increase (Oh, 2019). To explore how meaningful M&A's are measured, examining general trends, measurable costs, differences in rural and urban deals, and quality of care measurements should be considered.

Two strategies to improve healthcare systems are vertical and horizontal acquisition. A vertical acquisition or integration is defined as "when an organization acquires a company that provides a related service or product" (Williams, 2024). Whereas a horizontal acquisition is defined as "acquiring another organization within the same market" (Williams, 2024). Both can help with market expansion, diversification of revenue streams with more offerings, and improved quality and efficiency in many cases (Williams, 2024). This paper will focus on horizontal acquisition trends. According to the AMA, hospital markets had a 92 percent concentration rate in 2017, with 76 percent of hospitals as members of the hospital system showing

the rates at which consolidations are present (AMA, 2023). Generally, hospital consolidation leads to significant cost savings at acquired hospitals between 4 and 7 percent (Schmitt, 2017, and AMA, 2023). The cost efficiencies in horizontal mergers are measured in savings due to "enhanced operational efficiencies" (AMA, 2023). Whereas in vertical acquisitions like acquiring a physician practice, employment is "increased in these practices between 6 and 10 percent" (AMA, 2023). The AMA points out that with the amount of consolidation in healthcare systems that there are concerns for allowing for adequate competition to "allow physicians to have adequate choices and practice options" (AMA, 2023). With the elimination of multiple health systems or hospitals joining in these healthcare operations, it has the possibility to lead to less competition, potential price increases, and geographic disparities (AMA, 2023).

With hospital acquisitions, geographic distribution creates a significant challenge as more consolidations occur. In comparison to urban areas, rural regions face a greater risk at accessing care. As Mullins states, "Rural hospitals continue to close at unprecedented rates", especially since the major hospital burden that occurred during the COVID-19 pandemic, the rise of healthcare consolidations is back on the rise (Barnett, 2020). Critical Access Hospitals (CAH) are responsible for rural access to healthcare and are essential for these populations (Barnett, 2020). Since 2010, Barnett highlights that there have

been more than 150 closures of these hospitals, with the impact of mergers unclear (Barnett, 2020). On one hand, consolidating and joining larger healthcare systems may bring opportunities to CAHs and rural populations by offering a wider variety of in-care services, broader technology offerings, and the potential to have less of a burden with staff due to a wider healthcare network (Hayford, 2011). But, on the other hand, shifting services to a different location when mergers occur can reduce capacity for these new offerings, while posing an additional new geographical challenge for populations in which the previous location was dissolved (Hayford, 2011). With these challenges at hand, it is important to note that in one case study by Hayford that was researched on forty hospital mergers between 1990 and 2005, the majority of hospitals were within proximity, or already in danger of closing (Hayford, 2011). This could rule out the possibility of potential inequity of access to care.

One general trend with clinical integration focuses on mission-reinvested profits and local ownership, such as the LCMC case study focused on in this paper. With a more local market at hand, the direct needs of a population can allow for local medical opportunities and operational efficiencies to be addressed. Additionally, cross-market mergers across hospitals in different geographic regions are becoming more common to reduce administrative costs by centralizing these services (Schmitt, 2017). In the research by Trish and Herring, “the US

health insurance industry is highly concentrated and health premiums are high and rising rapidly,” and with the ability of centralized hospital systems through consolidation, it can lead to strengthening bargaining powers with insurers, employers, and suppliers (Trish, 2015). With higher market power in services, lowering overall hospital costs can allow for funding upgrades with technology, facilities, and hiring more staff to prevent hospital burnout or shortages by pooling resources.

When it comes to analyzing the average cost savings associated with M&A's, it is crucial to analyze the size of hospitals, multi-hospital system structures, and how mergers affect the cost and quality of care. It is important to note that while some mergers claim efficiencies, many mergers and empirical evidence demonstrate that prices rise significantly in the long run when competition is reduced (Gale, 2015). In the literature review by Arthur H Gale, concluding on the Robert Wood Johnson Foundation, hospital consolidation not only continuously results in higher prices, but physician-hospital consolidation has no evidence of either improved quality or reduced costs (Gale, 2015). It instead pointed to the fact that hospital competition improves the quality of care and patient outcomes, including lower mortality rates and better outcomes for cardiovascular diseases (Gale, 2015, and Hayford, 2011). These findings raise concerns about the differences in types of

healthcare consolidation and how to accurately pinpoint what potential outcomes of mergers may lead to.

Overall, examining the ethical considerations of hospital consolidation is an important step in understanding the assets and liabilities of different mergers and acquisitions among hospital systems, as they directly impact the public's access to healthcare, health equity, and affordability. One major ethical concern is that many mergers disproportionately result in the closure of services and facilities in rural areas. These regions already are put in place to serve vulnerable populations, making them at high risk for even less care. Research also points to long-term higher healthcare prices with consolidation, which may lead to financial hardship for patients. Additionally, as a consolidation deal takes many years to solidify, it can cause disruption in the continuity of care and depersonalization as the transition takes place. This creates a risk for the potential of poor quality in healthcare. Without community input on these decisions, it can result in distrust if transparency is not firmly established. Many instances of regulatory bypass by not communicating these mergers to the FTC have led to accountability issues and loopholes, which actively harms those employees. When these companies consolidate, there is a potential for the mission to be forgotten, and there needs to be an established way to stay in check.

Case study

LCMC Health, a leading non-profit health system in New Orleans, has settled a \$150 million deal to acquire three hospitals from a national chain (NOLA, 2022). This deal would allow for the acquisition of Tulane Medical Center, Lakeview Regional Medical Center, and Tulane Lakeside Hospital from HCA Healthcare (LCMC, n.d). The Tulane Health System notable as an "acclaimed teaching, research, and medical system" with more than 25 clinics throughout New Orleans, including these three hospitals (LCMC, n.d). According to their partnering statement, this partnership will allow for "increased access to comprehensive and specialty care across Southeast Louisiana, combining both community healthcare and academic medicine" (LCMC, n.d). With this acquisition in place, Tulane Medical Center will "shift its services to University Medical Center New Orleans and East Jefferson General Hospital," and Tulane Medical Center will be turned into a new nursing program and research space for Tulane Medical Center (LCMC, n.d). This allows for the gap in the current healthcare system to be filled by training and strengthening the urgent need for nurses in the greater community (Tulane University, n.d). Within this deal, all employees of these hospitals were assured to retain their jobs in the merger (Southwick, 2023).

The acquisition did face scrutiny with a court battle between the Federal Trade Commission (FTC) and LCMC. This

case was brought by the FTC which sought to block LCMC's acquisition saying that "the Louisiana health system was attempting to skirt federal approval of the deal.", The ruling was ultimately overturned with the deal "upheld the State of Louisiana's approval' and the acquisition was exempt from "Federal Antitrust Laws" (Southwick, 2023). This work by the FTC provides a foundation for potentially blocking M&As that allow anticompetitive hospital mergers. Antitrust authorities rely on evidence of undermining consumer welfare by reducing competition in hospital markets that lead to substantially higher prices. Evidence of this can allow violation of antitrust laws that threaten market dynamics and drive up healthcare costs (Schmitt, 2017). On the other hand, merging hospitals claim that M&As can reduce the cost of care, allow access to a wide variety of care and technology, and potentially lead to better health outcomes due to consolidation (Schmitt, 2017). The overruling of this court battle proved adequate evidence to not cause concern of violation of antitrust laws. However, in the future, the reduced market competition of only LCMC and Ochsner could raise serious antitrust concerns for the future.

With this acquisition, there are now two major healthcare system operators since the previously opened Tulane Medical Center, (owned by HCA Healthcare), has been acquired by LCMC. These two major systems are Ochsner Health and LCMC Health. LCMC Health is a predominantly New-Orleans-based non-profit

health system, while Ochsner Health expands through Louisiana (LCMC Health, n.d.). Now, due to this deal, LCMC currently manages nine hospitals across the New Orleans area (Muio, 2023). With only two main systems owning the majority of healthcare facilities, it is important to understand the roles of the health systems: 1) their responsibility to protect vulnerable patients seeking care, and 2) promoting health through equitable and accessible healthcare services and delivery.

It is important to note that HCA Healthcare is a nationwide for-profit operator of private hospitals, outpatient, and healthcare facilities (HCA, n.d.). It has been running the three hospitals that were acquired by LCMC since 1995 (Muio, 2023). With this healthcare network being a nationwide market, it closely adhered to national regulations from federal organizations such as the Centers for Disease Control, the National Institutes of Health, and the Food and Drug Administration (Institute of Medicine Committee, 1988). Given the acquisition, now the hospitals will be run by the state-focused organization LCMC. It is difficult to determine what potential outcomes of this local acquisition may mean for long-term improvements, but past local hospital mergers may be able to point to possible trends.

In New Orleans, the local players who drive decisions in the healthcare system beyond both LCMC and Ochsner include the local New Orleans Health Department (NOHD) and the

Louisiana Department of Health (LDH) at the state level. These health agencies play a significant role in influencing New Orleans' healthcare by developing, promoting, protecting, implementing, and improving community health through health policies and programs for all of Louisiana (LDH, n.d). The LDH includes a Health Standards Section within its regulations, where they are responsible for certifying and licensing healthcare facilities with regulatory compliance (LDH, n.d). These state-level agencies are directly informed of the news of an M&A and make sure that any mergers comply with state laws and regulations. Institutes and coalitions that can help with checks and balances of healthcare systems in New Orleans include institutes such as, Tulane University School of Public Health and Tropical Medicine, 504HealthNew, Healthcare Preparedness Coalition, and the Louisiana Action Coalition. Public Health schools such as Tulane University and Louisiana State University play a key role in public health and medical research, education, and practice within New Orleans and the state of Louisiana. This allows for contributions into training health professionals and generating knowledge to be applied to promote the well-being of the population from a medical, public health, and business perspectives (Tulane University, n.d). Many coalitions and organizations in the region - like 504HealthNet - allow for outreach and enrollment efforts for vulnerable populations to access community health center facilities. The Healthcare

Preparedness Coalition and the Louisiana Action Coalition enhance access to sharing of resources in an intra-regional cooperation to support health services (Healthcare Coalition, 2012). The examples of institutions and coalitions in the New Orleans area not only contribute to allowing for more access to health services, but also provide education, research, and checks and balances to help recognize and shape the healthcare challenges that this new acquisition could introduce.

Overview of Acquisition

The acquisition of the Tulane hospitals by LCMC has the potential to significantly reshape the healthcare infrastructure in New Orleans, raising both opportunities and concerns for the delivery of services. These concerns include a shift from a national to local operator, gaps in centralized urban inpatient care, possible strain or consolidation of specialty services, risks of the emergence of a duopoly, and lastly, the influence on medical education infrastructure.

The overall shift from a national, for-profit operator (HCA) attached to an academic health system (AHSs) to a local, non-profit (LCMC) could potentially localize decision-making but reduce access to federal-level resources. The impact on the healthcare infrastructure from a more localized system could lead to a greater alignment with the community's wants and needs. But, with less access to federal resources, this could pose

more challenges for getting research funding and help on the federal level if a healthcare overload occurs. Other ethical considerations focus on the now gap in centralized urban inpatient care for marginalized populations that rely on this central access to hospital services, including questions on patient autonomy and choice, access to care geographically, distributive justice, and public trust. With the exit of HCA and the consolidation of services under LCMC and Ochsner, the New Orleans healthcare market now functions as a near-duopoly, raising questions about long-term market competition and patient outcomes. In healthcare, a mixed duopoly is defined as “a situation where two companies together own all, or nearly all, of the market for a given product or service” (Oxford, 2024). In the context of this hospital system, a near duopoly, where LCMC Health and Ochsner Health dominate the hospital and specialty care in the region. While this can promote efficiency, it also raises concerns about pricing power, innovation, service accessibility, and limited incentives to expand outreach programs. Without significant competition, one or both systems may become complacent about expanding and maintaining excellence of care without third parties keeping the hospitals in check. Geographical considerations could also make one system to prioritize specific populations by income level, geographic location, or insurance status, and would in turn absorb the cost burden of providing care to those underserved populations. In

order to not exacerbate one system over another, local governing systems, coalitions, and institutions have a chance to proactively oversee the regulations and note where gaps in care are present. By overseeing these systems it can ensure that the health and properties are the priority and not just consolidation of the health system.

Ethical Considerations

Access to care

A critical ethical concern of the acquisition is its impact on equitable access to healthcare, particularly for already marginalized communities in New Orleans and the surrounding areas. With Tulane Medical Center, Lakeview Hospital, and Lakeside Hospital joining LCMC, the services are shifting to the University Medical Center New Orleans and East Jefferson General Hospital from Tulane Medical Center (LCMC). With services shifting from downtown New Orleans and the Central Business District’s Tulane Medical Center, it could cause trouble for residents in previously recorded low-income downtown neighborhoods, including Central City, Tremé, and parts of Mid-City (Mock, 2018). These neighborhoods are still historically impacted by Hurricane Katrina, due to displacement, lack of affordable housing or gentrification, where these hospitals are now being moved to. The residents in these areas now will need to travel further for care—especially emergency or specialty

services, due to public transit access potentially being more complex or time-consuming for these populations. A large portion of unhoused and vulnerable populations are located in Central New Orleans. These populations often relied on Tulane Medical Center's proximity and public health programs. The shift away from these hospitals, where previously they easily allowed walk-in ER visits, social work assistance, and hospital-affiliated public health outreach programs may lead to challenges (Tulane, n.d). With the relocation of services, these may be farther away and less accessible by foot. Service disruption in the relocation could lead to vulnerable populations falling through the cracks due to the restructuring of these programs and the geographic shifts. Another critical concern to be considered is the potential for emergency overcrowding due to service consolidation, leading to care delays, strain on hospital staff, and longer wait times (Sartini, 2021).

The Lakeview Regional Medical Center's acquisition could mean potential service realignments, switching to other hospitals, also making access more difficult for North Shore residents. Due to limited public transport across Lake Pontchartrain, it could lead to accessibility issues for low-income and elderly populations in this area (Destination GNO, 2025). Another possible shift in services is with Tulane's Lakeside Hospital, which has a history of serving suburban families with a focus on women's and children's care (LCMC, n.d). This shift

could lead to healthcare inequity among women and children which already struggles with some of the highest maternal mortality in the US (LDH, 2024). If healthcare services also experience alignments, it could impact both Metairie and Kenner residents, causing longer travel times and less immediate access, impacting those working-class suburban families' access. Families with little transportation access or time might fall through the gaps in this acquisition, which are often already in vulnerable positions.

Autonomy and Choice

This consolidation of healthcare systems could limit patient autonomy through restricted provider networks and fewer options for referrals, raising ethical concerns about freedom of choice in care. Often, network characteristics vary in different geographic regions, making it hard to see if specifically the New Orleans acquisition will have substantial variation in network care (Landon, 2018). Although physicians "tend to share patients" depending on the similar physician and patient characteristics within a population (Landon, 2018). Patients having autonomy over medical decisions and choice within-network providers is important as it allows patients to make informed decisions. With restricted provider networks due to mergers like LCMC Health's acquisition, it could mean the patients are limited in seeing doctors, specialists, or receiving

services within just these two health systems within New Orleans (Schneider, 1998). If a patient's current trusted provider is affiliated with a competing system, it could lead to insurance contracts or referral rules to prevent them from seeking or continuing care with the providers. This could lead to barriers in seeking second opinions and specialty services outside of a care network. With fewer choices, there is less patient autonomy, which could cause disrupted continuity of care, lack of flexibility, and even a loss of trust in the healthcare system.

Distributive Justice

Distributive justice necessitates an examination of who benefits and who may be left behind in these hospital mergers. Fisher defines distributive justice as “The fair and appropriate distribution of benefits, risks, and costs within a society” (Fisher, 2020). Potential beneficiaries of this may include Tulane University, LCMC, and the insured middle-class patients. All while those who may suffer include Medicaid-dependent parties, underinsured populations, and rural patients who relied on HCA’s network. In the case of the many populations that LCMC represents, the distributive justice states that similar cases should be treated in similar manners (Fisher, 2020). With a health system M&A, services are consolidated into fewer facilities, jeopardizing Medicaid-dependent and underinsured patients who rely on the safety-net hospitals for accessible care,

making it harder to navigate new, unfamiliar, and centralized health systems. On the other hand, the beneficiaries, such as Tulane University and LCMC Health, gain expanded space for nursing education and research, more streamlined services, better care coordination, and access to local and advanced specialty care that may not have been present before the acquisition.

From a resource allocation perspective, closely monitoring how LCMC is able to distribute medical equipment, staff, and funding as this system expands to be equitable and efficient in a larger landscape. While according to Tulane and LCMC’s agreement, “all employees will retain their jobs”, the questions of the new working conditions, a new healthcare workload and burden, and how new structural support is established are still up in the air (LCMC, n.d). With hospitals facing M&A’s or financial uncertainty, a specific population that could be impacted is nursing staff. Financial uncertainty or restructuring has led to reduced nurse staffing or higher patient-to-nurse ratios that can lead to burnout (Everhart, 2013). If resources or funding are disproportionately concentrated in certain hospitals, other hospitals may face staffing and investment issues, leading to a greater healthcare burden.

Transparency and Public Trust Ethics

An acquisition of this scale requires transparency to uphold public trust, yet the court battles and antitrust exemptions have led to skepticism. In the LCMC case, the legal battle with the FTC raised concerns over oversight and accountability (FTC Court Case, 2023). The main concern with this case highlighted that there was not clear public communication or community engagement in the decision-making process of this merger, potentially excluding the public in choices that affect their healthcare (Muoio, 2023). While the courts upheld that this deal was exempt from federal antitrust laws, this already raises concerns of regulatory oversight.

Due to early, limited public discourse on the deal, there are already trust issues building. The public, specifically vulnerable populations, are often those left out of these discourses and are the most impacted by the decisions. Transparency and disclosing the terms of the merger and rationale, while including regular updates on how it is being implemented and changed, is crucial in building trust. In order to do this, maintaining a clear, concise commitment to ethical governance, elaborating on healthcare system risks, and allowing for public accountability can foster mutual respect with the public. For the future of this merger, it is now more than ever important to uphold trust with this new health system and ensure the public is a part of the future of healthcare planning.

Final Thoughts

The LCMC acquisition serves as a case study not just in healthcare business but as an ethical example of the intersection between public health values, healthcare delivery, health transparency, and health accountability. While the long-term outcomes of this merger are still unfolding, its implications reach beyond the New Orleans community. Allowing for this case study to serve as a lesson on how future healthcare mergers may reshape the healthcare service landscape.

There are opportunities and risks to this consolidation. On one hand, local control offers the promise to be able to best serve the community's needs and make changes to the system. If this is matched by ethical responsibility among the two healthcare systems, and kept in check by my local third parties, this acquisition will be an important case for national health policy followers. On the other hand, ethical recommendations with M&A's in healthcare systems include ensuring transparency and community engagement, upholding justice by measuring outcomes in marginalized communities, and committing to healthcare inquiry as a main outcome, not just cost savings. While the emergence of a near-duopoly raises concerns and questions about competition, it remains clear that ensuring the community's needs are at the forefront of the healthcare system. Creating spaces for open dialogue with the public is crucial in building a healthy relationship with both the public, the

providers, and healthcare system governance. This allows for ethical concerns of access for vulnerable populations not to be overlooked in favor of efficiency or financial motivation.

Moving forward, healthcare mergers like the LCMC acquisition require clear ethical frameworks that prioritize community voice, health equity, and transparency. Third-party institutions, public health agencies, and academic partners are essential in monitoring and ensuring resources are allocated properly to address health gap concerns. Ultimately, mergers and acquisitions are not just about improving fiscal and administrative shifts; they are decisions that shape local communities and lives. Keeping in mind ethical considerations in cases like the LCMC-Tulane case serve as a reminder that looking out for the underserved populations is a priority of ethical decisions rather than just improving efficiency. Recognizing the inherent right to equitable healthcare is not just a moral responsibility, but the foundation for building a more efficient and inclusive health system.

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HOW DEMOGRAPHICS AND INCOME PLAY A ROLE IN HEALTHCARE ACCESS

by Dr. Harshavardhini Nallakannu

ABSTRACT

Receiving proper healthcare is still a big issue in the U.S., and many people face challenges based on where they live, how much education they have, or whether they can afford insurance. This paper looks at how these factors affect an individual's ability to access care. In many cases, your zip code can say more about your health than your genes. People with public insurance or no insurance often struggle to find care because of problems like not enough providers nearby or lack of transportation. Education also plays a big role; people with more schooling tend to have better health because they can get better jobs, understand health information, and find the help they need more easily. The articles reviewed in this paper stress the need to reduce health differences and make access fair for everyone, especially those living in underserved communities.

INTRODUCTION

Access to healthcare is measured by the timely use of personal health services to achieve the best health outcomes (Millman, 1993). Attaining good access to care means having health insurance that

allows entry into the healthcare system, timely access to needed care, a developed patient-provider relationship, and to provide a patient's perception of need (Agency for Healthcare Research and Quality (US), 2021). Where you live plays a major role in determining your overall health and life expectancy. In fact, almost 60% of your health is influenced by your zip code alone. This is largely because of factors tied to the community you live in - such as its level of wealth, the degree of community investment, and the availability of hospitals and health services. Compared to individual behavior or access to medical care, your social and physical surroundings have a greater impact on both personal and community health (Orminski, 2021). Another reason for ensuring proper access is to support education. In the U.S., populations with higher levels of education tend to live longer and experience better health compared to those with fewer years of schooling. This is because, in today's job market, individuals with more education are more likely to find employment that offers essential health-related benefits such as insurance, paid leave, and retirement plans. On the other hand, populations with lower education levels are more often employed in high-risk jobs that provide fewer protections and benefits. Additionally, higher education is closely tied to greater income, which significantly affects health. Populations with higher incomes are better able to afford nutritious food, regular physical activity, medical care, and transportation (Center on Society and Health, n.d.).

To understand the broader issue, we must first ask – what is health equity? The CDC defines it as a state in which everyone

has a fair and just opportunity to reach their highest level of health. When these conditions are not met, health disparities can arise – these are preventable differences in the burden of disease, injury, violence, or access to health opportunities that different populations experience. When individuals or communities lack access to the necessary resources for good health, this is where the concept of Social Determinants of Health comes into play (What Is Health Equity?, 2024).

In this article, we will discuss how individuals can make informed decisions by utilizing available resources to access healthcare and enhance overall health knowledge.

CURRENT SITUATION

A 2023 article by Tolbert et al. (2024) highlights that most uninsured people in the U.S. between the ages of 0 and 64 belong to working families. Around 74% had at least one full-time worker in the family, while 11% had a part-time worker. The majority, over 80%, had family incomes below 400% of the federal poverty level (FPL), and nearly half were below 200% FPL. Many of these workers don't receive health coverage from their jobs. Even when coverage is offered, the cost can be too high to afford. Between 2014 and 2024, health insurance premiums for families rose by 52%, growing faster than wages. As a result, many low-income families spend a disproportionate share of their income on healthcare (Tolbert et al., 2024).

A recent study by Allen et al. (2016) shows that barriers to healthcare are mostly due to broader system-level problems rather than individual choices. For people with low income and public insurance, challenges like unclear information about coverage, high costs, and limited access to services were reported almost twice as much as issues related to the patient or provider. Even small obstacles, such as trouble getting appointments or finding transportation, can delay or prevent people from getting the care they need. These problems reflect how the healthcare system is organized, especially for underserved groups, and are not simply a matter of personal responsibility. Many also experience multiple barriers at once, including discrimination based on income or gender, which makes it harder to use preventive services. Having insurance doesn't always mean people can get affordable or timely care, especially when the system is difficult to navigate or still too expensive. All of this shows that solving these issues requires changes in policies and the healthcare system, not just expecting people to do more on their own (Allen et al., 2016).

A REAL LIFE ACCOUNT OF STRUGGLING TO RECEIVE CARE

An article by Altman (2022) highlights the harsh reality faced by many individuals living in underserved zip codes across the U.S., such as 63106 in St. Louis, one of the poorest and least healthy in Missouri. The article shares the story of a man who lost both his

Medicaid and disability benefits after attempting to improve his situation by seeking employment. When the job offer fell through, he was left without health insurance or a primary care provider. The article also reveals how many individuals are unaware that Medicaid covers services like dental care, leaving them to suffer in silence due to lack of accessible information. This story reflects the difficult decisions countless Americans face daily, choosing between basic needs and healthcare. It shows how deeply a place of residence, income, and insurance status can determine whether someone gets the care they need and deserve (Two Zip Codes, a World Apart, 2022).

CONCLUSION: EVERYONE DESERVES A FAIR CHANCE AT HEALTH

The main point I want to leave with you is that where someone lives or how much money they make should not decide whether they get medical care. Everyone should be able to see a doctor, get tested, and , and be treated, no matter their background.

In the article, a man living in an underserved neighborhood in St. Louis had a serious health issue, but because he didn't have insurance and lived far from good hospitals, he couldn't get care right away. Still, he didn't give up. He looked for help in his community and found a clinic that finally gave him the care he needed (Two Zip Codes, a World Apart, 2022). His experience

shows how tough it can be for people in similar situations, and why the system needs to do better.

If you or someone you know is in this position, places like community health centers, local health departments, and free clinics can help. Even though the challenges are real, there is hope. By spreading awareness and supporting policies that make healthcare more equal, we can move toward a future where everyone gets the care they need, not based on their zip code, but on their right to live a healthy life.



Dr. Harshavardhini Nallakannu is a healthcare professional with a strong foundation in clinical medicine and public health, and passionate about driving data-informed improvements in healthcare systems. Currently she serves as a Hospital Operations Coordinator in a behavioral health department. She applies her expertise in health management, policy, and epidemiology to optimize patient outcomes and operational efficiency. With an MD and

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What Does it Mean to Die? Ethical Considerations for the Relationship Between Death and Personhood

By Erin Gannon

In society, there needs to be an official standard death for such legal processes as will writing, property rights, and the ability to charge for criminal murder. In healthcare, the legal standard of death affects questions about organ donations, termination of care, and considerations of insurance and payment. How we define death impacts the answers to those questions. The shift in the legal standard of death which includes the standard of “brain death” has brought with it a variety of ethical considerations for end-of-life questions.

This paper focuses on the ethics of defining death and its relation to a society's concept of personhood. If there can be multiple legal definitions of death, as it has been since the adaptation of the Uniform Determination of Death Act (UDDA), does this change how we value what it means to be a person and the idea of the meaning of life?⁸⁷ If so, should the Rule of Law have the power to impact society and cultures in such a way?

⁸⁷ National Conference of Commissioners on Uniform State Laws. *Amendments to Uniform Brain Death Act, Uniform Determination of Death Act*. [Chicago] :[The Conference], 1980.

First, this paper discusses the implications of decisions around the end of life for the concept of philosophy and personhood. Then, it discusses bioethical concerns around the current legal standards of death. Finally, it discusses whether such legal standards can and should reflect our understanding of personhood.

A Brief History of the Legal Concept of Brain Death

Until recent history, the definition of death has focused on cardiopulmonary standards that centered on the cessation of heart or lung functioning to declare a person dead.⁸⁸ With advancing technology that supports the functioning of the heart and lungs when they fail, humans, or more so their organs, can now survive beyond the traditional definition of death.⁸⁹ This extension of organ functioning beyond our historical understanding of failure has led to a cognitive dissonance for our society in the difference between a living body and a living person.

In the 1950s, with the advent of technology such as cardiopulmonary resuscitation, respiratory support, and organ transplants, patients could 'live' beyond the cardiopulmonary standard of death, defined by whether or not the heart or lungs were functioning.⁹⁰ In the 1960s, Harvard Medical School set out

⁸⁸ Doyen Nguyn, O.P., MD, STD, *Does the Uniform Determination of Death Act Need to Be Revised?* **Linacre Q.** 2020 Aug; 87(3): 317–333. Published online 2020 June 2. doi: [10.1177/0024363920926018](https://doi.org/10.1177/0024363920926018)

⁸⁹ Safar P. On the history of modern resuscitation. *CRIT CARE MED.*, (February 1996)

to investigate whether what, at the time, was an irreversible coma could be considered brain death.⁹¹ A nonfunctioning brain, known as brain death occurred when a person showed signs of unresponsiveness, lack of breath, no reflexes, or a flat electroencephalogram.⁹² The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research issued a report that called for a uniform definition of death based on a total brain standard to help encompass this new set of criteria.⁹³ The total brain standard is defined as the end of functioning of a person's entire brain.⁹⁴ The committee's goal for this standard was to have a legal standard of death that could apply to those patients to whom the cardiopulmonary standard may not apply. Additionally, the commission opted for a total brain standard rather than a higher brain standard as every 'total brain' death would also be a case of 'higher brain' death.⁹⁵ This decision was to ensure that the new standard had the highest level of scrutiny.

⁹⁰ De Georgia MA. History of brain death as death: 1968 to the present. *J CRIT CARE.* (August 2014)

⁹¹ Harvard Medical School, Ad Hoc Committee. "*A Definition of Irreversible Coma.*" *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* 205 (1968)

⁹² Michael A. De Georgia, MD, *History of brain death as death: 1968 to the present*, *JOURNAL OF CRITICAL CARE*, 29 673–678 (2014)

⁹³ *Id.*

⁹⁴ *Id.*

⁹⁵ Michael A. De Georgia, MD, *History of brain death as death: 1968 to the present*, *JOURNAL OF CRITICAL CARE*, 29 673–678 (2014)

In 1981, the Uniform Determination of Death Act (UDDA) was established, adopted by the American Bar Association and American Medical Association, and made into some form of law in all 50 states.⁹⁶ This act states, "an individual who has sustained either: 1. irreversible cessation of circulatory or respiratory functions or 2. irreversible cessation of all functions of the entire brain, including the brain stem, is dead."⁹⁷ The AAN laid out a primarily clinical test and instilled that required an apnea test before determining brain death.⁹⁸ The legal standard of total brain death has not altered much since the original U.D.D.A.

Outside of the legal standard of death, there are three: brain stem death, higher brain death, and whole-brain death.⁹⁹ People may be declared dead in some countries based only on brainstem death rather than whole-brain death.¹⁰⁰ Higher brain death implies that human life is equivalent to sentience in many philosophical theories.¹⁰¹ This standard is the death of the

⁹⁶ Youngner SJ. *Defining Death: A Superficial and Fragile Consensus*. ARCH NEUROL. 49(5):570–572 (1992)

⁹⁷ National Conference of Commissioners on Uniform State Laws. Amendments to Uniform Brain Death Act, Uniform Determination of Death Act (1980)

⁹⁸ AAN Summary of Evidence-based Guideline for Clinicians, *Update: Determining Brain Death in Adults*, (2010)

⁹⁹ Greer DM, Shemie SD, Lewis A, et al. Determination of Brain Death/Death by Neurologic Criteria: The World Brain Death Project. JAMA, 324(11):1078–1097 (2020)

¹⁰⁰ Anant Dattatray Dhanwate, *Brainstem death: A comprehensive review in Indian perspective*, INDIAN J CRIT CARE MED. 18(9), 96-605, (September 2014)

cognitive and conscious brain but may imply that patients in a coma or persistent vegetative state would be considered dead.¹⁰² As mentioned, whole-brain death theory combines the theories of brainstem death and higher brain death and includes the cessation of the entire brain functioning.¹⁰³ A key distinction drawn between these unofficial definitions of death is that higher brain death may be confused for a disorder of consciousness. Disorders of consciousness further complicate the ethics surrounding brain death.

A person has a disorder of consciousness when "[they] has difficulty maintaining wakefulness or has impaired awareness of self due to their medical condition."¹⁰⁴ There are four significant kinds of disorders of consciousness: Locked-In syndrome, minimally conscious state, persistent vegetative state, and chronic coma.¹⁰⁵ Locked-In Syndrome occurs when a patient is awake and conscious but is in complete or nearly complete paralysis.¹⁰⁶ Persistent vegetative states occur when patients

¹⁰¹ Robert Truog, MD, *Brain Death: At Once "Well Settled" and "Persistently Unresolved"* VIRTUAL MENTOR, 6, (August 2004)

¹⁰² *Id.*

¹⁰³ Bernat, J. L., *A Defense of the Whole-Brain Concept of Death*. THE HASTINGS CENTER REPORT, 28(2), 14–23, (1998)

¹⁰⁴ Shepard Center, *Learn About Disorders of Consciousness States and Causes*, [https://www.myshepherdconnection.org/disorders-consciousness/Intro-disorders-of-consciousness#:~:text=A%20disorder%20of%20consciousness%20\(DOC,dueto%20a%20medical%20condition](https://www.myshepherdconnection.org/disorders-consciousness/Intro-disorders-of-consciousness#:~:text=A%20disorder%20of%20consciousness%20(DOC,dueto%20a%20medical%20condition)

¹⁰⁵ *Id.*; Center for Health Ethics, *Concept of Personhood*, <https://medicine.missouri.edu/centers-institutes-labs/health-ethics/faq/personhood#:~:text=Moral%20personhood,acts%20are%20blameworthy%20or%20praiseworthy>.

have no awareness of self and their surroundings, and have no voluntary movement of the body or fact, but their respiration is intact.¹⁰⁷ Finally, when a patient is comatose, they are unresponsive to stimuli and in a deep unconsciousness that usually is not permanent.¹⁰⁸ These disorders are not considered legal or medical brain death but may affect a person's rationality, consciousness, or sense of self. While considered for this paper to be actual death, brain death falls under the classification of a disorder of consciousness.¹⁰⁹ These disorders play a prominent role in philosophical considerations of personhood as they call into question distinctions between the consciousness of a functional brain and that of a nonfunctional, dead brain.

The line between disorders of consciousness and brain death is murky. While clinical and legal standards clarify legal decision-making over death, is it possible that it draws too sharp of a line? One worry around brain death as a criterion is its ability to shape the concept of personhood. At the same time, the legal definition of death attempts to clarify the murky nature of the discussion of consciousness.

¹⁰⁶ Overview: Disorders of Consciousness, <https://www.nhs.uk/conditions/disorders-of-consciousness/#:~:text=Locked%2Din%20syndrome%20has%20similar,able%20to%20communicate%20by%20blinking> (August 6, 2018).

¹⁰⁷ *Id.*

¹⁰⁸ *Id.*

¹⁰⁹ Overview: Disorders of Consciousness, <https://www.nhs.uk/conditions/disorders-of-consciousness/#:~:text=Locked%2Din%20syndrome%20has%20similar,able%20to%20communicate%20by%20blinking> (August 6, 2018).

What Does it Mean to Be a Person?

Throughout history, humans have grappled with the concept of our existence. We have attempted to answer questions about the beginning, middle, and end of life. The concept of personhood has been at the forefront of many of these questions. If a standard of death centered around brain death calls into question philosophical theories of personhood, could that be reflected in the legal definition or vice versa? Should the legal standard of personhood be taken into account when defining death? Attempting to have a concrete definition of death that can apply in both medical and legal settings may have implications on what, as a society, we consider a person.

Personhood is the philosophical concept that defines what it means to be an individual moral agent.¹¹⁰ In philosophy, one can be a person either metaphysically or physically.¹¹¹ Metaphysical personhood is not considered physical. Instead, this kind of personhood focuses on a being's ability to have such things as rationality, consciousness, or moral acts.¹¹² Materialists believe to be a person means to be our physical bodies.¹¹³ At the

¹¹⁰ Center for Health Ethics, *Concept of Personhood*, <https://medicine.missouri.edu/centers-institutes-labs/health-ethics/faq/personhood#:~:text=Moral%20personhood,acts%20are%20blameworthy%20or%20praiseworthy>.

¹¹¹ Center for Health Ethics, *Concept of Personhood*, <https://medicine.missouri.edu/centers-institutes-labs/health-ethics/faq/personhood#:~:text=Moral%20personhood,acts%20are%20blameworthy%20or%20praiseworthy>.

¹¹² *Id.*

center of these theories is the 'mind-body' problem which focuses on questions concerning the relationship of conscious thought in our mind and its relation to our brain and physical bodies.¹¹⁴ So, concerning brain death, if death is the end of the person and if personhood identifies with brain functions like consciousness or rationality, then it could be that the death of a person is the death of the brain.

The relationship between personhood and consciousness in the medical may be relevant when discussing brain death. Legal personhood refers to the "standing or status that is bestowed upon one human being, by others, in the context of relationship and social being."¹¹⁵ On the other hand, consciousness is the state "in which a patient is awake, aware, alert and responsive to stimuli" and is a subjective awareness of the "content of the mind."¹¹⁶ In a research paper, "*Consciousness and Personhood in Medical Care*," the contrast between personhood and consciousness is further explored. The critical distinction is that personhood relies on relationships between two human beings rather than one person's relationship; in essence, the state of being aware.¹¹⁷ In relation to brain death,

¹¹³ *Id.*

¹¹⁴ Stanford Encyclopedia of Philosophy, *Dualism*, <https://plato.stanford.edu/entries/dualism/>

¹¹⁵ Kitwood, T. *Dementia Reconsidered: The Person Comes First*. Buckingham: OPEN UNIVERSITY PRESS. (1997)

¹¹⁶ <https://medical-dictionary.thefreedictionary.com/consciousness>

there has been confusion for family members between the line of a disorder of consciousness and death in disorders of consciousness.¹¹⁸ It may be that the blurred line between disorders of consciousness and brain death arises from our concept of personhood. Suppose the essence of being a person centers on rationality, which may only occur in consciousness. Could that mean those who suffer from consciousness disorders are no longer persons?

The legal concept of personhood focuses on individuals as decision-makers who should have informed consent and legal autonomy.¹¹⁹ A legal person has the legal rights to enter into a contract or own property in the same way that a person can.¹²⁰ Of late, even some courts have granted animals legal personhood rights.¹²¹ The legal definition of personhood as it relates to beings that either may become a philosophical person or have once been a philosophical person are highly contentious and still up for debate. Philosopher Anne Warren defines a person as an individual with moral standards to consider when looking at the

¹¹⁷ Blain-Moraes S, Racine E and Mashour GA, *Consciousness and Personhood in Medical Care*. FRONT. HUM. NEUROSCI. 12,306 (2018)

¹¹⁸ Devan Stahl, Ph.D., and Tom Tomlinson, Ph.D., *Death by Neurological Criteria: Caring for Families amid Tragedy*,

¹¹⁹ Need cite

¹²⁰ Legal Information Institute, *legal person*, https://www.law.cornell.edu/wex/legal_person

¹²¹ Legal Information Institute, *legal person*, https://www.law.cornell.edu/wex/legal_person

legal definition of personhood.¹²² Her theory put forth five factors to consider when granting something the legal rights of a person include: “1. consciousness, 2. reasoning 3. self-motivated activity, 4. capacity to communicate, and 5. presence of self-concepts or self-awareness.”¹²³ None of these elements are necessary to be considered a person, some of these are sufficient, but an individual without any of these is highly likely not legally a person.¹²⁴ In the context of abortion rights, she argued that if fetuses do not have any of the five of these elements; therefore, it is highly likely that they are not a legal person.¹²⁵ A being that is legally brain dead 1. lacks consciousness, 2. likely cannot reason, 3. Does not have self-motivated activity, 4. lacks the capacity to communicate in any form, and 5. are likely not self-aware. Under Warren’s concept of personhood, a brain-dead patient would likely not be considered a person. Personhood has many different definitions, factors to consider, and ways to apply in life. Should and could something so volatile be used to consider the ethics of brain death? The law has a rigid and more obtuse standard of personhood than other philosophical ones, like Mary Warren’s.

¹²² Warren, M. A., *On the moral and legal status of abortion*. THE MONIST, 57(1), 43–61 (1973).

¹²³ *Id.*

¹²⁴ *Id.*

¹²⁵ *Id.*

Philosophy and law have attempted to define what it means to be a person throughout history. A common thread is a being’s ability to feel, reason, and self-identify. When comparing the UDDA standard of death, a legally brain-dead person would not be considered a person. However, those with other disorders of consciousness also may not qualify as a person. Since personhood may not be the key definer of the distinction between life and death, something else could be. Relationships between loved ones and those declared brain dead could play a vital role in the definition of death.

If Death is a Spectrum, Does a Concrete Definition Lead to More Confusion?

Ever since implementing the brain death standard, there have been troubling responses from people whose loved one’s had either been declared brain dead or whose death is up for debate. These responses result from confusion about whether or not their family member is dead. There are two main reasons for this. First, the standard of brain death is not consistent across countries and even across states. Second, many disorders of consciousness appear outwardly similar, which leads those close to the individuals to believe they may still be alive. Ironically, attempting to implement a uniform standard of death may have led to confusion about the line between life and death.

To keep up with modern technology, countries have implemented the standard of brain death. This implementation

has caused controversies in countries whose cultural beliefs do not align with this concept. For example, there has been a fierce debate over the concept of heart transplants and brain death in Japan.¹²⁶ Many Japanese citizens have a combination of beliefs of religions, including Shinto, Taoism, Confucianism, and Buddhism.¹²⁷ Those that follow Shintoism believe that the end of a heartbeat is the confirmation of death and that any other declaration of death is unnatural.¹²⁸ Other beliefs, such as Taoism, believe in preserving the body to provide the soul with a place of rest.¹²⁹ There seems to be a direct conflict between these cultural beliefs and the use of brain death as a legal standard of death in Japan.¹³⁰ In the 1990s, medical establishments in Japan began to follow the concept of brain death; many in the Japanese population were adamantly against this view.¹³¹ This decision resulted in a dual definition of death in Japan, including brain death.¹³² In this case, there seems to be a large gap between the medical belief of death and the cultural

¹²⁶ John Robert McConnell, III, *The Ambiguity about Death in Japan: An Ethical Implication for Organ Procurement*, *JOURNAL OF MEDICAL ETHICS*, Vol. 25, No. 4 (Aug. 1999), pp. 322-324

¹²⁷ *Id.*

¹²⁸ *Id.*

¹²⁹ *Id.*

¹³⁰ *Id.*

¹³¹ *Id.*

¹³² *Id.*

view of what personhood means. In Japanese culture, to declare someone dead, or no longer a person, based on anything other than the end of a heartbeat is wrong. Dynamics between institutions such as the law and healthcare must consider the populations they serve. Even if something becomes a legal definition, it may not have the power to shift a cultural belief.

Moreover, in the United States, there are also multiple definitions of death. This lack of homogeneity is because the medical standard of death is state based, so each state can implement the UDDA. The idea that a person could be considered dead in one state and not be considered dead in another has placed an enormous strain on the individuals confronted with loved ones who have been declared brain dead. Perhaps the most extreme example of this is in New Jersey. The New Jersey Declaration of Death Act allows for a determination of death based on both cardiopulmonary and neurological standards; however, in Section 6 of the act, there is a stipulation that the physician authorized to declare death must make a good faith and reasonable effort to "determine whether this declaration would violate the personal religious or moral convictions of that individual."¹³³ With this exception, some have coined New Jersey as "the best place to be brain dead."¹³⁴

¹³³ 1991 N.J. ALS 90, 1991 N.J. Laws 90, 1990 N.J. S.N. 1208

¹³⁴ Alex Napolliello, *New Jersey best place for brain-dead patients, expert says*, (June 20, 2014), https://www.nj.com/news/2014/06/new_jersey_best_place_for_brain-dead_patients_expert_says.html

The case of Jahi McMath illustrates the strain and emotional turmoil this disconnect between state laws may have on the loved ones of patients in these situations.¹³⁵ After post-surgical complications, a 13-year-old girl, Jahi McMath, had her heart and lungs stopped working in a California hospital, where she was declared brain-dead two days later.¹³⁶ California follows a version of the UDDA, and the McMaths were encouraged to make a plan to take Jahi off of her life support, but they declined because of their religious beliefs.¹³⁷ Eventually, after a long legal battle, Jahi was transferred to New Jersey.¹³⁸ Jahi was declared dead in New Jersey from liver failure after five years of being attached to life-support.¹³⁹ This case put Jahi's family through immense emotional turmoil. Had there been uniformity across state lines, the decision for her family may have been more apparent. Even if it had been against their beliefs, the decision would have been taken out of their hands and reduced their emotional turmoil.

To add to the confusion of loved ones, brain death does not fit into the traditional concept of death that most people are used to seeing. A patient may still breathe with their cheeks still

¹³⁵ *McMath v. California*, 2016 U.S. Dist N.D. Cal, 3:15-cv-06042

¹³⁶ D. Alan Shewmon, Noriko Salamon, *The Extraordinary Case of Jahi McMath*, JOHNS HOPKINS UNIVERSITY PRESS, vol 64, num. 4, 457,478 (Autumn 2021)

¹³⁷ *Id.*

¹³⁸ *Id.*

¹³⁹ *Id.*

rosy and be legally and medically brain dead.¹⁴⁰ As was stated, the disorders of conscious incredibly similar to one another. For example, to a layperson's eye, there is minimal, if any, the distinction between someone who suffers from Locked-In Syndrome and someone who is brain dead. In most circumstances, loved ones of brain-dead patients believe that they are only suffering from a disorder of consciousness and are alive.¹⁴¹ On the one hand, some loved ones of patients who are not brain dead but have a disorder of consciousness feel that their family member has passed on.¹⁴² Adding even more complexity, there have been a few cases where physicians diagnosis patients as either in a comatose versus a vegetative state or comatose versus Locked-In Syndrome.¹⁴³ While the standard to be declared brain dead is likely strict enough that misdiagnosis is rare, the fact that disorders of consciousness are can appear to be on a spectrum may be a cause of concern for family members, just like with lack of uniformity in state laws, the confusion of the disorders adds additional strain on loved ones.

¹⁴⁰ Gary Greenberg, *Lights Out: A New Reckoning for Brain Death*, NEW YORKER, (January 15, 2014)

¹⁴¹ Joffe, A. Confusion about brain death. *Nat Rev Neurosci* 7, 590 (2006).

¹⁴² Kitzinger C, Kitzinger J. 'This in-between': How families talk about death in relation to severe brain injury and disorders of consciousness. In: Van Brussel L, Carpentier N, editors. *The Social Construction of Death: Interdisciplinary Perspectives*, PALGRAVE MACMILLAN; 2014. Chapter

12, <https://www.ncbi.nlm.nih.gov/books/NBK252967/>

¹⁴³ *Id.*

A final factor that adds to the confusion for family members is specific language for end-of-life decision-making. Colloquially things like ventilators and respirators are referred to as 'life-support.' However, if used on a patient who may be declared brain dead, there is an inherent contradiction. Also, the contingent use of 'brain' in the 'brain dead' rather than simply dead can lead to confusion. Loved ones may hear a, "Your loved one is brain dead. Would you like to take them off of life support?" and think their decision is the one that would lead to their loved ones being officially dead. One paper offered to use terms such as 'artificial corpus support' or 'replacing natural function' instead of life support to reflect the circumstances accurately.¹⁴⁴ The clarity in the language use may also help families accept that there is no more to do and help families in the process of acceptance of death.

The rule of law helps society function smoothly; therefore, if a legal concept adds confusion to an already difficult decision, it may not serve its correct purpose. Unfortunately, the lack of clarity and homogeneity of the legal definitions of death worldwide have led to familial confusion. With each layer of confusion added to the decision surrounding brain death, loved ones are burdened more and more.

¹⁴⁴ Medical Ethics Advisor, *Coverage of brain-dead patient on life support* "Profound lack of understanding about the concept of death," RELIAS MEDIA, (November 1, 2014), <https://www.reliasmedia.com/articles/110629-coverage-of-brain-dead-patient-on-life-support-profound-lack-of-understanding-about-the-concept-of-death>

Who Has the Final Say?

With all of these considerations: the push for a broader legal definition, a potential ability to shift concepts of personhood, and society seemingly filled with confused and grief-stricken loved ones, is there a correct way to define death? If so, should it be brain death? The utilitarian approach to bioethics focuses on decision-making that would result in the 'best' for society.¹⁴⁵ Rule utilitarianism 'focuses on rules as a guide to correct conduct and judges whether a rule is correct by the consequences the rule produces.'¹⁴⁶ The current definition of brain death seems to be the U.S. legal system's attempt to have a rule-based utilitarian approach to death.

The American health system is incredibly complex and relies mainly on laws to continue to function in a way that helps people. A legal definition of death must exist in our system for this very reason. The transition of care, legal rights in contract and property, and healthcare resources rely on legal declaration of death for patients to function. Modern medicine will only continue to make advances that will further push the legal standards in this country. So, while the UDDA may not apply to what health systems look like in fifty years, some version of a

¹⁴⁵ B. Furrow et. Al, *Bioethics: Health Care Law and Ethics*, WEST ACADEMIC PUBLISHING, 7 (2018)

¹⁴⁶ *Id.*

legal standard of death will exist. Whether or not personhood as a standard, or some other ethical concept, should be considered while making that legal standard could play a role in how our culture views death.

Lawmakers and healthcare providers should work together to ensure clarity going forward. While it is hard to say there could be an international standard for legal death, the United States could push to have a homogenous standard for legal death. Whether that be the UDDA, New Jersey's Death Act, or some other standard, people should be able to know that if they die in one state versus another, it will not impact the health care decisions made over their body. Additionally, a consideration of the emotional strife caused in cases where there is confusion and a diluted understanding of whether or not their loved one has passed should occur for the legal definition. If there was a uniform legal standard of death would significantly reduce this confusion.

Subsequently, should there be a concern when we rely too much on a legal standard to define the line between personhood and 'non-personhood'? One could argue that we define a life that directly correlates to personhood? For example, in a case from 1772 England concerning James Somerset, an enslaved man, who had escaped from the United States, was brought to England for trial.¹⁴⁷ At this trial, the judge 'granted' Mr. Somerset

¹⁴⁷ Lawrence Wright, The Elephant in the Courtroom, NEW YORKER, (March 7, 2022)

the rights of a legal person.¹⁴⁸ The idea that a legal system has the power of defining the rights to be a person is riddled with problems and illustrates how unreliable the Rule of Law can be when it comes to reality.¹⁴⁹ Something that has the capabilities of being politicized should not be able to dictate the very meaning of the end of life.

A slightly closer case to the issue of brain death is that of the use of personhood in pro-life advocacy. Before the Supreme Court case *Planned Parenthood v. Casey*, many pro-life advocates argued that a fetus should have a person's legal rights.¹⁵⁰ One of the main pro-choice counters to this argument was the utilitarian approach to advocating for the rights of the pregnant person and doing the most good for society as it exists before the birth of the fetus.¹⁵¹ Regardless of the political views on abortion, this argument of personhood versus the utilitarian goals of 'most good' for society has close ties to issues of brain death. One could argue that using a definition of personhood that would encompass other disorders of consciousness other than simply brain death would serve the utilitarian goal of doing the

¹⁴⁸ *Id.*

¹⁴⁹ *Id.*

¹⁵⁰ Glen A. Halva-Neubauer and Sara L. Ziegler, *Promoting Fetal Personhood: The Rhetorical and Legislative Strategies of the Pro-Life Movement after Planned Parenthood v. Casey*, *FEMINIST FORMATIONS* Vol. 22, No. 2, The Politics and Rhetorics of Embodiment (Summer 2010), pp. 101-123

¹⁵¹ *Id.*

'most good' for society by offering more organs to be donated. While this is not currently at issue legally, it begs whether we should allow philosophical concepts into the law?¹⁵² Creating a concrete, legal definition of death may always have implications for being a person. Therefore, those in charge should use this authority of personhood cautiously.

Creating a slightly more flexible legal standard that considers cultural and individual beliefs could help lessens the influence of the law over the conception of personhood. For example, a research study based in Australia focused on the low organ donation rate correlated with the general population's lack of understanding and trust in the brain-dead standard.¹⁵³ In the paper, the authors offer an alternate approach to using the 'dead-donor rule,' stating that it could be abandoned and not require a legal definition.¹⁵⁴ With this, they propose using various definitions of death, either of the brain stem or a person, to evaluate whether to accept a patient's organs for donation.¹⁵⁵ The argument for this position is that it would allow things such as consent and the consideration of loved ones to be far more involved in the discussion process.¹⁵⁶ This approach would shift

¹⁵² Celia Kitinger and Jenny Kitinger, *'This in-between': How families talk about death in relation to severe brain injury and disorders of consciousness*, *The Social Construction of Death: Interdisciplinary Perspectives*, PALGRAVE MACMILLIAN (2014)

¹⁵³ Kerridge IH, Saul P, Lowe M, *et al.* Death, dying and donation: organ transplantation and the diagnosis of death *Journal of Medical Ethics* 2002;28:89-94

¹⁵⁴ *Id.*

¹⁵⁵ *Id.*

the conversation of death from purely a hard and fast rule of medicine and law to one that is active and personal.

The concept of personhood and death go hand in hand, as 'whilst our ordinary understanding [of death] accommodates the biological definition, it also includes the thought that, for someone who has died, there will never again be anything it is like to be that person.' There may not be a correct, or even most correct, answer to the ethical questions asked in this paper. As a legal concept, brain death is likely to stay for the foreseeable future. While the line between the rule of law, politics, and philosophy is particularly blurry in this case, there may be a way to help reduce any of the adverse effects that such blurriness has on the loved ones of those being declared brain dead.

Laws help create a structure in society to help make the way we live our lives functioning and easier. While maybe overlooked as relevant to our everyday lives, death is as a part of life as anything else. The UDDA was created to keep up with an ever-changing world of medicine to provide that structure and ease to one of the most complex parts of life. While the act's creation has brought new and albeit concerning ethical issues, there may be a way to interpret the law while allowing individuals and loved ones to keep their voice during the decision-making process around death.

¹⁵⁶ *Id.*



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Bridging the Gap: A Review of Health Disparities in Low- and Middle-Income Countries

by Dr. Kinjalbahen Nayak

Abstract

Health disparities in low- and middle-income countries (LMICs) are predominantly avoidable and reflect the multifaceted interconnections among social, economic, and structural determinants. These disparities contribute to restricted or unequal access to healthcare, inconsistent standards of care, and unfavorable health outcomes. Complementary case studies highlight the critical role of social determinants, and this calls for comprehensive, equity-focused approaches. Such an integrated and all-encompassing strategy can ensure affordable and equitable opportunities for everyone.

I. Introduction

Definition of Health Disparities:

The National Institute on Minority Health and Health Disparities characterizes "Health Disparities" as "largely preventable differences in health that negatively affect people facing barriers to optimal health." These inequities are associated with intergenerational social, economic, and/or environmental

determinants and are observable not only in disease occurrence and outcomes but also in risk-related behaviors (National Institute on Minority Health and Health Disparities).

Overview of What Constitutes “LMICs” Based on World Bank Classifications:

To categorize countries based on income level, the World Bank relies on Gross National Income (GNI) per capita, and this is determined via the Atlas method. Based on 2024 data, “countries with a GNI per capita of \$13,935 or less are designated as LMICs for fiscal year 2026” (The World Bank).

Brief statement of the article’s goals:

This article explores health disparities in LMICs, with the emphasis on their global impact and significance. Insights from Medical Sociology and Public Health are applied so the systemic, economic, and geographic barriers can be examined. The discussion then turns to courses of action for health equity promotion.

II. Scope of Health Disparities in LMICs

This section explores the scope of health disparities in LMICs, examining factors including healthcare access, service availability, quality, and social determinants of health.

Access to Healthcare Services:

Research conducted by Peters et al. in 2008 indicates that “while access to healthcare has improved in developing nations, many people still face barriers, and hence such populations face a heavier burden of disease compared to their counterparts.” This limited healthcare access is due to factors including remoteness, service accessibility, affordability, acceptability, and quality, but such a situation can be prevented (Peters et al., 2008). This research also indicates the need for a thorough understanding of the local factors associated with healthcare access, and this method should include the critical component, which is service enhancement for neglected populations. Furthermore, the authors explore the significance of innovations, such as healthcare financing, service delivery, and regulation, in expanding healthcare access for low-income populations; however, it is imperative that these vulnerable populations have a voice in the development, execution, and evaluation of these strategies (Peters et al., 2008).

Quality and Availability of Care:

Roder-DeWan et al. conducted research in 2019, demonstrating that “in twelve LMICs, internet users tend to express low healthcare expectations.” The authors further clarify that the reduced expectations of health services result in diminished demand for quality, ultimately resulting in decreased pressure

on the healthcare system for enhancement (Roder-DeWan et al., 2019).

Social Determinants of Health (SDoH):

As reported by the World Health Organization (WHO), people in high-income countries live 18 years longer than those in low-income countries. For example, in 2016, LMICs encountered the most premature deaths from non-infectious diseases (WHO). Referencing the second example, WHO noted different cancer outcomes between affluent and poor residents within nations. Likewise, in Africa, the mortality rate among children under five remains alarmingly high due to uneven improvements in child healthcare between poor and rich subgroups (WHO).

III. Root Causes of Health Disparities

This section examines the root causes of health disparities, drawing on WHO data and the report *Communities in Action: Pathways to Health Equity*.

WHO data reveal that social factors such as education, income, employment, gender, and ethnicity intensely impact health. For instance, “individuals with lower socio-economic status have a higher risk of poor health outcomes compared to their counterparts” (WHO).

The report titled “COMMUNITIES IN ACTION: PATHWAYS TO HEALTH EQUITY” identifies two principal groups of root causes of health disparities. The first group addresses differences in the distribution of power and resources among different groups, whereas the second concerns the SDoH (National Academies of Sciences, Engineering, and Medicine, 2017).

IV. Consequences of Health Disparities

This section outlines the consequences of health disparities in LMICs, illustrated with an example from the WHO.

On the whole, health disparities lead to elevated morbidity and mortality across diverse health conditions, including infectious diseases such as HIV/AIDS, tuberculosis, and malaria; chronic diseases such as heart disease, cancers, and diabetes; maternal and child health challenges such as perinatal complications, neonatal disorders, and malnutrition; mental health problems such as depression and anxiety; substance use disorders, including tobacco use, alcohol, and drug-related problems; and injuries such as motor vehicle crashes, accidental falls, assaults, and suicidal behaviors.

In its latest WORLD REPORT ON SDOH-EQUITY, the WHO observes that the SDoH can lead to a significant decline in healthy life expectancy. For example, data indicate that “children in poorer countries are more likely to die before the age of five compared to their peers in richer countries, and closing this gap

between rich and poor populations in LMICs has the potential to save millions of lives annually” (WHO).

V. Case Examples

This section provides a brief overview of health disparities in India, highlighting two illustrative case examples based on the studies by Pandey et al. (2018) and Jayaprakash et al. (2024).

In their 2018 study, Pandey et al. elucidate a case from India that emphasizes the crucial role of health disparities in the nation. This case concerns a 22-year-old man in a rural setting with untreated bladder exstrophy, who managed his daily activities by creating his own urine bag. This example underscores the unequal delivery of resources and limited access to care in LMICs (Pandey et al., 2018).

In a 2024 study, Jayaprakash et al. examine the influence of COVID-19 on intensifying health disparities in India. The authors state that “the pandemic has caused substantial local disparities between states, and, to address these disparities, the Indian government needs to increase healthcare funding, enhance services, and upgrade healthcare infrastructure” (Jayaprakash et al., 2024).

VI. Strategies for Reducing Health Disparities

This section examines strategies for reducing health disparities in LMICs, drawing on insights from Ferreira et al. (2024), El

Arifeen et al. (2024), McCoy et al. (2023), and the World Economic Forum (2024) to highlight approaches for identifying vulnerable populations, evaluating interventions, and applying innovative methodologies.

Findings from Ferreira et al. (2024) indicate that “as a multidimensional measure, socioeconomic deprivation status approximates absolute deprivation.” Using this parameter, disadvantaged families can be identified in LMICs, and the advantage of this metric lies in its ability to establish a thorough baseline for evaluating policy (Ferreira et al., 2024). Given that this measure captures absolute disadvantage, it also enables the assessment of disparities across populations, locations, and temporal periods (Ferreira et al., 2024). Along with that, with the help of this index, we can examine the long-term outcomes of programs intended to foster equity and can use this instrument in countries with repetitive health surveys as well (Ferreira et al., 2024).

A study by El Arifeen et al. (2024) underlines the critical function of evaluation practices in successfully tackling health disparities (El Arifeen et al., 2024). In another study, McCoy et al. (2023) point out the demand for decolonization strategies, so that we can address the fundamental drivers of power disparities between high- and low-income countries (McCoy et al., 2023).

An article by Saville, M. on the World Economic Forum website emphasizes that “addressing only immediate needs is insufficient; instead, an all-inclusive plan incorporating social, economic, and political dimensions is essential.” As reported in this article, innovation is identified as a key driver in advancing health equity in LMICs, and such an innovative framework may involve the development of custom-made diagnostics, therapeutics, and immunizations. While reinforced and more operational distribution systems are essential to reach underserved populations, the integration of digital health platforms and AI-enabled tools can extend healthcare delivery, strengthen disease surveillance, and streamline healthcare workflows (World Economic Forum, 2024).

VII. Conclusion

In LMICs, health disparities are determined by societal, monetary, and structural elements, which give rise to biased access, compromised care, and unfavorable health outcomes. Two case examples from India reinforce that these challenges are real, and overcoming them requires tailored, context-specific initiatives. In order to ensure that everyone can achieve optimal health, ongoing efforts to promote equitable opportunities and social fairness must include health policy reform, appropriate evaluation frameworks, and innovative healthcare delivery approaches.



Dr. Kinjalbahen Nayak is a dentist and epidemiologist with a Bachelor of Dental Surgery, a Master of Public Health, and a Ph.D. in Epidemiology (ABD—All But Dissertation). Her research expertise includes health equity, social determinants of health, and the epidemiology of infectious and chronic diseases. She has extensive experience in data management, data analysis, and data visualization, using both qualitative and quantitative research methods. She has contributed to numerous health research projects, including oral cancer clinical trials, studies on substance use (tobacco, alcohol, drugs, and addiction), and mental health research. By integrating clinical, public health, and data-driven approaches, she strives to advance evidence-based interventions and address health disparities to improve population health outcomes.

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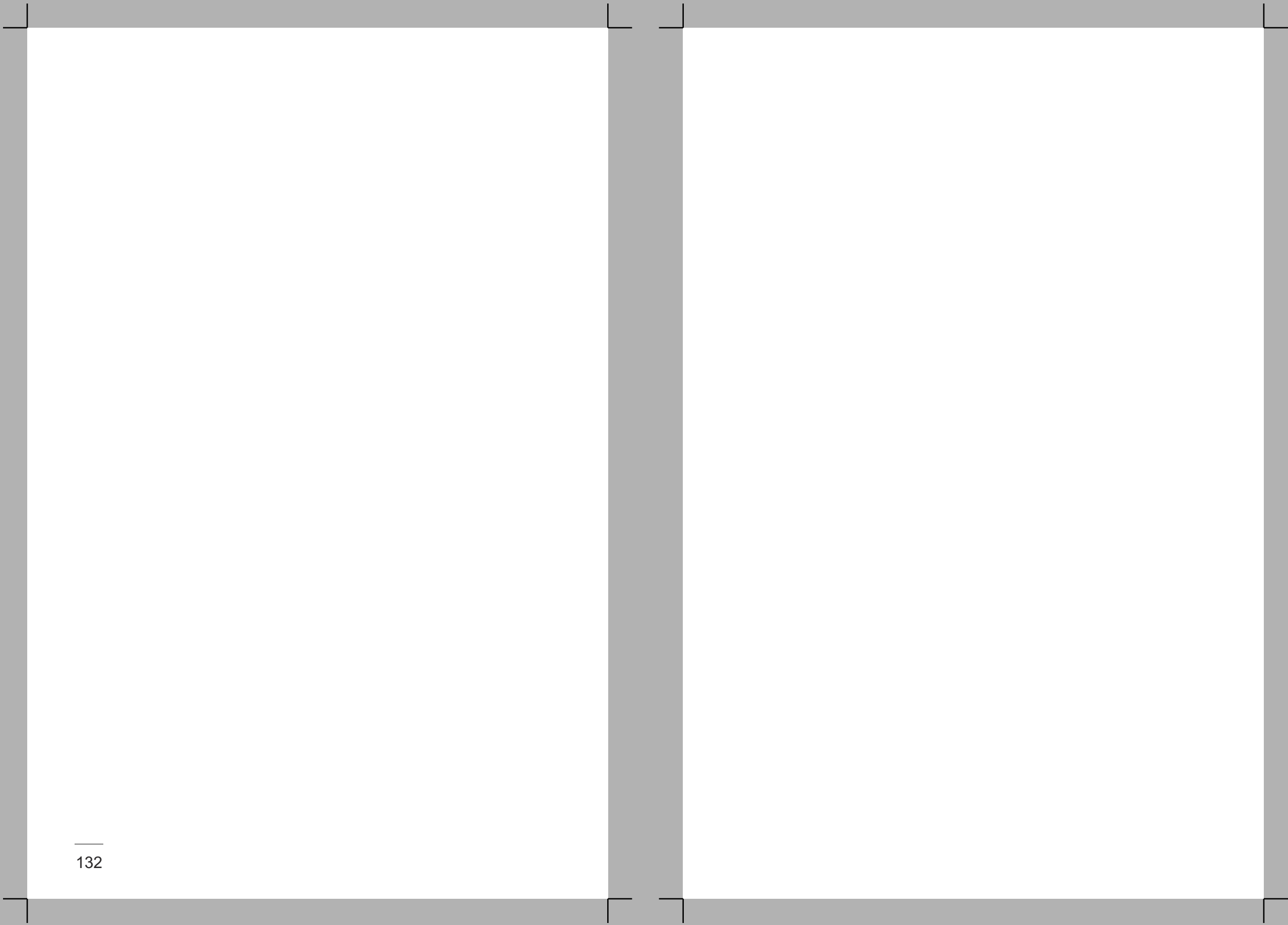
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