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### Undergraduate Journal of Public Health

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### Letter from the Editors

Madeline Cohen\* and Maya Nassif†

Dear Readers,

Thank you for taking the time to read the sixth edition of the *Undergraduate Journal of Public Health*. Over the past year, we navigated the evolving challenges brought about by the pandemic, matching uncertainty with immense resiliency, and are pleased to share with you a collection of important works authored by the next generation of public health leaders. The endurance of this pandemic illustrates the dynamic nature and permanence of public health; the need to research, discuss, and holistically understand all topics within this field is constant. As such, this journal examines a variety of complex, interdisciplinary public health issues, both inside and outside the scope of the pandemic, at the local, national, and global levels.

The influence of the pandemic is reflected in the number and subject matter of this year's submissions. We recorded the highest number of submissions since the journal's conception, representing a widespread, unprecedented motivation within undergraduates to explore the public health crises most meaningful to them. A number of these submissions investigated the pandemic directly, providing us with the unique opportunity to include a special section dedicated to pieces about COVID-19. Alongside the literature review, independent research, and perspective sections, this journal offers a unique blend of pieces which touch on core themes of public health that are applicable to all areas of academia.

We express our utmost gratitude to our editing team, whose dedication and constant eagerness to learn supported a final product even better than we could have possibly envisioned. To our faculty advisor Dr. Ella August, we thank you for your wisdom and trust in our team to create a volume of work that reflects what we find most dire to bring to the forefront of public health. Additionally, we are grateful for our PhD reviewers, whose breadth of experience offered a necessary perspective on this year's pieces. To MPublishing, we are indebted to your flexibility and kindness throughout this process in making this journal one that exhibits professionalism. Thank you to our cover artist, Yoo Young Chun, for your timely, artistic expression of public health. To the University of Michigan School of Public Health, thank you for your consistent support since the journal's first edition in 2017.

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The authors have no conflicts of interest to disclose.



Finally, to our authors whose pieces are the foundation of this publication, we thank you. Your desire and dedication to contribute to and expand the public health field have been inspiring to our entire team. Your investment in communicating the lived experiences and voices of those often marginalized by society advances one of the most important goals of public health: equity. We know your work will have a profound impact on readers and the academic community at large.

We reflect upon our time here with great fondness and are proud to present Volume 6 of the *Undergraduate Journal of Public Health*.

Sincerely, Madeline Cohen and Maya Nassif Co-Editors-in-Chief, 2021–2022

# Addressing the Prevalence of Healthcare-Associated Infections in India

Chinmayi Balusu\*

A principle rooted in the Hippocratic medical tradition is "first, do no harm," a core value for healthcare providers around the world. This principle is based on the importance of ensuring that no medical harm is incurred by patients before any procedures are performed. However, this principle is often violated through unseen infections that affect patients in the clinical setting. Healthcare-associated infections (HCAIs) are illnesses that originate within hospitals and healthcare facilities where patients receive treatment. The International Nosocomial Infection Control Consortium reports the HCAI prevalence in India as approximately 9.06 infections per 1,000 intensive care unit (ICU) patient days; the HCAI infection rate can vary between 4.4 and 83.09 percent across different hospitals in India, which is considerably higher than other wealthy countries (Iyer et al., 2015). Not only can HCAIs have a negative impact on patients' health, but they can also pose risks in the long run and present a financial burden. This article will address interactions between factors such as lack of resources for sanitation, knowledge gap in proper hospital hygienic practices, poor accountability procedures, and accuracy of hospital accreditation. Additionally, I explore ways for bridging the cultural gap by integrating Ayurvedic alternative medicine principles to allow for better retention of sanitation practices among communities at the local level. Overall, by working through these detailed factors, the Indian healthcare system can focus on going above and beyond its "do no harm" guideline and enhancing patients' lives by addressing behavioral and structural challenges related to infections originating in the clinical setting.

### Keywords

global health • healthcare • hospital infections • India • sanitation • cultural competence • accountability • hygiene

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### Introduction

Healthcare-associated infections (HCAIs) are illnesses that originate from within hospitals and healthcare facilities where patients receive treatment. They may occur in a time frame of 48 hours to 30 days after a patient's admission to a hospital. Settings with potential HCAI exposure include but are not limited to acute care hospitals, home care, ambulatory care, nursing homes, and family medicine clinics (Haque, Sartelli, McKimm, & Abu Bakar, 2018, pp. 2321–2333). The types of HCAIs include central line-associated bloodstream infection (when a catheter is placed directly into a vein that leads to the heart), catheter-associated urinary tract infections (infection of the urinary system related to the placed catheter), surgical site infection (infection occurring at the site where a surgical procedure was performed), and ventilator-associated pneumonia (lung infection developed in patients receiving respiratory ventilator assistance) (Centers for Disease Control and Prevention, 2014).

The International Nosocomial Infection Control Consortium reports the HCAI prevalence in India as approximately 9.06 infections per 1,000 intensive care unit (ICU) patient days; the HCAI infection rate can vary between 4.4 and 83.09 percent across different hospitals in India, which is considerably higher than other wealthy countries (Iyer, Sewlikar, & Desai, 2015). This may lead to higher morbidity and mortality rates, which can in turn present a greater economic burden for the healthcare system in India (Iyer et al., 2015). Patients who are affected by HCAIs may face extreme financial costs as their hospital stays are prolonged. A study tracking HCAIs in a tertiary care public hospital found that the mean length of hospital stay for HCAI patients who were matched with controls by age and gender was 11.96 days more than non-HCAI patients (Babbar, Biswal, Digamber, & Gupta, 2019). Therefore, the total cost to both the patient and the hospital may be two to four times larger than for a noninfected patient (Satpathy, Chaudhry, Gupta, & Kapil, 2013). A patient who is diagnosed with an HCAI and must stay in the hospital's intensive care unit can face a financial cost of up to INR 2,23,155.81 (approximately USD 2,932.81) per day (Kumar, Jithesh, & Gupta, 2016, pp. 398–403). Furthermore, HCAI patients may face a higher risk of long-term disability and resistance to antimicrobials and antibiotics in the years after their sickness. The health and financial burden of HCAIs cannot easily be resolved in the short term (Babbar et al., 2019).

Overall, HCAIs pose serious harm to the Indian healthcare system as they increase healthcare costs, decrease the quality of care delivered, and negatively impact patient health outcomes through various methods.

### Improving Effective Sanitation Practices

The main cause of HCAI transmission to patients in Indian hospitals is poor sanitation practices. Hospital staff who misjudge direct patient contact for routine examination, such as measuring blood pressure or temperature screening, or touching an object in a patient's room as still being sterile can inadvertently increase the risk of HCAIs due to the spread of bacteria from one patient to another (Satpathy et al., 2013). Effective sanitation is one of the most important factors in preventing HCAIs, as many studies have reported a significant reduction in HCAI transmission from patient to patient when hospital staff practiced good hand hygiene such as washing their hands or using alcohol-based disinfectants before and after coming into contact with patients (Allegranzi & Pittet, 2009, pp. 305–215).

Unfortunately, there is a knowledge gap between education and application in many hospitals. Everyone, including cleaning staff and practicing physicians, understands what healthy sanitation practices consist of, but many individuals express disbelief in their effectiveness (Joshi et al., 2012, pp. 340–344). Such skepticism may be accompanied by a shortage of available resources as well. For instance, in a qualitative study conducted at a rural teaching hospital, many healthcare professionals reported their preference for regular soap over alcohol-based disinfectants. Additionally, washbasins and hand sanitizers are not easily available, and staff reported how it was not feasible to sanitize equipment and their hands when going from patient to patient every single time (Joshi et al., 2012, pp. 340–344). The ideal practice of a hospital staff member being able to wash their hands 20 to 30 times each day is affected by the lack of clean water, overcrowded hospital environments, and understaffed shifts (Diwan et al., 2016; Pulla, 2020).

When it comes to handwashing techniques, studies report that practices may also vary from person to person among hospital staff due to multiple factors, including experience, personal attitudes, social norms, and peer pressure (Diwan et al., 2016). This gap is further exacerbated by a lack of strong administrative oversight that leads to misinformation and a shift of priorities. Implementing mandatory educational workshops for hospital staff to understand best practices for handwashing and limiting the spread of infection can greatly help reduce HCAI risk at the ground level.

### Accountability Frameworks

Accountability is equally as important as education when it comes to HCAI risk reduction practices. When there is infrastructure in place for staff to regularly report data about the prevalence of HCAIs among patients, it provides accountability and reinforces the guidelines that are set in place. Many institutions have reported the presence of HCAIs but have not firmly practiced a zero-tolerance policy (where the ultimate goal is to have zero patient cases of HCAIs) (Biswal, Mewara, Appannanavar, & Taneja, 2015, pp. 12–14). Accountability reporting procedures allow many stakeholder groups (e.g., administrators, policymakers, healthcare workers, patients) to weigh in and drive change to attain this goal of zero HCAIs among patients.

Fear of retaliation also plays a part in the issue of accurately reporting HCAIs and driving change. Hospital staff may be afraid of punishment if there is an increasing number of HCAIs occurring in a hospital, and they may purposefully avoid diagnosing patients with HCAIs (in favor of other less serious diagnoses) or fail to report HCAIs to higher officials. In doing so, essential information about the condition of a hospital's environmental standards is lost. On the other hand, hospital administrators may also face a barrier posed by local news media channels. Fear of media reports sparking outrage in the community has led to the rise of falsified HCAI data (Biswal et al., 2015, pp. 12–14). However, media coverage may also serve as the spark necessary to drive social awareness about HCAIs as hospitals are forced to accept responsibility for transparently addressing HCAI risk for citizens in their surrounding communities.

In order to address these issues, a strong "national benchmarking system of HCAIs with public reporting of results" must be put into place (Biswal et al., 2015, pp. 12–14). Currently, there is a severe gap in hospital accreditation as many hospitals do not adhere to health agencies' established guidelines, such as the Indian Public Health Standards, Indian Council of Medical Research guidelines, and Kayakalp guidelines (Pulla, 2020). These guidelines extensively address HCAI protocols; however, there is currently no infrastructure in place that legally requires hospitals to practice and

report infection control outcomes. Additionally, previous legislation such as the Clinical Establishments (Registration and Regulation) Act, 2010, has only been adopted at the state level of the legislature and is not mandated at the national level.

Therefore, it is increasingly important for the national government to require hospitals to maintain accreditation licenses that are strictly regulated by the existing National Accreditation Board for Hospitals and Healthcare Providers (NABH). Currently, only 714 hospitals are accredited by the NABH, which is a vast minority considering the many tens of thousands of hospitals in India overall. Implementing the formation of internal infection control committees within each individual hospital allows for more standardized surveillance of HCAIs that adapts to the needs of a hospital in tandem with a blanket national surveillance program associated with accreditation (Swaminathan et al., 2017; Centers for Disease Control and Prevention, 2021). However, there also needs to be a regional push to work with public hospitals located in rural areas that serve marginalized populations. It will not suffice to implement a national mandate and expect small-scale hospitals with a smaller financial endowment to be able to maintain perfect infection control standards. Ground-level realities such as overcrowding in rural hospitals, staff shortages, and lack of clean water and soap must also be addressed through a combination of more focused funding efforts and educational programs for not only hospital staff but also community members (Safdar et al., 2014, pp. 480-493; Link & Phelan, 1995, pp. 80–94; Anand, 2017).

### Bridging the Cultural Gap

The existing cultural framework related to health practices can especially be used as a strong launchpad for promoting sanitation and reducing HCAIs on a local scale. An important Indian cultural practice that is marginalized by institutionalized modern medicine is Ayurveda, an ancient natural system of medicine that focuses on bodily imbalances and stresses as the reasoning behind disease and illness (Johns Hopkins Medicine). The 3,000-year-old system is equally respected as Western medicine by many Indians, with many investigations of Ayurvedic products (such as herbs, minerals, and metals) underway. While Ayurveda's complexity is not yet fully understood, many studies have addressed the importance and effectiveness of traditional Ayurvedic plant products in purifying and disinfecting environments (Mohagheghzadeh, Faridi, Shams-Ardakani, & Ghasemi, 2006, pp. 161–184). A 2019 study demonstrated the effectiveness of garlic peel, turmeric powder, ajwain seed power, and loban fumigation in disinfecting surfaces that contained harmful drug-resistant methicillin-resistant Staphylococcus aureus (MRSA) bacteria, a strain that is highly implicated in nosocomial (originating in a hospital) infections (Bhatwalkar, Shukla, Srivastava, Mondal, & Anupam, 2019, pp. 203–206). As part of the burden is the lack of easily affordable and available disinfecting products, a potential solution is to further investigate the properties of Ayurvedic products in order to equip rural healthcare clinics with well-known, effective natural Ayurvedic products that can be found in most villages. Additionally, rural communities may be much more accepting of traditional, familiar disinfectant practices combined with proper sanitation practices rather than presenting Western disinfectant products. In this way, bridging the cultural gap can allow for better retention of sanitation practices among communities at the local level.

#### Conclusion

In conclusion, change must happen at the national and local levels simultaneously in order to combat HCAIs at the individual level effectively. Highly regulated government-level structural guidelines would set the standard for medical sanitation practices, but it is also not possible to expect to see a complete trickle-down of changes without behavioral interventions. At a local level, there must be a firm push for educational outreach efforts that focus on the community's specific needs rather than a one-size-fits-all model. In rural communities, more emphasis needs to be placed on considering traditional Ayurvedic practices in combination with Western medical practices. Acknowledging the continued relevance of non-Western biomedical knowledge in contributing to global health problems aids in breaking down the fear of modern medical procedures and bridging gaps between sanitation systems that share underlying core values. In the face of overburdened healthcare systems with limited resource bandwidth, such behavioral interventions can readily be implemented, even outside of India. Overall, through implementing these methods, healthcare systems can focus on going above and beyond the "do no harm" guideline to eliminate the harm caused by HCAIs and improve patient well-being.

### References

- Anand, C. (2017, February 11). When hospitals infect you. *The Hindu*. Retrieved from http://www.thehindu.com/sci-tech/health/When-hospitals-infect-you/article17289370.ece.
- Allegranzi, B., & Pittet, D. (2009). Role of hand hygiene in healthcare-associated infection prevention. *The Journal of Hospital Infection*, 73(4), 305–315. https://doi.org/10.1016/j.jhin.2009.04.019
- Ayurveda. Johns Hopkins Medicine. (n.d.). Retrieved from http://www.hopkinsmedicine.org/health/wellness-and-prevention/ayurveda.
- Babbar, P., Biswal, M., Digamber, B., & Gupta, A. (2019). Healthcare associated infections in intensive care units: A pilot study in a tertiary care public hospital in India. *Journal of Prevention and Infection Control*, 5(1). Retrieved from https://infectioncontrol.imedpub.com/healthcare-associated-infections-in-intensive-care-units-a-pilot-study-in-a-tertiary-care-public-hospital-in-india.php?aid=24069.
- Bhatwalkar, S. B., Shukla, P., Srivastava, R. K., Mondal, R., & Anupam, R. (2019). Validation of environmental disinfection efficiency of traditional Ayurvedic fumigation practices. *Journal of Ayurveda and Integrative Medicine*, 10(3), 203–206. https://doi.org/10.1016/j.jaim.2019.05.002
- Biswal, M., Mewara, A., Appannanavar, S. B., & Taneja, N. (2015). Mandatory public reporting of healthcare-associated infections in developed countries: how can developing countries follow?. *The Journal of Hospital Infection*, 90(1), 12–14. https://doi.org/10.1016/j.jhin.2014.12.011
- Centers for Disease Control and Prevention. (2014, March 26). Types of Healthcare-Associated Infections. Centers for Disease Control and Prevention. Retrieved from http://www.cdc.gov/hai/infectiontypes.html.
- Centers for Disease Control and Prevention. (2021, March 18). CDC 10 Essential Public Health Services CSTLTS. Retrieved from http://www.cdc.gov/publichealthgateway/publichealthservices/essentialhealthservices.html.

- Diwan, V., Gustafsson, C., Rosales Klintz, S., Joshi, S. C., Joshi, R., Sharma, M., Shah, H., Pathak, A., Tamhankar, A. J., & Stålsby Lundborg, C. (2016). Understanding healthcare workers self-reported practices, knowledge and attitude about hand hygiene in a medical setting in rural India. *PloS ONE*, 11(10), e0163347. https://doi.org/10.1371/journal.pone.0163347
- Haque, M., Sartelli, M., McKimm, J., & Abu Bakar, M. (2018). Health care-associated infections an overview. *Infection and Drug Resistance*, 11, 2321–2333. https://doi.org/10.2147/IDR.S177247
- Iyer, V., Sewlikar, S., & Desai, A. (2015). Healthcare acquired infection in India A literature review. *Journal of Microbiology, Immunology and Infection*, 48(2). https://doi.org/10.1016/j.jmii.2015.02.638
- Joshi, S. C., Diwan, V., Tamhankar, A. J., Joshi, R., Shah, H., Sharma, M., Pathak, A., Macaden, R., & Stålsby Lundborg, C. (2012). Qualitative study on perceptions of hand hygiene among hospital staff in a rural teaching hospital in India. *The Journal of Hospital Infection*, 80(4), 340–344. https://doi.org/10.1016/j.jhin.2011.12.017
- Kumar, P., Jithesh, V., & Gupta, S. K. (2016). A comparative cost analysis of polytrauma and neurosurgery Intensive Care Units at an apex trauma care facility in India. *Indian Journal of Critical Care Medicine: Peer-reviewed, Official Publication of Indian Society of Critical Care Medicine*, 20(7), 398–403. https://doi.org/10.4103/0972-5229.186220
- Link, B. G., & Phelan, J. (1995). Social conditions as fundamental causes of disease. *Journal of Health and Social Behavior*, Spec No. 80–94. https://doi.org/10.2307/2626958
- Mohagheghzadeh, A., Faridi, P., Shams-Ardakani, M., & Ghasemi, Y. (2006). Medicinal smokes. *Journal of Ethnopharmacology*, 108(2), 161–184. https://doi.org/10.1016/j.jep.2006.09.005
- NABH Accredited Hospitals. National Accreditation Board for Hospitals and Healthcare Providers. (n.d.). Retrieved from https://www.nabh.co/frmViewAccreditedHosp.aspx.
- Pulla, P. (2020, March 12). India's hospitals have an infection problem. Could accreditation be the way to go? *The Wire Science*. Retrieved from https://science.thewire.in/health/healthcare-acquired-infections-multi-drug-resistance-nabh-accreditation/.
- Safdar, N., Anderson, D., Braun, B., Carling, P., Cohen, S., Donskey, C., . . . Zerr, D. (2014). The evolving landscape of healthcare-associated infections: Recent advances in prevention and a road map for research. *Infection Control & Hospital Epidemiology*, 35(5), 480–493. doi:10.1086/675821
- Satpathy, S., Chaudhry, A., Gupta, S. K., & Kapil, A. (2013). P261: Study of Hospital Associated Infections (HAI) at tertiary hospital in India; Economic implication for developing countries. *Antimicrobial Resistance and Infection Control*, 2(S1). https://doi.org/10.1186/2047-2994-2-s1-p261
- Swaminathan, S., Prasad, J., Dhariwal, A. C., Guleria, R., Misra, M. C., Malhotra, R., . . . Srikantiah, P. (2017). Strengthening infection prevention and control and systematic surveillance of healthcare associated infections in India. *BMJ*, 358. https://doi.org/10.1136/bmj.j3768

### A Social Model of Mental Illness: The Key to Liberating Incarcerated Women From Ineffective Mental Health Treatment

Madeleine Salem\*

An assessment of public health literature suggests that correctional institutions have adverse effects on the mental health of prisoners, and this article responds to this issue by putting the current medical model of mental illness as it is applied in the criminal justice system under a critical lens, analyzing how it has proven insufficient in providing better mental health outcomes for inmates with mental illness. An expansion of the social model of mental health is proposed, one that is grounded in the belief that consideration of the social determinants of mental health is paramount to understanding why the mentally ill are disproportionately brought into the criminal justice system in the first place. Furthermore, federal studies have shown that incarcerated women experience mental health conditions at disproportionate rates, despite making up a smaller proportion of the prison population. Explaining this gender disparity has been an emerging area of research in criminal justice and mental health reform, and this article explores it by analyzing how the prison environment perpetuates it, investigating specific social circumstances that are particularly triggering to the mental health of incarcerated women, such as separation from children and increased exposure to sexual abuse and domestic violence. The article concludes with an examination of a case study of how the expanded social model is currently being applied to the specific context of incarcerated women's mental health, demonstrating its effectiveness and advocating for the widespread implementation of similar initiatives.

### Keywords

incarceration • mental illness • mental health • criminal justice • social determinants of health • gender disparities • gender-based violence • prison systems

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### Hospitals Are Not the Largest Mental Health Provider in the United States—Prisons Are

Dana was 22 years old, spoke in a soft voice with a bit of a country lisp, and stood at barely 5 feet tall. She was described as calm, relaxed, and extremely easy to talk to. She was also a mother and loved her children deeply. However, Dana was found to have taken her own life at the correctional facility she was imprisoned in. Her body was still warm when two correctional officers found her—and yet both of them failed to initiate a life-saving response (Davoren & Mustafa, 2018).

Unfortunately, Dana's story is only one instance of inmate mental health being overlooked, under-attended, and mistreated in the criminal justice system. According to a 2017 report by the Bureau of Justice Statistics, 37% of people in state and federal prisons and 44% of people in locally run jails have been diagnosed with a mental illness (Bronson & Berzofsky, 2017). As these numbers suggest, correctional institutions have essentially become "the largest provider of mental health services" in the United States (Gonzalez & Connell, 2014). However, prisons and jails are simply not suited to be psychiatric facilities. The prison environment has been shown to have negative impacts on the mental health of prisoners, regardless of whether they had a formal mental illness or not (Nurse, 2003). Moreover, a study conducted by a criminal justice reform nonprofit determined that despite the disproportionate mentally ill population in correctional institutions, 66% of people in federal prisons still reported not receiving any mental health care at all while incarcerated (Ring & Gill, 2017).

Given the large volume of evidence that exposure to correctional facilities seems to worsen mental health conditions, there has been a push for initiatives that mitigate this growing issue. Reforms such as crisis intervention teams and mental health courts have been implemented in an attempt to divert the mentally ill from the criminal justice system into community health services at the stage of arrest. Reentry programs have been developed to connect former inmates to social needs and support their reintegration into the community after their release. By the metrics of reduction of recidivism (relapse into criminal behavior) and success of connecting the mentally ill to mental health care, these reforms have proven to be extremely effective. One can observe, however, that these reforms occur at the stages of pre-incarceration and post-incarceration. This begs the question: what is being done to address the mental health needs of prisoners *during* incarceration?

Public health researchers and attorneys have found that most of the mental health treatments that people receive while in prison are primarily grounded in a medical model of mental illness, placing screening and medication at the forefront of care (*Inmates with Mental Illness Tell Their Stories*, 2015; Gonzalez & Connell, 2014). As such, the rising population of mentally ill inmates within the prison system has been attributed not only to the disproportionate rate at which people with psychiatric disabilities are arrested but also to the ineffective mental health treatments that lead to high rates of recidivism (Seltzer, 2005, p. 573; Gonzalez & Connell, 2014). I believe the reason for this effectiveness is that medical approaches to treatment, unlike successful divertive and reentry reforms, overlook a criterion that should be key for criminal justice reform: sufficient removal of an offender from the social circumstances that caused them to be arrested or incarcerated, to begin with.

This negligence of the social determinants of mental health during incarceration is especially prevalent in the treatment of a particular group of people who are often overlooked in conversations surrounding criminal justice, despite being the fastest-growing group of prisoners in the United States: women and girls (Santo, 2017). A study by the Bureau of Justice Statistics reported 66%

of women in prison having a history of a mental disorder—almost twice the percentage of men in prison—despite making up only 7% of the prison population; in local jails, 68% of women were reported to have been diagnosed with a mental health condition in comparison with 41% of men (Villa, 2017). These statistics have been a point of puzzlement for legal experts as they cannot quite explain why this gender disparity exists (Villa, 2017).

In an attempt to answer this question in an emerging area of research in criminal justice and mental health reform, this article argues that our current approach of basing in-prison mental health treatment primarily on a medical model of mental illness cannot sufficiently combat the rising populations of the mentally ill in correctional facilities. Instead, we need to expand our approach to mental health during the stage of incarceration to employ a social model of mental illness, focusing on addressing the social needs and environmental factors that directly contributed to the development and persistence of inmates' mental illnesses.

### A Critique of Cure Culture: Analyzing the Application of the Medical Model of Mental Illness in Criminal Justice

Oxford Medicine defines the medical model of mental health as operating by "assessing a patient's problems and matching them to the diagnostic construct using pattern recognition of clinical features" (Huda, 2019). It is rooted in the belief that mental disorders are "a product of physiological factors" that are physical and organic, related to the structure and function of the brain; as such, there is a central focus on "curing" psychiatric disability by "identifying it from an in-depth clinical perspective, understanding it, and learning to control and/or alter its course," usually by way of diagnosis and prescription of medication (Social and Medical Models of Disability: Paradigm Change, 2014).

While the medical model is certainly important in treating mental illness, it is not the most holistic model of mental illness to apply, especially in the context of incarcerated populations, in part due to the number of systemic barriers that stand in the way of inmates receiving proper medical treatment. One of the most prevalent barriers is the mismanagement of psychiatric medications, which may take the form of lack of access, overmedication, or mis-prescription (*Inmates with Mental Illness Tell Their Stories*, 2015; Davis, 2021). One example of this can be found in the story of Kristine Flynn, an inmate with bipolar disorder, who attempted suicide six days after her eight psychiatric medications were "abruptly discontinued by prison staff" for unknown reasons (*Women at Wisconsin's Taycheedah Prison*, 2009). In addition, women incarcerated at the Correctional Institute—Framingham have described experiences of being prescribed medication without being informed about what exactly they were being given or being prescribed overly large doses of powerful psychoactive medications that induced seizures, depression, and suicidal ideation because the prison staff just wanted to "quiet [them] down" (Davis, 2021).

These women are not alone in their struggle to access proper psychiatric medication administration. A study conducted by public health researchers Jennifer Gonzalez and Nadine Connell at the University of Texas (2014), which analyzed survey data from a nationally representative sample of U.S. prisoners, found that 50% of those who were medicated for mental health conditions at admission did not receive pharmacotherapy in prison. This is partially due to underfunded public health systems resulting in a limited supply of psychiatrists and psychologists able to give proper diagnoses, as well as diminishing correctional budgets not having the resources to connect all inmates in need of treatment programs (Gonzalez & Connell, 2014). Moreover, the same study

also found that the screening tools employed by correctional facilities are not even used for the purpose of diagnosis but instead used "to gauge the security risk of a new inmate at the institution." As a result, a positive screening for mental illness still would not lead to an inmate receiving pharmaceutical treatment from a medical professional (Gonzalez & Connell, 2014). Thus, solely depending on medication to reduce symptoms cannot be sufficient if the path to receiving medication is not reliable in itself.

Even so, the medical model's view of mental illnesses as distinct sets of symptoms with which to heuristically make diagnoses is inherently dangerous, especially when applied to the unique environmental context of prison. The symptoms of mental illnesses are "dynamic" and thus may present themselves differently across a variety of individuals and circumstances (Gonzalez & Connell, 2014). Gonzalez and Connell (2014) have discussed the various implications of this: for instance, there may be cases in which prisoners with mental illnesses that are more difficult to identify based on outward presentation are misclassified or undetected even by the most validated and reliable screening tools, much less by correctional employees with no substantive mental health training. Additionally, the specific environmental conditions of correctional facilities, including "crowded living quarters, lack of privacy, increased risk of victimization, and solitary confinement" (Gonzalez & Connell, 2014), pose severe adaptation challenges that may uniquely influence the presentation and perception of mental health symptoms for different inmates. In other words, the environmental context of prison has the potential to further complicate its own diagnostic process—a process that was not even perfectly reliable to begin with.

Overall, public health researchers and attorneys alike seem to agree that there are concerning issues that surround current medical approaches to treatment. Underfunded public health systems, scarce amounts of mental health providers, limited access to psychiatric medication, unreliable mental health screening procedures—these barriers and oversights, stakeholders contend, help perpetuate the growing mentally ill population in correctional facilities by contributing to the high rates of recidivism post-incarceration. A study by the Department of Preventive Medicine and Community Health at the University of Texas found that former inmates who received a professional diagnosis of any mental health disorder were 70% more likely to return to prison at least once than inmates not given a diagnosis, and the rates of recidivism are between 50% and 230% higher for persons with mental health conditions than for those without any mental health conditions (Gonzalez & Connell, 2014). Also, 61% of those who relied on pharmacotherapy to treat a diagnosed mental illness while in prison used no other form of treatment (Gonzalez & Connell, 2014); in the case of female inmates, it has been reported by Amnesty International that even when women attempt to access mental health services, they are simply given medication with no opportunity to undergo psychotherapeutic treatment. As these findings suggest, diagnosis and medication of a mental illness are simply not enough on their own to protect against symptomatic relapse and recidivism.

The volume of evidence supports the notion that the medical model approach of diagnosis and prescription is not sufficient for combating the poor mental health among incarcerated populations due to systemic barriers that prevent it from being applied to its full effectiveness. Upon further inspection, many of these systemic barriers seem to be financial, stemming from a lack of funding being put toward improving the quality of and access to treatment. Keeping this in mind, we can then consider the fact that while the medical model prioritizes care by diagnosis and clinical treatment, its ultimate goal is to "cure" the mental illness at hand. These considerations then beg the questions: how can the criminal justice system achieve this goal if it does not have the finances or the resources to do so? Even more, is "curing" its mentally ill population necessarily

even a goal for the criminal justice system? After all, clinical interventions and services that are more involved (and potentially more effective) than screening and prescription, such as specialized housing and therapeutic treatment programs, are often very expensive, and as the number of mental health classifications assigned to prisoners increases, so too does the demand for these expensive services (Gonzalez & Connell, 2014). Studies have shown that this actually provides prison administrators with an incentive to "keep mental health classification levels low as a mechanism to save costs associated with health care and pharmacotherapy" (Gonzalez & Connell, 2014). In this sense, one could argue that the prison environment actually resists the medical model in that it not only lacks sufficient resources to adopt medical treatments beyond screening and prescription but also has a financial incentive to not seek out those resources at all. Thus, the medical model of mental health seems to be both incompatible with the fiscal interests of prison administration stakeholders and insufficient at improving mental health outcomes in prisoners during and after incarceration.

Herein lies the most pressing criticism of the medical model: the symptomatic lens from which it views mental illness is simply too narrow for it to be effective for prison populations. And for institutional administrators to be invested in mental health treatments for their inmates, they should, according to public health stakeholders, "result in a sharp decline in offender recidivism and, by extension, a long-term cost savings" (Gonzalez & Connell, 2014). Therefore, effectively improving mental health outcomes in inmates would have to rely on a more holistic approach to treatment—one that could be provided by a social model of mental health.

### From Impairment to Social Creation: A Proposal to Expand the Social Model of Mental Illness

A key difference between the medical and social models of disability is their definition of disability itself. While the medical model defines disability as the "individual deficit" associated with physical impairment, the social model defines disability as a "social creation"—a relationship between people with impairment and a disabling society (Shakespeare, 2006). This distinction is important because it moves the responsibility of addressing disability from the shoulders of the individual to the shoulders of society. Individuals with impairments should not be expected to struggle in and conform to an able society that was not built for them; the able society should tear down and reconstruct itself to be accessible to individuals with impairments. "It is society which disables physically impaired people," wrote Tom Shakespeare (2006), professor of disability research, "[Impairment] is individual and private, [disability] is structural and public. While doctors and professions allied to medicine seek to remedy impairment, the real priority is to accept impairment and to remove disability." This is why it is imperative to turn our focus to government, policymakers, and other institutional stakeholders when discussing disability reform—holding them accountable for constructing a disabling society may pressure them to make top-level changes to how people with impairments are treated by the system. The social model thus becomes a powerful tool for creating this pressure, offering a new perspective on disabled bodies; it proposes that they are socially constructed, with "social attitudes and institutions determining far greater than biological facts" (Fogel et al., 1992).

Using this model, we can make the conjecture that mental illness itself is an impairment that places restrictions at the individual level, but that societal stigmas surrounding mental health and

the lack of structural support that comes with it are contributors to the disabling effects of mental illness. However, I would like to propose an expansion of the social model that more closely intertwines the relationship between individual impairment and societal disability: not only do societal and systemic factors pose disabling barriers to people with mental illnesses, they also contribute to the onset of mental illness as an impairment itself, acting as social determinants of mental health. This inclusion of the social determinants of mental health in the social model further emphasizes the placement of moral responsibility on the shoulders of society to remove these systemic burdens that influence both the development and perpetuation of disability (Shakespeare, 2006).

Having established this critical framework, I will now use this expanded social model as a lens through which to examine the disproportionate rates at which incarcerated women experience mental illness. According to a study published in the *Western Journal of Nursing Research* (1992), most female inmates come from "deprived environments fraught with social problems," with many of these problems being risk factors for poor mental health (Fogel et al., 1992). As such, this article aims to perceive and illuminate these social determinants of mental health that afflict women who become incarcerated as areas of focus in efforts to prevent incarceration, improve treatment during incarceration, and provide rehabilitation after incarceration. I focus on two specific social problems that are particularly salient to incarcerated women's mental health: (1) domestic violence and sexual assault, and (2) motherhood.

### 'I Just Learned to Stop Feeling': The Never-Ending Prison of Sexual Abuse and Domestic Violence

Women who are survivors of violence and abuse get funneled into the criminal justice system at inordinately high rates. The World Health Organization reports that female prisoners in the United States are three times more likely than male prisoners to have endured physical or sexual abuse prior to incarceration, with 60% of inmates in women's prisons nationwide and up to 94% in certain women's prisons having such a history (van den Bergh, Gatherer, Fraser, & Moller, 2011; Fact Sheet on Domestic Violence & Criminalization).

This victimization by domestic violence and sexual assault has been observed to be connected to a woman's reason for incarceration. "Violence perpetrated against women and girls can put them at risk for incarceration because their survival strategies are routinely criminalized," states Free Marrisa Now, an alliance of organizations and activists working to free a domestic violence survivor incarcerated for acting in self-defense. "From being [threatened and] coerced into criminal activity by their abusers to fighting back to defend their lives or their children's lives, survivors of domestic violence can find themselves trapped between the danger of sometimes life-threatening violence and the risk of spending the rest of their lives in prison." Reporters for the Marshall Project offer further support for this point, indicating that in cases where women are imprisoned on charges of violent crime, the attack oftentimes involves the woman committing an act of self-defense or retaliation against an abuser (Aspinwall, Blakinger, & Neff, 2020). Susan Ferrell, for instance, was a woman serving a life sentence in a Michigan prison before she died of COVID-19 in April 2020. She had been imprisoned for killing the husband she said had abused her for years (Aspinwall et al., 2020). Being at the mercy of institutions that criminalize acts committed under self-defense or coercion is demoralizing and destructive for survivors, for in their desperate attempts to either survive or break free from "climate[s] of terror and diminished, violated sense of self," they once

again find themselves in the shackles of yet another prison (Fact Sheet on Domestic Violence & Criminalization).

This cycle of trauma perpetuates poor mental and emotional health that already exists as a result of the abuse itself. Studies have shown that the rates of depression and anxiety disorders, as well as many other mental health problems, are higher in women who have experienced violence in comparison to women who have not (*Violence Against Women Prevalence Estimates*). In the case of women offenders, the National Institute of Corrections has found that their psychological trauma is often linked to their history of abuse, commonly manifesting in the psychiatric condition of post-traumatic stress disorder (PTSD) (Bloom et al., 2005).

The dire effect trauma has on mental health not only influences behavior leading up to incarceration but also follows incarcerated women into their cells long after the traumatic experience has passed. In an op-ed for the Marshall Project, Jennifer Toon, a former inmate in a Texas prison, recalled the night her cell block had discovered the news that a new inmate had just committed suicide (Toon, 2019). She remembered how the prisoners, usually wrapped up in their "jealousies, petty cliques and bitterness," instead banded together in solidarity against the prison chaplain's adamant denial of their request to hold a memorial service for the unknown young woman. She reminisced over the quiet prayers held in small groups, conversations that turned into confessions of their own mental health struggles.

"Many of us had contemplated suicide before," Toon wrote, "One of the most intimidating women on our unit revealed that even she had wanted to die, many times. She said, 'Y'all, my stepdaddy used to put his hands on me. I would go to school and see all the nice families picking up they kids, and I was like, why can't I have that? . . . I learned to just stop feeling.' Another lady spoke up about her crime, which she told us she'd committed against her abuser: 'I've always thought that I should have killed myself instead,' she said. 'If he were alive, maybe he would have gotten his life right, and I wouldn't be trapped in this place. Sometimes I just want it all to end."

(Toon, 2019)

These women are victims of the injustice that plagues our criminal justice system. It punishes those who are survivors of traumatic crimes; instead of acknowledging their bravery in defending themselves, extending compassion, and connecting these women to effective mental health services, the system entraps them in an environment that instead worsens their mental health further. Therefore, this vicious cycle of gender-based violence, the influences of trauma on victim behavior, and criminalization is an explanation not only for the disproportionate rates at which women are incarcerated but also for the disproportionate rates of adverse mental health in these women.

Unfortunately, the threat of sexual assault doesn't end once women are imprisoned —in fact, incarcerated women are the victims of one-third of all sexual abuse cases committed by prison staff, 70% of whom in women's correctional facilities are male (Aspinwall et al., 2020; Women in Prison: A Fact Sheet). According to records by Amnesty International, correctional officers have subjected female inmates to rape, other sexual assault, sexual extortion, and groping during body searches, and have also watched female inmates undress while they were in the shower or the toilet. Oftentimes, these women feel as if they cannot even safely report these misdemeanors. Many states grant guards access to files on an inmate's personal history that includes records of complaint (Women in Prison: A Fact Sheet), allowing officers to monitor women who speak out and retaliate accordingly. Guards

also use tactics such as threatening the inmate's children and visitation rights, issuing tickets that extend an inmate's time in prison, and placing inmates in segregation as a means of silencing these women from ever speaking out (*Women in Prison: A Fact Sheet*). Even if a complaint does somehow end up going through, strict and proportionate disciplinary action is never inflicted on the perpetrator (*Women in Prison: A Fact Sheet*). The hopeless circumstances brought upon by this imbalance of power, in addition to the trauma inflicted by the sexual abuse, further contribute to the poor mental health conditions of incarcerated women.

Evidently, the higher rates at which incarcerated women are exposed to domestic violence and sexual abuse inside and out of the prison environment influence their higher rates of psychological trauma. However, in institutions that primarily offer diagnostic and pharmaceutical treatments for mental health, these social factors and their effect on inmates cannot be directly addressed. Giving these women the tools and resources they need to develop healthy coping mechanisms and embark on their recovery journeys would be instrumental in improving their mental health, both during and after incarceration.

### "Being Ripped Apart All Over Again": An Exploration of the Emotional Toll Prison Takes on Mothers

In addition to domestic violence and sexual abuse, the prison experience of many incarcerated women is complicated by motherhood. The Prison Policy Initiative reports that of the 2.3 million women in the United States who will go to jail in a given year, 80% of them are mothers. And of all the women currently in state prisons, 60% of them have children younger than 18 (Santo, 2017). Given that many of these women are poor minorities with dependent children and a lack of adequate housing, they often have limited access to community-based health systems even prior to incarceration (Staton et al., 2003, p. 225). Additionally, these women are oftentimes single mothers before getting incarcerated; as such, being sent to prison is usually the first time they experience separation from their children (Friedman et al., 2020). This combination of lack of prior mental health support and departure from their children, on top of the stressful adjustment to a prison environment, maybe contributors to persisting separation anxiety, high distress, and overall poor mental health.

This effect has been demonstrated in a study published in the Western Journal of Nursing Research (1992), in which researchers compared the changes in the mental health of incarcerated mothers to that of incarcerated non-mothers over time. The study found that despite entering prison with about the same high levels of anxiety, the anxiety scores of the mothers remained high throughout the entire follow-up, whereas the anxiety scores of the non-mothers decreased over time (Fogel et al., 1992). The paper conjectured that separation from children as a source of severe anxiety, as well as a "fear that mother-child separation would result in dissolution of the child's bond with the mother," was a potent reason for this observed difference (Fogel et al., 1992). This fear is not unfounded: over half of mothers never had in-person contact with their children while incarcerated (Friedman et al., 2020). The bond between a mother and her children is one that is often very strong, with many mothers treasuring and being fiercely protective over their children. The strength of this bond may contribute to the intense separation anxiety that comes with incarceration. Furthermore, many children of incarcerated mothers are placed into kinship care or foster

care, commonly leading to the termination of the mother's parental rights and making it difficult for the mother to reunite with her child after release (Friedman et al., 2020). With children being the treasure of many mothers' lives, the knowledge that their identity as a mother may be stripped, and that they may never see their children again, would be very distressing. As such, it would make sense that many incarcerated mothers thus live in constant worry of the well-being of their children as well as in constant fear that their bond may be severed.

Even when incarcerated mothers are allowed to see their children, many barriers exist that make visitation and meaningful connection difficult. Ayana Thomas, for instance, "missed out" on being a mother to her children for the two and a half years she spent imprisoned (Santo, 2017). The geographic distance between her family's home in Virginia and her correctional facility's location in Connecticut made visits few and far between. This problem of great geographic distance between incarcerated women and their children is especially prevalent due to the lower number of women's prisons and the fact that the criminal justice system currently does not consider the location of the children when placing inmates who are mothers in correctional facilities (Friedman et al., 2020; Parenting From Behind Bars with Senator Cory Booker, 2017). Other barriers to visitation that mothers reported were financial constraints, lack of transportation, security procedures, and strict prison regulations (Fogel et al., 1992).

Furthermore, even when Thomas's children could come to see her, "they weren't allowed to embrace or hold hands for long before a guard would break them apart" (Santo, 2017). Other incarcerated mothers participating in qualitative studies expressed the same sentiments of how the prison's visiting environment "stifled meaningful emotional contact" by not granting privacy during visits, limiting the duration of phone calls and appointments, and restricting physical contact (Fogel et al., 1992; Friedman et al., 2020).

In particular, the security procedures mandated before the visit are itself dehumanizing and undignifying, emotionally taxing the mothers who have to endure it for the sake of seeing their children. Kyndia Riley, who grew up with both her parents being incarcerated, recalled how her mother had to deal with being stripped of her clothes and having a guard "fondle her while she was naked" before being allowed to see her visitors (*Parenting From Behind Bars with Senator Cory Booker*, 2017). Then, immediately after these invasive security checks, Riley's mother had to "go back to some happy place" and put on a brave face in order to hold a conversation with her daughter. "It was like her dignity had just been stripped," Riley said.

Additionally, for many mothers, going through the prison visitation process—enduring the security checks, seeing your loved ones for a short time under strict circumstances, saying goodbye for another extended amount of time—takes an extremely large mental and emotional toll. Ayana Thomas felt that the process was so "energy-draining" to the point of requesting her children not to visit her for the last nine months before her release as it would be easier to do her time without having to go through the vicious cycle of recovering from saying goodbye over and over again (*Parenting From Behind Bars with Senator Cory Booker*, 2017). "It would take me two days to recuperate from a visit," Thomas said. "From all the crying, from the whole . . . ripping you apart all over again."

All of these factors, from being separated from their children to enduring draining visitation procedures, are most likely contributors to the high rates of moderate-to-severe mental health problems experienced by incarcerated mothers (Stanton & Rose, 2020). Possible in-prison initiatives that address motherhood as a social determinant of mental health could prioritize maintaining familial connections and improving visitation procedures.

### A Case Study: How One Law Center Is Advocating for Incarcerated Abuse Survivors and Mothers

The implementation of mental health treatments should be built around addressing the social needs of inmates during their incarceration. In the specific case of female inmates, in order to achieve improved mental health outcomes and thus reduced recidivism, effective approaches should focus on (1) giving domestic abuse survivors the support and tools they need to cope with their psychological trauma through counseling, education, and legal assistance, and (2) maintaining and improving the degree of meaningful interactions between incarcerated women and their children. It is important to note, though, that this is not an exhaustive list—the issue of mental health in the criminal justice system is an intricately woven network of countless socioeconomic and systemic factors, and it would be near impossible to integrate all of them into a singular treatment model.

Still, this method of narrowing the scope of what social determinants to address in treatment has proven effective in the case of the Harriet Buhai Center for Family Law, one of the largest providers of family law and domestic violence assistance to low-income persons in Los Angeles. Since 2019, the Center has embarked on multiple projects relevant to addressing the social issues of domestic violence and motherhood as they pertain to incarcerated women. The core aim of these initiatives is to advocate for "the creation of a more gender-responsive system for abused and incarcerated women that addresses their lifetimes of trauma" (Helping Women Who Have Been Abused and Incarcerated, 2019).

One of these projects, the Community Legal Education Program, involves the Center's staff lawyers teaching interactive classes on child welfare, custody, domestic violence, support, and paternity to female inmates five days a week, granting them a certification at the end of the program that they can later present at court (*Helping Women Who Have Been Abused and Incarcerated*, 2019). The Center has stated:

The theme throughout the series is to encourage healthy parenting and reunification with children, to present information to help them understand and address domestic violence in their lives, and to comprehend legal processes to better equip them to succeed with their court cases.

The program was piloted at the Century Regional Detention Facility (CRDF) in 2019, where more than 3,000 female inmates have participated in it every year since. Because the program was so well received, the Center has expanded its reach to various probation offices in the area and hopes to continue the expansion across the country (*Helping Women Who Have Been Abused and Incarcerated*, 2019).

Another project the Center has initiated is the Women's Gender-Responsive Jail Project, in which the Center's staff works closely with Los Angeles County and Sheriff Department personnel as well as members of the Gender Responsive Advisory Committee to advocate for the interests of families with incarcerated mothers. Most recently, the project has released a report that "aims to bring attention to the ways in which family visitation with incarcerated mothers promotes public safety and child welfare and to advocate for improving visitation policies and programs at CRDF" (Helping Women Who Have Been Abused and Incarcerated, 2019).

Of course, further research into the effectiveness of programs such as these must be conducted before their widespread implementation. Other complicating nuances such as the sexual assaults

women face from correctional officers and the effects the incarceration of mothers has on their children should continue to be thoroughly studied and factored into the implementation as well. Regardless, there is still potential for effectively executed in-prison social programs that improve mental health outcomes for inmates with mental illnesses.

#### Much More Than Their Condition

In a conversation with a correctional officer, Dana—the imprisoned woman mentioned at the beginning of this article—had confessed that she had been raped by a family member and had his children, and was now living in fear of returning home and facing him again. The reason why she hurt herself, she said, was because "the only way he would leave her alone was if she wasn't living anymore" (Davoren & Mustafa, 2018).

It is stories like this that serve as a reminder to pause, take a step back, and remember that behind the studies and statistics lie real people. A person with mental illnesses who is unjustly funneled into the criminal justice system is more than a psychiatric diagnosis. They are more than another faceless body in a sea of inmates that institutions would prefer not to spend more of their correctional budget on. Every inmate is much more than their condition—they are, most of the time, simply victims of a bad deal of societal factors that landed them where they are. This, above everything, is what makes the social model of mental illness so compelling to me.

Here, I would like to clarify that my intention with this article was not to encourage a complete overhaul of the medical model of mental illness and diminish the importance of viewing psychiatric disorders as real illnesses with genetic and biological factors. Instead, my aim was to advocate for a more holistic approach to treating prisoner mental health than the medical model is capable of providing, by turning to the social factors that contribute to mental illness both before and after its onset. The criminalization of mental illness is enabled by the belief that mental illness is an individual failure, but as Tom Shakespeare has expressed (2006), the power of the social model lies in its ability to change the way people with disabilities are perceived. "The problem of disability is relocated from the individual, to the barriers and attitudes which disable her," Shakespeare (2006) stated. "It is not the disabled person who is to blame, but society." So, by addressing both the negative impacts of the inmate's environment before incarceration and the negative influences of the prison environment itself, implementing socially focused mental health treatments during incarceration could combat the enabling effects of imprisonment on poor mental health and better equip inmates for when their time for release and reentry does come. Ultimately, the social model of mental health has incredible potential to help mitigate the prison system's self-perpetuation of a growing mentally ill population as a result of ineffective in-prison mental health treatments liberating prisoners with psychiatric disabilities from a vicious cycle that has kept them in chains for far too long.

### References

Aspinwall, C., Blakinger, K., & Neff, J. (2020, May 14). What Women Dying in Prison From COVID-19 Tell Us About Female Incarceration. Retrieved from https://www.themarshallproject.org/2020/05/14/what-women-dying-in-prison-from-covid-19-tell-us-about-female-incarceration

- Bloom, Barbara, et al. (2005). A summary of research, practice, and guiding principles for women offenders. *PsycEXTRA Dataset*, doi:10.1037/e409682005-001.
- Bronson, Jennifer, & Marcus Berzofsky. (2017). Indicators of mental health problems reported by prisoners and jail inmates, 2011–12. *U.S. Department of Justice*, Bureau of Justice Statistics, June 2017, www.bjs.gov/content/pub/pdf/imhprpji1112.pdf.
- Davis, T. S. (2021, March 19). Overmedicated and caged-what's happening in women's prisons. Prism. Retrieved February 3, 2022, from https://prismreports.org/2020/09/02/overmedicated-and-cagedwhats-happening-in-womens-prisons/
- Davoren, K., & Mirza, M. Z. (2018, August 10). I Tried to Save a Prisoner on Suicide Watch. Retrieved from https://www.themarshallproject.org/2018/08/09/how-i-befriended-a-prisoner-on-suicidewatch "Fact Sheet on Domestic Violence & Criminalization." *FREE MARISSA NOW*, www. freemarissanow.org/fact-sheet-on-domestic-violence--criminalization.html.
- Friedman, Susan Hatters, et al. (2020). The realities of pregnancy and mothering while incarcerated. Journal of the American Academy of Psychiatry and the Law, Journal of the American Academy of Psychiatry and the Law Online, 13 May 2020, jaapl.org/content/early/2020/05/13/JAAPL.003924–20.
- Fogel, Catherine Ingram, et al. (1992). The mental health of incarcerated women. Western Journal of Nursing Research, 14(1), 30–47. doi:10.1177/019394599201400103.
- Gonzalez, Jennifer M. Reingle, & Nadine M. Connell. (2014). Mental health of prisoners: Identifying barriers to mental health treatment and medication continuity. *American Journal of Public Health* 104(12), 2328–2333. doi:10.2105/AJPH.2014.302043
- Helping Women Who Have Been Abused and Incarcerated: Harriett Buhai Center for Family Law. (2019, March 04). Retrieved from http://www.hbcfl.org/helping-women-who-have-been-abused-and-incarcerated/
- Huda, Ahmed Samei. (2019). The medical model in mental health. Oxford Medicine Online, Oxford University Press, oxfordmedicine.com/view/10.1093/med/9780198807254.001.0001/med-9780198807254.
- Inmates with Mental Illness Tell Their Stories. *YouTube, Rooted in Rights*, 19 August 2015, youtu.be/Hjfu2VR62tY.
- Nurse, J. (2003). Influence of environmental factors on mental health within prisons: Focus group study. *BMJ*, 327(7413), 480–483. doi:10.1136/bmj.327.7413.480
- Parenting From Behind Bars with Senator Cory Booker. (2017). *YouTube*, Marshall Project, 10 October 2017, youtu.be/KzCcaNe3ly0.
- Ring, Kevin, & Gill, M. (2017). Using time to reduce crime: Federal prisoner survey results show ways to reduce recidivism. *Prisonpolicy.org*, Families Against Mandatory Minimums, June 2017, www. prisonpolicy.org/scans/famm/Prison-Report\_May-31\_Final.pdf.
- Santo, Alysia. (2017). What is prison like for women and girls? *The Marshall Project*, 10 October 2017, www.themarshallproject.org/2017/10/10/what-is-prison-like-for-women-and-girls.
- Seltzer, Tammy. (2005). Mental health courts: A misguided attempt to address the criminal justice system's unfair treatment of people with mental illnesses. *Psychology, Public Policy, and Law, 11*(4), 570–586. https://doi.org/10.1037/1076-8971.11.4.570

- Shakespeare, Tom (2006). The social model of disability. In Lennard J. Davis (Ed.), *The Disability studies reader* (pp. 2–197). Psychology Press.
- Social and Medical Models of Disability: Paradigm Change. *Disability and Inclusion*, Art Beyond Sight, www.artbeyondsight.org/dic/definition-of-disability-paradigm-change-and-ongoing-conversation/#:~:text=The medical model of disability, clear disadvantages to the individual.
- Staton, Michele, et al. (2003). Substance use, health, and mental health: Problems and service utilization among incarcerated women. *International Journal of Offender Therapy and Comparative Criminology*, 47(2), 224–239. doi:10.1177/0306624X03251120.
- Stanton, Ann E., & Rose, Susan J. (2020). The mental health of mothers currently and formerly incarcerated in jails and prisons: An integrative review on mental health, mental health treatment, and traumatic experiences. *Journal of Forensic Nursing*, 16(4), 224–231.
- Toon, J. (2019, August 23). She was the new girl on our cellblock. Then she took her own life. Retrieved from http://www.themarshallproject.org/2019/08/22/mourning-a-stranger-s-suicide-in-prison
- van den Bergh, B. J., Gatherer, A., Fraser, A., & Moller, L. (2011). Imprisonment and women's health: Concerns about gender sensitivity, human rights and public health. *Bulletin of the World Health Organization*, 89(9), 689–694. doi:10.2471/blt.10.082842
- Villa, Manuel. (2017). The mental health crisis facing women in prison. *The Marshall Project*, 22 June 2017, www.themarshallproject.org/2017/06/22/the-mental-health-crisis-facing-women-in-prison.
- Violence Against Women Prevalence Estimates. (2021). *World Health Organization*, 9 March 2021, www.who.int/publications/i/item/9789240022256. Organization, 9 March 2021, www.who.int/publications/i/item/9789240022256.
- Women at Wisconsin's Taycheedah prison suffer medical neglect and receive worse mental health care than men. American Civil Liberties Union. (2009, November 25). Retrieved February 3, 2022, from https://www.aclu.org/press-releases/women-wisconsins-taycheedah-prison-suffer-medical-neglect-and-receive-worse-mental
- "Women in Prison: A Fact Sheet." Amnesty International, www.prisonpolicy.org/scans/women\_prison. pdf.

# Schistosomiasis: A Review of Other Public Health Interventions

Kayla Vuoso\*

Neglected tropical diseases are left, as their name suggests, abandoned without proper public health interventionist tools within afflicted communities. Millions of people globally interact with neglected tropical disease schistosomiasis (bilharzia), which can cause an immense burden depending on the region, the individual's socioeconomic status, and the infrastructure established to help combat the conditions within the country. This article focuses on a literary review of three intervention points for reducing the risk of people coming into contact with schistosomiasis: a health education campaign, a downscaling farming strategy through market gardening, and differing water-based intervention approaches. Driving awareness and public health efforts toward reducing initial infection and reinfection for endemic schistosomiasis is a proposal that is often last considered due to accepted drug treatments when infected. Therefore, these recommendations are based on minimizing the infection rate and reinfection in endemic areas rather than preventing and treating schistosomiasis.

### Keywords

schistosomiasis • neglected tropical disease • public health • education • intervention • endemic

### Neglected Tropical Disease: Schistosomiasis

Neglected tropical diseases are persistent across the globe, posing a public health threat to millions. With an emphasis on neglect, the diseases deemed "neglected" usually present within poor socioeconomic populations, therefore receiving little to no public health attention for intervention and treatment. Neglected tropical disease schistosomiasis poses a global toll on individual health, healthcare,

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and economic systems regardless of financial status. According to the Centers for Disease Control and Prevention's Global Health and Division of Parasitic Disease and Malaria (2018b), schistosomiasis, otherwise known as bilharzia, is second only to malaria as the most devastating parasitic disease afflicting people worldwide. More than 200 million people globally are infected with schistosomiasis, and the disease symptoms can appear months after initial infection (Global Health & Division of Parasitic Disease and Malaria, 2020).

Schistosomiasis is a tropical and subtropical disease caused by a parasitic worm called schistosomes. The species of schistosomes that are infectious to humans are urogenital *Schistosoma haematobium*, intestinal *Schistosoma mansoni*, and *Schistosoma japonicum*. Freshwater becomes contaminated with the parasite when an infected animal or human urinates or defecates in it, releasing the parasitic eggs, which hatch and survive only in water. According to Colley, Bustinduy, Secor, and King (2014), *Schistosoma* can follow a life cycle as such: a male and female trematode parasite reproduce fertilized eggs within the veins of a human host. The eggs can either be vacated through stool or urine or be retained. If retained, inflammation in the body occurs, and the host potentially dies. However, when the eggs exit the body, if reaching freshwater, they may hatch and infect a snail host, thus undergoing asexual reproduction shedding thousands of cercariae, which are infectious to humans. Cercariae can remain infectious within freshwater for one to three days. Once they penetrate the skin of a human host, it takes five to seven weeks to mature before becoming adults, able to produce eggs and repeat the cycle (Colley et al., 2014).

Chronic schistosomiasis, resulting from repeated exposure to infectious cercaria or development from an untreated initial infection, is endemic in many world regions. Without treatment, chronic schistosomiasis can persist for years and may include abdominal pain, an enlarged liver, blood in the stool or urine, problems passing urine, and an increased risk of liver fibrosis or bladder cancer (Global Health & Division of Parasitic Diseases and Malaria, 2018a). The global burden of schistosomiasis is primarily within Africa, South America, the islands of North America, and the Middle East; it is localized within the Asian countries China and the Philippines (Colley et al., 2014). Furthermore, the prevalence of chronic schistosomiasis is high as the initial infection occurs at a very early age. According to D. G. Colley et al. (2014), the first infection is usually a child at age two years. However, almost every long-term resident within an endemic region becomes infected with *Schistosoma* at some point in their life (Colley et al., 2014). While the highest prevalence is among children, other populations who frequently come into contact with water for daily activities such as laundry, bathing, and fishing are at risk of infection and developing chronic schistosomiasis.

Schistosomiasis carries a substantial burden on individual health, communities, and leadership. Thus, this parasite requires medical interventions and approachable civilian interventions. Disability due to communicable disease is the leading cause of disease burden in low-income countries, which is preventable. Schistosomiasis recorded 1.7 million disability-adjusted life years (DALYs) per year due to organ damage, hemorrhage, and cancer resulting from infection (King, 2010). However, a recalculation of DALYs using a conservative 2% disability weight yielded a more realistic DALY of 13–15 million in 2004 (King, 2010). Therefore, schistosomiasis intersects as a public health medical problem in addition to a public health environmental problem. The following sections examine multiple solutions to reduce the prevalence of schistosomiasis, not to eliminate the parasite. Most global public health organizations are focusing on treatment measures post-infection. Still, there must be further considerations to decrease human contact with infectious cercariae and host snails, potentially minimizing the ongoing infection cycle, reinfection, and chronic schistosomiasis.

### A Continuous Health Education Campaign

Health education is defined as "providing health information and knowledge to individuals and communities and providing skills to enable individuals to adopt healthy behaviors voluntarily" (Kumar & Preetha, 2012). According to the World Health Organization (2020), schistosomiasis is a global health threat to more than 700 million people. Therefore, educating the public within and in surrounding endemic areas about the neglected tropical disease is vital.

Health education involves understanding learned experiences that can help individuals and communities improve health outcomes through gained knowledge and influencing attitudes (Kumar & Preetha, 2012). Before researchers can conduct health education campaigns, they aim to understand the health literacy of people's knowledge, attitudes, and practices or conduct a knowledge, attitude, and practices (KAP) survey among the population studied. Through KAP surveys, the theory is that knowledge is the foundation for changing behavior and requires time knowledge-based formulation (Xu et al., 2019). A KAP survey reveals misconceptions and misunderstandings that may present barriers to behavior change through a formatted standardized questionnaire. The predefined questions allow researchers to evaluate qualitative and quantitative information and may reveal breaches in behaviors and knowledge on behaviors.

Limited or insufficient health literacy is associated with reduced protective behaviors and understanding how one becomes infected. Therefore, student health education about schistosomiasis should be constantly carried out and preserved, ultimately improving student cognition through long-term indoctrination on infection and transmission (Xu et al., 2019). However, this includes setting up special health education classes if countries do not have them already. Overall, children are the ideal canvas for instilling health behaviors that can benefit community outreach and change, leading to healthier communities in the long term.

An example of a continuous health education campaign is introducing material into the school curriculum. In Kenya, schistosomiasis was taught at school within the science subject as "bilharzia—a water-borne disease" (Takeuchi et al., 2019). In Tanzania, a health education campaign was encouraged by teachers to improve child personal hygiene relevant to the control of schistosomiasis, including the importance of clean drinking water, handwashing, and using latrines, through classroom teachings and health messages throughout the classroom (Lansdown, 2002). Health education within the school is essential to consider, given how young people become infected. The younger the intervention participants, the earlier the intervention can help lower the prevalence of chronic schistosomiasis.

### Market Gardening Strategy

The links between poverty and neglected tropical diseases are widely understood: it is an economic burden. However, providing for one's family was more of value for many people than working in jobs that posed a high risk of infection. Family members who work as fishermen, farmers, irrigation workers, and those collecting freshwater frequently exposed themselves to cercariae in endemic areas (Lund et al., 2019). There is a cycle within underdeveloped countries where living within endemic areas hinders income generation because income is mainly through physical labor resource—dependent livelihoods (Lund et al., 2019). Therefore, theoretically, schistosomiasis may be an important barrier to economic development, given that many physical labor jobs include

farming and fishing, which work closely with freshwater. Thus, this gives rise to a relationship that cannot break with schistosomiasis infection if one's livelihood is of more importance than one's health outcomes. For example, schistosomiasis leads to a severe health disparity in rural communities, especially among farmers. Farmers are aware of the risk of exposure, yet they have no alternative but to come into contact with freshwater for irrigation. Since irrigation ditches are prime snail habitats, scaling down farm sizes may be a tool to help reduce snail vector distribution into where people live and work.

A suggestive strategy to release people from becoming reinfected with contaminated water and help support the local economy all while building community is market gardening. According to Bachmann (2009), a market garden is "the commercial production of vegetables, fruits, flowers and other plants on a scale larger than a home garden, yet small enough that many gardening principles are applicable. The goal, as with all farm enterprises, is to run the operation as a business and to make a profit." Implementing a large-scale garden makes the point blatant: to drive money directly into the farmers' pockets, given that the earnings will be going straight back into their pockets. Market gardening can also serve as a community garden where locals can pay for fresh produce like community-supported agriculture (CSA).

The market gardening strategy is a suggestion highlighted for areas with other public health crises such as food insecurity, malnutrition, and vitamin deficiencies. Comorbidities are likely to present across hyperendemic regions of schistosomiasis. Therefore, introducing a possible solution to provide fresh produce with the potential to gain local capital is a step in a nontraditional direction in tackling a neglected tropical disease. Given the prevalence of neglected tropical diseases among poor socioeconomic climates like rural areas, introducing a solution to minimize poverty and schistosomiasis exposure is not the ultimate solution but the development toward a progressive outcome.

### Water-Based Approach

The further point is that farmers and civilians should eliminate outside contact with contaminated water sources, given schistosomiasis is a waterborne disease. In short, mass drug administration with praziquantel is the most popular control of schistosomiasis morbidity (Evan Secor, 2014). Given schistosomiasis has a life cycle presence central in water, targeting interventions to environmental approaches is a crucial component to highlight for public health. A past public health approach used a biological agent such as a chemical to interact and kill host snails, which ultimately proved toxic to aquatic animals, causing a loss of food supply for people within the endemic area (Evan Secor, 2014).

The most well-received intervention is introducing endod, the soapberry plant *Phytolacca dodecandra*, lethal to snails that may host schistosomiasis (Evan Secor, 2014). Other biological control approaches in reducing snail populations include introducing a predator prawn *Macrobrachium vollenhovenii*, a crayfish *Procambarus clarkii*, and other predatory fish indigenous to areas where host snails of schistosomiasis transmission are high (Evan Secor, 2014). Given this, evaluating geography, the species of the schistosomiasis, and the various host snail species is essential when introducing predatory species. Therefore, introducing nonindigenous species is a consequence to avoid. Furthermore, snail habitats are crucial to understanding disease transmission. Studies have shown that habitat correlates appeared to be effective predictors of snail abundance, such as mud, emergent

vegetation, and non-emergent vegetation (Wood et al., 2019). By using "precision mapping" such as drone or satellite observations, scientists can identify high-risk areas that may drive transmission (Wood et al., 2019). Identifying high-risk areas can expedite removing the vegetation that supports snails or introducing predatory species, which may help eliminate the snail clusters and reduce the rate of infection. However, these less invasive water interventions have not been as successful due to participation rates and low maintenance (Evan Secor, 2014).

Overall, it is vital to have safe, non-contaminated drinking and potable water in any community. The goal is to limit the overall contact an individual has with contaminated schistosome water to reduce the prevalence of infection or reinfection. To help with this goal, providing less infectious schistosomiasis water is vital. The ultimate achievement is providing communities with a safe and cost-effective treatment process that rids water of cercariae. Cercariae are present dead when stored in water for more than one to three days, depending on the temperature (Braun, Grimes, & Templeton, 2018). There are numerous ways to filter cercariae out of the water, including filter mediums, chlorination, and ultraviolet lighting. Still, the results have been presented variable and require further research to obtain reproducible information (Braun et al., 2018).

#### **Future Considerations**

For decades, schistosomiasis has been applied with the same strategies, utilizing mass drug administration and supplemental support to aid chronically ill patients. The future of care for this neglected tropical disease is to angle support toward public health applications that directly impact the people and that are not medicine-based. Helping, treating, and preventing the disease spread in masses of people do not define medicine but define the components of public health and what public health relationships with treatment can accomplish. It is time to continuously utilize interdisciplinary approaches, possibly even broader than those used now, to try and combat schistosomiasis. A system may include but isn't limited to initiating interventions for health education for youth, scaling down farms, and utilizing multiple water-based interventions to reduce the transmission of schistosomiasis.

#### References

- Bachmann, J. (2009, May). Market gardening: A start up guide. *ATTRA*. https://douglas.extension.wisc.edu/files/2010/05/Market-Gardening-Getting-Started-ATTRA.pdf
- Braun, L., Grimes, J. E. T., & Templeton, M. R. (2018). The effectiveness of water treatment processes against schistosome cercariae: A systematic review. *PLOS Neglected Tropical Diseases*, 12(4), e0006364. https://doi.org/10.1371/journal.pntd.0006364
- Colley, D. G., Bustinduy, A. L., Secor, W. E., & King, C. H. (2014). Human schistosomiasis. *The Lancet*, 383(9936), 2253–2264. https://doi.org/10.1016/s0140-6736(13)61949-2
- Evan Secor, W. (2014). Water-based interventions for schistosomiasis control. *Pathogens and Global Health*, 108(5), 246–254. https://doi.org/10.1179/2047773214y.0000000149
- Global Health & Division of Parasitic Diseases and Malaria. (2018a, April 11). Disease. Centers for Disease Control and Prevention. https://www.cdc.gov/parasites/schistosomiasis/disease.html

- Global Health & Division of Parasitic Diseases and Malaria. (2018b, April 11). Parasites— Schistosomiasis. Centers for Disease Control and Prevention. https://www.cdc.gov/parasites/schistosomiasis/index.html
- Global Health & Division of Parasitic Disease and Malaria. (2020, September 1). About Schistosomiasis. Centers for Disease Control and Prevention. https://www.cdc.gov/parasites/schistosomiasis/gen\_info/faqs.html
- King, C. H. (2010). Parasites and poverty: The case of schistosomiasis. *Acta Tropica*, 113(2), 95–104. https://doi.org/10.1016/j.actatropica.2009.11.012
- Kumar, S., & Preetha, G. (2012). Health promotion: An effective tool for global health. Indian *Journal of Community Medicine*, 37(1), 5. https://doi.org/10.4103/0970-0218.94009
- Lansdown, R. (2002). Schistosomiasis, helminth infection and health education in Tanzania: achieving behaviour change in primary schools. *Health Education Research*, 17(4), 425–433. https://doi.org/10.1093/her/17.4.425
- Lund, A. J., Sam, M. M., Sy, A. B., Sow, O. W., Ali, S., Sokolow, S. H., . . . de Leo, G. A. (2019). Unavoidable risks: Local perspectives on water contact behavior and implications for schistosomiasis control in an agricultural region of Northern Senegal. *The American Journal of Tropical Medicine and Hygiene*, 101(4), 837–847. https://doi.org/10.4269/ajtmh.19-0099
- Takeuchi, R., Njenga, S. M., Ichinose, Y., Kaneko, S., Estrada, C. A., & Kobayashi, J. (2019). Is there a gap between health education content and practice toward schistosomiasis prevention among schoolchildren along the shores of Lake Victoria in Kenya? *PLOS Neglected Tropical Diseases*, 13(8), e0007572. https://doi.org/10.1371/journal.pntd.0007572
- Wood, C. L., Sokolow, S. H., Jones, I. J., Chamberlin, A. J., Lafferty, K. D., Kuris, A. M., . . . de Leo, G. A. (2019). Precision mapping of snail habitat provides a powerful indicator of human schistosomiasis transmission. *Proceedings of the National Academy of Sciences*, 116(46), 23182–23191. https://doi.org/10.1073/pnas.1903698116
- World Health Organization. (2020, February 28). Schistosomiasis (Bilharzia). https://www.who.int/health-topics/schistosomiasis#tab=tab\_1
- Xu, D. C., Li, W., Juma, S., He, M. Z., Kabole, F., Wang, X. Y., & Yang, K. (2019). The effectiveness of schistosomiasis health education session in primary and secondary schools in Pemba Island, Zanzibar. Research Square. Published. https://doi.org/10.21203/rs.2.13577/v2

# Free at Last: An Introspective Guide into the Embedded Roots of Colonialism in the Current State of Healthcare in Ghana

Evelyn Boateng-Ade\*

The current state of healthcare in Africa is disastrous, especially when compared to that of Western societies. Statistics show that people are dying young and experiencing disability at an exponentially higher rate in Africa than people in Western society. The root of this inequality is attributed to multiple sources. Some speculate that this inequality is due to the state of Africa itself. The weak economy and corrupt leadership must have created these health issues in Africa. Others argue it is due to the lack of development of the African society. Underfunded social services, the lack of infrastructure, and the depletion of human and material resources play a role in the health disparities. These speculations scratch at the surface of issues of inequality in Africa but fail to address the underlying causes. These factors play a role in the lackluster healthcare system in Africa and are negatively affecting the health of Africans. It is evident that the ills of the healthcare system are caused not by Africans themselves but rather by the system of colonialism that is exploiting and depriving Africa continuously through corruption, the lack of self-agency, and the idolization of Western culture.

This article will examine the roots of colonialism embedded in the healthcare system in one country, Ghana, to model methods of change for the rest of the continent. Inequality is a radical force in society and can only be solved through radical means. Solutions to jumpstart the healthcare system in Ghana, and Africa as a whole, are necessary to release the ties of colonialism from Africa that exacerbate inequality in the healthcare system.

### Keywords

colonialism • Ghana • healthcare systems • radical

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### Scope of the Problem

Ghana was the first country to gain independence from British colonial rule on March 6, 1957. Moments after Ghana gained its independence, Kwame Nkrumah, the first president of Ghana, exclaimed, "Our independence is meaningless unless it is linked up with the total liberation of Africa!" (BBC, 2007). Nkrumah was adamant about the necessity of Africa as a whole to unite against imperialist forces because freedom is not equivalent to decolonization. Decolonization is the process of reversing and removing the effects of colonial rule, whereas freedom is just removing the direct presence of a colonial power. The direct absence of colonial rule does not undo the long-lasting and detrimental impacts of colonial rule. Decolonization takes intentional and purposeful work, and unfortunately Ghana, like most African countries, has never achieved this.

From the transatlantic slave trade to the scramble for Africa, to current neocolonial policies, colonialism is embedded into African society, and it affects every aspect of society. Colonialism is defined as "the founding of a state based on white supremacy," which is evident in the colonial rule of Ghana, where white supremacy is spread in an attempt to cripple the ability of the native people to surpass Western society (Barlow & Smith, 2019). In Ghana, the lasting effect of colonialism is seen most prominently in the economy. Ghana inherited a lackluster economy from British rule that was prone to inflation, budget deficits, and a wide array of economic problems (Whitfield, 2018). Colonialism is embedded within the economy, and without an overt attempt to dismantle it, any attempts to improve Ghana's economy will be fruitless. The political-economic system of capitalism is a direct remnant of colonization and ensures that global leaders can profit and extort the resources of Ghana and other developing nations. With the economy riddled with the remnants of colonization, this is bound to spill over into some of the most pivotal governmental functions, like healthcare. The problems in Ghana's current healthcare system are very well known to Ghanaians. The poor can't afford it, and the rich don't want it. Poor Ghanaians take any means possible to avoid the exorbitant costs of seeking healthcare in Ghana, while affluential Ghanaians rely on medical care abroad. This decreases the efficacy of the role of healthcare in Ghana. Additionally, a study of the West African healthcare system found that corruption is rampant in various forms throughout the system in Ghana (Agwu et al., 2019). In recent years, the government has made countless attempts to revamp the healthcare system. The implementation of universal health insurance, increasing the supply of ambulances and other first response teams, and millions of dollars of investment into healthcare, yet the state of Ghana's healthcare system appears the same (Okoroh et al., 2018; Blanchet, Fink, & Osei-Akoto, 2012; Ministry of Health). Health inequities stem from colonialism. Therefore, health inequities cannot be solved without first dissolving colonialist ties. Colonialism in itself creates health inequities by establishing policies that create social determinants of health that did not exist before colonial rule (Barlow, 2018).

One of the key social determinants of health that is debilitating the healthcare system in West Africa is access. Access is multifaceted and severely overlooked when evaluating social determinants of health. Access as a social determinant goes beyond the normative definition of one's ability to enter a place. It involves a more intricate relationship between the individual and their healthcare system, and whether this relationship encompasses availability, accessibility, accommodation, affordability, and acceptability (Penchasky & Thomas, 1981). Availability entails the supply of medical services and personnel that is equivalent to the demand or the entire population (Penchasky & Thomas, 1981). Accessibility means that individuals themselves can easily get to medical services. Accommodation is whether or not the methods that healthcare providers use match the patient's

needs (Penchasky & Thomas, 1981). Affordability questions if individuals can adequately afford to receive medical services. Finally, acceptability is whether a patient's attitudes and personal beliefs accept the methods of the healthcare system (Penchasky & Thomas, 1981). Often, aspects of access are neglected, and this leads to further misjudgments and miscalculations on the quality of healthcare. The question of who has access and what elements of access are adhered to for certain populations relates directly to colonialism.

In examining the healthcare system, it is important to understand the full range of healthcare that exists in Ghana. There are dual healthcare systems that make up the lives of Ghanaians: traditional medicine and the Westernized healthcare system. Traditional medicine is defined as "the knowledge, skills and practices based on the theories, beliefs and experiences indigenous to different cultures, used in the maintenance of health and in the prevention, diagnosis, improvement or treatment of physical and mental illness" (World Health Organization [WHO]). In Ghana, due to the lack of access and affordability of the Westernized healthcare system, many people rely on traditional medicine for their source of healthcare. In fact, a study examining the trends of traditional medicine in Africa found that "about 70% of the population depends primarily on [traditional medicine]" (Abdullahi, 2011). Yet traditional medicine remains completely unregulated and unmonitored by the government. The conjunction of unregulated traditional medicine and Westernized medicine combined with the extrapolating effects of colonialism is undermining the health of Ghanaians, and Africans as a whole.

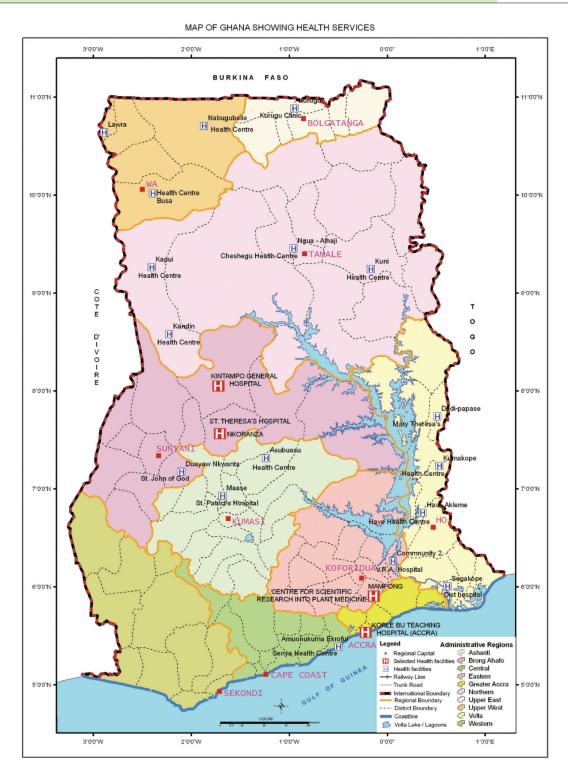
Ghana's healthcare system, like that of much of the developed world, is severely subpar. As globalized as society is today, there is no reason why a major hospital should not have basic drugs or why certain populations should have to travel for miles just to get to a hospital (Pheage, 2016–2017; figure 1). This, and so much worse, is commonplace in Ghana. And when considering the health experiences of marginalized people, like women or the LGBTQ+ community, it is heartbreaking. People are dying from completely curable diseases in unprecedented numbers (Pheage, 2016–2017; Aikins, 2013). Attempts at improving the conditions and dire health statistics are completely fruitless (Okoroh et al., 2018; Blanchet et al., 2012; Ministry of Health; Pheage, 2016–2017). From an introspection of history, Ghanaians, and many other underdeveloped nations, are trapped in an endless cycle of death, while others in developed nations live lives of luxury. As underdeveloped countries try to mimic the systems of these Western societies, they entrench themselves deeper in a cycle of death.

Capitalism is the economic and political system that keeps this cycle of death never-ending. At its foundations, capitalism depends on the exploitation of masses of people in order for profit to be maximized. Western societies are keenly aware of this and use the system of colonialism as a means to their end of luxury.

### Policy Alternatives

#### Current State of Healthcare

There are significant gaps in the research into the current state of healthcare in Ghana. These are attributed to various reasons. The first is the lack of a governmental organization in Ghana with a primary goal of transparency into the state of healthcare. To compare, in the United States, Healthy People 2020 is one of the numerous sources to find the current state of health and also the health goals for the country for the next decade (Healthy People, 2020). This is in the form of



**Figure 1.** A map of Ghana with a key labeling health facilities and major hospitals in Ghana. Source: Courtesy of Chronic *Non-Communicable Diseases in Ghana: Multidisciplinary Perspectives* by De-Graft Aikins

multiple comprehensive lists, infographics for easy accessibility, and is readily available online. The Ghanaian equivalent, the Ministry of Health's Policy Objectives, is out of date by three years and does not contain a comprehensive list of the problems impacting the healthcare system in Ghana (Ministry of Health). How can the problems facing Ghana's healthcare system be effectively solved if they are not even clearly known? This brings in another gap in the research that is directly tied to colonialism. All of the research, information, and education into the healthcare system are done solely in English. Yet there are over 50 native languages in Ghana. While English is the official language in Ghana, the United Nations (UN) proposes that only about 32% of Ghanaians are proficient in English (Dako & Quarcoo, 2017). This means that only 32% of the population can even understand the minimal medical research and information that is available to them. Further, the available research into healthcare in Africa frequently merges the problems of the entire continent into one. While the problems that exist are very similar across Africa, there are significant distinctions between regions, individual countries, and even different tribes. Research into specific countries in Africa is very hard to come by, and for some countries, almost impossible. Despite all of these limitations in the research, the dire state of healthcare in Ghana is uncontested. According to an article published in the *Africa Renewal* journal of the United Nations, "Approximately 1.6 million Africans died of malaria, tuberculosis and HIV-related illnesses in 2015" (Pheage, 2016–2017). Malaria, tuberculosis, and HIV are all diseases that have been eradicated, or are in very low prevalence, in the developed world. Yet they are still crippling the African healthcare system. Further, the article states, "Globally, 50% of children under five who die of pneumonia, diarrhea, measles, HIV, tuberculosis, and malaria are in Africa" (Pheage, 2016–2017). The disease burden of communicable diseases affects Africans exponentially more than the rest of the world. Chronic Non-Communicable Diseases in Ghana: Multidisciplinary Perspectives goes beyond this to argue that noncommunicable diseases in Africa are largely ignored when considering the disease burden, despite the fact that they are more prevalent, population-wise, than communicable diseases. The text demonstrates that in Ghana"[h]ypertension prevalence is now estimated at 37 percent in urban areas and 24 percent in rural areas. Diabetes prevalence rates range between 6 percent and 8 percent and peaks at around 9.1 percent among urban civil servants. The prevalence of common mental disorders (mainly depression and anxiety disorders) is estimated at 10 percent, while severe mental disorders (psychosis, schizophrenia) is estimated at 3 percent" (Aikins, 2013). Further, the prevalence rates of communicable diseases are less than those of noncommunicable diseases. Yet the majority of media, health interventions, and funding are prioritized toward communicable diseases. The forces of colonialism dictate the perception of the state of healthcare in Africa—which impacts funding and media attention. While noncommunicable and communicable diseases both greatly impact the health of Africans, communicable diseases, like malaria or tuberculosis, perpetuate the colonialist ideology of the inferiority of Africa. The fact that the West was able to eradicate these diseases, but Africa still has not been able to do this, spreads the idea of Western superiority and the need for the white man to "save" the African people. That Africans perpetuate this stereotype through increased funding toward communicable diseases is colonialism at work.

Simultaneously, colonialism has also severely deprived Africa of access to key medicines. As stated previously, communicable diseases that have been essentially eradicated in the developed world are still very prevalent in Africa, mostly due to the lack of access to medicine. While the lack of access to medicine can be attributed to multiple causes, "the major ones, according to the WHO, are the shortage of resources and the lack of skilled personnel" (Pheage, 2016–2017).

Africa is a continent of immense wealth and natural resources, yet it lacks the resources and personnel to provide medicine to its people. This fact is a direct result of colonialism. The *African Renewal* journal of the UN states that "less than 2% of drugs consumed in Africa are produced on the continent" (Pheage, 2016–2017). This means that almost all of the medicine used in Africa is dependent on colonialist powers. This gives Western governments and pharmaceutical companies direct power to control what medicines Africans have access to and who receives them. To describe the extent of this tragedy, in Zimbabwe, the lack of access to medicine is so extreme that painkillers are used as a "treat-all drug" (Pheage, 2016–17). The Western civilization is currently grappling with the effects of the overuse of pain medication, and these effects are not far behind African nations. The current state of healthcare in West Africa is dire, and its roots are intrinsically linked to colonialism.

# Colonialism Embedded into the System

Colonialism into the healthcare system in Africa is far-reaching; from the diseases that receive recognition, to where hospitals are located, to even the healthcare options available, colonialism has completely overtaken healthcare systems in Africa (Aikins, 2013; Agwu et al., 2018; Pheage, 2016–2017). The role of colonialism is seen most evidently within the dual healthcare systems.

Africans have relied on traditional medicine for centuries. It uses natural ingredients, like herbs, and emphasizes on the social and emotional equilibrium of patients rather than just treating diseases (WHO). This method of healthcare, although greatly un-researched, was held in high esteem and was a trusted method of healthcare prior to colonial rule. When Westernized healthcare systems were introduced during colonial rule, the role of traditional medicine shifted, and it was regarded as primitive and ineffective by colonial rulers. Through colonialism, this ideology is being mirrored in African people. Still, traditional medicine is the primary source of healthcare for the majority of Africans in rural areas (Abdullahi, 2011). And yet, this practice remains unregulated.

Traditional medicine methodology has become a trend in Western civilization under the euphemism of DIY skincare, expensive treatments like acupuncture, and much more. Traditional medicine is even being taught in medical schools in the United States (Abdullahi, 2011). Yet, when asked in a study about the role of traditional medicine, Nigerian medical students gave little weight to and even defamed the importance of traditional medicine (Abdullahi, 2011). This highlights an important aspect of colonialism: how it affects Africans psychologically. Hussein A. Bulhan, a scholar from Frantz Fanon University in Hargeisa, Somalia, describes the "colonization of values," a concept where people of color internalize self-defeating and demeaning beliefs tied to their culture and identity whiles simultaneously praising and idealizing beliefs about Western society (Bulhan, 2015). While Western civilization has been able to recognize the effectiveness of traditional medicine, Africans are still stuck in the mindsets of colonial times. This phenomenon of colonialism is best explained through internalized racism. This idea demonstrates that after years of institutionalized racism, lack of access on the basis of race, and personally mediated racism, prejudice, and discrimination, stigmatized people begin to accept and even perpetuate their role of inferiority and unworthiness (Jones, 2000). Africans have faced centuries of institutionalized and personally mediated racism, so it is no wonder that internalized racism is so common in Africa. The effect of colonialism at the individual level needs to be thoroughly evaluated to release the ties of colonialism.

# Previous Attempts to Improve the State of Healthcare

Improving the dire state of healthcare in Ghana is not a new task. There have been numerous attempts to make Ghana's healthcare more accessible, affordable, and increase the standard of living for Ghanaians over the years. The levels of effectiveness vary, but overall they all made little impact.

The most recent nationwide attempt at improving access to healthcare in Ghana was the National Health Insurance Scheme (NHIS), adopted in 2003. With out-of-pocket expenditures in Ghana at 26% of the total health expenditures, a rate almost double the recommended rate by the WHO, universal health insurance could have been a great stride toward progress for Ghanaians (Okoroh et al., 2018). The NHIS attempted to reduce the financial barriers to healthcare access through yearly premiums, a 2.5% levy on certain goods and services, and waiving premiums for vulnerable populations (Ayanore et al., 2019). Some studies showed that the NIHS helped improve access to healthcare for certain populations, adult women in the Accra metropolitan area, but the overall majority of studies showed that it made little impact on healthcare costs for insured people (Adua et al., 2017; Okoroh et al., 2018; Blanchet et al., 2012). Still, as of 2021, almost 70% of the population in Ghana is insured (Sasu, 2022). Arguably the most vulnerable population in Ghanaian society, rural people have remained uninsured (Okoroh et al., 2018). Despite its flaws, the NIHS does make a difference in out-of-pocket costs, with uninsured people paying up to 10 times more for healthcare when compared to insured people (Blanchet et al., 2012).

Another recent attempt at improving healthcare in Ghana was the implementation of new ambulances. In 2019, the Ghanaian Minister of Health, Honorable Kwaku Agyemang-Manu, announced that the government will be procuring 275 new ambulances for each of the 16 districts in Ghana (Ministry of Health). While this should be a great feat for the country of Ghana, many Ghanaian citizens were indifferent to such a boastful comment right before an election year. This lack of trust in their healthcare system stems from the years of corruption involving these very ambulances. Ghana has had an adequate supply of ambulances for almost a decade, and yet due to corruption, they are all virtually unusable. The Minister of Health himself describes this problem by stating,

for the past eight years, the nation's ambulance stock, which was supposed to be increased and maintained year after year was not done . . . even those which had already been purchased were not operational, money has already been paid but we cannot use them.

(Ministry of Health)

Corruption and misuse of money have made instances like this common in the Ghanaian health-care system, and even the government itself. There is a lack of appropriation and surveillance of budgets in Ghana, so money meant to improve governmental systems often disappears with projects remaining uncompleted.

All these attempts have one thing in common—the goal of not only improving the healthcare system but also primarily making it mirror the healthcare systems of the Western world. Colonialism has perpetuated the notion of Western normativity and placed Western ways of life as an ideal for developing nations. It limits the possibilities of what developing countries can do to what developed countries have already done, and this notion is false. Western society's healthcare system, while admittedly not at all a perfect system, works for the people it was meant for, white people. To try to mimic and mirror a system that was never even meant for you will always be fruitless.

When evaluating the entire developing world, tales like these are common. People are blatantly aware of the incompetence of their own governments but are rarely shown the way in which Western governments contribute to this. This is colonialism at work, and the best example of this is attempts by African countries to produce their own medicines. A majority of African countries are completely reliant on foreign powers for medicine and often spend a large portion of their resources on just procuring medicine. Attempting to combat this trend, South Africa decided to try to create its own pharmaceutical drugs (Pheage, 2016–2017). The production of drugs is already heavily regulated by Western powers like the United States through the Current Good Manufacturing Practices (Pheage, 2016–2017). The process of meeting regulation standards alone requires a great amount of funding and technical skill that most African countries are not equipped to deal with. In an attempt to combat rising prices of HIV/AIDS drugs, then President of South Africa Nelson Mandela led the charge for South Africa to produce and import cheap and generic HIV/AIDS drugs (Pheage, 2016–2017). In response, in 2001, 39 pharmaceutical companies sued South Africa for breaching their patent rights in order to halter their plans (Pheage, 2016–2017). Where South Africa saw an opportunity to save more lives and loosen their dependence on foreign powers, these pharmaceutical companies saw a loss in profit. This was an attempt at decolonizing the production of medicine and allowing Africans to create drugs for themselves by themselves, and colonialist powers would stop at nothing to delay it.

All these attempts also have one thing missing. The Ghanaian healthcare system consistently neglects some of the most vulnerable populations, women, and LGBTQ+ people. Women face atrocities in the healthcare system regarding methods of family planning services, access to quality prenatal and postpartum care, screenings for noncommunicable diseases, and so much more. Horror stories of women giving birth on floors or taking dangerous drugs in order to induce a miscarriage are all too common in Ghana, and there is nothing being done about it. Additionally, the stories of the LGBTQ+ population are basically unheard of because Ghanaian society suppresses, and is currently attempting to criminalize, this population to extreme extents. The LGBTQ+ population can barely even be themselves safely, let alone seek medical care safely. These gaps need to start being addressed in the Ghanaian healthcare system, and Africa as a whole.

### Policy Recommendations

The current state of healthcare in Ghana is riddled with remnants of colonialism. From its very root, Ghana's healthcare system is not its own but a mere imitation of the healthcare systems of Western society, a failed imitation, at that. The healthcare system of Western society strides ahead of that of West Africa, no argument. People live longer, have better health outcomes, have increased accessibility, and have overall better experiences in a British hospital compared to a Nigerian hospital. For generations, African governments have looked at these statistics to mean that they must abandon their own systems and mirror that of Western society. This mentality is the result of colonialism. Colonialism created the belief in Western superiority and African inferiority. Colonialism insisted that Africa needed Western society in order to survive. It enforced the building of the current healthcare system to perpetuate its inherent goals, and African leaders are unknowingly destroying their own healthcare system with every step to improve it. This is the harsh reality of colonialism in the developing world. Every step to progress ends with ten steps back. But this does not have to happen. Imitating the healthcare systems of other societies is fruitless, solely because those systems were made specifically for those societies. Africa has to make a healthcare system of its own, and the first step to achieve this is decolonization.

Decolonization by definition is reversing the effects of colonialism. This can happen in various ways, but the first step is always to determine whether colonialism is impacting a society in either a positive or negative way. Colonialism is like a cancer that affects society. You cannot remove the cancer in one place and leave it in another, or else it will just continue to grow and infect other organs. You must remove it from the body entirely. That is how colonialism operates. Colonialism is present in every governmental system and level and runs rampant throughout the minds of individuals. But colonialism's biggest strength will also lead to its downfall. Colonialism is able to flourish only because the people who are most affected by it do not even know it exists. When the majority of people realize that colonialism is the underlying cause of their stagnant state, colonialism has lost all of its power. People will begin to recognize colonialist mentalities and rebuke them. They will also begin to challenge the actions of the government that spread colonialist ideologies. The power of a society is truly its people, and when people become aware, they can take back control of their society.

Awareness of the problem, unfortunately, will not erase the effects of the problem. There need to be steps to alleviate the problem. One approach is to take advantage of the fact that people are aware of the problem to spark a perspective shift. This perspective shift should highlight social determinants of health. A social determinants perspective is a way to critique the healthcare system to ensure that it caters to the social determinants of health (Marmot, 2005; The National Academies Press, 2016). This will require the healthcare system and the government as a whole to shift their focus from mirroring the healthcare system of Western society to rather focusing on the specific social determinants of health that are riddling with Ghanaians. What specific issues are Ghanaians grappling with that are affecting their health? Poverty, lack of access to a healthy diet, poor quality of education, low availability of jobs, poor road infrastructure, and so much more are social determinants of health and aspects of Ghanaian society that are negatively affecting the health of Ghanaians. A social determinants perspective will directly address these issues, and more, and over time colonialism will no longer influence the healthcare system, and Ghanaian society as a whole.

The perspective shift alone, however, is not enough to dismantle the system of colonialism. Colonialism is a drastic force that requires an equivalent drastic force of decolonization to counteract it. In this instance, the entire healthcare system in Ghana needs to be dismantled and in its place a healthcare system built with the direct purpose of decolonializing health. This will completely restructure the healthcare system in Ghana from the ground up. This new system will have many considerations in place to offset colonialism, with the main goal of self-sufficiency. Ghana will use its own resources and knowledge to build a healthcare system that specifically caters to the needs of Ghanaians.

One key consideration of Ghana's new healthcare system must be to prioritize the dual healthcare system. Today, traditional medicine is being highly neglected by the Ghanaian healthcare system. Yet the majority of Ghanaians rely on traditional medicine for their primary healthcare (Abdullahi, 2011). By regulating Ghana's traditional medicine, Ghana will be able to take advantage of a huge resource that can streamline the healthcare system and cater it specifically to the Ghanaian people. A study examining the usage of traditional medicine in Africa found that "the ratio of traditional healers to the population in Africa is 1:500 compared to 1:40,000 medical doctors" (Abdullahi, 2011). Undoubtedly, not all methods of traditional medicine can be trusted for the government to sponsor. But a large number of them can have the potential of aiding the healthcare system.

Currently, in the midst of the COVID-19 pandemic, President Nana Akufo-Addo has announced plans to begin the construction of 88 new district hospitals (Ministry of Health). These hospitals can be a great starting point to implement a decolonialized healthcare system in Ghana

right now. Decolonization will not be an easy journey, but it is a journey that must be done for Ghana to be "free at last." Ghana can be the precedent for the rest of the world and continue the legacy of being the first to do it.

The first thing to consider in building decolonized hospitals is the location of these hospitals. As Figure 1 shows, there are hundreds of miles between the major health facilities, with some districts that do not even have one health facility. This should never happen. These decolonialized hospitals need to be strategically placed so that the most vulnerable and at-risk populations have access to them. This will demand an assessment of the 5 A's of Access and how this relates to the specific needs of the Ghanaian population. There also needs to be an evaluation of the costs and benefits so that the populations that are most affected by current health inequities gain access to these decolonialized hospitals first. This includes populations in rural areas that have no access to healthcare and populations of women and children that have never had access to family planning services, pediatrician checkups, and other services that will improve their quality of life. With the high rates of noncommunicable diseases in Ghana, there also needs to be considerations of where the highest cases of these diseases are located so that hospitals with screening capabilities and mass public health efforts to enforce a healthy lifestyle can be implemented.

With considerations of the location of these decolonialized hospitals, there also needs to be an evaluation of the structure of these decolonialized hospitals. This structure must be dependent entirely on the needs and wants of Ghanaian citizens. This will include paying attention to the patterns of Ghanaians and studying at what stage of a problem do Ghanaians decide to go to a hospital, what methods do they rely on in the absence of a hospital, what do they expect from a doctor, and a variety of other qualitative questions to make the hospital experience the best it can be. An accurate study that evaluates this can end up with a hospital system that is very much like the current system, or completely different. The point is that Ghanaians are put at the center of implementing it.

Further, the structure of decolonialized hospitals must also take advantage of traditional medicine and its practitioners. Traditional medicine included in the decolonialized hospital structure will foster a sense of community and cultural acceptance that is lacking in the current system. Traditional medicine has a focus on the interconnectedness of the land, body, and spirit which has great benefits for the physical and mental health of individuals. An attempt to rebrand and standardize traditional medicine will ensure that the most benefit will be reaped from traditional medicine.

Decolonization must start from the roots of the healthcare system, the education of health professionals. Health professionals should be taught to constantly and consistently question forms of colonialism, sexism, racism, homophobia, Islamophobia, and every other form of discrimination that can exist in the healthcare system. Constantly questioning these systems will reveal the gaps and flaws that exist and foster conversation on how to bridge them. Decolonialized hospitals should be built with Ghanaians at the core, regardless of their sex, gender, religion, or sexual orientation.

# Conclusion

"Theirs was to first make themselves and later the rest of the world live a healthy life" (Abdullahi, 2011). The Western societies that Ghanaians revere so much have never, and will never, had the intention of putting Africa first. Africans themselves are the only people that can do this, and this must happen right now.

Ghana's healthcare system is built on the foundations of colonialism. It perpetuates the inferiority of Ghanaians in the world scheme and leaves Ghanaians completely dependent on colonial powers to survive. This has a negative effect on the health of Ghanaians and leaves Ghana's healthcare system in a stagnant state.

Attempts at implementing less drastic measures to improve the state of healthcare have come to naught. Attempts to increase funding, build more hospitals, establish an ambulance system, implementation of universal insurance, produce their own medicine, and much more have done nothing to bridge the gap between health outcomes in the African and the Western world. This is the work of colonialism. Colonialism ensures that Africans are always able to be exploited for the use of the Western world. Whether this exploitation is in the form of the transatlantic slave trade or the stagnant healthcare system, it is all one and the same.

The problems in Ghana's healthcare system are not unique. In fact, it is more of a rule of developing countries. But Ghana can set the precedence and be the difference. A direct approach of decolonializing every governmental system, starting with the healthcare system, with the needs and wants of Ghanaians at the center, will change the never-ending cycle of death that has been plaguing Ghana for centuries. Awareness coupled with a perspective shift is necessary to dismantle the current healthcare system for one that is more aligned with the culture, values, and needs of Ghanaian society. One person cannot define what this new healthcare system will look like; it must be an intervention based on evidence and backed by the community itself. But there is one thing that is certain—change needs to come, and it needs to come now. Decolonialism is the key to Ghana being "free at last."

# References

- Abdullahi, A. A. (2011). Trends and challenges of traditional medicine in Africa. *African Journal of Traditional, Complementary, and Alternative Medicine: AJTCAM*, 8(5 Suppl), 115–123. https://doi.org/10.4314/ajtcam.v8i5S.5
- Adua, E., Frimpong, K., Li, X. et al. (2017). Emerging issues in public health: A perspective on Ghana's healthcare expenditure, policies and outcomes. *EPMA Journal 8*, 197–206. https://doi.org/10.1007/s13167-017-0109-3
- Agwu, P., Balabanova, D., Onwujekwe, O., Orjiakor, C., McKee, M., Hutchinson, E., . . . Ichoku, H. (2019). Corruption in Anglophone West Africa health systems: A systematic review of its different variants and the factors that sustain them. *Health Policy and Planning*, 34(7), 529–543. https://doi.org/10.1093/heapol/czz070
- Aikins, D., Agyei-Mensah, S., & Agyemang, C. (Eds.). (2013). *Chronic non-communicable diseases in Ghana: Multidisciplinary perspectives*. Sub-Saharan Publishers & Traders.
- Ayanore, M. A., Pavlova, M., Kugbey, N. et al. (2019). Health insurance coverage, type of payment for health insurance, and reasons for not being insured under the National Health Insurance Scheme in Ghana. *Health Economics Review* 9, 39. https://doi.org/10.1186/s13561-019-0255-5
- Barlow, J. N. (2018). Restoring optimal black mental health and reversing intergenerational trauma in an era of black lives matter. *Biography 41*(4), 895–908. doi:10.1353/bio.2018.0084.
- Barlow, J. N., & Smith, G. (2019). What the health (WTH)?: Theorizing southern black feminisms in the US south. *Agenda*, 33(3), 19–33. doi: 10.1080/10130950.2019.1668725.

- BBC. (2007). BBC World Service | Focus on Africa | "Ghana is free forever". *BBC News*. Retrieved March 14, 2022, from https://www.bbc.co.uk/worldservice/focusonafrica/news/story/2007/02/070129\_ghana50\_independence\_speech.shtml.
- Blanchet, N. J., Fink, G., & Osei-Akoto, I. (2012, June). The effect of Ghana's National Health Insurance Scheme on health care utilisation. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3426378/
- Bulhan, H. A. (2015). Stages of colonialism in Africa: From occupation of land to occupation of being. *Journal of Social and Political Psychology*, *3*(1), 239–256. doi:10.5964/jspp.v3i1.143
- Chronic non-communicable diseases in Ghana: Multidisciplinary perspectives. (2014). Retrieved from https://ebookcentral.proquest.com
- Dako, K., & Quarcoo, M. (2017). Attitudes towards English in Ghana. Legon Journal of the Humanities, 28(1), 20. doi:10.4314/ljh.v28i1.3.
- Jones, Camara Phyllis. (2000). Levels of racism: A theoretic framework and a Gardner's tale. *American Journal of Public Health*. August 2000. https://ajph.aphapublications.org/doi/pdf/10.2105/AJPH.90.8.1212
- Marmot, M. (2005, March 18). Social determinants of health inequalities. Retrieved from https://www.sciencedirect.com/science/article/pii/S0140673605711466
- Okoroh, J., Essoun, S., Seddoh, A. et al. (2018). Evaluating the impact of the national health insurance scheme of Ghana on out of pocket expenditures: A systematic review. *BMC Health Services Research*, 18, 426. https://doi.org/10.1186/s12913-018-3249-9
- Penchasky, R., & Thomas, W. (1981). The concept of access: Definition and relation to consumer satisfaction. *Medical Care*, 19(2), https://blackboard.gwu.edu/bbcswebdav/pid-9910815-dt-content-rid-68189968\_2/courses/71497\_202001/Penchansky%20and%20Thomas.pdf
- Pheage, T. (2016–2017). *Dying from lack of medicines*. Africa Renewal. (n.d.). Retrieved from https://www.un.org/africarenewal/magazine/december-2016-march-2017/dying-lack-medicines.
- Sasu, D. D. (2022, January 28). Ghana: Share of population by health insurance status 2021. *Statista*. Retrieved February 4, 2022, from https://www.statista.com/statistics/1283538/share-of-population-in-ghana-by-health-insurance-coverage/
- The Ministry of Health. (2019, July 23). Retrieved from https://www.moh.gov.gh/the-ministry/
- The National Academies Press. (2016). A framework for educating health professionals to address the social determinants of health. NAP.edu. (n.d.). Retrieved from https://www.nap.edu/read/21923/chapter/1.
- Traditional Medicine. (n.d.). Retrieved from https://www.afro.who.int/health-topics/traditional-medicine
- Whitfield, L. (2018). *Economies after colonialism: Ghana and the struggle for power*. Retrieved from https://ebookcentral.proquest.com.

# Developing a Black Student-Led Support Infrastructure at Wayne State University, a Predominantly White Institution

Kamali A. Clora\*, Miles N. Reuben†, and Kenya Swanson‡

In 2018, the Integrated Postsecondary Education Data System (IPEDS) named Wayne State University (WSU) the nation's fastest-improving university for graduation rates with an increase from 26% to 47% between 2011 and 2017. This growth was influenced by programs and organizations focused on narrowing the student population achievement gap, including men of color. Since 2016, WSU has utilized a culturally competent approach to support Black male students. The approach highlighted here is The Brotherhood, a student-led organization geared toward undergraduate Black men. As part of the larger initiative to increase graduation rates, this organization concentrates on social action and student engagement while encompassing facets of academic, social, and emotional wellness. We conducted a study to obtain quantitative and qualitative data about this organization's potential impact on Black male undergraduate students. Our results suggest that WSU Black males participating in The Brotherhood have performed better academically than other Black WSU students in their cohort. Additionally, we found that these members learned critical transferable skills applicable to their career fields. Here we describe the fundamental components of The Brotherhood that are attributed to these findings.

## **Keywords**

African American graduation rates • Student success • Student-led • predominately white institution • cultural competence • equitable education

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Conflicts of interest:

The authors have no conflicts of interest to disclose.



# Introduction

Wayne State University's (WSU) rise as a national model for student success reached a new milestone in May 2020, when its six-year graduation rate surpassed its goal of 50% more than a year before completion of its "Distinctively Wayne State" strategic plan (Taylor, 2020). This strategic plan focused on addressing the overall low graduation rate at WSU. More importantly, the plan developed a set of programming to alleviate the achievement gaps among students. Black students have the lowest graduation rates at WSU, with a six-year graduation rate of 34.6%. However, this percentage has increased nearly five times as much over the past decade. This is largely due to the number of culturally tailored programming implemented in the previous six years. All students have access to this programming as WSU is labeled as a Proposition 2 institution by the State of Michigan, meaning all university-funded programs are open to all students. Some programs are specifically tailored toward Black men, which included Warrior VIP and The Network. These programs foster community belonging for students through academic support and professional development. This also includes the Office of Multi-cultural Student Engagement, which offers resources centered on diversity and inclusion. The programming component studied in this project is The Brotherhood, specifically its impact on the student success of Black male undergraduates at WSU. The Brotherhood is a student-led organization that arose in 2017 from the Black student leadership created in spaces like Warrior VIP and The Network. Through empowerment, identity, mentoring, and community, The Brotherhood aims to help minority males toward academic success and learn leadership skills for their future careers. Initially, The Brotherhood intended to be a safe space for undergraduate Black men to commune and develop accountability among themselves. After establishing built relationships within the group, other aspects like academic growth and professional development followed to ensure members were fully supported in their pursuit of a degree at WSU. These efforts have been recognized throughout the university, with The Brotherhood receiving over \$23,000 of program funding from 2018 to 2020. With this study, we ask: has The Brotherhood contributed to the student success of undergraduate Black men at WSU? This article analyzes the efforts of The Brotherhood and its contributions to the Black student support infrastructure at WSU. Our goal is to present the results and concepts gleaned from the study as best practices for consideration at other institutions and their needs for supporting Black men. This study provides key takeaways shown by data to support undergraduate Black men in higher education.

# Methods

## **Population**

Thirty Brotherhood participants were selected to evaluate the impact of this organization on students. This chosen sample size was the total population of all Brotherhood members because including all cohorts from 2017 to 2019 in this study would allow us to gather accurate results. Participants for this study were considered eligible under the following criteria:

- Brotherhood membership
- Identify as a Black male

- A WSU undergraduate student at the time of Brotherhood membership
- 18 years of age or older

Requirements for Brotherhood membership consisted of students maintaining or increasing toward a cumulative grade point average (GPA) of 2.50 or above. Additionally, students needed to attend three academic events and two social events sponsored by The Brotherhood per semester. Brotherhood events were curated for Black undergraduate men and were developed by the collective interest of its members, but all students were welcome to attend.

## Protocol

The research staff completed the informed consent process as approved by WSU's institutional review board. Qualitative and quantitative data will be gathered from 30 members of The Brotherhood through an anonymous 10-question Qualtrics survey completed by participants. The survey will gather data on The Brotherhood's core objectives: professional development, academic success, and community belonging. The survey will also ask students to self-report their current or previous undergraduate GPA at Wayne State University. Current undergraduate student Kamali Clora will complete all data collection procedures under faculty mentor Kenya Swanson. These procedures will take place only online through email and Qualtrics. The Qualtrics survey will be anonymous and will not record any identifiable information. The Brotherhood membership roster and email information will be available only to Kamali Clora and Kenya Maxey. No participant information will be shared with anyone except the shared research team, nor will students be exposed to any physical or psychological harm. This project did not require follow-up procedures with participants, and all participants have access to the reported findings.

#### Timeline

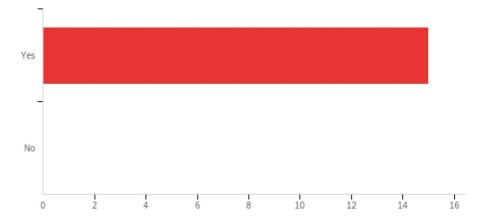
On Monday, September 27, 2021, Kamali Clora emailed the 30 Brotherhood members a voluntary 10-question Qualtrics survey to complete. This survey was anonymous and provided information that helped understand the impact The Brotherhood had on undergraduate Black males at WSU. Students had two weeks to complete this survey if they chose to do so. Participants were told that they may withdraw at any time and that the study posed no psychological or physical harm. Moreover, they received an adult research information sheet (Appendix A) and a detailed research protocol. This provided documentation of participant rights and transparency of study procedures. The survey data was collected and reported in averages to the Undergraduate Research Opportunities Program (UROP) with no identifiable information. UROP invites WSU students across all disciplines to engage in undergraduate research. The following instructions were included in the Qualtrics survey. Questions 1–9 asked participants to select responses on a 1–5 scale: 1—Strongly Disagree, 2—Moderately Disagree, 3—Neutral, 4—Moderately Agree, and 5—Strongly Agree. Question 10 was presented in free-response format.

- 1. The Brotherhood provided an inclusive, safe space where I felt accepted and free to express my ideas and beliefs.
- 2. The Brotherhood helped me discover more about my identity and learn more about the communities I am affiliated with.
- 3. The Brotherhood supported my mental and emotional wellbeing.
- 4. The Brotherhood improved my academic study skills through event programming and peer accountability.
- 5. The Brotherhood actively connected me with University resources to better navigate academia.
- 6. The Brotherhood improved my self-efficacy and determination to graduate.
- 7. The Brotherhood aided my ability to network with professionals in my career field.
- 8. The Brotherhood fostered career readiness opportunities that helped me develop my postgraduate goals.
- 9. The Brotherhood gave me the tools and opportunities to beneficially impact my campus community.
- 10. The Brotherhood is collecting quantitative data to evaluate the academic performance of our members in comparison to other Black students in their cohort. We ask if you could please provide your current cumulative GPA or if you have graduated, please provide your final undergraduate GPA? This data will be completely CONFIDENTIAL and have no identifiers. This information will be used to compile an average GPA from members of The Brotherhood (Example format: 3.00). If you choose not to provide this data, please write N/A.

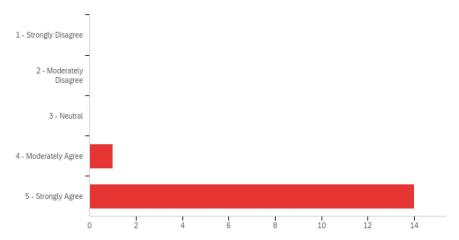
# Results

These graphs show the x axis as the number of survey participants and the y axis as the distribution of available responses. The following preliminary declaration was added to confirm participant consent. The survey response rate was 15 participants out of 30 (50%) over a 10-day survey collection period.

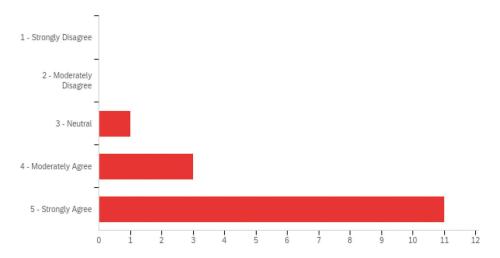
I hereby certify that I meet the criteria to participate in this study and consent to all study procedures. [Answer Selection: Yes or No]



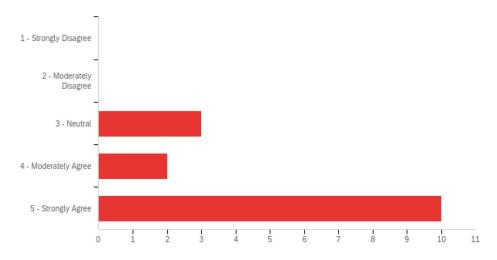
Question 1: The brotherhood provided an inclusive safe space where I felt accepted and free to express my ideas and beliefs.



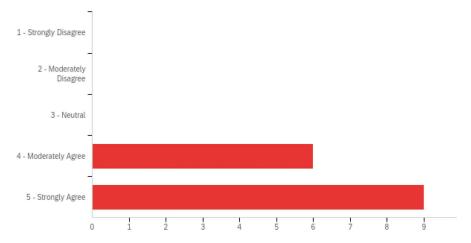
Question 2: The Brotherhood helped me discover more about my identity and learn more about the communities I am affiliated with.



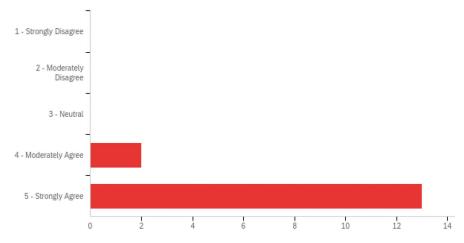
Question 3: The Brotherhood supported my mental and emotional wellbeing.



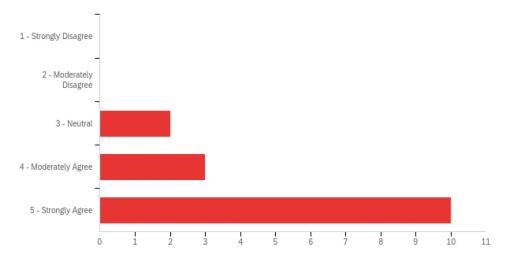
Question 4: The Brotherhood improved my academic study skills through event programming and peer accountability.



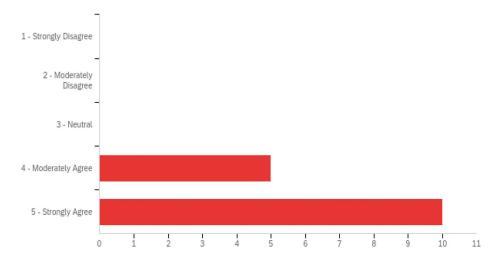
Question 5: The Brotherhood actively connected me with University resources to better navigate academia.



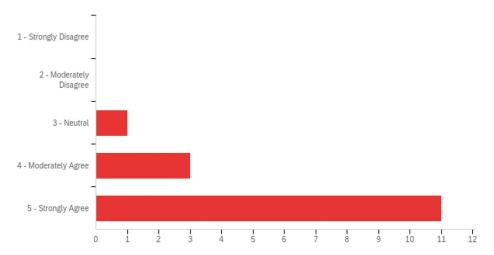
Question 6: The Brotherhood improved my self-efficacy and determination to graduate.



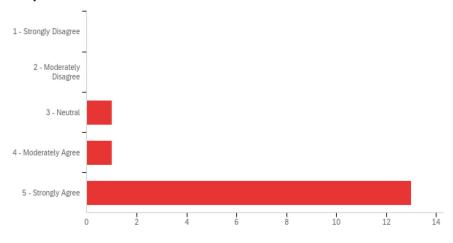
Question 7: The Brotherhood aided my ability to network with professionals in my career field.



Question 8: The Brotherhood fostered career readiness opportunities that helped me develop my postgraduate goals.



Question 9: The Brotherhood gave me the tools and opportunities to beneficially impact my campus community.



Question 10: The Brotherhood is collecting quantitative data to evaluate the academic performance of our members in comparison to other Black students in their cohort. We ask if you could please provide your current cumulative GPA or if you have graduated, please provide your final undergraduate GPA? This data will be completely CONFIDENTIAL and have no identifiers. This information will be used to compile an average GPA from members of The Brotherhood (Example format: 3.00). If you choose not to provide this data, please write N/A.

# Responses

N/A

4.0

3.2

3.88

3.2

3.5

2.87

3.61

2.8

3.14

3.7

2.98

3.23

3.24

3.56

# Analysis

Questions with the most positive feedback were Q1, Q5, and Q9. The mean responses to those questions are as follows.

- For question 1, 98.6% of participants strongly agreed that The Brotherhood provided an inclusive, safe space where they felt accepted and free to express their ideas and beliefs.
- For question 5, 97.4% of participants strongly agreed that The Brotherhood actively connected them with University resources to better navigate academia.
- For question 9, 96% of participants strongly agreed that The Brotherhood gave them the tools and opportunities to beneficially impact their campus community.

The question with the least positive feedback was question 3. For this question, 4.47 or 89.4% of participants strongly agreed that The Brotherhood supported their mental and emotional wellbeing. All other questions had a response rate of 90.6% for strongly agreeing with an average standard deviation of 0.51.

# Mean Survey GPA

- Survey participants had an average reported GPA of 3.35 (B average).
- 78.6% of survey participants had a reported GPA of 3.0 or above.

# Cohort Comparison GPA

- The mean GPA of all Black or African American students at WSU was 2.35 (C+ average)
- The mean GPA of all Black or African American male students at WSU was 2.32 (C average)
  (Wayne State University, 2021)

On a 4.0 GPA scale, survey participants have an average self-reported GPA of 25.75% higher than undergraduate Black males at WSU. This finding supports that Brotherhood members who completed the survey perform an entire letter grade higher than undergraduate Black males at WSU.

Following are the scale averages for responses to each question in their respective survey category:

# Community Belonging

- Question 1: 4.47 out of 5
- Question 2: 4.67 out of 5
- Question 3: 4.93 out of 5

Mean of questions 1-3: 4.69/5

# **Academic Success**

- Question 4: 4.60 out of 5
- Question 5: 4.87 out of 5
- Question 6: 4.53 out of 5

Mean of questions 4–6: 4.66/5

# Professional Development

- Question 7: 4.67 out of 5
- Question 8: 4.67 out of 5
- Question 9: 4.80 out of 5

Mean of questions 7–9: 4.71/5

The professional development category of the survey had the highest positivity rate, with 94.3% of participants strongly agreeing to the questions. The academic success category had the lowest positivity rate, with 93.2% of participants strongly agreeing to the questions.

### Discussion

#### Limitations

In reflection, giving participants only 10 days to complete the survey may have limited the number of survey responses due to the short amount of time. Additionally, we recognize that although self-report methodologies continue to be one of the most widely used assessments for capturing

qualitative and quantitative survey information, their limitations must be acknowledged. We note that asking participants to self-report their experiences in The Brotherhood and GPA data may not be precisely accurate to their real accounts, as well as recall bias and self-selection bias. It is worth mentioning that a 50% response rate could have affected the distribution of responses, which may have been a result of communication barriers like invalid email addresses. Finally, using a 1–5 rating scale was helpful for quantifying responses; however, it does limit the range and depth of the participant's responses. This makes the need for anecdotal data more important for capturing the thoughts and feedback of participants.

# Future Directions

Moving forward, comparing participants' responses with GPAs below 3.0 with students who had a GPA above 3.5 could reveal gaps within the survey evaluation. Cross-examining these responses could highlight areas of focus for The Brotherhood in the future. Also, collecting average semester GPAs from 2017 to 2019 would help to observe GPA trends between each year and assess the programming that possibly led to those trends. The GPA collection would have to be completed more accurately either through requesting transcripts from members or by the faculty advisor providing them. Regardless, this process will need a more extensive Institutional Review Board approval. To gather more anecdotal data, conducting individual interviews with participants could prove beneficial, especially because the survey is not intended to encompass all the experiences of The Brotherhood members.

From this study, we learned that The Brotherhood's structural components—institutional support, safe spaces, unique events, social action, and leadership development—are key factors that helped advance the success of Black undergraduate men at WSU. These components were crucial in helping establish the Black student-led support infrastructure at WSU. More studies may be warranted to gather a more robust understanding of this impact on Black undergraduate males. These five key components can be further studied within similar frameworks of other institutions to observe the repeatability of outcomes. The component of institutional support was developed through the individual connections between The Brotherhood members and senior administration at WSU. These connections provided The Brotherhood a gateway of connections to university resources and personnel. Additionally, the Black male undergraduate rate was a significant target area for WSU, as Black men had the lowest graduation rates. Due to The Brotherhood's aligned mission with WSU, faculty and administration admired these student-led efforts to help combat this issue. The second component, safe spaces, acted as a foundation for relationship development among members. The Brotherhood provided the after 5 p.m. help students needed. This was built on the philosophy that faculty and staff go home at the end of the business day and may not be accessible. Members were always provided with after-hours peer academic accountability and accepting conversation space to alleviate this problem. This allowed for relationships and trust to grow organically. With this foundation, the organization expanded the scope of impact to event programming and community involvement. The unique events component was a pivotal factor in maintaining the recruitment and retention of members. The events varied in subject and allowed members to engage with other students actively. These events fostered opportunities for in-person outreach and reflected The Brotherhood members' variety of interests. These events were new to the student engagement landscape at WSU, making them uniquely different from other campus programming. Brotherhood events appealed to Black students and were a model for other student

organizations at WSU. The fourth component of social action allowed members to deeply reflect on their identities through community service. The majority of this work was focused on the education of Black youth. Brotherhood members were able to realize their purpose in the community and socialization about society. The leadership development component celebrated the differences of each member and what they brought to the table. Members were given a chance to have ownership in events and planning sessions to promote leadership succession. This breakdown of each component is a glimpse of The Brotherhood's more extensive infrastructure.

According to the National Center for Education Statistics (NCES), undergraduate Black men across the United States have the lowest undergraduate graduation rates on average (NCES, 2019). The preliminary data collected supports The Brotherhood's fundamental components and can be used as best practices for developing similar spaces for Black men at other institutions. From this data, Black student-led support could be a pivotal factor in increasing graduation rates. However, given certain caveats within the data collection such as the 50% response rate that is not reflective of the total population of Black male undergraduates at WSU and self-selection bias, we cannot conclude that The Brotherhood has in fact helped to advance student success for Black men at WSU.

These results provide insight into specific components of The Brotherhood. This data does not include the entire context of The Brotherhood's impact on students. However, these findings provide evidence that the key fundamental components of The Brotherhood have advanced Black student success and established a foundation for more research opportunities that focus on undergraduate Black men. We conclude that the data supports the efficacy of The Brotherhood's work in community-building, academic success, and professional development for at least half of The Brotherhood's membership. More tangibly, the results show that survey participants perform a whole letter grade higher than other Black students in their cohort. Ultimately, WSU can do more to further promote student success, like many other institutions. However, this work cannot only be done by the administration, but the help of student contributions is also needed.

# References

- French, R. (2018). Once embarrassed by its graduation numbers, Wayne state becomes a model. *Bridge Magazine*, 15 November 2018. www.bridgemi.com/talent-education/once- embarrassed-its-graduation-numbers-wayne-state-becomes-model.
- Kirp, D. L. (2018) When your college has your back. *The New York Times*. www.nytimes.com/2018/03/02/opinion/sunday/graduation-rates- wayne-state.html.
- National Center for Education Statistics. (2019, February). *Postsecondary graduation rates*. Indicator 23: Postsecondary graduation rates. Retrieved from https://nces.ed.gov/programs/raceindicators/indicator\_red.asp
- Taylor, J. (2020). "WSU enrollment rate of black students down, graduation rates up. *The South End*, 26 February 2020. www.thesouthend.wayne.edu/features/article\_9a2a41e2-58cd-11ea-85b8-bf2a7744678c.html.
- Wayne State University. Retention/graduation. *Institutional Research and Analysis*, https://oira.wayne.edu/dashboard/retention-graduation.
- Wayne State University. *Learning Communities*, Wayne State University, 24 March 2016, https://wayne.edu/learning-communities/.

# Appendix A

#### Developing a Black Student-Led Support Infrastructure at a PWI

#### Research Information Sheet

Title of Study: Developing a Black Student-Led Support Infrastructure at a Predominantly White Institution

WSU Undergraduate Research Opportunities Program

Principal Investigator (PI): Kenya Swanson, M.Ed.

Academic Success Center 313-577-3224

#### Purpose:

Funding Source:

You are being asked to participate in a research study of analyzing the efforts of THE BROTHERHOOD and its contributions to the Black student support infrastructure at Wayne State University. Due to your affiliation as a member of THE BROTHERHOOD student organization, you have been selected as an eligible participant for this study. To obtain the information needed to meet the objectives of our project, we have sampled 30 BROTHERHOOD members. This sample size was decided because this is the total population of all BROTHERHOOD members and would provide accurate averages of our data. The study is being conducted online via Qualtircs survey and will be sent via email. Data received from participants will be important in evaluating the academic, cultural, and professional experiences of undergraduate Black male students in THE BROTHERHOOD. From our findings, we hope to provide key takeaways derived from data to better understand how to support undergraduate African American men in higher education.

#### Study Procedures

If you take part in the study, you will be asked to complete an anonymous 10 question multiple choice Qualtires survey sent via email. This survey takes approximately less than 5 minutes to complete. Qualitative and quantitative data will be gathered from 30 members of The Brotherhood through an ANONYMOUS 10 question Qualtrics survey completed by participants. The survey will gather data around The Brotherhood's core objectives: professional development, academic success, and community belonging. The survey will also ask students to report their current undergraduate GPA or the GPA they completed undergrad with at Wayne State University.

#### Benefits

As a participant in this research study, there will be no direct benefit for you; however, information from this study may benefit other people now or in the future.

#### Risks

There are no known risks at this time to participation in this study.

There will be no costs to you for participation in this research study.

Compensation
You will not be paid for taking part in this study.

Submission/Revision Date: 9/25/2021 Protocol Version #:IRB-21-09-3957 Page 1 of 2

Form Date: 03/2019

Developing a Black Student-Led Support Infrastructure at a PWI

All information collected about you during the course of this study will be kept without any identifiers.

Voluntary Participation /Withdrawal: Taking part in this study is voluntary. You are free to not answer any questions or withdraw at any time. Your decision will not change any present or future relationships with Wayne State University or its affiliates.

#### Ouestions

If you have any questions about this study now or in the future, you may contact Kenya Swanson or one of her research team members at the following phone number 248-901-6885. If you have questions or concerns about your rights as a research participant, the Chair of the Institutional Review Board can be contacted at (313) 577-1628. If you are unable to contact the research staff, or if you want to talk to someone other than the research staff, you may also call the Wayne State Research Subject Advocate at (313) 577-1628 to discuss problems, obtain information, or offer input.

#### Participation

By completing the survey you are agreeing to participate in this study.

# Appendix B

WAYNE STATE UNIVERSITY
I hereby certify that I meet the criteria to participate in this study and consent to all study procedures.
O Yes
O No
The brotherhood provided an inclusive safe space where I felt accepted and free to express my ideas and beliefs.
O 1 - Strongly Disagree
O 2 - Moderately Disagree
O 3 - Neutral
O 4 - Moderately Agree
O 5 - Strongly Agree
The Brotherhood helped me discover more about my identity and learn more about the communities I am affiliated with.  O 1 - Strongly Disagree O 2 - Moderately Disagree O 3 - Neutral O 4 - Moderately Agree O 5 - Strongly Agree
The Brotherhood supported my mental and emotional wellbeing.
O 1 - Strongly Disagree
O 2 - Moderately Disagree
O 3 - Neutral
O 4 - Moderately Agree
O 5 - Strongly Agree

The Brotherhood improved my academic

study skills through event programming and peer accountability.
O 1 - Strongly Disagree
O 2 - Moderately Disagree
O 3 - Neutral
O 4 - Moderately Agree
O 5 - Strongly Agree
The Brotherhood actively connected me with University resources to better navigate academia.
O 1 - Strongly Disagree
O 2 - Moderately Disagree
O 3 - Neutral
O 4 - Moderately Agree
O 5 - Strongly Agree
O 3 - Strongly Agree
The Brotherhood improved my self-efficacy and determination to graduate.  O 1 - Strongly Disagree O 2 - Moderately Disagree O 3 - Neutral O 4 - Moderately Agree O 5 - Strongly Agree
The Brotherhood improved my self-efficacy and determination to graduate.  O 1 - Strongly Disagree O 2 - Moderately Disagree O 3 - Neutral O 4 - Moderately Agree
The Brotherhood improved my self-efficacy and determination to graduate.  O 1 - Strongly Disagree O 2 - Moderately Disagree O 3 - Neutral O 4 - Moderately Agree O 5 - Strongly Agree The Brotherhood aided my ability to network
The Brotherhood improved my self-efficacy and determination to graduate.  O 1 - Strongly Disagree O 2 - Moderately Disagree O 3 - Neutral O 4 - Moderately Agree O 5 - Strongly Agree  The Brotherhood aided my ability to network with professionals in my career field.
The Brotherhood improved my self-efficacy and determination to graduate.  O 1 - Strongly Disagree O 2 - Moderately Disagree O 3 - Neutral O 4 - Moderately Agree O 5 - Strongly Agree  The Brotherhood aided my ability to network with professionals in my career field.  O 1 - Strongly Disagree
The Brotherhood improved my self-efficacy and determination to graduate.  O 1 - Strongly Disagree O 2 - Moderately Disagree O 3 - Neutral O 4 - Moderately Agree O 5 - Strongly Agree  The Brotherhood aided my ability to network with professionals in my career field. O 1 - Strongly Disagree O 2 - Moderately Disagree

The Brotherhood fostered career readiness

opportunities that helped me develop my postgraduate goals.
O 1 - Strongly Disagree
O 2 - Moderately Disagree
O 3 - Neutral
O 4 - Moderately Agree
O 5 - Strongly Agree
The Brotherhood gave me the tools and opportunities to beneficially impact my campus community.
O 1 - Strongly Disagree
O 2 - Moderately Disagree
O 3 - Neutral
O 4 - Moderately Agree
O 5 - Strongly Agree
The Brotherhood is collecting quantitative data to evaluate the academic performance of our members in comparison to other Black students their cohort. We ask if you could please provide your current cumulative GPA or if you have graduated, please provide your final undergraduate GPA? This data will be completely CONFIDENTIAL and have no identifiers. This information will be used to compile an average GPA from members of The Brotherhood (Example format: 3.00). If you choose not to provide this data, please write N/A.
$\rightarrow$
Powered by Qualtrics ☐

# A Case Study of the Barriers to Eradicating Polio in Nigeria and India's Urban and Rural Settings

Emily Kopp\*, Noah Zimmerman†, Ann Yu‡, and Alexandra Pejas§

In this study, we examined polio eradication efforts in the urban and rural areas of Nigeria and India. Our method utilized past literature and databases to support our comparison of the different issues Nigeria and India had with distributing the oral polio vaccine (OPV). The data showed that Nigeria had issues with political and social misconceptions about the OPV in both urban and rural areas while India had technical issues with vaccine distribution. Therefore, it was necessary for the Global Polio Eradication Initiative to implement polio campaigns, reorganize their plan in vaccine distribution, and provide more vaccines to children in isolated areas where there is poor medical infrastructure in both Nigeria and India. We conclude that there needs to be a greater cultural understanding among vaccine distributors and improvements to the vaccine distribution technology in Nigeria and India.

# Keywords

Vaccinations • polio • cold chain development • India • Nigeria • socio-economic development

# Introduction

The polioviruses, *poliomyelitis*, are enteroviruses, a group of viruses that develops in the gastrointestinal areas of the human body and sometimes can impact the nervous system. Polio is transmitted through person-to-person contact via hand-to-hand-to-mouth and can follow with the excretion of feces (Nathanson & Kew, 2010, p. 1213). The Salk polio vaccine was introduced in 1955 (Nathanson & Kew, 2010, p. 1219). Jonas Salk was the first to develop an inactivated polio vaccine (IPV) using monkey kidney cells (Baicus, 2012). While the IPV was effective, there were

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Conflicts of interest:

The authors have no conflicts of interest to disclose.



some disadvantages to the vaccine, including the inefficiency of producing and distributing the vaccine (Baicus, 2012). The oral polio vaccine (OPV) was launched in 1961 by Albert Sabin with a higher success rate (Nathanson & Kew, 2010, p. 1219).

In response to the polio epidemic, the Global Polio Eradication Initiative (GPEI) became the main player in eradicating polio worldwide. As a public–private partnership, the initiative worked with the World Health Organization (WHO), Rotary International, the United States Centers for Disease Control and Prevention (CDC), the United Nations Children's Fund (UNICEF), Bill and Melinda Gates Foundation, and Gavi (Global Polio Eradication Initiative, 2020). Based on the GPEI, polio was eradicated in Nigeria in 2016 and in India in 2014 (Global Polio Eradication Initiative, 2020). The increased political support, expansion to children in isolated areas, and reevaluation of India's and Nigeria's eradication plan all contributed to the final success in eradicating polio in the twenty-first century (Aylward & Tangermann, 2011).

The purpose of this article is to analyze how polio eradication in the 1990s–2010s failed to succeed in Nigeria and India based on private and public interventions within rural and urban areas in both countries. The article will also provide a case study on these two countries to analyze the multiple stakeholders that influenced the barriers in distributing the polio vaccine among rural and urban areas within Nigeria and India. The journal articles mentioned in this literature review will attempt to support our analysis and case studies.

# Review of the Literature

Although the polio vaccine was developed successfully in the 1950s, there were many issues with the distribution of the polio vaccine in many lower- to lower-middle-income countries. Factors including high incidences of vaccine failures, high incidences of polio from the OPV, the lack of availability of the IPV, and ethical issues with the distribution of vaccines in many countries all contributed to the multiple inefficiencies of polio eradication (Thomas, 2005). Countries like Nigeria, India, and many others were unable to gain access to the polio vaccine through barriers from the political environment, the lack of social mobilization and community intervention, and the lack of knowledge around vaccines (Lahariya, 2007).

# Nigeria's Urban Setting

Taylor et al.'s research (2017) was trying to understand vaccine hesitancy among different demographics within Nigeria. The study surveyed 3,306 male and female individuals within 1,653 households from rural, semi-urban, and urban areas that were identified as either high- or low-performing areas. The study focused on three high-risk states in northern Nigeria from 2013 to 2014. Questions from the survey concerned household socioeconomic status, family health conditions and access to resources, household and community development, and level of knowledge in polio vaccination. Due to the high refusal rate of the OPV in Nigeria overall, the researchers tried to hypothesize why there was vaccine hesitancy based on how certain backgrounds and demographics influence health behavior. The authors discovered that wealthier households and higher female literacy rates were in correlation with a lower risk of OPV refusal. However, in urban areas, they found that higher levels of wealth and education correlated with having a higher risk of OPV refusals. The results of the study support the purpose of our research in which it distinguishes the many demographics and

how they factor into the refusal rate for the polio vaccine. Taylor et al.'s research connects to the overall aspect of how the polio vaccine was distributed among urban areas in Nigeria, and based on their results, we can conclude that it was also very challenging for the GPEI as well as private and public institutions within Nigeria to integrate the polio vaccine within urban settings.

From Maryam Yahya's perspective (2007), one of the major barriers to polio eradication in northern Nigeria was the political and cultural views on the vaccine. Yahya analyzed how much of the rejection of the vaccine came from political and cultural influence. Many political and religious leaders spread misinformation and rumors about the vaccine's safety, thus creating fear among certain communities and individuals. Rumors about the vaccine included how the vaccine can harm their children and how "white men" created the vaccine to poison Nigerians. On the other hand, Yahya also described how family dynamics in a Nigerian household can also play in getting a vaccine. According to Yahya, due to the cultural norm of the husbands usually making final decisions in the household, many fathers have the authority to determine whether their children get vaccinated or not. Yahya addressed that the fear of the vaccine mainly stems from a lack of education, literacy, and ignorance. The author later concluded that the failure of polio eradication in northern Nigeria came from the lack of basic primary healthcare provision and the weak relationship of trust between the Nigerian government and Western countries and influence. This study can be used to interpret how condensed populations in urban areas are heavily affected by poliovirus due to many households not getting vaccinated based on their personal beliefs and the spread of misinformation.

A final research article was examining how the diplomacy and the boycott on polio eradication in northern Nigeria created a health crisis with the poliovirus in the country (Kaufman & Feldbaum, 2009). Judith R. Kaufman and Harley Feldbaum explained the diplomatic actions taken by the GPEI, the United Nations, and the U.S. government to resolve the issue of rejecting the polio vaccine in Nigeria. The authors described the situation in Kano, where the boycott was held, and then illustrated how outside third parties responded to resolve the health crisis using a case study. The article concluded how using diplomatic actions was better to resolve the political issue within Nigeria. It also stated how there is a need to acknowledge the political issues in science as well as provide accurate scientific information on the vaccine to integrate polio eradication in such lower-middle-income countries where there is a lot of stigma around outside interventions. The authors further emphasized the need to intervene not only on a policy level but also using local and community-based interventions to spread accurate information about the vaccine.

The aforementioned studies provide information on how different determinants influence health behavior in terms of polio eradication in Nigeria. These studies will provide us with historical background and analysis on how polio eradication was resolved and implemented in Nigeria's urban cities. Based on the information we have, this will be helpful for our case study when we examine the differences in how Nigeria and India handled the polio vaccine.

# Nigeria's Rural Setting

The obstacles and methods of the distribution of the polio vaccine in rural Nigeria are not very well researched; actions and research done by Samuel Bawa et al. (2018) discuss the obstacles and solutions to vaccinating children in hard-to-reach areas within Nigeria. The research group conducted vaccination trials in 2,311 hard-to-reach areas in the Bauchi, Borno, Kano, and Yobe states

in North-East Nigeria. Research done by Ophori, Tula, Azih, Okojie, and Ikpo (2014) can corroborate the arguments by Bawa et al. by providing evidence in current trends of the polio vaccine within different states in Nigeria, as well as by going into further detail about the obstacles in the way of mobile vaccination teams. A third study by Ghinai, Willott, Dadari, and Larson discusses the major obstacles in the distribution of the polio vaccine in North-East Nigeria. The most important aspect of this study is its methods of collecting information through local rumors and information. Local information provides a broader understanding of intra-country affairs that would not normally be available. While these studies mainly focus on the North-East states of Nigeria, it is important to note that a majority of rural areas, and therefore hard-to-reach rural areas, are in the South of Nigeria. This drawback of these studies makes it difficult to differentiate between the methods used in distributing the polio vaccine between rural and urban settings.

A final research study was done by Abimola, Malik, and Mansoor (2013); they discussed the obstacles that got in the way of distributing vaccines to Nigeria. The religious divide between the North and the South of Nigeria creates a large division between cultures and people, as well as a distrust of the government by the North. The research group also identifies Islamic extremist groups like Boko Haram as creating political instability through political violence, predation on citizens, and anti-education. The research into these obstacles can help further corroborate the troubles that the GPEI, as well as the Nigerian government, has in distributing the vaccines, shown by Bawa et al. and Bauchi et al.

# India's Urban Setting

India did initially manufacture the polio vaccine within its borders, yet this was discontinued in 1974. From that point on, the OPV was imported from abroad and distributed to strictly urban communities until 1981. Vaccinating those who lived in larger cities was first prioritized, primarily due to the ease of access. These urban areas struggled with the virus mainly due to cramped conditions—a symptom of India's vast population—minimal public healthcare, and extremely poor sanitation (Thacker, Vashishtha, & Thacker, 2016). There have been studies comparing the incidence of polio within the urban and rural populations of individual cities, such as Lucknow, India (Chaturvedi et al., 1978). The northern regions of Uttar Pradesh and Bihar are most frequently used as cases for these kinds of studies, primarily because efforts to eradicate polio were especially high in those places.

However, there is very little research done on the difference between polio eradication between the rural and urban areas in India. The main distinctions are made among the regions, but the locations of their populations are not specified. This provides ample opportunity for us to create this divide in our research and determine whether urban or rural Indians received quicker and more reliable access to the vaccine, and how that affected the country's overall progress toward eradication.

# India's Rural Setting

Few research papers have looked into the difficulties of distributing the polio vaccine, as well as vaccines more generally, in the rural areas of India. Bonu et al. (2003) examined representative samples from four rural areas of Northern India, comparing using National Family Health Surveys from

1992–93 to 1998–99 as before and after samples, respectively, in order to determine the success of the national polio immunization campaign, Pulse Polio Initiative (PPI) (2003). The study concluded that while the PPI was successful in reducing gender-, caste-, and wealth-based inequalities, it did not have an impact on religion- and region-based inequalities. The researchers also found that the PPI campaign, which was applied to the first round of polio vaccines, increased immunization rates of children living in rural areas of India by 25%. The second round of vaccinations, which were not administered by the PPI campaign, only saw increases in immunization of 2%.

Research conducted by Samant et al. (2007) discusses that even the best vaccines are limited by distribution complications. If vaccines are exposed to high temperatures, they can lose their potency (2012). In areas such as rural India, access to refrigerators and coolers to store vaccines is limited, meaning that the vaccine's effectiveness diminishes as they are moved from larger medical centers to smaller centers. By focusing on one rural district of central India, these researchers studied the "cold chain" (meaning the system of storage and transportation that are designed to keep the vaccines at the correct temperature until they can be administered) as the vaccine moved from urban to rural areas. This study found that as the distance from the district hospital increased, the cold-chain compliance score—which measures the degree to which vaccine storage protocols are being upheld—decreased by an average of 0.16 units per kilometer. However, this study is limited by its scope as it only looked at one district of rural India. This study also did not test the potency of the vaccine, meaning that the study looked at protocol compliance and not necessarily efficacy.

A final study by researchers with the RAND Corporation can help contextualize the findings of Samant et al. (2007) and Bonu et al (2003). This study looked at 43,416 children living in rural India during 1993 and 1998 (Datar, Mukherji, & Sood, 2007). The study found that the availability of health infrastructure in rural areas only had a modest effect on immunization coverage. Furthermore, they found that having community health workers in a village did not increase immunization coverage. Their research concluded that having a hospital or primary healthcare facility near a rural village resulted in higher immunization coverage than lower-level facilities like subcenters or dispensaries. This correlation is associated with having more access to the cold chain of vaccines. They also found that literacy among mothers and whether or not the child belonged to a scheduled caste/tribe household also affected immunization coverage. Altogether, this study concluded that improvements in community outreach, increased funding to auxiliary nurse midwives, and female literacy programs will be the most effective measures to increase immunization coverage in rural India.

# Methodology

We developed a case study on how the polio vaccine was eradicated in rural and urban areas in two countries: India and Nigeria. These countries were specifically chosen for this research because Nigeria and India were among the last few countries that still considered the poliovirus as endemic, and both countries encountered many different barriers while obtaining the polio vaccine. It was also important for us to look into different regions within India and Nigeria, so we examined urban and rural regions in both Nigeria and India to analyze how different demographics factor into the distribution of the vaccine within these communities. We looked specifically at urban and rural areas to factor in disparities among geographical areas that helped us interpret our case study. Our

independent variables were India's and Nigeria's key effects on polio eradication and our dependent variable was the timeline and efficiency of polio eradication in both countries. The main key effect in India was the technological costs related to the transportation of vaccines. On the other hand, the key effect in Nigeria was misconceptions about the OPV.

To gain a better understanding of the barriers to eradication in Nigeria, we segmented our research into the politics and religious beliefs in rural and urban areas. We utilized databases and news articles throughout the 1990s to understand how the spread of rumors about the vaccine restricted people from obtaining it, how the government became involved in preventing the vaccine from distributing within the country, as well as how data on the number of vaccines distributed within both urban and rural communities helped interpret the challenges of integrating polio eradication in Nigeria. Additionally, we examined the barriers to transporting the polio vaccine in rural and urban India. More specifically, we looked at how effective compatible cold-chain implementations were in maintaining the potency of the polio vaccine in India, and how this barrier affected rural areas only.

Because our research has more of a qualitative approach, we utilized data from past research on polio eradication in Nigeria and India, ranging from different costs and challenges to how the government influenced the entry of the polio vaccine in both countries. With the existing literature, we used these studies to investigate key issues on the different approaches from each country and to apply theoretical ideas and methods to create a more comprehensive and successful approach to polio eradication within Nigeria and India.

# Results and Findings

# Nigeria

Although polio cases worldwide have declined around the early 2000s due to the introduction of the OPV and the launch of the GPEI in 1988, Nigeria had been facing a surge in cases with polio becoming endemic in the country until the beginning of 2013 when vaccine coverage increased to 60% (Abimbola, Malik, & Mansoor, 2013). The number of wild poliovirus cases jumped from 62 in 2011 to 122 cases in 2012 after immunization activities in Nigeria were suspended (Lowther et al., 2013). The barriers around polio eradication in Nigeria were based not on the lack of technology to distribute the vaccine but rather on the political and cultural beliefs around the vaccine. With vaccine boycotts and rumors going about the vaccine, there became a major rejection of the polio vaccine, thus creating a surge in cases in Nigeria in the early 2000s (Kapp, 2003). The number of wild poliovirus cases increased from 202 in 2002 to 355 in 2003, which then created a high alert in the WHO and GPEI (CDC, 2004). The halt of polio campaigns and immunization programs in northern Nigeria jeopardized the WHO's 15 years of work put into the Polio Eradication Initiative and the United States' \$3 billion in funds for developing the vaccine (Kapp, 2003).

In August 2003, northern Nigeria, especially the Kano State, suspended the polio vaccine in response to misinformation on how the vaccine was contaminated. Much information was construed to antifertility, describing how the vaccine was intended to sterilize young Muslim women (Kaufmann & Feldbaum, 2009). However, more hesitancy was based on past failures of vaccine trials. Pfizer implemented the drug Trovan into the Kano State to help with the meningitis outbreak in 1996 (Frishman, 2009). During their drug trial, Trovan was given to 100 children, and

another 100 children were given chloramphenicol. As a result, 11 of the children died due to the implications of Trovan and chloramphenicol. Others suffered from severe health outcomes such as paralysis, blindness, and brain damage (Frishman, 2009). A Nigerian report later revealed the outcomes of the drug trial in 2000, which led to demands in compensation for damages toward Pfizer (Frishman, 2009). Thus, the skepticism, rumors about the polio vaccine, and past failures of drug trials that occurred in Nigeria have led many Nigerians to reject the polio vaccine.

# Urban Setting

Much of the misinformation and hesitation of the polio vaccine can be applied to urban areas in Nigeria. While urban areas are more affluent and many residents in urban settings are more likely to get vaccinated, there is still much avoidance of the polio vaccine. Such skepticism revolves around the Western influence that involves many Nigerians believing how the vaccine is there to harm them instead of protecting them from the poliovirus (Renne, 2006). Much propaganda in Nigeria is based on Western influence trying to destroy Nigeria's Muslim population through sterilization and vaccine campaigns (Abimbola et al., 2013). For instance, Zaria City, a city in northern Nigeria that has well-established academic institutions and hospitals, had many suspicions around the safety of the OPV. Many parents are not allowing their children to get vaccinated due to much distrust in Western interventions and the Nigerian government. Since the OPV has four doses, only 15% of the 339 children in Renne's experiment finished the entire process, which overall has led to lower rates of completed polio vaccination in Zaria City (Renne, 2006).

Despite the advancement in urban areas in education and wealth, much of the hesitancy and refusal of the polio vaccine in urban areas still came from high expectations of government services that were not met by the Nigerian government. People who expected the government to provide more information and distribution of the OPV had higher rates of refusing the vaccine (Taylor et al., 2017). Since urban households with higher education levels and more wealth had higher risks of refusing the OPV than in rural settings, the negative political views on both the local and national government as well as polarized views on Western intervention in Nigeria have led to a lack of success in eradicating polio in urban areas (Taylor et al., 2017). Furthermore, the communal aspect had a huge impact on the rapid spread of misinformation in regard to the OPV. This illustrates how the rapid spread of information formed a common mistrust toward the government, further creating a challenge to convince urban residents in getting a polio vaccine.

Because urban areas in Nigeria have residents who have higher education and high literacy rates, there seems to be a correlation between systemic problems and polio vaccine rates. Much of the rural areas in Nigeria have weak academic infrastructure, creating disparities in literacy rates between rural and urban areas. Overall, Nigeria has a literacy rate of 56.9%, with urban regions having a literacy rate of 74.6% and rural regions having a literacy rate of 48.7% (Olojede, Adekunle & Samuel, 2013). Families who have higher literacy rates are more likely to have their children vaccinated (Renne, 2006). Higher income also results in a higher chance of obtaining the polio vaccine. Only 4.3% of children did not get the vaccine in the highest wealth quintile and 36.1% of children did not get the vaccine in the lowest wealth quintile in Zaria City (Renne, 2006). Although there has been a strong correlation between higher education levels and a higher likelihood of getting vaccinated, there seems to be little connection in urban areas. Many parents did not feel obligated to vaccinate their children due to negative news and information given through news sources and mass media (Itimi, Dienye, & Ordinioha, 2012). Immunization was more common in rural areas than

in urban areas in southern Nigeria due to the lack of encouragement of vaccination through public health interventions as well as the rapid spread of negative outcomes of immunization through mass media, deterring many parents to vaccinate their children (Itimi et al., 2012). Based on the mistrust in the Nigerian government and Western influence, much of the refusal of the OPV comes from political agitation and skepticism about the government instead of the correlation between education and income; this indicates that even in urban areas, there has been much conflict in the benefits and doubts about the OPV. Therefore, there are much more overpowering factors such as the tendency to believe propaganda and misinformation than just higher levels of socioeconomic status that determine the high rates of OPV refusals in urban settings.

Because of the many cultural differences and misinformation about the polio vaccine, the GPEI needed to tackle the situation in a more efficient way that tailored toward many Nigerians. The lessons learned mainly referred to educating communities on the importance of immunization through marketing strategies such as hanging posters, visiting schools, and getting religious and political leaders to promote the vaccine (Larson & Ghinai, 2011). (Larson & Ghinai, 2011). The GPEI used mass media such as radio stations, posters, and street banners in their favor to get the importance of immunization around to get people who were more resistant to getting the vaccine (Larson & Ghinai, 2011). The goal was to reduce the false information from spreading more as well as breaking the conspiracy theories entirely through community engagement, proving to the public that much of the information was factually wrong (Abimbola, 2014).

# Rural Setting

Similar to the urban areas, the rural areas of Nigeria provided obstacles in the distribution of the polio vaccine in terms of skepticism. Rumors apart from birth control being added to the OPV associating it with fears of cancer and HIV caused periodic cases of vaccine refusal and polio outbreaks (Ghinai, Willott, Dadri, & Larson, 2013). The roots of such conflicts and rumors are derived from regional rivalries between the North, East, and West since independence over disagreements on the national census results, civil war, religious clashes, and Islamic revivalism. These conflicts sparked rumors that the polio campaign was part of a Western agenda to reduce Muslim communities (Yahya, 2007). These rumors extended to donor-based aid as common thought process by Nigerian religious and medical leaders was that "the West" was fighting against the Middle Eastern Muslim countries and therefore were fighting against the Muslim world (Yahya, 2007). These instances in the majority rural state of Kano were highly similar to those involved in urbanized locales. Dissimilar to urban areas, however, was the prominence of local healers as an obstacle to the distribution of the polio vaccine. There were clashes between local definitions of polio, often referred to as "Shan-inna" in the Hausa community, and the biomedical definition of polio. These differences as well as the heritage of shaman-like healers gave further rise to the boycott of the polio vaccine (Yahya, 2007). The healer's influence within local communities provided a significant obstacle that large-scale foreign aid organizations cannot get past and only further drives religious-based obstacles in the distribution of the polio vaccine.

Further beyond the anti-Western sentiment in Nigeria was the Islamist regime of the Boko Haram group that created political and structural obstacles to getting the vaccine to hard-to-reach areas. Militants created an incursion against health workers not only by physically blocking infrastructure and launching attacks on aid groups but also by further exacerbating the anti-Western thought that led to the polio vaccine boycott (Abimbola, Malik, & Mansoor, 2013). In 2014–2015,

the Global Vaccine Action Plan (GVAP) attempted to reach "2311 preselected, non-urban, hard-to-reach and underserved communities" in the states of Bauchi, Borno, Kano, and Yobe (Bawa et al., 2018). Through direct mobile outreach programs and teams, GVAP was able to increase coverage of supplemental OPV doses in children up to 5 years old (Bawa et al., 2018). The lack of medical infrastructure in these hard-to-reach wards limits vaccine distribution, and combined with internal conflicts, vertical intervention becomes difficult to achieve (Ophori et al., 2014). GVAP efforts as a horizontal, patient-focused intervention are more effective as it can circumvent socioeconomic issues such as misperceptions of routine immunization by local medical health professionals, the influence of religion by local health professionals, and inadequate cold-chain equipment to transport the vaccine by local agencies (Ophori et al., 2014).

Through this circumvention by horizontal intervention, OPV distribution rose by an average of 34% among children up to the age of 5. In a breakdown of specific age groups, vaccination rates of children under 1 year of age increased by 38%, from 23% at the start of the trials to 61% at the end. OPV rates of children from ages 1 to 5 increased by 30%, from 60% at the start of the trials to 90% at the end of the trials (Bawa et al., 2018). Horizontal integration helps pick up the "low-hanging fruit" that many foreign aid organizations ignore in their large-scale planning efforts. The horizontal integration approach also helps to bypass political conflicts within the country, such as Nigeria's issue of religious warfare and militant groups as well as corruption in the executive. According to the data collected by GVAP, this method is seemingly more effective than large-scale aid projects. Therefore, in rural settings, the greatest threat to polio eradication were not the obstacles of anti-Western sentiment but political and socioeconomic issues.

### India

Due mainly to its population size, India struggled with combatting the incidence of polio for a long time and only began successfully vaccinating its citizens around the early 1990s—thanks to the combination of involvement from trusted, internal professionals as well as external international organizations (John & Vashishtha, 2013). Only after the implementation of the WHO and Indian government's National Polio Surveillance Project (NPSP) in 1997—which introduced heavy surveillance and national immunization days—was India able to make considerable progress and steered itself onto a sustainable track of herd immunity, rather than temporary resistance (Schaffer, 2012). Eradication did differ between rural and urban centers to an extent, mainly due to vaccine transportation costs associated with the former areas and population congestion in the latter.

# Urban Setting

Urban communities in India tended to be the first to receive polio treatment, yet these patterns did vary from region to region. Overall, much of the concern with urban populations was the issue of overcrowding. Since polio is most commonly spread through fecal matter, improper sanitation systems and the close proximity of people in city centers created the perfect environment for the disease to become endemic (Chaturvedi et al., 1978). An additional concern for urban centers specifically was the travel of workers to and from urban and rural settings. It was not uncommon for people to work in urban areas, but then return to their rural homes afterward, which exacerbated the issue of polio spreading as they brought the disease back with them to these communities (CDC, 2011). Since these hubs were hotspots for disease transmission, quite a bit of focus was

placed on urban areas at first, as opposed to rural ones. For example, specific wastewater testing for all three strands of the poliovirus was introduced in Mumbai in 2001, while subsequent cities like New Delhi or Patna received this treatment later on, in 2010 and 2011, respectively (CDC, 2011). However, although efforts were made to increase the sanitation quality of these cities, a major issue India faced was the dissemination of true information regarding polio vaccination of children. Many Indian families simply did not understand the value of vaccinating their children or were subject to misinformation of its side effects, as was the case in Aligarh—one of the largest sources of polio in the country (Hussain, McGarvey, Shahab, & Fruzzetti, 2012).

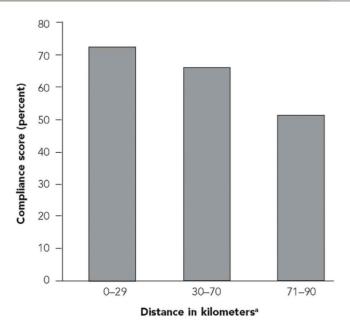
The main source of success for the eradication campaign in urban centers was thus linked to bridging these information gaps and intense documentation campaigns, led by both national and international vaccination teams—most notably Rotary International. In the early 1990s—when the strategy for targeting polio changed considerably—urban centers were the first areas of focus. For example, a pilot polio immunization campaign—the precedent to the NPSP—was conducted in Delhi at first (John & Vashishtha, 2013). Bringing together specialized teams to collaborate with trusted local leaders, organize an array of annual immunization days, and maintain vaccination records was the primary reason why India managed to eradicate polio by the mid-twenty-first century (Schaffer, 2012). Therefore, the methodological approach to this issue was functional and produced desirable results, while the sheer number of people in India was what prolonged the process.

# Rural Setting

Throughout the process of distributing vaccines in the rural areas of India, several programs were implemented. In 1995, the PPI was carried out as a means of distributing the polio vaccine to children under the age of 5. Using the years 1993 and 1999 as pre-intervention measures and post-intervention measures respectively, researchers Bonu, Rani, and Baker found that child immunization increased from 48% to 73%. In determining gender-based differences between immunizations, the researchers concluded that male children were significantly more likely than female children to receive vaccines (Bonu et al., 2003). The data also showed that wealth-based inequalities worsened with the introduction of the PPI. A study by the RAND Corporation came to similar conclusions regarding immunization programs in rural India (Datar et al., 2007). This study found that having community health workers in a village did not result in higher immunization coverage. Furthermore, this study found that having a hospital or primary healthcare facility near a rural village resulted in higher immunization coverage.

The effectiveness and availability of technology for transporting vaccines have been looked at by several studies. The National Immunization Programme of India found that only 58% of subcenters had coolers, also known as vaccine carriers. Moreover, cold-chain equipment was underprovided. Out of the 75,000 proposed units of ice-lined refrigerators, only 2,876 were available; 250,000 vaccine carriers were proposed to be given out to subcenters, but only 35,500 units were available. This study also noted that the potency of the OPV was only accepted in 63% of India's stock when measured in 1988 (Bachani & Bansal, 1990).

A study on the availability of cold-chain equipment in a rural district of India found that cold chain compliance averaged 60% across 46 facilities. As the distance between the community health center or a sub-health center from the district hospital increased, on average the cold-chain compliance score decreased (Samant et al., 2007).



**Figure 1**. Comparison of compliance score and distance (Samant et al., 2007).

Samant et al. found that when a vaccine is not kept in a well-maintained cold chain, the vaccine's potency will decrease. This study found that cold-chain compliance decreased as distance increased, by an average of 0.16 units in compliance per kilometer (Samant et al., 2007).

### Discussion

Based on our results and findings, we hypothesize that the major barrier in polio eradication in Nigeria was from the misinformation spread through word-of-mouth and propaganda in mass media and the government, which thus created much reluctance in getting vaccinated. This led to many issues in both urban and rural areas due to many negative beliefs and conspiracy theories about how the polio vaccine was developed to sterilize young girls and how much Americans were there to attack Nigerians through the vaccine. Overall, the GPEI had more of an issue in eradicating polio through a cultural lens in Nigeria than through the technology issues itself. Much of the cultural barriers and the rejection of the vaccine thus created a spike in cases in the early 2000s. Through our results, we also found that education and income played a factor in the risk of not getting vaccinated, but in urban settings, it was more about the massive and rapid spread of the negative information about the OPV that impacted the public more than their individual knowledge about immunization.

Additionally, we also discovered that many rural areas were more likely to become inoculated because they did not have advanced infrastructure, including roads to rural areas, to produce and distribute the OPV. The lack of medical resources and services capable of distributing the OPV became a huge challenge in needing to develop a more horizontal public health intervention than a vertical one to accordingly create a more efficient outcome from the GVAP. The horizontal intervention was to not only focus on eradicating the poliovirus but also improve the medical infrastructure in rural areas, integrate a vaccination plan that tried to gain more trust in the community, and develop a better plan in getting the OPV to the communities that are most at risk with the poliovirus.

In comparison to urban cities in India, Nigeria and India had many similar challenges regarding polio eradication. Much of the resistance came from misinformation and false beliefs about the effects of the vaccine, which led to many households rejecting any vaccination for their children. In India specifically, the lack of information regarding the proper application of the vaccination for households was an additional barrier to efficient immunization. With many urban areas having more of a condensed population, it was much more likely for residents to have poorer sanitation systems, have a higher risk of obtaining the virus, and be more susceptible to receiving wrong information about the vaccine through word-of-mouth and mass media. Therefore, much of the interventions through GPEI were focused on getting the right information and facts to these urban communities to break the common belief and theories about the vaccine. Successful practices included having internal and external third parties collaborate with local leaders to spread the correct information to increase the numbers of people who were vaccinated, as well as guide them in the application process. However, a difference in implementing public health strategies in urban settings in Nigeria and India was that religion was a major influence in Nigeria. Since Nigeria has a major Muslim population, religious and mosques were also utilized to spread information on immunization and polio vaccination in urban settings. Furthermore, India utilized more international organizations that were involved in polio vaccine campaigns, such as Rotary International, to promote the vaccination practices, while the GPEI was the major third party in trying to eradicate polio in Nigeria. Governmental initiatives, like the NPSP, were key in India's massive success as they united the eradication campaigns into one collective effort and ensured that all the vaccinations were properly documented.

The main difference in the treatment of rural and urban areas in India was the issue of distribution. Since the vaccines were developed in or delivered to the urban hubs directly, safe transportation was not necessarily a barrier to treating urban populations. For the rural regions, on the other hand, methods like cold-chain equipment had to be developed, tested, and improved to ensure that children there were being properly immunized. Community health workers and local leaders were efficient ways to both persuade Indians living in urban areas to utilize the vaccinations and teach them how to administer the vaccine, yet this was not the case for rural dwellers. Access to a hospital or healthcare facility was necessary for those populations to effectively immunize. Therefore, even though both rural and urban India were affected by technological barriers related to the eradication of polio because treatment for strands 1 and 3 was not initially available in the country, rural regions struggled with technology more as a result of the transportation costs related to distribution. The main factor that led to the successful eradication was the Indian government and international organizations focusing an equitable amount of effort on vaccination campaigns in both types of areas.

In Nigeria's rural settings, the main barrier to the distribution of the polio vaccine was primarily as a result of cultural and political troubles, while in India's rural settings, they were primarily technological. Although both regions had social issues, India with a gender gap in vaccinations and Nigeria with sterilization rumors, the main obstacles to the distribution in each were vastly different. Studies of India's ability to properly transport the virus show that although child vaccination rates have risen, the lack of technological infrastructure makes it difficult to distribute the OPV to rural and hard-to-reach areas in India. Unlike in Nigeria, horizontal integration of using local knowledge, such as having more local healthcare workers, was not effective in Indian rural communities. Within India's rural regions, the main problem was that cold-chain technology was not developed enough to maintain a potent vaccine. Getting the vaccine to the hospitals in a timely

and efficient manner was difficult in both India and Nigeria. However, in Nigeria, technology was not the barrier. Political strife and religious extremism turned to violence often made it difficult for healthcare distributors and aid groups to get the vaccine to the healthcare workers in hard-to-reach wards. Cultural interactions within the communities that caused resentment of Western medical practices, along with armed militant groups such as Boko Haram, made getting the vaccine on the roads to the communities that needed them extremely difficult. Along with this, the lack of medical infrastructure in these regions made distribution even more difficult.

#### Limitations

Our research was limited based on the amount of time we had to conduct our research, the restrictions with living in a current pandemic, and many factors regarding the different demographics in Nigeria and India. Since we were limited to only a semester to complete our results and findings in our case study, we were unable to collect as much information and to provide a thorough research on both countries as we desired. Additionally, with our current situation concerning the pandemic, researching a remote setting was a burden in finding information about our topic since we were only able to utilize online resources.

In regard to limitations specifically tailored to Nigeria and India, because we decided to do a case study on urban and rural areas, it was challenging to find quantitative data on specific regions within each country such as the number of cases of polio and the number of people vaccinated in urban and rural settings. Much of the data provided was on the country as a whole rather than segmenting them into different regions. Similarly, differentiating polio eradication in urban and rural settings in Nigeria was difficult due to the limited amount of research available. Most of the research was about northern Nigeria and covered Nigeria as an entire country, overlooking details in urban and rural areas. Since there was minimal research done, we were limited to further analyzing the issue in more well-known areas in Nigeria such as Lagos, one of the most populated cities in Nigeria.

A related issue existed for India—there were isolated studies that focused on the rural and urban centers of certain regions like Lucknow, but the research lacked in investigations regarding the country as a whole. Therefore, we used much of our interpretation based on the research we utilized in this study.

Furthermore, information collected by Nigeria was more based on the cultural and political barriers the country had with polio eradication. Since there was not much information on technology problems with the distribution of the OPV in Nigeria, it was difficult to compare technological issues that happened in Nigeria to India. There were some issues with technology for India—mainly regarding the low efficacy of vaccines that treated strands 1 and 3 of the poliovirus—yet the reason for this is not expanded on in any of the studies we found; thus, we were unable to comment on this disparity with full confidence in our information.

#### Conclusion

Overall, polio eradication had many barriers and challenges in Nigeria and India because of cultural and technological differences. Thus, it is necessary for global organizations such as the WHO to implement vaccine campaigns more effectively and efficiently by focusing more on horizontal public health interventions. Nigeria and India were both countries that needed stronger infrastructure

and better ways to spread information about the OPV. Nigeria's urban areas were more likely to refuse immunization due to misbeliefs about the vaccine from the mass media and government propaganda. On the other hand, Nigeria's rural areas were more susceptible to poliovirus due to the lack of medical infrastructure and healthcare resources in distributing the OPV. India's condensed urban population puts many residents at risk due to poor sanitation. This population was more likely to receive false information regarding the OPV by word-of-mouth. Communities in rural India had less access to the OPV. Even when vaccines were accessible, a lack of technology in their cold-chain transportation system resulted in rural communities receiving less potent vaccines.

As we face new global pandemics, the lessons of polio eradication campaign to minimize discrepancies in vaccine distribution can be applied to future pandemics and eradications. As we have learned from polio eradication campaign in Nigeria, controlling the narrative on vaccines is critical in ensuring effective distribution. From the challenges faced by India in OPV distribution, we know that going into the next large-scale vaccination campaign, we must ensure that countries are given adequate technology to distribute vaccines safely and effectively. Researchers and scientists must collaborate to develop comprehensive systems for collecting data and distributing vaccines. By establishing these networks, we can overcome the obstacles presented by large-scale vaccination efforts.

#### References

- Abimbola, S. (2014). Integration, community engagement, and polio eradication in Nigeria. *Lancet Global Health*, 2(6), e315. https://www-clinicalkey-com.proxy.lib.umich.edu/#!/content/playContent/1-s2.0-S2214109X14700348?returnurl=https:%2F%2Flinkinghub.elsevier.com%2Fretrieve%2Fpii%2FS2214109X14700348%3Fshowall%3Dtrue&referrer=
- Abimbola, S., Malik, A. U., & Mansoor, G. F. (2013). The final push for polio eradication: Addressing the challenge of violence in Afghanistan, Pakistan, and Nigeria. *PLoS Medicine*, 10(10). https://doi.org/https://doi.org/10.1371/journal.pmed.1001529
- Aylward, B., & Tangermann, R. (2011). The global polio eradication initiative: Lessons learned and prospects for success. *Elsevier*, 29, D80–D85. https://doi.org/https://doi-org.proxy.lib.umich.edu/10.1016/j.vaccine.2011.10.005
- Bachani, D., & Bansal, R. D. (1990). Logistics management in Universal Immunisation Programme. *Indian Journal of Public Health*, 34(4), 179.
- Baicus, A. (2012). History of polio vaccination. *World Journal of Virology*, *1*(4), 108–114. https://doi.org/10.5501/wjv.v1.i4.108
- Bawa, S., Shuaib, F., Saidu, M. et al. (2018). Conduct of vaccination in hard-to-reach areas to address potential polio reservoir areas, 2014–2015. *BMC Public Health 18*, 1312. https://doi.org/10.1186/s12889-018-6194-y
- Bonu, S., Rani, M., & Baker, T. D. (2003). The impact of the national polio immunization campaign on levels and equity in immunization coverage: evidence from rural North India. *Social Science & Medicine*, 57(10), 1807–1819.
- Chaturvedi, U. C., Mathur, A., Singh, U. K., Kushwaha, M. R., Mehrotra, R. M., Kapoor, A. K., Rai, S., & Gurha, R., G. (1978). The problem of paralytic poliomyelitis in the urban and rural population

- around Lucknow, India. *Epidemiology and Infection*, 81(2), 179–187. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2129770/?page=7
- Center for Control Disease and Prevention. (2004). Progress toward poliomyelitis eradication Nigeria, January 2003–March 2004. *Morbidity and Mortality Weekly Report*, 53(16), 343–346. https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5316a3.htm
- Centers for Disease Control and Infection. (2011). Progress toward poliomyelitis eradication India. Morbidity and Mortality Weekly Report, 6o(43), 1482–1486. https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6043a3.htm
- Datar, A., Mukherji A., & Sood, N. (2007). Health infrastructure & immunization coverage in rural India. *Indian Journal of Medical Research*, 125(1), 31.
- Frishman, A. (2009). Major reason for Nigerian boycott of polio vaccine. *Health Affairs*, 28(6). https://doi.org/https://doi.org/10.1377/hlthaff.28.6.1860-a
- Ghinai, I., Willott, C., Dadari, I., & Larson, H. J. (2013). Listening to the rumours: What the northern Nigeria polio vaccine boycott can tell us ten years on. *Global Public Health*, 8(10), 1138–1150. https://doi.org/10.1080/17441692.2013.859720
- Global Polio Eradication Initiative. (2020). [..Org]. Global Polio Eradication Initiative. https://polioeradication.org/
- Hussain, R. S., McGarvey, S. T., Shahab, T., & Fruzzetti, L. M. (2012). Fatigue and fear with shifting polio eradication strategies in India: A study of social resistance to vaccination. *PLoS ONE*, 7(9), e46274. https://doi.org/10.1371/journal.pone.0046274
- Itimi, K., Dienye, P. O., & Ordinioha, B. (2012). Community participation and childhood immunization coverage: A comparative study of rural and urban communities of Bayelsa State, south-south Nigeria. *Niger Med Journal*, 53(1), 21–25. https://doi.org/10.4103/0300-1652.99826
- John, J. T., & Vashishtha, V. M. (2013). Eradicating poliomyelitis: India's journey from hyperendemic to polio-free status. *Indian Journal of Medical Research*, 137(5), 881–894. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3734678/
- Kapp, C. (2003). Surge in polio spreads alarm in northern Nigeria. *The Lancet*, *362*(9396). https://doi.org/https://doi.org/10.1016/S0140-6736(03)14826-X
- Kaufmann, J. R., & Feldbaum, H. (2009). Diplomacy and the polio immunization boycott in northern Nigeria. *Health Affairs*, 28(4). https://doi.org/https://doi.org/10.1377/hlthaff.28.4.1091
- Lahariya, C. (2007). Global eradication of polio: The case for "finishing the job." *Department of Community Medicine*, 85(6), 487–492. https://www.scielosp.org/pdf/bwho/2007.v85n6/487-492/en
- Larson, H. J., & Ghinai, I. (2011). Lessons from polio eradication. *Nature*, 473, 446–447. https://www-nature-com.proxy.lib.umich.edu/articles/473446a
- Lowther, S.A., Roesel, S., O'Connor, P., Landaverde, M., Oblapenko, G., Deshevoi, S., . . . Wassilak, S. (2013). World Health Organization regional assessments of the risks of poliovirus outbreaks. *Risk Analysis*, 33, 664–679. https://doi.org/10.1111/risa.12032
- Nathanson, N., & Kew, O. M. (2010). From emergence to eradication: The epidemiology of poliomyelitis deconstructed. *American Journal of Epidemiology*, 172(1), 1213–1229. https://doi.org/https://doi.org/10.1093/aje/kwq320

- Olojede, A. A., Adekunle, A. A., & Samuel, E. A. (2013). Analysis of rural literacy as a panacea for socioeconomy development of Nigeria. *International Journal of Sociology and Anthropology*, 5(9), 381–390. https://doi.org/https://doi.org/10.5897/IJSA2013.0465
- Ophori, E. A., Tula, M. Y., Azih, A. V., Okojie, R., & Ikpo, P. E. (2014). Current trends of immunization in Nigeria: prospect and challenges. *Tropical Medicine and Health*, 42(2), 67–75. https://doi.org/10.2149/tmh.2013-13
- Renne, E. (2006). Perspectives on polio and immunization in Northern Nigeria. *Social Science of Medicine*, 63(7), 1857–1869. https://doi.org/https://doi-org.proxy.lib.umich.edu/10.1016/j. socscimed.2006.04.025
- Samant, Y., Lanjewar, H., Parker, D., Block, L. Tomar, G. S., & Stein, B. (2007). Evaluation of the cold-chain for oral polio vaccine in a rural district of India. *Public Health Reports*, 122(1), 112–121.
- Schaffer, T. C. (2012). Polio eradication in India: Getting to the verge of victory and beyond? *Center for Strategic and International Studies*, 1–12. https://www.csis.org/blogs/smart-global-health/polio-eradication-india
- Taylor, S., Khan, M., Muhammed, A., Akpala, O., Strien, M. ven, Morry, C., Feek, W., & Ogden, E. (2017). Understanding vaccine hesitancy in polio eradication in northern Nigeria. *Elsevier*, 35(47), 6438–6443. https://doi.org/https://doi-org.proxy.lib.umich.edu/10.1016/j.vaccine.2017.09.075
- Thacker, N., Vashishtha, V. M., & Thacker, D. (2016). Polio eradication in India: The lessons learned. Pediatrics: Official Journal of the American Academy of Pediatrics, 138(4). https://doi.org/10.1542/peds.2016-0461
- Thomas, G. (2005). Controversy: Polio eradication programme. *Indian Journal of Medical Ethics*, 2(4), 115–118. https://www.researchgate.net/profile/Sandhya\_Srinivasan4/publication/7161673\_After\_the\_floods\_health\_services'\_responsibilities\_in\_a\_crisis/links/5587e74008aef58c03a068c7. pdf#page=11
- Yahya, M. (2007). Polio vaccines—"no thank you!" barriers to polio eradication in Northern Nigeria. *African Affairs*, 106(423), 185–204. https://doi.org/https://doi.org/10.1093/afraf/adm016.

# Effects of Social Determinants of Health on Infant Mortality in Washtenaw and Wayne County, Michigan

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Infant mortality is the death of an infant within the first year of life, and an infant mortality rate is the number of infant deaths per every 1,000 live births. This rate is a very useful statistic because it indicates population health and varies drastically between populations. It is hypothesized that these variations in infant mortality are associated with variations in social determinants of health, which are social factors that affect health outcomes. To study the effect of social determinants of health on infant mortality, two populations—Washtenaw County, Michigan, and Wayne County, Michigan—were studied because, although they share a border, they are very different regarding their average infant mortality rates and various social determinants of health. Infant mortality and social determinant of health data for each county were collected for the years 2010 to 2018 from the Michigan Department of Health and Human Services (MDHHS) and the United States Census Bureau (USCB), respectively. After assessing the strength of association between infant mortality and social determinants of health via a binomial regression, no association was found between the infant mortality rates and any one specific social determinant of health for either county. However, one social determinant is not likely to be a good predictor of infant outcomes, so several determinants must be targeted at once to implement meaningful interventions. This could include implementing programs for low-income, minority expecting mothers that educate participants on their heightened risk for infant mortality, provide more patient-provider interactions, and perform home visits for those who do not have reliable transportation. By better understanding how various social determinants of health affect the risk of infant mortality, more focused efforts can be made to address these determinants for vulnerable populations.

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#### Keywords

Infant Mortality • Infant Mortality Rate • Population Health • Social Determinants of Health • Community Health Needs Assessment • Washtenaw County • Wayne County • Michigan

#### Introduction/Background

Infant mortality is the death of an infant within the first year of life and continues to be a very prominent public health issue within developed nations such as the United States (Centers for Disease Control and Prevention (CDC), 2020). Analyzing infant mortality within a population is a useful method for evaluating population health, which is defined as the health outcomes of a group of individuals, such as a geographic population, and the distribution of health outcomes within this group (Institute for Healthcare Improvement, 2021). Infant mortality is often analyzed by calculating an infant mortality rate, which is the number of infant deaths within a population for every 1,000 live births (CDC, 2020). Infant mortality rates are useful indicators of population health because they vary drastically between populations, but the reasoning behind these variations is still unknown (CDC, 2020).

The United States has one of the highest infant mortality rates among developed countries with a rate of 5.7 in 2020 (CDC, 2020), compared to an average of 3.4 from comparable countries in 2017 (Peterson-Kaiser Family Foundation [KFF], 2019). Just as these rates vary by country, they also vary by state and even county. For example, Michigan is well above the United States' average with an infant mortality rate of 6.22 in 2018 (CDC, 2018). In addition to variations based on geographic population, infant mortality rates also vary based on social factors such as maternal race and ethnicity. In 2017, infants born to Black, non-Hispanic mothers in the United States experienced an infant mortality rate of 10.97, whereas the average rate for infants born to mothers of all races and ethnicities was only 5.79 (Peterson-KFF, 2019). While the reason for this variation based on population remains unclear, it is hypothesized that social determinants of health play a large role.

Social determinants of health are conditions in people's lives that affect health risks and outcomes and are divided into five categories: economic stability, education access and quality, healthcare access and quality, neighborhood and built environment, and social and community context (United States Department of Health and Human Services [USDHHS], 2021). Most previous research suggests that social determinants of health may contribute to variations in infant mortality by qualitatively assessing this relationship through systematic reviews, case studies, and "calls to action." For example, one study acknowledged that social determinants of health are likely primary contributors to infant mortality and suggested potential interventions such as improving perinatal health outcomes, improving women's health prior to pregnancy, and promoting quality healthcare services (Lu & Johnson, 2014). However, this study only addressed hypothetical solutions by qualitatively assessing which social determinants should be targeted to improve health outcomes for infants. In addition, one scoping review found that this is a common theme for most infant mortality research regarding social determinants of health, as most articles focused qualitatively on individual and public policy level interventions (Reno & Hyder, 2018). The authors, therefore, suggested that more research needs to quantitatively analyze the social determinants of health that previous research has hypothesized to affect infant mortality rates (Reno & Hyder, 2018).

Contrary to this previous research, the goal of this study was to take a more quantitative approach to determine whether particular determinants have more influence than others because even in populations with very different social determinants of health, infant mortality continues to be a public health crisis. For example, Washtenaw County, Michigan, which houses the University of Michigan in Ann Arbor, and Wayne County, Michigan, which includes the city of Detroit, are very different demographically despite sharing a border, as Wayne County has much higher rates of poverty, unemployment, percent uninsured, and much more diversity in terms of race and educational attainment (United States Census Bureau [USCB], 2018). Despite these demographic differences, the Community Health Needs Assessments (CHNAs) for both counties drew similar conclusions. CHNAs are mandatory territorial health assessments conducted by local hospitals that identify primary health needs and issues of a community (CDC, 2021). The CHNAs for both Washtenaw County (Michigan Medicine et al., 2021) and Wayne County (Henry Ford Health System, 2019) identified preconceptual and perinatal health as a primary concern for the community, despite Washtenaw County having an infant mortality rate of 5.4 in 2018 (MDHHS, 2018), which is below the Michigan average, and Wayne County having an infant mortality rate of 10.7 in 2018 (MDHHS, 2018), which is higher than the Michigan average.

This study aimed to determine whether differences in the social determinants of health in populations can be used to explain differences in infant outcomes and whether one determinant could be best used to explain these differences. For example, does the higher poverty rate in Wayne County correlate to its higher infant mortality rate? Is infant mortality most directly correlated to unemployment rate? If so, would addressing issues regarding the unemployment rate help to decrease infant mortality rates? Based on these questions, it was hypothesized that by studying these two demographically different populations with two different infant mortality rates, the difference in infant mortality could be attributed to the social determinants of health that vary between these populations. Therefore, if it can be determined that particular determinants have a more significant influence on infant mortality rates than others, then vulnerable populations can be more easily identified, and implementation efforts can be better catered to these populations and their needs.

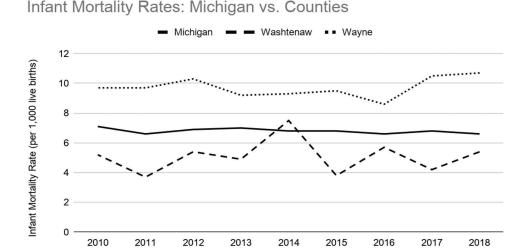
#### Methods

To analyze various social determinants of health and their effect on infant mortality rates, Washtenaw County, Michigan, and Wayne County, Michigan, were compared due to their differences regarding their average infant mortality rates and various social determinants of health. Because social determinants of health are divided into five categories—economic stability, neighborhood and built environment, healthcare access and quality, social and community context, and education access and quality (USDHHS, 2021)—data published by the USCB were collected that fell into at least four of the five categories. These data included poverty rate, unemployment rate, percentage uninsured, race, and educational attainment per each county's total population from 2010 to 2018 and are represented in Tables 1 and 2. This time period was chosen because the Patient Protection and Affordable Care Act (PPACA) mandated CHNAs for hospitals in 2010, and these CHNAs are usually followed by implementation plans (Michigan Medicine, 2021). Therefore, the period 2010–2018 would reveal any effects of implementation efforts that have been achieved thus far regarding infant mortality rates.

For the first analysis, with data displayed in Table 1, poverty rate was analyzed using the general population poverty rate, and race was divided into four categories: White, Black, Asian, and other, with the "other" category including Hispanic/Latino, American Indian and Alaskan Native, Native Hawaiian and other Pacific Islander, and two or more races. Education was also divided into four categories: less than high school, high school or equivalent degree, some college, and college degree or more. To analyze any significant differences between the social determinants of health data for the two counties, each determinant for each county was compared to the same determinant for the other county using independent *t*-tests. *P*-values were then calculated, as displayed in Table 1, and any *p*-value less than 0.05 was considered statistically significant.

For the second analysis, with data displayed in Table 2, some of the social determinants of health were defined differently, so the data were more condensed for the binomial regression. For example, race was reduced to only two categories: White and non-White. In addition, education was also reduced to only two categories: high school/equivalent degree or less and some college education or more. Infant mortality rate data were then collected for both counties, as well as the state of Michigan, from data published by the Michigan Department of Health and Human Services (MDHHS) from 2010 to 2018 and are represented in Figure 1 and Table 2. Each social determinant of health and the corresponding infant mortality rate for each county was assessed utilizing a binomial regression to evaluate if each determinant could be used to explain variation in infant mortality. *P*-values were calculated once again, as displayed in Table 2, and any *p*-value less than 0.05 was considered statistically significant.

#### Results



**Figure 1**. Graph of infant mortality rates (per 1,000 live births) for Washtenaw County (MDHHS, 2018), Wayne County (MDHHS, 2018), and the state of Michigan (MDHHS, 2018) from 2010 to 2018.

Figure 1 depicts the infant mortality rates for Washtenaw County, Wayne County, and the state of Michigan from 2010 to 2018. The state of Michigan's average is steady and consistent around a

rate of 7. Wayne County's average rate is consistent around 10, which is well above the Michigan average. Washtenaw County's average rate is less consistent, varying mostly between 4 and 6 over the eight-year span. Washtenaw's rate peaked at around 8 in 2014, which is above the Michigan average, but it is well below the Michigan average every other year.

**Table 1**. Social determinants of health data including means, ranges, and *p*-values from independent *t*-tests for Washtenaw County, Michigan, and Wayne County, Michigan, from 2010 to 2018 (USCB, 2018). *P*-values less than 0.05 are considered statistically significant.

Social Determinants of Health for Washtenaw and Wayne County, Michigan (2010–2018)									
Determinants		Statistics	Washtenaw	Wayne	P-value				
Poverty Rate		Mean	15.04	24.06	<0.00001				
		Range	12.90–16.90	21.60–26.20					
Unemployment Rate		Mean	6.690	13.70	0.001083				
		Range	3.600-10.20	7.900–21.50					
Uninsured Rate		Mean	5.578	10.60	0.006280				
		Range	2.700-8.500	5.900-15.60					
Race Percentages	White	Mean	74.00	53.10	<0.00001				
		Range	73.35–74.68	52.37-53.54					
	Black	Mean	11.98	39.38	<0.00001				
		Range	11.47–12.47	38.54-40.51					
	Asian	Mean	8.572	2.972	<0.00001				
		Range	7.700–9.810	2.520-3.400					
	Other	Mean	1.214	2.191	<0.00001				
		Range	.9800–1.500	1.770-2.410					
Education Percentages	Less than High School	Mean	5.096	14.67	<0.00001				
		Range	4.310–6.340	13.08–16.11					
	High School or Equivalent	Mean	15.34	30.25	<0.00001				
		Range	14.25–16.86	29.68–30.89					
	Some College	Mean	25.69	32.55	<0.00001				
		Range	24.23–27.41	32.00–33.24					
	College or More	Mean	53.87	22.52	<0.00001				
		Range	50.22-56.96	21.05–25.21					

Table 1 depicts social determinants of health data for both Washtenaw and Wayne County, including poverty rate, uninsured rate, and percentages for race and educational attainment. *P*-values are also depicted, and every *p*-value for every determinant comparison between the two

counties is much lower than 0.05. This means that all these social determinants of health are significantly different between the two counties.

**Table 2.** Social determinants of health data (USCB, 2018) and infant mortality rate data for Washtenaw County, Michigan (MDHHS, 2018), and Wayne County, Michigan (MDHHS, 2018), from 2010 to 2018, including means, ranges, and *p*-values from binomial regressions. *P*-values less than 0.05 are considered statistically significant.

Social Determinants of Health versus Infant Mortality for Washtenaw and Wayne County, Michigan (2010–2018)									
County	Determinants		Statistics	Determinants	Infant Mortality Rate	P-value			
Washtenaw	Poverty Rate		Mean	15.04	5.089	0.665			
			Range	12.90-16.90	3.7–7.5				
	Unemployment Rate		Mean	6.690	5.089	0.534			
			Range	3.600-10.20	3.7–7.5				
	Uninsured Rate		Mean	5.578	5.089	0.456			
			Range	2.700-8.500	3.7–7.5				
	Race Percentages	White	Mean	74.00	5.089	0.799			
			Range	73.35–74.68	3.7–7.5				
		Non-White	Mean	26.00	5.089	0.799			
			Range	25.32–26.65	3.7–7.5				
	Education Percentages	High School or Less	Mean	20.43	5.089	0.596			
			Range	18.78-23.20	3.7–7.5				
		College or More	Mean	79.57	5.089	0.600			
			Range	76.80–81.21	3.7–7.5				
Wayne	Poverty Rate		Mean	24.06	9.722	0.697			
			Range	21.60-26.20	8.600-10.70				
	Unemployment Rate		Mean	13.70	9.722	0.725			
			Range	7.900–21.50	8.600-10.70				
	Uninsured Rate		Mean	10.60	9.722	0.786			
			Range	5.900-15.60	8.600-10.70				
	Race Percentages	White	Mean	53.10	9.722	0.676			
			Range	52.37-53.54	8.600-10.70				
		Non-White	Mean	46.90	9.722	0.676			
			Range	46.46-47.63	8.600-10.70				
	Education Percentages	High School or Less	Mean	44.92	9.722	0.423			
			Range	42.78-46.61	8.600-10.70				
		College or	Mean	55.07	9.722	0.426			
		More	Range	53.38-57.21	8.600-10.70				

Table 2 depicts both infant mortality and social determinants of health data, including poverty rate, unemployment rate, percent uninsured, and race and education percentages for both Washtenaw and Wayne County. The table also displays *p*-values from the binomial regressions. All *p*-values are greater than 0.05, meaning that there is no significant correlation between any social determinants and infant mortality for either county.

#### Discussion

As depicted in Table 1, Wayne County has much higher rates of poverty, unemployment, percent uninsured, and much more diversity in terms of race and educational attainment (USCB, 2018). These differences in social determinants of health between the two populations were found to be significantly different, as all the *p*-values from independent *t*-tests in Table 1 are less than 0.05, indicating that Wayne County has significantly higher rates of poverty, unemployment, and percent uninsured, significantly more racial diversity, and significantly lower educational attainment, making this population more vulnerable than that of Washtenaw County to facing systemic health inequities.

Despite these demographic differences, as well as the differences in infant mortality rates as depicted in Figure 1 and Table 2, the CHNAs for both Washtenaw County (Michigan Medicine et al., 2021) and Wayne County (Henry Ford Health System, 2019) identified preconceptual and perinatal health as a primary concern for the community. From the first analysis, the infant mortality rates for the two counties were found to be significantly different from one another, as Washtenaw County had an infant mortality rate of 5.4 in 2018 (MDHHS, 2018), which is below the Michigan average, and Wayne County had an infant mortality rate of 10.7 in 2018 (MDHHS, 2018), which is higher than the Michigan average. Looking at these rates over time from 2010 to 2018 in Figure 1, although there is some minor fluctuation, the infant mortality rate for Wayne County was consistently higher than the state of Michigan average, whereas the infant mortality rate for Washtenaw County was consistently lower than the Michigan average.

Because both the social determinants of health and the infant mortality rates between the two counties were found to be significantly different from one another, the hypothesis remained that the variation in social determinants of health could be used to explain the variation in infant mortality rates. However, after assessing the association between the infant mortality rates and each social determinant of health for both counties, all the *p*-values were found to be much greater than 0.05, as displayed in Table 2. This means that no association was found between the infant mortality rates and any one specific social determinant of health for either county. This does not indicate, however, that social determinants of health are not a contributing factor to variation in infant mortality, but only that of the five social determinants studied in this analysis over the course of 2010 to 2018, none are directly associated with these variations.

As previously mentioned, this study is one of the first to quantitatively analyze the effects of social determinants of health on infant mortality, and there are several limitations that could have impacted these results. For example, only five specific social determinants of health were chosen for this study, and there are many others that could be impactful on infant mortality as well; perhaps other determinants such as distance from a hospital or methods of transportation could be considered for future studies. In addition, this study only ran binomial regressions between each social determinant and the infant mortality rates. It is likely that many social determinants overlap

to influence high infant mortality rates, so future studies could conduct multiple linear regressions analyzing multiple social determinants of health together or controlling for confounding variables. Lastly, data for both infant mortality and the social determinants of health were gathered for the years 2010 to 2018, which is only an eight-year window. Perhaps by gathering more data over a longer period of time, different trends may appear in the results.

#### Conclusion

Based on this analysis, no single social determinant of health was found to be associated with infant mortality variation for Washtenaw or Wayne County, despite the significant differences between the two populations. This means that one social determinant of health is not likely to be a good predictor of infant outcomes. Instead, high infant mortality rates are likely a result of interactions between several determinants that, together, increase an infant's risk. Therefore, simultaneous targeting of multiple determinants is necessary to implement meaningful interventions. According to the CHNAs for both Washtenaw and Wayne County, local hospitals are already making efforts to do so. For example, Washtenaw County has initiated a Centering Pregnancy program in which a small group of low-income expectant mothers with similar due dates receive group prenatal support programming (Michigan Medicine et al., 2021). By promoting more prenatal education, more interaction between patients and caregivers, as well as interactions between patients in similar circumstances, babies delivered to Centering Pregnancy mothers have experienced decreased infant mortality and low birth rate and increased breastfeeding uptake (Michigan Medicine et al., 2021).

Wayne County has made similar efforts by initiating a program in Detroit to help pregnant and nonpregnant Black women address the social determinants of health that may lead to preterm and low birth rate deliveries (Henry Ford Health System, 2019). This program does so by increasing awareness of the disparities that exist regarding infant mortality, the importance of pre- and interconception health, and education regarding topics related to pregnancy, birth, and parenting such as breastfeeding, proper nutrition, making a birth plan, and common pregnancy discomforts (Henry Ford Health System, 2019). Similar to the Washtenaw program, this group-based prenatal care also brings together women of similar gestational ages and allows for more prenatal education and more interaction between patients and their caregivers (Henry Ford Health System, 2019). However, this program also implements home visits with patients to provide extra support until the baby turns 1 year old, which is the age limit for measuring infant mortality (Henry Ford Health System, 2019). This model, more so than that of Washtenaw, addresses additional social determinants of health such as limited transportation and distance from healthcare facilities. As a result, this program has seen zero preventable infant deaths among group prenatal care participants and better-than-average rates of low birthweight births and preterm births since 2016 compared to Michigan and Detroit averages (Henry Ford Health System, 2019).

Based on the short-term results of programs like these, infant mortality is a public health crisis that can be prevented if proper steps are taken to ensure every expecting mother of all incomes, races, insurance statuses, education backgrounds, and so on is given not equal but equitable treatments based on their needs. More programs like these need to be implemented in disadvantaged communities, and as these programs age and evolve, further research should be conducted to evaluate long-term trends and effects of targeting multiple social determinants of health on infant

mortality. This research should also be expanded to other health outcomes as well, not just infant mortality, as disparities in health outcomes exist in many different forms, including maternal mortality, substance abuse disorders, suicide rates, and so on. To truly implement meaningful interventions for any public health crisis, research and efforts need to be focused on the simultaneous targeting of various social determinants of health. By better understanding how these determinants affect the risk of infant mortality, more focused efforts can be made to address these determinants for vulnerable populations.

#### References

- Centers for Disease Control and Prevention. (2018). *Infant mortality rates by state* [Interactive map]. CDC. gov. https://www.cdc.gov/nchs/pressroom/sosmap/infant\_mortality\_rates/infant\_mortality.htm
- Centers for Disease Control and Prevention. (2020, September 10). *Infant mortality*. CDC.gov. https://www.cdc.gov/reproductivehealth/maternalinfanthealth/infantmortality.htm#:~:text=In%20 addition%20to%20giving%20us,the%20United%20States%2C%202018
- Centers for Disease Control and Prevention. (2021). What is a community health assessment? CDC.gov. https://www.cdc.gov/publichealthgateway/cha/plan.html
- Henry Ford Health System. (2019). *Community Health Needs Assessment 2019*. HenryFord.com. https://www.henryford.com/-/media/files/henry-ford/about/community/chna-2019-final-henryfordcom.pdf?la=en&hash=970B01A7591C24F654C36D4AC8653D21
- Institute for Healthcare Improvement. (2021). *Population health*. IHI.org. http://www.ihi.org/Topics/Population-Health/Pages/default.aspx
- Lu, M. C., & Johnson, K. A. (2014). Toward a national strategy on infant mortality. *American Journal of Public Health*, 104(S1), S13–S16. https://doi.org/10.2105/AJPH.2013.301855
- Michigan Department of Health and Human Services. (2018a). *Infant deaths, live births and infant death rates, Washtenaw County residents, 1989–2018, single year* [Data set]. https://vitalstats.michigan.gov/osr/chi/Indx/frame.html
- Michigan Department of Health and Human Services. (2018b). *Infant deaths, live births and infant death rates, Wayne County residents, 1989–2018, single year* [Data set]. https://vitalstats.michigan.gov/osr/chi/Indx/frame.html
- Michigan Medicine. (2021). Community health needs assessment. UofMHealth.org. https://www.uofmhealth.org/community-health-needs-assessment
- Michigan Medicine, St. Joseph Mercy Ann Arbor, & St. Joseph Mercy Chelsea. (2021). 2021 Community health needs assessment. UofMHealth.org. http://www.med.umich.edu/pdf/2021-CHNA.pdf
- Peterson-Kaiser Family Foundation. (2019, October 18). What do we know about infant mortality in the U.S. and comparable countries? Healthsystemtracker.org. https://www.healthsystemtracker.org/chart-collection/infant-mortality-u-s-compare-coun ries/#item-start
- Reno, R., & Hyder, A. (2018). The evidence base for social determinants of health as risk factors for infant mortality: A systematic scoping review. *Journal of Health Care for the Poor and Underserved*, 29(4), 118–1208. https://doi.org/10.1353/hpu.2018.0091

United States Census Bureau. (2018). 2018: ACS 1-year estimates subject tables (S1701) [Data set]. American Community Survey. https://data.census.gov/cedsci/table?q=poverty%20by%20 race&t=Poverty&g=0500000US26161,26163&tid=ACSST1Y2018.S1701&hidePreview=true

United States Department of Health and Human Services. (2021). *Social determinants of health*. Health. gov. https://health.gov/healthypeople/objectives-and-data/social-determinants-health.

## The Impacts of Climate Change on Black Girls' and Women's Health: Using Theory to Mitigate and Organize

Naomi Michelson\*

The purpose of this paper is to explore the possible health effects of climate change on Black girls' and women's health in the United States and analyze Black women-centered solutions for climate change mitigation. Anthropogenic climate change is projected to have a deleterious effect on human health, with rising heat levels, increasing levels of air pollution, and extreme weather events interacting to cause a multitude of adverse human health outcomes. At the crux of sexism and racism, Black women are projected to face a unique set of health outcomes. Racist-built environments, a legacy of hypersexualization, and a sociopolitical environment entrenched in gendered racism all create a complex set of adverse health outcomes. Furthermore, the health effects of intergenerational racialized trauma posit Black women as more susceptible to certain health conditions under climate change. Likewise, the unique positionality of Black women also means that Black womencentered methodologies lead to stronger mitigation strategies. Employing Black feminist theory, Black queer feminist theory, and Womanism to combat climate change could create more holistic, intersectional solutions. Fighting gendered racism requires a restructuring of power, thereby centering Black women as leaders in the climate movement is imperative to achieving environmental justice.

#### Keywords

climate change • Black feminism • Black queer feminism • Womanism • mitigation • solutions • gendered racism • sustainability • intersectionality • environmental racism

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#### Introduction

Climate change—the impending, indomitable, undeniable consequence of anthropogenic air pollution—is projected to cause a myriad of adverse human health consequences. Increasing levels of air pollution, rising heat levels, and extreme weather events interact to create complex environmental and human health outcomes, disproportionately affecting those made vulnerable by systems of white supremacy and colonialism. At the crux of sexism and racism, Black women are projected to face a unique set of health outcomes under climate change. Interlocking systems of oppression have created a sociopolitical environment that institutionally degrades the health of Black women (Prather et al., 2018). Structurally racist built environments have made Black women more susceptible to air pollutants and natural disasters, while the sociopolitical effects of climate change target the historical hypersexualization and exploitation of Black women (Prather et al., 2018). In light of the hold that gendered racism has over determining the effects of climate change, Black women-centered theory and methodology are key to mitigating the climate crisis. The utilization of Black queer feminism and Womanism to inform sustainability practices will improve health outcomes, center those on the margins, and garner collective action in the fight against climate change.

#### Climate Change and Health

Climate change is set to be the global crisis of the century. Anthropogenic greenhouse gas emissions have generated a steep rise in global temperatures, facilitating an increase in storms, droughts, floods, sea-level rise, and other adverse weather events (Watts et al., 2021). The multifaceted health effects associated with climate change are projected to increase global rates of morbidity and mortality, inhibit economic development efforts, and lead to massive fiscal losses around the world (Watts et al., 2021). Furthermore, the polluting forces behind the climate crisis are shown to increase rates of chronic health conditions among those exposed, creating populations that are even more susceptible to the adverse health outcomes of climate change (Watts et al., 2021).

Atmospheric pollutants are projected to cause a slew of adverse respiratory health effects. Carbon dioxide, particulate matter, ozone precursors, and other greenhouse gas pollutants are emitted at drastically high levels from power plants, factories, vehicles, and industrial agriculture (Watts et al., 2021). While these pollutants heat up the atmosphere, they also damage respiratory, cardio-pulmonary, and maternal health (Watts et al., 2021). Moreover, as emissions rise, the environment across a plethora of countries will become less suitable for farming. The changing atmosphere will deplete soils, dehydrate crops, and destroy freshwater resources. Without a stable source of food and water, rates of malnutrition and diarrheal diseases will increase dramatically. As environments become uninhabitable, rates of migration are set to rise (Watts et al., 2021). Thus, climate change is projected to increase levels of displacement.

Rising global atmospheric temperatures are set to increase the frequency and severity of weather events, including heat waves and wildfires (Watts et al., 2021). Exposure to high levels of heat can result in heat exhaustion, heatstroke, cardiovascular failure, compromised medications, and death. Wildfires can cause an increased rate of dangerous air pollutants, including carbon dioxide, particulate matter, and ozone precursors (Watts et al., 2021). As a result, those exposed to wildfires can experience cardiopulmonary mortality, lower respiratory disease,

diabetes, rheumatic disease, neurodegenerative disease, asthma, preterm birth, and low birth weight (Watts et al., 2021). Furthermore, the mental health effects of experiencing a severe weather event often go underreported. Solastalgia, post-traumatic stress disorder (PTSD), anxiety, and depression are often reported at higher rates following a highly destructive storm (Watts et al., 2021).

As extreme weather events increase, pathogen ecology changes with it. Droughts can contribute to an increased rate of dust storms, increasing human exposure to diseases such as coccidioidomycosis and hantavirus (Watts et al., 2021). In the event of a rainstorm, floodwaters are often filled with human sewage, exposing populations to waterborne diseases (Watts et al., 2021). Furthermore, the increasing rates of storms and floods can increase potential habitats for mosquito populations, driving up rates of mosquito-borne diseases such as malaria, dengue, and West Nile virus (Watts et al., 2021). The compounding forces of climate change are increasing the geographic spread and incidence of infectious diseases, threatening public health systems across the globe.

#### The State of Black Girls' and Women's Health Today

State-sponsored racist and sexist violence against Black girls and women in the United States has informed health outcomes for centuries. The Biopsychosocial Model of Racism states that the stress of experiencing gendered racism generates an allostatic load of cortisol within the body (Goosby & Heidbrink, 2013). High levels of cortisol are normal for sporadic experiences of stress, but chronic exposure to cortisol can take a toll on the body, increasing the risk of hypertension, diabetes, anxiety, and other ailments (Goosby & Heidbrink, 2013). Evidence has shown an epigenetic vertical transmission of allostatic load, allowing chronic stress to pass on intergenerationally (Goosby & Heidbrink, 2013). This intergenerational gendered racialized trauma experienced by Black women in the United States is a direct result of the legacy of slavery and colonialism (Barlow & Jones, 2018). Structures of white supremacy that began during slavery have lasted to this day, continuing to shape the health of Black girls and women in the United States (Gee & Ford, 2011).

The hypersexualization of Black women is directly linked to the biases created to justify slavery. Enslaved women were subject to legal rape, sexual violence, and economic exploitation (Prather et al., 2018). An estimated 58% of all enslaved Black women experienced sexual assault by white men (Prather et al., 2018). Once slavery was abolished, Jim Crow laws and lasting stereotypes reinforced the hypersexualization of Black women in order to justify rape and other forms of sexual exploitation. Today, these stereotypes have caused high levels of sexual assault within the Black community and poor mental health among Black girls.

Centuries of extraction, exploitation, white supremacy, and colonialism have created the contemporary built environment of the United States. Redlining has segregated neighborhoods by race, resulting in higher rates of food deserts, inaccessible transportation, and underfunded housing in Black communities (Gee & Ford, 2011). Former laws during slavery that once prohibited Black individuals from accessing education have since become structures that limit the educational resources available to primarily Black neighborhoods. Generational poverty has persisted, as the built environment cyclically bars Black individuals from accessing education, nutrition, and other resources necessary for economic advancement (Gee & Ford, 2011). Consequently,

rates of diabetes, malnutrition, and asthma are disproportionately high in the Black community, due to the compounding forces of food deserts, poverty, stress, and exposure to pollutants (Gee & Ford, 2011).

The state of Black girls' and women's health is linked to power. While colonial forces have spent centuries attempting to eradicate the power of Black women—through institutionalized economic and sexual exploitation, state-sponsored violence, and eugenicist reproductive health policies—the steadfast power of resiliency has created space for a variety of Black women–centered healing practices (Barlow & Johnson, 2021). Womanism, precolonial rituals, spirituality, and collective consciousness-raising all serve as sites for strength and wellness (Banks-Wallace & Parks, 2004) (Maparyan, 2018). Public health interventions must center Black women by using these methods to promote the health, leadership, and power of Black girls and women (Barlow & Johnson, 2021).

#### The Impacts of Climate Change on Black Girls' and Women's Health

Gendered racism influences chronic health outcomes, and climate change exacerbates them (Figure 1). While the human body can adapt to minor insults, repetitive injuries will quickly reach the limits of adaptation—particularly when they have been weakened through other chronic stressors, including housing insecurity, food and water insecurity, intergenerational racialized gendered trauma, sexual violence, poverty, and other determinants of health (Gee & Ford, 2011). The stress induced by climate change is set to act in a similar manner. Rather than introducing a new set of problems, it will exacerbate the health consequences of preexisting structural disparities. Figure 1 shows the synergistic health effects of climate change and structural racism, and the multitude of ways in which they intersect. The majority of research into the field of climate change and health focuses on race and gender as separate categories. Very little research has specifically explored the nuanced health outcomes that Black women will face. This article focuses on combining the gendered health effects of climate change with the preexisting structures of white supremacy that determine health in order to begin to understand the intersection between climate change and Black girls' and women's health.

The heat hypothesis states that hotter temperatures can lead to increased aggressive motives and behaviors (Anderson, 2001). With increasing levels of ambient heat under climate change, rates of violence could be projected to increase. The institutionally enforced hypersexualization of Black girls and women makes them most vulnerable to heat-related sexual violence and intimate partner violence. As sexual violence increases, the incidence of sexually transmitted diseases is bound to increase as well. Rates of HIV and other immunosuppressing diseases could increase due to climate change, increasing the population's vulnerability to other adverse effects of climate change. Research has also shown the existence of an abuse-to-prison pipeline for Black girls, with harsher sentences doled out for Black girls (Black Women and Sexual Violence, n.d.). In one study of an Oregon justice system, 76% of the incarcerated women were survivors of sexual abuse by the time they turned 13 (Black Women and Sexual Violence, n.d.). Increased ambient temperatures due to climate change could therefore increase the rate of sexual assault against Black women and girls, facilitate the spread of sexually transmitted diseases, and increase the number of incarcerated Black girls. In order to protect the safety and well-being of Black girls, further research into these trends must be a priority.

Anthropogenic emissions of carbon dioxide, particulate matter, ozone, and other harmful air pollutants are projected to increase adverse respiratory health outcomes (Watts et al., 2021). Black women, who are more likely to live in disproportionately polluted neighborhoods, are therefore most likely to experience deteriorated respiratory health (*Disparities in the Impact of Air Pollution*, 2020). Underlying chronic cardiopulmonary, cardiometabolic, and respiratory diseases make individuals far more susceptible to dying from infectious disease, and those living in over-polluted neighborhoods are therefore at the highest risk. This could be seen in the case of COVID-19. As the disease swept across the country, disproportionately high rates of morbidity and mortality were seen within the Black community (*The COVID Racial Data Tracker*, n.d.). Greenhouse gases emitted within racially segregated neighborhoods are likely to increase the incidence of infectious diseases within the Black community.

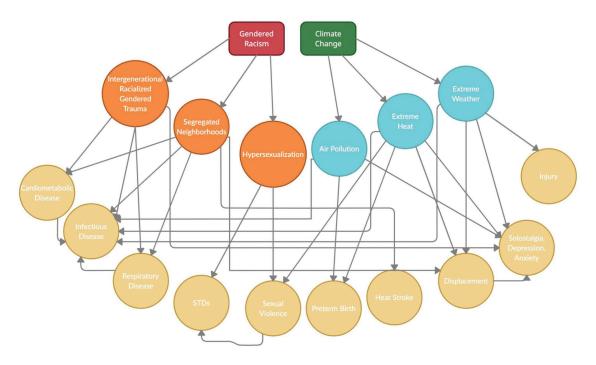
The role of the caretaker is often handed to women, and as a result, women have increased rates of contact with the sick. Consequently, they may end up contracting the illness of those they care for. Black women, who already experience intergenerational gendered racialized trauma as a major determinant of health, are therefore likely to experience the highest rates of infectious disease. Furthermore, there is a history of relegating Black women into caretaking roles. The stereotype of "the Mammy," a role created during slavery to justify the exploitation of Black women, has continued to reinforce the idea of Black women as martyrs, jeopardizing their own health for the comfort of others (Carter & Rossi, 2019). As it exists today, this stereotype could directly result in higher rates of infectious diseases among Black women under climate change.

Black infant and maternal mortality are being exacerbated by climate change ("At the Intersection of Climate Change and Environmental and Reproductive Justice," n.d.). A recent California study found that for every 10 degrees Fahrenheit of warming, there is an average 8.6% increase in preterm birth (Basu, Chen, Li, & Avalos, 2017). For Black women, there is an average increase of 14.9% (Basu et al., 2017). Furthermore, an association between exposure to high doses of ground-level ozone and preterm birth has also been found, noting that Black women had the highest levels of preterm birth (Bekkar, Pacheco, Basu, & DeNicola, 2020). Black women living in urban neighborhoods, often places with the highest levels of heat and ground-level ozone, are therefore at the highest risk of experiencing adverse maternal and infant health outcomes. An allostatic load as a result of intergenerational gendered racialized trauma has already led to higher rates of maternal mortality within the Black community, and an increased incidence of preterm birth from climate change could exacerbate those rates (Guidi, Lucente, Sonino, & Fava, 2021). Further research is needed to explore the causal links between heat, ground-level ozone, and Black maternal health, but the primary research that has been done suggests that climate change is a direct threat to the health of Black mothers.

In the event of a natural disaster, Black women are left disproportionately more vulnerable to disease, injury, assault, displacement, and even state-sponsored violence. The World Health Organization states that women experience higher rates of morbidity and mortality following natural disasters (*World Health Organization*, n.d.). As women are often in the caretaker role, there is a precedent for them to put the welfare of their family before their own health (*World Health Organization*, n.d.). As discussed earlier, the stereotype of "the Mammy" makes this circumstance even more critical for Black women (Carter & Rossi, 2019). Further research is needed into the intersectional analysis of natural disaster morbidity and mortality, but it is likely that compounding racial and gender stereotypes may result in increased rates of injury and illness among Black women. Furthermore, natural disasters are more likely to cause lasting devastation in predominantly poor,

Black communities. Following Hurricane Katrina, the hardest-hit areas of New Orleans (and the most underfunded) were the predominantly Black ones, in which 50% of poor families were female-headed (Ransby, 2006). Consequently, the highest rates of displacement occurred within the Black community. Shelters for those who have been displaced can be incredibly dangerous, with high rates of disease transmission, sexual violence, and malnutrition (Ransby, 2006). These problems stem from the sheer disregard for poor, Black communities by the United States. Welfare programs had been cut back, natural disaster defenses were underdeveloped, and the police only instigated more violence (Ransby, 2006). During Hurricane Katrina, Sharli'e Dominique, a Black trans woman, was arrested for using the women's bathroom in a safe shelter ("A New Orleans Trans Evacuee's Story," 2011). This blatant act of racist transphobia put the health and safety of Sharli'e Dominique at risk in the midst of a natural disaster, showing that the police cared more about arresting a Black trans woman than protecting the welfare of those displaced by Hurricane Katrina. Clearly, Black women are particularly vulnerable following extreme weather events. However, institutional solutions exist to protect the welfare of Black communities in the case of a disaster—they just need to be put in place.

Beyond physical health, the mental health effects of climate change are incredibly pertinent. Populations who have been displaced by climate disasters experience solastalgia, or the painful loss of home (Albrecht et al., 2007). Younger generations face mounting levels of eco-anxiety as the future remains incredibly uncertain under climate change. Anxiety, depression, and PTSD spike after traumatic natural disaster events, and the stress of poverty deepens as climate change destroys the livelihoods of numerous workers (Makwana, 2019). Black women already face higher rates of depression and anxiety due to the stress of experiencing gendered racism, structural inequalities, and inequitable levels of poverty. Adding on climate change-induced stressors would only exacerbate current rates of poor mental health.



**Figure 1.** The synergistic health effects of gendered racism and climate change.

#### Mitigation Strategies: A Case for Black Feminist Practices

The notion that Black women are dying at higher rates to benefit private corporations is not a new one; it is just being reiterated by the climate crisis. Just like imperialism, anthropogenic climate change is inextricably linked to a history of theft, power, and greed (Dias, 2020). Imperialism has been enacted through the homogenization of countries and the extraction of natural resources and labor for cheap profit. Environmental imperialism, similarly, is the extraction, commodification, and degradation of the global commons by wealthy countries at the expense of others. Fossil fuel emissions from wealthy corporations have acidified the oceans, killing the fish that many island nations rely on as their only source of protein. Powerful petrochemical plants are built in low-income, majority-Black communities in Louisiana, poisoning the surrounding landscape and exposing residents to carcinogenic toxins (Singer, 2011). These actions, performed by wealthy nations and corporations, have fractured and degraded environments across the globe, mirroring and building upon the destructive forces of colonialism. As such, mitigation research must "study up" to find the structural roots of the climate crisis (Tallbear, 2014). Critiquing larger structures allows for a broader distribution of issues to be targeted. Black women do not lead single-issue lives, and thus Black women-led mitigation campaigns will not simply address one issue. Shaping mitigation efforts through the lenses of Womanism and Black queer feminism will not only center those most affected by the climate crisis but also create space for decolonization.

Black queer feminism is integral to the design and implementation of mitigation efforts. It is the belief that the marginalized must be centered and that all feminist work must actively fight racism, sexism, and heterosexism (Sullivan, 2019). Through this lens, targeting colonial structures of gendered racism and heterosexism is the key to mitigating climate change. Taking steps to incorporate antiracist and antisexist activism into the sustainability movement can create campaigns that fight for environmental justice. Too often, climate mitigation campaigns focus broadly on the needs of the white and the wealthy. Solar energy sources are pushed as the prime sustainability practices, despite the fact that renters have no control over switching to renewable energy sources. Veganism is promoted as the best diet to fight climate change, and yet vegan alternatives are inaccessible in food deserts. Black queer feminist solutions would create sustainable solutions that are accessible and directly impact the corporations responsible for greenhouse gas emissions. Creating grassroots coalitions between queer Black women and indigenous organizations to lobby for progressive mitigative actions would be a step in the right direction. Beyond that, climate change-related surveillance must take an intersectional approach to data collection and organization (Osborne, 2015). Data is often stratified into categories of race, class, and gender, without considering the complex interactions between all three (Osborne, 2015). Due to this, data that centers the unique experiences of Black women is often underreported. Moreover, campaigns and interventions that rely upon such data are left without the evidence for an intersectional approach. Restructuring surveillance systems to take into account the interlocking systems of oppression would allow for the creation of evidence-based mitigation programs that specifically center Black women.

Structural-level mitigation campaigns also consistently fail to center historically Black communities. The DC Department of Transportation has been implementing a tree planting program to increase urban greening within the city. However, the majority of the program has been clustered in wealthier, white wards (Interactive Map, 2018). Despite the fact that wards 7 and 8,

historically Black neighborhoods, need urban greening the most to increase shade and combat ground-level ozone pollution, they have received the least attention from the program. Using Black queer feminism to center those who have been on the margins of sustainability campaigns is key to creating a collective sense of self-efficacy in the fight against climate change. Thus, allocating funds to create university programs and political coalitions on environmental racism would begin training a new generation of changemakers. Beyond additive change within the political system, policies that create racist built environments *must* be abolished and replaced with ones that funnel money into Black communities. The money exists; we just need to ensure it is used for the right resources.

Using Womanism to inform sustainability practices and heal Black women can create a two-pronged campaign to mitigate climate change and reverse the adverse health effects of gendered racism (Harris & Crawford, 2021). Womanism is social change rooted in the everyday experiences and problem-solving skills of Black women with the goal of ending all oppression, restoring the balance between human and nature, and embracing the spiritual dimension (Harris & Crawford, 2021). This spiritual connection between Black women and nature is key to creating collective action to fight the environmental degradation of climate change. Similar to indigenous environmental activism, Black women's spirituality can be used to inform activism, lobbying, and sustainable practices. Using spiritual community centers as sites of environmental activism would allow for trusted community leaders to become key informants and for a wider array of generations to join the fight.

The everyday experiences and rituals of Black women can be used to create lasting mitigation campaigns. Plasticity is not innate to human nature, and many mainstream sustainable practices are difficult to maintain. To create flexible and sustainable solutions, womanist strategies that use Black women's everyday experiences would be adaptable, resilient, and centered upon wellness. These Womanist spiritual practices can also improve mental health outcomes (Heath, 2006). As climate change poses a serious risk to the mental health of the global population, solutions for healing are as pertinent as they have ever been. Connecting sustainability practices to spiritual health would allow for healing within the environment, the body, the mind, and the soul.

There are two bills working their way through congress right now that have the potential to address the adverse health effects Black women specifically face under climate change. The Social Determinants for Moms Act of 2020 would create a task force for grants and studies concerned with the social determinants of maternal health, with a focus on maternal morbidity, mortality, and racial disparities (McBath, 2020). The grants used from this program could create further research opportunities to explore the intersection between climate change and Black maternal health outcomes, with a particular focus on the effects of heat and ground-level ozone. Using this bill to specifically fund Black women-led research teams would not only approach research from a critical intersectional point of view but also help diversify the academic establishment. Similarly, the Black Maternal Health Momnibus Act of 2020 is a powerhouse of a bill. It covers everything from funding community-based organizations that improve maternal health and promote equity, to diversifying the perinatal workforce, to promoting payment models that provide access to high-quality and non-clinical perinatal care, and even investing in community-based initiatives to reduce levels of climate change–related risks for pregnant women (Underwood, 2020). This bill clearly promotes grassroots, diverse, and non-clinical efforts to protect maternal health—even denoting a specific focus on the role of climate change. Passing the Black Maternal Health Momnibus Act would garner the collective action needed by community-based organizations to mitigate climate change

and protect Black maternal health. Centering the health of Black women at the structural level is the first step in undoing centuries of institutional violence. Both of these bills were introduced in the house in early 2020 and must continue to receive enough support to work their way through the legislative process.

#### Conclusions: A Call for Research and Action

The anthropogenic climate crisis is set to deteriorate the health of humans and the environment, with a disproportionately large impact on those made vulnerable by sociopolitical systems of white supremacy. Gendered racism is a major determinant of health, and thus Black girls and women are made particularly vulnerable to the health effects of climate change. However, limited research into the field of climate change and health has specifically focused on the health of Black women. The research that does exist focuses on Black maternal mortality, once again relegating the field of Black women's health to just one cause. All aspects of health under climate change must be researched, including mental health, sexual health, respiratory health, and spiritual health. Centering Black women in the fight against climate change is imperative to garnering collective action, promoting wellness, and abolishing structures of inequity. An immediate allocation of resources is necessary to promote research into the field of gendered racism and climate change—and Black women must be at the helm of the projects. Furthermore, additional research using tenets of community-based participatory research to uplift local communities would be of particular use to this field, especially when developing lasting sustainability practices. Unless immediate drastic action is taken by every governing body across the globe, climate change is going to be the future. Public health practitioners need to ensure that the future will be safe, healing, and joyful for Black women and girls.

#### References

- Albrecht, G., Sartore, G.-M., Connor, L., Higginbotham, N., Freeman, S., Kelly, B., Stain, H., Tonna, A., & Pollard, G. (2007). Solastalgia: The distress caused by environmental change. *Australasian Psychiatry: Bulletin of Royal Australian and New Zealand College of Psychiatrists*, 15(Suppl 1), S95–S98. https://doi.org/10.1080/10398560701701288
- A New Orleans Trans Evacuee's Story. (2011, August 29). *TransAdvocate*. https://www.transadvocate.com/a-new-orleans-trans-evacuees-story\_n\_4266.htm
- Anderson, C. A. (2001). Heat and violence. *Current Directions in Psychological Science*, 10(1), 33–38. https://doi.org/10.1111/1467-8721.00109
- At the Intersection of Climate Change and Environmental and Reproductive Justice. (n.d.). *New Security Beat*. Retrieved May 2, 2021, from https://www.newsecuritybeat.org/2020/07/intersection-climate-change-environmental-reproductive-justice/
- Banks-Wallace, J., & Parks, L. (2004). It's all sacred: African American women's perspectives on spirituality. *Issues in Mental Health Nursing*, 25(1), 25–45. https://doi.org/10.1080/01612840490249028-22
- Barlow, J. N., & Johnson, B. M. (2021). Listen to black women: Do black feminist and womanist health policy analyses. *Women's Health Issues*, 31(2), 91–95. https://doi.org/10.1016/j.whi.2020.11.001

- Barlow J. N. & Jones T. C., (2018). Reclaiming health for black women and girls: A conversation with Dr. Jameta Nicole Barlow. *Journal of Critical Thought and Praxis* 7(2), 64–65.
- Basu, R., Chen, Hong., Li, D.-K., & Avalos, L. A. (2017). The impact of maternal factors on the association between temperature and preterm delivery. *Environmental Research*, 154, 109–114. https://doi.org/10.1016/j.envres.2016.12.017
- Bekkar, B., Pacheco, S., Basu, R., & DeNicola, N. (2020). Association of air pollution and heat exposure with preterm birth, low birth weight, and stillbirth in the US. *JAMA Network Open*, 3(6). https://doi.org/10.1001/jamanetworkopen.2020.8243
- Black Women and Sexual Violence. (n.d.). Retrieved May 5, 2021, from https://now.org/wp-content/uploads/2018/02/Black-Women-and-Sexual-Violence-6.pdf
- Carter, L., & Rossi, A. (2019). Embodying strength: The origin, representations, and socialization of the strong black woman ideal and its effect on black women's mental health. *Women & Therapy*, 42(3–4), 289–300. https://doi.org/10.1080/02703149.2019.1622911
- Dias, K. M. (2020). *Environmentalism and the legacy of colonialism*. Human Rights Pulse. Retrieved December 13, 2021, from https://www.humanrightspulse.com/mastercontentblog/environmentalism-and-the-legacy-of-colonialism
- Disparities in the Impact of Air Pollution. (2020). Retrieved December 13, 2021, from https://www.lung.org/clean-air/outdoors/who-is-at-risk/disparities
- Gee, G. C., & Ford, C. L. (2011). Structural racism and health inequities. *Du Bois Review : Social Science Research on Race*, 8(1), 115–132. https://doi.org/10.1017/S1742058X11000130
- Goosby, B. J., & Heidbrink, C. (2013). Transgenerational consequences of racial discrimination for African American health. *Sociology Compass*, 7(8), 630–643. https://doi.org/10.1111/soc4.12054
- Guidi, J., Lucente, M., Sonino, N., & Fava, G. A. (2021). Allostatic load and its impact on health: A systematic review. *Psychotherapy and Psychosomatics*, 90(1), 11–27. https://doi.org/10.1159/000510696
- Harris, F. B., & Crawford, K. C. (2021). A womanist and interfaith response to climate change. In S. E. Silvern & E. H. Davis (Eds.), *Religion, Sustainability, and Place: Moral Geographies of the Anthropocene* (pp. 355–381). Springer. https://doi.org/10.1007/978-981-15-7646-1\_15
- Heath, C. D. (2006). A womanist approach to understanding and assessing the relationship between spirituality and mental health. *Mental Health, Religion & Culture*, 9(2), 155–170. https://doi.org/10.1080/13694670500116938
- Interactive Map: DC Is Planting Thousands of Trees, But Inequity Remains. (2018). *NBC4 Washington*. Retrieved May 5, 2021, from https://www.nbcwashington.com/news/local/dc-is-planting-thousands-of-trees-but-inequity-remains/54358/
- Makwana, N. (2019). Disaster and its impact on mental health: A narrative review. *Journal of Family Medicine and Primary Care*, 8(10), 3090–3095. https://doi.org/10.4103/jfmpc.jfmpc\_893\_19
- Maparyan, L. (2018). Womanism and black women's health. *Meridians: Feminism, Race, Transnationalism*, 16(2), 329–332.
- McBath, L. (2020, March 10). H.R.6132–116th Congress (2019–2020): Social Determinants for Moms Act of 2020 (2019/2020) [Legislation]. https://www.congress.gov/bill/116th-congress/house-bill/6132

- Osborne, N. (2015). Intersectionality and kyriarchy: A framework for approaching power and social justice in planning and climate change adaptation. *Planning Theory*, 14(2), 130–151. https://doi.org/10.1177/1473095213516443
- Prather, C., Fuller, T. R., Jeffries, W. L., Marshall, K. J., Howell, A. V., Belyue-Umole, A., & King, W. (2018). Racism, African American women, and their sexual and reproductive health: A review of historical and contemporary evidence and implications for health equity. *Health Equity*, 2(1), 249–259. https://doi.org/10.1089/heq.2017.0045
- Ransby, B. (2006). Katrina, black women, and the deadly discourse on black poverty in America. *Du Bois Review: Social Science Research on Race*, 3(1), 215–222. https://doi.org/10.1017/S1742058X06060140
- Singer, M. (2011). Down cancer alley: The lived experience of health and environmental suffering in Louisiana's chemical corridor. *Medical Anthropology Quarterly*, 25(2), 141–163. https://doi.org/10.1111/j.1548-1387.2011.01154.x
- Sullivan, M. J. (2019). Black queer feminism. In M. J. Sullivan, *African American studies center*. Oxford University Press. https://doi.org/10.1093/acref/9780195301731.013.78530
- Tallbear, K. (2014). View of Standing With and Speaking as Faith: A Feminist-Indigenous Approach to Inquiry | Journal of Research Practice. Retrieved May 5, 2021, from http://jrp.icaap.org/index.php/jrp/article/view/405/407
- *The COVID Racial Data Tracker.* (n.d.). The COVID Tracking Project. Retrieved May 5, 2021, from https://covidtracking.com/race
- Underwood, L. (2020, July 13). H.R.6142–116th Congress (2019–2020): Black Maternal Health Momnibus Act of 2020 (2019/2020) [Legislation]. https://www.congress.gov/bill/116th-congress/house-bill/6142
- Watts, N., Amann, M., Arnell, N., Ayeb-Karlsson, S., Beagley, J., Belesova, K., . . . Costello, A. (2021). The 2020 report of The Lancet Countdown on health and climate change: Responding to converging crises. *The Lancet*, 397(10269), 129–170. https://doi.org/10.1016/S0140-6736(20)32290-X
- World Health Organization. (n.d.). Gender Climate Change and Health. Public Health and Environment Department. Retrieved May 1, 2021, from https://www.who.int/globalchange/publications/reports/gender\_climate\_change/en/

### You Are Where You Live: Food Environment and Obesity in Detroit

Kylie Scott\*

A growing body of research in Detroit, MI, supports the complex relationship between the city's urban food environment and its obesity epidemic. The Detroit Community Health Assessment identified lower life expectancy and increased obesity prevalence among Detroit residents compared to the state of Michigan, spurring ineffective policy that attributes poor health outcomes to factors at the individual level rather than the population level. This article explores inequitable healthy food access in Detroit in relation to obesity, analyzing the city's urban food environment in the context of historical disinvestment. This comprehensive literature review was performed utilizing journal articles from large electronic databases including PubMed. Current research identifies socioeconomic status as a key determinant in equitable healthy food access in urban food environments, suggesting the decision to procure a healthier diet is constrained more so by affordability than preference. The evidence proposes subsidization of healthy foods at farmers' markets or community gardening initiatives as beneficial solutions to addressing the healthy food inequity in Detroit.

#### Keywords

obesity • food swamp • socioeconomic status • healthy food equity

Obesity across the globe has nearly tripled since 1975 (World Health Organization [WHO], 2020). In fact, a majority of the world's population live in nations where overweight and obesity kills more than being underweight (WHO, 2020). The proverb "you are what you eat" refers to a collective acknowledgment of diet's role in maintaining a healthy lifestyle. However, recent research has actually determined the food environment to be equally—if not more—influential. The food environment is the combined physical and social factors that influence how an individual gets their nutrition (Puhl & Heuer, 2010, p. 1025). Typically, this is measured by distance to the nearest grocery store, but a more encompassing definition captures a wide range of elements

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that influence how we eat: subsidized meal programs at schools, affordability of nearby supermarkets, or the number of fast-food restaurants in a city block (Taylor & Ard, 2015, p. 108). The flight of high-quality grocers to the suburbs in 1980s Detroit, MI, has transformed the city into a food swamp. Food swamps are defined as communities where "large amounts of energy-dense foods sold in venues. . . 'inundate, or swamp out,' the 'relatively few' healthy food choices residents have" (Taylor & Ard, 2015, p. 103). Consistent, well-funded interventions that address aspects of the food environment at the crux of the obesity problem are preferred to educational efforts reprimanding individual behavior (Puhl & Heuer, 2010, p. 1024). Detroit's status as a food swamp has critical implications on residents' health outcomes. The complex relationship between Detroit's urban food environment and its obesity epidemic will become clearer through the following analysis of food environment models, the obesity crisis, and the influence of socioeconomic status (SES) on food equity, viewed through a lens of the historical deterioration and recent gentrification efforts that characterize the city.

#### "Food Desert" versus "Food Swamp" Models

The food desert model views the food environment as devoid of healthy dietary options. The U.S. Department of Agriculture characterizes food deserts as "regions of the country [that] often feature large proportions of households with low incomes, inadequate access to transportation, and a limited number of food retailers providing fresh produce and healthy groceries for affordable prices" (Dutko, Ver Ploeg, & Farrigan, 2012, p. 1). The food desert model describes communities where residents live farther than 10 miles from the nearest supermarket. Indeed, the food desert model is most useful for rural counties in the United States, given they have only 3.8 grocery stores on average (Morton & Blanchard, 2007, p. 7). Therefore, rural counties are food deserts where diet quality is limited most by distance to a grocery store.

Despite inherent similarities between the two models, urban environments are better characterized as food swamps than food deserts. While food deserts emphasize distance to a grocery store as the main limitation to a healthy diet, residents of a food swamp face complex obstacles more characteristic of a bustling metropolis. These communities become oversaturated in high-calorie, low-cost food selections such that healthy options become scarce (Taylor & Ard, 2015, p. 103). Typically, these unhealthier options are more heavily advertised to demographics in urban environments, populations that had a 12% average poverty rate in the 2016 U.S. Census (Kyzyma, 2018, p. 13). Television ratings measured in a 2014 study found that "child/adolescent exposure to food-related ads . . . was significantly higher in areas with higher proportions of . . . lower-income households" (Powell, Wada, & Kumanyika, 2014, p. 1). With a corner store on every block to satisfy the desires of relentless advertising, it is understandable that a less healthy diet might become the norm in the city. In the context of socioeconomic status, cost becomes a more influential factor in healthy food selection than availability. Detroit boasts of "96 full-line grocery stores; 1,110 small grocers, convenience stores, mini marts, and liquor stores; [and] 279 specialty food stores" (Taylor & Ard, 2015, p. 1). Despite numerous accessible grocers in Detroit, a relatively large proportion of the city's shoppers face strict financial constraints. A 2019 analysis reported Detroit's poverty rate of 39.4% as one of the highest among major U.S. cities (Beavers, Atkinson, & Alaimo, 2020, p. 150). Additionally, Detroit leans heavily into federally subsidized food programs—37.7% of residents in 2012 rely on Supplemental Nutrition Assistance Program

(SNAP) benefits to buy their groceries (Taylor & Ard, 2015, p. 116). In examining the interplay of food selection with access, the preponderance of the evidence suggests unhealthy food selection in Detroit is more attributable to the financial barriers of shopping from higher-quality grocers rather than traveling to or accessing one.

While urban food environments are an emergent area of exploration across the nation, research limitations restrict progress for needed action. Indeed, Detroit and other cities are often—and incorrectly—called food deserts due to inconsistent research under the food desert model. Typically, studying urban food environments with the food desert mindset emphasizes distance from healthy food as the point of intervention. This mindset manifests in efforts such as an establishment of a healthier grocer downtown or integration of produce sections in a convenience store (Taylor & Ard, 2015, p. 104). However, the omittance of smaller establishments that illustrate the community's agency in determining its unique food environment—namely, community-supported agriculture, food cooperatives, and urban gardens—is a detrimental limitation of prior research efforts (Taylor & Ard, 2015, p. 106). These considerations have the potential to shift the view of the "urban food environment" further from reality and could mean the difference between categorization as a food desert or food swamp. This distinction becomes particularly critical when informing interventions for leadership among urban populations to focus on, keeping in mind that different strategies are more efficacious in food deserts than food swamps (Braveman, 2014). For example, a strategy such as opening a new grocery store in Detroit fails to address the root causes of inaccessible healthy food among low SES individuals in urban environments—namely, affordability. As our understanding of urban food environments continues to increase, more careful consideration of these factors must be taken into account during research.

#### History of Detroit's Food Environment

The lasting effects of discriminatory practices in the twentieth century contributed to the shaping of Detroit into a food swamp over the decades. Disproportionate grocery store closings in the cities occurred as the "residential character" of urban environments began to shift (Eisenhauer, 2001, p. 125). Across the nation, urban supermarket closings in the 1980s became more frequent than openings—so much so that by the end of the 1990s "the poorest 20% of urban neighborhoods had 44% less retail supermarket space than the richest 20%" (Eisenhauer, 2001, p. 128). Moreover, discriminatory redlining rooted in federal housing policy contributed to disinvestment in increasingly diverse communities, a consequence of which is observed in the flight of higher quality grocers to the suburbs (Eisenhauer, 2001, p. 126). The occurrence of supermarket flight out of the cities and into suburbia has been coined "supermarket redlining" by food-access researchers, and the "tipping of the scales" toward higher proportions of less healthy corner stores over the years has transformed Detroit into the food swamp it is today (Eisenhauer, 2001, p. 125).

Currently, Detroit residents with the luxury of transportation and time prefer to shop for their groceries outside of the city, whereas residents at or below the poverty line without such advantages are forced to frequent the most convenient—but not necessarily the healthiest—grocery options. Of course, independent of financial considerations, the typical Detroit shopper would prefer a grocer that provides healthy offerings and a positive shopping experience. Indeed, Beavers et al. identified negative perceptions of corner stores among Detroit residents, citing food quality, store cleanliness, and price gouging as the most principal areas of concern (2019, p. 150). The tendency of wealthier residents to migrate outside of the city limits for healthy food only emphasizes the food equity gap

in urban food environments based on socioeconomic status, posing serious health implications for the population of individuals without the means or time to commute for healthier groceries.

#### Obesity as a Public Health Problem

An individual is considered "overweight" or "obese" when their weight is higher than what is considered healthy. For adults, weight-to-height ratio called Body Mass Index (BMI) is typically used to screen individuals from underweight (BMI < 18.5 kg/m²) to severe or morbid obesity (BMI ≥ 40 kg/m²) (Hruby & Hu, 2015, p. 2). Gender-specific growth charts are used for children and define overweight and obesity in consideration of natural weight fluctuations that occur during development (Hruby & Hu, 2015, p. 2). Regardless of measurement, characterization as "overweight" or "obese" carries serious health implications. Type 2 diabetes, high blood pressure, cardiovascular disease, and some forms of cancer are just a sampling of the major health problems for which excess body fat increases risk (Hruby & Hu, 2015, p. 2). Psychosocial implications include mental health problems such as depression, eating disorders, anxiety, and substance abuse, which are rooted in discrimination that obese individuals often experience because of their weight (Sarwer & Polonsky, 2016).

Prevalence, economic burden, and emphasis on prevention mark obesity as a pressing public health problem. While the prevalence of overweight adults has plateaued from 1960 to 1994, the prevalence of obese adults continued to trend upward from 13% to 23% (Hruby & Hu, 2015, p. 3). The catastrophic interplay between skyrocketing obesity rates and the occurrence of comorbidities is reflected in the analysis of the National Health and Nutrition Examination Survey (NHANES) database, which found "years of life lost were 1 to 9 for those with low BMI compared with 9 to 13 for those with a high BMI" (Pi-Sunyer, 2009, p. 9). In addition, obesity's economic toll burdens the community as well as the individual. National spending on obesity-related diseases is thought to account for 21% of total U.S. healthcare expenditures (Hruby & Hu, 2015, p. 12). Moreover, cyclical gain and loss of body fat caused by biological barriers to weight loss suggests a specific need for preventative action. Among those "who intentionally achieve weight loss of ≥10% body weight," 80% will gain that weight back within a year (Mehta, Smith, Muhammad, & Casazza, 2014, p. 1). Given this added difficulty for overweight individuals to lose weight—and keep it off—comprehensive primary prevention efforts that avoid victim-blaming would be most effective overall in addressing the obesity epidemic (Puhl & Heuer, 2010, p. 7).

Obesity is often attributed to poor decision-making; but in reality, the social and environmental factors at play are the true influencers of diet. Prior and current national public health efforts address obesity with legislation that removes consumer autonomy. For instance, the historic New York City soda tax in 2012 spearheaded by Mayor Michael Bloomberg proposed limiting the sizes of sugary drinks. The obesity initiative sparked controversy as New Yorkers questioned "Nanny Bloomberg's" authority in controlling individual diet choices (Gostin, Reeve, & Ashe, 2014, p. 1). An additional example is Michelle Obama's "Let's Move" Campaign, the pinnacle of which implemented new nutritional standards for school meals nationwide. However, such cafeteria interventions—for instance, the 2010 Healthy, Hunger-free Kids Act—focused more on managing student diet decisions than holding food producers responsible. Granted, future research is necessary to determine the true efficacy of Obama's initiative, but childhood obesity has certainly not decreased to the impressive 5% prevalence rate that the administration projected for 2030 (White House Task Force on Childhood Obesity to the President, 2010). Policies that focus on controlling the

consumer emphasize the looming presence of weight stigma in legislation (Puhl & Heuer, 2010, p. 1024). Claiming to approach the issue through a lens of personal accountability, Mississippi legislators attempted to tackle obesity through a 2008 State House Bill that "proposed to prohibit restaurants from serving food to any person who is obese" (Puhl & Heuer, 2010, p. 1024). Rather, societal factors such as availability of healthy food—or oversaturation of *unhealthy* food—impact obesity risk, as illustrated in a national study that found a positive association between food swamp prevalence and obesity rates (Cooksey-Stowers, Schwartz, & Brownell, 2017, p. 8). An additional factor, socioeconomic status, plays a role along with race or ethnicity (Eisenhauer, 2001, p. 131). Clearly, the higher-level spheres of influence, rather than just intrapersonal behaviors, impact obesity risk more substantially than the Bloomberg and Obama initiatives suggest.

#### Detroit's Food Swamp and the Obesity Epidemic

Critical implications of Detroit's food environment are higher obesity rates, lowering life expectancy, and increasing prevalence of obesity-related illness. Analysis conducted by the Detroit Community Health Assessment in 2018 found that the obesity epidemic hit Detroit harder compared to the state as a whole: 37% of Detroit adults were obese (compared to 31% of Michigan adults), and Detroit life expectancy at birth was 72 years (compared to 78 years at the state level) (Coulter, Reyes, Taylor, Adams, & Larsosa, 2018, p. 6, 9). These statistics might contrast public knowledge regarding the obesity epidemic—with increasing efforts to promote healthy food equity in Detroit, why are obesity rates increasing? The answer lies in the interplay between Detroit's food swamp environment and a key social determinant of health: socioeconomic status.

Recent movements to bridge food environment quality between Detroit's poorest to that of the rest of the city typically culminate in gentrification practices, such as the installment of high-end grocers downtown. However, despite the "public relations flurries" that depict urban supermarket openings as "trendy" once again, this is not the reality—national grocery store closings still outnumber openings in the city (Eisenhauer, 2001, p. 125). A recent example of one such gentrification effort was the opening of Whole Foods in Detroit's Midtown neighborhood in 2013. Whole Foods–Detroit's goals were to appeal to middle-upper-class shoppers and outreach to lower-income shoppers through nutrition classes and offering space for community gatherings (Jung & Newman, 2014, p. 25). However, "community-focused" branding failed to hide the obvious price increases experienced when shopping at Whole Foods—dubbed "Whole Paycheck" by critics—versus lower-end supermarkets. Ethnographic research by Jung and Newman delved into this stereotype further, sharing commentary from business stakeholders who danced around the crux of the issue: affordability. Despite public perception as financially unattainable, Whole Foods–Detroit's manager, John Smith, claimed Whole Foods "prices were actually competitive because they offered the highest quality food for the most competitive price" (Jung & Newman, 2014, p. 28). As much as Whole Foods claims to want to bridge the gap in healthy food equity among Detroiters, higher prices raise questions of whether low-income shoppers will actually make this trade-off between food quality and cost.

Therefore, merely opening another grocery store will not improve Detroit's obesity epidemic since this solution neglects three constraints faced by individuals of a low SES that, in conjunction with the food environment, play a critical role in obesity prevalence: affordability, norms, and time. As illustrated with the Whole Foods case study, the increased cost of higher-quality or organic

foods presents a challenge for low-income individuals to make the most of their dollar. More often than not, the most economic choice for individuals below the poverty line is to purchase the cheapest food with the highest caloric density—often, fast food (Cooksey-Stowers et al., 2017, p. 12). Additionally, community norms strongly influence shopping behavior. Powell et al. demonstrate a higher frequency of unhealthy food advertisements in areas with proportionally higher low-income households (2014, p. 6). When influenced by such advertisements, it becomes easier to fall into that community norm of shopping from the nearest corner store or fast-food restaurant (Powell et al., 2014, p. 10). Finally, the time required to shop from higher-quality grocers is more expendable for individuals of a higher SES. Low-paying jobs typically require more time and energy out of the day. Moreover, accessible transportation indicates less time sacrifice for a high SES shopper to commute to the grocery store (Cooksey-Stowers et al., 2017, p. 12). Transportation poses a significant barrier for low SES people; most people shop within two miles of their home, yet between 10% and 50% of the urban poor do not have access to a car (Eisenhauer, 2001, p. 130). This leaves public transportation as a viable means of commute; although this option is accessible, it lacks efficiency. Indeed, declining investment in public transport from the city to suburban grocery stores has left the urban shopper with an inefficient, time-consuming system (Eisenhauer, 2001, p. 130). A comprehensive solution to obesity in Detroit should address its food swamp environment considering all three barriers faced by low SES individuals.

#### Future of Food Equity in Detroit

Policy has the potential to produce meaningful change in food swamps by promoting healthier food options in the city and urban agriculture practices. Food swamps are plagued by the oversaturation of unhealthy corner stores that crowd out healthier grocers. A shift away from "restriction" policy could manifest in the implementation of "monetary incentives to existing food stores to stock healthy food items [or] the . . . subsidization of farmers' markets . . . to facilitate access to fresh fruits and vegetables" (Chen & Florax, 2010, p. 2). Either avenue is a step in the direction of ensuring equitable access to healthy foods regardless of SES or location. Moreover, community-maintained urban agriculture has become increasingly important in redefining Detroit's food system. This is reflected in a 2013 amendment to the local zoning code made by Detroit's City Council. The new policy resulted in the recognition and standardization of Detroit's various agricultural practices, in essence streamlining the legal process for community gardening initiatives (Taylor & Ard, 2015, p. 126).

A qualitative analysis by Beavers et al. sought to investigate the effectiveness of Detroit's community gardening movement by assessing study participants' perceptions of a local gardening program's influence on diet. The study's primary investigators utilized a community-based participatory research approach through which decision-making power was distributed equally among researchers and community stakeholders (Beavers et al., 2020 p. 152). Data were collected in the form of semi-structured interviews with 26 members of Keep Growing Detroit's Garden Resource Program (Beavers et al., 2020, p. 154). Through this program, members gain access to gardening resources—such as seeds and plants—as well as a wealth of educational support from community leaders (Beavers et al., 2020, p. 150). A consistent theme across the interview series was a noticeable shift in diet after joining the Garden Resource Program. Following enrollment, the majority of participants observed a noticeable increase in vegetable uptake (Beavers et al., 2020, p. 155). In

fact, some interviewees reported having access to higher-quality produce than what was typically accessible in a typical Detroit grocery store (Beavers et al., 2020, p. 157). Additionally, participant responses regarding food security after joining the garden program are a testament to these initiatives' impact on healthy food selection for low SES individuals. Most interviewees agreed that gardening saves money on food, with some reporting financial benefits as sparking their initial interest in agricultural practices (Beavers et al., 2020, p. 159). This study is limited in that participants' perceptions, while powerful, will remain just that until they are validated quantitatively (Beavers et al., 2020, p. 165). Without a doubt, further research conducted in tandem with community stakeholders is necessary to fully assess the efficacy of urban agriculture in bridging Detroit's food equity gap.

#### Conclusion

Detroit's complex obesity epidemic is the culmination of socioecological factors—namely, its food swamp environment—rather than human behavior, creating healthy food inequity among more economically disadvantaged groups in the city. Comorbidities associated with obesity undoubtedly impact the city's health—Detroit citizens currently experience a life expectancy six years shorter than that of the average Michigander. These detrimental health effects are the result of historical disinvestment in Detroit's infrastructure, which has created a food swamp system difficult to navigate as a low SES individual. Initiatives that blame decisions at the individual level miss incredible opportunity for large-scale change that could be initiated by addressing issues such as healthy food affordability. Subsidization of farmers' markets serves as a great opportunity for low SES community members to support local vendors and access healthier groceries. Additionally, urban agriculture opportunities in Detroit further the food equity movement toward a future where healthy, affordable food is equally accessible. Comprehensive, prevention-based public health efforts in Detroit's urban landscape are necessary to make strides against obesity by narrowing the healthy food equity gap.

#### References

- Beavers, A. W., Atkinson, A., & Alaimo, K. (2020). How gardening and a gardener support program in Detroit influence participants' diet, food security, and food values. *Journal of Hunger & Environmental Nutrition*, 15(2), 149–169. https://doi.org/10.1080/19320248.2019.1587332
- Braveman, P. (2014). What are health disparities and health equity? We need to be clear. *Public Health Reports*, 129(Suppl 2), 5–8.
- Chen, S. E., & Florax, R. J. G. M. (2010). Zoning for health: The obesity epidemic and opportunities for local policy intervention. *The Journal of Nutrition*, 140(6), 1181S–1184S. https://doi.org/10.3945/jn.109.111336
- Cooksey-Stowers, K., Schwartz, M. B., & Brownell, K. D. (2017). Food swamps predict obesity rates better than food deserts in the United States. *International Journal of Environmental Research and Public Health*, 14(11), 1366. https://doi.org/10.3390/ijerph14111366
- Coulter, B., Reyes, A. G., Taylor, R. S., Adams, C., & Larsosa, J. (2018). Detroit community health assessment. *City of Detroit, Detroit Health Department*, pages 6 and 9.

- Dutko, P., Ver Ploeg, M., & Farrigan, T. (2012). Characteristics and influential factors of food deserts. *U.S. Department of Agriculture, Economic Research Service*, 1.
- Eisenhauer, E. (2001). In poor health: Supermarket redlining and urban nutrition. *GeoJournal*, 53(2), 125–133. https://doi.org/10.1023/A:1015772503007
- Gostin, L. O., Reeve, B. H., & Ashe, M. (2014). The historic role of boards of health in local innovation. *JAMA*, 312(15), 1511. doi:10.1001/jama.2014.12498
- Hruby, A., & Hu, F. B. (2015). The epidemiology of obesity: A big picture. *PharmacoEconomics*, *33*(7), 673–689. https://doi.org/10.1007/s40273-014-0243-x
- Jung, Y., & Newman, A. (2014). An edible moral economy in the motor city: Food politics and urban governance in Detroit. *Gastronomica*, 14(1), 23–32. https://doi.org/10.1525/gfc.2014.14.1.23
- Kyzyma, I. (December 2018). Rural-urban disparity in poverty persistence. *Institute for Research on Poverty*, 34(3), 7.
- Mehta, T., Smith Jr., D. L., Muhammad, J., & Casazza, K. (2014). Impact of weight cycling on risk of morbidity and mortality. *Obesity Reviews*, 15(11), 870–881. https://doi.org/10.1111/obr.12222
- Morton, L. W., & Blanchard, T. C. (2007). Starved for access: Life in rural America's food deserts. *Rural Realities*, 1(4). Retrieved October 13, 2020, from https://www.ruralsociology.org/assets/docs/rural-realities/rural-realities-1-4.pdf
- Pi-Sunyer, X. (2009). The medical risks of obesity. *Postgraduate Medicine*, 121(6), 21–33. https://doi.org/10.3810/pgm.2009.11.2074
- Powell, L. M., Wada, R., & Kumanyika, S. K. (2014). Racial/ethnic and income disparities in child and adolescent exposure to food and beverage television ads across U.S. media markets. *Health & Place*, 29, 124–131. https://doi.org/10.1016/j.healthplace.2014.06.006
- Puhl, R. M., & Heuer, C. A. (2010). Obesity stigma: Important considerations for public health. *American Journal of Public Health*, 100(6), 1019–1028. https://doi.org/10.2105/AJPH.2009.159491
- Sarwer, D. B., & Polonsky, H. M. (2016). The psychosocial burden of obesity. *Endocrinology and Metabolism Clinics of North America*, 45(3), 677–688. https://doi.org/10.1016/j.ecl.2016.04.016
- Taylor, D. E., & Ard, K. J. (2015). Research article: Food availability and the food desert frame in Detroit: An overview of the city's food system. *Environmental Practice*, 17(2), 102–133. https://doi.org/10.1017/S1466046614000544
- White House Task Force on Childhood Obesity Report to the President | Let's Move! (2010). Retrieved February 3, 2022, from https://letsmove.obamawhitehouse.archives.gov/white-house-task-force-childhood-obesity-report-president
- World Health Organization. *Obesity and overweight*. Retrieved November 12, 2020, from https://www.who.int/news-room/fact-sheets/detail/obesity-and-overweight

# Addressing Explanation of Benefits as a Barrier to PrEP for Adolescents in Public Health Entities

#### Evan Hall\*

Pre-exposure prophylaxis (PrEP) is a revolutionary medical advancement to prevent HIV infection upon exposure. However, since its introduction in 2012, PrEP largely remains inaccessible to adolescents who do not wish to disclose their PrEP usage through an explanation of benefits (EOBs) and who are covered under a parent/guardian insurance. This literature review uniquely documents the concept of insurance as a barrier to PrEP access because of EOBs and how non-governmental organizations (NGOs), including community-based organizations (CBOs), have addressed this insurance policy problem. Based on the results of this review, a new approach to resolving EOBs as a barrier to PrEP access for adolescents has the potential to be implemented at the state level across the country. The approach focuses on clarifying the definition of "endanger" under HIPAA to grant adolescents the privilege of medical disclosure as it relates to EOBs.

#### Keywords

implementation sciences • health policy • HIV • PrEP

**Research Question:** What are the recommendations for governmental and nongovernmental organizations (NGOs) to address parental/guardian disclosure through explanation of benefits (EOBs) of adolescents who are taking PrEP and are insured under a parent or guardian?

#### Introduction

Pre-Exposure Prophylaxis (PrEP) is a once-daily prevention medication taken orally to prevent HIV infection upon exposure. Tenofovir disoproxil fumarate/emtricitabine as PrEP was approved by the U.S. Food and Drug Administration (FDA) in 2012 (American Academy of Pediatrics, 2012). The pharmaceutical company Gilead Sciences marketed PrEP as Truvada. Since then, Gilead

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Sciences formulated another option for PrEP known as Descovy, which the U.S. FDA approved as PrEP in 2019 (U.S. Food & Drug Administration, 2019).

The Centers for Disease Control (CDC) recommends PrEP for those who are susceptible to HIV infection from sex or injection drug use (CDC, 2021). Recently, new recommendations from the CDC in 2021 expanded criteria for accessing PrEP, which encompasses more versions of PrEP, including generic options, where previously only brand names Truvada and Descovy were available to clients (Buhl, 2021).

In 2015, the CDC estimated the number of individuals at increased susceptibility to HIV who would be eligible for PrEP was around 1.1 million adults, capturing key populations, such as the LGBTQ+ community, young Black men who sex with men, and Black women (Huang, Zhu, Smith, Harris, & Hoover, 2018). Since PrEP's introduction as Truvada, the percentage of people on PrEP has increased dramatically. In 2012, there were approximately 8,768 PrEP users, while data from 2016 shows 77,120 PrEP users (AIDSVu, 2018). The CDC projects that 44% of African Americans and 25% of Latinos from these key populations could potentially benefit from PrEP, but data showed only 1% of African Americans and 3% of Latinos were prescribed PrEP (Rosenberg, 2018).

The scope of this literature review defines adolescents as individuals from 13 to 26 years old. In 2017, adolescents aged 13–24 accounted for 21% of the new HIV infections in the United States (Hosek & Henry-Reid, 2020). Compared to the national average (14.1 per 100,000) and White counterparts (10.8 per 100,000) in this age group, Black (95.4 per 100,000) and Latino (31.3 per 100,000) populations saw greater rates of HIV infection. PrEP is an effective tool for those 18 years and older, and physicians can prescribe PrEP to those under the age of 18 to reduce the number of new HIV infections in adolescent populations (Harriet Lane Clinic, n.d.). However, much of the research for sexual and reproductive health has left out 13– to 26-year-olds in PrEP access and implementation programs.

Between 2013 and 2017, PrEP awareness increased in US Men who have sex with Men (MSM) population (Sullivan et al., 2020). For those aged 18–24, the percentage of those who knew or had heard of PrEP as a method of HIV prevention increased by 42.2%. The general willingness to use PrEP in adolescents increased after 2013 but stabilized at around 60%. More recently, Wood et al. found limited awareness of PrEP in adolescents (Wood, Lee, Barg, Castillo, & Dowshen, 2017). Current research has focused primarily on MSM populations, with few studies in the United States looking into PrEP awareness among trans-identifying youth and adolescent females. Studies thus far conducted in trans-identifying youth and adolescent females have a relatively small sample size compared to MSM or Black American populations (Horvath, Todd, Arayasirikul, Cotta, & Stephenson, 2019; Yusuf, Fields, Arrington-Sanders, Griffith, & Agwu, 2020). Black and Latinx adolescents in high HIV prevalence areas show a need for distinct prevention strategies to increase awareness of and willingness to use PrEP (Taggart, Liang, Pina, & Albritton, 2020).

The Society of Adolescent Health and Medicine pointed to limited provider knowledge and capacity to assess HIV susceptibility in adolescents as a barrier to adolescents receiving comprehensive help (Society for Adolescent Health and Medicine, 2018), such as the prescription of PrEP. Most adolescent health providers (93.2%) in a 2018 survey said that they had heard of PrEP. Even so, providers' willingness to prescribe PrEP for adolescents remained well below their awareness at 64.8% and 77.8%, respectively. The willingness to prescribe PrEP is seen in US pharmacy data. From 2012 to 2017, only 2,590 (~1.5%) prescriptions for PrEP were among youth, 18 years of age and younger. For those 18–24 years old, the percentage climbed slightly to a range of 9.5–15.4% of all total prescriptions of PrEP (Paer, Mattappallil, Bentsianov, & Finkel, 2020).

When PrEP was approved by the FDA in 2012, legal and policy researchers aimed to understand barriers to accessing PrEP under current state laws. An analysis from all 50 states found that no laws specifically prohibited minors' access to PrEP (Culp & Caucci, 2013). However, minors' ability to consent to PrEP in most states without parental consent remains unclear. As of 2021, the CDC has listed only three states (Connecticut, Iowa, and Maryland) that have specific provisions for a minor's ability to consent for HIV PrEP (CDC, 2021). Hence, there are few inherent legal barriers to accessing PrEP.

Certain states allow minors to have the right consent to STI/HIV testing (Minors' Authority to Consent to STI Services, 2017). Additionally, minors can consent to the treatment of STIs/HIV. However, upon test result outcomes and creation of a care plan in some states, a provider can disclose medical information to a parent or guardian without the consent of the minor (English & Ford, 2004). Depending on the place of prescription, a minor's ability to consent varies from state to state. For instance, if a provider prescribes PrEP at a Title XI clinic in Michigan, a minor does not need parental consent. On the other hand, a minor will require parental consent if the provider prescribes PrEP in a non-Title XI clinic (MDHHS, n.d.). Based on the location of a minor, a Title XI clinic may not be a feasible option for the prescription of PrEP without parental consent based on state jurisdiction. This complex categorization of consent and disclosure becomes even more challenging when one considers how explanation of benefits (EOBs) may hinder PrEP uptake for adolescents. EOBs are a statement sent by an insurance company to the covered individuals explaining what treatments and/or services were paid by insurance (HealthInsurance.Org, 2022).

The purpose of this article is to conduct a systematic review of the literature to inform policy on PrEP disclosure for adolescents in the United States. I separated the materials for this literature review into two searches. The goal of the first search was to find articles within the current literature that discuss insurance coverage as it relates to PrEP, and the second search aimed to find what resources exist for providers of PrEP on PrEP and insurance coverage.

#### Methods

There were two main searches for this literature review. This first search utilized the University of Michigan Library Search, which is built in three main layers, from user interface to indexes to data sources. The keywords of the aggregate initial search of articles included "Adolescents", "Youth", "Access", "Insurance", "HIV", and "PrEP". The source format from the aggregate search was narrowed to include only articles. We selected "Pre-Exposure Prophylaxis" as a subject to filter out articles that did not address PrEP. Applicable articles contained in the literature review included EOBs under insurance coverage.

The second search looked for materials that were used in a clinical or community-based organization setting surrounding PrEP and insurance coverage. We utilized the Google Search engine. The keywords of the aggregate initial search included "PrEP Toolkit," "PrEP", "HIV", "Adolescents", "Youth", "Insurance", "United States", and "PDF". The selection process from this first search decided whether the material included PrEP Clinics or PrEP Navigators. A final review filtered out any material that did not discuss EOBs under insurance coverage.

I filtered the articles based on content relevancy to the literature review through a qualitative ranking process. The process included a numerical ranking on a scale of 1–3 and a short explanation

to justify the article's relevance to the research question. Figure 1 details the filtering of articles and materials in the literature review process.

From research on PrEP access, I identified the categories of barriers facing adolescents. Then, I contextualized the barriers in current PrEP usage/uptake in adolescent populations in the United States. Conversely, information from the PrEP toolkits outlined possible solutions to problems surrounding parental/guardian disclosure in EOBs. I devised possible solutions, elaborating on their implementation on an organizational and policy level.

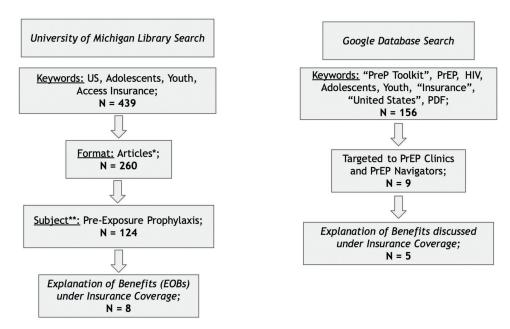


Figure 1. Literature review of PrEP-related documents flow breakdown.

### Results

The final set of articles from both searches (n = 13) included two main categories of papers. In the first, a total of eight papers from the research literature discussed PrEP access, specifically insurance coverage for minors and adolescents (Kay & Pinto, 2020; Saleska et al., 2021; Mullins & Lehmann, 2018; Fisher, Fried, Puri, Macapagal, & Mustanski, 2018; Macapagal, Nery-Hurwit, Matson, Crosby, & Greene, 2021; Sinead et al., 2016; Moskowitz et al., 2020; Macapagal, Kraus, Korpak, Jozsa, & Moskowitz, 2020). In the second search, five clinic or PrEP navigator materials discussed EOBs in PrEP toolkits (MDHHS, n.d.; AIDS Education & Training Center Pacific, 2017; PleasePrEPme.org, 2020; Department of Health District of Columbia, n.d.; Para, 2020; AIDS Free Pittsburgh PrEP Subcommittee, 2017; HIV/AIDS Section – Medical Team, 2016; New York State Department of Health AIDS Institute, 2020; U.S. Department of Labor, Employee Benefits Security Administration (EBSA), n.d.).

<sup>\* =</sup> Articles include scholarly journal articles, newspaper articles, book chapters, conference proceedings, and more

<sup>\*\* =</sup> Subject defines topic of interest

# Discussion

# Insurance Navigation as a Barrier to Access PrEP

In 2020, Kay and Pinto discussed anticipated barriers to PrEP implementation from 2007 to 2017, such as parental consent or approval for PrEP prescription (Kay & Pinto, 2020). However, depending on the type of insurance an individual has, the magnitude of these barriers is different. For instance, those who are covered with state/federal government insurance, such as Medicaid, may not face difficulties of cost but face problems of eligibility and state-specific requirements (Guth, Garfield, & Rudowit, 2020). Because adolescents who qualify for Medicaid or Children's Health Insurance Program (CHIP) are the sole recipients of insurance services, EOBs are not directed to parents/guardians, lessening concern around disclosure. Hence, the scope of this review solely focuses on private insurance.

Several papers on HIV prevention cite concerns of insurance for adolescents pursuing PrEP. A cross-sectional analysis from New Orleans and Los Angeles on the use of PrEP among adolescent cisgender men found insurance might affect the access to PrEP in terms of the client provider relationship (Saleska et al., 2021). Also, the researchers noted that insurance coverage more broadly is a barrier to PrEP access. In a more diverse population of adolescents and young adults, including broader gender, racial, and ethnic categories, studies found that insurance and disclosure remained a difficulty for PrEP access, even when health coverage was present (Mullins & Lehmann, 2018; Fisher et al., 2018). For sexual and gender minority adolescents assigned male at birth, there were concerns of parental involvement in the PrEP process as it relates to insurance (Macapagal, Nery-Hurwit, Matson, Crosby, & Greene, 2021). The ethical concern of EOBs disclosing the use of PrEP to a parent or guardian has been paired with equal concerns that high co-pays and insurance navigation can impact adolescent access to PrEP (Sinead et al., 2016). On top of this, perceptions from adolescents suggest an inability to navigate insurance and healthcare coverage systems without support (Moskowitz et al., 2020). For those under the age of 18, more stringent resource allocation in terms of health insurance and finances cites a problem of coverage for minor adolescents (Macapagal et al., 2020). Generally, insurance coverage is limited for sexual minority adolescents, making PrEP inaccessible on multiple fronts (Culp & Caucci, 2013; Huebner & Mustanski, 2020). PrEP may be an effective tool at preventing HIV, but insurance has shown in multiple ways how access remains limited.

### PrEP Navigation Resource Evaluation

The scope of research on accessibility to PrEP in adolescent populations has primarily focused on identifying what barriers exist. However, there is limited research on practical solutions for community-based organizations (CBOs) and NGOs on the matter of EOBs for adolescent clients as discussed earlier. In other words, the research has clearly demonstrated that disclosure of the use of PrEP by an adolescent through an EOB to their parent or guardian is a defined barrier to access. However, there are no present concrete solutions offered to mitigate these negative outcomes.

There are possible solutions to this logistical problem with PrEP and insurance in legal discourse. The Guttmacher Institute released "Protecting Confidentiality for Individuals Insured as Dependents" in early September 2021 (Public Policy Office, 2021). The outline provides what innovative solutions states in the United States have implemented to address border confidentiality

concerns. In 2021, "14 states have provisions that serve to protect the confidentiality of individuals as dependents." Some states like Massachusetts, New York, Washington, and Wisconsin have protections specific to EOBs, which allow insurers to mail an EOB directly to the patient instead of the policyholder. Some states include broader confidentiality provisions under the protections for minor dependents, outlining that an "insurer may not disclose private health information, including through an EOB, without minor's authorization."

The complex matter of insurance disclosure is discussed in PrEP toolkits meant for clinics, including providers of PrEP and PrEP navigators. A PrEP navigator "provides intensive care coordination, support and services to HIV negative individuals who require assistance in accessing and remaining in PrEP care" (POZ, 2020). The National HIV and PrEP Navigation Landscape Assessment outlined problems with EOBs at a specific clinic, where there were concerns of sexuality of disclosure (NMAC Capacity Building Division, 2017).

In the state of Michigan, the Michigan Department of Health and Human Services (MDHHS) PrEP Provider Toolkit establishes different scenarios through *Getting PrEPped* on how to approach insurance coverage (MDHHS, n.d.). For instance, if a patient is insured and can cover the costs for PrEP, there may be assistance programs to cover co-pays and deductibles. Other PrEP toolkits have done similar case studies on navigating insurance (AIDS Education & Training Center Pacific, 2017; PleasePrEPme.org, 2020). A PrEP toolkit from DC highlights limitations to accessing PrEP for adolescents, including insurance coverage and EOB (Department of Health District of Columbia, n.d.). However, there are no counterpoints to overcoming this hurdle. In the mix of PrEP toolkits, a majority focus on PrEP and insurance but leave out how to address or handle EOB with adolescent clients (Para, 2020; AIDS Free Pittsburgh PrEP Subcommittee, 2017; HIV/AIDS Section - Medical Team, 2016; New York State Department of Health AIDS Institute, 2020).

## Policy Practice to Address Disclosure

Solutions at the interpersonal and organizational level with PrEP navigators and CBOs/NGOs, respectively, have demonstrated innovative approaches to addressing the challenges that come with EOBs surrounding PrEP. Policy-level initiatives need to affect a broader demographic of adolescents. A policy change will create standards of public health measures that insurance companies must comply with or face violations at the state level (U.S. Department of Labor, Employee Benefits Security Administration (EBSA), n.d.).

A model of legislative success comes from the State of California. Outlined in the civil code division of persons, confidentiality of medical information applies to disclosure of medical information by providers (Civil Code -Civ Division 1. Persons [38–86] Part 2.6 Confidentiality of Medical Information [56–56.37], 2014). This legislative action encompasses not only insurance companies but also medical providers, such as physicians, which would otherwise have the ability in some states to disclose the use of PrEP by a minor to their parent or guardian. The policy change allows recipients insured by a primary policyholder, such as a parent, guardian, or spouse, to request that sensitive medical information not be disclosed to the primary policyholder.

As outlined by policy scholars, the state of California now clarifies the term "endanger" that federal HIPAA privacy regulations leave undefined as "fears that disclosure of his or her medical information could subject the [individual] to harassment or abuse" (Khan, 2015). The civil code outlines that covered individuals do not need evidence of endangerment or explanations as to why they feel disclosure warrants endangerment, such as physical demarcations or emotional accounts of trauma.

The American Civil Liberties Union (ACLU) of California developed the website MyHealthMy-Info.org to clarify the process of submitting a confidential communications request (ACLU of Northern California & ACLU of Southern California, 2021). The website provides the necessary form to fill out along with different language options. The drop-down menu enables users to find their healthcare provider or insurance company, which opens a new page for the request filing process for that insurance company.

At the national level, the Protect Our Ability to Counter Hacking (PATCH) act attempted to create a Vulnerability Equities Review Board that would outline policy to address personal information in technology, including health (Lieu, 2017). The PATCH act was brought before the house but was never passed.

In a recent Biden administration policy change, guidance on the Affordable Care Act Implementation Part 47 outlined new PrEP coverage guidelines for insurance companies (Departments of Labor, Health and Human Services (HHS), and the Treasury, 2021). This implementation has been interpreted that an insurer must not charge co-pays, coinsurance, or deductible payments for the quarterly clinic visits and lab tests required to maintain a PrEP prescription (Ryan, 2021). However, as compliance lags from insurance companies to remove costs of PrEP, they at the very least cannot deny PrEP prescription and subsequent maintenance services to policyholders (Saloway & Benk, 2021). In essence, this would alleviate the burden of costs related to PrEP, but it is unclear whether such implementation would impact EOBs and disclosure.

## Conclusion

The importance of providing PrEP for adolescents who are susceptible to HIV is critical to achieving broader goals of ending the HIV epidemic. However, many barriers exist for adolescents who would like to start PrEP, including cost associated with PrEP, geographic location, and provider competency. As this literature review suggests, EOBs that could disclose sensitive information to policyholders, such as parents or guardians, are an additional barrier to accessing PrEP. A small fraction of states have laws that protect minors in this situation, but few are comprehensive enough to avoid endangering the adolescent/minor. This literature review recommends that states attempt to review and implement changes to civil or public health codes that would further define HIPAA's terminology of "endanger" and hold insurers accountable to EOB disclosures. Furthermore, states can facilitate this process holistically with NGOs and CBOs to essentially eliminate the barrier of adolescents seeking PrEP who are covered under another policyholder's private insurance. There are, without a doubt, immensely valuable outcomes that could lie on the horizon with policy changes on EOBs that would empower individuals to access PrEP without fear of losing their agency.

# References

ACLU of Northern California & ACLU of Southern California. (2021). Keep it confidential. MyHealthMyInfo. Retrieved from https://myhealthmyinfo.org

AIDS Education & Training Center Pacific. (2017, February). PrEP toolkit contents. AETC Pacific Bay Area | North Coast. Retrieved from https://paetc.org/about/local-partners/bay-area-north-central-coast/

- AIDS Free Pittsburgh PrEP Subcommittee. (2017, September). PrEP toolkit for providers. *AIDS Free Pittsburgh*. Retrieved from http://www.aidsfreepittsburgh.org/perch/resources/preptoolkitupdated-10-5-17.pdf
- AIDSVu. (2018, March 18). Mapping PrEP: First ever data on PrEP users across the U.S. Awareness Days. Retrieved from https://aidsvu.org/prep/
- Buhl, L. (2021, July 6). New PrEP guidelines aim to expand access, but uptake will depend on clinicians. The Body Pro. Retrieved from https://www.thebodypro.com/article/new-prep-guidelines-expand-access-uptake-depend-on-clinicians
- CDC. (2021, January 8). State laws that enable a minor to provide informed consent to receive HIV and STD services. *Policy, Planning, and Strategic Communication*. Retrieved from https://www.cdc.gov/hiv/policies/law/states/minors.html
- CDC. (2021, June 11). Pre-exposure prophylaxis (PrEP). *Preventing New HIV Infections*. Retrieved from https://www.cdc.gov/hiv/clinicians/prevention/prep.html
- Civil Code -Civ Division 1. Persons [38–86] Part 2.6 confidentiality of medical information [56–56.37]. (2014, January 1). *California legislative information*. Retrieved from https://leginfo.legislature.ca.gov/faces/codes\_displaySection.xhtml?lawCode=CIV\sionNum=56.107
- Culp, L., & Caucci, L. (2013, January). State adolescent consent laws and implications for HIV pre-exposure prophylaxis. *American Journal of Preventive Medicine*, 44(1), 119–124. Elsevier Inc. doi:10.1016/j.amepre.2012.09.044. Retrieved from https://www.cdc.gov/phlp/docs/prephiv-wb.pdf
- Department of Health District of Columbia. (n.d.). *PrEP is DC's key HIV prevention practice*. PrEP. Retrieved from https://doh.dc.gov/sites/default/files/dc/sites/doh/service\_content/attachments/DC%20Providers%20PrEP%20Handbook.pdf
- Departments of Labor, Health and Human Services (HHS), and the Treasury. (2021, July 19). FAQs about affordable care act implementation part 47. Department of Labor. Retrieved from https://www.dol.gov/sites/dolgov/files/EBSA/about-ebsa/our-activities/resource-center/faqs/aca-part-47.pdf
- English, A., & Ford, C. A. (2004, March). *The HIPAA privacy rule and adolescents: Legal questions and clinical challenges*. Guttmacher Institute. Retrieved from https://www.guttmacher.org/sites/default/files/pdfs/pubs/psrh/full/3608004.pdf
- Fisher, C. B., Fried, A. L., Puri, L. I., Macapagal, K., & Mustanski, B. (2018). "Free testing and PrEP without outing myself to parents": Motivation to participate in oral and injectable PrEP clinical trials among adolescent men who have sex with men. *PLoS ONE*, *13*(7). doi:10.1371/journal. pone.0200560
- Guth, M., Garfield, R., & Rudowitz, R. (2020, March). *The effects of medicaid expansion under the ACA: Updated findings from a literature review*. Henry J Kaiser Family Foundation. Retrieved from https://files.kff.org/attachment/Report-The-Effects-of-Medicaid-Expansion-under-the-ACA-Updated-Findings-from-a-Literature-Review.pdf
- Harriet Lane Clinic. (n.d.). FAQ. PrEP Is for Youth. Retrieved from https://prepisforyouth.org/faq
- HealthInsurance.Org. (2022). What is an explanation of benefits? *Glossary*. Retrieved from https://www.healthinsurance.org/glossary/explanation-of-benefits/
- HIV/AIDS Infection Medical Team. (2016, September 27). PrEP plan of action toolkit. *Florida Health*. Retrieved from http://www.floridahealth.gov/diseases-and-conditions/aids/prevention/\_documents/PrEP-toolkit.pdf]

- Horvath, K. J., Todd, K., Arayasirikul, S., Cotta, N. W., & Stephenson, R. (2019). Underutilization of preexposure prophylaxis services among transgender and nonbinary youth: Findings from project moxie and techstep. *Transgender Health*, 4(1), 217–221. doi:10.1089/trgh.2019.0027
- Hosek, S., & Henry-Reid, L. (2020, January). PrEP and adolescents: The role of providers in ending the AIDS epidemic. *Journal of Pediatrics*, 145(1), 1–6. doi:10.1542/peds.2019-1743
- Huang, Y. A., Zhu, W., Smith, D. K., Harris, N., & Hoover, K. W. (2018). HIV preexposure prophylaxis, by race and ethnicity—United States, 2014–2016. *Morbidity and Mortality Weekly Report*, 67, 1147–1150. doi:10.15585/mmwr.mm6741a3external icon
- Huebner, D. M., & Mustanski, B. (2020). Navigating the long road forward for maximizing PrEP impact among adolescent men who have sex with men. *Archives of Sexual Behavior*, 49(1), 211–216. doi:10.1007/s10508-019-1454-1
- Kay, E. S., & Pinto, R. M. (2020). Is insurance a barrier to HIV preexposure prophylaxis? Clarifying the issue. *American Journal of Public Health*, 110(1), 61–64. doi:10.2105/AJPH.2019.305389
- Khan, L. (2015, January 9). New California health privacy law goes into effect. *Covington*. Retrieved from https://www.insideprivacy.com/health-privacy/new-california-health-privacy-law-goes-into-effect/
- Lieu, R. (2017, May 17). H.R.2481 PATCH Act of 2017. *Congress. Gov.* Retrieved from https://www.congress.gov/bill/115th-congress/house-bill/2481
- Macapagal, K., Kraus, A., Korpak, A. K., Jozsa, K., & Moskowitz, D. A. (2020). PrEP awareness, uptake, barriers, and correlates among adolescents assigned male at birth who have sex with males in the U.S. *Archives of Sexual Behavior*, 49(1), 113–124. doi:10.1007/s10508-019-1429-2
- Macapagal, K., Nery-Hurwit, M., Matson, M., Crosby, S., & Greene, G. J. (2021). Perspectives on and preferences for on-demand and long-acting PrEP among sexual and gender minority adolescents assigned male at birth. *Sexuality Research and Social Policy*, 18(1), 39–53. doi:10.1007/s13178-020-00441-1
- MDHHS. (n.d.). *PrEP provider toolkit*. MDHHS. Retrieved from https://www.michigan.gov/documents/mdhhs/PrEP\_Provider\_Toolkit\_MDHHS\_547647\_7.pdf
- Minors' Authority to Consent to STI Services. (2017, March 1). KFF. Retrieved from https://www. kff.org/hivaids/state-indicator/minors-right-to-consent/?activeTab=map¤tTimeframe=0&selectedDistributions=do-states-allow-minors-to-consent-to-sti-services&sortModel=%7B%22colId%22:%
- Moskowitz, D. A., Macapagal, K., Mongrella, M., Pérez-Cardona, L., Newcomb, M. E., & Mustanski, B. (2020). What if my dad finds out!?: Assessing adolescent men who have sex with men's perceptions about parents as barriers to PrEP uptake. *AIDS and Behavior*, 24(9), 2703–2719. doi:10.1007/s10461-020-02827-z
- Mullins, T. L. K., & Lehmann, C. E. (2018). Oral pre-exposure prophylaxis (PrEP) for HIV prevention in adolescents and young adults. *Current Pediatrics Reports*, 6(2), 114–122. doi:10.1007/s40124-018-0163-x
- American Academy of Pediatrics. (2012). FDA update, news articles HIV-1 PrEP drug can be part of strategy to prevent infection in at-risk adolescents FDA update, news articles. Retrieved from https://www.fda.gov/files/science%20&%20research/published/HIV-PrEP-drug-can-be-part-of-strategy-to-prevent-infection-in-at-risk-adolescents.pdf

- New York State Department of Health AIDS Institute. (2020, January). *Pre-exposure prophylaxis (PrEP) toolkit for community based organizations (CBOs)*. AIDS Institute. Retrieved from https://www.health.ny.gov/diseases/aids/general/prep/docs/prep\_toolkit.pdf
- NMAC Capacity Building Division. (2017, August). *National HIV and PrEP navigation landscape assessment*. NMAC. Retrieved from http://www.nmac.org/wp-content/uploads/2017/11/National-HIV-and-PrEP-Navigation-Landscape-Assessment-Report.pdf
- Paer, J. M., Mattappallil, A., Bentsianov, S., & Finkel, D. (2020). 984, HIV pre-exposure prophylaxis (PrEP) prescription rates among adolescents and young adults (AYAs) at an urban academic medical center in Newark, NJ from 2017–2019: A quality assessment of HIV prevention for high risk youth within the epicenter of the NJ HIV epidemic. *Open Forum Infectious Diseases*, 7(Suppl 1), S520–S521. doi:10.1093/ofid/ofaa439.1170
- Para, M. (2020, August 27). *PrEP implementation in your clinic*. Chicago: Midwest AIDS Training + Education Center.
- PleasePrEPme.org. (2020, January). Helping people access pre-exposure prophylaxis: A frontline provider manual on PrEP research, care and navigation. *PrEP Navigator Manual*. Retrieved from https://www.pleaseprepme.org/sites/default/files/file-attachments/PleasePrEPMe%20PrEP%20Navigation%20 Manual%20EN\_JUNE2020.pdf
- POZ. (2020, September 16). PrEP Navigator. *Listings*. Retrieved from https://www.poz.com/job/prep-navigator-venice-family-clinic
- Public Policy Office. (2021, October 1). Protecting confidentiality for individuals insured as dependents. Guttmacher Institute. Retrieved from https://www.guttmacher.org/state-policy/explore/protecting-confidentiality-individuals-insured-dependents
- Rosenberg, J. (2018, March 16). Despite increasing rates of PrEP usage, disparities remain among African Americans, Latinos. *News*. Retrieved from www.ajmc.com/view/despite-increasing-rates-of-prep-usage-disparities-remain-among-african-americans-latinos
- Ryan, B. (2021, July 21). PrEP, the HIV prevention pill, must now be totally free under almost all insurance plans. *NBC News*. Retrieved from https://www.nbcnews.com/nbc-out/out-health-and-wellness/prep-hiv-prevention-pill-must-now-totally-free-almost-insurance-plans-rcna1470
- Saleska, J. L., Lee, S. J., Leibowitz, A., Ocasio, M., Swendeman, D., Rotheram-Borus, M. J., . . . Razvan, P. (2021). A tale of two cities: Exploring the role of race/ethnicity and geographic setting on PrEP use among adolescent cisgender MSM. AIDS and Behavior, 25(1), 139–147. doi:10.1007/s10461-020-02951-w
- Saloway, S., & Benk, R. (2021, July 29). The federal government is making HIV prevention treatment free but there's a catch. *NPR*. Retrieved from https://www.npr.org/2021/07/29/1022255279/feds-are-making-hiv-prevention-treatment-free
- Sinead, D. M., Hosek, S., Celum, C., Wilson, C. M., Kapogiannis, B., & Bekker, L. G. (2016, October 18). Preventing HIV among adolescents with oral PrEP: Observations and challenges in the United States and South Africa. *Journal of the International AIDS Society*. doi:10.7448/IAS.19.7.21107
- Society for Adolescent Health and Medicine. (2018). HIV pre-exposure prophylaxis medication for adolescents and young adults: A position paper of the society for adolescent health and medicine. *The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine*, 63(4), 513–516. doi:10.1016/j.jadohealth.2018.07.021

- Sullivan, P. S., Sanchez, T. H., Zlotorzynska, M., Chandler, C. J., Sineath, R. C., Kahle, E., & Tregear, S. (2020). National trends in HIV pre-exposure prophylaxis awareness, willingness and use among United States men who have sex with men recruited online, 2013 through 2017. *Journal of the International AIDS Society*, 23(3), e25461. doi:10.1002/jia2.25461
- Taggart, T., Liang, Y., Pina, P., & Albritton, T. (2020). Awareness of and willingness to use PrEP among Black and Latinx adolescents residing in higher prevalence areas in the United States. *PLoS ONE*, 15(7), e0234821. doi:10.1371/journal.pone.0234821
- U.S. Department of Labor, Employee Benefits Security Administration (EBSA). (n.d.). Health benefits coverage under federal law. *Compliance Assistance Guide*. Retrieved from https://www.dol.gov/sites/dolgov/files/ebsa/about-ebsa/our-activities/resource-center/publications/compliance-assistance-guide.pdf
- U.S. Food & Drug Administration. (2019, October 3). FDA approves second drug to prevent HIV infection as part of ongoing efforts to end the HIV epidemic. *Press Announcements*. Retrieved from https://www.fda.gov/news-events/press-announcements/fda-approves-second-drug-prevent-hiv-infection-part-ongoing-efforts-end-hiv-epidemic
- Wood, S., Lee, S., Barg, F. K., Castillo, M., & Dowshen, N. (2017, May 1). Young transgender women's attitudes toward HIV pre-exposure prophylaxis. *Journal of Adolescent Health*, 60(5), 549–555. doi:10.1016/j.jadohealth.2016.12.004
- Yusuf, H., Fields, E., Arrington-Sanders, R., Griffith, D., & Agwu, A. L. (2020, May 11). HIV preexposure prophylaxis among adolescents in the US: A review. *JAMA Pediatrics*, 174(11), 1102–1108. doi:10.1001/jamapediatrics.2020.0824

# "Model Minority" Mental Health: An Examination of the Barriers to Effective Care Among Young AAPIs

Cala Mae Renehan\*

Young Asian American Pacific Islanders (AAPI) are uniquely vulnerable to a growing burden of mental health challenges. This literature review explores the AAPI cultural factors and beliefs that shape mental health and mental healthcare-seeking behaviors. It discusses the AAPI family hierarchy as a barrier to young AAPIs feeling validated in their mental health experiences as well as how the value of "saving face" can prevent seeking care in order to protect the familial reputation. Through the exploration of the unacceptability of psychological expressions of distress in many AAPI cultures, it examines how the existing Western mental healthcare system is incompatible with other expressions of mental distress such as physical symptoms. This literature review then reviews how discrimination in the form of the model minority stereotype not only causes poor mental health outcomes but also prevents young AAPIs from viewing treatment as a viable or acceptable source of care. Acculturation as a risk factor is discussed by linking acculturative stressors to poor mental health outcomes. To address these issues, this literature review discusses culturally competent mental health care and increased AAPI representation in the mental healthcare workforce as potential solutions or interventions to be implemented to better meet the needs of the target population. While there is currently limited empirical evidence on the efficacy of cultural competency, they have become more commonly identified as an intervention strategy by both practitioners and patients themselves. Finally, increased representation of AAPI people in the mental healthcare workforce may encourage young AAPIs to seek care and view treatment as legitimate sources of support.

# Keywords

mental health • Asian American Pacific Islanders (AAPI) • youth/adolescent/young adult • discrimination • acculturation • cultural values • cultural competency

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# Introduction

Asian American Pacific Islanders are the fastest-growing racial group in the United States: between the years 2000 and 2019, the population grew by 81% (Budiman & Ruiz, 2021). Moreover, 58% of U.S.-born Asians are 22 years of age or younger (Budiman & Ruiz, 2021). Yet the mental health of young<sup>1</sup> Asian American Pacific Islanders (AAPI)<sup>2</sup> is often overlooked.

According to the Anxiety and Depression Association of America, "Asian-Americans are three times less likely to seek mental health services than other Americans" (2020). AAPI cultural values and beliefs shape how mental health is perceived, if and how care is pursued, and can influence mental health outcomes overall. These values and beliefs often translate into risk factors for adverse mental health outcomes that are unique to the AAPI experience, which can decrease the efficacy of the current mental healthcare system. This article will investigate how the cultural values and unique risk factors for adverse mental health outcomes for young AAPI people act as barriers to seeking care and/or preventing care altogether. By highlighting how their experiences are inherently mismatched with the existing mental healthcare framework, it will offer suggestions on how culturally competent care is a solution to this misalignment and the failure to consider culture in the mental health setting.

# Cultural Values and Stigma Beliefs

It is important to examine AAPI cultural beliefs and values because "culture shapes the expression and recognition of psychiatric problems" (Kramer, Kwong, Lee, & Chung, 2002). Cultural beliefs and values not only construct how young AAPI people experience mental health outcomes but may also determine whether they vocalize their experiences or seek help. In many Asian cultures, there is great value placed on the family as a hierarchy and collective unit. Multiple generations may live in one household where one has an assigned role based on their age, gender, and social class in which the person "is expected to function within that role, submitting to the larger needs of the family" (Kramer et al., 2002). Younger individuals often occupy a lower position within the hierarchy. This may cause an invalidation of feelings by higher-ranking family members because "they are aware of the traditional beliefs about mental illness perceived by their parents and other family members" (Fogel & Ford, 2005). Furthermore, when beliefs about mental health conflict within the hierarchy and thus disturb coexistence, there may be a disruption of young AAPI's ability to submit to those collective familial needs.

While it is stigmatized across many cultures, the "stigma of mental disorders is much more severe among Asians and ethnic minorities than among white Europeans or Americans" (Hsu

<sup>1.</sup> In this article, the category of "young AAPIs" will broadly include youth, adolescents, and young adults. While many of the risk factors or cultural values discussed are applicable to all AAPIs no matter their age, this article aims to call attention to their impact on the younger population as it is such a vulnerable and formative time of life. There is a lack of existing literature that focuses specifically on younger AAPI mental health—most articles speak about AAPI mental health generally and in no context to age range.

<sup>2.</sup> The category "Asian American Pacific Islander" encompasses dozens of countries and further, hundreds of ethnic or cultural groups within those countries. This article is not designed to generalize the beliefs or values of *all* Asian American Pacific Islander people. This article draws upon existing literature and is meant to highlight that the AAPI community as a whole is underserved with its mental healthcare needs.

et al., 2014). Additionally, in many AAPI cultures, it is believed stigma extends beyond the individual to impact the entire family (Kramer et al., 2002). The cultural value of "saving face" describes "the ability to preserve the public appearance of the patient and family for the sake of community propriety" (Kramer et al., 2002). This communicates to young AAPIs that they cannot discuss their experiences not only in fear that they will be stigmatized but that their entire family will suffer because of those experiences as well. The value of saving face and the low position young AAPIs occupy in the family hierarchy can result in worse mental health outcomes as they may feel the need to suppress their emotions to protect the family reputation. The desire to "save face" may also steer them away from seeking treatment altogether. It is important to note that seeking treatment involves seeking support for treatment in the first place. Ultimately, intergenerational stigma makes it inappropriate for young AAPIs to confide in or seek support from one's parents during mental distress. TedxYouth speaker Alan Phan illustrates why the inability to confide in a parent as an AAPI youth is so damaging. Phan recalls the rejection he faced from his mother when trying to confide in her about his emotions and suicidal ideations. Phan explains the commonality he identified among his AAPI peers: their parents thought mental illness was taboo or "for the weak and losers of life," they "lacked a trusted adult to discuss things like mental health," and that because of this, they "bottle up emotions until they burst" (TedX Phan, 2020). Phan's experience highlights how the absence of a parent's support (or familial support, generally) can exacerbate mental distress and invalidating one's experience as legitimate or worthy of attention. The role of intergenerational stigma is a powerful influence on the treatment decisions young AAPIs may make.

Within many AAPI cultures, there is an "unacceptability . . . attached to psychological expression of distress" (Grover & Ghosh, 2014). This unacceptability results in the belief that "psychological issues should not be discussed outside the family and that physicians need to be consulted only for physical symptoms" (Grover & Ghosh, 2014). This produces a somatic expression of mental illness itself in order for one's distress to be considered acceptable. The belief that mental health is not as "legitimate" as physical health actually alters how mental distress is experienced. The somatic manifestation can make identifying mental distress more difficult as traditional diagnostic tools and mainstream understandings of mental illness do not consider somatic experiences, resulting in existing services being unsuitable for this population. Mental health services in the United States like psychotherapy operate under "assumptions that some take for granted, like 'talking about it will make you feel better" (McLean Hospital, 2020). There is an inherent mismatch between existing treatments and how mental illness manifests in young AAPIs; "talking about it" does not address or alleviate somatic symptoms like headache or joint pain because it fails to recognize that the experience of mental distress in this population is fundamentally different. The difference in how mental distress is experienced by this population is not commonly understood or acknowledged in existing treatment settings.

# Discrimination + Acculturation: Risk Factors for Poor Mental Health Outcomes

AAPI youth experience an array of unique risk factors for adverse mental health outcomes. Racial discrimination is a known risk factor for poor mental health outcomes among racial minorities (Williams, 2018). Among AAPI youth particularly, racial discrimination is correlated with poor self-esteem, depressive symptoms, the internalization of AAPI stereotypes, and more (Lee et al., 2009). For example, the "model minority" stereotype that AAPIs are "the ones who excel in

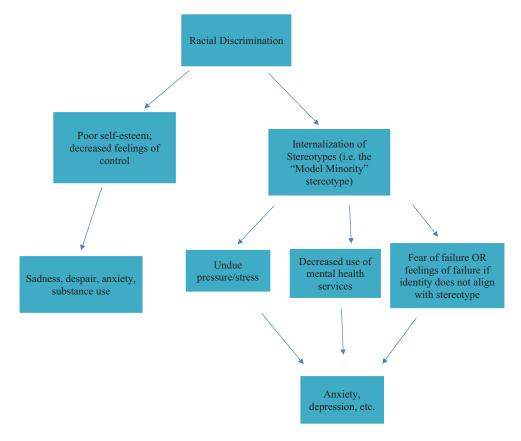


Figure 1. Racial discrimination and mental health outcomes among AAPI youth.

education, are diligent and responsible, and are silent rather than vocal" may be damaging to mental health due to the pressure of upholding or fitting the stereotype (Lo, 2010). Anything that does *not* align with the model minority stereotype may be internalized as a failure. Internalization can lead to an overwhelming fear of failure and undue pressure to succeed, which can cause stress, anxiety, etc. As shown in figure 1, this internalization may alter treatment-seeking behaviors or prevent care from occurring at all as it insinuates an unacceptability in receiving care, exacerbating symptoms further (See Figure 1). It can also be an obstacle to care as "the psychological and behavioral problems exhibited by Asian American youth are often overlooked because of the model minority stereotype and their cultural values" (Lo, 2010). Ultimately, discrimination is a powerful determinant of poor mental health, and whether an individual seeks or receives appropriate care.

The stress of acculturation also presents as a risk factor for adverse mental health outcomes in younger AAPIs. The experience of acculturation is marked by the "difficulty of balancing two different cultures" as one is "expected to respect the culture and values of their home country in the family and household environment while they grew up in the American culture at school with friends/colleagues" (Lee et al., 2009). Acculturative stressors include language barriers (e.g., having an accent or learning the nuances in non-native language or affectation), environmental factors (e.g., a lack of diversity or others of the same racial identity in the immediate community), and intercultural relations (e.g., opposing cultural customs) (Miller, Yang, Farrell, & Lin, 2011). While acculturative stress is a risk factor for poor mental health among AAPIs regardless of age, younger AAPIs may be more severely influenced by it because young adulthood, adolescence, and youth are

all considered to be an impressionable time in life due to development and identity exploration/ formation (Gwon & Jeong, 2018). Thus, having to continuously change (or choose) one's cultural identity based on the setting they are in may create confusion and stress for younger persons, leading to negative mental health outcomes. It should also be acknowledged that acculturative stress as a risk factor may be unnoticed in treatment settings because it differs from common stressors of the general population. The unique risk factors that young AAPIs experience often result in an unmet need and delay in care. Their lived experiences demand a new, original approach to mental healthcare and encourage them to seek care.

# Future Directions: Culturally Competent Care and AAPI Representation in the Mental Healthcare Workforce

As previously mentioned, Asian Americans are less likely to seek and receive mental health services compared to the general population (Anxiety and Depression Association of America, 2020). This reality coupled with the fact existing mental health services are already unsuitable with the values and unique risk factors among young AAPIs reveal possible ways to mitigate the unmet need for care and improve service provision.

First, practicing clinicians should be required to be trained in cultural competency so that they are attuned to the needs of young AAPIs. Culturally competent care describes when clinicians "understand each person's values, experiences and personal beliefs, and strive to provide services that support their goals and are aligned with their cultural values" (National Alliance on Mental IIIness, 2022). Examples of culturally competent mental healthcare in the context of the AAPI population may include practices like addressing notions of shame and "saving face," a clinician having knowledge about "cultural bound syndromes" (i.e., Hwa-byung, a Korean syndrome reflective of a DSM-V diagnosis of major depression), and providing linguistically appropriate care (National Alliance on Mental Illness, 2022). Other efforts may include the incorporation of family members to address group stigma beliefs. For example, even if destigmatization efforts prove effective for the individual, the efforts may be overpowered by the stigma beliefs of their family. There is limited evidence on the efficacy of cultural competency trainings in direct correlation with service provision improvements, health outcomes, and increasing rates of those to seek care, particularly within mental healthcare and by race/ethnicity. However, as cultural competency trainings have become more common in the *general* health workforce, some studies have shown improvements in measurements of practitioner knowledge and patient satisfaction in correlation to such trainings (Jongen, McCalman, & Bainbridge, 2018). Furthermore, some patients themselves have identified a need for trainings. Ryann Tanap, author of Why Asian Americans and Pacific Islanders Don't Go to Therapy published on NAMI's website, reflects on her own mental health experience in young adulthood: "I didn't know of any mental health professionals who understood my experience, culture and heritage," and that "part of me wondered if therapy was only meant for white people" (2019). After her discussion of how Western psychotherapy is incongruent with AAPI values and experiences, she explains how she thinks the mismatch may be solved: "I have identified what I need: a mental health professional trained in cultural competency" (Tanap, 2019). Cultural competency on a broad scale may include diversifying and increasing representation in the mental healthcare workforce by striving "to recruit and train Asian American mental health professionals" (Li & Seidman, 2010). In 2015, only 5% of psychologists in the United States identified as Asian (Lin, Stamm, & Chrisitidis, 2018). A larger, prominent representation of AAPIs in the workforce may help to break down stigma beliefs. The visibility of AAPIs in the workforce may encourage people to seek care by disproving the belief that care is unacceptable or misaligned with occupying an AAPI identity. Cultural competency practices and initiatives may realign the existing care infrastructure to better support the lived mental health experiences of AAPI young people.

In order to bridge the gap of unmet mental healthcare among AAPI young people and to prevent further mental health disparities from occurring or worsening, immediate action must be taken. Culturally competent practices and AAPI representation in the mental healthcare workforce can validate the lived experiences of these young people, empower them to seek care and support, and contribute to conversations within their community that eliminate the stigma surrounding the issue and legitimize mental health as a vital component of health and well-being. These two solutions may serve as the impetus for a positive transformation in perceptions, understandings, and lived mental health experiences among young AAPIs.

# References

- Anxiety and Depression Association of America. (2020). Asian Americans/Pacific Islanders. https://adaa.org/finding-help/asian-americans
- Budiman, A., & Ruiz, N. G. (2021) Key facts about Asian Americans, a diverse and growing population. *Pew Research Center*. https://www.pewresearch.org/fact-tank/2021/04/29/key-facts-about-asian-americans/
- Fogel, J., & Ford, D. E. (2005). Stigma beliefs of Asian Americans with depression in an internet sample. *Canadian Journal of Psychiatry. Revue canadienne de psychiatrie*, 50(8), 470–478. https://doi.org/10.1177/070674370505000807
- Grover, S., & Ghosh, A. (2014). Somatic symptom and related disorders in Asians and Asian Americans. Asian Journal of Psychiatry, 7(1), 77–79. https://doi.org/10.1016/j.ajp.2013.11.014
- Gwon, S. H., & Jeong, S. (2018). Concept analysis of impressionability among adolescents and young adults. *Nursing Open*, *5*(4), 601–610. https://doi.org/10.1002/nop2.170
- Hsu, G. L. K., Wan, Y. M., Chang, H., Summergrad, P., Tsang, B. Y., & Chen, H. (2008). Stigma of depression is more severe in Chinese Americans than Caucasian Americans. *Psychiatry*, 71(3), 210–218. https://doi.org/10.1521/psyc.2008.71.3.210
- Jongen, C., McCalman, J. & Bainbridge, R. (2018) Health workforce cultural competency interventions: A systematic scoping review. *BMC Health Services Research*, 18, 232. https://doi.org/10.1186/s12913-018-3001-5
- Kramer, E. J., Kwong, K., Lee, E., & Chung, H. (2002). Cultural factors influencing the mental health of Asian Americans. *The Western Journal of Medicine*, 176(4), 227. Retrieved from https://proxy.lib.umich.edu/login?url=https://www-proquest-com.proxy.lib.umich.edu/scholarly-journals/cultural-factors-influencing-mental-health-asian/docview/1782245059/se-2?accountid=14667
- Lee, S., Juon, H. S., Martinez, G., Hsu, C. E., Robinson, E. S., Bawa, J., & Ma, G. X. (2009). Model minority at risk: Expressed needs of mental health by Asian American young adults. *Journal of Community Health*, 34(2), 144–152. https://doi.org/10.1007/s10900-008-9137-1

- Li, H., & Seidman, L. (2010). Engaging Asian American youth and their families in quality mental health services. *Asian Journal of Psychiatry*, 3(4), 169–172. https://doi.org/10.1016/j.ajp.2010.08.008
- Lin, L., Stamm, K., Christidis, P. (2018). How diverse is the psychology workforce? *American Psychological Association*. https://www.apa.org/monitor/2018/02/datapoint
- Lo, Y. (2010). The impact of the acculturation process on Asian American youth's psychological well-being. *Journal of Child and Adolescent Psychiatric Nursing: Official Publication of the Association of Child and Adolescent Psychiatric Nurses, Inc*, 23(2), 84–91. https://doi.org/10.1111/j.1744-6171.2010.00227.x
- McLean Hospital. (2020). Why Asian Americans don't seek help for mental illness. https://www.mcleanhospital.org/essential/why-asian-americans-don't-seek-help-mental-illness
- Miller, M.J., Yang, M., Farrell, J.A., & Lin, L.L. (2011). Racial and cultural factors affecting the mental health of Asian American. *American Journal of Orthopsychiatry*, 81(4), 489–497. https://doi.org/10.1111/j.1939-0025.2011.01118.x
- National Alliance on Mental Illness. (2022). Asian American and Pacific Islander. *National Alliance on Mental Illness*. https://www.nami.org/Your-Journey/Identity-and-Cultural- Dimensions/Asian-American-and-Pacific-Islander
- Phan, A. (2020). TEDxYouth@YostPark: The difficulties of communication in an Asian-American family. TED Conferences. https://www.ted.com/talks/alan\_phan\_the\_difficulties\_of\_communication\_in\_an\_asian\_american\_family/up-next
- Tanap, R. (2019). Why Asian-Americans and Pacific Islanders don't go to therapy. *National Alliance on Mental Illness*. https://www.nami.org/Blogs/NAMI-Blog/July-2019/Why-Asian-Americans-and-Pacific-Islanders-Don-t-go-to-Therapy
- Williams, D. R. (2018). Stress and the mental health of populations of color: Advancing our understanding of race-related stressors. *Journal of Health and Social Behavior*, 59(4), 466–485. https://doi.org/10.1177/0022146518814251

# Global Pandemics: The Manifestation of Societal and Economic Havoc

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The rise of contagious disease within recent history has highlighted the ineffectiveness of the American systems set in place to deal with pandemic policies and preparedness. The confused relationship between federal and state powers as it relates to delegating roles during national health emergencies was especially highlighted during the Trump administration, understood through their decisions during the COVID-19 pandemic. Applying the protection motivation theory, a heavily research psychological theorem, to behaviors seen during past and current pandemics can offer insight into the reactionary missteps of both the government and citizens today.

# Keywords

Pandemic • authority • policies • emergency preparedness • reactionary relationships

# Introduction

During the recent COVID-19 pandemic, a contentious debate was sparked by the questionable decisions, or lack thereof, by the United States government: for instance, the inefficient system of authority between the federal and state level due to the ambiguities in the role of government in emergency preparedness. There is a confusing system of authority between the federal and state levels due to the ambiguities in the role of government, highlighted specifically during the Trump administration, in emergency preparedness. This confusion contributes to the breakdown of national unity, heightening of mass panic, and acceleration of death among citizens. Large businesses, multi-international trade, governmental systems, and the individuals themselves are significant stakeholders in these situations; however, they are constrained in their powers to control the spread of viral diseases. It is important to emphasize public health to make informed decision-making on

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the part of governments. Without it, there would be negative impacts of poor leadership on pandemic preparedness and public trust, as seen by applying the protection motivation theory.

The government has failed in protecting small businesses as well as individuals who work for large-scale employers. In terms of policy formation, the U.S. federal government was unable to assure complete financial assistance toward smaller businesses, leaving employers and employees unsure on how to proceed; there is a fear of not only being exposed to the disease but also of running out of money to cover expenses to stay open. "NFIB Small Business Optimism Index fell 8.1 points in March to 96.4" which was recorded as the largest monthly decline in the survey's history. The index components included 9 of 10 with a declining trend. This is evidence of the economic disruptions escalating as small businesses struggle to keep their doors open" (National Federation" of Independent Businesses). During the COVID-19 pandemic, a small-business relief program provided debt relief to local operations to continue to operate their business and pay their employees. However, many local and small businesses will be unable to open their doors after the risk of pandemic disease dissipates as the small-business loan program hit its \$350 billion cap and is now out of money, as of the beginning of April. Continuing into May 2020, "congressional leaders and the Trump administration have failed to reach agreement on adding hundreds of billions of dollars to replenish the program" (Tankersley et al., 2020). On the day of the launch of Trump's 350 billion small-business relief program, technical glitches and failure to swiftly launch left hundreds of businesses without support. In circumstances of pandemic diseases, the government gives guidelines to follow in order to stop the spread of disease. However, despite the United States' 2 trillion dollar relief bill passed during the ongoing COVID-19 pandemic, there was an absence of provisions for worker safety protections, specifically for the medical workers, people in prisons, those in meatpacking, and those on the front lines of treating the coronavirus.

The protection motivation theory is a useful framework for understanding human nature when experiencing a pandemic disease crisis by evaluating human motives, vulnerability, social distancing behaviors, and reactions. The efficiency of response attempts to measure both the threat and the response by evaluating an individual's perception of how well the response "mitigates a given threat" (Carey & Sarma, 2016). The threat of disease, use of coercive measures, and fear work as variables which influence each other—as one increases, so do the others. The protection motivation theory studies human behavior under pressures and factors in their fears to calculate how they are going to respond. In times of pandemic disease, a difference in human responses creates hostile effects on society and the economy. Because of fear surrounding the pandemic, the United States government is closing down the economy to stop the spread of disease and forcing individuals to remain indoors, causing the abrupt end of consumer activity. The relationship between pandemic disease and economic consequences is complex and multifaceted, and so, in order to formulate effective emergency health policies, the United States must incorporate economic considerations that include decision-making processes of human nature and civil liberties of fear-focused Americans.

# Theoretical Framework

The protection motivation theory, which was first developed by R.W. Rogers and later expanded on by other psychologists, states that fear is a confounding variable in cases of global pandemic emergency responses. The protection motivation theory proposes that fear is composed of three crucial parts: the predicted event's level of harm to one's health, the probability of the event to occur, and

the efficacy of an effective response. The three factors introduced in this theory provide clarity and explanations for the way humans act in the way that they do. The theory is "aimed at explaining the cognitive mediation process of behavioral change in terms of threat and coping appraisal" (Plotnikoff & Trinh, 2010). It places an emphasis on the factors that cause fear to manifest and provides the reasoning behind the decision-making of individuals during periods of mass hysteria. The fear and response of humans act as a major catalyst for the direction the economy moves. The lack of definition of governmental roles when forming a response to a pandemic disease lowers the efficacy of a protective response and therefore heightens the level of fear within citizens. During the Trump administration, certain organizations that focus on pandemic diseases were removed, therefore, leading to less enforcement and defined roles under our current situation. When prioritizing policies affecting pandemic disease, one must consider the feelings of individual citizens and ways of protection. For instance, when businesses and companies receive no financial support from the government, they lose their ability to comfort their investors and secure protection for their money. Some businesses are also struggling because they entered the pandemic crisis with an accumulated amount of debt prior to the incident. If so, they are less likely to maintain a profitable business with the added health threats and precautions changing their business models. During times of pandemic disease, the predicted level of noxiousness is high as is the probability of a company not being able to financially recover. Therefore, by the protection motivation theory, fear is at an all-time high, causing the investors to pull their money and wreaking havoc on the American economy. With the correct public health and emergency preparedness framework set in place at both a national and state level, citizens will have the proper information to reduce their fears and create a more rational world under pandemic crisis. The Australian government and handling of the COVID-19 pandemic can serve as a more efficient response and emergency preparedness framework. The Australian government administration issued an "action plan" for all citizens to follow in cases of "All stages," "Low numbers of COVID-19," and "Increasing COVID-19 cases in your community." With an increase of COVID-19 cases, further restrictions are phased into place and citizens are fully informed of each step and the numerical date that warrants those restrictions.

# Research Statement

The role between state and federal government is a complex relationship that is magnified during pandemic disease crisis. In order to have a cohesive and rational public response, the executive branch should lend support and a figurehead of unification to state-led initiatives. The decision-making at all levels should incorporate the infringement of civil liberties in a cautious way, considering the societal and economic ramifications on the public. The interconnected nature of our society and our world has played a beneficial role in the development of business of trade and culture but becomes a threat when placed under pandemic circumstances, increasing the likelihood of a disease to spread and an economy to fall. The discussion of these important and difficult topics highlights that human rights and economic considerations need to be made in order to inform the decisions to reopen the nation.

#### The Role of Federalism in Pandemic Disease

As the pandemic disease continues to be an ongoing threat to America, we must formulate the most effective response possible to alleviate the fears of the public, avoid mass hysteria, and provide relief

to the American economy. Another primary goal is to ensure the health and safety of their citizens and prevent further death and illness. Social distancing as a government enforcement, for instance, is the curtailment of civil liberties rather than full citizen lockdown. A very different response from the public and the economy is formed when full quarantine on a national level is applied. The public health leaders and government leaders must unite to create awareness of highly coercive measures and the ramifications of their decisions. In compliance with the protection motivation theory, people may overact, create major concern, and strengthen mass hysteria as the disease spreads. Therefore, the federal government must acknowledge and act in more consideration of fear and civil liberties during pandemic crisis. Cognizant leadership is necessary and requires a close look at the economic consequences of their actions. Federal leadership must also work efficiently across federal and state lines.

In instances of pandemic diseases, the United States has not explicitly defined roles in the government on emergency preparedness (Howell, 2020). There are some federally suggested positions where the Federal Emergency Management Agency (FEMA) and the National Security Council are tasked with some response, but there are no specific instructions laid out in constitutional terms. Our constitution is very limited and does not apply to many things. In the place of constitutional guidelines, the executive government has prepared a "playbook" formed from past pandemic precedents to "assist U.S. Government experts and leaders in coordinating a complex U.S. Government response to a high-consequence emerging disease" (National Security Council, 2016). Each section of the playbook answers a different series of questions that should inform the decisions of federal leaders at every level of the disease spreading. The pandemic playbook, formed from past precedents, was formed to assist the U.S. government and leaders in formulating and coordinating policies and responses to emerging infectious diseases (National Security Council, 2016). However, when the COVID-19 pandemic began to emerge as a threat to U.S. citizens, the Trump administration failed to provide a unified response, broadcasting conflicting messages at both a federal and state level. Public health advisors continue to speak out about the importance of self-isolation, while executive leaders are discussing lifting federal bans on social distancing. The "playbook" was even deemed not a part of the current coronavirus strategy. But why have a document that lays out the rules if no one enforces or sets laws in place to utilize them? The playbook urges unification at a state and federal level, but our American reality during COVID-19 is acting far different than predicted. The answer is in part due to our constitution. The president has power over Health and Human Services and the Centers for Disease Control and Prevention (CDC) and can choose whatever guidelines he wants without legal or legislative consequence.

America does have some preparedness plans but none with such great detail that has prevented the mass casualties and economic despair the COVID-19 pandemic has brought. During the instance of the COVID-19 pandemic, state and federal are tested to an extent never seen before. Specifically, through the Commerce Clause, the power and authority can be granted to Congress to propose public health measures and quarantine restrictions. However, the Public Health Service Act also authorizes the secretary of Health and Human Services to lead federal public health responses. The 10th amendment also gives states the authority to take public health emergency actions within their own state jurisdictions. Therefore, emergency laws can vary by state. Under the presidency of Donald Trump, some claim he has power under the Commerce Clause to invoke national quarantines and public health emergency restrictions. The executive branch should have a clearly defined role to play and procedures to follow because the president has so much power. The role should be providing support to the states and acting as a figurehead of unification. There should be a procedure, like the pandemic playbook, where decisions are made based on the level of threat and set in

place. This new and updated "playbook" would make sure necessary precautions are made and ensure there is no confusion. The primary goal of it would be to ensure healthy citizens and make a healthy path to recovery with clear hierarchy of decision-making, which our current system lacks. President Trump's relief effort, for instance, aimed to provide relief for small businesses has not been deemed "a tremendous success" or "executed flawlessly," which he boasts at his COVID conferences toward the American public. The bill holds major flaws bailing out large corporations and saving local businesses, serving rather as a gradual "stepping stone" in assuring financial assistance than complete relief.

It is important to recognize that diseases are a geographically confined issue, meaning there are different levels of disease contraction and risk depending on location. Although pandemic disease is a global issue, the necessitation of supplies and concentrations of the disease vary, demanding a different response from an epidemiological stance to different areas (Howell, 2020). For instance, during the COVID-19 pandemic, there is a higher volume of disease and death in New York, with over 200,000 confirmed cases compared to Wyoming with less than 250 confirmed cases. There is more demand for governmental assistance in New York as it has a higher level of disease on a geographical level. There is a gravitational pull down to the lower level of authority. It is rare in a public health crisis to have a national response because the situation is rare and because this is constitutionally structured according to our federalist system. Even when we have had federal responses, such as H1N1 and SARS, enumerated powers were not defined. Because emergency preparedness and the relationship between federal and state powers are not explicitly enforced in government documents such as the Constitution, the public debates the balance which the president and governors are to follow (Howell, 2020).

Past precedents of pandemic disease have rather ushered a limited framework to follow. FEMA, for instance, stresses the local quality of disasters, like natural disasters. The organization discusses the role of the federal government being there to support local organizations rather than create a new federal approach from scratch. In a similar way, FEMA's pandemic template "provides guidance to assist organizations in developing a pandemic plan. Guidance and sample information is provided for reference and organizations are encouraged to tailor Pandemic Influenza Continuity Plans to meet specific organizational needs and requirements" (Federal Emergency Management Agency, 2006). Therefore, the decision made on both a federal and state level must be carefully produced, calculating the correct path based on the contrasting geographical needs and human nature itself. There are situations when federal decision-making is necessary during pandemic disease crisis. The federal government should lend its support to the state level of powers in order to provide a cohesive response to a pandemic crisis. With the current COVID-19 pandemic, there is limited inherent authority as president to manage public health crisis or deliver ventilators. Sometimes, the courts have allowed the executive office to take emergency actions without Congressional approval. The laws in this area are very enigmatic. For the president to take the lead in action during a pandemic crisis would be a last resort. The presidential "powers under pandemic disease do not substitute for essential vigorous actions by state and local governments" (Farber & Bell, 2020). The power that the president has during times of pandemic disease is the authority under Article II of the Constitution that comes from declaring a national state of emergency. There are not "any clear answers here, and the result could turn on the direness of the situation and the compelling need for the actions taken by the President" (Farber & Bell, 2020). But governors such as Governor Cuomo, the governor of New York, demanded President Trump use his power to instate the "Defense Production Act" in response to production needs. Governor Cuomo's response to Trump's refusal to sign the act into

action echoed the disappointment and irritation present in many Americans. "I look at actions, not words" he states. "They're doing the supplies? Here's my question. Where are they? Where are the ventilators? Where are the gowns? Where's the PPEs [personal protective equipment]? Where are the masks? Where are they? Where are they if they're doing it?" (The Associated Press, 2020). His frustration with the federal government's lack of support toward states is evident in this excerpt. The lack of ventilators and supplies becomes a prioritizing issue for the federal government to handle. Whereas a state-level official does not have the power to demand and create supplies, a federal official does. This is where FEMA's definition of acting as support for the state governments is invoked. The federal government should aim its focus to help and provide support to the local governments rather than starting a new federal plan. This is because local governments know the area well and can predict the needs of the community more accurately in line with the protection motivation theory.

# Benefit Analysis of an Interconnected World

There are moral and ethical concerns about the participation of the workforce and trade—not only how the participation of the workforce contributes to the economic recession but how it serves as a direct connection to other factors of the economy such as keeping children from school, reduction in inbound international travel, reduction in outbound travel/leisure activities, and reduction of transportation use (Prager et al., 2017). Pandemics would not occur if the world weren't interconnected, but also there would not be global trade that could shut down. In instances of global panic surrounding disease, consumerism is the first aspect of human culture to suffer. People stop spending on unnecessary products and services, such as eating out at restaurants and supporting small businesses. Fear stigmatizing foreign trade and its role in spreading disease strain trade relationships, as do the tweets from President Trump that blame China for the matter. This raises ethical concerns about the role a president as a figurehead plays during pandemic crisis and whether Trump is the correct person for easing the public's fears and sustaining relationships with other countries. Unprofessional actions such as using Twitter as a mode of addressing major citizen and U.S. concerns lends citizens to question the reliability of their executive administration, heightening levels of fear due to the protection motivation theory.

During pandemic disease, it is difficult for the public to work, difficult to find a job, and hard for businesses to prosper as citizens are forced to stay inside. However, there is a class dimension to this concept. Wealthier people will find it easier to work from home and have spacious and accommodating spaces. Poorer communities, on the other hand, are in closer units and sometimes forced to be on the front lines to be working in menial labor jobs. When looking from a standpoint of an economist, the data interconnects when a person analyzes the demographic of who is contracting the COVID-19 disease. There is a differential impact on different races. According to the Illinois Health Department, "African Americans in Illinois, for example, accounted for 29% of confirmed cases and 41% of deaths, yet they make up only 15% of the state's population" (Cooney, 2020). The issue of pandemic disease as a human right can be far more multifaceted than originally presented. African Americans may be contracting the disease at a higher rate than other races due to the racial wealth gap in the United States. Poorer communities lack the resources and education to prevent the spread of those diseases. Mortality and morbidity rates in association with pandemic disease correlate to socioeconomic status. Therefore, forced quarantine orders can be viewed as a racial dilemma as well as an economic one. The disparities are stark in cities where high concentrations of American Americans live. According to the Economic Policy Institute, "Only 20% of black workers

reported being eligible to work from home, compared with about 30% of their white counterparts." Many African Americans are more susceptible to the disease because they live in medically underserved areas and cannot economically compensate to work from home. It is necessary to improve health and wealth issues in these community-wide so that they are not disproportionately affected during times like pandemics. The suggestion of Universal Basic Income (UBI) programs may reduce health disparities by making sure every single person is granted money that would help them live above the poverty line. "UBI could be set at a level to ensure that everyone's basic needs are met. This would reduce much of the stress faced by the working poor or families on benefits" (Smith, 2020). Smith claims that the UBI trials should measure health outcomes and the improvements associated with it. Cost-saving of the improved health outcomes, especially with mental health, would outset the cost of creating a universal income system. People are suffering under social distancing orders in both an economical sense and due to health disparities. A reduction of health disparities would lower stress and risk of fear, and according to the protection motivation theory, would likely reduce a pandemic's negative effects. Human rights and economic considerations need to be made in order to inform the decisions to reopen the nation. Sometimes, the gap between human intention and human behavior in times of crisis makes results hard to predict. However, studies have formulated a predictable human response replacing the way one handles decision-making and policy formation. Pandemics "can cause economic damage through multiple channels, including short-term fiscal shocks and longer-term negative shocks to economic growth" (Madhav et al., 2017). The comparison between past pandemic crisis and the downfall of global economies highlights the threat of disease as a major contributor, creating public fear which affects policies and the consequential actions of humans. Past precedents set by the SARS pandemic, the ongoing coronavirus pandemic, and the 2008 financial crisis serve as examples to be examined in relation to federal decision-making, economic recessions, and predictions of human behavior. As businesses start to fail under stressful conditions, investors pull their money and lose faith in these companies. Therefore, the GDP and stock markets start to lower at unprecedented levels. Studies of past pandemics in association with the economic conditions coupled with "stock-market history shows that investors do react to epidemics and pandemics. However, other issues also affect markets and, in common with victims of the diseases, market performance will also depend on the strength or weakness of prevailing conditions. For example, "the avian flu epidemic of 1997 coincided with the Asian crisis, and preceded the Russian debt and LTCM crises of 1998" (Fidelity International, 2006). Goods, services, and people can travel more easily in a globally connected world. Disease can spread more swiftly because of this, but also knowledge can spread more easily as well. Technology and trade act as a "double-edged sword" in terms of pandemic disease because with good knowledge other countries can prepare once there is an outbreak, coordinate with each other to help, and minimize the negative effects. When economic discourse under pandemics occurs, the United States' reaction and policies are important to rebuilding the economy. With the collapse of the United States' economy, effects reverberate on other countries due to the recession. The United States plays a major role in trade and consumerism in the world; therefore, recession would have a considerable negative impact on other parts of the globe. The United States must rework its emergency health policies to incorporate economic aspects, placing an emphasis on the role of fear in decision-making in order to avoid recession. With the development of the coronavirus pandemic, the United States must be prepared to plan and respond to the economic ramifications associated with an emergency response. Pandemic disease raises "an issue that economists have long grappled with: How can a society assess the trade-off between economic well-being and health?" (Porter & Tankersley, 2020). Diseases and viruses attacking at a mass

scale have posed a theoretical threat, for public health and economic reasons, to the United States for decades (Prager et al., 2017). An evaluation of past epidemics and their responses such as SARS and influenza can provide insight on the complete economic and social ramifications of pandemic disease, and applying the protection motivation theory, we may be able to predict human behavior and minimize mass hysteria surrounding the pandemic. The protection motivation theory discusses the "efficacy of a protective response" but not the cultural and national implications of things like being to be told to stay home. Stay-at-home orders decrease the immediacy of the threat and catalyze anger as it decreases the threat that would increase fear. Angry protests such as those occurring in Michigan due to COVID-19 apply the protection motivation theory to both the disease and the steps we take to solve the disease. Citizens would be more hysterical if the stay-at-home orders were not put in place and the pandemic disease magnified on a rapid level. By applying the "protection motivation theory," a calculation on whether fear would be higher with either stay-at-home orders or less government intervention can be made. Stay-at-home orders reduce the predicted pandemic's level of noxiousness and the probability of the disease spread. However, the efficacy of a protective response can be interpreted in many ways. From an epidemiological standpoint, orders to isolate from each other stop the spread of disease and are very effective in managing levels of control. From a civil liberties standpoint, orders for self-isolation violate human rights as a need and can highlight the stark health disparities in America. Even though the efficacy of a protective response is questionable in its role in pandemic disease government orders, the decisions are effective in the other two areas of fear reduction when compared to what would happen with no set rules in place.

#### Civil Liberties as a Threat to Order

When civil liberty issues and public health interests' conflict, the federal government should act as a consoling figurehead for citizens to follow. The United States government should have a clear and concise plan of how citizens should approach COVID-19 as case rates increase. A more direct power of authority and unified approach between Congress, States, and the Federal government leads to more efficient handlings of protocol. Therefore, mass confusion and questioning of authority would be reduced. The United States federal government should implement phases similar in nature to the Australian government's COVID-19 protocol, which have numerical data to support the implementation of the restriction.

Congress and the president must work together to delegate supplies and provide an assurance of human rights. It is the job of leaders to decide which solution provides the most positive impact with the least number of detrimental effects. For instance, with an outbreak, inmates in jail are in close quarters, and the mechanisms in pandemics are not supplied first to inmates. Without basic materials such as soap, it would necessitate putting every inmate, despite their level of crime, in solitary confinement as a precautionary public health measure. Full solitary confinement for a low-level crime would not ethically stand (Sharfstein, 2020). A proposed solution would be to reduce the prison population. But morally letting prisoners out into the public would create fear, lose money for prison companies, and have multiple other consequences (Sharfstein, 2020). This scenario shows a solution does not necessarily stand without its consequences, but it is the job of leaders to decide which solution provides the most positive impact with least number of negative outcomes. But most prisons are run at the state level: there are 122 federal prisons and 1,719 state prisons. By the mentality presented here, the governors of the states have the most discretion in these matters to deal with the incarcerated.

The line between infringing on the individual rights of citizens and protecting the health of citizens is very blurred and difficult to define. Exploring the different possibilities toward managing fear on national and state levels may help formulate a correct national response. A strong and forceful approach in the early stages of disease progression is a very sound approach to pandemic disease. The World Health Organization (WHO) agrees with this approach, suggesting phases of recommended actions to reduce the spread of disease. The phases include "planning and coordination, situation monitoring and assessment, reducing the spread of disease, continuity of health care provision, and communications" in order to maintain "to and build public trust in public health authorities before, during and after an influenza pandemic, to support coordination and the efficient use of limited resources among local, national, regional and international public health partners, to provide relevant public health information to the public, to support vulnerable populations having the information they need to make well-informed decisions, to take appropriate actions to protect their health and safety; and to minimize social and economic disruption" (World Health Organization, 2008). If the government takes control early on, mass hysteria can be prevented and overall fear among the general public would be reduced. A reduction of fear, based on the protection motivation theory, would equate to a decrease in economic ramifications and would therefore shorten the necessary infringement on citizens' civil liberties (Plotnikoff & Trinh, 2010).

Our government was founded upon the principles of freedom and civil liberties; however, there are laws that allow the limitation of civil liberties during times of national crises. National security should be weighed in higher consideration than human rights. Human rights need to be addressed after the mass hysteria and panic are controlled in order to provide the optimal path toward recovery—a state of emergency qualifies a state of necessary measures. The risk of disease and the heightening of fear shift the value that citizens equate to their freedom. We should rely on our government's abilities to not completely undermine all civil liberties, and if they were to infringe on these rights, it is for the sake of stopping the spread of disease. We should not let this fear cloud our decision-making and instead look at the situation rationally before protesting or disagreeing with governmental steps of disease prevention. Investment in an emergency may not have immediate gratification and effects because pandemics are rare occurrences, but they help lessen the burden when disasters do occur (Madhay, 2017). Due to the myriad of factors that contribute to the negative impacts of pandemic disease, it is difficult to pinpoint a correct evaluation and solution to the problem of heightening fear and downfalls of the economy. But this study provides insight on preparation and how we must emphasize public health and emergency preparedness in our governmental spending. We should have heavy funding on vaccination developed, we should heavily emphasize public health education in our American school system, and we should allocate more money for emergency preparedness and supplies before events like COVID-19 occur.

### Conclusion

There is no single perfect response to a public health emergency; it is a complex and unique situation that demands individual analysis based on the current conditions and the political and social impacts (Madhav, 2017). We must take into account factors beyond the financial history of recession, and a successful plan of action ought to place a greater emphasis on exploring the underlying reasoning of fear manifestation and how to minimize fear itself. A greater emphasis on controlling fear and utilizing the protection motivation theory should inform the decision-making of authority

figures and determine the reactions of the public. State and federal governments must unify and address the aforementioned fears in order to mitigate concerns both financially and from a human rights perspective. In order to mitigate these fears, they need to have a set plan and agency that controls and has a procedural response to pandemic disease. In a "post-COVID-19" world, the government should be more knowledgeable of the roles it should play if another pandemic disease were to occur and correctly shift more funding to emergency preparedness. New ways of planning and coordination in public health, such as public health education, will provide leadership across federal and state lines and integrate pandemic preparedness into a national emergency framework.

# References

- Baghiani-Moghadam, M. H., Seyedi-Andi, S. J., Shokri-Shirvani, J., Khafri, S., Ghadimi, R., & Parsian, H. (2015). Efficiency of two constructs called "fear of disease" and "perceived severity of disease" on the prevention of gastric cancer: Application of protection motivation theory. *Caspian Journal of Internal Medicine*, 6(4), 201–208
- Bell, R., & Farber, D. (2020). Presidential power in a pandemic. *Legal Planet*, 26 March. legal-planet. org/2020/03/18/presidential-power-in-a-pandemic/.
- Carey, R. N., & Sarma, K. M. (2016). Threat appeals in health communication: Messages that elicit fear and enhance perceived efficacy positively impact on young male drivers. *BMC Public Health, BioMed Central*, 27 July. www.ncbi.nlm.nih.gov/pmc/articles/PMC4962518/.
- Cooney, E. (2020). African Americans may be bearing the brunt of Covid-19, but data limited. *STAT*, 9 April. www.statnews.com/2020/04/06/flying-blind-african americans-disparities-covid-19-data-limited/.
- Federal Emergency Management Agency. (2006). Pandemic influenza continuity of operations annex template. *FEMA*. https://www.fema.gov/pdf/about/org/ncp/pandemic\_influenza.pdf
- Fidelity International. (2006). What happened to the stock markets during previous pandemics? http://www-stat.wharton.upenn.edu/~steele/Pandemic/Resources/FidelityPandemic.pdf
- Howell, J. P. (2020). The lawfare podcast bonus edition: Steve Vladeck on emergency powers and coronavirus. https://www.lawfareblog.com/lawfare-podcast-bonus-edition-steve-vladeck-emergency-powers-and-coronavirus
- Human Rights Dimensions of COVID-19 Response. (2020). *Human Rights Watch*, 7 April. www.hrw.org/news/2020/03/19/human-rights-dimensions-covid-19-response#.
- Madhav, N., Oppenheim, B., Gallivan, M., et al. (2017). Pandemics: Risks, impacts, and mitigation. In *Disease control priorities: Improving health and reducing poverty* (3rd ed.). Washington, DC: The International Bank for Reconstruction and Development / The World Bank. PMID: 30212163.
- Moore (ed.) (2009). Global business and terrorism. Cheltenham, UK: Edward Elgar.
- Mortality Risk Valuation. (2018). EPA, Environmental Protection Agency, 8 February. www.epa.gov/environmental-economics/mortality-risk-valuation#what is vsl.
- National Security Council. (2016). Playbook for early response to high consequence emerging infectious disease threats and biological incidents. Available Online: https://assets.documentcloud.org/documents/6819268/Pandemic-Playbook.pdf

- Plotnikoff, R. C., & Trinh, L. (2010). Protection motivation theory: Is this a worthwhile theory. *Exercise and Sport Sciences Reviews*, 38(2), 91–98.
- Popken, B. (2020). Small business loan program just hit its \$350 billion cap and is now out of money. NBCNews.com, NBCUniversal News Group, 16 April. www.nbcnews.com/business/business-news/small-business-loan-program-just-hit-its-350-427 billion-cap-n1185406.
- Porter, E., & Tankersley, J. (2020). Shutdown spotlights economic cost of saving lives. *The New York Times*, 24 March. www.nytimes.com/2020/03/24/business/economy/coronavirus-economy. html 432
- Prager, F., Wei, D., & Rose, A. (2017). Total economic consequences of an influenza outbreak in the United States: Economic consequences of influenza. *Risk Analysis*, 37(1), 4–19. https://doi.org/10.1111/risa.12625
- Rose, A., Asay, G., Wei, D., & Leung, B. (2009). Macroeconomic impacts of shutting down the U.S. borders in response to a security or health threat, chapter 13. In H. Richardson, P. Gordon, & J. Moore, II (Eds.), *Global business and the terrorist threat*. Cheltenham, UK: Edward Elgar.
- Sander, B., Nizam, A., Garrison, L. P., Postma, M. J., Halloran, M. E., & Longini, I. M. (2009). Economic evaluation of influenza pandemic mitigation strategies in the United States using a stochastic microsimulation transmission model. *Value in Health*, 12(2), 226–233. https://doi.org/10.1111/j.1524-4733.2008.00437.x.
- Senior, J. (2020). How a bakery survives the pandemic apocalypse. *The New York Times*, 19 April. www. nytimes.com/2020/04/19/opinion/small-business coronavirus.html.
- Sharfstein, J. (2020). Considering human rights in restriction response strategies to COVID-19. Johns Hopkins Bloomberg School of Public Health. https://podcasts.apple.com/us/podcast/public-health-on-call/id1501336958.
- Small Business Resources in Response to Coronavirus. (2020) NFIB, 11 May. www.nfib.com/content/analysis/coronavirus/latest-on-coronavirus-from-nfib/.
- Smith, M. (2020, April 27). Universal basic income could improve the nation's mental health. *The Conversation*. https://theconversation.com/universal-basic-income-could-improve-the-nations-mental-health-123816
- Tankersley, J., Cochrane, E., Flitter, E. (2020). Small-business aid funds run dry as program fails to reach hardest hit. *The New York Times*, 15 April. www.nytimes.com/2020/04/15/us/politics/coronavirus-small-business-program.html.
- The Associated Press. (2020). 'Where are the Ventilators?': Governor Cuomo pleads for more help for New York. *The New York Times*. https://www.nytimes.com/video/us/politics/100000007051271/cuomo-coronavirus-update.html
- Tunner, J., Day, E., Crask, M. (2002). Protection motivation theory: An extension of fear appeals theory in communication. *Journal of Business Research*, *Elsevier*, 12 April. www.sciencedirect.com/science/article/abs/pii/0148296389900088.
- World Health Organization. (2008). World Health Organization outbreak communication planning guide. Guide de l'OMS Sur La Planification de La Communication Lors Des Flambées de Maladies, 30.
- Yurtoğlu, N. (2018). History studies. *International Journal of History*, 10(7), 241–264. doi:10.9737/hist.2018.65

# Limited Access to Healthcare: Examining Factors Leading to Higher COVID-19 Hospitalization and Death Rates Among Black Americans

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The novel coronavirus (COVID-19) has shed light on racial disparities in healthcare access. An analysis of hospitalization and death rates supports that Black Americans are disproportionately impacted by the pandemic when compared to their white counterparts. With no credible biological basis for this disparity, social determinants of health, specifically access to healthcare, have been examined to help explain the devastating impact on the Black community. National data demonstrates that Black Americans experience higher rates of unemployment brought on by the pandemic, leaving them without their typical employer-sponsored health insurance. Lack of Medicaid expansion across all 50 states only exacerbates this uninsured rate, leaving many without an insurance safety net. In the case of treatment and prevention services, historically segregated Black communities face a lack of access to COVID-19 tests in their own neighborhoods. Simultaneously, Black patients are more likely to access care at a later time, with many being tested for COVID-19 in a hospital rather than an ambulatory environment. Finally, the lack of cultural competency of the medical staff and workforce hinders the formation of collaborative relationships between patients and providers. This furthers feelings of dissatisfaction with one's care, perpetuating mistrust and misbeliefs surrounding vaccination and COVID-19 treatment. Access to healthcare, due to its strong ties to policy, requires policy intervention: a national effort to expand coverage across all states, dedicating health resources to historically disadvantaged communities, and providing culturally relevant information about the pandemic to marginalized populations.

# Keywords

COVID-19 • health disparities • healthcare access • health insurance • Black Americans

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# Introduction

The severity of the 2019 novel coronavirus (COVID-19) pandemic was clear when, nearly a year after the virus's identification, the United States surpassed 500,000 known coronavirus-related deaths (Tompkins, Smith, Bosman, & Pietsch, 2021). In March of 2021, less than a year after top infectious disease experts projected an unspeakable estimate of 240,000 deaths in the upcoming year, COVID-19 became the leading cause of death in the country, outpacing cardiovascular disease and cancer (Tompkins et al., 2021). Leaving no region untouched, the virus has ravaged both heavily populated cities and rural communities, and underscored the severity of racial disparities. According to the Centers for Disease Control and Prevention (CDC), non-Hispanic Black or African American individuals are three times more likely to be hospitalized and two times more likely to die of COVID-19 when compared to their non-Hispanic white counterparts (Centers for Disease Control and Prevention [CDC], 2021). With no credible evidence that people of color have a genetic or biological predisposition for contracting the virus, the attention has shifted to social determinants of health to decipher the disproportionate impact of COVID-19 on Black Americans (Gravlee, 2020). Social factors like socioeconomic status, neighborhood and physical environment, access to quality healthcare, and occupation have undoubtedly impacted the lives of minority communities and go on to impact health outcomes like life expectancy and mortality (Artiga & Hinton, 2018). Healthcare access, in particular, is measured through the analysis of four main components: coverage, services, timeliness of care, and the competency of the workforce (Agency for Healthcare Research and Quality [AHRQ], 2016). These four components will be dissected further and used as a framework to evaluate healthcare access in the United States. The following aims to specifically explore the role of the healthcare system and its level of access for Black Americans in exacerbating Black hospitalization and death rates due to COVID-19 and how perceived racism precedes these disparities in access to care.

# Methodology

This literature review was conducted through the use of the University of Michigan Library, PubMed, JSTOR, and Google Scholar. Articles selected focused on racial disparities pertaining to COVID-19 hospitalization and death rates, centering on Black Americans. Search terms differed based on the determinant of healthcare access (coverage, services, timeliness, workforce competency) and included COVID-19, U.S., healthcare access, disparities in healthcare access, COVID-19 testing kits, Black patients, African Americans, timeliness, cultural competency, race-concordant, Medicaid, Medicaid expansion, healthcare coverage, healthcare costs, racial disparities COVID-19, medical mistrust, and COVID-19 vaccine hesitancy. Sources consisted of a variety of cross-sectional studies, surveys, interviews, and review articles. Further nationwide statistical data was obtained through online databases of organizations like the CDC. Additional relevant sources were gained through the bibliography of other useful sources. Due to the recency of the topic and its social implications, reputable news articles from The New York Times were used for introductory and background information. Pertinent information from peer-reviewed articles was used to further explore the role of racial disparities in access to healthcare as a social determinant of higher COVID-19 hospitalization and death rates among Black Americans.

# Healthcare Coverage

Coverage involves one's ability to pay for the costs that accompany receiving care and is the main determinant of whether or not one will be able to enter the healthcare system (AHRQ, 2016). Those who are uninsured are more likely to delay care for financial reasons, leading to overall poor health status. Job loss, brought about by the recent pandemic, has posed a threat to the health coverage for millions of Americans. A study, focusing on Black women from Atlanta, Georgia, conducted a series of interviews to assess the perspectives of Black Americans surrounding COVID-19 (Chandler et al., 2021). When asked to rate the degree to which COVID-19 impacted their daily life, on a scale of 1 (no effect at all) to 5 (an extreme effect), 71% of participants responded with a numerical value of 5 (Chandler et al., 2021). Simultaneously, 83% of participants identified financial issues, like job loss, difficulty finding work. and altering spending habits, as a major concern due to COVID-19 (Chandler et al., 2021). For instance, a 21-year-old interviewee who recently moved to the community and lived alone responded by saying, "It's so hard for me to find a job because no jobs [are] hiring because of this [COVID-19] going on" (Chandler et al., 2021). Other women, living with a partner, expressed concerns about losing their job indefinitely and needing to rely on their partners for support (Chandler et al., 2021).

This trend is evident across the nation with employment decreasing 13% during the first months, February to April, of the pandemic, disproportionately greater among Black Americans with a 15% decrease (Sloan, Duddy-Tenbrunsel, Ferguson, & Kornfield, 2020). Analysis by Avalere Health, a healthcare consulting firm based in Washington, D.C., indicates that this decrease in employment leaves two million Black Americans vulnerable to losing their employer-sponsored health insurance (Sloan et al., 2020). Without this type of coverage, many individuals are forced to shift to different forms of insurance or settle for having no coverage at all. With programs like Medicaid being the next alternative for many unemployed Black Americans, individuals living in states that have not expanded the program are at risk of losing healthcare coverage entirely (Sloan et al., 2020). Conversely, states that have expanded the Affordable Care Act's (ACA) Medicaid Program, 36 states and the District of Columbia, have proved to be in a better position when faced with the challenges of COVID-19 (Cross-Call, 2020). This expansion provides critical coverage to all people with an income below 138% of the federal poverty line, insuring over 12 million people (Cross-Call, 2020). Especially in the case of minimizing racial disparities, states that have expanded the program have narrowed the gap in uninsured rates of white and Black adults by 51% (Cross-Call, 2020). Non-expansion states, however, have seen only a 33% decrease in the gap in uninsured rates of white and Black adults (Cross-Call, 2020). Furthermore, with 27% of Black Americans dealing with underlying health conditions, like asthma, heart disease, and diabetes, along with working low-income and frontline jobs, many Black individuals are in a particularly hazardous position (Cross-Call, 2020). The expansion provides this essential coverage for many individuals suffering from underlying health conditions and working high-exposure jobs (Cross-Call, 2020). Along with this lack of expansion of Medicaid on the state level, the federal government has not engaged in any educational efforts to alert newly unemployed individuals of their eligibility for subsidized plans (Blumenthal, Fowler, Abrams, & Collins, 2020). The absence of safety nets like Medicaid leaves those unemployed, disproportionately Black Americans, with no way to cover expensive healthcare costs, inherently reducing access to care and resulting in widespread chronic illnesses and increased vulnerability to COVID-19 (Blumenthal et al., 2020).

While some government-subsidized care has been provided, it appears to have fallen short. The Provider Relief Fund, established by Congress through the Coronavirus Aid, Relief, and Economic Security Act, aimed to support providers for lost revenue during the pandemic (Appleby, 2020). Under the Trump administration, this fund—indirectly assisting uninsured patients—allowed providers to apply for reimbursement after providing care to those who lacked healthcare coverage (Appleby, 2020). Even though the fund helped hospitals struggling with reduced income, many patients did not know about the existence of this coverage (Appleby, 2020). Furthermore, hospitals and providers were not required to publicize this relief package (Appleby, 2020). Aside from lack of awareness, the criteria for eligibility also posed as an obstacle. To qualify for coverage, the individual cannot have any healthcare coverage: even limited coverage, only covering family planning services, would disqualify a patient (Appleby, 2020). Additionally, "COVID-19 must be the primary diagnosis"; an initial diagnosis of a heart attack followed by a COVID-19 positive test may leave a patient ineligible (Appleby, 2020). Described as an "incomplete fix," this program provides weak support to those eligible and neglects the health and well-being of those unaware of this critical access to care (Appleby, 2020). Per the United States Department of Health and Human Services (HHS), COVID-19 vaccines are completely free, even for those without insurance; in order to get free treatment, an uninsured individual is required to "talk to any health care provider in your area to see if they will agree to bill the federal government for other COVID-19 related care (i.e., testing and treatment)" (HHS, 2021). This leaves the option of costless care in the hands of providers who must volunteer to participate in the Health Resources and Services Administration (HRSA) Uninsured Program, reimbursing providers for providing care to the uninsured, and undoubtedly limits access to coverage, especially for those not living multiple healthcare facilities or clinics. Even with the presence of government-subsidized COVID-19 care, the incomplete implementation and follow-through leave many struggling to adapt to a reality of being uninsured, without any autonomy over their own health.

# Healthcare Services

Access to healthcare also depends on the availability of preventive services, in this case readily accessible COVID-19 tests and neighborhood testing sites (AHRQ, 2016). One's ability to have a stable source of care, along with preventative services, is instrumental in having better overall health and reducing health disparities (AHRQ, 2016). However, one's access to services, in this case COVID-19 testing sites, is closely linked to where patients live and how much they earn. After a large-scale review of COVID-19 testing sites, it was evident that communities of color face issues of high demand and limited supply (Vann, Kim, & Bronner, 2020). Further analysis of city and state health department databases also depicted fewer testing sites in areas populated by racial minorities when compared to white and wealthier neighborhoods (Vann et al., 2020). Testing sites in predominantly Black neighborhoods, despite serving more individuals than predominantly white locations, were scarce and distantly located, with fewer sites available per person (Vann et al., 2020). Using a measure known as potential community need or average demand of tests, investigators found majority-Black neighborhoods to have a potential community need that was 46% higher than that of majority-white neighborhoods across Dallas County, Texas (Kim, Vann, Bronner, & Manthey, 2020). Similarly, across southern Florida, majority-Black areas had a 13% larger potential community need than majority-white neighborhoods (Kim et al., 2020).

The fragmentation of service is a direct indicator of high death and hospitalization rates among people of color, specifically Black Americans. A study, attempting to understand the compounding effects of racial segregation and income equality, examined confirmed cases and deaths due to COVID-19 in numerous metropolitan areas (Yu et al., 2021). The results depicted a higher incidence rate of COVID-19 in areas with greater Black-white segregation (Yu et al., 2021). Income inequality also worsened the impact of COVID-19 in specific areas: areas with a higher GINI coefficient (higher income inequality) exhibited a higher growth rate in the case of deaths and incidence of COVID-19 (Yu et al., 2021). The researchers concluded that the combination of income inequality and racial segregation produces a "synergistic effect," drastically deteriorating health outcomes for certain areas and demographics (Yu et al., 2021). Poor communities suffer the inevitable effects of poverty due to income inequality, and racially segregated areas experience a lack of access to social, medical, and informational resources to better control their health. Especially for Black communities, racial segregation has been legally enforced through racist housing practices and exacerbated by white flight, gentrification, and disinvestment (Yu et al., 2021). Hypersegregation only furthers long-standing inequities in access to health resources, concentrating services in predominantly upper-class, white areas and marginalizing communities of color. Access to healthcare services, while explicitly connected to the healthcare aspect of the social determinants of health, is also a nod toward one's built environment and neighborhood atmosphere. Tying in multiple social determinants of health, access to services also inherently impacts timeliness of care, a critical aspect of care when considering a highly infectious disease like COVID-19. Overall, after examining disparities in access to health-related services, it is clear that limited access to healthcare functions at the intersection of multiple barriers to care.

# Timeliness of Care

Along with general access to services, timely access is critical for healthcare to be of use for a patient. Specifically, timeliness of care refers to the deliverance of care when its need is recognized (AHRQ, 2016). Unfortunately, this is often not the case for Black patients who are three times more likely than their non-Hispanic white counterparts to learn of their COVID-19 positive result through an emergency room or a hospital test (Anderson, 2020). In a retrospective cohort analysis of COVID-19 patients at California's Sutter Health, even after adjusting for sex, comorbidity, income, race/ethnicity, and socioeconomic factors, Black patients were 2.7 times more likely to be hospitalized (Azar et al., 2020). Moreover, once hospitalized, 24.6% of Black patients were transferred to the Intensive Care Unit (ICU) compared to 10.7% of non-Hispanic white patients (Azar et al., 2020). The researchers theorize that this greater admission rate is indicative of Black patients being at a more advanced stage of their illness at the time they are first tested for COVID-19 (Azar et al., 2020). This delay of care can be attributed to previously discussed factors like limited testing services in their neighborhoods since Black patients are more likely to be tested in a hospital than in an ambulatory environment (Azar et al., 2020). Reflecting on previous research of Sutter Health, the researchers also found that Black patients were more likely to access care at a later time (Azar et al., 2020). Given California's status as a state that has expanded its Medicaid, it is unlikely that this consistent untimely access to care is solely due to lack of coverage (Azar et al., 2020). Therefore, later access to care may function independently of an individual's state of coverage and be subject to more implicit, yet influential, factors.

In fact, unconscious biases of providers and patients' negative experiences with the healthcare system can fuel mistrust and compel Black individuals to seek care at a later stage and only in extreme circumstances (Azar et al., 2020). This was especially apparent in the Michigan COVID-19 Recovery Surveillance Study (Fleischer, Hirschtick, & Mattingly, 2021). Using a sample of 2,000 COVID-19 cases accessed through the Michigan Disease Surveillance System, researchers obtained a total of 638 surveys illustrating the experiences of Michigan residents with COVID-19 (Fleischer et al., 2021). Black respondents reported having worse experiences seeking healthcare, with 8.7% of Black patients believing their experiences were worse than those of other races and 18.9% of white respondents believing their experiences were better than individuals of other races (Fleischer et al., 2021). In fact, 10.6% of Black respondents reported feeling "emotionally upset" after receiving COVID-19 testing or treatment due to how they were treated because of their race (Fleischer et al., 2021). Finally, 23% of Black respondents also mentioned being afraid to reveal their COVID-19 status to friends or family (Fleischer et al., 2021). Similar findings through a national web-based survey inquiring about avoidance of urgent, emergency, or routine medical care relating to COVID-19 underlined the significantly higher prevalence of reported urgent or emergency care avoidance among Black adults compared to white respondents (Czeisler et al., 2020). This prevalent fear and hesitation prevent countless Black Americans from receiving the time-sensitive care they need. Especially in the case of a potentially fatal and highly contagious disease like COVID-19, time is a precious resource and critical for better health outcomes in the Black community.

# Workforce Competency

Access to healthcare relies on the workforce; a team of culturally competent and knowledgeable providers is critical for equitable access to quality care (AHRQ, 2016). Evidence suggests that diversity in healthcare providers, instrumental to the formation of race-concordant relationships between the patient and physician, is transformational in delivering meaningful and effective care (Schoenthaler, Allegrante, Chaplin, & Ogedegbe, 2012). Race concordance refers to a sharing of identity between a physician and their patient, specifically in regard to race (Shen et al., 2018). A study in New York found patients in race-concordant relationships with their provider partook in longer doctor appointments and viewed their health-related decisions as a collaborative rather than a disconnected effort (Schoenthaler et al., 2012). This collaborative communication also led to high adherence to health-related instructions like taking medication on time (Schoenthaler et al., 2012). However, this collaborative communication between provider and patient is often hindered by implicit bias by the healthcare providers, often in race-discordant relationships (Milam et al., 2020). In the case of Black patients, medical personnel may be making decisions regarding life-prolonging measures, such as encouraging "do not resuscitate" (DNR) directives despite the wishes of the patient (Milam et al., 2020). With the sudden inundation of patients and an ill-prepared healthcare system, overwhelmed providers may be influenced by their racial biases and amplify the growing health gap. This lack of cultural competency and listening to the patient's needs and experiences are detrimental to a patient's, oftentimes a Black patient's, sense of security when in a healthcare setting.

Conversely, the Black community's perception of the healthcare workforce and the institution, in general, can also impact their will to access the care available. A study, examining the

relationships between COVID-19-related medical mistrust and vaccine and treatment hesitancy among Black Americans, interviewed 101 HIV-positive Black Americans about the negative impacts of COVID-19 (Bogart et al., 2021). The sample showed high levels of mistrust and hesitancy related to COVID-19, the vaccine, and potential treatment (Bogart et al., 2021). After being provided with a list of conspiracy beliefs about COVID-19, 97% of participants supported at least one mistrust belief; the most prevalent belief was regarding the government's dishonesty and withholding of information (Bogart et al., 2021). Over 50% of participants showed hesitancy regarding a future vaccine or treatment, and a third of respondents reported that they would not get vaccinated or treated (Bogart et al., 2021). In general, greater COVID-19 mistrust was significantly associated with greater vaccine hesitancy (P < 0.0001) and treatment hesitancy (P < 0.0001) (Bogart et al., 2021). This study supports that medical mistrust, due to historic traumatic events and structural racism, continues to be high and serves as a legitimate barrier to care, especially in the case of an infectious and life-threatening disease like COVID-19.

The foundation of the current medical system rests on a history of mistreatment and abuse of Black Americans. Inhumane experiments on enslaved people, forced sterilizations of Black women, and the devastating Tuskegee syphilis study, which withheld critical treatment from Black men so that doctors could track the course of the disease, mark the dark past of the current healthcare establishment (Hostetter & Klein, 2021). However, it is simplistic to assume that current medical mistrust is due to these historical events alone. Contemporary experiences of discrimination, racial bias, under-treatment of pain, and inequitable access to facilities and insurance fuel growing hesitancy and fear of reaching out for care (Hostetter & Klein, 2021). Simultaneously, understandably hesitant Black individuals are forced to experience a cycle of victim-blaming, "labeled as non-compliant" and unwilling to benefit from treatment (Hostetter & Klein, 2021). With the Black community already experiencing daily stressors due to deep-rooted systemic racism, mistrust of information and medical personnel only widens the health gap and prevents those most disadvantaged from getting the care they need.

### Conclusion

The healthcare system has been at the center of the COVID-19 pandemic, providing critical care and support for millions of people. However, as an institution rooted in a racist past that continues to fall short when looking at equitable access to care, it is hard to ignore its position in a country grappling with racial disparities in health, especially in the case of COVID-19 hospitalization and death rates of Black Americans. Further examination of coverage, services, timeliness of care, and cultural competency of the workforce has demonstrated a significant gap in coverage, access to COVID-19 testing sites, and timely care for Black Americans, inevitably contributing to the disproportionate burden of COVID-19 on the Black community (AHRQ, 2016). Moreover, the cultural incompetency of clinicians and the inability to form a collaborative patient-centered relationship between the provider and patient has fueled Black mistrust and lack of faith in the healthcare system, discouraging those who desperately need help from seeking it.

While these racial disparities have always existed, the devastating impact of COVID-19 across all communities has brought these deeply rooted inequities to the surface, further marginalizing communities of color. In fact, these disparities are a direct reflection of whose health and life are valued and considered a priority in American society. The national response to the pandemic should

be rooted in ensuring existing health-related racial disparities are not exacerbated. On the federal level, purposeful efforts to expand healthcare coverage to the uninsured across all 50 states must be prioritized (National Association for the Advancement of Colored People [NAACP], n.d.). Policy interventions should also aim to prevent further restrictions on Medicaid, providing those recently unemployed with a sense of security when it comes to paying for the costs of healthcare (NAACP, n.d.). Historically underserved communities should be supported with resources dedicated to education, prevention, and treatment services, improving the fragmentation of healthcare access in segregated neighborhoods (NAACP, n.d.). The Black Coalition Against COVID (BCAC), for instance, is dedicated to providing credible and relevant COVID-19 information to minority communities (BCAC, 2022). Working with influential figures in communities across the country, networking with subpopulations including faith, small business, community service organizations, and medical and academic institutions, BCAC focuses on combatting misinformation and promoting scientifically supported COVID-19 prevention recommendations (i.e. vaccination) (BCAC, n.d.). Along with other Black health advocacy groups, BCAC has reached out to the Biden administration requesting the availability of testing kits to local faith-based organizations for distribution to residents in the Washington, D.C., area (BCAC, n.d.). The Coalition also hosts town halls spotlighting Black medical professionals to debunk myths and provide culturally appropriate information about COVID-related care and building community trust (BCAC, n.d.). The BCAC is a powerful example of simultaneous political lobbying and the boosting of community education. Societal change, coupled with equitable access to healthcare while focusing on historically targeted and disadvantaged communities of color, is imperative for the current system of care to be effective in addressing the needs of all Americans.

# References

- Agency for Healthcare Research and Quality. (2016, May). Chartbook on access to healthcare.
- Agency for Healthcare and Research Quality. (2016). https://www.ahrq.gov/research/findings/nhqrdr/chartbooks/access/elements4.htm
- Anderson, C. (2020, May 25). Sutter health finds black patients get coronavirus diagnoses at later stage than white peers. *The Sacramento Bee.* https://www.sacbee.com/news/coronavirus/article242969276. html
- Artiga, S., & Hinton, E. (2018, May 10). Beyond health care: The role of social determinants in promoting health and health equity. Kaiser Family Foundation. https://www.kff.org/racial-equity-and-health-policy/issue-brief/beyond-health-care-the-role-of-social-determinants-in-promoting-health-and-health-equity/
- Appleby, Julie. (2020, October 2). Trump's COVID program for uninsured people: It exists, but falls short. *Kaiser Health News*. https://khn.org/news/fact-check-president-trump-executive-order-covid-program-for-uninsured-people-falls-short/
- Azar K. M. J., Shen Z., Romanelli R. J., Lockhart, S. H., Smits, K., Robinson, S., Brown, S., & Pressman, A. R. (2020, May 21). Disparities in outcomes among COVID-19 patients in a large health care system in California. *Health Affairs*, 39(7), 1253–62. https://doi.org/10.1377/hlthaff.2020.00598
- Black Coalition Against COVID-19 [BCAC]. (n.d.). *National efforts*. https://blackcoalitionagainstcovid. org/national-efforts/

- Blumenthal, D., Fowler, E. J., Abrams, M., & Collins, S. R. (2020). Covid-19 implications for the health care system. *New England Journal of Medicine*, 383,1483–1488. DOI: 10.1056/NEJMsb2021088
- Bogart, L. M., Ojikutu, B. O., Tyagi, K., Klein, D. J., Mutchler, M. G., Dong, L., Lawrence, S. J., Thomas, D. R., & Kellman, S. (2021). COVID-19 related medical mistrust, health impacts, and potential vaccine hesitancy among black Americans living with HIV. *Journal of Acquired Immune Deficiency Syndromes*, 86(2), 200–207. https://doi.org/10.1097/QAI.0000000000002570
- Centers for Disease Control and Prevention. (2021, March 12). Risk for COVID-19 infection, hospitalization, and death by race/ethnicity. Centers for Disease Control and Prevention. https://www.cdc.gov/coronavirus/2019-ncov/covid-data/investigations-discovery/hospitalization-death-by-race-ethnicity.html?CDC\_AA\_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2F2019-ncov%2Fcommunity%2Fhealth-equity%2Fracial-ethnic-disparities%2Finfographic-cases-hospitalization-death.html
- Chandler, R., Guillaume, D., Parker, A. G., Mack, A., Hamilton, J., Dorsey, J., & Hernandez, N. D. (2021) The impact of COVID-19 among black women: Evaluating perspectives and sources of information, *Ethnicity & Health*, 26(1), 80–93, DOI: 10.1080/13557858.2020.1841120
- Cross-Call, J. (2020, October 21). *Medicaid expansion has helped narrow racial disparities in health coverage and access to care.* Center on Budget and Policy Priorities. https://www.cbpp.org/sites/default/files/atoms/files/10-21-20health2.pdf
- Czeisler, M. E., Marynak, K., Clarke, K. E. N., Salah, Z., Shakya, I., Thierry, J. M., . . . Howard, M. E. (2020). Delay or avoidance of medical care because of COVID-19–related concerns United States, June 2020. *Morbidity and Mortality Weekly Report*, 69(36), 1250–1257. http://dx.doi.org/10.15585/mmwr.mm6936a4
- Fleischer, N., Hirschtick, J., & Mattingly, D. (2021, January 29). *Michigan COVID-19 recovery surveillance study. Data report 2: Black-white differences in access to care, recovery, and the social impact of COVID-19.*University of Michigan School of Public Health. https://sph.umich.edu/mi-cress/
- Gravlee, C. (2020, June 7). Racism, not genetics, explains why Black Americans are dying of COVID-19. *Scientific American*. https://blogs.scientificamerican.com/voices/racism-not-genetics-explains-why-black-americans-are-dying-of-covid-19/
- Health and Human Services [HHS]. (2021, December). COVID-19 care for uninsured individuals.

  U.S. Department of Health and Human Services. https://www.hhs.gov/coronavirus/covid-19-care-uninsured
- Hostetter M., & Klein S. (2021, January 14). Understanding and ameliorating medical mistrust among Black Americans. *The Commonwealth Fund*. https://www.commonwealthfund.org/publications/newsletter-article/2021/jan/medical-mistrust-among-black-americans
- Kim, S. R., Vann, M., Bronner, L., & Manthey, G. (2020, July 22). Which cities have the biggest racial gaps in COVID-19 testing access? *FiveThirtyEight*. https://fivethirtyeight.com/features/white-neighborhoods-have-more-access-to-covid-19-testing-sites/
- Milam, A. J., Furr-Holden, D., Edwards-Johnson, J., Webb, B., Patton, J. W., Ezekwemba, N. C., . . . Stephens, B. C. (2020). Are clinicians contributing to excess African American COVID-19 deaths? Unbeknownst to them, they may be. *Health Equity*, *4*(1), 139–141. https://doi.org/10.1089/heq.2020.0015

- National Association for the Advancement of Colored People. (n.d.). Respond to coronavirus with equitable health care access. NAACP. https://naacp.org/coronavirus/respond-to-coronavirus-with-equitable-health-care-access/
- Schoenthaler, A., Allegrante, J. P., Chaplin, W., & Ogedegbe, G. (2012, June). The effect of patient-provider communication on medication adherence in hypertensive black patients: does race concordance matter? *Annals of Behavioral Medicine*, 43(3), 372–382. https://doi.org/10.1007/s12160-011-9342-5
- Shen, M. J., Peterson, E. B., Costas-Muñiz, R., Hernandez, M. H., Jewell, S. T., Matsoukas, K., & Bylund, C. L. (2018). The effects of race and racial concordance on patient-physician communication:

  A systematic review of the literature. *Journal of Racial and Ethnic Health Disparities*, 5(1), 117–140. https://doi.org/10.1007/s40615-017-0350-4
- Sloan, C., Duddy-Tenbrunsel, R., Ferguson, S., & Kornfield, T. (2020). COVID-19 projected to worsen racial disparities in health coverage. *Avalere*. https://avalere.com/press-releases/covid-19-projected-to-worsen-racial-disparities-in-health-coverage
- Tompkins, L., Smith, M., Bosman, J., & Pietsch, B. (2021, March). Covid-19: U.S. surpasses 500,000 Covid-19 deaths, a monumental loss. *The New York Times*. https://www.nytimes.com/live/2021/02/22/world/covid-19-coronavirus
- Vann, M., Kim S. R., & Bronner, L. (2020, July 22). White neighborhoods have more access to COVID-19 testing sites: ANALYSIS. *ABC News*. https://abcnews.go.com/Politics/white-neighborhoods-access-covid-19-testing-sites-analysis/story?id=71884719
- Yu, Q., Salvador, C. E., Melani, I., Berg, M. K., Neblett, E. W., & Kitayama, S. (2021). Racial residential segregation and economic disparity jointly exacerbate COVID-19 fatality in large American cities. *ANNALS of the New York Academy of Science*. https://doi.org/10.1111/nyas.14567

# Review of Women's Health during the COVID-19 Pandemic: Impact on Sexual and Reproductive Healthcare

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The COVID-19 pandemic has caused unmeasurable loss and dramatically changed the lives of many people across America. Many of its harmful effects have had an especially large impact on women's health. This literature review discusses the impact COVID-19 has had on women's sexual and reproductive healthcare (SRH) in the United States, with a focus on disparities. SRH is defined holistically, including mental health and fertility preferences. Before the pandemic, there were many reasons access to preventative care was limited in the United States, including financial, geographical, and logistical barriers. When the healthcare system shifted its focus to COVID-19, preventative SRH care often fell through the cracks, further restricting access to high-quality care. Additionally, the recession caused by the pandemic worsened the financial burden of healthcare, and massive job loss left many people uninsured. The increased barriers to healthcare also applied to abortion access, which is already severely restricted due to restrictive legislation. Likewise, the COVID-19 had a unique effect on the physical and mental health of pregnant women and mothers. Not only are pregnant women at elevated risk for severe symptoms when infected with COVID-19, but stay-at-home orders impacted maternity care. Stress due to the pandemic also had specific effects on pregnant women and mothers. Like most aspects of the pandemic, women of color and low-income women were especially at risk for gender-specific barriers and negative health outcomes. Future policy must acknowledge these disparities and focus on expanding access through insurance policy and low-cost clinics.

#### Keywords

women's health • COVID-19 • preventative care • access to care • sexual and reproductive health • cancer screening • motherhood • telehealth • racial disparities in health • prenatal care • childbirth • mental health

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#### Introduction

Sexual and reproductive healthcare (SRH) is central to individual health and public health (Keller & Sonfield, 2019). The COVID-19 pandemic has introduced new barriers to obtaining SRH. This has impacted people of all ages and genders, especially women, people of color, youth, and sexual and gender minorities.

#### Preventative Care

Since March 2020, many people in the United States have been facing additional difficulty accessing healthcare, especially SRH. In a national study of cisgender women who have engaged in penile–vaginal sex administered from April to May 2020, one in three participants reported that they had to delay or cancel a reproductive care visit or had trouble accessing birth control. Black, Latina, and queer women reported even more difficulty getting access to sexual and reproductive health education, abortion, and contraception care than the general population (Lindberg, VandeVusse, Mueller, & Kirstein, 2020b).

People living in poverty, immigrants and undocumented people, and residents of rural areas also had increased barriers to care (Ott et al., 2020). The economic recession caused by the COVID-19 pandemic has made the cost of healthcare an even more significant barrier than it was before. Lindberg et al. (2020b) also found that one in four women were worried about affording contraception. Concerns about affording contraception were even more common for Latina women, queer women, and low-income women (Lindberg et al., 2020b). Additionally, federally qualified health centers and community-based clinics were especially hard-hit by budget, personal protective equipment, and staff shortages, forcing them to prioritize other urgent patient concerns during the pandemic. A decrease in resources spent on reproductive health by community clinics primarily impacts those who rely on lower-cost care, especially youth and underserved populations. Additionally, people living in rural areas have limited access to healthcare clinics due to physical distance, so if one clinic focuses its resources on COVID-19, local patients may not have other options (Ott et al., 2020). Low-income immigrant women face additional barriers because they may not be able to access federally funded clinics and are more likely to be uninsured (Desai & Samari, 2020). While COVID-19 impacted everyone, those who were already underserved by the healthcare system faced the most additional barriers to SRH due to the pandemic.

#### **Telehealth**

During the pandemic, there has been a shift toward telehealth services, which are an effective and safe alternative for many forms of healthcare. Like all forms of healthcare, telehealth is not accessible to all people, and there are disparities drawn by many different social identities, including race, age, geography, class, and ability. Among Medicare beneficiaries, women are less likely than men to have digital access (Roberts & Mehrotra, 2020). Racial disparities in access to healthcare and access to technology are also displayed in telehealth. Black and Hispanic people had lower usage of telehealth, and Black patients were more likely to use audio-only telehealth (Pierce & Stevermer, 2020). Black and Hispanic people are also less likely than the population overall to have either a computer or smartphone that would give them digital access (Roberts & Mehrotra, 2020).

At the August 2020 LA County Women and Girls Initiative Town Hall, Andrea Garcia, director of Community-Centered Initiatives at the LA County Department of Public Health, represented the LA City/County Native American Indian Commission. She shared that Native Americans lack digital access, especially those experiencing homelessness. Black and Native American people make up a disproportionate percentage of people experiencing homelessness (US Department of Housing and Urban Development, 2020).

Access to physical technology is not the only barrier to telehealth. Even though telehealth removes the requirement of physical proximity, people living in rural areas have reduced use of telehealth and are more likely to use audio only, likely because people living in rural areas and on tribal lands are less likely to have high-speed digital access (Pierce & Stevermer, 2020; Jaffe, Lee, & Huynh, 2020). Additional challenges in healthcare utilization often affect adults older than 65, including technology literacy and lack of technology support; the desire to utilize telehealth and trust of the internet; and ability, including mental acuity, hand—eye coordination, visual acuity, and auditory acuity (Kruse et al., 2020). Overall, women are more likely to utilize telehealth than men (Coleman et al., 2020). However, it is important to consider these intersecting factors when discussing women's health, as women's experiences are not solely based on their gender.

Even when used to its full potential, telehealth has inherent limitations for sexual and reproductive health. For example, the shift toward telehealth has caused a decrease in the use of long-acting, reversible contraceptive methods (LARC) because they must be inserted by a provider (Ott et al., 2020). LARCs are the most effective form of nonpermanent birth control. Winner et al. (2012) found that those using oral contraceptive pills, a transdermal patch, or a vaginal ring had a risk of contraceptive failure that was 20 times higher than the risk among those using LARCs, including the intrauterine device (IUD) and implant, although the risk is relatively low for all methods.

Fewer in-person routine appointments have prevented screening for sexually transmitted infections (STI) and contraceptive needs (Ott et al., 2020). Additionally, women, especially adolescents, may lack the privacy to discuss sexual and reproductive care with their provider in a telehealth visit during stay-at-home orders (Ott et al., 2020; Lindberg, Bell, & Kantor, 2020a).

# Sexually Transmitted Infections

Early in 2020, national infection rates of chlamydia, gonorrhea, and syphilis were higher than in 2019, following the trend of the last five years. In the spring, infection rates dropped due to a decrease in testing, not an actual decrease in cases ("2020 STD Prevention Conference," 2020). Bonett, Petsis, Dowshen, Bauermeister, & Wood (2021) found that from February 2019 to November 2020, STI testing rates decreased, but test positivity rates for chlamydia and gonorrhea increased (Napoleon et al., 2020). Chlamydia positivity rates increased by 10% in women and 18% in men between 2019 and 2020 (Pinto et al., 2021). Testing for chlamydia and gonorrhea decreased by approximately 59% for female patients (versus 63% for men) at its low point but gradually rebounded to about 15% below baseline by June 2020 (Pinto et al., 2021). The pandemic caused clinic closures and fears of going to see a healthcare provider, resulting in fewer tests. When testing is delayed, infected people have more time to pass the STI to others before receiving a diagnosis (Napoleon et al., 2020).

A rise in STIs should be thought of as a women's issue because untreated STIs in people with uteruses may lead to pelvic inflammatory disease, ectopic pregnancy, chronic pelvic pain, and adverse fetal and neonatal outcomes (Cohen et al., 2020). It is essential that testing centers continue to operate following COVID-19 precautions while expanding telehealth pretest screenings

and self-administered at-home tests ("2020 STD Prevention Conference," 2020; Napoleon et al., 2020). Though in-person activity has returned because of vaccine availability, STI testing may still be restricted due to medical supply chain disruptions. STI testing should be regarded as critical healthcare, and the test supplies needed should be prioritized (Bonett et al., 2021).

#### Sexual Health Education

COVID-19 has also impacted sexual and reproductive health education for adolescents. Sexual health education is primarily done in schools, but in many districts it was not transferred into the online curriculum. What has been missed may not be made up, especially with budget limitations due to the recession (Lindberg et al., 2020a). Maryjane Puffer, executive director of the LA Trust for Children's Health, stated, "With schools being closed, much of the informal communication about navigating the world for youth is very limited. Health education, while being provided, is not the same virtually as it would be in class." She went on to explain that youth who are sexually active or have experienced nonconsensual sexual activity now have limited access to the services provided at schools. Additionally, they may lack the privacy to discuss sexual health with trusted adults at school while learning at home. The transition to online learning was difficult for schools with tight budgets, and sexual health education and services were not often prioritized.

#### **HPV Vaccinations**

Cervical cancer is one of the most common causes of death for women worldwide. In the United States, over 4,000 people die of cervical cancer every year, with disproportionately high rates in low-income, Black, and Latinx women (Montealegre et al., 2020). The human papillomavirus (HPV) vaccine can prevent 90% of HPV-related cancers if given as recommended, between the ages of 9 and 12. During the pandemic, HPV vaccination has dropped by 73%, and while wellness visits for younger children have recovered, visits for preteens and teenagers remained low as of October 2020. Telehealth visits should be combined with in-person vaccinations, possibly through community partnerships, to increase accessibility to address historic disparities in underserved communities (American Cancer Society, 2020).

# Cancer Screenings

As the COVID-19 response was prioritized by healthcare systems, care for patients using preventive services was limited. This includes cancer screenings, which can help doctors find and treat several types of cancer before they cause symptoms, when the disease is often easier to treat and less likely to be deadly ("Cancer Screening Overview," 2021). However, cancer screenings were deemed nonessential and put on hold at the beginning of the pandemic to reduce transmission of COVID-19 and decrease the burden on the medical system, which led to a sharp decrease in screening (Cavallo, 2020).

Between March and May 2020, an estimated 285,000 women in the United States missed their breast cancer screening, and 40,000 missed cervical cancer screening (Mast & Munoz, 2021). After the stay-at-home order was lifted on June 12, cervical cancer screening rates at Kaiser Permanente in Southern California were still 24–29% lower for the next three months, as compared to the same

period in 2019. As rates recover, it is unclear if those who missed their routine screenings are now receiving care or if those screened are primarily people who were due for screening after reopening (Miller et al., 2021). Because of the second COVID-19 wave in the winter of 2020, another delay in screenings was recommended for low-risk patients as of December 2020. As of October 2021, screening recommendations are dependent on local COVID-19 prevalence and vaccination status, but screenings are still treated as a low-priority, non-urgent procedure (French, 2021). The drop in breast and colorectal cancer screenings and treatment due to COVID-19 could result in nearly 10,000 additional deaths in the next 10 years because detection and treatment are delayed. These effects will likely have a greater impact on historically underserved populations, who already had higher rates of death due to cancer and are most affected by COVID-19 (Sharpless, 2020; Singh & Jemal, 2017).

#### **Abortion Access**

Abortions can be performed via a surgical procedure or by mifepristone, an oral medication that induces abortion. Typically, people who are prescribed mifepristone must receive it from their healthcare provider in person. In order to prevent the spread of COVID-19, a federal court temporarily blocked the requirement for in-person visits to receive mifepristone ("Federal Court Blocks," 2020). From July 2020 through January 12, 2021, doctors (and in some states, advanced practice clinicians) could prescribe the abortion pill via telehealth visits and deliver it to patients by mail. This allowed pregnant people to receive abortions without the risk of COVID-19 exposure ("Federal Court Blocks," 2020; Reproductive Access Project, 2021). Additionally, "No-touch abortions" eliminated the requirement for people to have a blood test or ultrasound before a medication abortion, further protecting patients from COVID-19 exposure and allowing clinics to save personal protective equipment (Jones et al., 2020).

However, on January 12, 2021, the Supreme Court upheld the U.S. Food and Drug Administration's (FDA) regulation requiring in-person visits to receive mifepristone. Patients now must pick up abortion pills at a medical facility, although they generally will take the pill at home (Barnes, 2021). This ruling increases the risk of patients being infected with COVID-19 while accessing abortion care and adds unnecessary barriers to care as they will need to coordinate transportation, make more time in their schedule, and possibly find childcare.

Abortion is not always covered by insurance, and even with insurance there are often out-of-pocket costs. Low-income people and people of color are most impacted by the recession and more likely to not be able to access abortion services (National Institute for Reproductive Health, 2020). However, in some states, there are programs to address this barrier. In California, Medi-Cal does cover abortion services, and pregnant people can enroll in coverage the same day they have their appointment, with a process called "presumptive eligibility" (National Health Law Program, 2020; Department of Health Care Services, 2021).

# Pregnancy and Motherhood During COVID-19

Pregnant people are more susceptible to viral infection, and data on coronavirus are consistent with this vulnerability (Sharma et al., 2020; Zambrano et al., 2020). Pregnant women with COVID-19 are also more likely to have symptoms and require more intensive healthcare, including ICU

admission, invasive ventilation, and extracorporeal membrane oxygenation (Zambrano et al., 2020). Though the risk of death remains low, there is an increased risk for death associated with pregnancy in patients with COVID-19. Zambrano et al. (2020) reported 1.5 deaths per 1,000 cases in pregnant women, and 1.2 deaths per 1,000 cases in nonpregnant women, with an adjusted risk ratio of 1.7. Hispanic women had an adjusted risk ratio of 2.4, meaning pregnancy put them at an even greater risk of dying due to COVID-19. Pregnant and nonpregnant Black women had higher rates of death due to COVID-19 than the corresponding general populations (Zambrano et al., 2020).

Vertical transmission of COVID-19 needs to be studied further, but some evidence suggests vaginal delivery and cesarean birth do not cause transmission of COVID-19 from the birthing parent to the infant (Sharma et al., 2020; Weigel, 2020; Martinez-Perez, 2020). Cesarean deliveries in people with COVID-19 were associated with maternal health complications in a study of 82 pregnant people, likely due to the stress of surgery (Martinez-Perez, 2020). Birthing parents with confirmed or suspected COVID-19 may stay in the same hospital room as their newborn after birth with safety precautions if they feel well enough to provide care (Wycoff, 2021).

Though their increased risk means pregnant people should protect themselves from COVID-19 and follow safety guidelines to the best of their ability, this was especially challenging for essential workers, single mothers, people experiencing homelessness, and others who were unable to stay at home during the peak of the pandemic (Zambrano et al., 2020).

## **Fertility Preferences**

People's decisions about having children are impacted by their social and economic contexts. COVID-19 has caused economic instability and a general unease about the future, and studies predict a large decrease in births during and following the pandemic. One study by economists predicted 300,000 fewer births in 2021 in the United States (Kearney & Levine, 2020). A national survey in May 2020 found that 34% of women decided to delay having children or wanted fewer children because of the pandemic. Black women, Latina women, queer women, and low-income women were more likely to report this change (Lindberg et al., 2020). While it is too soon to fully evaluate the connection between birth rate and the COVID-19 pandemic, in January 2021, the birth rate in the United States had decreased by 9.41% from January 2020, following the prediction by Kearney and Levine (2020). However, since March 2021, the decline had slowed to below 1% (Morse, 2021). The misalignment with the prediction may have been because Kearney and Levine (2020) did not predict the vaccine would become widely available as quickly as it did.

#### Prenatal Care

Telehealth is a viable method to provide safe care to pregnant women. When some prenatal appointments are moved to telemedicine, women seem to have comparable outcomes and feel a slightly higher level of satisfaction with their care. However, the home monitoring tools used in virtual care can also be expensive and are not always covered by health insurance. These tools may include blood pressure cuffs, scales, and a fetal Doppler, and together cost around \$100 (Freyer et al., 2020; Butler et al., 2019; Weigel et al., 2020). Before COVID-19 vaccines became available, allowing for

in-person prenatal care, the high out-of-pocket price of home monitoring tools may have been a barrier to adequate care, especially for low-income mothers.

# Disparities in Pregnancy Care

Even before the pandemic, pregnant Black and Native people faced disproportionately high rates of maternal morbidity and mortality due to systemic racism. The pandemic is expected to increase rates of complications and poor outcomes as access to care is limited, which will only further decrease Black and Native women's trust in the healthcare system and deter them from seeking help (Connor et al., 2020). Pregnant immigrants may also experience more negative health outcomes because the pandemic has especially impacted low-income immigrant communities. Immigrants, especially undocumented people, also face an additional layer of stress navigating misinformation about health and fear of immigration enforcement while accessing prenatal care, and before the pandemic already had less access to prenatal care than other U.S. residents (Fabi & Ludmir, 2021; Wycoff, 2021).

# Giving Birth During a Pandemic

COVID-19 also presented challenges for people during birth. Family members who had planned to travel for the birth were unable to because of COVID-19, especially before the vaccine was available. Hospitals also limited the number of support people attending the birth. Changes in birth plans can be very stressful for pregnant people (Weigel, 2020; Fakari & Simbar, 2020). At the August 2020 LA County Women and Girls Initiative Town Hall, Nourbese Flint, program manager for Black Women for Wellness, an advocacy and community health nonprofit, stated, "A lot of folks are rethinking their whole birthing plan... there is just a lot of confusion and fear about going to the hospital.... Tied with the already disproportionately high maternal mortality and morbidity and infant mortality and morbidity in the black community, that only exacerbates what we've already been seeing." As Flint stated, Black and Indigenous women are significantly more likely to die of pregnancy-related causes. Hospital restrictions on the number of support people who can be present during childbirth may leave women of color without adequate support or advocacy from family, friends, and/or doulas (Ott et al., 2020).

# Breastfeeding and COVID-19

With proper hygiene, there is no evidence of COVID-19 transmission through breastfeeding, and breastfeeding boosts the immune system of infants, protecting them from infectious disease (Lubbe, Botha, Niela-Vilen, & Reimers, 2020). Breastfeeding parents with COVID-19 should take precautions by wearing a mask when within 6 feet of their infant and washing their hands for 20 seconds with soap and water before caring for their child. Parents with COVID-19 may also express breast milk and have a healthy caregiver, who is vaccinated and not at increased risk for severe illness from COVID-19, feed the milk to the baby. After the isolation period, breastfeeding and skin-on-skin contact should be encouraged when possible (Lubbe et al., 2020; "Breastfeeding and caring," 2021).

Due to COVID-19, it may be challenging for new parents to receive lactation support, which can make breastfeeding difficult. Whenever possible, newborn follow-up visits should be held in

person, where providers can evaluate feeding and weight gain. If additional services were needed before the COVID-19 vaccine was available, lactation support should have been done virtually whenever possible ("Breastfeeding people," 2021). Not only was virtual lactation support (telelactation) safer during the peak of the pandemic, it was often more affordable and more accessible for busy parents and those who do not live near lactation resources (Dhillon & Dhillon, 2020; Grubesic & Durbin, 2020; Schindler-Ruwisch & Phillips, 2020). However, there are logistical and technical difficulties with telelactation, and it may be challenging to collect accurate information on the infant's weight or diagnose oral issues (Demirci et al., 2019). The necessity of virtual lactation consultations may have decreased the standard of care for new mothers during the height of the pandemic. If the lactation consultant and parents are fully vaccinated and not at risk for serious illness from COVID-19, lactation support can now be performed in-person following CDC guidelines ("Breastfeeding people," 2021).

#### Maternal Mental Health

There has been a well-studied link between poor mental health during pregnancy and unfavorable maternal and infant outcomes (Alder et al., 2007; Field et al., 2010). Fear and stress due to COVID-19 caused increased symptoms of anxiety and depression during pregnancy (Masjoudi et al., 2020; Salehi et al., 2020; Berthelot et al., 2020). Women who felt the most threatened by COVID and the least confident about their safety precautions had higher rates of mental health issues and birth complications (Qi et al., 2020). This stress may have stemmed from fear of the virus itself, financial stress associated with the recession, and/or the stress of drastic changes to their lives and birth plans (Salehi et al., 2020; Qi et al., 2020; Rashidi & Simbar, 2020). Previous mental health diagnoses, financial strain, and low household income were correlated with poor mental health, including depression and anxiety (Cameron et al., 2020).

In April 2020, prenatal and postpartum depression and anxiety had increased to about 33–36%, from the non-pandemic population comparison of 13–25% (Cameron et al., 2020). Due to isolation and social distancing measures, pregnant people were less able to rely on the support of friends and relatives (Rashidi & Simbar, 2020). Because social support is an important defense against mental health concerns during and after pregnancy, new parents may have experienced additional stress leading to poor mental health (Qi et al., 2020; Etiebet, 2020).

The stress of COVID-19 and isolation also affected mothers of older children. In a national survey of self-reported stress due to the COVID-19 pandemic in late March 2020, there was a striking gender gap in respondents who stated, "worry or stress related to the coronavirus has had a negative impact on their mental health." Fifty three percent of women overall reported that stress had impacted their mental health, while only 37% of men claimed the same. The gap was even wider among parents of children under 18. Stress in mothers increased to 57% compared to women overall, while stress in fathers decreased to 32% (Hammel & Salanicoff, 2020).

Though multiple factors contribute to this disparity, women's higher rates of anxiety during the pandemic align with gender roles in the home and the unequal distribution of family caregiving responsibilities (Hammel & Salanicoff, 2020). During the pandemic, as children spend more time at home, women have taken on even more work as caregivers for children and other family members. Among married heterosexual couples, before the pandemic, women spent 10.9 hours per day on childcare, compared to 7.2 hours spent by men. During the pandemic, women increased their

childcare time by 6.1 hours per day, compared to 4.7 hours by men (Alon et al., 2020). Furthermore, there has been a significant increase in depression and anxiety in mothers, with symptoms that interfere with their daily activities, including job performance, schoolwork, and relationships. This especially affected mothers who have low household incomes, low social support, and low marriage quality and who experienced employment loss and financial strain (Cameron et al., 2020).

#### Conclusion

As the U.S. healthcare system prioritizes COVID-19, resources have been diverted from the sexual and reproductive health programs that many people rely on (Desai & Samari, 2020). Rapid change was necessary to avoid the spread of COVID-19, but some preventative measures unintentionally decreased the quality of sexual and reproductive care. For example, the shift to telehealth, while effective in maintaining stay-at-home orders, is not accessible to all and restricts the health services that can be available. Additionally, hospitals and clinics were forced to delay non-urgent services in order to keep up with the demands of COVID-19, but many of these services are necessary to prevent future disease. While COVID-19 needed to be prioritized, reproductive care is still essential. Many people are facing additional barriers to accessing contraception, STI testing and treatment, abortion, and obstetric care. Due to high unemployment and the recession, the cost of healthcare may hinder people from accessing care more often than before the pandemic.

Like all aspects of COVID-19's effects, the impact on reproductive care has followed existing social inequities, disproportionately affecting Latinx and Black, LGBTQ+, and low-income women.

#### Recommendations

Women need accurate, up-to-date information so that they can make informed choices and community support to help them through these challenges (Etiebet, 2020). Policy makers must realize that access to SRH is necessary for people to maintain wellness and autonomy, and the healthcare system must be reformed to support this need (Lindberg et al., 2020b; Ahmed, Dawson, Donovan, Keller, & Sonfield, 2020). It is also important to center those who have been the most marginalized to ensure our approach to sexual and reproductive health is equitable and accounts for diverse needs (Connor et al., 2020; Ahmed et al., 2020). A community-based approach, where those who the program seeks to benefit are involved in decision-making, best ensures that real needs will be met (Lindberg et al., 2020b; Desai & Samari, 2020; Etiebet, 2020). Options to improve access to SRH during and after the COVID-19 pandemic include:

- Lifting the FDA's restrictions on medication abortion
- The requirement for an in-person visit to access mifepristone, the abortion pill, a change by the Trump administration, described in Abortion Access. The Biden administration could immediately suspend the enforcement of this requirement and review the other FDA restrictions on mifepristone ("Tell the Biden Administration," 2021).
- Creating reliable platforms online where pregnant people can learn from each other and healthcare professionals while staying safe in their homes
- During the pandemic, there are additional barriers to forming communities among pregnant people and creating relationships with providers. Online forums where women and professionals

- could talk would make up-to-date information accessible and make pregnant people feel more supported (Etiebet, 2020).
- Developing telehealth
- With telehealth, many SRH services, including contraceptive prescription, medication abortion, preexposure prophylaxis to prevent HIV, and some prenatal and postpartum care, can be provided without risk of exposure to COVID-19. Even as in-person activity returns after the development of the vaccine, telehealth can be used to expand access to care by removing geographic, transportation, and childcare barriers. The federal and state agencies must eliminate unnecessary restrictions on telehealth and its insurance coverage (Ott et al., 2020; Ahmed et al., 2020).
- Expanding of access to comprehensive insurance coverage
- The recession during the pandemic has caused many people to lose their jobs, and therefore their health insurance. Ensuring coverage removes a large financial barrier from many essential health services, including sexual and reproductive health (Lindberg et al., 2020b). This includes expanding the Affordable Care Act and Medicaid, specifically including SRH expenses, such as contraceptives and HIV medication. It also includes repealing the Hyde Amendment, which prevents federal funds from covering most abortions (Ahmed et al., 2020).
- Continuing local programs to support sexual and reproductive health
- For example, LA County has created important policies to improve access to SRH, such as offering free STI/HIV testing (Division of HIV and STD Programs, n.d.). The state of California has also created programs to support sexual and reproductive health, including the Black Infant Health program which provides free group support sessions, life planning services, and case management ("Black Infant Health," 2021). Local programs that provide basic, necessary services at a low cost have a huge effect on community health and should be expanded to locations that do not have these resources.

#### References

- Ahmed, Z., Dawson, R., Donovan, M. K., Keller, L. H., & Sonfield, A. (2020, April 8) *Nine things congress must do to safeguard sexual and reproductive health in the age of COVID-19. Guttmacher Institute.*Guttmacher Institute. https://www.guttmacher.org/article/2020/04/nine-things-congress-must-do-safeguard-sexual-and-reproductive-health-age-covid-19
- Alder J, Fink N, Bitzer J, et al. (2007). Depression and anxiety during pregnancy: A risk factor for obstetric, fetal and neonatal outcome? A critical review of the literature. *Journal of Maternal–Fetal and Neonatal Medicine*, 20(3),189–209. doi: 10.1080/14767050701209560.
- Alon, T., Doepke, M., Olmstead-Rumsey, J., & Tertilt, M. (2020, August 27) The impact of the COVID-19 crisis on women's employment. *Econofact*. https://econofact.org/impact-of-the-covid-19-crisis-on-womens-employment
- American Cancer Society (2020). Safely resuming and promoting cancer screening during the COVID-19 pandemic. https://www.acs4ccc.org/wp-content/uploads/2021/07/ACS\_Guidance\_on\_Cancer\_Screening-Report\_October-2020\_Toolkit.pdf
- Barnes, R. (2021, January 12). Supreme Court restores requirements for medication abortions, siding with Trump administration. *Washington Post.* https://www.washingtonpost.com/politics/courts\_law/supreme-court-medication-abortion/2021/01/12/3720192c-4617-11eb-a277-49a6d1f9dff1\_story.html

- Berthelot, N., Lemieux, R., Garon-Bissonnette, J., Drouin-Maziade, C., Martel, É., & Maziade, M. (2020). Uptrend in distress and psychiatric symptomatology in pregnant women during the COVID-19 pandemic. *Acta Obstetricia et Gynecologica Scandinavica*. doi: 10.1111/aogs.13925.
- Black Infant Health. (2021, October 5). California Department of Public Health. https://www.cdph.ca.gov/ Programs/CFH/DMCAH/BIH/Pages/Default.aspx
- Breastfeeding and caring for newborns if you have COVID-19 (2021, August 18). Centers for Disease Control and Prevention. https://www.cdc.gov/coronavirus/2019-ncov/if-you-are-sick/pregnancy-breastfeeding.html?CDC\_AA\_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2F2019-ncov%2Fneed-extra-precautions%2Fpregnancy-breastfeeding.html
- Breastfeeding people: Interim guidance on breastfeeding and breast milk feeds in the context of COVID-19 (2021, July 17). Centers for Disease Control and Prevention. https://www.cdc.gov/breastfeeding/breastfeeding-special-circumstances/maternal-or-infant-illnesses/covid-19-and-breastfeeding. html#:~:text=For%20all%20home%20visits%20regardless,than%206%20feet%20apart
- Bonett, S., Petsis, D., Dowshen, N., Bauermeister, J., & Wood, S. M. (2021). The impact of the COVID-19 pandemic on STI/HIV testing among adolescents in a large pediatric primary care network. *Sexually Transmitted Diseases, Publish Ahead of Print*. https://doi.org/10.1097/olq.0000000000001427
- Butler Tobah, Y. S., LeBlanc, A., Branda, M. E., Inselman, J. W., Morris, M. A., Ridgeway, J. L., . . . Famuyide, A. (2019). Randomized comparison of a reduced-visit prenatal care model enhanced with remote monitoring. *American Journal of Obstetrics and Gynecology*, 221(6), 638.e1–638.e8. https://doi.org/10.1016/j.ajog.2019.06.034
- Cameron, E. E., Joyce, K. M., Delaquis, C. P., Reynolds, K., Protudjer, J. L. P., & Roos, L. E. (2020). Maternal psychological distress & mental health service use during the COVID-19 pandemic. *Journal of Affective Disorders*, 276, 765–774. https://doi.org/10.1016/j.jad.2020.07.081
- Cancer screening overview: Health professional version (2021, June 2021). National Cancer Institute https://www.cancer.gov/about-cancer/screening
- Cavallo, J. (2020, August 10). Measuring the impact of the plunge in cancer screenings during the COVID-19 pandemic: A conversation with Stephen B. Edge, MD. *The ASCO Post.* https://ascopost.com/issues/august-10-2020/measuring-the-impact-of-the-plunge-in-cancer-screenings-during-the-covid-19-pandemic/
- Cohen, M. A., Powell, A. M., Coleman, J. S., Keller, J. M., Livingston, A., & Anderson, J. R. (2020). Special ambulatory gynecologic considerations in the era of coronavirus disease 2019 (COVID-19) and implications for future practice. *American Journal of Obstetrics and Gynecology*, 223(3), 372–378. https://doi.org/10.1016/j.ajog.2020.06.006
- Coleman, L., Farrell, A., Khan, I., Wiseman, J., Mph, E., & Quatman, C. (2020). Age Trending Gender Differences in Musculoskeletal Telehealth Utilization. Presented at International Geriatric Fracture Society Virtual Annual Meeting. https://www.geriatricfracture.org/uploads/7/0/8/8/70883861/coleman\_-\_age\_trending\_gender\_differences\_in\_musculoskeletal\_telehealth\_utilization\_igfs.pdf
- Connor, J., Madhavan, S., Mokashi, M., Amanuel, H., Johnson, N. R., Pace, L. E., & Bartz, D. (2020). Health risks and outcomes that disproportionately affect women during the Covid-19 pandemic: A review. *Social Science & Medicine*, 266, 113364. https://doi.org/10.1016/j.socscimed. 2020.113364

- Demirci, J., Kotzias, V., Bogen, D. L., Ray, K. N., & Uscher-Pines, L. (2019). Telelactation via mobile app: Perspectives of rural mothers, their care providers, and lactation consultants. *Telemedicine and e-Health*, 25(9). https://doi/10.1089/tmj.2018.0113
- Department of Health Care Services (2021). Presumptive eligibility for pregnant women. https://www.dhcs.ca.gov/services/medi-cal/eligibility/Pages/PE.aspx
- Desai, S., & Samari, G. (2020). COVID-19 and immigrants' access to sexual and reproductive health services in the United States. *Perspectives on Sexual and Reproductive Health*, 52(2), 69–73. https://doi.org/10.1363/psrh.12150
- Dhillon, S., & Dhillon, P. S. (2020). Telelactation: A necessary skill with puppet adjuncts during the COVID-19 pandemic. *Journal of Human Lactation*, *36*(4), 619–621. https://doi.org/10.1177/0890334420958623
- Division of HIV and STD Programs (n.d.). STD screening and treatment services. LA County Department of Public Health. http://publichealth.lacounty.gov/dhsp/STDClinics.htm
- Etiebet, M. A. (2020, May 5). Keeping pregnant women safe during the pandemic. *Scientific American Blog Network*. https://blogs.scientificamerican.com/observations/keeping-pregnant-women-safe-during-the-pandemic/
- Fabi, R. E., & Ludmir, J. (2021). Pregnancy, pandemics, and public health policy: The disparate impact of COVID-19 on pregnant immigrants. *Women's Health Issues*, 31(3), 195–197. https://doi.org/10.1016/j.whi.2020.12.001
- Fakari, F. R., & Simbar, M. (2020). Coronavirus pandemic and worries during pregnancy; A letter to editor. *Archives of Academic Emergency Medicine*, 8(1), e21. https://doi.org/10.22037/aaem.v8i1.598
- Federal Court Blocks FDA Restriction That Unnecessarily Imposes COVID-19 Risks on Patients Seeking Abortion Care. (2020). American Civil Liberties Union. https://www.aclu.org/press-releases/federal-court-blocks-fda-restriction-unnecessarily-imposes-covid-19-risks-patients
- Field, T., Diego, M., Hernandez-Reif, M., et al. (2010). Comorbid depression and anxiety effects on pregnancy and neonatal outcome. *Infant Behavior and Development*, 33(1), 23–29. doi:10.1016/j.infbeh.2009.10.004
- French, V. (2021, October 20). Coronavirus (COVID-19) and women's health care: A message for patients. American College of Obstetricians and Gynecologists. https://www.acog.org/womens-health/faqs/coronavirus-covid-19-and-womens-health-care
- Grubesic, T. H., & Durbin, K. M. (2020). The complex geographies of telelactation and access to community breastfeeding support in the state of Ohio. *PLOS ONE*, 15(11), e0242457. https://doi.org/10.1371/journal.pone.0242457
- Hammel, L., & Salganicoff, A. (2020, April 6). Is there a widening gender gap in coronavirus stress? Kaiser Family Foundation. https://www.kff.org/policy-watch/is-there-widening-gender-gap-in-coronavirus-stress/
- Jaffe, D. H., Lee, L., & Huynh, S. (2020). Health inequalities in the use of telehealth in the United States in the lens of COVID-19. *Population Health Management*, 23(5). https://pubmed.ncbi.nlm.nih.gov/32816644/
- Jones, R. K., Lindberg, L., & Witwer, E. (2020). COVID -19 abortion bans and their implications for public health. *Perspectives on Sexual and Reproductive Health*, 52(2), 65–68. https://doi.org/10.1363/psrh.12139

- Kearney, M. S., & Levine, P. B. (2020, December 17). The coming COVID-19 baby bust: Update. Brookings. https://www.brookings.edu/blog/up-front/2020/12/17/the-coming-covid-19-baby-bust-update/
- Keller, S. H., & Sonfield A. (2019) More to be done: Individuals' needs for sexual and reproductive health coverage and care. *Guttmacher Policy Review*, 22, 8–15. https://www.guttmacher.org/gpr/2019/02/more-be-done-individuals-needs-sexual-and-reproductive-health-coverage-and-care
- Kruse, C., Fohn, J., Wilson, N., Nunez Patlan, E., Zipp, S., & Mileski, M. (2020). Utilization barriers and medical outcomes commensurate with the use of telehealth among older adults: Systematic review. *JMIR Medical Informatics*, 8(8), e20359. https://doi.org/10.2196/20359
- Lindberg, L. D., Bell, D. L., & Kantor, L. M. (2020a). The sexual and reproductive health of adolescents and young adults during the COVID -19 pandemic. *Perspectives on Sexual and Reproductive Health*, 52(2), 75–79. https://doi.org/10.1363/psrh.12151
- Lindberg, L. D., VandeVusse, A., Mueller, J., & Kirstein, M. (2020b). Early Impacts of the COVID-19 Pandemic: Findings from the 2020 Guttmacher survey of reproductive health experiences. https://doi.org/10.1363/2020.31482
- Lubbe, W., Botha, E., Niela-Vilen, H., & Reimers, P. (2020). Breastfeeding during the COVID-19 pandemic a literature review for clinical practice. *International Breastfeeding Journal*, 15(1). https://doi.org/10.1186/s13006-020-00319-3
- Martínez-Perez, O., Vouga, M., Cruz Melguizo, S., Forcen Acebal, L., Panchaud, A., Muñoz-Chápuli, M., & Baud, D. (2020). Association between mode of delivery among pregnant women with COVID-19 and maternal and neonatal outcomes in Spain. *JAMA*, 324(3), 296. https://doi.org/10.1001/jama.2020.10125
- Masjoudi, M., Aslani, A., Khazaeian, S., et al. (2020). Explaining the experience of prenatal care and investigating the association between psychological factors with self-care in pregnant women during COVID-19 pandemic: A mixed method study protocol. *Reproductive Health*, 17(98), 1–7. doi:10.1186/s12978-020-00949-0
- Mast, C., & Munoz, A. (2021, July 17). Delayed cancer screenings—A second look. *Epic Health Research Network*. https://ehrn.org/articles/delayed-cancer-screenings-a-second-look
- Miller, M. J., Xu, L., Qin, J., Hahn, E. E., Ngo-Metzger, Q., Mittman, B., Tewari, D., Hodeib, M., Wride, P., Saraiya, M., & Chao, C. R. (2021). Impact of COVID-19 on cervical cancer screening rates among women aged 21–65 years in a large integrated health care system: Southern California, January 1– September 30, 2019, and January 1–September 30, 2020. MMWR. Morbidity and Mortality Weekly Report, 70(4), 109–113. https://doi.org/10.15585/mmwr.mm7004a1
- Montealegre, J. R., Duncan, D. L., & Chiao, E. Y. (2020, August 21). Cervical cancer screening in the COVID-19 era. *Baylor College of Medicine Blog Network*. https://blogs.bcm.edu/2020/08/21/cervical-cancer-screening-in-the-covid-19-era/
- Morse, A. (2021, September 21). *U.S. births declined during the pandemic: Fewer babies born in December and January but number started to rise in March.* United States Census Bureau. https://www.census.gov/library/stories/2021/09/united-states-births-declined-during-the-pandemic.html
- Napoleon, S. C., Maynard, M. A., Almonte, A., Cormier, K., Bertrand, T., Ard, K. L., & Chan, P. A. (2020). Considerations for STI clinics during the COVID-19 pandemic. *Sexually Transmitted Diseases*, 47(7), 431–433. https://doi.org/10.1097/olq.000000000001192

- National Health Law Program (2020). An advocate's guide to Medi-Cal services: Chapter VI: Reproductive and Sexual Health Services. https://healthlaw.org/wp-content/uploads/2020/02/NHeLP-MediServicesGuide-Complete-Ch6.pdf.
- National Institute for Reproductive Health (2020). Gaining ground: Proactive reproductive health and rights legislation in the states 2020: 2020 year in review. https://www.nirhealth.org/wp-content/uploads/2020/12/NIRH\_2020\_End-of-Year.pdf
- Ott, M. A., Bernard, C., Wilkinson, T. A., & Edmonds, B. T. (2020). Clinician perspectives on ethics and COVID-19: Minding the gap in sexual and reproductive health. *Perspectives on Sexual and Reproductive Health*, 52(3), 145–149. https://doi.org/10.1363/psrh.12156
- Pagaoa, M., Grey, J., Torrone, E., Kreisel, K., Stenger, M., & Weinstock, H. (2021). Trends in nationally notifiable sexually transmitted disease case reports during the US COVID-19 pandemic, January to December 2020. Sexually Transmitted Diseases, 48(10), 798–804. https://doi.org/10.1097/olq.00000000001506
- Pierce, R. P., & Stevermer, J. J. (2020). Disparities in use of telehealth at the onset of the COVID-19 public health emergency. *Journal of Telemedicine and Telecare*, 1357633X2096389. https://doi.org/10.1177/1357633x20963893
- Pinto, C. N., Niles, J. K., Kaufman, H. W., Marlowe, E. M., Alagia, D. P., Chi, G., & Van Der Pol, B. (2021). Impact of the COVID-19 pandemic on chlamydia and gonorrhea screening in the U.S. *American Journal of Preventive Medicine*, 61(3), 386–393. https://doi.org/10.1016/j. amepre.2021.03.009
- Qi, M., Li, X., Liu, S., Li, Y., & Huang, W. (2020). Impact of the COVID-19 epidemic on patterns of pregnant women's perception of threat and its relationship to mental state: A latent class analysis. *PLOS ONE*, 15(10), e0239697. https://doi.org/10.1371/journal.pone.0239697
- Reproductive Health Access Project. *No Touch Medication Abortion Protocol.* (2021, May). https://www.reproductiveaccess.org/wp-content/uploads/2020/03/03-2020-no-touch-MAB.pdf
- Roberts, E. T., & Mehrotra, A. (2020). Assessment of disparities in digital access among medicare beneficiaries and implications for telemedicine. *JAMA Internal Medicine*, 180(10), 1386. https://doi.org/10.1001/jamainternmed.2020.2666
- Salehi, L., Rahimzadeh, M., Molaei, E., Zaheri, H., & Esmaelzadeh-Saeieh, S. (2020). The relationship among fear and anxiety of COVID-19, pregnancy experience, and mental health disorder in pregnant women: A structural equation model. *Brain and Behavior*, 10(11). https://doi.org/10.1002/brb3.1835
- Schindler-Ruwisch, J., & Phillips, K. (2020, October 28). Breastfeeding during a pandemic: The impact of COVID-19 on lactation services. *American Public Health Association Annual Meeting*. https://apha.confex.com/apha/2020/meetingapp.cgi/Session/62140
- Sharma, S., Burd, I., & Liao, A. (2020). Special issue on COVID-19 and pregnancy: Consequences for maternal and neonatal health. *American Journal of Reproductive Immunology*, 84(5). https://doi.org/10.1111/aji.13354
- Sharpless, N. E. (2020). COVID-19 and cancer. *Science*, *368*(6497), 1290–1290. https://doi.org/10.1126/science.abd3377

- Singh, G. K., & Jemal, A. (2017). Socioeconomic and racial/ethnic disparities in cancer mortality, incidence, and survival in the United States, 1950–2014: Over six decades of changing patterns and widening inequalities. *Journal of Environmental and Public Health*, 2017, 1–19. https://doi.org/10.1155/2017/2819372
- Tell the Biden Administration: Safe access to abortion now (2021). American Civil Liberties Union. https://action.aclu.org/petition/tell-biden-administration-safe-access-abortion-now?ms= www.actionpage&initms=www.actionpage&ms\_aff=NAT&initms\_aff=NAT&ms\_chan= web&initms\_chan=web#readmore
- The U.S. Department of Housing and Urban Development: Office of Community Planning and Development. (2020, September). The 2018 annual homelessness assessment report (AHAR) to Congress. https://www.huduser.gov/portal/sites/default/files/pdf/2018-AHAR-Part-2.pdf
- Weigel, G. (2020, March 17). Novel coronavirus "COVID-19": Special considerations for pregnant women. Kaiser Family Foundation. https://www.kff.org/womens-health-policy/issue-brief/novel-coronavirus-covid-19-special-considerations-for-pregnant-women/.
- Weigel, G., Frederiksen, B., & Ranji, U. (2020, February 26). Telemedicine and pregnancy care. Kaiser Family Foundation. https://www.kff.org/womens-health-policy/issue-brief/telemedicine-and-pregnancy-care/
- Winner, B., Peipert, J. F., Zhao, Q., Buckel, C., Madden, T., Allsworth, J. E., & Secura, G. M. (2012). Effectiveness of long-acting reversible contraception. *New England Journal of Medicine*, *366*(21), 1998–2007. https://doi.org/10.1056/nejmoa1110855
- Wyckoff, A. S. (2021, October 19). Rooming-in, with precautions, now OK in revised AAP newborn guidance. *AAP News*. https://www.aappublications.org/news/2020/07/22/newbornguidance072220
- Zambrano, L. D., Ellington, S., Strid, P., Galang, R. R., Oduyebo, T., Tong, V. T., . . . Krause, K. (2020). Update: Characteristics of symptomatic women of reproductive age with laboratory-confirmed SARS-CoV-2 infection by pregnancy status United States, January 22–October 3, 2020. *MMWR. Morbidity and Mortality Weekly Report*, 69(44), 1641–1647. https://doi.org/10.15585/mmwr.mm6944e3
- 2020 STD Prevention Conference. (2021). https://www.cdc.gov/nchhstp/newsroom/2020/2020-std-prevention-conference.html

# The Effects of the COVID-19 Pandemic on Social Media Usage and Body Image Perceptions in Young Adults

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The coronavirus pandemic resulted in wholly unprecedented shifts in daily life and routine. This included more individuals working from home, utilizing video chatting software daily, and increased social media usage (SMU) during lockdowns. SMU has consistently been shown to increase during crises. Social media and video chat usage are on the rise, but many do not acknowledge the negative impacts of high usage. However, high SMU has been associated with negative body image perception and reduced self-confidence. It has also been associated with the development of other disordered behaviors and conditions such as eating disorders and anxiety. Through a comprehensive literature review of recently published studies, there appears to be a strong association between young adults who increased their SMU during the pandemic and suffered from a negative body image perception and reduced self-confidence. As an example, adding more body-positive programming aimed at improving body image perceptions and self-confidence will likely contribute to a reduced chance of developing associated behaviors. Furthermore, mitigation strategies such as mindfulness, cognitive reappraisal, and dialectical thinking should be encouraged and widely accessible in the United States regardless of insurance coverage. However, further research will be needed to determine if these effects will persist post-pandemic and which mitigation strategies are most effective.

#### Keywords

social media usage • covid-19 • body-image perception • young adults

#### Introduction

The COVID-19 pandemic, a massive crisis, led to increased social media usage (SMU). The unprecedented nature of the pandemic led to many schools, organizations, and workplaces going fully

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remote. Many individuals may have been motivated to use social media to "maintain relationships" and "pass time" (Bowden-Green, Hinds, & Joinson, 2021). Indeed, as many individuals suddenly returned to their homes and altered their routines, social media proved to be one constant. It also led to COVID-19-related stress responses (i.e., stress caused from hearing news about the pandemic), which are believed to be associated with SMU. This is because social media became flooded with celebrities, and common folk alike, posting about their time in isolation and new news updates. Findings from a study showed that COVID-19 stress was positively associated with tendencies toward addictive SMU and that individuals with higher levels of COVID-19-related stress are at an increased risk of addictive SMU (Zhao & Zhou, 2021). In addition to increased stress, individuals often reported high levels of loneliness due to forced isolation. In another study, participants found that they spent more hours/day on social media during the pandemic and that perceived feelings of loneliness predicted both social media use and anxiety (Boursier, Gioia, Musetti, & Schimmenti, 2020). Therefore, SMU seems to potentially mediate negative health outcomes.

Young adults, including college students, are believed to be an already vulnerable population for mental health concerns. In several studies with a college student sample, there was a pronounced rise in the prevalence rates of mental health problems (45%) such as acute stress (34.9%) and depressive (21.1%) and anxiety symptoms (11.0%) (Ma et al., 2020). Students who had more than three hours/day of social media coverage of COVID-19 were also 2.13 times more likely than students with less than one hour/day to have acute stress symptoms (Ma, Zhao, Li, Chen, Wang, Zhang, Yu, Jiang, Fan, & Liu, 2020). Overall, remote work and life during COVID-19, in addition to the stress of living through a pandemic, correlated to increased SMU.

#### Methods

This literature review was conducted through a comprehensive search of the most recent and up-to-date literature using PubMed and Google Scholar. The search yielded many relevant articles dating back to 2016. Besides two articles that generally explored the relationship between social media and perception, the rest of the sources were from 2019 to 2021 and focused on this relationship during the pandemic. The key search terms used include "social media usage," "covid-19," "mental health," "body image," "depression," "self-confidence," "effects," and "mitigation strategies." The articles found utilized a variety of methods including clinical trials, mixed methods, meta-analysis, systematic reviews, and more. Future papers should further explore the impacts of other factors such as race, ethnicity, geography, and more on this phenomenon.

# High SMU

High SMU has been commonly associated with negative self-perception of body image along with other health concerns. SMU provides an opportunity for social comparison and exposure to unrealistic beauty expectations. It has also been shown that body dissatisfaction is likely to result from frequent use of social media (Mills, Musto, Williams, & Tiggemann, 2018). Among women, high body dissatisfaction is also known as a primary risk factor for the development of eating disorders and is correlated with lower self-esteem and even depression (Mills et al., 2018). Disordered behaviors occur from a plethora of combined contributing causes, yet there have been significant correlations found between media usage and disordered eating. For instance, disordered eating attitudes

have been linked to lower self-esteem (p < 0.001), worse body image (p < 0.001), body desired to achieve (p < 0.001), and the use of social media (p < 0.001) (Aparicio-Martinez et al., 2019).

Social media volume and frequency is another consideration as a higher frequency of use has a stronger association with behaviors such as disordered eating. Compared with those in the lowest quartile, participants in the highest quartiles for social media volume and frequency had significantly greater odds of having eating concerns (adjusted odds ratio 2.18, 95% CI 1.50–3.17 and adjusted odds ratio 2.55, 95% CI 1.72–3.78, respectively) (Sidani, Hoffman, Hanmer, & Primack, 2016). Another health concern is that increased media usage has been associated with a higher risk of miscarriage (Zhang, Liu, Han, & Yin, 2021). This has been postulated to be due to the increased stress inadvertently caused by using social media. Furthermore, nighttime-specific SMU predicted poorer sleep quality even after controlling for anxiety, depression, and self-esteem (Woods & Scott, 2016). Therefore, high levels of SMU contribute to negative health outcomes such as disordered eating, poor sleep, miscarriage, and body dissatisfaction.

While increased SMU can worsen mental health, it can also serve as a mediator for stress. Despite constant and important discourse on burnout, it is also important to consider that high SMU can be attributed to positive perceived impacts for individuals. Individuals with serious mental illness have long reported benefits from interacting with peers online, such as greater feelings of group belonging, social connectedness, and the ability to cope with day-to-day challenges (Naslund, Aschbrenner, Marsch, & Bartels, 2016). Another consideration is also what type of social media one chooses to engage with and look at with more frequency. For example, looking at positive news and body-positive influencers may, in fact, potentially contribute to a more positive impact. According to previous research, media is an important component for coping if it provides support and connection through the dissemination of factual and positive information while avoiding the overflow of sensational and false news (Pahayahay & Khalili-Mahani, 2020). Therefore, it is important to recognize that SMU can also have some positive contributions to mental health and overall health.

# Zoom and Body Image

The use of videoconferencing platforms has skyrocketed due to restrictions from the COVID-19 pandemic; however, this extended use may have negative effects on body image. Constantly staring at your virtual image may have a negative impact. To understand potential impacts, it is important to first liken using videoconferencing to staring at a mirror for several hours a day. More than a third of participants in an Australian study identified new appearance concerns while on video, and those individuals also reported an increased interest in obtaining future beauty treatments and aesthetic procedures (Pikoos, Buzwell, Sharp, & Rossell, 2021). Nearly 81% would cite that the pandemic caused a decline in their body image perception (Padley & Pace, 2021). In a survey of dermatologists, 86% indicated that patients referenced videoconferencing as a reason for new cosmetic concerns and procedures (Rice, Siegel, Libby, Graber, & Kourosh, 2021).

However, some other factors for an uptick in beauty treatments and aesthetic procedures may be that working from home provides more downtime to heal from treatments and elective procedures were on pause for part of the pandemic. Due to this uptick, many healthcare professionals are discussing ways to help patients make informed choices in aesthetic procedures. An example mitigation technique includes encouraging physicians to counsel patients on the impacts of mirror-gazing behavior, which is exacerbated by videoconferencing (Daar, Chiodo, & Rohrich, 2021).

Other questions should also be addressed, such as how much videoconferencing is needed for the patient's occupation and potential symptoms of body dysmorphic disorder (BDD; 15% of plastic surgery cosmetic patients have BDD) (Daar et al., 2021). Another consideration is that unlike selfies on platforms like Snapchat where users are somewhat privy to the changes it makes to their features, videoconferencing platforms project an unknowingly distorted image. This is because many front-facing cameras distort facial proportions, and a bad angle can only worsen this perception. It is important to candidly discuss the impacts of increased use of videoconferencing on self-perception.

# Impacts and Prevalence of Image Retouching and Editing

In an increasingly social media—centered world, there has been a rise in usage of social media and a correlated rise in retouching and editing of images. It has been estimated that two-thirds of all photos on social media have been edited in some way (Spector, 2017). Furthermore, 46% of individuals doubt social media images, and 58% distrust dating sites due to edits (Spector, 2017). Therefore, the rise in retouching is also impacting, in addition to ourselves, our perceptions of each other. Image retouching and editing, although common, have detrimental negative effects on an individual's well-being. Simply taking and editing a selfie can result in a more negative mood and facial dissatisfaction (Tiggemann, Anderberg, & Brown, 2020). Taking it a step further, even viewing selfies online has been shown to have negative impacts on well-being and body confidence. This is because seeking and placing importance on feedback from others is another harmful component of selfie practices and a potential mechanism linking selfie engagement to well-being and body confidence (McLean, Jarman, & Rodgers, 2019). Although these effects are commonly spoken about for women, other studies have noted similar negative effects for men. For instance, a recent study suggested manipulation and concern about selfies posted may be risk correlates for body dissatisfaction for both men and women (Lonergan et al., 2019).

Digital manipulations in advertising and daily life have had detrimental public health effects, and therefore strategies must be put in place to mitigate harm. Many individuals (personal brands) and companies utilize social media advertising practices that feature edited photos. A way to incentivize change on a policy level may be via tax incentives combined with corporate social responsibility initiatives to reduce the use of digitally altered images (McBride, Costello, Ambwani, Wilhite, & Austin, 2019). However, other findings signal that disclaimer labels (i.e., this image has been edited) on digitally modified images are not as helpful for body images as images departing from thin-ideal (Giorgianni, Danthinne, & Rodgers, 2020).

#### Discussion

The COVID-19 pandemic has contributed to increased SMU and video chat usage due to the added stressors and more time at home. Eighty one percent of studied individuals cited that the pandemic caused a decline in their body-image perception (Padley & Pace, 2021). The frequency and volume of SMU has furthered the already negative impacts of altered and edited images. Therefore, we can consider the pandemic as a contributing factor to increased negative self-perception and reduced self-esteem in young adults. Increased usage has also been shown to contribute to other disordered behaviors such as eating disorders and anxiety as well as other negative health outcomes like diminished sleep and miscarriages (Sidani, Hoffman, Hanmer, & Primack, 2016).

Many young adults are especially vulnerable at this critical time in their lives, education and careers. The shift to relative social isolation and minimized in-person interaction has, of course, impacted the mental and emotional well-being of these individuals. Given that these are unprecedented times, individuals may feel the pressure to not contribute their own worries and concerns to others that they live and work with.

It can be difficult for individuals to identify and treat disruptions in behavior and the detrimental effects of SMU. Although mental health programs have risen in prominence, many cultural and religious communities still stigmatize mental illness. Many individuals may not think their condition warrants seeking out help or may reach out to close friends and family who may dismiss their concerns. In the United States, it is also difficult to find mental health services that are accessible and take the appropriate health insurance. Telehealth visits are an attempt to broaden accessibility and provide services even if a provider is far away, but these visits can still be quite costly and require a stable internet connection. Unlike other behaviors, it is incredibly difficult to completely "disconnect" when many aspects of work and education depend upon the utilization of social media and the internet. Even now, there is also very real stigmatization for mental health that is still prominent for individuals pursuing careers in healthcare. This can also be a roadblock to people who want to seek out help but fear it may be a "black mark" on their record.

In addition to a rise in usage, many companies and individuals are developing robust social media platforms in order to market themselves or their products. This increased exposure to constant editing and advertising is another potential contributing factor to worsening mental health. Just as food commercials were known for many years to use fake food and embellishments that looked more visually appealing, a similar process is occurring with social media branding. Given the fact that two-thirds of all photos on social media have been edited in some way, it is an exceptionally prevalent phenomenon (Spector, 2017). Therefore, it is crucial that this phenomenon is recognized by the healthcare and political community to mitigate its detrimental impacts on self-perceptions.

How SMU impacts other age groups beyond college-age individuals, as well as various gender identities and ethnic and racial groups, is still an area of research that requires further study. Many of the existing studies found were sampled from predominantly white women. Furthermore, many of the sampled individuals may have had preexisting conditions that could confound the results. Some of the studies indicated that this was controlled for, but it is a potential confounding factor for other findings. In order to gain a more representative and comprehensive understanding of how COVID-19 impacted different groups' self-perceptions, it is necessary to collect more diverse and representative samples. That information will prove to be a valuable tool for determining other potential confounding factors and how differences in the environment and other factors contribute to this phenomenon.

If the uptick in elective procedures is somehow attributed to an increased virtual presence, then it may make sense for providers to suggest mitigation measures and to identify any abnormalities in patient habits that could be a cause for concern. Providers should inform patients of potential aesthetic procedures on mental health and worsening self-perception due to SMU and the pandemic. By identifying problematic habits, providers can predict whether a patient should seek additional help from another professional provider or other programs. Having several resources and options available allows the patient to choose one that they are most comfortable with, such as a peer support group. It is especially helpful for providers to allow for and promote programs that specifically uplift individuals who face community mental health stigmas. These types of programs can

be advertised in a variety of routes whether during a follow-up appointment or via informational postings in community spaces.

#### Conclusion

The detrimental effects of high SMU are an area of research that should continue to be of emphasis and pertinence during and following the COVID-19 pandemic. Low self-perception and diminished self-esteem can be the root causes of a myriad of other disordered behaviors and thoughts such as eating disorders and anxiety. Further research should be conducted to see what other impacts, confounding variables, or effects may take place for other demographic groups and whether these changes continue post-pandemic. As mental health continues to be stigmatized in many communities, it is important that this issue is addressed and not taken lightly. Mitigation strategies should include programming that is helpful for diverse groups of participants. Given that some individuals cite social media as a coping strategy for stress and an outlet that provides a sense of community, it may make sense to bring mitigation strategies directly to social media. Providers will play a crucial role in informing the patient of potentially problematic behaviors and all the options available to them. From a broader standpoint, destigmatizing mental illness and promoting body-positive movements are both good avenues for reducing these detrimental impacts on young adults.

### References

- Aparicio-Martinez, P., Perea-Moreno, A. J., Martinez-Jimenez, M. P., Redel-Macías, M. D., Pagliari, C., & Vaquero-Abellan, M. (2019). Social media, thin-ideal, body dissatisfaction and disordered eating attitudes: An exploratory analysis. *International Journal of Environmental Research and Public Health*, 16(21), 4177. https://doi.org/10.3390/ijerph16214177
- Boursier, V., Gioia, F., Musetti, A., & Schimmenti, A. (2020). Facing loneliness and anxiety during the COVID-19 isolation: The role of excessive social media use in a sample of Italian adults. *Frontiers in Psychiatry*, 11, 586222. https://doi.org/10.3389/fpsyt.2020.586222
- Bowden-Green, T., Hinds, J., & Joinson, A. (2021). Personality and motives for social media use when physically distanced: A uses and gratifications approach. *Frontiers in Psychology*, 12, 607948. https://doi.org/10.3389/fpsyg.2021.607948
- Daar, D. A., Chiodo, M. V., & Rohrich, R. J. (2021). The zoom view: How does video conferencing affect what our patients see in themselves, and how can we do right by them?. *Plastic and Reconstructive Surgery*, 148(1), 172e–174e. https://doi.org/10.1097/PRS.00000000000008031
- Giorgianni, F., Danthinne, E., & Rodgers, R. F. (2020). Consumer warning versus systemic change: The effects of including disclaimer labels on images that have or have not been digitally modified on body image. *Body Image*, *34*, 249–258. https://doi.org/10.1016/j.bodyim.2020.07.007
- Lonergan, A. R., Bussey, K., Mond, J., Brown, O., Griffiths, S., Murray, S. B., & Mitchison, D. (2019). Me, my selfie, and I: The relationship between editing and posting selfies and body dissatisfaction in men and women. *Body Image*, 28, 39–43. https://doi.org/10.1016/j.bodyim.2018.12.001
- Ma, Z., Zhao, J., Li, Y., Chen, D., Wang, T., Zhang, Z., Chen, Z., Yu, Q., Jiang, J., Fan, F., & Liu, X. (2020). Mental health problems and correlates among 746 217 college students during the

- coronavirus disease 2019 outbreak in China. *Epidemiology and Psychiatric Sciences*, 29, e181. https://doi.org/10.1017/S2045796020000931
- McBride, C., Costello, N., Ambwani, S., Wilhite, B., & Austin, S. B. (2019). Digital manipulation of images of models' appearance in advertising: Strategies for action through law and corporate social responsibility incentives to protect public health. *American Journal of Law & Medicine*, 45(1), 7–31. https://doi.org/10.1177/0098858819849990
- McLean, S. A., Jarman, H. K., & Rodgers, R. F. (2019). How do "selfies" impact adolescents' well-being and body confidence? A narrative review. *Psychology Research and Behavior Management*, 12, 513–521. https://doi.org/10.2147/PRBM.S177834
- Mills, J. S., Musto, S., Williams, L., & Tiggemann, M. (2018). "Selfie" harm: Effects on mood and body image in young women. *Body Image*, 27, 86–92. https://doi.org/10.1016/j.bodyim.2018.08.007
- Naslund, J. A., Aschbrenner, K. A., Marsch, L. A., & Bartels, S. J. (2016). The future of mental health care: peer-to-peer support and social media. *Epidemiology and Psychiatric Sciences*, 25(2), 113–122. https://doi.org/10.1017/S2045796015001067
- Padley, R. H., & Di Pace, B. (2021). The psychological impact of remote communication on body-image perception: Cosmetic surgery on the rise. *Aesthetic Plastic Surgery*, 1–3. Advance online publication. https://doi.org/10.1007/s00266-021-02554-3
- Pahayahay, A., & Khalili-Mahani, N. (2020). What media helps, what media hurts: A mixed methods survey study of coping with COVID-19 using the media repertoire framework and the appraisal theory of stress. *Journal of Medical Internet Research*, 22(8), e20186. https://doi.org/10.2196/20186
- Pikoos, T. D., Buzwell, S., Sharp, G., & Rossell, S. L. (2021). The zoom effect: Exploring the impact of video calling on appearance dissatisfaction and interest in aesthetic treatment during the COVID-19 pandemic. *Aesthetic Surgery Journal*, sjab257. Advance online publication. https://doi.org/10.1093/asj/sjab257
- Rice, S. M., Siegel, J. A., Libby, T., Graber, E., & Kourosh, A. S. (2021). Zooming into cosmetic procedures during the COVID-19 pandemic: The provider's perspective. *International Journal of Women's Dermatology*, 7(2), 213–216. https://doi.org/10.1016/j.ijwd.2021.01.012
- Sidani, J. E., Shensa, A., Hoffman, B., Hanmer, J., & Primack, B. A. (2016). The association between social media use and eating concerns among US young adults. *Journal of the Academy of Nutrition and Dietetics*, 116(9), 1465–1472. https://doi.org/10.1016/j.jand.2016.03.021
- Spector, N. (2017, May 30). So it's fine if you edit your selfies . . . but not if other people edit theirs? NBCNews.com. Retrieved October 5, 2021, from https://www.nbcnews.com/business/consumer/so-it-s-fine-if-you-edit-your-selfies-not-n766186.
- Tiggemann, M., Anderberg, I., & Brown, Z. (2020). Uploading your best self: Selfie editing and body dissatisfaction. *Body Image*, 33, 175–182. https://doi.org/10.1016/j.bodyim.2020.03.002
- Woods, H. C., & Scott, H. (2016). #Sleepyteens: Social media use in adolescence is associated with poor sleep quality, anxiety, depression and low self-esteem. *Journal of Adolescence*, 51, 41–49. https://doi.org/10.1016/j.adolescence.2016.05.008

- Zhang, X., Liu, J., Han, N., & Yin, J. (2021). Social media use, unhealthy lifestyles, and the risk of miscarriage among pregnant women during the COVID-19 pandemic: Prospective observational study. *JMIR Public Health and Surveillance*, 7(1), e25241. https://doi.org/10.2196/25241
- Zhao, N., & Zhou, G. (2021). COVID-19 stress and addictive social media use (SMU): Mediating role of active use and social media flow. *Frontiers in Psychiatry*, 12, 635546. https://doi.org/10.3389/fpsyt.2021.635546