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Letter from the Editors

Shichi Dhar* and Christopher Giang†

Dear readers,

It is with great pleasure and excitement that we share with you the eighth volume of the Undergraduate Journal of Public Health at the University of Michigan. We are delighted to present a wide array of articles, highlighting the passion and commitment of our undergraduate authors to the interdisciplinary and collaborative field that is public health. We feature articles that provide a glimpse into multifaceted issues across the world, from Detroit to South Africa to Dharamshala, India, illustrating crucial public health topics for the first time, notably substance use, occupational health and, immigration. Through our latest volume, we provide space for community-centered research, exploration, and critical dialogue regarding historical inequities that continue to plague our present-day.

We are thrilled to feature student authors hailing from diverse backgrounds, spanning the state of Michigan as well as institutions nationwide and internationally, offering perspectives on issues at the local, national, and global levels. We hope that this collection of articles continues to exemplify our publication's mission: to spotlight student-driven and student-reviewed work. At the heart of our journal this year lies a commitment to fostering a deeper understanding of mental health issues and promoting strategies for enhancing well-being at all levels. We have curated a special section on "Mental Health and Wellbeing", comprising five insightful pieces that explore some of the most pressing issues in the mental health realm, highlighting issues such as stigma and barriers to mental health care

We would like to express our gratitude to our dedicated undergraduate editorial board, whose careful review and insightful feedback enriched the articles and blog posts submitted this year, and whose collaborative efforts culminated in the creation of this volume. We are thankful to our PhD student reviewers for their time, expertise, and specialized feedback, which enhanced the quality of the articles in this journal.

We also extend our sincere appreciation to our faculty advisor, Dr. Ella August, whose unwavering mentorship and guidance empowered us to grow as leaders, critical thinkers, and visionaries.

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We are grateful for our talented cover artist, Yoo Young Chun, whose ability to encapsulate the themes of our journal in beautiful and artistic imagery has once again amplified the themes of our featured articles. We also thank MPublishing for their patience and diligent efforts in elevating our journal to a level of professionalism that we could not have attained alone.

Lastly, we wish to extend our sincere appreciation to our authors, whose substantial contributions form the foundation of this publication. Without them, we would not be able to do what we do and for this, we are immensely grateful. Their diverse backgrounds, interests, lived experiences, commitment to lifelong learning, and drive to innovate leave us hopeful for a brighter and more equitable future. We wish all those in our journey to publication the best in their future endeavors. We are thankful for this opportunity and will forever cherish this experience.

Sincerely,
Shichi Dhar and Chris Giang
UJPH Coeditors-in-Chief 2023–2024

Narcan Access: The Ins and Outs of The Expanding Policy in Ohio

Harley Okenyi*

All across the United States, the opioid crisis remains rapid and deadly. The number of people dying from drug overdose, in just 2021, is over six times the number in 1999 (“Understanding the opioid overdose epidemic,” 2023). Thousands of public health officials and organizations, policymakers, and law enforcers are constantly deriving new ways to combat this epidemic. Specific to the state of Ohio, in 2012, a new network of opioid overdose education and naloxone distribution programs was coordinated by the Department of Health (Ohio Department of Health, n.d.). Deaths Avoided with Naloxone, DAWN, is named after Leslie Dawn Cooper, a woman who suffered from substance use disorder and died from a witnessed opioid overdose. As of 2012, Project DAWN is in 82 of Ohio’s 88 counties, the first site established in Leslie’s hometown, Portsmouth, Ohio. Project DAWN has over 167 opioid overdose education and naloxone distribution program locations that include community organizations, emergency services, and correctional facilities. (Ohio Department of Health, n.d.). This new program includes laws that enable pharmacists to provide Narcan without a prescription without criminal liability. Project DAWN aims to combat a crisis that grows larger every day, addressing numerous public health issues in Ohio step by step. The goal of this is to investigate and discover the reactions, consequences, and effects of increased access to Narcan.

Keywords

Project DAWN • opioid crisis • drug overdose • naloxone distribution program • Narcan • substance use disorder • public health

Introduction

Ohio’s new Naloxone policy, allowing pharmacists to distribute Narcan with no prescription, focuses on the public health issue of substance use, specifically opioid addiction, but also inherently

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addresses violence. Substance use disorder is defined as a “chronic relapsing disease”, and impacts the entire population in every location it spreads in, plaguing not only those who use the substances but also those who live in the community around them through increased criminal acts, health care needs, and an upsurge in health and economic costs (Lo et al., 2020). Substance disorder is a dense disease, introducing dealers and gang wars in the communities it infects. Substance use disorder drives people beyond their right mind, causing intoxicated driving and outbursts, domestic violence, and gun violence.

Naloxone reverses the overdose caused by opioid drugs, the most brutal outcome of substance use (Ohio Department of Health, n.d.). With increased access to naloxone and no prescription needed, users nearing overdose or who have overdosed will be given a second and possibly life-changing chance to consider rehabilitation. The issue of violence surrounding substance use will ultimately lessen. Narcan makes room for new possibilities and less trafficking of these opioids, switching the nature of violence to one of healing and peace.

Through the Lens of Public Health

Population health is defined as “the health outcomes of a group of individuals, including the distribution of such outcomes within the group” (Kindig & Stoddart, 2003). The policy of increased access to naloxone was created as an approach to solve a public health issue while increasing population health. The opioid epidemic affects communities, cities, and regions at large. Death rates from opioid overdose rates have increased for all age groups in the United States from 1999–2016, but were highest for those aged 25–34, 35–44, and 45–54 (Collins et al., 2020). Opioid use spans all ages and even races, as it never relates directly to one person. To be put simply, many people are involved in the crisis, and the increased availability of Narcan will affect all those involved. Also, those who use opioids, supply opioids, help people with opioid addiction, and care for their well-being are all affected by this policy. Like a domino effect, those already dealing with the epidemic, that *population* of people are now provided with a tool that has the potential to stabilize the growing spread.

Widespread Availability

Narcan will transform the way we treat the opioid epidemic and shift the stereotypes surrounding addiction and overdose. Used to reverse opioid overdoses, Narcan is now available over the counter, prescription-free. Although a bright idea on the surface, those who see the realities of the epidemic reveal contrasting points of view. Free clinics and harm reduction groups for those dependent on opioids admit fears of the price and stigma surrounding the medication (Lo et al., 2020). A two-dose pack of Narcan is free to those with Medicaid or private insurance (Hoffman, 2023). Outside of Medicaid, many insurance companies do not cover over-the-counter medicines, and individuals must pay out-of-pocket for Narcan, a cost of approximately ten dollars (Hoffman, 2023). Thus, many individuals who truly need Narcan will not be able to afford it. Free clinics and harm reduction groups observe real people with a real disease daily and can see that the additional fee of Narcan will drive them away from it. Although a policy is aimed toward the people they work with and patients they see, the concealed factors make it so the targets of the policy do not reap its true benefits.

The Origins and Consequences of Fear

A main perspective on this policy is that of the pharmacists who are now allowed to distribute Narcan with no prescription. Initially, in light of the new policy came a sense of doubt and fear of societal judgment. A common barrier to naloxone is independent pharmacists and their refusal to stock nasal sprays and in turn, sell Narcan. On the basis of not wanting to engage with people who use drugs, independent pharmacists in rural and impoverished areas lack a sense of urgency to proactively combat this epidemic (Hoffman, 2023). The pharmacists have a lack of understanding of the policy and the price of the medicine. Educating pharmacists on the policy in detail and staging interventions would be the key to changing the stigma, and this key stakeholder perspective.

A Shift in Ohio

Ohio, the epicenter of the nation's opioid epidemic, has made a conscious effort to ensure their pharmacists are well-informed which contrasts with the stigma the nation's general pharmacists population seems to share (Thompson et al., 2018). In a survey conducted by the *Journal of Pharmacy Practice* in 2018, Ohio pharmacists were surveyed regarding their knowledge, barriers, perception, and comfort surrounding the new policy (Thompson et al., 2018). The results of the study showed that Ohio pharmacists have the proper education and training to identify individuals at risk for overdose, but have a lack of knowledge on the protocol, who they could dispense naloxone to, and who could provide patient education (Thompson et al., 2018). At first, this aligns with the previous perspective, but after this study, a requirement has been put into place that addresses opioid use and proper dispensing of naloxone. Conclusions from this study state that overall, "Ohio pharmacists were open to dispensing naloxone per physician protocol . . . and knowledgeable about the medication and confident in their ability" (Thompson et al., 2018). The implementation of this study deconstructed the education barrier and turned the perspective of pharmacists around where it matters most. Pharmacists are now more inclined to work with customers and dispense naloxone with the proper information and training as opposed to having little to no knowledge about it at all (Thompson et al., 2018).

Both clinical and harm reduction groups and distributing pharmacists agree on the policy's attempt to address the opioid crisis (Thompson et al., 2018). Both perspectives focus on the essential users of Narcan, those more inclined to overdose. In the case of the pharmacists' stakeholder point of view, there is a solution: education. Pharmacists against the policy are still scared and in a way ignorant (Thompson et al., 2018). Ohio has made changes from this point of view, and with new fixes along the way every day, the price and education barriers will be erased or addressed, and these stakeholders could find a way to unite on the terms of the policy, keeping those in need at the core.

The Legality of Narcan

The state of Ohio government states in section 3715.502 of the Ohio Revised Code as well as rules 4729:1-3-04 and 4729:2-3-04 of the Ohio Administrative Code the terms of this policy. The legislation comes from House Bill 558 at the 134th General Assembly of the Ohio Legislature passed

in 2023 (Ohio, 2023). The first non-prescription naloxone, or Narcan, was approved by the U.S. Food and Drug Administration (Substance Abuse and Mental Health Services Administration [SAMHSA] n.d.). This issue is regulated at the state level as the Ohio government, not the federal government, has written the law.

In the US Constitution, the 10th Amendment states, “Powers not delegated to the United States by the Constitution, nor prohibited by it to the States, are reserved to the States respectively, or to the people” (U.S. Const. amend. X). As per this amendment, since it does not specifically state the federal responsibility to regulate access to naloxone, the responsibility is handed off to each state to create its legislation concerning the medicine. The Ohio State Government or the Ohio Legislature, because of the 10th amendment, has the authority to regulate increased access to Narcan, the prescription requirement, and the safety of the pharmacists that dispense it. House Bill 588 was introduced in the House and Senate of the government of Ohio, reported by their committees, and passed by the two houses of Ohio Senate and House in 2023. The bill was eventually signed by the governor, passing the law again with the authority granted by the 10th Amendment.

Similarities Across the Country

South of Ohio, the state of Texas has a Naloxone Standing Order Request. This standing order gives any pharmacy in Texas the ability to request, and distribute naloxone, allowing the pharmacist to dispense it under the authority of the delegating physician in Texas (Texas Targeted Opioid Response, n.d.-b). Similar to Project DAWN, this standing order comes from the Texas Opioid Training Initiative which offers education to health professionals on preventing overdose and distributing naloxone (Texas Targeted Opioid Response, n.d.). Almost identical to Ohio’s new policy and actions, this Texas initiative takes charge of the growing opioid epidemic, informing and creating increased access to Narcan. This program has distributed over 300,000 doses of naloxone, saving thousands of lives and increasing the health of the population, dose by dose (Texas Targeted Opioid Response, n.d.).

Uncertainty and Concerns

Although this policy is rooted in legitimacy and honesty, increased access to Narcan comes with increased consequences, such as the lack of education in pharmacists, which is detrimental to those who need naloxone. A further concern also involves education for those who administer Narcan. How to recognize an overdose or to be self-aware of one incoming is a strong worry of researchers and physicians. Obviously, with increased access comes increased demand, and demand in rural areas (Collins et al., 2020). The stigma surrounding opioids and overdose is already great, and access to Narcan in rural or even suburban communities might be low if there is a reputation around the medication. All somewhat social consequences, the policy is inherently excellent, having small obstacles on its way to completeness.

Conclusion

The State of Ohio’s increased access to Naloxone is a policy made to aid in the public health issue of opioid overdose. Many stakeholders take a position either for or against the policy. The education of

pharmacists is a leading barrier to the fulfillment of the policy to its best. Certain laws were made to increase the effectiveness of the policy, and regions outside of Ohio have begun implementing similar policies. A laser-focused program keen on the active education of healthcare professionals across the nation is crucial to the success of accessible naloxone. With education comes information and the ability to use an informed voice beyond initial horizons. Implementing this, as well as Narcan utilization and “how-to” programs are essential to ensuring the general population is knowledgeable too. A seemingly minuscule take, educating the source leads to stronger, more engaged populations. A population health issue at its core, the policy will naturally protect more people from opioid overdoses, acting as a proactive policy fighting a cruel epidemic.

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A Call to Improve Breastfeeding Education and Counseling in South Africa

Maya Wolock*

Despite the immense body of evidence demonstrating that breastfeeding is a significant predictor of infant, child, and maternal health, rates of exclusive breastfeeding in South Africa remain suboptimal. This paper delves into the importance of breastfeeding, briefly highlights the historical context of breastfeeding in South Africa, explains the roles of the formula market and the HIV/AIDS epidemic in the disparate rates of breastfeeding, and recommends policies to address these issues.

Keywords

lactation consulting • South Africa • breastfeeding education • HIV epidemic • formula marketing • infant nutrition • nutrition policy

Breastmilk and Population Health

At both the population and the individual levels, breastfeeding is essential for the health and well-being of children across the lifespan. The World Health Organization recommends that infants consume breast milk, without adding solids or formula, until 6 months of age. This is known as exclusive breastfeeding (EBF) (2021). In infants, the short-term benefits of EBF include but are not limited to, reduced rates of GI infections/diarrheal diseases, necrotizing encephalitis, respiratory tract infections/pneumonia, malnutrition, and sudden infant death syndrome (Eidelman et al., 2012; West et al., 2019). Additionally, the protective effects of breastfeeding can extend into the long-term: improved outcomes for allergic disease, celiac disease, inflammatory bowel disease, diabetes types 1 and 2, and neurodevelopment are positively associated with initiation and duration of breastfeeding (Eidelman et al., 2012).

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Due to breastfeeding's protective effects against a wide variety of adverse infant outcomes, the Global Burden of Disease report rated suboptimal breastfeeding as the second most significant risk factor in children under 5 (Roberts et al., 2013). The burden of disease is measured with a statistic referred to as Disability-Adjusted Life Years, or "DALYs." DALYs are measured in years and consider both years of life lost due to premature death and years of life lived with impaired quality of life. The loss of one DALY symbolizes one year loss of optimal health (World Health Organization, n.d.). In 2010, suboptimal breastfeeding accounted for the loss of 47.5 million DALYs globally (Roberts et al., 2013). As a result, *The U.N. Decade of Nutrition* has made one of its targets to increase global rates of EBF to 50% by 2025 (Vitalis et al., 2021). Though the health benefits of breastfeeding are immense, so are the barriers. This paper will focus on the structural and health system factors that prevent parents from making fully informed decisions on infant feeding in South Africa.

Breastfeeding in the South African Context

In South Africa, subpar rates of breastfeeding impair the population's health. In 2018, the prevalence of EBF in all infants under 6 months in South Africa was around 32%, far from the target of 50% by 2025 (World Health Organization & United Nations Children's Fund, 2022). In addition, these rates may be deceptively high, as only 23.7% of infants between four and five months are still being exclusively fed human milk (Nieuwoudt et al., 2019). Notably, formula sales have risen significantly, and companies have seen a 33% per capita increase in sales from 2004 to 2015 (Lake et al., 2019).

The low rates of EBF in South Africa negatively impact population health. As mentioned previously, breastfeeding can reduce the risk of a variety of adverse infant outcomes, including malnutrition and diarrheal disease. In low- and middle-income countries, including South Africa, malnutrition and diarrheal diseases are the leading causes of infant death (West et al., 2019). In fact, experts have been able to measure the burden of disease caused by insufficient breastfeeding rates at the population level in South Africa: a staggering 18% of child DALYs lost in South Africa were attributable to suboptimal breastfeeding in 2010. Comparatively, suboptimal breastfeeding accounted for 7.6% of child DALYs lost globally in the same period (Roberts et al., 2013).

There are many reasons for the low rates of EBF and the subsequent high burden of disease, however, the most concerning may be the continued inconsistent postnatal counseling by health-care workers in South Africa. Explanations for this phenomenon include the legacy of changing breastfeeding recommendations through the HIV epidemic and the targeting of healthcare professionals by the formula market (Vitalis et al., 2021).

The HIV Epidemic, Formula Use, & Breastfeeding Recommendations in South Africa

As the HIV epidemic continues to change in South Africa—thanks to scientific advances and improved treatment access—breastfeeding recommendations and policies have also evolved. For many years, due to the HIV epidemic, the government provided free formula (Vitalis et al., 2021). This decision was based on the risk of vertical transmission or the risk of transmitting HIV from mother to child through birth and breastfeeding. However, starting in 2004, the South African government has provided eligible citizens with free access to antiretroviral therapy (ART), the primary form of treatment for HIV (Burger et al., 2022). In individuals living with HIV, appropriate

use of ARTs can reduce their viral load to where the risk of passing HIV from the birthing parent to the child is reduced from a 15–40% risk to a 2% risk (Eke et al., 2023). In 2011, the Tshwane Declaration of Support for Breastfeeding was passed in South Africa. The Tshwane Declaration aligned South Africa's breastfeeding recommendations for individuals living with HIV to those outlined by the WHO and ended the provision of free formula (Vitalis et al., 2021). Now, given the low (less than 2%) risk of vertical transmission with adherence to ART regimens, recommendations for EBF are the same between HIV- and HIV+ parents on ART regimens (which are freely available in South Africa) (West et al., 2019).

However, even with the updated guidelines, there is evidence that HIV+ women, despite adherence to ART regimens, continue to be less likely to breastfeed. After the Tshwane Declaration, the odds of stopping breastfeeding by 14 weeks in HIV+ mothers were 2.1 times higher than the odds of stopping breastfeeding by 14 weeks in HIV- mothers, according to research from 2014 through 2017 (Horwood et al., 2020). While there are many factors contributing to this disparity, there is strong evidence that the policy changes have created confusion for families and healthcare workers alike (Nieuwoudt et al., 2019). Healthcare providers are not providing clear and consistent counseling on breastfeeding for HIV+ parents (Nieuwoudt et al., 2019). Current policies must be supplemented to improve children's health outcomes and reduce disparities for the children of HIV+ parents.

The Formula Market as a Barrier to Exclusive Breastfeeding

In addition to confusion on best-practice infant feeding as a result of the HIV epidemic, the formula market also introduces barriers to raising exclusive breastfeeding rates in South Africa. In 1981, the World Health Assembly passed the "International Code of Marketing of Breast-milk Substitutes" (often referred to as "the Code"), to protect families against predatory marketing of breast-milk substitutes (World Health Organization & United Nations Children's Fund, 2022). Despite the Code's regulations, formula marketing still represents one of the greatest challenges to improving rates of breastfeeding; in the last 20 years, rates of EBF have moderately improved globally, yet, concurrently, sales of formula milk have almost doubled (World Health Organization & United Nations Children's Fund, 2022).

South Africa has attempted to improve breastfeeding policy, though their success is debatable. In 2012, South Africa passed R991, which was legislation meant to enforce "the Code". However, since then, violations remain and marketing tactics have evolved (Doherty et al., 2022). While South Africa is considered to be "substantially aligned" with the code, violations are widespread, especially within private sector hospitals (World Health Organization & United Nations Children's Fund, 2022). The formula industry frequently sends representatives to contact healthcare workers. In addition, there are often educational talks and trainings for employees hosted by formula companies that ultimately promote their products. In a qualitative study on public and private sector employees, it was found that almost all of the employees studied from the private sector felt that formula companies were a crucial source of information for their practice (Doherty et al., 2022). The health professionals studied were all people identified as frequently caring for birthing parents, including pediatricians, lactation consultants, midwives, nurses, and others. Some participants reported that their hospitals have deals with certain commercial milk brands and are paid to promote them (Doherty et al., 2022). Worryingly, many employees in both sectors shared the false belief that commercial milk has become so advanced that it is equivalent to breastfeeding. They recited many of the

tactics that formula companies use to market their products back to the researchers to explain this stance (Doherty et al., 2022). In short, the formula companies continue to target healthcare professionals to push their products, despite the passing of R991, especially in the private sector hospitals.

It is important to understand that the population of South Africa is not equally affected by these predatory practices. The uninsured population makes significant use of the private sector on an out-of-pocket basis. South Africa is also implementing its new health insurance system (NHI), which will make greater use of the private sector for populations with lower socioeconomic status (Doherty et al., 2022). This means that the populations in which breastfeeding might be the most critical intervention to avoid future healthcare costs and loss of DALYs may soon receive lower-quality breastfeeding counseling from the private sector (Doherty et al., 2022).

Moving Forward: Policy Recommendations

The combination of years of free distribution of formula due to the HIV epidemic and formula companies violating the Code has led to insufficient postnatal counseling in South Africa, and subsequently, lower rates of EBF. To combat this, I outline three potential recommendations to improve rates of EBF through better breastfeeding counseling practices:

1) Creation of an Independent Monitoring System

Though R991 has been in action since 2012, there are some gaps in the legislation that the formula industry takes advantage of (Doherty et al., 2022). While there are legal provisions for formula companies' communication with the healthcare system, there are widespread violations, which undermine South Africa's true alignment with the Code (Doherty et al., 2022; Lake et al., 2019). These factors explain the lack of appropriate breastfeeding counseling and in part explain overall low rates of EBF.

To date, there has been no enforcement of violations of R991 (Doherty et al., 2022; Lake et al., 2019). This suggests that there is a need to create a monitoring system that investigates how formula companies interact with health professionals. This monitoring system could also have a system for families or other healthcare professionals to identify and report a violation of the code. While legislation identifies sanctions to be used in case of a violation, the lack of independence of the monitoring body has prevented any punishments from taking place. If an independent monitoring body was established, it could be a part of the National Department of Health (NDoH), the Department of Women, Youth, and Persons with Disabilities, or any other part of the government that is free of influence from the formula market.

2) Prohibition of Corporate Donations and Requirements for Disclosure

This recommendation is two-pronged. First, South African governments must prohibit donations of equipment or services from the formula industries, in order to better align legislation with the Code. This would severely limit conflicts of interest for health professionals and remove incentives to promote formula milk. This is especially important for the private sector. Second, since enforcement of this may be complicated, healthcare workers and researchers must also be required to disclose funding sources or personal conflicts of interest to their institutions. These institutions will have a requirement to disclose these to the NDoH, in order to improve enforcement of the current provisions of R991.

3) *Investment in Ongoing Education for Health Professionals*

As stated earlier, the legacy of changing policies due to the HIV epidemic has led to confusion among healthcare workers, and diminished quality of breastfeeding education for HIV+ parents (Nieuwoudt et al., 2019). Overall, healthcare professionals also have misconceptions about the quality of formula due to excessive marketing and targeting by the industry (Doherty et al., 2022; Lake et al., 2019). For these reasons, academics, health professionals, and others have called for an investment in ongoing education programs for healthcare workers. Formula companies aim to fill a gap in knowledge by hosting educational events for healthcare professionals (Doherty et al., 2022; Lake et al., 2019). To stop this predatory practice, there must be investments in the South African health infrastructure, in order to fill these gaps in a manner best aligned with the WHO guidelines. These investments should focus on educating healthcare workers on infant feeding best practices as well as how to identify conflicts of interest. This education must come from a source with no profit motivation. In short, due to a lack of investment in ongoing education for healthcare providers, formula companies step in, leading to insufficient and sometimes inaccurate counseling on infant nutrition. To solve this, there must be conscious efforts to fill these knowledge gaps with WHO-aligned education for healthcare professionals.

Conclusion

While promoting EBF is complicated, and many determinants influence infant feeding choices, it is clear that improving the health workforce's ability to promote breastfeeding is crucial in preventing excessive child DALYs lost. I recommend better enforcement of the Code and other WHO guidelines through a variety of policy initiatives, in order to ultimately improve EBF for all families, including those with HIV+ status. First, there must be improved enforcement of R991. The government should invest in creating an independent monitoring system to ensure that formula marketers do not engage in illegal practices. Second, there must be new legislation that prohibits monetary and equipment donations from the formula industry, and healthcare workers must also be held accountable for reporting such donations and/or contact attempts. Finally, the lack of understanding of best-practice infant feeding on the part of healthcare workers demonstrates the need for improved education of healthcare professionals. In summary, the substantial disease burden caused by suboptimal rates of breastfeeding in South Africa necessitates the creation and enforcement of policies that promote breastfeeding, in order to improve health across the lifespan.

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From the Middle East to America: Examining Acculturative Factors of Adolescent Immigration

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Global immigration necessitates acculturation which is the process of adapting to cultural norms while maintaining aspects of origin-country culture. Acculturation is the process through which individuals adapt to the culture, norms, and belief systems of their host country (Sayegh & Lasry, 1993; Yeh et al., 2008). Acculturation is difficult for adolescents because they are undergoing identity formation throughout immigration. For Middle Eastern individuals in particular, cultural differences, threat of harmful stereotyping, and socioeconomic difficulties further complicate this process. This study examined factors that relate to acculturation for Middle Eastern immigrants who immigrated during adolescence. Eight participants were interviewed for this study and interview transcriptions were analyzed using thematic analysis. Results found three overarching themes related to community, personal identity, and American infrastructure. Further research should be conducted to explore each of these constructs in detail to ensure Middle Eastern adolescent immigrants can receive acculturative support and to reduce the stigma held by the American public around Middle Eastern individuals.

Keywords

mental health • immigration • Middle East • adolescent immigration • acculturation

Research on the immigration experience has revealed the importance of acculturation for the physical, emotional, and social well-being of immigrants (Clarke & Isphording, 2016; Park, 2011; Reimers, 1983). Acculturation involves balancing cultural identities with an emphasis on adopting the host-country culture to a greater extent (Sayegh & Lasry, 1993; Yeh et al., 2008). Two key demographic features, age at the time of immigration and country of origin shape the context of the transition and relate to the extent to which the immigrant may adapt to American culture (Cheung et al., 2010; Kimbro, 2009; Marvasti, 2005; Reimers, 1983). Thus, this review will address

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acculturation in the context of adolescent immigration and in the context of Middle Eastern immigration to the United States (US). Adolescence is a particularly vulnerable time for immigration as the process of identity formation may be challenged by the need to balance two sets of cultural values and expectations (Goodenow & Espin, 1993; Mann, 2004; Phinney, 1989). Immigrants of Middle Eastern origin are important to examine as descent from the region rapidly increases due to political and economic struggles. Between 2000 and 2019, MENA immigrant population doubled from 596,000 to 1.2 million (Harjanto & Batalova, 2022). Their experiences provide insight on how cultural differences and American stigmatization, relate to acculturative outcomes (Buda & Elsayed-Elkhouly, 1998; Fuligni & Tsai, 2015; Minardi, 2021). Thus, this literature review will analyze the circumstances of adolescent immigration and the circumstances of immigration from the Middle East to better understand the unique processes of acculturation for these populations.

Challenges with Immigration & Acculturation

Being an immigrant poses many challenges that serve as barriers to acculturation (Dustmann & Fabbri, 2003; Noels et al., 1996; Reimers, 1983; Valentín-Cortés et al., 2020). A significant barrier includes lack of proficiency in the language of their new country, which can prevent immigrants from finding jobs, leaving them and their dependents in unfavorable socioeconomic conditions (Galarneau & Morissette, 2004; Noels et al., 1996; Stören, 2004). Their lack of language proficiency and unfavorable socioeconomic status can prevent immigrants from interacting with natives and therefore lead to social isolation (Clarke & Isphording, 2016; Dustmann & Fabbri, 2003; Watkins et al., 2012). Having social connections, whether it be with individuals from the same country of origin or from the new country, is associated with greater financial, social, and psychological success of immigrants (Ahmad, 2011; Nakhaie & Kazemipur, 2012). These social connections in the new country may help immigrants cope with the natives' locals' stereotypes about and discrimination towards them (Ahmad, 2011; Subervi-Velez, 1986).

Depending on their country of origin, immigrants may experience poor treatment from natives (Casanova, 2012; Marvasti, 2005; Reimers, 1983). For example, if an individual from Latin America or Africa migrates to a southern state in the US, they may face discrimination and difficulty finding a job to a greater extent than a European immigrant, due to larger discrepancies in their physical appearance and cultural norms (Nakhaie & Kazemipur, 2012; Reimers, 1983). Living in a nation that is culturally sensitive and has low levels of discrimination against immigrants is associated with better acculturative outcomes (Alegria et al., 2017). Better acculturative outcomes also occur when immigrants have informed expectations about society in the new country and the natives' perception of immigrants prior to immigrating (Idema & Phalet, 2007; Kim et al., 1996; Nghe et al., 2003).

Immigrants who have false expectations about the societal norms such as gender roles in the new country may have greater difficulty acculturating (Idema & Phalet, 2007; Kim et al., 1996; Nghe et al., 2003). Exposure to media depicting the host country norms of the new country prior to immigration may aid in acculturation by providing immigrants with realistic expectations about life in the new country (Subervi-Velez, 1986; Zhou & Cai, 2002). Furthermore, exposure to origin country media post-immigration allows immigrants to maintain some connections to their heritage, which is an important facet of acculturation (Subervi-Velez, 1986; Zhou & Cai, 2002). Challenges associated with immigration including language barriers, social isolation, discrimination, and false

expectations can be considered barriers to acculturation because they make it more difficult for individuals to adapt to the social norms, belief systems, and practices of the new country (Chung et al., 2000; Nghe et al., 2003; Noels et al., 1996). It is important to consider that the aforementioned challenges and overall process of acculturation may differ depending on age at the time of immigration (Renzaho et al., 2017; Stevens et al., 2004).

Acculturation & Immigration During Adolescence

Age at the time of immigration can have a major impact on acculturative outcomes (Renzaho et al., 2017; Stevens et al., 2004). Immigration specifically during adolescence poses a unique set of challenges (Dorner et al., 2008; Gönültaş & Mulvey, 2020; Kirchengast & Schober, 2005; Perez, 2016). Adolescents have lower neuroplasticity than children, thus acculturation may be slower in adolescents than in children because it may take longer for them to adopt the societal norms of the new country (Gershoff et al., 2014). Thus, adolescents with adaptable dispositions and emotion-regulation skills often have more favorable acculturative outcomes than their peers (Gopnik et al., 2017; Hermansen, 2017; Zhou, 2013). Mood disorders may be partially attributable to assuming significant responsibilities at a young age, such as serving as translators for their families (Dorner et al., 2008; Orellana, 2003; Umaña-Taylor, 2003). These health issues that arise due to immigration reduce acculturation and hinder adolescent development (Gershoff et al., 2014; Goodenow & Espin, 1993).

Adolescent development is characterized by the process of identity formation, which according to Erikson's theory of psychosocial development, is the main task associated with adolescence (Erikson, 1968; Kidwell et al., 1995; Mitchell et al., 2021). Erikson proposed that in this stage of identity versus role confusion, the main concern of adolescents is cultivating a sense of identity and solidifying this identity through meaningful social connections (Erikson, 1968; Kidwell et al., 1995; Mitchell et al., 2021). If immigrant adolescents can develop social connections, their acculturation levels and identity formation are both bolstered (Sirin, Gupta, et al., 2013; Thomas & Jong Young Choi, 2006). Unfortunately, experiencing meaningful connections and developing friendships is especially difficult for adolescent immigrants who feel alienated due to cultural and linguistic differences (Alivernini et al., 2019; Caravita et al., 2019; Chow, 2007). Additionally, school bullying of immigrant adolescents is more common than bullying of non-immigrants, and the resulting social isolation leads to lower levels of acculturation and hinders identity formation (Caravita et al., 2019; Caravita, Strohmeier, et al., 2019; Gönültaş & Mulvey, 2020). Social barriers to acculturation and identity formation are not limited to the school environment, because societal perception of immigrants may also impact ego identity formation and acculturation among adolescents (Bhugra, 2013; Hashemi et al., 2019; Phinney, 1989).

Ego identity development among immigrant adolescents varies depending on country of origin and the extent to which they feel accepted by the host-country natives (Bhugra, 2013; Phinney, 1989). For those unable to pass as natives, race and religion-based stereotypes can impact immigrant adolescents' identity, acculturation, self-esteem, and overall development (Bhugra, 2013). Maintaining home-country customs, such as religious practices and cultural traditions, may help immigrant adolescents cope with the challenges of moving, however it may also cause stress and hinder acculturation if these customs are rare and highly stigmatized in the new country (Hashemi et al., 2019; Minardi, 2021; Stuart & Ward, 2018).

Acculturation & Middle Eastern Immigrants

Children, adolescents, and adults from the Middle East all face a particularly unique transition when migrating to the United States due to differences in cultural and religious values, as well as the threat of harmful stereotypes (Hashemi et al., 2019; Minardi, 2021; Stuart & Ward, 2018). Understanding the context of Middle Eastern immigration is relevant when analyzing acculturative factors of the transition (Aly & Rajan, 2009; Falah, 1996; Foad, 2013; Witty, 2011).

Middle Eastern immigration to the United States has been prominent since the 1800s, with political climates varying the circumstances of the Middle Eastern immigration experience (Aly & Rajan, 2009; Foad, 2013). Between the 1940s and 1960s, political instability in the Middle East was the primary motive for immigration, however strict regulations only allowed those who were highly educated and prepared for skilled labor (Coleman, n.d.; Falah, 1996; Foad, 2013; “Immigration Act of 1924,” 2019; Shakry, 2015; Witty, 2011). Acculturation during this period was aided by laws which ensured that immigrants had their paperwork and economic plans sorted before arriving to America, thus mitigating some of the bureaucratic difficulties associated with transition (Falah, 1996; Witty, 2011). In 1965, laws that limited non-European immigration were revoked and Middle Eastern immigration to the US soared (“Immigration Act of 1924,” 2019; Shakry, 2015). By allowing immigrants from different statuses and contexts to enter the US, the process of acculturation broadened, and the American ethnic landscape changed from one of white dominance to cultural diversity (Coleman, n.d.; Falah, 1996; Foad, 2013; “Immigration Act of 1924,” 2019).

With cultural diversity came the increased prominence of stereotyping, especially for immigrants from the Middle East, who were engaged in several political tensions with the US during the late 20th and early 21st centuries (Reyna et al. 2013; Timberlake & Williams, 2012). Stereotyping hinders acculturation because it alienates immigrants thus increasing feelings of isolation (Seeman, 2014; Timberlake & Williams, 2012). Stereotyping of Middle Eastern individuals was perpetuated through American media (Campbell, 1997; Rettberg & Gajjala, 2015; Semaan, 2014). For instance, during the Israel-Palestine conflicts of the 1948, American newspapers cemented their solidarity with Israel by portraying Palestinians as a detestable people to gain support from the American public (Baker & Sawafta, 2015; Semaan, 2014). Furthermore, American depictions of conflicts with Iran and Libya in the 1970s and 80s shaped the perception of the Middle Eastern man as a dangerous terrorist (Campbell, 1997; Rettberg & Gajjala, 2015, Semaan, 2014). These instances embedded harmful tropes about Middle Easterners into the American subconscious because the “average American is uneducated about the Middle East [and] they tend to conflate all countries and cultures in that part of the world” (Campbell, 2017, p. 178). The negative image of Middle Eastern individuals in American media only worsened after the 9/11 attacks in New York City because Arab-hate and Islamophobia became a means of nationalism in the so-called ‘War on Terror’ (Rettberg & Gajjala, 2015; Salaita, 2006). Because of these damaging stereotypes, Middle Eastern immigrants are predisposed to challenges with feeling accepted, and thus becoming acculturated in America (Reyna et al., 2013; Seiter, 1986).

In addition to stereotypes hindering the acculturation of Middle Eastern immigrants, differences in religious beliefs can also pose a challenge to acculturation (Cesari, 2009; Hashemi et al., 2019; Tubergen, 2007). Immigration to America is unique for Middle Eastern individuals who come from Islamic countries and must adjust to a secular culture (Cesari, 2009; Tubergen, 2007). Islam is the most common religion of the Middle East, and with it comes ingrained expectations that define norms around gender roles, modesty, and overall code of conduct (Hashemi et al., 2019;

Terman, 2017). In the Middle East, it is common for Muslim women to conserve their modesty by wearing hijab, however in the West, the veil is seen as a mechanism of oppression that puts women in a subordinate position (Manley, 2017; Terman, 2017). Thus, not conforming to American ideology about modesty may hinder the acculturation of Middle Eastern women (Manley, 2017; Terman, 2017). Moreover, in the Middle East, it is common for women to hold domesticated roles, whereas in the West, women are, often expected, to join the workforce (Foroutan, 2018). Immigrants often have financial struggles and maintaining the Middle Eastern norms of women as homemakers upon immigration may impact their financial stability and therefore their acculturation (Foroutan, 2018). These religion-based cultural differences make the immigration and acculturation experience uniquely challenging for Middle Eastern immigrants as they attempt to adjust themselves to new expectations while also maintaining the values of their home-countries (Hashemi et al., 2019; Montgomery & Foldspang, 2007; Ward et al., 2018).

Our Focus

General trends in the literature indicate that immigration is accompanied by a variety of stressors that may hinder acculturation (Dustmann & Fabbri, 2003; Noels et al., 1996; Valentín-Cortés et al., 2020; Reimers, 1983). Acculturation is often impaired by financial struggles, lack of language proficiency, social isolation, discrimination, and culture shock (Dustmann & Fabbri, 2003; Noels et al., 1996; Reimers, 1983; Valentín-Cortés et al., 2020). Challenges with identity formation and social contexts cause adolescents specifically to experience unique acculturative processes (Beck et al., 2012; Hermansen, 2017; Schaafsma & Sweetman, 2001). Focusing on adolescents will provide insight into the process of acculturation for individuals navigating a critical developmental period (Cheung et al., 2010; Chiswick & Miller, 1999; Minoura, 1992). Due to the vast diversity among immigrant experiences, this paper will focus on adolescent immigrants specifically of Middle Eastern origin and Muslim faith. It will explore how stereotyping, religious differences, and cultural differences impact acculturation among Middle Eastern immigrants. Additional acculturative factors that will be explored include socioeconomic status (SES), education, social support, and pre-existing familiarity with the United States. Therefore, this paper will address the following question: What factors relate to the acculturative outcomes of Middle Eastern individuals who immigrated to the US during adolescence?

Method

Participants

In June of 2023, the researchers recruited eight participants for this qualitative study through personal connections. These participants are all of Middle Eastern descent, coming from Turkey, Algeria, Palestine, Egypt, Kuwait, and two participants from Lebanon. Three males (pseudonyms NA, SA, IE) and five females (pseudonyms NS, GM, AK, NH, TS) participated in this study. All participants immigrated to the United States during adolescence between 13 and 18 years of age ($M=15.5$; $MD=15$) between the years of 1983 and 2007 to the states of California (NA, GM, TS, SA, NS), Georgia (AK), New York (IE), and Missouri (NH). They all currently reside in California. Researchers collected the following demographic data from each participant: age at the time of immigration, country of origin, year of immigration, and whether the participant immigrated alone or with others (see Appendix B).

Procedure

Participants were asked to partake in semi-structured interviews in June of 2023. Participant verbal consent was obtained to record responses and use their data. Interviews occurred over Zoom and lasted an average of thirty minutes. Each interview consisted of ten open-ended questions about the participant's immigration experience, focusing on factors related to their acculturation, English-language proficiency, the presence of assistive school programs, the impact of religion during their transition, and other facets of socio-cultural adaptation (see Appendix A). Researchers asked follow-up, open-ended questions to ensure the responses could be extensively analyzed. All interviews were recorded, transcribed, and then analyzed using qualitative coding techniques.

Transcription & Coding

After acquiring data through recorded interviews, the interviews were transcribed using Zoom so they could be coded. Each transcript was cleaned and verified by both researchers. Based on the participants' responses, the researchers generated a codebook using thematic analysis and identified nine main factors relating to acculturation among those who immigrated from the Middle East to America during adolescence which were organized into three overarching themes. These factors were defined and verified through four rounds of reading, coding, and discussion. To qualify as a factor of acculturation, at least four of the eight participants needed to mention it during their interview. This was done to ensure that the factors were representative of the sample. In addition, if every factor mentioned by every participant was included, succinctness would be compromised and the factors would not be generalizable. The number of times each factor was mentioned throughout the interviews was recorded such that the frequency of the factors relative to each other would be evident.

Results

Nine factors relating to acculturation emerged from the interviews and were grouped into three overarching themes: community, identity, and American infrastructure.

Community

Participants' acculturation was enhanced by support from family who immigrated with them, from family and friends who had immigrated before them, and from those they met in the US. Community support was operationalized to include a socioemotional dimension and a physical dimension. The socioemotional dimension entailed forming bonds, collaborating on adapting to American customs, and comforting one another when coping with changes. The physical dimension involved factors such as financial assistance, housing security, and guidance for admittance into school/work environments.

Family Support

Family support entails emotional, intellectual, and financial assistance from members related to the participant. In the interviews, family support was discussed twenty-four times throughout the transcriptions by seven out of eight of the participants. Participants explained that immigrating with

family members helped them adjust to American society and customs. Having family members “compare notes” on the Americans that they worked with allowed participants to “understand and imitate American mannerisms.” Participants noted that although immigrating with family members furthered their acculturation, at times it forced them to take on additional responsibilities such as language brokering for parents and caring for siblings while parents worked. Those Participants who had family members that had already been living in the US utilized these connections to understand the American education system, culture, housing market, and social etiquette. Participants who immigrated to the US alone noted that perceived isolation and sadness due to separation from family inhibited hindered their acculturation because the participants they were “constantly thinking about family back home.”

Social Support

Another aspect that was valued by participants in the acculturation process was social support, which was mentioned twenty-two times by seven participants. During the initial transition, some participants relied on preexisting social connections for shelter and guidance on navigating the American job market. For participants who immigrated without social connections in America, there was a trend of seeking other immigrants and/or Americans from the same ethnic origin. Because our participants all identify as Muslim, the mosque was essential in helping participants develop social circles and “feel at home” in the US. Social connections helped immigrants feel less culturally isolated and allowed them to learn about how other Middle Eastern individuals found success in integrating into American society. These connections also enabled some participants to find jobs and obtain financial assistance. Some participants connected with non-Middle Eastern immigrants at school with whom they could “relate to” and discuss “how weird American food was and how hard American school was.” The participants who struggled to make friends reported that lack of social bonds prevented them from “connecting to American society.”

Identity

Participants revealed that immigration impacted their identity formation which had consequences for their acculturation. Immigration contributed to participants’ mental health struggles, difficulty adapting to cultural differences, and discrimination, all of which challenged their formation of a Middle Eastern-American identity. Researchers operationalized identity as mental-health, personality, and value-based characteristics of participants. Identity was shaped by the mental processes, values, religion, and social adversity that accompanied acculturation.

Mental Health

Mental health was a significant factor related to identity and acculturation, mentioned by seven participants a total of eleven times. For some participants, positive mental health characteristics such as resilience and determination were related to successful acculturation. For these participants, the mindset of “adapt or go home” propelled them to overcome their challenges and to continue pursuing their goals in America. In addition to resilience and determination, the development and expression of independence also related positively to acculturation, allowing participants to feel strong, responsible, and capable in their ability to succeed. Other participants were challenged with negative mental health outcomes during their immigration. These participants felt culturally isolated by language barriers and physically isolated due to ostracization and lack of work

opportunities. Notably, depressive symptoms occurred as a result of isolation, thus inhibiting identity formation and reducing motivation to acculturate.

Cultural Differences

The impact of cultural differences between their country of origin and the US on identity formation and acculturation was discussed frequently, totaling eighteen mentions across all eight participants. Cultural differences include any mention of differences in norms between the origin country and America. Interviews indicated that cultural differences impacted participants' willingness to adopt an American identity. For instance, many participants were fascinated by multiculturalism in America and felt excited to immerse themselves in the culture and learn about the world through these interactions. For other participants, certain aesthetic features of American culture, such as long nails, dyed hair, and "weird music," made participants feel uncomfortable and reduced their motivation to acculturate and "fit in." Discomfort with aspects of American culture led some participants to have difficulty "viewing [themselves] as having an American identity." Adjusting to cultural norms around work was found to make acculturation difficult. In the Middle East, it is common for men to hold financial responsibility for the family, however the financial structure of the US often requires two sources of income for survival. This caused conflict in some families and added stress to the participants' transition. It is also common for students to have jobs in America, unlike in the Middle East. For one participant, not working caused her to be othered by her peers, who assumed this choice came from a place of entitlement. For those who balanced both school and work, valuable lessons about adulthood were learned, however the need to "grow up and be responsible very quickly" came at the cost of enjoying "teen life and doing things without thinking of consequences."

Religion

Seven participants mentioned the role of religion in their acculturative process and identity formation, for a total of twelve times. All participants were Muslim. For many, Islam "reminded [them] of home and brought comfort" during the transition which allowed them to better acculturate. In the Middle East, Islam is ingrained in the culture, so continuing to pray, celebrate religious holidays, and connect with God post-immigration allowed the participants to retain their cultural identity. Islam also instilled a value system into participants that "set guidelines on how to behave" as they navigated a change in the societal moral structure. Some participants noted that their religious identity shaped their social identity. For example, participants were less likely to succumb to peer pressure around sex, substance use, and delinquent behaviors, such as disrespecting authority figures, when it went against their religious values. For some participants, being outwardly Muslim caused them to feel outcasted which hindered their acculturation. Despite this, these participants continued to practice religion and form identities centered around religion.

Discrimination

Five participants experienced discrimination against their Middle Eastern heritage and Islamic identity. Discrimination negatively impacted identity formation and acculturation and was mentioned sixteen times throughout the interviews. Negative attitudes against Arabs caused participants to be alienated by schoolmates and society as a whole. Physical appearance played a significant role in this process. Participants who experienced higher levels of discrimination were more visibly

Middle Eastern, most often through the presence of a beard or hijab. Those who did not mention instances of discrimination were less distinctly Middle Eastern, being either white passing or ethnically ambiguous. Participants who immigrated after 9/11 experienced more discrimination because there was a common belief “that every Muslim and every person from the Middle East was a terrorist.” Discrimination caused social rejection, harassment, career disadvantages, and mental health struggles, thus hindering identity formation and acculturation.

American Infrastructure

Participants noted that acculturation was greatly impacted by certain factors that were specific to American infrastructure. Infrastructure was operationalized as the language, school system, and economy of the United States.

English Language

All eight participants noted that English-language proficiency was essential for acculturation. English was mentioned in the context of acculturation twenty-six times across all interviews. Participants who had learned some level of English prior to immigrating felt as though knowing English “made the transition easier,” by allowing them to “become part of society,” “watch American television,” and “fit in with Americans.” Four participants emphasized how using television and music to learn English also taught them about American culture and behaviors which aided in their acculturation. Participants noted that English was essential for success in school and job attainment. Those who were not fluent in English prior to immigration had greater difficulty in school, social settings, and in the workplace. Although all participants noted the importance of English proficiency for acculturation, one particular participant explained that they still struggled with English because of the “American accent” and the rapid speech rate.

School Assistance

School assistance was found to be entirely useless in immigrant acculturation. All of the participants stated that their school did nothing to aid their transition to the US. One participant mentioned that their school offered English-Second-Language classes but the “teachers were not too nice and did not do anything to help.” Three participants described how the education system was much more rigorous than it had been in their origin countries and no programs existed to support their academic transition. One participant noted that their school had cultural clubs, “but there was no Arab or Algerian cultural club.” One participant expressed that perhaps their schools did offer support for international students, however they were not made aware of these programs. Another participant proposed that because American schools are very large, they likely do not have the resources to offer “special attention” to immigrant students.

Finances

Money was mentioned seventeen times across all participants as helpful for acculturation. Seven of the eight participants experienced significant financial struggles upon moving to the US due to their parents working low-wage jobs. Poor finances limited acculturation by preventing participants from accessing education and tutoring. Acculturation was further hindered because inability to

Table 1. Factors Relating to Acculturation of Middle Eastern Immigrants

		Factors Relating to Acculturation of Middle Eastern Immigrants								
		Community		Identity		American Infrastructure				
		Family Support	Social Support	Mental Health	Cultural Differences	Religion	Discrimination	English Language	School Assistance	Finances
# of times mentioned		24	22	11	IS	12	16	26	S	17
Contexts that the Factor was Mentioned In		Easing the transition	Easing the transition	Independence or Isolation	Fashion, Music, Gender Norms	Coping Mechanism or Source of Discrimination	Social Rejection, Career Disadvantages	Integrating into Communities	Rigorous Education System	Poor finances increased struggle

afford trendy clothes and new technology prevented participants from forming social connections with Americans. One participant who came from a wealthy family noted that money aided her acculturation because she could afford tutoring services like English lessons and entertainment like dance classes and movie tickets that allowed her to socialize with Americans.

Discussion

This qualitative study was designed to examine factors that relate to the acculturative outcomes of Muslim, Middle Eastern individuals who immigrated to the US during adolescence. The results indicate that factors related to acculturative outcomes of Middle Eastern adolescent immigrants include community-based, identity-based, and American infrastructure-based factors. Immigrating with family members and forming social connections with others from the same ethnic origin enhanced acculturation for participants by providing socioemotional, financial, and cultural support. These findings align with existing literature which has found that family and social support are associated with higher levels of acculturation (Chung et al., 2000; Edwards & Lopez, 2006; Sanchez et al., 2019). Past research has also demonstrated the role of the mosque in building collective self-esteem and providing emotional support (Nguyen et al., 2013; Nguyen, 2017). This study reveals the importance of the mosque in the establishment of social support for Middle Eastern immigrants. One participant noted “The community at the mosque helped my mom get involved in event planning so she would not be bored at home and they helped my dad find a job with better pay.”

Not only did community impact the extent to which these participants could acculturate, but the importance of identity-based factors on acculturation was revealed. Previous research has found that adolescence is the period in which identity formation occurs, and that culture shock, bullying, and socioeconomic challenges associated with immigration often negatively impact identity formation (Bhugra, 2013; Caravita et al., 2019; Erikson, 1968). This study agreed with the literature because participants noted that depressive symptoms, social isolation, and cultural differences led to identity confusion which made it more difficult to adjust to life in the US. Previous research also aligns with our findings that immigrants who feel accepted by natives and are native passing have better acculturative outcomes (Bhugra, 2013; Phinney, 1989). One participant explained, “I think that when I could blend in with White people, no one really stared at me or talked to me with hesitation or weird looks but when I was wearing [hijab] some people were more hesitant to speak with me and I definitely noticed people staring and being less likely to smile at me or reply when I said hello.” This study expanded upon the literature because participants noted that being resilient, strong in their morals, and independent allowed them to better acculturate.

Because adolescent Muslim, Middle Eastern immigrants are a very specific population, literature on their acculturation in the United States is very limited (Reyna et al., 2013; Seiter, 1986). Research has found that discrimination against those from the Middle East is common in the US (Reyna et al., 2013; Seiter, 1986). Previous research has also shown that proficiency in the language of the new country aids in acculturation (Park, 2011; Stören, 2004). This study concurred with previous findings (Park, 2011; Reyna et al., 2013; Stören, 2004). Participants who had better English skills were able to communicate with natives, succeed in school, and find jobs which supported their acculturation. This study also identified that insufficient finances and the difficulty of US schools serve as acculturative obstacles for participants. One participant rooted much of her familial conflict to money struggles. Her mother was forced to work to make ends meet in America, which she

had never had to endure in the Middle East which led to familial tensions. The American economy is significantly stronger than the economies of Middle Eastern countries (“GDP per Capita,” n.d.). Lack of sufficient finances can hinder acculturation due to ~~because~~ inability to afford trendy clothes, tutoring, and entertainment can further alienate Middle Eastern immigrants from the American population, which can prevent them from feeling integrated into society.

Conclusion

Through this research, the main factors related to acculturation for Middle Eastern, adolescent immigrants in the US were revealed. Factors that assist and hinder acculturation were discussed. In the future, this study should be replicated with a larger sample size. Given that many of the participants in this study immigrated to California, future research should also examine participants from other states to understand how the state of relocation relates to acculturative outcomes. Results of this study suggest that further research should be conducted on the role of religious institutions in enhancing immigrant acculturation. The three overarching themes that emerged around acculturation imply that future research should examine how community, identity, and infrastructure independently relate to acculturation in more depth.

Findings from this study imply that the American public should be better educated about religious and cultural diversity such that a climate of tolerance and acceptance can be fostered. Elimination of discrimination through destigmatizing media campaigns may benefit the identity formation and acculturation of Middle Eastern adolescent immigrants. It is also hoped that this study prompts discourse on school programs to enhance acculturation. School programs could be developed that prepare immigrant students for the rigor of the American curriculum and teach them about obtaining higher education and jobs. School programs could also connect immigrant students with each other and with natives who are willing to provide social support for immigrants and teach them about American culture and behaviors. It is hoped that implementation of such programs and continued research on Middle Eastern adolescent immigrants will spark policy change that can ease the acculturation processes for this population.

While we were able to grasp a comprehensive understanding of the factors of acculturation for our participants', our study contained limitations regarding sample size, demographics, and time. We used a narrow sample size of eight participants which limits the extent to which we can generalize these findings. Moreover, our participants all currently reside in California. As a diverse state, this may influence their view of American society differently than someone who resides in a less diverse state, regardless of the fact that they all originally immigrated to various states. Lastly, our participants immigrated to America between the years of 1983 and 2007, a 24 year range. Given that political circumstances, media representation, and general knowledge impact how certain groups are treated in a society, the year in which the participant immigrated may have impacted their acculturation in ways we did not consider.

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Appendix A

Interview Questions

1. What were some factors that eased the transition for you and made you feel more acculturated?
2. What were some factors that made the transition more difficult?
3. How did you adjust to America socially?
 - a. How did you meet your social group?
 - b. How did ethnicity/race influence your connections?
4. Did you immigrate alone or with others?
 - a. (*Alone*) Given that you immigrated alone, how did this affect your acculturation?
 - b. (*With others*) Given that you immigrated with others, how did this affect your acculturation? What were the experiences of those you immigrated with?
5. How did your school assist your transition both academically and socially?
 - a. What services were provided to assist you in acclimation to new academic and cultural expectations?
6. Can you describe your comfort level with English at the time you immigrated to the US? Did that play a role in your immigration experience or acculturation process?
7. Can you describe the predominant attitude about your middle eastern heritage in the place you moved to?
 - a. How did your ethnic origin influence your acculturation?
8. Given that you came from a predominantly Muslim country, how did Islam influence your acculturation process?
9. (Prime with specific information about interviewee; i.e. white passing, wears hijab) How did your physical appearance influence your ability to acculturate?
10. A psychologist named Erikson described adolescence as the time in which we undergo identity formation. Can you describe the relationship between your immigration experience and your adolescent identity formation?

Appendix B

Table B1. Participant Demographics

Pseudonym	Country of Origin	State of Relocation	Age at Immigration	Year of Immigration	Immigration Alone or With Others
NA	Lebanon	California	18	1983	Alone
GM	Lebanon	California	14	1997	Mom, Dad, Brother
AK	Turkiye	Georgia	13	1992	Mom, Dad
TS	Algeria	California	16	2007	Mom, Dad, Sister, Sister
SA	Palestine	California	18	1988	Alone
NS	Egypt	California	14	1989	Alone
IE	Kuwait	New York	18	1986	Mom, Dad, Brother
NH	Iran	Missouri	13	2002	Dad

The Impact of Race and Socioeconomic Status on Transplant Accessibility and Outcomes: A Literature Review

Arulvel Rajeswaran*

Due to the high demand but low supply of donor organs, issues of organ allocation arise as patients on the waitlist are prioritized to determine who gets the next available organ. This literature review will review articles related to the racial and socioeconomic disparities in organ transplants and how they affect transplant access and outcomes. Patients of Black and minority (Hispanic and Native American) races had significantly lower rates of organ transplants as well as worse transplant outcomes including graft failure and post-operative complications (Bryce et al., 2009). Similarly, patients from lower socioeconomic status (SES) backgrounds (i.e. poverty or lack of private/commercial insurance) had lower rates of organ transplant surgeries but there has been no significant research done on the effect that SES specifically has on transplant outcomes. Further directions for future research should be investigating the role of SES on transplant outcomes. The findings of this literature review highlight the need for measures to make organ allocation more equitable; this can be done by factoring in the social determinants of health (SDOH) when prioritizing potential organ recipients to compensate for race and SES decreasing accessibility to transplants.

Keywords

social determinants of health • transplant surgery • access to healthcare • race • socioeconomic status

Introduction

Transplant surgeries are considered the golden standard of care for organ failure for patients worldwide since they give them a new organ that acts as a lifesaver and a new chance (Wang & Hart, 2021). Individuals with conditions leading to organ failure are referred by their physicians for

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organ transplants (*The Organ Transplant Process* | *Organdonor.Gov*, n.d.). Patients are then evaluated for transplant eligibility and are placed on the registry to receive a donor organ once one is available. Depending on the type of organs, donor organs can either be harvested from recently deceased individuals who have volunteered as donors or from living volunteers (*Organ Donation & Transplantation*, n.d.). The Organ Procurement and Transplantation Network then matches patients on the registry with donor organs as they become available. Matching is based on several criteria including “blood type, body size, the severity of the patient’s condition, geographic proximity to the donor, and the patient’s time spent on the registry” (Matching Donors and Recipients | *Organdonor.Gov*, n.d.).

With over 40,000 transplant surgeries performed in 2022 alone, there is still an increasing need for donor organs because every ten minutes, another person is added to the transplant waiting list (*The OPTN/SRTR Annual Data Report*, 2023). As of March 2024, more than 104,000 patients are waiting for a donor organ on the national registry (*Waiting list/process*, 2024). Due to the high demand but low supply of donor organs, issues of organ allocation arise as patients on the waitlist are prioritized to determine who gets the next available organ. The aforementioned prioritization and matching parameters – which differ for each organ but generally include factors like waiting time and the likelihood of survival – do not consider SDOH (*How we match organs* 2024). For this review, SDOH includes non-biological factors that influence health including race/ethnicity, SES, access to healthcare, education, etc. This literature review aims to answer the question “What is the Impact that Race and Socioeconomic Status have on Transplant Accessibility and Outcomes?”.

Methods

This paper reviewed articles (including studies and other literature reviews) that discuss the role of race and SES on organ transplant access and outcomes. 25 publications from the United States between 2005 and 2023 were selected for this review using PubMed and Google Scholar. Search terms inputted into the databases included “organ transplant” AND “race” OR “socioeconomic status”. All of the articles used to answer the research question were studying the impact of race and/or SES on organ transplants. More specific searches were performed to find research on the effect that SES has on the outcomes of transplant surgeries, with no success. After reading the abstracts to identify the studies’ goals and results, articles were categorized based on whether they studied race, SES, or both. Then, they were subcategorized based on whether they focused on how these factors influence access to transplant surgeries, outcomes of the surgery, or both.

Race

According to four studies on transplant disparities, access to kidney transplants appears to be impacted by race, with Black and minority (i.e. Native American, Hispanic) patients having to wait longer for a transplant or having a lower likelihood of receiving a donor organ. A prospective study that followed 1056 patients referred for kidney transplant between 2010 and 2012 and conducted follow-up interviews post-transplant found that Black patients had a lower likelihood of kidney transplant and living-donor transplant (Wesselman et al., 2021). Similarly, a cross-sectional study done by reviewing kidney transplant recipients from the Scientific Registry of Transplant

Recipients found that, compared with white recipients, Black recipients had a 37% lower likelihood of a living donor kidney transplant (Killian et al., 2021). Additionally, a retrospective study of adults undergoing dialysis between 2005 and 2014 found that non-Hispanic Black and Hispanic patients have lower access to kidney transplantation compared to non-Hispanic whites (Ku et al., 2019). The researchers compared the prevalence of comorbidities (co-existing health issues) that could potentially influence transplant eligibility between race/ethnicity groups, to prevent it from being a confounding variable (Ku et al., 2019). Lastly, a 2005 editorial mentioned that minority patients (specifically African Americans and Native Americans) are at greater risk of end-stage renal disease (ESRD) but also less likely to receive an organ transplant once ESRD develops (Gaston & Benfield, 2005). According to a medical record analysis of patients at a kidney transplant center who were referred for transplant and a longitudinal follow-up of up to five years, even when accounting for socioeconomic, demographic, and clinical factors, Black patients had a 59% lower rate of kidney transplant than white patients (Thamma et al., 2013). Despite different methodologies, all the aforementioned articles have established a relationship between race and transplant accessibility, suggesting significant disparities that limit individuals from specific racial backgrounds from accessing life-saving care.

Some of the studies done about kidney transplants, though, mention kidney transplants and living donor transplants separately. While recipients still receive the core benefit of a functioning kidney when they receive it from a deceased donor, living donor organs are considered more beneficial because, according to the University of Pennsylvania, “kidneys from a living donor are generally healthier, last up to two times longer than deceased donor kidneys, and usually start working immediately after transplant, compared with deceased donor kidneys that may have delayed function” (*Living Donor Kidney Transplant*, 2023). Additionally, the quality of life of patients before the transplant is also affected since recipients of living donor kidney transplants (LDKT) can receive the surgery without starting dialysis while patients waiting for a deceased donor organ will have to undergo dialysis while waiting for an organ. This ultimately might prevent patients from carrying out obligations like going to work, which might further impact one’s financial stability and ability to afford a transplant surgery (*Living Donor Kidney Transplant*, 2023).

Similar racial disparities were found in liver transplants as well: according to three studies, Black and Native American patients, along with racial minorities in general, are disadvantaged in access to liver transplants. One study was an analysis of discharge data from the National Inpatient Sample between 2016 and 2019, identifying adult patients with chronic liver disease who underwent a liver transplant. Researchers found that compared to white patients, Black and Native American patients had decreased liver transplant rates (Mansour et al., 2022). Similarly, a study that followed patients through the transplant process found that evaluation, waitlisting, and liver transplantation were less likely if patients were, among other characteristics, Black (Bryce et al., 2009). The study also found that differences due to these disparities were more pronounced in the evaluation and listing stages than in the transplantation stage since national oversight and review occur for the latter (Bryce et al., 2009). The results from Bryce et al. suggest a bottleneck earlier in the referral process that slows movement through the process for some showing that race plays a bigger role in referrals and evaluation than in the actual waiting period. Similarly, a 2009 literature review of racial/ethnic disparities in liver transplantation found that at each step in the transplant process, racial/ethnic minorities appear to be disadvantaged despite the inherent analytical and statistical biases present in many of the reported studies (Mathur et al., 2009).

Similar to kidneys, there are two types of liver transplants: deceased donor or living donor transplants (*Types of Liver Transplant*, 2023). In the latter, part of the liver from someone in an established relationship with the recipient is transplanted (*Types of Liver Transplant*, 2023). Due to the regenerative nature of livers, despite only half of the liver being transplanted to the recipient, both the donor and the recipient will have regenerated fully functioning livers within 6 to 8 weeks (*Types of Liver Transplant*, 2023). While living donor transplants provide added benefits, the additional requirements (i.e. the donor has to have an established relationship with the recipient, the donor has to be 18–55 years old, etc.) may pose additional obstacles in finding suitable donors (*Types of Liver Transplant*, 2023).

Some studies have focused specifically on how race influences different steps of the solid organ transplantation process. A 2022 literature review of inequities in access to organ transplants found that racial and ethnic minorities, among other groups, were less likely to be referred, evaluated, and added to the waiting list for organ transplants (Park et al., 2022). A report from The Diversity and Minority Affairs Committee of the American Society of Transplantation states that “participants noted that minority populations were more likely to be adversely affected by limited preventive medical care, lack of counseling regarding transplant options, and delays in transplant referrals for organ transplantation.” (Higgins & Fishman, 2006). They also noted that some of these consequences may be from the reduced presence of professionals from minority communities training in transplant-related specialties, which is a factor not mentioned in other studies and suggests further action to increase diversity in the population of transplant-care providers (Higgins & Fishman, 2006).

While research on the impact that race has on transplant surgery outcomes is not comprehensive, existing research predominantly suggests that African American, Black, and Hispanic patients are more likely than white patients to experience kidney graft loss and failure. A 2006 analysis of the United States Renal Data System database aimed to determine the presence of racial disparities in graft loss and death in groups with and without lupus nephritis, an autoimmune condition that affects kidney function. The study found that African-American kidney recipients with the condition, compared to non-African-American recipients, had an increased risk for graft loss (Nee et al., 2013). Additionally, in the elderly (60+) population of kidney transplant recipients on the UNOS database, Black kidney recipients were more likely than whites to experience kidney graft failure (Ilori et al., 2015). A literature review on disparities in kidney outcomes stated that studies document worse outcomes for Black patients – among other factors – and better outcomes are reported in Hispanic and Asian kidney transplant recipients but the distinct roles of racial versus socioeconomic factors remain unclear from these results (Gordon et al., 2010). Another study using the UNOS database with a retrospective cohort methodology found that “the estimated 10-year probability of graft survival was 56% for African-Americans and 64% for Hispanics compared to 75% for whites” (Press et al., 2005). While access to treatment may be affected by race due to mediating factors like SES, location, and lack of insurance, the outcome of the transplant surgery being affected by one’s race with no known biological factor is concerning. More research should be done to determine the association between race and the quality of the transplant center in which the surgery takes place. It might be plausible that, due to redlining and other historically racist housing segregation policies, Black and other minority patients get transplants done at local, lower-quality facilities than white patients. A 2023 cohort study examining the impact of redlining on the treatment and survival of breast cancer in women aged 60–99 years found that historical redlining is associated with differential treatment receipt, lower likelihood of receiving surgery, and poorer

survival of breast cancer-specific mortality (Bikomeye et al., 2023). While not studying transplant surgeries, this research sheds light on the potential effects that historically racist policies may have on organ transplant access and outcomes.

Socioeconomic Status

For kidney transplants, three studies show that SES and health insurance are associated with the likelihood a patient has of getting the transplant they need; Bryce et al., 2009, Mansour et al., 2022, Park et al., 2022, and Wesselman et al., 2021 have been mentioned in previous sections as they found that race had a significant impact on transplant accessibility. A prospective study that followed patients referred for kidney transplants mentioned earlier also found that lower income and public insurance – along with race – were each associated with a lower probability of any kidney transplant, with an alarming subdistribution hazard ratio of 0.49 for LDKT (Wesselman et al., 2021). A literature review of disparities affecting pediatric kidney transplants found that the absence of health insurance poses an important barrier to transplant (Amaral & Patzer, 2013). However, even after adjustment for insurance status and neighborhood poverty, disparities persist; this goes to show that lack of insurance is not the only barrier or determinant affecting pediatric kidney transplants (Amaral & Patzer, 2013).

Similarly, three studies found that private and commercial insurance seems to be positively associated with liver transplant accessibility. Firstly, a study that analyzed pediatric patients (aged 5 to 15) from the Scientific Registry of Transplant Recipients found that after adjusting for socioeconomic factors like neighborhood deprivation and insurance, racial disparities were not present for wait-list mortality (Wadhvani et al., 2021). This suggests an interplay between SES and race, potentially indicating that the racial disparities seen in transplant accessibility may be due to SES disparities between races. It was also found that patients who lacked commercial insurance were less likely to undergo evaluation, waitlisting, and liver transplantation (Bryce et al., 2009). In an analysis of discharge data from the National Inpatient Sample between 2016 and 2019, by identifying adult patients with chronic liver disease who underwent a liver transplant, researchers found that patients with private insurance had a liver transplant rate almost twice as high as that of those with Medicare, while patients without insurance had the lowest rate of transplantation (Mansour et al., 2022). Insurance access can be used as a proxy for SES since employment offers health insurance and private insurance is available for purchase, if an individual uses Medicaid or Medicare or if they are uninsured, it can reasonably be assumed that they are of low SES. This assumption allows a connection between SES and transplant accessibility for liver transplants.

For solid organ transplants in general, lower SES was also seen to be associated with decreased accessibility to transplant services. A 2022 literature review of inequities in access to organ transplants found patients in lower socioeconomic status groups were less likely to be referred, evaluated, and added to the waiting list for organ transplants (Park et al., 2022). Similarly, a retrospective analysis of medical charts for 183 pediatric kidney, liver, and heart transplant candidates who had been referred for evaluation found that the most common barrier to listing was financial, with public insurance being indirectly associated with time to listing – ultimately, delayed time to listing for pediatric transplant patients is associated with increased risks of mortality and morbidity (Steinberg et al., 2021). An analysis of the UNOS registry data, including 33,893 adult heart transplant recipients between 1994 and 2014, found significant associations between lower SES markers

(including neighborhood SES, Medicare, and Medicaid) and negative heart transplant outcomes (including death, retransplant, and hospitalization), independent of baseline clinical characteristics (Wayda et al., 2018).

There was no significant research available about the relationship between SES and transplant outcomes, suggesting a gap in the literature that future research should try to cover.

Discussion

With the same trends being consistently found by studies investigating different organ transplants, it is concerning that there is little to no policy being made or action being taken to reduce these disparities.

The wide scope of this literature review is a limitation of its findings as it included a broad range of transplant studies including kidney, liver, and heart transplants. Race and SES might play distinct roles in different types of transplants. However, the decision to include all organs was taken to evaluate common trends and disparities in transplants as a whole. Further research should be done to determine the different roles these disparities play in the transplant process of each organ. Since UNOS coordinates transplants for all organs, the enlisting process should not vary significantly, except between deceased donors and living donors since the latter is not available for all organs (What is UNOS, 2023).

Additionally, another limitation of the review is that it included studies regarding pediatric transplants as well as adult transplants. While UNOS is also responsible for organ allocation for pediatric patients, they get “pediatric priority” on the waitlist for organs like kidneys because being on dialysis may cause developmental delays (*Pediatric transplants*). Since just listing before the individual’s 18th birthday is enough for a patient to be considered “pediatric” even if they receive the transplant after they become an adult, it might be counterintuitive to count patients above 18 as pediatric for research (*Pediatric transplants*). Another limitation of this review and the research included in it is that only a limited number of the included studies discuss data from races other than white, Black, Hispanic, and Native American minorities. Since there was no filter to include only these groups in the review, this is likely the result of fewer studies focusing on other races. This points to another future direction that researchers should take to make research more inclusive and generalizable.

Furthermore, more disparities affect one’s likelihood of organ transplantation: research shows that other factors cause differences in transplant rates. For example, a 2022 cross-sectional study that investigated the impact of SDOH on additions to state-level kidney and liver transplant waitlists found that urbanicity was independently associated with waitlisting (Johnson et al., 2022). Innovations are being developed, though, to combat the temporal and geographical constraints and disparities in organ transplants. For example, the ex-vivo heart perfusion mechanism allows prolonged perfusion time so donor hearts can last longer outside of the body between organ harvest and transplant, thereby reducing temporal disparities and allowing time for more tests to confirm organ viability and recipient matching (Bryner et al., 2021). This would allow for more equitable allocation of the organ where travel and time constraints do not prevent those who need the organ the most from receiving it.

Research shows consistent reports that race and SES affect the accessibility of transplant surgeries, but significant action is yet to be taken to make these procedures more equitable. In

March 2023, lung organ allocation in the US shifted to a continuous distribution system that prioritized patients based on a composite allocation score (CAS) that considers medical and biological factors like waitlist survivability, blood type, and height to determine their priority for a lung transplant (Calhoun et al., 2023). If a similar measure that included SDOH – like race or SES – could be developed, access and outcomes of transplants may become more equitable since differences in access would be accounted for. Such measures, however, may generate feelings of disadvantage to those who do not explicitly benefit from adding these measures, so changes to the practice must be made carefully. Additionally, a review of 10 national data sources related to transplant surgeries concluded that there is a need for improved SDOH data collection systems in end-stage organ disease and transplant patients “via enhanced inter-registry collaboration, incorporation of standardized SDOH variables into existing data sources, and transplant center and consortium-based investigation and innovation” (Chan et al., 2022). Taking measures to increase the collection of SDOH data and making it accessible to researchers will allow more study on the different disparities that exist within the field of organ transplants, and ultimately, allow for more equitable outcomes.

Conclusion

To answer the research question, the literature review of studies and reviews regarding the role of race and SES in organ transplants shows that patients of Black and minority (Hispanic and Native American) races had significantly lower rates of organ transplants as well as worse transplant outcomes. Additionally, patients of lower SES (i.e. poverty or lack of private/commercial insurance) had lower rates of transplant but there was no significant research on the effect of SES on transplant outcomes. Therefore, the research question cannot be fully answered based solely on current research findings. Future directions for research include investigating the role of SES on transplant outcomes.

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Perinately Acquired HIV: Viral Evolution and its Implications for Adolescents

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This literature review explores the implications of viral evolution on the health outcomes of adolescents with perinately acquired HIV, offering recommendations for enhancing public health practices. Since the emergence of HIV in the 1980s, perinatal transmission from parent to child has become increasingly prevalent in developing countries. Antiretroviral therapy (ART) has greatly improved the life expectancy of children with perinately acquired HIV, allowing them to reach adolescence. ART plays a critical role in suppressing HIV and reducing the risk of transmission. Nevertheless, low adherence or lack of treatment can lead to viral evolution and drug resistance, posing significant threats to adolescents. Challenges faced by adolescents with perinately acquired HIV are multifaceted, including increased viral evolution and difficulties in adhering to ART. The impact of stigma, behavioral factors, and social and familial dynamics contribute to low adherence rates. Global inequities and systems-level challenges further complicate the situation, particularly in resource-limited settings. Adequate public health infrastructure and innovative approaches, such as long-acting injectable ART, are imperative to address these structural barriers and reduce drug resistance among adolescents. Comprehensive data collection and longitudinal studies are needed to understand the long-term consequences of perinately acquired HIV and its impact on viral evolution. A multidisciplinary approach involving healthcare providers, virologists, and social scientists is crucial to meeting global HIV goals and addressing the specific needs of this vulnerable population.

Keywords

human immunodeficiency virus • parent-to-child transmission • pediatric HIV treatment • adolescent health • global health

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Introduction

HIV (human immunodeficiency virus) is a chronic, treatable virus that originally spread across the globe in the 1980s. One critical route of HIV infection is perinatal transmission, where HIV is transmitted from a parent to their child during pregnancy, labor and delivery, or breastfeeding. Today, most children who acquire HIV via this route (also called vertical transmission) have access to lifesaving treatment and live into their adolescence and beyond. Adolescence is an important time for this population, given the potential for HIV evolution as a result of behavioral changes and life transitions. This literature review explores how HIV evolution impacts the health outcomes of adolescents living with perinatally acquired HIV globally. Drawing upon existing research, I seek to synthesize the biological implications of life-long HIV infection and the behavioral challenges for adolescents in order to make recommendations for future public health practices that improve health outcomes for adolescents living with HIV.

Basic Principles of HIV, Treatment, and Viral Evolution

HIV is a disease that attacks the body's immune system. It can be spread through sexual contact, sharing needles to inject drugs, and during pregnancy (CDC, 2022). This paper will focus on the latter, also called perinatally acquired HIV. Perinatally acquired HIV can occur prepartum (through the placenta), intrapartum (through the exposure of the infant's skin to maternal blood and vaginal secretions), and postpartum (through breast milk) (Ahmad, 2010). The use of antiretroviral therapies (ART) in pregnant individuals living with HIV lowers the chance of perinatal transmission to less than 1% (NIH, 2023b). Without ART, the transmission rate is about 30% (Ahmad, 2010). There is no cure for HIV, so someone infected with HIV will have the disease for the duration of their life. (CDC, 2022)

ART is a treatment regimen that typically includes a combination of three HIV drugs belonging to at least two of the seven different drug classes (NIH, 2023a) The HIV drug classes are 1) Non-nucleoside reverse transcriptase inhibitors (NNRTIs), 2) Nucleoside reverse transcriptase inhibitors (NRTIs), 3) Protease inhibitors (PIs), 4) Fusion inhibitors, 5) CCR5 antagonists, 6) Integrase strand transfer inhibitors (INSTIs), 7) Post-attachment inhibitors (NIH, 2021). Each class is grouped by the mechanism it uses to fight HIV and inhibit viral replication (NIH, 2021).

The modern ART drug regimen was released in 1996 (NIH, 2018). It suppresses HIV, allowing people living with HIV (PLWH) to live long, healthy lives. Antiretroviral treatment is an effective treatment for HIV because it prevents the virus from replicating, therefore preventing within-host genetic evolution in the virus (Bandera et al., 2019). A longitudinal study looking at 18 patients over 5 years showed that patients with low-level viremia who adhered to ART saw no genetic evolution for HIV over this period (Vancoillie et al., 2017). Additionally, ART adherence prevents the transmission of HIV, decreasing the odds of between-host evolution (Alizon & Fraser, 2013).

When an individual living with HIV does not receive ART treatment, or when adherence to treatment is low, it can lead to virus evolution. Genetic evolution of HIV can be dangerous because it can lead to HIV treatment resistance. By constructing a viral phylogeny (a diagram of evolutionary relationships) of HIV in an individual, we can better understand the history of HIV infection. By taking a viral sample at two different time points, scientists can compare phylogenies and detect HIV viral evolution through the presence of a temporal signal or new

population structure (Bandera et al., 2019). This technique has been used to compare viral evolution over long follow-up periods in ART-naïve patients and patients taking ART (Bandera et al., 2019; Brodin et al., 2016). Phylogenies constructed from this study suggest that ART prevents viral evolution because treated HIV lacks novel phylogenetic structures (Brodin et al., 2016). When undertreated HIV evolves and creates a drug-resistant mutation, these mutations differ significantly. Transmission and replication fitness vary greatly and are often influenced by the viral genetic background (Bandera et al., 2019). Drug resistance emerges through suboptimal ART adherence, which occurs when the drug is taken inconsistently and becomes ineffective. This occurs because drug resistance mutations that code for reverse transcriptase or protease can become dominant within several months of the initiation of treatment (Rong et al., 2007). Resistant strains of HIV can be spread from a parent to their child through vertical transmission (Leitner, 2019). Additional drug resistance, therefore, has serious implications for teens living with perinatally acquired HIV.

Treatment Challenges For Adolescents with Perinatally Acquired HIV

This section will focus on the impacts of the aforementioned HIV evolution on the treatment and health outcomes of adolescents living with perinatally acquired HIV. Historically, children born with HIV in the 1980s and 1990s were prescribed suboptimal treatment regimens that were the standard of care at the time (such as monotherapy or dual therapy). These treatments were ineffective because they can lead to viral rebound. The aforementioned population, now adults, are more likely to have multi-class drug resistance (Yusuf & Agwu, 2020). Today's teens living with HIV have always been recommended ART, however, many still face barriers that prevent them from obtaining treatment or maintaining medication adherence. Adolescents who acquire HIV perinatally are an important population to study from an evolutionary lens. This group is at higher risk for drug resistance due to "early ART initiation, exposure to multiple treatment regimens, and long-term treatment exposure" (Yusuf & Agwu, 2020). First, the unique HIV treatment challenges for adolescents living with perinatally acquired HIV will be outlined. Subsequently, the behaviors that lead to drug resistance, and how public health efforts can address these root causes, will be explained.

Adolescents living with perinatally acquired HIV face increased challenges in HIV treatment compared to their teen or adult counterparts living with behaviorally acquired HIV. Second-line therapy is used when a PLWH develops treatment failure to their initial ART drug regimen (Alene et al., 2019). In 2019, it was shown that among adolescents living with perinatally acquired HIV in South Africa who had been retained in care for over 10 years, over 40% were on second-line ART. Teens on second-line ART had poorer immunological outcomes, including higher CD4 counts and lower viral suppression rates compared to individuals on their initial ART treatment. (Anderson et al., 2019). The majority of adolescents living with HIV reside outside of the United States. Even in this developed nation, about 18–25% of adolescents with early acquired HIV (perinatally or behaviorally) experience triple-class drug resistance (Yusuf & Agwu, 2020). Given high rates of resistance, the World Health Organization recommends regular viral load testing for adolescents (Broyles, 2023). This is challenging given the cost and access barriers that exist with this type of medical care.

Another modern challenge in treating adolescents with HIV is proper ART dosing. Puberty in adolescents may affect drug metabolism. Oftentimes, information from ART clinical trials performed with adults is extrapolated to adolescents. This is an issue in the area of HIV treatment because adolescents, one of the populations with the highest potential for drug resistance, are not sufficiently represented in ART research (Yusuf & Agwu, 2020).

Low Adherence among Adolescents

A significant source of HIV evolution and drug-resistant mutations is low adherence to ART. The full effect of viral suppression cannot be reached if ART is taken irregularly. Low adherence can lead to the progression of HIV, opportunistic infection, HIV transmission, and drug resistance (Hudelson & Cluver, 2015). One study measuring virological suppression among adolescents and adults in southern Africa showed that adolescents were significantly less likely to reach 100% adherence within a year of starting treatment compared to adults (Nachega et al., 2010). Another retrospective study in South Africa showed that older adolescents (ages 15–19) were more likely to have unsuppressed viral load compared to adults (Evans et al., 2013). Perinatally infected youth are also more likely to be prescribed less potent drug regimens due to drug resistance, therefore, missing a dose may have more of an impact on ART efficacy (MacDonell, 2012).

Adolescents living with perinatally acquired HIV experience very specific barriers to ART adherence, which I will examine through a socio-ecological lens. Compared to teens who acquired HIV behaviorally, teens with perinatally acquired HIV cite feeling “sick to the stomach” or feeling bad as a main barrier to taking ART medication (MacDonell et al., 2012). This could be because perinatally infected youth may be more likely to be prescribed more complicated drug regimens that have more side effects compared to other teens living with HIV. Also at the individual level, barriers to adherence include HIV-related stigma, forgetfulness, depression, and substance use. On the interpersonal level, lack of caregiver assistance, late-in-life parent disclosure of the child’s HIV status, and lack of caregiver support with clinic visits are all recorded barriers to ART adherence. On the community level, reported barriers include long travel times to clinics, long wait times, or lack of peer support groups (Ammon et al., 2008). The next section will address the systems or government-level barriers that exist, and how public health infrastructure could be improved in order to address the needs of adolescents living with perinatally acquired HIV.

Global Inequities and Systems-Level Challenges

While both familial and individual barriers impact low adherence in adolescents living with perinatally acquired HIV, larger-scale public health infrastructure challenges also impact adherence rates. Patterns of drug resistance among adolescents living with perinatally acquired HIV can also be attributed to inadequate public health infrastructure in developing countries where perinatally acquired HIV occurs most often. Systems or policy-level barriers vary depending on the country. In the United States, low adherence has been associated with food insecurity, as hunger can exacerbate ART side effects (Young et al., 2018). Additionally, in a survey of nearly 400 adolescents living with HIV in the United States, non-adherent teens were significantly

more likely to report problems with medical insurance and problems with transportation to clinic visits (Rudy et al., 2009). Though this survey did not include teens living with perinatally acquired HIV, the findings illustrate the systemic barriers faced by young people who rely on US health systems.

The main focus of adolescent HIV research lies outside of the US in lower and middle-income countries. 90% of children living with perinatally acquired HIV live in sub-Saharan Africa (Frigati et al., 2020). In these areas, comorbidities are especially common among adolescents living with perinatally acquired HIV, making this population even more complex to treat (Frigati et al., 2020). Notably, as children with HIV age into teenagers, they are less likely to be retained in care, especially after the age of 15. The healthcare transition describes a teen's experience of moving from pediatric to adult healthcare settings (Ritchwood et al., 2020). Healthcare transitions often occur at younger ages (15 or below) in resource-limited areas and between 17 and 24 in high-resource settings (Ritchwood et al., 2020). A study conducted in South Africa showed that outcomes post-healthcare transition were worse in older adolescents, evidenced by a decline in viral suppression within three years of the transition (Davies et al., 2017). One systematic review of transition outcomes from pediatric to adult care reported that transition outcomes were worse for adolescents who already had unsuppressed viral levels in pediatric care. This shows that adolescents who are already vulnerable to drug resistance are often hit hardest by the healthcare transition, increasing the potential for viral evolution.

Further Recommendations and Conclusion

In order to meet the 95–95–95 goals set by UNAIDS, which aims to have 95% of people living with HIV to know their status, receive ART, and have viral suppression, the needs of adolescents living with HIV must be addressed. In the United States, clinical approaches for adolescents living with perinatally acquired HIV should emphasize a holistic care model that addresses food insecurity, problems with insurance, and inadequate transportation. Existing literature suggests some recommendations to ameliorate the global disparities and negative health outcomes for adolescents living with HIV. Interventions that educate healthcare providers on how to promote self-management among pediatric patients could improve healthcare transition outcomes (Mutumba, 2019). Very recent advances in long-acting injectable antiretroviral therapy may be the answer to low treatment adherence among adolescents, but more research is needed to understand the acceptability and feasibility of this strategy (Toska, 2023). One approach to improving health outcomes for youth with perinatally acquired HIV is to collect more comprehensive data and increase longitudinal studies following teens into adulthood. There is hardly any data on the global incidence and prevalence of adolescents living with perinatally acquired HIV (Yusuf & Agwu, 2020). This is an important limitation in this area of research in part because it deprives global policymakers of easily citable metrics they could use to pass legislation. Additionally, there is scant longitudinal research on teens living with HIV. Without such research, we do not know exactly how HIV evolves in a host for their entire lifetime (Yusuf & Agwu, 2020). The lack of virological insight makes it difficult to know whether current ART medication strategies are sufficient to maintain long-lasting health for adolescents living with perinatally acquired HIV. Providers, virologists, and social and behavioral scientists must work in tandem to address the complex and specific needs of adolescents with perinatally acquired HIV.

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Per- and Polyfluorinated Substances (PFAS); a Literature Review

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This literature review aims to assess contemporary research on human exposure to Per- and Polyfluorinated Substances (PFAS) using the PubMed database. A series of research papers were acquired and examined, revealing novel exposure routes (firefighting, blood transfusions), associations with renal cell carcinoma, impact on DNA methylation, and links to pregnancy and early infant health. PFAS is also associated with adiposity, heart disease, and impaired immune response post-vaccination. The literature suggests potential interventions through blood and plasma donations. Limitations in the scope and scale of research, along with gaps in the understanding of the carcinogenic potential of PFAS and the efficacy of interventions in reducing PFAS exposure, were identified. Further public health research should address these gaps and limitations to enhance our understanding and address the negative health outcomes associated with PFAS exposure.

Keywords

Per- and Polyfluorinated Substances (PFAS) • Human exposure • Epidemiological studies • Intervention strategies • Public health implications • Toxicity • Health outcomes

Introduction

Per- and Polyfluorinated Substances (PFAS) are a group of hydrophobic lipophobic chemicals with the capability of repelling water and oils. PFAS are commonly referred to as the forever chemicals, owing to their long half-life ranging from several years to multiple decades, and persistence in the human body and environment (Domingo & Nadal, 2019). This long life span is due to the atomic geometry and structure of the chemical. PFAS chemicals have been used in an industrial setting

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for several years, commonly found in non-stick cookware, food packaging, and water-repellent clothing (Domingo & Nadal, 2019). While novel pathways for exposure exist in air and food, water contamination is the most common vector for exposure (CDC, 2021).

PFAS is a studied and listed toxicant with an acute LD50 (the amount of the substance that causes death in 50% of studied organisms) in rats ranging between 430–680 mg/kg (CDC, 2021). Additionally, in vivo testing with rats has determined statistically significant Hepatic, Immune, Reproductive, and Developmental impairment with exposure to PFAS (CDC, 2021). Additionally, in vitro testing (tests conducted outside of a living organism, but rather in a controlled laboratory) associated PFAS exposure with the potential of being carcinogenic (CDC, 2021).

Methods

Despite increasing concern centered around PFAS and exposure, contemporary literature regarding exposure in humans is deficient. This paper aims to analyze health literature available in the PubMed database, an open-source biomedical and scientific database maintained by the National Library of Medicine at the National Institutes of Health, focusing on human exposure to Per- and Polyfluorinated Substances (PFAS). The criteria for the existing literature to be included within the review dictated that the article must be a peer-reviewed clinical trial with a defined cohort published between 2015 and 2023 (while the paper must have been published by 2015, several studies retrospectively analyzed data gathered before 2015, but published results as early as 2015). The PubMed database was fed five search terms to acquire the contemporary sources for the literature review, which were then read and reviewed to examine the current health literature available on PFAS. The terminology used in the PubMed database to collect sources for the literature review included “PFAS” “Exposure” “Human” “Cohort” and “Clinical Trial”. A total of fourteen sources were found in the database which included these search criteria.

A Scope of Existing Literature

Novel Routes of Exposure

Research from two sources determined exposure routes and levels of bioaccumulation in humans. One paper by Hansen, (2016), and another study by Averina (2020). The research into this realm has focused on areas, activities, or behaviors that have confirmed high levels of PFAS and how through human contact bioaccumulation of the chemical increases. For instance, research was conducted on populations of firefighters who frequently encounter PFAS in fire-resistant foam. Such research is extremely beneficial in tailoring policy interventions on the behavioral and structural level to curb exposure to PFAS. Two of the fourteen studies rendered by the search explored and investigated novel routes of PFAS exposure.

Findings from ongoing research by Solrunn Hansen, a professor at UiT University of Norway, shed light on the bioaccumulation of PFAS. Through comparison of differing rates of consumption of fish from lakes affected by aqueous film foaming foams (a precursor chemical which emulsifies into PFAS) to PFAS serum (amount of a substance present in the liquid component of blood, known as serum) concentrations in a cohort (Hansen et al., 2016). The research discovered a biological gradient increase of PFAS accumulation in the bloodstream as more fish from the affected

water were consumed to a statistically significant degree (Hansen et al., 2016). This knowledge is important for both public health authorities and individual consumers. PFAS is a known toxicant, and as such avoiding exposure by limiting consumption of contaminated fish is an important tool for decreasing the potential of exposure to PFAS.

An in-depth investigation by Maria Averina, a PhD researcher at the University Hospital of North Norway, sought to determine the potential of exposure to PFAS as well as other inorganic heavy metals through blood transfusion. The study sought to examine three separate cohorts of donors across Norway (Averina et al., 2020). The results of the study indicated that PFAS serum concentrations were found to be over the concentration limit of 0.91 ng/ml in 100% of the donors tested (Averina et al., 2020). Additionally, that concentration increased in concert with the age of the donors. Research suggests that blood and plasma transfusion is a novel route of transmission of PFAS (Averina et al., 2020). This preliminary research is important for health officials in avoiding worsening health outcomes by contaminating patients and increasing their PFAS concentrations through transfusions. Further, it raises the concerns for and requirement of donor screening of PFAS to maintain the safety and quality of donated blood and avoid the negative health outcomes associated with PFAS exposure.

Renal Cell Carcinoma

The most common kidney cancer, renal cell carcinoma, is a serious health condition requiring treatment and observation. Linking renal cell carcinoma to PFAS exposure will fill a gap in the carcinogenic understanding of PFAS as well as the disease itself. Only one of the fourteen studies acquired by the review parameters explored the relationship between PFAS and Renal Cell Carcinoma.

The study in question was conducted by Joseph J Shearer, a Ph.D. researcher at the NIH National Cancer Institute. The study examined the odds ratio of development in a cohort of pre-diagnostic cohort when compared to serum concentrations of PFAS in the cohort to a 95% confidence interval (Shearer et al., 2021). The odds ratio test yields three results, an odds ratio (OR) which indicates the odds of the event occurring, a confidence interval OR which indicates significance, as well as a p-value which determines the strength of the test when less than 0.05. The results found a positive association with renal cell carcinoma risk when exposed to PFAS (doubling in serum concentration, OR continuous = 1.71, 95% CI = 1.23 to 2.37, P = .002) and a greater than twofold increased risk among those in the highest quartile vs the lowest (OR = 2.63, 95% CI = 1.33 to 5.20, p = .007) (Shearer et al., 2021). Thus, the study found that PFAS concentration was a risk factor for renal cell carcinoma to a significant degree (Shearer et al., 2021). This research is extremely beneficial for public health officials in the strategy to mitigate renal cell carcinoma. By mitigating exposure to PFAS officials can prevent a potential vector of disease. The topic requires further testing to determine the strength of the association.

DNA methylation

DNA methylation is the chemical reaction in which methyl groups are added to DNA, and the addition affects the transcription and translation interactions within the body. Transcription and translation are biological processes responsible for the creation of proteins. Complications with these processes arise due to methylation and result in epigenetic defects and health issues. PFAS

has been linked to methylation, but associations are weak, and the area has not been actively studied (CDC, 2021). Of the fourteen studies, only one focused on DNA methylation.

A study conducted by Yiyi Xu (2020), a researcher at the University of Gothenburg, sought to compare serum PFAS concentrations with DNA methylation in blood samples of a cohort exposed to PFAS in drinking water (Xu et al., 2020). The results determined that DNA methylation was found to be associated with PFAS exposure through drinking water in the high vs low exposure group (Xu et al., 2020). However, there was no statistical association between PFAS concentrations and epigenetic age acceleration (Xu et al., 2020). The link between PFAS and methylation is helpful in risk assessment efforts. Public health officials can use this information to assess the potential risks associated with PFAS exposure, and thus develop targeted strategies for risk reduction and reduction.

Pregnancy and Early Infant Health

In vitro testing has found PFAS to be potentially harmful in development and early life. As such, understanding the endpoints of pregnant women exposed to PFAS is extremely critical for public health officials understanding of infant and early life health. Of the fourteen studies rendered in the search 2 covered pregnancy and early child life (Preston et al., 2020). (Timmermann et al., 2022).

A clinical study conducted by Clara Timmerman, a Ph.D. researcher at the University of Copenhagen, examined the relationship between PFAS serum concentration, prolactin (a breast-feeding-inducing hormone), concentrations, and breastfeeding (Timmermann et al., 2022). COX regression was used to determine the relationship between the three factors (concentrations of PFAS and prolactin, vs. breastfeeding termination (Timmermann et al., 2022). COX regression is a statistical model used for analyzing the time for an event of interest to occur. The study sought to understand the endpoint between exposure and termination of breastfeeding, a behavior that is important in early life development. The results of the study concluded that the observed and tested PFAS increased serum concentrations were associated with a statistical increase in terminating breastfeeding at any given time after childbirth. However, Serum PFAS was not statistically associated with reductions in prolactin concentrations, suggesting alternative bio-mechanical pathways interference by PFAS (Timmermann et al., 2022). Breastfeeding is a critical component of development in infants, the understanding of PFAS's role in terminating breastfeeding enhances the medical field's understanding of the pollutant's role in infant development. Further, the study's findings indicate the need for increased research to determine the importance and impact of PFAS on infant development.

A second study conducted by Emma Preston, from the Chan School of Public Health, sought to determine the relationship between PFAS concentrations and glucose tolerance during pregnancy (Preston et al., 2020). This was conducted by determining serum FPAS concentrations and the effects of exposure to multiple PFAS on continuous glucose 1-hour post-50-g GCT, using Bayesian kernel machine regression (BKMR) (Preston et al., 2020). Due to the nature of glucose testing, multivariate analysis was used to limit the effect of confounding variables such as age and BMI. Ultimately the testing determined that PFAS was not statistically associated with glucose tolerance categories (Preston et al., 2020). Suggestive evidence however did find that associations of PFAS concentration and glucose tolerance differed greatly across vulnerable population subgroups (Preston et al., 2020). While the study did not determine a causal relationship between

PFAS exposure and glucose tolerance, the research did uncover a potential association in vulnerable groups. This enhances the need for further research to understand this link and potentially raise public health awareness within these groups.

Adiposity and Heart Disease

Contemporary literature has (non-significantly) linked PFAS serum concentrations to increased risk of obesity and heart disease (CDC, 2021). Understanding the endpoint of heart disease and obesity regarding PFAS exposure is extremely critical in curbing the burden and DALYs (disability-adjusted life year) impacted by the issue. Heart disease is the number one cause of death in the U.S., and obesity is a growing issue specifically in that region (Ahmad and Anderson 2021). Public health should pay special attention to the issue and its potential causes regarding PFAS. Of the fourteen studies acquired by the search five included clinical trials into adiposity or heart disease.

A randomized clinical trial conducted by Andres Cardenas, from Harvard Medical School, sought to determine the relationship between PFAS concentration and adiposity, between two cohort groups of intervention and placebo, measuring over a 15-year follow-up. PFAS measured at baseline and 2 years after randomization (Cardenas et al., 2018). The results found the PFAS had differing effects by treatment group. Each doubling in PFAS was associated with a 1.03-cm increase in hip girth in the Diabetes Prevention Program trial for the placebo group (95% CI, 0.18–1.88 cm; $P = .02$) but not the lifestyle intervention group (-0.09 cm; 95% CI, -0.82 to 0.63 cm; $P = .80$). No associations were observed for changes in mean waist circumference (Cardenas et al., 2018).

Similarly, a randomized control trial was conducted by Pi-I D. Lin, from Harvard Medical School, sought to compare the risk of hypertension and blood pressure level to PFAS serum concentrations, using the same 2-treatment cohort as the study by Andres Cardenas (Lin et al., 2020). The results of the study determined a statistically significant association between doubling PFAS concentrations and systolic blood pressure at baseline (β per doubling: 1.49 mmHg, 95% CI: 0.29, 2.70), with a non-significant association of PFAS and hypertension within the placebo and treatment arm (Lin et al., 2020).

A similar randomized control study conducted by Gang Liu, a nutritionist at Harvard School of Public Health, compared PFAS measured at baseline while body weight was measured at 6, 12, 18, and 24 months. The cohort included obese men and women assigned to 1 of 4 diet groups (Liu et al., 2020) PFAS concentrations were not significantly associated with concurrent body weight or weight loss during the first 6 months. However, in women higher PFAS concentrations at baseline were associated with statistically significant higher levels of weight regain (Liu et al., 2020).

Lastly, within the category, a randomized control study conducted by Andres Cardenas, This study quantified and measured baseline concentrations of 9 PFAS types randomized to a lifestyle intervention or a placebo. The study found that doubling PFAS concentrations was associated with higher insulin resistance to a significant degree. However, there was no statistically significant association between PFAS and the development of Diabetes (Cardenas et al., 2017).

The findings of these studies are extremely beneficial in the creation and approach of public health policy regarding obesity and heart diseases. The links between PFAS exposure and insulin resistance, weight regain, as well as blood pressure highlight the importance of addressing pollutant exposure as a potential solution to reducing the burden of obesity and heart disease. The findings of

these studies suggest that public health practitioners should investigate PFAS reduction as a means of reducing the burden of heart disease and obesity.

Vaccination and Immune Response

PFAS has been linked to an impaired response to antigens in CDC literature (CDC, 2021). Ensuring vaccination is safe and efficacious is a tenet and cornerstone of public health. As such, Public Health agencies should pay special attention to critical endpoints regarding PFAS exposure and immune response.

A clinical study conducted by Katrine Kielsen, a researcher from the University of Denmark, sought to understand the relationship between PFAS and anti-body response post-vaccination (Kielsen et al., 2016). The results found that doubling PFAS concentrations reduced diphtheria antibody concentrations by as much as twelve percent (Kielsen et al., 2016). The diphtheria antibody is crucial for providing immunity against diphtheria, a decreased concentration increases the susceptibility to diphtheria and the resulting negative health outcomes (Kielsen et al., 2016).

Blood and Plasma Donations

Lastly, a randomized control trial sought to test the efficacy of blood and plasma transfusions as a potential intervention for PFAS exposure. Conducted by Robin Gasiorowski, from Macquarie University, the study sought to understand whether frequent blood and plasma donations would lower PFAS serum concentration in a cohort of firefighters exposed to PFAS (Gasiorowski et al., 2022). The results found that the mean level of PFAS was reduced significantly by plasma donation (-2.9 ng/mL; 95% CI, -3.6 to -2.3 ng/mL; $P < .001$), and blood donation (-1.1 ng/mL; 95% CI, -1.5 to -0.7 ng/mL; $P < .001$) but remained unchanged in control. For PFAS, significant reductions were found in the plasma donation but not significant in the blood or control group (Gasiorowski et al., 2022). This study offers a practical approach to reducing the concentration of PFAS and is a beneficial tool for public health officials. Specifically, for populations such as firefighters who are subjected to high rates of exposure. Public health officials should review the implications of plasma donation for addressing PFAS exposure in populations.

Limitations Across Contemporary Literature

Across most of the literature, a persistent limitation within clinical research was the cohort size and representation. Many of the studies struggled to fit a large response pool or have large cohorts for testing. Of particular interest were the studies of “Cord blood gene expression supports that prenatal exposure to perfluoroalkyl substances causes depressed immune functionality in early childhood” as well as “Associations between serum concentrations of perfluoroalkyl substances and DNA methylation in women exposed through drinking water”. These studies lacked participants, such that confounding factors and biases within the data had a drastic effect on the statistical power and validity of the study. Similar to this issue a recurring gap within the existing literature was the homogeneity of the cohort population. Of particular interest in this was the study “Effect of Plasma and Blood Donations on Levels of Perfluoroalkyl and Polyfluoroalkyl Substances in Firefighters in Australia: A Randomized Clinical Trial”. This study focused on populations with firefighters, due

to the nature of the work, by in large firefighters are in better physical shape than an average person, which in turn may make them more resilient to negative health outcomes. Finally, a common factor that was a limitation was the age of the cohort and the date of recording. Of particular interest were the studies “Association of Perfluoroalkyl and Polyfluoroalkyl Substances with Adiposity” and “Per- and poly-fluoroalkyl substances and blood pressure in pre-diabetic adults-cross-sectional and longitudinal analyses of the diabetes prevention program outcomes study”. These studies retrospectively analyzed cohorts from 1996. However, generally within average serum concentrations of PFAS have dropped drastically since then, as the cohort failed to create a representative trial of average participants comparable to the population today. Additionally, a potential limitation of this review is the chosen search terms. The inclusion of “clinical trial” may have created a skew in results towards studies fitting such a criterion. In turn, this would potentially overlook relevant epidemiological cohort studies, ignoring potentially relevant data.

Gaps within the Literature

Throughout the literature, several gaps occurred in the research. One of the more prevalent was a lack of studies regarding the carcinogenic potential of PFAS. As stated, PFAS has been associated with cancer development during in vitro testing with rats (CDC, 2021). Of the linked studies, only one had covered renal cell carcinoma; however, the lack of data regarding cancer incidence and burden was seemingly surprising and disquieting. Future public health should seek to fill this gap and investigate the carcinogenic potential of PFAS exposure.

Additionally, in vitro testing in mice has associated PFAS concentrations with negative endpoints in early childhood development (CDC, 2021). Specifically, locomotion, infantile weight, growth, and survival. None of the research covered any aspect of the topic of early life developments in response to PFAS exposure (CDC, 2021). While one study examined breastfeeding termination in response to PFAS serum concentrations, the lack of research into infantile health in response to PFAS presents a glaring gap within public health research. Public health research should focus on closing this gap and understanding the critical endpoints of exposure to PFAS in developing children, as they are an at-risk population with a specific statistical likelihood of developmental defects.

Lastly, a glaring gap within the research data was the validity of potential interventions for PFAS exposures within humans. The terminology and search criteria for this literature scope included a defined human population cohort, with a clinical trial, exposed to PFAS, however only a single intervention for the reduction of serum level PFAS occurred in the entirety of the results. Due to both the acute and long-standing toxicity associated with exposure to PFAS, public health should exhaust more resources into the research on potential therapies and reductions of serum levels of PFAS in humans, especially due to their extremely long half-life and ability to persist in both the environment and human body.

Conclusion

Per- and Polyfluorinated Substances (PFAS) are a group of chemicals that have both acute long long-term health complications. This research scope sought to evaluate the existing literature on clinical trials regarding the exposure of humans to PFAS. Using these parameters, fourteen sources were found. After evaluation, limitations in the research included understanding both the

carcinogenic, developmental, and interventions for PFAS exposure. Ultimately, public health bodies must invest more time, effort, and resources into the study of PFAS exposure to ensure a greater understanding and ability to combat the growing health burden caused by the forever chemical.

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The Overarching Cost of Beauty in Mauritania

Melanie Konin*

This research paper outlines the risks women in Mauritania - including girls at the extremely young age of five years old - take to secure marriage and appear attractive to those who are male-identifying. Over time, the United States has become more inclusive with a broader spectrum of sizes that they carry in stores. However, not much long ago, the beauty standard in American society was to look as thin as possible (Wiseman et al., 1992). Girls in the United States would undergo dangerous diets, supplements, and bizarre exercises to stay thin, where in Mauritania, their beauty standard revolved around the complete opposite (Wiseman et al., 1992). Instead, girls in Mauritania grew up in environments where the standards of beauty perpetuated obesity. Mauritanian men claimed that skinny women looked like skeletons and they'd prefer not to sleep with "a bag of bones" (Esposito, 2022). Obesity in Mauritania was seen as a status symbol as many people believed larger women were wealthy because their husband had the financial means to gorge her on copious amounts of food. Therefore, women who were looking for potential suitors would try to become as large as possible to appear desirable to other men.

The consequences of this risky beauty tradition have experienced an uptick in the last few years, where the tradition of leblouh and gavage (force-feeding) has become more prevalent. While force-feeding has extreme health effects such as diabetes, kidney failure, and osteoarthritis, women are refusing to prioritize their health because the urge to stay beautiful and marry young is all-consuming in the eyes of many (Esposito, 2022). Most women have averted towards black market drugs like cortisone, apertamin - an appetite stimulant with a history of side effects - and even livestock medication with side effects of weight gain. These are real human beings, who are putting their lives on the edge to satisfy men. The abysmally underdeveloped education system in Mauritania along with minimal female involvement in government appear to make the odds of women choosing what they want to look like appear bleak.

Keywords

beauty standards • leblouh • gavage • force-feeding • Mauritanian women

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History of Leblouh

Mauritania is a country in Northern Africa with a population of about five million people. It is one of the wealthiest countries in its region regarding natural resources, specifically iron and petrol. But for a country so saturated with natural resources, it's surprising that they haven't been able to make societal progress. According to WorldAtlas, Mauritania was recently ranked 159 out of 189 countries on the Human Development Index (HDI) - a standard measure of a country's development in terms of personal well-being, standard of living and education. Mauritania's poor ranking revealed failures in environmental protection, rampant poverty, poor education systems, and "rigid traditions with social stereotypes" (Sawe, 2019). One of the most concerning traditions in Mauritania is leblouh, or gavage, which translates to force-feeding. This isn't like the common practice of merely disregarding health and eating as many cheeseburgers as one wants until they are full. Leblouh involves bowls of couscous that have to be flushed down with camel milk - which has a high-fat content - for breakfast. A typical girl who is practicing leblouh blows through 3,000 calories for breakfast alone - which equates to twenty cheeseburgers. This lifestyle would allow girls to put on weight extremely fast. Their lunches and dinners revolve around greasy and heavy meals, all to repeat the next day. While the leblouh tradition is far more common in rural parts of Mauritania, Harvard University claims that about 25% of all women in Mauritania follow the leblouh practice. In rural areas, it increases to nearly 75% (Esposito, 2022). It's far more prevalent in rural areas due to tradition having a tighter hold on rural residents, as well as the lack of utilization of women for just about everything except childcare. The barren dunes only compound this by creating an atmosphere of isolation for the most remote settlements.

In an ironic twist on the concept of American weight loss programs, many girls are sent to fattening camps - tents where young girls are force fed by their grandmothers or mothers so that they can focus on their enlarging. It can go as far as the establishment and planning of ideal weight gain periods based on the availability of food. For example, during the Mauritanian rainy season, crops are plentiful, and therefore the force feeding is highly enforced so that women can take advantage of the food. In other seasons, like droughts, leblouh is still prominent, but it can be more of a struggle to reach their 16,000 daily calories because there are not as many crops available. Because of the culturally enforced importance of securing a marriage and building a family, they have gone as far as to instill the fattening process at a young age to adjust their stomachs to an increase in appetite - which in the long run makes the process of leblouh less painful. These camps are usually heavily monitored for these younger girls, and are sometimes threatened with time away from hanging out with their friends if they do not finish their food. Consequently, force-feeding leaves these girls feeling inferior to men and suffering a mental battle with their own self (Haworth, 2011). Similarly, these girls feel that they are destroying their own future. Tijanniya - daughter of a livestock dealer - is rather frustrated and shows her passion for sports, and she's fearful that she "won't be able to run fast when fat" (Haworth, 2011).

In addition, children are occasionally physically abused and tied up until they consume each meal. One specific example is the "Zayar" technique. The Zayar technique "involves positioning a girl's toes between two sticks and pinching it when she resists leblouh" (Esposito, 2022). A 2013 study from Harvard pulls data from girls who were abused in the process of leblouh. It was evident that "over 61% of those who experienced gavage reported being beaten during the process and 29% reported having their fingers broken to encourage participation" (Esposito, 2022). Surprisingly, the perpetrators behind the beatings are commonly the girls' mothers. Unreported World recorded a

documentary where Sahar Zand - a famous radio presenter - speaks with the Mauritania mothers first hand. She firsts asks them “how could you inflict such pain and torture on your own daughters?” Zand translated the mothers response, and it is along the lines of “this is a society where a woman’s biggest power is to be beautiful, and to be beautiful, you have to be fat” (Zand, 2022). Again, the stigma behind pleasing a man is so heavily influenced, that mothers will put their daughters under such dangerous circumstances.

Improper Drug Use and Failing Drug Regulation

To provide a deeper understanding of how dangerous these situations can be, Sahar Zand not only tried eating with these girls firsthand, but she also went to small shops in the capital (Nouakchott) to see how easy it was to get a hold of the Black Market drugs commonly used. For leblouh, young girls will get on birth control at a very early age - usually before menstruation begins to fasten the start of puberty. Despite these girls knowing that the practice of leblouh is rather dangerous, they are desperate to put on weight so that they can further fit the standard of Mauritanian women. Zeinebouh (a practicing girl) fears that if she went against tradition “she would lose her it-girl status among her female friends.” Additionally, women still try to seek out healthier alternatives as they are fearful of the risks and damages leblouh causes. Hawer (another practicing girl) states that she bought medication heavy in cyproheptadine hydrochloride (with a side effects of increased appetite) because her pharmacist told her “it was the least dangerous” (Haworth, 2011). While obtaining such high doses of birth control can be expensive and more difficult than black market drugs, most of the rural population averts to steroids or livestock medication to gain weight at an extraordinarily fast pace. In the documentary from Unreported World, Sahar Zand dresses like a Mauritanian woman in disguise and pretends that she was an average woman trying to gain weight. She and a few natives drive over to the busier parts of Mauritania, and hidden behind the jewelry being sold are various types of medication that continues to be sold to women who want to gain weight. She even tells the seller “I’ve got a wedding to attend, and I want to meet someone” in order to avoid unnecessary questions (Zand, 2022). No identification was required, and Zand was easily able to obtain the medication. Most of the medication that’s prescribed has no label and broken seals - which makes it increasingly difficult for regulation officers and pharmacists to know what drugs to ban, and this continues to fuel the root cause of a young girl’s inability to escape from these harmful traditions.

This brings the next concern, poor regulation of prescriptions and raging incorrect prescription drug use in Mauritania. The Global Health Security Index - a standard of measure used to assess various public health systems and prevention of disease - was last updated in 2021

for Mauritania, vividly states “Mauritania does not have a national legislation or regulation in place requiring prescriptions for antibiotic use for humans” (WHO Country Cooperation Strategy at a Glance:Mauritania, 2016). Because of the poor regulations in a country where the names of prescription Drugs - Aceptomin, Steroids, Dregdreg - are generalized to “fattening medication”, it can be difficult for officials to ban or prohibit these exchanges. To degrade the lack of regulation to a greater extent, the Pharmaceutical Law of Mauritania has made provisions requiring prescriptions unavailable online (WHO Country Cooperation Strategy at a Glance:Mauritania, 2016). And as of 2019–2022, the World Health Organization “has made no reference to a legislation in place requiring prescriptions for antibiotic use by humans” (WHO Country Cooperation Strategy at a

Glance:Mauritania, 2016). The inability to properly regulate the transmission of medication in a country is unfortunate because little girls in Mauritania are paying the steep price of these beauty standards since there is no law protecting them from these practices.

To compare the regulations of prescriptions in the United States, it can be extremely difficult to obtain any medication that is not over the counter. Even medication such as Delsym (cough syrup) is prohibited to be bought unless one is eighteen years or older. In a similar sense, people have found a sense of being “high,” or extremely drowsy when taking more than the directed amount - which is why the regulation of medication in America as a whole is so highly enforced. In addition, the United States requires that medications are regulated by the Food and Drug Administration before they are even put on the market (U.S. Food and Drug Administration, 2015). The FDA “inspects the facilities where drugs are manufactured” along with “reviewing the drug professional’s labeling and assures appropriate information is communicated to health care professionals and consumers” (U.S. Food and Drug Administration, 2015). In terms of birth control, which is used in Mauritania for weight gain, a female in the United States can only be given a pack for the duration of a month during menstruation. Females in the United States have to be given a prescription to pick up the contraceptive since birth control is not an over-the-counter medication. Whereas in Mauritania, a girl could easily pick up birth control pills which are good for however long she wants if she can afford it. However, these birth control pills have increased side effects of moodiness and irritability, not just the coveted unhealthy weight gain. In Mauritania, the birth control method commonly used is the oral contraceptive (pill) due to the fact that weight gain is a notable side effect. Girls who have not even started menstruation will be forced by their supervisors to take these medications that kick start puberty, which leads to a multitude of health concerns.

Short-Term Health Effects in Adolescents

The process of leblouh can lead to many unhealthy consequences. While most of these are short-term effects such as bloating, nausea and constant vomiting, they can still be extremely uncomfortable for a five or six-year-old girl to endure (Haworth, 2011). In the current process of leblouh, consuming up to 16,000 calories a day can leave a girl feeling bloated, and full. For younger girls, most of the liquid is thrown up because the settling of the food is intolerable. After they throw up their food, these girls tend to have minimal to no energy to go out with friends or play outside. Instead, they lie down and eventually nap to manage the discomfort. According to the MD Anderson Cancer Center, “overeating causes the stomach to expand beyond its normal size to adjust to the large amounts of food” (Blackburn, 2018). In a psychological sense, it interferes with the leptin receptor. The leptin receptor is responsible for signaling the hypothalamus that you are full, it also lets the body know when one is hungry. Overeating past the point that your mind is telling you not to can reduce the effectiveness of the leptin receptors - creating a mental imbalance when it comes to eating. While this is the intended purpose - to increase a girl’s appetite - it can be an extraordinarily painful experience for the time being. Besides the obvious - weight gain - overeating can produce excess gas because the intestines are working twice as hard to digest all of the food. In addition to the body trying to break down the food, and the fastening of the metabolism, young girls “may experience a temporary feeling of being hot, sweaty, and dizzy” (Blackburn, 2018). Most women who have already been through many years of the leblouh tradition still experience these symptoms but to a lesser degree. Once a woman understands that this is the “norm” and these

symptoms of discomfort are the cost of beauty, the severity of the short-term health effects are not as prominent when compared to a girl who is significantly younger.

Long-Term Health Effects in Mauritanian Women

As more people are becoming educated on leblouh in Mauritania, researchers have been able to pull more data in regard to the long-term effects of force-feeding. One of the largest concerns has been the spike in diabetes, heart disease, kidney failure, and osteoarthritis in a woman who is larger in size - similar to how Americans would handle a patient who is obese (Esposito, 2022). Harvard states that “due to leblouh, these national health concerns disproportionately impact women: as of 2016, 18.5% of Mauritanian women were obese, compared to only 6.6% of men” (Esposito, 2022). And, unfortunately, these chronic diseases are being passed down to their offspring, which plays a role in younger girls developing these diseases at a younger age. A long-term effect of prescribed contraceptives, such as the birth control pill consists of decreased bone mineral density (Golden, 2022). According to a study at the Lucile Packard Children’s Hospital at Stanford University, “40% of adult bone mass is accrued during adolescence” which correlates to the significant growth spurts during puberty (Golden, 2022). However, when birth control is consumed in moderate amounts “contraceptive methods may have an impact on peak bone mass acquisition and could potentially affect future fracture risk” (Golden, 2022). For girls in Mauritania whose nutritional status is nowhere near the adequate amount in regards to calcium, increased intake of the birth control pill and malnutrition can lead to decreased bone density. If proper treatment is found, bone density can easily be cured with supplements such as Vitamin D. However, the lack of treatment and accessibility to health care in Mauritania, only worsens their health status, and over time leads to osteoarthritis. Osteoarthritis is one of the most common forms of arthritis, the Centers for Disease Control and Prevention refers to it as “degenerative joint disease or wear and tear arthritis.” While most Mauritanian women brush off the joint pain and swelling because they are unfamiliar with these chronic diseases, and don’t have the financial means to see a physician, multiple researchers have come to the consensus that their diagnosis is most likely osteoarthritis. In relation to rapid weight gain, obesity increases the risk for osteoarthritis because the “extra weight puts more stress on joints” (CDC).

Another long-term health effect of leblouh consists of diabetes. More often than not, overeating foods that are not high in nutrients, and are rather fattening can lead to diabetes. According to the International Diabetes Federation (IDF), diabetes was once extremely rare in the African region, and through time there has “witnessed a surge in condition” (Peer et al, 2014). There has been an increase in both Type I Diabetes, and Type II Diabetes in children, younger children specifically. While people with Type I Diabetes naturally need more insulin, for younger girls in Mauritania, Type I Diabetes is common in people who binge eat. The McCallum Place - a center in the United States - specializes in the correlation between overeating and diabetes. They state that people with Type I Diabetes are at risk for “developing brittle bones with wide swings of blood sugars from high to low with mood instability, irritability, and fatigue” (Nicol, 2017). While the temporary feelings of irritability and fatigue relate back to the short-term effects of force-feeding, a long-term consequence is Type I Diabetes. On the other hand, Type II Diabetes stems from improper eating, not fueling the body with proper supplements, and consuming unhealthy foods. These foods are usually high in fat and spike one’s cholesterol levels. While many Americans would

blame fast food restaurants, Mauritanian girls pose a higher risk for Type II Diabetes because of their high fat intake. The calorie-dense foods include camel milk, couscous, overbearing amounts of peanut oil, and cups of pure animal fat. When these are consumed in such a high quantity, and in an excessive amount, it can be damaging to the amount of sugar and fat that the pancreas has to fuel out. With poor access to health care and a large percentage of people in Africa living in poverty, it can be difficult to get an accurate number of people with diabetes in Mauritania. To provide more context, Dr. Vadel Lemine - one of the doctors in Nouakchott's hospital states the numerous victims of leblouh patients who suffer from diabetes and high blood sugar. He expresses his concern about the escalation of numbers, but finds it difficult to provide "exact figures" as it can be frustrating that his "advice, as a doctor, hasn't been heard enough" (Wedoud, 2010). If proper regulation and accessibility to healthcare were more attainable, researchers should be able to see a decrease in these cases, not an increase in declining health. To give a deeper understanding of how unfortunate the healthcare system is in Mauritania, "the country only has 0.18 physicians for every 1000 citizens" (Esposito, 2022). In comparison to the United States, there are about "2.59 physicians for every 1000 citizens" (Esposito, 2022). This disparity is another factor that aids in the difficulty of attaining healthcare information, and the treatment methods available to lessen the rates of diabetes and osteoarthritis. From another standpoint, a study from the National Library of Medicine: *Type II Diabetes in Mauritania: Prevalence of Undiagnosed Diabetes, The Influence of Family History and Maternal Effect* vaguely shows the gaps in Mauritanian healthcare systems which inhibit the ability for citizens to receive proper care. While there is not much information available, the method of this study was obtained from about 1,278 adults who filled out a questionnaire along with fasting serum glucose tests and underwent multiple screenings. To prove the fact that there is minimal health information, out of the 1,278 adults, only 421 were able to give a "detailed family history of diabetes and clinical characteristics" (Meiloud et al., 2013). From this study, the results concluded that "the prevalence of diabetes in the Mauritanian population could be higher than currently thought" (Meiloud et al., 2013). While diabetes is still fairly high in Mauritanian men, the gap between women and men for cases of undiagnosed diabetes is largely accounted for by forced feeding (Esposito, 2022). This is because Mauritanian men are supposed to appear slim, and Mauritanian women are supposed to appear curvaceous and busty.

The Pressure to Follow Societal Norms

Despite all of these health concerns, diabetes and osteoarthritis showing increasing trends, Mauritanian women refuse to go against the leblouh tradition. When Sahar Zand spoke to these mothers firsthand, they continued to say "this is a society where a woman's biggest power is to be beautiful and to be beautiful, you have to be fat" (Esposito, 2022). The power of marriage in a country that is mainly dominated by the male figure plays a significant role in the behavior and ongoing trends that are evident with women in Mauritania. For instance, 55-year-old Achetou Mint Taleb explains how slim girls bring shame to families, and while she had two daughters of her own whom she force-fed, she is proud to say that they married quickly and both had children before they were 17 years old (Wedoud, 2010). While Mauritanian men see beauty in fatter women because leblouh creates a false illusion of maturity and early menstruation, the costly side effects completely counteract the purpose of wanting to start a family at such a young age. If Mauritanian men wanted to create a family for the purpose of raising a child, wouldn't it be beneficial for the child's mother to

still be healthy to raise the child? To provide an example, a 2015 study that is supported by Harvard University found that “nearly one out of three girls aged between 15 and 19 gets married.” In addition, a Mauritanian victim, a woman who was 29 years old shares her experience of starting leblouh at just four years old, married by 12, and pregnant by 13 after her first menstruation cycle. While she prefers to stay anonymous, she emphasizes the mental and physical risks of starting a family as a young teenager. As there are a multitude of physical consequences like dysmenorrhea - discomfort within the first menstrual cycle- osteoarthritis and diabetes from obesity, mental health issues in younger girls who are automatically expected to take on maternal duties become increasingly prevalent. The transitional switch from being a young girl to automatically being sent for marriage because of menstruation, and then arranged to have sexual intercourse with males much older, and birthing a child brainwashes a girl to believe that leblouh, early marriage, and the power of being obese is normal - it also jeopardizes a girls self-esteem and feeling of self-worth. As a result, this leaves many girls in the upcoming generation with the pressure to undergo these practices, and with nobody stopping this cycle, leblouh becomes a dangerous normality.

Education for Adolescence in Mauritania

However, despite the popularity of force-feeding in Mauritania, it truly comes down to the regions these women grow up and live in. As it was previously mentioned, force-feeding is more common in rural areas than urban. While there is loads of data that back up “pre-coup awareness campaigns” and the startup of a female-only gym in Nouakchott (capital of Mauritania), not much is being done for women who live in rural areas. This is likely due to customs that have been highly instilled for generations of women, something especially prominent in rural areas. Once women in Mauritania became more aware of these pre-coup awareness campaigns - areas where women are educated on the prioritization of health over marriage - progress was made. For example, in 2003, the rates of leblouh in urbanized areas started to lessen, and by 2009, there was a striking increase in the number of women who started attending the gym. One woman named Yeserha Mint Mohamed Mahmoud was one of the very few women who decided to take deeper measures to educate women who practice leblouh by spreading awareness but also digging at the root cause - separating the association between male validation and self worth. Additionally, Mahmoud states the societal unfamiliarity involved in these traditions, such as knowing the difference between gaining healthy weight over periods of time and consuming livestock medication - with life threatening side effects - to gain pounds at a destructive rate. After these women were properly educated, they took more serious measures as to what they were eating. Because the diets in Mauritania are so calorie-dense, such as eating couscous and pure lard, many women were unaware of how fattening these foods were. Yeserha Mahmoud believes that Mauritanian women decide to follow these practices because leblouh and gavage are only what they are accustomed to. Rather than looking into the root cause of force-feeding, many Mauritanian women brushed it off and just followed the rest of society.

Another factor that plays into the lack of understanding of the dangers of leblouh, especially in rural areas, consists of reaching the audience. Alongside Yeserha Mint Mohamed Mahmoud, are Aminetou Mint Ely and Many Mint Haidy - women who are a part of non-governmental organizations (NGOs) - who believe that little progress can be made without “partnering with local community groups and traditional information sources” (Esposito, 2022). Back in 2007, when May Mint Haidy was interviewed with the New York Times, she stated “only 25% of Mauritanian

women watched TV and even fewer tuned into radio programs.” As a result, many women like May Mint Haidy have been struggling to reach the rural parts of Mauritania to educate themselves on the dangers of leblouh. However, many suggestions such as “forging connections with religious leaders, expanding the role of mosques to encompass both worship and education” are some of the ways NGOs are trying to provide advocacy to Mauritanian women and girls (Esposito, 2022). In a society like Mauritania, where tradition carries heavy virtue, one of the easiest ways to reach an audience is through religion and spirits. Lemrabott Brahim - an activist in Mauritania - explains the difficulty of exterminating the culture of leblouh because “its something deeply- rooted in the minds and hearts of Mauritanian mothers, particularly in remote areas where the uneducated villagers still strongly believe in the tradition.” By educating the Mauritanian public on the health issues that arise from force-feeding, and the damage being done when you encourage force-feeding on younger generations, Mauritanian people are more inclined to listen. In addition, another victorious program that is slowly catching more attention is the Sahel Women’s Empowerment and Demographic Dividend project. While this program is not directly centered on Mauritanian women and force-feeding, it encompasses many other African nations like Mali and Niger where child marriage is popular. The Sahel Women’s Empowerment and Demographic Dividend project is successful in spreading positive affirmations to women, making them acknowledge their worthiness, and empowering them to avert against the societal norm of looking better for a man.

The Price of Beauty for a Mauritanian Woman

Overall, there is definite evidence that Mauritanian women are heavily dependent on males, and male domination in the Mauritanian society is oppressive. As these victims live in a society where tradition has a large influence, it can be extremely difficult and tiresome to go against custom, no matter the health effects or scientific information to prove the contrary. While there are many activists such as Mariam Mint Ahmed and Sahar Zand who try to garner attention to these issues and educate affected young girls, the fatal health effects, forced childhood marriage and the lack of education for younger girls prove the inhumanity that arises through leblouh and gavage. It is of no doubt that the price of beauty for Mauritanian women is so steep that women will undertake these drastic measures at the cost of their own health.

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“Exploring the Effects of COVID-19 on the Racial Disparities and Inequities of Maternal Health: A Survey-Based Study”

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Utilizing a cross-sectional survey design, undergraduate researchers at the University of Pittsburgh launched an investigation into the impact of the COVID-19 pandemic on maternal health, with a particular focus on inequity in care. This study utilized a survey, titled COVID-19 Maternal Health Experiences (CMHE) Survey, to explore stress levels and personal accounts of perceived differences in maternal health care in the United States following March 2020. It was hypothesized that the pandemic, having upended and permanently reshaped health systems in the U.S., would reveal broader truths about privilege and inequity in the context of women’s health and motherhood. The responses gathered from 119 participants, predominantly from Pennsylvania, revealed heightened stress concerning health and childcare since the national outbreak of the pandemic. The homogeneity of participant demographics limits this survey results’ generalizability and the ability to perform a racial analysis, emphasizing the need for diverse samples in future research. Despite limitations, the findings of this study highlight the importance of continued research on issues in maternal health care, as well as the importance of providing mothers of all ethnic backgrounds with equitable care and an outlet to express concerns related to their physical, mental, and emotional health.

Keywords

maternal health • COVID-19 • health inequalities • stress • racism in healthcare • healthcare experiences

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I. Introduction

Evidence of systemic racism and discrimination are gradually receiving more attention in the medical field and specifically in maternal health (Kamal, et al., 2019). This recognition brings to light the fact that the infant mortality rate (number of infant deaths per 1,000 live births) is not only the highest in the United States among comparable countries but also significantly higher for Black populations in America (Kamal, et al., 2019). Notably, Black mothers are disproportionately affected by adverse maternal health conditions and are dying from preventable complications at a rate that is between 3 and 4 times that of white mothers (Taylor, et al., 2019). These national trends are also evident in data collected specifically within the city of Pittsburgh, Pennsylvania; in fact, the 2019 report “Pittsburgh’s Inequality across Gender and Race” spotlights that Black women living in Pittsburgh have a higher maternal mortality rate than Black women living in 97% of similar cities (Howell, et al. 2019). Looking at the data at both a national and local scale, it is imperative that work is done to address this discrimination found in maternal health care.

Furthermore, the COVID-19 pandemic has placed a strain on the United States’ healthcare infrastructure, which has further exacerbated the discrimination faced by Black women. With these additional strains, now more than ever, Black women have shown immense concern over being able to receive adequate prenatal care and an overall positive birthing experience (Erickson, 2020; Minkoff, 2020; Gur, et al., 2020). As students approaching careers in healthcare following the outbreak of one of the deadliest pandemics in modern history, we were acutely and personally aware of the wave of effects that COVID-19 was having on life in the United States. The pandemic not only revealed vulnerabilities within our healthcare infrastructure but also laid bare the stark disparities that exist, particularly within maternal care. It was our shared conviction that understanding the repercussions of COVID-19 on maternal health, specifically in a racially diverse community like Pittsburgh, could serve as a microcosm of the larger healthcare challenges faced worldwide. We embarked on this research project with a deep sense of responsibility to shed light on the unfiltered experiences of mothers and to explore the potential role of the pandemic in exacerbating maternal stressors, as well as pre-existing racial divides in maternal care. We hope that through this study, and future studies, anecdotes from a diverse group of people can be collected and shared in a way that will be sustainable and accessible to all, ultimately allowing mothers of all backgrounds to feel heard while also providing a starting point for further exploration of the effects of COVID-19 on maternal health inequity.

2. Methods

2.1 Overview

This exploratory study, developed and dissected at the University of Pittsburgh, used a cross-sectional survey to gather quantitative and qualitative data on maternal health, with the hypothesis that COVID-19 had a significant impact on maternal health and potentially disparate effects on Black and white mothers. To acquire a complete, accurate portrayal of the realities and potential inequities in maternal health as it stands today, we designed a survey, which we titled the COVID-19 Maternal Health Experiences (CMHE) Survey. Through the use of both multiple-choice and open-ended questions in the CMHE Survey, we were able to gain a better understanding of overall trends as well as individual experiences relating to maternal care.

2.2 Survey Design

We employed this cross-sectional survey design to investigate the impact of the COVID-19 pandemic on the maternal health of mothers in the United States. The study aimed to compare the personal experiences of Pittsburgh mothers before and after March 2020 and assess how COVID-19 influenced stress levels and access to healthcare, with a focus on racial disparities between Black and white mothers.

The CMHE Survey was designed as an online survey consisting of multiple-choice questions, scale items, and open-ended questions to gather both quantitative and qualitative data. In order to collect demographic information, participants were given the opportunity to disclose personal information including race/ethnicity, education level, household income, and employment status. Participants were then asked about their maternal health experiences before and after March 2020. Specific questions addressed changes in stress levels, access to healthcare, and any COVID-19-related health concerns they may have encountered. Participants were also asked about their health-care-seeking behaviors.

2.3 Participants and Survey Recruitment

Participants in this study included self-identified mothers mostly residing in Pennsylvania, but also from other states across the country. Originally, we intended to recruit participants solely from the Pittsburgh metropolitan area. However, given our limited capabilities and financial resources to recruit within local communities, we decided to rely on online social media platforms to share the CMHE survey, thus increasing our scope from Pittsburgh citizens to those living anywhere in the United States. With this decision, we were able to increase the number of participants who responded to the CMHE survey while also being able to analyze potential trends found in maternal health experiences throughout the country. The sampling frame for recruitment included mothers in the United States, with the objective of obtaining a diverse and representative sample. Participants were recruited through advertisements on social media platforms, such as Instagram and Twitter, and physical flyers dispersed throughout the University of Pittsburgh's campus and surrounding areas across Pittsburgh. Physical flyers were posted at public establishments including, but not limited to, bus stops, maternity stores, and lactation clinics.

Data collection took place between July 21, 2021 and March 28, 2022. Informed consent was obtained from all participants prior to survey participation. To further ensure data quality, participants were reminded during this section, as well as throughout the CMHE survey, that their responses were confidential and anonymous; furthermore, nearly all survey questions were entirely optional and visibly so. Only the survey responses that contained answers to at least half of the questions and had an attempted demographics section were carried forward into data analysis because only these participants provided enough information to analyze productively. By the end of data collection, 145 responses had been recorded, out of which 119 met the requirements for data analysis.

2.4 Methods of Analysis

Quantitative data were analyzed through creating histograms, plotting distributions, and calculating means and proportions. Qualitative data from open-ended questions, however, underwent thorough manual content analysis by two individuals to identify common themes, patterns, and

narratives related to the research questions. To prevent bias, all qualitative data was read and studied by the investigators separately, with findings compared and combined to ensure a comprehensive and rigorous analysis of the reported information.

3. Results

The CMHE survey was divided into four sections: demographic questionnaire, stress level identification, anecdote collection, and vaccine experience questionnaire. Each section addressed a different major research question and therefore all data from separate survey sections required unique, deliberate approaches to analysis.

3.1 Participant Overview

The participants of the CMHE survey self-identified similarly especially in terms of gender identity, ableness, ethnicity, and marital status. Overall, the population of participants is more homogenous with the majority identifying themselves as female, not differently abled, white, and married. Over half of the participants also reported being employed for wages and having a household income

Table 1. Numbers of Survey Participants Who Self-Classified For Each Demographic Category

Demographic Categories	Number of Participants (n = 119)
Gender Identity	
• Female	115
• Nonbinary	1
• No response	3
Differently Abled?	
• No	102
• Yes	10
• Prefer not to say	5
• No response	2
Marital Status	
• Single, never married	12
• Married or domestic partnership	103
• Divorced	2
• No response	2
Ethnicity	
• White	103
• Hispanic or Latino	5
• Black or African American	7
• Asian/Pacific Islander	2
• Multiracial	1
• Prefer not to say	3
• No response	2

(Continued)

Demographic Categories	Number of Participants (n = 119)
Highest Level of Education	
• High school diploma or equivalent	6
• Vocational or trade school	1
• Some college	17
• Associate or 2-year degree	9
• Bachelor's or 4-year degree	20
• Some graduate or professional school	8
• Graduate or professional degree	56
• No response	2
Employment	
• Employed for wages	80
• Self-employed	6
• Out of work and looking for work	5
• Out of work but not looking for work	6
• Homemaker	38
• Student	8
• Unable to work	5
• No response	2
Household Income	
• \$1-\$9,999	4
• \$10,000-\$24,999	1
• \$25,000-\$49,999	10
• \$50,000-\$74,999	17
• \$75,000-\$99,999	19
• \$100,000-\$149,999	39
• \$150,000 and greater	20
• Prefer not to say	7
• No response	2
Household Size	
• 2	10
• 3	47
• 4	38
• 5	11
• 6	8
• 7	1
• No response	3
Residence Location by Geographic Division	
• New England	1
<i>Massachusetts</i>	83
• Middle Atlantic	1
<i>Pennsylvania</i>	1
<i>New York</i>	1

(Continued)

Table 1. (Continued)

Demographic Categories	Number of Participants (n = 119)
• East North Central	2
<i>Illinois</i>	6
<i>Indiana</i>	1
<i>Michigan</i>	2
• West North Central	2
<i>Minnesota</i>	5
<i>Iowa</i>	3
• South Atlantic	3
<i>West Virginia</i>	4
<i>Maryland</i>	2
• West South Central	3
<i>Oklahoma</i>	
<i>Texas</i>	
• Mountain	
<i>Colorado</i>	
• Pacific	
<i>California</i>	
<i>Hawaii</i>	
• No response	

of at least \$100,000 or greater. The majority of survey respondents were based in Pennsylvania, although there were also participants from 15 other states including California, Colorado, Hawaii, Illinois, Indiana, Iowa, Maryland, Massachusetts, Michigan, Minnesota, New York, Oklahoma, Texas, and West Virginia.

3.2 How did COVID-19 impact participants' stress levels?

The CMHE survey prompted participants to report their current perceived stress levels in relation to multiple topics. For each of the categories, a mean "stress rank" will be provided. This will be the average response to the respective scenario, with a minimum rank of one representing "low stress" and a maximum rank of five representing "high stress." Survey participants were given stress rank options of one, two, three, four, or five for each question.

Out of the specific scenarios provided to participants, certain categories elicited, on average, the most heightened levels of stress:

1. Health-Related Stress: A substantial proportion of participants reported fear surrounding their own health (mean stress rank = 4.08 out of 5) and the health of their loved ones (mean stress rank = 4.15 out of 5). As many survey participants had experienced pregnancy at some point following the outbreak of the pandemic, many of them also reported stress of contracting COVID-19 and, specifically, it ultimately affecting their pregnancy (mean stress rank = 4.18 out of 5).

Table 2. Mean Stress Rank Associated with Various Scenarios

Scenario Capable of Eliciting Stress Possibly Exacerbated by COVID-19	Mean Stress Rank (1 to 5)	Median	Mode
Self contracting COVID-19 (n= 120)	4.08	4 (30%)	5 (45%)
Self contracting COVID-19 and it affecting their pregnancy (n= 120)	4.18	5 (58%)	5 (58%)
Encountering negative work-related situations (e.g. working under dangerous conditions, potential of losing one's job, etc.) (n= 119)	3.39	4 (26%)	5 (28%)
Coping with financial difficulties (n= 119)	2.87	3 (19%)	1 (24%)
A loved one contracting COVID-19 (n= 121)	4.15	4 (29%)	5 (46%)
Receiving quality prenatal care (n= 118)	2.79	3 (29%)	3 (29%)
Having a positive birthing experience (n= 117)	3.54	4 (33%)	4 (33%)
Having adequate support for childcare (n= 121)	3.79	4 (19%)	5 (44%)

2. Concerns of Childcare: Participants commonly reported stress associated with balancing work responsibilities and childcare needs as schools and daycare centers across the country experienced sporadic closures. Therefore, the struggle to maintain a work-life balance under these conditions appeared to be a significant source of stress for many respondents (mean stress rank = 3.79 out of 5).

Certain other prompts given to participants generated results indicative of low to average stress regarding the respective topics. The scenarios which yielded reports of average to below average stress are as follows:

1. Stress Involving Work: This category asked participants to consider the stress they related to potential job loss and the possibility of working under dangerous conditions during COVID-19 (mean stress rank = 3.39 out of 5).
2. Stress Surrounding Financial Difficulties: Financial worries, such as job loss, reduced income, and economic uncertainty, similarly accounted for a minimal self-reported increase in stress levels for CMHE survey participants (mean stress rank = 2.87 out of 5).
3. Concerns of Receiving Proper Prenatal Care: This category included worries about the accessibility of healthcare services, potential disruptions in prenatal care, and the safety of healthcare environments, and did not result in above-average stress levels among our sample (mean stress rank = 2.79 out of 5).
4. Stress of Having a Positive Birthing Experience: Worries about labor and delivery procedures, access to support persons during childbirth, and the health and well-being of the newborn, among other pressing concerns, contributed mildly to the stress reported by many survey respondents (mean stress rank = 3.54 out of 5).

3.3 How did COVID-19 impact participants' maternal health experiences?

Overall, participants' responses to the open-ended question asking them to comment on their maternal health experiences during the COVID-19 pandemic reflected themes of worry, isolation, and disruption, which all seem to be inherently tied to stress, namely the heightened levels of stress experienced by participants. These responses were then further analyzed in the context of the three categories or "groups" each of the participants' answers were sorted into.

3.3.1 Worry

This study utilized the Oxford Languages Dictionary definition of worry as "a state of anxiety and uncertainty over actual or potential problems." Here we highlight the terms "anxiety" and "uncertainty" as key emotions centered around responses containing the theme of worry. A representative response mentioning worry contains the quote, "I live in constant fear of everything I have being taken away from me [. . .] I would call the fear 'crippling' at this point." In this response, we highlighted the mentions of "constant" and "crippling" fear as indicators of the anxiety and uncertainty this individual was experiencing due to the pandemic.

There were 28 mentions of worry throughout all of the responses received, 3 three of which were found in responses from mothers of young children (i.e. individuals who gave birth no more than three years prior to COVID-19), 17 in responses from mothers with pregnancy experiences both prior to and during COVID-19, and finally 18 in responses from pregnant individuals and/or first-time mothers during COVID-19 (i.e. individuals whose pregnancy experiences occurred solely during the pandemic). To better be able to find comparisons between these groups of people, we also looked at the percentage of responses containing worry for each group. We found that worry was mentioned in 3 three of the 7 seven responses from the first group, 17 of the 45 responses from the second group, and 8 eight of the 45 responses from the third group. We suspect that a potential reason for the proportion of responses containing themes of worry being lower for the third group than the second group might be due to the fact that the former group might not have known what a "non-COVID" pregnancy might feel like, while the latter group had personally experienced both.

Table 3. Number of Mentions of Themes of Worry, Isolation, and Disruption in Participants' Responses

	Number of Mentions of Each Theme		
	Worry	Isolation	Disruption
Group 1: Mothers of young children (gave birth before COVID-19) (n=7)	3 (43%)	2 (29%)	4 (57%)
Group 2: Mothers of young children and pregnant during COVID-19 (n=45)	17 (38%)	17 (38%)	31 (69%)
Group 3: Pregnant and/or first-time mother during COVID-19 (n=45)	8 (18%)	17 (38%)	28 (62%)

3.3.2 Isolation

The theme of isolation seemed essential to include while analyzing the participants' reactions and experiences to lockdown policies and the pandemic overall. Based on our own understanding of the term and its use in the survey responses, we defined isolation as either being physically separated or feeling emotionally separated from others in a way that ultimately caused sadness. An example of this theme can be found in the response of a mother reflecting her COVID-19 pregnancy to one occurring pre-pandemic, "Postnatal community (mental health) support was much reduced from my 2016 pregnancy to my pandemic pregnancy in 2020. As I suffer from postpartum and general depression, this caused me great harm." Here, we see that this individual felt alone and isolated due to the lack of mental health support. This response, in particular, is interesting as it directly compares the participant's experience during the pandemic to their experiences before the pandemic, suggesting further evidence that maternal health experiences were greatly affected, and potentially negatively affected, during COVID-19.

The responses seemed to be relatively consistent across the three groups with 2 two out of the 7 seven responses in group one and 17 out of the 45 responses in both groups two and three containing themes of isolation. The fact that both groups two and three had the same proportion of responses reflecting feelings of isolation is likely a coincidence but continues to demonstrate the adverse impact the pandemic has had on these participants' experiences.

3.3.3 Disruption

Based on the open-ended response data, disruption became our third and final theme largely reflected in nearly all the participants' stories. Utilizing the Cambridge English Dictionary's definition of disruption as "the action of preventing something, especially a system, process, or event, from continuing as usual or as expected" and often in a stress-inducing manner. One of the participants in the first group mentioned that they "have missed out on the relationships with extended family and postponed having another child; [their] kiddos have little to no experience with other children their age and haven't been to a grocery or other store since March [2020]." This response, in particular, powerfully highlights a number of the ways in which the pandemic has negatively affected the maternal health experiences expressed by the mothers and pregnant people who responded to the CMHE survey. We also found the mention of postponing another child to be particularly impactful as it emphasizes the need to even rethink family planning as a result of the pandemic.

This was largely the most mentioned theme with 4/7 (57%), 31/45 (69%), and 28/45 (62%) responses containing references to disruption in groups one, two, and three, respectively. We felt that this theme was best able to encompass a lot of the changes participants were experiencing due to the pandemic and relating specifically to maternal healthcare.

3.4 *What were participants' experiences with the vaccine?*

An inquiry into survey respondents' COVID-19 vaccination status revealed valuable insights into vaccination patterns among pregnant people and mothers of young children.

Participants who reported receiving a federally-approved COVID-19 vaccine (106 of 119) were asked to provide information about when they had first been administered their vaccination. The responses indicated that, on average, participants had been vaccinated at relatively standard times

Table 4. Vaccine Questionnaire Responses of Individuals Unvaccinated Against COVID-19

Would the participant be willing to receive a vaccine against COVID-19 if made easily accessible to them? (n = 13)			
Definitely Yes	Probably Yes	Probably Not	Definitely Not
0	1 (8%)	6 (46%)	6 (46%)

throughout early 2021. This suggests that there were no discernible patterns of vaccine precedence among the sample. This may be indicative of equitable vaccine distribution and accessibility within the communities in which participants were living at the time.

For participants who had not yet received a vaccine against COVID-19 (13 out of 119), the next survey question was related to their willingness to do so if it were made easily accessible. The responses were categorized into four options: “Definitely yes,” “Probably yes,” “Probably not,” and “Definitely not.”

Of the 13 respondents to this question, none expressed a strong willingness to get vaccinated, even in the case of accessibility being improved. One participant indicated a degree of openness to vaccination; this individual may benefit from information and support to address potential concerns and barriers. Six participants expressed hesitancy by selecting “Probably Not.” Five out of six of these participants were white, and one selected their ethnicity to be Hispanic or Latino. When given the opportunity to provide elaboration, one individual reported that they “still feel like [the vaccine] is a little experimental,” without specific reference to potential side effects related to pregnancy. The final six respondents to this question firmly indicated that they would “Definitely Not” consider getting vaccinated even with improved accessibility. Of these six individuals, five were white, and one indicated that they were Black. One respondent in particular shared that their reasoning for remaining unvaccinated was a product of their belief that “[the COVID-19 vaccine] doesn’t work.” These findings were very much in line with views shared by many people within the United States; ultimately, it is crucial to respect individual choices and simultaneously work to ensure that accurate information about vaccines is readily available for those who may reconsider their stance.

4. Discussion

Although the CMHE survey aimed to reach a diverse group of mothers residing in the United States, the demographic composition of participants revealed a certain degree of homogeneity that prevented analysis of potential racial disparities. Specifically, our sample was overwhelmingly female (115 out of 119), not differently abled (102 out of 119), married (103 out of 119), white (103 out of 119), having received a bachelor’s degree or higher (84 out of 119), belonging approximately to the upper-middle to upper class based on household income (78 out of 119), and residing to Pennsylvania (83 out of 119). This homogeneity in participant demographics may be attributed to the limitations of our recruitment methods and the challenges associated with achieving a truly representative sample of the United States (or even of a city as diverse as Pittsburgh, Pennsylvania).

Limitations that may have influenced participant demographics were numerous. Notably, the CMHE survey was released while the COVID-19 pandemic caused capacity to be limited in certain public spaces, and many people (especially pregnant people) avoided these spaces to reduce

their risk of contracting the disease; therefore, in-person flyer-ing was difficult and perhaps somewhat ineffective at recruiting participants. Advertising of the CMHE survey was resultingly mainly online and, in conjunction with a survey that itself was online, limited the population to being people with access to a device with internet accessibility. As previously mentioned, the CMHE survey was originally intended to be restricted to only participants residing in Pittsburgh, Pennsylvania; however, with minimal resources to help boost recruitment efforts, we quickly realized that would yield a low number of participants and therefore decided to expand our scope to the entire United States. Furthermore, we expect that even potential participants who came into contact with flyers and/or online advertisements may have decided against completing the survey due to lack of trust in the research community, especially considering the personal nature of many of the CMHE survey questions. Future research efforts should consider more targeted recruitment strategies and greater outreach to ensure a more diverse participant pool.

Lack of diversity in participants was immediately evident in responses to the portion of the CMHE survey which asked participants to report their stress levels in relation to a list of topics. Again, certain topics seemed to evoke, on average, more heightened levels of stress from nearly all participants regardless of personal demographic information, such as the likelihood of contracting COVID-19. Concerns of childcare were also universally quite high, as the widespread closure of schools and daycare centers combined with returning to the office after many months of remote work were expected to introduce a complex new set of challenges for parents of various socioeconomic backgrounds.

Interestingly, certain prompts given to participants yielded results indicative of low to average stress. Comparing these results to the average demographic information of survey respondents further raised our suspicion of the potential influence of homogeneity among the sample, particularly homogeneity that on average was very white and likely would fall within the category of upper-middle to upper class according to the Social Security Administration's 2022 wage data (*National Average Wage Index*, 2022). For example, average reported stress levels related to risk of job loss and the possibility of working under dangerous conditions were, on average, not significantly high for the CMHE survey participants. It is possible that the economic stability and job security typically associated with our sample demographics may have contributed to the relatively modest stress rank for this category. Similarly, financial worries, such as job loss, reduced income, and economic uncertainty, were expected to contribute to the overall self-reported increase in stress levels; however, the economic stress experienced by our participants, while notably present, did not reportedly exceed their pre-pandemic financial concerns to a significant degree. It is essential to consider that our sample, which primarily comprises upper-middle to upper-class mothers, may have had more financial stability and resources to cope with the economic impact of the pandemic, which could account for the relatively modest heightening of financial stress levels.

While concerns about receiving proper prenatal care during the pandemic were evident in our sample, including worries about the accessibility of healthcare services, potential disruptions in prenatal care, and the safety of healthcare environments, these concerns did not result in above-average stress levels for a few potential reasons. It is possible that the relatively high socioeconomic status of our sample allowed respondents to navigate these concerns with a greater degree of resilience and confidence. We also predict that, as many survey participants had reported already having experience with pregnancy and/or maternal healthcare from prior to the onset of the pandemic, those whom were the mother of multiple children had been able to mitigate the overall impact of COVID-19 on their level of stress simply by being familiar with the birthing process

and potentially by having connections to a trusted birth team. The final category of note was related to stress surrounding having a positive birthing experience; although this category showed responses most similar to that of the aforementioned “high stress” categories, again, it is possible that the financial and healthcare resources available to our sample provided a level of comfort and security that contributed to an overall modest level of stress related to birthing experiences in the midst of the pandemic. Regardless, worries about labor and delivery procedures, access to support persons during childbirth, and the health and well-being of the newborn, among other universal yet naturally urgent concerns, potentially contributed greatly to the stress reported by many survey respondents.

While our data and sample made it impossible for us to definitively answer the initial research question, new questions and observations emerged during data collection and analysis. By enabling the sharing of personal anecdotes, the CMHE survey offered an opportunity for survey participants to express themselves. Because of its anonymity, many participants felt comfortable with describing their frustrations, fears, disappointments, and more in regards to the COVID-19 pandemic and their maternal health experiences. Therefore, despite our inability to make direct comparisons and draw conclusions regarding the pandemic’s impact on maternal health (due to low survey participation and undiverse sample demographics), we uncovered a rich tapestry of maternal experiences, shedding light on the challenges and concerns faced by mothers during this extraordinary period.

The original hypothesis that the COVID-19 pandemic may exacerbate the racial divide seen in maternal care in Pittsburgh remains a critical question. Although we could not provide a conclusive answer in this study, our findings indicate the importance of continuing this exploration. The narratives shared by our participants underscore the complex interplay of systemic inequities and personal experiences, highlighting the need for a more in-depth investigation into the intersection of race, maternal health, and the pandemic. Future research efforts should delve deeper into this critical issue, employing a larger and more diverse sample to capture the nuanced differences in experiences among mothers of color and white mothers.

One notable aspect of our research approach was the inclusion of open-ended questions that encouraged participants to share their personal anecdotes in an intentionally unfiltered manner. Personal anecdotes, in many cases, transcended quantitative data in capturing the true essence of the maternal experience in this unprecedented time. This approach should be further implemented in future research as a means to capture the multifaceted nature of maternal health and its intersection with social and healthcare systems.

5. Conclusion

While our study faced some limitations, such as a homogenous participant demographic and questions left unanswered, it nonetheless offered invaluable insights into the experiences of mothers during the COVID-19 pandemic. Our study underscores the need for continued research on the racial disparities in maternal care and the potential exacerbating impact of the pandemic. Furthermore, the qualitative narratives shared by our participants reveal the power of personal anecdotes in gaining a deeper understanding of the complexities of maternal health during times of crisis. These findings lay the foundation for future research in the realm of maternal health and healthcare equity.

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Homelessness: A Public Health Perspective on a Present Crisis

Margaret Martin*

Addressing increasing rates of homelessness is a matter of great importance in North America due to adverse consequences on health, particularly in marginalized populations. Rates of homelessness as well as associated health issues in unhoused populations have continued to play a considerable role in countless communities. Therefore, to pursue solutions to the current crisis of homelessness from a public health perspective, this article seeks to place multiple proposals for solutions in conversation. This article contends that to effectively address homelessness from a public health perspective a multi-faceted approach must be implemented, led by a coalition of leaders from a variety of disciplines, comprehensively addressing homelessness, and supporting the unhoused.

Keywords

homelessness • public health • health care • human rights • and comprehensive solutions

Introduction

Homelessness is a widespread issue affecting individuals and communities across North America. In the United States of America alone, over half a million individuals are unhoused each night (Mosites et al., 2022). The debate over proposed solutions to homelessness has recently become highly visible to me as this issue has risen to the forefront of city council meetings in my hometown of Bend, Oregon. I was able to discuss issues around homelessness, such as public health and safety concerns, with city officials who expressed the immense difficulty and complexity of finding solutions to this issue that are both effective and agreeable. Unfortunately, due to Bend being a relatively small community, there is no significant research on methods of addressing homelessness

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in the town and its surrounding areas. However, there are anecdotes such as this in towns big and small across North America, asserting the stark reality of the current homelessness crisis. In this article, I would like to address homelessness from a public health perspective, providing insight into potential causes, adverse effects on health, and proposed ways forward. To make lasting progress in combating this crisis, homelessness must be addressed through a comprehensive approach led by a multi-disciplinary group of leaders from public health, policy, and humanitarian organizations. With each field contributing their experiences and expertise it would be possible to work towards a conclusive, successful effort to confront homelessness.

Potential Causes and Risk Factors

Potential causes of homelessness in North America are innumerable, as such a broad issue affects countless individuals across the continent, however, trends have been identified relating to determinants of homelessness. Often, these broad determinants can be found in flaws in public infrastructure, such as high unemployment rates or a lack of affordable housing (Allegrante & Sleet, 2021). Community resources such as access to education, public transportation, and affordable health care also play a role in determining which communities and individuals are more susceptible to homelessness (Allegrante & Sleet, 2021). Additionally, it is important to note that racial inequities and discrimination can exacerbate the prevalence of homelessness among minority groups who are overrepresented among unhoused individuals (Mosites et al., 2022). One in twenty non-Hispanic white individuals report experiencing homelessness in their lifetime as compared with one in twelve Hispanic individuals and a striking one in six non-Hispanic Black individuals (Fusaro et al., 2018). The disparity in rates of homelessness between Black and white individuals remained significant despite data adjustments to account for variables such as education and veteran status (Fusaro et al., 2018). Veterans are also statistically at higher risk of becoming unhoused (Donovan & Shinseki, 2013). In the United States, Veterans have a higher risk of experiencing PTSD, unemployment, and substance abuse which contributes to their likelihood of becoming homeless (Donovan & Shinseki, 2013). Specifically, “among US veterans who were diagnosed with opioid use disorder in 2012, 35% were experiencing homelessness,” (Mosites et al., 2022). These potential causes and risk factors will inform an improved understanding of the effects of homelessness with regard to public health and proposed solutions to this crisis.

Adverse Effects

In examining the epidemic of homelessness from a public health perspective, I found it generally unsurprising to discover the extreme health risks associated with being unhoused. For example, unhoused individuals are reported to have increased rates of invasive cancers with significantly lower survival rates compared to housed individuals (Mosites et al., 2022). Additionally, those experiencing homelessness report higher rates of cardiovascular disease, human immunodeficiency virus (HIV), and infectious diseases such as COVID-19 and group A *Streptococcus* (Mosites et al., 2022). Substance abuse is also a disease that unhoused people are statistically associated with in higher numbers than housed populations, “homeless persons experience high rates of health problems such as [. . .] alcohol and drug addiction” (Francescutti & Sleet, 2021). The reality of the severe risk of potentially life-threatening health issues experienced at high rates by unhoused individuals, in

comparison to housed people, points to a significant need for a public health-led response to the crisis of homelessness in North America.

Proposed Solutions

A myriad of solutions has been proposed to confront the issue of homelessness from a public health perspective. One such proposal calls on the Housing First Model in its most simplistic form, by advocating for the provision of a minimum of temporary housing before addressing any other aspects of experiencing homelessness (Francescutti & Sleet, 2021). The Housing First Model is founded on the premise that housing is a universal human right as established by the United Nations in 1991 (Elder & King, 2019). Housing is a critical determinant of any individual's health, so it is understandable for housing to be addressed urgently in any approach to the current homelessness crisis. Past implementations of the Housing First Model at the federal level in the United States resulted in more than 80% of individuals remaining housed a year after assistance (Thompson, 2013). The Housing First Model addresses the adverse effects of homelessness by providing shelter alongside services that support housing stability, healthcare access, and employment (Donovan & Shinseki, 2013). It is important to note, however, that there are potential barriers to proper implementation of the Housing First Model. Particularly resource limitations such as poor access to housing and inadequate program staffing (Thompson, 2023). By confronting additional aspects of homelessness outside of a need for shelter such as health risks, income, and quality of life, the Housing First Model can effectively engage with homeless and unhoused individuals.

A comprehensive effort to alleviate rates of homelessness while supporting the unhoused is offered in the article "Public Health and Homelessness: A Framework", in which a layered approach to the crisis of homelessness is offered (Mosites et al., 2022). More specifically, the authors, whose associations with the Centers for Disease Control and Prevention (CDC) demonstrate their expertise, propose first expanding healthcare access and disease prevention for the unhoused through the implementation of pop-up clinics, vaccination efforts, and handwashing stations among other suggestions (Mosites et al., 2022). Due to the recency of this framework, there is not yet data to inform the success of the proposed approach. This focus on health is echoed in the article "Homelessness is a Public Health Issue", in which the authors advocate for the implementation of the Housing First Model in a way that would provide "access to health care, employment, and other supportive services that promote long-term housing stability, reduce recidivism, and improve quality of life" (Donovan & Shinseki, 2013). More comprehensive ways of addressing homelessness are compelling in that they look at the whole experience of homelessness to best support unhoused individuals.

An additional key aspect of any complete effort to address homelessness is an emphasis on future stability. The United States federal strategy, *Home Together*, is focused on economic security as a way of obtaining and maintaining stable housing (Elder & King, 2019). The *Home Together* program works to increase financial independence and allow unhoused individuals to become self-sufficient by advocating for the incorporation of these interventions alongside efforts to provide healthcare and housing (Elder & King, 2019). This need to account for future financial independence and stability is echoed by authors Donovan and Shinseki who also advocate for efforts toward long-term stability to improve quality of life for unhoused individuals (2013). According to Elder and King, living in temporary housing is associated with exacerbated health difficulties (2019). In keeping with the literature, I firmly believe that promoting the long-term success of unhoused individuals

is critical. Simply providing temporary housing or health care services will not succeed in ensuring stable futures with a lessened risk of once again becoming unhoused.

Of course, many programs have already been implemented to address homelessness. In the United States specifically, housing subsidies and the National Housing Trust Fund, which was established by Congress following the recession of 2008 with the goal of providing safe and affordable housing, are just two examples of such efforts (Elder & King, 2019). It cannot be denied that efforts already made to combat homelessness have not been entirely unsuccessful, “the United States reduced homelessness by 13% between 2010 and 2018,” (Elder & King, 2019). However, the fact remains that rates of homelessness have begun to increase, resulting in staggering statistics such as, “On a single night in January 2020, 580,466 people (about 18 out of every 10,000 people) experienced homelessness across the United States—a 2.2% increase from 2019” (Francescutti & Sleet, 2021). Despite some success emanating from program implementations over the last decade, current rates of homelessness along with the risk of adverse health effects suggest the need for a comprehensive effort to support the unhoused and decrease overall rates of homelessness.

Concluding Thoughts

If we as communities believe that there is an obligation to care for community members experiencing homelessness, then it is critical for comprehensive solutions to be considered and implemented effectively. There can be no debate that homelessness is a growing crisis across North America. After reviewing several proposed solutions to homelessness from a public health perspective, the literature points to a multi-faceted approach, aimed at completely addressing the wellness of the unhoused while also targeting root causes of homelessness, as being the best way to move forward. With the participation of multi-disciplinary leaders from public health, policy, and humanitarian organizations, significant progress could be made towards combating the homelessness crisis in a complete and compassionate way.

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Breathless in the Motor City: Unveiling the Legacy, Challenges, and Mitigation Strategies of Air Pollution in Detroit

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This paper delves into the historical trajectory, current status, and consequential ramifications of air pollution in the city of Detroit. With a specific emphasis on the pollutants NO₂, SO₂, PM_{2.5}, and O₃, the study scrutinizes the health implications and societal burdens arising from the escalating air pollution levels against the backdrop of Detroit's historical evolution. Despite regulatory endeavors, Detroit's enduring role as an industrial and manufacturing hub substantiates the escalating health and economic toll of air pollution. These costs disproportionately impact vulnerable demographics, including the elderly, children, and individuals with chronic illnesses. The paper underscores racial disparities in the distribution of this burden.

To address these challenges, the paper advocates for a mitigation strategy inspired by the European Union's NEC Directive. The proposed approach involves intensified monitoring of pollutants, implementation of targeted policies, and enhanced industrial regulations. Ultimately, this paper comprehensively examines the historical legacy, contemporary, and future dimensions of air pollution in Detroit, delineating the profound impact on the city and its residents, while offering strategic recommendations for mitigation.

Keywords

Air Pollution • Detroit • Health Implications • Racial Disparities • Mitigation Strategies • Environmental Impact

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Legacy of the Issue and Introduction

An investigation into the air quality of Detroit today requires introspection into the past. Detroit's history is inexorably linked to that of the automotive industry and manufacturing. Emerging in the post-World War two boom as the center of American automotive manufacturing Detroit blossomed into an economic and industrial American powerhouse ("Environmental Justice in Detroit," n.d.). The city quickly grew and expanded around the all-encompassing automobile, and large plants were created within the city while urban development centered around personal car ownership and highways, moving away from a more traditionalist close-knit walkable urban design. This large growth occurred in the early half of the 20th century; an era marked by a *laissez-faire* attitude towards environmental protections. Shortsighted environmental policy ensured lax standards on emissions from the burgeoning automotive plants, while poor urban planning prioritized a drivable spaced-out city over a traditionalist city that relied on low-emission public transport ("Environmental Justice in Detroit," n.d.). This boom would come to a sudden and abrupt crash, as racial tensions, and financial downturn within the automotive industry, destroyed the city's economy and the exodus of upper- and middle-class residents eroded property values within the city. The result was a poorly planned city that had short-sighted environmental policy and emitted industrial waste into the air unperturbed for nearly a half decade ("Environmental Justice in Detroit," n.d.). However, growing public concerns about the effects of air pollution led to the state passing Act 348 in 1965, establishing the state's first air pollution control law ("Air Quality Politics in Michigan," n.d.). The act proved to be ineffective at stopping the rates of air pollutants in the city of Detroit, as citizens continued to be negatively affected by industrial air pollution. The passing of the Clean Air Act in 1970 by the EPA, however, brought greater regulation on Detroit's air pollution setting emission standards, and a baseline fine of \$10,000 for emitters (Stern, 1982). Sadly, Detroit and Michigan as a whole struggled to comply with EPA standards, even as far as 1972, ("Air Quality Politics in Michigan," n.d.). The EPA eventually intervened, imposing its fines and plans on the state to ensure it fell under compliance with the Clean Air Act (Stern, 1982). This move was contested by major industries such as Dow Chemical and Detroit Edison, who cited inaccuracies within EPA testing, and that EPA standards were redundant, setting the stage for opposition between industry and environmental regulation within the city that persists today ("Air Quality Politics in Michigan," n.d.).

Specific Pollutants and Sources

The air of today's Detroit is awash with both organic and synthetic pollutants, due to the lingering manufacturing power of the city, and the city's poor automobile-based design. The first polluter is known as the "point source", a stationary emitter such as a factory smokestack, while the latter is known as a "mobile source", a moving polluter such as a car or a lawnmower (Walding, 2016). The primary actors in the narrative of Detroit's air pollution are NO₂, SO₂, PM_{2.5}, and O₃ (Walding, 2016). NO₂ refers to Nitrogen dioxide which is created by point sources but also industrial processes (von Schneidmesser, 2015). SO₂ refers to sulfur dioxide, which is created through industrial processes and energy generation, it is mostly a result of point source emitters. PM_{2.5} refers to particulate matter, mixtures of tiny chemicals, metal compounds, solids, and liquids that persist in the atmosphere. The designation of 2.5 references their respective size in micrometers as they are

a result of point and mobile sources, respectively (von Schneidmesser, 2015). Lastly, O₃ refers to Ozone, specifically ground-level ozone. Created through industrial processes and car emissions, it is both an emission from point and mobile sources (von Schneidmesser, 2015). Within the city of Detroit, point sources refer to industrialized zones within the city, such as steel plants on Zug Island, or Marathon petroleum refineries (Lougheed, 2014). Mobile sources within the city refer to the multitude of high-traffic highways such as I-75, which cut a swath through the city (Lougheed, 2014). These pollutants constitute the major source of air pollution in Detroit.

Standards

A downward trend in the emission of air particulates has been observed in the city of Detroit across the last 14 years (Walding, 2016). However, while air quality in Detroit remains largely below EPA guidelines it is still a health threat to the thousands of individuals that call Detroit home. Air pollution is not uniformly issued across Detroit as it is often fluctuation due to several factors, including weather conditions, time of day, and season (Martenies et al, 2017). However, using data obtained from Michigan's 2017 Air Emissions Reporting System, Detroit on average experiences NO₂ at 23.5 ppb, with a minimum (min) recording of 5.8 ppb, and a maximum recording of 214.2 ppb (Martenies et al, 2017). EPA guidelines set a recommended limit of 53 ppb. (Environmental Protection Agency, 2014), and while the daily average exposure falls within safe guidelines, days can fluctuate to exceed the recommended EPA value by as much as a recorded 4x. Such fluctuations reveal a serious trend in Detroit air pollution. While average exposure values generally fall within the safe EPA regulation, fluctuations can lead to massive exposures and subsequent negative health effects among the exposed. Ozone (O₃) experiences an average ppb exposure of 38.3, with a minimum recording of 6.8 ppb and a maximum recording of a Q₁ recording of 103.8 ppb, a value exceeding EPA regulation by 1.48x. The EPA regulation is set at 0.07 ppm (70 ppb) (Environmental Protection Agency, 2014). SO₂ had an average daily exposure of 1.1 ppb with a minimum recording of 0.0 ppb and a maximum recording of 19.4 ppb (Martenies et al, 2017). The EPA recommendation is a 75 ppb SO₂ exposure for a 1-hour standard (Environmental Protection Agency, 2014). Lastly, PM_{2.5} was 10.7 microgram per cubic meter ($\mu\text{g}/\text{m}^3$) with a minimum reading of 2.0 $\mu\text{g}/\text{m}^3$ and a maximum reading of 82.4 $\mu\text{g}/\text{m}^3$, the maximum reading was 2.35x the EPA guidelines of 35 $\mu\text{g}/\text{m}^3$. While the general average exposure to some of these pollutants falls well within acceptable EPA guidelines, the heavy fluctuation of the city's air pollution exposes Detroit residents to periods of 1–4x EPA acceptable guidelines and can lead to negative health outcomes.

Health Effects of Air Pollution

Exposure to air pollution is causally linked to several negative health outcomes. Ecological studies have concluded a causal relationship between air pollution and cardiovascular disease, cancer development, respiratory illness, and stroke (Keswani et al, 2022). Meta-analysis research has even conducted an estimation of dose-response gradients with air pollution. Using such methods, peer-reviewed research has found that a “10 $\mu\text{g}/\text{m}^3$ increase in PM_{2.5} levels was associated with a 2.5% increase in the relative risk of myocardial infarction (MI)” (Keswani et al, 2022). Similarly, “every 10 $\mu\text{g}/\text{m}^3$ increase in exposure to PM_{2.5} was associated with a 22% increased risk of all-cancer mortality in a linear concentration-response relationship.” (Keswani et al, 2022). PM_{2.5} is

thus a significant causal factor in both cancer and respiratory illness and has even demonstrated a biological gradient, to both infections. This means the large fluctuations of PM_{2.5} within the city exacerbate the risk of the disease along a linear trend. Additionally, air pollution has been linked to immunological dysregulation, inflammatory bowel disease, chronic kidney disease, end-stage renal disease, and decline in glomerular filtration rate, higher risk of tuberculosis and COVID-19 infections (Keswani et al, 2022). As these links lack the necessary criteria to prove direct causality (under Bradford Hill's criteria), they cannot prove that increased exposure leads to all the negative health outcomes listed. However, increased and continued research into the field will aim to identify other potential negative health outcomes associated with air pollution exposure. Beyond direct links to disease outcome, air pollution's greatest health effect is that of the syndemic factor. Broadly speaking a syndemic factor is a factor that forms synergistic interactions between multiple health threats which contribute to the excess burden of the disease. In this way, exposure to air pollution enhances the burdens of at-risk populations who already have a disease or medical health risks.

At-Risk Populations

Air pollution in the form of SO₂, NO₂, O₃, and PM_{2.5}, poses a significantly increased risk for the elderly, children, and people with chronic respiratory illness (such as asthma) (Simoni et al, 2015). For older populations, outdoor air pollution poses an increased threat to their respiratory health. Research has “shown significant positive associations between respiratory hospital admissions and levels of SO₂, PM₁₀, and O₃ in persons aged 65 years or older” (Simoni et al, 2015). The strongest association was that of PM_{2.5}, which is found to be the most threatening for the elderly (Simoni et al, 2015). The exact reasoning for this is still unclear to public health officials, but a meta-analysis of over 33 studies has found that “each 10 µg/m³ increase in PM_{2.5} was associated with a 0.51% (95% CI, 0.30–0.73%) increase in respiratory mortality” (Simoni et al, 2015). Such research has established a dose-response gradient for elderly populations, proving causal mortality increase due to PM_{2.5} exposure. Contextually within the city of Detroit, elderly people are at an increased risk of negative health outcomes related to air pollution. Previous studies have calculated relative risks associated with increases in air pollution chemicals. A value over 1 in a relative risk test indicates that the pollutant exposure has caused more disease outcomes than normally expected, and thus exposure to the pollutant increases the likelihood of the disease. PM_{2.5} and O₃ have been shown to be associated with a relative risk of 1.012 and 1.026, respectively, for pneumonia hospitalization in elderly Detroit residents (Schwartz, 1994).” Similarly, the relative risk for COPD (chronic obstructive pulmonary disease) revealed a relative risk of 1.02 for PM_{2.5} and a relative risk of 1.028 for ozone exposure (Schwartz, 1994). Thus, within the city, the pollutant has statistically increased the burden of the two diseases to a causal level. Such research has concluded that elderly Detroit residents will face increased hospitalization for COPD and Pneumonia than the national average due to air pollution (Schwartz, 1994). Ultimately, contemporary research has concluded that existing levels of ozone and fine particulate matter in the city of Detroit (which fall within EPA regulations) pose a statistically increased risk for elderly residents in the city (Schwartz, 1994).

For children, air pollution poses an increased threat as well, owing to children's increased respiration rate (compared to that of adults), underdeveloped organs, and on average a higher time spent outside than adults (Brumberg et al, 2021). In children exposure to ambient air pollution has been found to “. . . manifest as exacerbations of chronic diseases (eg, asthma) but air pollution

also appears to be associated with the development of major pediatric diseases, including adverse birth outcomes, abnormal lung and neurodevelopment, and pediatric cancer, as well as obesity and cardiovascular disease risk.” (Brumberg et al, 2021). As such air pollution exposure is statically associated with chronic disease development into adulthood and linked to adverse neural and organ development and cancers (Brumberg et al, 2021). Contextually within Detroit, children are hospitalized for asthma (related to air pollutant exposure), at a tremendous rate, as the childhood asthma hospitalization rate was three times the childhood asthma rate for Michigan children (Detroit: current status of Asthma, 2021). Sadly, public health data on children’s development due to Detroit’s air pollution is an underdeveloped subject. Potential prospective cohorts following disease development could help to establish a baseline relative risk assessment and shed much-needed light on the situation within the city.

Lastly, individuals with chronic respiratory illness face increased susceptibility to air pollution. Air pollution causes increased inflammation in the respiratory tract, leading to increased hospitalizations and mortality in populations that are burdened by respiratory chronic illness (Brumberg et al, 2021). Within the greater context of Detroit, citizens suffer increased asthma burdens, likely related to ambient air pollution as public health has associated exposure to asthma development (though not causally proven within the city) (Brumberg et al, 2021). The rate of adult Detroiters with asthma was 29% higher compared to the rest of the state (Detroit: Current Status of Asthma, 2021). Public health surveillance as recently as 2021 has found that Detroiters living with asthma face an increased risk of hospitalization compared to the state average. In 2019 alone there were 1,458 hospitalizations from asthma in Detroit, with a hospitalization rate that is 4x the state average (“Environmental Justice in Detroit,” n.d.). Similarly, the rate of asthma mortality for Detroit residents was over 3x the state average (Detroit: Current Status of Asthma, 2021). Thus, Detroit’s residents with asthma will disproportionately face increased mortality and hospitalizations due to the city’s air pollution.

Racial Disparities

Detroit has a long history of racial and ethnic disparities. Redlining, predatory race-based employment, loaning, and racial rioting are the foundation of the city’s history (Schulz et al, 2016). Unfortunately, air pollution is no exception; negatives will disproportionately affect African Americans and ethnic minority groups. Contemporary research has concluded that African Americans and ethnic minority groups (such as Latino ethnic populations) disproportionately experience negative health effects associated with air pollution (Schulz et al, 2016). Such populations are more likely to be situated in the city’s lowest valued areas and are more likely to be situated at a close distance to point and mobile sources (in this case mobile sources would refer to highway proximity) (Schulz et al, 2016). Quantitatively, public health case studies have concluded that within the city of Detroit “census tracts with greater proportions of people of color (POC) experience a heightened burden of environmental exposures and health risks ($-0.12, p < 0.001$).” (Schulz et al, 2016). For context, the study found that the proportions of POC experienced a statistically significant burden from air pollution using a cumulative risk index, which compares census data of populations with their locations and hazards to determine if such populations experience disproportionate health outcomes (Schulz et al, 2016). Such research concluded that Detroit POC populations face the burden of air pollution to a statistically significant disproportionate effect. Contemporary and

historical explanations determine that “these findings are consistent with evidence suggesting that patterns of White flight and economic disinvestment from many urban communities, such as those described above for Detroit, have contributed to the disproportionate representation of African Americans and Latinos in neighborhoods that experience multiple exposures and vulnerabilities” (Schulz et al, 2016). Additionally, another racial disparity responsible for the increased burden on POC is asthma. Detroit faces enhanced asthma rates compared to other Michigan cities and populations. As examined above air pollution leaves those with asthma extremely susceptible to hospitalization and mortality, even when pollution levels fall within EPA standards. However, the brunt of Detroit’s asthmatics are disproportionately POC. A 2019 Michigan state-funded ecological study found that “In 2019, the rate of asthma hospitalization among Black persons in Detroit was 31.0 per 10,000. The rate among white persons in Detroit was 7.9 per 10,000” (Detroit: current status of Asthma, 2021). Such data found conclusively the burden of asthma in the city was statistically experienced by African Americans in the city. Public health research links such a chronic burden to the localization of African Americans closer to point and mobile sources. Research has found that long-term exposure to air pollution has a causal linkage to chronic disease development, primarily in asthma (Brumberg et al, 2021)

Costs

The costs of such exposures are tremendous on both the health of Detroit citizens and the city’s economy is tremendous. Both in terms of GDP (a measure of economic activity) and DALYs (disability-adjusted life years) a metric determining lost years due to premature mortality and disability relating to disease, and mortality. In Detroit, exposures to O₃ PM_{2.5} so₂ and NO₂, resulted in an estimated 10,000 DALY yearly, representing over 6.5 billion annually in impacts (Martenies et al, 2017). Air pollutant exposure accounts for 3,300 asthma emergency department visits yearly (Martenies et al, 2017). The breakdown for attributable burden between the pollutants for DALYs found that 97% of 10,000 were related to PM_{2.5}, 1% related to O₃, 0.06% related to So₂, and 1.3% related to NO₂ (Martenies et al, 2017). Monetary costs related to each pollutant varied slightly, with the 6.5 billion health cost broken down, 78% of the burden was due to PM_{2.5}, 21% for O₃, 0.03% was due to SO₂, and finally, 0.5% was due to NO₂ (Martenies et al, 2017). Further, an estimated 5.5% of annual city deaths can be attributed to PM_{2.5} while 1.5% can be attributed to ozone exposure (Martenies et al, 2017). Research has concluded that both health costs and GDP costs are the most heavily associated with PM_{2.5} and ozone (Martenies et al, 2017). Unequivocally the costs of air pollution within the city are an immense burden on the citizens residents, medical infrastructure, and economy. Unaddressed, these costs will hamper the city’s development and pose a growing public health crisis. An estimated 570,000 school days are missed due to air pollution in the city, due to asthma attacks and hospitalizations (Martenies et al, 2017). Despite falling within acceptable EPA limits, ambient air pollution in the city presents an egregious public health crisis to the city of Detroit, with annual costs that burden and impoverish its citizens and their futures.

Impact on the Environment

Beyond human health impacts, air pollution has a profound and damaging effect on the environment of Detroit. Unfortunately, there is a marked lack of information on the environmental effects

of air pollution within the city of Detroit. As such quantitatively defining the environmental impacts that Detroit's air pollution levels incur is nearly impossible. The effects of air pollution on the environment have been studied in other ecological studies but have yet to be compiled on the city of Detroit itself. This is an extreme shortcoming of public health and environmental initiatives, as air pollutants have been found to have a profound effect on environmental ecology. Ozone exposure is a phytotoxin, which can impair plants' photosynthesis and oxidize plant tissues (von Schneidemesser, 2015). Therefore, it has a negative effect on crop yield, specifically in wheat, maize, and soybeans, costing an estimated 11–18 billion dollars worth of damages to the US agricultural economy (von Schneidemesser, 2015). Likewise, SO₂ emissions have been found to have an adverse effect on ecosystems through acid deposition. When SO₂ meets water and air, it undergoes a chemical change to sulfuric acid, which during precipitation causes deforestation, acidification of waterways, and the mortality of aquatic life (von Schneidemesser, 2015). PM_{2.5} is responsible for meteorological changes, including precipitations, humidity, and haze (von Schneidemesser, 2015). The shortcoming of public health officials to quantify the damages of Detroit's air pollution on the environment reflects a lack of respect and investment in environmental surveillance and health from the US government. To ensure a healthier Detroit environment, public health systems should quantify these health problems through prospective cohorts, and syndemic surveillance.

Mitigation Strategy and Program Potential

Despite falling within EPA limits, air pollution is a disastrous public health crisis affecting the city of Detroit. Left unaddressed, this pollution will lead to lasting economic and health damage and increasing racial disparity. Thus, mitigation should offer strategic interventions that are specialized for the citizens' unique situation, rather than follow vague national guidelines.

Perhaps the most comprehensive strategy with proven results comes from the European Union. Under the directive "NEC Directive, (2016/2284/EU)", the EU set about reducing levels of SO₂, fine particulate matter, NO₂, and ozone (European Environment Agency, 2023). Lauded as the most stringent enforcement by the Union, the directive put in place aggressive monitoring of pollutants in European nations, pollutant level targets for EU member countries, and the development of tailor-made air quality control plans for each member nation's unique situations (European Environment Agency, 2023). The beauty of the EU plan was its flexibility and strict implementation of monitoring sites. States were able to create tailor-made plans that maximized cost-effectiveness and benefits for their particular pollution situations. Additionally, accurate monitoring allows states to identify polluters and impose taxes as well as limits on industry. Introspection of the most effective measures implemented by the directive reveals mitigation strategies that have been tried and proven to lower emissions and improve air quality. Using Italy as a case study, adherence to the NEC directive has been incredibly successful as the 2020 goal of a 65% reduction to a baseline SO₂ from 2002 was reached, primarily through reductions in emissions from the switch from coal to natural gas (De Marco, 2019). Similarly, nitrogen dioxide reductions showed a decreasing trend from reductions in road transport (De Marco, 2019). Much of the reductions were attributed to steps taken from the interpretation of data obtained from accurate monitoring which allowed the country to implement strategies to best reduce emissions, rather than follow a blanket reduction plan that may have fit poorly for the country (De Marco, 2019). Monitoring sites were also instrumental in

predicting the effects changes to emissions would have in the future and how strategies could be maximized for health and economic benefits (De Marco, 2019)

For Detroit, a similar step should be undertaken as in an EU state. Initially, the state should implement accurate monitoring stations across the city, gathering surveillance and identifying polluters to an accurate degree. While the state of Michigan does have a comprehensive air quality system, only seven stations measure the air quality in the city of Detroit (Walding, 2016). Additional stations are required, specifically around the city's point sources and pollution for more accurate data. Such data would also serve to differentiate where pollutant reductions would be the most beneficial. A contemporary research paper compared multiple reduction strategies for air pollution within the city including reductions on the leading sources of emissions, targeting reductions in areas that have the most health effects, and blanket city-wide levels (Martenies et al, 2018). Using dispersion modeling as a quantitative impact health assessment, the conclusion of the research determined that the most effective strategies ". . . focused on emission sources with the highest health impacts per ton of pollutant emitted provided the greatest health benefit per ton of pollutant reduced" (Martenies et al, 2018). This was in contrast to "strategies targeting the larger emitters increased inequalities and sometimes provided minimal health benefits." (Martenies et al, 2018). The study concluded that blanket reductions on the largest emitters such as those under the EPA plan would prove to be less effective than strategic reduction. A move away from blanket reduction strategies to one of strategic planning based on where emission reduction would ensure the most cost-beneficial and optimized outcome. Following a system like the EU's reduction plan would prove the most effective for Detroit, as it would first establish accurate monitoring sites, which would in turn help to determine where setting reductions from emitters would be the most beneficial. Similarly, additional data gathered could help the city plan where to implement other reforms best, such as investment in public transport.

Conclusion and Notes

Ultimately, the city of Detroit has a long history related to air quality. Owing to its history as a manufacturing base, the city's layout predisposes it to increased susceptibility to negative health outcomes relating to air pollution. Through EPA policies, the city has managed to fall within acceptable pollutant guidelines, but large fluctuations in pollutant levels expose the city's residents to the negative health outcomes associated with air pollutant exposure. The burden of such outcomes is immense and deprives the city of both capital and its citizens of an unperturbed and healthy life. Further, this burden disproportionately affects the city's African American and minority groups, exacerbating the historic and contemporary disparity these groups have experienced. Reduction in air pollution should become a focal point of environmental regulation and activism within the city. Detroit should follow a mitigation strategy tested in Europe. The city should focus on first instituting quantitative measurement sites throughout the city to accurately create a tailor-made plan that creates a balanced and cost-effective reduction strategy rather than following a national blanket emission reduction plan which has historically proven to be ineffective.

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Global Medical Supply Inequities

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The global issue of medical supply inequity exists as some countries have excess medical supplies, which leads to large amounts of medical supply waste resulting in both economical and environmental harm. However, many countries face the opposite issue and instead have a shortage of necessary, life-saving medical supplies. The duality of the issue is a harsh and widespread reality throughout the world. For example, the United States generates about 4.7 million pounds of medical waste yearly (Zygourakis et al., 2015; Thiel et al., 2020). In contrast, India, especially during the COVID-19 epidemic, faced a massive shortage of essential equipment like N-95 respirators, face shields, as well as ventilators. To reduce the worldwide inequities that arise due to the imbalance of medical supplies, Blueprints for Pangaea (B4P), a medical surplus recovery organization was founded. B4P, headquartered at the University of Michigan in Ann Arbor, redistributes unused medical supplies to places in need both locally and internationally, effectively reducing medical supply inequities one shipment at a time. This paper aims to explore the key components and global dynamics contributing to medical waste and to consider B4P as a potential model for addressing this problem.

Keywords

healthcare • sustainability • medical waste • nonprofit • equitable • resources • medical devices

Introduction

Medical supply waste is defined as the disposal of unutilized tools and equipment by hospitals and healthcare facilities. Currently, managing medical supply waste is an urgent issue in the field of

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healthcare, yet it lacks adequate recognition. The problem prevails in both developed countries that contribute to the waste of functional materials, and in underdeveloped countries where disparities are evident with the lack of access to basic life-saving supplies. Inadequate access to medical supplies serves as a major barrier to achieving quality healthcare in low and middle-income countries, as it prevents proper interventions needed to diagnose and rehabilitate patients. The World Health Organization (WHO) approximates that 50–80% of medical equipment and supplies in developing countries are not functional, which presents a major hurdle in competent healthcare practice, and heightens negative medical outcomes for even basic illnesses (Moyimane et al., 2017).

On the other hand, healthcare facilities in developed countries, such as the United States, are often in possession of excess supplies and equipment. This results in a large portion of these unused resources to be discarded in landfills. The unnecessary disposal of these resources can be classified as medical supply waste. Medical supply surpluses are often generated as a consequence of healthcare facilities ordering more supplies than needed, resulting in an excess inventory (Khan, 2023). In 2015, a study of 58 neurological procedures conducted at the University of California, San Francisco (UCSF) Medical Center found that 13% of surgical supplies went unused and were discarded - contributing to the estimated 4.7 million pounds of medical waste that United States hospitals alone generate yearly (Zygourakis et al., 2015; Thiel et al., 2020). Consider the UCSF Medical Center, for example, where one of the most discarded supplies was “surgifoam”, a sponge used to control bleeding, valued at nearly \$4000 per sponge (Healthcare Finance News, 2016). Such disposals can add up to \$765 billion dollars per year (Mirza, 2017). It is also important to consider the environmental impacts of this medical supply waste, especially as these resources gradually saturate landfills across the globe. The United States healthcare system is the second largest industrial contributor to landfill waste, and such waste emits sufficient pollutants and greenhouse gasses that negatively influence community health (Association, 2022). A global issue of medical supply inequity exists as there is a stark contrast between the surplus of medical resources some countries have, while others face medical supply shortages; Blueprints for Pangaea, a medical supply recovery organization, aims to address these inequities through the redistribution of unused medical supplies.

Case Study: Comparing Medical Supply Excess and Need

In order to contextualize the impact that excess medical supplies and corresponding supply waste have had, it is important to examine both ends of the spectrum: countries with a medical supply surplus and countries facing extreme medical supply shortages. Consider how India, for example, dealt with an extensive medical supply shortage during the COVID-19 pandemic. During India's first wave (March 2020 - Nov. 2020; peak occurring in ~Sept. 2020) and second wave (Feb. 2021 - May 2021; peak occurring in ~April 2021) there were extreme medical supply shortages observed throughout the country (Natarajan & Prasad, 2021). Initial reports of a lack of basic medical supplies came during the early days of India's first wave, when hospitals recorded complete stockouts of N95 respirators (Ray, 2020). However, the reports concerning a lack of available respirators were soon trumped by the extreme shortage of ventilators, oxygen concentrators, and additional supplies essential for keeping infected and deteriorating patients alive (Sarfranz et al., 2022). An oxygen concentrator is a device designed to assist patients with taking in oxygen, while a ventilator is a life-support machine that breathes for patients who cannot on their own. A lack of life-sustaining supplies such as oxygen concentrators and ventilators was observed during India's second wave, and

as a result healthcare workers were often put into an impossible position to decide which patient received life-support and which patient did not (Kapoor et al., 2023). As such, many obstacles faced by India during the COVID-19 pandemic have been emphasized by abrupt equipment shortages. A survey-based study from 2020 was distributed to board-certified physicians providing care to critically ill patients at Indian hospitals, which included 481 hospitals in phase one (March 25, 2020 - April 6, 2020) and 320 hospitals in phase two (April 20 2020 - April 30, 2020), and found that 71% of respondents were “unaware of their personal protective equipment stock or [knew] that their current stock would not last [over] a week” (Haji et al., 2020). The same study also found that only 17% of respondents from phase one reported “having enough [personal protective equipment] stock to manage (Haji et al., 2020). It is clear that India, along with many other developing countries, faced significant challenges regarding patient and provider care during the COVID-19 pandemic that were brought upon due to a lack of basic supplies. While more developed countries also faced shortages in medical supplies during this time period, medical facilities in these regions had the opportunity to purchase and acquire higher amounts of supplies earlier, which alleviated some of the consequences and pressures they faced during the pandemic.

It is valuable to identify the existence of these supply shortages, as they directly impact both patient care and healthcare workers' health. There is a strong relationship observed between the acceleration of disease and the number of infectious patients seeking both care and testing (Bhattacharya et al., 2020). In the case of SARS-CoV-2 (an acute respiratory syndrome that causes COVID-19), virus transmission is observed mainly through airborne particles (CDC, 2020). Thus, with the drastic increase in the number of individuals seeking healthcare during COVID-19, there was an adjacent increase in need for personal protective equipment (PPE) to prevent the spread of infection among patients (Bhattacharya et al., 2020). For context, PPE is a broad term that encapsulates any specialized equipment or clothing that is worn by an employee (most often healthcare workers) to protect themselves against infection (Personal Protective Equipment (PPE) for Infection Control, 2023). Furthermore, maintaining optimal PPE levels is also identified as a key to minimizing COVID-19 infection in healthcare workers (Haji et al., 2020). Common PPE utilized by healthcare staff during the COVID-19 pandemic includes gloves, surgical face masks, goggles, gowns, face shields, air-purifying respirators (removing contaminants such as gasses, vapors, or aerosols from the air often through the use of filters or cartridges), and N95 respirators (respiratory protective device characterized by a close facial fit and capacity for filtration of airborne particles).

On the opposite end of the issue, there are a plethora of healthcare facilities that dispose of usable equipment every year, and partake in exacerbating the effects of medical supply waste. Products most often disposed of include unopened clinical kits, leftover materials from post-surgical procedures, and surplus hospital equipment (Atasu et al., 2017). Waste generation is commonly observed in more developed nations, primarily because they have access to a reliable inventory of medical equipment and a larger budget. Therefore, countries in this category can purchase and receive the newest medical supplies to replace existing supplies with much greater ease than India, for example. Consider the United States, a country that massively contributes to medical supply waste. In 2014, a study conducted by a research team at Johns Hopkins discovered that healthcare facilities within the United States dispose of ~5.9 million tons of “reusable medical products” every year (Atasu et al., 2017). More specifically, a further report utilized data from this study to determine that major hospitals of the United States dispose of unused operating room surgical supplies worth \$15.4 million per year (Wan et al., 2014). It is important to establish that these supplies are wasted through disposal, as they have potential to be effectively salvaged and utilized to ease supply

shortages in areas of need. Although many types of medical supplies are disposed of out of necessity (expiration dates, quality assurance, regulatory requirements), there is a massive amount of supplies wasted when it could be allocated towards relieving shortages in underdeveloped nations (Atasu et al., 2017). The United States is a prime example of this, and it is valuable to acknowledge the persistence and wide-range of this issue, in hopes of addressing the medical supply waste and aiding in the recovery of unused supplies.

A Potential Solution for Reducing Healthcare Inequities: Blueprints for Pangaea

The massive waste of medical supplies has prevailed as a lesser-recognized public health issue for years, and there are a limited number of individuals and organizations dedicated towards addressing this global issue. With knowledge of the disparities created by medical supply waste in mind, Blueprints for Pangaea (B4P), a 501(c)(3) not-for-profit medical surplus recovery organization, was founded in 2013 to provide sustainable solutions targeting inefficient health care resource distribution (Blueprints for Pangaea, n.d.). B4P operates through a current network of nine united university chapters, and the organization's headquarters resides at the University of Michigan. B4P partners with US hospitals, healthcare facilities, and suppliers to reallocate excess, unused medical supplies that would otherwise be discarded to various countries and areas of need internationally (Blueprints for Pangaea, n.d.). As a whole, Blueprints for Pangaea strives to alleviate health inequities and address the problem of medical supply wastage by redistributing surplus medical resources from areas of surplus to those in need.

B4P uses a comprehensive model in order to handle and execute shipments locally and internationally. By collaborating with various healthcare partners, the organization receives excess medical supplies and equipment, which are then stored in a designated warehouse. Specifically, in Ann Arbor, B4P's largest medical supply donor is Michigan Medicine (hospital system located in Ann Arbor, MI). Many of B4P's recipient organizations include local organizations like Hope Clinic, the Shelter Association of Washtenaw County, student run free clinics at the University of Michigan and Wayne State University, along with many other partner organizations. B4P's most recent local shipment was conducted with the Planned Parenthood of Michigan, donating about \$9,000 worth of medical supplies. Since the organization headquarters are in Ann Arbor, there are many local disparities that B4P aims to address. In addition to medical shipments, Blueprints for Pangaea also hosts an annual *Day of Service* to engage with the local community, performing various service projects. These include creating care packages that are donated to the Shelter Association of Washtenaw County located a few minutes from the University of Michigan campus. Also, various blankets are made, which are then donated to children's hospitals in the Metro Detroit Area.

Global partners also exist as Blueprints for Pangaea has conducted multiple international shipments to Mexico, Syria, Ukraine, India, and many other countries. After receiving medical supplies in the B4P warehouse, a team of members then inventories the received medical supplies, filtering by type, expiration date, and quality. Simultaneously, another group of members consolidates a list of various potential recipients, and begins comparing each recipient's supply needs with the warehouse inventory. After taking financial and logistical matters into consideration, the organization holistically chooses a recipient whose need most closely matches B4P inventory to ensure the best use of resources. Critics may argue that the medical supply reallocation process is futile,

as on occasion, organizations donate supplies that the recipient already possesses, or supplies are damaged or expired (Compton et al., 2018). For example, Haiti was in desperate need of medical supplies after a major earthquake in 2010, and while they received many donations, much of it was damaged or unusable given the hospital's circumstances and environment (Compton et al., 2018). However, Blueprints for Pangaea eradicates these barriers by implementing a meticulous inventorying process, ensuring each pallet of supplies sent to a recipient is unexpired, up to the standard for quality, and compatible with the hospital's abilities and needs.

Blueprints for Pangaea does face some of its own challenges as an organization. The inventorying process described above is tedious and time consuming. B4P organizes volunteering events to engage with the community and spread awareness regarding the issue of medical supply wastage. Thus, other organizations around the Ann Arbor campus as well as local high schools help by attending the inventorying events and sorting through donated medical supplies. The entire inventorying process is continuously being revised as the team evaluates and finds room for improvement. Additionally, the organization requires funding to conduct the various shipments of medical supplies and pay for warehouse rental fees. Part of B4P's finance department is solely dedicated to continuously sourcing and writing various grants. The majority of B4P's funding comes from grants that are applied for, some of which are through the University of Michigan itself. A portion of the organization's funding also comes from donors, which consists of other healthcare organizations, high net-worth individuals, or companies such as Colgate and Zipcar. To mitigate some of the challenges that B4P faces, the organization is currently in the process of developing an inventorying app which can scan various medical supplies' barcodes and input the necessary data into a database that members can analyze. B4P's unique model and commitment to its mission keeps the organization motivated and successful despite the difficulties encountered as a medical surplus recovery organization. This has permitted the organization to execute many local and international shipments since its founding in 2013.

To highlight B4P's tangible impact, in August 2021, the organization executed a shipment to India in response to the COVID-19 pandemic. The shipment entailed sourcing various PPE items, specifically N95 respirators, face shields, and surgical masks. To ensure the proper medical supplies requested by the recipient organization in India, Manav Sadhna, were received, B4P consulted its major supplier, Michigan Medicine, as well as additional clinics. Local clinics identified in the metro-Detroit area, Community First Health Centers and Lake Huron Medical Center, were able to contribute their excess PPE supplies and monetary donations to support B4P with shipment expenses. After the supplies were received in India, they were distributed at various COVID-19 vaccine distribution centers in "68 low-income communities in Ahmedabad and 946 villages across Gujarat" (Manavsadhna, 2021). With the help of B4P, Manav Sadhna was able to deliver over 4,500 medical kits to rural communities (Manavsadhna, 2021). Healthcare providers were able to utilize the face shields and N95 respirators to protect themselves from contracting the virus (Health and Awareness – Manavsadhna, n.d.). In addition, the surgical masks were given to patients as they arrived at the various centers. Overall, twelve pallets of medical supplies worth over \$200,000 were donated to Manav Sadhna, B4P's recipient organization in India (Blueprints for Pangaea, n.d.). B4P's model allows the organization to reduce existing inequities in areas that lack medical supplies, and thus help patients receive the best care possible.

As mentioned previously, Michigan Medicine is the major supplier for B4P's headquarters. The hospital system sends a few pallets of medical supplies to the B4P warehouse on a biweekly basis. These pallets go through the inventorying process as volunteers come to the warehouse and are led

by B4P members. This helps the organization estimate what types of medical supplies are donated and the quantity of these supplies. Inventorying allows B4P to accurately match what exists in the warehouse to recipient needs and requests. Michigan Medicine is one of the largest hospital systems in the state of Michigan and has just over one thousand hospital beds (Kar, 2021). As a result, large amounts of unused medical supplies are generated that would otherwise be discarded to landfills. B4P's operation model helps reduce this wastage and gives supplies a new purpose towards alleviating health inequities globally.

Medical supply wastage is a prevalent issue that affects areas worldwide in a disproportionate manner. As some countries deal with large amounts of medical supply surplus, others are left without the basic medical necessities needed to provide proper care to patients. Moreover, the majority of excess supplies generated ends up in landfills exacerbating growing environmental concerns. Blueprints for Pangea aims to address and reduce the disparities that arise from this problem by reallocation of excess medical supplies to those with greatest need. The B4P model exemplifies that tangible change can be created by reallocating medical supplies both locally and globally. In the future, B4P aims to expand to have global chapters, which can help inform new audiences of medical waste, propose new ideas to tackle the problem, and take global action in order to address medical supply inequities.

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The Effect of Socioeconomic Barriers on Health Outcomes in Patients with Inflammatory Bowel Disease

Joanna Chait*

I was diagnosed with Ulcerative Colitis (UC), a chronic condition characterized by inflammation of the large intestine and rectum, in 2019. Seven months after my initial diagnosis, I was approved for infusions of Entiviyo, a medication commonly used to treat UC and Crohn's Disease. However, before I entered remission on this treatment, I was prescribed many different oral and rectal medicines, including a different biologic medication. As none of the therapeutics effectively mitigated my symptoms, I was hospitalized a few times, requiring multiple blood transfusions. Infusions of the drug cost the insurance company \$38,000 per dose. I am extremely fortunate to have my medical expenses covered by my insurance plan, which I have access to through my father's employer. Receiving infusions of Entiviyo required me to be absent from high school frequently and took up a lot of time. I was lucky, however, that as a student, I could afford to take as many excused absences as necessary. My parents had to take off from work frequently to take me to and from appointments. I was especially fortunate to have retired grandparents nearby who could often drive me to and from my doctor's visits and infusion appointments to help share the responsibility with my parents.

Keywords

Inflammatory Bowel Disease • Ulcerative Colitis • Crohn's Disease • Social Determinants of Health • social barrier Score • healthcare access • patient health outcomes

Cover Page

Abstract- Patients who experience more severe symptoms of Ulcerative Colitis are associated with having greater socioeconomic challenges or higher social barrier scores (SBS).

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Inflammatory Bowel Disease describes two conditions, Ulcerative Colitis and Crohn's Disease, characterized by gastrointestinal (GI) tract inflammation. Ulcerative Colitis is a type of Inflammatory Bowel Disease (IBD) characterized by large intestine inflammation. Research has shown that multiple social determinants of health (SDOH) hinder achieving desirable health outcomes in the Inflammatory Bowel Disease community. These include financial strains, poor health literacy, and lack of access to education. Additionally, social barriers disproportionately affect non-Hispanic Black and Hispanic people.

Background- Social determinants of health are environmental conditions that influence health outcomes. Such factors include access to education, access to healthcare, neighborhood and housing, socioeconomic background, and one's social network. In data collected from IBD patients, 56.2% of Hispanic Patients experience financial strain, 40% of non-Hispanic Black patients, and 24.85% of non-Hispanic Whites. The cost of out-of-pocket care for IBD patients is three times greater than that of non-IBD patients. IBD patients also have higher costs due to the time required to receive treatment. These costs are estimated to be \$26,555. Social determinants of health (such as financial strains, poor health literacy, and lack of access to education) make it more difficult for IBD patients, especially non-white patients, to receive health care. Therefore, their symptoms are more severe because patients cannot receive treatment for their illnesses. IBD is costly, in both time and money, to have and treat. Socioeconomically challenged people are further disadvantaged because IBD treatment is expensive even with high-quality insurance. Additionally, having the disease can require patients to be absent from work, which serves as an extra financial barrier. Lack of medical literacy and education makes it more difficult to advocate for medical treatment. It makes it more difficult to contact doctors, advocate for one's needs, and fill out paperwork.

Assessment- Social determinants of health (such as financial strains, poor health literacy, and lack of access to education) make it more difficult for IBD patients, especially non-white patients, to receive health care. "The annual aggregate economic burden of CD in the United States was 6.3 billion (USD) in 2013"(Quiros et al., 2021, p.1).

Recommendation- To correct the problem, I propose that the government should grant additional sick leave to people with qualifying chronic illnesses and disabilities. This would effectively reduce the additional costs in time and money that patients with chronic illnesses including IBD incur in order to receive effective treatment and withstand the physical burden of illnesses. Additionally, the state of Michigan should create a universal financial assistance program (FAP) to cover healthcare costs for people who have remaining expenses that are not covered by their current insurance plans. This program would improve the quality of healthcare insurance to which patients with chronic illnesses, including IBD, have access to.

Navigating the healthcare system put my experience into perspective; my family relied on our privileges to absorb the burden of my Ulcerative Colitis. Because of this, I realized the role that socioeconomic factors play in mitigating the financial and temporal costs required to receive treatment for Ulcerative Colitis.

Through learning about the social determinants of health, I have learned that many factors influence health outcomes. In particular, financial strain, poor health literacy, and lack of access to education serve as barriers to minimizing the severity of disease symptoms and achieving remission for people with Inflammatory Bowel Disease (Damas et al., 2022).

Patients who experience more serious symptoms of Ulcerative Colitis are more likely to have higher social barrier scores or values that indicate socioeconomic disadvantages (Damas et al., 2022). These challenges include financial strains, poor health literacy, and lack of access to education. Social barriers disproportionately affect non-Hispanic Black and Hispanic people (Damas et al., 2022). A 2018 study found that socioeconomic status (SES) is associated with poor outcomes for patients with IBD, defined as any Crohn's Disease (CD)-related hospitalization (Anyane-Yeboa et al., 2022). SES is a greater predictor of poor health outcomes than race. "IBD literature also illustrates that those with worse outcomes across the IBD care continuum are more frequently Black/African-American patients" (Nguyen et al., 2020).

Background

Inflammatory Bowel Disease (IBD) describes two conditions, Ulcerative Colitis and Crohn's Disease (CD), characterized by inflammation of the GI tract. In both illnesses, one's immune system attacks the body, resulting in inflammation (Centers for Disease Control and Prevention, n.d.). "A flare is a period of time when symptoms and inflammation from ulcerative colitis or Crohn's disease become active" (*Causes of Flares*, n.d.). In Ulcerative Colitis, inflammation is concentrated in the large intestine and rectum. In Crohn's Disease, inflammation occurs in the gastrointestinal (GI) lining. Common GI-related symptoms include diarrhea, blood in the stool, rectal bleeding, feeling of urgency when moving bowels, abdominal pain, and constipation (*Signs and Symptoms of Crohn's Disease*, n.d.). This can result in weight loss, loss of appetite, fatigue, malnutrition, and anemia (*Signs and Symptoms of Crohn's Disease*, n.d.). Other symptoms of IBD include changes or loss in vision, swollen joints or joint pain, nocturnal sweating, osteoporosis, loss of a normal menstrual cycle, kidney stones, fever, rashes, and skin complications (*Signs and Symptoms of Crohn's Disease*, n.d.).

Common treatments for IBD include 5-aminosalicylic acids, an anti-inflammatory medication often administered rectally, immunomodulators or medications that act over a long time to calm the immune system, or corticosteroids—faster, acting anti-inflammatory drugs. Biologic medications are frequently used, sometimes in combination with other medications, to treat the condition. These drugs are often given by infusion and turn off the inflammatory immune system response to certain proteins (*Understanding Biologics and Inflammatory Bowel Disease*, n.d.). The most common type of biologic medication prescribed to treat IBD is called Tumor Necrosis factor-alpha (TNF-alpha blockers), which block a protein that causes inflammation in the GI tract (*Understanding Biologics and Inflammatory Bowel Disease*, n.d.). "Even with proper medication and diet, as many as two-thirds to three-quarters of people with Crohn's disease will require surgery at some point during their lives" (*Crohn's Disease Treatment Options*, n.d.). After 30 years of having the disease, up to 30% of people with Ulcerative Colitis will require surgery (*What Is Ulcerative Colitis?*, n.d.).

Social determinants of health are environmental conditions that influence health outcomes, including where individuals live, work, and play. These factors include access to education, access to healthcare, neighborhood and housing, socioeconomic background, and one's social network. Social barriers influence Inflammatory Bowel Disease (IBD) outcomes and disproportionately affect Hispanics and non-Hispanic Blacks with IBD. Data collected from IBD patients in the United States demonstrate that 56.2% of Hispanic patients experience financial strain, 40% of non-Hispanic Black patients do so, and 24.85% of non-Hispanic Whites do so (Damas et al., 2022). Low socioeconomic status (SES) is associated with worse healthcare outcomes, specifically greater morbidity and increased healthcare resource utilization in patients with IBD (Gu et al., 2022).

Social factors that determine health outcomes, such as financial strain, poor health literacy, and lack of access to education, make it more difficult for IBD patients, especially non-white patients, to receive health care. As a result, IBD patients in this racial group experience “higher hospitalization rates, longer stays, increased hospitalization costs, higher readmission rates, and more complications after IBD surgery” (Anyane-Yeboah et al, 2022, p.2429). Additionally, Black and Hispanic IBD patients had longer hospital stays than their white peers.

The direct annual cost of care for IBD patients (\$22,987) is three times greater than those without the condition (\$6956) (Park et al., 2019). Also, people with IBD face twice the annual out-of-pocket costs compared with a control group (Park et al., 2019). The costs are estimated to be \$26,555 on average in the first year (Park et al., 2019). IBD patients face additional financial challenges compared to non-IBD patients in the same socioeconomic class because the costs of treatment for the disease serve as an additional financial burden. Access to specialized care is also unequal—Black/African-American patients were found to be less likely to undergo annual visits to a gastroenterologist or IBD specialist” (Anyane-Yeboah et al, 2022). Lack of access to specialized care prevents patients from receiving proper treatment therefore causing worsening disease symptoms.

Patients with IBD pay significant costs in time to receive proper health care compared to patients without IBD (Park et al., 2019). Spending time to receive proper treatment can require patients to take time off from their jobs. “IBD patients are increasingly incurring higher costs associated with workplace productivity losses” (Park et al., 2019). Being absent from work means that IBD patients earn less money. “Patients with IBD also absorbed significantly higher wage-related opportunity loss” (Park et al., 2019). The amount of wages IBD patients lost due to missing work to receive treatment was an even more significant value than the average out-of-pocket monetary costs (Park et al., 2019). A lack of medical literacy makes navigating the healthcare system more difficult, specifically filling out paperwork (Damas et al., 2022). One study says that 22.22% of patients with IBD “did not feel comfortable completing medical forms” (Damas et al., 2022). This trend was the most prominent among Hispanics and non-Hispanic Blacks. 27.48% of Hispanics, 50% of non-Hispanic Blacks, and 15.57% of non-Hispanic Whites reported feeling uncomfortable completing medical forms (Damas et al., 2022). Also, “Higher patient education correlates with a reduction in health care costs” (Click et al., 2016). Access to education improves health outcomes in patients with IBD by improving their ability to receive proper treatment, lowering their costs overall.

Assessment

Social determinants of health, particularly financial strains in tandem with the cost of time and money required to receive treatment, make it difficult for IBD patients to attain proper health care, leading to poorer disease outcomes. This is especially true for Black and Hispanic patients, who are disproportionately socio-economically disadvantaged, and as a result, this group experiences worse health outcomes. IBD is a costly condition, in both time and money, to have and treat. Of adults with IBD, 23% face financial challenges due to medical bills (Nguyen et al., 2020). Socioeconomically challenged people are further disadvantaged because IBD treatment is expensive, even with high-quality insurance. “The annual aggregate economic burden of CD in the United States was 6.3 billion (USD) in 2013” (Quiros et al., 2021, p.1).

For economically disadvantaged people, it is even harder to receive IBD care because of the cost. Results from the National Health Interview Survey in 2015 talk about cost-related nonadherence (CRN) in patients with IBD, when patients delay medical treatment to reduce costs (Nguyen et al., 2020). According to this research, “16% of patients reported CRN, and 31% reported cost-reducing behaviors” (Nguyen et al., 2020). Due to its exorbitant cost, many IBD patients fail to maximize their treatment options because they cannot afford to do so. The inability to utilize proper medical interventions can lead to worse health outcomes characterized by more intense symptoms of IBD. Severe flares of IBD can cause patients to be hospitalized and increase their length of stay. Those who face financial challenges lack access to treatment, resulting in more prevalent symptoms and increased hospitalizations. Hispanic and non-Hispanic Black people experience disproportionately socio-economic challenges, which explains why these racial groups encounter worse health outcomes.

The time required to receive proper care for IBD is another reason IBD patients delay treatment, which inevitably leads to worse health outcomes. “We also found that 29.07% of patients reported delaying medical care in the last 12 months. The most common cause of medical care delay was waiting long hours to see the doctor (15.9%)” (Damas et al., 2022). Those with less flexible jobs are more unable to take time off work for being sick and to receive treatment, and therefore avoid or postpone treatment, leading to worse disease outcomes. Socioeconomically disadvantaged people are more likely to have blue-collar occupations, which prevents them from being able to take time off to receive care and therefore leads to more prevalent diseases in this population. Another economic barrier that many IBD patients from underprivileged backgrounds face is a lack of access to high-quality health care, if they have access to health care at all. Research on IBD patients suggests that “10% of patients deemed health care unaffordable” (Nguyen et al., 2020). One experiment sought to measure the effectiveness of increasing healthcare access by implementing a financial assistance program (FAP), to yield better disease outcomes in patients with IBD requiring treatment in the form of Biologic medications (Gu et al., 2022). The FAP increased patient access to biologics by discounting costs and eliminating steps like pre-authorization by insurance (Gu et al., 2022). The researchers concluded that the FAP positively impacted the healthcare of patients with IBD (Gu et al., 2022). Therefore, it is more evident that lack of quality assurance impedes patients’ ability to obtain the proper treatment, which can cause worse disease outcomes. Financially disadvantaged people struggle to attain high-quality insurance. Therefore, they are more likely to experience more prevalent diseases resulting from a lack of access to treatment, like biological therapies.

Recommendations

A possible short-term solution is to create a universal state-wide financial assistance program (FAP) in Michigan to cover healthcare costs for people who have remaining expenses that are not covered by their current insurance plans. This would include but not be limited to patients with IBD expense of healthcare costs for IBD patients without health insurance or high-quality health insurance. The program would cover the costs of treatment and reduce out-of-pocket patient costs for patients with IBD and other chronic illnesses. The service would cover the finances of any healthcare-related costs for the enrollees. This coverage would include but not be limited to hospitalizations, medications, blood transfusions, surgeries, procedures, and medical imaging. Additionally, it would decrease the time required to receive treatment by eliminating steps required

to obtain traditional healthcare insurance like pre-authorization. The FAP would improve disease outcomes amongst socioeconomically disadvantaged patients, eliminating the typical time and money needed to receive treatment. This would allow patients to receive the proper treatment more quickly, decreasing the prevalence of their symptoms more rapidly. Increases on income taxes would be used to generate revenue tax credits, which would make up the revenue base for the program. The level of tax hike needed to fund this program would be relatively minimal.

There has been some emerging evidence to suggest that patients receiving virtual health care, compared to standard in-person care, have reported greater Quality of Life (QoL) and IBD-related knowledge (Kuzhiyanjal et al., 2023). However, study results show that health outcomes between the two groups are about the same (Kuzhiyanjal et al., 2023). Telemedicine is a more convenient method for patients to receive medical treatment (Kuzhiyanjal et al., 2023). It improves the efficiency of healthcare delivery and has decreased the cost of care (Kuzhiyanjal et al., 2023). Greater use of telehealth could increase access to care for IBD patients facing financial strain and improve the medical literacy of this population.

A long-term solution is to expand employment benefits for patients with disabilities and chronic illnesses including IBD to limit the expenses in both time and money that come with the disease. A proposed recommendation is automatically granting additional sick leave to patients with chronic illnesses every year, to compensate for the missed work needed to receive healthcare or the physical burden of IBD. The Department of Labor would establish criteria to qualify for benefits. Employees apply by submitting official medical documentation as proof of having a qualifying illness or disability. One method of accomplishing this goal is for Congress to pass a mandate financed by employers, requiring them to provide their employees extra time off every year without additional consequences. Employees would have to apply to be granted the extra time off by the federal government. In order to receive the additional benefit they would need to provide official medical documentation that demonstrate

Conclusion

Social barriers, primarily financial strain, poor health literacy, and lack of access to education, prevent IBD patients from obtaining better health outcomes. Patients from low-income backgrounds, who are disproportionately non-Hispanic Black and Hispanic, experience more severe IBD disease symptoms. Lack of access to care among this patient population has led to worse outcomes and more severe disease. The exorbitant cost of medical treatments for IBD and the time required to receive proper treatment are the two most significant factors that limit IBD patients with low socio-economic status from accessing care.

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Biosocial Analysis of the DREAMS Program in Tanzania

Sydney Hastings-Wilkins*

In Tanzania, the HIV epidemic is impacting many people throughout the country. However, this impact is not equally distributed among all people. Different areas in Tanzania suffer higher prevalence rates of HIV than others. In addition, females, especially adolescent girls and young women (AGYW), are at greater risk when it comes to HIV infection. These inequitable prevalence rates are caused by a number of factors, including but not limited to gender-based violence, lack of education, and involvement in transactional sex and sex work.

In order to address HIV in Tanzania, U.S.-based groups including President's Emergency Plan for AIDS Relief (PEPFAR), the Centers for Disease Control and Prevention (CDC), and ICAP have designed and implemented the DREAMS program, which aims to protect AGYW from HIV infection via empowerment, education, and testing services. While this is a multi-faceted intervention that aims to protect women and address more than just the biological factors that spread disease, there are possible unintended consequences that can lead to harm.

Keywords

global health • adolescent girls and young women (AGYW) • HIV/AIDS interventions • Tanzania

Introduction

Sub-Saharan Africa is widely known to be the current center of the HIV/AIDS epidemic. Thus, current interventions addressing HIV have focused on this geographical area. While there has been success in decreasing the prevalence of HIV in sub-Saharan Africa, an epidemic remains, specifically

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among women aged 15–24, referred to as Adolescent Girls and Young Women (AGYW), who account for two-thirds of new infections (Saul et al., 2018). In Tanzania, HIV is the leading cause of adult mortality (*Tanzania - The World Factbook*, 2022). As of 2019, 1.7 million people in Tanzania were living with HIV (United Nations Children’s Fund [UNICEF] United Republic of Tanzania, n.d.). Though HIV is widespread, only 60.6% of the population in Tanzania infected with HIV are aware of their positive status (ICAP, 2018). This proportion is far below the 90% goal that the Joint United Nations Programme on HIV/AIDS (UNAIDS) promotes.

Background

While this is a disease that impacts many, the distribution of HIV is far from equal. Geographically, prevalence rates of HIV vary greatly in Tanzania. Prevalence is as high as 11.4% in Njombe and 11.3% in Iringa and as low as less than 1% in Lindi and Zanzibar (ICAP, 2018). Other regions with the highest prevalence rates include Mbeya and Mwanza (UNICEF United Republic of Tanzania, n.d.). Furthermore, there is a significant sex-based disparity in the prevalence of HIV in Tanzania. According to the United Nations Children’s Fund, “adolescent girls and young women have been disproportionately affected by new HIV infections compared to male counterparts” (UNICEF United Republic of Tanzania, n.d.). The HIV prevalence rate of women aged 15–49 is 6.0, while the rate for men within the same age group is only 3.3 (Joint United Nations Programme on HIV/AIDS [UNAIDS], n.d.). Though women in Tanzania are disproportionately infected by HIV, they are more likely to be aware of their positive HIV status (ICAP, 2018). However, this is likely caused by the prevention of mother-to-child transmission (PMTCT) programs. It is also possible that, due to the patriarchal society, men choose not to find out their status so they do not feel obligated to participate in safer sex practices.

There are a number of reasons for this disparity in HIV infections. These factors include “a history of sexually transmitted infections (STIs), alcohol use, multiple sex partners, early marriage, being out of school, inconsistent condom use, and engaging in transactional sex,” which are associated with “vulnerability to HIV among AGYW” (Saul et al., 2018). Additionally, experiences with violence are also linked with this heightened HIV risk for AGYW. These risk factors can easily be connected with realities of life for AGYW in Tanzania. The prevalence of recent intimate partner violence (IPV) among women aged 15–49 is 29.6% (UNAIDS, n.d.). This rate is even higher among young women. For women aged 15–19, 30.1% have experienced IPV and for women aged 20–24, 34.2% have experienced recent IPV (UNAIDS, n.d.). For multiple sub-Saharan African countries, including Tanzania, one in three women report experiencing some form of sexual violence during childhood (Saul et al., 2018). Gender-based violence (GBV) is extremely common in Tanzania, accounting for part of the increased prevalence of HIV among women, specifically those who are younger.

In addition to GBV, there are other factors present in Tanzania that put women at an increased risk for HIV infection. While transactional sex is one of these risk factors, it is more complex than a simple unbalanced power dynamic. In Tanzania, women engage in transactional sex even if they are not poor (Lees, 2014). These relationships exist outside of the common narrative surrounding sex work and power dynamics. Studies have found that “financial or gift exchanges can ensure obligations between the partners and such transactions can also help women with social mobility and economic independence” (Lees, 2014). This less stigmatized form of sex work creates an

environment in which women are more likely to engage in transactional sex. Though this can have economic and social benefits, it does increase risk of HIV infection. Even if transactional sex isn't as stigmatized, unequal power dynamics between men and the women engaged in it create an environment in which asking for condom use is more difficult. In Tanzania, this general attitude toward transactional sex as being somewhat normal can potentially increase the number of women who participate, without altering the balance of power, which in turn increases the risk of HIV infection for women.

Several other factors leave AGYW in Tanzania at higher risk for HIV infection. As listed previously, early marriage, being out of school, and inconsistent condom use are also linked to increased risk for HIV infection (Saul et al., 2018). In Tanzania, three in ten girls are married before their 18th birthday (Odhiambo, 2020). Additionally, the median age of first birth for women in Tanzania is 19.8 years (President's Emergency Plan for AIDS Relief [PEPFAR], 2019). Early marriage is common in Tanzania, putting AGYW at an increased risk for HIV. Young birth age for mothers can also put the children at risk, especially if the mother is HIV-positive. While more women than men are aware of their HIV status, around 65%, that still leaves a great number of mothers unknowingly putting their children at risk. However, PMTCT interventions in Tanzania have managed to provide antiretroviral treatment to 84% of women (UNAIDS, n.d.). In terms of education, only 27% of girls complete upper secondary school in Tanzania (Campaign for Female Education [CAMFED], n.d.). Studies have shown that full-time education is protective for both sexes in terms of HIV infection (Lemme et al., 2013). The low proportion of girls completing school puts them at an increased risk for HIV. According to Joint United Nations Programme on HIV/AIDS (UNAIDS), only 55.1% of women aged 15–49 have their demand for family planning satisfied by modern methods (UNAIDS, n.d.). This proportion is much lower for AGYW aged 15–19, at only 40.9%. Even if AGYW attempt to engage in safe sex, there is no guarantee that their demand will be met. The combination of all these factors creates a dangerous environment for AGYW in which HIV infection is disproportionately likely compared to their male counterparts.

Response

DREAMS stands for Determined, Resilient, Empowered, AIDS-free, Mentored, and Safe. As an intervention, it is designed to prevent HIV infection in sub-Saharan Africa, specifically targeting adolescent girls and young women (Centers for Disease Control [CDC], 2022). Within Tanzania, the program has functioned in nine different districts (PEPFAR, 2019). Specific priority groups within Tanzania have been identified as orphans and vulnerable children in school aged 10–14, AGYW aged 15–19 who are out of school/sexually active, and AGYW aged 15–24 engaging in transactional and commercial sex work (PEPFAR, 2019). The DREAMS intervention includes a core package of services that aim to: “(1) empower adolescent girls and young women and reduce their risk, (2) strengthen the families of AGYW, (3) mobilize communities for change and (4) reduce the risk of men who are likely to be male sex partners of AGYW” (Saul et al., 2018). Each of these categories includes different multi-faceted approaches to addressing HIV infection among AGYW in sub-Saharan Africa.

The first category of core services focuses on the empowerment of AGYW. These services include condom promotion and provision, oral Pre-exposure prophylaxis (PrEP), post-violence care (including post-exposure prophylaxis (PEP)), HIV testing services, expanding & improving

access to voluntary, comprehensive family planning services, and social asset building (Saul et al., 2018). This set of interventions primarily engages with the biological aspect of HIV prevention and treatment. However, the program does not simply diagnose and treat blindly. Consider the story of Hilda, for example, a teenage girl who joined the DREAMS program (ICAP Global Health, 2019). When she joined, she was unaware of her positive HIV status, but due to testing services made available by the DREAMS program, she was not only diagnosed but also counseled on her diagnosis (ICAP Global Health, 2019). This counseling helped Hilda disclose her diagnosis to her mother, who now acts as a “treatment supporter” (ICAP Global Health, 2019). Although this is only one story from one girl, this narrative reveals how the DREAMS program goes beyond testing and treatment within this category of services to help AGYW in a variety of ways.

The second category targets the families of AGYW in order to further prevent risk. Parenting/caregiver programs, which increase caregivers’ knowledge, skills, and comfort with talking to their children about sexual health and monitoring their children’s activities, are an important part of this sector (Saul et al., 2018). In addition, educational subsidies for transition to and attendance of secondary school have been proven to increase girls’ attendance in school and lower risky behaviors. As education has been shown to be a protective measure, this directly responds to the biosocial environment. This category also promotes combination socio-economic approaches. For example, DREAMS includes social empowerment interventions such as discussion groups on gender-based violence/intimate partner violence (GBV/IPV) and couples communication, mentoring, and comprehensive, evidence-based HIV prevention curricula (Saul et al., 2018). On the economic side of things, the DREAMS program in Tanzania has an intervention called WORTH+, educating AGYW on financial literacy, small businesses, and income-generating activities (CDC, 2022).

The last two categories include interventions that aim to change communities and protect male sexual partners. One method of this is school-based HIV and violence prevention, “in order to provide accurate information, provide referrals to health centers for services not provided in school, and to build prevention skills among large numbers of young people in a community” (Saul et al., 2018). DREAMS also uses community mobilization to create support networks and address social norms that increase risk of HIV infection for AGYW by engaging boys/men, community leaders, and the community as a whole (Saul et al., 2018). While the majority of the intervention package focuses on addressing risks that disproportionately impact AGYW, the DREAMS program also provides medical services, such as HIV testing, HIV treatment, and voluntary medical male circumcision, that are targeted toward male sexual partners of the women in these communities. According to researchers from the London School of Hygiene and Tropical Medicine, “given the prevailing social norms regarding young people’s sexual activity, there is increasing recognition of the importance of engaging the whole community, including parents, teachers, religious and local leaders, in order to prevent HIV among young people” (Lemme et al., 2013). The DREAMS program follows this advice, engaging AGYW, their families, their potential partners, and their communities as a whole.

The DREAMS intervention has been designed in a way that focuses on many features of the biosocial context of HIV in Tanzania. This layered approach aims to do more than treat HIV. While testing and treatment are fundamental parts of this initiative, this program does not end at the medical response. Instead, the program empowers AGYW and promotes economic independence, attempting to address the socio-economic structural factors that leave AGYW vulnerable. This program responds to the environment of HIV in Tanzania, which disproportionately impacts adolescent girls and young women. By understanding the risk factors that directly impact the chances

of AGYW contracting the virus, such as GBV/IPV, lower education levels, lack of safe sex practices, and lack of economic opportunities and literacy, DREAMS contends with the structures that exist and responds to them in a long-lasting and sustainable way. These layers effectively work to promote safe sex, keep girls in school, create economic opportunities, and change community-wide practices and sentiments.

Unintended Consequences

Despite the fact that the DREAMS program works effectively to address many aspects of the bio-social context and local moral world in Tanzania, there are still possible unintended consequences that can occur. One possible unintended consequence is an increase in gender-based violence and/or intimate partner violence due to the increased economic empowerment for women created by the DREAMS program. This increase in economic empowerment may cause men to feel threatened, resulting in a violent backlash (Bolis & Hughes, 2015). Increases in GBV/IPV can also be caused via increased use of violence as a method of control, in which “men may use violence as an instrument to disrupt women’s market-oriented activity, seize women’s income, or exert authority over managing” (Bolis & Hughes, 2015). This is not a guaranteed result of increasing women’s economic empowerment, but it is a realistic one, given the misogynistic qualities of society in Tanzania and the already high rates of GBV and IPV.

Due to the government of Tanzania’s direct involvement with this program, in addition to multiple U.S. agencies, this potential unintended consequence can result in structural violence. By creating conditions in which women may be at an increased risk for physical harm, the government risks worsened health outcomes, despite all the positive interventions that the DREAMS program provides. However, while the program does not directly outline this potential consequence, it does provide many resources for women who may face GBV or IPV. These resources eliminate the probability of creating structural violence for these groups of women. One example of these resources is the Intervention with Microfinance for AIDS and gender equity (IMAGE) program that some groups have implemented, which has been shown to decrease IPV among participants. This program incorporates “microfinance with a training curriculum on HIV prevention, gender norms, and gender-based violence” (Saul et al., 2018). The potential increase of GBV and/or IPV is a serious unintentional consequence for the DREAMS program coordinators to consider. Nonetheless, the program is currently avoiding creating a situation of structural violence by offering resources as part of the core package that aims to decrease this potential harm and protect women from violence.

Another harmful unintended consequence that can potentially occur with the DREAMS program in Tanzania is coloniality. The DREAMS program is a program that is funded by President’s Emergency Plan for AIDS Relief (PEPFAR) and developed by Columbia University’s ICAP Global Health, the Centers for Disease Control, United States Agency for International Development (USAID), and the Gates Foundation (United States Agency for International Development [USAID], 2021). While these organizations work with Tanzania’s Ministry of Health, Community Development, Gender, Elders and Children, the program has been primarily developed by U.S.-based organizations. Additionally, the DREAMS program was not developed specifically for HIV in Tanzania, but for HIV in sub-Saharan Africa (USAID, 2021). This continuation of colonial-like power structures in which the U.S. is determining the goals, implementation tactics, and lessons without direct input from the intended beneficiaries or grassroots organizations can undermine

the effectiveness of the intervention and potentially create harm. The power dynamics that exist in the DREAMS program due to the colonial legacy inform the program's priorities based on the U.S. based social construction of knowledge. What is true, necessary, and valuable is determined by these institutions. This can prevent the DREAMS program from truly addressing the needs of the communities in Tanzania, because instead of allowing the people impacted by HIV or health disparities to lead this program, the program developers have made assumptions about what kind of help these people need and the capabilities they have when it comes to health interventions. Education is a fundamental part of this program, but when only teaching information designed by U.S. organizations, the DREAMS program falls short of adequately addressing the local moral world and moral complexity that may be unseen to these educators.

Conclusion

The DREAMS program in Tanzania works toward the empowerment of adolescent girls and young women in a way that promotes sustainable change within their communities. By keeping girls in school, teaching them about safe sex practices and gender-based violence, and working with families, the program attempts to make societal changes surrounding respect towards women, consent, and more. This is an important feature in the program because it responds to the biological *and* social factors that play into the disproportionate HIV infection of AGYW. However, the program is not without its faults, as there is a clear lack of active leadership by grassroots organizations or intended beneficiaries in the development and implementation of the program.

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A Desert Mirage, Myth of Detroit's Food Desert

David Safta*

This piece challenges the contemporary view of the city of Detroit as a “food desert”. Despite a low number of traditional supermarkets, the city of Detroit has developed a unique web of food networks. Only 10% of Detroit qualifies as a food desert, considering these alternative modes of food viability. However, these initiatives often go unnoticed, perpetuating misconceptions and biases against the city and its residents. Detroit's relationship with food access is much more nuanced, as the city faces food insecurity along more racial lines. Although alternative food networks contribute to a more nuanced understanding of Detroit's food access, the issue of food security persists in various pockets of the city. Communities that experience food insecurity within the city are most often occupied by minority groups.

The piece highlights the unresolved issues of Detroit's issue of food security, as many of the city's minority communities struggle with food insecurity related to a turbulent past of racism and xenophobia. This paper will examine the disparity in the city's food security as well as the resulting health burden incurred by the city. Additionally, this paper will examine potential mitigation strategies in addressing this issues. Ultimately, this paper will determine the history and current status of Detroit's food insecurity, how it affects the city's residents, and potential strategies to mitigate any disparities in food security.

Keywords

Food insecurity • Alternative food networks • Urban food systems • Community food projects • Food redlining • Institutionalized racism • Mitigation strategies

Introduction

The city of Detroit is often looked at as a failed city. Dilapidating and crumbling, crippled by the exodus of the auto-industry and racial riots in the post nineteenth century. Contemporary observers

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point to a mirage of issues to illustrate this belief, the housing crisis, educational disparity, poverty, and the food desert. Yet the reality of the city is not so simple or clear cut. Detroit is often pointed to as a prominent food desert, an area that lacks outlets for the distribution of nutritionally adequate foods for its residents. This definition permeates from casual observers to journalists and researchers (“Treat Everybody right”, 2016). The reality of the situation, like much of Detroit, is a much more nuanced subject, Detroit is not a food Desert but rather presents a multifaceted food network that has unequal food insecurity rooted along racial line.

Historical Evolution

Rooted in the city's early history, Detroit's issue of food insecurity has evolved and changed just as much as the city. Beginning in the early nineteenth century, the great migration north brought a large influx of former agrarian African American, with many coming to Detroit (Sugrue, 2014). African Americans came seeking employment in the burgeoning auto industry, but instead found an institutionally racist system that relegated them to undesirable jobs and gave worse treatment and service (Sugrue). These would include lower wages as well as assignment to more hazardous jobs than their white counterparts (Sugrue). This would permeate to the food industry, with food markets actively discriminating against African Americans, by refusing them service, and often refusing to hire them (Sugrue). This would create a habitual rift between Detroit African American residents and traditional food systems like grocery stores and supermarkets, a disconnect that has led to much hesitancy for traditional food systems to work within the city of Detroit (Meyersohn, 2020).

Inextricably linked to Detroit's racist history is the connection of food insecurity to white flight. White flight refers to the mass exodus of primarily white Detroit residents to the suburbs in the middle and late nineteenth century to the suburbs (Meyersohn, 2020). White flight brought much of Detroit industry and amenities out of the city, as companies sought to follow the burgeoning suburban market. As a result primarily African American populace were left in Detroit as jobs, opportunities, and food markets left (Meyersohn). Supermarkets and grocery stores would leave the city during white flight for the suburbs, disproportionately leaving African Americans in a state of food insecurity. This mass exodus to suburbs would also serve to keep many traditional food systems from returning, as managers and company officials were hesitant to re-expand into the city which they viewed as unprofitable (Meyersohn). As a direct result there were fewer supermarkets and grocery stores within the city, leaving many great distances from the nearest food center. This issue is compounded by Detroit's layout. Detroit is organized as a spread-out city, with large spaces between buildings, paired with a lack of public transport (Fowler, 2021). Such a layout fit well for the motor city, where private cars were the primary mode of transport (Fowler). Consequently, Detroit's layout has contributed to its own food insecurity, creating great distances between residents and traditional food systems like grocery stores and a lack of public transport to mitigate said distance, leaving many Detroit residents in a difficult situation to access food (Taylor and Ard., 2015). The history of racial segregation in the food markets, has led to a mass exodus of these markets, in addition to a city layout unable to handle a scarcity in these food markets worked to create a food security issue that affects Detroit today.

Detroit is Not a Complete Food Desert

Detroit's historical evolution of food security has given many contemporary observers their justification for marking the city as a food desert. The lack of supermarkets throughout the city seems to be proof enough that the city qualifies for the title ("The History and Conflict", 2013). Yet in reality this skewed viewing ignores the truth of the city's relationship with food inequality. Detroit has evolved to form many alternative food systems to meet residents needs for food security and has worked to positively affect the problem ("The History and Conflict" Accounting for these alternative modes of food viability, only 10% of Detroit can truly be classified as a food desert (Taylor and Ard., 2015).

The city of Detroit has taken action to address its issues of food insecurity, ranging from food stamp programs to community agricultural projects, farmers markets, and other food assistance programs (Dorsey, 2016). These alternative food projects have been implemented throughout the city and provide for much of the nutritional needs of the city's residents, mitigating the effects of a lack of traditional food systems like supermarkets within the city. Programs such as the Green-grocer project which has been distributing economic incentives to food providers within the city (Bastian and Napieralski, 2016), as well as local urban gardening projects like the Garden Resource Project Collective, which sponsored local urban growing and farmers markets to sell grown produce throughout the city (Taylor and Kerry, 2015). These programs and incentives make up a large proportion of the city's food network yet are often unaccounted for when the city's food adequacy is inspected ("The History and Conflict", 2013).

While these programs have been effective and have been sustaining the city, they are often not observed by causal and professional observers to the city or are often discounted as unviable ("The History and Conflict, 2013). Combined with the lack of traditional food systems that are the primary source of nutrition for the suburbs creates a misconception that Detroit is a desolate waste (Dorsey, 2016). This misunderstood legacy is entirely detrimental to the city of Detroit and has a lasting impact on the city and its residents, contributing to Detroit's reputation as a failing city, a city unable to adequately feed its people (Dorsey). Further it ignores and undermines and mitigates the ingenuity of Detroit residents who have worked to better their community, portraying them as impoverished and struggling to feed themselves (Dorsey). Subsequently, such a belief works on what is described as "color blind" racism directed towards the cities African American populace. Color blind racism coined by Eduardo Silva, describes an informal mode of racism by criticizing a race or ethnicity indirectly by broadly criticizing their conditions (Krause, 2021). The perception of Detroit's food insecurity fits this, as many use this criticism of the city as a thinly veiled expression of their racist prejudices of the African American residents as failing (Dorsey). While this misconception of Detroit as a complete food desert is inflated, it is not entirely unmerited. There are certain zones within the city that do struggle with food insecurity, but like most of the city's issues there is much more nuance to this issue which must be further examined to understand the issue.

The legacy of the city's food insecurity is rooted in a fundamental misunderstanding of the city's food system. Oftentimes researchers examine Detroit's food systems like many other cities, classifying areas without traditional supermarkets and grocery stores as desert zones, devoid of food availability ("The History and Conflict", 2013). While this examination may be justified in other contemporary American cities, it fundamentally ignores Detroit's unique food network, discounting the food programs, urban farming, and individual agency of food providers throughout the city (Dorsey, 2016). Changing the perception and understanding of Detroit's relationship with food insecurity would encompass recognition of these alternative food systems both from the casual and professional observer. Enhanced

media focus would serve both to change the cities perception and further to bring more attention to the city's alternative food networks and work to grow into a more mainstream term ("Treaty Everybody Right", 2016). Beyond recognition economic investment into these programs as a solution to the city rather than the current fixation on traditional food systems would create a plausible solution to the cities areas that remain in a state of food insecurity (Bastian and Napieralski, 2016). Growing the existing infrastructure within the city and working with the city's residents and local business rather than looking to the food systems that abandoned the city could prove to be a upstream and plausible solution to a problem that has often eluded traditional solutions (Bastian and Napieralsk).

While Detroit is Not Entirely a Food Desert, Food Insecurity Disproportionality Affects African Americans

The city of Detroit cannot be called a complete food desert, much of the city has access to nutritionally adequate foods through alternative means of food acquisition. However, the city does have a food security issue, which is an issue that disproportionately; affects African American residents in the city (Taylor and Kerry, 2015). The region has had a long-lasting history of racial discrimination, that extends into the food systems of the city. Traditional supermarkets and grocers have long document histories of discrimination, both by refusing services as well as often refusing to hire African Americans (Sugrue, 2014). This longstanding history has served to create a permanent rift between African American residents and the chain stores, contributing to the decisions of many of these companies to leave the city during the period of white flight (Meyersohn, 2020). As a result there are a disproportionately fewer amounts of supermarkets and grocery stores in areas that have higher African American population demographics. In a phenomenon often referred to as "food redlining", predominantly African American neighborhoods experience limited access to affordable and health food options (Taylor and Kerry). Combined with the lack of public transport within the city, creates a situation where African Americans residents in Detroit have an inordinately low access to nutritionally adequate foods then other racial elements (Taylor and Kerry). However, as previously discussed, the city has alternative routes of food access such as urban farming collectives and food programs which provide an alternative route for food access (Dorsey). Yet even these route are not fully open to the city's African American residents, due to their limited scope, prevalence and inability to effect change on the entirety of the city, compounded by the lack of infrastructure for the transport and storage of perishable fruits and vegetables creates a difficult situation in reaching African American residents (Taylor and Kerry). Further other socio-economic factors pertaining to African Americans that prevent them from fully accessing these resources, both in a lack of public transport to them, and in their often-high prices (Taylor and Kerry).

This legacy of systemic racism and discrimination prevails today and has a lasting effect on Detroit's African Americans population. The issue of food discrimination is a major impediment on the health of the city's African American residents. Compared to other racial demographics within the city African Americans are much more likely to develop food related diseases like obesity and heart disease ("Treat Everybody Right", 2016). This has created major public health complications in the city, as many of these residents have limited access to proper medical care within the city (Bopido-Memba, 2007). Per one hundred people, city residents will lose a combined eleven years of life due to food insecurity, compared to seven years of life lost in metro Detroit residents (Bopido-Memba). Outside of health issues this legacy has created hesitancy for growth amongst

modern grocery stores and food markets (Meyersohn, 2020). Many executives view investment into the city's food market as unviable, quoting a lack of community capital as a reason for hesitancy for investment (Meyersohn, 2020). Executives' historic relationship of the city's residents and traditional food systems also plays a role, as market executives are hesitant to re-engage in a situation that was once deemed untenable (Meyersohn). These factors have contributed to an estimated 30,000 Detroit residents lacking access to a full-scale grocery (Bopido-Memba). These factors have contributed to a reliance on convenience stores and fast outlet food in predominantly African American communities, which while cheaper are less nutritious and contribute to negative health outcomes (Bopido-Memba). Nonetheless, some recent reengagement by chain markets have occurred in the city, such as the building of a Whole Foods Market and Meijer (Taylor and Kerry, 2015). These markets opened with considerable tax incentives with Whole Foods receiving five point nine million dollars in grants and tax incentives and Meijer received an estimated few million dollars. (Taylor and Kerry). This exorbitant price tag only brings in two markets to the cities and has received criticism from local residents, as such large chains have traditionally failed the city, rather than investing in local market alternatives (Taylor and Kerry).

Managing this long-lasting legacy will require addressing generational problems that are rooted in the cities institutionalized racism, and cooperation between state and local government and African American residents. Economic investment should be moved into growing and expanding local initiatives such as the Greengrocer projects into areas that have large African American population (Dorsey, 2016). Projects like the Greengrocer provide funding to locally owned small stores to expand operations, modernize their stores and provide advertising for their business. These alternative food systems have proven to be an effective solution to food instability, but they lack the necessary infrastructure to effectively reach the city's most underserved residents (Taylor and Kerry, 2015). Investments into these alternative systems would further work to create job opportunities in the city, as many of these projects are based and run by local residents seeking to impact change on the city (Taylor and Kerry). Further funding should be reorganized away from traditional food systems like Whole Foods who historically have a weaker efficacy and have underserved the community (Taylor and Kerry). In addressing this legacy policy makers and activists should work in conjunction with African American residents in the city. Historically, solutions to the cities food insecurity problem have ignored and worked independently of the African American population, and subsequently ignored the underlying racial issues of the problem ("Taylor and Kerry). Alternatively solutions have treated Detroit African Americans as an impoverished group and presented solutions in a paternalistic manner ("Treat Everybody Right", 2016). As a result these solutions have never truly combated the problem and have proven to be ineffective ("Treat Everybody Right"). Future attempts to fix the issue of disproportionate food security upon Detroit African Americans should look to invest and build local groups and business, and work in conjunction with local African American communities ("Treat Everybody Right").

Conclusion

The city of Detroit faces a myriad of issues, controversies, and misconceptions. One of the city's most prevalent issues is food insecurity, the belief that large portions of the city of Detroit lack access to nutritionally viable foods. The reality of the situation is much more complex. Much of the city has worked to foster and grow alternative food systems outside of the traditional method

of supermarkets and grocery stores (Dorsey, 2016). These systems are often ignored when observing the city yet provide a substantial route of access to nutritional foods for city residents (“The History and Conflict”, 2013). This long-term effect skews the perception of the city's inhabitants as impoverished (Dorsey, 2016). Yet the city still does have a food security issue centered around race. Stemming from a history of racial inequality Detroit's food insecurity disproportionately affects African American residents (Taylor and Kerry, 2015). Solving the issue surrounding generational inequality would require the growth of alternative food mechanisms that have proven to work for much of the city into these predominantly African American areas that are the most effected by food insecurity. This growth of industry would need to be created with dialogue of the local residents the industry seeks to benefit (“Treat Everybody Right”, 28).

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Malnutrition's Role to the Risk of Developing Schizophrenia: A Literature Review

Emma N. Spring*

Some evidence suggests that nutritional factors in-utero may contribute to the development of schizophrenia in offspring. To better understand the relationship between in-utero exposure to nutritional deficiency as a determinant of schizophrenia, a narrative review was conducted. Natural studies involving prenatal exposure to famines were identified and described. The relationship between malnutrition, low birth weight, and obstetric complications was evaluated as implicated in schizophrenia development. In addition to malnutrition, various micronutrients and the complementary biological mechanisms were reviewed including, iron, Vitamin D, and folate. Given the inherent link between poverty and malnutrition, associations between income and risk of schizophrenia were examined. The review concluded that prenatal malnutrition may be associated with an increased risk of schizophrenia. Given the relatively high prevalence of nutritional deficiencies during pregnancy, this work has the potential to offer substantial benefits for the intervention and prevention of schizophrenia in the population. More work and research are needed to directly observe malnutrition's impact on schizophrenia, but such opportunities are limited due to ethical considerations. To address these limitations, future research could explore innovative methodologies to bridge the gap in understanding and provide insights into the complex interplay between prenatal malnutrition and schizophrenia.

Keywords

malnutrition • pregnancy • schizophrenia • prenatal health

Introduction

Schizophrenia is a debilitating disease characterized by a range of symptoms such as lack of insight, hallucinations, delusions, distorted or illogical speech, and social withdrawal. It affects an estimated

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7.2 in 1000 persons in the United States (McGrath, 2008). Schizophrenia is not solely a mental illness but rather a physical brain disease, as evidenced by the smaller whole brain volumes and larger lateral ventricles observed in individuals with schizophrenia (Picchioni, 2007). The disease typically develops in young adulthood, with an earlier onset and greater incidence for males compared to females (Venkatesh, 2008). The etiology of schizophrenia is complex, involving genetic predisposition, environment, and brain structure and function (National Institute of Mental Health, 2023). Risk of schizophrenia development has further been found to involve obstetric complications, low birthweight, and perinatal hypoxia (Piccioni, 2007; Brown, 2008). Malnutrition serves as one example of an obstetric circumstance that can detrimentally impact overall health. Undernutrition or malnutrition is described by a deficiency, excess or imbalance of nutrients that can increase the risk for disease, prolonged illness, low birth weight, low immunity, and impaired physical and neurological development (Saunders, 2010); (Wahlbeck, 2001). These negative health effects associated with malnutrition may be recognized as components of biological injury that heighten the risk of developing schizophrenia.

To better understand the relationship between in-utero exposure to nutritional deficiency as a determinant of schizophrenia, a narrative search was conducted. This review aims to explore the existing evidence on the association between prenatal malnutrition and the risk of schizophrenia. Understanding the role of nutrition during pregnancy in the etiology of schizophrenia is crucial for developing effective preventive strategies and interventions.

Natural Experiments

The findings of natural experiments and the examination of specific micronutrients provide valuable insights into the potential impact of prenatal malnutrition on schizophrenia.

Tragic events, like periods of famine, though not a controlled experiment, can provide a valuable foundation for conducting stronger experiments that surpass mere observation (Stein, 1975). Two separate and notable natural studies observed the association between prenatal exposure to famine and the later development of schizophrenia — the Dutch Hunger Winter and Chinese Famine.

The Dutch Hunger Winter occurred between 1944–1945 after a Nazi blockade of Holland, exacerbated the already compromised food access that had been further endangered by a frozen winter for those living in the Netherlands. The daily food rations during this time were severely limited, consisting mainly of just bread and potatoes. The event has allowed for the study of the impact of famine on health outcomes, due to detailed records of food rations and impacted individuals for decades after (Susser, 1992; Schultz, 2010). The Dutch psychiatric registry compared psychiatric outcomes in adulthood for unexposed and exposed birth cohorts in cities that experienced and did not experience the height of the famine from October 15–December 31, 1945. These babies were then followed throughout their life and evaluated periodically for mental health outcomes between 1970–1992, when the subjects were aged 24–48 years. Studies from this cohort highlight an increase in neurodevelopmental tube defects, a common precursor to the development of schizophrenia (Stein, 1975; Brown, 2008). More notably, the study found a significant, 2-fold increase in the risk of schizophrenia in the exposed birth cohort compared to non exposed cohorts (Brown, 2008).

A study in the Anhui Province of China in the 1950s amidst a massive famine also looked into the development of schizophrenia. Caloric data was not available but the cohort had a much larger

sample size and perhaps more accurate results than that of the Dutch cohort. Researchers relied on the birth cohorts of 1960 and 1961 at the height of the famine to observe schizophrenia incidences and trends. Similar to the Dutch famine study, there was an approximate 2-fold increase in the risk of schizophrenia (St. Clair, 2005).

However, given that the diagnostic criteria for schizophrenia has changed over time, it is hard to make accurate associations between these natural experiments' famine and schizophrenia development. The last evaluation of outcomes in Dutch winter famine were given in 1992. Since then, the Diagnostic and Statistical Manual of Mental Disorders (DSM) has gone through a total of five revisions, with numerous changes in the requirements needed to make a schizophrenia diagnosis (Substance Abuse and Mental Health Services Administration, 2016; Regier, 2013).

Therefore, applying the most recent edition, DSM V, when examining associations would offer the most accurate information. The research may still hold value, but there is a need for caution and nuanced interpretation of the findings, taking into account the changes in diagnostic criteria over time. Researchers should consider reexamining the data using the latest criteria to ensure the continued relevance and applicability of the study's conclusions.

Specific Nutritional Deficiencies

Various micronutrients and their biological mechanisms were reviewed to potentially identify specific associations between prenatal malnutrition causing nutrient deficiencies and schizophrenia development including folate, essential fatty acids, vitamin D, iron, and protein-calorie malnutrition.

Folate: Folate deficiency can impede the synthesis and repair of DNA and hinder the production of methyl donors and the methylation of DNA. Specifically, inadequate folate can inhibit the conversion of homocysteine (hcy) to methionine, leading to a buildup of hcy, which has been shown to cause adverse effects on fetal brain development, and is implicated in schizophrenia development (Hama, 2020; Moustafa, 2014). Maternal folate supplementation immediately before pregnancy lowers neural tube defects by up to 80% (Wald, 2011). Neural tubes are crucial structures that form in early embryonic development and eventually develop into the spinal cord and brain (Singh, 2023). Supplementation, in this context, refers to the intentional intake of additional folate through dietary sources or supplements to address potential deficiencies. Supplementation has also been shown to lower risk of severe language delay, improve cognitive function, and reduce neurodevelopmental delays overall which have been associated with an increased risk of schizophrenia (Kirkbride, 2012). A limitation falls in the fact, however, that no clinical cohort has directly examined the relationship between maternal folate and schizophrenia.

Essential Fatty Acids: Docosahexaenoic acid (DHA), an omega-3 fatty acid, has been correlated with decreased neonatal neurological abnormalities, which are implicated in schizophrenia development (Sun, 2017).

Vitamin D: A study suggests that individuals born during the winter months, particularly in urban areas, face a higher risk of Vitamin D deficiency due to reduced sunlight exposure. This deficiency has been associated with an elevated likelihood of developing schizophrenia (McGrath, 2008).

Iron: Iron deficiency reduces hemoglobin, increases anemia, and compromises oxygen levels (Mayo Clinic, 2022). When a fetus is exposed to iron deficiency in utero, this can result in fetal

hypoxia. Fetal hypoxia is associated with an increased susceptibility to schizophrenia. Further, iron affects dopaminergic neurotransmission and myelination both of which have been implicated in the pathway of schizophrenia (Cannon, 2002).

Protein-Calorie Malnutrition: A deficit in protein-calories increases dopamine and serotonin, which causes turnover and dysfunction in the hippocampus (Bronzino, 1997). This is associated with low cell counts, low dendritic branching, long-term potentiation, bad spatial performance, and reduced prepulse inhibition all of which are associated with risk of schizophrenia development when exposed in-utero (Bronzino, 1997). An appropriate and well-proportioned amount of protein supplementation reduced the incidence of small for gestational age births by 21%, while supplementing too much increased the risk of schizophrenia (Ota, 2015).

All micronutrients supplemented together (Vitamin A, zinc, calcium, iron, iodine, magnesium, Vitamin C, Vitamin E, Folic acid, marine oil, fatty acid) led to a decrease of 11%–14% in the number of babies born with LBW (da Silva Lopes, 2017).

The influence of bodily functions during refeeding must be accounted for, however. When people are malnourished, thiamine (or Vitamin B) stores become depleted. Refeeding, the process of reintroducing and increasing the intake of nutrients to address malnutrition or starvation, however, seems to prompt an even greater thiamine deficiency, which may increase the development of schizophrenia, not the malnutrition itself (Mehanna, 2009; Ishida, 2023). Under normal circumstances, vitamin B supplementation has been shown to reduce the symptoms of schizophrenia (Firth, 2017).

Income

The link between poverty and malnutrition has been well-established, and there is evidence of associations between income and the risk of schizophrenia (Hakulinen, 2020; Ridley, 2020). The psychiatric stress responses due to social class in the face of famine is a confounding factor that may increase low birth weight pregnancies and affect schizophrenia risk (Borders, 2007; Khashan, 2008). Low income can be both a casual factor for schizophrenia and a result of a downward drift or decrease in social status (Ridley, 2020; Werner, 2007). Chronic psychosocial stress has been associated with low birth weight neonates in low-income women, with factors such as food insecurity, chronic illness in the home, increased crowding, unemployment, and poor coping skills significantly contributing to this outcome (Borders, 2007). Furthermore, research has established a bidirectional causal relationship between poverty and mental illness, with negative income shocks and poverty-related risks contributing to the development and worsening of mental health conditions (Ridley, 2020; Jensen, 2017). Poverty-related risks such as food insecurity, infectious diseases, environmental contaminants, and psychological stressors have been shown to converge and affect children's neurocognitive development through various biological pathways, including malnutrition, inflammation, and neuroendocrine stress responses (Jensen, 2017). Furthermore, maternal psychological stress and distress during pregnancy have been found to be predictors of low birth weight, prematurity, and intrauterine growth retardation (Rondó, 2003). The release of catecholamines, placental hypoperfusion, and restriction of oxygen and nutrients to the fetus are believed to contribute to fetal growth impairment and preterm delivery, both examples of biological injury that increase schizophrenia development risk (Omer, 1986; Copper, 1996). Additionally, maternal exposure to severe adverse life events, particularly death of a close relative during the first trimester,

has been associated with an increased risk of offspring schizophrenia, independent of other risk factors (Khashan, 2008). The mechanisms underlying these associations involve neurodevelopmental abnormalities and potential programming of abnormal brain growth due to the effects of stress hormones on fetal development (Khashan, 2008). These findings highlight the importance of assessing and addressing psychosocial stressors during pregnancy to mitigate adverse outcomes and reduce the risk of schizophrenia in offspring.

A significant obstacle hinders the undertaking of experiments aimed at directly studying the impact of malnutrition on the development of schizophrenia. Specifically, conducting extensive randomized trials that involve exposing pregnant women to suboptimal nutritional conditions to assess adverse effects on their offspring raises crucial ethical considerations. Further, malnutrition is associated with other health problems, such as vitamin deficiencies, weakened immune system, and cardiovascular issues, which may increase the risk of schizophrenia separate and apart from a state of malnutrition itself (Picchioni, 2007).

Conclusion

The review concluded that prenatal malnutrition may be associated with an increased risk of schizophrenia. This work has the potential to offer substantial benefits for the intervention and prevention of schizophrenia in the population. In addition, this work may benefit those who are at higher risk of stress-inducing life events, including those impoverished, famished, and those with other health complications. Proper maternal nutritional supplementation or even pregnancy education may decrease the risk of schizophrenia in offspring later in life. More work and research are needed to directly observe malnutrition's impact on schizophrenia.

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The Impact of COVID-19 on Nurse Burnout

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The COVID-19 pandemic has led to millions of deaths and hospitalizations all over the world. Not only has the pandemic increased anxiety among healthcare workers, but it has heightened the already challenging environment. Nurses have been especially impacted by the pandemic due to their essential role in patient care, as they spend a significant amount of time directly working with patient populations. Due to a shortage of personal protective equipment, uncertainty about regulations, and testing accuracy, nurses were put into situations where they could potentially contract COVID-19 themselves. Furthermore, due to staff shortages, nurses were moved to different wards where they have to adapt quickly to new responsibilities leading to high levels of stress and unfair expectations. Nurse burnout has strong implications on patient care as well. Nurses' dissatisfaction with their jobs had led to an increase in adverse events such as medication errors, decreasing patient satisfaction with their hospital stay. Additionally, the adjustment to the pandemic in nursing schools has negatively affected nursing students' perceptions of the field. Some suggestions to alleviate nurse burnout include prioritizing the wellbeing of all healthcare workers, involving nurses in administrative decision-making processes, and fostering a better work environment. If the nurse burnout issue is not addressed, patient care quality and hospital outcomes will decline, having a negative impact on all stakeholders. This review found that burnout has a negative impact on patient care satisfaction and the desire for students to pursue nursing. Interventions such as increasing nurse autonomy and decreasing patient to nurse ratios can protect nurses from burnout.

Keywords

mental health • burnout • nursing • COVID-19 • nursing students • patient satisfaction • patient care • personal protective equipment (PPE)

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Introduction

COVID-19 is a respiratory illness caused by the SARS-CoV-2 virus (World Health Organization, 2022). The pandemic caused by this virus has created a major strain in the United States hospital system. At the beginning of the pandemic, the unknown effects of COVID-19 and its variants caused hospitals to become overwhelmed with logistical challenges, especially in rural and lower-income areas (ASPE, 2022). For many healthcare workers, hospital guidelines were constantly changing, and there was no standardized care nor information about COVID-19 (Giannis et al., 2021). The personal protective equipment (PPE) supply was decreasing and reported to be inadequate; many staff viewed the shortage of PPE to be a sign of a lack of administrative support (Giannis et al., 2021). Hospitals are still facing workforce and PPE/resource shortages, leading to increased stress among staff (ASPE, 2022). Due to these challenges, 19.8% of respondents from the April 2020 McKnight's survey had felt pressure to admit patients who had been treated for COVID-19 in the hospital as they were unequipped to treat them. (Berklan, 2020).

One of the major concerns for healthcare workers during the pandemic is their own physical and mental health. Healthcare workers worry about becoming sick themselves, suffering COVID-19 symptoms, and spreading COVID-19 to their family members (ASPE, 2022). One United Kingdom observational study states that healthcare workers were seven times as likely to have severe COVID-19 compared to non-essential workers (Mutambudzi et al., 2021). Healthcare professionals also witnessed their colleagues getting sick and, in some cases, dying from contracting COVID-19, leading to more stress and anxiety (ASPE, 2022). Two-thirds of respondents from the McKnight's survey said that staff called in sick or quit due to COVID-19 concerns (Berklan, 2020). Worries about COVID-19 symptoms and spread were associated with poor mental health among nurses.

Nurses are particularly affected by the COVID-19 pandemic because they directly attend to patients. Compared to physicians who only spend approximately 15% of their time with patients, nurses spend approximately 37% of their time directly providing care to patients, with indirect care and service-related activities accounting for the rest of their time (Brooks et al., 2021; Gardner et al., 2010). They are responsible for performing physical exams and health histories; providing health promotion, counseling, and education; administering medications; and coordinating care with collaboration from many health professionals (American Nurses Association, 2023). In a study that observed the association between patient satisfaction and nurses' work in England, Aiken et al. found that patients' perceptions of care were significantly negatively impacted by their lack of confidence in either nurses or doctors and decreased with "missed nursing care" (Aiken, 2018). Missed care was defined as when a nurse missed treatments, was unable to complete necessary pain management, and lacked time to comfort and talk to patients. With more cases of missed care from the nurse, there was an overall decrease in patient satisfaction. Although this association was found prior to the pandemic, the increase in cases of missed care could be attributed to nurses being constantly worried about their own health and exposure to COVID-19 while they take care of patients. A nurse's ability to provide care consistently and positively is essential to ensure optimal patient care.

Nurses view their jobs as important and meaningful, but they are simultaneously putting their own lives at risk to help others. This dilemma causes nurses to have a higher risk of experiencing burnout. Nurse burnout is defined as the "emotional and physical exhaustion that is . . . the result of a high-stakes, demanding job that frequently exposes them to human suffering" (Clarke, 2022). The Maslach Burnout Inventory (MBI) has measured burnout through three components: emotional

exhaustion, depersonalization, and reduced personal achievement (Sullivan et al., 2022). Emotional exhaustion is defined as “the depletion of one’s emotional resources and feeling like one has nothing left to give to others” (Sullivan et al., 2022). Depersonalization is when negative feelings towards work develop (Sullivan et al., 2022). Lastly, reduced personal achievement manifests as feeling like one’s accomplishments do not meet personal expectations (Sullivan et al., 2022). Studies have shown that more nurses are becoming more burnt out compared to pre-pandemic times (Boev, 2012). Shah et al. reported that among 50,000 US registered nurses surveyed in 2018, 9.5% of nurses were leaving their current employment and among that number 31.5% say they were leaving because of burnout (Shah et al., 2021). Sexton et al. had found that there were increases in reports of emotional exhaustion among nurses each year since 2019 (Sexton et al., 2022).

This paper will examine the COVID-19 related factors that led to nurse burnout and how these factors directly affected patient care in the United States as well as discuss current interventions. Nurses are crucial for ensuring that patients feel comfortable and safe in the hospital. This paper will examine elements of patient experience that may be negatively impacted if nurses continue to leave the field. I also will be reviewing the impacts of COVID-19 on nursing students and their interest in the field. Nursing students are the future of nursing, so it is important to evaluate the effects of the COVID-19 pandemic on their interest in the field. With the decrease in future nursing students (Kells and Jennings, 2022), there is a great negative implication towards the future of patient care. Finally, I will examine recommendations that could improve the national nurse burnout issue.

Patient Satisfaction and Nurse Burnout

Addressing nurse burnout is important because it is closely tied with the quality of patient care. In a 2004 Gallup Poll, patient satisfaction surveys showed that nurses’ ability to anticipate needs, help calm fears, and respond to requests positively impacted a patient’s overall satisfaction (Blizzard, 2004). Gallup also found that a patient’s interaction with the hospital staff was a predictor of the patient’s overall hospital satisfaction.

Patient experiences were found to be closely associated with a nurse’s relationship with their work. A study conducted by Leiter et al. suggested that a nurse’s affect such as exhaustion, intention to quit, and work meaningfulness cannot be hidden from patients (Leiter, 1998). The study found that patients on units where nurses found their work more meaningful were more satisfied with their hospital stay. Conversely, patients in units with exhausted staff were less satisfied with their stay. Nurse cynicism was also found to lower patient satisfaction with interactions with nursing staff. Leiter et al. hypothesized that feelings of frustration from perceived inability to provide the best care for patients are likely to be shown towards the patient due to how many interactions patients have with nurses (Leiter, 1998). A more recent study conducted in 2010 also supported the impact of nurse’s satisfaction with their work environment on patient satisfaction. Nurses who reported a favorable perception of their work environment also had high patient satisfaction scores (Gardner et al., 2010). On the contrary, nurses who had a steadily declining perception of their work environment had also a similarly decreasing trend in patient satisfaction scores (Gardner et al., 2010). Based on these two studies conducted decades apart, there seems to be an association illustrated between nurse satisfaction and patient care. When nurses felt more positive about their job there seemed to be a positive association with patient satisfaction of their care. However, if nurses felt discontent with their job, patient satisfaction decreased directly as well.

With an increase in nurse burnout, there was also an upward trend in patient adverse events and less safety management occurring in hospitals. In a study conducted in Iran, as the burnout prevalence increased among nurses, so did the number of adverse events (AEs) including events such as “Pressure ulcer”; “Patient fall”; “Medication errors” such as inappropriate medication use or patient harm while medication is in control of a healthcare professional, patient, or consumer (U.S. Food and Drug Administration, 2019); “Surgical wound infection,” “Infusion or transfusion reaction,” “Patient and family verbal abuse,” and “Patients or family complaints” (Kakemam et al., 2021). Kakemam et al. used binary logistic regression to find a relationship between burnout dimensions and AEs. Detachment, a measure of burnout, was found to increase the risk of all AEs, while low productivity and emotional exhaustion had reduced the risk of some AEs or had no effect on AEs, respectively (Kakemam, 2021). The study suggested that detachment negatively affected the relationship between the provider and the patient leading to low quality patient care. To support the previous points, Seul Ryu and Shim found decreases in patient safety management activities with increased levels of burnout in Korea (Seul Ryu and Shim, 2021). As echoed by previous studies above, psychological detachment from work because of burnout led to indifference towards patients. Burnout also decreased concentration which was hypothesized to increase the number of patient safety incidents (Seul Ryu and Shim, 2021). However, higher compassion satisfaction (CS) — defined as “a pleasant emotion that comes from the ability to help others” — could mitigate AEs that may arise as a nurse’s CS improved job satisfaction and lowered levels of physical and emotional burnout (Seul Ryu and Shim, 2021).

Nurse Burnout COVID-19 Factors

COVID-19 has brought many new challenges for healthcare professionals, especially nurses. Overall, there has been an increase in anxiety and depression among nurses during the COVID-19 pandemic. In the Intensive Care Units (ICU) across the United States, nurses are experiencing moral distress, burnout, anxiety, depression, and post-traumatic stress disorder (PTSD) (Guttormson et al., 2022). Using an observational cross-sectional study design, Sagherian et al. also found that nursing staff who care for COVID-19 patients similarly have worse insomnia, fatigue, and higher PTSD symptom severity compared to other nurses (Sagherian et al., 2020). Those who worked more than forty hours per week had higher PTSD symptom severity. Repeated exposure to trauma and constant worry about contracting COVID-19 and spreading COVID-19 to their families also increased the risk of developing PTSD (Sagherian et al., 2020). Over half of the nurses in the above-mentioned study have reported that their life was threatened or they might die due to caring for COVID-19 patients (Sagherian et al., 2020). The respondents who felt that their life was threatened or they might die due to COVID-19 had a higher PTSD risk — 61.4% were at risk for PTSD compared to 27.8% who did not feel threatened (Sagherian et al., 2020).

Nurses experienced fear, stress, and uncertainty about the possibility and consequences of contracting COVID-19. A study by Barrett et al. (2020) demonstrated with a cross-sectional data analysis that healthcare workers in New Jersey had a higher prevalence of COVID-19 infections than non-healthcare workers, and nurses represented a majority (62.5%) of the positive tests among healthcare workers. Nurses brought up in interviews that they were stressed about contracting COVID-19 from an asymptomatic patient due to false negatives and a lack of information regarding antibody testing (LoGiudice and Bartos, 2021). One nurse said that “chances are that a

reasonable percentage are gonna get critically ill and we know you're gonna spread it to your family members" (Norful et al., 2021). Another nurse expressed concerns about giving COVID-19 to their grandparents so she avoids visiting them because "it will be too high of a risk to go see them and possibly pass the disease onto them" (Norful et al., 2021). The separation and distancing from families added an additional layer of stress on healthcare workers.

One of the biggest issues during the COVID-19 pandemic was the lack of PPE. In a descriptive study conducted by Norful et al. (2021), physicians expressed that they "tried to get [hospital scrubs] to wear while [they are] at work and [were] denied." Respondents in a different study said that they have to "[reuse] surgical masks and N95s, [order] off-brand gowns and shoe covers, and [use] house-made hand sanitizers" (George et al., 2021). A survey by the American Nurses Association (ANA) found that nine out of 10 nurses feared going to work due to inadequate PPE, and nurses have been forced to create their own surgical masks (American Nurses Association, 2020). The lack of PPE has been associated with depression and is a high risk for anxiety and PTSD as well among Michigan nurses (Arnetz et al., 2020). Younger nurses have expressed their desire to leave the workforce due to a lack of PPE and support from the administration (Guttormson et al., 2022).

On the other hand, wearing PPE has also led to a lot of stress for nurses. In one interview study, all the registered nurses have expressed experiencing exhaustion from wearing PPE and N95 masks (LoGiudice and Bartos, 2021). They were worried that the methods to sanitize and clean PPE will damage masks and therefore increase the risk of getting infected with COVID-19. Nurses sometimes wore N95 masks for weeks or until they were "visibly soiled" and "until damaged" (LoGiudice and Bartos, 2021). Soiled and damaged PPEs are ineffective at protecting nurses against the virus. Due to the shortages in PPE, nurses were forced to balance between having enough PPE and their health. Wearing PPE for long periods of time also had negative consequences on nurses' physical health. A questionnaire for ICU nurses in India showed that nurses experienced headaches, extreme sweating, and difficulty breathing (Jose et al., 2021). Additionally, nurses had nasal bridge scarring, indentation, and pain on the back of the ears as adverse reactions. Latex gloves led to sweaty skin and skin chapping (Jose et al., 2021).

In addition to PPE shortage, nurses gained or switched to new roles with new expectations due to a large number of COVID-19 patients. Some staff were pulled from their normal work to attend to the massive number of patients. For example, healthcare workers who usually saw patients with concerns in their specialty were all asked to focus on the influx of COVID-19 patients. One nurse said, "on the [Labor and Delivery unit] it's now mandatory that we float to other units if needed . . . We are all expected to take on more responsibilities in an effort to help other team units" (Morley et al., 2020). A team of unqualified nurses might be caring for six ICU patients at one time (Morley et al., 2020). Critical care nurses often only care for one or two patients at a time which is considered busy already (Krischke, 2017). Furthermore, taking away nurses from their original ward has led to increased patient demands for those who remain at the ward (George et al., 2021). Nurses were also taking on additional roles and responsibilities "from witnessing advance directives and setting up virtual communication platforms to cleaning patient rooms and emptying bins" (Morley et al., 2020). With COVID-19, nurses were also now responsible for "monitoring adherence to proper mask wearing, ensuring proper handwashing, and conducting signs and symptoms assessment" (George et al., 2021). In the Labor and Delivery units, nurses picked up duties such as phlebotomy and housekeeping (mopping floors) because staff did not want to enter COVID-19 rooms (George et al., 2021). The extra tasks, shifting of job responsibilities, uncertainty of work routine have led to

nurses leaving their jobs because they were feeling overwhelmed. Nurses also reported that management was refusing to hire more staff, therefore nurses continued to feel uncertain about their job responsibilities and whether they will have to substitute in for another role (George et al., 2021).

COVID-19's Impact on Future Nurses

Nursing students are also feeling the negative impacts of COVID-19. In a study examining levels of anxiety and depression among nursing students, researchers found that the pandemic has both positively and negatively influenced nursing students' perceptions of the field (Kells and Jennings, 2022). Some students became more interested in helping during the pandemic and making a positive impact on people's lives. 31.9% of respondents reported that the pandemic has strengthened or reaffirmed their desire to become a nurse (Kells and Jennings, 2022). However, 17.6% of respondents reported a decrease in interest, less confidence, and/or negative affect or drive associated with the pandemic (Kells and Jennings, 2022). Students became more aware of the dangers, risks, and challenges associated with healthcare; they also reported feeling that there was a lack of support and respect for nurses at the frontlines.

The COVID-19 pandemic had also directly affected nursing students' learning experiences. The transition to online learning in the United States led to many challenges such as the format of learning, professor and student relationships, peer relationships, and general anxiety and stress. A qualitative study conducted by Wallace et al. (2021) found that students felt that professors had trouble teaching online, and the students were unsure about when and how to ask questions and approach their professors. Students were also isolated, unable to form in-person study groups and ask questions to their peers. In general, students were not in an environment where they could focus on their studies. Michel et al. (2021) supported Wallace's above findings with similar results from a quantitative and qualitative survey regarding undergraduate students' perceptions of their education during COVID-19. Students also struggled with their study environment and the constant change in course schedules and guidelines (Michel et al., 2021). They have expressed concerns about how the virtual environment disconnected them from the feelings associated with direct patient care. Even in direct clinical care, COVID-19 has also impacted on-site learning. A cross-sectional study in Belgium noted that students had to switch clinical sites which led to concerns about learning opportunities (Ulenaers et al., 2021). Some students were moved from hospital units to a nursing home, where they say they have less opportunity to practice technical skills. One student said that they are "missing out on learning opportunities by not being able to do [their] elective internship in heart surgery" and they already had "four similar internships in this [nursing home] field" (Ulenaers et al., 2021).

Interventions Against Burnout

Hospitals with the best work environments were found to have the lowest burnout rate and highest patient satisfaction. A study conducted by Brooks et al. (2021) analyzed 463 hospitals in 4 states to examine the relationship between nurse burnout and patient satisfaction as well as whether work environments are associated with the outcomes. Work environment was measured using the Practice Environment Scale of the Nursing Work Index that comprised nurse participation in hospital affairs, nursing foundations for quality of care, nurse manager ability, leadership and support

of nurses, staffing and resource adequacy, and collegial nurse-physician relations (Brooks et al., 2021). In hospitals with poor work environments, hospitals improving their work environment from poor to best led to a 12% increase in patient satisfaction (Brooks et al., 2021). Brooks et al. attributed Magnet designation hospitals — hospitals where “nursing leaders successfully align their nursing strategic goals to improve the organizational outcome” (ANA Enterprise, 2023) — to improved patient outcomes (Brooks et al., 2021). Patient experience will likely improve by investing in “Magnet-like qualities” through fostering relationships between nurses, administrators, and physicians and giving nurses more decision-making authority.

These findings were supported by Aiken et al. (2012) who suggested an improvement in hospital work environments was a “relatively low-cost strategy” to improve patient satisfaction. Some of these changes included increasing the percentage of Bachelor of Science in Nursing (BSN) nurses and lowering the patient-to-nurse ratio (Aiken et al., 2011). Higher patient-to-nurse ratios were found to increase odds on patient deaths and failure-to-rescue, while higher percentage of BSN nurses decreased those odds. Aiken et al. (2011) also echoed that better nurse work environments — environments where doctors and nurses have good working relationships, nurses are involved in hospital affairs, management listens to patient care problems identified by nurses, and institutions invest in the education of nurses and quality improvement of patient care — were essential for patient outcomes. In fact, without a good work environment, adding nurse staffing to reduce workloads had an insignificant effect. In the worst staffed hospitals, better work environments were found to decrease the odds of mortality and failure-to-rescue by approximately 2% or 3% (Aiken et al., 2011). Furthermore, in the best staffed hospitals, better environments decreased the odds by approximately 12% and 14%, respectively (Aiken et al., 2011). Sagherian et al. (2020) found that 30-minute breaks had a protective role on nurses’ mental health due to decreasing fatigue levels, PTSD symptom severity, and psychological distress. In the United States, volunteering programs have been established to relieve overwhelmed hospitals (Giannis et al., 2021).

Current approaches are mainly individual-based, but there is a need for an organization-level change. As mentioned earlier, Brooks et al. (2021) suggested that a more organization-level solution is allowing nurses to be more involved in decision-making regarding their practices and be at a position of change. The study called for an increase in organization-wide initiatives that foster well-being and engage all clinicians, including nurses, in creating a positive work environment. Furthermore, leaders in the hospital should be guiding nurses and healthcare workers about when PPE is and is not essential (Morley et al., 2020). Organizations should be supporting healthcare workers with enough PPE and prioritizing the health of healthcare workers by delaying treatment and procedures when PPE is unavailable, reassuring nurses and doctors that they can save more people by protecting themselves first.

Conclusions

Due to the COVID-19 pandemic, there has been an efflux of nurses and an increase in burnout, depression, and anxiety among nurses at the frontline. Nurses are the hospital staff who work the most closely with patients and highly impact patient satisfaction with their hospital experience. However, this close relationship increases the chances of nurses contracting COVID-19, and these nurses can spread it to their families and loved ones. The shortage of PPE exacerbates these concerns and has been a factor to nurses expressing their desire to leave the field. Nursing students

have also felt that their competencies and learning have been impacted. Many students are unable to practice what they learned in the field, and those who can often had their clinical sites switched and/or expressed concerns about contracting COVID-19 themselves. Furthermore, when nurses are burnt out, they are unable to provide the best care possible for patients. Adverse events were associated with increase in nurse burnout manifestations such as detachment with one's work. While addressing nurse burnout has been an issue since before the pandemic, it is necessary to intervene in the increasing burnout among nurses during the COVID-19 pandemic. Most research has only focused on individual-based strategies, but more researchers have expressed that there needs to be change in the organizational-level such as involving nurses in decision-making more often. It is critical for hospital administration and healthcare workers to work together to tackle these issues to provide quality patient care.

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Keeping Color in Mind: Racial Disparities within Mental Health Care

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Health is a fundamental human right, not a privilege, or is it? Systematic issues curated throughout history have fostered the existence of public health disparities at all levels. Still, the level of impact and who it has affected most almost directly correlates with the color of one's skin. While medical health inequality remains a pressing matter for disadvantaged groups, the mental health concern for people of color (POCs) is neither researched nor discussed enough. Despite the multitude of barriers, it is critical to address mental well-being to prevent and eliminate suicides, introduce strategies to reduce the impacts of mental illness and consider the role that race has when administering tests and treatment. The review of relevant literature will analyze the current research done on racial prejudices and how they adversely affect marginalized groups, why they continue to exist despite prior efforts, and proposed solutions to challenge these discrepancies. Its objective is to increase awareness and education regarding mental health disparities and how they relate to people of color to ultimately aid in diminishing the continuation of these unjust practices and catalyze vital changes in both POCs' right to impartial access and quality of mental health care.

Keywords

Racial Disparities • Mental Health Care • Mental Healthcare Access • Race and Mental Health • Mental Health Inequity • Minority Mental Health

Trends of Mental Health Care Discrimination - what is happening

Vulnerable communities, in regards to mental health care, are overlooked, dismissed, and consistently receive less access to and poorer treatment compared to their white counterparts. Using three

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distinct measures of access- the utilization of any mental health services, outpatient care, and the use of psychotropic medication- medical expenditure survey panels from 2004–2012 identified significant disproportionate trends across black, Hispanic, and Asian populations (Cook et al. 2017). However, the measures of access used in the research excluded homeless populations and included analyses that predated the Affordable Care Act (ACA). Homelessness and the ACA encompass those who struggle with financial burdens, meaning the study excluded the people within these groups who have the greatest difficulty in gaining access to mental health care. Despite these limitations, the vast differences in access between races are evident: in Black and Hispanic populations, racial prejudice increased regarding access to mental health care and medication distribution, and the disparities in Asians were found to be greater than any other group (Cook et al., 2017). Similar findings also proved through survey data that students of color face high levels of mental health concerns and congruently discrimination in treatment use (Lipson et al., 2018). These discoveries confirm that prejudices for minorities are prevalent in younger and older adults.

Although several studies have revealed mental health for racial-ethnic minorities is poorer in comparison to whites, little has been done to alleviate these injustices. In fact, they continue to increase (Cook et al., 2017). Lipson et al., (2018) stated a “growing body of evidence demonstrating a connection between mental health and college degree completion.” Younger adults are the most vulnerable as mental illnesses first onset in their mid-20s. In this sense, students of color who are the most at-risk for developing mental illnesses are also the ones who are most discriminated against when accessing mental health care or treatments. Society sets up young minority persons for hardship: poor mental health could potentially cause complications in completing their education which means they are less likely to find higher-paying jobs leading to financial strain. Those obstructions in turn create an even harder time for a racial-ethnic person to access mental health care and treatment they so desperately need. And even then, it will still not be the same degree of quality as a white person would receive. Society also fails to consider cultural implications that determine people of color’s experiences with mental health care.

Patient versus Provider: Preferences and Perceptions

Cultural differences greatly impact how receptive varying communities are to the topic of mental health as well as mental health care. It is vital to consider how patients of color perceive mental health and treatment and how providers must be culturally competent in how they deliver care to reduce racial inequality. In a study conducted by Lee et al. (2021), African American and Asian American participants were administered questionnaires to better understand their perspectives on the value of mental health issues, treatment, and provider preferences. They found despite the two groups’ vulnerability to mental health issues, African Americans endorsed the screening needs for depression more so than Asian Americans and preferred to seek treatment from a physician rather than medication more than Asian Americans. The variance can be explained by comparing and contrasting the cultures and cultural barriers of both minorities. African Americans have a high risk and are more predisposed to depression, substance abuse disorders, and post-traumatic stress disorder than other racial groups (Lee et al., 2021). Nonetheless, African Americans have a greater sense of community and because of this, they are more willing to acknowledge and communicate mental health problems. Instead of severe actions like suicide, African Americans rely on harmful coping mechanisms like drugs and alcohol that lead to depression. On the other hand, while Asian

Americans in the study were well aware of the mental health concerns in their communities, they still were less likely to endorse mental health care screening and treatment involving communication with a physician. Other research found suicidal ideologies affected older Asian Americans at the highest rate and African Americans at the lowest (Lee et al., 2021). This may be because of Asian customs where it is taboo to speak about how one feels as the family takes priority over individuals. The generational trauma passed down from the Asian immigrant experience could also be a large contributor to these statistics.

Furthermore, cultural barriers hinder these groups' ability to acknowledge or seek mental health care: these inequalities can be attributed to the fact that these populations are unlikely to seek help to begin with which may be due to cultural differences as many racial minorities do not acknowledge mental health or do not necessarily have the appropriate language to be able to bring it to light. Stigma, biases, and language barriers also prevent POCs from seeking mental health diagnoses or treatment. Interviews with white mental healthcare providers were thematically analyzed and provided insight into how their prejudice and perceptions of race, specifically black patients, influence their care. The investigation showcased that "mental healthcare providers can value intersectionality and still hold to racist ideologies" (McMaster et al., 2021). In this respect, institutions and mental healthcare providers are also accountable for the discrepancies in racial-ethnic group care and must incorporate cultural competency education in their practices. Cultural competency is an approach that calls for providers to understand the backgrounds of their patients along with their self-reflection (Kirmayer & Jarvis, 2019). It is crucial for uncomfortable topics for white providers, such as race, to be brought up and discussed in practice. Kirmayer and Jarvis (2019) mention that discomfort can be reduced through community projects or by including black voices in teaching cultural competency. These activities allow providers to gain a greater understanding of minority identities and better their communication and care with their patients of color. To implement lasting changes in mental health care discrimination, it is critical to understand the needs and preferences of POCs, re-evaluate and reconstruct their systems to provide culturally competent care, and how both factors interact with each other to promote intersectionality.

Review of Strategies to Combat Disparities

In earlier literature, little to no efforts were made to protect racial-ethnic minorities from inequities in mental health care. In recent years, several models have been created to address race, identify what problems remain, and call for policies to enact proper change. Psychiatrists Kirmayer and Jarvis (2019) discuss the context of culture while reviewing and outlining the strengths and limitations of varying existing strategies such as cultural competence of institutions and health care systems, cultural safety, and the usage of language interpreters. These specific methods underline how mental healthcare systems must be conscious of and realize the importance of examining the context of historical oppression, social climate, and discriminatory power dynamics. These multifaceted factors play pivotal roles in cultivating quality policies to ensure equitable healthcare for minority demographics. Implementing community-based targeted interventions and policy reforms is imperative to address pervasive biases and accessibility barriers. For instance, an effective approach may include introducing cultural competency training in community health programs, and ensuring healthcare professionals deliver care to patients from diverse backgrounds with humility. Initiatives based on culturally tailored care could provide spaces for those from minority backgrounds to

access culturally sensitive resources, reduce implicit biases in care, and receive support from peers or healthcare providers who understand their specific needs. Alongside establishing cultural humility for racial-ethnic minorities, policy reforms could ensure standardized equitable access by addressing systemic barriers that perpetuate disparities in mental healthcare. Removing financial obstacles (Cook et al., 2017) could allow individuals to access necessary mental health services, unrestricted by insurance conflict or financial burden.

Additionally, educating and promoting mental health initiatives (Lee et al., 2021) and addressing race in clinical settings (McMaster et al., 2021) could serve to destigmatize mental illness and raise awareness of available resources for the targeted communities. Reforms such as these could also allocate funding for community outreach programs and mental health education campaigns to empower underserved people to seek appropriate care. Thus, the challenge for public health workers, policymakers, and mental health care providers is to further research and utilize upstream approaches while considering cultural contexts to ultimately reduce discrimination and inequality for people of color. By addressing the social determinants and building on existing strategies, mental healthcare systems can develop holistic practices to combat the burdens related to race.

Conclusion

Mental health care injustices based on race, persistently harm those most in need of mental health services. This is emphasized by the of failure institutions and providers to recognize the needs and preferences of minority communities, effectively deterring POC adults from accessing and receiving fair treatment. It is well understood that mental health disparities and many other health discrepancies are inherently linked to the intersectionality of race, socioeconomic status, and cultural background. Achieving just treatment for disadvantaged people requires a deeper understanding of the minority experience and the incorporation of cultural competence into both clinical settings and everyday life.

Disparities in mental healthcare remain an emerging area of study with much to explore regarding challenges in quantitative methodology and a lack of transparency in participant representation. Researchers must extend beyond current limitations, recognizing the complexity of mental health injustices and the systemic forces that perpetuate them. Therefore, research models must critically consider the systematic issues hindering equality in mental health care to facilitate nuanced understandings of target demographics and enable the development of unique, curated mental healthcare interventions. As advocates for underserved populations, it is imperative to push for research exploring the complex intersectionality of mental health with other aspects of identity and experiences. This expanded agenda will enable nuanced understandings of target demographics to create unique and curated mental healthcare interventions. Ideally, health would and should be a right as national health organizations advocate. Yet, it is how we, as a society, allow social determinants of health to contribute to health disparities in all aspects; further understanding of the minority experience, and how to incorporate cultural competence into practice, not just in clinical settings but in everyday life, is necessary to encourage just treatment for disadvantaged people everywhere.

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Lifestyle Medicine as a Public Health Solution for Treatment-Resistant Depression (TRD)

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Treatment-resistant depression (TRD) is defined as failing to fully remit after 2 antidepressant treatments of adequate dose and duration. A study that analyzed commercial insurance claims, Medicaid, and the Veterans Administration populations showed TRD to be a very costly healthcare disorder thereby making TRD a major public health concern for policymakers. Studies were analyzed and the results of the cost-effective lifestyle medicine practices in treating TRD are shared. Recommendations include further funding and resources and more advanced research in using lifestyle medicine to treat TRD and other mental health problems.

Keywords

TRD • Treatment-resistant depression • lifestyle medicine • depression • mental illness • public health

Treatment-Resistant Depression is a Public Health Concern

Approximately 14.8 million people over the age of 18 had at least one major depressive disorder (MDD) episode in the US, making it the leading cause of disability in 2020 (ADAA, 2020). As much as 60% of MDD patients are considered to have treatment-resistant depression (TRD) depending upon the remission criteria (Eisendrath et al., 2016). Most commonly, TRD is defined as failing to fully remit after 2 antidepressant treatments of adequate dose and duration (Eisendrath et al., 2016). Compared to non-TRD MDD patients, patients with TRD have a remarkably higher risk of all-cause mortality (Li et al., 2019).

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Since previous studies showed the costliness of TRD to the healthcare system, Pilon et al. analyzed commercial insurance claims, Medicaid, and the Veterans Administration populations, which demonstrated that TRD was a very costly healthcare disorder (Pilon et al., 2019). TRD poses higher costs of healthcare resource utilization compared to treatment-responsive MDD or non-MDD patients (Li et al., 2019). Hence, TRD is a public health issue of particular concern to policymakers and the healthcare industry treating it.

TRD, Substance Use Disorders, and Drug Treatments

Brenner et al. found that patients with TRD were at greatest risk for substance use disorders (SUD) compared to MDD patients (Brenner et al., 2020). Patterns varied, depending on if a TRD patient had a history of SUD or not. Sedative use disorder in TRD patients had a 2- to 3-fold increase compared to MDD patients. Despite this, the currently recommended approaches for treating TRD include switching within and between different classes of antidepressants; combining antidepressants with medications, such as anticonvulsants or antipsychotics; using psychotherapy alone or alongside pharmacological therapy; and neurostimulation (Brenner et al., 2020). Brenner et al. determined that comorbidity of SUD may be a risk factor for TRD; hence, management and alternative treatments for both TRD and MDD patients not yet suffering from TRD need to be explored.

While selective serotonin reuptake inhibitors (SSRI) are the most commonly prescribed antidepressants today, they are not as effective as their popularity may suggest. Irwin Lucki, PhD, an expert on the opioid epidemic, noted that as much as 50 percent of depressed patients are resistant to SSRI therapies (*Opioids*, 2019). First discovered in the 1950s, SSRI may perhaps be outdated. The upcoming sections will share some psychotherapy programs that successfully integrated lifestyle medicine.

Treating TRD With Lifestyle Medicine

Lifestyle Medicine is a low-cost and potentially safer means to prevent, promote, and manage health and well-being by considering patients' lifestyles; this includes sleep habits, food intake, movement, and more (Sarris et al., 2014). One notable TRD lifestyle medicine approach is Mindfulness-Based Cognitive Therapy (MBCT). MBCT is an 8-week group training program for depression that integrates mindfulness meditation techniques with cognitive behavioral therapy elements (Eisendrath et al., 2016). MBCT has been proven to reduce rumination in remitted and currently depressed patients. Eisendrath et al. conducted a randomized study of 173 TRD patients assigned to either MBCT or a Health Enhancement Program (HEP) which consisted of physical fitness, music therapy, and nutritional education, as well as treatments-as-usual, or standard care, pharmacotherapy. In both the primary and secondary analysis of participant survey measures, MBCT significantly reduced depression severity compared to HEP. Although rates of remission improved in MBCT for TRD patients, results were not statistically significant. Nonetheless, TRD patients reported MBCT to be a useful treatment.

In previous studies, TRD patients typically have concentration problems with their assigned therapies, but Eisendrath et al. found that their subjects were able to concentrate and carry through with their MBCT or HEP. Additionally, these depressed subjects reported they were looking for

nonpharmacological treatments and found MBCT and HEP to be empowering. Overall, adding these alternative treatments to TRD patients' lines of treatment is recommended.

There are many known lifestyle-based and nonpharmacological approaches for improving mental health and emotional well-being, among them dietary changes (Morton, 2018). Recently, researchers have shown reductions in depressive symptoms and improved mental health among those who adopted a Mediterranean-style diet (Parletta et al., 2017). Exercise has also been shown to alleviate depression yet widely underused antidepressant (Morton, 2018). Exposure to natural environments may improve emotional well-being (McMahan & Estes, 2015). Blue and green exposure and/or light therapy may be an effective therapy for depression (Morton, 2018; Lam et al., 2016; Tuunainen et al., 2004).

A good night's sleep is crucial for optimal mental and emotional health (Sarris et al., 2014). Modifications to one's lifestyle, such as reduction of alcohol and cigarette smoking, and increased physical exercise showed some improvement in sleep and stress disorders (Merrill et al., 2007). Positive thinking training was seen to improve older adult's life satisfaction (Taherkhani et al., 2023). Participation in service activities or volunteering was shown to positively reduce depressive symptoms and major depression in relation to stress disorder (Griep et al., 2023). Mindfulness based meditation proved to be a promising intervention for treating anxiety and mood disorders (Hofmann et al., 2010). Positive social interactions were also shown to reduce the likelihood of depression (Stafford et al., 2011). Attention should be given to such evidence-based lifestyle medicine strategies listed above for combating depression.

Religious Integrated Psychotherapy for Depression Significantly Reduced Symptoms

Religious psychotherapy was found to be at least as effective as conventional psychotherapy for patients with depression and anxiety (Paukert et al., 2011). Clinical psychotherapy or behavioral activation psychotherapy has been a well-supported method to treat patients with mental health problems, but has the ability to reduce symptoms by nearly 50% of the time (IsHak et al., 2023). A systematic review of 11 articles was conducted to see if religious integrative psychotherapy was more successful (Paukert et al., 2011). Nine of the 11 studies examined only depression, and all showed significant reduction of symptoms. None of the 11 studies showed to have a lesser effect when compared to conventional therapy methods.

These 11 studies only studied Christian and Muslim participants. At first look, one may find that religious psychotherapy was more successful for Muslims compared to the control secular psychotherapy. However, the researchers state that the Muslim study participants reported a high level of religiosity. Therefore, the Muslims may have been more willing to adapt the religious practices more comfortably. Further research should be conducted for religious integration in psychotherapy for TRD patients as alternatives to pharmacological treatments and therapies.

TRD, Lifestyle Medicine, COVID-19, and Telehealth

The COVID-19 pandemic altered the lives of people around the world, including patients with TRD, who may have found it hard to receive treatment. That is why, Navarro et al.'s November 2020 paper regarding their on-going clinical trial aimed to "evaluate the effectiveness of an Internet-based

adjuvant lifestyle-based intervention for patients with TRD” was quite notable. TRD can be exacerbated by stressors that have become more common due to the COVID-19 pandemic, such as poor physical health and economic struggles. Information and communications technologies and video conferencing were proposed. Navarro et al. hypothesize that by their 1-year follow-up, the lifestyle program group will show greater adherence and therefore benefit of the intervention. While no follow-up report was found, this study demonstrates a cost-effective approach to treating TRD that may be considered and easily duplicated.

Conclusion

We recommend that time, resources, and funding be allocated to support the cost-effective lifestyle medicine interventions for TRD, MDD, and mental health problems in general. The idea that TRD could be successfully treated by combining lifestyle medicine with technology and religious integration alongside (and, hopefully, in place of) pharmaceuticals is promising. As such, lifestyle medicine deserves the attention of public health physicians and practitioners, health policy advocates, health education specialists, and other key stakeholders. The goal of this paper was to introduce lifestyle medicine to fellow public health researchers in hopes that they will further explore the benefits for TRD patients.

Further research on the cost-effectiveness and efficacy of lifestyle medicine as compared to modern pharmacological medicine is also recommended. A concerted effort to better understand lifestyle medicine from a public health perspective may have major implications on the population's overall health and economic well-being.

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The Effects of Stigma Against HIV and Tuberculosis on Healthcare-Seeking Behavior Among Tibetan Refugees in Dharamshala, India

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HIV and tuberculosis are highly impactful diseases in India, causing severe morbidity, mortality, and suffering for millions. The stigmatization of these diseases unnecessarily exacerbates suffering for those afflicted, compounding to the existing physical and emotional burden of diagnosis. Individual interviews with healthcare workers were conducted at Delek Hospital and the Tibetan Children's Village to identify the existence and effects of stigma in the Tibetan refugee population in Dharamshala, India. Respondents reported a high burden of tuberculosis in the community, complicated by the refugee status and unique infrastructural challenges of the population. The burden of HIV in the community is remarkably low, although it may be underreported. All healthcare workers noted the tangible influence of stigma, yet many believed that stigma has decreased as the disease has become normalized. Respondents reported detrimental consequences to patient mental health as a result of both disease diagnosis and stigmatization, ranging from elevated anxiety and depression to isolation and suicide. Finally, stigmatization of both tuberculosis and HIV are connected with four major behavioral consequences in patients: delayed healthcare visits, resistance to disclosing their diagnosis, traveling to far-away hospitals, and refusal to follow treatment regimens. Stigmatization, and its consequences to patient mental health and disruption of healthcare-seeking behaviors, serves as a dangerous barrier to effective public health interventions and disease elimination in Dharamshala.

Keywords

Mental health • stigmatization • human immuno-deficiency virus (HIV) • tuberculosis (TB) • healthcare-seeking behaviors

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I. Introduction & Literature Review

Throughout history, public health and disease have never existed in isolation; they have been embedded in a myriad of social, cultural, psychological, economic, and political influences. As such, disease-related stigma, or the fear of social ostracization or rejection that affects an affected individual's self-perception, thoughts, and actions, is inherently linked to disease itself. Although an intangible force, stigma has the immense capacity to control the way individuals and a broader society think about and act toward disease, potentially detrimentally affecting a patient's mental health, exacerbating suffering, perpetuating disease transmission, and diminishing the efficacy of treatment regimens. This study project investigates the effects of stigmatization of HIV and TB in Dharamshala on patients' mental health and healthcare-seeking behaviors.

A. Immunology, Epidemiology, and Social Determinants of Tuberculosis & HIV

Today, a quarter of the human population is infected with *M. tuberculosis*, and 26% of these cases are found in India, making the country a dominant focus area for tuberculosis treatment and control (Ministry of Health and Family Welfare, 2021). Tuberculosis infection risk is highly inequitable and heterogeneous, varying by gender, occupation, geographic location, and socioeconomic status. Often considered a neglected disease of the poor, tuberculosis infection and transmission are exacerbated significantly by poverty (Creswell *et al.*, 2011). Lower socioeconomic status and caste often correlate with undernutrition, high housing density, and poor sanitation (World Health Organization). High housing density and poor sanitation increase the likelihood of transmission. Men are up to three times more likely to contract tuberculosis in India, as women are more likely to stay at home or partake in domestic work, limiting their exposure. High-risk populations include healthcare workers, who experience a higher risk of exposure, and prisoners, slum dwellers, and miners, who work and/or live in high-density areas. Tuberculosis cases in India are also highly geographically heterogeneous. Prevalence and incidence rates are higher in urban areas rather than in rural areas, where there is greater population density to facilitate transmission. The northern and western areas of the country exhibit higher rates of infection than the south and east (Paralkar, 2008).

Human Immunodeficiency Virus (HIV) demonstrates widely different basic immunology, mechanism of transmission, symptoms, history in India, and socioeconomic determinants of infection than tuberculosis. The populations most at-risk of developing an HIV infection are sex workers, intravenous drug users, and long-distance truck drivers, although infection is by no means limited to these groups (Solomon *et al.*, 2016). Additional risk factors include the presence of ulcerative sexually transmitted infections, the irregular or infrequent use of condoms, frequent sexual contact, and an earlier age of sexual initiation. More broadly, low literacy, education, economic status, and sexual orientation are believed to influence the risk of contracting HIV (Narain *et al.*, 1994). A wide variety of occupational, socioeconomic, and demographic factors influence the distribution of HIV infection in India.

B. Stigmatization of HIV and TB in India

Stigma has permeated throughout history. The term *stigma* itself originates from the ancient Greek, meaning "to carve, to mark as a sign of shame, punishment or disgrace" (Economou *et al.*, 2020).

Colloquially, the term was used to refer to the process of branding or cutting slaves, criminals, and traitors to publically and permanently identify them as immoral or exiled people (Bos *et al.*, 2014). More broadly, stigma theoretically serves to promote social cohesion by recognizing and devaluing individuals who deviate from prescribed social norms. Essentially, stigma allows a community to sacrifice an individual for the maintenance of the status quo (Bhanot, 2021). This stigma may be subtle or overt, ranging from averting eye contact to explicit physical or verbal violence. Stigma exists only as a result of its social context; stigma is grown from the interactions, prejudices, judgments, and actions within a social group, rather than a single individual. As such, it is intrinsically linked to powerful human emotions and broader social dynamics.

HIV and TB have both been highly stigmatized diseases historically. While tuberculosis has defined the disease landscape of India for centuries, HIV was first detected in India in only 1986 (Solomon *et al.*, 2016). The novelty of the disease, as well as the initial uncertainty surrounding its transmission and epidemiology, provides a unique context for the development of social stigma and anxiety. At the outbreak of the epidemic in the early 1980s, the unfamiliarity of the disease compounded with its high mortality led to substantial fear among affected and unaffected populations. Later, the correlation between extramarital sexual intercourse and the transmission of HIV challenged India's social norms of monogamous heterosexual relationships. The association of the disease with immorality created a culture of shame and blame surrounding the illness, regardless of the actual mechanism of transmission. This stigma led to job loss, school expulsion, physical and emotional violence, and social ostracism for affected individuals (Lalhruaimawii *et al.*, 2022).

The stigma surrounding HIV is perpetuated through an inadequate understanding of HIV transmission, which in turn increases public fear and exacerbates stigma and discrimination. 55% of respondents in *A National Survey on HIV-related Stigma and Discrimination in Urban India* believed that PLHIV were "promiscuous" and 66% believed that HIV infection was a punishment for such immoral behavior. The existence of this stigma is highly visible; 61% of respondents reported that they would feel ashamed if they were infected with HIV, and 58% if a family member tested positive for HIV. Although most respondents did not endorse discrimination and segregation of HIV-positive individuals, a worrying proportion approved of these extreme actions. 12% of respondents believed that HIV-positive individuals should be "kept separate from the community." This stigma was further enacted through physical assault among 13% of PLHIV (Chakrapani and Bharat, 2014).

Stigmatization of HIV exists within a deeper context of gender and sexuality within India. When disaggregated by gender, these data reveal a worrying image of highly gender-based HIV stigmatization. 17% of women living with HIV reported physical assault due to their disease status, compared to 6% of men. Twice as many women reported being deprived of property, receiving sub-optimal healthcare, and being excluded from social gatherings than men. Additionally, self-stigma, or feelings of shame, blame, or guilt, were significantly higher for women than men (Chakrapani and Bharat, 2014). HIV-positive women were far less likely to receive visitors from either side of their family than HIV-positive men (Green *et al.*, 2007). Taboos around sexuality and premarital sexual relationships discourage adolescents, particularly women, from testing for HIV and other sexually-transmitted illnesses. The decreased economic independence and social status of women can also exacerbate the effects of HIV stigmatization in India. Men who have sex with men, transgender individuals or *hijras*, and sex workers are at increased risk of domestic violence and familial rejection after an HIV diagnosis because of existing stigmatization of these orientations or

professions (Misra *et al.*, 2000). Stigmatization of HIV can delay seeking healthcare, disrupt treatment, and exacerbate patient suffering. Prior to a diagnosis, those who fear stigmatization, particularly those from marginalized communities, may delay testing for HIV. This is particularly relevant for sex workers, who may risk temporary or permanent loss of employment due to their HIV status. When patients fear judgment or ostracization for their HIV-positive status, they may be hesitant to test or reveal their diagnosis. Without familial and community support, a patient faces additional challenges: costs of medication, transportation to and from clinics, hidden medication routines, etc (Ekstrand *et al.*, 2018). These additional barriers caused by stigmatization prevent successful medical interventions and instead perpetuate transmission of the disease.

Meanwhile, the longevity and omnipresence of tuberculosis in India led to the cultivation of a different narrative. In India, multiple studies have measured the perception of stigma among tuberculosis patients. Like HIV, misunderstandings about the transmission of TB influence stigmatization of the disease. A common misperception is that TB is a hereditary disease, and as such, stigma extends to the immediate family of a patient, in addition to the patient themselves. Additionally, as poverty is a strong social determinant of infection, tuberculosis is highly linked with the caste system, and lower caste individuals may be more highly stigmatized (Baral *et al.*, 2007). This association with the caste system is unique to Indian society, and likely does not play a substantial role in Tibetan communities.

Stigmatization of tuberculosis in India is real and readily perceived by patients. A study conducted in 2020 reveals that 73% of the community members surveyed demonstrated stigmatizing attitudes towards TB patients (Thomas and Stephen, 2020). Many TB patients perceived stigma with family and friends, and 31.5% of patients never disclosed their diagnosis as a result of perceived or anticipated stigma (Kamble *et al.*, 2020). 10.3% of patients experienced real avoidance by their friends due to their diagnosis, demonstrating the tangible impact of tuberculosis stigma on social relationships. In a similar study by Rajeswari *et al.*, 75% of TB patients reported wanting to hide their disease from others (Rajeswari *et al.*, 2020).

Like HIV, narratives surrounding TB may affect patients' healthcare seeking behaviors. Many patients fear that revealing their diagnosis may threaten their marriage prospects, disrupt their family structure, and isolate them from their family or friends. These factors can affect an individual's willingness to share their diagnosis with others and receive adequate treatment for their condition. Delay in treatment is five times higher in patients who report high levels of stigma compared to those with low levels of stigma (Chakrabartty *et al.*, 2017). Stigma is estimated to impact tuberculosis treatment dropout rates, which remain incredibly high (Thomas and Stephen *et al.*, 2020). Insufficient research exists on TB stigmatization in India, resulting in a lack of adequate local and government policies to protect TB-positive patients.

C. Unique Challenges of Tuberculosis Infection in the Tibetan Refugee Community

The rates of tuberculosis prevalence are notably higher in the Tibetan refugee community in India, as compared to Tibetans in Tibet and Indians in India. Although the exact prevalence varies by community, the rate of tuberculosis for Tibetan refugees in Dharamshala, India is approximately 835 per 100,000 persons (Dierberg *et al.*, 2016). Meanwhile, the prevalence rate for Tibetans in Tibet is lower, at 758 (Zhang *et al.*, 2014), and the rate for Indians in India is lower still, at 181 per 100,000 (Dierberg *et al.*, 2016). Various genetic, physical, and social factors affect the increased risk of Tibetan refugees to tuberculosis infection.

Beyond the genetic factors involved, the process of migration itself is incredibly physically and emotionally difficult, increasing the risk of illness among refugees. Migrants are often unable to access healthcare on their journey or immediately after, due to their physical movement, language barriers, and low resources. These challenges can delay diagnosis and treatment, allowing TB to persist in the migrant community. Migration itself may also increase exposure to infection through high-density conditions and malnutrition. When arriving in India, integrating into the host community generates further challenges, including finding employment and housing, which further delay seeking healthcare (Migration Health Division, 2012).

Stigmatization of tuberculosis within Tibet has been correlated with discrimination and disruption of treatment regimens in some individuals (Zhang *et al.*, 2020). This fear of stigmatization results in poor self image, low self esteem, and anxiety among patients. Stigmatization causes unnecessary psychological distress in patients and exacerbates their overall trauma. However, there is only one available study on the impact of stigma of tuberculosis in Tibet; others pertain to China.

D. Unique Challenges of HIV Infection in the Tibetan Refugee Community

The Tibetan Refugee Community in India repeatedly reports low levels of HIV infection. Little recent research has measured HIV incidence or prevalence among Tibetan refugees in India. The most recent numbers are from 2015, now almost a decade ago, and report only 60 HIV cases among Tibetans in India (Wangchuk, 2015). These low levels contradict the growing concerns of health professionals about HIV transmission in Tibetan communities in India, as well as the higher rates of infection in Tibet and in India as a whole. While it is possible that the incidence of HIV at that time was so low, it is likely underreported. This underreporting may be due to Tibetans receiving healthcare services at non-Tibetan (Indian) hospitals or due to the absence of sufficient case detection programs. More recent data and more comprehensive case detection programs may be needed to fully understand the burden of HIV in the Tibetan community in India.

HIV/AIDS has been steadily rising in Tibet and China in recent years, although data is infrequently disaggregated to showcase the Tibetan Autonomous Region alone. In Tibet, there is significant misinformation surrounding HIV/AIDS transmission and medication. Many of the educational materials in Tibet are written in Chinese dialects, rather than regional languages, creating inaccessible information and language barriers to services. Additionally, there is a common misconception that HIV medications are poisonous, as some may cause side effects. In some rural areas, out-of-date anti-retroviral drugs are sold to unsuspecting patients. Additionally, there is a general cultural hesitancy, as in India, to discuss sexual relationships and to utilize contraceptives. There is a shared feeling of embarrassment surrounding testing and prevention services that inhibit their use (Siqi, 2016). This taboo surrounding sexual relationships mirrors that in India, and therefore leads to similar stigmatization of HIV-positive patients. In China, there is definitive stigmatization of HIV-positive patients. In a study by Cao *et al.* in 2011, 56.4% of respondents believed that people who acquire HIV through sexual contact or drug use “deserve it”. This demonstrates an alarmingly high level of blame toward PLHIV. 80% of non-HIV positive respondents reported feeling afraid of PLHIV, further ostracizing them and stigmatizing their condition (Cao *et al.*, 2011). Although this study does not apply to Tibet specifically, it provides insight on potential cultural norms and perceptions in the region.

Overall, despite the unique cultural context compared to India, similar incidences and bases for stigmatization of HIV and TB exist in Tibet. This research will supplement the existing literature

by analyzing stigma in the Tibetan refugee community within India, a previously understudied population. HIV and tuberculosis are highly nuanced diseases, with far-reaching medical, social, economic, and mental or emotional consequences on the Indian nation. To improve the efficacy of treatment cascades for both illnesses, as well as to validate and fully understand the unique experiences of affected individuals, researchers must seek to understand the nuanced narrative of stigma and its effects on patient mental health and suffering.

II. Methodology

A. Study Population and Setting

This study was conducted among healthcare workers in Dharamshala, India. The healthcare workers included five nurses, one psychiatrist, and one doctor at Delek Hospital. One nurse works at the McLeod Clinic, and four nurses and one doctor work at the main campus of Delek Hospital in Dharamshala. Additionally, the study included one nurse and one doctor at the Tibetan Children's Village, a school for Tibetan refugee children. All healthcare workers belonged to the Tibetan community, with one exception. One participant was a volunteer, foreign psychiatrist who has lived in McLeod Ganj for decades and is intimately familiar with the community's dynamics. These interviewees were selected, according to relevant professional experience and availability, per the recommendation of one of the lead physicians at Delek Hospital.

B. Data Collection & Analysis

Individual interviews using a semi-structured questionnaire were utilized to collect data. Informed consent and consent for recording were acquired for all interviewees. One interviewee declined to be recorded, but consented to having notes taken on their comments. All interviews were conducted in April 2023. Interviews with the healthcare workers were conducted in private rooms at the hospital, school, or clinic. All interviews were conducted in English. The interviews were transcribed and coded, identifying major themes and sub-themes among the interviews.

III. Results & Discussion

The major themes for analysis were identified after the successful completion of all interviews, based on frequent comments made by interviewees. The themes identified are listed in Table 1 and are expanded upon in detail below.

A. Unique Challenges as a Refugee Community

Addressing the public health needs of the Tibetan community is complicated by the dispersed nature and refugee status of the population. The circumstances of settlement in India affect the transmission of tuberculosis among Tibetans. Many parents send their children to Tibetan boarding schools, as doing so facilitates a stronger cultural connection with the broader community in India. These boarding schools are often overcrowded and under-resourced, contributing to the spread of tuberculosis among school children. Additionally, a large number of Tibetan refugees live

Table 1. Major themes and subthemes from interviews are identified via manual coding. The number of interviewees who individually reported or referenced each thematic element is listed. The total number of discrete references by all participants is calculated.

Theme	Subtheme	Number of Interviewees Reported	Total References
Tibetans as a refugee population	The <i>dispersed population</i> of the refugee community poses additional social and health challenges.	1	1
	There is an increased <i>difficulty in ensuring drug compliance</i> due to the dispersed population of the refugee community.	1	2
Sources of Stigma	There is a common misconception that HIV or TB is <i>incurable</i> .	2	5
	HIV is associated with a particular <i>narrative of transmission and "immorality"</i> (sexual promiscuity, illegal drug use, etc.).	4	5
	There is a <i>fear of infecting</i> yourself or those close to you.	4	5
	There is a <i>lack of awareness</i> about disease transmission which exacerbates stigma.	3	4
Existence of Stigma	There are high tuberculosis rates in the community.	5	6
	Despite these high rates, there is a decreased burden of tuberculosis now.	6	8
	Explicit reference to stigma denial.	3	6
	Explicit example or reference to anticipated stigma by a patient.	1	1
	Patient experiences discrimination for disease status.	4	5
	Patients suffer from decreased marriage prospects.	1	1
	Patients are generally isolated, either physically or socially.	6	10
	Patients are separated or banished from their families (isolation).	2	2
	Patients are socially excluded (isolation)	1	1
	Physical touch in non-medical settings with patients is purposefully minimized.	1	1
	Patients are blamed for their condition.	3	4
	Patients are dehumanized.	1	1

(Continued)

Table 1. (Continued)

Theme	Subtheme	Number of Interviewees Reported	Total References
Healthcare-Seeking Behaviors	Patients decided not to disclose their disease status to family or friends.	3	6
	Patients delay healthcare.	4	5
	Patients demonstrate resistance to receiving treatment.	4	6
	Patients purposefully opt to receive treatment at far-away hospitals.	5	7
Mental Health	Stigma specifically exacerbates or leads to mental health problems.	2	2
	Patients experience suicidal ideation or commit suicide.	2	5
	Patients express a lack of hope for the future.	5	5
	Patients experience self-doubt.	2	2
	Patients experience loneliness	3	4

in monasteries or nunneries, where they practice Tibetan Buddhism in exile. These locations are similarly high-density and facilitate the spread of tuberculosis.

As reported by interviewed healthcare workers, the dispersed nature of the Tibetan refugee communities in India as a whole complicates TB elimination efforts. The far distance between communities and a healthcare center may pose financial and structural barriers to TB diagnosis and treatment. Fortunately, the ZeroTB team at Delek Hospital is actively addressing this issue by traveling to schools and monasteries to identify cases and provide medical guidance. Still, challenges persist. Healthcare workers interviewed reported difficulties ensuring medication compliance among dispersed populations.

An additional factor in the development of stigma is the size and the political stability/vulnerability of the community. The Tibetan refugee population is comparatively small and isolated, as well as a particularly “gossipy” community, potentially allowing the impacts of stigma to be more strongly felt (Interviewee 10). In smaller communities, where members are familiar with each other, individuals may fear greater ostracization and judgment for their health condition. This is supported by Schroeder *et al.* who determined that stigma is stronger in rural communities (Schroeder *et al.*, 2020). While there are various confounding variables between this study and that of Schroeder *et al.*, it is likely that the small population and rural nature of the Tibetan refugee community predisposes it to stigma. This is exacerbated by the complicated political and cultural stability of the Tibetan community in India. Many Tibetans already feel like outsiders within India, forced to leave their homes and often their families. Migrant populations tend to be stigmatized for their refugee status, and, as explained by Baranik *et al.*, “refugees are more vulnerable to stigma” from outside of the community (Baranik *et al.*, 2017). In order to further understand the unique stigma experienced by Tibetans as refugees, it may be necessary to speak with members of nearby non-Tibetan communities and identify the central narratives.

As evidenced below, many of the stories provided by Tibetan healthcare workers pertain to Indian individuals. Many healthcare workers expressed greater concerns over stigma in Indian communities. Three explained that the Buddhist nature of the Tibetan community encourages compassion for all and therefore decreases the experience of stigma. However, all interviewed healthcare workers were members of the Tibetan community and therefore represent an inherently biased sample in this regard; members of the Tibetan community may be hesitant to criticize their own community through discussions of stigma. To avoid potential othering or misrepresentation of the two communities, this paper does not attempt to explain the perceived difference between the Indian and Tibetan communities. Quantitative and qualitative data from both communities would be necessary to evaluate this perception.

B. Existence of Tuberculosis Stigma

When first arriving in India in the mid-twentieth century, the tuberculosis burden for Tibetan refugees was incredibly high. As such, the existence of the disease became slowly normalized and accepted as part of life. As reported by one interviewee: “When we first came here in the early seventies, every other person had tuberculosis. It was everywhere . . . Now, I think it’s just accepted” (Interviewee 10). Other interviewees shared that “TB used to be a very big deal many years back” (Interviewee 6) and “Nowadays it’s a little better” (Interviewee 8). Many interviewees reported that the previously high rates and curable nature of tuberculosis in the Tibetan refugee community may have contributed to a sense of normalization and therefore decreased negative attitudes and stigma toward tuberculosis patients.

Although still high, the prevalence of tuberculosis in the Tibetan refugee community has been steadily declining in the past few decades. Prior to the COVID-19 pandemic, the Tibetan community in Himachal Pradesh experienced a 20% annual decrease in TB incidence (Interviewee 5). Six interviewees reported a previously higher prevalence, with a notably decreased burden in recent years. The emphasis placed on the current decreased burden speaks to the changing disease landscape and the potentially changing role of stigma in Dharamshala.

The most common reported source of stigma surrounding tuberculosis is the fear of infection. As explained by three interviewees, “TB is an infectious disease. There’s always a stigma associated with it” (Interviewee 5), “There was a level of fear surrounding catching TB” (Interviewee 4), and “People get scared when they hear TB” (Interviewee 7). Three interviewees reported some form of blame on the infected individual for their condition. Often the blame was on the patient, but in one case, parents blamed their child’s school for his tuberculosis. Patients and the school alike were blamed for poor nutrition and not taking sufficient preventative measures in all three cases.

The existence of stigma towards tuberculosis itself was debated in the interviews. Many interviewees clearly communicated the existence of stigma and its impacts on tuberculosis patients. One of the most common consequences of stigma was social exclusion or physical isolation of tuberculosis patients. This physical separation can start as a small, isolated action. One nurse shared that “I heard that people used to stay away from TB patients” (Interviewee 8), and another supported this observation, explaining that, “They can separate a little, separate a little bit from that person” (Interviewee 6). In some cases, family members go so far as to banish tuberculosis-positive individuals from the family and local area: “I’ve seen instances, there was one patient who was told to go back to her family because of the TB. And the father isolated her, basically. Told her to go away, don’t come back. Instead of like, helping her” (Interview 5). These stories do not exist in isolation,

but are heartbreakingly common: “There is this Indian girl, she is married and she has, I think, a four or five-year kid. But after her husband’s family knew that she had TB, they kicked her out. Yeah. So her brother is taking care of her now” (Interviewee 8). In other cases, the fear of physical and social contact extends beyond the immediate family:

[Explaining the experience of an Indian man and his family.] He was diagnosed with TB. So when we called his wife, his wife was very sad. Then wife was asking ‘sister, what to do in our community? People stop talking, people stop coming.’ Then after a few days, then she starts asking, ‘Can I go to the office? Can I go for a walk? Like that?’ she says. ‘Before I have so many friends. Now they stop’ (Interviewee 7).

Even the most minor of actions of social exclusion can be devastating to tuberculosis patients, as they signal that the individual is unwanted in the community. Sometimes, people will vacate a room if a tuberculosis patient enters, ostracizing them (Interviewee 8). The same nurse explained the experiences of a tuberculosis patient who wanted to shop for spices to add to his food:

“So he went inside the restaurant and on the table there were like, I think three ladies, something they did like this. *covers mouth with elbow* So he felt that what they are doing, it was for him. He said that he felt very sad when they did it. And then he said, from now on, ‘I’m not going to buy. I’ll ask someone to buy’” (Interviewee 8).

This exclusion and isolation can be exacerbated in cases of multi-drug resistant tuberculosis (MDR-TB), as there are greater risks and therefore fears of infection. One interviewee attributed stigma to not only family members and friends, but worryingly, to healthcare workers as well, saying that healthcare workers “don’t want to spend lots of time” with MDR patients (Interviewee 9). This minimal attention could be highly detrimental medically, both physically and mentally, for MDR patients, who already experience the compounded burden of limited treatment efficacy, greater medication side effects, and longer illness periods. This aforementioned isolation can expand beyond interpersonal interactions and into highly discriminatory practices. One interviewee shared his previous patient’s concerns that tuberculosis would impact their job and marriage prospects, explaining that “She was very concerned about her career as well, her marriage, whether she will find a good, decent boyfriend or not, whether somebody will reject her because of her TB status” (Interview 5). In one case, this fear of discrimination in employment was enacted, rather than anticipated: “He came from Tibet. I think he was not getting work due to his health issues. He did [eventually] get a work, but first is I think he’s not getting work due to the TB stigma because it might spread to the other people” (Interviewee 8). From these reports, it is clear that stigma surrounding tuberculosis infection exists in Dharamshala, and that it may be enacted in discrimination, specifically in employment and marriage prospects. The consequences of this stigma, isolation, and discrimination will be further explained in *Impact of Stigma on Patient Mental Health*.

While many interviewees were adamant that stigma existed, others believed that its prevalence had dwindled dramatically in recent years as tuberculosis infections decreased. As explained by three interviewees, tuberculosis stigma denial is commonplace in Dharamshala. Such denial can complicate active case detection, as explained by Interviewee 5, “There was a big denial. Some of us, we deny that there’s no stigma, on the baseline level. It is there . . . We tend to ignore, take it lightly. But stigma is there” (Interviewee 5). While this interviewee demonstrated a conscious recognition

of the role of denial, stigma denial itself was observed in a separate interview. One interviewee when asked if stigma complicates or prevents timely diagnosis and treatment, reported the relative absence of stigma, explaining: "Patients have less stress as we do, because it's [TB] common . . . Everybody comes . . . Even if they do the test once, if it is positive, they come to collect the result like that every day . . . they are happy to treat . . . They want to come here" (Interviewee 4). The same interviewee shared her personal story with tuberculosis, somewhat contradicting her later reported lack of stigma in the Tibetan community and demonstrating a fear of discrimination due to her tuberculosis-positive status:

"When I was in nursing school, I used to take the medicine to get supplies from here. One of our doctors saw my medicine. [He asked,] 'Oh are you taking this?' [She replied,] 'No, it's for other people.' Otherwise, they will not admit me. I get admission problem" (Interviewee 4).

This contrast is difficult to explain but is highly informative. Denial or lack of awareness does not wholly account for the three well-informed healthcare workers who reported a relative absence of tuberculosis stigma. It is possible that as tuberculosis is normalized and fear subsides, stigma also dissipates. It is worth noting that the interviewee's personal experience occurred decades ago, and therefore may speak to the changing perceptions of stigma over the past few decades. Another interviewee, when asked about the prevalence of tuberculosis stigma, explained that "I wouldn't say that so much. It's not as I said, with TB right? Because so many people had it" (Interviewee 10). Another nurse recognized the historical influences of tuberculosis stigma, but similarly believed it did not exist today:

"I've heard a lot about TB stigmas and all. But I think it has decreased . . . Because these days people come with whenever they get school symptoms and everything, they'll just come and do the TB checking. So I think these people are not that much hiding about their TB symptoms" (Interview 8).

Following these comments, it is absolutely possible that the stigma towards tuberculosis has decreased in Dharamshala as tuberculosis infection has become more normalized. Meanwhile, another possibility is that as tuberculosis infections have become commonplace, so have the discriminatory actions correlated with infection. This would make the discriminatory consequences of stigma increasingly difficult to identify. Additionally, it is possible that the characteristics and narrative surrounding tuberculosis stigma in the region have changed, but its exact quantitative prevalence has not. This contradiction cannot yet be reconciled.

C. Existence of HIV Stigma

The aforementioned relative normalization of tuberculosis does not apply to HIV, which remains a relatively new and low-burden disease in the Tibetan community. Additionally, as compared to tuberculosis, no interviewees denied the existence of HIV stigma; in fact, most vehemently communicated its detrimental impact.

Stigmatization of HIV is not only derived from a fear of transmission but also a perceived disruption of the cultural norm of heterosexual monogamy. Transmission of HIV is believed to occur only through sexual contact, particularly extramarital sexual relationships. This

simplistic relationship is clearly conveyed by two interviewees, who explained that “mainly [the general public] they’ll think that HIV comes to only sex. . .” (Interviewee 7) and that “People think that if you were sexually active like that” then you can contract HIV (Interviewee 4). This direct correlation between sex, a culturally taboo topic, and HIV contributes to its stigmatization:

“HIV gets lost in stigmatization because you have this tendency of like, you have done some scene, you have extramarital affairs, you have slept with some other so that is a big drawbacks, that kind of stigmatization” (Interviewee 7).

Aside from the sexual connotation, HIV is also perceived as an illness that only afflicts people who engage in risky or deviant behavior. One interviewee exemplified this belief and correlated

HIV with alcohol use and “shady things” (Interview 7). This stigmatization is clearly perceived by patients, who fear judgment from their community as a result of this correlation with sexual activity. It is common for HIV patients to hide their illness because they are “afraid that it’ll get out to the community and people will treat them differently” (Interviewee 4). In one instance, a patient was so afraid of this stigmatization, even more so than the disease itself: “She seemed so frightened, really, of the disease . . . because of the social repercussions” (Interview 10). Like with tuberculosis, a common result of HIV stigmatization is the unnecessary physical and social isolation of affected individuals. One nurse explained:

“It’s sad to see some patients when they [family members] bring the food, they will bring the food paper on a plastic plate . . . They don’t want to touch it . . . And they won’t go to the patient. They will call nurses . . . They won’t touch the patient at all . . . They don’t want to show their face. I don’t know how they feel. But they will act like she or he is useless” (Interviewee 7).

This isolation can exacerbate fears over the disease itself, as well as loneliness and self-blame. Overall, HIV stigmatization is incredibly real in the Tibetan community, and results in isolation of affected individuals for fear of transmission and punishment for perceived violation of social norms.

D. Impact of Stigma on Patient Mental Health

This stigmatization profoundly impacts how a patient perceives themselves and how others perceive them, affecting their mental health and overall recovery from tuberculosis or HIV. However, it is difficult to discern the source of patient mental health difficulties, as they are compounded by the disease itself, stigmatization, discrimination, and medication side effects.

On one hand, the impact of a tuberculosis diagnosis itself and the subsequent symptoms can naturally impact a patient’s mental health. The debilitating symptoms and impending treatment regimen can “mak[e] them a little anxious” (Interviewee 6). Anxiety, depression, and low self-esteem were frequently reported mental health changes. These changes were visibly observed in patients, particularly those with complicated or MDR TB: “We have seen, especially among the college women students who were diagnosed with TB, initially they were okay, but during the course of the treatment, they become very depressed. They lose their self-esteem” (Interviewee 5). The story of one particular woman, an MDR-TB patient who sadly lost both of her parents to tuberculosis, was shared by her doctor:

“By the end of treatment, she had become very psychologically, physically drained. She was not the person that we saw her before and she was very short in confidence . . . We had to admit her for another one year because if we had sent her back to home, she had developed some suicidal ideas, tendencies, and her family, both parents had expired” (Interviewee 5).

The exact mental health consequences depend on the specifics of diagnosis (pulmonary vs. extrapulmonary, drug-resistant or non-drug resistant, etc.) as well as the individual’s unique conditions (Interviewee 9). In MDR-TB, the two-year course of treatment can be particularly disruptive to a patient’s life and can be “demoralizing” (Interviewee 6). HIV and TB-coinfected patients often “were really depressed,” more so than patients with either single infection (Interviewee 6). However, with prompt treatment, the physical symptoms are quickly mitigated and a non-MDR TB patient can return to normal life in just a few weeks. The hospital staff reassure anxious patients that:

“You’ll deal with some kind of anxiety, of course, sleepless night. But you have to ensure, you have to convince them that it’s temporary. There’s always a light at the end of tunnel. You’ll have this difficult time but eventually you’ll come through and come over it” (Interviewee 5).

Both Delek Hospital and the Tibetan Children’s Village clearly recognize the importance of acknowledging and addressing a patient’s mental well-being, in addition to their physical disease state. Mental and emotional struggles in tuberculosis and HIV patients are common, and must be addressed by healthcare professionals in order to decrease the suffering of the patient.

To complicate the matter, tuberculosis medications, particularly isoniazid, can have side effects that affect a patient’s physical and mental health. Common side effects include a loss of appetite, change in urine color, nausea, weakness, fatigue, numbness, and blurred vision (CDC, 2016). Isoniazid, a popular tuberculosis treatment medication, can cause medication-induced psychosis, anxiety, and depression (Yang *et al.*, 2017). These medication side-effects compound existing mental health conditions: “TB medicine itself is very toxic. You’ll have lots of side effects with those medications. Some psychological side effects also anxiety, insomnia, depression and plus the background of psychosocial dynamics that exist in the family” (Interviewee 5). It can be difficult to determine which mental challenges are caused by medication and which were pre-existing or worsened by a patient’s diagnosis.

These mental health challenges are exacerbated significantly by the experience of stigma, which often attributes blame or shame to a patient, and worsens physical and social isolation. As explained by one healthcare professional, stigma has direct impacts on patient mental health:

“And some of them had personal experience, obviously. And with those kind of stigmatization, you tend to feel very low. You tend to feel low on self esteem. Your confidence level goes down. As a result, you’ll have lots of psychological thing, especially mental illness with the TB patient” (Interviewee 5).

Another indirect impact of stigmatization is the increased physical and social isolation of patients. The constant isolation can contribute to a feeling of loneliness, particularly if patients do not have sufficient family support. As explained by a former MDR TB patient and then relayed by a nurse, in the “beginning you will feel like lonely and you will be very unhappy” (Interviewee 7). Interviewees

reported that patients without a supportive family or social network needed greater amounts of time to recover, suggesting that mental well-being directly impacts treatment efficacy. Families and friends can help emotionally support patients, encourage them to continue treatment during difficult periods, and serve as a source of accountability for their recovery, as explained by one nurse:

“But if they have their family, families, then it’s easier. Family can convince them, even if you are not able to. But some TB patient, if they are alone, they don’t have anyone to look after them . . . But some patients, I think those patients who have their family support, they get better quicker . . . But some some patients, I don’t think they have parents or family because they came from Tibet alone . . . They need more time because they are alone . . . You don’t want to live alone or feel alone” (Interviewee 8).

These feelings of isolation or loneliness are exacerbated without a supportive family network, which may be complicated by the ongoing migration from Tibet and the subsequent disruption of family dynamics. Additionally, while most Tibetan patients are accompanied by at least one family member or friend, those without family support require increased engagement with the health system. Although essential to ensure a successful recovery, this can lengthen periods of hospitalization and increase feelings of social isolation. One doctor explained, “We do get patients who don’t have any family support. They are on their own. And some of them are drug addicts, homeless. When they come to us, we keep them till the end of treatment” (Interviewee 5). In these situations, patients feel “pretty isolated being there for two years without family” (Interview 10).

At its worst, this stigmatization can cause severe deterioration of a patient’s mental health to the point of suicide. The aforementioned MDR patient who faced employment discrimination as a result of his TB status struggled severely with stress and hopelessness. After a few months receiving treatment, he decided to end his own life (Interviewee 8). This devastating phenomenon is not uncommon, as explained by one healthcare worker:

“It’s not restricted to the stigmatization. It has lots of implications, both physical and mental . . . And we have seen people to the extent of committing suicide . . . Because of the discrimination, because of the loss of job, because of not able to meet their own aims, because they are like out of work with the TB. So, yeah, it has a huge implication. We talk stigma, but yeah, psychosocial, mental, everything” (Interviewee 5).

Clearly, stigmatization of TB and HIV can have incredibly life-threatening consequences for patients, who already must struggle with the physical and emotional difficulties of their disease, and compounds the trauma they experience.

Regardless of the precise source of the mental health challenges, there is a clear recognition among healthcare workers that “the physical health and the mental health both should be they go together” (Interviewee 6). Importantly, the medical staff in the Tibetan community seem uniquely aware and receptive to the mental burden of tuberculosis and HIV infections, in addition to the physical and pathological changes.

E. Impact of Stigma on Healthcare Seeking Behaviors

This stigma, while harmful on its own and in regards to its consequences to patient mental health, is doubly dangerous if it alters patient healthcare-seeking behaviors. This investigation revealed

four major behavioral consequences of stigmatization of TB and HIV: delayed healthcare visits, resistance to disclosing their diagnosis, traveling to far-away hospitals, and refusal to follow treatment regimens. In order to effectively prevent transmission and eliminate these two diseases, early diagnosis, and thorough treatment are essential; without them, TB and HIV will persist and spread. Stigma, therefore, helps sustain transmission and perpetuates patient suffering.

For both HIV and TB, concerns over how a patient's family or broader community would perceive them led to conscious delays in seeking healthcare. When symptoms first arise, so may fears of illness and its corresponding stigma, particularly the isolation that ensues. Before patients even knew they were TB or HIV-positive, stigma influenced their behavior. Particularly within a small community, fears of disease status spreading may make people hesitant to test. As explained by one interviewee about HIV: "They're [Tibetan community members are] very frightened to talk to anyone even go to a doctor, because if they do that, everyone will know and . . . they will not be accepted in their family anymore" (Interviewee 10). Such statements clearly correlate fears or anticipation of stigma with delays to receive early testing and treatment services. The impact of this delay in seeking healthcare, specifically with regard to tuberculosis, is explained by one healthcare worker:

"You know that you have some TB-like symptoms, but you will not access health care on time thinking that you'll be stigmatized . . . You don't go to the hospital on time, you don't seek health care, and when you're staying with your family with those kinds of symptoms, you risk spreading it" (Interviewee 5).

Delaying a diagnosis does not prevent disease progression, but actually allows the pathogen to grow and spread more easily. When a patient does not know their disease status, they are less likely to take adequate prevention measures and risk spreading the illness to their family and friends. As such, stigma-motivated delays in healthcare are incredibly dangerous to a community's health.

Similarly, fear of stigma can prevent a patient from revealing their diagnosis and taking necessary measures to prevent disease transmission. This correlation between anticipated stigma and diagnosis disclosure was clearly explained by one healthcare worker: "You fear that you will go through that same stigma, and as a result, you will not disclose your TB status" (Interviewee 5). One HIV and TB co-infected patient did not want to disclose her disease status for fear of stigmatization and therefore stopped taking treatment, afraid that the medication would connect her to the illnesses. When a nurse followed up with the patient about her treatment adherence, she "refused" to take the medication. The nurse explained that "she's worried that everybody knows about her diagnosis. She's worried about that . . . [The patient explained,] 'I was known to many of the people around in Delhi. If they know my diagnosis, I'm not comfortable'" (Interviewee 4). This hesitation or refusal to disclose their diagnosis can affect a patient's willingness and ability to follow through completely with a treatment regimen. While patients have a right to maintain privacy regarding their diagnosis, failure to disclose their disease status may place close contacts at risk. Additionally, if their family or close friends do not know their disease status, the patient may not have a robust emotional support network and may have a difficult time appropriately following treatment regimens.

Even if patients do not overtly fear ostracization from the community, they may worry about how their diagnosis will affect those around them because of socially ingrained messages surrounding HIV or TB. One nurse explained that she herself did not share her TB-positive status with her family because she "thought that they will get stressed and they will be worried like that"

(Interviewee 4). She waited until after her treatment was finished, opting to spend weeks alone in the hospital without her family's support, to finally share her diagnosis.

The most common change in patient behavior in response to stigma was the decision to receive treatment at a hospital outside of the patient's local community. Five healthcare workers shared stories of patients who traveled hours away to receive treatment for fear that news of their diagnosis would spread easily at a local hospital. This finding was relevant for both Tibetan and Indians; Tibetans traveled outside of Dharamshala for treatment, while Indians often came to Delek Hospital from other areas of India. For Tibetans, this need to travel to far-away hospitals was found more in HIV-positive patients than TB-positive patients. The stigmatization of the disease, coupled with the small nature of the community, drove HIV patients to travel hundreds of miles to receive treatment:

"You don't want to go to a place where people know you. Some of the Tibetans who have HIV, they don't seek help, care from our hospital. They really prefer going to other hospital. Because it's a smaller community and they don't want people to know . . . So people, Tibetan especially, even if they have HIV, they don't seek health attention from a place where Tibetans are working . . . We hear and see people, Tibetan people going to some other hospitals in the south or in New Delhi, accessing health care . . . I mean, that shows the stigma is quite strong. That makes you move hours" (Interviewee 5).

This trend was echoed clearly by other interviewees, who explained that Tibetan patients will not receive HIV treatment services as Tibetan hospitals:

"One lady was very, what do you say, worried. She took it from Indian hospital, not from our hospital. Thinking that the world will spread around the Tibetan community like that . . . So in terms of keeping it secret, people are afraid that it'll get out to the community and people will treat them differently" (Interviewee 4).

This fear of isolation and ostracization expanded into concerns over patient safety for one Tibetan healthcare worker:

"They won't go to the Tibetan hospital because it's a very little society . . . Maybe they will go to some Indian hospital. Like they'll keep some confidential . . . It was because of confidentiality and for their safety only" (Interviewee 7).

This concern about confidentiality and safety is worrying: patients clearly anticipate social consequences for their HIV status and are prepared to take drastic measures to receive treatment. Traveling such far distances can compound the burdens of HIV, further draining financial resources, requiring additional time investment, and additionally disrupting patient life.

Reportedly, this trend of seeking treatment at far-away locations out of fear of stigma is similar for TB-positive Indian patients. One nurse shared that patients travel "from all over India . . . From South India and then Sikkim, Nepal and then Himachal" to receive treatment at Delek Hospital (Interviewee 4). However, in addition to the impact of stigma on these patients, it is also possible that Indian patients are traveling long distances because of the reputation and efficacy of Delek Hospital. The motivating factors for travel for Indians are less apparent than for Tibetans.

IV. Limitations

While this research provides a crucial look at stigma within the Tibetan refugee community, a previously underexplored topic, certain factors restrict the quality and generalizability of this work. This research was limited by resource and time constraints, including sufficient access to participants. This research aptly analyzes the perspectives of healthcare providers, but therefore inherently does not represent the experiences of all Tibetans in Dharamshala. This research would be strengthened by greater inclusion of non-medical voices, including but not limited to, former patients, their family members and friends, and non-affected laypeople. Additionally, active TB patients were excluded from the study in order to avoid adding to their emotional burden. The exclusion of active patients, while necessary for ethical reasons, complicated the inclusion of patient voices due to the dispersed nature of the community; after treatment is complete, patients tend to return to their community, which is often hours away. In order to produce a study that accurately portrays the individualized experiences of TB and HIV patients, it would be necessary to recruit more affected participants with a non-healthcare background. This study would benefit from greater inclusion of TB or HIV-patient voices, as well as those of their family and friends. It would also be beneficial to recruit more non-Tibetan voices, as they may provide an outsider perspective through which to analyze the role of stigma in the Tibetan community. It may, understandably, be difficult for a community to identify the precise influences of stigma from within. Finally, this project would benefit from a greater understanding of the nuances of the experiences of Tibetan refugees, as well as the unique role of Tibetan culture, religion, and refugee status on the effects of stigma, provided by greater time and integration within the community.

V. Recommendations for Further Studies

Further studies must address the aforementioned limitations, particularly through recruitment of affected or previously affected individuals. Such a study would allow tuberculosis or HIV-positive individuals to contribute their own knowledge and experiences, and in doing so, greatly augment the general understanding of the impact of disease and stigma on mental health.

Further research may disaggregate findings by patient gender and analyze the experiences of stigma in a broader context of gender and sexuality in the region. Additionally, a comparative study of the experiences of stigma between the Tibetan and Indian populations in Dharamshala would be highly informative. Such a study would help identify the nuances and improve understanding of the Tibet experience in India, as well as identify sociocultural and religious factors correlated with the development of stigma.

VI. Conclusion

HIV and tuberculosis are impactful and variably stigmatized diseases in the Tibetan community in Dharamshala, India. Individual interviews with healthcare workers conducted at Delek Hospital and the Tibetan Children's Village revealed patterns in the impact of stigma on patient mental health and healthcare seeking behaviors, including delayed healthcare visits, patients' resistance to disclosing their diagnosis, traveling to far-away hospitals, and refusal to follow treatment regimens. These findings are unique to the Tibetan refugee population in Dharamshala, but do not yet provide

a fully nuanced understanding due to resource and time constraints. The stigmatization of these diseases unnecessarily exacerbates suffering for those afflicted and their families, compounding to the existing physical and emotional burden of diagnosis. Stigmatization, and its consequences to patient mental health and disruption of healthcare-seeking behaviors, serves as a dangerous barrier to effective public health interventions and disease elimination.

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