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Letter from the 2022-2023 Editors

Avery Tomaso* and Geetanjali Rastogi†

Dear Readers,

Thank you for taking the time to read the seventh edition of the *Undergraduate Journal of Public Health*. Although we are emerging from the COVID-19 pandemic, its effects can still be felt in our political, economic, and social landscape. It is of the utmost importance to keep public health and scientific research at the forefront of our thinking to navigate this “new normal” and mitigate the massive impacts it has had on already disempowered populations. In an era of misinformation where some question the validity of scientific research, we feel it is important to continue to produce and promote reliable and research-backed information – in particular in the field of public health.

Given its applied nature, sound public health guidance draws from research in multiple fields. To that end, our journal authors and editors come from a variety of disciplines and are interested in a variety of prominent public health issues. Our authors come from our home state of Michigan and from institutions across the country, representing interdisciplinary public health issues at the local, national, and global levels. The articles that were chosen to be featured in this year’s edition of the journal are reflective of our goal as a publication: to highlight the issues being actively researched and discussed in the field. Based on this year’s submissions, we decided to include a special section on HIV/AIDS, with three pieces that examine the impacts of the virus within different populations.

We want to express our unconditional gratitude to our editorial team who have worked since September to make this year’s edition of the journal the best it can be. Our journal would not be possible without their dedication to producing a polished final product. We also would like to thank our faculty advisor Dr. Ella August for her willingness to help and guide us through the process and for her support in our endeavors from the start. Additionally, we would like to thank and acknowledge our Ph.D. reviewers, who brought a new breadth of experience and level of knowledge to the final stages of the editing process; our authors and their work greatly benefited from your eyes. Publishing this journal would not be possible without the guidance and support of MPublishing, and we thank them for raising our journal to a level of professionalism we could not have achieved

*University of Michigan, atomaso@umich.edu

†University of Michigan, grastogi@umich.edu

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without their guidance. Many thanks to our cover artist Yoo Young Chun for once again taking our journal's themes and expressing them in a beautiful and artistic way for our cover. Finally, to the University of Michigan School of Public Health, thank you for your support since the journal's first edition in 2017.

Ultimately, the people we need to thank most are our authors – without whom this publication would not have been possible. We greatly admire your dedication to your chosen fields and would like to acknowledge the great accomplishment that it is to have your work published as an undergraduate student. We know you will all go on to make significant contributions to the field of public health and that your work will continue to have an impact on readers and on the academic world at large.

We reflect on our time here with great enjoyment and are very proud to present Volume 7 of the *Undergraduate Journal of Public Health*.

Sincerely,
Avery Tomaso and Geeta Rastogi
Co-Editors-in-Chief, 2022–2023

Behind Walls: Mass Incarceration as an Oppressor of Reproductive Justice in the United States

Anna Razvi*

The purpose of this study is to determine if and how mass incarceration denies women of color their right to reproductive justice in the United States. By analyzing the prison system's legal framework as well as its practices, the study aims to analyze both known and unknown barriers to reproductive justice in the correctional setting. Data on such policies and practices was collected through personal interviews as well as through podcast interviews with formerly incarcerated women and a lawyer knowledgeable in prison healthcare laws within the United States. The findings from this data indicate that incarcerated women are not just denied necessary reproductive healthcare but also essentially punished by the prison system for existing as reproductive individuals. Furthermore, this oppression disproportionately harms women of color due to the disproportionate mass incarceration of black and brown people in the United States, which stems from the criminalization of poverty and the "war on drugs" that began in the 1970s. These findings imply that there are a large number of women who have and continue to be dehumanized and threatened behind walls. Reproductive healthcare is necessary healthcare; thus, it must be prioritized in prison reform and legislature.

Keywords

reproductive health • maternal health services • health services accessibility • human rights • incarcerated women • correctional institutions

Mass Incarceration: Instrument in Reproductive Oppression for Women of Color

Since the 1970s, the rate of incarceration for women has surpassed that of men (Ricker, 2020). This rate disproportionately affects Black and Latina women as a result of the "war on drugs" and the criminalization of poverty (Hayes, Sufrin, & Perritt, 2020). Ricker (2020) states that in 2017,

*George Washington University, annarazvi@gwmail.gwu.edu

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225,000 women were incarcerated in local, state and federal jails. Although African-American women only make up 13% of the United States' female population, they account for 50% of the U.S. incarcerated female population (Mearns, 2011). This demonstrates a grossly disproportionate number of women of color in prison, usually serving extensive sentences for first-time, nonviolent crimes (Ricker, 2020).

Beyond the social and economic consequences of mass incarceration, women of color must also face difficulties in accessing reproductive and prenatal healthcare in prison (Dyer, Hardeman, Vilda, Theall, & Wallace, 2019). Dyer et al. (2019) studied childbirth outcomes for incarcerated women in Louisiana and found a 3% higher risk of preterm births among Black women in parish jails. Furthermore, women in prison are suppressed of their reproductive rights, or what Hayes et al. (2020) refers to as reproductive justice: the right to choose if and when to have children, the right to not have a child, and the right to raise their existing children with the proper resources and support. In prison, women can be separated from their newborn children after 24 hours, be unable to access an abortion without payment or a court order, and sometimes be sterilized without consent, as done with women in California until 2010 (Hayes et al., 2020).

The issue of the oppression of reproductive rights for women of color through the system of mass incarceration results in the degradation and dehumanization of both mothers and their children; take, for example, Kima, an incarcerated African-American woman who was convicted for shoplifting, a nonviolent crime. Kima gave birth to a baby girl named Koia while in prison and was only allowed to spend 12 hours with her postpartum before a child service worker took Koia to place her into child protective service's custody. After that, Kima was allowed to spend time with her daughter only under the supervision of an officer, with one wrist handcuffed (Hayes et al., 2020). The first days a mother and her newborn child spend together are arguably the most valuable and vital ones, and yet Kima was denied this right due to her status as an incarcerated woman. Furthermore, she was denied the proper support to raise her children, a violation of reproductive justice (Hayes et al., 2020). In Texas, an incarcerated woman went into preterm labor and asked for medical attention but was ignored until 12 hours later, when she delivered a child with the umbilical cord wrapped around their neck. The available nurse did not do anything to assist the woman, and the child died before paramedics could arrive (Sufrin, Kolbi, & Roth, 2015). These women were denied their right to motherhood, consequently resulting in physical and mental trauma that they will be unlikely to address due to a lack of access to healthcare both inside and outside of prison. Considering that Black women are two to three times more likely and Latina women are one-and-a-half times more likely than white women to be incarcerated, these violations of reproductive rights disproportionately occur to women of color (Sufrin et al., 2015).

The lack of reproductive healthcare and rights for incarcerated women of color is, at its core, an interpersonal issue due to the nature of mass incarceration. Between 2000 and 2013, the rate of female incarceration rose by 30%, with a disproportionate number being women of color (Sufrin et al., 2015). These women, who are already at a higher risk of adverse perinatal outcomes (Nabukera et al., 2009), are subjected to even higher rates of adverse outcomes in prison (Sufrin et al., 2015). Two-thirds of incarcerated women are mothers and primary caretakers of children (Hayes et al., 2020); the children of women of color are more likely to be placed into foster care due to the absence of a male partner, who is also more likely to be incarcerated (Freudenberg, 2002). These children undergo severe mental trauma, as indicated in a study with children of color in foster care between the ages of 15 and 17, where all but one participant had a diagnosed mental illness (Scott, 2008). Scott (2008) found that these disorders were further aggravated by

their separation from their biological families. The oppression of reproductive rights of women of color is not isolated to just these women – rather, it creates a domino effect that harms entire communities of color.

Another aspect of reproductive justice is the right to decide when to have children as well as not have children; this brings up the question of access to abortions and contraception, both of which are inconsistent among prisons in the United States. Abortions are not elective procedures, though they are often defined as one. An abortion must be completed within the timeframe of three months, as most doctors will not perform abortions after the twelfth week of pregnancy due to risks to the patient and child, while elective procedures are not limited by any timeframe (Planned Parenthood, 2020). Sixty-eight percent of prison healthcare providers report providing abortions, but there are variations in assistance regarding transport, cost, and other factors; there are no defined and enforced guidelines regarding access to this procedure. Access to contraception in correctional facilities is even more difficult or impossible to obtain, even though it is extremely necessary as 60% of incarcerated women reported in a survey that they would prefer to start birth control prior to their release (Sufrin et al., 2015). This results in the complete suppression of all aspects of reproductive justice, and it severely affects women of color, who are already victims of prejudice and discrimination in the forms of racism, sexism, health and housing inequities, and colorism; along with these issues, they lose a part of their humanity through reproductive oppression in prisons and jails. Considering that pregnancy outcomes in correctional facilities were not reported until recently in 2019, it is evident that more research and data should be required of U.S. prisons and jails regarding women's access to reproductive healthcare (Hayes et al., 2020).

The impact of mass incarceration and its oppression of reproductive rights reach far beyond the communities directly affected by it. This oppression results in a violation of human rights, as stated in the Supreme Court ruling on the *Estelle v. Gamble* case in 1976. The court ruled that “deliberate indifference to serious medical needs” was a violation of the Eighth Amendment, granting incarcerated men and women a right to healthcare. However, it is evident that this ruling has never been strictly enforced due to the lack of policy regarding this issue. This lack of widespread and enforced policy is also illustrated by the *Monmouth County Correctional Institution Inmates v. Lanzaro* case in 1987. The Third Circuit Court of Appeals, covering Delaware, New Jersey, and Pennsylvania, determined the right to abortion as a right to healthcare; this is the only case in the country that clearly defines abortion as a healthcare service that the state must pay for in the context of correctional facilities. However, due to the lack of policy, this ruling has not been strictly enforced either. This issue can and must be addressed at the national level through the passing of federal policies; the absence of these policies violates the very foundation that the United States was built on (Sufrin et al., 2015).

Little is known about the real barriers to reproductive healthcare that incarcerated women of color face on a day-to-day basis, and even less is known about the effects on the health of these women caused by reproductive oppression. The reproductive oppression that occurs to women of color behind bars promotes the harmful health disparities seen in this demographic in the United States; evaluating the barriers to reproductive health services will help to understand what policies and regulations must be put into place to prevent this oppression. This article will study women of color's access to reproductive healthcare in prison to determine the barriers and disparities contributing to the suppression of reproductive rights and to understand how mass incarceration has played a significant role in health disparities for women of color.

Conceptual Framework

Reproductive justice is a framework itself that encompasses several different facets, and it is critical to the understanding of reproductive health and rights for incarcerated women, especially women of color. Barriers to reproductive justice that incarcerated women face include a multitude of issues that include shackling, financial instability, and a lack of gender-sensitive policies; thus, this article will differentiate between social and physical barriers in order to gain a nuanced understanding of the varied issues that contribute to the oppression of reproductive justice in prison.

When addressing physical barriers such as prison healthcare systems, factors such as state and federal law, funding, and policies within the system must be considered. In order to examine this and other physical and legal barriers, research and data that evaluate disparities or determine different barriers that attribute to the issue may be useful. Social interactions, the implications of race, and other social barriers presented to incarcerated women are most effectively assessed through studies that account the experiences of incarcerated women or survey health professional biases.

Reproductive Justice in Prison

The reproductive justice framework was first mentioned in the 1970s by Black female activists such as Frances Beal and Toni Cade Bambara; it was later adapted in 1994 at the Black Women's Caucus in Chicago (Ross, 2016). Reproductive justice is inherently intersectional and focuses on bodily autonomy for women of color. It is not only concerned with reproductive rights, as it does not only encompass the moral right to healthcare but instead emphasizes the total well-being of women and recognizes reproductive healthcare as a component in "the protection of physical, mental, spiritual, political and economic social well-being of women and girls" (Ross, 2016, p. 1). Reproductive justice is defined on three levels: every woman has the right to choose when and if to have a child, the right to not have a child, and the right to raise existing children with the proper resources and support in a healthy environment (Hayes, Sufrin, & Peritt, 2020; Sufrin, Kolbi, & Roth, 2015). Ross states that reproductive justice is essentially "reproductive rights embedded in a human rights and social justice framework" (2016).

This presentation of reproductive justice encompasses the main areas of reproductive health and is inclusive of all women. Though reproductive justice is a universal framework, it is very rarely considered in the context of correctional facilities, where the very nature of jails and prisons places constraints on an individual's freedom. Furthermore, this definition is centered around reproductive healthcare as it pertains to pregnancy and children but fails to consider the components of reproductive healthcare that are not necessarily related to this. This includes menstrual healthcare and preventative care such as treatment and testing for sexually transmitted diseases. The framework of reproductive justice is not a major point of focus in the field of research concerning reproductive healthcare in prison; thus, the few studies, including Agénor (2019) and Fortuna et al. (2019), that reference this concept all unanimously agree upon the three components of reproductive justice.

For the purpose of this study, reproductive justice will be defined as it is most widely used: the right to choose when and if to have children, the right to not have children, and the right to raise existing children within a safe environment with the necessary resources.

Physical and Legal Barriers

Physical and legal barriers to reproductive care within prison are varied and complex; they are also often connected to social barriers. One of the most commonly discussed and influential legal barriers are the disparities across prison healthcare systems. In general, correctional facilities and their policies are not gender-specific; they are never built with incarcerated women in mind, and this greatly disadvantages the fastest-growing incarcerated population (Skerker, Dickey, Schonberg, MacDonald, & Venters, 2015). The variations in policies among prisons in the United States are wide-ranging. In a survey of 286 correctional healthcare professionals, 68% indicated that incarcerated women had access to elective abortions, and only 54% reported providing assistance with making appointments (Sufirin, Creinin, & Chang, 2009). In another study by Kelsey, Medel, Mullins, Dallaire, and Forestell (2017), 31.4% of 53 correctional facilities reported having no onsite OB/GYN care, and 86% reported not charging for these visits. Reproductive healthcare is a right that anyone should have access to; charging for this service is a blatant exploitation of incarcerated women, who are already more likely to be of a low socioeconomic status (Kajstura, 2017). Skerker et. al (2015) explained the lack of gender-specific policies and practices within prisons well: “most prisons are designed to serve men and not women . . . and much less women of color, who have experienced a history of bodily autonomy suppression.” Furthermore, Sufirin et. al (2009) noted that abortions were more accessible to incarcerated women in states with Democratic or bipartisan legislatures, reflecting the legal barriers that restrict incarcerated women and further deprive them of their reproductive rights. Besides access to abortions and other reproductive services, state prisons often fail to provide the necessary nutrition, clothing, and rest for pregnant women (Shlafer, Hardeman, & Carlson, 2019). There is also a lack of resources for incarcerated women regarding sanitary and hygiene products (Van den Bergh, Gatherer, Fraser, & Moller, 2011).

It is evident that prison health systems and the disparities present among them are widely researched and discussed; this legal barrier is perhaps one of the most important factors in access to reproductive justice for incarcerated women, so it is important that this be thoroughly assessed and evaluated. Studies covering this barrier succeed in providing a comprehensive overview of how deeply this issue affects reproductive justice. However, this barrier, as defined by studies in the field, is not inclusive of other aspects of reproductive health, such as contraceptive use, testing, or screening.

A less commonly discussed physical barrier is the shackling of pregnant women. Shackling, or the use of handcuffs or “belly chains,” is commonly used on pregnant women in prisons; 36 states permit the practice regardless of a woman’s history of violence (Ocen, 2012). In a survey of 53 women’s prisons in the United States conducted by Kelsey et al. (2017), 17.4% reported shackling during labor, while 56.5% reported shackling women after birth. This practice is highly dehumanizing for pregnant women, who are already physically incapacitated and in severe pain, making the need for shackles unnecessary. Additionally, many women in prison are serving sentences for first-time nonviolent offenses, proving the use of shackling to be completely unnecessary (Ricker, 2020). Not only is this practice dehumanizing, but it also carries deeper implications for African-American women, who have a history with “historical devaluation, regulation and punishment of their exercise of reproductive capacity” (Ocen, 2012). African-American women’s history of slavery and the historic loss of their bodily autonomy combined with the phenomenon of mass incarceration mean that shackling affects this group of women the most (Willingham, 2011). It is evident that though shackling may be inherently physical, it is also social in nature.

Shackling is a physical barrier that should be evaluated when discussing reproductive justice as it pertains to incarcerated women of color; childbirth in a chosen and safe environment is critical to the reproductive justice framework, and shackling inhibits this. The social implications for African-American women are considered in these studies by taking the intersectionality of race and gender into account, as is done in this study. However, studies that discuss shackling fail to address how shackling may impact the physical and mental health of incarcerated pregnant women, who already undergo considerable stress and other health issues. The health impacts of shackling may provide further proof of the harmful nature of this practice.

For the purpose of this study, disparities across healthcare systems as well as shackling will be the main focus of addressing physical and legal barriers.

Social Barriers

Social barriers are more difficult to evaluate and assess as there are less markers by which these barriers may be measured. A common social barrier that is discussed in this field is the prevalence of sexual abuse of pregnant women; this may manifest in different ways, but most often in the form of strip searches. Sexual abuse, both previous and in prison, traumatizes women, strips them of their dignity, and may even deter them from receiving reproductive or prenatal healthcare. Sexualized violence toward incarcerated women is normalized due to the fact that male prison guards and other staff are essentially immune and rarely face any consequences for the abuse of their authority (Ocen, 2012). The sexualized violence toward women of color has implications as it furthers the abuse of authority and control between white men and black women, essentially continuing the cycle of sexual violence that is native to slavery (Willingham, 2011). In general, women in prison can be coerced into sexual relationships in exchange for basic needs or the fear of being placed in solitary confinement, which further separates a woman from her existing children (Skerker, Dickey, Schonberg, MacDonald, & Venters, 2015).

More specifically, sexual violence is presented in the form of strip searches in correctional facilities. Strip searches are routine in prisons but are often used to coerce incarcerated women; they can be forced to strip or face the consequences of noncooperation, which are usually solitary confinement (Strip Searching as Sexual Assault, 2001). These strip searches do not just dehumanize a woman; they strip a woman of her bodily autonomy. This is demonstrated by a prisoner's statement that "I was never allowed to forget that, being a prisoner, even my body was not my own. . . . I was compelled to submit to be undressed and searched" (Strip Searching as Sexual Assault, 2001). Without bodily autonomy, reproductive justice cannot exist, making abusive strip searches a violation of a woman's reproductive rights. Furthermore, strip searches deter women from receiving healthcare, as they are often forced to strip before they enter a health facility, as described by an incarcerated woman in a facility in Michigan: "At about the sixth month of pregnancy, the strip-searches become difficult. By this time, my emotional state was up and down, and most of the time I left the 'strip room' in tears from shame and humiliation" (Ocen, 2012). The psychological stress of these searches is unhealthy for anyone, especially for a pregnant woman who is already experiencing several psychological and physical stresses.

The research on sexual assault in prison, specifically strip searching, sheds light on the day-to-day situations and experiences incarcerated women face, which is a topic not often discussed in the field of incarceration and women. This barrier also provides insight into the relationships between prison staff and incarcerated women, which may play a role in the perceived accessibility

to reproductive healthcare within prison. The research on strip searches and other forms of sexual abuse in prison lacks data regarding physical and mental impacts of strip searching as well as how widespread this practice is. Little is documented about the actual experiences of women within prison, which is a critical component in understanding how social barriers play a role in the oppression of incarcerated women. Social barriers to reproductive justice within prison are not well documented due to incarcerated women and their experiences being inaccessible; sexual violence is one of the few issues within prison life that have been researched, and even then not as thoroughly as physical barriers. It is apparent that more research must be conducted not only on sexual abuse but also on other forms of discrimination or abuse incarcerated women may face but are still unknown. As strip searching is the one main perspective on social barriers, it will also be the barrier evaluated within this study. However, as other social barriers may be uncovered, they will also be included.

The oppression of reproductive justice within jails and prisons is the main interest of this study; to begin to assess and determine this multifaceted issue, an understanding of the intersection of the three main concepts outlined is needed. Reproductive justice serves as the basis for this study's focus, but on its own, it does not suffice in addressing the research questions of interest. Social interactions and prison healthcare systems must be addressed through other concepts, such as physical and social obstructions. These concepts are necessary in understanding the broad framework of reproductive justice and the ways in which it is suppressed within prisons and jails. Considering both social and physical influences while assessing reproductive justice will provide an in-depth, more accurate picture of what stands in the way of an incarcerated woman of color's access to reproductive justice.

Methods

This study aims to understand if and which physical and social barriers within prison contribute to an oppression of reproductive justice for women of color. To understand social barriers, the stories of previously incarcerated women concerning access to reproductive justice will be the most vital. These perspectives will capture incarcerated women's experiences that are currently absent in the knowledge base regarding this issue. Physical and legal barriers must be assessed through the accounts of individuals who are well-versed in prison healthcare policies and laws in the United States. These perspectives qualify as a form of qualitative data, which describes how people experience the given concepts outlined in the conceptual framework. Collecting this type of data will enable a deeper understanding of how and if social and physical barriers stand in the way of reproductive justice in prison.

Sources of Data

In order to capture these perspectives in their most true form, conducting interviews will be the most accurate tool in collecting this data as it will provide information directly from valid sources. This study relies on an emic perspective (Harris, 1999), or one that lends authority to the women who have experienced social and physical barriers within prison to provide and validate the data I am seeking.

Through interviews, I collected data while directly interacting with participants to gain a better understanding of their thoughts and feelings, which are inaccessible through other modes

of data collection. Merriam explains that “Interviewing is necessary when we cannot observe behavior, feelings, or how people interpret the world around them” (2009). This form of data collection is the only method that provides the necessary evidence to understand what barriers exist both within prison walls and outside of them, which can only be sourced from the women who have spent time inside correctional facilities as well as those knowledgeable in prison healthcare policy.

However, due to the protected status of women who are currently incarcerated, I interviewed previously incarcerated women. To answer my research questions, a very select population of previously incarcerated women must be sampled; in order to sample participants who have perspectives of interest, specific criteria were set to obtain useful and specific data. This criterion method only collects information from targets that fulfill all established criteria (Miles & Huberman, 1994).

Tools for Collecting Information from These Sources of Data

To collect this data, I plan to interview one or more women who were previously incarcerated in a women’s correctional facility in the United States or hold proximity to these barriers in another way. In order to understand the ways in which race affects these experiences, a woman of color will be interviewed. The criteria for this sample will include

- (1) were mothers to children or were pregnant while in prison,
- (2) identify as White or African-American; identify as a cisgender woman, or
- (3) hold some other form of proximity to social and physical barriers.

To access this sample, I contacted prison advocacy groups for women in the United States by phone and/or email to request to be put in contact with women who (1) fit the given criteria and (2) are interested in participating in the study. After that, I directly contacted these participants and interviewed them over a video-conferencing platform such as Zoom or Skype. I have formulated an interview protocol that is nearly identical for both participants; the protocol addresses a basic overview of the participants’ background, their understanding of the social and physical barriers that stood in their way from receiving reproductive healthcare as well as their personal experiences and feelings regarding their time in a correctional setting.

Results

“I mean it was devastating. It was so bad, even to the point where my experiences of being pregnant behind walls make me never want to have kids again,” said Ms. Miyhosi Benton, a formerly incarcerated woman and current associate director of Advocacy and Strategy at the Women and Justice Project, a nonprofit organization that advocates for incarcerated women and change in the justice system (Miyhosi Benton, personal interview, February 16, 2021). Her experiences are not unique or rare: They are a product of an inhumane system and its policies and practices. These policies and practices present themselves in two patterns: punishment and control and a general lack of safety. These themes manifest themselves in both physical and social barriers; by evaluating these patterns, we come to understand the driving forces behind the oppression of reproductive justice behind walls.

Physical Barriers and Punishment and Control

In regard to physical barriers' obstruction of reproductive justice, a clear pattern has emerged between the United States' laws and policy and the lack of access to reproductive healthcare in the carceral setting as a result of that. Moreover, this pattern falls within a theme that is intertwined with the United States' incarceration system and the laws that govern the said system. That theme consists of what Ms. Austin Donohue, a lawyer, describes as "A framework of 'we [the United States] want to punish people who do things wrong,' versus rehabilitate them" (Austin Donohue, personal interview, February 8, 2021).

The aim to punish rather than rehabilitate runs deep within the system. That notion is reflected in the system's everyday practices, according to Ms. Miyhosi Benton. She said:

If prison is the punishment then what are these additional atrocities that I'm experiencing? . . . The level of control and punishment that they [correctional officers] have to stick to overshadows safety, overshadows just the health of any individual that is unfortunate enough to be behind those walls.

(Miyhosi Benton, personal interview, February 16, 2021)

That need to control and punish unavoidably manifests in every physical facet of the incarceration system, meaning that it will also unavoidably "overshadow just the health of any individual." This perspective dictates the level, accessibility, and quality of healthcare inside walls, thus contributing to the oppression of reproductive justice that has been well documented in previous studies (Skerker, Dickey, Schonberg, MacDonald, & Venters, 2015; Van den Bergh, Gatherer, Fraser, & Moller, 2011; Ocen, 2012).

The notion that the prison system within the United States is built to punish rather than rehabilitate people correlates with the legal framework, or rather lack thereof, that supports the right to reproductive healthcare in the carceral setting. Donohue explained, "That is a right, essentially, the Eighth Amendment to the Constitution prohibits cruel and unusual punishment while you're incarcerated, and the court has said that means that you have to have healthcare" (Austin Donohue, personal interview, February 8, 2021). Though the Eighth Amendment entitles incarcerated people the right to healthcare, there is no guarantee of the quality or types of healthcare inmates have access to – and this includes reproductive healthcare. Donohue said, "I don't think there is a guarantee that they'll get that [prenatal/reproductive care], and the reason for that is because there is no statutory right, no statutory or Constitutional right for them to get those things" (Austin Donohue, personal interview, February 8, 2021).

Due to the lack of court precedent, incarcerated women hold no right to reproductive healthcare under U.S. law, as there is no "statutory or Constitutional right for them to get those things." Healthcare looks extremely different across federal and state correctional facilities, and much of the access that incarcerated people receive is at the discretion of these prisons and even individual prison officials. Federal prisons often provide a more comprehensive level of healthcare due to the long-term nature of such facilities; however, this level of quality still varies among these facilities (Sufirin, Creinin, & Chang, 2009; Kelsey, Medel, Mullins, Dallaire, and Forestell, 2017). The nation's lack of enforcement or attention to the absolute necessity of reproductive healthcare is a major physical barrier that effectively oppresses reproductive justice, in which a woman has the right to choose when to have a child, to not have a child, and to raise existing children with the proper support (Hayes, Sufirin, & Peritt, 2020; Sufirin, Kolbi, & Roth, 2015).

When a proper reproductive healthcare system is not even in place in prisons and jails, it is inevitable that not only will women not be able to access their reproductive rights but that it will disproportionately affect women of color, who are victims of mass incarceration (Ricker, 2020). The absence of this necessary resource virtually punishes women for being reproductive beings; this is only a manifestation of the theme of punishing, rather than rehabilitating incarcerated people, as explained by the notion that “if you’ve committed a crime, you should be punished for it.” More specifically, the women of color behind walls who suffer from a loss of reproductive justice and humanity are victims to the continuous cycle of the dehumanization of brown and black people in the United States (Willingham, 2011). This data on U.S. law and policy only confirms that “most prisons are designed to serve men and not women . . . and much less women of color, who have experienced a history of bodily autonomy suppression” (Skerker, Dickey, Schonberg, MacDonald, & Venters, 2015).

Another physical manifestation of the goal to punish rather than rehabilitate is the practice of shackling incarcerated people, including pregnant women. According to Kelsey, Medel, Mullins, Dallaire, and Forestell (2017), 17.4% of 53 women’s prisons in the United States reported shackling during labor, while 56.5% reported shackling women after birth. The use of shackling for pregnant women and new mothers is often excessive or completely unnecessary and puts women in uncomfortable, sometimes dangerous, situations. Ms. Benton, speaking of her own traumatic experience said:

So, later on, late in my pregnancy I started to make a fuss about just the level of pain that I was experiencing, because they was putting the shackles around my waist incredibly too tight. . . . And then I was shackled illegally when I gave birth to my daughter. Cause immediately right after I gave birth, when they did take me to the prison ward that’s inside Westchester Medical Center – where they house all incarcerated people, men and women, where there’s no privacy between the two, which is super barbaric and very unsanitary – they did shackle me immediately after giving birth.

(Miyhosi Benton, personal interview, February 16, 2021)

The shackling of pregnant women is unnecessary in the sense that these women are not in a physical position to pose a potential threat; it is also dangerous as it physically and mentally damages pregnant women who are already under considerable strain. Furthermore, Ms. Benton was illegally shackled while giving birth to her child, which is a violation of New York State’s 2009 Anti-Shackling Law, which banned the shackling of pregnant incarcerated women during and after labor and delivery (Montgomery, 2015). This illegal shackling not only made labor and delivery more painful and difficult but also dehumanized the beginning moments of this woman’s motherhood, which is a direct violation of the reproductive justice framework (Hayes, Sufrin, & Peritt, 2020; Sufrin, Kolbi, & Roth, 2015). This also demonstrates that the prison system seeks control and power, even if it is against the law, which only contributes to the ideology of punishment that is entrenched in the healthcare system behind walls. The shackling of pregnant incarcerated women also unavoidably affects African-American women, thus continuing the cycle of what Ocen (2012) describes as the “historical devaluation, regulation and punishment of their [African-American women’s] exercise of reproductive capacity.”

The need to punish and control within the prison system stems from the notion that “If you’ve done something wrong, if you’ve committed a crime, you should be punished for it” (Austin

Donohue, personal interview, February 8, 2021). This belief runs so deeply that it even undermines the safety and humanity of those behind bars – but in reality, “That’s the goal of prison, to make you feel subhuman” (Austin Donohue, personal interview, February 8, 2021). Ms. Benton recalled a traumatizing experience as a new mother in prison:

I was taking my daughter on her first checkup after being born and – they [correctional officers] had me shackled and handcuffed, and I had to carry her carseat with her in it, and I was walking with the carseat and, because I have long legs, my, my strides with the shackles just didn’t work, so I kept tripping. And I kept saying to myself while I was carrying my child – and it’s thirty-five pounds with the base and then the car seat, it’s thirty-five pounds – I’m carrying that on top of being shackled and handcuffed. And I kept saying to myself like, “don’t fall, like, just don’t trip. Like, I don’t wanna harm my baby. Like whatever happens, I just don’t want any harm to come to my very young child.” And, I did fall with her in the carseat and like, once again, they didn’t think anything of it. They just helped me pick up – I was bleeding from the shackles being dug into the back of my ankle.

(Miyhosi Benton, personal interview, February 16, 2021)

The lack of concern for human life within the prison system is not subtle or hidden; it is explicitly demonstrated in the everyday lives of incarcerated women. As a mother to a newborn, Ms. Benton was subjected not just to the individual trauma of being shackled but also to the emotional and mental stress of protecting her child from harm. It is evident that the prison system does not use shackling as a means to protect but rather as a means to punish and control “wrongdoers,” even if it means that a woman will bleed “from the shackles being dug into the back of my ankle.” The stressful, traumatic experiences of shackling that incarcerated pregnant women undergo dehumanize them and risk the health of them and their child; it is only obvious that shackling physically oppresses reproductive justice (Ocen, 2012; Hayes, Sufrin, & Peritt, 2020; Sufrin, Kolbi, & Roth, 2015).

U.S. law’s lack of oversight and accountability regarding prison healthcare in general erases the notion that there is a uniform prison healthcare system in place, let alone a uniform reproductive healthcare system. The power left to prison officials and correctional officers implies that each incarcerated woman will face a different barrier dependent upon where she is incarcerated; it also implies that this issue is inherently a social issue as well. However, it is clear that the lack of access to a woman’s right to reproductive justice in prison is universal; the absence of such critical policies and their enforcement puts incarcerated women’s health at risk and effectively punishes them for being reproductive beings (Sufrin, Creinin, & Chang, 2009; Kelsey, Medel, Mullins, Dallaire, & Forestell, 2017; Skerker, Dickey, Schonberg, MacDonald, & Venters, 2015). Shackling, a barrier that is well documented, is another physical barrier that carries immense social implications for African-American women (Willingham, 2011; Ocen, 2012). It also further contributes to putting a woman’s mental and physical health at risk and dehumanizes her simultaneously. The lack of reproductive healthcare policies combined with the practice of shackling confirms that reproductive justice is not being oppressed but rather that it has no place in the prison system, which is disproportionately harming women of color (Ricker, 2020).

The absence of U.S. legislation that guarantees incarcerated women access to quality reproductive healthcare implies that reproductive justice does not exist within the incarceration system; but the fact that women are inhumanely, and even illegally, shackled while accessing any sort of healthcare implies that reproductive justice is not just oppressed but rather eradicated within the system.

Social Barriers and Lack of Safety

In terms of social barriers, there is a clear relationship between a lack of safe spaces for incarcerated women and authoritative figures such as correctional officers and healthcare professionals. The power assigned to these roles creates a threatening environment for women, who are already in extremely vulnerable positions and have little to no autonomy over any aspect of their lives behind walls. This power dynamic gives way to sexual assault and dehumanizing attitudes and practices in the social context.

Jacqueline Williams, who was previously incarcerated, repeatedly mentioned the toll of the physical constraints of a carceral setting on pregnant women on the *Women's Health, Incarcerated* podcast. Along with this physical and mental trauma, Williams references correctional officers and their responsibility in enforcing such physical constraints and in removing safe physical spaces for women behind walls. Williams explains this as, "You're never in a safe place. Whether you are at risk from a correctional officer coming in and barking at you, to another person in your room or your cell harming you or being too near to you or stealing from you" (podcast, episode 8, page 1, line 26–28). From Williams' description, it is evident that correctional officers are present not to protect incarcerated women but rather to control them in an animalistic way by "coming in and barking at you." Correctional officers are a physical manifestation of the carceral system's motive to punish, rather than rehabilitate people. This lack of safety creates the environment in which women are often sexually harassed and assaulted by correctional officers, who as the most direct source of authority in the correctional setting are neither questioned nor held accountable (Ocen, 2012). Furthermore, the environment enforced by these officers also allows them to sexually coerce women by using solitary confinement or the withdrawal of basic necessities as threats (Skerker, Dickey, Schonberg, MacDonald, & Venters, 2015).

Strip searching is another common practice that creates a dangerous environment in which correctional officers may abuse their authority and power, furthering the notion that there truly is no sense of safety for women behind walls (Strip Searching as Sexual Assault, 2001). Ms. Benton also affirmed that strip searching was a common and everyday practice:

Yes, you had to be strip searched every time. You leave the facility, every time. You go to a visit in the facility, that's just a part – once again, that's like, the everyday standard procedure, you have to be strip searched. And it's done by a woman, and with the limited amount of women in a facility, it's like jumping through hoops just to make sure the woman is there in order to be strip searched. Now, you can be patted down and frisked by a man, which still is crazy.

(Miyhosi Benton, personal interview, February 16, 2021)

Though having a member of the same sex conduct full-body strip searches created some sense of protection for Ms. Benton, a heterosexual woman, it does not erase the control and dehumanizing aspects of such a practice, especially for pregnant women.

Ms. Benton explained her own traumatizing experiences with searches while she was pregnant, saying, “I mean, I felt violated. I felt like they were stripping me of my self-worth and dignity. I felt like, I mean I felt traumatized. Like I experienced sexual assault in my, in my time prior to prison. So to then have to be subjected to men touching me unwantedly, you, you are then reliving experiences that you had before” (Miyhosi Benton, personal interview, February 16, 2021). And Ms. Benton’s experience is not unique – incarcerated women are three times more likely to report sexual assault prior to prison than incarcerated men (Van den Bergh, Gatherer, Fraser, & Moller, 2011). These women are not only violated by this practice but also subjected to reliving past trauma; this is not just harmful to women’s physical and mental health, it is grossly inhumane (Ocen, 2012). The dangerous, unsafe environment and situations created by strip searching and correctional officers also achieve the aim to punish and control incarcerated women, further demonstrating how this notion is deep-rooted in both the physical and social barriers to reproductive justice (Strip Searching as Sexual Assault, 2001).

This lack of safety is also evident from the reproductive healthcare standpoint. Not only is there a lack of privacy for the sensitive and personal aspects of reproductive healthcare, there is also a loss of bodily autonomy due to the physical constraints of prison and the correctional officers enforcing them. She added:

Another situation that was a huge barrier, physically, in terms of accessing reproductive [healthcare] is that once I did get the visit, the officer was in the room with me during my appointments the whole time. I didn’t feel comfortable with sharing my concerns because I just felt like there was no confidentiality. There was not a safe space to be able to even speak honestly with my doctor about what I thought was going on in my body with a complete stranger in the room with us at all times.

(Miyhosi Benton, personal interview, February 16, 2021)

The private and personal nature of reproductive healthcare is one of its inherent facets, and to have that removed most directly by the presence of correctional officers prohibits quality care due to the fact that there is no longer “A safe space to be able to even speak honestly with my doctor about what I thought was going on in my body.” Furthermore, correctional officers rob these women of their own bodily autonomy in the sense that they cannot make choices in the doctor’s office to maintain and care for their bodies due to the sense of danger presented. Pregnancy is perhaps one of the most stressful as well as sacred experiences for a woman, and that experience becomes wholly traumatic and impersonal when armed figures of authority are present. It is evident that correctional officers are a direct tool in the oppression of reproductive justice as a whole (Ocen, 2012; Ross 2016; Sufirin, Kolbi, & Roth, 2015). Moreover, this disproportionately affects more women of color as they are most often the victims of mass incarceration (Ricker, 2020).

Another space that gives room to a dangerous, unsafe environment is the doctor’s office. Besides correctional officers, healthcare professionals are the main authoritative figures that incarcerated women interact with when receiving or accessing medical care, both reproductive and otherwise. Ms. Benton recalled her own experience with the onsite gynecologist at the federal prison where she was incarcerated:

Inside of prison, there is an onsite OB/GYN, who is horrific. She was horrific, she was a white lady. Like when she was doing checkups, she was doing rectum cavity searches

and all this other strange stuff, without no forewarning to the women. I don't know, she was really abusing and really causing a lot of harm.

(Miyhosi Benton, personal interview, February 16, 2021)

Though healthcare professionals are not directly associated with the prison system as correctional officers may be, it is evident that these figures are prone to engaging in harmful practices that may be driven by a lack of prison-specific training (Tuite, Browne, & O'Neill, 2006). Doctors, in theory, are meant to guide and protect their patients, rather than “doing rectum cavity searches” and “abusing and really causing a lot of harm.” They are an essential component of quality reproductive healthcare, but if the figure most responsible for an incarcerated woman's reproductive healthcare fails to respect her, then there is no doubt that reproductive justice is oppressed in the American prison system (Ross, 2016; Sufrin, Kolbi & Roth, 2015; Hayes, Sufrin, & Peritt, 2020). Furthermore, the dehumanization and degradation that Ms. Benton and other women experienced in the medical setting created a dangerous environment that established a sense of distrust in healthcare and healthcare professionals, which may have further deterred them from accessing reproductive healthcare in prison as well as outside.

These figures of authority use their power to control and dehumanize incarcerated women by creating an unsafe environment where a woman can never be truly comfortable. Without a sense of safety and security, these women cannot make sound decisions about their reproductive health, which ultimately oppresses any sense of reproductive justice.

Physical and Social Barriers and Reproductive Justice

How do prison healthcare systems present physical barriers that contribute to the denial of access to reproductive healthcare for incarcerated women? In what ways do interactions or relationships between incarcerated people and prison staff, such as correctional officers and nurses, deter incarcerated women from receiving reproductive healthcare services such as prenatal checkups as well as reproductive justice as a whole? There are numerous physical and social barriers that stand in the way of incarcerated women accessing reproductive healthcare and reproductive justice. Examining these barriers affirms that prison policies, practices, and laws negatively impact a woman's right to reproductive justice (Ross, 2016; Sufrin, Kolbi, & Roth, 2015; Hayes, Sufrin, & Peritt, 2020). State and federal laws regarding the prison system as well as internal policies and practices are influenced by the notion that prison is a place to punish. This ideology costs incarcerated women their safety, health, and humanity, subsequently traumatizing these women instead of rehabilitating and supporting them. Moreover, women of color, who are victims of mass incarceration, disproportionately suffer from this oppression of reproductive justice, which carries severe historical and social implications as well.

Conclusion

As of 2019, approximately 222,000 women are currently incarcerated in the United States (Incarcerated Women and Girls, 2020). This number signifies that hundreds of thousands of women are subject to dehumanization, degradation, and punishment for existing as reproductive beings. The right to reproductive autonomy and healthcare is a human right, and yet it is not recognized by the U.S. prison system simply because these women have been labeled as

“wrongdoers” (Ross, 2016; Shlafer, Hardeman, & Carlson, 2019; Hayes, Sufrin, & Peritt, 2020; Sufrin, Kolbi, & Roth, 2015). Women of color have historically been victims of exploitation and dehumanization due to both race and sex within the United States, and the mass incarceration system only perpetuates this exploitation (Willingham, 2011; Ocen, 2012). It is critical to expose the barbaric practices within the prison system in order to bring about prison reform regarding reproductive healthcare and autonomy. Perhaps even more critical than reform is the movement to destigmatize incarcerated people, who have been viewed as less than human beings since the inception of the incarceration system in the United States. For many women, incarceration is a painful and traumatic experience, but they continue to fight for their rights behind walls: “I think it’s important to know that no matter how many barriers they put in place from preventing mothers from being mothers, or women from being able to support each other, that women still find miracles to do it and make it happen” (Miyhosi Benton, personal interview, February 16, 2021).

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Weighing Government Intervention During the Global Covid Health Crisis

Samantha Staudinger*

Keywords

government intervention • Covid-19 • patent law • health disparities • economic incentives • health policy

Introduction

Inequitable access to vaccines has been cited as the most significant failure in the global fight against Covid-19, exacerbating the damage it has inflicted in low- and middle-income countries and contributing to the risk that new coronavirus strains would emerge to threaten all countries (Coggi & Regazzoni, 2022). Thus, a key question is whether governments should waive drug patent laws and require pharmaceutical companies to transfer their technologies to help deliver vaccines in a timely fashion globally, especially to low- and middle-income countries. This debate was highlighted in the *New York Times* article “What Would It Take to Vaccinate the World Against Covid?” (Goodman et al., 2021), with the *Times* strongly arguing for such intervention in an accompanying editorial entitled “America Is Failing Its Moral Test on Vaccines” (*New York Times* Editorial Board). This specific debate is the latest in an ongoing debate about whether governments should – and, if so, to what extent – actively intervene in the economy during a public health crisis like Covid-19 or AIDS/HIV. Noted Stanford University economist John McMillan’s book *Reinventing the Bazaar: A Natural History of Markets*, which puts forth a view of markets as tools that address societal needs without ideological perspective, provides helpful insights into this debate. As discussed later, simply waiving patents represents an imperfect solution, one potentially resulting in curtailment of technological innovation – due to loss of economic market incentives that emanate from patents – that may be critically needed to address future variants. Instead, a balanced approach is called for whereby government intervention focuses on increasing manufacturing infrastructure both domestically and abroad. Furthermore, the justification for opening up patents to allow for this additional manufacturing should emphasize national self-interest in preventing future outbreaks and new variants rather than framing it in purely ethical terms.

*University of Michigan, sammiest@umich.edu

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Case Example: “Pharmaceutical Catch-up” during the Covid-19 Global Crisis

The distribution of Covid vaccines fundamentally involves supply and demand: The high demand for vaccines can be resolved by expanding the global supply correspondingly. However, slow vaccine production and the resultant low supply may lead to the rise of new and potentially more dangerous variants, further increasing demand in a vicious cycle referred to as “pharmaceutical catch-up” (Okan et al., 2022). A simple solution appears to be increasing vaccine production through the government waiving enforcement of vaccine patents held by major pharmaceutical companies like Pfizer, Moderna, and Johnson & Johnson. This action would allow other manufacturers to step in and provide the needed extra vaccine doses. However, simply voiding patents would not necessarily suffice to meet the end goal of providing the necessary resources (i.e., vaccines) in the most timely and efficient manner. In particular, technology transfer and availability (in terms of machinery, software, etc.) and access to necessary raw materials must also be addressed.

Due to the global risk of new variants emerging, global leaders and countries must function on a unified front to safeguard against both present and future threats (Goodman et al., 2021). To that end, the *New York Times* editorial board asserts the need for high-income countries such as the United States to intervene by helping low- and middle-income nations build manufacturing facilities and offer technical expertise, which in turn aids the collective global effort to overcome the Covid health crisis. The dilemma emerges in that the waiving of vaccine patents may hinder future innovation needed to address potential variants, but at the same time, the waiver can lessen the possibility of variants emerging in the first place by addressing the crisis in a timely global manner. Consequently, the economic and social/ethical stakes involve whether to prioritize intellectual property and future innovation or to waive patent protections to immediately aid low- and middle-income countries and potentially avert a prolonged global health crisis.

The Problem at Stake: Protecting or Waiving Patents

By examining the ideological conflict of protecting or waiving patents through the lens of McMillan, who views markets as tools that address societal needs without an ideological perspective, it becomes clear that the government should seek to provide incentives and design the market around self-interest. As McMillan emphasizes, no one is in control of a market, but rather, everyone is in charge, thereby granting participants autonomy in decision-making. The only limits to this freedom, according to McMillan, are the extent of the resources available and the rules of the marketplace.

By applying this framework to the case of pharmaceutical companies in a global health crisis, it appears that, in attempting to protect their patents, these companies are simply responding to the “incentives” present in the government-designed marketplace, namely those where investments are optimal. However, as the cost of research and development to create new drugs and vaccines is expensive and uncertain, balancing incentives with patents alongside advancing innovation should become an essential aim of government intervention.

One could argue that the weakening of intellectual property hinders innovation for the future, including the development of new treatments to prevent more pandemics, since pharmaceutical companies follow the market to ensure optimizing their profit. This pro-patent argument relies on

the assumption that innovation is a high-stakes dice roll. According to an Massachusetts Institute of Technology (MIT) study, only approximately 14% of all drugs in clinical trials eventually win approval from the Food and Drug Administration (FDA), with approval rates for specific illnesses ranging from a high of 33.4% for infectious-disease vaccines to a low of 3.4% for cancer (Wong et al., 2019). Nonetheless, the companies are not the primary source of the low success rate of the global drug market. Companies will do what it takes to maximize their profits for future innovations to cover their research costs, as such efforts are expensive and uncertain. Thus, although it may appear that successful drugs are priced unnecessarily above their manufacturing cost, such a high cost is a direct result of patent laws, enabling the grant of monopoly rights to the innovator. Thus, the challenge for those who believe patent law is flawed is to devise an alternative market design that would induce better outcomes for long-term innovation.

On the other hand, one can contend that the weakening of intellectual property is necessary to address a health crisis in a timely and ethical manner by sharing essential information and associated technology. This anti-patent argument was seen, for example, when European institutions challenged the American company Myriad Genetics' patent monopoly on the genetic work associated with the *BRCA1* gene of breast cancer (Lecrubier, 2002). In particular, the European institutions contended that Myriad's monopoly would have the unintended consequence of posing another barrier to breast cancer healthcare, namely the high cost of screening for the *BRCA1* gene. Moreover, they contended that such a monopoly would also have a long-term effect in that Myriad's collection of DNA samples of the *BRCA1* gene – the only such sample bank in the world – would give them ultimate control over the raw material for future research. In this way, a snowball effect could occur, whereby Myriad's gain of a monopoly would enable it to secure even more patents and thus build a larger barrier against future *BRCA1* gene research. Hence, one could argue, like the European institutions did, that the weakening of such intellectual property is necessary to propel and expand current and future research on said treatments on both a national and an international level.

Potential Solution: Government Intervention in the Name of National Self-Interest

As the *New York Times* editorial board and McMillan both point out, simply waiving patents in the designed market of pharmaceuticals yields a solution that, in the words of McMillan, “admits no ideal solution” (McMillan, 2002). In recognition of such shortcomings, the *Times* editorial board proposes a two-prong effort focused on ramping up vaccine production: both internationally – with the U.S. joining together with other high-income nations to help low- and medium-income countries build and operate their own manufacturing plants, following a playbook established by the President's Emergency Plan for AIDS Relief (PEPFAR) back in 2003 – and domestically via the creation of publicly owned manufacturing plants run by private entities akin to the “Government-Owned, Contractor-Operated” (GOCO) facilities that both the Departments of Defense and Energy utilize (*New York Times* Editorial Board). The *Times* justifies its proposal based mainly on ethical considerations, calling it a “moral test.” In contrast, McMillan, who views markets as non-ideological entities, would evaluate the proposal from an economic perspective, with market participants motivated by both profit and self-interest, including government self-interest.

Considering first the international side of the *Times* proposal, their argument for high-income nations agreeing to open up and aid vaccine manufacturing in low- and middle-income countries is one that McMillan would approve. Since there is uncertainty toward the future regarding the potential need for rapid and extensive responses for supplying booster shots and addressing localized outbreaks and variants, efforts to produce and deliver vaccines domestically must coexist with steps to do so elsewhere due to the global nature of the crisis. In doing so, the designed international market for vaccines should account for the self-interest of high-income countries, wherein helping low- and middle-income countries would, in turn, benefit them in the long term by ending the pandemic. Moreover, high-income countries assisting low- and middle-income countries would enable the necessary global distribution to be regionally concentrated. This approach would allow for better adaptation to changing and uncertain circumstances, such as the possible need for booster shots and addressing sudden outbreaks and variants.

Likewise, on the domestic side of the *Times* proposal, agreement from McMillan can be seen. Here, U.S. government support in the form of building GOCO-type vaccine production facilities for private entities to operate serves to satisfy both private and public (both government and the general public) interests. By balancing private economic autonomy and government intervention in this way, the designed market would simultaneously account for the self-interest of the United States to protect itself from future health crises and the profit motivation of the private pharmaceutical companies.

In doing so, the private market for pharmaceutical companies would contain and promote both positive freedom – the capacity to act upon one’s free will – and negative freedom, or freedom from external constraints from the government. At the same time, government intervention in increasing both manufacturing infrastructure and the accessibility of raw materials would address the current health crisis and safeguard its changing and unpredictable nature in the future. For instance, similar to how Goodman et al. (2021) argue that the root issue with the Covid vaccine is that “many raw materials and key equipment remain in short supply,” McMillan asserts in his example of the AIDS health crisis in Africa that the roots of the shortcomings in the global pharmaceutical market lie not in companies’ policies but instead in countries’ poverty (McMillan). Without basic healthcare and infrastructure in place, McMillan argues that the effects of more accessible and cheaper drugs would still be limited in fighting AIDS, thereby leading him to contend that economic growth from governmental intervention is the only reliable source for addressing AIDS (McMillan, 2002). Similarly, Hoen et al. (2011) cite addressing regulatory issues, strengthening supply chains, and establishing current pharmacovigilance systems as additional actions that were needed beyond waiving the AIDS patent for success. In this way, the private pharmaceutical companies’ successes are correlated with governmental intervention to ensure the necessary resources for said success are available during global health crises.

However, in contradiction to the title of the *New York Times* opinion piece “America Is Failing Its Moral Test on Vaccines,” framing the argument as a moral imperative is counterproductive when viewed through McMillan’s lens: it is unwise to criticize companies for seeking maximum profit as such profits are a necessary evil for fueling innovation. As a result, as McMillan contends, pharmaceutical companies are simply following market incentives, ensured by patents that, in turn, allow for future innovation. Consequently, McMillan would agree with the editorial board in championing government intervention, but he would propound that it should emphasize national self-interest rather than framing it as an ethical matter.

As McMillan argues, ethical matters are unproductive without the economic infrastructure to support them, while economic matters are ineffective if participants do not have their healthcare needs met (McMillan, 2002). In this way, it becomes clear that not only is the economy a necessary pipeline to taking morally “correct” actions, but the reverse is true as well: taking morally correct actions requires that a sufficient economic pipeline exists. Hence, government actions must not overly discourage private company participation in the marketplace, lest the economic pipeline runs dry.

Conclusion

The global Covid-19 health crisis has brought upon the world an unprecedented public health challenge, one that has thus far resulted in over 750 million confirmed cases of Covid-19, including over 6.8 million deaths reported to the World Health Organization (WHO) as of January 2023 (WHO Coronavirus Dashboard). This challenge necessitates a thoughtful and coordinated response to meet it effectively, one that seeks to also not produce unintended consequences, such as limiting future innovations that may be critically needed to address variants and new outbreaks. In that regard, the *New York Times* proposal represents a balanced approach using select government intervention focused on increasing vaccine manufacturing infrastructure both domestically and abroad. This proposal is not only justifiable under ethical conditions, as strongly argued by the *Times*, but seen to be justifiable under economic and self-interest – especially national self-interest – reasoning when viewed through the lens of the noted Stanford economist John McMillan. Thus, it is highly worthy of immediate implementation by not just the United States but other high-income nations as well.

Appendix A

Passage from “What Would It Take to Vaccinate the World Against Covid?”:

The problem is that many raw materials and key equipment remain in short supply. And the global need for vaccines might prove far greater than currently estimated, given that the coronavirus presents a moving target: If dangerous new variants emerge, requiring booster shots and reformulated vaccines, demand could dramatically increase, intensifying the imperative for every country to lock up supply for its own people. The only way around the zero-sum competition for doses is to greatly expand the global supply of vaccines. On that point, nearly everyone agrees. But what is the fastest way to make that happen? On that question, divisions remain stark, undermining collective efforts to end the pandemic.

Some health experts argue that the only way to avert catastrophe is to force drug giants to relax their grip on their secrets and enlist many more manufacturers in making vaccines. In place of the existing arrangement – in which drug companies set up partnerships on their terms, while setting the prices of their vaccines – world leaders could compel or persuade the industry to cooperate with more companies to yield additional doses at rates affordable to poor countries.

Those advocating such intervention have focused on two primary approaches: waiving patents to allow many more manufacturers to copy existing vaccines and requiring the pharmaceutical companies to transfer their technology – that is, help other manufacturers learn to replicate their products.

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Some experts warn that revoking intellectual property rules could disrupt the industry, slowing its efforts to deliver vaccines – like reorganizing the fire department amid an inferno.

“We need them to scale up and deliver,” said Simon J. Evenett, an expert on trade and economic development at the University of St. Gallen in Switzerland. “We have this huge production ramp up. Nothing should get in the way to threaten it.”

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Many public health experts say that patent waivers will have no meaningful effect unless vaccine makers also share their manufacturing methods. Waivers are akin to publishing a complex recipe; tech transfer is like sending a master chef to someone’s kitchen to teach them how to cook the dish.

“If you’re to manufacture vaccines, you need several things to work at the same time,” the W.T.O. director-general, Ngozi Okonjo-Iweala, told journalists recently. “If there is no transfer of technology, it won’t work.”

Even with waivers, technology transfers and expanded access to raw materials, experts say it would take about six months for more drug makers to start churning out vaccines.

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Changing that calculus may depend on persuading wealthy countries that allowing the pandemic to rage on in much of the world poses universal risks by allowing variants to take hold, forcing the world into an endless cycle of pharmaceutical catch-up.

“It needs to be global leaders functioning as a unit, to say that vaccine is a form of global security,” said Dr. Rebecca Weintraub, a global health expert at Harvard Medical School. She suggested that the G7, the group of leading economies, could lead such a campaign and finance it when the members convene in England next month.

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But other health experts accuse major pharmaceutical companies of exaggerating the manufacturing challenges to protect their monopoly power, and implying that developing countries lack the acumen to master sophisticated techniques is “an offensive and a racist notion,” said Matthew Kavanagh, director of the Global Health Policy and Politics Initiative at Georgetown University.

With no clear path forward, Ms. Okonjo-Iweala, the W.T.O. director-general, expressed hope that the Indian and South African patent-waiver proposal can be a starting point for dialogue. “I believe we can come to a pragmatic outcome,” she said. “The disparity is just too much.”

Appendix B

Passage from “America Is Failing Its Moral Test on Vaccines”:

The United States is well on its way to protecting Americans from the coronavirus. It's time to help the rest of the world. By marshaling this nation's vast resources to produce and distribute enough vaccines to meet global demand, the United States would act in keeping with the nation's best traditions and highest aspirations while advancing its geopolitical and economic interests. It is a moment of both obligation and opportunity.

Unfortunately, instead of a bold, comprehensive strategy to vaccinate the world as quickly as possible, the Biden administration has thus far made a string of tactical decisions: donating millions of doses to countries in need, signaling its support for patent waivers that might expedite vaccine production efforts and nudging two companies – Merck and Johnson & Johnson – to collaborate on increasing supply. These are good steps, but they are not nearly sufficient to meet the moment. The United States and the rest of the world's wealthiest nations are facing a great moral challenge.

Increasing manufacturing capacity has proved tricky. The global demand for vaccines may be high now, but once the coronavirus pandemic recedes, it will plummet back to normal levels. Increased public ownership, for its part, would ensure that vaccine-production capacity is ready for future pandemics, which are inevitable – potentially including new coronavirus variants for which routine boosters may be required.

To this end, the administration should consider taking a page from the Department of Energy playbook: Create publicly owned manufacturing facilities and contract with private companies to run them. (Several of the D.O.E.'s federally owned laboratories are run by private companies like General Electric and Bechtel.)

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Efforts to dramatically increase domestic production should be paired with efforts to do the same elsewhere. The coronavirus is here to stay for the foreseeable future. If new variants require different boosters and localized outbreaks require rapid response, it will be far easier to manage those eventualities with regionally concentrated supplies. That kind of distributed capacity will also leave the world much better prepared for future pandemics.

Low- and middle-income countries have been clamoring for the chance to manufacture their own doses – many of them have infrastructure that could be repurposed, and expertise making other complicated pharmaceuticals that could be built upon. If wealthier nations are concerned about those countries' ability to manage this challenge safely or quickly, they should step in to help. This worked before. The 2004 BARDA initiative to increase flu vaccine production in low-income countries achieved a fivefold increase since the program began. While the work was hard, the strategy was simple: Invest in companies in low-income countries, help them build facilities and support them as they cultivate expertise.

Vaccinating the globe will require leadership and a level of international cooperation that many people may consider impossible. But if the United States provides that leadership and demands that cooperation, millions of lives will be saved, and the world will have a new template for solving some of the many challenges that transcend our borders.

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The Role of Doulas in Addressing Disparities, Barriers, and Potential Solutions to Navigating Reproductive Loss

Jon Musai*, Noelle Shields[†], Lucy Zhang[†], and Buu-Hac Nguyen[†]

Reproductive loss can take many forms. Common experiences include abortions, stillbirths, or miscarriages. Especially in a post-Roe time and space, the health disparities and stigmas that exist surrounding reproductive loss and those experiencing pregnancy loss have become even more apparent. Health disparities continue to exist through sociodemographic factors such as ethnicity, gender, race, and socioeconomic status. As found in existing literature on individuals' experiences with reproductive healthcare, each person's experiences strongly correlate with their identities. The level of reproductive care and compassion received vary dramatically as a result, with people of color and lower socioeconomic statuses receiving lower quality of care when seeking it out. Trends in unintended pregnancies and access to support resources also reinforce the idea that health disparities are at play. Additionally, intersectionality, or the overlapping of an individual's multiple identities, plays an important role in the disparities seen within reproductive healthcare as discrimination and other structural factors are designed to benefit certain groups of individuals while putting others at a disadvantage. Studies and surveys of individuals who have experienced pregnancy loss have addressed the existence of these inequalities within reproductive healthcare. Through a reproductive justice perspective, this literature review aims to bring attention to the disparities present in reproductive healthcare and how the work of reproductive loss doulas, who are full-spectrum doulas who honor all reproductive experiences, may address these disparities with sensitive and compassionate care. While addressing nationwide disparities in pregnancy loss, this literature review uses the state of Michigan to also analyze the current legislative efforts designed to expand access to critical reproductive healthcare services.

Keywords

reproductive justice • reproductive loss doula • reproductive loss • health disparities

*University of Michigan, jmusai@umich.edu

[†]University of Michigan

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Introduction

The term “reproductive loss” can be used to describe loss in many forms, be it from abortion, still-birth, or miscarriage. Pregnancy loss in all its forms is unfortunately a common event that does not biologically discriminate between race, socioeconomic status (SES), or ethnicity. Regardless, using social determinants of health to pinpoint disparities in access and quality of reproductive grief care helps loss workers like doulas determine where resources are most needed (Chor et al., 2018). Health disparities, as defined by the Centers for Disease Control and Prevention (CDC), “are preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations” (Health Disparities | DASH | CDC, n.d.). Sociodemographic features like SES, language, and age can all have physical effects on health outcomes, with systemic issues like racism even causing measurable changes in pathophysiology. These identities do not exist in a vacuum, and different identities interact to produce unique experiences with abortion and loss.

Rooting the discussion of pregnancy loss in the reproductive justice framework helps identify and address disparities as they intersect to create individual experiences with oppression. The term “reproductive justice,” coined by the group Women of African Descent for Reproductive Justice in 1984, is “the human right to maintain personal bodily autonomy, have children, not have children, and parent the children we have in safe and sustainable communities” (Williams, 2019). Therefore, reproductive justice shifts the conversation from one of choice to that of access in order to maintain an individual’s bodily autonomy. One way in which current models of health can promote this reproductive justice framework is through the integration of reproductive loss doulas during pregnancy loss experiences.

A reproductive loss doula seeks to support a person’s unique pregnancy loss journey while prioritizing this individual’s safety and bodily autonomy (Taylor, 2021). Therefore, reproductive loss doulas may address the stark disparities that exist within reproductive loss experiences by supporting a person’s social identity while offering affirmative and inclusive care during these outcomes. Reproductive loss doulas may serve as community-based resources that assist clients in navigating economic, medical, and social challenges that arise from reproductive loss (Chor et al., 2018). The objective of this article is to not only identify reproductive loss disparities and the structural barriers that perpetuate these health inequities but also apply a reproductive justice framework to advocate for the important work that loss doulas provide in addressing these disparities.

Stigma and Reproductive Loss

The stigma surrounding reproductive loss prevents those who have experienced it from speaking about it in both social and medical discourse. This stigma not only perpetuates the widespread belief that reproductive loss is a rare occurrence but also further isolates those who experience it. Further, the misinformation and lack of reliable statistics on reproductive loss incidence reinforce the misconception that reproductive loss is a deviant and unusual pregnancy outcome (Kumar et al., 2009). In actuality, reproductive loss is a common occurrence: nearly one in five pregnancies will end in abortion in the United States (Jones, 2019). Further, one in four pregnancies is estimated to be affected by miscarriage (Miscarriage – Symptoms and Causes, 2021). Openly discussing reproductive loss in its many states could help reduce stigma and allow those experiencing loss to find community within each other.

Miscarriage and Stillbirth Disparities

Despite the common frequency of reproductive loss, certain communities disproportionately demonstrate higher rates of loss and pregnancy termination (Pregnancy and Infant Loss | CDC, 2020). People of color and other marginalized identities also face reduced access to resources and services that can provide the proper care to individuals experiencing reproductive loss. Miscarriage is defined as fetal death before the twentieth week of gestation, whereas stillbirth is defined as fetal death after the twentieth week of gestation (Pregnancy and Infant Loss | CDC, 2020). Black birthing women have a nearly two-time greater risk of miscarriage and stillbirth relative to White birthing women (Stillbirth | CDC, 2020).

There are certain risk factors that heighten an individual's likelihood of experiencing miscarriage, which are disproportionately experienced by minoritized communities. For instance, stress, abuse, chronic exposure to social and economic disadvantage, and legal stressors contribute to higher rates of miscarriage (Mukherjee et al., 2013). These factors contribute to the weathering of communities of color and/or lower SES, which may induce imbalances in inflammatory and neuroendocrine pathways that result in miscarriage (Li et al., 2018).

Miscarriage and stillbirth are associated with poor care of the pregnant person during the pregnancy (Bommaraju et al., 2016). Therefore, miscarriage and stillbirth evoke feelings of guilt and emptiness for the birthing individual and result in emotional trauma and higher levels of stress and anxiety (Corcoran et al., 2017). Due to this stigmatization, an individual's support system may avoid conversations surrounding miscarriage and stillbirth, which results in feelings of "disenfranchised grief" (Burden et al., 2016). This term describes the feeling that the birthing individual's grief is not validated by their friends, family, and health professionals. Nevertheless, research demonstrates that feelings of isolation subside once people become aware that miscarriage and stillbirth are common experiences (Fairchild & Arrington, 2022). A strong connection to the roles of loss doulas and this important validation of feelings can thus be made, as loss doulas play a large part in supporting and validating the experiences of individuals undergoing pregnancy to further destigmatize miscarriage on a larger scale.

Stratified reproduction reveals that people experience reproduction differently based on sociodemographic factors, such as race and income. For instance, due to intrusive surveillance, people of color and/or lower SES may perceive miscarriage as a personal wrongdoing that is indicative of poor care during pregnancy (Bommaraju et al., 2016). Nevertheless, due to the value of childbearing adorned onto wealthy White individuals, these individuals are more likely to receive the benefit of the doubt regarding the miscarriage (Bommaraju et al., 2016). This difference in treatment is especially jarring given that approximately 90% of unintentional pregnancy loss is due to genetic abnormalities, which are frequently undiagnosed (Baldwin, 2022). Therefore, by understanding how reproductive loss is rooted in stratified reproduction, loss doulas can avoid generalized attitudes toward this experience and offer care that is responsive to individual needs. Overall, reproductive loss doulas can practice cultural humility and patient-centered care to address the effects of discrimination on the reproductive loss experiences of people of color and/or lower SES (Chor et al., 2018).

Medical Racism and Coercion

In addition to miscarriage and stillbirth, people of color and people of lower SES have disproportionately higher rates of unintended pregnancies. For instance, 63% of surveyed pregnancies among Black women and 48% of those among Hispanic women are unintended, compared with the 42%

among White women (Troutman et al., 2020). Further, 64% of women with an income below the Federal Poverty Level reported an unintended pregnancy, compared to the 37% of women with an income 200% above the Federal Poverty Level who reported an unintended pregnancy (Dehlendorf et al., 2013). These higher rates of unintended pregnancy may reflect the access to and use of contraception for people of color and/or lower SES as related to the history of medical abuse and reproductive coercion against these communities.

Beginning in the early twentieth century, the eugenics movement imposed draconian efforts to eradicate “undesirable” traits from the human gene pool (Stern, 2020). Historically, poor and minority women were forced and/or coerced to be sterilized by the government while being encouraged to use contraception in efforts to restrict childbearing within these communities (Stern, 2020). The eugenics movement used compulsory sterilization to restrict the reproductive capacity of people of color and/or lower SES (Stern, 2020). In the early twentieth century, California’s Asexualization Acts allowed for the sterilization of 20,000 Black and Mexican individuals (*America’s Forgotten History of Forced Sterilization*, 2020). The goal of these laws was to “protect society from deleterious genes and the social and economic costs of managing ‘degenerate stock’.” By 1970, nearly 70,000 Americans – overwhelmingly working class people of color – had been forcibly sterilized (*America’s Forgotten History of Forced Sterilization*, 2020).

During the 1990s and continuing in the twenty-first century, coercive federal and state policies encouraged sterilization in exchange for welfare benefits and/or sentence reduction. These policies sought to restrict the fertility of those who relied on government assistance as an effort to reduce poverty (Romero & Agénor, 2009). Commonly referred to as “child-exclusion policies,” these government regulations limited additional income support to families who birthed an additional child while enrolled in Temporary Assistance to Needy Families (TANF). TANF predominantly services Black and Hispanic women, suggesting that these family-cap regulations disproportionately infringe on the sexual, reproductive, and privacy rights of these welfare recipients.

These aforementioned factors all contribute to overall distrust of the healthcare system, as well as possible skepticism about the intention of contraception. Nearly twice as many Black and Hispanic individuals believed that government uses birth control to limit minority population relative to White respondents (Harper, 2012). This finding highlights that improving knowledge of the efficacy and safety of birth control options may ameliorate race-based disparities in contraceptive usage and unintended pregnancy rates.

This history of reproductive coercion, partnered with modern-day financial barriers may explain differences in contraceptive adherence and preferences between people of color and white individuals, resulting in higher rates of unintended pregnancies (Dehlendorf et al., 2013). While medical distrust is still prevalent, it is not a valid excuse to blame patients for reproductive decisions when the medical system and government at-large should be responsible for healing past wounds and ensuring equitable access to care.

Unintended births have been associated with poor medical and social outcomes, such as pre-eclampsia, preterm birth, hindrance of educational goals, and increased risk of poverty (Health Disparities in Abortion and Family Planning Workshop, 2019). Long-acting reversible contraceptives (LARCs) have the lowest failure rate of any reversible birth control method; however, people of color are less likely to use LARCs, compared to White individuals (“Seeking Causes for Race-Related Disparities in Contraceptive Use,” 2014).

The lack of awareness of different contraceptive methods and options and prevalent medical mistrust is an issue that can be addressed through the work of loss doulas as well. By increasing

awareness and knowledge regarding different contraceptive methods, loss doulas may work to reduce exposure to the medical and social risk factors associated with unintended pregnancies, especially for people of color and/or lower SES. In addition to providing emotional and physical support during the pregnancy loss experience, loss doulas may also provide information surrounding contraception to empower clients to make informed decisions about their reproductive capacity.

Unintended Pregnancy and Reproductive Loss

Discussion of reproductive loss disparities cannot occur without recognizing the role of unintended pregnancy in reproductive decision-making. As mentioned previously, approximately half of unintended pregnancies end in abortion (Unintended Pregnancy and Abortion Worldwide, 2022). Further, the trends in unintended pregnancies closely mirror the rates of pregnancy loss. For instance, Black and Hispanic women have significantly higher abortion rates relative to White women (Kortsmit, 2021). Surveyed women with incomes less than 100% of the Federal Poverty Level have an abortion rate that is nearly six times higher than the rate of women with incomes greater than 200% of the Federal Poverty Level (*Abortion in the Lives of Women Struggling Financially*, 2022). Further, the Guttmacher Institute revealed that 75% of abortion patients across the United States identify as poor or low-income (Jerman, 2022). Lastly, surveyed women who do not have a college education also demonstrate higher abortion rates relative to women with college degrees (Jones & Jerman, 2017).

Overall, these findings reveal that minoritized communities experience pregnancy termination at higher rates than socially advantaged communities. This may be due to the higher rates of unintended pregnancies among people of color and/or lower SES (Jones & Finer, 2012). Further, people of color and/or lower SES face systemic hardships such as exposure to higher levels of stress and discrimination along with lower qualities of living and working conditions, which may offer potential reasons for why these individuals decide to seek abortion care at higher rates (Jones & Finer, 2012).

While loss doulas are generally thought of as a support system for lost intended pregnancies, their expertise as reproductive health educators and trained emotional support personnel can be used for unintended pregnancy loss as well. Loss doulas focus on the emotional and overall well-being of their clients with no judgment, no matter if the pregnancy ended in abortion or miscarriage.

LGBTQ+ Community and Reproductive Loss

LGBTQ+ individuals also experience disparities in reproductive loss. For instance, heteronormative conceptualizations of pregnancy continue to exclude transgender men and nonbinary individuals from conversations surrounding miscarriage, stillbirth, and abortion (Zucker, 2020). Fifty-six percent of LGBTQ+ patients report blatant discrimination in medical settings (including harassment and lack of provider knowledge), with nearly 20% of transgender individuals being denied healthcare due to their gender identity (Zucker, 2020). Despite a subset of sexual minority groups demonstrating higher rates of pregnancy termination relative to heterosexual individuals, only 23% of surveyed abortion clinics in 2017 provided transgender-specific or gender-affirming care (Jones et al., 2020). Therefore, the systemic erasure of queer pregnancy experiences from medical care and social discourse may contribute to higher rates of substance abuse and negative mental health outcomes among LGBTQ+ individuals following reproductive loss (Zucker, 2020).

Denial of reproductive health services to queer patients may also contribute to adverse clinical outcomes following reproductive loss. For instance, nearly half of documented miscarriages result in a dilation and curettage procedure, which is a surgical procedure. If the placental and fetal tissue are not completely removed during this surgery, an infection that may induce septic shock can occur (American Pregnancy Association, 2022). This is especially significant for queer patients as inaccessibility to gender-affirming and competent medical care may result in unsafe miscarriage management, which can increase the likelihood of medical complications like septic shock (Zucker, 2020). Loss doulas who can focus on all-encompassing and individual care may be some of the best candidates for focusing on gender-affirming care in reproductive experiences. Working alongside medical professionals to ensure all of a patient's needs are met appropriately is of the utmost importance to doulas.

Structural Factors Contributing to Reproductive Loss Disparities

Structural factors play a prominent role in contributing to reproductive loss disparities. A 2005 study measured discrimination against African American women while receiving family planning services and defined race-based discrimination as a provider not listening to the patient, the patient receiving sub-optimal service compared to others, and providers making assumptions about sexual history. Of the 79% of women who reported experiences with healthcare providers regarding family planning or birth control services, 67% reported race-based discrimination when obtaining such services (Thorburn & Bogart, 2005). Physicians and nurses often fall prey to inaccurate stereotypes that patients of color have more sexual partners than their white counterparts, further discouraging patients of color from seeking preventative reproductive care. Furthermore, studies have shown that Black individuals who outwardly express their Afrocentrism more directly in regard to fashion, dress, and mannerisms face higher rates of discrimination (Williams & Mohammed, 2008). This only furthers the lack of access to reproductive care and mistrust for the medical system that African Americans experience (Williams & Mohammed, 2008).

Other structural barriers, such as difficulty in accessing transportation and affording abortion care, contribute to delaying this care. In addition to demonstrating higher rates of pregnancy termination, people of color are more likely to have late-term abortions, which exposes these individuals to greater medical risks (Jones & Finer, 2012). While major abortion complications occur in less than 1% of reported cases, the safety of this procedure does significantly decrease with increasing gestational age (Jones & Finer, 2012). In fact, the University of California–San Francisco revealed that Black women are more than twice as likely as White women to experience abortion-related mortality (Health Disparities in Abortion and Family Planning Workshop, 2019). This finding suggests that because minoritized identities obtain higher rates of late-term abortion, these same individuals may be subject to higher rates of mortality due to the medical complications that arise from a late-term abortion.

Further, individuals with limited education demonstrate higher levels of late-term abortion, which may be due to a lack of knowledge of reproduction and lower levels of health literacy (Jones & Finer, 2012). This may contribute to these individuals experiencing increased difficulty in obtaining necessary information about pregnancy termination options and/or finding a healthcare provider (Jones & Finer, 2012). Depending on the unique circumstances of the individual's reproductive loss experience, loss doulas may address this gap in knowledge by assisting these individuals

in understanding and accessing the different options available for pregnancy termination and management. Focusing on cultural competence and person-first reproductive education is just one way loss doulas can provide services that are mindful of each client's needs and the systemic barriers they face when accessing reproductive care. Overall, these findings reveal that minoritized communities may have more negative reproductive loss experiences in the clinical environment due to discrimination and inaccessible medical information.

Structural Barriers to Abortion Care

Structural barriers to abortion care create substantial long-term effects that disproportionately target minoritized communities. One in four women with Medicaid coverage who seek an abortion are forced to continue the pregnancy due to the restrictions imposed by the Hyde Amendment (The Hyde Amendment, n.d.). Compulsory childbirth presents much more serious public health and economic issues when compared to abortion. Carrying a pregnancy is nearly 14 times riskier than receiving an abortion. Further, individuals who do not obtain a desired abortion are four times more likely to live in poverty and three times more likely to experience unemployment (*Findings from the Turnaway Study*, 2020). The self-perpetuating cycle enforced by the expense of abortion is extended when abortions are removed as an option altogether, impacting the financial stability and educational opportunities of the birthing individual (*Findings from the Turnaway Study*, 2020).

Further, when compared to individuals who received desired abortion care, those who were denied this care demonstrated a higher risk for eclampsia and postpartum hemorrhage (*Findings from the Turnaway Study*, 2020). Given that Black maternal mortality is nearly five times greater than that of White birthing individuals, these medical complications disproportionately affect people of color (Pregnancy and Infant Loss | CDC, 2020). This highlights that allowing individuals to receive timely and safe abortion care may prevent these individuals from experiencing the adverse health outcomes associated with unintended childbirth (Dehlendorf et al., 2013).

In addition to a heightened risk for medical complications, individuals who are denied access to abortion care are more likely to stay in contact with abusive partners (*Findings from the Turnaway Study*, 2020). This is especially significant for people with disabilities and people of color, who are already much more likely to experience sexual assault or intimate partner violence (*Findings from the Turnaway Study*, 2020). Restricting access to abortion care not only prevents individuals from receiving necessary medical intervention but also directs minoritized individuals to sustained violence. Consequently, abortion-seeking individuals will experience higher rates of psychological abuse, rape, reproductive coercion, and pregnancy-related homicide if they are forced into childbirth (*Findings from the Turnaway Study*, 2020). Overall, barriers to reproductive care can result in a multitude of repercussions, including economic and employment consequences, that can perpetuate already-existing instabilities.

Socio-economic Disparities in Reproductive Loss

Economic hardship is also a significant structural barrier that limits access to safe and desired abortion care. A first trimester abortion costs around \$500, whereas second and third trimester abortions can cost more than \$3,000 (Pregnancy Decision Line, 2022). In 2021, the Federal Reserve estimated that one out of three Americans do not have the financial means to cover unexpected expenses, such as abortion care (Abortions Later in Pregnancy, 2019). Therefore, financial insecurity functions as a critical barrier that may prevent people from obtaining on-time abortion care.

Nearly 28% of women of reproductive age and 40% of low-income women rely on Medicaid (Coverage for Abortion Services in Medicaid, 2022). Further, women of color are more likely than White women to be enrolled in Medicaid (*For Women of Color, Access Is Threatened*, 2022). In 2015, 31% of Black women and 27% of Hispanic women of reproductive age were enrolled in Medicaid, compared with 16% of White women (*For Women of Color, Access is Threatened*, 2022). Nevertheless, there are substantial efforts aimed at restricting the scope of Medicaid coverage.

The Hyde Amendment severely limits the use of federal funds for abortion care in Medicaid (The Hyde Amendment). It also limits abortion coverage by other federally funded programs, including the Indian Health Reserve, Medicare, Americans with Disability Act, and health insurance for federal employees (The Hyde Amendment). Further, the Affordable Care Act does not require insurance plans to cover abortion, resulting in 25 states passing laws that restrict abortion coverage in their health insurance marketplaces except in the specific situations of incest, rape, and life endangerment (Coverage for Abortion Services in Medicaid, 2022). As a result, safe and legal abortion care becomes an unaffordable option for minoritized communities, which comprise a significant share of Medicaid programs.

Additionally, the Turnaway Study – a national longitudinal study involving 1,000 women seeking abortion care – reported that the total out-of-pocket costs for an abortion procedure are equivalent to one-third of the personal monthly income of more than half of the surveyed individuals (Roberts et al., 2014). This finding suggests that financial barriers to abortion care trap minoritized communities in a self-perpetuating cycle of economic hardship, resulting in individuals forgoing food, rent, and utilities to afford an abortion (Roberts et al., 2014).

Transportation represents another significant barrier to abortion care access, especially for those of lower SES status, and has been sustained by the overturn of *Roe v. Wade*. Nearly 20% of individuals across the United States would need to travel at least 43 miles to reach the nearest abortion clinic (Travel Far to Access Services, 2022). This distance is particularly relevant to the substantial minority of lower-income individuals who live in rural areas as they travel longer distances to access abortion care (Travel Far to Access Services, 2022).

Following the recent rollback of *Roe v. Wade*, most individuals seeking abortions will travel farther than they would have previously to reach the nearest abortion clinic (*Travel Far to Access Services*, 2022). For these individuals, the travel distance will increase on average from 36 miles to 274 miles to their nearest abortion provider (*After Roe V. Wade*, 2022). Further, 72% of abortion facilities offer abortion up to 12 weeks of gestation, whereas only 34% of facilities offer abortion up to 20 weeks, and only 16% provide abortion up to 24 weeks (Jerman & Jones, 2014). Therefore, minoritized individuals – who already demonstrate higher rates of late-term abortion – may need to travel longer distances to access necessary abortion care in this post-Roe environment given the stark reduction in clinics offering late-term abortions (Jones & Finer, 2012). Living further away from an abortion clinic corresponds to increased travel and lodging costs, which contributes to an individual's inability to receive abortion care at the time they seek out these services (*After Roe V. Wade*, 2022). Socio-economic barriers to doula care.

Legislative Barriers

In Michigan, there are state-specific abortion regulations that further create structural barriers to accessing abortion care (Michigan's 24-Hour Waiting Law., n.d.). For instance, Michigan Medicaid and private health insurance coverage of abortion is prohibited in all cases except life endangerment

(Guttmacher Institute., n.d.). These regulations can be interpreted as violations of the reproductive right to not bear children by using insurance restrictions to create barriers to receiving reproductive care.

Additionally, Michigan's 24-Hour Waiting Law requires that medical information must be disclosed to individuals seeking an abortion 24 hours before the procedure (Michigan's 24-Hour Waiting Law., n.d.). This information includes depictions of fetal development corresponding to gestational age, prenatal and parenting services, and a written summary of the abortion procedure; however, portions of this State-mandated information are misleading and not supported by scientific evidence (Michigan Abortion Wait Time., n.d.).

These waiting periods create substantial logistical obstacles that the abortion-seeking individual must oftentimes navigate alone. For instance, Michigan's 24-Hour Waiting Law represents 24 hours where the individual must find childcare services – if they already have children. Further, these waiting periods are also 24 hours, during which the individual must pay for lodging, food, and any additional expenses that may arise when obtaining abortion care (Michigan Abortion Wait Time, n.d.). People of lower SES are disproportionately affected by these state-specific restrictions as they are less likely to have substantial savings to cover these necessary expenses.

Post-Roe Implications

The recent overturning of *Roe v. Wade* has further exacerbated barriers to reproductive healthcare (*After Roe V. Wade, 2022*). With *Roe v. Wade's* reversal, individuals need to travel longer distances to access abortion-providing clinics. Further, state-mandated waiting periods force individuals to make multiple medically unnecessary visits to abortion providers, forcing them to stay away from work and/or caregiving responsibilities. (Michigan Abortion Wait Time., n.d.). *Roe v. Wade* disproportionately harms minoritized communities, which already face substantial burdens when seeking reproductive healthcare.

The post-Roe environment has also exposed those seeking abortion care to criminalization which has contributed to miscarriage rates and stillbirth experiences (Hurtado & Maglione., n.d.). Currently, 38 states have laws that criminalize harm to the fetus that may have resulted in miscarriage or stillbirth. These laws ascribe separate victim status to the fetus, indicating that self-induced abortions, drug use during pregnancy, and child endangerment can be used to prosecute miscarriage and stillbirth (Hurtado & Maglione., n.d.). Now that reproductive rights are no longer constitutionally protected, individuals may seek dangerous and unsafe alternatives for pregnancy termination that may result in a greater risk of miscarriage and stillbirth. Given that people of color and/or lower SES demonstrate higher rates of miscarriage and stillbirth, this exposes these communities to increased criminalization and violence following *Roe's* overturning (Hurtado & Maglione., n.d.).

In this post-Roe environment, reproductive loss doulas may be of particular importance to these communities (*Importance of Doulas, 2021*). Loss doulas can assist individuals in navigating barriers to reproductive healthcare and limiting the harm and trauma caused by these barriers. Given that 13 states currently ban abortion, reproductive loss doulas can provide logistical support by picking up out-of-state clients from airports and arranging accommodations to ensure that clients can safely arrive to their appointments (*After Roe V. Wade, 2022*). Further, loss doulas can connect clients to resources – such as abortion funds – that cover travel costs associated with abortion

care, including childcare, hotels, and gas money. Reproductive loss doulas can also help clients navigate the complex legal requirements to access an abortion, along with correcting any inaccurate information about pregnancy termination (*Our Communities Hold the Solutions*, 2022). Using both nonjudgmental and affirmative care, reproductive loss doulas can empower the autonomy and dignity of their clients as they navigate the best option for managing their pregnancy during this particularly hostile time for reproductive rights (*Our Communities Hold the Solutions*, 2022).

Role of Doulas in Reproductive Loss Disparities

Recent over-medicalization of abortion may interfere with the emotional processing of this experience, especially as surgical abortions account for most of the pregnancy termination procedures (Diamant & Mohamed, 2022). Further, minoritized communities are subject to greater medical risks following this procedure due to their higher rates of late-term abortion (Jones & Finer, 2012). Therefore, reproductive loss doulas may provide compassionate support to these individuals to ameliorate feelings of fear and anxiety during pregnancy termination. For instance, the integration of a loss doula in the clinical setting can assist with processing patient emotions through dedicated care, listening sessions, grief counseling, resource referral and promoting physical wellbeing, which reduces patient pre- and post-procedure anxiety (Chor et al., 2018). Consequently, this may allow the medical staff to better focus on the technical aspects of the surgical procedure to prioritize patient safety. Overall, this highlights the beneficial impact of doulas on the patient's experience during an abortion procedure (Chor et al., 2018).

Compassionate support has also been shown to induce positive effects on the wellbeing of an individual experiencing reproductive loss (Chor et al., 2018). Therefore, reproductive loss doulas may be important to people who experience higher rates of miscarriage and stillbirth. One way in which loss doulas can address the stigmatization and isolation of pregnancy loss is by accompanying clients to appointments to confirm the miscarriage or stillbirth and offering nonjudgmental support to assist with the emotional processing of these events (Chor et al., 2018). Further, loss doulas can work with clients to create unique grieving rituals through creative expression and/or engaging in spiritual activities to honor the loss (*Importance of Doulas*, 2021). These strategies highlight how loss doulas can serve as social support systems to minoritized individuals who experience higher rates of reproductive loss (*Importance of Doulas*, 2021).

Expanding Access to Reproductive Loss Doulas

Despite the documented importance of reproductive loss doulas in managing reproductive loss, current models of health and policy continue to exclude loss doulas from healthcare settings (Chen & Fradet., n.d.). The National Health Law Program revealed that hospitals and medical providers may not always understand the scope of doula care, resulting in strained relationships between doulas and the clinical staff (Chen & Fradet., n.d.). Further, during the COVID-19 pandemic, doula work was frequently referred to as “non-essential,” which allowed healthcare providers and policymakers to restrict doula accompaniment during pregnancy termination. These interpersonal and institutional barriers to doula work serve as reflections of the targeted erasure of community-based birth workers by a patriarchal medical system (Chen & Fradet., n.d.).

Financial barriers also limit the accessibility of doula services. Healthcare payers largely restrict adequate compensation for doula services (Chen & Fradet., n.d.). This results in out-of-pocket remuneration for doulas, which is a feasible option for mainly White and/or higher SES individuals. Doula services can cost from \$500 to \$2,000, and compounded with the costs of abortion, these services may be financially inaccessible to people of color and/or lower SES (Chen & Fradet., n.d.). Nevertheless, there are current federal and state policy efforts that seek to expand insurance coverage of doula care (Robles-Fradet, 2021). Specifically, these legislative efforts seek to mitigate the financial barriers that restrict access to support services for minoritized communities.

As of 2022, states are in various stages of planning and implementing Medicaid coverage of doula services to improve the birthing experience and outcomes for people of color (Robles-Fradet, 2021). Currently, six states allow for reimbursement of doula work through Medicaid, while six other states plan to acquire Centers of Medicare and Medicaid Services approval to allow Medicaid to cover doula services (Robles-Fradet, 2021). The Michigan Department of Health and Human Services recently proposed a policy to allow Medicaid coverage of community-based, prenatal, labor and delivery, and postpartum services as an attempt to address racial disparities that exist within pregnancy and childbirth (*MDHHS Proposes to Cover*).

Despite efforts to implement doula coverage in Medicaid, these proposed plans exclusively focus on providing doula support to individuals throughout their pregnancy, childbirth, and postpartum experience. These state policies fail to identify reproductive loss support as a service that doulas can provide, revealing a gap in current legislation as policymakers fail to proactively address the diversity of experience in reproductive loss by dismissing the need for reproductive grief support in the scope of doula services (*Our Communities Hold the Solutions*, 2022). This exclusion further perpetuates the stigma surrounding reproductive loss, potentially resulting in delay of care, isolation, and clinical complications that arise from the unsafe management of reproductive loss experiences. Therefore, policy efforts should identify reproductive grief care as a tenet of doula work to more comprehensively address the stark disparities in reproductive healthcare (Chen & Fradet., n.d.).

Current policies should include federal and state-wide insurance coverage for support for all pregnancy outcomes, including abortion, miscarriage, and stillbirth. Further, policies should address the disconnect between doula work and clinician knowledge by educating both clients and medical providers on the benefits of doula support during reproductive loss (*Our Communities Hold the Solutions*, 2022). Given the limited number of reproductive loss doula training programs, states should also invest in resources to support community-based models of support, trauma-informed care, and reproductive justice to expand and strengthen the doula workforce (*Our Communities Hold the Solutions*, 2022).

Integrating the reproductive justice framework into loss doula care is crucial to dismantling the systems of discrimination, oppression, and power that contribute to reproductive loss disparities (*Our Communities Hold the Solutions*, 2022). Loss doulas expand upon standard knowledge of providing informational, physical, and emotional support by centering pregnancy loss in the reproductive justice framework (*Importance of Doulas*, 2021). This framework gives loss doulas the ability to understand how systems of medical racism, economic oppression, and policy discrimination intersect to violate the reproductive rights of minoritized communities (*Importance of Doulas*, 2021).

The structural barriers that limit access to safe and affordable reproductive healthcare highlight the specific need for loss doulas to serve as community assets. Through this framework, loss doulas can use their community-based knowledge to connect clients to local resources that address the wider economic and social issues within the community that contribute to disparities in reproductive loss (*Our Communities Hold the Solutions*, 2022). Broadly, loss doulas can assist individuals in

navigating unstable housing and working conditions, food insecurity, caregiving responsibilities, and transportation.

No individual should have to make the decision as to whether to maintain their personal well-being or carry a fetus to term despite having decided themselves that they are unable to or do not want to continue the pregnancy. Therefore, expanding access to loss doulas may mobilize individuals to pursue their desired option for pregnancy management.

Conclusion

Overall, reproductive loss doulas provide emotional, physical, and informational support for anyone experiencing reproductive loss (Chor et al., 2018). However, like other forms of reproductive health, access is limited only to those who can afford it and those who feel safe and unjudged in obtaining care (Chen & Fradet., n.d.). In addition to demonstrating higher levels of reproductive loss, minoritized communities also disproportionately face barriers in accessing the proper resources to manage their pregnancy outcomes. Therefore, to promote reproductive justice, current models of health must emphasize a person's social identity when counseling patients on reproductive loss of all kinds. Overall, loss doulas may serve as community-based resources to affirm and validate the reproductive autonomy of marginalized communities through person-centered support (*Our Communities Hold the Solutions*, 2022).

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A Review of Primary, Secondary, and Tertiary Prevention Strategies for Alzheimer's Disease

Heather O'Donnell*

This article explores the non-modifiable and modifiable risk factors for Alzheimer's, as well as the Alzheimer's primary prevention, secondary prevention, and tertiary prevention strategies that can be implemented. Alzheimer's is the sixth leading cause of death in the United States and the most expensive chronic disease (Alzheimer's Association, 2020). It has a detrimental physical, psychological, and financial impact on patients and caregivers (Alzheimer's Association, 2020). People can reduce their risk of developing Alzheimer's by eating a healthy diet, using hearing aids for hearing loss, engaging in regular physical activity, spending time with other people, doing mentally stimulating activities, reducing alcohol consumption, and avoiding tobacco (Livingston et al., 2020). Early screening and diagnostic tools are important because they allow people living with Alzheimer's to establish an effective care plan and to take advantage of treatments, which are most effective in the early stages of the disease (Guzman-Martinez et al., 2021). Some screening and diagnostic tools include biomarkers, scalable screening technologies, and cognitive assessments (Guzman-Martinez et al., 2021). Primary and secondary prevention strategies must address the needs of minority populations, who have a higher risk of developing Alzheimer's compared to the general population (Livingston et al., 2020). Federal public health initiatives, such as the National Alzheimer's Project Act, the Dementia Prevention Action Plan, and the Behavioral Risk Surveillance System, play an important role in Alzheimer's public health research, surveillance, and prevention strategies (Chong et al., 2021; Kelley et al., 2018).

Keywords

primary • secondary • tertiary prevention • modifiable risk factor •
non-communicable diseases (NCD) • risk reduction

Introduction

Alzheimer's is a chronic and fatal neurodegenerative disease that accounts for between 60% and 80% of all cases of dementia, a group of conditions that cause cognitive decline and impair a

*Rutgers University, hao14@scarletmail.rutgers.edu

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person's ability to perform daily activities (Dziendzikowska & Grodzicki, 2020). It occurs due to brain tissue damage, the loss of neural connections, and the formation of tangles (twisted strands of tau protein threads) and plaques (abnormal clusters of amyloid protein fragments) in the brain (Dziendzikowska & Grodzicki, 2020). According to the CDC National Center for Health Statistics, the 2018 age-adjusted national cause-specific death rate for Alzheimer's was 30.5 per 100,000 (CDC, 2019). In 2018, there were 122,019 recorded deaths from Alzheimer's in the United States, making Alzheimer's the sixth leading cause of death and disability-adjusted life years in the United States and the fifth leading cause of death among Americans aged 65 and older (Alzheimer's Association, 2020). Although the mortality rates associated with cardiovascular disease, cerebrovascular disease, and HIV decreased between 2000 and 2018 due to medical advances, the Alzheimer's mortality rate increased by 146.2% (Alzheimer's Association, 2020). The number of Americans living with Alzheimer's is projected to increase from 5.8 million in 2020 to 13.8 million by 2050 if there is no way to prevent, slow, or treat Alzheimer's (Alzheimer's Association, 2020). In 2020, the total healthcare cost for the treatment of Alzheimer's was \$305 billion, with the cost projected to increase to over \$1 trillion by 2050, making Alzheimer's the most expensive disease (Alzheimer's Association, 2020). Population aging, which refers to the increasing proportion of people who are aged 60 years or over, contributes to the rising prevalence of Alzheimer's and the rising demand for caregivers, who face an increased risk of adverse physical and mental health outcomes (Alzheimer's Association, 2020). Public health professionals must address the escalating Alzheimer's epidemic through the implementation of primary prevention strategies, which aim to prevent the illness from developing; secondary prevention strategies, which aim to diagnose and treat the disease before the disease becomes advanced and disability becomes severe; and tertiary prevention strategies, which aim to reduce the impact of a disease by minimizing suffering and improving quality of life.

Primary Prevention

Primary prevention aims to decrease the proportion of people who develop Alzheimer's by intervening on the non-modifiable risk factors and the modifiable risk factors. Non-modifiable risk factors cannot be changed, while modifiable risk factors can be changed. The non-modifiable risk factors include female gender, older age, family history, and genetic predisposition. The modifiable risk factors can be grouped into four subdivisions: vascular (blood vessels) risk factors, lifestyle risk factors, psychosocial risk factors, and developmental risk factors. Some vascular risk factors include type 2 diabetes mellitus, heart disease, stroke, hypertension (high blood pressure), high cholesterol, obesity, and long-term exposure to air pollution (Edwards III et al., 2019).

Lifestyle risk factors include physical inactivity, which increases psychological stress and is associated with vascular and metabolic issues, poor nutrition, smoking, which increases air particulate matter and the production of plaques and tangles, and excessive alcohol consumption (Stephen et al., 2021). Obesity, hypertension, and high cholesterol and triglyceride levels have a stronger association with dementia risk in mid-life than late life (Stephen et al., 2021). A study has shown that individuals with more excess weight experience more brain cell loss and less blood flow to the brain (Dake et al., 2021). This demonstrates the importance of maintaining a healthy weight at an early age to prevent the irreversible negative effects of excess weight on the brain, especially after middle age, when the risk of developing Alzheimer's sharply increases (Dake et al., 2021). Diabetes and physical inactivity have a stronger association with dementia risk later in life (Stephen et al., 2021). People can reduce their risk of Alzheimer's and improve their overall health by making

lifestyle changes, such as eating a healthy diet, exercising regularly, achieving and maintaining a healthy weight, and treating medical conditions (Stephen et al., 2021).

Psychosocial risk factors include lower educational attainment, lower socio-economic status, poor social engagement, and low levels of intellectual stimulation (Crous-Bou et al., 2017). About 19% of Alzheimer's cases worldwide are attributable to lower educational attainment, making lower educational attainment the most important modifiable risk factor for Alzheimer's as well as the earliest (Crous-Bou et al., 2017).

Developmental risk factors include sleep deprivation, depression, epilepsy, traumatic brain injury, hearing loss, which leads to social isolation, a loss of cognitive stimulation, brain atrophy (a loss of connections between neurons), oral diseases, which trigger an inflammatory response, infections, chronic work-related stress, and early childhood stress (Crous-Bou et al., 2017). Stress triggers neuroinflammation (an inflammatory response in the brain) and oxidative stress (physiological stress that occurs due to the release of harmful chemicals called free radicals) (Crous-Bou et al., 2017). In a study of 2,000 individuals aged 71–78 years, work-related stress was associated with a 55% increased risk of Alzheimer's (Galvin, 2017).

Modifiable risk factors cause about a third of Alzheimer's cases worldwide, demonstrating that risk factor reduction can aid in Alzheimer's prevention (Crous-Bou et al., 2017). One lifestyle risk factor reduction strategy is regular physical activity due to its increase of neuroplasticity (the brain's ability to change and adapt due to new knowledge and experiences) and high-density lipoprotein (HDL) cholesterol, as well as its reduction of inflammation and plaque formation (Crous-Bou et al., 2017). In the Hisayama Study, higher participation in daily physical activity was associated with a 50% reduction in risk of Alzheimer's (Zhang et al., 2021). Aerobic exercise improves oral fluency and executive function through its protective effects on neuronal health and hippocampus volume (Zhang et al., 2021). A prospective study found that a one-year aerobic exercise training program improved memory ability and blood flow to the brain (Zhang et al., 2021).

Another lifestyle risk factor reduction strategy is adherence to the MIND Diet for Neurodegenerative Delay, a combination of the Mediterranean diet and the Dietary Approaches to Stop Hypertension (DASH) diet (Janoutova et al., 2020). The Mediterranean diet includes fruits, vegetables, fish, legumes, whole-grain cereals, low-fat dairy products, monounsaturated fatty acids, little red meat, and moderate amounts of red wine and caffeine (Janoutova et al., 2020). The DASH diet includes low-fat dairy products, fruits, vegetables, small amounts of sweets and meats, and a limited amount of sodium, total fat, saturated fat, and cholesterol (Janoutova et al., 2020). A longitudinal study including 960 participants of the Memory and Aging Project found that the MIND Diet was associated with a slower rate of cognitive decline and that it improved executive function, memory, and visual construct (Grande et al., 2020). Evidence also supports the long-term use of omega-3 supplements and antioxidant vitamins, such as carotene, vitamin C, or vitamin E, in cognitively healthy mid- and late-life subjects to decrease the likelihood of developing Alzheimer's (Guzman-Martinez et al., 2021). Vascular risk factor reduction strategies should focus on intervening in the risk factors for cardiovascular disease and Alzheimer's, such as diabetes, hypertension, and high cholesterol. Some strategies include early screening and intervention of vascular risks, better blood pressure monitoring, resin therapy for cholesterol lowering, and the maintenance of optimal cardiovascular health. Other strategies include folic acid supplementation to lower homocysteine levels, the management of blood glucose, blood pressure, blood lipid, and weight, and pharmaceutical uses like metformin and other anti-diabetic drugs, antihypertensives, and catheter ablation and oral anticoagulants. An example of a cardiovascular risk reduction intervention is

the Systolic Hypertension in Europe (Syst-Eur) trial, a randomized controlled trial that included 2,418 non-demented adults aged 60 and older with systolic hypertension. The researchers found that an active hypertension treatment of enalapril, hydrochlorothiazide, nitrendipine, or a combination of these reduced the incidence of dementia by 50% (Hsu & Marshall, 2017). Psychosocial risk factor reduction strategies include individual education, meditation and yoga to improve mindfulness (the human ability to be fully present and aware of one's thoughts, feelings, sensations, and surrounding environment) and to reduce stress, frequent social engagement, and participation in cognitive activities, such as solving crossword puzzles, reading, playing games, and learning different languages (Langa, 2018). These strategies increase cognitive reserve, the brain's ability to maintain normal cognitive performance for a longer period and to resist age-related neuropathological changes, including progressive neuronal loss and cellular damage (Langa, 2018). An example of a cognitive-related intervention in the United States is the Advanced Cognitive Training for Independent and Vital Elderly, (ACTIVE) study, a randomized controlled trial that included more than 2,800 cognitively healthy adults older than 65 years who attended ten group sessions during a six-week period, where they received training in reasoning, memory, or processing speed (Crous-Bou et al., 2017). After the ten-year follow-up, the researchers found that the adults who received cognitive interventions exhibited better cognitive functioning and less functional decline in daily living activities compared with the control group (Crous-Bou et al., 2017). The long-term effects on cognition play an integral role in public health prevention because they decrease the overall burden of Alzheimer's (Crous-Bou et al., 2017). Another study showed that living in a neighborhood with institutional resources, such as recreational facilities, community centers, and libraries, was associated with better cognitive function after controlling for individual risk factors for cognitive decline (Langa, 2018). In the World-Wide Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGERS) trial, a multidomain lifestyle intervention that combined cognitive training, dietary counseling (high-protein snacks, glycemic control, MIND Diet), social interaction, management of vascular and metabolic risk factors, and exercise incorporating strength and aerobic training boosted cognitive scores among healthy elderly people who were at risk for dementia, regardless of socioeconomic or sociodemographic factors (Hodes et al., 2018).

A 2017 cross-sectional study validated the multiple findings of observational studies regarding the association between cognitive performance and hypertension, obesity, vascular risk factors, diabetes mellitus, and depression (Galvin, 2017). Dementia shares many common lifestyle risk factors and protective factors with other non-communicable diseases (NCDs), which are illnesses that cannot be transmitted from one person to another and have multiple causes (Stephen et al., 2021). Some NCDs, such as diabetes and obesity, are also risk factors for dementia (Stephen et al., 2021). Therefore, the most cost-effective and feasible dementia preventative interventions will target multiple factors for multiple NCDs (Stephen et al., 2021). Primary prevention policies for dementia can incorporate existing programs and campaigns related to other NCDs, including population health promotion that emphasizes tobacco cessation, alcohol use disorder rehabilitation, weight management, increased physical activity, and adequate nutrition, and specific strategies that address socially active lifestyles, cognitive-stimulating activities, and childhood or formal education (Stephen et al., 2021). The 2017–2025 WHO Global Action Plan on the public health response to dementia states that dementia preventative measures should converge with mental health, existing NCDs, and aging efforts worldwide (Stephen et al., 2021). Public health professionals, researchers, and policymakers can establish evidence-based multidomain interventions at the individual,

community, and population level that target dementia specific risk factors when treating NCDs (Stephen et al., 2021).

The 2020 Lancet Commission on Dementia Prevention describes population-based interventions and individually targeted interventions for Alzheimer's primary prevention. Population-based interventions include improving access to childhood education, providing high-quality, affordable health and social care services, and decreasing the risk of brain trauma by requiring helmets and seatbelts in occupational and transport settings. Other interventions include developing policies that promote social, cognitive, and physical activity across the life course, developing social public health policies that decrease hypertension risk in the population, establishing international and national policies to decrease population exposure to air pollution, examining the risks for hearing loss throughout the life course and reducing excessive noise exposure, and strengthening international and national efforts to decrease exposure to smoking and other addictive substances in childhood, adolescence, and adulthood. Individually targeted interventions include preventing head trauma where an individual is at high risk, treating hypertension and aiming for a mean systolic blood pressure level of less than 130 mm Hg in midlife, and participating in smoking cessation programs. Other interventions include sustaining mid-life and late-life physical activity, refraining from drinking 21 or more units of alcohol per week, using hearing aids for hearing loss, and making lifestyle changes (Livingston et al., 2020).

Preventive interventions must address racial and ethnic disparities in Alzheimer's risk that occur due to the following socioeconomic factors: low household income, low education attainment, and low literacy level (Livingston et al., 2020). Socially disadvantaged populations, including Asian, Black, and ethnic minority groups, have the highest risk of developing Alzheimer's (Livingston et al., 2020). They will reap the greatest benefits from preventative interventions that improve access to education, decrease excessive noise exposure, and decrease hypertension, obesity, and diabetes rates by increasing the availability of nutritious foods and by establishing more physical activity-supportive built environments (Livingston et al., 2020). Other populations that have an increased Alzheimer's risk include older adults, Hispanics, American Indians and Alaska Natives, and individuals with developmental disabilities (Olivari et al., 2020). The use of linguistically, culturally, and age-appropriate public health prevention strategies is necessary to improve access to and the quality of care, which will decrease disparities among these populations (Olivari et al., 2020). Partnering with organizations that focus on these populations can increase intervention effectiveness and impact on disparities (Olivari et al., 2020). Accurate and timely data and community involvement play a crucial role in the development of prevention strategies (Olivari et al., 2020).

Secondary Prevention

Secondary prevention aims to target the pre-symptomatic or preclinical stage and prevent the development of Alzheimer's symptoms through the appropriate use of screening and early diagnostic tools, including biomarkers, scalable screening technologies, and cognitive assessments, followed by prompt treatment (McDade et al., 2021). The five stages of Alzheimer's screening, diagnosis, and care in secondary prevention are as follows: the detection of the disease through screening, the assessment of individuals for cognitive impairment or Alzheimer's pathology, the differentiation of Alzheimer's from other causes of cognitive impairment using blood work analysis for

thyroid hormone or vitamin B12 deficiencies, computed tomography (CT) or structural imaging with magnetic resonance imaging (MRI) for the detection of head injury, stroke, or tumors, the diagnosis of Alzheimer's using biomarkers, brain imaging, mental status tests, and physical and neurological exams, and the immediate treatment and monitoring of patients, which is the responsibility of a patient-centered dementia care team (Galvin et al., 2021). During the preclinical stage, the neuropathological changes indicative of Alzheimer's are present decades prior to the emergence of clinical symptoms that result in an Alzheimer's diagnosis (Guzman-Martinez et al., 2021).

The preclinical stage is the most opportune time for Alzheimer's screening, diagnosis, and treatment because the screening and identification of individuals with preclinical Alzheimer's precede therapies that slow or prevent the onset of Alzheimer's more effectively during the preclinical phase than the clinical phase, when significant neurodegeneration has already occurred (Guzman-Martinez et al., 2021). The first phase of Alzheimer's disease is the pre-clinical or the pre-symptomatic stage, which is characterized by neuropathological changes in the hippocampus and mild memory loss (Breijyeh & Karaman, 2020). These changes occur without clinical symptoms and with no functional impairment in daily living activities (Breijyeh & Karaman, 2020). The second phase is the mild or early stage, which is characterized by slight impairment in daily living activities, disorientation of time and place, mood changes, depression, and a loss of memory and concentration (Breijyeh & Karaman, 2020). The third phase is the moderate stage, which is characterized by neuropathological changes in cerebral cortex regions, increased memory loss, a loss of impulse control, difficulty in reading, writing, and speaking, and difficulty recognizing family and friends (Breijyeh & Karaman, 2020). The fourth phase is the severe or late stage, which is characterized by the buildup of tangles and plaques, a spread of the disease to the entire cortex region, an inability to recognize family and friends, an inability to move, and difficulties in urination and swallowing (Breijyeh & Karaman, 2020). One of the primary causes of death for Alzheimer's patients is pneumonia, which occurs when impaired swallowing allows food to enter the lungs, causing an infection (Breijyeh & Karaman, 2020). Other common causes of death include malnutrition, falls, dehydrations, and other infections (Breijyeh & Karaman, 2020).

Treatments that delay the clinical onset of dementia in individuals with preclinical Alzheimer's will increase longevity, decrease lifetime risk, and decrease the number of Americans ages 65 and older living with dementia by 2.2 million by 2040 (Zissimopoulos et al., 2018). Due to the lack of disease-modifying (ability to slow the progression of a disease by targeting the underlying cause) treatments for symptomatic individuals, it is important to prevent neurodegeneration, cognitive decline, and dementia (Guzman-Martinez et al., 2021). Screening programs during the preclinical phase will improve the quality of life and chances of survival for millions of people worldwide, decrease the global economic impact of Alzheimer's, and allow researchers to design trials for individuals with preclinical Alzheimer's (Guzman-Martinez et al., 2021). Although positron emission tomography (PET) imaging of amyloid and the measurement of cerebrospinal fluid levels of tau and amyloid proteins increase diagnostic confidence, they are expensive and invasive evaluation methods that carry the risk of over-diagnosis (ten Kate et al., 2018). Despite the predictive value of screening for neuropsychological symptoms in individuals without clinical symptoms, biomarkers that are sensitive to pathological change can improve prognostic accuracy (ten Kate et al., 2018). The National Institute on Aging-Alzheimer's Association (NIA-AA) and the International Working Group (IWG) suggest the use of reliable, inexpensive, and non-invasive biomarkers to classify preclinical Alzheimer's as the disease stage in which amyloid plaques, tangles, and hallmarks of neurodegeneration are evident, even in the absence of clinical symptoms (ten Kate et al., 2018).

Early-stage biomarkers should predict the risk and timing of cognitive decline in a cost-effective, non-invasive, and reliable manner (ten Kate et al., 2018). Clinical trials in individuals without Alzheimer's would benefit from biomarkers that can detect pathological changes over time and in response to treatment, monitor treatment effects and reflect disease progression, and be reproducible and reliable in a multicenter setting (ten Kate et al., 2018). Neuroimaging techniques enable researchers to detect and quantify functional, structural, and molecular brain changes that are characteristic of Alzheimer's preclinical and clinical stages (ten Kate et al., 2018). Imaging and fluid biomarkers that can identify individuals with preclinical Alzheimer's include amyloid and tau protein buildup, a low amount of glucose production, and neurodegeneration as measured by MRI (McDade et al., 2020). Blood-based biomarkers measure specific proteins associated with the neuropathological hallmarks of Alzheimer's and can screen large populations due to their lower costs, reduced invasiveness, and increased acceptance by patients (Ojakaar & Koychev, 2021). Digital biomarkers and scalable screening technologies monitor functional, sensory, cognitive, and behavioral changes in individuals at risk for Alzheimer's, decrease the burden on the healthcare system, and allow patients to monitor their own risks throughout their lives (Ojakaar & Koychev, 2021). Examples of digital biomarkers include wearable devices, smartphones, and infrared sensors, which obtain information about health-related aspects of daily life, such as sleeping, walking, and taking medications (Ojakaar & Koychev, 2021). Monitoring programs can use biomarkers to identify individuals who would benefit from targeted interventions of specific risk factors and disease-modifying treatments using amyloid clearance therapies, which are in the development process (Ojakaar & Koychev, 2021).

An early and accurate Alzheimer's diagnosis facilitates the development of an effective care plan, which requires coordination between the patient, family members, caregivers, social services, payers, specialists, and healthcare professionals, and non-pharmacological interventions that mitigate cognitive decline, decrease caregiver burden, and decrease healthcare costs by about \$7 trillion (Galvin et al., 2021). Examples of non-pharmacological interventions include psychological treatment, cognitive simulation, and lifestyle changes, all of which decrease severity and rate of disease progression (Galvin et al., 2021). An early diagnosis also benefits individuals by decreasing anxiety and improving social support (Galvin et al., 2021). However, in the current healthcare system, individuals suspected of having Alzheimer's often receive continuous referrals and wait years for a diagnosis and treatment (Dickens & Ramaesh, 2020). Since cognitive decline is gradual, clinical manifestations of Alzheimer's are not apparent to patients and caregivers until later stages of the disease (Dickens & Ramaesh, 2020).

An ideal cognitive screening test should maintain adequate specificity (a test's ability to identify a negative result for an individual who does not have the disease) and sensitivity (a test's ability to identify a positive result for an individual who has the disease) (Iatraki et al., 2017). It should also be brief, easily administered and scored, and uninfluenced by sociodemographic factors (Iatraki et al., 2017). The Mini-Mental State Examination (MMSE) is the most commonly used screening tool for cognitive impairment (Iatraki et al., 2017). It is an 11-question test that assesses orientation, attention, memory, language and visual-spatial skills, comprehension, motor skills, and problem-solving skills (Iatraki et al., 2017). It asks individuals to repeat a sequence of words, identify an object, name three unrelated objects, and name the city, state, and country they are in (Iatraki et al., 2017). It has demonstrated reliability and validity in neurologic, psychiatric, and geriatric populations (Iatraki et al., 2017). However, it is not the best option for primary care because it is time-consuming and requires special training for administration and scoring (Iatraki et al., 2017).

Cognitive screening tools that are better options for cognitive screening of elderly rural populations in medical and primary care settings are the Test Your Memory Test (TYM) and the General Practitioner Assessment of Cognition (GPCog Patient Scale) (Iatraki et al., 2017). The TYM assesses specific aspects of memory-related cognitive function, takes 5–10 minutes to complete with little supervision, and is easily scored by non-medical professionals (Iatraki et al., 2017). The GPCog-Patient Scale consists of a one-minute memory test in which a physician has a short conversation about memory with the patient and an informant interview with the caregiver about the patient's cognitive function (Iatraki et al., 2017). This screening tool demonstrates a need for more detailed cognitive assessments (Iatraki et al., 2017). The "Mini-Cog test" requires patients to memorize a short list of words, draw a clock face, and repeat the memorized words (Dickens & Ramaesh, 2020). The Montreal Cognitive Assessment (MOCA) requires a 15-minute planned interview and evaluates the following cognitive functions: concentration, memory, language, conceptual thinking, calculations, orientation, visuospatial skills, attention, and executive functions (Dickens & Ramaesh, 2020). Physicians should use cognition tools in conjunction with normal screening blood tests, discussions with carers and relatives, and an investigation of the patient's medical history (Dickens & Ramaesh, 2020).

In 1984, the Alzheimer's Disease and Related Disorders Association (ADRDA) and the National Institute for Neurological and Communicative Disorders and Stroke (NINCDS) collaborated to establish the diagnostic criteria for Alzheimer's, which was then updated in 2011. These criteria comprise probable Alzheimer's disease, possible Alzheimer's disease, and definite Alzheimer's disease. Probable Alzheimer's disease can be diagnosed by dementia that is confirmed by progressive memory loss, impaired daily life activity, agnosia (a loss of perception), aphasia (a loss of the ability to understand and express language), and apraxia (a motor skills disorder that makes it difficult to speak). These symptoms begin from age 40 to 90 years in the absence of brain diseases. Possible Alzheimer's disease is applied in the absence of neurological or psychiatric disorders that are not the main cause of dementia. Definite Alzheimer's disease is confirmed by a histopathological evaluation obtained from an autopsy or biopsy (Breijyeh & Karaman, 2020).

There are four public health priorities to improve screening and diagnosis in secondary prevention: increasing awareness of the clinical value of early detection in the population by educating people about Alzheimer's and its treatment options, educating healthcare professionals about the clinical features of early-stage Alzheimer's and the most effective ways to communicate with Alzheimer's patients, non-dementia specialist healthcare professionals to take appropriate action early, and establishing a step-by-step process that will stratify patient risk and help healthcare professionals decide whether to conduct further cognitive assessments or make subsequent referrals to dementia specialists (Galvin et al., 2021). Alzheimer's education programs should train healthcare professionals to discuss cognitive symptoms with their patients, take discussion of memory concerns from the patient or family members seriously, use dementia screening instruments with high validity and reliability for the detection of dementia, and acknowledge the predictive value of subjective concerns about cognitive problems (Galvin et al., 2021). The collection of data on normal and abnormal cognitive aging will help healthcare professionals identify risk factors and early clinical symptoms of Alzheimer's (Galvin et al., 2021). Community education will empower patients to take charge of their cognitive health and destigmatize Alzheimer's by dispelling the notion that a person with Alzheimer's is sick or elderly (Galvin et al., 2021). It will help people learn how to identify Alzheimer's stigma, become more comfortable talking about stigma, interact with people and families affected by Alzheimer's disease, and avoid making negative judgments

that are untrue about people with Alzheimer's (Herrmann et al., 2018; Johnson et al., 2015). Eliminating the stigma associated with Alzheimer's is important because stigma can prevent individuals and families from receiving a diagnosis, benefitting from treatments, developing a support system, participating in research, and planning for future medical, long-term, and end-of-life care (CDC, 2015). The 2015 Gerontological Society of America's Kickstart, Assess, Evaluate, Refer (KAER) model provides educational resources and clinical tools that guide primary care teams in the initiation of conversations with patients about cognitive health, the detection and diagnosis of dementia, and the provision of community-based resources for individuals (Gerontological Society of America, 2015).

Tertiary Prevention

Tertiary prevention aims to target the clinical stage and the disability stage when primary prevention and secondary prevention are unsuccessful (Ojakaar & Koychev, 2021). The goal of tertiary prevention is to increase life expectancy and quality of life, improve well-being, prevent complications of Alzheimer's, and limit disability and immobility (Ojakaar & Koychev, 2021). Tertiary prevention interventions are most effective when they are implemented in the earliest stages of Alzheimer's (Ojakaar & Koychev, 2021). Researchers established a multidisciplinary rehabilitation program to examine the effects of cognitive rehabilitation, cognitive stimulation, physical training, computer-assisted cognitive training, art therapy, and occupational therapy on cognitive decline (Ojakaar & Koychev, 2021). They found that the program decreased depressive symptoms and improved cognition and quality of life in patients with mild Alzheimer's in the intervention arm, but not in patients with moderate Alzheimer's (Ojakaar & Koychev, 2021). This underscores the importance of screening and early diagnosis in secondary prevention.

Successful Alzheimer's management requires open physician, caregiver, and patient communication, behavioral approaches, caregiver support, and pharmacological interventions (Papageorgiou & Yiannopoulou, 2020). Open physician, caregiver, and patient communication allows physicians to identify symptoms, evaluate and diagnose, and provide guidance (Papageorgiou & Yiannopoulou, 2020). Behavioral approaches include established routines, communicative strategies such as using simple language, providing enjoyable activities, calm and respectful interactions, saying no only if safety is concerned, consistency and simplification of the environment, timely planning for legal and medical decisions and needs, cognitive behavioral therapy, exercise therapy, light therapy, and music therapy (Papageorgiou & Yiannopoulou, 2020). Caregiver support interventions include planned short rest periods for the caregiver and psychoeducation, which teaches caregivers how to prepare for the effects of Alzheimer's on cognition, function, and behavior, how to avoid situations that can worsen symptoms or endanger the health of a person with Alzheimer's, and how to develop support networks (Papageorgiou & Yiannopoulou, 2020). Caregiver support interventions are an important part of tertiary prevention because the increasing Alzheimer's morbidity and mortality rates as well as the increasing number of patients dying at home indicate that there is an increasing number of Alzheimer's caregivers (Taylor et al., 2017). Education, case management, and respite care reduce the physical, emotional, and financial burden of caregiving and improve the quality of care for Alzheimer's patients (Taylor et al., 2017).

Although current pharmacological interventions cannot stop or reverse Alzheimer's disease progression, they can temporarily improve symptoms (Papageorgiou & Yiannopoulou, 2020). There are

two categories of FDA-approved medications: the acetylcholinesterase inhibitors (AChEIs) donepezil, galantamine, rivastigmine, and the N-methyl-D-aspartate (NMDA) antagonist memantine (Papageorgiou & Yiannopoulou, 2020). AChEIs prevent the breakdown of acetylcholine, a neurotransmitter that activates muscles and assists with processing speed, short-term memory, and learning (Papageorgiou & Yiannopoulou, 2020). Alzheimer's patients have lower acetylcholine levels due to the degeneration of cholinergic neurons, which are nerve cells that use acetylcholine (Papageorgiou & Yiannopoulou, 2020). AChEIs improve communication between nerve cells and decrease cognitive decline during the first year of treatment (Papageorgiou & Yiannopoulou, 2020). In randomized placebo-controlled trials up to 52 weeks duration, all three AChEIs slowed or stabilized cognitive decline and improved cognition and activities of daily living (Papageorgiou & Yiannopoulou, 2020). Temporary discontinuation of these drugs leads to rapid decline and a higher likelihood of nursing home placement (Papageorgiou & Yiannopoulou, 2020). The FDA-approved rivastigmine and donepezil for mild, moderate, and severe Alzheimer's, and galantamine for mild and moderate Alzheimer's (Papageorgiou & Yiannopoulou, 2020). NMDA antagonist receptors work by blocking the action of NMDA, a glutamate receptor and neurotransmitter that helps regulate breathing, learning, memory formation, and neuroplasticity (Papageorgiou & Yiannopoulou, 2020). Alzheimer's patients have an excess amount of glutamate, which damages and kills healthy brain cells (Haque & Levey, 2019). Memantine can treat moderate and severe Alzheimer's as monotherapy or in combination with an AChEI (Haque & Levey, 2019). It is associated with better cognitive, neuropsychiatric, and behavioral symptoms, and improved ability to perform activities of daily living (Haque & Levey, 2019). Other medications include antipsychotics and antidepressants, which can treat behavioral, psychiatric, and cognitive symptoms (Papageorgiou & Yiannopoulou, 2020). Selective serotonin reuptake inhibitors, such as citalopram, escitalopram, and sertraline, can treat anxiety and depression (Papageorgiou & Yiannopoulou, 2020). The development of a personalized Alzheimer's treatment regimen factors in the patient's comorbidities, disease stage, and frequency and intensity of cognitive, behavioral, and psychological symptoms (Papageorgiou & Yiannopoulou, 2020).

According to the 2020 report of the Lancet Commission, tertiary prevention interventions that benefit Alzheimer's patients include physical activity, cognitive training, psychosocial management of treatment and care, discussions with a psychiatrist or neurologist, and telemedicine (Livingston et al., 2020). Other interventions include the provision of holistic post-diagnostic care for patients and caregivers that addresses cognitive, psychological, medical, environmental, social, and cultural needs, and the detection and management of physical problems, such as sensory impairment, diabetes, pain, falls, and incontinence (Livingston et al., 2020). Caregivers and healthcare professionals must monitor hydration, sleep, and nutrition status; manage vascular risk factors (diabetes, hypertension, hyperlipidemia); treat deficiencies in vitamin D, vitamin B12, and folate; treat thyroid and electrolyte disorders; and treat systemic diseases that can influence cognition, such as pain, constipation, and infections (Papageorgiou & Yiannopoulou, 2020). Individuals with dementia have higher rates of cerebrovascular disease, anxiety and depression, pneumonia, incontinence, electrolyte disturbance, skin ulcers, diabetes, and Parkinson's disease compared to the general older population (Livingston et al., 2020). Since multimorbidity accelerates functional decline and lowers the quality of life for people with dementia and their caregivers, the management of comorbidities is a critical public health intervention at the tertiary level (Livingston et al., 2020).

Federal Public Health Initiatives

The National Health and Medical Research Council National Institute for Dementia Research (NNIDR) Dementia Prevention Special Interest Group has established the Dementia Prevention Action Plan, which incorporates public health preventive strategies at the primary, secondary, and tertiary prevention levels. The first strategy is to create public health and clinical practice guidelines for dementia prevention across the life course in primary care and other settings. Some dementia prevention interventions include secondary prevention in memory clinics for those at high risk, the development of occupational and environmental policy to decrease hearing loss, air pollution, and traumatic brain injury, and the prioritization of early life educational attainment. The second strategy is to train primary care providers to lead dementia prevention efforts. The Medicare Benefits Schedule should increase focus on dementia prevention through the creation of new Medicare Benefits Schedule item numbers and modification of existing items, such as the health check for individuals aged 45–49 years who are at risk of developing chronic diseases. Private health insurers can broaden the scope of preventive health services to address dementia risk factors and reward individuals who participate with greater rebates for health services or lower insurance premiums. The third strategy is to fund research for evidence-based interventions for modifiable risk factors for dementia. The fourth strategy is to establish health promotion programs using findings from dementia risk reduction and implementation research. The fourth strategy is to improve the diversity of dementia prevention public health campaigns. The fifth strategy is to organize a coordinated dementia prevention effort that includes government, nongovernmental organizations, industry, education, research, all levels of the health sector, policymakers, and the community. The sixth strategy is to coordinate public health messaging on dementia risk factors that relate to chronic diseases, such as cardiovascular disease and diabetes (Chong et al., 2021).

In 2011, President Barack Obama signed into law the National Alzheimer's Project Act (NAPA), which has funded Alzheimer's research and has instituted many large clinical trials to study Alzheimer's interventions (Olivari et al., 2020). NAPA aims to prevent and treat Alzheimer's by 2025 through the establishment of infrastructure for effective research practices, the translation of preventive practices into community health settings, and the cooperation with large organizations worldwide to enhance targeting efforts (Olivari et al., 2020). Public health strategies include utilizing timely population-based data to set priorities, implementing public education campaigns, and improving core competencies for healthcare professionals (Olivari et al., 2020). In 2005, the CDC and the Alzheimer's Association partnered to establish the Healthy Brain Initiative to combat the Alzheimer's public health crisis (Kelley et al., 2018). The most recent publication, *Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2018–2023*, described 25 actions that state and local public health agencies can take to support cognitive health (Kelley et al., 2018). The CDC also established the Behavioral Risk Factor Surveillance System, which provides annual data on caregiving surveillance and cognitive decline, and the Healthy Aging Data Portal, which provides public health professionals and policymakers with access to state, regional, and national health-related data on older adults (Kelley et al., 2018). Public health professionals can use evidence-based information and surveillance data at the local, state, and federal levels from this report to help Americans maintain optimal cognitive health (Kelley et al., 2018).

Conclusion

Despite being historically perceived as merely an aging or medical issue, Alzheimer's is a serious public health epidemic with a tremendous and rapidly increasing global, national, and regional burden that takes a physical, emotional, and economic toll on patients, caregivers, families, the healthcare system, the government, and society (Healthy People, 2020, 2021). The number of people living with Alzheimer's will continue to exponentially increase each year and double by 2030 due to longer life expectancies and population aging (Healthy People, 2020, 2021). To address the Alzheimer's public health crisis, public health professionals must collaborate with healthcare professionals, policymakers, and non-governmental organizations on the development of a multidisciplinary approach that consists of primary prevention strategies based on the identification of modifiable and non-modifiable risk factors and protective factors, secondary prevention strategies based on screening, early detection, cognitive screening assessments, and intervention at the presymptomatic stage, tertiary prevention strategies based on rehabilitation, caregiver support, pharmacologic interventions, cognitive training, the provision of geriatric care services, opportunities for social interactions, the management of comorbidities, and the mitigation of the effects of the coronavirus pandemic on Alzheimer's patients, and federal public health initiatives (Healthy People, 2020, 2021). The inclusion of Alzheimer's in Healthy People 2020 for the first time highlights the public health threat that Alzheimer's poses to the United States (Healthy People, 2020, 2021). According to Healthy People 2020, important public health interventions include increasing the availability and quality of diagnostic tools, promoting cognitive decline risk reduction, strengthening public health surveillance, and reducing the number of people with undiagnosed dementia (Healthy People, 2020, 2021). Other interventions include decreasing the severity of cognitive, behavioral, and neuropsychiatric symptoms through medical management, promoting healthy behaviors, increasing public awareness of Alzheimer's, reducing preventable hospitalizations, and supporting family caregivers with legal, social, and behavioral resources (Healthy People, 2020, 2021). During the next decade, the public health sector must make progress in improving the early diagnosis and management of Alzheimer's, researching the effect of genetic, environmental, lifestyle factors on Alzheimer's risk across the life course, and implementing effective interventions to delay or prevent the onset of Alzheimer's (Healthy People, 2020, 2021). These objectives can reduce Alzheimer's morbidity and mortality rates, improve the quality of life for Alzheimer's patients and their caregivers, and optimize cognitive health outcomes for all Americans.

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Dispelling Myths Regarding Cisgender Sexual Minority Women and Breast Cancer

Rachel Troy*

Lesbian and bisexual cisgender women have higher rates of breast cancer and breast cancer mortality than their heterosexual counterparts (Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, 2014). There is not much known about why this is the case, although most researchers revert to the common hypotheses that the increased prevalence of obesity, substance abuse, and nulliparity (not having given birth) among lesbian and bisexual women contribute to incidences of breast cancer (Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, 2014). These hypotheses place individual responsibility on sexual minority women with breast cancer as opposed to identifying complicated, underlying structural problems. This literature review argues that homophobia and bisexual invisibility, in conjunction with fatphobia and inaccurate research methodology, have prevented clinicians and scientists from thoroughly examining the ways in which increased rates of alcohol abuse, the physiological effects of stress due to discrimination, and a lower rate of receiving mammograms caused by perceived negative judgment from healthcare providers contribute to the higher prevalence of breast cancer among lesbian and bisexual women.

Introduction

Limited research conducted on the relationship between sexual minority status and breast cancer in cisgender women has determined that lesbian and bisexual women are more likely to suffer from breast cancer than heterosexual women (Meads & Moore, 2013). A UK study conducted on pairs of sisters in an attempt to control for genetic risks found that the heterosexual sisters had a 14.6% chance of developing breast cancer and that the lesbian sisters had a 29.6% chance of developing breast cancer (Meads & Moore, 2013). In addition, lesbian and bisexual women with breast cancer may generally have a higher mortality rate than heterosexual women, with one U.S. government

*University of Michigan, rachmt@umich.edu

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study finding that they are three times more likely to die from the disease (Meads & Moore, 2013). Based on the few studies that have attempted to understand the link between lesbianism, bisexuality, and breast cancer, most have come to the conclusion that lesbian and bisexual women are putting themselves at an increased risk of developing breast cancer by engaging in individual “risky behaviors” such as a poor diet or lack of exercise (McPhail, 2014), excessive smoking and drinking, and choosing not to give birth (Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, 2014). While individual behaviors certainly have a role in increasing disease risk, it is worth scrutinizing the previously cited reasons for disparate outcomes in breast cancer development and mortality among sexual minority women and shifting the focus to understanding how institutional and structural inequities contribute to these risk factors.

Interrogating the Risk Factors: Body Mass Index and Exercise

While it has previously been proven that lesbian and bisexual women may be more likely to be overweight or obese than heterosexual women (McNamara & Ng, 2016), there is conflicting evidence as to whether that is the case. Despite earlier research regarding sexual minority women and their association with increased body weight, there was not much research examining the factors that contributed to this disparity and ways to reduce it (Bohmer et al., 2007). If lesbian and bisexual women are, in fact, generally more overweight and obese than heterosexual women, it’s worth considering why. It has been hypothesized that sexual minority women are stress eating as a means of coping with life events such as being closeted, coming out, dealing with discrimination, or struggling to find a community (Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, 2014). Another possibility is that sexual minority women experience less fatphobia, or discrimination based on larger body size (McPhail, 2014), from potential female partners than heterosexual women experience from potential male partners and, as a result, are making less of an attempt to lose weight for purely aesthetic reasons (Bohmer et al., 2007). Without aesthetic motivations, sexual minority women whose overall health could benefit from a lower body weight may not choose to reduce their weight.

Additionally, it has previously been proposed that a lack of exercise is the root cause behind increased weight in sexual minority women and that providers should urge their lesbian and bisexual female clients to exercise more (McNamara & Ng, 2016). However, the same study that proposed this reasoning later contradicted it with the inclusion of a statistic that stated that lesbian and bisexual women exercise just as much on average than heterosexual women (McNamara & Ng, 2016), and an even more recent study concluded that women on a more homosexual end of the sexuality spectrum are significantly more physically active and less significantly obese than heterosexual women (Fricke & Sironi, 2020). Whatever the reasons for larger body size among sexual minority women, if in fact a true phenomenon might be, the lack of focus and thorough research on the underlying societal and cultural causes of supposed obesity among sexual minority women pushes one to reexamine whether many medical researchers and practitioners are genuinely concerned for lesbian and bisexual women’s health. It may be the case that using higher weight and its historical association with physical deviance from societal norms in conjunction with sexual minority women’s sexual deviance from societal norms serves as a way of finding individual fault with their relatively increased breast cancer risk (McPhail, 2014). Examining researcher and practitioner motivations, however, may not prove as valuable to understanding the relationship between

obesity and breast cancer prevalence among sexual minority women as looking into whether sexual minority women are actually more obese as a whole than their heterosexual counterparts.

Per a recent study, there are no disparities in body mass index (BMI) and obesity diagnoses by sexual orientation, and there are no significant differences between BMI measurements and, by association, rates of obesity and high weight in lesbian women, bisexual women, and heterosexual women (Wolfgang et al., 2022). There are also conflicting studies regarding the role that obesity and its various definitions play in increasing breast cancer risk. Postmenopausal women who are obese, classified by the National Institutes of Health (NIH) as a BMI greater than 30, have a 20–40% increase in breast cancer risk than women who have a “normal” weight, classified by the NIH as a BMI between 18.5 and 24.9 (Munsell et al., 2014). However, a higher BMI and waist size are not themselves risk factors for breast cancer development (Song et al., 2022), but high blood sugar, diets high in fat, and a lack of regular exercise often associated with obesity are (Sun et al., 2017). Additionally, the average BMI of women in the Song study who ended up developing breast cancer (23.4) was slightly lower than that of the women in the study without breast cancer (23.6), and this study, unlike the Munsell study, accounted for women who were postmenopausal as well, enhancing its relevance and accuracy because breast cancer risks increase after menopause (Sun et al., 2017). If sexual minority women are not, in fact, more obese than heterosexual women, body size may not be to blame for disparate outcomes in breast cancer diagnoses and mortality.

It’s worth noting that BMI is rooted in research that excluded people of color and women and is therefore a somewhat inaccurate measure of health (Hicken et al., 2018), and that BMI does not consider the effects of the ratio of muscle to fat mass independent of body weight on health (Iyengar et al., 2019). Using BMI as a sole metric may skew views of the fitness and overall health of sexual minority women, who tend to have more lean muscle mass on average than their heterosexual counterparts (Bohmer et al., 2007). It also has been found that waist circumference is a better indicator of disease risk and overall health than BMI, since it predicts visceral and abdominal fat percentage, which are statistically significant indicators of many diseases, more accurately (Hicken et al., 2018). While the correlation between BMI and breast cancer has been disproven, a higher body fat percentage is shown to correspond with a higher risk of acquiring breast cancer (Iyengar et al., 2019). A Women’s Health Institute study used DEXA scanning machines to measure the amount and type of body fat in a cohort of postmenopausal women every three years for a span of 12 years and tracked cases of breast cancer among participants (Iyengar et al., 2019). The researchers found that a 5% increase in whole body fat resulted in a 28% increased chance of acquiring invasive breast cancer, and that a 5% increase in abdominal fat resulted in a 46% increase in invasive breast cancer (Iyengar et al., 2019). They also found that while an increase in BMI generally correlated with an increase in overall body fat, 48.3% of the women in the highest quartile of abdominal fat were distributed among the three lowest quartiles of BMI (Iyengar et al., 2019). The results of the Women’s Health Institute study indicate that breast cancer risk is often more complicated than body size or even body fat percentage alone, and that understanding whether obesity is at the root of increased breast cancer in sexual minorities requires further research examining body fat percentage and placement.

It is worth noting that unfortunately, while there is copious existing research on the relationship between sexual orientation, BMI, and body size, very little public domain research is available specifically on differences in waist circumference and the percentage values of different kinds of body fat in women by their sexual orientation. The fault may lie not with researcher motivations but with research methodology and funding: the most accurate tools to measure body composition,

the DEXA scan machine, takes at least 30 minutes to work, has a maximum weight capacity of 350 pounds, and is expensive to acquire (Body Composition and Bone Density Testing, 2019). Despite the many failings of BMI as a measure of health and the lack of sufficient availability of research on sexual minority women using more accurate metrics, Song's finding that body weight does not vary on average by sexual orientation (Song et al., 2022) is quite shocking considering the common stereotype that sexual minority women are overweight (McPhail, 2014). This research indicates that the underlying cause of increased breast cancer acquisition and death rates in lesbian and bisexual women is most likely not weight-related but a result of other factor(s).

The conflicting evidence and recent developments in research regarding the relationship between obesity, sexual orientation, and breast cancer suggest that the common assumption that lesbian and bisexual women are at a higher risk of breast cancer (McPhail, 2014) due to their supposed obesity is rooted in homophobia and fatphobia, and thus requires further scrutiny. There is also a need for a more holistic and less-biased view of identifying causes of obesity in sexual minority, cisgender women. Perhaps measuring abdominal body fat percentage, cholesterol levels, triglyceride levels, and blood sugar and asking about diet and exercise habits are better ways for healthcare providers to know whether a larger lesbian or bisexual patient is healthy overall instead of recommending more frequent aerobic activity, as McNamara and Ng suggested (McNamara & Ng, 2016). In tandem with a body fat or weight circumference measurement, these metrics could potentially replace BMI as an indicator of breast cancer risk and overall health. This more holistic approach, in addition to mammograms and genetic screening for breast cancer, might be a more accurate way to measure and reduce incidences of breast cancer in a sexual minority woman than by looking at the number on the scale.

Interrogating the Risk Factors: Sexual Minority Status and Alcohol Consumption

Increased alcohol intake is a known risk factor for breast cancer, even in those who are not alcoholics: Moderate alcohol use has been found to be associated with a large increase in breast cancer risk among women who were not initially considered high risk for the disease (McDonald et al., 2013). In one study, women who consumed 3–4 alcoholic beverages per day had a 32% increase in breast cancer risk compared to non-drinkers, women who consumed 4 or more alcoholic beverages per day had a 46% increase in breast cancer risk compared to non-drinkers, and women who consumed just one alcoholic beverage per day were at a 5% increased risk of developing breast cancer compared to non-drinkers (McDonald et al., 2013). Breast cancer is the “number one cancer caused by alcohol among women globally,” and, as a result, alcohol is considered a class 1 carcinogen by the International Agency for Research on Cancer (World Health Organization, 2021). Sexual minority women tend to drink alcoholic beverages more frequently and at a higher quantity than heterosexual women, and lesbian women are three times more likely to suffer from alcoholism at some point in their lives compared to heterosexual women (Mcnamara & Ng, 2016). Both lesbian and bisexual adolescents and adults have higher rates of cigarette smoking, alcohol, and drug abuse and addiction compared to their heterosexual counterparts (Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, 2014). Alcohol use is a “behavioral risk factor” for breast cancer exhibited by many lesbian and bisexual women (Meads & Moore, 2013), and in one study, alcohol use was more prevalent among women with breast cancer

than women who were cancer free (Song et al., 2022), though women with breast cancer may be using alcohol to cope with the suffering brought on by their condition and treatment.

While it is convenient for healthcare providers and researchers to dismiss alcohol abuse among lesbian and bisexual women as a “behavioral risk factor” and to simply advise sexual minority, female patients to quit their substances, it is important to consider the societal factors, such as stress stemming from a lack of acceptance from others in their lives, that could drive lesbian and bisexual women to various addictive drugs and how these factors may relate to breast cancer. Hughes et al. posited that alcohol abuse is more prevalent among all marginalized groups, stating that “Risks related to alcohol use do not stem from sexual orientation per se, but are more likely a consequence of cultural and environmental factors associated with being part of a stigmatized and marginalized population” (Hughes, 2005). Lesbian and bisexual women also have higher rates of alcohol abuse than gay and bisexual men (Hughes, 2005), which coincides with the fact that sexual minority women are discriminated against for both their gender in addition to their sexual orientation, based on sociological theories expanding on Kimberle Crenshaw’s theory of intersectionality (Cabrado et al., 2013). Stress, also a risk for the development of breast cancer, often coexists with substance abuse, since alcohol, drugs, and cigarettes are common ways to relieve stress (Meads & Moore, 2013). While more intersectional research is needed when it comes to sexual minority, cisgender women, and substance abuse, particularly regarding bisexual women and sexual minority women of color, there is also a need to see whether the heightened substance abuse among lesbian and bisexual women is responsible for their breast cancer rates, if stress levels associated with their sexual orientation and the coinciding discrimination are the unaddressed, underlying cause, or if increased breast cancer risks among sexual minority women are a result of some combination of these factors.

The Link Between Psychological Stress, Discrimination, and Breast Cancer

Psychological stress and its biological consequences are associated with an increased breast cancer risk in women (Anatova et al., 2011). Cortisol, a hormone that plays a role in human physiological responses to psychological stressors, also plays an essential part in mammary gland development and estrogen activity in the mammary tissues, so an abnormally large amount of this hormone may lead to a suppressed immune system in the mammary gland, leaving breasts more vulnerable to the development of cancer (Anatova et al., 2011). There is a positive association between a woman’s exposure to stressful life events and her likelihood of developing breast cancer (Chiriac et al., 2018). Lesbian and bisexual women often undergo a series of stressful life events that heterosexual women do not, including grappling with their sexual identity, facing the consequences of either coming out of or staying in the closet, witnessing and experiencing homophobia or biphobia from others, and struggling to find a community, acceptance, and potential romantic or sexual partners (Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, 2014). These external stressors due to homophobia and sexism could provide one explanation for increased breast cancer development and mortality in sexual minority women.

Lesbian and bisexual women generally experience higher stress levels than their heterosexual counterparts over the course of their lifetime (Meads & Moore, 2013). In a 2015 study conducted by Juster et al., a control group of heterosexual, cisgender women and an experimental group of

sexual minority, cisgender women were exposed to the same stressor (Juster et al., 2015). Both groups of women were exposed to identical stressors. Before and after 40 minutes, their levels of cortisol, a hormone often associated with stress, were measured via a blood test. The group of lesbian and bisexual women had higher cortisol levels overall than the group of heterosexual women, showing that not only do lesbian and bisexual women experience more societal and discriminatory stressors than heterosexual women over the course of their lifespan but their bodies have an increased stress response to the exact same stressors, as well as to day-to-day short-term stressors (Juster et al., 2015). This finding is in line with Dr. Arline Geronimus's "Weathering" hypothesis: Originally employed to describe the negative health consequences of experiencing racism and sexism, weathering refers to the negative physical stress that the emotional stress of oppression places on the body, increasing the risk of negative health outcomes (Geronimus, 2006). It is possible that sexual minority individuals experience a similar "weathering" phenomenon due to institutionalized homophobia. Given the positive association between being a sexual minority woman and increased stress hormone levels, and the positive association between stress hormone levels and breast cancer incidences, it is possible that increased stress caused by societal difficulties may be an underlying factor in their increased risk of breast cancer morbidity and mortality in sexual minority as compared to heterosexual women.

Interrogating the Risk Factors: Sexual Minority Women, Parity, and Breast Cancer

Nulliparity, or the condition of not having given birth, is a large risk factor for breast cancer among lesbian and bisexual women (The Health of Lesbian, Gay, Bisexual, and Transgender people report, 2012). Recent research conducted by ACOG supports the previous finding by asserting that nulliparity is associated with an increased risk of breast cancer ("Practice Bulletin Number 179: Breast Cancer Risk Assessment and Screening in Average-Risk Women," 2017) and that breast feeding, which is often associated with giving birth, reduces various forms of breast cancer (Anstey et al., 2017). However, while lesbian women were far less likely to become pregnant than heterosexual women, bisexual women were 22% more likely to become pregnant than heterosexual women (Hodson et al., 2017). This data demonstrates why health researchers, especially those studying breast cancer, need to avoid treating sexual minority, cisgender women as a homogenous group and consider the different lived experiences of lesbian versus bisexual women for the sake of research accuracy. The statistics from the Hodson study mentioned earlier also suggest that while bisexual women may have higher rates of breast cancer than heterosexual women, nulliparity may not be a contributing factor to this risk (Hodson et al., 2017), contradicting previous research (Meads & Moore, 2013). While nulliparity is prevalent among lesbians and is, in fact, a breast cancer risk, it is one that is quite hard to reduce given the various social, legal, and financial barriers presented to lesbian singles or couples pursuing alternative reproductive technologies to give birth (Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, 2014). Health plans often fail to cover infertility treatment for lesbians, or for bisexual women in a lesbian couple (Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, 2014). Additionally, there is a need to honor and respect the choices of women who prefer not to give birth, whose partners give birth instead of them, who choose to adopt, or who choose not to raise children.

Perceived Discrimination, Lack of Access, and Preventative Care

A major, previously unidentified risk factor for the increased rates of breast cancer mortality in lesbian and bisexual cisgender women is the general reluctance to receive mammograms, which are an effective way to reduce the risk of mortality in people with breast cancer (“Practice Bulletin Number 179: Breast Cancer Risk Assessment and Screening in Average-Risk Women,” 2017). Lesbian women are less likely to receive mammograms than heterosexual women (McNamara & Ng, 2016) despite the fact that consistent mammograms after the age of 40 have been proven to reduce the risk of breast cancer mortality (“Practice Bulletin Number 179: Breast Cancer Risk Assessment and Screening in Average-Risk Women,” 2017). One study that examined the relationship between race, sexual orientation, and likelihood of mammography found that white, bisexual women were 30% less likely to receive mammograms than white, heterosexual women, and black, lesbian women were 20% less likely to receive mammograms than black, heterosexual women, although it is worth noting that the sample size of black women was not sufficient enough to conclude significance (Agénor et al., 2020), illuminating the fact that research surrounding health outcomes in sexual minority women, particularly sexual minority women of color, is often difficult due to a lack of willing participants (Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, 2014). While some research exists as to the rates of mammogram procedures by various sexual orientations, very little research has been conducted on the reasons behind this reluctance to get a mammogram. However, one study examining experiences with discrimination in healthcare by sexual orientation found that sexual minority women were less likely to be satisfied with their primary care providers than heterosexual women due to perceived discrimination and treatment (Mosack et al., 2013). It is possible that lesbian and bisexual women are hesitant to visit the doctor for mammograms out of a lack of access to health providers who are competent when it comes to their sexual orientation, or out of a general fear of the healthcare system due to their own negative past experiences or those shared with them by other sexual minority women.

Fear of discrimination from health professionals is most likely a risk factor for increased breast cancer mortality rates among lesbian and bisexual women, as this fear may deter them from routine checkups and mammograms that allow for early detection of the disease and a healthier lifestyle in general. Research conducted by Khalili and others identified a need for LGBT+ competency training for faculty physicians and a more effective way for patients to identify LGBT+ competent healthcare providers (Khalili et al., 2015). Many lesbian and bisexual women who may have had prior negative or discriminatory experiences with the healthcare system may avoid disclosing their sexual orientation during a healthcare appointment in fear of being outed to others, and this apprehension is especially prominent in individuals who receive health insurance through their workplaces (Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, 2014). In one survey reported in “The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding,” 16% of doctors stated that they would be uncomfortable treating a gay patient (Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, 2014), further proving that many providers are not equipped to provide competent care for LGBT+ individuals. It is possible that the lack of LGBT+ competency among doctors is due to a lack of representation, as LGBT+ individuals, especially sexual minority women, are underrepresented in the medical field. While 29% of the United States’ general population aged 29–34 currently identifies as LGBT+, with

the majority of these individuals identifying as bisexual women (Williams Institute, 2020), only 6.3% of recent medical graduates within that same age range identified as lesbian, gay, or bisexual, with the majority of these individuals identifying as male (Mori et al., 2021). Perhaps an increase in “out” sexual minority women in the medical field would allow sexual minority female patients to feel more comfortable seeking preventative healthcare without fear of experiencing sexism and homophobia, as well as allow for increased awareness and competency in the field as a whole.

It’s also quite possible that the barriers lesbian and bisexual women face when it comes to receiving preventative breast cancer care are not only mental and emotional but also financial. Adult lesbians are less likely to have health insurance than adult heterosexuals, and this disparity becomes more pronounced when monogamous couples are compared (Khalili et.al). Twenty-nine percent of cisgender bisexual women live in poverty compared to 17.8% of cisgender heterosexual women, while the cisgender lesbian poverty rate, according to this study, is quite comparable to that of cisgender heterosexual women, at 17.9% (Williams Institute, 2020). Sexual minority women with health insurance most likely have acquired it through their place of work, resulting in a previously stated fear of being outed to their workplace by their provider (Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, 2014), and those who do not have insurance may struggle to afford care, resulting in an even more difficult time finding a competent provider that they feel comfortable with. In order to increase preventative breast cancer care among lesbian and bisexual women (and decrease the risk of mortality by association), health care providers, as well as workplaces and insurance networks, should identify themselves as LGBT+ competent, and healthcare institutions such as medical schools and hospitals should make LGBT+ competency training mandatory.

Barriers to Effectively Researching Sexual Minority Women and Breast Cancer

Inadequate research methodology could contribute to risk factors for increased breast cancer acquisition and mortality in lesbian and bisexual women, as mentioned earlier, and further knowledge is required to protect lesbian and bisexual women from breast cancer. For instance, in many studies, lesbian and bisexual women are placed into a homogenous category as opposed to two separate categories, despite having very different healthcare needs, which may render research results inaccurate (Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, 2014). In many studies and publications examining the link between sexual orientation and breast cancer in women, bisexual women are completely overlooked (a phenomenon often called “bisexual invisibility”), while lesbian women are compared to heterosexual women (San Francisco Human Rights Commission LGBT Advisory Committee). Bisexual invisibility could be negatively impacting the breast cancer rates and overall health of bisexual women, since they represent such a large portion of the LGBT+ community, especially of sexual minority women: While only 0.2% of young women polled in one study identified as “Gay” or “Lesbian,” 8.4% identified as bisexual (San Francisco Human Rights Commission LGBT Advisory Committee). Bisexual women may go unnoticed by healthcare professionals, since there is often an assumption that they are either heterosexual or lesbian depending on whether they are dating a man or a woman at the time of their appointment, which may decrease their quality and individuality of care (San Francisco Human Rights Commission LGBT Advisory Committee). This misunderstanding

between patients and providers can be remedied if providers routinely take sexual histories at appointments, asking not only about one's current sexual activity status but also about one's past sexual patterns and self-identification.

It's very difficult for researchers to find an adequate number of lesbian and bisexual female subjects for studies examining breast cancer development and mortality risks, for a variety of reasons (Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, 2014). For instance, the age disparity among women with breast cancer may have a hidden effect on the current understanding of the link between sexual minority status and breast cancer, as well as the methodology of studies that are attempting to resolve this gap in the general knowledge. An increase in age is a risk factor for breast cancer development, as aging leads to more genetic mutations that could increase breast cell proliferation or decrease the body's immune response (Sun et al., 2017). Aging is also a risk factor for breast cancer mortality: A study conducted in 2016 found that 99.3% of all breast cancer-associated deaths in the United States were reported in women over 60, and 71.2% of breast cancer-associated deaths in the United States were reported in women over 40 (Sun et al., 2017). Breast cancer mainly affects older women, and much fewer older women openly identify as lesbian or bisexual than younger women: While 30% of people ages 18–24 identify as LGBT+ nationwide, that number decreases to 16% of people ages 50–64 and 7% of people over 65 years old (Williams Institute, 2020). Given the inverse relationship between age and LGBT+ identity status, and the direct relationship between age and breast cancer risk, it's possible that the true effect of sexual minority status on breast cancer risk will not be known until younger people who are more likely to be public or "out" with regard to their sexual orientation grow older, acquire breast cancer, and become available as research subjects.

Additionally, many bisexual or lesbian women are reluctant to share their sexual orientation with researchers or on surveys for fear of a breach in confidentiality, and many will avoid even participating in studies relating to sexual orientation for this reason (Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, 2014). This discomfort and lack of trust is often mutual, as the healthcare provider or researcher conducting patient examinations for studies is likely not only to be heterosexual, cisgender, and male, but to feel uncomfortable taking the sexual history of any patient, and to feel especially uncomfortable if they suspect their patient is LGBT+ or if their patient has shared their LGBT+ sexual orientation or gender identity (Khalili et al., 2015). It is possible that healthcare professionals' reluctance to discuss matters pertaining to sex and prejudice regarding sexual minority clients is a result of the lack of focus on LGBT+ issues in healthcare education, especially in medical school curricula (Khalili et al., 2015). Integration of LGBT+ topics into standardized healthcare education could be a possible solution to healthcare professionals' discomfort and lack of knowledge with regard to their LGBT+ patients.

The lack of adequate research on lesbian and bisexual women's health is also exacerbated by institutional and governmental factors. For instance, sexual orientation is not yet a required category for demographic data collection conducted by cancer research organizations in the United States of America or in the United Kingdom (Meads & Moore, 2013). So far, cohort studies have not measured the relationship between sexual orientation and breast cancer incidences, which means that health policies, particularly those related to breast cancer, are potentially inaccurate (or at the very least, lower quality) and leave sexual minority women behind (Meads & Moore, 2013). Lesbian and bisexual women are more likely to live in liberal states and territories such as Washington, D.C., New York, or California, than in conservative states like Arkansas or Wyoming, and they are more likely to live in urban areas than rural areas (Williams Institute, 2020), so it is possible that there

is a response bias in previous breast cancer research studies towards sexual minority women living in big cities in liberal states, when their living situations and potential for further discrimination might affect their rates of breast cancer and other ailments. Another possibility is that governments of more conservative states, the boards of religious hospitals, and the higher-ups at religious universities routinely refuse to fund LGBT+ health studies due to homophobia masked as religious or “moral” reasons, making it especially difficult for scientists who wish to create more knowledge about sexual orientation and breast cancer to conduct their studies.

Conclusion

There is much that can be done to raise awareness – and, as a result, decrease incidences – of breast cancer and breast cancer mortality among lesbian and bisexual women. LGBT+ competency training for healthcare professionals, a system to penalize providers who are homophobic or who make LGBT+ patients feel uncomfortable, and an increase in self-identified LGBT+ or allied healthcare professionals may encourage sexual minority women to attend regular checkups. Access to affordable medical care and government-sponsored rather than workplace-sponsored insurance will make lesbian and bisexual women more likely to attend mammograms and breast exams and motivate them to take better care of their overall health and well-being. Body neutral education emphasizing health metrics other than body size or BMI could encourage providers to focus on promoting more healthful diets and decreased substance use rather than weight loss, helping sexual minority women mitigate risk factors for breast cancer without the anxiety that comes with homophobia or fat stigma.

Additionally, LGBT+-identified (or LGBT+-competent) mental healthcare professionals and increased access to them may help lower stress levels brought on by significant life events experienced by lesbian and bisexual patients, and reducing said stress could potentially reduce the associated risk of breast cancer. Educating lesbian and bisexual women on why alcohol use is an unhealthy coping mechanism for discrimination-related stressors and providing healthy alternatives could also reduce this risk. The creation of funding or grants for medical scientists who specifically perform research on lesbian and bisexual women’s health could help them overcome financial barriers and lead to more accurate research methodology and outcomes. Complete confidentiality in these research studies, or, alternatively, a research administrator that discloses their own sexual minority status, might make more lesbian and bisexual women comfortable enough to participate in breast cancer risk studies and more willing to disclose their sexual orientation. If these procedures are implemented within healthcare spaces, industry, and education, it is possible that sexual minority women may see a decrease in disproportionate breast cancer cases and mortality.

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Stratified Post-Reproduction: An Analysis of Black Women's Barriers to Postpartum Depression Treatment

Beatriz Brockey*

Stratified reproduction is defined as a systemic devaluation of one group's reproductive capacity over another's (Harris & Wolfe, 2014). This article seeks to analyze the effects of stratified reproduction on the experiences of Black women with postpartum depression. Beginning with a thorough analysis of postpartum depression, its prevalence, and its methods of treatment, the article then goes on to evaluate the existing research done on postpartum depression in Black women specifically. After analyzing evidence that indicates higher rates of mental illness among Black mothers, the article examines stratified reproduction, and a new term "stratified post-reproduction" is defined. In comparison, stratified post-reproduction, a term coined by the author, serves to elucidate the ways in which the prioritization of and concentration on white women's post-birth experiences by the medical community at large leads to a lower quality of treatment of non-White women and mothers of other marginalized groups (Primm et al., 2010). This creates a system that increases the rates of postpartum depression among Black women and keeps Black women from seeking post-birth care for this depression. The chapter concludes by offering community-based, feminist, and Black-centered approaches to treating and caring for Black mothers in the period directly after birth. It is important to center Black voices and experiences in conversations about systemic oppression, and thus the article cites research analyzing interviews done with Black mothers and focuses on research conducted by people of color and women.

Keywords

postpartum depression • race • Black • women • Black women • depression • mental health • intersectionality • PPD • postpartum • stratified reproduction

Introduction

In any exploration of a reproduction-related topic in the United States, it is imperative to mention the long and deeply harmful history of stratified reproduction. Simply put, stratified reproduction

*University of Michigan, beatrizb@umich.edu

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refers to a system wherein the reproductive capacity of a more politically and socially powerful group is valued at a higher level than that of different, less powerful groups. In the United States, this has historically entailed the devaluing and stifling of the reproduction of people of color, as well as those in low-income areas, while emphasizing and prioritizing the reproduction of wealthy White women (Harris & Wolfe, 2014). Efforts to enforce stratified reproduction have included mass sterilization and targeted distribution of birth control to incarcerated individuals, immigrants, and disabled people in order to lower their birth rates (Harris & Wolfe, 2014). Many parts of this system of stratified reproduction continue to be present today in the ways in which medical practitioners and government-controlled systems such as Medicaid operate (Albert et al., 2021; Moniz et al., 2017). Using these concepts of stratified reproduction and reproductive justice, this article seeks to specify the ways in which inequalities in birth prioritization affect post-birth experiences.

Stratified post-reproduction describes a system through which marginalized people are given unjust access to resources to properly care for themselves after birth. In many cases Black women specifically are not provided with education and screening to diagnose their postpartum depression (PPD). However, if they are diagnosed, they may not seek treatment as a result of medical-based trauma or racism. And further, if they do seek treatment, they are often treated poorly by a medical system rooted in racist practices (Moniz et al., 2017). Ultimately, this article will argue that due to the underlying causes of systemic medical racism and general stratified reproduction, Black women experience stratified post-reproduction. Starting with examining the relatively limited data on racial disparities in rates of diagnosis, I then look at rates of treatment-seeking among Black women, disparities in access to diagnoses, reasons for low treatment-seeking, and PPD treatment quality for Black women. I end with a review of alternative solutions that may help more adequately assess the specific needs of Black women with PPD.

PPD Definition and Rates of Diagnosis

Non-psychotic PPD refers to the type of depressive episodes that begin within six months of the delivery of a child and which, if untreated, can persist long term (Miller, 2002). The American Psychiatric Association describes PPD as “emotionally and physically debilitating” (“What is,” n.d., Introductory section, para. 6) and characterizes it as lack of interest by mothers in previously enjoyed activities or in the baby itself, depressive thoughts, suicidal ideation, trouble sleeping or lack of energy, “feelings of being a bad mother,” or “fear of harming the baby or oneself” (“What is,” n.d., Symptoms section). PPD of some kind is relatively common, affecting about 10–20% of women in the United States within a six-month period after birth (Miller, 2002). This high rate of PPD indicates a need for attention and follow-up by medical providers on the health of mothers post-birth.

Although there is little research on racial/ethnic differences in rates of PPD, studies of specific regions have shown that racial minority populations are more likely to experience PPD. In one study based in New York City between 2004 and 2007, Liu and Tronick (2012) found that Asian and Pacific Islander women had the highest rates of PPD, followed by Hispanic and Black women, with White women having the lowest rates. This study concludes that in this instance sociodemographic factors account for higher rates of PPD among Black women. Another study in Wisconsin between 2016 and 2017 determined that “the odds of experiencing PPD were 2.2 times more likely among women who reported experiencing racial bias, compared to those who did not” and stated that “among the women who reported experiencing PPD, . . . , the odds of experiencing racial bias

were 6 times higher for non-Hispanic Black women than other racial/ethnic groups” (Shour et al., 2021, p. 26). According to Shour et al. (2021), “[The Wisconsin] study was consistent with previous results indicating that women – particularly women of color – experience both racial discrimination and PPD at higher rates than their White peers” (p. 28). Considering the higher rates of PPD among women of color, treatment options and follow-up appointments in these groups must be altered to cater to the specific needs of these women, and more research must be done to analyze the best way to offer treatment. Further studies in other areas of the United States are also necessary in order to be able to fully comprehend the extent of these disparities in PPD occurrence.

Despite the fact that these findings are concentrated on specific areas (Wisconsin and New York City) and within specific years (2004–2007 and 2016–2017), the trends found indicate that marginalized women are in fact more likely to experience PPD. There are also limitations to both of these studies because they use Pregnancy Risk Assessment Monitoring System data, which is largely amassed through self-reported information collected by health departments (Shulman et al., 2018). This may lead to false or under-reporting. Nevertheless, this cannot discount the value of this data because of both studies’ thorough analyses of social determinants as they relate to PPD outcomes. The patterns in these two studies introduce the ways in which racism affects the mental health of Black women and specifically how systemic bias can lead to higher rates of PPD. Liu and Tronick (2012), as well as Shour et al. (2021), assert that more research is needed to fully determine if there is a causal relationship between anti-Black discrimination and higher rates of postpartum depression and, more broadly, all of the reasons behind these racial/ethnic disparities. Nevertheless, both studies make it clear that there is an emergent trend of research results showing higher rates of PPD among Black women.

PPD Options and Rates of Treatment

Though some trends indicate they have higher rates of PPD, Black women also have lower rates of treatment for PPD (Kozhimannil et al., 2011). Traditional treatment for PPD includes the prescription of antidepressant medication, usually selective serotonin reuptake inhibitors (SSRIs) (Miller, 2002). Therapies are also often considered in the treatment plan, including cognitive behavioral therapy, which seeks to confront negative and intrusive thought patterns, and interpersonal psychotherapy, which seeks to strengthen relationships between couples or between mother and baby (Miller, 2002). Despite the fact that these courses of treatment are largely effective in managing PPD and preventing the disorder from causing long-term health effects to mothers and their babies, Black women have a significantly lower rate of treatment-seeking than White women (Gjerdingen, 2003; Kozhimannil et al., 2011).

One article by Kozhimannil et al. (2011), entitled “Racial and Ethnic Disparities in Postpartum Depression Care Among Low-Income Women,” studied the lack of access to PPD treatment for low-income women through an analysis of Medicaid program data for New Jersey women between 2004 and 2007. Among the 29,601 women in the study, around 13,000 women were White and 13,500 were Black. Though the results are geographically specific and cannot be directly applied nationally, the large sample size that was examined suggests that the trends found can be applied as a case study of the larger disparities in PPD care. The study found, for example, that there were “particularly low treatment initiation rates for black women” (Kozhimannil et al., 2011, p. 622). Specifically, low-income White women with PPD in the study had a 9% initiation of treatment

rate, whereas Black women had a rate of 4% (Kozhimannil et al., 2011). Follow-up care was also low for Black women at a rate of 54% in comparison to a rate of 64% for White women. Moreover, only 24% of Black women, versus 28% of White women, were offered continued care (Kozhimannil et al., 2011). Furthermore, Black women who did fill a prescription for antidepressants related to PPD treatment were much less likely to refill the prescription and continue taking the medication (Kozhimannil et al., 2011). This study serves as a microcosm, indicating that though Black women are affected by PPD and may need varied treatment, they are not receiving the help they need. This evidence indicates that disparities do exist between Black and White women in treatment-seeking, alongside rates of PPD in general. Examining why these disparities persist will aid in examining what can be done to provide adequate treatment to Black women dealing with PPD.

Access to Diagnosis and Information for Black Women with PPD

Before treatment-seeking and treatment-continuation rates can continue to be addressed, it is crucial to acknowledge that many Black women do not have the same access to adequate, specialized screening services and/or educational materials regarding PPD diagnosis as White women do (Tandon et al., 2011; Zittel-Palamara et al., 2008). First, there are historical and ongoing disparities in the access to hospitals and healthcare centers for Black communities (Yearby, 2018, pp. 1119, 1121). In "Racial Disparities in Health Status and Access to Healthcare: The Continuation of Inequality in the United States Due to Structural Racism," Yearby (2018) conducts a review of studies on racial segregation as it affects access to healthcare. They found that with an increase in the African American population of an area, there was an increase in closures and relocations of healthcare facilities, a reduction of hospital beds, and an increase in what is termed "physician flight," the movement of healthcare professionals to more affluent and white communities with the closures of facilities (Yearby, 2018, p. 1121). If Black women cannot access a place to receive healthcare, they are inherently restricted from accessing the mental health services or places for diagnosis of PPD that would have been included in those facilities.

Additionally, when they do have access to healthcare facilities, Black women require culturally and racially specific diagnosing processes by medical professionals that cater to how they experience PPD in unique ways that may differ from White women. As a result of Black women's distinctive social positioning, their experience as mothers with PPD may be different from that of other racial groups. Stratified post-reproduction is set up to support White women's reproductive capacity in the United States, so it is not surprising that post-birth care is also set up to tend to the needs of White women without seeking to address the specific experiences of other racial groups. In their article, "Stratified Reproduction, Family Planning Care and the Double Edge of History," Lisa Harris and Taida Wolfe (2014) write:

Reproductive injustices persist, and are tied to particular women's social, political and economic marginalization and relative vulnerability in the face of dominant medical, legal, social and political structures. Achieving reproductive justice, and generating an unstratified experience of reproduction, requires grappling with the ways in which identity, social position and power intersect to produce reproductive experience and reproductive healthcare.

(p. 543)

In the medical field, then, it is imperative that the diagnosing and screening systems for PPD not be standardized across racial groups in such a way that experiences and histories are homogenized and the specific needs of Black women and other women of color are ignored.

In one qualitative study, "Postpartum Depression Among African-American Women," Linda Clark Amankwaa (2003) found six distinct themes that differentiate the experience of Black women with PPD from that of other groups: "stressing out," "feeling down," "losing it," "seeking help," "feeling better," and "dealing with it" (p. 301). This is among the first studies to conduct in-depth interviews to discern the experience of PPD from the point of view of Black women specifically. These six themes showed trends among the women of feeling as though they had to survive without help and under conditions of severe and long-lasting distress (Amankwaa, 2003). There were also patterns of self-talk in the women's experiences in which they labeled themselves as "weak" or fundamentally flawed for struggling with symptoms of PPD (Amankwaa, 2003, p. 305). This shame or embarrassment is described in the article as a product of the stereotype of the strong Black matriarch that can infiltrate Black women's conceptions of themselves (Amankwaa, 2003). Amankwaa (2003) found that "it seems that African American mothers are reluctant to expose any frailty, thus making it difficult for professionals to provide adequate diagnosis and treatment. Findings of this study may assist mental health clinicians to sensitively assess African-American women for PPD" (p. 314). These feelings are associated with systemic racism specific to the Black experience, which affected how the women in this study dealt with PPD. A medical professional without this kind of knowledge might not diagnose these women with PPD if they did not know what unique symptoms and experiences to look for.

These findings help to emphasize the importance of deconstructing our system of stratified post-reproduction. The devaluing of the post-birth process in Black women and the medical system's lack of understanding and research regarding the Black experience with PPD are continuations of the racism inherent in historically stratified reproduction in the United States. This example of stratified post-reproduction gives us one of many reasons why Black women are often not diagnosed with PPD and don't know that they have it. Clinicians may not diagnose PPD in Black women if they are not aware of their specific experiences with it and how the disorder might present itself.

Furthermore, a recent National Public Radio (NPR) article entitled "Black Mothers Get Less Treatment for Their Postpartum Depression" suggests that the language regarding PPD and mental illness in general may be contributing to lower rates of diagnoses in Black women (Feldman & Pattani, 2019). This piece introduces mental health specialist Alfee Breland-Noble, an associate professor of psychiatry at Georgetown University Medical Center, and their work to understand the disparities in treatment for women of color. According to Breland-Noble, the resources currently set up to screen for PPD "were developed based on mostly white research participants" (Feldman & Pattani, 2019, Screening tools are not one-size-fits-all section, para. 2). However, Black women may have different ways of communicating their symptoms or even experiencing those symptoms that may not be caught by this kind of screening. For example, Breland-Noble states, "African Americans are less likely to use the term depression, but they may say they don't feel like themselves" (Feldman & Pattani, 2019, Screening tools are not one-size-fits-all section, para. 3). Additionally, the research detailed in the article demonstrates that Black women, along with members of other marginalized groups, are more likely to experience physical symptoms as outward demonstrations of their mental illnesses (Feldman & Pattani, 2019). The availability of information like this and the continued lack of support for screening for PPD in Black women suggest that

the system of stratified post-reproduction is still in many ways ingrained in the medical system in the United States. Changing diagnosis practices to include the symptoms and experiences of Black women, or at least seeking to acknowledge the ways in which current screening methods fall short, is imperative. Without these adjustments Black women will continue to seek treatment at lower rates because they are unaware that they have PPD.

It is crucial that primary care providers and physicians ensure that their patients, regardless of race, have access to education and adequate screening tools to assess their mental health in the postpartum period. A study by Tandon et al. (2011) analyzing “three screening tools to identify perinatal depression among low-income African American women” found that the women studied had high rates of PPD (28.4% of the sample) that could be better analyzed with more sensitive use of screening tools (p. 155). Though the use of un-modified screening tools may sometimes be useful to detect PPD, especially in non-Black women, Tandon et al. (2011) argue that “practitioners should consider using lower cutoff scores than those recommended by screening tool developers to most effectively identify low-income African American women in need of depression treatment” (p. 8). This would mean modifying the screening tools already available to make them even more likely to catch symptoms of PPD in Black women. These recommendations should be followed by healthcare workers to ensure that there are sensitive and appropriate diagnoses of PPD, especially in a population where it is so prevalent. The lowered sensitivity present currently in these tools does not adequately account for the differences in Black women’s experiences with PPD.

Likewise, a survey of marginalized women in California by Declercq et al. (2022) indicates that just being asked by a physician about mental health and emotional states postpartum contributes to higher levels of treatment. Specifically, “being asked about depressive symptoms was very strongly related to receiving counseling. Women with depressive symptoms who reported being asked about their feelings of depression were almost 6 times more likely to report receiving counseling” (Declercq et al., 2022, p. 138). Providing access to postpartum mental health resources in healthcare settings is one way to encourage more women of color and marginalized women to seek further screening. It is clear that providers need to make adjustments to ensure more Black women are given sensitive and accurate diagnoses regarding their PPD.

Treatment-Seeking for Black Women with PPD

Beyond the struggles of Black women to be diagnosed with PPD, there are also difficulties in treatment-seeking that cause them to avoid counseling even if they know they are battling mental illness. These difficulties vary, demonstrating the ways that racism and stratified post-reproduction are pervasive in the entirety of the medical system. Many Black women do not seek medical support as a result of medical-based trauma (Markin & Coleman, 2021), stereotypes about Black women that infiltrate their self-perceptions and everyday lives (Amankwaa, 2003), and legitimate fear of having their children taken away by child welfare workers (“Child Welfare,” 2021). These are just a few key factors among many that prevent Black women from seeking treatment, but they are worth examining in order to fight the system of stratified post-reproduction.

The issue of medical-based trauma for Black women is one that spans the entire history of the United States because of the ways in which racism is structurally embedded in the U.S. healthcare system (Hardeman et al., 2016). Black women have historically faced rape, forced sterilization, experimentation without consent, and various other violations by healthcare professionals

(Harris & Wolfe, 2014). Having learned of any these wrongdoings by supposed medical professionals or others, a Black woman might understandably feel uncomfortable or fearful about seeking medical care. Now, stories about medical racism often involve the experiences of Black women in childbirth. A paper for the American Psychological Association by Markin and Coleman (2021) asserts:

Black women, as a cohort, are at risk of experiencing childbirth as a traumatic event and subsequently developing posttraumatic stress reactions, largely because of negative interactions and communications with medical professionals and systems during childbirth that are characterized by the simultaneous experience of both racism and sexism.

(p. 2)

Black women are more likely than other groups to have serious complications in childbirth and leave with post-traumatic stress responses as a result of implicit and explicit biases by medical providers (Markin & Coleman, 2021). It is not hard to imagine why they might not feel comfortable leaving their newborn child at home and returning to the hospital, the site of their traumatic birth experience, only to be forced to deal with discrimination once again in a postpartum medical setting.

Beyond the hospital, there are also barriers to treatment in supportive community environments, such as support groups. According to a study by Chan et al. (2020), Black women face higher barriers to accessing community-based care. They conclude that “discriminatory processes and racial biases at the institutional, departmental, or provider level may account for the higher rate of hospital-based care for Black women compared with other groups of minority women” (Chan et al., 2020, p. 227). The study, which sampled close to one million women in California, found that physicians are most likely to refer Black women to psychiatric facilities or inpatient hospital care rather than community-oriented solutions (Chan et al., 2020). Community-based or outpatient care solutions normally provide an alternative to overly medicalized environments or separation from an infant (Chan et al., 2020). Chan et al. (2020) also assert that the reason for this discrepancy in solution recommendations between White and Black women is a result of structural racism and inequality. Alternatives to inpatient hospitalization could entail home visits with other people who have experienced PPD or services to manage mental health in general, such as breathing or meditation classes (Nguyen, 2017). As Chan et al. (2020) note, psychiatric hospitalization should be considered a last resort, especially since there are potentially negative health outcomes related to mother–child separation. However, the higher rates of inpatient hospitalization for Black women indicate that there may be barriers to accessing community-based solutions (Chan et al., 2020). In these cases, women may be discouraged, fearing that if they go to these institutions, they will be victims of further abuse, cause harm to themselves and their baby, or re-expose themselves to the place of their birthing trauma (Chan et al., 2020; Markin & Coleman, 2021). This once again demonstrates the lack of attention and value placed on Black women’s experiences after birth, which can lead to treatment avoidance and potential worsening of PPD.

Besides trauma that may come from medical settings during birth or dealing with institutionalized racism on a daily basis, there is evidence to suggest that some Black women internalize the stereotypes held against them. They may be subject to negative thought patterns that can contribute to both their PPD and lack of treatment-seeking. A qualitative systematic review of PPD

help-seeking barriers by Dennis and Chung-Lee (2006) synthesizes different internal barriers for marginalized women as a result of external discrimination and abuse. Black women, who are often not trusted or believed when it comes to their own pain, may not believe they are worthy of seeking out the care they deserve (Morais et al., 2022). Some women of color may view their emotional issues as unimportant compared to their expected role as childcare providers and thus not communicate these problems (Dennis & Chung-Lee, 2006). Others may simply believe that they must be strong and deal with it instead of doing what they view as admitting weakness by discussing their symptoms with someone (Dennis & Chung-Lee, 2006).

Amankwaa's qualitative study (2003), mentioned in the previous section, further describes the existence of an internal dialogue experienced by Black women battling negative stereotypes. Just as it is important for medical professionals to understand Black experiences with these stereotypes, it is important to work toward dismantling these stereotypes altogether. These harmful images may stop women from seeking treatment as well as inhibiting the process of their diagnosis with PPD. In her study on African American women and PPD, Amankwaa (2003) notes that the perpetuation of the idea of the strong woman by family members and the idea of the idealized matriarch by the mainstream media sometimes causes Black women to associate asking for help with weakness. Within the group Amankwaa (2003) assessed she found that "the idea of being a 'Strong Black Woman' may have hindered some of the participants from getting the treatment that they needed. In other cases, it may have prevented mothers from accepting the diagnosis of depression as legitimate" (p. 310). These stereotypes that infiltrate all areas of public life in the United States stop women from seeking treatment even when they are given education to be able to self-diagnose or seek diagnosis (Amankwaa, 2003). Attention to these potential barriers to treatment is crucial in dismantling the system of stratified post-reproduction and placing more value on the lives and birth experiences of Black women.

Another key reason Black women do not seek out treatment for PPD is that they are afraid, often legitimately so, that they will be deemed unfit mothers and have their children taken away from them (Dennis & Chung-Lee, 2006). An article by the Child Welfare Information Gateway (2021) addresses the "racial disproportionality and disparity in child welfare" (p. 1). The review puts together several research projects that confirm that Black families are more likely to be suspected of mistreatment of children and more likely to be investigated by child protective services ("Child Welfare," 2021). It is estimated that while about 37% of all children are investigated by Child Protective Services, Black children are investigated at a rate of 53% (Kim et al., 2017). These investigation cases are also more likely to be confirmed, and Black children are more likely to be in and stay in foster care ("Child Welfare," 2021). Overall, the article states that while Black children make up "roughly 14 percent of the child population," they make up "23 percent of the foster care population" ("Child Welfare," 2021, p. 3). The reasons stated for these unequal rates are overwhelmingly related to structural and institutional racism and bias by caseworkers and reporters ("Child Welfare," 2021). Black women, being aware of these disproportionate rates, may become afraid that if they reveal any sign of trouble, they will be investigated. They are not wrong to worry. Black children are being removed from their families mostly due to systemic racism at high rates. Black mothers may feel that they are prioritizing the well-being and safety of their children by not disclosing their mental illness, rather than seeking treatment for themselves. This is another example of stratified post-reproduction because it demonstrates the ways in which state-sponsored discrimination (in this case with the child welfare service) works to devalue the post-birth experience for Black women. This prejudice may create barriers to their access to treatment and prevent them from

comfortably raising their kids. In a society that does not value the reproductive capacity of Black women, it is no surprise that their capacity as mothers is not valued postpartum.

Generally, Black women in the United States are subject to both higher rates of PPD and lower ability to access care. This perfectly represents the lack of attention and respect given to the rights of these women to care for themselves and their families before and after they give birth.

Poor Treatment Quality for Black Women with PPD

Nevertheless, there are Black women who despite all of these barriers to diagnosis and access to treatment find resources to help them recover from PPD. However, they may face another consequence of stratified post-reproduction: the treatments offered to Black women with PPD are often riddled with bias and a lack of culturally sensitive care. The history of psychotherapy in general has been dominated by White-centric views of psychological well-being. In *The International Handbook of Black Community Mental Health*, Joseph L. White (2020) writes about the model upon which modern psychology is built. White (2020) explains:

The deficit model of psychology was the predominant lens/model in which white traditional “worldview” psychology interpreted and viewed Black people and our culture. The deficit model suggested that African-Americans were somehow deficient/inferior to whites with respect to intelligence, various abilities, family structure, and other factors.

(p. xxix)

This basis for psychological thinking was created by White men who carried deeply racist ideologies and held that Black people are abnormal and deficient. White (2020) advocates for a multicultural model of psychology, which, he says, “assume[s] that all cultures have strengths and limitations and rather than being viewed as deficient” (p. xxx). However, historically and currently this is not the method with which most counselors operate. Black women experiencing PPD, thus, often do not receive the specialized care they deserve. The treatment options that work for White women suffering from PPD may not work for Black women. In fact, the study by Shour et al. (2021) mentioned previously also indicates that there are measures for treatment and counseling of Black women with PPD that are underutilized but often more effective than those used for White women. Their study found that since Black women generally experience worse maternal mental health as a result of racial discrimination, “programs should be designed and implemented to decrease the frequency of racial prejudices and discrimination and to mitigate adverse maternal mental health effects within communities when such racial prejudices occur” (Shour et al, 2021, p. 28). These programs are not yet in place however, and Black women are not often approached by psychologists utilizing the “holistic approach” that this article recommends. Shour et al. (2021) assert:

There is the need to invest in culturally sensitive interventions in the form of social support that could promote positive coping methods to deal with racial bias. The use of support systems and racial identity development may be an uplifting coping mechanism to reinforce positive psychological self image, especially in African American women experiencing PPD.

(p. 28)

Black women benefit from counseling that includes prayer and spirituality at higher rates than White women, as well as treatment plans that

[i]nclude leaning on the shoulders of and drawing strength from African American ancestors to sustain a positive self-image, relying on social support mechanisms, avoiding contact with certain situations, and directly challenging the source of the problem using pacific or de-escalation means.

(Shour et al., 2021, p. 30)

If the findings of these studies fail to be incorporated into treatment practices, more Black women suffering from PPD will be victims of discriminatory systems that center the White experience. These systems do not account for Black women's unique experiences dealing with the intersections of their identities and thus exemplify a challenge to receiving adequate treatment. White-centered programs further demonstrate how, even after birth, White maternal health is valued over Black maternal health. Methods of stratified post-reproduction – including the extension of stigma against Black mothers to the postpartum period – have created a system that does not typically do its job to support Black women. The odds are stacked against Black women in terms of diagnosis of PPD, treatment-seeking, and the lack of culturally sensitive treatment itself.

Discussion: Treatment Solutions that Address the Needs of Black Women with PPD

It is imperative to view the myriad problems in PPD healthcare in the context of possible solutions. These solutions promote the dismantling of oppressive systems that account for the higher rates of PPD among Black women, alongside the lower rates of treatment-seeking. Recently, more research has been conducted, especially by people of color, to find better counseling systems that can help lessen the barriers to getting much-needed mental health support.

One treatment recommendation is the feminist approach to postpartum care (Davis-Gage et al., 2010). This approach takes into account culturally specific experiences and the benefits of taking advantage of cultural and community centers and resources in counseling for PPD. The authors suggest that “a feminist counseling approach enables the clinician and the client to examine [systems of marginalization] collaboratively and to assess the effect of contextual and oppressive conditions on women's psychological health” (Davis-Gage et al., 2010, p. 125). The article entitled “Developmental Transition of Motherhood: Treating Postpartum Depression Using a Feminist Approach” describes this approach to treatment as focusing on the individual experience of each woman. It suggests a method of social support for “multiethnic women” that is reminiscent of White's multicultural model for therapy described earlier (Davis-Gage et al. 2021, p. 119; White, 2020). Though this is a relatively new concept introduced to the field of treatment for PPD, it is an approach that may help center Black women in their experiences and adapt to their specific needs.

Another list of recommendations for mental health providers was compiled by Keefe et al. (2016), based on first-person accounts of Black and Latina mothers who experienced PPD. The most commonly stated suggestions by these women were:

For professionals to develop strong therapeutic alliances by (1) conveying knowledge and understanding of postpartum depression; (2) listening carefully to the mothers'

concerns and empathizing with them; (3) offering validation and reassurance that the mothers' symptoms would improve; (4) providing emotional support; (5) building trusting relationships; and (6) establishing more services that are accessible, have flexible appointment times, and are parent- and child-friendly.

(Keefe et al., 2016, p. 505)

These women express a desire for stronger counseling relationships that revolve around the individual experience and listening. This may serve to counter stratified post-reproduction by centering and valuing marginalized women's experiences and incorporating them into support system models. Similarly, Watson et al. (2018) suggest that participating in CenteringPregnancy, a program that focuses on social support and group sessions, may aid in decreasing PPD in Black women. Results of their study analyzing the effectiveness of this program in Black women indicate that there is more success with this program over traditional forms of care for PPD (Watson et al., 2018). Pao et al. (2018) also found that, though social support does have a "strong positive association against PPD" (p. 111), Black populations have less access to it. These programs that are more community-based could help decrease the likelihood of bringing up post-traumatic stress due to difficult birthing experiences and medical trauma in general because they would likely be separate from overly medicalized settings. And if they included a strong focus on education, they could increase the availability of self- and professional diagnosis.

These suggestions demonstrate the need for future implementation of PPD treatment that is culturally sensitive and positively supports and caters to the needs of Black women. These recommendations seek to dismantle the current system of stratified post-reproduction that places more value on the White after-birth experience. They place emphasis on respecting Black women and their individuality in an effort to empower these mothers. It may finally allow them to seek the help that they deserve but have not always been granted access to. Hopefully in the future, these new procedures for care, among others, will allow us to rectify the significant disparities in the rates of Black women having PPD and seeking services to treat it.

Conclusion

Dismantling stratified post-reproduction is imperative to achieving equal access to resources to treat PPD. Black women experience higher rates of PPD compared to other racial groups and have lower rates of treatment-seeking. These disparities and others that have been enumerated in this article are due to the systemic mistreatment of Black women and structural racism. Physicians and psychology experts need to be made aware of these disparities and trained in the specific needs of Black women in the diagnosis and treatment of PPD. Moreover, new and better systems of social and community-based care should be implemented and advertised to Black women so that their post-reproductive health is supported.

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Listening to the Voices of Gay and Bisexual Men and Other Men Who Have Sex with Men in Kenya: Recommendations for Improved HIV Prevention Programming

Myla Lyons*, Gary W. Harper†, Laura Jadwin-Cakmak‡, Adrian Beyer,§ and Susan M. Graham¶

Young gay and bisexual men and other men who have sex with men (GBMSM) are a key population at high risk for new human immunodeficiency virus (HIV) infections in Kenya; thus, increased efforts are necessary to reduce their health risks. This qualitative study describes recommendations offered by young GBMSM in Kenya regarding the development and delivery of culturally appropriate HIV prevention services. Both young GBMSM Community Members and Peer Educators recommend that future HIV prevention efforts enhance economic empowerment, provide mental health and substance use services, and incorporate arts-based health promotion strategies. In addition, participants recommended that public health professionals increase the ease of access to HIV prevention services for GBMSM and that researchers disseminate findings from HIV prevention research back to the community.

Keywords

GBMSM, Kenya, HIV, mental health

Introduction

Young gay and bisexual men and other men who have sex with men (GBMSM) in Kenya face multiple challenges to their health and wellbeing due to cultural stigma and discrimination (Puryear et al.,

*University of Michigan, lyonsmp@umich.edu

†University of Michigan, gwharper@umich.edu

‡University of Michigan, ljadwin@umich.edu

§University of Michigan, beyerad@umich.edu

¶University of Washington, grahamsm@uw.edu

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2020; Kunzweiler et al. 2014; Korhonen et al., 2018; Kunzweiler et al., 2018). One serious health issue faced by young GBMSM in Kenya is high rates of human immunodeficiency virus (HIV) (Sanders et al., 2013; McKinnon et al., 2014; Programme NASC, 2014). GBMSM in Kenya also report high rates of mental health issues and substance misuse, and these health challenges are associated with increased HIV risk and poorer health outcomes for GBMSM living with HIV (Harper et al., 2015; Granderson et al., 2019; Korhonen et al., 2018; Puryear et al., 2020; Ogunjabo et al., 2021). In a recent study of a large, diverse population of Kenyan GBMSM, 31% of participants reported moderate-to-severe depressive symptoms, 44% reported hazardous alcohol use, and 51% reported problematic substance use (Korhonen et al., 2018). Alcohol use has been shown to decrease HIV viral suppression among GBMSM living with HIV in Kenya, as well as general adult populations living with HIV in East Africa, and has been linked to negative HIV outcomes (Korhonen et al., 2018; Puryear et al., 2020; Kunzweiler et al., 2017). In other regions of Sub-Saharan Africa, a recent study on substance misuse finds that substance misuse leads to an increased risk of acquiring HIV among young GBMSM and also creates a barrier to adherence for those living with HIV (Ogunjabo et al., 2021). These studies have demonstrated that GBMSM living in countries where sexual and/or gender minorities face cultural discrimination, such as Kenya, need culturally appropriate services for the prevention and treatment of HIV, mental health challenges, and substance use disorders in addition to human rights advocacy to prevent abuse. The high rates of HIV and substance use among Kenyan and other GBMSM living in countries where sexual and/or gender minorities face cultural discrimination need culturally appropriate services for the prevention and treatment of HIV, mental health challenges, and substance use disorders in addition to human rights advocacy to prevent abuse.

Research focused on HIV prevention for GBMSM in Kenya suggests that engagement with community-based organizations and GBMSM Community Members can improve the effectiveness of these efforts (Graham et al., 2018; Doshi et al., 2021). Young GBMSM in Kenya often experience limited social support yet experience intense social and structural stigma (Kunzweiler et al., 2018; Jadwin-Cakmak et al., 2022). In order for these various health promotion efforts to be the most effective, they need to actively engage young GBMSM in their development and execution. Although recent advances in HIV prevention and care for GBMSM in Kenya have led to increases in the presence of affirming clinic environments and general adherence support services, these are not sufficient to promote consistent and sustained use of HIV prevention modalities such as Pre-exposure prophylaxis (PrEP) for many young GBMSM experiencing ongoing HIV risk (Graham et al., 2022; Bourne et al., 2022; Operario et al., 2022). There remains a need to increase community support and programming for the prevention of HIV among young Kenyan GBMSM (Graham et al., 2018). Thus, the current study is focused on recommendations provided by young GBMSM in Kenya regarding specific improvements that can be made in existing and future HIV prevention programs for young Kenyan GBMSM.

Methods

Participants

This secondary analysis uses data from the qualitative phase of the Shauriana Project, which was conducted in 2019 in Kisumu, Kenya. A total of 40 HIV-negative young GBMSM with varying levels of PrEP experience and interest (referred to as Community Members), as well as 20 GBMSM who were working as Peer Educators in HIV testing, prevention, and treatment programs, participated in individual in-depth interviews (IDIs). Community Member participants

met the following inclusion criteria: assigned male sex at birth and currently identify as a man, aged 18–30 inclusive, resident of Kisumu, reported at least one act of anal or oral intercourse in the previous six months with another man, self-reported as not living with HIV, and willing and able to provide informed consent and participate in an IDI. Peer Educator participants had all of the same inclusion criteria except HIV status and age, and the additional criterion of currently working as a peer educator or in a similar role in an HIV testing, prevention, or treatment program in the Kisumu area. The Shauriana Project was focused on HIV prevention. Subsequently, the Community Member inclusion criterion “self-reported as not living with HIV” was selected to have participants share about their personal experiences with HIV prevention. Peer Educators were asked to share about their experience helping with HIV prevention; therefore, their HIV status was not relevant to the Shauriana Project. Overall, the Shauriana Project sought to recruit individuals who were perceived to be good key informants, defined as a person who is thoughtful and comfortable talking about the study topics and is good at describing their thoughts and feelings. Community Members ranged in age from 20 to 30 (mean = 26.4), and the majority identified as bisexual (47.5%), whereas Peer Educators ranged in age from 22 to 45 (mean = 26.6), and the majority identified as either gay (35%) or bisexual (also 35%). See Table 1 for a summary of participant demographics.

Table 1. Participant Demographics

Community Members (<i>n</i> = 40)		Peer Educators (<i>n</i> = 20)	Combined (<i>n</i> = 60)
Age			
Mean = 26.4 years (range: 20–30)		Mean = 26.6 years (range: 22–45)	Mean = 26.4 years (range: 20–45)
Sexual orientation			
Gay	16 (40.0%)	7 (35.0%)	23 (38.3%)
Bisexual	19 (47.5%)	7 (35.0%)	26 (43.3%)
MSM	5 (12.5%)	4 (20.0%)	9 (15.0%)
Other	0 (0%)	2 (10.0%)	2 (3.3%)
Highest educational level			
Primary school	1 (2.5%)	1 (5.0%)	2 (3.3%)
Secondary school	11 (27.5%)	7 (35.0%)	18 (30.0%)
Certificate	6 (15.0%)	5 (25.0%)	11 (18.3%)
Diploma	15 (37.5%)	5 (25.0%)	20 (33.3%)
Bachelor's degree	4 (10.0%)	0 (0%)	4 (6.7%)
Master's degree	0 (0%)	1 (5.0%)	1 (1.7%)
Currently attending school	3 (7.5%)	1 (5.0%)	4 (6.7%)
Current employment			
Part-time	16 (40.0%)	15 (75.0%)	31 (51.7%)
Full-time	4 (10.0%)	1 (5.0%)	5 (8.3%)
Casual laborer	5 (12.5%)	0 (0%)	5 (8.3%)

Community Members (<i>n</i> = 40)		Peer Educators (<i>n</i> = 20)	Combined (<i>n</i> = 60)
Sex worker	2 (5.0%)	2 (10.0%)	4 (6.7%)
Not working/in school	3 (7.5%)	0 (0%)	3 (5.0%)
Not working/not in school	4 (10.0%)	1 (5.0%)	5 (8.3%)
Other	6 (15.0%)	1 (5.0%)	7 (11.7%)
Religion			
Christian	37 (92.5%)	17 (85.0%)	54 (90.0%)
Muslim	3 (7.5%)	3 (15.0%)	6 (10.0%)
Ethnic tribe			
Luo	35 (87.5%)	16 (80.0%)	51 (85.0%)
Luhya	3 (7.5%)	1 (5.0%)	4 (6.7%)
Digo	1 (2.5%)	1 (5.0%)	2 (3.3%)
Baganda	0 (0%)	1 (5.0%)	1 (1.7%)
Other	1 (2.5%)	1 (5.0%)	2 (3.3%)
Length of time as Peer Educator			
Less than 1 year	N/A	1 (5.0%)	N/A
Between 1 and 2 years	N/A	11 (55.0%)	N/A
Between 2 and 5 years	N/A	6 (30.0%)	N/A
More than 5 years	N/A	2 (10.0%)	N/A

Qualitative Interview Guide

The research team, which included U.S.-based researchers with extensive experience working with young Kenyan GBMSM and local Kenyan collaborators who identified as GBMSM, created a semi-structured qualitative interview guide for the parent study from which these data were taken. Throughout the course of qualitative interviewer training, modifications were made to the guide to ensure its utility with regard to young GBMSM in Kisumu. Grounded in phenomenological and constructivist frameworks, the guide provided a general structure for discussion but required participants to provide their own conceptualizations of terms and phrases based on their lived experiences. The guide included the following topics: physical and mental health issues affecting GBMSM in Kenya, thriving/coping as a GBMSM in Kenya, experiences with PrEP for HIV prevention, and how to improve PrEP services for GBMSM. The structure and content of the questions did not follow any predetermined theory or framework, which allowed for an inductive inquiry into participants' thoughts, feelings, and experiences related to HIV prevention. Data for the current study primarily came from the section that focused on how to improve PrEP services and other health services for young GBMSM.

Procedures

Participants for the parent study were recruited through outreach activities held at community-based organizations (CBOs) and GBMSM-friendly health clinics. These activities were conducted by

interviewers who were all GBMSM from Kisumu and were active in various CBOs. Recruitment, screening, and informed consent took place verbally with potential GBMSM participants in accordance with our inclusion criteria and stratified sampling framework. Interviews took place in private rooms at one of the collaborating CBOs or clinic research sites and were audio-recorded. The interviewer debriefed with the participant after the interview, provided him with a monetary incentive, and shared information about local GBMSM-friendly resources and services. Interviews were conducted in a mix of English, Dholuo, and/or Kiswahili, based on the most comfortable language for the participant. A local transcriptionist experienced in GBMSM-focused research simultaneously translated and transcribed the recordings. Transcripts were de-identified and quality-checked to ensure accuracy of transcription. The Institutional Review Boards of the University of Washington and the University of Michigan, as well as the Maseno University Ethics Review Committee, provided approval for, and oversight of, the research protocol.

Data Credibility and Analysis

Several strategies were used to enhance credibility during data collection, including prolonged engagement and persistent observation. Sixty transcripts from the Shauriana Project were coded and analyzed using an interpretative phenomenological analysis to maintain the authenticity of the data collected about participants' lived experiences. This approach acknowledges the expertise of the participants on the issue of desired HIV prevention efforts for young Kenyan GBMSM. Categories were created after synthesis of the shared experiences noted in the 60 transcripts, as well as the unique experiences within this group of participants. The lead author, after becoming thoroughly familiar with the transcripts, conducted a thematic analysis where she identified emerging themes. These themes and representative quotes were discussed with the study co-authors who led the Shauriana Project to validate interpretations of the transcript. The co-authors were also consulted during continuous iterations of the codebook to collapse, conjoin, eliminate, and refine codes.

Results

Data from the qualitative interviews revealed that both young GBMSM Community Members and Peer Educators recommended that existing and future HIV prevention efforts be improved by incorporating the following elements into programs: (a) economic empowerment training, (b) mental health and substance use services, and (c) arts-based health promotion strategies. In addition, participants recommended that public health professionals and researchers work to (a) increase ease of access to HIV prevention services for GBMSM and (b) disseminate findings from HIV prevention research back to the community. The following paragraphs provide more detailed information about each of these thematic areas and include representative quotes to provide a more nuanced understanding of each theme. They also include information about the participant, including type of participant (Community Member or Peer Educator), their self-identity regarding sexual orientation, and their age.

Economic Empowerment Training

Participants shared that they were in need of support in developing occupational skills that they believed would assist them in obtaining financial security – this, in turn, would assist in

preventing them from acquiring HIV. In general, they reported frequent employment discrimination. Without job security, young Kenyan GBMSM may engage in behaviors that prioritize financial security and increase their vulnerability to HIV and other sexually transmitted infections, such as transactional sex work. Sex work with proper condom use coupled with PrEP adherence and or post-exposure prophylaxis (PEP) usage can maintain sexual health. However, young GBMSM who engage in sex work may be offered a substantial increase in pay for condomless sex. Men who engage in sex work are also vulnerable to rape, and young GBMSM's stigmatization presents a barrier to reporting rape and sexual assault to police. HIV prevention programs that incorporate economic empowerment elements by hiring young GBMSM community members, providing job skills training, improving financial literacy and education, and delivering programs that provide further financial support may lead to better community member outcomes. In the following quote, a participant shares his ideas about how organizations that are providing HIV prevention services to young GBMSM can also facilitate economic empowerment:

There could be support that could enable [young GBMSM] to earn any training or that could enable them to earn the income or something that can make them active in the society.

(Peer Educator, Bisexual, 28)

Provide Mental Health and Substance Use Services

Participants also recommended that HIV prevention programs include efficacious group therapy and other forms of psychological support, including a focus on overcoming substance misuse, and that these services be created specifically for young Kenyan GBMSM. They noted that substance use is frequently used as a coping mechanism for mental distress among young GBMSM in Kenya. Unfortunately, reliance on substance use to mitigate these stressors can produce negative outcomes in some young GBMSM, resulting in behaviors that contribute to more stressors, including acquiring HIV. For example, a community member elaborates, "after being inebriated and engaging in drugs he [a young GBMSM] wasn't himself . . . and having sex with somebody [then] ends up being infected" (Community Member, Gay, 30). Participants called for greater access to GBMSM-specific mental health services, including groups focused on reducing substance use and increasing psychological support. The following quotes demonstrate specific recommendations by participants regarding the need for increased mental health and substance misuse services.

If there can be something that the organization can create . . . like a station where people who are addicted on drugs can talk and interact and mingle there to give themselves healthy advice as a way forward and move on like that.

(Peer Educator, Bisexual, 28)

What can really help is psychological support . . . because you cannot expect somebody to go and take PrEP when he is really struggling with life.

(Community Member, MSM, 25)

Incorporate Arts-Based Health Promotion Strategies

Participants expressed a need for HIV prevention programs to include health education components that use artistic and creative mediums to reach the GBMSM community, such as films, plays, and other forms of artistic expression. They expressed that arts-based health promotion programs and strategies would help educational efforts to permeate the GBMSM community and shared that artistic expression adds an emotional salience to the educational program components. In addition to behavior change, community members felt that their contributions to the production of educational content can produce a cathartic effect. They felt that positively contributing back to the community and artistically expressing themselves may benefit young GBMSM's mental health. Therefore, strategies that incorporate multiple forms of creative and artistic expression should be included in future programming. In the following first quote a participant shares how his CBO has used art-based activities to facilitate creative expression and stimulate discussion around health-related issues, and in the second quote a participant discusses the benefits of attending group therapy and learning new coping skills.

I've engaged my art through the organization I work with. Basically [my organization] uses art to create alternative dialogue spaces for LGBT persons, more so MSM. So after reducing my [alcohol] consumption and using my creativity, I came up with pieces, like short plays, with other like-minded peers within my circle who identify as bisexuals as well. We managed to stage some shows talking about drug abuse amongst MSM, and talking about social, productive health issues among the bisexual persons.
(Community Member, Bisexual, 28)

As we attend group therapies, we learn more. We see movies like "I am Samuel." They can bring a story about one MSM and the general population, how they cope in the community, how they overcome their needs.

(Peer Educator, MSM, 22)

Increase Access to HIV Prevention Services

Participants requested that PrEP and other HIV prevention and healthcare support be continued for young GBMSM, but that the programs be delivered in a manner that is easier to access both physically and culturally. They shared that this could be accomplished through expanding the geographic locations where HIV prevention services are offered and providing monetary transportation support. In addition, they suggested creating prevention materials that are culturally appropriate for residents of rural areas and are offered in the local languages spoken in these areas. Participants noted that oftentimes HIV prevention programs for young GBMSM are targeted at or stationed in more urban areas. This geographical positioning makes it difficult for young GBMSM to find transportation to program sites and often prohibits young GBMSM living in rural areas from receiving necessary services. In addition, members of the young GBMSM community who are able to travel may not be able to go to the same urban site continuously. To address these barriers, participants suggested implementing mobile clinics where PrEP can be distributed throughout the community rather than from one potentially inaccessible location. Furthermore, they recommended that HIV

prevention programs consider providing transportation stipends and services for other basic needs such as food to encourage young GBMSM's participation. The following quotes illustrate participants' concerns with both physical limitations to accessing HIV prevention services and language barriers.

The [concern I have with these organizations is] distance. If they can find a way to have a mobile clinic that is moving around to clients providing dates, like this date we'll be in Nyalenda, on this date we'll be in Kajulu, on this date we'll be in Kondele.

(Peer Educator, Bisexual, 28)

Another thing- not all people know English, and not all people understand Swahili. So, for those who are in the interior areas like maybe for example people like Luos or Luhyas who don't understand all the languages, there can be other facilitators who can do that in the language that they can understand better in their particular interior areas.

(Peer Educator, Bisexual, 24)

Disseminate Findings from HIV Prevention Research

Participants raised concerns regarding researchers conducting research on HIV prevention programs and strategies for young GBMSM, and them not disseminating their findings to young GBMSM community members and CBOs. They urged researchers to translate disseminated research materials into native languages and engage community members in the dissemination process. Participants shared that improving research dissemination is critical for maintaining and building upon community trust and for empowering community members. Young GBMSM provided feedback, saying that they feel researchers come to their sites and probe their community members without returning back to the community with results. They stressed that research findings and results of interventions must be accessible to and targeted toward the young GBMSM, as their voluntary participation allows for this research to occur.

We need to know how we are going to be engaged in this research, when terminating the research, even if you have some program to implement, we need to know, we need to be engaged up to the end of this research, we don't want to be used. I do know these researches, and I thank God for that because there was one, which I refused to attend, people [researchers] just come for ideas and information- they look for money, they forget about you. . . . We have to know the end result of the research and the way forward after you have completed.

(Community Member, Gay, 28)

Discussion

This qualitative study sought to explore the Kenyan GBMSM's perspective regarding how to improve existing and future HIV prevention programs specifically for their community. Participants

recommended that programs should include enhancing economic empowerment through the inclusion of job skills training and financial literacy skills, a strong focus on mental health and substance use, and the incorporation of arts-based health promotion strategies that can provide an emotional and cathartic outlet for participants. In addition, they stressed the importance of increasing access to HIV prevention services both geographically and culturally, through geographic expansion, transport support, and translation of materials into local languages. Finally, participants urged HIV prevention researchers to disseminate findings from their research activities to community members.

Economic Empowerment

The risk environment for young GBMSM is not just about behaviors that transmit HIV, but it also includes economic circumstances, as many young GBMSM have difficulties finding stable sources of income and may be discriminated against in the workplace once they do find employment. The lack of steady income has led some young GBMSM to engage in sex work to obtain needed resources, and they may use substances to tolerate the circumstances they face while engaging in sex work. Incorporating economic empowerment activities into HIV prevention programs will likely reduce participation in both sexual risk behaviors and substance misuse. Future HIV prevention programs should prioritize providing opportunities to enhance economic empowerment through offering vocational classes and financial literacy training, as well as creating income-generating projects. Economic empowerment support groups have been suggested as an underutilized intervention for both people living with and at risk for HIV in Kenya (Kibicho et al., 2015), and membership in a microfinance group has been shown to be related to improved HIV outcomes in Kenya (Genberg et al., 2021).

Arts-Based Health Promotion Programs

Exploring risk behaviors and prevention strategies in a relatable way through group therapies and artistic expressions may increase receptivity to programming. To maintain a beneficial and just relationship with Kenyan GBMSM, it is of the utmost importance that data analyses and research results are effectively shared with community members, their organizations, and programs meant to serve the GBMSM community in a manner that is understandable and usable. This may be accomplished using an array of strategies that are developed in collaboration with GBMSM and GBMSM-specific CBOs. HIV prevention programs for young GBMSM in Kenya may also utilize arts-based health promotion activities such as plays, movies, and other creative media that promote empathy, understanding, and connection among GBMSM community members. This junction of knowledge and emotional salience may be more likely to contribute to behavior change, specifically safer sex practices and avoidance of hazardous alcohol use (Kombo et al., 2017; Abdullahi et al., 2021; McKay et al., 2018). With regard to mental health and substance use, future programs may create arts-based modules or components focused on exploring young Kenyan GBMSM's concerns regarding stigmatization and discrimination, or incorporate group discussions and skills-building activities focused on reducing substance use. Some participants may also require more tailored substance use services that could be provided at no cost for those engaged in the intervention. This is especially vital for PrEP programs, given that alcohol use can be a barrier to PrEP adherence (Van der Elst et al., 2013).

Increasing Physical Accessibility

In order to reach young GBMSM living outside of urban centers, HIV prevention programming should expand its geographical reach by providing transportation, transportation reimbursement, and/or incorporating mobile health clinics, which have been shown to be feasible for the delivery of HIV prevention services (Nelson et al., 2020). Community clinics in rural areas also may redesign their programming to provide HIV prevention services specifically for GBMSM on designated days and times each month, to increase safety and accessibility for these young men.

Increasing Cultural Accessibility

Although an increasing number of studies have enrolled GBMSM in PrEP programs for HIV prevention, recent research has found variable levels of self-reported PrEP uptake and adherence, with very low numbers of participants (0–14.6%) found to have protective levels of PrEP in their bloodstream (Graham et al., 2022; Kimani et al., 2021; Van der Elst et al., 2013). Graham et al.'s (2022) mixed-methods study conducted community charrettes with Kenyan GBMSM to better understand the low rates of PrEP adherence and found many reported barriers to current PrEP programs. Based on these data they recommend that future PrEP programs provide accurate, non-stigmatizing information about PrEP, deliver PrEP at GBMSM-friendly clinics by trustworthy healthcare providers, provide individualized peer support from other GBMSM, create opportunities to connect with other GBMSM in group settings to discuss sexual health, and provide supportive HIV prevention services to all GBMSM regardless of whether or not they are taking PrEP (Graham et al., 2022). Research findings should be disseminated to community members in accessible and usable formats. GBMSM may benefit from research dissemination materials being formatted as infographics, pictures, and other forms that are easily understandable and shareable over social media. Advancements in research regarding HIV can be translated not only into English and Swahili (the two Kenyan national languages) but also into local languages such as Dholuo or Luhya to promote access by GBMSM living in rural areas. In order to enact these recommendations, future PrEP and HIV prevention efforts for young GBMSM will need to include active participation from community members and organizations. Graham et al.'s findings also demonstrate the need to address multiple aspects of GBMSM's lives when attempting to prevent HIV.

Conclusion

Future research directions in HIV prevention programming for young Kenyan GBMSM should include the development of mental health promotion programs created specifically for young Kenyan GBMSM. Studies testing the effectiveness of these mental health programs would be necessary to assess the influence of improved mental health on HIV prevention. Future research programs might benefit from including research centered on the creation and evaluation of program elements that encourage conversations about substance use. In addition, studies on the effectiveness of various economic empowerment strategies and their influence on HIV prevention are needed.

Strengths and Limitations

One major strength of this study is the use of qualitative inquiry via open-ended, in-depth interviews to center community voices. Recruitment was done throughout the community, resulting in a

large sample size and breadth of data from 60 different GBMSM from different backgrounds and locations. Interviews were conducted by trained and trusted community members and advocates who identified as GBMSM, which promoted safe and trusting conversations. Limitations include the secondary analysis nature of this study, as the data came from a larger study initially focused on developing and evaluating a PrEP-focused HIV prevention intervention. This may have led to sampling bias, as recruitment was rooted in PrEP interest (though purposive sampling stratified by level of interest in PrEP), and the Community Member sample was limited to HIV-negative GBMSM. An additional limitation is that, for the current analysis, none of the original analysts were Kenyan.

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Re-establishing HIV/STI Testing Services Through University Student-Oriented Centers During the COVID-19 Pandemic

Evan Hall*

The COVID-19 pandemic saw the disruption of HIV/STI testing services at crucial student-oriented spaces at the University of Michigan, including the Spectrum Center, an LGBTQ+ event and education space, and Wolverine Wellness, a well-being initiative through the University Health Services, alongside massive disruptions to testing seen elsewhere around the country (Zapata et al., 2022). HIV/STI testing resumed in October during the Fall 2021 semester at the University of Michigan at Wolverine Wellness and Spectrum Center. At the Spectrum Center, the oldest LGBTQ+ college center in the country, I had the unique opportunity to partner with professional and student staff to foster an environment sensitive to cultural needs, including awareness of how sexual and gender identity intersects with student sexual health and well-being. Additionally, at both sites, COVID-19 protocols from the state and university were also established in the new workflow of testing services. The re-introduction of HIV/STI testing services through student-oriented sites at the University of Michigan required a reassessment of work flow standards and engagement with the campus student population.

Keywords

HIV, COVID-19, testing, public health

Background

The human immunodeficiency virus (HIV) and sexually transmitted infections (STI) pose a danger to one's health and well-being, including long-term health problems if left undiagnosed (HIV.gov., 2021). Data from the CDC estimates that one in every 500 college students is infected with HIV

*University of Michigan, ejdhall@umich.edu

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as of 2020. By the age of 25, when nearly half of all Americans aged 18–24 years are enrolled in college or graduate school (Hanson, 2022), one in two individuals will contract an STI (Johnson & Jackson, 2021). In a survey conducted for first-year students at primary college institutions, two in five were tested for HIV at least once in their lifetime (Caldeira et al., 2012). Hence, access to testing services to gain knowledge of one's status is a crucial part of knowing one's HIV status and overall health (Subbarao, & Akhilesh, 2017). Without proper access to HIV/STI testing over the course of a student's experience at a college, there may be increased susceptibility to HIV/STI infections or transmission in student sexual networks. Even more so, where individuals are tested is an important first engagement with HIV/STI services and subsequent routine testing. For instance, clinical settings, such as a hospital or primary care provider office, might offer different resources than an LGBTQ+ community center or sexual health-specific clinic (Lee et al., 2014). These comprehensive cultural resources may increase the likelihood of return testing or engagement with different healthcare resources at the location.

The COVID-19 pandemic created massive disruptions to HIV/STI testing services across the country and at the University of Michigan. Colleges and universities across the state of Michigan suspended services or reserved testing for only those who were symptomatic for HIV or STIs. The current HIV/STI infection rates among college students and the need for testing establish the importance of reopening HIV/STI testing services at the Spectrum Center and Wolverine Wellness.

Studies have shown that a competent and robust health workforce supports better HIV program outcomes (Akoku et al., 2022). The AIDS Education and Training Center Program (AETC) in 2016 emphasized the importance of strengthening the HIV workforce, highlighting “the need for comprehensive strategies to ensure a healthy pipeline,” including the need for collaboration (AETC Southeast, 2016). AETC states a priority of “recruiting [linkage to care] professionals that are culturally and linguistically concordant with the populations they service.” Therefore, the collaboration between the Spectrum Center and Wolverine Wellness and Unified HIV Health and Beyond (UHHB) is essential to scaffolding necessary sexual education and HIV/STI testing.

Field Background (Site, Location, Duration)

The setting of HIV/STI test counseling for these field notes took place in the United States, the only developed country with an ongoing HIV epidemic (Straube, 2021). The state of Michigan in 2020 had an average rate of new HIV diagnosis of 6.1 per 100,000 people (CDC, 2022), and rates of STIs have steadily increased since 2016 (MDHHS, 2022). There are no specific testing data for HIV/STI rates at the University of Michigan, but in February 2022, healthcare professionals reflected on the heightened negative social perceptions of STIs on campus (Kassa, 2022). Before this, I was certified as an HIV/STI test counselor in May 2021 after completing the last of three virtual training sessions by the Michigan Department of Health and Human Services (MDHHS) in Counseling, Referral, and Testing (CTR). Subsequently, I trained in-person at UNIFIED–HIV Health and Beyond (UHHB), the community-based organization providing HIV/STI services for Spectrum Center and Wolverine Wellness, in August 2021. I led the HIV/STI testing services as the Lead HIV/STI Test Site Counselor in a clinical role, working directly with students and community members for testing. Prior to testing services resuming in the Fall 2022 semester, Spectrum Center staff, specifically those working the front desk and phone, were educated on how to discuss

HIV/STI testing service offerings and what information needed to be referred to trained HIV/STI test counselors. For instance, Spectrum Center staff could tell individuals when and where testing took place, but not, for instance, provide medical advice to whether or not a client should be tested. Testing resumed at the Spectrum Center on National Coming Out Day, October 11th, 2021, providing free confidential culturally competent walk-in HIV/STI testing services to not only students, but anyone in the community. HIV/STI testing services were provided every Monday apart from academic breaks and closures based on staffing availability during the evening at the Spectrum Center. While Spectrum Center testing services were walk-in only, Wolverine Wellness remains appointment based. Testing was conducted for both Fall and Winter semesters with a temporary pause in services during May 2022 at the Spectrum Center to adjust for summer hours and demand for testing from a smaller student population on campus, and services remained the same at Wolverine Wellness. With this, appointment-based testing was initiated at the Spectrum Center to accommodate all individuals seeking to get tested, but not to burden the Center's staff with open periods of operations from the school year. Walk-in testing at the Spectrum Center subsequently resumed with the beginning of the Fall 2022 semester. However, a delay in the initiation of services was seen during the first week of classes based on staffing shortages and determination of operating hours, for which HIV/STI testing may be conducted outside these hours.

Programming for HIV/STI-related topics was provided on prominent recognition days, such as World AIDS Day in December and National Youth HIV/AIDS Day in April. These recognition days serve as unique opportunities for community-based organizations and advocacy groups to tailor events and programming to populations impacted by the cause. Notably, the Spectrum Center opened its doors for testing services on a Sunday to accommodate National Youth HIV/AIDS Day with success in the delivery of testing and knowledge around the importance of sexual health for youth populations, including college students (Spectrum Center, 2022). The emerging Monkeypox (MPV) crisis in the United States (Sutfin, 2022) prompted a collaborative event between the Spectrum Center, MDHHS, and UHHB to hold a lunch-in conversation regarding the most up-to-date information for the virus, including access to prevention tools, treatments through the form of vaccines, and methods of group/self advocacy to affirm the ongoing struggle of minoritized populations in public health.

Observations

1) **Sexual education of students**

- a) The inherent geographic and cultural diversity of the University of Michigan establishes a spectrum of sexual education knowledge among students who engage with HIV/STI testing services. Some individuals were educated with comprehensive sexual education, covering methods of HIV/STI prevention, consent, and contraception. However, many students, especially those originating from the state of Michigan, did not receive sufficient sexual education, including pertinent education on HIV/STIs (SIECUS, 2021).

2) **Sexual history of students**

- a) The sexual history of students can vary immensely. Periods of sexual exploration are not unique to college students but are distinctly present for younger individuals discovering their gender and/or sexual identities (Bishop et al., 2020). HIV/STI

testing services at colleges/universities uniquely serve young individuals who have not engaged in sexual activity or who are re-engaging in sexual activity after periods of abstinence or monogamy. Sexual history informs a student's decision to seeking HIV/STI testing, meaning updated sexual education and tools must be available to ensure improved sexual practices.

3) PrEP among students

- a) Pre-exposure Prophylaxis (PrEP) is a proven HIV prevention medication, either orally or injection administration, that prevents HIV infection upon exposure (Holmes, 2012). Each client tested at Spectrum Center & Wolverine Wellness is screened for PrEP need and eligibility. Although PrEP is often of interest for susceptible student priority populations, there are accessibility challenges. For instance, if a student is on their parent's insurance and does not feel comfortable having PrEP show up on an explanation of benefits, there are few options available for accessing PrEP (Hall, 2022). Additionally, a small but important population on campus does not have insurance to cover PrEP medication or any other medical services (Bauer-Wolf, 2018). Because HIV/STI testing services are free from federal and state grants through UHHB, insurance is not required nor is any insurance taken.

Recommendations

The sustainability of free HIV/STI testing services is uncertain for the Spectrum Center and Wolverine Wellness. Currently, only one individual operates the testing facilities through the University of Michigan with occasional support from UHHB paid staff at Wolverine Wellness. HIV/STI test counselors at the center are volunteers, and unpaid, contributing to the difficulty to find individuals to work the positions. Additionally, there is a lengthy three-part training process to become an HIV/STI test counselor certified through the state of Michigan. Two trainings require ample time during business days to attend training, which coincides with a typical school day, preventing students who are interested in becoming a test counselor to be fully trained. We need a more streamlined process of training individuals, specifically students, and financial compensation to improve the availability of testing. A streamlined training would reduce time-burden on the trainee and cut-down on the total time it takes to become an HIV/STI test counselor. Free HIV/STI testing was nearly suspended in 2019 by University Health Services, yet student advocacy prevented such a measure (Nouhan, 2019). We cannot guarantee free HIV/STI testing at the University of Michigan, by which staffing support from culturally competent students is necessary to support better sexual health on campus. There are gaps in service that can be supplemented through an increase in staffing and simplifying the process to become a trained HIV/STI test counselor.

Conclusion

HIV/STI testing services at the University of Michigan's Spectrum Center and Wolverine Wellness provide a plethora of tests to students and community members each year through walk-in and scheduled appointments, which further the knowledge of germane sexual health education. There are many benefits to free testing through the centers including (1) increased

knowledge of sexual education and preventative tools; (2) culturally competent gender and sexual affirming services; and (3) increased PrEP uptake among college students. However, there are essential steps needed to sustain free HIV/STI testing services including (1) streamlined training sessions and (2) reasonable compensation for test counselors. My personal experiences as an HIV/STI test counselor at the University of Michigan have informed better workflow processes and elucidated best practices to engaging student populations. After re-establishing testing services from the height of the COVID-19 pandemic, there is a demand for HIV/STI testing among student and community members, and necessary problems to address for the future.

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The Unspoken Plight of HIV Gripping Asian/Pacific Islander Communities in America

Sharon E. Shaw*

The Human Immunodeficiency Virus (HIV) pandemic has had a significant impact on various communities and demographics in the United States. Although special attention has been given to African, Latin, Hispanic, and non-Hispanic white American communities, Asian American and Pacific Islander (A/PI) communities are often overlooked in HIV prevention efforts. Regardless of how statistically reassuring HIV diagnoses by ethnicity may seem, HIV poses a threat to the A/PI community. The “model minority” stereotype, lack of cultural and linguistic accommodations in HIV education, and cultural barriers may account for the lack of HIV testing and prevention in A/PI communities. The “model minority” stereotype projected onto A/PI individuals and their health gives a false sense of security about their current health status. Lack of education leads to misconceptions around HIV spread and transmission within A/PI communities. Cultural barriers continue to impact disclosure of HIV status among A/PI individuals and have a role in limiting HIV prevention efforts in these communities. Personal accounts and studies on HIV-positive Asian Americans show the lasting impact the “model minority” label, gap in HIV education, and cultural barriers have on combating HIV in A/PI communities. HIV needs to be addressed in A/PI communities, and public health measures, HIV education, and A/PI HIV support groups may encourage greater HIV awareness, testing, and prevention in A/PI communities.

Keywords

Asian/Pacific Islander • HIV prevention • HIV education • model minority • cultural barriers

Introduction

When we picture Human Immunodeficiency Virus (HIV)-plighted communities, the focus seems to be on how it has ravaged African American, Latin/Hispanic American, and non-Hispanic white

*University of Michigan, shshaw@umich.edu

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American communities. Research on these groups is necessary as they encompass the majority of HIV diagnoses in the United States. The breakdown of HIV diagnoses by ethnicity shows that in 2019 African Americans accounted for 42% of new diagnoses, 29% for those of Hispanic/Latino origin, 25% for white Americans, and a mere 2% for those of Asian origin (CDC, 2021). Given the demographics of HIV cases, Asian American communities are often overlooked as they represent a small proportion of U.S. cases. For instance, Ivy Arce, a Chinese American and New York resident, recounts her own experience as an underrepresented HIV-positive Asian American. She noted that while living with HIV through the early 1990s, Asian/Pacific Islander Americans (A/PIA) with HIV only represented 0.02% of NYC cases, which “made me feel like I wasn’t even a full number as a person” (Murphy, 2021). However, HIV prevention efforts among Asian Americans should not be overlooked. HIV does exist in Asian American communities, regardless of how insignificant the percentage seems in comparison to those of other minority groups. Lack of attention to HIV prevention methods among Asian Americans could have significant consequences: Low HIV incidence now does not guarantee that HIV rates among A/PIA communities will not drastically increase in the near future.

With the United States’ commitment to end the HIV/AIDS epidemic by 2030, it seems even more essential to address nuances hindering HIV prevention efforts within the A/PI community (White House, 2021). However, contrary to the United States’ goal to end this epidemic, numbers have been increasing, with nearly 42% more Asian American and Pacific Islanders testing HIV positive from 2010 to 2016 (Sen, 2021). Yet there are a variety of limitations in reaching A/PIA communities about HIV prevention and treatment. Most notably, the “model minority” stereotype and lack of HIV education, coupled with cultural barriers, are significant drivers of low rates of HIV testing and misconceptions around HIV among A/PI communities today.

“Model Minority” and the Mirage of Exemplary Health Outcomes

Misconceptions about HIV among Asian Americans are pervasive, and those revolving around the “model minority” stereotype place A/PI communities at risk for increasing HIV transmission and spread.

The term “model minority” was derived from sociologist William Peterson in the 1960s and his characterization of Japanese Americans in the *New York Times* (Lee, 2017). Peterson’s emphasis on how “inherent cultural qualities . . . enabled Japanese Americans to overcome racial prejudice and succeed where other minorities have failed” has expanded to include all Asian Americans (Lee, 2017, p.15). Although this concept of model minority emphasizes positive characteristics such as the resilience and hard-working attitude of Asian Americans and Pacific Islanders, this stereotype perpetuates false ideologies and beliefs, including ones regarding the health outcomes of A/PI individuals (Sabato, 2014). This “model minority” stereotype has in fact allowed an “association of positive health outcomes with Asian Americans” to “become ingrained in American society” (Lee, 2017, p. 19).

Ivy Arce’s experience with the AIDS activist group ACT UP resonates with misconceptions regarding Asian American health outcomes in society. Arce recalls how she lived almost “entirely alone as a woman of Chinese descent living with HIV” (Murphy, 2021). She endured suspicion in the broad HIV community in her participation with ACT UP during the 1980s–90s: “People constantly asked me why I was there. . . . Was I for somebody else? Was I a nurse? A mole with

the police?” (Murphy, 2021). Suspicion over Arce’s HIV-positive status shows how the “model minority” stereotype can perpetuate beliefs that Asian Americans are unlikely to have HIV as they are perceived to have positive health outcomes.

False Perceptions of Cleanliness and Safety

Arce’s experience is not an isolated incident. The stereotype of “model minority” has not only affected how other Americans respond to HIV-positive Asian Americans but has been internalized by A/PI individuals themselves. The “model minority” designation has affected their own response and attitudes toward HIV, especially toward prevention methods such as routine HIV testing. Asians are known to have one of the lowest rates of HIV testing than any other race in America and the highest rates of undiagnosed HIV. In 2013, 22% of Asians or around one in five Asians had undiagnosed HIV (CDC, 2017). According to John Guigayoma, a gay Filipino American, among the top reasons cited for Asian American and Pacific Islander hesitance in testing is that “Asians are clean” (Guigayoma, 2014). Even a Vietnamese participant in a HIV study expressed the common misconception in the A/PI community that HIV is a result of “risky behavior of bad people” (Pichetsurnthorn, 2019). Considering this within the context of the “model minority” label, Asians may seem unlikely to engage in risky or “unclean” behaviors that would put them at risk for contracting HIV.

Previous studies have shown that contrary to the model minority stereotype, “young Asian men who have sex with men (MSM) are as likely as or more likely than other MSM groups to engage in *unsafe sex*” (Bingham et al., 2003; Choi et al., 2004, p. 475; Peterson et al., 2001; Ruiz et al., 1998). Even Guigayoma (2014) himself states that he has realized that the sex life he was living “of multiple partners and unpredictable condom use . . . was actually the sex life I wanted to have.” Guigayoma’s personal account and prior studies on MSM among Asian American and Pacific Islander men serve as clear indicators that Asian Americans do engage in risky behaviors, regardless of stereotypes implicating that Asians are “clean” as America’s “model minority” group.

Interactions Increasing Risk of HIV Transmission and Spread

Given that Asian Americans do engage in risky sexual behaviors, contrary to the false mirage of exemplary behavior associated with “model minority,” interactions between sexual partners can be indiscriminate of race. Although HIV is statistically more prevalent in other minority groups, risky behaviors involving Asian Americans with other demographics will likely affect HIV rates among A/PIA communities. For instance, Daniel Tsang, a professor of politics of sexualities at the University of California Irvine (UCI), notes that Vietnamese Americans may not have many homosexual Vietnamese friends and therefore “tend to find their sexual partners mostly through ‘the institutions of the Anglo gay world’” (Tsang, 1993). Given that the CDC reports that white Americans make up 25% of new HIV diagnoses, the interaction between homosexual Asians and white Americans likely impacts HIV diagnoses among Asian Americans and Pacific Islanders (CDC, 2021).

Tsang (1993) also mentions how Joseph Carrier, a UCI-trained anthropologist, warns that although the incidence appears low, sexually active men in the Vietnamese gay community with Anglo and Latino interactions are capable of spreading AIDS within the Vietnamese American community. Carrier’s study underscores how six AIDS-positive Vietnamese individuals he

interviewed have all claimed to have only sexual interactions with Anglo partners. In the cases of these six men, where A/PI individuals have multiple partners and unpredictable condom use, sexual encounters with HIV-positive non-Hispanic white, African, or Latin/Hispanic Americans can further the spread of HIV in A/PI communities.

Ignorance around the impact of the “model minority” stereotype contributes to the complacent HIV approach to A/PIA communities and can lead to a delayed preventative response to HIV spread in these populations. Guigayoma recounts how he first tested for HIV at 21 and realized that he “didn’t really know anything about any of the men I’d [he’d] ever been with” (Guigayoma, 2014). Considering that Guigayoma had encountered men of unknown HIV status, a positive diagnosis would have led to multiple partners being exposed to HIV, potentially setting off a dangerous string of HIV spread and transmission. Fortunately, Guigayoma’s test results have been negative, but there have been incidents where lack of testing among A/PIA individuals led to a sudden positive diagnosis and exposure of partners to HIV. A study on homosexual A/PIA men in San Francisco found that out of the 13 participants who tested positive for HIV, eight men (62%) did not know they were infected with the virus beforehand (Choi et al., 2004, p. 477). Furthermore, five of these eight men had engaged in unprotected intercourse within the past six months. The study concluded that “a large proportion of men had never tested and many who were HIV-positive were unaware of their infection and engaged in unprotected anal intercourse” (Choi et al., 2004, p. 477). This study and Guigayoma’s personal account show how essential it is to address model minority stereotypes to encourage higher rates of HIV testing and prevention in A/PIA communities.

Lack of Comprehensive HIV Knowledge and Education Within A/PIA Communities

Misconceptions around HIV and the lack of testing not only stem from the wide acceptance of the model minority stereotype but can be attributed to the lack of knowledge about HIV among immigrant families and friends as well. A study by Yoshika and Schustack (2001) found that most of the Asian men interviewed cited their families’ lack of knowledge about HIV as a barrier to disclosure of their HIV status. One interviewee stated that his main concern with informing friends was their misconceptions around HIV transmission: “he’s scared of something . . . like if you talk to him you will give him AIDS. They are not educated. They have the same mind like back home” (Yoshioka & Schustack, 2001). His comment gives insight as to why HIV remains a highly stigmatized and sensitive topic among Asian Americans, considering that education on HIV abroad may be minimal. Even Tsang (1993) noted that a Vietnamese volunteer at an AIDS show in the UCI’s Fine Arts Gallery was “shocked when he realized that Vietnamese-Americans can and do get AIDS.” A recent study in Kansas on HIV-positive A/PI individuals found that “participants had incomplete or incorrect information about HIV transmission, progression, and treatment” (Pichetsurnthorn, 2019). Particularly, a Japanese male in the study expressed his perception that HIV is a “gay disease” rather than one that can be transmitted heterosexually as well (Pichetsurnthorn, 2019). Without comprehensive education on HIV transmission, scientifically unfounded beliefs, including that Asians are not susceptible to HIV/AIDS or that HIV is solely transmitted homosexually, can limit HIV testing and prevention efforts in A/PI communities.

Another study by Chin and Kroesen (1999) on HIV-positive Asian/Pacific Islander American (A/PIA) women found that lack of knowledge about HIV in Asian communities can lead to

discriminatory behaviors. One woman recounted how after informing her church leader about her diagnosis, she was told to bring her own plate and utensils to church lunches (p.230). This incidence clearly illustrates how even an “emotionally compassionate” church leader engaged in discriminatory behaviors due to a lack of knowledge about HIV transmission, which has long ago been shown to not be transmissible by casual contact (Chin & Kroeson, 1999, p. 230). Another respondent confirmed that fear of disclosure among HIV-positive A/PIA individuals stems in part from fear of discrimination, including reactions such as “oh my gosh, don’t go near, don’t eat what she give you, things like that” (Chin & Kroeson, 1999, p. 230). As shown by these incidents, misconceptions around the transmission of HIV and its influence on the treatment of HIV-positive A/PIA individuals seem to stem from a lack of HIV education among A/PI communities. Without adequate resources and access to comprehensive HIV education, misconceptions around HIV transmission and stigma around HIV diagnosis can lead A/PI individuals to conceal their status or refuse HIV testing.

Culture as a Limiting Factor in HIV Disclosure and Prevention Efforts

Although heavy emphasis has been placed on the role of the model minority stereotype and lack of education in spreading misconceptions around HIV among the A/PIA community, culture does play a notable role as well. The impact of culture is largely seen in the disclosure of HIV status to family members and friends. HIV-positive Asian patients, both male and female, have cited cultural barriers that prevent them from disclosing their status to family members and culturally related friend groups (Chin & Kroeson, 1999; Choi, 2004; Yoshioka & Schustack, 2001). Asian cultures emphasize collectivism, and the struggle of one family member can become a burden for the whole family to carry (Chin & Kroeson, 1999). Additionally, the HIV diagnosis of an A/PI individual can be regarded as a shame the whole family must carry (Pichetsurnthorn, 2019). HIV-positive Asian American individuals share similar concerns about overburdening others in their family. In an interview with an Asian American woman, although she wanted to tell her brother about her HIV diagnosis, her concerns about burdening him (i.e. “I don’t want to bog him down with my problems”) prevented disclosure of her HIV status (Chin & Kroeson, 1999). Another woman expressed concern for her mother’s health if she revealed her HIV diagnosis and caused her mother to bear her responsibilities for being HIV positive. Male HIV-positive Asian American patients expressed similar views, with one Indonesian man noting that he refused to disclose his HIV status to his family because they would “feel sad and they feel they lose face” (Yoshioka & Schustack, 2001, p. 79). A Vietnamese male also emphasized how being gay was already a source of embarrassment to his family and revealing HIV would bring “double shame” to his family (Pichetsurnthorn, 2019). Yet these cultural attitudes limit disclosure and fuel the model minority stereotype that Asian Americans rarely contract or are less susceptible to HIV and typically have good health.

Many interviewees have also confessed that they would rather tell family members that they have another disease such as terminal cancer or, more commonly, pretend that they are healthy than disclose their HIV-positive status (Yoshioka & Schustack, 2001). This may be linked to stigma around homosexuality in Asian cultures, as seen in a study in Beijing, China. Participants in the Chinese study identified fear of others knowing about their homosexual behaviors as the main reason for avoiding HIV testing (Song et al., 2011). Cultural factors are therefore important to consider when addressing preventative approaches to HIV in A/PI communities.

Intervention Methods

Certainly, the model minority ideal and lack of HIV education have perpetuated misconceptions while undermining the agency for HIV testing among A/PI communities. Yet there are methods to promote greater HIV awareness among Asian Americans today.

Educational interventions, such as educational workshops or programs, and counseling are promising methods to address misunderstandings around HIV susceptibility and transmission in A/PIA communities (Sen, 2021). A study targeting Chinese massage parlor women in Los Angeles showed that HIV knowledge increased with participation in an HIV prevention program (Takahashi et al., 2013, p. 516). A three-month follow-up survey to the program showed long-term retention of HIV knowledge as well (Takahashi et al., 2013, p. 516).

Additionally, educational methods should be language inclusive, particularly in Asian communities where some may not be fluent in English and are more comfortable speaking in their native language, especially when discussing sensitive topics like sexually transmitted diseases and HIV. Sabato (2014) notes that A/PI communities face a “profound language barrier for a demographic group with more than 100 languages and dialects,” considering that most HIV-related programs and services are only offered in English and Spanish. Given that over 50% of Vietnamese and Chinese individuals are not fluent in English and less than 20% of Samoans and Guamanians have English proficiency, educational interventions must be language inclusive to reach Asian American and Pacific Islander communities (Sabato, 2014).

Networking and support groups should also be more publicized. This would allow A/PI individuals with HIV and their family members to build a safe community and receive emotional support and information on how to cope with and handle HIV. Group interactions fostered by networking and support groups can also “encourage meaningful exchange” between stigmatized HIV-positive A/PI individuals and those in their community who are perceived as non-stigmatized and likely unfamiliar with or harbor misconceptions around HIV (Sen, 2021). In particular, networking is likely more effective in the dissemination of information on HIV prevention. For instance, Guigayoma notes that he discovered pre-exposure prophylaxis (PrEP) only through a friend, which led him to contacting his doctor about beginning the prevention regimen. The impact of support groups on family members is apparent as Pham, founder of a local Orange County organization called The Vietnamese Parents and Friends of Lesbians and Gays (Hoi Than Huu Viet Nam Dong Tinh), recounted how he had an emotional meeting with a mother. The mother, who only spoke Vietnamese, gratefully told Pham how “my son was so lucky to have found you” (Tsang, 1993). Furthermore, Pham notes that “Most of the parents who come to the meeting do not speak English” (Tsang, 1993). Therefore, although publicizing support groups is necessary, meetings should be language inclusive as well to make information accessible to all community members, particularly immigrant parents of individuals who have contracted HIV.

Overall, it seems evident that HIV among A/PI communities cannot be overlooked despite the reassurance provided by statistics on HIV-positive Asian Americans today. The false comfort provided by the model minority stereotype does not ensure that HIV-positive diagnoses among A/PI communities will remain low and insignificant to public health measures that prioritize the plight of HIV among other minority groups. Both the model minority stereotype and lack of HIV education contribute to misconceptions around HIV transmission and lead to the lack of HIV testing in A/PIA communities. Using culturally and linguistically informed HIV education methods and publicizing A/PI HIV support groups to spread awareness of HIV transmission

are potential ways of addressing this unspoken plight of HIV gripping A/PI communities in the United States today.

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