Evaluating The Sociotechnical Factors Behind Racial and Ethnic Differences in Utilization of Breast Reconstruction Services Post Women's Health and Cancer Rights Act (WHCRA)

A Research Paper submitted to the Department of Engineering and Society

Presented to the Faculty of the School of Engineering and Applied Science

University of Virginia • Charlottesville, Virginia

In Partial Fulfillment of the Requirements for the Degree

Bachelor of Science, School of Engineering

Nhut Vy P. Nguyen

Spring 2023

On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

Advisor

Kent A. Wayland, Department of Engineering and Society

Introduction

As the mortality rate of breast cancer decreases over the years due to improvements in prognosis and disease management, there is a shift from its treatment to post-mastectomy care. Mastectomy is a type of treatment that may remove one or both breasts depending on how much tissue must be removed. While mastectomy has success in achieving locoregional disease control by removing one or both breasts, it could lead to detrimental psychosocial stress related to body esteem and identity. Beyond the biological function of breasts, their significance is deeply invested in social, cultural, and political aspects of society. These factors shape the way breasts should be understood and how they look and feel since there are many psychological consequences that impact identity, self-satisfaction, and overall quality of life (Coll-Planas et al., 2017).

While not without flaw, one important process that works to address the improvement of a patient's psychological well-being post-mastectomy is breast reconstruction. Between 2009 and 2014, breast reconstruction following mastectomy rose by 62% among women 18 years and older (Miller et al., 2017). Due to the significant outcomes of breast reconstruction on quality of life, it must be accessible to all eligible patients. The Women's Health and Cancer Rights Act (WHCRA) was enacted to address accessibility by mandating insurance coverage for breast reconstruction post-mastectomy (Xie et al., 2015). However, many past studies have indicated the effects of the WHCRA are understudied and the utilization of breast reconstructive surgery remained low in the U.S. (Alderman et al., 2011; Xie et al., 2015). Furthermore, a study has found "significant racial/ethnic disparities in breast reconstruction utilization" before and after the passage of WHCRA (Xie et al., 2015).

Despite the importance of the WHCRA, the effects remain poorly understood, and the accessibility of breast reconstruction remains limited for non-white patients (Liston et al., 2022). The significant implications of breast reconstruction stress the need for a policy review of the WHCRA. Are the differences in utilization of breast reconstructive services post-mandate indicative of a health disparity or are there other explanations? Throughout this paper, specific mechanisms and sociotechnical factors that contribute to the variation in the utilization of breast reconstruction post-mandate will be evaluated. The investigation will identify the underlying reasons behind why there is such a difference in receipt of breast reconstruction and potential ways to address and reduce such differences.

Brief Overview of The Effect of Mastectomy and Breast Reconstruction

To fully grasp the significance of the WHCRA and its implications, it is essential to first explore why patients must have the choice to elect breast reconstruction services. In 2022, over 200,000 people were diagnosed with breast cancer with as many as 50% of them electing mastectomy procedures (Giaquinto et al., 2022). While there are less invasive treatments for breast cancer, in cases where there are uncontrolled large tumors and a high risk of new or recurrent tumors, a mastectomy is the only option.

Although a mastectomy is an effective treatment for breast cancer, it has a significant impact on a patient's well-being, body image, and sense of self. There are many severe psychological effects of a mastectomy since women may face distress and disfigurement as a result of the loss of their breast(s). Breast reconstruction services, which are reconstructive procedures performed after a mastectomy to rebuild the breasts, can be an important procedure that addresses these issues (Alderman et al., 2006). Additionally, there are various types of breast reconstructions that can be done immediately after mastectomy or later on. Some studies have

shown that women who chose post-mastectomy breast reconstructive surgery displayed lower levels of depression as compared to patients who did not (Gardikiotis et al., 2016). Furthermore, research has shown improvement in quality of life and many psychological, social, and functional benefits of breast reconstruction over the years (Gardikiotis et al., 2016). While breast reconstruction is not the only choice for patients, it is necessary to be an option in the complex decision-making process post-mastectomy. Since it is a necessary option, it must be accessible and equitable to all patients who are eligible.

Overview of The Women's Health and Cancer Rights Act

Due to the many benefits of breast reconstruction on patients' quality of life and years of lobbying from women's health advocates, the Women's Health and Cancer Rights Act (WHCRA) was signed by President Bill Clinton in 1998 (Wilkins & Alderman, 2004). The federally mandated health insurance providers cover breast reconstruction following mastectomy, surgery to reconstruct the other remaining breast for symmetry, and "care for physical complications and prostheses in all stages of mastectomy" (Xie et al., 2015). Additionally, legislation was passed to penalize noncompliant insurers later in 2001.

Prior to the enactment of the WHCRA, there were reports of "horror stories of "drive-through mastectomies." Women were coerced by their insurance companies into four-hour outpatient mastectomy procedures to save money (Wheeler, 2019). Furthermore, many insurance companies denied coverage for breast reconstruction on the basis that these procedures are "cosmetic," and thus not necessary for health (Wilkins & Alderman, 2004). However, many healthcare professionals emphasized that rebuilding new breasts after mastectomy is reconstructive, and for many women, a necessary aspect of breast cancer recovery (Wilkins & Alderman, 2004).

Due to the shifting perception of breast reconstruction, many breast cancer survivors, breast cancer and plastic surgeons, researchers, and policymakers lobbied intensely to ensure its coverage by law. Eventually, the legislation passed in hopes of removing the barrier to the receipt of breast reconstruction. Despite its important implications, the effect of WHCRA remains understudied and the few studies that have been conducted have found "significant racial/ethnic disparities in breast reconstruction utilization" (Xie et al., 2015).

Prior Policy Review Efforts and Literature Review

There have been prior studies and policy analyses on the WHCRA after its passage. In a study conducted by Xie et al. published in 2015 using the Surveillance, Epidemiology, and End Results (SEER) database, utilization of breast reconstruction increased by 31% in 1999 and 36% in 2000 after the WHCRA (Xie et al., 2015). However, their study found significant differences in receipt of breast reconstruction amongst racial/ethnic groups that were consistent with the existing literature as mentioned in the preceding section (Alderman et al., 2006; Xie et al., 2015). Race-based inequality in healthcare has been well-documented in many different areas of medicine, including breast reconstructive surgery. SEER data and studies have shown African-Americans, Hispanics, and Asians are significantly less likely to undergo reconstruction compared to white patients; African-American and Hispanic women were half as likely and Asian women were one-third as likely (Wilkins & Alderman, 2004).

The study conducted by Wilkins and Alderman also investigated the weaknesses of the WHCRA. They cited loopholes in the WHCRA that did not address payer compliance and enforceable penalties, as well as, failing to address physician reimbursement (Wilkins & Alderman, 2004). A major failure of the WHCRA is the oversight of 44 million Americans who do not have access to health care coverage of any kind. As the study stated, no insurance

probably means no reconstruction for uninsured women who have limited economic resources, to begin with (Wilkins & Alderman, 2004). Financial barriers and socioeconomic status may explain the lower rates of reconstruction, especially in marginalized populations. While there may be systemic disparities in breast reconstruction utilization, some argue that the lower rates of breast reconstruction for non-white patients are due to differing cultural values and inherent distrust in the health system (Rubin et al., 2013; Wilkins & Alderman, 2004). This paper will investigate all key actants involved in the process of breast reconstruction and review all possible factors that may contribute to the significant gap between racial/ethnic groups.

Methods

In order to investigate the research question, a policy review will be conducted to analyze the WHCRA. The review will involve looking at policy processing, content, and outcome based on the framework of evidence-based policy as outlined in the Brownson et al study (Brownson et al., 2009). The first domain in the framework is policy processing, which involves recognizing and identifying the main factors that inform the policy process such as political factors, the national mood, and the necessity of compromise that affects the policy. In addition, this research will identify key actants involved in the passage of the WHCRA through scholarly literature and the published hearing before the Senate's Subcommittee on Healthcare in 1997 (United States, 1997). The hearing offers accounts of actants such as state senators, the National Breast Cancer Coalition, physicians, and breast cancer survivors that advocated for the passage of the mandate. The contents will illustrate the initial reasons why the WHCRA is necessary for patients who have undergone mastectomy. By identifying these actants, the research can get a full understanding of the WCHRA's role in breast reconstruction utilization. Evaluating this hearing will also reveal different viewpoints and dissenters of the act, along with their justifications.

Then, the policy content will be reviewed to identify specific policy elements that are effective. After, a comprehensive literature review will be conducted using academic secondary sources to analyze both quantitative and qualitative data. Prior studies that have produced empirical data will offer insight into the evaluation of the effects of breast reconstruction utilization post-mandate and help determine specific sociotechnical factors that contribute to usage differences.

WCHRA Policy Process

There are key factors that are important to policy adoption, which include the problem and the politics behind the policy (Brownson et al., 2009). Is the problem or conditions regarding it worthy of governmental intervention and how do the politics of the inside and outside of the government influence the policymaking process? The hearing before the Senate's Subcommittee on Healthcare in 1997 gives insight into these questions.

The proposed legislation that laid the foundation for the WHCRA was Senate Bill 249, which was championed by Senator Alfonse d'Amato in 1997 and 1998, along with 28 other co-sponsors (United States, 1997). Other key actants that advocated for the bill are U.S. senators, U.S. representatives the President of the National Breast Cancer Coalition, healthcare professionals, and breast cancer survivors. Senator Feinstein proposed that the WHCRA require health insurance plans to: cover the length of hospital stays post-mastectomy, cover breast reconstruction following mastectomy, and prohibit them from financially penalizing a physician for providing medically necessary care (United States, 1997). In the hearing, there were many breast cancer survivors accounts, who are often also medical professionals themselves. They spoke of outpatient mastectomies and reconstructive surgeries, in which they received minimal care and were sent home on the same day of the procedures. Senator Dianne Feinstein personally testified that it was near impossible to leave the hospital after such procedures without an

overnight stay.

The advocacy for the passage of the WCHRA did not proceed without dissenters. Dr. Gail Wilensky, a health economist, argued that there does not seem to be a big enough problem to require breast cancer coverage and new legislation since outpatient mastectomy remained "relatively small" (United States, 1997). Furthermore, he raised concerns about the role of the federal government in areas traditionally handled by the States and the implications of this federal mandate on healthcare. Additionally, the American Association of Health Plans (AAHP) argued that the advocates promoted the WHCRA by "publicizing misconceptions of health plan practices based on anecdotes," causing unfounded concerns over health care practices (United States, 1997). Furthermore, the federal government should not interfere with the free market and the existing regulatory environment.

In response, representative Sue Kelly argued that if there is no problem with "drive-through mastectomies" and coverage of reconstructive surgery, then there would not be stories of women suffering from the consequences (United States, 1997). Many advocates in the hearing argued that the legislation should be upheld to place the decisions with the physician and patient, rather than allowing insurance companies to have all the say involving post-mastectomy care. Furthermore, the Center for Patient Advocacy insisted that the "anecdotes" are not isolated events and affect real human being lives, and the government should care more about the health of millions of patients rather than the market.

Despite the policy advocacy, the bills died without coming to a vote. However, after a further push, the U.S. Senate enacted a significantly reduced version focused on only insurance coverage for breast reconstruction following a mastectomy (Tweedy, 2018). While the WHCRA ended up becoming diminished, its implications are still significant in the access to breast

reconstructive surgery. The passage of the WHCRA heavily relied on political advocacy and countless testimonies from women who have undergone mastectomies or breast reconstruction before the federal mandate.

The hearing illuminated the complex factors that were involved in the WHCRA passage and process. It was clear that while there was political pushback, there was a demonstrated need for *all* breast cancer survivors to have health coverage and access to the necessary procedures post-mastectomy. Although many advocates emphasized health coverage for all women, they did not address the barriers that women of color face in health care in particular and how such factors could potentially impact the outcome of the WHCRA.

WHCRA Content and Outcome Review

Policy evaluations of the WHCRA are crucial to understanding the impact of policies on a social and individual level. To identify and evaluate the outcomes, a systematic literature review can be conducted.

The study conducted by Xie et al. evaluated the effectiveness of the federal mandate on the utilization of breast reconstruction by using a difference-in-differences (DD) approach to identify changes in breast reconstruction use before and after the WHCRA, especially in states that did not have state law mandating similar coverage to the WHCRA (Xie et al., 2015). In 2000, the rate of breast reconstruction utilization increased by 36%, especially in states that did not have pre-existing laws mandating reconstruction (Xie et al., 2015). The results suggested that the WHCRA achieved its goal since there is improved access to reconstructive services. However, their study found significant racial/ethnic disparities in breast reconstruction utilization, which was consistent with other existing studies. Their study demonstrated that non-white patients were at least 50% less likely to undergo breast reconstruction than white patients

(Xie et al., 2015). The alarming results demonstrate a need to further evaluate whether the WHCRA helped reduce or exacerbated racial disparities in terms of breast reconstruction utilization.

The study performed by Xie et al. is one of many studies showing differences in the receipt of post-mastectomy based on racial/ethnic identities. Another study done by Epstein et al. over the course of 10 years (2005 to 2014) showed that breast reconstruction utilization increased from 33.2% to 60.0% (Epstein et al., 2018). Despite the significant increase, racial/ethnic differences were found similar to the study from 14 years ago. In 2014, a higher utilization rate was found among white patients with differences in overall breast reconstruction utilization of 8.17%, 14.77%, and 19.03% with Black, Asian, and Native American patients, respectively (Epstein et al., 2018). While there is a reduction in differences from 2005 to 2014, these differences remain significant. These findings indicate that the WHCRA does increase accessibility in certain aspects but remains lacking in equity of care. The differences highlight that there could be potential gaps that the WHCRA has not addressed such as sociotechnical factors, which would affect the overall rates of breast reconstruction utilization for minority patients.

Sociotechnical Factors Affecting Utilization Rate

While the federal mandate increased access to breast reconstructive surgery, it may have not addressed other sociotechnical factors that serve as barriers for patients. Identifying and addressing them would help give further legislation and reforms to have equitable outcomes. Many factors may contribute to differences in surgery utilization and outcomes which include healthcare literacy, access to insurance/healthcare affordability, quality of providers, and social factors such as mistrust in healthcare (Hart & Momoh, 2020). Patients who are non-white are

less likely to see higher-quality providers and lack insurance coverage (Hart & Momoh, 2020). While the majority of plastic surgeons believe in the benefits of breast reconstruction, they have reduced their practice due to poor reimbursement and lack of coverage (Epstein et al., 2018). Such sentiments disproportionately affect Medicaid patients since reimbursement rates are 25% less than other insurance payers, which would affect many minority patients (Epstein et al., 2018). Additionally, minority patients are more likely to receive care at hospitals with poorer surgical outcomes, which widens the mistrust between medical care and patients of color (Gaskin et al., 2012).

Furthermore, many minority patients often have increased severity of breast cancer, which makes them more likely to undergo autologous reconstruction, a more aggressive treatment due to the increased severity of the disease. However, autologous reconstruction is underused and is not provided by all medical centers, which could be due to poor access to specialized surgeons, longer recovery time, and more hospitalization, which would result in a financial burden (Epstein et al., 2018). The socioeconomic status of patients undergoing treatment plays a major role in breast reconstruction utilization. Work-related concerns limit many women from pursuing reconstruction; the potential risk of losing a job or receiving regular income is a much higher concern for women of lower socioeconomic status. Unfortunately, Latino women commonly cite job-related concerns as a reason for not undergoing reconstruction (Hart & Momoh, 2020).

Contrasting Perspectives (Disparities vs Differences)

Some have argued that the differences in utilization rates are not indicative of healthcare disparities. Furthermore, it was argued that distinguishing between differences and disparities can be challenging in elective procedures that target quality of life, such as breast reconstruction

(Rubin et al., 2013). Health disparities are defined as "preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations" by the Centers for Disease Control and Prevention (CDC). Based on the results presented in this literature and policy review, the differences indicate a disparity in utilization for minority patients. Lack of access to breast reconstruction methods due to insurance coverage issues and sociotechnical factors contributing to the differences are preventable and can be addressed, especially with further legislation or policy reforms to the WHCRA.

Conclusion

Despite differing opinions on the accessibility of breast reconstruction, especially surrounding the WHCRA, the potential effects of breast reconstruction on patients' post-mastectomies are significant. Even after two decades post-WHCRA, the differences in breast reconstruction utilization rates between white and minority patients remain consistent and well-documented. Factors such as economic status, access to insurance coverage, and quality of care have been identified as significant determinants of utilization. These factors indicate a health disparity within breast reconstruction, which necessitate a plan to address them to achieve equitable care as intended with the original WHCRA. Reforms or new legislation must address limitations by mandating coverage for appropriate and high-quality consultations. Furthermore, they must be able to address the socioeconomic disparities that the WCHRA still poses. These can be achieved by legislation that protects workers' rights regarding health care in particular. While legislation may not solve the overarching systemic complex issues, it can gradually set the foundation to reduce health disparities overall.

References

Alderman, A. K., Atisha, D., Streu, R., Salem, B., Gay, A., Abrahamse, P., & Hawley, S. T. (2011). Patterns and Correlates of Postmastectomy Breast Reconstruction by U.S. Plastic Surgeons: Results from a National Survey [Outcomes Article]. *Plastic and Reconstructive Surgery*, *127*(5), 1796–1803. https://doi.org/10.1097/PRS.0b013e31820cf183

Alderman, A. K., Wei, Y., & Birkmeyer, J. D. (2006). Use of Breast Reconstruction After Mastectomy Following the Women's Health and Cancer Rights Act. *JAMA*, *295*(4), 383–388. https://doi.org/10.1001/jama.295.4.387

Brownson, R. C., Chriqui, J. F., & Stamatakis, K. A. (2009). Understanding Evidence-Based Public Health Policy. *American Journal of Public Health*, *99*(9), 1576–1583. https://doi.org/10.2105/AJPH.2008.156224

Coll-Planas, G., Cruells, M., & Alfama, E. (2017). Breast Surgery as a Gender Technology: Analyzing Plastic Surgeons' Discourses. *Studies in Gender & Sexuality*, *18*(3), 178–189. https://doi.org/10.1080/15240657.2017.1349504

Epstein, S., Tran, B. N., Cohen, J. B., Lin, S. J., Singhal, D., & Lee, B. T. (2018). Racial disparities in postmastectomy breast reconstruction: National trends in utilization from 2005 to 2014. *Cancer*, *124*(13), 2774–2784. https://doi.org/10.1002/cncr.31395

Gardikiotis, I., Azoicai, D., Dobreanu, C., Petrescu, I., Lazar, A., Manole, A., & Ghetu, N. (2016). Socio-Epidemiological Points of View Regarding Quality Of Life in Patients With and Without Breast Reconstruction after Mastectomy for Cancer. *Revista de Cercetare Si Interventie Sociala*, *52*, 92–104.

Gaskin, D. J., Dinwiddie, G. Y., Chan, K. S., & McCleary, R. (2012). Residential Segregation

and Disparities in Healthcare Services Utilization. *Medical Care Research and Review*, *69*(2), 158–175. https://doi.org/10.1177/1077558711420263

Giaquinto, A. N., Sung, H., Miller, K. D., Kramer, J. L., Newman, L. A., Minihan, A., Jemal, A., & Siegel, R. L. (2022). Breast Cancer Statistics, 2022. *CA: A Cancer Journal for Clinicians*, *72*(6), 524–541. https://doi.org/10.3322/caac.21754

Hart, S. E., & Momoh, A. O. (2020). Breast Reconstruction Disparities in the United States and Internationally. *Current Breast Cancer Reports*, *12*(3), 132–139. https://doi.org/10.1007/s12609-020-00366-z

Liston, J. M., Samuel, A., Camacho, T. F., Anderson, R. T., Campbell, C. A., & Stranix, J. T. (2022). The State of Breast Cancer Reconstruction in Virginia: An Evidence-Based Framework for Identifying Locoregional Health Disparities. *Annals of Plastic Surgery*, *89*(4), 365–372. https://doi.org/10.1097/SAP.0000000000003276

Miller, A. M., Barrett, M. L., & Elixhauser, A. (2017). *Breast Reconstruction Surgery for Mastectomy in Hospital Inpatient and Ambulatory Settings, 2009-2014*. 20.

Rubin, L. R., Chavez, J., Alderman, A., & Pusic, A. L. (2013). 'Use what God has given me': Difference and disparity in breast reconstruction. *Psychology & Health*, *28*(10), 1099–1120. https://doi.org/10.1080/08870446.2013.782404

Tweedy, A. E. (2018, May 12). *Insuring Breast Reconstruction by Ann Tweedy*. UCLA Law Review. https://www.uclalawreview.org/insuring-breast-reconstruction/

United States (Ed.). (1997). *Women's Health and Cancer Rights Act of 1997: Hearing before the Subcommittee on Health Care of the Committee on Finance, United States Senate, One Hundred Fifth Congress, first session, on S. 249, November 5, 1997*. U.S. G.P.O. : For sale by the U.S. G.P.O., Supt. of Docs., Congressional Sales Office.

Wheeler, L. (2019, November 20). More Surgeons Sue Insurers Over Post-Cancer Breast Operations. *Bloomberg Law*. https://news.bloomberglaw.com/health-law-and-business/more-surgeons-sue-insurers-over-post-cancer-breast-operations

Wilkins, E. G., & Alderman, A. K. (2004). Breast Reconstruction Practices in North America: Current Trends and Future Priorities. *Seminars in Plastic Surgery*, *18*(2), 149–155. https://doi.org/10.1055/s-2004-829049

Xie, Y., Tang, Y., & Wehby, G. L. (2015). Federal Health Coverage Mandates and Health Care Utilization: The Case of the Women's Health and Cancer Rights Act and Use of Breast Reconstruction Surgery. *Journal of Women's Health*, *24*(8), 655–662. https://doi.org/10.1089/jwh.2014.5057