Breast Cancer, Bodies, and Boundaries: Queering Solutions for Equitable Healthcare

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My mother once told me: "I tell doctors that my partner is my sister so she can be present during my appointments and hospitalization without prejudice." [1] My mom, who identifies as an LGBT individual, was diagnosed with breast cancer when I was in my first year at UC Berkeley. I began the project of analyzing scientific, medical, and legal discourse around healthcare as an exploration into my mom's experiences with the health care system as an LGBT breast cancer patient.

Although the LGBTQ (lesbian, gay, bisexual, transgender, and queer) communities are diverse and represent a wide range of different races, ethnicities, ages, abilities, socioeconomic statuses, and identities, the discrimination and stigma surrounding these social and gendered minorities is common, including in healthcare. The literature highlights that "racism and sexism, as well as other forms of oppression, such as homophobia, ageism, and ableism, operate as mutually reinforcing systems of inequality" and intersect with associated health risks and opportunities to inhibit health and well-being.[2] In addition, language barriers substantially block access to care. In this way, LGBTQ breast cancer patients may have their health needs ignored or denied by health care providers.

Sexual orientation or gender identity is rarely acknowledged and has limited the ability of many researchers [1]to understand needs, and consequently, "the development of public policies and programs that seek to improve the LGBTQ populations' health and well-being." [3] The largest national cancer registries and surveys do not collect data about sexual orientation. About 1 in 8 women in the US will develop invasive breast cancer during their lifetime; however, some scholars currently believe that lesbians have an increased risk of developing breast cancer, based on a "cluster of risk factors" theory. A culmination and overlap of financial, legal, and societal barriers, including conscious or unconscious discrimination and biased treatment, marginalizes LGBTQ needs in healthcare.

Little data is available on breast cancer rates and experiences among LGBTQ individuals. [3] Diagnosis and treatment have further effects on individuals because of the expectations of and systemic and social bias toward certain identities. Heteronormativity,

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1 Sue Sarkin, Sue Sarkin, email message to author, November 3, 2013. Mary K. Anglin, "Whose Health? Whose Justice? Examining Quality of Care and Forms of Advocacy for Women Diagnosed with Breast Cancer," in *Gender, Race, Class, and Health*, ed. Amy J. Schulz and Leith Mullings (San Francisco: Jossey-Bass, 2006), 313-341.

2. Jeff Krehely, "How to Close the LGBT Health Disparities Gap," Center for American Progress, accessed September 25, 2013.

which plays a large role in healthcare, asserts that heterosexuality is the only sexual orientation or only norm and thus sexual and marital relations are most (or only) fitting between people of opposite sexes. Consequently, a "heteronormative" view is one that involves alignment of biological sex, sexuality, gender identity and gender roles. It ranges from explicit to softer versions where "norms" are not explicitly *advocated,* but as they are considered to be norms, everything else becomes "other." That, in itself, creates barriers. This structural violence against LGBTIQA communities, where identities have to either be hidden or disclosed to health care professionals, further complicates the access and treatment patients receive.[4]

I have several research questions that have resulted from my extensive studies over this summer and the past two years. First, in what ways does identity shape access to quality health care? Second, what types of interactions do LGBTQ breast cancer patients have with their health care providers and physicians? And lastly, how do LGBTQ breast cancer survivors understand themselves and their journey through diagnosis, treatment, and survivorship? To begin addressing these questions, I'll examine how intersectional feminist frameworks are essential to analyze these survivors' experiences.

Intersectional feminist frameworks allow me to think more deeply about concepts such as objectivity and neutrality, language, and heteronormativity as well as intertwine and highlight the experiences of LGBTQ breast cancer survivors and critically examine health care policy formation.I believe that personal accounts stress the value of the individual in a system where most of the time we just end up as statistics; these experiences are unique, and they matter. This project examines, through my methodology, research design, and subject matter, whether science and the biomedical paradigm uncover the depth and breadth of the human experience.

Medical research and policy formation have used and favored the positivist biomedical paradigm, which employs supposed neutral treatment, leading to a silencing and marginalization of identities that are not explored in the objective viewpoint of this model; the positivist biomedical approach, widely supported and funded for health care policy, is assumed to be more authoritative and superior, yet there are many limitations to the quantification and measurement of these inequalities, such as the biases in health care policy that result from the narrow scientific research designs. Lynn Weber has pointed out that policy formation in Congress has focused on proving cause and effect in research studies, which isolates and excludes large factors in the generation of these inequities and results in underdiagnosis, lack of care and treatment, and increased death and burden among groups who are lower in this "scientifically" formed hierarchical social order, often placing blame of health disparities on individuals rather than structures that reflect power differentials.[5] intersectional feminist research is "rooted in principles of social justice" that encourage an "engaged subjectivity and reflexivity" and should be used as an additional and highly valued approach for amending health disparities. [5,6] A major difference between these structures is the questioning of relations of[2] power in this

2 Jeanelle de Gruchy, "Straight Talking?" review of *Heterosexism in Health and Social Care*, by Julie Fish, British Medical Journal Publishing Group, June 2, 2007. Lynn Weber, "Reconstructing the Landscape of Health Disparities Research: Promoting Dialogue and Collaboration Between Intersectional and Biomedical Paradigms," in *Gender, Race, Class, and Health*, ed. Amy J. Schulz

intersectional approach as a mechanism for examining social and various other inequalities in their generation and maintenance at various institutional and individual levels that interact with healthiness in societies.[5] Using the collaborative approach of both paradigms, I hope to expand understandings of the human experience of breast cancer, bridge these health disparities, and contribute to better health care research and policy in holistically caring for individuals with breast cancer.

Throughout this summer I contacted at least 40 cancer and LGBTQ organizations, and my response rate for my research was very low. I now have 10 survivors who have contacted me about sharing their stories. I began thinking critically about my position as a researcher and reconsidered the additional barriers that LGBTQ breast cancer survivors face in contacting me. As part of my research I've focused on eliminating the power dynamics that operate between the researcher and researched and centering LGBTIQ perspectives. One survivor told me that she had to overcome a lot of fear to contact me but felt hopeful and inspired after we spoke.

So far I've interviewed survivors who live in the Bay Area, such as San Francisco and Sacramento, and one survivor from Apple Valley, a rural small town area in Southern California. I've noticed that geographical region has a large impact on these survivors being able to get the care that they need, such as the difference in availability of resources and openness toward LGBTQ communities.

Additionally, all survivors seem to have experienced multiple health problems arising around the time of their breast cancer diagnoses, and most even experienced problems arising as a result of their treatment. One survivor told me "as a lesbian growing up I spent 30 years punching my way of out of walls and it's daunting to have new ones" again as a breast cancer survivor.[7] Survivors actively and independently have to search for resources, no matter where they've been in California and have expressed that they would like more guidance and support before and after treatment.

The survivor in Apple Valley communicated that her doctors express heteronormative views, especially at her primary care appointments, whereas the Bay Area survivors all commented that this was generally not a problem for them. All the women in the Bay Area were married either before or after the Supreme Court's recent decision on marriage equality and expressed that this decision and their partners gave them immense stability. The survivor in Apple Valley is not married to her partner and felt that she's not comfortable bringing her partner to her appointments because her sexuality would have been the elephant in the room. Instead, "they don't ask and [she] doesn't tell."[8]

Body image and societal expectations of women also appeared in almost every interview: Breast reconstruction was presented as the norm, making many of the

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and Leith Mullings (San Francisco: Jossey-Bass, 2006), 21-59.

4. Sandi Morgen, "Movement-Grounded Theory: Intersectional Analysis of Health Inequities in the United States," in *Gender, Race, Class, and Health*, ed. Amy J. Schulz and Leith Mullings (San Francisco: Jossey-Bass, 2006), 394-423.

survivors question where they fit. Many spoke about the narrow constructions of womanhood and wondered about what women's health really encompassed. Inclusivity in the women's community seems to be a challenge, especially for the lesbian community, who had various experiences with breast reconstruction.

Furthermore, survivors had many concerns about profitability and efficacy with foundations such as the American Cancer Society and Susan G. Komen. S. Lochlann Jain refers to this as "cancer everywhereness now drops into a sludge of nowhereness." This phenomenon, known as pinkwashing, highlights how mainstream breast cancer movements may detract from the critical issues of breast cancer and reinforce certain identities by denying the various experiences and differences that exist in women with breast cancer. Within this framework, the act of pinkwashing highlights not only economic investment in sickness but also the commitment to silencing of queer voices and bodies. The denial of quality healthcare to LGBTQ breast cancer patients is situated within an environment quite literally toxic to the queer body.

One of the last main concerns survivors had was about going beyond Western medicalization of illness. Currently complementary and alternative medicine options are not covered under the Affordable Care Act, and in order to receive this care, survivors experienced a lot of emotional and financial strain. One survivor commented that she doesn't have a retirement fund available and that her partner now spends most of her time at work, and this strain has lead them to the brink of divorce. Survivors went through bodily and psychological changes throughout their treatment and now experience themselves differently. They expressed that breast cancer is more than a physical ailment. True critical thinking about holistic health and care is necessary.

In conclusion, some resources for improving the health care for LGBTQ individuals range from breaking down socially enforced stigma and stereotypes to recognizing the diverse needs of these communities, establishing mentoring program, providing more preparation of what to expect during cancer treatments and survivorship, and explaining *why* the resources would be helpful, even if patient can't see it currently. Additionally, requirements include LGBTQ cultural humility training in medical schools and by state licensing boards. Health care initiatives need to consider that "without shifting the policy and regulatory focus towards the significant improvement of the quality of care for LGBT Americans," the efforts made toward ensuring equal access to health care will not address discriminatory attitudes and practices and will provide no relief for LGBT patients.[9] In all, health care improvement is crucial, and factors like intersectionality, personal barriers, and unique emotional responses need to considered and understood, and heteronormativity, workplace discrimination, and [3]cultural

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3 Interview 4 conducted with a lesbian-identified breast cancer survivor. Interview 1 conducted with a lesbian-identified breast cancer survivor.

6. Travis Franklin Chance, "'Going to Pieces' Over LGBT Health Disparities: How An Amended Affordable Care Act Could Cure the Discrimination That Ails the LBGT Community," *Journal of Health Care Law & Policy* 16.2 (2013): 375-402.

incompetency elicit and embody prejudiced practices and behaviors that need to be corrected if LGBTQ individuals are to ever attain the rights and care they deserve.

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