

RESOURCES AS RESISTANCE:
AN INTERSECTIONAL FEMINIST APPROACH TO HEALTHCARE ACCESS AND
ADVOCACY THROUGH PATIENT NAVIGATION

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ABSTRACT

RESOURCES AS RESISTANCE: AN INTERSECTIONAL FEMINIST APPROACH TO HEALTHCARE ACCESS AND ADVOCACY THROUGH PATIENT NAVIGATION

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Many structurally marginalized social groups in the U.S. commonly experience restricted access to healthcare. Barriers to accessing quality resources for health, wellness, and illness prevention stem from and reinforce systemic inequalities. Navigating the healthcare system and autonomous patient self-advocacy are therefore tremendously difficult. However, members of structurally marginalized social groups are not simply passive victims. Many rural Humboldt County, California residents maneuver through barriers to healthcare by utilizing local resources as a means of survival and resistance. I use an Intersectional Feminist and Disability Studies framework to examine the relationships between what is, for many, a disempowering healthcare system, those who are adversely impacted, and some of the strategies of resistance used to obtain healthcare resources in Humboldt County despite barriers. Patient navigation models are one mode of resisting and overcoming barriers to healthcare access, and the patient navigation model developed by the Humboldt Community Breast Health Project (HCBHP) exemplifies one such mode. I use semi-structured qualitative conversations,

participatory action research, and document analysis to inform my case study of HCBHP and their patient navigation model. My methodology and project overall are grounded in my commitment to collaborative horizontal knowledge production. My investigation of institutional barriers to healthcare and the use of local resources as resistance through the theoretical lenses of Intersectional Feminism and Disability Studies, attendant to interlocking relations of power, privilege, and oppression may provide a more comprehensive model for examining issues of health, wellness, and illness prevention beyond the scope of this project. Given the unique understanding of inequality, agency, and resistance that Intersectional Feminism and Disability Studies employ, my research may also contribute to wider community mobilization around autonomous patient self-advocacy and patient navigation. Finally, my research will enrich the growing body of Intersectional Feminist literature on health and wellness and strengthen the burgeoning relationship between Intersectional Feminism and Disability Studies.

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For every person resisting, and for Amazon warriors. In Solidarity.

TABLE OF CONTENTS

ABSTRACT	iii
ACKNOWLEDGEMENTS	v
TABLE OF CONTENTS.....	vii
LIST OF FIGURES.....	ix
INTRODUCTION.....	1
LITERATURE REVIEW	4
The Obama Administration: Discourse of Change and the Realities of Health Care	6
Privilege or Basic Human Right? The Social Construction of the Body, Illness, & Health Care	10
Models of Resistance and Alternative Ways of Knowing	18
Patient Navigation Models.....	28
METHODS	33
Epistemology: Knowledge Production Informing Research and Research Informing Knowledge Production.....	34
Methodology: Strategy of Inquiry	38
Methods: Tools for My (Intersectional Feminist) Belt	41
CASE STUDY	45
HCHBP and Community Relationships.....	48
HCBHP Mission.....	50
HCBHP Goals	51
HCBHP Guiding Principles	51
HCBHP Guiding Principles continued	52

HCBHP's Grassroots.....	52
Patient Navigation Model and Client Services at HCBHP	59
DISCUSSION	68
HCBHP: Resources as Resistance	68
CONCLUSION	78
REFERENCES.....	82
APPENDIX A	89

LIST OF FIGURES

Figure	Page
Figure 1. Map of California counties (California State Association of Counties Website).....	47
Figure 2. Humboldt Community Breast Health Project office	53
Figure 3. Wigs, breast prosthetics, and other client resources at HCBHP	63
Figure 4. HCBHP's Amazon Breast Nest	63
Figure 5. HCBHP living room	65
Figure 6. HCBHP resource library	67

INTRODUCTION

"Resistance is feasible even for those who are not heroes by nature, and it is an obligation, I believe, for those who fear the consequences and detest the reality of the attempt to impose American hegemony." -Noam Chomsky

Issues of health, wellness, and illness prevention touch the lives of all people.

However, there are vast disparities in healthcare access and differently positioned social groups in the U.S have vastly different experiences with the mainstream healthcare system. The US has been steadfastly gripped by the healthcare debate since President Obama took office in January 2009, though in reality, substantive attention to healthcare reform has ebbed and flowed over the last several administrations. People and social groups in the U.S. occupy very different social locations within the larger interlocking systems of power, privilege and oppression that form the foundation of U.S. society, culture, and its dominant social institutions. Kirk and Okazawa-Rey describe, social location as,

[A] way of expressing the core of a person's existence in the social and political world. It places us in particular relationships to others, to the dominant culture of the United States, and to the rest of the world. It determines the kinds of power and [systemic] privilege we have access to and can exercise, as well as situations in which we have less power and privilege [i.e. systemic oppression]...social location is where all the aspects of one's [complex, multiple, fluid, and intersecting] identity meet..." (Kirk and Okazawa-Rey 2007, 71).

Experiences with and access to quality healthcare are widely skewed by social location. Nevertheless, people develop and employ widely diverse forms of resistance

to navigate the profit-driven healthcare system and gain access to what are often life-saving resources. These realities drive the key questions of my research: What obstacles do they face in doing so? Second, what are disparities in healthcare resource access? How are structurally marginalized social groups affected by healthcare disparities? At the same time, how do they exercise autonomy and resistance within the healthcare system?

I've explored these questions through an examination of bodies of literature surrounding issues of healthcare and access using a theoretical and methodological approach dedicated to disrupting systemic hierarchy and power relations within academia and the production of knowledge more generally. Moreover, I employed what's often referred to as a "Lens of Intersectionality" to, among other things, expose and interrogate how people and groups of people are positioned within interlocking and mutually constructive social systems of race, gender, ethnicity, ability, sexuality, class, and others (Garland-Thompson 2004, 75), as well as the impacts of this positioning. "These systems intersect to produce and sustain ascribed, achieved, and acquired identities—*both those that claim us, and those that we claim for ourselves*" (75, emphasis added). I used Feminist Disability studies concurrently as a lens of analysis, which includes the ability/disability system as a category for understanding complex bodies (75). An Intersectional Feminist and Disability Studies framework allowed "interrogation of the discursive and concrete ways people" are affected by systems of inequality (Urban 2008, 12).

Resistance is an implied possibility whenever power is exercised (Stoddard 2007, 212). I frame my methods chapter as resistance, and outline how knowledge production can be an emancipatory process. Knowledge, much like dominant U.S. social institutions, can be a site of *both* oppression/punishment, *and* site of support/resistance/social change (Anderson and Hill Collins 2004, 218). Knowledge is produced *both* with the intent to and/or function of maintaining systems of inequality, *and* with the intent or function of disrupting systems of inequality, as well as the ideologies that sustain those systems.

Next, I present a case study of the Humboldt Community Breast Health Project and their patient navigation program as an example of local grassroots resources as resistance to an inadequate healthcare system, itself informed by systems of power, privilege, and oppression. Finally, I provide recommendations for action-orientated change.

LITERATURE REVIEW

"I suffer no illusions that this will be an easy process. It will be hard. But I also know that nearly a century after Teddy Roosevelt first called for reform, the cost of our healthcare has weighed down our economy and the conscience of our nation long enough. So let there be no doubt: health care reform cannot wait, it must not wait, and it will not wait another year."

-President Barack Obama, February 24, 2009

President Obama's words may have stirred up sentiments of "hope" and "change" that became familiar rhetoric over the span of his campaign and time in office. For some, these words sounded like empty promises, and were confirmed when crucial aspects of the people-over-corporations healthcare proposal were taken off the table. Many Americans have had to be innovative with the few healthcare options they have and simultaneously make the best of what little they have. Self-advocacy as well as self-prescribed and directed measures of health, wellness, and illness prevention are acts of resistance to a system that doesn't work equally for everyone. Self-advocacy is intimately related to access to reliable information and resources; in fact, people must often be or become self-advocates *in order to gain access* to available information, healthcare resources, and decent healthcare more generally. This can be an incredibly daunting, but not impossible, process to undertake, particularly for those struggling to survive and thrive despite myriad illnesses and disabilities. I have organized the bodies

of literature at the foundation of this project into three categories, although in reality, all three intersect with and support one another. First, I discuss documents that shed light on the current state of healthcare in the United States in order to provide a “snap shot” of the current national healthcare conversation. This body of literature is comprised of government documents including executive orders, transcripts from the White House Forum on Health Reform, and remarks by President Obama at the ceremonial swearing in of Health and Human Services Secretary, Kathleen Sebelius, as well as publications assessing the challenges to health care in the twenty-first century and the gaps in the current health system¹. In this section, the snap shot of government rhetoric is compared against the current climate of access to healthcare in America. I discuss the systematic marginalization of many Americans and restricted access to resources of health, wellness, and illness prevention, as well as interrogate how systems of power, privilege, and oppression operate within the profit-driven medical system, sometimes referred to as the medical industrial complex.

I examine how bodies, illness, and healthcare are constructed using a Disability Studies framework, which includes the ability/disability system as a category of analysis to understand how people are differently positioned to access healthcare. Finally, I discuss different models of resistance to the for-profit medical system and how they are organized methodologically to exemplify actions and ways of knowing that differ from

¹ This research investigates the current state of health care in the US from Obama’s 2008 election victory to the present. For a broader temporal analysis of health care in the United States see Philip J. Funiglio. 2005. *Chronic Politics: Health Care Security from FDR to George W. Bush*. Lawrence, Kansas: University Press of Kansas.

and resist the hegemonic, or dominant, discourse on health and access to healthcare in the United States, such as patient navigation models, the wounded healer model, health collectives and alternative ways of knowing that differ from mainstream narratives about healthcare, access, and rights to wellness.

The Obama Administration: Discourse of Change and the Realities of Health Care

In this discussion “mainstream” healthcare refers to healthcare resources for health, wellness, and illness prevention that are connected to government funding, such as MediCare or MediCal programs, or care that is generally funded by third party payers such as insurance companies. Mainstream healthcare is also an ideology normalized through the social construction of health and wellness, as well as illness and bodies (Freund et. al. 2003, 7). Healthcare, as an ideology, is constructed and sustained by rhetoric supported and normalized by media and government (195). In this research I use this construction of mainstream healthcare in juxtaposition to what I frame as resources as resistance, or resources for health, wellness, and illness prevention that fall outside of and resist the mainstream healthcare system.

The topic of healthcare reform followed Obama on the campaign trail, and has stayed on the American consciousness during his time in office. Healthcare insurance premiums have grown four times faster than wages in the past eight years and every thirty seconds in America a bankruptcy is filed due to the cost of healthcare (United States Government *b* 2009). Even currently insured individuals and families are only “one stroke of bad luck” away from joining the nearly 46 million uninsured (McLaughlin

et. al. 2004, xiii). Millions more Americans have healthcare but cannot comfortably afford it. The Congressional Budget Office estimates that by 2025 one fourth of the national economy will be “tied up” in healthcare if the cost increase trend continues (United States Government *b* 2009). Americans spend nearly twice the average amount on healthcare per person than any other “developed” country, and more on health than on food or housing (Marmor et. al. 2009).

In December 2008 over 30,000 Americans participated in “Health Care Community Conversations” framed by a seven-question guide distributed by the Obama transition team (United States Government *a* 2009). These conversations were designed for American people to become involved, to share their opinions, and to have their voice heard regarding healthcare reform, and were the first action taken by the Obama administration to respond to America’s healthcare crisis. The most frequent responses from all over the country, including the responses from the Health Care Community Conversations in Humboldt County, California, reflected Americans’ concerns about the high costs, lack of emphasis on prevention, preexisting conditions limiting insurance access, and inadequate care. The government website for health reform reports that many Americans agree that the system is broken, inadequate, inaccessible, and beyond affordability (United States Government *a* 2009). The online synthesis of these conversations provides countless testimonies speaking to each of these problems and concerns. One report from Portland, Oregon echoes the sentiment of many US residents:

We felt strongly that the health care system in its current state is clearly NOT FOR US. It is not designed to benefit or help us. Who is it for? Who does it benefit? We suspect that the answer is big corporations, because none of us know any individuals who feel that the healthcare system really meets their needs. It's bureaucratic, disempowering, overwhelming, confusing, and frustrating in more ways than we can list.

Obama acknowledges these realities in his statements regarding healthcare reform.

Reiteration of the facts surrounding the state of the healthcare system does not, in itself, change them.

The President's words at the start of this chapter paint a vivid picture of healthcare in America in 2009-10. Obama's solution-based statements and justifications for refusing nationalized healthcare are tied to the interests of capital. As the community group from Portland asked, "Who is the system for?" And if it is not working how can it be fixed using the same old capitalist blueprint? The basic goal of modern capitalism is to turn money into more money, and the dynamics of capitalism produce increasing amounts of inequality, in addition to enormous amounts of wealth (Johnson 2006, 42-43). "[T]he American health system is powerfully dominated by large for-profit industries" including corporate hospitals, insurance companies, pharmaceutical and medical technology research industries (Freund et. al. 2003, 336). These industries have consolidated their economic interest and, subsequently, their power. While the current administration gives the topic of healthcare reform priority attention, I am concerned that the rhetoric is a Potemkin for building big business and the medical industrial complex. Interest groups and corporate money are effective political pressures, and government is quite clear that the interests of the medical industrial complex must be considered in

healthcare policy. Budget deficits and market competition were just as important an issue as any other in the congressional discussions of Obama's proposed healthcare reform bill during spring 2010 and at the White House Forum on Health Reform in March 2009.

The White House Office of Health Reform was established by executive order on April 8, 2009. Obama established this office in the interest of "providing all Americans access to affordable and high-quality healthcare" (United States Government *c* 2009). This office is meant to provide leadership to the executive branch and perform nine other defined functions. The Executive Order called for the Department of Health and Human Services to create a similar Office of Health Reform and collaborate closely with the White House Office of Health Reform.

Former Kansas Governor Kathleen Sebelius was sworn in as the 21st Secretary of the Department of Health and Human Services on April 29, 2009. At the ceremonial swearing in of Secretary Sebelius President Obama said,

We must realize that fixing what's wrong with our healthcare system is no longer just a moral imperative -- it's an economic and fiscal imperative. If we want to make companies more competitive and reduce our budget deficits in the future, we need to tackle healthcare reform right now (United States Government *d* 2009).

This statements sounds as if the people's health, families, and livelihoods are not as serious a material consequence as the United States budget deficit.

The Obama administration and the general public seem to be agreement about the state of healthcare in America, but deep differences exist within discussions of solutions. All Americans do not experience barriers, obstacles, and risks connected to reliable quality wellness and acute care to the same extent (Angel et. al. 2006; Freund et. al. 2003,

12; United States Government *e* 2009). The report “Hard Times in the Heartland; Healthcare in Rural America” (United States Government *e* 2009) provides evidence of how certain populations are systematically marginalized by the medical industrial complex. The report states that insufficient provider networks, lack of adequate and affordable health coverage, and difficulty accessing high-quality care can lead to poor health for people who live in rural America (2009). The report concludes that the US health system must be reformed to provide affordable, high quality healthcare to those who need it most.

The ability to access care is based on the ability to pay, so without question, those with less means to pay receive a far smaller slice of the available resources (Angel et. al. 2006; Wallace 2003). Marginalized Americans are more likely to be living in poverty and to suffer negative health consequences, be uninsured, and receive lower quality care (Angel et. al. 2006, 27; Freund et. al. 2003, 305; Pollack and Kronebusch 2004, 206). Families without complete family coverage are not only at risk of poor health and medical indebtedness, but also often lack an important marker of full social citizenship based on oppressed social positioning, and must struggle for basic security (Angel et. al. 2006, 34; hooks 2000, 2). This cycle becomes a vicious one and spirals out of control, as families remain poor in part due to the costs of healthcare and illness prevention.

Privilege or Basic Human Right? The Social Construction of the Body, Illness, & Health Care

Article 25 of the United Nations Universal Declaration of Human Rights (UDHR) drafted in 1948, substantiates that,

Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and the necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control (Laqueur and Rubin, eds. 1989, 201).

Despite the fact that the UN UDHR has the status of international law, and was written with the intent of protecting the very basic human rights of all the world's citizens, the reality is that there are deep and abiding systemic barriers preventing many from accessing even basic human rights such as health and well-being. Furthermore, the current state of healthcare in United States demonstrates a serious disregard for the basic human rights of its own citizens by its government (Freund et. al. 2003, 335). Barriers to healthcare, among innumerable other barriers and human rights violations, are products of interlocking systems of power, privilege and position, which shape all social institutions in the United States and impact one's life literally from cradle to grave (Freund et. al. 2003, 3; Johnson 2006, 42). Put differently, one's social location within interlocking systems of inequality often determines whether or not one has access to the human rights enshrined in the UN UDHR including healthcare, or, if one experiences patterns of denial and refusal when seeking healthcare (Kirk and Okazawa-Rey 2010, 15).

Oppression works through power and inequality, and members of dominant social groups generally have built-in economic, political, and cultural power, often referred to as privilege (15). In addition to phrases like "interlocking systems of power, privilege and oppression," and the "lens of intersectionality," many Intersectional Feminist

scholar-activists use “The matrix of oppression and resistance,” and “the matrix of domination and privilege” to highlight the existence of racism, sexism, classism and others *as systems of power* pervading every aspect of our society (as opposed to individual bigotry only), and to highlight their argument that systems of inequality are interlocking and mutually reinforcing. These phrases are also meant to highlight another core argument among Intersectional Feminist; peoples’ identities are multiple, fluid, and interlocking as well (Johnson 2006; hooks 2000). People generally experience systemic oppression and privilege simultaneously based on their particular social location.

Scholar-activists working with a lens of intersectionality both within and outside the field of Disability Studies similarly argue that these systems inform, shape, and reinforce dominant, U.S. social construction of bodies, illness, and of healthcare (Freund et. al. 2003, 4 & 36; Garland-Thompson 2004, 81; Johnson 2006, 49).

Health and illness are connected to strength and power, both monetarily and otherwise, and thus are gendered, classed, and racialized (Brownsworth and Raffo, eds. 1999; Freund et. al. 2003; hooks 2000; Jung 2002; Sherwin 1992). The healthcare system as an institution does not merely mirror the power and privilege structures of the larger society, but also perpetuates them (Freund et. al. 2003, 255; Sherwin 1992, 228). Health is constructed in the United States by dominant voices, while marginalized social groups have a pre-fabricated reality blanketed over them (Morgan, 1998, 83). Put differently, members of structurally privileged social groups in the U.S. (those with white skin privilege within the U.S. system of racism; those with gender/sex privilege in the U.S. systems of patriarchy and genderism; those with class privilege within the US

system of classism, those with the privilege associated with able-bodiedness in the US system of ableism, and so forth), enjoy greater institutional access, as well as agenda setting power and cultural authority, which enables the dominance of particular voices, theories, perspectives, norms and standards, and the exclusion of others (Johnson 2006). Members of structurally privileged social groups are able to set the agenda and social structure to further their own groups' goals and interests, are heard because of the legitimacy and cultural authority privilege conveys, and are able to create policies and practices (Freund et. al. 2003, 307; Urban 2008, 25). Furthermore, members of socially privileged social groups both develop and deepen ideologies to maintain the status quo, including the systemic privilege they enjoy.

As Johnson further explains, "for every social category that this privileged, one or more other categories are oppressed in relation to it" (Johnson 2006, 38). Oppression is also systemic, and as mentioned, forms an intricate relationship with systemic privilege; in fact, one cannot exist without the other (Johnson 2006, 39). This is not to say that members of structurally marginalized social groups lack agency, or that resistance to interlocking systems of inequality is without reward. I argue that the opposite is true. However, systems of inequality in respect to health, wellness, and healthcare limit access for members of structurally marginalized social groups, who have far more limited options than do people who most benefit from systemic privilege (Freund et. al. 2003, 323). One may simply become complacent within systems of inequality, or may resist using any of the innumerable, creative, and life changing means available, as many people and communities are doing. Although not futile, resistance and transformative

social change more broadly is a difficult, long-term process, full of obstacles, whether in the context of healthcare or otherwise.

Mainstream health discourse frames public health through the activities undertaken collectively to promote the health of the society. “Improving the practice of public health is the mission of community-based research and in many ways the history of public health is the history of community based research” (Blumenthal and Yancey 2004, 5). Moreover, within the confines of a for-profit medical system, resources for health, wellness, and illness prevention serve as powerful means of social control (Freund et. al. 2003; Johnson 2006, 91). Medicalization refers to the unintentional or intentional expansion of the domain of medical jurisdiction, and requires the continuous transformation of “ordinary worldviews” (Morgan 1998, 85).

The US health care system is for profit, in the interest of capital, and produces systemic marginalization and restricted access for the many people in the U.S. who are already receiving less than optimal care. The federal, state, and local governments play a major role in influencing the insurance status and medical care of the population, providing direct coverage, and subsidizing private coverage (Chernew and Hirth 2004, 263; Freund et. al. 2003, 328). The government is supposed to regulate private firms, though the private firms are in fact regulating the government (Pollack and Kronebusch 2004). The gap between healthcare defined as a basic human right or as a privilege is dictated in this country by the ebbs and flows of capital interest in the medical industrial complex (Blumberg and Nichols 2004, 35). The for-profit healthcare system continues a trend of premium and spending increases as insurers seek to maintain profitability (Levit

et. al. 2003, 239). hooks argues that restricted access is not contingent on money alone and that class is about more than money (2000, 157). She argues further that until class is understood as a integral component of the matrix of domination and that social problems cannot be solved in the long term with more money, the framework in place now will continue to serve the interests of a “predatory ruling class while rendering the rest of us powerless to create meaningful changes in our lives across class” and to disrupt other positions of inequality (158).

The health system constructs a medicalized view of marginalized people’s experiences silencing the voices of the “patients” and disrupting autonomy and knowledge production outside of the mainstream discourse that privileges those positioned in dominant social groups and oppresses others. In the same way that systems of power and privilege construct marginalized groups as oppressed and unable or unwilling to transcend this social position, illness and poverty silence and render invisible those whom the current medical system fails (Daniels 2008, 141; Johnson 2006, 110).

Feminist Disabilities Studies scholar-activist Garland Thompson argues that the meaning of health and illness are further compounded by the “social performance of disability” (Garland-Thompson 2004, 79). People with disabilities or who are ill are often portrayed as helpless, dependant, weak, or incapable. Garland-Thompson discusses how disability and subsequently representations of health, are both identity categories and cultural concepts that intersect with other social positions (76). “Health is produced not just by having access to medical prevention and treatment but also, to a measurably great

extent, by the cumulative experience of social conditions across the lifecourse" (Daniels 2008, 79). The inability to access and pay for quality healthcare leaves those with unequal access more vulnerable to illness and poverty, and the system of inequality and oppression reproduces itself (Johnson 2006, 52; Pollack & Kronebusch 2005, 210).

Everyone is simultaneously privileged and oppressed based on different social positions inescapably attached to her or his own positionality. Regardless of privileged status in some area or another of our lives, healthcare makes very little room for people to succeed in using the system and to feel empowered during the process. Groups that are especially vulnerable include low income people and families, children, people of color, immigrants or people perceived to be immigrants, veterans, people with chronic disease or other "pre-existing" conditions, the elderly, and people with psychiatric or substance abuse disorders. Access to resources for health, wellness, and illness prevention are more or less limited for *vulnerable* populations. The healthcare system is purposefully complex to discourage the oppressed, work to pit people against each other in order to "divide and conquer", and create conflict and barriers to coalition building for the interest of capitalism and fields of power (Angel et. al., 2006, 12). The matrix of domination and privilege in the health system looks something like a hall of mirrors as health and the healthcare system work to create and sustain poverty (Kirk and Okazawa-Rey 2010, 219).

Lock argues, "one of the master symbols of contemporary medicine and of North American society as a whole is that of control" (1998, 61). Social positioning and social oppression make people vulnerable and obtaining social services becomes difficult.

Systemic privilege and oppression based on race, class, gender, ability, ethnicity, sexuality and powerlessness form part of a cycle of poverty in which the inability to exert control over bureaucratic processes in combination with low levels of community resources reinforce inferior social status. People's ability to act as effective agents on their own behalf is affected by advanced medical and social needs, economic disadvantage, discrimination, and impaired decision making, in addition to the systems of power, privilege, and oppression in which our society is embedded (Pollack and Kronebusch 2005, 210). Engaging in instrumental action and health autonomy are difficult due to these barriers and systems of inequality (Angel et. al. 2006, 52).

Schulz, Freudenberg, and Daniels argue, "The goal of 'health for all' requires moving beyond documentation [of the disparities] to action" (2006, 371). Even so, non-cooperation is extremely risky and difficult particularly for "vulnerable population" who face obstacles such as continual surveillance, threats and punishments ranging from loss of disability (SSI) income, to deportation, to the removal of children from "unfit" (i.e. disabled) parents, and others. While action orientated change is a powerful and plausible road to change, the matrix of domination operates to obscure these huge risks that oppressed social groups disproportionately face, and therefore make them appear at fault for their situation due to a lack of action- a discourse known as "blaming the victim" (Johnson 2001, 110). Victim blaming allows those who benefit most from systems of power, privilege, and oppression to remain oblivious to the operation of systemic privilege in the connection to material disparities. When even a few people break rank from the files of good daughters and sons of capitalism and begin to create or participate

in alternative ways of navigating the system we disrupt the dominant narrative and work towards justice and change in our healthcare system.

Models of Resistance and Alternative Ways of Knowing

As I previously mentioned action and resistance to the mainstream healthcare system and systems of inequality takes innumerable forms. Theoretical frameworks, activist strategies, and alternative healthcare models are only some of the many ways of reimagining healthcare in order disrupt cycles of power, privilege, and oppression. “Intersectionality” refers to “an integrative, feminist perspective that recognizes and emphasizes the intersection of gender with other systems of inequality based on race, class, sexuality, ability and nation, among others” (Kirk and Okazawa-Rey 2007, 16). Power, privilege and oppression include, are mobilized through, and are maintained by, the simultaneous operation of systems and ideologies of racism, classism, sexism, heterosexism, ableism, ageism, xenophobia, nationalism, and others. Urban (2010) further explains Intersectionality as an interdisciplinary feminist lens or framework committed to both theory-building and activism (or “praxis,” defined by Paulo Freire as reflection and action upon the world in order to change it), whose proponents argue that racism, patriarchy, classism, heterosexism, ableism, ageism, and others are mutually reinforcing, interlocking systems of power, privilege, and oppression that impact all social institutions and relations in the U.S. Proponents work to expose the operation of and ultimately eradicate these systems, arguing that genuine social change cannot happen if one focuses on a single system alone, or in isolation from others. Rather,

transformative social change work and the long-term goal of creating a more just world for all the earth's inhabitants, including the earth itself, requires the eradication of all intertwined systems of inequality as well as the ideologies that support them, *simultaneously*. Put differently, Intersectional Feminists argue that all systems of power, privilege, and oppression must be dismantled for inequality to truly be "over" (Johnson 2006, 79; Weber 2006, 36).

Intersectional Feminists similarly regard identity as fluid, multiple, evolving and intersectional, meaning identity is also comprised of the intersections of race, class, gender-identity, sex, sexual orientation, age, ability and others. As such, people can be systemically privileged in some respects and oppressed in others simultaneously (Johnson 2006, 49)." As Burnham explains, "...numerous Black feminist theorists have advanced the view that Black women's experience as women is indivisible from their experiences as African Americans. They are always 'both/and,' so analyses that claim to examine gender while neglecting a critical stance towards race and class inevitably do so at the expense of African American women's experiences" (Burnham in Kirk and Okazawa-Rey 2010, 16).

Moreover, proponents of Intersectional Feminism view difference and diversity as strengths (as opposed to causes of division and fragmentation), and foreground the importance of building coalition and solidarity across lines of difference as a crucial avenue by which context-specific, non-hierarchical, egalitarian and inclusive analyses, forms of activism, and visions of a more just world may be built in order to bring about that more just world for all (Urban 2010).

Speaking again of ideologies used to support systems of power, privilege and oppression, it is extremely important to note that constructions and representations of members of structurally marginalized social groups as “other” (as inferior, sub-human, deviant, deficient, threatening, and even expendable), and/or as passive victims, and/or without intelligence, voice and agency for instance, are roundly rejected by Intersectional Feminists (Johnson 2006, 10). Intersectional Feminists and those using an intersectional lens within Disability Studies work tirelessly to expose and dismantle these and other constructions and representations and thus, the role they play in “justifying” inequality and maintaining the status quo, including restricted access to healthcare, by blaming the victim (Freund et. al. 2003, 163; Johnson 2006, 110).

Integrating Intersectional Feminist and Disability Studies theories supports and strengthens both fields (Garland-Thompson 2004, 74; Smith 2004, 2). Garland-Thompson goes on to argue that her proposed framework of Feminist Disability Studies supports a “universalizing view” of disability that has the potential to replace the “minoritizing view” that engenders dominance and oppression within the ability/disability system (76). She claims,

Integrating disability as a category of analysis, a historical community, a set of material practices, a social identity, a political position, and a representational system into the content of feminist- indeed into all inquiry- can strengthen the critique that is feminism (100).

Integrating Intersectional Feminist and Disability Studies creates a lens for evaluating the full range of humanity, a complex understanding of the cultural history of the body, and the experience of embodiment (Garland-Thompson 2004, 75-76; Smith 204, 3). This

framework encourages analyses of people holistic and unique, rather than compartmentalized by their illness and embodiment. Disability and illness as socially constructed categories operate in four aspects: 1) as a system for understanding and disciplining bodily variations, 2) as a relationship between bodies and their environment, 3) a set of practices that define and produce the ability/disability system, and 4) a way of describing the instability of embodiment (Garland-Thompson 2004, 77). Disability Studies changes the focus from the mainstream hegemonic “ideology of cure” to an interrogation of the “exclusionary attitudes, environmental, economic [and political] barriers embedded within systemic social inequality” (87).

Consciousness raising and liberatory political education are powerful liberatory tools against systemic inequality (hooks 1994, 59). Lynn Weber argues for reconstructing the landscape of health disparities research through promoting dialogue and collaboration between Intersectional Feminist and biomedical paradigms (2006, 21). She asserts that although health disparities research has increasingly become a priority in recent years, the bulk of the research remains dominated by the hegemonic biomedical paradigm that silences social bodies, whether advertently or inadvertently (22). The biomedical paradigm constructs hierarchical relationships between researchers and “research subjects”, and medical professionals and patients. On the other hand Intersectional Feminist scholarship takes the stance of subjectivity and reflexivity, inclusive of collaborative relationships resembling a partnership (24).

Weber argues further that biomedical and Intersectional Feminist paradigms are differently situated in the landscape of health disparity research and policy, with the

biomedical paradigm in the dominant position (25). Scientific knowledge and research produce many great benefits for health, wellness, and illness prevention, and integrating an Intersectional Feminist framework honors the knowledge people have about their own bodies and experience as legitimate and valuable to create more complex and complete understandings of health disparities. Intersectional Feminists work to “shift the center²” of analysis and knowledge production by honoring the voices and experiences of those whom are most often excluded from “center-view”. Intersectional Feminism provides tools for bridging the gap between health disparities research and social action, which is a key problem for biomedical scholars (33). For further dialogue and collaboration to address and disrupt health disparities in connection to systemic inequality researchers should:

- begin dialogue on recognized points of convergence;
- incorporate a power-relational analysis into research;
- seek a better balance between measurement and meaning in research;
- level the playing field for critical paradigms;
- promote the use of plain and accessible language in research and practice;

² ‘Shifting the center’ means putting at the center of our thinking the experiences of groups that have formerly been excluded. Otherwise, many groups simply remain invisible. When they are seen, they are typically judged through the experiences of White people, rather than understood on their own terms; this establishes a false norm through which all groups are judged. Shifting the center is not just about illuminating the experiences of oppressed groups, however, but changes how we understand the dominant culture and groups who have more power and privilege than others. “The exclusionary thinking we have relied upon in the past simply does not reveal the intricate interconnections that exist between the different groups composing American society” (Anderson and Hill Collins 2004).

- and privilege the perspectives of marginalized people (43-49).

Learning to self-advocate within the medical industrial complex in a way that suits an individual person's needs and life is a powerful action and form of resistance against a system that attempts, and often succeeds, in predetermining outcomes based around systemic social positioning. Emancipatory education and ally³ support through collaborative efforts and coalition building have the potential to facilitate community efforts to redesign its health and social services systems, and transform both the community and its members (Bulbeck 1998; de la Cruz and Badura 2003). The first crucial step is beginning an honest dialogue and communicating. Every person and community is unique and there is no recipe for liberation that will work the same from one place to another. There are models of resistance and alternative ways of knowing oneself and understanding the social construction of the body and person, health, and illness, as well as the roots of inequality, that can be used to inform one's own community action plan. Intersectional Feminist and Disability studies frameworks can offer alternative ways of examining and understanding the issues faced by diverse communities, and help "shift the center" to make room for alternative ways of knowing and being that have been and continue to be systemically invisibilized by dominant medical policy and discourse in the U.S. The same may be said for modes of health and wellness including, but not limited to vastly diverse models of health and wellness

³ Andrea Ayvazian defines ally as "a member of a dominant group in society who works to dismantle any form of oppression from which she or he receives the benefit [...] allied behavior is intentional, overt, consistent activity that challenges prevailing patterns of oppression, makes privileges that are often invisible visible, and facilitates the empowerment of persons targeted by oppression" (2007, 725).

developed by indigenous nations around the U.S., a diverse array of health collectives and non-profit organizations, and myriad creative strategies for resistance including, but not limited to, patient navigation models.

Feminist and Disability Studies theorists, among others, have made great strides in exposing the operation of, naming, and assessing the medical industrial complex, its inadequacies and therefore, its consequences. The process of exposing and naming are vital forms of action and resistance. In turn, many Feminists and other groups and organizations have compiled pamphlets, 'zines, and published texts to encourage people to challenge dominant ideologies constructing doctors and/or the mainstream medical system as expert, or the only viable option, while simultaneously empowering themselves with knowledge and trusting themselves to be experts about their own bodies. Women's health collectives and clinics are amazing examples of the determination and resilience needed to create spaces that address the needs of the individuals who participate in those groups. One exceptional example is the Boston Women's Health Book Collective, who since 1970 have been revising and publishing the pivotal text, *Our Bodies, Ourselves*. The women of this organization recognize that too much medical care still focuses on expensive solutions of drugs and surgery, rather than on preventative and management strategies (2005, x). They assert,

Too often, women's life experiences, from childbirth to menopause, are seen as diseases to be treated rather than natural healthy processes that sometimes have problems. And too many of us still don't have the knowledge and resources to participate effectively in maintaining our health (2005, x).

The women's health movement, of which health collectives are a part, emerged in the late 1960's and 1970's, and the women's health agenda of the early 1990's helped to lay the foundation for grassroots organizing around health and wellness, as we know it today (Weisman 1998, 37). Collectives are models for navigating the current health care system, engaging in critical analysis and dialogue about the politics of health and systemic inequalities, organizing for change, and challenging the mainstream science industry, policy, and dominant knowledge (Boston Women's Health Collective 2005, 708; Weisman 1998, 69). Additionally, collectives are examples of real people who dared to step outside of a box that was not a good fit. This is both inspirational and reassuring. Many collectives are happy to correspond with other people who are seeking guidance or coalitions, and the most recent edition of *Our Bodies, Ourselves*, features a chapter on organizing for change (2005, 748).

Health collectives are useful tools for filling the gaps of the inadequate healthcare system and resisting systems of power privilege and oppression. For example, here in Humboldt County, California, a network of United Indian Health Services Clinics has been operating since the 1970s. The clinics serve those who are eligible through Indian descent, and offer both western and native healing practices (UIHS).

Collectives, like the Boston Women's Health Book Collective, and the theoretical framework of an integrated Intersectional Feminist Disability Studies create a forum and validation for personal narratives to operate as resistance against a failing profit driven medical system. Personal narratives operate as sites of resistance in at least two ways. First, narratives disrupt hegemonic mainstream discourse about health, wellness, illness

prevention, and bodies. Second, in many cases personal narratives serve as a part of a persons healing process or practice of wellness. Breast cancer and breast health narratives are one example of the highly politicized and sometimes contested uses of narratives as personal resistance and a tool for systemic change (Garland-Thompson 2004, 83).

Breast cancer narratives in particular address the intersections of multiple social locations of identity, and thus power, privilege, and oppression, due to the highly sexualized, gendered, and public construction of breasts on the one hand, and the largely invisible and silencing social construction of breast cancer or breast health on the other (84). For example, the women of the National Breast Cancer Coalition advocate that women use their personal narratives of breast cancer to capture the attention of their legislators (Knopf-Newman 2004, 5). Breast cancer activist and Intersectional theorist Knopf-Newman chronicles the personal activist narratives of Rachel Carson, Betty Ford, Rose Kushner, and Audre Lorde in a process of connecting breast cancer narratives to human rights, embodiment and autonomy, personal advocacy, and the politics of disease in order to make a politicized call to action to challenge the hegemonic mainstream construction of illness and bodies (2004).

The biomedical paradigm constructs a dominant discourse that breast cancer falls into narratives of family history or personal choices, and otherwise remains inconclusive about environmental and social causation of the disease (23). Rachel Carson's brave public outcry "initiated a transformation in the relationship between humans and the natural world and stirred an awakening of public environmental consciousness" (Lear

2002, x). Her public protest through congressional testimonies and the publication of *Silent Spring* (1962) confronted the issue of the destruction of nature, and were framed as a debate over the quality of all life (Lear 2002, xviii). While publicly fighting the dynamics of a capitalistic system that valued profit over the health of the environment and people, and working to demand science and governments be held accountable, Carson was also privately fighting breast cancer. Knopf-Newman considers the tension between ‘private’ and ‘public’ as Carson straddled this line, “as it set in motion prominent paradigm shifts in breast cancer research and activism” (2004, 30).

Knopf-Newman uses Audre Lorde’s prose for the title of her book, *Beyond Slash, Burn, and Poison: Transforming Breast Cancer Stories into Action* to transform the mainstream consciousness about breast cancer, and uses Lorde’s critique of the “breast cancer establishment” naming breast cancer as a political disease, “one that is greatly affected by race, sexuality, gender, and class (xii, 26). Audre Lorde, who identified as a black, lesbian, feminist, mother, “warrior poet”, “broke the silence within feminist public spheres about the ways in which compulsory white heteronormativity and femininity negatively affect the emotional and physical healing process for many women” (Knopf-Newman 2004, 109-110). In an interview Lorde explained, “I want my poems [and] all of my work, to engage, and to empower people to speak, to strengthen themselves into who they most want and need to be and then to act, to do what they believe” (Lorde in Knopf- Newman 2004, 113). In Lorde’s personal account of breast cancer, *The Cancer Journals*, she juxtaposed parallel battles of South African apartheid and her own breast cancer (1980). Lorde’s account is most often noted for her resistance to the

invisibilization of her identify and of her disease, specifically surrounding personal choice versus social expectations, and breast prosthetics. Lorde challenges the social expectation that directs women to maintain an appearance of conformity and thus in some ways make breast cancer invisible (44).

Lorde's resistance to the social construction of breast cancer and women's bodies illustrates a patient centered framework for healing, surviving, and thriving. Lorde takes caution to note that some women may find healing strength in wearing prosthetics, but that people should guide their own path (60). I argue for an Intersectional Feminist Disability Studies framework, in part, because the model works to foreground the experiences and realities of people, especially those whose voices are traditionally oppressed. Theoretical frameworks and narrative centered activism intersect and support action on the ground.

Patient Navigation Models

Patient navigation is one specific site of resistance that can be understood through an Intersectional Feminist Disability Studies lens, and that incorporates personal narrative. Statistics show an estimated one-third of breast cancer patients experience significant distress and/or impairment in their lives after their cancer diagnosis, and the distress has been found to persist into long-term survivorship (Davis et. al. 2008, 263), but I argue distress is synonymous with cancer. This distress, and often fear, can be detrimental to decision making and ability to manage treatment, as well as the subsequent

outcomes. Furthermore, breast cancer patients often make important decisions with limited understanding and knowledge about the diagnosis and treatment options when faced with the complex system of care. Despite the fact that emotional distress is clearly linked to quality of life and quality of cancer care, many clinicians fail to recognize distress among cancer patients, and on the other hand patients are often hesitant to share their emotional feelings because of fear of being labeled with a psychological problem or distracting medical team members away from the primary concern of treating the cancer (564). Patient navigation is one way for breast cancer patients and their providers to address some of the barriers patients face including.

- patient and clinician attitudes and beliefs,
- patient's potential low-level of health literacy,
- presence of physical symptoms taking precedence,
- and clinicians' lack of knowledge about distress (Davis et. al. 2008, 565).

Patient navigation is generally defined as a type of barrier-focused intervention or case management to assist cancer survivors to navigate through the healthcare system (Davis et. al 2008, 565), though a variety of specific definitions exist in the literature. First conceived in the early 1990's by breast cancer surgeon Harold Freeman, patient navigation was created to address the barriers women face when diagnosed with breast cancer, and the disparities between those who are diagnosed (Schwaderer et. al. 2007, 634). In June 2005 President Bush signed the Patient Navigation Outreach and Chronic Disease Prevention Act into law. The Patient Navigation Act put patient navigation models into a professionally serious and necessary position, but some critics argue that

the Act did not go far enough to establish standards for quality care (Davis et. al. 2008, 565). Patient navigators facilitate timely delivery of care, connect survivors with resources, provide educational information about survivorship, as well as deal with the logistic issues of financial issues and health insurance (565).

Patient navigators need to address,

- 1) access to quality care issues,
- 2) the emotional and practical concerns of the cancer survivor,
- 3) family concerns, and
- 4) the patient navigator needs to be involved “across the continuum of care from the time of diagnosis into long-term survivorship” (Davis et. al. 2008, 562).

When the approach is effective patients’ fear and anxiety begin to decrease as the navigator provides knowledge and understanding (Wilcox 2009, 7).

Patient navigation research serves as site of collaboration between navigators, health disparities researchers, and patients. As patient navigation programs grow around the country consulting key stakeholders is critical to program development (Davis et. al. 2008, 561). Studies dedicated to discussing the needs of medically underserved cancer patients and collaboration shift the center, as traditionally marginalized people have an opportunity to provide input on models of care to meet their needs. Though many patient navigation programs exist more research about patient navigation models is needed to understand the cost and effectiveness with the aim of better serving patients, and providing service to many patients (Schwaderer et. al 2007, 634).

Patient navigation programs have been implemented at all stages of cancer care, but there is an inconsistency in opinions regarding who should serve in the role of navigator (professional or lay person) and about the scope of their work (Davis et. al. 2008, 566). Competing arguments for who is best fit for oncology patient navigation can simultaneously hold merit because of the personalized nature that makes patient navigation successful for different people. Likewise, the complex medical system involves many disciplines and thus patient navigators from different disciplines can be equally successful (Wilcox 2009, 7). Davis et. al. argue that social workers serve as effective patient navigators because social workers have historically worked with individuals and communities to address social barriers that impede the well being of underserved clients (571). They further argue that duties of patient navigators are consistent with two core social work functions: empowering individuals to seek needed services and empowering communities to provide and improve those services. Much of the literature asserts that oncology nurses are best fit for patient navigation roles because of their specialized medical knowledge about cancer and patient care (Schwaderer et. al. 2007, 633). Though the literature calls for more research and asks, “Who would best fill the position- professional nursing staff with greater knowledge of oncology issues or skilled community members who are familiar with the community and its resources?” (638).

On the other end of the spectrum, the patient navigation literature reflects that anyone who is dedicated to helping remove barriers for a patient has the potential to be an effective patient navigator. In Guynup’s personal narrative of her breast cancer diagnosis

she shares that though she considers herself an apt researcher, the fear of her diagnosis left her too petrified to gather the information she so desperately needed. Rather, her husband dedicated himself to doing to the research, sharing only what she needed to know, and served as a liaison between her and her medical team (Guynup 2004, 1). Lay people serving as patient navigators opens up possibilities for new models that can serve a greater number of people's needs, namely because many social workers and oncology nurses are already spread too thin, and also because of the cost effectiveness of utilizing models that implement more affordable lay person labor or volunteer efforts, such as in peer patient navigator models (Schwaderer et. al. 2007, 634).

Patient navigators guide patients through the complex medical and healthcare system and make a difference for those patients who may otherwise fall through the cracks. Though patient navigation models are different based on the needs of the patient and community served, all models are based on Freeman's founding vision,

No person with cancer should go untreated. No person with cancer should be bankrupted by a diagnosis of cancer. No person with cancer should be forced to spend more time fighting their way through the healthcare system than fighting their disease (Freeman in Schwaderer et. al. 2007, 638).

METHODS

Barriers and restricted access to healthcare are problems I am intimately connected to and interested in on personal as well as academic levels. My personal experiences with mainstream healthcare in the U.S. and the current state of both my well being and the well being of those I love, in connection with my politics regarding healthcare rights, are driving forces behind my investigation of resources outside of the mainstream healthcare system, and for framing them as resistance. There is no objective or apolitical scholarship or knowledge, and “neither one’s theories nor one’s methodological tools are benign” (Urban 2008, 6). I strive to remain critical and transparent about this reality and the subsequent impact on my work (Reinharz 1992, 232). Humboldt County residents, myself included, like so many other US residents, employ many resources that are outside of the scope of mainstream healthcare. I’ve chosen to look closely at patient navigation because of my own experiences as well as my connection with the Humboldt Community Breast Health Project throughout the duration of my thesis work, both of which I describe in the sections to follow. In this research, patient navigation serves as one lens to highlight how resources can be assessed and employed as a form of resistance to the dominant medical paradigm in the United States.

In this chapter I outline my theoretical and practical approach to research as *epistemology, methodology, and methods*. I contend that each of these are intrinsically interconnected and both co-constituted and inform one another. Naples argues, “The

specific methods we chose and how we employ those methods are profoundly shaped by our epistemic stance” (2003, 3). My chosen methodologies (or strategies of inquiry), and methods (or specific research tools) are shaped and refined through my evolving process and dedication to work within my own position grounded in my epistemological framework (or ways of knowing) (Kirk and Okazawa-Rey 2010, 52).

For organizational purposes however, I discuss epistemologies, methodologies, and methods in three separate sections, even though my intention is not to compartmentalize these elements or the discussion of my process. I discuss how my theoretical framework connects to my research in the epistemology section. Next I discuss the case study of the Humboldt Community Breast Health Project in the methodology section. Finally, I give descriptions of how my research tools informed the study of patient navigation client services at HCBHP and their overall work as resistance to an inadequate health care system.

Epistemology: Knowledge Production Informing Research and Research Informing Knowledge Production

Epistemologies describe theories and frameworks of knowledge, knowing, and knowledge production, and define who can know (Huemer 2002, 435; Kirk and Okazawa-Rey 2010, 52). Epistemological theories serve as tools for making sense of how one understands and defines truths, and how new truths are produced (Goldman 2002, 461; Hawthorne 2004, 26; Lakoff 1980, 179). In this section I explore the production of knowledge and hierarchies of knowledge, and work to disrupt hegemonic, or dominant, discourses about research (Kirk and Okazawa-Rey 2010, 53).

My research starts from a very personal place... I'm mad. I'm mad that the healthcare system in place appears broken for people close to me and for myself. I am mad that so many people face barriers to accessing quality healthcare. I am mad that major health insurance companies have the power to string me along, lie to me, and deny coverage that I am entitled to within my contract, and that I am left feeling powerless. I am mad that these same companies refuse to work diligently to make loved ones well, even though the means exist. I'm mad that big business gets to decide who is sick, who receives care, and ultimately decides the quality of your life and mine. I'm furious that these conditions are only a snapshot of the material realities of the mainstream healthcare system in the United States.

My goals and motivations are to join efforts at exposing, dismantling, and creating alternatives to systemic power relations in connection with accessing healthcare resources. "*We're not the ones who are broken. It's the model that's broken. The model of Western thought about bodies itself, and much more besides*" (Wilchins 2002, 34-5, emphasis added). My intentions are to expose tools that can be used to resist the broken system, and contribute to Intersectional Feminist and Disability Studies literature determined to disrupt and ultimately dismantle systems of oppression and inequality.

My theoretical framework for assessing resources as resistance is situated within Garland-Thompson's argument for the integration of Intersectional Feminist and Disability studies theories (2004), and Weber's argument for collaboration between Intersectional Feminist and biomedical paradigms (2006). My research is designed from an advocacy and participatory epistemology, and my own life experiences and

perceptions (Garland-Thompson 2004, 92; Naples 2003, 191). Intersectional Feminism calls for personal responsibility by turning the (Intersectional Feminist) lens inward to interrogate my position and how I am situated within and thus affecting the research (Brodsky 2003, 9). This process of self- reflexivity in research attends to the complexity of power relations, which is crucial in helping avoid reproducing systemic inequality, however unintentional such reproduction may be (Hesse-Biber et. al. 2004, 13). These approaches to research and knowledge production transcend disciplinary boundaries in dedication to non-hierarchical knowledge production and production of emancipatory knowledge (hooks 1994, 61). Self-reflexivity that interrogates and actively disrupts systems of power, privilege, and oppression should be part of any research. “Unequal power relationships between the researcher and the research participants serve to transform the participant into object,” or unequal “other” (Hesse-Biber et. al. 2004, 12). Self-reflexive research projects framed in an Intersectional Feminist lens focus on developing knowledge in ways that embrace the agency of the co-participant (i.e. not “research subject”), rather than objectifying people or positionalities. This type of knowledge production aims to resist socially constructed systems of power, privilege and oppression.

My aim is to consciously disrupt dominant research discourses that support the position that the only authentic knowledge is measurable or scientific (Kirk and Okazawa-Rey 2010, 53), and that ascribe to notions of researcher objectivity (Hesse-Biber, et. al 2004, 3; Urban 2008, 10). Positivism, the epistemic belief that the only credible knowledge comes from positive affirmation of theories through strict scientific

method and some other analytic epistemologies are hegemonic modes of knowledge production that work to “prove” or “disprove” ostensibly objective truths. Positivism positions ways of knowing into hierarchically dualistic categories: such as rational versus emotional (Hesse-Biber et. al. 2004, 12). Many feminists and other critical theorists critique this paradigm because one cannot be truly objective. That is, I cannot compartmentalize personal context and experiences and be separate from my context and experiences to fit the concept of *objective*. Positivism is both a reflection and an extension of the dominant mode of producing knowledge held by those who most benefit from system of inequality and helps to maintain unequal power relations (Hesse-Biber et. al. 2004, 11).

The Humboldt Community Breast Health Project does not self-identify with the specific theoretical language of any of the theories I have adopted or utilized in this project. The women I spoke with shared their personal perspectives on what the organization does and how they do it. Some participants referred to the “why they do what they do” as their personal philosophy, and others spoke in depth about their own experiences or perspective. These are the sentiments I refer to as one’s positionality. I regard positionality as my position grounded in my identity- both personally adopted and socially produced, and simultaneously privileged and oppressed (Kirk and Okazawa-Rey 2010, 56; Sterk and Elifson 2004, 134; Urban 2008, 10). My own understanding of ways of knowing and of knowledge production is contextually based and conceptualized from my own experiences. My epistemological framework for this research is the product of my own experiences and personal worldviews, which I cannot separate from myself

(Tutty et. al. 1997, 65), in connection with my understanding of the integration of Intersectional Feminism and Disability Studies.

I don't think an organization or person is innately more valuable because of *self identifying* as Feminist or Intersectional Feminist, or Disability Studies and Intersectional Feminist, in order to work actively against systemic and systematic socialized modes of hierarchy (Kirk and Okazawa-Rey 2010, 15). HCBHP is an organization grounded in integrity, commitment, dedication, and love, and for me embodies an incredible and valuable organization providing critical services. Employing an Intersectional Feminist understanding of knowledge production aided me in assessing the potential power imbalances that could likely exist in my research design regardless of my methodological choices (Naples 2003, 197). To this end I actively refused the position of researcher authority and expert (hooks 1989, 46). Rather I addressed the research as a learning process for myself (Fernandes 2003, 84), and worked to recognize and meet the needs of my co-participants (Brodsky 2003, 12).

Methodology: Strategy of Inquiry

Methodology is theory and analysis of how research should proceed (Hesse-Biber et. al. 2004, 15; Kirk and Okazawa-Rey 2010, 53). My methodologies are the ways I interrogate, assess, and explore the problems I have defined through Intersectional Feminism and Disability Studies. Methodologies are the acts that inform my processes and provide specific direction for procedures in my research design. The feminist mantra "the personal is the political and the political is personal" (Thompson 2010, 44), is true

on many levels of observation for my research because I am affected personally, the politicized nature of healthcare in America today affect the lives of so many socially marginalized people, and because personal acts of resistance serve as catalysts for political change (hooks 2000, 11; Daniels 2008, 97; Schulz et. al. 2006, 371).

I took a participatory position in my preliminary field research in order to collaborate with my co-participants in the ways Garland-Thompson and Weber argue for, and to participate in the creation of knowledge from many directions. I invited and encouraged my co-participants to inform the direction of the research. My methodology overall was designed from my participation with the Humboldt Community Breast Health Project and my process of coming to identify their services, specifically patient navigation services, as resistance. This approach, coupled with specific and deliberate methods, framed and resulted in the case study and subsequent analysis of this research. I take Sterk and Elifson's epistemological approach to case studies, "Case studies are not a data gathering technique, but rather a methodological approach incorporating multiple methods, including interviewing, observation and document [analysis]" (2004, 142).

My collaboration with HCBHP for the purposes of this research was a relationship of community and academic collaboration (Stoecker 2005, 13). The goals of my community-based research design aimed to,

- facilitate collaborative processes,
- integrate knowledge and action for mutual benefit of all partners,
- promote a co-learning and empowering process,

- and disseminate findings and knowledge gained by all participants (Blumenthal and Yancey 2004, 16).

I became familiar with HCBHP's client services framework and approach to patient navigation first as a volunteer grant writer. My research design and framework for collaboration grew from this angle. For the context of my case study, distinguishing between which knowledge I had about HCBHP as a result of "research", and which knowledge was derived from my experiences within the organization as a volunteer was difficult. I gathered much of my information about the organization from their internal records and personal testimonies of staff and volunteer people while doing my own volunteer work. My research and work as a volunteer grant writer informed much of this study. For the purposes of grant writing I wrote from the point of view of the organization. In this sense I learned the story and the history of the organization and did my best to represent an insider's position. While I do assert my association with HCBHP in my community and worked in collaboration on this research as an ally to the organization, I feel as though framing the discussion by speaking about HCBHP as "they" rather than "we" is most appropriate, and have written the case study from this point of view. Additionally, the HCBHP is a grassroots organization and there is little published research about them at this time, and thus citing sources in traditionally academic guidelines was challenging. Within the context of this case study I give appropriate citations for information from direct interview quotes, and official documents. In all other cases the information contained herein was obtained through my exposure and involvement with HCBHP as both a volunteer and a researcher.

I sought approval from the executive director on my research design and collaboration ideas. Other staff members and the board of directors were also consulted about my research intentions, and I moved forward with gathering data specifically for my case study only after I had received permission and enthusiasm from the organization. Key members of the HCBHP agreed to review my work and provide feedback before this research was made available to the public in order to protect the privacy of the organization and clients, and ensure that my representation of HCBHP was accurate. This process aided in my methodological framework of collaborative knowledge production, but also assured that I hadn't included any information that I was privy to as a volunteer grant writer, but may not have had the same level of access to as a researcher. Next, I describe the specific methods I employed to shape the case study of the Humboldt Community Breast Health Project.

Methods: Tools for My (Intersectional Feminist) Belt

My research is first and foremost grounded in participatory observation because prior to when I was “doing research” I was merely living in my own skin as a person affected by and interacting with the mainstream medical industrial complex. One method of gathering knowledge is not necessarily better than another (Hesse-Biber et. al. 2004, 11), and I’ve employed a mixed-methods approach to suit my epistemological and methodological frameworks. “Qualitative inquiries seek to develop a complex and holistic understanding, often based in the natural setting, from the perspective of the [research] participant” (Sterk and Elifson 2004, 134).

My preliminary exploration of resources and resistance stemmed from conversations I had with Humboldt Community members framed by the Community Conversation guide for assessing health care needs in this country, distributed by the Obama Administration in December of 2008. I conducted ten exploratory conversations using this questionnaire, and the themes that came up most frequently were *restricted access to healthcare* and *challenges navigating the healthcare system*. I intentionally framed my “interviews” as conversations so to work against systemic power relations of researcher as expert, and disrupt hegemonic politics of naming.

I began my volunteer grant writing position just as these preliminary conversations were wrapping up. The grant research I did was informed by in depth conversations with the executive director, and focused on understanding the history and operation of HCBHP, and specifically of their patient navigation program. The executive director and I met approximately every two to three weeks for a four-month period. Our conversations generally lasted one to two and a half hours, and were initially informed by the grant proposal requirements, and later by the document we had produced. Though the executive director was the person I worked most closely with during that stage of my research I also connected with several other staff people and volunteers.

The grant writing research process was also heavily informed by documents I received from HCBHP, including other grant applications, annual reports, brochures and other print materials meant for publicity and outreach, newsletters, and website content. The information I gleaned from this process became the foundation for the case study chapter that follows.

Once I had an agreement with HCBHP and a plan to feature their organization in my thesis research as the example of local resources as resistance against an inequitable healthcare system I shifted the focus of my research design. I had in depth conversations with staff members, which I set up directly through the organization, and with former clients with whom I was previously acquainted from the community. Conversations took place at the HCBHP office, and in the homes of the women I interviewed, and generally lasted close to two hours. I sent my conversation guide, (APPENDIX A), and abstract out to participants via email prior to our conversations. I took a semi-structured approach to these conversations to promote collaboration during conversations, and because I already had access to all the information required to write a grant to support their patient navigation program. I began each conversation by referencing my interview questions and asking the participant to share the information she thought to be most pertinent to the study. “The assumption underlying semi structured interviewing is that the study participants are knowledgeable, have a meaningful perspective to offer, and are able to make this explicit in their own words [and the researcher] is an active participant” (Sterk and Elifson 2004, 137). This approach resulted in rich and detailed accounts of HCBHP and the operation of patient navigation and other client services in the lives of women surviving with breast or gynecologic cancer in a climate of inadequate healthcare. All conversations were recorded with participant permission, and later transcribed and coded by theme. I have preserved the depth of these interviews in the case study chapter by integrating much of the participant’s original language with my own narrative about the organization.

Additional information for the case study comes from document analysis of reports about the study area by the California Center for Rural Policy, a local health research group, and the local American Cancer Society. The bulk of the statistics provided herein are from these two sources. Findings and results were developed as a continuing and fluid process during the course of this research, and results and findings were discussed often with partners at HCBHP.

CASE STUDY

I first learned about the Humboldt Community Breast Health Project when I began looking at access to local resources as resistance against a failing National healthcare system, and thereafter found myself continually drawn to HCBHP's model and their work. In this chapter I discuss how I came to be associated with HCBHP, which I will often refer to as "the Breast Health Project" or simply "the Project" to keep in sync with the women who are the organization, their mission and history with specific focus on the Project's patient navigation model and services, and the ways this model supports my theoretical claims about resources as resistance.

Imagine a community resource where women have the opportunity to access free mammograms, pap tests, and colonoscopies, where there is a genuinely safe place for those faced with a breast or gynecologic cancer diagnosis or concern to seek support and answers in their rural community classified as a medically underserved area (US Department of Health and Human Services; California Center for Rural Policy), and where a small community bands together to raise upwards of \$150,000 annually to keep the doors to this important place open (HCBHP 2009). This place is the Humboldt Community Breast Health Project in Arcata, CA, serving the communities of Humboldt and Del Norte Counties since 1997. I may sound as if I am romanticizing the organization. In fact, I am overjoyed that such a model of success and care exists, and the women and community members who comprise the Breast Health Project deserve praise and recognition beyond what I am capable of. In my nine months of document

analysis, participant observation, action research, and in-depth interviews I have learned of an organization of exemplary vision and action.

The combined population of Humboldt and Del Norte counties, on the far northern coast of California, is fewer than 200,000 people. The rural area is geographically large, as well as isolated. The nearest metropolitan area, Redding, is 140 miles away to the East, and it takes nearly three hours to travel there on a slow and difficult road, with access subject to weather conditions. The metropolitan area of Santa Rosa is 225 miles and a four-hour drive, and San Francisco is an additional hour to the South from Santa Rosa. Approximately 20% of the population in Humboldt and Del Norte counties are low-income as opposed to 12.5% of the population for the state of California, and 13.1% for the nation (California Center for Rural Policy). According to the California Center for Rural Policy's report *Rural Poverty and its Health Impacts: A Look at Poverty in the Redwood Coast Region*, low-income community members are significantly less likely to have received a Pap test or breast cancer screening compared to non low-income community members. All parts of this service area are designated as Medically Underserved (MUA) and Health Care Professional Shortage Areas (HPSA). Medically Underserved Areas are characterized by the percentage of population below poverty, percentage of population age 65 and over, infant mortality rate, and primary care physicians per 1,000 population (US Department of Health and Human Services).

Humboldt County has the highest age adjusted death rate for individuals diagnosed with breast cancer in the state, at 39.3% (CCRP 2009). The Breast Health



Figure 1. Map of California counties (California State Association of Counties Website)

Project's perspective is that this reality may reflect the disparity in medical care accessible in an isolated rural area, lack of insurance, misunderstanding and mistrust of the medical system that exists with many of the most rural populations, poverty, transportation factors, cultural barriers, and late detection as the result of a myriad of

other unknown factors. For women of all races, Humboldt County is one of eight with the highest incidence of breast cancer per capita for the state of California. Since 1995, breast cancer has been the leading malignancy diagnosed in the county (CCRP 2009).

There is currently no gynecologic oncologist in HCBHP's local service area. Not only must women travel out of the area to see a specialist, but also clients often have acute needs because of late diagnosis. This is especially troubling because the invisible nature of gynecologic cancer results in late detection for many women. The area's lack of specialists and resources is compounded by financial limitations and cultural barriers to care that affect many of HCBHP's clients. This data is astounding, and the Humboldt Community Breast Health Project works to meet the needs of the women who are represented in these statistics.

HCHBP and Community Relationships

I saw a woman wearing a sandwich board advertising a dream vacation raffle to benefit breast cancer one Saturday afternoon during Spring 2009 at our community farmer's market. I approached her because breast cancer is a cause that I often reach into my pockets for, and I wouldn't mind a dream vacation, but also with the motive of learning about local resources to health, wellness, and illness prevention. I spoke with her for a handful of minutes, long enough to buy raffle tickets and know that HCBHP was an organization that I absolutely had to follow up with for the purposes of my

research⁴. Shortly after that initial exposure I found myself at the same lunch table with the Project's executive director at a training for community healthcare providers and affiliates. At this meeting I came to realize that HCBHP embodies "what I was talking about". I was looking for local models of resources and services available for community members to help people become their own best medical advocates and to serve the *needs of people* without equivocation. These sentiments are written into HCBHP's mission statement and embodied by the organization's close to 200 volunteers and tirelessly dedicated staff people.

I worked with the Breast Health Project as a volunteer grant writer in the fall of the same year, and came to understand what they do and why they do it on an intimate level. These are the experiences that I use to frame my case study of the Humboldt Community Breast Health Project, the work that they do, their commitment to women and their support people in our community, and their long term dedication to working within a broken healthcare system for patient centered and socially equitable change.

A significant amount of community support and dedication is required to keep services free of charge so that *every* woman can access the services and be supported in becoming her own best medical advocate. In 2009, 3,900 volunteer hours were recorded and an estimated 89 of the 318 volunteers on file were seen regularly. One volunteer patient navigator, a retired nurse and breast cancer survivor, explained her perspective on how my research could be of benefit to the Project and to equitable resource access,

⁴ I didn't win the dream vacation but I will try again this year and in following years. To buy your own raffle tickets please visit HCBHP's website at www.hcbhp.org.

I think it's always beneficial to have these conversations. Everyone you have talked to about your research has had to think about these issues, and everyone who reads this research will think about these issues. That's where the real benefit lies.

The director of client services at HCHBP is an RN, and also a breast cancer survivor.

She reflected on how this research can be used to give back to the organization,

"Anything that you can learn about us that gives us access to keep the door open so that women can continue to come through it is beneficial."

In keeping with my commitment to horizontal collaborative knowledge production, which is inclusive of my dedication to acknowledging my own researcher subjectivity and working with HCBHP to represent the organization's own framework I will first allow the organization to speak for itself in telling their history and story. The following are the mission, goals, and guiding principles, as framed by the Breast Health Project.

HCBHP Mission

The Humboldt Community Breast Health Project (HCBHP) is a grass roots organization of cancer survivors and support people providing information assistance services to those facing a breast health concern or a diagnosis of breast or gynecologic cancer. Our vision for our community is a seamless network of community support which includes medical providers, hospitals and other community organizations willing to offer the human hand to promote health and healing (HCBHP website).

HCBHP Goals

Our goals are to:

- Offer healing support and advocacy enabling you to become your own best medical advocate.
- Provide up-to-date and comprehensive information about breast health concerns and breast or gynecologic cancers.
- Support communication between you and the medical professionals providing your care.
- Create opportunities for you to further your own healing by volunteering to help others facing the upheaval of cancer (HCBHP website).

HCBHP Guiding Principles

- Kindness is our core value.
- We value the individual process; we nourish hope; we witness our priorities and challenge each other toward growth while making room for uncertainty and the transformation of suffering into wisdom.
- We promote healthy survivorship through honesty in our presentation of information.
- We seek to reduce unnecessary suffering, fear and trauma. We honor each client's process and choices with individualized care and respect. We listen and respond with compassion.
- The experience of wanting to be cured is equal in importance to the need to be healed and informs all that we do.
- We blend patient advocacy and the wounded healer⁵ model. We acknowledge and share our personal woundedness and experience. We witness the possibility of wholeness and create the opportunity for clients to wonder and to realize their innate healing abilities.
- We value each person's unique story.
- We commit to remembering our grassroots origin with the opportunistic expansion of our services. As we bring together the grassroots and institutional energies, expertise and compassion, we truly create a network of treatment, support and healing.

⁵ The wounded healer paradigm, first used by Carl Jung, holds that deep within each healer lies an inner wound, which plays a significant and essential factor contributing to healing the patient, with healing benefits for the healer as well (Miller and Baldwin 1987: 141).

HCBHP Guiding Principles continued

-We are dedicated to achieving a higher service standard of care by redefining the patient experience of breast and gynecologic cancer to one which supports health and healing.

-We collaborate with other organizations and healthcare providers to build upon each other's strengths in order to make the most effective use of our resources.

-We value the therapeutic relationship by serving as a resource of support to the medical community.

-We provide an atmosphere of hope and healing through an environment which is safe, warm, and welcoming.

-The open circle is our structure. Our circle is ever-expanding, invites others in, and is capable of letting go when friends feel the need to move on.

-Though we focus on breast health and breast cancer we provide access to information and support to all.

-We seek to identify barriers to care and to equalize access for all.

-We are committed to keeping our services free.

-We endeavor to live and to serve consciously in the present moment (HCBHP website).

HCBHP's Grassroots

In 1997 Dr. Julie Ohnemus, a local family practice physician, was diagnosed with breast cancer at the age of thirty-six. Dr. Ohnemus found insufficient resources to address her diagnosis in this isolated rural community. She received some of her treatment at Stanford's medical center, and she found something else in the Palo Alto area she considered invaluable- an organization of breast cancer survivors offering services of support, information, and guidance. Dr. Ohnemus brought the vision and



Figure 2. Humboldt Community Breast Health Project office

purpose of the Palo Alto project, called the Breast Cancer Connection⁶, back to Humboldt County and women with breast cancer in this local community began to come together in processes of healing and surviving, molding the Project to suit the unique needs of women in Humboldt and Del Norte counties. The Humboldt Community Breast Health Project in its current form is the product of that network of survivors. At the time of this research Dr. Ohnemus serves on the Board of Directors for HCBHP.

⁶ See the Breast Cancer Connection's website for more information at <http://www.bccnections.org/>.

The Breast Health Project promotes healthy survivorship through education, healing support, and hope. HCBHP works to encourage and enable each person to become their own best medical advocate. As survivors of breast and gynecologic cancers they heal through service and bearing witness to others, a framework grounded in the Wounded Healer model. The organization challenges the community to address breast and gynecologic health concerns responsibly and holistically.

Since 1999 the Project's volume of clients has continued to grow every year with the largest increment of new clients seen in 2008 (up 27% from 2007) (HCBHP 2009, 3). The organization is client centered and comprised of survivors, offering support and care from those who have "been there." One client said:

If I was destined to get cancer, thank God I moved to Humboldt County first. I could never have gotten through the utter terror, remained brave for my kids, read the dizzying amount of information, or learned how to really talk to my doctors without HCBHP.⁷

The kind of compassion and devoted attention that volunteers and staff offer women who walk through the door with a breast or gynecologic cancer diagnosis or concern is "job one" at the Breast Health Project because the volunteers and staff know from their own cancer journeys what is most necessary for women who are overwhelmed and fearful. The testimonies of client, turned volunteer, turned staff member speak for themselves,

When I arrived at the Breast Health Project, it was maybe 10 days or so after I was diagnosed- that was the first time that I felt safe since I had heard the doctor say 'I'm sorry to tell you, you have breast cancer and its the bad kind.' I came through the door and the woman who greeted me was a volunteer, and she did not say, 'what is your diagnosis, what's your

⁷ This quote is from HCBHP's archives, not from an interview I conducted.

insurance,' she didn't ask me anything. She said 'congratulations on finding your way here.' It was just stunning to be received in that way. And I got through the door and I will never forget it. They had a little blue futon and I saw that couch and I had an overwhelming desire to lie down and go to sleep, that sense of having arrived in a place of being safe. I remember the feeling very well. She listened to my story. She basically said 'tell me what brought you here,' and she didn't ask anything else of me. I was really in control of what I wanted to share, and what to ask, and she was very well informed and gave me a lot of information and showed me the library and told me what the resources were and told me when I could meet Julie Ohnemus and it was just fabulous. I left and had several other appointments later that day, and when I got home there was a package waiting for me on my front door. It was from that volunteer. She had spent time photocopying information about my particular type of breast cancer and had delivered it. For the second time in a matter of only a few hours I felt as if I was indeed safe.

This sentiment of security is not an anomaly. Another client said,

When I learned about my breast cancer diagnosis I called the Breast Health Project, and the woman that answered the phone- a warm liner⁸, said, 'Welcome to the sisterhood', when I told her what I was calling about. When I heard her words I felt this big warm hug come across the phone. It was so wonderful.

Women mainly utilize HCBHP services, though some men face breast cancer concerns, and some people who are faced with a breast or gynecologic cancer concern or diagnoses may identify as male. The Breast Health Project has provided services for men who have breast cancer. Family members and support people of woman clients also access services for information, support, and community, in order to be better allies to their loved ones during the cancer process, and also when loved ones are lost to the battle.

⁸ HCBHP uses the term *warm liner* to refer to survivor volunteers, who answer what is traditionally referred to as a "hot line", and to greet and assist drop-in clients.

Though the Breast Health Project's primary service area is Humboldt and Del Norte Counties, in 2008 15% of their clients diagnosed with breast cancer were from out of our area. One HCBHP staff woman reflects,

Our service area is Humboldt and Del Norte and we try to restrict to that but we have trouble saying 'no'. And because our resources are limited we are trying to be better about that, but we aren't great. For instance, when a woman calls from Ukiah [Mendocino County, south of Humboldt County] and she needs something, and what we have is not available where she lives its really hard to say 'sorry'. So I end up doing a fair amount of consulting by phone and by email, and it makes such a huge difference. That little bit makes such a huge difference to someone who doesn't have access to the type of services we offer.

The current economic climate is straining HCBHP clients as well as the Project's capacity to meet their needs, but the doors stay open, at the sacrifice and dedication of volunteers and staff people. I haven't heard anyone at the Project use the word *bereavement* in the description of their position, but the task is a part of their experience and their labor of love. As one staff person noted, "*a lot of those women that I have cared about have died, so I've been to a lot of funerals and I held lots of grieving family members hands, and sat with a lot of spouses after their women have died.*"

While the Breast Health Project aims to serve all women who walk through their doors, they have three target populations: Latinas, Native American Women, and rural women. The communities of Humboldt and Del Norte include a six percent Native American population and a growing eight percent Latino/a population according to the US Census Bureau, though these numbers are projected to be higher as this research is taking place during a census year. HCBHP faced budget cuts in the recent economic downturn. In an effort to keep client services available they were forced to make the

difficult decision to suspend the funding for Latina and Native American outreach. The Project strives to hold onto its programs because they understand the importance of removing obstacles for women in their community.

The director of client services shared with me how the Latina outreach operated when there was a funded position and how the Project works to still meet Latina patient needs to the best of their ability with their current resources,

Our Latina Outreach Coordinator did an amazing job at reaching the Latina population and really removed a lot of obstacles to get those women in for screening and those who were diagnosed in for treatment. Going through the cancer journey is hard enough but not speaking the language- it's really a nightmare, and she worked so hard to ease that for Spanish-speaking women. We would have to sit together because I had to give the medical information and then she would translate. It was really great working with her. Both of us feel so much pain over not being able to be in that community anymore because they need us, but we don't have the money, we are contracted down.

When asked how HCBHP continues to serve the needs of the women from the Latina community who come through the doors now that the outreach coordinator position has been cut, the staff member responded,

The outreach has stopped so the referrals have stopped. [The coordinator] would go to a lot of health fairs and go to the churches, and make connections and a lot of women came in that way, well that's not happening anymore. Now it's harder for women to know about us and harder for them to have the courage to call. But we set up an extension so that they get transferred to a message right away that [the coordinator] put on the machine that is entirely in Spanish and tells them what to expect, and that they are to leave their phone number and a Spanish speaking person is going to call them back. So then I get that message, and I have two Spanish-speaking volunteers and I contact them with the number. They call and give them information and then the volunteer and I go back and forth with each other about how to handle the case, but its so much more cumbersome and takes so much more time. And having someone on the staff is entirely different; you can really make headway that way. [The

coordinator] is a person who cares a great deal about fairness and justice in a lot of arenas of society, and she was a tremendous advocate for Latinas.

The local physician who does the mobile medical unit referred a lot of women here. Several women who live in Fortuna/Ferndale area who are survivors themselves and are connected in the Hispanic population down there are doing their own outreach- at church, at the grocery store, wherever, but in a less formal way. It still does go on, but the number of women who we are serving has gone down. Also, we have a good relationship with the local Spanish language newspaper, El Heraldo, and I've written a lot of articles and they've been translated into Spanish and printed in the paper. We buy ads during the awareness campaigns of September (gynecologic), October (breast), and January (cervical). There is still a very high rate of cervical cancer in the Latina population so we definitely put some of our resources toward that in January and we do have some community support with that effort.

Though budget cuts were close to 50% in the last two fiscal years the organization has stayed close to its roots and its commitment to maintaining client services, with the generosity of community members and the dedication of many supporters to work in volunteer capacities when laid off from paid staff positions as a result of the cut backs (HCBHP 2009, 2). I spoke with another volunteer about her changing roles at the Breast Health Project,

I received the support as a client, and after a year I was asked if I wanted to become a warm-liner, and then a staff position came open, and I did that. But I got laid off a year and half ago and I just kept coming in- but I still come in as a nurse, not just simply a warm liner- my job hasn't changed, but I just don't get paid anymore. We [HCBHP] fell on hard times, I don't work as many hours as I did when I was paid, but I like what I'm doing, so I'm still here. There is a certain strength that comes with being a grass roots organization, we have almost 200 volunteers- some people only knit hats, but there are almost 200 people who put some of their time, and many, many more people who put their money in.

In 2008 68% of the Project's revenue was generated by special community events, donations, and raffles (HCBHP 2009, 4). The 7th Annual Vacation Raffle raised a record \$81,169, and the 5th annual Sales for Survivors included 24 businesses and raised \$5,728. Combined concert and speaking events raised an additional \$26,119. The Project also manages a special project, the Angel Fund, of private donations restricted specifically for use by clients in need of food, gas, transportation, and other specific needs. These fundraising efforts are impressive to say the least for a grassroots organization, and are critical to continuing to provide client services and patient navigation as major grant cycles come to an end. Regardless of community need and the successful track record of HCBHP, grants are less easy to secure in the current fiscal climate in the U.S. Nonetheless HCBHP patient navigation services have not gone away.

Patient Navigation Model and Client Services at HCBHP

The primary goal at the Breast Health Project is to ensure that every woman in the community has equal access to quality healthcare and has her needs met. Client services, including patient navigation, are the tools HCBHP employs to help their clients access quality care. One woman aptly stated, “*‘Quality’ can be defined a lot of ways, but I think it means you treat people with dignity, not that you have designer furniture in the waiting room.*” HCBHP operates as a drop-in center and a safe place for sharing. The long list of services the Project provides include patient navigation, medical consultation planning, support groups, an educational newsletter, community-wide outreach and education about early detection and breast health, a resource library, prosthetics and wigs, and

individualized information searches including financial referrals. The Breast Project's peer patient navigators (survivor volunteers) operate a warm-line, serve as support "buddies" to clients matched by diagnosis, and can accompany clients to doctor's appointments. To address the inadequacies of mainstream health care the Project remains committed to providing services free of charge to women who may otherwise feel alone as they face a cancer diagnosis. One woman described why her personal need for the information and support she received from the Project were essential to her process,

When I was diagnosed something happened in me, like all my dominos rearranged and I could not access my intellectual self, so all that experience that I had in medicine was of no use to me at the moment and I was overwhelmed with fear. And I needed desperately to get access to information. When I finally did get access to the information, it truly was for me the antidote to the fear and it helped me to settle down and think through my situation, and for me to make really good decisions that were based on accurate information and weren't just fear driven.

Another woman said,

I remember looking at the doctor's face and I could see his mouth moving and all I could hear was a roar, this huge roar, I mean I really perceived what seemed to be a sound that drowned out all the words. Now I realized later that I actually did absorb some of what he had said but I didn't perceive it as a speech. My entire visual field was rotating, like a big pin wheel, but that's the physical reaction I got that really interfered with being able to hear or even see properly, so I'm really aware, I have an awareness of what people are experiencing. Some people need to hear it again and again before it really registers. That's what the Breast Health Project can do that a busy oncology office cannot- take the time to sit and be sure the client can access the information on her terms.

Women who do not have the background necessary for understanding the complexities of their diagnosis and treatment options are at risk for less than optimal outcomes. HCBHP

seeks to identify barriers to care and to equalize access for all. The Project strives to improve access to information and support for underserved communities by identifying and overcoming economic, geographic and cultural barriers relative to clients' breast and gynecologic healthcare. A staff person explained,

The level of education a woman has plays a serious role in access to both information and resources. Can she understand, for instance, the statistics that are involved in survival rates, and when she had to weigh her options and risk versus benefit can she understand all of that? Our experience is that a lot of rural women just gloss over those aspects while you are talking to them about it because there is nothing for it to land on. So those women really need a place like the Breast Health Project where someone has the time to sit with them and go over it until they really do understand and are making an informed decision, because without understanding its not informed consent.

Women in the area are faced with myriad obstacles to accessing equitable quality care. Often those facing a cancer concern and other chronic illnesses are inflicted with a debilitating sense of fatalism. Clients who walk through the doors are offered a cup of tea and compassion.

The most important thing is to listen to her story, and when she is finished ask, 'is there anything else you want to tell me about?' and really take that witnessing to the deepest possible level so that she feels really seen and really heard. One of the obstacles or barriers to healing in the traditional medical model is that the specialists are under so much pressure- time pressure, financial pressure, etc, and they have so much responsibility of what they have to accomplish in such a short time that its impossible for them to be with the whole person because we are all so complex.

HCBHP considers their definition for Patient Navigation as narrower than other organizations' definitions. The Project defines patient navigation as removing obstacles that might be in the way including financial, educational, or something as simple as how to communicate with a busy oncology office. At the Breast Health Project patient

navigation means helping each woman to be her own best medical advocate. All clients receive support and follow-up from the Project's staff and volunteers, but the client's needs are the center of her treatment.

We don't do it for them, that's not what navigation is for us. It's very rare that we will call a doctors office on behalf of a client. For some people even to know that they have a right to question or to ask, and to think about how they are going to instill that right changes their experience in a positive way. We want clients to think of treatment and recovery as a team thing and they are the center of the team.

In some cases survivor volunteers are also nurses by trade and do actual medical navigation, though other survivor volunteers do not operate in this specific role. Though not an official requirement, HCBHP prefers that nurse patient navigators also be cancer survivors.

[Nurse patient navigators] who have survived cancer can use their own experience, their own wound, to relate to the fresh new wound of a woman who comes through the door for services, and that really heals. Once one goes through treatment and recovers, and then chooses to become a patient navigator or warmliner- that's the wounded healer model at work. We [nurses] do it because we are bound to the Project. The process is transformative, and the wounded healer model goes the whole cancer continuum of care. We all live with that uncertainty about remission. Staying connected [to the project] helps to ease that.

HCBHP services also include: free wigs and prosthetics donated by the American Cancer Society and local people and stored in an area called the “Amazon⁹ Breast Nest”,

⁹ It is said that the Amazon warriors of Dahomey have their right breasts cut off to make themselves more efficient archers (Lorde 1980, 34).



Figure 3. Wigs, breast prosthetics, and other client resources at HCBHP



Figure 4. HCBHP's Amazon Breast Nest

care packages called chemotherapy kits in bags hand-painted by volunteers, medical record binders, and warm hats and socks sewn and knitted by volunteers. In 2009, 34 chemotherapy kits and 49 medical record binders were distributed. One client shared her thoughts about the sock and hat projects, “*The socks were great. They appeared as a brightly wrapped package just as I was going into surgery! My aunt loves her chemo hat.*”

HCBHP’s navigation process is informed by their client’s needs reflected in the four support groups, and one-on-one consultation and navigation sessions. Currently the Project facilitates four support groups; advanced disease support group, gynecologic cancer support group, breast cancer support group, and Amazon Writers, a peer led group for survivors who want to explore writing as a path to healing. A total of 588 combined support group attendees participated in 2009. Forthcoming research by my colleague Laura Atkins explores how social support is connected to the healing and coping process and how support groups are also integral to the exchange of information. Her findings come from in-depth interviews and surveys from clients of the Breast Health Project.¹⁰ One staff person I spoke with reflected on her experiences participating in support groups,

The most important thing that happened to me during my cancer journey, besides being welcomed when I first arrived at the Project, was attending the support group, and the reason it was important was because the other women were role modeling for me how to do what I had to do. So the night before I had my first chemotherapy I was at the group and the

¹⁰ To access Laura Atkins’ research, *The Humboldt Community Breast Health Project: Social Support among Women with Cancer*, go to <http://humboldt-dspace.calstate.edu/> and search Laura Atkins.

woman sitting across from me had just finished chemotherapy and radiation and her hair was starting to grow back, she had this wonderful head of curls and I remember looking at her and thinking, ‘What I have to do- well that’s what it looks like, its not my worst fears, its not what I’m imagining.’ To just have someone point the way just by being present, not to mention that she was alive, so this fear that I had that this diagnosis was a going to be a death sentence- every woman who walked in front of me proved to me that it wasn’t. So I came to the support group the whole time, then I finished my treatment, and recovered and I realized that the only way for me to really express my gratitude for what had been done for me- because the services had been offered to me at no charge, and I mean I could write a check and make a donation but that wouldn’t even touch the way I felt about it- and so I decided the best way to show my gratitude was to come back and be a volunteer and be one of those women who would point the way for the women who would be coming behind me.



Figure 5. HCBHP living room

In 2009 the Project served 201 new clients and reported a variety of referral sources including medical offices, agencies, family/friends, outreach events, media, and print materials/brochures¹¹. Based on information from the American Cancer Society, HCBHP estimates that they saw 87% of the 79 new cases of breast cancer in Humboldt and Del Norte counties in 2009, and 70% of the 110 new cases in 2008. Based on the American Cancer Society statistics, in 2008, the Project estimates they saw more than 50% of women with gynecologic cancer. The American Cancer Society estimates 30 new cases of ovarian and cervical cancer (the two most commonly diagnosed of the five types of gynecological cancer) in our area each year, and the Breast Health Project saw 25 women diagnosed with any of five types of gynecologic cancer. These statistics carry the weight of a double edged sword, because on the one hand they reflect the grim and unfortunate rate local women are diagnosed with the disease, but on the other hand there is solace in knowing the Breast Health Project is able to reach so many of those people to assist with access to care that they need with the least amount of trauma. Individualized sessions with HCBHP nurses helped 31 women prepare for decision-making prior to important medical appointments.

The organizers at the Breast Health Project know that the patient navigation program and other client services are critical for providing clients with equal access to quality care. Patient Navigation has been an integral component of the HCBHP mission since the organization's inception in 1997. Over half of the Project's clients need

¹¹ At the time of writing the 2009 annual report is forthcoming, and will be available on HCBHP's website.

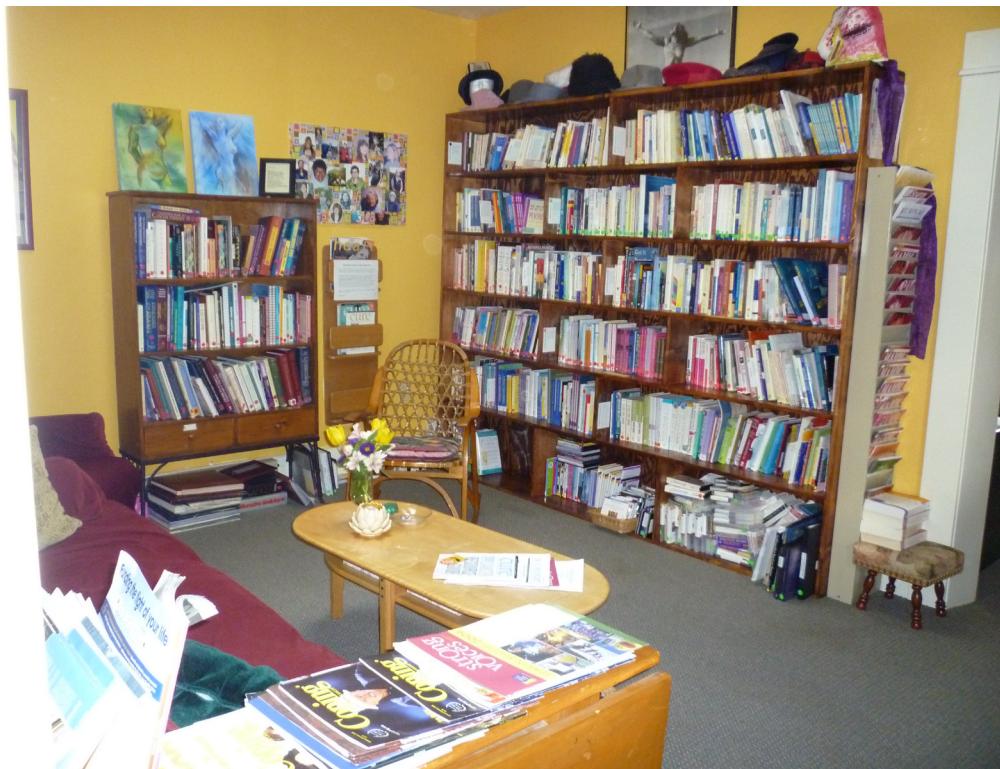


Figure 6. HCBHP resource library

information about financial resources to pay for their treatment. HCBHP assist clients in completing the appropriate forms and applying to a variety of local resources. Staff and volunteers educate and provide information in a kind, relaxed, and understanding atmosphere of care. The Breast Health Project is supplementing the inadequacies of the mainstream medical system, with a combination of first hand experience and compassion.

DISCUSSION

Humboldt Community Breast Health Project is an example of community resources as resistance to an inadequate healthcare system in several ways, and I feel as though I could have focused on any of their services to support my argument for a collaborative knowledge based health delivery paradigm. Patient navigation was the best lens for analysis because the basis of the model is patient centered and varies based on the specific needs of each person. The potential for patient navigation reaches beyond the scope of breast and gynecologic cancer and has important implications for patient autonomy and rights more generally. From an Intersectional Feminist Disability Studies approach patient navigation considers the whole person and does not compartmentalize any one socio-positioning of a person's entire social position. The relationship between patient and navigator disrupts traditional dichotomous power relations by design. Though the patient navigators at HCBHP are trained nurses, navigators can have different qualifications depending on the goal of the patient navigation program.

HCBHP: Resources as Resistance

The Project does not self-identify as an Intersectional Feminist organization nor do they claim to operate within an Intersectional Feminist and Disability Studies framework. Staff people wanted to be sure to learn all the details of my project well in advance to protect the integrity of the organization and wanted to be sure that I wasn't going to portray them within theories they don't ascribe to themselves. One of the many

reasons the Breast Health Project is an important and compelling study to support my arguments is because of their very client centered and grassroots structure. The framework of Intersectional Feminism and Disability Studies calls for a new approach to a bio-medical paradigm that without collaboration from other arenas fails to treat people holistically. Nevertheless, I contend that the Project's action on the ground, as well as mission, goals, and guiding principle, exemplify an Intersectional Feminist and Disabilities Studies based approach, and serve as an example of the work that can be done to resist systemic inequality in the realm of healthcare. A new and necessary paradigm emerges when knowledge and practice meet from multiple different directions and intersect. In my collaborative work with the Breast Health Project *resistance* was understood and defined in several ways. The women I worked with on this research defined resistance for themselves and framed their perspective of the HCBHP within the theoretical arguments they described for themselves, on their own terms. Some of the ways I report the Project resists unequal medical systems are from my own observation, and others are from the perspective of women speaking for the organization. The Client Services Coordinator reflected on her position,

Between the work that I do in the office with the consultation and navigation, and then facilitating the support groups it's a lot of relationships, and it's a lot of women, and it's a lot of caring. And I'm in this chair because of my professional background, but what I do arises almost entirely from my basic humanity.

Some of the ways client's and staff people interpreted and defined resistance were beyond what I imagined or anticipated, even after having worked as a volunteer. These

findings are a testament to the importance of collaborative knowledge creation, and justify framing my methodology as such. Two different survivor clients gave one particular example; as a way to support one another and endure the difficulties of radiation, the women in a support group would make a time race of getting in and out of radiation the quickest. These were stories told by women wearing smiles, and remembering fondly, as they shape their own meanings out of resistance, and defined how their experiences at the Breast Health Project can be understood in those terms.

Much like Lynn Weber discusses in her argument for promoting dialogue between Feminist Intersectional and biomedical paradigms, the Breast Health Project sponsors a program that brings healthcare professional specialists together with patients to sit down in the living room at the Project and level the playing field, or flatten the hierarchy that is often constructed between “experts” versus “patients”. This program, called Face-to-Face, brings in a different specialist every other month. Guests in 2009 included medical doctors with specialties in OB/GYN and oncology, a Breast Medical Specialist, an MD from North Coast Hematology and Oncology, a chiropractor from the Osteoporosis Center, and a registered nurse Certified Hypnotherapist. The requirements the Breast Health Project holds the specialists to are simple, 1) no white coats, 2) no ties, and 3) no formal presentations. Project organizers feel as though these requirements in themselves work to flatten the hierarchy that systemically exists between doctor (expert) and patient (victim).

The goal of the Face-to-Face program is for women to learn in an environment that is less stressful and intense than a doctor's office, and to do so in an environment where the power differential isn't so great. The organizing staff member shared,

We are just hanging out in the living room so [the women] get to see that this doctor "God" is just a person, they drive their car, they go to the bathroom, they are just people, and to demystify that whole thing about, "They have all the answers and you don't". Because in fact what a woman brings to the table in terms of her diagnosis and her treatment is something that science cannot measure, and its huge in terms of the outcome of her healing. And so what [the Face-to-Face program does] to strengthen women to be their own best medical advocates is say "No, no, he doesn't have all the power over here- you have a huge amount over here that he can't measure it", and that is really powerful. So lets name that and let's bring that up, and let's show that to the doctors, and lets balance things, lets level things. Its really, really successful.

Specialists are eager and willing to participate. Doctors share feedback that they enjoy participating and that they have learned from the process. They have the opportunity to begin to understand what a woman who has cancer actually needs aside from chemotherapy, radiation, and surgery. The process of healing goes far beyond the medical interventions that the guest specialists engage with in their professional work.

Another lens for understanding HCBHP's model as resistance to an inadequate medical system is their working relationship with the American Cancer Society to support and serve cancer patients in the community. The organizations collaborate to make the best use of their resources and to avoid duplication of services. American Cancer Society (ACS) offers web sources and transportation funds for patients to travel to appointments, as well as one support group per month for general cancer patients. The

American Cancer Society does not offer patient navigation services. I spoke with a client about her perception of the relationship between HCBHP and the local ACS,

Locally the ACS does not offer one of their programs called Reach To Recovery because we [the Humboldt area] have the services at the Breast Health Project. Instead the Cancer Society focuses their resources elsewhere and it has been a cooperative relationship. It really could have become an adversary relationship, and it's really a credit to all the people involved that it has not.

Although they may not use the phrase, I contend that the Breast Health Project continually engages in self-reflexive analysis. The sensitive nature of the services offered by the Breast Health Project and community impact make assessing their limitations and risks a crucial part of the organization's efforts, not least of which are challenges that arise from the current economic climate and the fact that the type of services offered are not covered by third party payers. Though one of the Project's guiding principles is to remain dedicated to keeping services free, the staff acknowledges that a time may come when services must be billed to insurance companies in order to keep the organization open. HCBHP's success and longevity, is in part, a result of the organization's willingness to be flexible. HCBHP's clients are their most important assets, and thus the risks and limitations of the organization's performance are best countered by actively and purposefully building their donor base among clients and supporters, as well as other creative strategies. For example, navigators help women access high-level quality care through free medical trials.

As previously mentioned, many clients volunteer after treatment, which strengthens the organization and also provides opportunity for further healing of the

survivor through their service to others. This model of survivors-helping/healing-survivors serves to support clients giving back to HCBHP in effort to sustain free services. Clients may become volunteers when they have completed treatment, and work as peer patient navigators, operate the warm line, provide “buddy” support, transportation, and can accompany clients to medical visits. Survivor volunteers work for public education, fundraising, and community outreach initiatives as well. In some cases volunteers are capable to guide patient navigation and assist with assessment through proper training and support from the Project’s expert personnel.

I’ve identified three ways that the Breast Health Project participates in role modeling, and argue that these roles are further testament to the Project’s use of resources as resistance against an inadequate healthcare system. The Project participates in role modeling in more than one way. First, role modeling happens in support groups and through the wounded healer model. Additionally the Breast Health Project has role modeled for other burgeoning organizations with similar visions. The Breast Health Project’s model for patient navigation can be utilized by other nonprofits working to address cancers and other chronic illnesses. There has been a demonstrated interest in the Humboldt community to replicate the Patient Navigation model that HCBHP employs, and the Project’s model can be successfully used in other rural communities as well. For example a local organization called Community Health Alliance has contacted the Breast Health Project to learn about their model, with particular interest to set a similar program up for people with diabetes, and there has also been conversation about setting something up for men with prostate cancer.

The Breast Health Project defines continued success of the organization through the services provided to women in need in the Humboldt and Del Norte community, and working with new clients. Based on the growing numbers of new patients the Breast Health Project has seen on an annual basis and the network of survivor and ally volunteers HCBHP expects to successfully serve women who walk through their doors. They measure success of their patient navigation program through client reports during support group discussions and also through the documentation and tracking of all navigation sessions with patients, which are compiled into monthly reports. Patient navigators are working with clients to develop materials for anonymous assessment of the patient navigator program. Clients are encouraged to take responsibility for learning how to negotiate their health needs and medical care including medical information and financial resources information.

One staff member spoke about her perception and experience of HCBHP's success,

Success is based on the energy, power and commitment of this small group of women who have been diagnosed with breast cancer who said, “it can be better than this” and “what is it going to take?” They got together and were driven by their own experience of the disease, and were driven and built it from the ground up, and for those of us who get better to come back and volunteer. And that’s what it takes. That’s where the energy to make something like this comes from. This is long-term relationship and it’s the relationship that creates the healing- the ability to stay present, to continue to witness while that woman goes on her journey. Continuing encouragement, support, and education is crucial.

As a process of this research I have learned about the necessary means to keep doors to the Breast Health Project open, and it happens largely with support from

community members, especially as government and corporate funders continue to tighten their purse strings. I frame this case study within a call to action to do work towards supporting community resources that are laboring to catch those of us falling through the cracks, or provide services to treat people like whole people, and strive to help people become their own best medical advocate- like the Humboldt Community Breast Health Project does.

The literature reflects that nurses and social workers are presumed to be the best fit for the role of navigators because it's basically what they are trained to do. Client centered communication skills are the most important aspect of patient navigation and set the model apart from other modes of healthcare delivery, or lack there of. The right person with the goal in mind and superb communication skills can be trained in the knowledge of resources and be successful at the job. Necessary requirements could include ability to work within boundaries, compassionate communication, and active listening. The Breast Health Project predominantly sets the bar for patient navigators to also have personal experience with cancer, though personal experience is not a requirement of all patient navigation models in general. Above all else, patient navigators should possess qualities to best meet the needs of the patient and help that person to become her own best medical advocate. These qualifications open up the opportunity for more affordability and overall flexibility in patient navigator models. The most important aspect of implementing a patient navigator model as resistance to a system that is providing inadequate or incomplete care is that patients have access to

people dedicated to their wellness and access to information and resources. We must imagine practical delivery systems as well as systemic paradigm shifts.

This illustration of patient navigation and HCBHP is in effort to be solution oriented by modeling action-based access and advocacy within the framework of naming the systemic problems in healthcare that are embedded within social institutions at large. For me, resistance begins simply with naming the ways I understand and experience the inadequacies of our healthcare system. In noting that people are not simply passive victims to the mainstream healthcare, I resist.

Every person I spoke with for this research expressed some sentiment that the state of healthcare in this nation is in trouble. The complicated systems of power and privilege that have negatively impacted the country's healthcare delivery system seem untouchable as rhetoric of hope and change turns into lukewarm attempts to make healthcare law without leveling out the playing field between pharmaceutical and insurance companies on one side and those of us struggling to access the care we need.

One of the clients at the Breast Health Project had a brilliant example of the normative ableism built into U.S. social fabric. **INVALID**. How do you pronounce that word? “In-val-id?” or “In-valid”? They are the same word but the first means someone who is disabled, and the second means null and void. There is a norm that says someone who is disabled is worth less, and a sense of moral superiority of the able and the well in society. Though the notion is taboo in some senses, I believe there is popular sentiment that people who are sick may have deserved it somehow. People have to go through evaluations of self-worth, and determine a positionality and worth within the social

category of “ill” or diseased. One of my dearest childhood friends lost her mother to breast cancer three years ago and as she and I grieved together she said something that was astonishing to me and that I have brought to this research. My friend talked about how many family members processed their grief by letting go of her mother well before she had passed. While everyone is surely entitled to their own processes I can’t help but wonder, and truthfully, dwell on how my friend’s mother may have examined her own worth as a whole person, inclusive of her disease, as her loved ones mourned her passing while she still breathed life.

Individual, community, and national levels for implementing theory, vision, and action are the foundation for the kind of integrated collaborative new knowledge paradigm of the traditional biomedical paradigm with Intersectional Feminist Disabilities Studies analysis that Weber argues for, and forefronts Disabilities Studies along with more privileged theoretical frameworks that Garland-Thompson argues for in order to create a global shift in the way health and wellness is understood, and bodies are branded.

CONCLUSION

My research uses patient navigation as one lens of analysis for resisting inadequacies and failures of the hegemonic mainstream healthcare system. The problems are many and are supported by global capitalist interest and power relations (hooks 2000). I argue that change comes from individual acts of resistance that can catalyze into change on a larger scale. I recognize the impact individual acts of resistance make- consider Julie Ohnemus for one, and the theoretical endeavors of women using breast cancer narratives as resistance and change making mechanisms; Audre Lorde, Marcy Knopf-Newman, and Rachel Carson. Likewise the women that HCBHP process their own cancer experiences, and connect to one another in the wounded healer model, through their own personal narrative. Additionally, research co-participants got to the core of the theoretical framework I presented through their own cancer narratives and self- empowerment.

Consider the endeavors of people who battle insurance companies while simultaneously battling illness. These individual acts of resistance collectively become community resistance, and have catalyzed into resources to continue processes of surviving and thriving. The U.S. makes some progress as it simultaneously takes steps backwards in attempts to humor bi-partisan demands and support of a system ridden with power-over relations that keeps people structurally trapped by policy, regulation, and social stigma. Nonetheless, as one of the co-participants from HCBHP said, the value of having these conversations lies in encouraging people to think about these issues and

relentlessly engage with the stark reality of the nation's healthcare until the least and the last of us are given an equal chance to survive and thrive. Perhaps change at the national level is difficult to see from within the framework we are living in, but I contend that the collective engagement with these issues disrupts the status quo, and I am driven by possibilities for real, transformative social change, both within and beyond the realm of healthcare.

There is something fundamentally wrong with the perspective that the "undeserving poor" are going to use all of the resources, and this flaw is connected with micro, meso, and macro levels of analysis. Kirk and Okazawa-Rey's "head, heart, and hands" model of social change calls for implementing an Intersectional model that employs theory, vision of a more just world, and informed action to make the change one wants to see (Kirk and Okazawa-Rey 2007). "Our society needs to consider the means to health as a basic human right that a government should provide, (just as it protects freedom of religion and freedom from political repression)" (Freund et. al., 2003, 335).

My arguments build on existing research and my intention is to strengthen the ties between fields of study that already have existing connections, namely Intersectional Feminism and the field of Disability Studies. My study reinforces the findings of existing research about systemic inequality in the US healthcare system, and offers suggestions for a new framework for understanding how some socially marginalized people interact and exist within the mainstream healthcare system and other social systems. More research should be dedicated to grassroots organizations that are laboring to make change, and more research should be dedicated to exploring the operations of

systemic power, privilege, and oppression within this nations for –profit medical system that is letting so many precious people fall through the cracks.

Regardless of these fruitful forms of resistance, governmental policy change is necessary. As a scholar I have the privilege to access models for transforming policymaking and to organize around this cause (Weisman 1998). Understanding historical context, formulating an analysis of healthcare, and transforming healthcare policymaking are crucial elements of grassroots efforts at addressing and bringing about healthcare reform (Chernew and Hirth 2004, 289). Understanding potential strategies and calls to action in the arena of comprehensive healthcare reform is empowering and encourages community building in the feminist fashion of “each one, teach one”, where education as the practice of freedom can itself operate as a mode of community building and resistance (hook 1994, 35; hooks 2000, 8). As Freund et. al. argue, perhaps the current critical state of healthcare will encourage public discourse on the moral and political issues of healthcare in the U.S. (2003, 335).

In a “broken” system that largely treats only the symptoms of the patient and not the whole person, adopting an ethic of holistic health works to challenge the mainstream health system and provide a vehicle for liberation. Physicians and healthcare providers play a part in an individual’s healing processes, but people can also look within themselves to find the power to heal (Asetoyer 2003, vii; Northrup 2002, 23). Healing cannot happen suddenly as the result of policy change but must be a movement towards dismantling the oppressive ideologies that have made our society and our bodies *ill*. Lorde calls us each to action, ‘Because I am woman, because I am black, because I am

lesbian, because I am myself, a black woman warrior poet doing my work [I] come to ask you, are you doing yours?" (Lorde in Knopf-Newman 2004, 114).

"As long as profit rather than health defines corporate priorities, we shall see more breast cancer across the globe because it is an effect of global capital's arrogance" (Eisenstein in Knopf-Newman 2004, 146). Through an examination of the matrix of domination and social positioning, capitalism, the social construction of health, illness, and bodies, alternative ways of knowing and frameworks of resistance, breast cancer, and patient navigation, I frame resources as resistance and implore researchers and communities to change-orientated action, exercised through our research efforts, spending and general engagement with the medical industrial complex and capitalism more broadly, volunteer and direct action energy, lobbying, and other creative strategies that best serve communities and survivor/thrivers.

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APPENDIX A

Conversation Guide

(My methodology and orientation to research overall is grounded in a commitment to collaboration. My intention is to learn *your* stories and perspectives, through semi-structured conversations, where you inform what is important about this study. These questions are merely a place to begin and an attempt to be transparent about how I am approaching this study. We are not bound to these questions in our conversation!)

Demographic information for this study will be limited to information about the organization or institution at which the co-participant is employed, how long the participant has worked at that organization, and how long the participant has worked and lived in Humboldt County.

Tell me about the client resources available at the organization where you work.

How do you define quality health care resources?

How do define “access” to quality health care resources?

How do you perceive access to quality health care resources locally?

Is there equality of access?

Root of disparities?

Do you perceive barriers to accessing quality local health care resources?

If yes, what are your perceptions of barriers to accessing quality health care resources?

Who, in your opinion, do these barriers effect?

In your opinion what are the origins of barriers to access?

What do you perceive is the role of federal health care policy regarding access to health care?

Role of policy and barriers to access?

Recommendations regarding policy?

How do you define patient navigation?

What are your perceptions of strategies for patient navigation?

How can this study benefit HCBHP, or patient navigation models more broadly?

Do you have other thoughts that may be important to this study?

Additional probe questions for each of the above inquiries will include questions meant to understand how the particular organization the co-participant works for connects to the study questions (i.e. regarding quality care, barriers to care, access to care, patient navigation models, and the effects of policy).