

AN ABSTRACT OF THE THESIS OF

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Breast cancer statistics in the United States are staggering. As the number of women diagnosed grows, so does the number of women who are writing about their experiences. This thesis is a multi-textual work which includes both the stories of women with breast cancer as well as the thesis author's personal journal entries. Women's experiences are used to examine and critique current institutional and cultural responses to breast cancer. Experience literature reveals that efforts against breast cancer in the United States are emerging from two distinct ideologies which are identified as Cure and Prevention in this work. This thesis address the most prevalent issues within Cure and Prevention, and analyzes how these mindsets are shaped by definitions and expectations of femininity. The following pages elucidate how engendered values and socialization play out through the Cure and Prevention paradigms. Ultimately, the Prevention model will be shown as the one that most resolutely addresses the issue of breast cancer. Women's experiences and expertise are critical for understanding the ramifications of Cure and Prevention responses to breast cancer; women are informing and bridging misunderstandings between Cure and Prevention thinking.

Breast Cancer Experience Literature:
Women's Stories as Cultural Critique

by Karla R. Cohen

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I understand that my thesis will become part of the permanent collection of Oregon State University libraries. My signature below authorizes release of my thesis to any reader upon request.

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Karla R. Cohen, Author

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Dedication

To Mom, Dad and JoMarie with all my love. For always believing my hands would hold this final product.

Preface

One shared radical tenet underlying feminist research is that women's lives are important (Reinharz, *Feminist Methods in Social Research* 241).

Consistent with feminist research, it has been crucial as I address the subject of breast cancer in my thesis that I consider myself in thoughts and words. Self-reflexivity aligns me with the women whose bravely-shared experiences I refer to here. It bridges the researcher/object distance created by traditional positivist research, allowing me to see these women -- and myself -- as both subjects and agents. I am not and can not be a detached observer. As a woman, I also run a significant risk (currently 1 in 8 in my lifetime) of being diagnosed with breast cancer. To alienate and create anomalies of the women I discuss by assuming myself somehow immune destroys the notion that the personal is political. Aligning myself with women who have breast cancer is a radical feminist process.

Feminist theories and research have instilled in me a working foundation of the language and dynamics of women's oppression, including American cultural gender expectations which I will address at length. However, it is from my experience as a critical and creative writer that this thesis takes its shape. What follows is not intended to be a medical text. What follows is a story about stories.

As an answer to these calls for responsibility, creativity and self-realization, I have peppered this work with periodic vignettes (all italicized and bordered) from a journal I kept throughout this academic and spiritual journey: pieces of my life from the age of eleven as a two-breasted girl to the two-breasted woman I am today, and how that lived experience spoke to my thinking, researching and writing about breast cancer.

These journal entries provide one kind of text in this multi-textual (and textured) thesis. To fully address the issue of breast cancer, our discussion must include many voices and many ways of knowing beyond those of traditional Western medicine. Following this belief, I have included within this work the written stories (both poetry and prose) of women with breast cancer as well the spoken words captured in a video entitled, *All I Know: Women and Breast Cancer in Oregon*.

Breast Cancer Experience Literature: Women's Stories as Cultural Critique

Chapter One

Introduction

In Oregon in 1993, 550 women died of breast cancer. Another 2100 were diagnosed with the disease (Oregon Breast Cancer Coalition). Nationwide, 46,000 women died of breast cancer in the same year (National Breast Cancer Coalition). When I heard these shocking statistics, I decided to learn more about breast cancer, and it quickly became the subject of this work. I began by paying closer attention to the discussion going on in mainstream America: television, radio, newspapers and magazines. My intentions and determination were as serious as the statistics that originally prompted me; what I discovered, however, were a culture and a power structure too consumed with celebrations of survival to acknowledge the dead. The voices I heard spoke of breast cancer as little more than an inconvenience; they seemed oblivious to the pain and fear breast cancer creates for women. Understanding this disparity between our reactions has been the drive of my research.

As a feminist, I needed to focus on the women themselves; they are the closest to this condition. My background in (and love of) writing led me to their

autobiographies. The experience literatureⁱ of women with breast cancer is another kind of text included in this work.

I will also use the stories from a 28-minute video entitled, *All I Know: Women and Breast Cancer in Oregon* (Femagistic Media 1996). Created by the Women and Breast Cancer in Oregon Video Project, *All I Know* presents narratives from eight women around the state who are living with breast cancerⁱⁱ. My purpose is to contextualize these narratives by placing them within an existing framework of stories by and about women with breast cancer. I look at this work not as a film/video scholar, but as a reader. My interest and emphasis are not on editing decisions or the framing of shots, but on the stories which ultimately emerge; I am looking at narrative/textual, rather than visual, content. I look at the video not to critique it, but to foreground it to discover how the stories in it contribute to the current national discussion about breast cancer.

ⁱA great deal of controversy exists around the words "breast cancer survivor." Many women embrace the idea of *surviving*, of *being* a survivor; many do not. Much of the dilemma lies in defining exactly what a survivor is. If she lives five years past diagnosis? Ten years? Concomitantly, being a survivor implies being cured although a cure for breast cancer does not yet exist. Recurrence is not unusual more than twenty years after the original diagnosis. Out of respect for this contention (as well as my own concerns with the word "survivor"), I have chosen to use the terms "women with breast cancer" and "women living with breast cancer." Additionally, I refer to the stories of women with breast cancer as "experience literature" (and experience stories) rather than survivor literature. The former accommodates the works of women who have died of breast cancer.

ⁱⁱ The narrators in *All I Know: Women and Breast Cancer in Oregon* are referred to in the video by their first names only. This is how I will identify them as well. Their names are Sandy, Elki, Kay, Cindy, Lina, Ali, Marci and Alicia.

Since the early 1970's, women with breast cancer have been publishing their stories (Kushner 1973, Lorde 1980, Metzger 1981, Rollin 1976). These experiences, however, seemed to disappear from the mainstream, reemerging only recently, some twenty years later. Today, a dialogue has emerged among women with breast cancer and subsequently between women and their caregivers. Biographical and autobiographical works documenting women's struggles with breast cancer are filling the shelves of bookstores and libraries as well as cyberspaceⁱⁱⁱ (Batt 1994, Brady 1991, Brinker 1995, Britton 1984, Butler & Rosenblum 1991, Cederberg et al 1994, Chechik 1987, Feldman 1994, Gross & Ito 1990, Kahane 1995, Kaye 1991, Latour 1993, Lorde 1988, Lynch 1986, Mayer 1994, Middlebrook 1996, Miller 1993, Royak-Schaler & Benderly 1992, Shockney 1995, Soffa 1994, Wadler 1992, Wilber 1993, Williams 1991, Wittman 1993). Women are telling their stories in unprecedented numbers. *All I Know: Women and Breast Cancer in Oregon*, and my discussion of the stories it presents, not only add to this important litany, but regionalize it.

ⁱⁱⁱ In March of 1995, I began subscribing to an internet discussion group on the subject of breast cancer. Open to anyone with email access and an interest in breast cancer, this list currently serves 900 men and women from 30 countries. Subscribers include women (and a few men) with breast cancer, oncologists and other traditional and alternative caregivers, friends and family of women with breast cancer, researchers, etc. Although I will not be quoting list members directly, the experiences they share, their questions, fears and hopes have greatly informed my understanding of breast cancer and the women living with it.

Without undermining the works I mention above, it is vitally important that I address right away issues of race and class. Women are finally breaking free from systematic silencing, but within the breast cancer dialogue, the most privileged women are the ones most published, read and discussed nationally. With few exceptions, of women with breast cancer, it is white middle to upper-middle class women who 1) seem to have the luxury of time and money in order to put their stories on paper 2) have been afforded a voice in a classist and racist society and 3) have the greatest access to the esoteric world of writing and research (either their own or that of other women). Relatively speaking, on library and bookstore shelves as well as in *All I Know*, Jewish women's words abound, lesbian voices are few but loud, and women of color are virtually invisible. Ironically, perhaps, I will emphasize the work of Audre Lorde, an African-American lesbian. Writing in the early 80's about her own breast cancer experience, Audre Lorde addresses like no one since issues of race, class, sexual orientation and gender as they relate to breast cancer. Hers is the voice America was most afraid, but **needs** to hear, and I will show why throughout this work.

Cure and Prevention: an Overview

Experience literature reveals that efforts against breast cancer in the United States are emerging from two distinct ideologies which I have labeled Cure and Prevention. In *All I Know: Women and Breast Cancer in Oregon*, Sandy

Polishuk reads her poem from which the video takes its name. Perhaps better than any prose, this piece illustrates the Cure/Prevention split and its ramifications. Sandy's response to her illness, which comes from a Prevention perspective, is at odds with the thinking of the Cure. Her frustration is obvious.

They tell us it's an acceptable risk,
Only three per million.

All I know is
I have cancer.

Last month I heard about
Three more friends,
So far this month, one more.

My parents didn't get cancer,
Nor their friends,
At our age.

I am tired of band-aids,
Focus on cures.
I want the causes removed,
Prevention at the source.

I want health above profits,
Regulation over growth.
Priorities for the long haul.

I want my grandchildren to grow up
And walk in a rain forest.
I want eagles to lay eggs that hatch.

All I know is
 Acceptable risk is unacceptable thinking.
 Throw the bums out (Sandy, "All I Know" from the video *All I Know*)^{iv}.

I will address the many differences between these ideologies, but it is vital to note that a fundamental contrast lies in the Cure's emphasis on working with the system (in this case, the breast cancer establishment^v), versus Prevention's focus on changing it. Breast cancer experience stories, including those in *All I Know: Women and Breast Cancer in Oregon*, not only reflect these contrary approaches, but reveal one common dynamic at work in them both: culturally-constructed femininity, its roles and imperatives.

The following pages are an attempt to elucidate how engendered values and socialization play out through the Cure and Prevention paradigms. *All I Know* provides local voices for the latter. Using the stories from the video as a focal point, I will touch on what I believe are the most prevalent issues within the Cure and Prevention mindsets and analyze how definitions and expectations of femininity shape and galvanize them. Ultimately, I wish to show how the

^{iv} "All I Know" by Sandy Polishuk was originally pulished in *1 in 3: Women with Cancer Confront an Epidemic*. Ed. Judy Brady. Pittsburgh: Cleis Press, Inc., 1991.

^v The term "breast cancer establishment" will be referred to often. Included are such entities as the American Medical Association, the American Cancer Society, the National Cancer Institute, the Susan G. Komen Foundation and the Department of Defense. Most importantly, the establishment collectively designates those organizations which provide the bulk of the public's medical information (i.e. receive the most media attention) and control the bulk of research dollars. Founded in 1982 by Nancy Brinker in memory of her sister, Susan Goodman Komen, the Komen Foundation is "the nation's largest private funder of research dedicated solely to breast cancer" (Brinker xxi). The foundation also sponsors an annual series of 5K runs across the country entitled *The Race for the Cure*. The purpose of these events (which attract hundreds of thousands of women and men nationwide) is to raise research dollars toward a cure and awareness of mammographic screening for breast cancer.

Prevention model in regard to these engendered values is the one that will most resolutely address the issue of breast cancer.

Naomi Wolf asserts in *The Beauty Myth* that historically, as women have gained any kind of power -- social, economic, political, personal -- there has always been an equal, opposing backlash waiting in the wings to relieve them of their gains (10-11). This counterattack has usually focused on the spheres of domesticity or beauty/body image -- in other words, on culturally constructed ideas about femininity. Depictions of and responses to breast cancer in our society reflect a similar backlash, a new attempt to rein in women's growing power by asserting gender roles of past decades.

This reactionary stance and the efforts to deconstruct it are critical pieces of the Cure and Prevention models respectively. The Cure emphasizes the miracles of modern Western medicine and the necessity of funneling as many dollars as possible into research institutions. Additionally, the loudest and most publicized voices for this approach, the American Cancer Society and the Susan G. Komen Foundation, emphasize not only a cure, but the indispensability of traditional feminine beauty and body for healing and survival.

The Cure model arises out of a masculinist tradition. Paternalistic in its assurance, this model holds women accountable for what Lina in *All I Know* refers to as "their part in getting the cancer." Connections to the cosmetics industry and major department stores serve to feminize breast cancer, seemingly because breasts, makeovers and shopping all fall into the realm of what is considered "essentially" feminine. Further discussion of this model will reveal it as a means of controlling women, those with breast cancer and those millions who may be diagnosed in the future. Effectively addressing breast cancer will require ending masculinist control over and socialization of women.

Many experience stories, including those from *All I Know*, provide a model for Prevention as an alternative to the one described above. An integrated approach that began in the 60's with Rachel Carson's ecological treatise *Silent Spring* and continued in the 70's and early 80's with the writings of Audre Lorde and Rose Kushner, the Prevention model challenges the controls of an engendered society. The works of these three revolutionaries were systematically submerged and only recently excavated as more women with breast cancer scrutinize the politics of their experience. Focusing on how women with breast cancer look, for example, is illuminated through the Prevention paradigm as not only a distraction from substantive issues, but as a means of rendering these same women invisible. This approach challenges the medical establishment, pointing out flaws and hypocrisies in the information presented to women with breast cancer and to the public at large. Prevention ideology says that breast cancer is a preventable condition, brought on mostly by human disconnection from the earth, corporate greed, and the devaluation of women's bodies and experiences.

In this light, I contend that the Cure model represents severe patriarchal control over women: command of our bodies, lives and deaths, yet with no visible assailant to hold accountable. Assumptions made by Cure ideology, collectively called "risk factors," call into question what we eat, if we drink, when and if we have children, if our periods started too early, or menopause too late, etc.^{vi} Certainly, a core of evidence exists to implicate these factors in the development of breast cancer. What is important is not to question the medical evidence itself, but to analyze the gendered, valued system from which such evidence is gathered and presented to the public.

^{vi} A more detailed discussion of risk factors can be found in Chapter Four.

Further, I assert that it is no accident that this cancer, which ends more than 46,000 women's lives a year, is situated in patriarchy's most sexualized, medicalized and commodified body parts. Breast cancer is the inevitable physical manifestation of oppression, abuse and greed, a carnal sign of dis-eased cultural notions of femininity and "woman's place." This metaphor is simultaneously the converse and compliment of Susan Sontag's discussion of cancer in *Illness as Metaphor* (1978). Sontag observes how cancer (as opposed to Tuberculosis) has been treated by society (i.e. cancer as if it were a manifestation of personal flaws, shortcomings and problems). Our society continues to place blame on individuals with cancer, attributing the condition to inappropriate personal habits and practices. The discussion needs to be re-framed [not as societally-defined personal ills creating cancer, but] as societal ills creating cancer within individuals. Sontag makes clear that the former has historically dominated the discourse. As a result, the power structure has avoided any accountability. The Prevention model tells us we must attend to this (symbolic) connection if we are to honor women's experiences and women's ways of knowing, and truly progress toward an end to breast cancer.

Cure and Prevention ideologies are easily defined, but women with breast cancer are not. As I will show, the work of some women, such as Nancy Brinker and Virginia Soffa, is readily categorized as Cure or Prevention oriented (respectively). Many more women, however, fall somewhere in-between, or believe they advocate one approach over the other, even though their words do not show it. And then there are women who seem to have a foot in both worlds. Experience literature demonstrates that issues arise (particularly regarding beauty expectations) which dissolve the boundaries between Cure and Prevention. Women with breast cancer are subsequently forced to move between these two mindsets. Such vacillations can be difficult for the woman experiencing

them, for they demand reconciliation. I will recognize these moments of personal struggle and the impact such lived contradictions have on the discourse of Cure and Prevention.

In her essay "The Master's Tools will Never Dismantle the Master's House," Audre Lorde writes that "an old and primary tool of all oppressors" is "to keep the oppressed occupied with the master's concerns" (*Sister Outsider* 113). Profit, narrow definitions of feminine beauty, and the race for the cure are the master's concerns. They are the concerns dictating the actions and focus of the breast cancer establishment. The struggle for prevention that occurs outside of the establishment is the one that will be effective: the radical struggle that challenges the status quo, that challenges socially-constructed notions of femininity. For as Lorde writes, "the master's tools will never dismantle the master's house. They may allow us temporarily to beat him at his own game, but they will never enable us to bring about genuine change" (*Sister Outsider* 112-113).

Chapter Two

Mammograms / Shammograms

Positionality

There is breast cancer in my family, but I am not a woman with breast cancer. I share with millions of women a deep concern about breast cancer, but that vantage point in my case is one of relative ease. Standing some distance away from diagnosis (however near or far), observations and analysis roll readily from my tongue and pen. To not recognize this privileged place is tantamount to lying. As I have said, my intention is to take a critical look at culturally-constructed femininity and its role in shaping responses to breast cancer. Although I may not agree with the thinking of the Cure model, I understand where ideas come from. My doubts lie with the establishment's ideology -- **not** with the good intentions of women who are living with and working against breast cancer. But I believe the personal is political, and it is these women's stories which reflect and expose the breast cancer establishment. I proceed now with caution, hyper-aware of my place in this discussion, yet committed to deconstructing ideas I see as ultimately harmful to women.

Diagnosis

Echoes. Women's voices expressing so much common experience and emotion they often parrot each other verbatim. Description of the diagnosis -- **the** moment when they were told they had breast cancer -- has become a textual convention for opening an experience story (Altman 1996, Batt 1994, Brinker 1995, Cederberg et al 1994, Chechik 1987, Feldman 1994, LaTour 1993, Lynch 1986, Miller 1995, Soffa 1994, Wadler 1992, Wittman 1993). One of the earliest breast cancer experience stories, Betty Rollin's *First, You Cry* (1976), takes its name from the universality of women needing to know -- and needing to tell --

what it's like to feel a lump or to hear a positive breast cancer diagnosis. *All I Know* also reflects this need. Its narrators open with a diagnosis sequence that presents a kind of Everywoman story. Each of the eight women shares only a few sentences of her own moment, but together they create a whole. Sandy begins this multi-voiced monologue with a statement that quickly sets an ominous scene: "It was a hot fall night..." She continues briefly, recounting the discovery of a lump and an appointment with a doctor to be "reassured... but she was not reassuring." So the story continues, pieced together by seven more women, and finally ending with Alicia's ironic understatement: "It was intense." We imagine it was. This is our fear. Like an answer to the question that has passed over millions of American lips since 1963, "Where were you when Kennedy was shot?" no woman ever forgets the details of where she was when she found out she has breast cancer.

I was very young. Probably only 11. I had touched or somehow bumped my developing breasts. They hurt and felt hard underneath the nipples. Breast cancer. I had breast cancer. I ran to my mother in a teary-eyed panic, telling her I had breast cancer. She gingerly felt around my nipples as I sat, embarrassed, but too frightened to care. She seemed to feel the "mass" I felt, and for what was probably my piece of mind, called our pediatrician and described my condition. "Breast budding," he said. "Very common." To this day, my breasts are about the same size, shape and texture. I continue to search their hard terrain for cancer.

Misdiagnosis

An important common thread weaves through these diagnosis stories: **mis**-diagnosis. Five of the eight women in *All I Know* disclose having been misdiagnosed, either by inept hospital personnel or diagnostic equipment

failure. Elki, for example, "wasn't worried because [she'd] had a mammogram just six months before [the diagnosis]." So convincing were Ali's doctors' assurances that nothing was wrong, her husband left town before the pathology reports came in. As a result, Ali was alone when found out that previously biopsied "fibrous tissue" was a malignant tumor. These are not isolated cases, but a microcosm of a nationwide phenomenon. Accounts of misdiagnosis appear again and again in experience literature (Altman 1996, Batt 1994, Brinker 1995, Butler & Rosenblum 1991, Cederberg et al 1994, Chechik 1987, Kushner 1973, Mayer 1994, Miller 1995, Wadler 1992) yet Cure ideology continues to push for mammography. In her book, *Examining Myself: One woman's story of breast cancer treatment and recovery*, Musa Mayer discusses her own misdiagnosis in a larger context:

I didn't know then that failure to diagnose breast cancer has become one of the leading grounds for malpractice suits in this litigious age, and that this charge results in the largest financial settlements, each averaging about \$200,000, according to a recent study by the Physician Insurers of America... I simply assumed my situation was unique, or at least uncommon. Some months later, I was stunned to find that in my support group of eleven, *eight* reported similar experiences with their gynecologists" (51).

From every medium in which women with breast cancer are telling their stories, they are sharing the everyday reality of **misdiagnosis**. Many of them scream in anger and frustration, believing they have been robbed of precious months and days of living Ironically, it is society's demand for "ladylike" behavior, the socialization of our sex, that kept them from crying out earlier.

"...nothing showed up on the mammogram," Marci tells us. "Even, you know, right after I felt the lump, we did a mammogram, we did an ultrasound... This is probably nothing."^{vii} But it was something. Marci was diagnosed with breast cancer.

Reminiscent of commands to "Test, Test, Test" for AIDS and HIV, "Have a Mammogram" has become a breast cancer mantra. Significantly, these diagnostic and screening urges have been **inaccurately** equated with prevention. Continually, popular media and the breast cancer establishment tell us our "best protection" from breast cancer is a mammogram, clouding the true purpose of mammography which is to **detect** any existing tumors. Far from **preventing** this condition, mammograms (when accurate) only assist us **after** we develop tumors. Despite this, the thinking of the Cure model tells women, "Perhaps the best line of defense against breast cancer is mammography" (Nancy Brinker *The Race is Run One Step at a Time* 69).

Barbara Brenner, Executive Director of Breast Cancer Action in San Francisco addresses the medical establishment's inaccurate equation of prevention and detection in her organization's newsletter. Referring to the unveiling of a breast cancer awareness postage stamp, she relates that the head of the breast clinic at San Francisco General Hospital appeared at the press

^{vii} Dialogue from the video has been transcribed verbatim. Any editing has been for length only. Punctuation follows and shows as closely as possible narrator pauses, emphasis, intention, etc.

conference declaring that "...the stamp honors, among others, 'those who can prevent [breast cancer] through proper screening.' If doctors treating breast cancer can't tell the difference between prevention and detection, is it any wonder that the rest of the world can't?" ("Let Them Lick Stamps," Newsletter #37, 2).

Brenner goes on to address the sources of "the rest of the world's" information on mammography: "After all, the American Cancer Society and the Susan G. Komen Foundation have for years promoted mammograms as your best prevention. Anyone who thinks about it for ten seconds recognizes that mammograms don't prevent breast cancer. And those who investigate the matter even a little bit will learn that mammograms don't even detect breast cancer in a large number of cases" (2).

The American Cancer Society and the Komen Foundation are arguably this country's most publicized and respected voices on the subject of breast cancer. Women look to them for information and guidance. The inability to define and distinguish prevention from early detection leads women to believe they actually **are** working for prevention by having their yearly mammograms. In reality, they have come no closer to keeping themselves or any other women from developing breast cancer, and the agenda of the Cure paradigm continues to envelop a national dialogue.

Controversy over the effectiveness of mammography is growing, but the rate of increase appears unable to surpass that of the Breast Cancer Establishment's ability to publicly laud the technology. This creation of medical science is a cornerstone of mainstream America's talk about breast cancer. The American Cancer Society's authoritative voice reminds us to be screened, and implies that we are responsible for our cancer should we fail to follow the establishment's advice. Public service announcements admonish women in the guise of education. Magazines that target women readers are filled with articles on how to reduce your risk of getting breast cancer: get a mammogram. Even the music industry has begun promoting mammography with the release of a major label, star-studded compact disc compilation entitled, *Women for Women* (Polygram Records 1994). Inside this c.d. are informational pictures of (typical) tumor sizes. Tumors purportedly discovered by mammography are contrasted with the much larger ones found by regular or occasional breast self-exam. The message is clearly that mammograms discover lumps which breast self-exam can not; the reliability of mammography is unquestioned. Also presented in these unusual liner notes is the National Cancer Institute's recommendations for breast screening (guidelines which are shared by the American Cancer Society). A "baseline" mammogram between the age of 35 and 40 (depending on personal risk factors), screening thereafter every year or two between 40 and 50, and annually from that time forward.

Sharon Batt, a Canadian journalist who became an avid breast cancer researcher and investigative reporter following her own misdiagnosis makes this observation about mammography in her exhaustive work *Patient No More: the Politics of Breast Cancer*: "[In] North America by the early 1990's, many women believed mammography was synonymous with early detection and saved lives. And women under 50 who, according to the research, had the least to gain from the technique and the most to risk, were its most enthusiastic adherents" (40). Hidden from the general public has been a large body of research showing **no** correlation between mammography and decreased mortality rates, particularly in pre-menopausal women (Batt 1994, Soffa 1994). Furthermore, the entire concept of **early** detection is questionable in that the average tumor has been growing 6 to 8 years by the time it is discovered (Batt 1994, Love 1995, Soffa 1994).

Equally concealed from the public has been the reality that mammograms conducted on pre-menopausal women are virtually useless. Breast expert Dr. Susan Love explains that "Before menopause, the breast tissue tends to be denser, because your breasts have to be ready to make milk at a moment's notice. After menopause, the breasts go into retirement and the breast tissue is replaced by fat. Cancer shows up against fat tissue, but not against dense breast tissue" (Dr. Susan Love's *Breast Book*, Second Edition 255). Dr. Love attributes this pre-menopausal tissue conundrum to an over-abundance of false-positive diagnoses.

Healthy but dense breast tissue is mistaken for cancerous, and the result may be unnecessary biopsies and lumpectomies -- not to mention a terrifying experience for the woman herself.

One need only listen to women with breast cancer to know, however, that a contrary pattern also exists: false negatives. Mammograms are misinterpreted; malignant tumors are not picked up at all or are passed over as "fibrocystic disease" (a catch-all phrase for most benign breast lumps). Women like Barbara Rosenblum are sent home with a breast lump and told by their doctors "to stop drinking coffee. They would watch it" (*Cancer in Two Voices* 23). Caffeine is a widely implicated culprit in the hardening of breast tissue. Following three misdiagnoses, and with a right breast that had swollen to twice the size of her left, Barbara Rosenblum filed a lawsuit against Kaiser hospital. "No single, individual doctor in the Kaiser system caught [the cancer]. And because of their collective incompetence, I am going to die within the year, at the age of forty-four or forty-five, depending on how I can stretch the time from this moment...And because of their incompetence, and because I was furious enough to fight, I got a malpractice settlement for \$296,000. All in one check" (86).

I'm 19. Agile, experienced hands palpitate my breasts, one, then the other. The beginning of my yearly gynecological exam. "Fibrocystic disease," the doctor tells me. "The hard, dense tissue... fibrocystic disease." Following the pelvic exam and the doctor's reassurance that fibrocystic disease isn't necessarily a precursor to cancer, I go home to tell the people who love me that I have a disease. And that I'll never drink coffee again.

Diane Craig Chechik chronicles her own misdiagnosis and subsequent (successful) lawsuit in *Journey to Justice* (1987). Chechik took on her doctor of more than twenty years (and the establishment) after two inaccurate mammograms and vehement rejections of a cancer diagnosis. Despite a lump that she could feel (growing) for two years, her doctor refused to ultrasound or biopsy. Also a family friend, Diane's doctor took her fears of cancer as a personal attack on his medical abilities and responded with anger and further insistence of her good health. When the relationship finally disintegrated, Diane had been the one betrayed and sacrificed. By the time a proper diagnosis was forthcoming at another hospital, she had stage two breast cancer, including involvement of her lymph nodes. She decided to fight the establishment, won, and published her revealing victory for the world to read. Yet how many women in this country know her story? How many in the breast cancer establishment have looked at her experience in the context of **so many** others yet refused to question mammography's dependability?

In the early 1970's, following her misdiagnosis, Rose Kushner began investigating the breast cancer establishment. She recorded her experience and her findings for the world to read (*Breast Cancer: A Personal History and an Investigative Report* 1975); in the late 1990's, misdiagnosis is still be a common occurrence: a thread more than twenty years long despite major advances in diagnostic technology. Cure ideology insists that women have regular

mammograms; it explicitly tells women that **preventing** breast cancer hinges on this detection technology. The breast cancer mortality rate, however, has remained constant for the last forty years (Batt *Patient No More: the Politics of Breast Cancer* 1994). The Cure also implies an order to women to self-protect: get a mammogram or risk getting breast cancer.

Elki from *All I Know* wasn't worried because she had had a mammogram. Her gynecologist believed so strongly in this detection device that his shock at the lab report was uncontrollable, "It couldn't be! It couldn't be!" he exclaimed. Sadly, Elki corrects him. "It was cancer."

Kay, another narrator in the video, was informed by one doctor that she had a "teeny bit of cancer." That to treat this minor affliction, she "would probably just have to take a pill or something." After a final diagnosis of "3 or 4 different kinds of cancer with a full 6 months of chemotherapy and 6 weeks of radiation," Kay is left asking, "They say get a second opinion, but what good does it do when you get three and they're all wrong?"

Mammograms and Money-Making

In *Patient No More*, Sharon Batt points out the monetary stakes for participating industries should mammography be challenged and/or its use reduced. "Certainly the parties behind the [mammography] ads, companies like Kodak -- one of the leading manufacturers of mammographic films -- and

General Electric – which makes mammography machines – are not wholly disinterested in mammography. Some physicians invest in mammography clinics, then refer patients to the same testing centers" (43). Profit, suggests Batt, not women's lives, is at risk if mammography is questioned and/or doubted. A masculinist system such as capitalism depends on this money-over-life attitude, and it is part of the ideology generated by the breast cancer establishment.

Industries that design and build the technology, however, are not the only ones benefiting financially from mammography. Nordstrom department stores^{viii} and Chevron service stations^{ix} have chosen to include mammograms as part of their services. These kinds of marketing strategies are irresponsible and opportunistic: they exploit women's fear of breast cancer to lure potential customers. Women themselves are reduced by these tactics to an untapped consumer base.

Moreover, Nordstrom's and Chevron's mammography offers reinforce essentialist stereotypes of women and femininity. Being female, for example, is traditionally viewed as pre-determining a need to shop and buy, and in

^{viii} In October of 1995, Evanston and Glenbrook Hospitals opened centers for breast health and mammography in the Old Orchard Shopping Center in Skokie, Illinois (Morrall, Katherine. "Mammograms at the Mall." *Hospitals and Health Networks*. November 5, 1995).

^{ix} According to the Associated Press, twenty free mammographic screenings were offered to female motorists at a Lake Oswego Chevron Station on August 23, 1996 in conjunction with Portland, Oregon's *Race for the Cure*. Chevron is a co-sponsor of the events (*The Gazette-Times* August 14, 1996).

particular, a need to buy those products that feed feminine vanity and materialism such as clothes and accessories. Working from this premise, it follows that mammograms would be made available at the mall -- a place women are presumed to spend a great deal of time. Subsequently, blaming women who do not get a mammogram becomes even easier. Edwin Ness, Vice President of Glenbrook Hospital: "We hope setting up a center in a non-threatening environment women frequent will eliminate excuses for not having a mammogram" (Morrall 47). Few excuses are left when the screening center is as close as the next store over.

Just as stereotypes about women and shopping trivialize women, connecting breast cancer to those stereotypes trivializes breast cancer. Mammography needs to be recognized as significantly more involved than buying a new pair of shoes. This denigration is created by the Cure model as a vehicle for economic gain.

Chevron's mammography services, although limited, also reinforce stereotypes of women and femininity. Historically, in high schools throughout the United States, girls have been placed in Home Economics classes while boys take Auto or Wood shop. Cultural boundaries around femininity prohibit girls from being involved in such dirty -- and possibly dangerous -- work. Furthermore, tending to car bodies has been classified as men's responsibility. Women's responsibility is tending to their own bodies. Connecting breast cancer

to this kind of gender-based division of labor is significant. It distracts. It detours the discussion about breast cancer back to conceptions of woman's place. Using women to advertise and sell cars is a familiar tradition within our capitalist patriarchy. (Heterosexual) male-fantasy scenarios objectify women and render us virtually indistinguishable from the cars we accessorize. An enormous cognitive leap is required to move away from this sexist cultural practice and toward Chevron's purportedly pro-woman, care-taking approach. "You can tune up your body, while you're having your car tuned up," says the Lake Oswego Chevron Station owner. "This might prompt some questions and give you that little nudge to have a mammogram. [Maybe] this will send more women to their doctors" (*Gazette-Times* August 14, 1996).

Conclusion

I have already pointed out that the media supports messages to women to trust and utilize mammograms. This information is passed down to the breast cancer consumer from powerful entities such as the American Medical Association, the American Cancer Society and the National Cancer Institute. "Father Knows Best" resonates through the ideology of these patriarchal institutions. Particularly for women, our socialization regarding science and authority teaches -- indeed **trains** -- us not to question the opinions and advice of our doctors. Traditional notions of femininity require being seen, not heard. In the case of mammography, these gender expectations translate into unwavering

dependence on fallible technology. Those women who **do** challenge mammography and choose not to be screened are blamed if/when they develop breast cancer in the future.

Chapter Three

Race for the Cure / Race for Our Gender

Positionality

It is not my intention to judge the woman who has chosen the path of prosthesis, of silence and invisibility, the woman who wishes to be 'the same as before.' She has survived on another kind of courage, and she is not alone. Each of us struggles daily with the pressures of conformity and the loneliness of difference from which those choices seem to offer some escape. I only know that those choices do not work for me, nor for other women who, not without fear, have survived cancer by scrutinizing its meaning within our lives, and by attempting to integrate this crisis into useful strengths for change (Lorde, *The Cancer Journals* 10).

The line between critical analysis and judgment is a fine one, and I about to walk it more precariously than ever. My critique is systemic, not personal, but it is through the stories of individual women that institutions reveal themselves. Deconstructing women's beliefs and choices does not mean that those beliefs and choices were not healing or helpful to them in some way. But do these beliefs and choices improve life for all women who now have, or may one day develop, breast cancer? Do they **transform** the Cure's dominance within breast cancer discourse or merely perpetuate it? These are the questions that guide me as I proceed.

Beauty, Femininity and the Cure

(Breast cancer is) a disease that tears into the depths of a woman's soul and threatens what she often cherishes most, her femininity and self-image. Today, a woman over thirty-five is at the forefront of an exciting era. She's at a new pinnacle in terms of career, family, romance and sexuality. Often she is starting over in one or more of these areas. Breast cancer threatens to take it all away. And what it leaves in its place is a

woman with a disease that is hard to discuss, difficult to endure and nearly impossible to prevent (Brinker, *The Race is Run One Step at a Time* xv).

Along with mammography, the search for a cure for breast cancer dominates popular discourse and imagery. A cure -- that chemical, surgery, hormone or gene therapy that will make women with breast cancer well -- has captured our imaginations. Mystery and mystique surround it; it is represented as a romantic search reminiscent of archeological digs, treasure hunts and unexplored territories. Efforts to find a cure also tend to focus on traditional American expectations of femininity and female beauty. In addition to early detection, stereotypical femininity and ladylike behavior are seen as the best tools with which to combat this disease. Look good -- feel better is the philosophy,

In fact, *Look Good... Feel Better* is an outreach program co-sponsored by the American Cancer Society, the National Cosmetics Association and the Cosmetics, Toiletry and Fragrance Association (American Cancer Society brochure 1992). It functions as its name implies: to help women with breast cancer look good, because looking good is believed to have a causal relationship with feeling and being better. These programs provide to women with cancer assistance in make-up application as well as hair, skin and nail care (American Cancer Society brochure 1992). Looking good follows strict societal definitions. Looking

feminine and normal by conventional definitions is promoted as a facilitator for the healing process.

Reach to Recovery (another program of the American Cancer Society) appears on the surface to be extremely beneficial: "one woman reaching out to share and support another in a time of need" (American Cancer Society brochure 1982^x). In *The Journey Beyond Breast Cancer*, however, Virginia Soffa provides a much different perspective on Reach to Recovery's expectations: "Typically, a woman isn't accepted into...Reach to Recovery unless she has both conformed to standard medical treatments and 'beat her cancer.' If a woman's cancer returns, she can be removed from acting as a patient support volunteer" (155).

Prosthetics and reconstruction are emphasized as the tools necessary to facilitate *Reach to Recovery's* mission: "Reach to Recovery is successful when a woman who has had breast cancer is able to return to her normal activities, is proud of herself, is informed about her disease and her treatment and resumes her very special place with her family and friends" (American Cancer Society brochure 1982). Further evidence of *Reach to Recovery's* priorities lies in the program's relationship to the corporate beauty industry: "The sample Avon items that Avon provides me as a Reach to Recovery volunteer further exemplify Avon's commitment to women. Avon wants all women to feel beautiful. During

^x Although this brochure is dated 1982, it was part of the literature sent by the American Cancer Society upon request in 1995.

a medical crisis such as breast cancer, when a woman may be doubting her femininity, Avon is there for her as well" (Shockney, *Joining the Club: the Reality of Breast Cancer* 180).

Programs such as *Look Good...Feel Better* and *Reach to Recovery* are helpful to some women and not to others. But in a larger context, they further the Cure ideology by minimizing breast cancer's scope. Asking questions about prevention, for instance, becomes irrelevant, because these programs prioritize getting **past** the disease over challenging it. Returning to life before breast cancer translates into denying breast cancer. In *Joining the Club*, Lillie Shockney shows how this thinking is manifested. Describing a visit from a friend while she was in the hospital, Shockney says, "Laura was glad to see me...Because of her weak stomach, she didn't ever stay in the room very long. 'See, you said that you would look different, but you don't to me. Other than wearing your glasses instead of your contact lenses, you look just the same,' she said. I told her that I look different under my clothes. She was unimpressed. She simply replied by telling me that no one could see under there, 'so it doesn't count.' " (*Joining the Club* 124). Within Cure ideology, invisibility is made synonymous with recovery and health.

Like the *Look Good...Feel Better* program of the American Cancer Society, Diane Noyes' optimism for the future lies in beauty and looking good by American cultural standards. In her book, *Beauty and Cancer*, Noyes' asserts that

looking good leads to feeling good; feeling good increases women's ability to complete the cancer treatments prescribed for them (*Beauty and Cancer* xv).

According to Noyes, two worlds exist: a world of the healthy and a world of the ill. "Clothes, make-up, hairstyles and headwraps that make you look good are an important bridge to the healthy world" (*Beauty and Cancer* 8). Lillie Shockney

vehemently reiterates Noyes' connection between beauty and health:

It is a known fact...if a woman doesn't feel comfortable in her clothes and, even more importantly, comfortable in her appearance, it will be evident in every aspect of her life. It lowers a woman's self-esteem. It prevents her from being able to restore her soul, to move on beyond the point where cancer has taken her, and on to the point of beginning her true emotional recovery (*Joining the Club: the Reality of Breast Cancer* 188).

Cure ideology has feminized breast cancer, shrouded it in pretty pastel pink. And although the exact origin of the pink ribbon (the symbol for breast cancer awareness) is uncertain, the ribbon's impact is not. Initially homemade, created from pieces of pink fabric, the ribbon has blossomed into an accessory industry (Brenner, "Let Them Lick Stamps," *Breast Cancer Action Newsletter* #37, 2). Earrings and pins in every medium, every glittering pink gem, adorn designer gowns at fund-raising soirees. Pink flows freely even beyond the ribbon: Race for the Cure visors; T-shirts and running shoes; lipstick and blush. Anything and everything -- as long as it's pink.

Lillie Shockney's *Joining the Club: the Reality of Breast Cancer* epitomizes the Cure's focus on cultural notions of femininity as indispensable for surviving

breast cancer. Femininity's signifiers adorn the book's cover: two shades of pink framing two pastel butterflies and the perennially pink Breast Cancer Awareness ribbon. Even before page one, it is clear that readers are entering the traditional feminine sphere. Shockney's club is an ironic metaphor for such a serious shared reality; it is reminiscent of the PTA and the Ladies auxiliary to any men's organization. As an American woman, it is significant that I feel compelled to ask whether the story in *Joining the Club* will recount an experience with a deadly malignant condition or a Tupperware party. 46,000 women a year lose their lives to breast cancer -- this is no Tupperware Party. And yet, Shockney's approach to breast cancer is shared by millions. Years of socialization instill within us the meaning of the feminine, the role it assigns to us. Cure ideology uses traditional femininity to distract women from substantive issues. It undermines serious discussions of breast cancer by continually returning to women's socialized roles, fears and preoccupations.

Invisibility: Two Breasts

"Up to 50% of women diagnosed with breast cancer are candidates for lumpectomy," writes Musa Mayer, "though only about half of them choose it" (*Examining Myself* 29). Mayer's theory is that medical practitioners are not encouraging breast conserving procedures, but are opting instead for full removal of one or both breasts.

Sociologists Susan Ferguson and Alice Gates look at the medical establishment's encouragement of breast surgery and report that "...in our examination of breast augmentation and reconstruction, it becomes clear that women with a different number of breasts or different sized breasts are considered deviant" ("Deformities' and 'Diseased': the Medicalization of Women's Breasts" 3). Paradoxically, though breasts are made central to female identity and worth, they are removed without fanfare.

Ferguson and Gates assert that "medicalizing" (read: pathologizing) the removal of one or both breasts creates a secondary disease for women with breast cancer. Missing one or both breasts becomes in itself a physical health deficiency which must be cured (18-19). To accomplish this, the Cure model prescribes reconstruction.

Author Karen de Balbian Verster explores the relationship between women, cancer and breasts in "Tabula Rasa." Describing her experience with two radiation technicians following a lumpectomy she says, "[J]ust about the whole world's seen [my breasts], though George and Ben have scrupulously managed to see only the right one. I imagine this isolation of the defective part is a carefully worked out consideration of my feelings. If they saw both at the same time they might get aroused since two breasts equal a woman while one breast equals a patient" (*The Breast* 75). Prosthetics and reconstruction complete

Verster's circle, facilitating the transition **back** from patient to woman through the appearance of two breasts.

"If you have had a mastectomy," asserts Nancy Brinker, "you will **need** to wear a breast prosthesis, which is an artificial device replacing your breast. Besides the obvious advantage of making the body look 'normal,' the prosthesis will keep your body weight balanced (*The Race is Run One Step at a Time* 166, emphasis added). Sandy, from *All I Know*, provides an alternative perspective. Regarding a prosthesis she says, "I just, I don't know, it seems, I can't... it just always felt like a very alien idea to have this thing on you to look like you have something you don't." Sandy's language suggests she is grappling with this imperative. Her struggle illuminates one place where Cure and Prevention ideologies collide.

Sandy challenges the Cure's articulation of a single breast cancer reality -- i.e. that a woman who has had a mastectomy will **need** to wear a prosthesis. Her opinion, however, is not one she seems to have come to easily. She has had to mediate between the Cure's equation of two-breastedness with normality and beauty, and Prevention's emphasis on breast cancer visibility.

It's hard. It's hard to be a one-breasted woman. Yet, it's really important to me. The day I got my diagnosis, I went out and bought Audre Lorde's *Cancer Journals*. And, I remember sitting up in the middle of the night (I couldn't sleep), reading it. And she talks about how terrible it is, really, what we do to each other by hiding. And how we don't know each other (Sandy, *All I Know*).

Women who question prosthetics and reconstruction begin to embrace Prevention ideology. They distance themselves from the Cure's breast/body image preoccupation. This process toward liberation isn't always an easy one, as Sandy tells us, but it is a necessary one nonetheless.

The language of popular American discourse shames and repels those women who appear publicly with one or no breasts. In *Examining Myself*, Musa Mayer invites readers to join her as she struggles with difficult choices and inevitable contradictions -- including her decision to succumb to cultural expectations and wear a prosthesis. "Were it acceptable for a single-breasted woman not to wear a prosthesis in public, and were I able to do so without undue self-consciousness, there's no question in my mind that this is the choice that would feel most natural to me" (122). Mayer's initial reaction to her post-mastectomy body is also telling, referring to herself as a "circus freak," "half man, half woman" (38). This self-abnegation encapsulates American culture's emphasis on breasts and sex/gender identity. Women who choose to remain breastless add to the "moral contagion" characterization of cancer observed and articulated by Susan Sontag in *Illness as Metaphor*^{xi} (6). Shunning feminine propriety and

^{xi} Sontag developed the idea of being "morally contagious" to explain a phenomenon. She observed that family members and friends of people with cancer often separate themselves from their ill loved one. They create this distance **despite** understanding that cancer can not be caught (like the common cold) through contact with the afflicted. Essentially, they were removing themselves from the behaviors and practices of the person with cancer rather

decorum, which dictates (the appearance of) two breasts, is a subversive act; as such, it is responded to with disgust, disbelief and a kind of personal/national betrayal.

"I believe that socially sanctioned prosthesis is merely another way of keeping women with breast cancer silent and separate from each other," writes Audre Lorde. "For instance, what would happen if an army of one-breasted women descended upon congress..." (*The Cancer Journals* 16). Indeed. Prevention ideology reveals that prosthetics and reconstruction are not **necessities** for women's well-being. Rather, they are the Cure's tools for keeping women with breast cancer from seeing and knowing each other. These tools preoccupy women with fears of abnormality. They channel women's energy into body image anxieties. More and more women, however, are looking back to Audre Lorde.

Women **are** resisting what is expected of them: invisibility and traditional American definitions of attractiveness -- despite a life-threatening illness and body ravaging treatment (Batt 1994, Chechik 1987, Kahane 1995, Kaye 1991, Kushner 1973, Lorde 1980, Lynch 1986). They problematize the need for prosthetics and reconstruction. They **want** people to see them -- one breasted, no breasted -- to know what they are going through and why. When they feel sick,

than the person her/himself. Out of fear, they were escaping from cancer's risk factors and reminders.

they want it to show. They will not attempt to look good to make others feel better as Cure thinking requests: "Remember that seeing you look good is equally important to your friends and family as it is to you -- sometimes more so. Do make an effort to look your best, even if it's just a little lip gloss and blusher -- for their sake" (*The Race is Run One Step at a Time* 166).

Invisibility: Hair

Femininity and ladylike decorum also dictate that women have -- or appear to have -- hair. "...nothing can prepare a woman for the shock and embarrassment of baldness," writes Nancy Brinker (*The Race is Run One Step at a Time* 158). When chemotherapy causes a woman to lose her hair, the Cure model mandates wigs, hats or headwraps. Sandy in *All I Know* rejects the idea of a wig just as she did prosthetics. Narrator Cindy describes the pain of losing her hair as well as the personal dilemma she faced as a bald woman.

We had this unspoken routine, my husband and I. I'd go get the towel, and I'd go get the shampoo. And he would just get up from wherever he was and he would just kind of come out and just stand by the counter by the sink. And I'd wash my hair, and there would be more and more of it everyday on my hands, And then I'd cry, and I'd lean on his shoulder and cry and then we'd just go on. And then, finally, on Independence Day of '94 -- which was my last day with hair, really -- I was so tired of it, I went and sat on the toilet and just pulled my hair out into the trash basket in the bathroom. And just kind of cried...And I tried the wig on. And I hated it. I hated it in the store. I hated buying it. I hated everything about it. And I wore it through my entire bald phase for maybe five minutes in the bathroom... And I got hats. And I bought scarves. And I was initially worried, with a baseball cap, that you'd see the back. And I wore a scarf underneath, and tried to hide it. And then I, I wasn't fooling anybody. And I wandered around the house with no

hat on at all. And just kept this hat hanging on a door knob in case anybody came over.

If one exists at all, the line between covering and disguising is thin. For Cindy, however, this distinction is significant. She chose to cover her hairless head, but she drew the line at trying to look like she has something she does not. Like Sandy, Cindy demonstrates the contradictions that can arise when Cure and Prevention meet: when our socialization collides with our lived experience.

Cultural standards of beauty are the same for women with and without breast cancer. They require constant upkeep and discipline. They are unattainable for most of the female population. They consume time, energy and money (precious resources –particularly for women with breast cancer who face income-draining and immune system-draining treatment). They take us away from living. I wonder if any woman can come to a place in our demanding culture when she truly believes she looks good. And if she can reach this self-acceptance, will she be able to **feel** good, or has the road to looking good been too costly?

It is important to recognize that many women are demonstrating an interdependence between the aspirations of Prevention and the (beauty) imperatives of the Cure that is enlightened and useful. A hat, for example, seems to create for Cindy a sense of comfort and strength. From this place, she is able to operate within a Prevention framework and challenge the breast cancer establishment. A hat lessens her feelings of vulnerability, allowing her

confidence and anger to emerge. Audre Lorde even admits that “[cosmetic breast forms] can still serve a function...” **But**, she qualifies, they serve a function “...for the woman who is free enough to choose when and why she wears one or not” (*The Cancer Journals* 67). Such concepts of choice and consent are tenuous ones for women within patriarchy. And they will remain particularly difficult for women with breast cancer as long as the pressures of Cure ideology control the discourse.

Invisibility: Anger and Imagery

Cindy's struggle with hats and hair loss aligns with the beauty/body concerns of the Cure model; her anger and frustration with the breast cancer establishment, however, do not.

[The] women of my generation are really dropping like flies because of [breast cancer]. The statistics are going up; I understand it's one in eight women in their lifetime now. And it infuriates me when I read reports where officials try to deny that, or explain that, well, yeah, you'd have to live to be like ninety years old, so it's not **really** one in eight women. But it is one in eight women. I **know** women... Everybody knows somebody [with breast cancer]. Everybody has a personal experience. It's just infuriating to try to play it down and act like it's really nothing to be concerned about. Because it's something to be **more** concerned about than we are.

Anger is forbidden within the Cure model. It is considered categorically unfeminine -- an emotion reserved for men's righteous indignation. Anger should be replaced with the resignation prescribed by conventional femininity: a silent suffering like any other in a woman's life. Women trained in this approach

learn to raise their voices at high-society fund-raisers only -- in order to work with and praise the establishment. From this perspective, medicine's only downfall has been a lack of breast cancer research money. Fundraising efforts by the Komen Foundation will change that^{xii}.

Musa Mayer illustrates how deeply ingrained messages regarding women and anger really are. After several traumatic -- and possibly life-threatening -- experiences with oncologists, gynecologists and plastic surgeons, she still believed her anger was unacceptable:

Throughout my treatment, I tried to contain my anger about what had happened to me and keep it from contaminating my relationships with the medical people who took care of me, since I was so dependent upon them. A targetless, helpless rage ran around and around inside me, building up a charge, seeking an outlet. The least infraction could release my pent-up wrath. In the end, though, there was no one to blame; it was no one's fault I had cancer (*Examining Myself* 46).

Systematically suppressing women's anger limits the questions they might ask. It restricts the information they may discover. Mayer attributes her relationship with anger to a "natural tendency" (*Examining Myself* 53) -- a character flaw rather than a potentially conditioned response. The establishment is well served by creating her "dependence" and "helpless rage." Had Mayer not been so duly socialized, she might find a productive way to channel her anger.

^{xii} "Since its inception (in 1982), the foundation has raised more than \$39 million, funded more than two hundred national grants, and is the nation's largest private funder of research dedicated solely to breast cancer" (Brinker *The Race is Run One Step at a Time* xxi).

The Cure discourages not only anger, but seemingly any woman's chosen expression that strays from "polite conversation." When Dorothea Lynch was diagnosed with breast cancer in 1978, she began documenting her experience in writing and photographs (taken by her photographer partner, Eugene Richards). After an unsuccessful attempt to locate photos of a mastectomy (to see what one "looks like" -- they were told such pictures were "unsuitable" for "non-medical" people; *Exploding Into Life* 16), Dorothea and Eugene decided they must take some of their own for the women who were sure to follow. The final result was a posthumously published work entitled *Exploding Into Life* (1986). Carefully chosen, relatively few, words allow the photographs to hold the foreground: Dorothea shattered upon hearing the diagnosis; Dorothea exposing a fresh, weeping, sutured mastectomy incision; Dorothea in the midst of hours of chemo-induced vomiting; Dorothea bald, weak and frightened on a doctor's examining table. Raw. Real. One woman's uncensored experience. "All I am doing," says Dorothea about the "rubber tit" provided by the "lady from the medical fitters," "is making myself more acceptable to polite society" (*Exploding Into Life* 38). Very quickly, this kind of frankness in experience literature and public discourse was drowned out by sounds of hope, cheer and survival.

Dorothea's images contrast profoundly, for example, with those provided by Nancy Brinker in *The Race is Run One Step at a Time*: Nancy at fundraising events for the Susan G. Komen Foundation, Nancy with Annie Pearl Foster,

"twenty year-breast cancer survivor" (55). Brinker includes a few mastectomy photos, but they are juxtaposed with photos of reconstructions. The Cure's message is one of triumph, not tragedy. "Talk happiness," it tells women. "The world is sad enough without your woe" (Nancy Brinker quoting Ella Wheeler Wilcox, *The Race is Run One Step at a Time* 179). No anger. No pain. No death.

Positive, hopeful stories of victory over breast cancer still dominate our nation's discussion, but the number of notable exceptions is growing. In addition to authoring *The Journey Beyond Breast Cancer*, Virginia Soffa organized a traveling exhibit entitled *The Face of Breast Cancer* (156). This photographic essay only includes women who have **not** triumphed over breast cancer. It tells the stories of women who have **died** of breast cancer. Another work, Christina Middlebrook's work *Seeing the Crab* is -- as its subtitle explains -- *A Memoir of Dying*.

This kind of sanitized approach to breast cancer accounts in part for the establishment's resistance to prevention ideology. The language of prevention defies sugar-coating; it can be very ugly. On the other hand, language surrounding a cure is refined. It is pretty, even glamorous, like pink ribbons. Discussions of HIV/ AIDS and breast cancer are very much alike in this way: if talk focuses solely on a cure, the unpleasant language of true prevention can

remain unspoken: (oral and anal) sex, semen, vaginal fluid, blood, condoms...
pesticides, toxic waste, smog-filled air and undrinkable water... ^{xiii}

Conclusion

Statistically (and anatomically), it seems logical enough to categorize breast cancer as a "woman's disease." Cure ideology, however, uses this label to invoke essentialist notions of Woman and femininity. This woman's disease, it declares, simply calls for womanly solutions. Rather than revealing breast cancer for what it is -- a debilitating and fatal condition -- Cure ideology reduces breast cancer to a fashion crisis. No industry has emerged to help men with cancer to "look good...feel better." Traditional feminine socialization -- by design -- stifles women; as women with breast cancer grow louder, the establishment responds by bringing us back to what is really important: our beauty.

It is not surprising that as a culture, we are disturbed at the sight of one-breasted and bald women. Our definitions of beauty are so rigid, so demanding in their specifics, that two breasts and hair are barely worth mentioning. To speak of bodies so basic, is redundant: two breasts, some hair -- these are

^{xiii} A brief discussion of the environment can be found in Chapter 4. For further information on connections between the environment and breast cancer, readers are directed to the works presented in this paper as well as the work of Drs. Samuel Epstein, John W. Goffman and Mary S. Wolff. Another strongly suggested resource is the Environmental Research Foundation and its newsletter, *Rachel's Hazardous Waste*.

fundamentals. Large breasts, perky breasts, long hair, silky hair -- these are beautiful.

Programs like *Reach to Recovery* and *Look Good...Feel Better* are in a unique position if they can transcend the Cure ideology that guides them: they could deconstruct our culture's narrow ideas of feminine attractiveness. Through the telling experience that is breast cancer, they could reveal how beauty is used against women to control us, divide us, and manipulate our energy. They could play an integral role in **re-defining** beauty in this country. Programs like *Reach to Recovery* could take the pressures of unrealistic beauty off women with breast cancer. They could help women locate the beauty that has been and always will be theirs with or without breasts and hair. Imagine the role **this** revelation might play in healing.

The Cure's preoccupation with the appearance of breasts mirrors and informs our culture's same obsession. That so many women are developing cancer of this part of their bodies is the (un)natural result of what Alicia in *All I Know* calls a loss of the "sacred, sensual, sexual nature of breasts." It is the result of an unholy exploitation and commodification of nurturance incarnate:

The sacred sexual sensual nature of breasts
Has been exploited and twisted
Into a profit-making money machine
Seducing customers into buying everything
From auto parts on some greasy mechanic's calendar
To vitamins in natural food magazines.

Someone somewhere decided the ideal breasts
Were equivalent to those of a sixteen-year old pregnant girl-woman

Minus the pregnant belly.
 These so-called perfect breasts have become synonymous
 With desirability and attractiveness.

Is it any wonder that women get surgical implants
 To boost their self-esteem?
 Conforming their breasts to this manufactured image,
 Thousands of identical Barbie doll boobs? (*All I Know*)

While misogyny may not literally cause breast cancer, the irony Alicia asks us to witness should not be underestimated. Cancer is manifesting -- in unbelievable numbers -- in the objectified and appropriated bodies she describes. As a culture, we can explore this metaphorical relationship, or simply choose to ignore it and learn nothing about ourselves.

Wearing a bra for the first time was horrible. Boys at school teased and popped the closure strap against my back. Everybody stared. They saw me differently. As differently as I saw myself -- not like a girl anymore, but like a being in developmental limbo; unwittingly and reluctantly having entered into the realm of adult sexuality, yet feeling neither sexual nor like an adult. Somehow, somehow, I just knew: I was an object for men now. Walking tits.

Feminine. Non-confrontational. Cloaked in beauty and silence. To our deaths will women be sent minding our place. Ladies to the end.

Chapter Four Risk Factors / Blame Factors

Positionality

*Outside my window,
 Breast cancer is almost palpable in the air,
 the water.
 Not breast cancer itself,
 But the words which represent it,
 are launched by voices,
 propelled by air currents
 and foamy tides.
 Ideas float toward earth in breezes,
 But never settle;
 great gusts of wind
 assure their re-ascension.*

*I imagine that women unknown to me,
 But whom I call sisters,
 Sit as I do,
 perched on the edge
 of living room recliners
 and unmade beds.*

Straining to hear.

*These words could save our lives.
 Listening.
 Hoping.*

*Waiting for voices
 That will remove us from breast cancer's risk groups
 and out of harm's way.*

*Anything -- anything
 to ease our minds.*

*Katie Couric talks to us from The Today Show.
 We open McCall's and Self.*

Sandwiched between the latest winter fashions

*And a quiz to rate our bedroom behavior,
This life and death information
Might not be so hard to swallow.*

*But still,
 we rock,
 holding ourselves tightly,
Anticipating.*

*What finally reaches us
Fills me with rage and grief.*

Risk Factors

There's a lot of theories about why people get cancer and some of them encourage you to 'take responsibility' for your part in getting the cancer, and I had a very difficult time with that. And I had a very difficult time with just, the whole focus of the AMA cancer community, because I feel like the focus is on either that woman and what she inherited or how she lives her life (Lina, *All I Know*).

The American Cancer Society tells women that their chances of developing breast cancer are high if: they eat a high fat diet; they began menstruating before the age of 12; they had their first child after age thirty; they never had children; they entered menopause after age 55; they are old; they drink, they are fat or they have a history of breast cancer in their immediate family (American Cancer Society brochure, 1995). Similar to the detection/prevention equation, breast cancer's risk factors have become indistinguishable from its causes.

Information on risk factors is provided to women at face value with little or no explanation about the whys and hows. Subsequently, women learn that

belonging to one or more of these categories leads to the development of cancer. Unexplained, risk factors imply that poor, and possibly immoral, lifestyle choices give women breast cancer. "Seventy to 80 percent of the women who get breast cancer," however, "have none of the known risk factors except for age" (Batt, *Patient No More* 198). This manipulation of risk factors by the establishment creates a climate of blame for women with breast cancer, and for all women who fear developing breast cancer. Prevention ideology diffuses this blame by problematizing risk factors and situating them in a framework far larger than individual women, our histories and behaviors.

Looking Beyond the Blame: Environment

In 1962, Rachel Carson used words to paint a picture of a "town in the heart of America where all life seemed to live in harmony with its surroundings" (*Silent Spring* 1). The town she describes sounds like a dream. "Along the roads, laurel, viburnum and alder, great ferns and wildflowers delighted the traveler's eye through much of the year" (1-2). This town is the kind of place where casual passers-by decide they will settle. Farmlands prosper. Colors blaze and change with the seasons. Deer roam in the countryside. Streams are cold and clear. Birds migrate overhead. Carson says this town does not exist, but she creates a place that readers will fondly recognize or longingly wish for.

"Then a strange blight crept over the area and everything began to change. Some evil spell had settled on the community: mysterious maladies swept the flocks of chickens; the cattle and sheep sickened and died. Everywhere was a shadow of death" (*Silent Spring* 2). New life became unsustainable in this town: newborn animals, vegetation, fish in the once crystal streams all died. "There was

a strange stillness. The birds, for example -- where had they gone... It was a spring without voices" (2). A silent spring.

Silent Spring is Rachel Carson's warning for the future -- a profoundly somber prediction. But it was also an observation of the present. Carson says that every one of the devastating events she describes -- the death, the silence -- had actually happened somewhere before (3). She implores all of us to bear witness and keep the destruction from happening again.

In *Silent Spring*, Carson describes in detail the chemistry of household and commercial pesticides. She informs readers about "chlorinated hydrocarbons": chemicals such as DDT that are absorbed through the lungs and accumulate in fatty tissue (21). She talks about malathion, an insecticide generously used against mosquitoes and the Mediterranean fruit fly in the 1950's (31-32). Malathion belongs to another group of chemicals called "organic phosphates" which were discovered as a by-product of chemical weapons research in the 1930's (28). By design, these products target the central nervous system.

Carson gives readers important information. Knowing what is being sprayed into the air, soaking into the soil and absorbing into our lungs is critical. Even more important, however, *Silent Spring* emphasizes that these are man-made (17) pesticides. The beautiful town Carson creates did not die from an "evil spell" (2) as its citizens fear. On the contrary, "No witchcraft, no enemy action had silenced the rebirth of new life in this stricken world. The people had done it to themselves" (3).

Ironically, Carson had written only half of *Silent Spring* when she herself was diagnosed with breast cancer in 1960 (Batt, *Patient No More* 303). Her work bordered on scandalous and was nearly banned. Today, the Prevention model returns to Rachel Carson -- to *Silent Spring*'s fusion of science and poetry, fact and passion -- for guidance.

Environmental connections play a major role in *All I Know: Women and Breast Cancer in Oregon*; every narrator touches on the subject. The loudest and most strident voice, however, belongs to Elki. Elki radiates strength and vulnerability, fear and pain and anger. Every carefully chosen word is charged with frustration and urgency, spirituality and conviction.

From our childhood, we're accumulating poisons in our bodies all the time. The fact that they can't find a cause means they're looking in the wrong place. I think, when the food manufacturers say that there's only a small amount of pesticide in a piece of food, and it's... below a limit of danger, they're not acknowledging the fact that **everything** we eat has some pesticides. Every chemical we use in our cleaning or our hair dye or our make-up, all have chemicals, and they're not looking at what an accumulation of these things over time do. Again -- they cop out. They say it's an acceptable level. Well, I've got seven million 'acceptable level' pesticides in my body. What's it doing? (Elki, *All I Know*).

Elki advocates for holistic changes -- great sweeping changes to the way we live our daily lives. She questions how our society as a whole eats and cleans, grooms and produces. The Prevention ideology Elki is embracing looks to the environment to more accurately address the breast cancer epidemic. This approach removes blame from individual women; it shifts the focus from personal behaviors to cultural/societal behaviors.

Transforming the breast cancer dialogue is not easy, of course. Elki describes her own struggle to be heard by the establishment:

They have a run each year. The Komen Foundation sponsors a Race for the Cure. They interviewed women all week long, the week of the run. Again, they talked about mammograms and early detection. And interviewed some really bright women, and none of them talked about environmental factors. So, I went into my yearly 'write to the Komen Foundation routine' and I wrote a letter, as I did last year and the year before, saying that I want these eighteen thousand women to scream, not for a cure, but for a way to prevent it. (Elki, *All I Know*).

Like many women, *All I Know* narrator Alicia **did** look to the establishment's risk factors when she was diagnosed with breast cancer. She looked to her own body and behavior. "I was only 32 years old," she tells us. "There were no warnings. I thought I'd lived a pretty healthy lifestyle." Finding no answers, Alicia looked to the environment. "I thought I was kind of safe because I live way out here in the country. But what I'm discovering is that the Willamette Valley has major toxicity going on in the air."

By looking specifically at the Willamette Valley, Alicia presents a regionally unique discussion of the environment. Narrator Marci does as well. She looks to her home in Oregon to discover what might have caused her breast cancer: "I think to myself, okay, was it growing up in Eugene and breathing smoke every summer of my life for twenty years? Intense smoke from field-burning. Is that what happened?" Marci allows us to return to -- and re-examine - the town Rachel Carson described more than thirty years ago.

Lina, in *All I Know*, proposes a veritable planet-full of environmental explanations for cancer:

...there are so many things that are put on the woman who gets cancer, without looking at the whole world and all the pollutants in the world and how much the environment might affect her and how little work is being done toward preventing cancer. And that's something I'm very concerned about. I feel like there could be so much more done to help us not get cancer than is being done.

Instead of looking at the "whole world," the Cure model has looked to women and chosen to stop there.

Looking Beyond the Blame: Hormones

Four of the American Cancer Society's risk factors involve our bodies' hormonal environments. Women are considered high risk for breast cancer if: 1) they do not have children, 2) they were past the age of thirty when they had their first child, 3) they began menstruating before age twelve, and 4) they began menopause after age 55 (American Cancer Society brochure, 1995). These risk factors, however, are not presented to women within a hormonal context; they tend to appear in list form with no explanation at all.

Cure ideology traps women in a no-win situation: on the one hand, the Cure presents these factors at face value as if there were something inherently cancer-causing in each of them. A message is sent to women that choosing not to have children (or being unable to have children) is literally hazardous to our health.

We also learn from these risk factors that there is an objective standard of normalcy for our bodies' development. Bodies that begin menstruating after age 12 and cease menstruating before age 55 are normal, functioning bodies. They are good bodies, and good bodies do not get cancer.

On the other hand, when these risk factors **are** provided a hormonal context, our hormones become the cause of breast cancer -- they betray us. Breast tumors are tested to determine whether or not they are estrogen receptor positive (ER+). ER+ tumors literally feed off estrogen to live and grow (Batt, *Patient No*

More). As such, estrogen has been implicated in the development of breast cancer; estrogen has become a risk factor.

Tamoxifen, the most frequently prescribed breast cancer treatment in the world (Batt, *Patient No More* 113), works by inhibiting the body's production of estrogen (Soffa, *The Journey Beyond Breast Cancer* 197). The medical establishment is so convinced that estrogen is dangerous that a clinical trial is currently underway to study Tamoxifen as a breast cancer **prevention** medication (Batt 114). Researchers are manipulating the hormones of 8,000 women who are considered high risk for breast cancer -- but are otherwise healthy -- to make this determination. Once again, choice and consent become problematic concepts here. Women have not been forced to participate in the Tamoxifen trials, of course, but the label "high risk" generates an enormous amount of fear: it implies that for these women, breast cancer is unavoidable. Few options remain when the **same** voice -- the Cure's voice -- says it might have a way to prevent the inevitable.

Like Cindy in her struggle with hair and Sandy in struggle with prosthetics, Sharon Batt is pulled between Cure and Prevention, between her socialization and her lived experience regarding estrogen. "I feel the frustration that always surfaces when I think about breast cancer and hormones. Estrogen, the hormone made by women's bodies and essential to our femaleness, seems undeniably linked to breast cancer. I have breast cancer, so my hormones have

betrayed me" (*Patient No More* 112). Cure ideology is sending a strong message to women about our bodies: there is something inherently wrong with estrogen. Not only is such thinking biologically unsound, it feeds an anti-woman culture, and furthers women's self-doubt and hatred. Batt articulates a feeling of being betrayed by her body, but she is also able to challenge the ideology that instilled those feelings in the first place: "In my gut...I can't accept that the alternative is for women to submit to experiments to change our hormonal balance" (*Patient No More* 112).

Once again, the Cure model has chosen the easiest explanation for breast cancer, and the easiest way to prevent it: "medication is a simple and immediate solution, while behavioural changes take longer to bring about" (Batt 129). There are many ways, however, in which the estrogen/breast cancer link can be and should be problematized. Sharon Batt and Rachel Carson, for example, distinguish between "endogenous" and "exogenous" hormones. The former are produced by our bodies. The latter enter our system from an outside source (*Patient No More* 115, *Silent Spring* 237). Cure ideology implicates the estrogen that our bodies naturally produce (endogenous), but it does not scrutinize the estrogen we take in that originates externally. For example, xenoestrogens (such as pesticides and herbicides) and other estrogenic products (such as common household cleaners) contain chemicals which mimic the effects of estrogen within our bodies (Altman, *Waking Up, Fighting Back* 71-72). Nor does Cure ideology

seem willing to implicate hormone replacement therapy or the Pill. Hormones are give to younger women for a variety of reasons including migraines, period regulation and growth (Rothman & Caschetta, "Treating Health: Women and Medicine"). Rachel Carson also discusses chemicals that may disrupt liver function and subsequently lower the body's supply of B-vitamins. B-vitamins regulate endogenous estrogen in order to maintain safe levels (*Silent Spring* 237).

By settling for easy answers, the Cure paradigm vilifies women's hormones. It characterizes our bodies as defective and self-destructive. "To map the interplay between female hormones and breast cancer, we need more researchers who will approach the female body with wonder and respect for its difference from the male norm" (Batt 137). We need Prevention ideology.

Looking Beyond the Blame: Genetics

The Cure's risk factors reach even further into women's bodies, blaming us for cancer down to our very DNA. The "breast cancer genes," BRCA 1 and BRCA 2, are becoming familiar words in this country -- words which connote hope for curing breast cancer in the near future -- yet genetics only account for 5 to 10% of all breast cancer cases (Batt *Patient No More* 167).

In *All I Know*, Marci shares her take on and struggle with breast cancer and its genetic link. "I'm pretty sure, but...there's not exactly proof, that my family...has a genetic predisposition to breast and ovarian cancer." Marci, however, has not subscribed to the idea that she is somehow deficient on a

cellular level. She believes in a more complex theory about breast cancer involving genetics and the environment.

...it's only one step; so you can get close, that you can have a genetic mutation and that means just as it says, that you are susceptible to breast cancer. It doesn't mean necessarily that your genes will suddenly go crazy. But it does mean that all other influences, and I count many environmental influences, probably get you over the line in which your cells can no longer handle it (Marci, *All I Know*).

What Marci articulates is the "multi-hit" or "trigger" theory. "The multi-hit theory," explains Sharon Batt, "proposes that two or more mutations must take place before cancer develops" (*Patient No More* 171). The multi-hit and trigger theories confirm that indeed, our cells will **not** suddenly "go crazy." They must be set off by another source -- such as an environmental toxin.

Researchers working in the Human Genome Project, a gene "sequencing" research endeavor, intend to locate and map **every** human gene by the year 2005. A mere part of this project has been the "breast cancer gene." Gene mapping, gene patenting and the Human Genome Project are about discovery. They are part of the Cure perspective. Far from having women's best interests at heart, these geneticists attempt to surpass other teams of researchers. Success in their field (and the money, prestige and accolades which accompany it) mandates that they locate genes before others have the opportunity (Altman, *Waking Up, Fighting Back* 45). This masculinist model of competition is the Cure's game -- the Cure's war. Women's bodies are the playing field and battleground.

Like fixations on beauty and body, "the focus on breast cancer genetics... deflects our attention and resources from the search for the roots of the disease in our culture" (Batt 183)^{xiv}.

Looking Beyond the Blame: the Cancer Personality

Susan Sontag undertook *Illness as Metaphor* in response to the theories that attributed her own breast cancer to a pre-disposed "cancer personality" (Batt *Patient No More* 143). As I mention in my Introduction, Sontag documents socio-historical notions of cancer as a manifestation of severe and chronic emotional repression -- of a flawed character. Pop psychology theories typified by the Simonton^{xv} approach and Bernie Siegel's *Love, Medicine and Miracles* (1986) continue to work through a "cancer personality" framework. They ask people with cancer why they invited cancer into their lives.

Sharon Batt, Musa Mayer and Treya Killam Wilber (in *Grace and Grit*) write at great length about their explorations into alternative healing, part of which involved confrontations with emotional/ psychological approaches to cancer. And although these women critique such approaches, they also recognize

^{xiv} Ethical concerns regarding gene mapping and engineering extend far beyond what I cover here. Some insurance companies, for instance, are refusing to provide coverage to women known to carry the gene(s); BRCA1 and BRCA2 are said to constitute a "pre-existing" condition (Altman *Waking Up, Fighting Back*).

^{xv} The Simonton approach refers to the "mind/body" healing techniques designed by Carl Simonton, head of the Simonton Cancer Center in California and his former wife, psychologist Stephanie Matthews Simonton.

their seductiveness: even emotional/psychological explanations for breast cancer provide a *terra firma* -- a sense of control -- that random chance does not. Musa, in particular, recognizes herself in the description of the "cancer personality": "Nice, sweet, the doormat. Slow to anger and quick to put the needs of others before her own" (*Examining Myself* 76).

A corollary of the cancer personality theory is appealing as well; it proposes that if we have made ourselves sick, we can make ourselves well. Again, Cure and Prevention ideologies have collided, and women like Musa Mayer must negotiate the contradictions. In *Examining Myself*, she grapples with the cancer personality, acknowledging it as punishing, yet realizing it is virtually irresistible in its potential for answers -- and healing.

In *The Journey Beyond Breast Cancer*, Virginia Soffa credits the sudden disappearance of a breast lump to the self-healing power of visualization (66). [Her doctor, furious that he could no longer find the growth when Soffa was prepped for a previously scheduled biopsy -- yet determined not to be cuckolded -- incised the better portion of Soffa's breast. He found nothing (66-67)]. The significance here is that Soffa's belief in regenerative and self-healing powers is not predicated on having created or "invited" illness. She proposes that it is possible to possess self-healing abilities even though something outside of us made us sick.

Musa Mayer recounts psychologist Lawrence Le Shan's study of 500 cancer patients. "'The cancer patient,' he concluded, 'almost invariably is contemptuous of himself (sic), and of his (sic) abilities and possibilities'" (*Examining Myself* 96-97). Gloria Steinem has documented (and critiqued) how young girls' self-confidence and self-esteem are systematically destroyed as they enter adolescence. They are called on in classes less than their male peers, steered away from Math and the Sciences, told to abandon their dreams as "unfeminine," for boys only, or simply out of reach... (*Revolution From Within* 1992). Abuse, discrimination, the internalization a multitude of anti-girl and anti-woman messages, just could lead us to be "contemptuous" of ourselves, our abilities and possibilities.

Women bear a unique burden and a special blame in that the "cancer personality" also describes traditional feminine socialization: repressed anger; repressed hostility; self-sacrifice. Women are taught early on that we are good and that we will be loved if we take care of others instead of ourselves. Cure ideology tells us this as well: "Fair or not, don't be surprised to discover that just when you need to be comforted and nurtured more than at anytime in your life, *you* are the one doing much of the comforting and nurturing. That, my friends, goes with the territory of being a woman" (Brinker, *The Race is Run One Step at a Time* 180). If there is a "cancer personality," women are trained to embody it. If

such a personality type is imaginary, the establishment has still succeeded in blaming individuals for cancer.

I had another friend who said... she was so glad she had cancer, because now she knew what to do not to get it again and that was that she had never said 'no.' She was never able to say 'no.' And I think that goes with women of my generation. We were brought up to serve, to be quiet, to not complain, and that's the kind of women I see in these support groups; nice, sweet ladies, just like me, and they're the ones who've gotten it, and it's almost like they buried themselves to take care of everybody else, and this is what happened for whatever reason (Kay, *All I Know*).

Arguably, the "never say no" portion of traditional female socialization hasn't yet disappeared. Based on her experience coming of age in the 1940s and 50's, however, Kay develops a theory. Breast cancer as metaphor: socialized femininity, woman's role and place, as cancer's breeding ground. Through our conditioning, woman are buried alive, a protracted spiritual killing, until the bodies of 46,000 a year finally succumb.

So effective are insinuations of blame that even women who have exposed and criticized risk factors have trouble shaking guilty feelings.

'I've always worried it might be in the family,' my mother confided, when I raised the subject. She had some cousins who had breast cancer, and then her sister Min was diagnosed. With my premenopausal diagnosis, my two younger sisters were now considered high risk. Although I knew this reaction was irrational, I felt vaguely guilty about this, as if I were some kind of tainted seed, fouling the family bloodline. The thought of my five nieces also stirred queasy feelings. Three were adolescents, the other two had the innocent vulnerability of childhood; if Aunt Min was my early warning, was I theirs? (Batt 167).

The Cure's cancer personality acts as a directive. It controls women's lives and decisions. In *My Breast*, for example, Joyce Wadler speaks of toying with the possibility that a prolonged, stressful, working trip to France may have caused her breast cancer. She should not have gone. Whether or not Wadler's introspections are accurate or even possible, the message is unmistakable: women should not be flying abroad, furthering their careers. They should be home, less driven and more focused on others. Wadler's breast cancer is her own fault.

Conclusion

Many women who are telling their stories discuss some process or phase of blaming themselves for their cancer (Batt 1994, Butler & Rosenblum 1991, Chechik 1987, Mayer 1994, Shockney 1995, Wadler 1992, Wilber 1993). We are taught to hold ourselves responsible for every difficulty in our lives from violent male partners to dysfunctional children to cancer. We must have done something wrong. Something to deserve our pain, our malaise. If we were only better wives and mothers, we would not get beaten, and our kids would have turned out all right. With risk factors as a guide, the Cure model uses women's socialized self-blame against us.

Not only does Prevention ideology move the discourse away from blaming women, it opens the door to larger questions about access and power. Who are the guardians of information in our stratified society? How much should marginalized, underserved people be allowed to know? And is a paternalistic power structure discriminately picking and choosing what it wants women to know about breast cancer?

Risk factors are handed to women, unaccompanied by commentary or explanation. Subsequently, they carry with them an implied hyper-text which sounds something like this: cancer is **our** fault because we transgressed against our maternal natures or abandoned the upkeep of our girlish figures and let ourselves grow fat. Or we dared to get old, hags and spinsters who should have died while still young and beautiful. Perhaps we were born defective, drowning in the pool of our mothers' mutated genes, our periods started too early and stopped too late. Risk factors as presented by the breast cancer establishment leave women with a battle that begins and ends in our own bodies, and both camps are within us.

Chapter Five

What Women Know (And How They Know It)

Research

When a positive breast cancer diagnosis is forthcoming, women are usually given a matter of days to make the most important decisions of their lives; fear panic and a doctor's authoritative voice become their guides. "As soon as he (the doctor) walked in the room I could just, I knew, I said, 'it's bad, isn't it?' and he said, 'it's malignant, you have breast cancer and you have about ten days to make a decision (Cindy, *All I Know*). Alienated to a great extent from the diagnostic process, women are thrust into positions of intense responsibility once a diagnosis has been made. As quickly as possible, not only do women need to let the reality of a life-threatening illness sink in, they have to become oncologists, radiation technicians, surgeons... Cindy articulates the enormity of these options, of having to choose quickly between lumpectomy, chemotherapy and radiation or mastectomy, chemotherapy and no radiation. "And I just got hysterical," she tells us. "I was just crying and saying, 'I think I'm gonna die. I feel like I just got a death sentence.'" Lina took on her treatment options like "a job (she) wanted to do really well because (her) life depended on it." Everyday, Lina created lists of what she wanted to learn and people she wanted to talk to. And she gathered a team of friends to assist with the enormous amount of work

ahead. She, like many other women diagnosed with breast cancer, became a researcher.

- Every woman has a militant responsibility to involve herself actively with her own health. We owe ourselves the protection of all the information we can acquire about the treatment of cancer and its causes, as well as about the recent findings concerning immunology, nutrition, environment, and stress. And we owe ourselves this information *before* we may have a reason to use it (Lorde 73).

This "militant responsibility" Audre Lorde defines falls on us as a consequence of the Medical Establishment's marginalization. Gaps in information or no information at all (apart from the multiple choice options described by Cindy) have transformed women with breast cancer into instant medical students cramming for the exam of their lives.

Like any academic endeavor, the role of researcher requires not only focus and diligence, but balance. Sharon Batt, Musa Mayer and Treya Wilber explored both alternative and traditional Western treatments and found the volume of options overwhelming. Batt, in particular, struggled with needing medical expertise, yet recognizing the danger of any woman ceding too much control over her body to a patriarchal institution. Contrary to what she had always learned, Musa discovered that her doctors had no answers for her following her diagnosis. She wanted to find empowerment in the decision-making process, in personally tailoring her treatment, but was petrified of making the wrong decision. She wanted objective, easily quantified information telling her what would help her and what wouldn't. Becoming a researcher was her only clear option.

Patient empowerment is good and advisable in any situation, but the gender dynamics at work here are worth discussing. It would appear women with breast cancer have two possibilities: entrust their care to their doctors

completely, or become doctors themselves. The added burden of the latter understandably may lead women to revert to the former, and the feminine deference of the Cure paradigm is sealed. In *Cancer in Two Voices*, Sandra Butler says of her partner Barbara Rosenblum,

Once the diagnosis was made, once the cancer was discovered, she began to research obsessively. Chemotherapy first? Surgery first? Radiation with lumpectomy was ruled out. There was a blur of days filled with doctors, examinations, treatment recommendations, yellow pads filled with questions and answers, and Barbara with her pocket tape recorder chronicling each doctor's answers in case she grew too anxious and could not hear what was being said (23).

Unfortunately, questioning physicians often happens only **after** a disaster.

Barbara was misdiagnosed for over a year; she and Sandy were left with no choice but to engage in intensive research, to shadow doctors as if they were medical students in a teaching hospital. The time to educate ourselves about cancer is, as Audre Lorde warns, **before** we have reason to apply our findings.

Using her own investigative research, Rose Kushner was able to end the "one-step" procedure of biopsy/mastectomy (from which a woman awakens not knowing if she has had a lump or an entire breast removed). Kushner credits the women's liberation movement, media attention and consumer rights activism with creating a shift from extended radical mastectomies to radical and finally, the modified radical^{xvi}.

^{xvi} The extended radical mastectomy (a 19th Century procedure still occasionally performed throughout the 1970's) removes the breast, the lymph nodes, the pectoral muscles and a section of the ribcage. The radical, or Halsted, mastectomy, a turn-of-the-century procedure rarely done today, leaves the

[W]omen have demanded the opportunity to have some say in their destinies. What [this] has done is to send physicians and surgeons back to their books and classrooms to learn more about the biology of breast cancer (Kushner, "The Politics of Breast Cancer" 189).

Following history's patterns, backlash quickly followed Kushner's words, checking the power she and other women were gaining and expressing about breast cancer. Only now do we see a renewal of their activism. Still, the struggle to emerge through a rock-solid status quo is long and difficult. Kushner is our legacy, squelched by backlash, returning through the stories of women with breast cancer.

Research is difficult not only because it is an extra burden on top of surgery, chemotherapy and the work of survival, but because it is out of reach for many women with breast cancer. Medical resources are more accessible to some women than others. Lillie Shockney, for example, was employed at Johns Hopkins University Hospital at the time of her diagnosis; Barbara Rosenblum and Sandra Butler are writers and academics; Treya Wilber's husband Ken is an internationally renowned philosopher/psychologist. It is still possible, however, to call "experts" those women who are unable, due to material or circumstantial constraints, to concentrate on researching breast cancer.

Inadvertently, I had touched the place where my right breast begins to swell into fullness. And there beneath my fingers was a lump. It was as if this fleshy thickening had wanted my attention, had deliberately, insistently, pushed itself up against my fingers (Wittman *Breast Cancer Journal: a Century of Petals* 7).

Women have learned to ignore this way of knowing our bodies and health. The mitigation of our knowledge as "women's intuition" and "old wives' tales" has led

ribcage in tact, but it does remove the fat between the skin and chest wall. Common today (in addition to lumpectomy which removes only the tumor and surrounding tissue) is the modified radical mastectomy through which only the breast and lymph nodes are removed (Kushner "The Politics of Cancer" 188).

us to trust technology over sensation. And yet, this fundamental relationship with our physical selves must be primary -- over and above our relationship with our physicians. Simply by virtue of living in our bodies, we know them best, what they feel like, when they change. In the examining room, we can declare ourselves lay experts.

Now who's in a better position in this circumstance to know... the person whose body it is? The person who knows what her breast feels like? Or a doctor who does medical evaluations, routinely, an array of them... and now looks back on a chart and tries to tell us what was... there? (Chechik, *Journey to Justice* 128-129).

Diane Craig Chechik had to wade through several apathetic attorneys first, but these are the closing words of a malpractice hearing against her doctor of twenty years. She won.

What Women Know (And What They Do Not)

Honoring the stories of women with breast cancer (especially those which subvert the Cure paradigm) means honoring what those women know outside the realm of "hard," linear (medical) science. The ultimate in agency is recognizing those women with breast cancer as **the** most knowledgeable of their bodies and condition. This reality granted, what and how women with breast cancer know about causes, treatment, prognosis, prevalence, etc., tend to differ greatly from science, and therefore tend to be invalidated by the medical institution. What women know is about possibility and promise.

The breast cancer establishment refuses to recognize its own contradictions and misunderstandings. Such a process requires recognizing and relinquishing privilege and **listening** to women. Conceding a lack of omniscience is not typically part of Western patriarchal medicine. Nor, certainly, is it a part of the Cure perspective. It needs to be.

Women with breast cancer do not have all the answers, but their experiences prove that it is possible to learn from what women **do** know, rather than discounting them for what they don't. This difference in approach epitomizes the Prevention and Cure models respectively. And it is the recognition of this difference that gives *All I Know: Women and Breast Cancer in Oregon* its name.

In the video, for example, Alicia contributes something that she has learned -- something she **knows**: "there is a definite correlation between dioxin and breast cancer." She does not know how polluted air goes from our lungs into breast tissue to create cancer, but she **does** know that "Weyerhaeuser is 10, 15 miles from here by the way the crow flies, and they've been putting dioxins into the environment for years and years and years." Does she have to know the rest? Must she know the physiology -- the multitude of electrical, hormonal and metabolic processes? Western medicine would say "yes" and scold her for her lack of scientific evidence and expertise. Women, however, can begin to say "no" and regard Alicia's words as valuable and instructive.

Marci also asks questions about the source of her cancer: was it the smoke from field burning? Was it the pesticides and fertilizers on the crops she used to pick as a child? Her on-camera search ends with a confession: "I don't even know." But Marci acknowledges possibilities, and possibilities are critical when we heed Elki's words: "The fact that they can't find a cause means they're looking in the wrong place." Perhaps what women know will lead them to the right place.

Kay leads us back to gender socialization and the expectations placed on the women of her generation. Now in their 50's and 60's, the women of her generation "were brought up to serve, to be quiet, to not complain..." **These** are the women who are getting cancer for, as Kay says, "whatever reason." Kay can not pinpoint the reason; perhaps she does not know or does not have the words to explain. But she **does** have a theory. She **does** know what was expected of her peers, and she knows they are dying of breast cancer now. Her experience provides yet another way to think about breast cancer if we choose to listen -- if the Cure chooses to listen.

All Sandy knows is that she has cancer. And three friends were diagnosed last month; one more this month. Cindy knows that the number of women afflicted with breast cancer is extraordinary -- and that it is being minimized by the establishment. What Cindy knows can not be disputed: her sister, her

neighbor, her friend and herself all have or have died from breast cancer. This way of knowing must be validated.

The voices of women with breast cancer are critical to the learning process. Through their stories, we are able to see the complexities of this issue. We need to listen to the expertise of women with breast cancer. We need to listen to the women we have lost.

Connections

While the Cure paradigm focuses on mammograms, risk factors and looking good, Ali asks: "what's happened to the beautiful places?" Prevention ideology asserts that human disconnection from and destruction of the earth has had dire consequences for both. Essentially, this is the environmental perspective I have already discussed, but another step further. This human connection to earth is not about humans managing the earth or living on earth. It is about being inseparable and indistinguishable from the earth. "I think there's a metaphor," Ali continues,

...if we bury more of nature, we're just burying more of our problems. It's like we just bury the problem with cancer. We don't look and dig into all aspects that might be causing the really almost epidemic proportions of cancers we're seeing. And not just breast cancer, but all kinds of diseases that people say, 'well, they're diseases of old age,' but they're diseases of the earth that are manifesting in people.

Rather than settling for the simplicity of blame and early detection, Prevention delves into the complex relationship among humans, non-human animals and the planet.

"A lot of people are getting cancer; a lot of people are dying. It's a really toxic world we've created at this point, and I'm a part of that." Alicia speaks these words not to blame, but to create a web of human accountability. We are all implicated, and we all must change. Breast cancer should be a wake-up call, Ali tells us -- "a symptom of a deeper healing that needs to be done on how we treat the earth, how we treat one another, and a healing just of how we value life in general." Through such an analysis, the Cure paradigm's one-dimensional explanations for breast cancer fall away, superficial and short-sighted.

Terry Tempest Williams' *Refuge* typifies an integrated, holistic approach to breast cancer. It is a journey through landscapes: Utah's Great Salt Lake, nearby Bear River Migratory Bird Refuge and women's bodies. These three places sound separate, different, easily differentiated and distinguished. Williams' purpose, however, is to communicate a connection among these natural bodies. An autobiographical work, *Refuge* documents an important time in Williams' life: the rise of the Great Salt Lake, a subsequent threat to the Bear River Migratory Bird Refuge, and her mother's second diagnosis of cancer. "Volunteers are beginning to reconstruct the marshes just as I am trying to reconstruct my life...[M]ost of the women in my family are dead. Cancer" (3). An epilogue recounts Terry's own diagnosis of breast cancer following her mother's death. Profoundly and beautifully, Williams shows us that we are no different than the Lake or the birds she knows by name at the Refuge. Not only symbolic and metaphorical, our interconnection is literal. Change in one is change in all others. This is what she knows.

Simplification is a sure sign of privilege. Easy answers never come from the margins. Individuals who have been defined, restricted and persecuted by societal definitives tend not to embrace such notions of "black and white." Re-connecting with the earth, with each other, requires diligence; it requires the

courage to ask essay questions rather than multiple-choice. The Cure paradigm asks for unconditional trust in one-word answers, technology, and a singular approach to our bodies and healing. Dismissing the environment and human pollution is easier than discussing it -- truthfully, openly, rigorously. "Risk factors" are their multiple-choices; we choose one and assign it to ourselves, an easy answer to a condition that may end our lives. Those in power, those with little or nothing to lose (except research money and reputation) give us answers reminiscent of elementary school, rejecting the more sophisticated, provocative dialogue of nuance and possibility. As a part of this system, we glean to these easy one-dimensional explanations in a life-threatening situation. We cling to a way of thinking we've always known -- a way of looking and living that is familiar to us. Breast cancer provides enough change, enough disruption, enough fear.

Something important has happened. Something spiritual, life altering. The result of research, my subconscious and a high fever colliding.

Something is wrong and getting worse. Thinking I am going to be sick, I gather my strength and walk to the bathroom, one arm around my partner Jodi.

Suddenly, the feelings and sensations that have been developing gradually over an hour speed up. I am sobbing, more afraid than I can ever remember being in my life, trying to focus on Jodi's face, yet knowing I am losing her. Hot. Flushed. Shaking. I back away from my body, watch myself panic, listen to myself yell.

I call out several times to my roommate Mary. She runs to me. I ask for a doctor. "Call a doctor, a doctor, doctor." I'm dying. I'm fading. You're slipping away. Jodi. My family. I see my funeral. I hear my voice from far away.

We slump down on the bathroom floor, my hands held by treasured friends who speak soft words of reassurance. Of life. I drift in and out, sometimes present with Jodi and Mary, other moments leaving them for some other place, my body still in the bathroom, but not my mind or soul.

Unable to vomit, I am eventually returned to bed where I continue to drift and return. Mary calls my name when I frown or shake or talk out loud. She says that my head is twitching and wonders why. I'm too distracted to explain that I am nodding "yes" and shaking "no" in tune with a conversation only I can hear. A discussion in my mind requiring few words, sometimes only a sound, because the women with whom I speak know exactly what I'm talking about. They understand me, and I them, for at this moment we are all women with breast cancer.

I speak with these women about needle biopsies, being ER+, taxol and tamoxifen and the damage it does to the eyes. I inform Mary about adriamycin, a commonly prescribed chemotherapy drug that can damage the heart as it kills cancer cells. To protect the heart, another drug is prescribed; one, unfortunately, that can also tear up the stomach. And I remember the man on the breast cancer list who said it caused his wife to vomit sheets of stomach tissue.

My "sleeping" and "waking" realities are inseparable. Mary continues to call my name when the pain of my "conversations" shows on my face. I open my eyes, always with a start and a new fear. Tears roll down my cheeks. What am I afraid of, Mary asks. Why am I crying? I'm still convinced that the doctors are coming. Or perhaps they already have, and I will soon open my eyes to the white of a hospital room. I catch a glimpse of Mary picking up a water bottle for a drink, and I think she is a nurse hanging an IV bag. She calls to me again and I wake up startled, believing someone is going to take my blood. My new women friends and I talk about the needles we face over and over again and how our veins are weakening. I hear Jodi breathing behind me and think it is my respirator. The conversation in my head continues and finally, finally I need to throw up. The result of chemotherapy, I believe, and the end of my time as a woman with breast cancer. I purge until empty and exhausted, feeling not like my "old" self, but returned to the familiarity of my body. Instinctively, I know that nothing will ever be the same.

Luxury is a fever that breaks.

Chapter Six Conclusion

Our dialogue around breast cancer ends when we are directed no further than our own self-image. We need to find a new way to talk about this condition -- with discovery rather than blame, gravity rather than frivolity. It is painful to hear women who are fighting for their lives find attribute their breast cancer to failings in themselves and their living. It is disheartening when they refer to their bodies as enemies, and find salvation in mammograms, pink ribbons and a ladylike death. But I have also heard hope. Other women vehemently denounce the blame. They are finding new ways to think about their diagnosis. They are creating new possibilities for understanding -- and someday ending -- breast cancer. They are re-examining the voices that place responsibility for the whole world on their shoulders.

Victim-blaming, an old and effective tool of patriarchal oppression, has left women to suffer, silent and solitary. In the 1970's, consciousness-raising groups achieved a temporary end to this isolation; they facilitated support and sisterhood and provided a source of responsibility for women's pain other than the women themselves. Backlash from a threatened power structure has severed these bonds, renewed our isolation and diffused the collective power of women. Support groups are bringing women together again, but perhaps the strongest

and most enduring source of breast cancer consciousness in the 1990's is flowing through experience literature.

Referring to the concept of *jouissance* coined by French feminists, author Ann Rosalind Jones says that "to write from the body is to recreate the world" ("Writing the Body: Toward and understanding of L'écriture feminine 252). The *jouissance* is about resistance: resistance of a psychosexual nature. It is a tactic for reclaiming women's sexuality from the hands of Western, masculinist phallocentrism. Jones asserts that the *jouissance* is an intrinsically French idea, but she also believes it can speak to American women and should be embraced by them. Women with breast cancer can recreate and reclaim the body by writing from it; they can wrest their beauty and sexuality, their very lives from the hands of a sexist culture that equates breasts with womanhood, femininity and worth.

As I have watched *All I Know*, read the current literature around breast cancer, and heard women's stories over the internet, I have realized that women **must** tell their stories. "How do I disclose and to whom?" asks Barbara Rosenblum in *Cancer in Two Voices*. "Under what conditions does disclosure become relevant? Give it language, it becomes exposed to air. It breathes, it's alive...to tell is to make real. I must. I am impelled to reach out" (39). Women with breast cancer also yearn to hear stories from other women with breast cancer. "I wanted stories. I hungered to read about the particular doubts, the fears, the isolation, the small satisfactions, the frustrations and triumphs -- in

short, the entire inner life of the woman living through a breast cancer diagnosis, its treatment and aftermath (Mayer, *Examining Myself* 73).

Barbara Rosenblum and Musa Mayer show us that choosing to share a breast cancer story is like taking off a hat that disguises a hairless head. It exposes. But it must be done. The vulnerability, the pull toward staying silent while wanting to be heard -- this is the place where Cure and Prevention meet. Writing builds a bridge between these ideologies so that women may cross between them. It bridges the gap in understanding between Cure and Prevention and creates a new mythology: a woman-centered mythology. What the future holds for breast cancer hinges on women's words.

Women with and without breast cancer are obliged to listen to experience stories. We must bear witness, so Musa Mayer will no longer have to decry that "[M]ore of my sex die unremarked and uncelebrated than men do, a sad and final chauvinism" (157). Telling our truths was once part of our oral tradition. Now they are recorded by pens and keyboards, on paper and through cyberspace.

I was going to die, if not sooner then later, whether or not I had ever spoken myself. My silences had not protected me. Your silence will not protect you. But for every real word spoken, for every attempt I had ever made to speak those truths for which I am still seeking, I had made contact with other women while we examined the words to fit a world in which we all believed, bridging our differences. And it was the concern and caring of all those women which gave me strength and enabled me to scrutinize the essentials of my living (Lorde, *The Cancer Journals* 20).

When I began studying breast cancer two years ago, I had just asked my mother if she'd had her yearly mammogram. I introduced myself to the breast cancer list as a woman with fibrocystic disease and a high-risk family history. Other women have been my liberation. Where I am now is less fatalistic, less passive. No longer do I live in a box of biological or cultural inevitabilities.

Today. Early morning. Can't sleep. Breast cancer clings to me like skin. That fresh layer following a scrubbing or a sunburn that has peeled. Deceptive in its shining beauty, painful to the touch. I contemplate my left nipple. It itches and seems to be puckering on the right side. A gold-leafed journal sits on the desk in front of me -- a present from a friend. I open it for the first time, listen to the crack of its binding and prepare to write. This is my story.

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