The Cultural Construction of Risk Understandings through Illness Narratives

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A study of breast cancer screening and treatment decisions suggests that risk understandings are influenced by the dominant illness narrative of restitution within Anglo-Western cultures. Restitution stories reflect the cultural values of personal responsibility and control in combating disease and returning to a life of normalcy. In the context of breast cancer, individuals seek restitution by following the dictums of biomedicine, which promotes early detection as prevention, aggressive treatment as cure, and reconstructive surgery as concealment. Our findings suggest that these risk understandings contribute to the consumption of health-care interventions that exceeds medical guidelines in this country.

In the spring of 1992, Emma, a 41-year-old married woman, was diagnosed with early-stage breast cancer in one breast. She was given two treatment alternatives from her doctor: (1) lumpectomy (breast-conserving surgery [BCS] with removal of cancerous tissues) followed by radiation or (2) mastectomy, the complete removal of the breast with or without reconstruction. Although medical research since the mid-eighties (Fisher et al. 2002) shows that there is no significant difference in the long-term survival rates between women with breast cancer who are candidates for and undergo lumpectomy surgery versus those who choose mastectomy surgery, Emma chose mastectomy with reconstruction. This is what she said about her decision:

> *Emma:* So, I had the choice of a lumpectomy or mastectomy, and I would say, believe it or not, the hardest decision process was determining between a lumpectomy or mastectomy with reconstruction. I just went back and forth and back and forth. I knew that if I got the mastectomy, I would definitely get the reconstruction with it. That much I knew. I just personally did not want to have a mastectomy. But what is interesting, somehow, psychologically, even though statistics show that a lumpectomy would certainly be effective, psychologically, I felt the mastectomy would accomplish it better than a lumpectomy. So, I guess all those factors went into the decision.
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> *Interviewer:* More effective in . . . ?
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> *Emma:* Eliminating the cancer and the eventual cure.
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> *Interviewer:* Psychologically, it feels more reassuring?
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> *Emma:* It does. It does. And there is no basis for it. I've heard it voiced by other women, which is very interesting.

Surprisingly, Emma's choice of mastectomy over lumpectomy is representative of many women's choices regarding early-stage breast cancer (e.g., DCIS [ductal carcinoma in situ]) treatment in the United States. While the percentage of eligible women who chose a breast-conserving treatment increased significantly from 57% in 1992 to 72% in 1999, a large number of women continue to choose mastectomy, the intrusiveness of which exceeds current medical standards (Baxter et al. 2004). The results of a recent survey show that 74% of women diagnosed with early-stage breast cancer chose BCS even though 82% of their physicians recommended the procedure (Fagerlin et al. 2006). Despite a consensus recommendation from the National Institutes of Health (NIH) that lumpectomy plus radiation was their treatment of choice for early-stage breast cancer (NIH 1990), the United States continues to have the highest rate of mastectomy surgery among 21 industrialized countries (http://www.breastcancer.org). This is an important concern, especially since increases in the availability and sophistication

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of mammographic screening have contributed to DCIS now accounting for approximately 20% of all breast cancer cases (http://www.natlbcc.org).

Although medical statistics suggest that mastectomy may be overused in this country, focusing on the relative rate of mastectomy versus BCS reveals limited insight into the underlying motivations for these decisions (Fagerlin et al. 2006; Lantz, Zemencuk, and Katz 2002). Why would a person knowingly undertake a far more severe form of treatment when a lesser one would suffice? To answer this question, we consider the framing of individual risk understandings by the broader cultural discourses surrounding the disease. Descriptive accounts from women treated for breast cancer provide the research context for interpreting the construction of risk understandings in health-care decisions. Our informants' stories suggest that their screening and treatment decisions are influenced by the predilection toward restitution narratives in Anglo-Western societies. Reflecting culturally structured values toward illness, the dominant narrative of restitution is reinforced by the long-established biomedical model through its emphasis on personal agency, control, and survival (Klawiter 2000). It connects breast cancer to the display of normative femininities, mobilizes hope and faith in science and interventionist medicine, and promotes biomedical research and early detection.

The mind-set that women must follow the twin doctrines of the biomedical model (early detection and radical mastectomy) has been perpetuated, until recent years, by leading medical institutions that continue to have prevailing cultural currency within the breast cancer survivor community. Individual decisions are embedded within this model of illness, which envelops the historical development of breast cancer treatment and prevention procedures and the social discourses that define survivorship within a middle-class, Anglo-Western context (Lupton 2003). We find that our informants largely oversubscribe to these discourses that shape and define individual understandings of the nature of the disease and the risks associated with detection, treatment, and reconstructive surgery. Consistent with the plot of the restitution narrative, over 100 years of public messages have encouraged women to be vigilant in detection, aggressive in treatment, and conformist in maintaining appearances. Despite recent medical findings that show that breast cancer has significant biological variability and that it is the nature of these biological factors rather than the speed of detection and aggressiveness of treatment that is more likely to determine survival, the dogma of biomedicine continues to persist (Batt 1994; Leopold 1999).

Women's decisions in the context of breast cancer reveal an overdependence and deep-seated faith in biomedicine (Carey 2006) that exceeds evidence-based medicine, which is defined as the specific use of current best evidence in making decisions about the care of patients (Sackett et al. 1996). The impact of these beliefs in restitution through aggressive detection and treatment is reflected in a broader sense by statistics on overall health-care consumption in this country. From breast cancer and heart surgery to diabetes, there have been numerous reports from general interest (Deyo and Patrick 2005), business (Carey 2006), and public health (Cutler and Mcclellan 2001; Wennberg 2002) publications raising concerns about the overconsumption of and runaway spending on medical treatments. Although there are many underlying factors, such as medical incentive systems, access to health care, and availability of information and technology, that contribute to this complex issue, these reports also point to the unique cultural underpinning that exists in this country toward embracing interventionist medicine (Payer 1988). Simply disseminating medical statistics or using decision aids to inform consumers about their health-care options is not sufficient; we must also address the deeply entrenched illness narratives that frame their interpretations of medical and risk information. Until we understand why patients often choose difficult and expensive treatments that may not necessarily yield improvements in their quality of life or their odds of survival, increased efforts in education and intervention alone will not be enough to offset these implicit cultural biases (Whelan et al. 2004).

The current study provides several theoretical and practical contributions. First, it extends our understanding of motivations (e.g., self-transcendence [Celsi, Rose, and Leigh 1993] and reflexive doubt [Thompson 2005]) for volitional risk-taking behavior by examining decisions as the embodiment of culturally reinforced illness narratives and metaphors that are distributed throughout society (Arnould and Thompson 2005). Second, it illustrates how seemingly individual decisions are reflections of culturally endorsed meaning systems of biomedicine and illness, thereby facilitating knowledge of how future health-care strategies can be negotiated. This understanding could shed light on the overconsumption of health-care practices that do not lead to improvements in patients' welfare (O'Connell 2005) and the overtreatment of chronic conditions (Deyo and Patrick 2005; Wennberg 2002). Finally, it expands the cultural framework of illness narratives (Frank 1995) beyond an individual or interpersonal context to examine the construction of risk understandings through narratives at a broader sociocultural level. It focuses on how the sociocultural narrative of restitution is embraced in the individual pursuit of biomedical interventions related to detection, treatment, and bodily reconstruction. It also explores the emergent defiance against restitution and the adoption of alternative narratives that are more consonant with the lived experiences of breast cancer.

ILLNESS NARRATIVES AND CULTURAL UNDERSTANDINGS OF RISK

In modern societies, advances in science and technology have created an ever-increasing awareness of the nature of risks, hazards, and dangers in our lives (Beck 1992). This focus on risk information reflects the most characteristic theme of contemporary Anglo-Western culture—the belief that we can exert control over each and every experience, including death itself (Prior 2000). The underlying assumption is that probability statistics used for risk assessment not only quantify but also tame uncertainty (Press, Fishman, and Koenig 2000). The democratization, availability, and appeal of risk information empowers individuals to actively negotiate and choose the risks they are willing to assume (Schrader-Frechette 1991). This is reflected in the now standard practice of requiring informed consent from patients in health-related decisions, which reinforces the idea that individuals are fully accountable for the risks to which they are exposed or choose to undertake (Douglas 1992).

While most average members of Western industrialized societies have access to medical information about their health, screening and treatment decisions are ultimately reliant upon the individual interpretation and understanding of this information. Research shows that there is an innate desire for humans to infer personal meanings from risk information in order to arrive at decisions (Shore 1996). People do not approach objective risk information as empty vessels but instead understand risks within the context of the real world in which they live (Lupton 2003). Especially in the complex domains of medicine and health care, scientific information cannot convey the social, cultural, and personal dimensions of illness. In this context, individual risk perceptions, experiences, and actions are better understood within the framework of others' personal narratives, historical accounts, and societal discourses (Mattingly 2000; Morris 1998). Illness narratives allow shared risk understandings to emerge and enable individuals to make some sense and order out of fear or diagnosis of a deadly disease (Becker 1974).

Frank's (1995, 1998) conceptualization of illness narratives provides an effective lens for examining the cultural values that frame individual risk understandings. Although stories about illness may come in a variety of forms (e.g., written, textual, oral), they are linked together by their overall understanding and articulation of illness and illness events, otherwise known as a narrative type. Different cultural contexts make available different narrative types, which are defined as the most general story lines that can be recognized underlying the plot and tensions of illness narratives. Frank (1995, 76) argues that creating a "general unifying view" of the individual experience of illness is advantageous because it helps to sort out both personal and cultural preferences for narrative types. However, sociocultural and institutional contexts may steer people toward certain narratives, and as a result, other narrative types may not be heard. While there are different approaches to categorizing illness narratives (e.g., story lines and life trajectories), Frank (1995, 1998) identifies three general types of stories: the *restitution story*, the *chaos story*, and the *quest story*.

The restitution story is culturally preferred and thus is the most prevalent type of illness narrative distributed within Anglo-Western cultures such as North America, Britain, and Australia (Lupton 2003). Consistent with the historical ascent of biomedicine and the superiority of technology in these cultures (Davis-Floyd 2003), restitution stories are optimistic and emphasize asserting control, becoming well, and "doing something" about the illness. The plot of the restitution narrative has the basic story line: "Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again" (Frank 1995, 77). Metaphoric phrases like "good as new" are at the core of the restitution narrative. Restitution stories can be told prospectively, retrospectively, and institutionally. Prospective restitution stories give patients the courage to face their upcoming treatments, no matter how numerous or severe, while retrospective restitution stories reassure patients that they are well, no matter how sick they were before. Medical institutions also prefer restitution stories, which promote control and cure through biomedicine. The grand narrative of the biomedical model reduces illness to a biological mechanism of cause and effect, while medicine itself is deconstructed into smaller and more controllable units (e.g., specialties and subspecialties, biology and microbiology; Morris 1998).

Chaos stories represent the opposite of restitution—their plots imagine life never getting better. Chaos stories provoke anxiety, deny control, and destroy the hope that modern medicine seeks to provide. The chaos story is diametrical to the restitution story in its emphasis on physical decline, lack of successful treatment, and resultant social, financial, and personal problems. Chaos stories are not only hard to acknowledge or hear, but, if told, are quite rare (e.g., Middlebrook 1996; Picardie 2000). Lived chaos makes reflection and, consequently, storytelling often impossible.

The quest story, by contrast, involves representing the illness experience as a "lived quest," or a condition from which something can be learned. Quest stories are told to keep chaos at bay. They provide an alternative story line for individuals to describe their illness experiences in terms of positive life changes, such as becoming involved in patient advocacy and making significant vocational and personal adjustments. Even though quest stories may not involve complete recovery from the illness as in restitution stories, they are far more socially tolerable, and thus more often heard, than stories of chaos. The quest narrative provides an understanding of the illness experience in a way that makes it not transitory, as in restitution stories, as it recognizes the moral duty of sharing the illness experience. Quest stories are often told as testimonials of living with cancer.

Within the breast cancer community, narratives that build on restitution stories and discourses of control and certainty through biomedicine are desired and promoted by medical institutions and dominant survivor groups (Lupton 2003). Stories of restitution are infused with military metaphors and postulate that winning the battle against cancer is ultimately linked to early detection and aggressive treatment. Once that battle is won, life will go on as though the illness and suffering never happened. Even when medical treatments are failing, cancer victims are still expected to continue fighting the sickness by following a linear, biomedical model of cancer, providing them with the "glories of a war hero" even if they do not actually get better (Erwin 1987, 202). This is consistent with the belief in Anglo-Western societies that acquiescence, fear, and denial (i.e., chaos sto-

TABLE 1

PROFILE OF PARTICIPANTS

Pseudonym	Age	Occupation	Education	Marital status	Cancer diagnosis
Cassie	51	Grade school teacher	College degree	Married mother	10 years ago
Emma	52	Training administrator	College degree	Married	11 years ago
Hannah	30	Marketing manager	College degree	Married	2 years ago
Holly	53	Communications director	Graduate degree	Married mother	2 months ago
Ivy	51	Industrial buyer	High school	Single	2 years ago
Lacy	49	Social worker	College degree	Married mother	5 years ago
Leann	47	Legal assistant	Some college	Married mother	12 years ago
Lesley	46	Family care giver	Some college	Married	1 year ago
Lydia	54	Executive director	Some college	Single mother	20 years ago, 7 years ago, 1 year ago[a]
Pamela	49	Business owner	College degree	Married mother	5 years ago
Paula	62	Accountant	College degree	Single mother	2 years ago
Rena	37	Medical assistant	High school	Single mother	3 years ago

[a] Lydia was also diagnosed with ovarian cancer.

ries) are not socially acceptable ways of dealing with disease.

Our informants' narratives, such as Emma's story presented earlier, reflect the overarching influence of the restitution imperative in the construction of risk understandings associated with the detection and treatment of disease as well as the risk of irreparable loss. These understandings are made manifest in the overuse of mastectomy surgery as well as the rising popularity of body restoration through reconstruction (Baxter et al. 2004). While belief in restitution may have positive consequences, such as motivating proactive cancer screening, it may also be maladaptive when some part of the illness condition remains chronic, when recurrence likelihoods are unpredictable and unknown, or when treatments are not working. Restitution stories are not consonant with an insidious disease such as breast cancer, in which the "well" are not clearly separated from the ill. Often survivors are faced with the realization that returning to the same life that was lived before is impossible because of the future risks that they face. This awareness can lead to an emergent defiance against restitution, which we later present in terms of abandoning treatment and body victimology. These changed risk understandings may also motivate the adoption of alternative discourses, such as quest stories, which help one to live a life with cancer. However, the continued consumption of interventionist medicine reflects our cultural proclivity toward restitution that competing ideologies must confront if they are to provide viable alternatives for framing risk understandings.

METHOD

In order to understand the construction of consumer risk understandings within the context of breast cancer decisions, a hermeneutical approach (Thompson 1997) was employed in this study. This approach provides an in-depth understanding of the lived experiences of women who had been diagnosed and treated for breast cancer. This research method allows us to delve phenomenologically into the thoughts, feelings, and behaviors of informants while also accounting for the social and situational constraints of each individual's experiences. We asked our participants to describe their experiences with the diagnosis of breast cancer and their subsequent decisions regarding treatment. Since our objective was to understand why consumers make more invasive medical choices than may be necessary, we focused only on women who had undergone mastectomy.

We conducted in-depth interviews with 12 participants. Our sample was diverse in many characteristics, such as occupation, education, and marital status (table 1). The informants ranged in age from 30 to 62. Although eight of the women had been diagnosed within the past 5 years, four women had been diagnosed more than 10 years ago. Consistent with the phenomenological approach, we also visited breast cancer walks, hospitals, and breast-care clinics, besides immersing ourselves in the breast cancer media (i.e., books, magazines, brochures, Web sites, and television programs such as *Lifetimes's Breast Cancer Heroes*). This provided us with an understanding of the vernaculars and discourses surrounding detection, treatment, and cure in the breast cancer community.

THE PROMISE OF RESTITUTION THROUGH BIOMEDICINE

> I think about you as sort of the Delta Strike Force, the Green Berets, the elites. (Fran Vasco, president of the National Breast Cancer Coalition, addressing a group of activists [Erikson 1995])

Although heart disease kills roughly 12 times more women than breast cancer each year, breast cancer evokes more fear among women in this country (Andruss 2006). As a disease, cancer has been invested with feral personalities and described as "insidious," "mysterious," "lawless," "savage," and, above all, "relentless," which serves to ingrain cancer phobia within the American psyche (Patterson 1987, vii). Unlike other illnesses such as heart disease or other cancers such as lung cancer, which have better-known risk factors and implied lifestyle choices such as sedentary habits or smoking, the nature of breast cancer as a disease is poorly understood (Andruss 2006). This anxiety surrounding breast cancer is further abetted by the potentially selective and biased presentation of information by both medical and nonmedical media. For example, in a large-scale study, McMenamin et al. (2005) found that 66% of women overestimated their risks of developing breast cancer, 88% underestimated the age at which it was most likely to occur, and 56% underestimated the 5-year survival rate. Both institutional and commercial images, stories, and statistics have been accused of misleading the public by exaggerating the risks associated with breast cancer and by describing risk reduction in relative rather than absolute terms (Gigerenzer 2002; Love 2005).

Invoking fear has often been a conscious tactic deployed by the medical establishment, activist communities, and public interest groups (e.g., the American Cancer Society) to attract attention and funding in support of the breast cancer cause. As a result, it has also contributed to a larger rhetoric of fear that is now used by public health campaigns to encourage women to seek early medical attention (Kolker 2004). These campaigning discourses leverage on the heightened sense of anxiety surrounding breast cancer and the promise that an increase in control and certainty can be achieved through the provision of probabilistic risk information and early detection (Press et al. 2000). Messages about breast cancer through the filters of fear first appeared after World War II, when offers of hope took the form of solutions from technology-based medical breakthroughs and idealized schemes for early detection (Batt 1994; Lerner 2000; Patterson 1987). The American Cancer Society and other cancer organizations used combat metaphors to liken the "war" on breast cancer to the recent American military triumph (King 2004; Lerner 2001). In this militarized narrative, breast cancer is the enigmatic enemy and biomedicine is the weapon of choice against this enemy. To achieve restitution, the pervading narrative gives meaning as to what medicine expects from the ill person (personal responsibility) and to what other social institutions expect from medicine (risk information and solutions). The framing of the fight against breast cancer in military terms is consistent with the restitution story line, which advocates quick and complete recovery through biomedicine.

The biomedical model that has been popularized by the medical establishment, as well as mass media, suggests that cancer is treatable, manageable, and even curable (Saillant 1990). This model focuses on anatomy and physiology as causes of disease at the cellular, hormonal, and genetic levels rather than evaluating social and environmental contributions to the disease (Rosser 2000). Due to its emphasis on treatments at the cellular level, the biomedical model prescribes the "slash" (surgically removing the cells), "burn" (killing the cancer cells through radiation therapy), and "poison" (through chemotherapy) technique as its primary treatment method (Love 2005; Stabiner 1997), which further elevates the position of technological and medical intervention. Our historical understanding of the pathology of breast cancer as a linear model also parallels the restitution story by promoting cure and closure through aggressive treatments to regain control and return to normalcy (i.e., "the earlier it is detected, the more preventable it is"; "the more we cut, the better the cure"). Biomedicine, as tied to the "war" metaphor and the linear model of breast cancer, clearly lays the responsibility on individuals to achieve restitution by undergoing aggressive technological and cellular treatments, which follow the twin doctrines of early detection and radical surgery. In this context, a patient is responsible for exerting control over the disease and returning to health and life as before. Thus, the emphasis on personal responsibility for abating risks of occurrence, recurrence, and loss pervades all phases in the fight against breast cancer from early detection to aggressive treatment to concealment.

Early Detection Equals Prevention: Screening and the "Preventable" Disease

Through the development of mammography machines, biomedicine responded to the anxiety revolving around breast cancer and provided women with a means of personal control by promoting early detection. However, early detection is not a panacea for prevention. The current prescriptive guideline is not to recommend mammography for women under age 40 because of the doubtful benefits of early screening. For women under 40, most randomized controlled studies show no effect on mortality after 7 years of follow-up (Love 2005). Moreover, over one-fourth of invasive breast cancers are not detected by mammography in 40–49-year-olds due to the high density of their breast tissues, compared to one-tenth in women over 50. The potential risk of a false negative is that diagnoses and treatments could be delayed. However, 30% of women who begin annual screening at age 40 will get a false positive, which leads to additional testing and biopsies that are unnecessary (Love 2005).

Despite the above statistics that might suggest otherwise, our informants display an unquestioning confidence in biomedical advancements in screening and express a desire to exert some sense of control over the disease. The restitution narrative is culturally appealing because it promotes a mindset that, as long as individuals are vigilant about their health, disastrous outcomes can be averted. In the case of screening for breast cancer, women feel accountable for personally negotiating health risks and avoiding illness, even to the point of undergoing extreme procedures that may not be beneficial. Consistent with the restitution story line of "early detection equals prevention," our informant Lydia chooses to dismiss public health statistics about breast cancer screening and views risk as the personal responsibility of individual women (Press et al. 2000). Consequently, Lydia was outraged when medical practitioners refused to perform a mammogram for her 28-year-old daughter. She confronts the advice of her daughter's medical practitioners: "She does monthly breast exams, she gets a yearly mammogram. . . .

They [the doctors] laughed in her face when she went and asked for it. She got really angry, told me about it. I called up, and said 'don't you ever, ever laugh at this woman again for asking for this. Now I'll pay for it. . . . Here she is with a mother with breast cancer twice, and you don't think this is a good idea'?"

As a two-time breast cancer survivor, Lydia takes the lesson of early detection to heart. She overrides current insurance policies regarding screening and pays for her daughter's yearly mammogram to ensure that she gets screened, despite the problematic statistics of mammography for women under age 40 (Lerner 2001; Stabiner 1997). Lydia's knowledge of her own risk factors makes her acutely aware of her daughter's risk for breast cancer, and she feels personally responsible for abating such risks. Therefore, she persists in the hope that screening could prevent the risk in her daughter.

This confidence in early detection through mammography screening seems unshakable in women, despite evidence of the overpromotion of screening programs and the risks of false positives and false negatives (Gigerenzer 2002; McMenamin et al. 2005). In her criticism of the mass adoption of screening mammography, Batt (1994) suggests that it stems from our belief that we can escape sickness, pain, and the threat of death through the medicalization of health. This belief in restitution through biomedicine promotes the use of screening in an attempt to protect individuals from the risk of breast cancer. However, scientific knowledge is often not fail-proof. For example, our informant Paula detected her cancer through breast self-examination, despite having had multiple false-negative mammogram results: "But, so consequently, I got a mammogram every 6 months. And, the surgeon said the cancer had been there for 10 years. I found it myself with a breast self-exam. It was a week after I had a mammogram and a sonogram. But, I can't say. . . . They found the other one with the mammogram. So, I can't say, you just need to do it all. The mammogram and the breast self exam."

Paula had been on hormone replacement therapy (HRT) for 10 years when HRT was found to increase breast cancer risks. As a result, she was having a mammogram every 6 months, but it failed to detect her initial breast cancer, although a subsequent mammogram did detect the second breast cancer in the other breast. Despite the failure of both the mammogram and sonogram to detect her first cancer, Paula does not question the validity of the biomedical model:

> *Interviewer:* How did you feel about it when you realized you had breast cancer for 10 years and you were going for your mammogram and it wasn't detected?
>
> *Paula:* I just thought, well, I've done everything I could do. If I got it anyway, I was amazed to hear them say it had been 10 years . . . since I had large bosoms to start with, and mine was way over here under my arm. . . . Because it was there under the arms, you wonder why the sonogram didn't show it. But it didn't. And I went to the same one [doctor], year after year after year, so it wasn't like I was switching around. And I can't say they weren't good, . . . it was just something that was missed.

Even though both the mammogram and the sonogram failed to detect her cancer, Paula was relieved of the potential guilt of not being vigilant in monitoring her health; she had done everything she could. Not only does Paula continue to have faith in the doctrine of early detection, she still perceives mammography screening as the best prevention against breast cancer. Like Lydia, she also insists that all female members in her family go for a mammogram: "I have two sisters, we each have two girls. So far, all the grandchildren have been girls. It was kind of a wake-up call. Everyone went to get mammograms, no matter how old they were. Both my daughters did. All of their daughters did. And so we are just on a preventative nature cause the sooner you can find it the less treatment is if you get it."

The narratives of Lydia and Paula highlight the fact that an increase in the diagnosis of DCIS has coincided with the widening use of mammography since 1980 (Baxter et al. 2004). Despite the benign nature of DCIS, women have been prone to undertake aggressive treatments for it, which has prompted concerns of overdiagnosis and overtreatment (Fisher and Welch 1999). However, Lydia and Paula seem to discount any concerns over the risks of false positives as they insist that their daughters undergo mammography screening. Our reliance on the efficacy of early detection as prevention is appealing, but it could actually inhibit us from pursuing other solutions that are even more promising (Love 2005).

Consonant with the restitution story, women have been encouraged to take control of their own health and bodies through the cultural norms of early detection and personal responsibility. Such public health messages have been perpetuated by the Women's Health Movement, as well as popular media, for over a century (Fosket et al. 2000). Increasingly, the advent of screening techniques and genetic tests also holds out the admonition that individuals are personally culpable for assessing and controlling the risks to which they are susceptible (Lock 1998). In the past decade, public campaigns of early detection have further evolved into campaigns for prevention. But prevention in its new context refers to each woman's individual responsibility to prevent the disease in her self alone. Prevention, in other words, has been privatized (Leopold 1999). The imperative of the restitution story is so pervasive that women (such as Paula and Lydia) are often unable to question the screening technique or to shift the responsibility away from themselves.

More Is Better: Mastectomy and the "Curable" Disease

Popularized by William Halsted, the classical radical mastectomy was the treatment of choice from the 1890s up until about 1975 (Lerner 2000). The procedure, which involves complete removal of the breasts, surrounding chest tissues, and lymph nodes, is founded on a linear model of breast cancer starting as a single focus within the breast. Removing as much of the cancerous tissues as possible is viewed to offer the best hope for a cure. Although this linear view of breast cancer has since been invalidated by subsequent findings, which has led to less invasive procedures and more systemic treatments such as chemotherapy (Lerner 2000; Love 2005), the "more is better" mind-set persists.

Five years prior to her own diagnosis, Holly helped her younger sister cope with a breast cancer diagnosis and its attendant treatment (lumpectomy and radiation). As a result of this family history (sister and maternal aunt with breast cancer), Holly started seeing a breast-care specialist and had a mammogram every 6 months. When her doctor gave her the option of either a lumpectomy or a mastectomy, not only did she choose to have a mastectomy but she also suggested having a prophylactic mastectomy in the remaining breast. Having witnessed her sister living with the fear of recurrence is instrumental in Holly's pursuit of the more definitive treatment of a bilateral mastectomy:

> The more I thought about it, talked to people, there is just a combination of reasons from trivial to serious that, going into a decision like this . . . I'd still be going to mammograms every 6 months. And I'd, every time there is a little shadow, I'd have to get another biopsy, and you know, chances . . . it is a funny thing. You know your chances are higher. You've had it in one breast; it is aggressive. When cancer reoccurs, it can be the same thing, or it can be invasive. They can't tell you what's going to happen. And it could occur in the other breast. So my chances are higher. How much higher? Well, we're talking, you know, one in 100 rather than one in 250 or something, but those are the kinds of odds, you just kind of look and say, what am I willing to live with? And you know what am I ultimately going to be comfortable with? And it, I describe it as kind of jumping into ice water. I do have choices. I don't have to do this. I could have the lumpectomy. And I could live with this hanging over my head all the time, and that's just not for me.

Like Holly, Rena also chose bilateral mastectomy because of her fear of recurrence:

> But what was really the trigger for me is when I went to have this conversation [with her doctor], I sat down in the waiting room, and a lady sat down next to me. And I could see her drain tubes, and so we just started talking, and sure enough, her sister had breast cancer and had one breast removed, and it came back in the other side. I can't remember if she passed away. But this girl had the same thing. *It* came in one breast, they removed it. *It* came back in the other one. I said, you just confirmed my, you know, my decision. And in fact now I know another lady that had breast cancer and it came back in the other.

Although current medical thinking would suggest that a lumpectomy provides similar, and at times better, assurance for long-term survival (Baum et al. 2005; Fisher et al. 2002; Veronesi et al. 2002), both Holly and Rena cling to the biomedical model that emphasizes aggressive treatment as a means of regaining control over the disease and reducing the risk of recurrence. This long-held presumption of biomedicine is sustained through restitution stories that emphasize fighting the disease with the ultimate responsibility of preventing its return. Overall, our informants find mastectomy more psychologically reassuring than lumpectomy, even though many had the choice of a lumpectomy first. In the context of breast cancer, the definitive nature of mastectomy appeals to our informants' beliefs in personal responsibility for reducing the probability of recurrence, despite evidentiary findings that are contrary to this belief. After nearly 2 decades of patient education and National Institutes of Health consensus statements, recent research still shows significant variations in knowledge and attitudes toward treatment options that cannot be explained by the lack of information alone (Fagerlin et al. 2006; Katz et al. 2005).

The biomedical intervention of mastectomy also resonates with the way that cancer is constructed in this culture (Sontag 1977). Cancer is seen as the danger within, a malign agent that strikes with no warning in our body. Informed by biomedicine, women learn to view the body as dangerous, conceived of as an object that can be manipulated and rendered safe, according to the restitution story, by disposing of the dangerous parts—their breasts. Diseases and symptoms are frequently described using impersonal terms "it" or "the" disease rather than referring to "my" and "I." This usage signifies that patients do not view their disease as part of themselves but as an entity that exists apart (Cassell 1976). Only by removing it from one's body can one become healthy and eliminate the risk of recurrence. When given the option of a lumpectomy, many women perceive this medical advice as conflicting with their belief in the possibility of complete restitution. For example, Pamela scoffs at the advice given by Dr. Susan Love in her *Breast Book,* which is regarded by many as the "bible" for women with breast cancer (O'Neill 1994): "I think in one chapter in there, she says you shouldn't make the decision about the mastectomy, you should wait, or something like that. I thought wait? Wait for what? I mean, I thought this was ridiculous. You know, like you know, have the lumpectomy and if it comes back, then you can do it. And I'm like, who wants it to come back? Get over it. I didn't agree with it, I didn't agree with her sentiments at all."

At the time of Pamela's diagnosis, her family was dependent on her to provide a stable home environment. She was the president of her sons' PTA, and her husband was the president of a major corporation headquartered in a different city, and he only came home on weekends. She lost her father that same year to pancreatic cancer, and her younger sister was urging her to choose the most definitive treatment option. They had lost their mother earlier in life, and they are now the only surviving members of that family. Acutely aware of obligations and responsibilities toward her loved ones, Pamela could not afford to wait for another disruption in her life and went forward with what she perceived to be the most certain choice for herself and her family.

Similar to Pamela, Holly's sense of personal responsibility for finding a cure was reinforced by concerned family members who also subscribe to the discourses of the biomedical model and the restitution narrative. Holly reports, "So, my thought processes, my family, my three daughters, were all three immediately going, 'Mom, just have them both off. Just please, we want you around, just please have it taken care of.' By that, they meant mastectomy."

In choosing to overrule her doctor's recommendation, Rena is also concerned about her responsibilities as a single mother, and she will not allow what she perceives as any possibility of recurrence:

> [I said to the doctor:] "My baby is 7 years old. I have got to see her get married. You hear so much about women dying of breast cancer, and I can't be one of those. I just can't risk it. I'm a single mom, the kids are so great, and this is what we have to do." And she's like, "Well, go home and think about it." . . . I said, "I don't need to think about it." [She said] "Just do it, Rena" . . . and "Do you want to see another doctor in the practice?" and I said, "No. I've known all along what we are dealing with." And she said, "Well, go home and think about it anyway." So I made my appointment for 4 weeks, or whatever. And I called her back, and I said, "I don't need to wait. I said I want bilateral mastectomy. And I don't want reconstruction. I don't want to ever worry about me."

In their interviews with women who were undergoing early-stage breast cancer treatments, Charles et al. (1998) find that women often perceive their treatment options not as a matter of choice but rather as the only decision possible in order to allay any potential feelings of self-doubt that they could have done more. Consistent with the restitution story, the decision to do everything possible helps them to persist in being hopeful and remaining positive, "By having chemo and radiation, *I have done everything that I can do* now. So because I have done everything, I have to live with the thought, I have done it, I am going to live" (Charles et al. 1998, 78).

Similar to our informants' narratives, studies of women who undergo prophylactic mastectomies in response to positive genetic mutation test results also reveal that they have a felt responsibility toward taking the necessary steps to reduce their risk (Hallowell 2000). Overall, this imperative of personal responsibility is so strong that Holly, Rena, and Pamela all acknowledge that they must undergo the most aggressive treatments available to fight the cancer and its potential recurrence. As portrayed in Emma's feelings described in the opening vignette, this commitment to biomedicine is reflected in the choice of many women who undergo the more severe treatment of mastectomy instead of following the less invasive prescription of lumpectomy. In spite of prescriptive medical recommendations, our informants' risk understandings have long been shaped by the restitution story, which is revealed in the urgency of their felt responsibilities and their beliefs in the conservative dictum of "more is better" long espoused by biomedicine.

"Good as New": Concealment through Reconstruction

In addition to the cultural norms of control and personal responsibility in the context of illness, the restitution narrative has also produced the expectation of concealment, which is motivated by a general sense of horror toward disease (Patterson 1987; Wilkinson 2000). Breast cancer is especially susceptible to such an imperative because of the deep-seated ways in which femininity is situated within the female body (Saywell et al. 2000). Health-care and support-group practices surrounding mastectomy and postoperative recovery have been designed to reaffirm and reproduce this idealized, gendered identity (Lorde 1980). Not only is recovery accomplished by the removal of cancerous cells but it is also signified by the recovered feminine form, and where this is not the case, the evidence of loss is concealed (Wilkinson 2000). An archetype of this corporeal model is the wearing of breast prostheses or the undergoing of breast reconstruction following mastectomy. Considering breasts as the iconic representations of both female sexuality and femininity, the asymmetry of mastectomy represents an assault on beauty and perceptions of normality. Mastectomy is therefore perceived as a violation of normalized femininity and as something that should be hidden and treated as a source of shame.

Paula was initially diagnosed with cancer in one breast, and she underwent mastectomy with reconstruction. During the reconstruction process, she was diagnosed with cancer in the remaining breast and ended up undergoing bilateral mastectomy instead. As a result, she had to endure repeated surgeries before she obtained the desired physical appearance. She reports:

> I had 40 treatments of radiation. . . . I had quite a bit of cancer. And the most important thing was to get rid of the cancer. I worried about how it looked later. . . . My plastic surgeon decided he would do an implant. . . . It was a saline solution implant. And it was small, but it held a quart, and we filled it up. Every week, I went and got 60ccs of saline. I couldn't see it fill up. I didn't have enough skin because of the radiation burns. He thought I had had enough skin left to have this implant, and it would stretch enough to make a bosom. Well, it didn't. So then when it broke open because of my infection, they took it out. . . . They moved the fat and muscle around and grafted some skin so I had some skin that was not radiation burned to make me a bosom. So, in the meantime, he said, I think you should go get a mammogram in the other breast before we start doing all this stuff. . . . So then I went to get the mammogram. They decided I had cancer in the left breast. So, then instead of me getting my reconstruction, I got my left breast taken off. So then we had to wait for that to heal, and 6 weeks ago, I had my new bosom. [3 years after initial diagnosis]. . . . And I got my bosoms. Today is my first day to wear a bra

> [smiling] . . . during all this time I wore the prostheses. I hated it. . . .
>
> I did not realize you get a prescription, that your insurance will pay for it. And these things [prostheses] are very expensive. . . . And I was thinking, how can I buy two of these things? I didn't plan on wearing them very long. But I didn't want to go in public completely flat-chested. But, they gave me a prescription, so the insurance paid for them . . . that was a deciding factor for me. Because I might have decided because of the bras are like $60 a piece, and then I think the prosthesis is like $300 or $400. So, you are talking about a big investment for a few weeks or maybe 1 year [which turned out to be 3 years for her], or at least for me. I thought I'm going to have me an operation.

As the oldest participant among our informants, Paula shows the strongest adherence to the corporeal model of feminine identity, which is consistent with her age cohort and upbringing. Paula has lived her entire life in the South, in a culture that values and expects feminine gentility and decorum. In contrast to our other informants, who were all casually dressed, Paula wore a suit to the interview, with impeccable make up and perfectly coifed hair. From her remarks, it was clear that she would have never entertained the thought of getting by with wearing the prostheses, even if it meant enduring years of surgery and physical pain.

The restitution narrative powerfully structures expectations of how a woman diagnosed with breast cancer will behave, from the initial shock and grief of diagnosis to the eventual return to "living a normal life again" free of unseemly evidence of the illness or its effects (Wilkinson 2000). The concealment imperative as dictated by restitution means that for postmastectomy women, the first priority is to restore their now defective body through artificial cosmetic remedies (Wilkinson 2000). Therefore, the primary theme that often emerges concerning reconstruction decisions relates to the desire of returning to normalcy, as is evident from this interview with Emma:

> *Emma:* The thing that would be the determining factor for me in the end was very simple. I simply asked for photographs. And once I saw the photographs of women [with reconstruction], I said, "Sure, no problem." You know, let's go ahead and do it [the mastectomy].
>
> *Interviewer:* Tell us a little bit about seeing the pictures of them.
>
> *Emma:* Oh, I was so relieved because it was, it is very natural in appearance. . . . You realize right away that you can, you know, you can wear bathing suits again, and you can really go on. Particularly when you are in your early 40s and get a diagnosis, it is an important factor for me. So, the decision came instantly once I saw that. And I realized that I could just continue on. It was worth it. It was worth it. And I also knew my insurance would cover it. It was another factor.

Although appearance may be secondary to survival in the battle against breast cancer, the sense of mutilation and loss of control can be as debilitating as the disease itself. Women's decisions to undergo breast reconstructions are often the final step toward realigning the body to restore femininity, normalcy, and a sense of control (free from the hassles of prostheses; Crompvoets 2006). In the case of Paula, her "bosoms" are an integral part of her feminine identity, and she can never feel complete without them, whereas for Emma, it is about regaining normalcy and control in a life that had been well ordered up to her cancer diagnosis. Although Rena insists that she would not consider breast reconstruction because of her fear of difficulty in detecting recurrence, she still feels compelled to conform to societal norms of femininity, and she prefers to wear prostheses when in public:

> *Interviewer:* I know you have reservations about going through the mastectomies and reconstructions, but if there was medical evidence saying that you could never get cancer from reconstruction, would you consider it?
>
> *Rena:* And then if they could promise me that I would never have any problems with the implants, wouldn't have any reactions, they'd never leak, they wouldn't change their shape . . . no, I still wouldn't do it.
>
> *Interviewer:* Why are you wearing forms at all?
>
> *Rena:* Well, because I'm overweight. And I feel like a little old fat man that's got this little sucked in chest and then this big belly. Because I thought, why I don't need breasts to feel ok, and . . . I felt like there was nothing but this big fat belly, so I really, to be quite honest, I needed something to balance it. You know, I looked awful. . . . Well, I don't know. Because, I think that I don't want to . . . okay, this might be kind of stupid . . . I don't want to stand out, you know, look different. But if I were in a comfortable setting, then I wouldn't mind standing out. Does that make sense?

Although Rena has no trouble telling people that she has no breasts, she still feels the pressure to maintain a feminine appearance in public. She is comfortable with showing her empty chest privately to family and friends because she believes that if she can share her experiences with others, people will be better informed and less fearful of a cancer diagnosis (she lifted her blouse to show us her chest at this point of the interview). She also acknowledges that if she were more confident about her body, she would not have to wear forms at all. Nevertheless, Rena conforms to the norm of concealment by wearing prostheses daily in an attempt to return to a life of normalcy, or to life before cancer.

Through the lens of the restitution story, in our "implacably optimistic breast cancer culture" (Ehrenreich 2001, 49) exemplified by such activities as the *Race for the Cure*, breast cancer becomes a disease of resilient, reconstructable feminine bodies (Klawiter 2000). The medicalization of women's breasts enables breast cancer to be transformed from a disease of debilitating loss and personal anguish to one of reconstructable normalcy and public survivorship (King 2004). The promise of restitution thus protects women from the risks of losing their gendered identities—the price they pay for a cure. For many of our informants, the cultural norm of concealment actually facilitates their pursuit of the more aggressive form of treatment (mastectomy) by providing an option for complete restoration of their feminine bodies (reconstruction). For survivors, breast cancer then becomes a momentary setback that can be won by following the biomedical and corporeal models of mastectomy and reconstruction. In 1998, these models were further endorsed by the enactment of the Federal Breast Cancer Reconstruction Law, or the Women's Health and Cancer Rights Act (WHCRA), which requires medical insurance to cover the cost of reconstruction after mastectomy.

Framed from the perspective of the restitution story, breast cancer is a preventable, treatable, and curable disease if patients follow the dictums of biomedicine. With early detection, risk of occurrence is contained; with mastectomy, risk of recurrence is reduced; and with reconstruction, the risk of irreparable loss is eschewed altogether. Complementing the restitution story are the discourses of fear, personal responsibility, control, and concealment that surround cancer in modern Western societies (Lupton 2003). These discourses are endorsed and communicated through countless sources, such as medical statistics, popular media, and word-of-mouth within the breast cancer community. Together, they promote the individual pursuit of restitution, where patients seek out and endure severe biomedical interventions and treatments that hold out the promise that life can soon be back to normal or "good as new." This paradigm received a particularly powerful endorsement from ex–First Lady Nancy Reagan when she underwent a mastectomy in 1987, despite her physician's recommendation for a lumpectomy. In the 6 months following Reagan's decision, there was a 25% reduction in the use of BCS among white, middle-class women aged 50–79, whereas it was steadily increasing prior to this event (Nattinger et al. 1998). Even though most activists acknowledged that Reagan had the right to make her own choice, it was also undeniable that, for years to come, her action shaped women's perceptions of what would be appropriate behavior (Leopold 1999).

DEFIANCE AGAINST RESTITUTION: ABANDONING TREATMENT AND BODY VICTIMOLOGY

Breast cancer is such a dreaded disease because it is associated with the most fearful form of death, a slow and lingering process. "Every time a cancer patient gets a cold, or wakes up feeling weak or has an unexplained fever or unexplained pain, no matter how many years they've been in remission, they think, 'it's back'" (Patterson 1987, 307). Although the dominant illness narrative of restitution and the linear model of disease promote the pursuit of aggressive treatment in an effort to regain control, such a health-care strategy is not compatible with the reality of breast cancer. Frank (1995) contrasts this linear, modernist view of medicine with the postmodernist view, which is more consistent with the pathology of breast cancer and other chronic conditions in which one is never cured from the disease and individuals have varying experiences and responses to medical treatments. Although the dominant discourses revolving around breast cancer are shaped by the restitution story, alternative stories may actually come closer to describing the changed reality of what a cancer survivor would face. With the risk of recurrence never completely out of their minds, some survivors come to realize that the expectation of complete restitution is not realistic. With respect to breast reconstruction, they recognize that, even though the procedure may restore (and even improve) the body's feminine form in appearance, in reality, they no longer feel natural or complete (Hallowell 2000). Thus, although it is difficult to accept, the restitution story does not quite fit the lived experiences of survivors and the nature of the risks associated with breast cancer. It is at this point that survivors may turn to alternative frames, such as the quest story, to give meaning to their experiences, to make sense of them and begin to formulate a revised identity and new context for living after the disruption of illness (Hyden 1997).

In her research on breast cancer social movements, Klawiter (2000) suggests that a culture of action often defines how social practices are enacted and embodied. The dominant "pink ribbon" subculture, which draws upon biomedicine and emphasizes individual agency, control, and survival, has been decried by many feminists as oppressive to women in its promotion of normative femininities and its support of technocentric treatments (Batt 1994; Ehrenreich 2001). In this cultural context, treatments such as mastectomy and chemotherapy are seen as the greatest source of hope and to terminate treatment is synonymous with giving up hope of restitution, a taboo (Luoma and Hakamies-Blomqvist 2004). This illness narrative that privileges an aggressive stance to regain control and to win one's battle with cancer could be grating to someone who does not subscribe to this cultural norm, as our informant Ivy asserts:

> Because, when you think about it, do I, am I making the right decisions? Do I really want to inject [chemotherapy], what do you call that? Just looking at all those things go into your body, and it is just a kind of tingly warm feeling, and then within 24 hours, you are sick like a dog. So like, after one treatment, I had doubts, is this really helping me or not? They say it is helping me, you know, but like I couldn't really believe it. I could put my body in more jeopardy than anything. It kills your cancer cells, but it also kills some of your good cells too.

As an Asian American who immigrated to this country in her late teens, Ivy believes in a more moderate and holistic curative strategy, which is consistent with her own priorities (Lupton 2003). Being a Buddhist, she prefers a natural healing process rather than what she perceives as a drastic and unnatural approach taken in chemotherapy. One of the means that breast cancer patients use to regain control over their lives is making consumption decisions that determine their well-being, such as selecting medical treatments or terminating them (Pavia and Mason 2004). Against the advice of her oncologist and her friends, Ivy terminated her chemotherapy program prematurely, perhaps as a means to impose her own values and priorities in this process. According to Ivy, there are more important things to her than improving her chances of survival: "You know, they say, you cannot do that, you have to go through that . . . giving you the chance to survive. So they say, even if it is 10% or even if it is 25%, I should take it, it is worth it. That is what they say. Then, I just turned to them, and said I am a firm believer of quality of life. You know, because, if I am going to live, I want to live freely with agility. I just don't want to live just for, you know, the heck of it."

The relentless focus on individual responsibility for early detection and successful treatment has contributed to the cultural imperative of forced optimism that is considered morally oppressive by some (Wilkinson and Kitzinger 2000). Our value judgments and ideological commitments are an integral part of how we approach and perceive risk, a part that needs to be explored and made explicit if we are to understand more fully how risk is calculated, perceived, and accepted by patients, physicians, and institutions (Douglas and Wildavsky 1982). Priorities about risks are set at both the individual and cultural levels, and we rely on our ideological commitments in guiding and shaping what these priorities will be (Simpson 2000). Yet, to date, breast cancer activism has been narrowly defined from the privileged, medical, and institutional location of a predominantly white and middle-class constituency (Anglin 1997). As a nonmember of this culture, not only did Ivy refuse the aggressive chemotherapy program prescribed by her oncologist but she also rebelled against the restitution story's corporeal model:

> *Ivy:* I mean the breast, why is it so important? Because some women think it is power if you have big breasts, you know, it is power. . . . I always wanted big breasts too, so I was amazed when this [reconstructed] breast is really, really big, because they didn't know how the healing process would go. They made it big, so I felt so unbalanced because one was so big, and then I told my plastic surgeon, you know, I always wanted big breasts, and he said, oh we can work on that, and we can make the other side to match. And then, I said no more, I like my breasts although I had always wanted big breasts before, but it always gets in my way. You know, so I told him I wanted this one to be matched, you know, with my original one. So he said okay. . . they adjusted my size three times to match my original one.
>
> *Interviewer:* You went three times.
>
> *Ivy:* Yeah, because . . . they don't do it all at once, you know. They cut it and they reshape it. When they cut it, they lift it a little, and there is this piece of flesh hanging from the side. And then I told him, you did a lousy job on my tummy. What's this thing hanging? And he said, oh no, this is going to be wonderful. I said, what? So then he used the flesh to reconstruct a nipple, and then after that, I am supposed to go back to get it tattooed, you know, on my nipple, which I have never done. I don't know. I'm still kind of . . . maybe that will make me feel finished, complete, to get closure. I still feel kind of, maybe, this is not important. I don't know; I know who I am.

Although Ivy went along with the biomedical prescriptions of aggressive treatment and reconstruction initially, she began to question the efficacy of these treatments in midcourse. Perhaps not being completely indoctrinated in the restitution narrative, she rejected these cultural norms and chose not to complete the reconstruction of her breast by not getting her nipple tattooed. This cultural variation in breast reconstruction is borne out by national statistics that show that Asian American women are significantly less likely to receive breast reconstruction as compared with Caucasian women, despite having similar access to medical care (Wilkins and Alderman 2004). Like many women who undergo breast reconstruction, Ivy came to realize that the reconstructed breast is not "real" or "good as new," thus recognizing that complete restitution is really an illusion. Fitting in with the plot line of the quest story, Ivy adapts to the realization that she does not need a reconstructed breast to be her old self:

> *Interviewer:* Do you feel comfortable now looking at yourself?
>
> *Ivy:* I'm, how can I put it? I like to stay naked, you know. I mean until now, I just don't like to wear clothes. . . . So, when I started living alone [after her divorce], I just walk around naked at home. . . . I have never been to a nudist camp or anything like that . . . but it is comfortable for me. So maybe that's got something to do with it, too, you know. Because I liked my body, and then, it just never bothered me. . . . After surgery, I started to cover myself, and I had never seen my body. But then, because it wasn't important. I just wanted to get well. I just wanted my hair to grow, you know, my breast back to normal size.
>
> *Interviewer:* Are you back? Are you back to walking around without clothes?
>
> *Ivy:* I mean I still do. I still do, but it is still kind of . . . then I said to myself, who gives a damn? You know, because I know my self-worth. . . . That's how I see it. But until I regain my confidence, it is going to be . . . it is just missing body parts, I'm not crippled. You really have to think about it this way. I have all my five senses working, and it is just a scar.

Not only does Ivy reject the promise of restitution by not completing the reconstruction but she also learns to accept a changed body by insisting that she is not a lesser person than before. Women with breast cancer quickly discover that they are expected to conceal their scarred breasts, that these wounds are somehow "shameful or obscene" (Wilkinson 2000, 271) while other wounds, like a scarred hip, are not. It is therefore not surprising that, when Ivy chose to rebel against the imperative of concealment, she compared herself to amputees who are able to show their loss of limbs with impunity and dignity. It is said that the thousands of women who undergo breast cancer surgery each year are a hidden population. With the all-pervasive discourse of concealment supported by the practices of vast medical and cosmetic industries, its continued dominance is assured.

The breakthrough in the campaign for breast cancer survivors was achieved by reconfiguring the disease from a stigmatized, personal, and private tragedy dealt with in isolation to a neglected epidemic worthy of public debate and personal activism. The definition of survivorship now evokes an enriching, affirming experience during which women affected by breast cancer transform themselves from patients to triumphant survivors (Ehrenreich 2001; King 2004). However, the rhetoric promoted by these dominant survivor subcultures is still the restitution story—that breast cancer is an individually curable disease. This convinces women that they can control cancer through preventive approaches such as early detection and severe surgery while completing restitution through reconstruction. In contrast to the pink ribbon culture, a multicultural feminist view challenges the emphasis on survival and the hegemonic display of normative femininities that obscures other dimensions of the suffering experience (Batt 1994; Ehrenreich 2001; Klawiter 2000). By exposing the lived experience of breast cancer, as well as encouraging a diversity of discourses beyond restitution, women may expand the collective risk understandings associated with the illness.

DISCUSSION

Our current understanding of risk is primarily founded on the different individual-level and situational factors (e.g., personality, perceptions, estimations, context, and emotions) that come into play when a decision involving risk is made (Bettman et al. 1998). Most consumer research on decision making under uncertainty falls within this framework by focusing on these factors to explain variation in responses to risk-related information such as breast screening results (Kahn and Luce 2003; Luce and Kahn 1999) and public health communications (Block and Keller 1995, 1998; Cox and Cox 2001). However, these models do not describe how individuals actually make decisions under risk (Johnson 2004). For example, prospect theory suggests that the framing of risk outcomes in the context of gains or losses would influence treatment choice (Tversky and Kahneman 1981). Therefore, given equivalent survival rates, prospect theory would predict the choice of the less invasive BCS rather than the sure loss of mastectomy.

More recently, a socialized orientation to understanding risk that accounts for the roles of values and ideologies as communicated by risk discourses is being recognized (Douglas and Wildavsky 1982; Schrader-Frechette 1991; Thompson 2005). In Anglo-Western cultures, risk understandings are firmly rooted in our philosophical and historical traditions of rugged individualism and manifest destiny. Consequently, health is conceptualized as a condition that should be sustained largely through individual effort. According to this ideology, the prevention of health risks thus becomes the domain of individual responsibility. It is, therefore, not surprising that much of the rhetoric pertaining to health care starts out with an assumption that individuals should be made responsible for behaviors believed to place them "at risk" for contracting disease (Lock 1998). Over time, this cultural value has evolved into the battle mentality that we take in combating illness (e.g., ex-President Nixon's declaration of the "war on cancer"; Patterson 1987).

From the standpoint of restitution, mastectomy signifies a total victory over breast cancer whereas lumpectomy seems to represent something more akin to a truce, which the untrustworthy enemy may not honor. This is similar to the widespread adoption of obstetrical procedures in this country that reflect the cultural belief in the superiority of technology over nature in taming the unpredictable birth process (Davis-Floyd 2003). Our informants' narratives also reflect a deep-rooted faith in the biomedical model that battles cancer with technocratic prowess, despite receipt of different medical recommendations or possessing different levels of medical knowledge. Furthermore, the burden of personal responsibility is so ingrained that women often feel that they are to blame for not detecting the disease earlier or for having failed to pursue the most aggressive treatment. As a result, even though the dominant illness narrative of restitution is clearly incompatible when it comes to chronic conditions such as diabetes, hypertension, and cancer (where recurrence and metastasis risks are always present), we often pursue overly aggressive treatments with limited efficacy (e.g., bone marrow transplant for terminal-stage breast cancer patients; Deyo and Patrick 2005).

Unfortunately, this long entrenched cultural worldview has proved difficult to overcome. Research shows just how easily a powerful celebrity role model can reverse years of NIH consensus statements and legislative initiatives (Nattinger et al. 1998). Furthermore, despite widespread information dissemination and requirements for physicians to discuss breast cancer treatments, women still do not translate this information into accurate risk assessments regarding their treatment options (Fagerlin et al. 2006). Instead, they rely on stories of survivorship and restitution in constructing their risk understandings. In order to facilitate informed decision making, the medical and breast cancer communities must take action to address the folk theories of cancer that are distributed throughout society. The practical implications from this study and other research (e.g., Batt 1994; Ehrenreich 2001; Klawiter 2000) suggest that alternative ideologies that are more consistent with the reality of breast cancer must be supported to allow other cultural risk understandings to emerge. Furthermore, public education and health information regarding breast cancer should include these alternative survivor (or nonsurvivor) stories to present a more balanced perspective on the illness.

The course of our study also highlights a distinction that is often obscured in past research about biomedicine (Lupton 2003; Thompson 2005). In this study, Western, technology-based, interventionist medicine is described as biomedicine, which is consistent with the literature (Ferguson 2000; Potts 2000). It encompasses accumulated historical medical knowledge, as well as dominant social discourses revolving around illness, that are attributed to the medical establishment and health-care institutions. Since the 1990s, an area of biomedicine known as evidence-based medicine has emerged (Sackett et al. 1996). Although medical professionals are expected to use the best evidence information to frame questions regarding patients' problems and to formulate treatment solutions, adherence to evidence-based medicine is generally low (Bloom et al. 2004). Similar to birth interventions that are in place, biomedical practices regarding cancer have also become institutionalized and are resistant to change, despite evidence or pronouncements by the medical community to the contrary (Davis-Floyd 2003; Lerner 2001).

This study also presents a rare interpretation of illness narratives situated not only in an individual or institutional domain but also in a wider social and cultural arena (Hyden 1997). Narratives, perhaps more than metaphors (e.g., Sontag 1977), have profound implications not only on how we perceive illness and interact with people who are ill but also on how we approach treatment strategies and cope with health risks. Illness narratives allow us to convey, express, and formulate our experiences of illness and suffering, thus providing a platform for shared cultural experiences (Frank 1995, 1998). In Anglo-Western societies, the emphasis on technology (based on the biomedical model) in conjunction with the cultural norm of restitution has contributed to the current medicalization of risk (Simpson 2000). From this cultural context comes an escalating commitment to new technologies that allow us to discover information about the origin and development of disease and enable us to intervene at earlier and earlier stages, even before a disease occurs (as in the use of prophylactic surgeries).

The norm of restitution encourages individual responsibility for taking advantage of the latest scientific advances for preventing and treating diseases. Glassner (1999) suggests that our fear toward breast cancer is sustained because it resonates with our cultural anxieties and its attendant risks are continually and consistently inflated in popular media. Together, these commitments heighten the anxiety revolving around breast cancer and lead women to feel like failures for not catching it earlier. Medical information dissemination needs to better reflect the incidence of breast cancer instead of creating excessive anxiety in younger women while encouraging complacency in older women. For example, although the illness tends to be experienced by mostly older women, discussions about breast cancer tend to portray much younger women (e.g., 47% of media reports on breast cancer discuss women who were diagnosed before age 40, while only 3.6% of all breast cancers occur among women at this age; Carey 2006; Deyo and Patrick 2005).

Although alternative stories such as the quest story may more appropriately resemble the individual survivor's experience of living with breast cancer, the prevalent rhetoric of survivor subcultures is still grounded in restitution. For some women, enduring harsh biomedical treatments and coming to the realization that restitution is not possible could arouse anger and disillusionment toward the predominant ideologies and the institutions that perpetuate them. This is reflected in the less dominant (compared to the pink ribbon subculture exemplified by the National Breast Cancer Coalition) breast cancer activist community, which, in defiance of the biomedical model, mobilizes anger against institutions of biomedicine and the health-care system. It promotes alternative representations of breast cancer that include women living with cancer and dying from the disease instead of only privileging the survivors. Another ideology is the environmental justice movement that assembles feelings of injustice and outrage against the cancer industry (i.e., chemical companies responsible for polluting the environment and health-care institutions that promote biomedical interventions instead of real prevention through the control and regulation of cancer-causing agents).

Breast cancer is a complex disease about which there exist multiple, conflicting, and evolving knowledges. This multiplicity of knowledges has important implications in determining the individual construction of risk understandings, the development of curative strategies, and the institutional shaping of policy concerning health-care practices. It is therefore not surprising that the current landscape in the breast cancer community includes alternative ideologies that challenge the dominance of restitution and biomedicine. However, in this context, the ascent of biomedicine has silenced any dissenting voice for over a century. More recently, because of the lack of progress in reducing breast cancer incidence and the overwhelming dominance of the pink ribbon subculture, alternative discourses are being voiced (Batt 1994; Ehrenreich 2001; Leopold 1999). Especially when competing risk knowledges (e.g., linear vs. nonlinear models of cancer) are being debated, alternative narratives are more likely to be heard and to confront the status quo (Swidler 1986). However, in order to overcome the hegemony of restitution, competing ideologies must develop alternative risk understandings that are also consonant with the cultural values of personal agency and control. The ideological frames that we bring to risk understandings at the individual, institutional, and societal levels must be challenged before alternative, nonlinear, and postmodern perspectives can be accorded legitimacy and balance in the current landscape of health risks. We hope that this research will direct more attention to the recognition and conceptualization of these alternative discourses within an expanded composition of illness narratives.

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