ABSTRACT


Research on stress and coping has attempted to explain how people deal with difficult life events, such as the diagnosis of a potentially life-threatening disease. Little attention, however, has been given to how people work together to cope with and manage the emotions evoked by such events. The present study looks at women who joined four breast cancer support groups to help them cope with the emotional fallout of the disease. Data from participant observation in these four groups, in addition to 35 in-depth interviews, are used to develop an analysis of how the women learned to cope collectively with their disease. Seven emotion-work strategies are identified and discussed, including: (a) seeking information; (b) concealing illness; (c) engaging in sexualized joking; (d) practicing compensatory femininity; (e) creating and sharing medicalized stories; (f) taking on the identity of breast cancer survivor; and (g) redefining illness as a blessing. The analysis shows how these strategies were influenced by the class-based resources the women brought with them to the groups. It also illustrates how these strategies (and thus the women’s coping efforts) were influenced and constrained by the mainstream breast cancer culture.
LIVING WITH BREAST CANCER: 
EMOTION-WORK STRATEGIES IN BREAST CANCER SUPPORT GROUPS

by

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BIOGRAPHY

Jacqueline Clark was born in Asheville, North Carolina, on August 3, 1970. After graduating from Charles D. Owen High School, she attended High Point College in High Point, North Carolina. Unhappy in High Point and eager to return to the mountains, she transferred to the University of North Carolina-Asheville, where she earned a Bachelor of Arts degree in Sociology. She then went on to earn an M.A. in Sociology, with a minor in Appalachian Studies, from Appalachian State University. She remained in Boone, North Carolina, for several years, teaching part-time in the Sociology Department at Appalachian State University. Realizing that part-time teaching was not a fruitful career, she entered the Ph.D. program at North Carolina State University in 1996. She is now an Assistant Professor at Ripon College in Ripon, Wisconsin.
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Chapter One

INTRODUCTION

In 1991 my mother was diagnosed with breast cancer. At forty-six, she was slightly younger than most women who are diagnosed with the disease (the majority of whom, in the United States, are over fifty years old [Love 2000]). She, like other breast cancer patients, was faced with limited options for treatment. She could have a lumpectomy (surgery to remove the cancerous lump in her breast and a small rim of normal tissue around it [Love 2000]) followed by adjunctive therapy (chemotherapy and/or radiation), or have a mastectomy and likely avoid follow-up treatments. After consulting with her oncologist and surgeon, she decided to have a mastectomy, and thus had her right breast surgically removed.

While the physical pain caused by this surgery was significant, the emotional trauma that my mother endured as a result of her illness was even greater. She felt anxious about her changed body, and mourned the loss of her breast. More importantly, she feared what the future might hold. Would she face a recurrence? And, if so, would she die of breast cancer, like her friend, who, a few years earlier, had passed way after a long and painful struggle with the disease?

Although my mother’s cancer was found early and her prognosis was positive, her fears were well founded. Because breast cancer is a slow-growing cancer, it is not uncommon for those who have had the disease to face a recurrence ten or even twenty years after initial diagnosis (Love 2000). Nor is it unusual for women to die of the disease. According to the Centers for Disease Control and Prevention (CDC), over 40,000 women in the United States die from breast cancer every year.
As this would suggest, breast cancer is a serious disease that affects many women and their families.

But even after my mother’s experience with breast cancer, I never imagined that, as a sociologist, I would want to devote further attention to the disease and the emotional struggles that it evokes. By the time I was in graduate school and starting to think about my dissertation project, my mother had lived almost ten years without any signs of recurrence. And as far as I was concerned, she, and therefore I, were both finished with the disease. However, this was not to be the case.

Early in 2001 I was having lunch with a professor, who, several years prior, had been diagnosed with breast cancer. Knowing that my mother had also had the disease, my lunch companion started telling me more about her own diagnosis and treatment. I was struck by how her experience differed from my mother’s. After a biopsy confirmed that she had cancer, this professor asked well-connected friends to help her get an appointment with a surgeon. They were able to get her an appointment several weeks sooner than her own physician had been able to manage. The professor then researched treatment options and discussed them with “Jan,” her oncologist. In contrast, my mother, a working-class woman, relied on her doctors for advice, did little (if any) research on her own, and had few social networks that she could draw upon to help her negotiate her way through the medical system.

But this conversation left me wondering what happens to other working-class, poor, and/or minority women who lack the resources to deal with breast cancer in the ways that this professor did. I suspected and later confirmed that many of them die. Poor women, research shows, have a thirty- to forty-percent higher mortality rate for breast cancer than women who
are not poor (<http://www.cdc.gov/omh/Highlights/2005/HOct2005.htm>; Altman 1996), and African-American women, who are disproportionately poor, are almost one-and-a-half times more likely to die of breast cancer than white women.

These disparities are partly explained by a lack of access to medical care (Weitz 2006; Altman 1996). Without health insurance, many women do not seek help, and when (and if) they do, their disease has often progressed such that it is no longer treatable. Yet, even when screening and medical care are readily available, poor and/or minority women do not fare as well with the disease as their wealthier (mostly white) counterparts (Altman 1996). They often lack the resources – formal education, the ability to find and understand medical information, and connections to those in the medical system – helpful for coping with their disease (Lerner 2001). Thus even poor and minority women who survive breast cancer often have a more difficult time coping with it than women from more privileged backgrounds (Lerner 2001; Altman 1996).

Learning more about these disparities made me angry. I was upset by the needless suffering caused by breast cancer and was concerned about how the medical system reinforced class and racial inequalities. I resolved to put these feelings to use, and so began to think about a dissertation project related to breast cancer and coping.

At my advisor’s prodding, I interviewed my mother and professor friend about their experiences with breast cancer. I also started to read illness narratives that documented the experiences of a variety of women who had suffered from the disease. As a result of these pursuits, my academic interests in breast cancer became more focused. I wanted to learn more about how women helped one another cope with the disease, as well as the
specific emotion-work strategies that they used to do so. In the following section, I will
discuss exactly how I went about designing a dissertation project and collecting data that
addressed these issues.

SETTING AND METHOD

The data from this study derive, in part, from observation of four breast cancer
support groups in central North Carolina. These groups, each of which are described in detail
below, varied in size, focus, and format. All, however, existed to provide support to women
who had been diagnosed with breast cancer. Each also welcomed women who had
completed treatment for the disease. In fact, a number of participants in each group had
recovered from the disease several years prior.

I learned about three of the groups (York, Upton, and Bellesmith) through contact
with the American Cancer Society, and about the fourth (Hogart), later, through a member of
Upton. To gain access to the groups, I contacted each group leader, identifying myself as a
graduate student who was interested in studying “how women cope emotionally with breast
cancer.” In my account to the leaders I emphasized my connection to the disease, disclosing
that my mother had had breast cancer when I was a senior in college. All of the leaders were
receptive to my inquiries, and eventually granted me access to their respective groups. But
before doing so, each wanted to verify that their participating members would be comfortable
with me attending group meetings. Within one to two weeks, all of the leaders had contacted
me, reporting that their members had agreed to allow me to attend and study the groups.
Members of York and Upton, however, asked that I not take notes during their meetings,
request that I honored throughout the data collection process.\textsuperscript{7}

When I first attended each group, I was asked to introduce myself and explain my research interests. I told participants how I became interested in studying breast cancer support groups, and emphasized how I wanted to learn more about how women coped emotionally with the disease. I also made it clear that I would maintain the women’s confidentiality by never identifying them or their groups by name in any of my academic work. At subsequent meetings, I repeated this information. Group leaders also generally made a point of introducing me to new members before meetings officially started, so that these women would be aware of my status as a researcher.

I began attending Upton and York, both of which were affiliated with large urban hospitals, in August and September of 2001, respectively. I continued to observe both groups on a regular basis until August of 2003. During this two-year period, I observed York, which met on a bi-monthly basis, approximately 46 times. I observed Upton, which met once a month, a total of 23 times. Meetings for each group typically lasted between one and two hours, during which time members talked about their diagnoses, treatment, health status, and emotional struggles.\textsuperscript{8} Because I could not take notes during these meetings, I tape recorded my observations immediately afterwards. I then wrote full fieldnotes as soon as possible upon leaving the field.

In August of 2001, I also began observing Bellesmith, a group which met in a boutique that sold prosthetics, wigs, and other aesthetic accessories for breast cancer patients. Although the group was supposed to meet once a month, it convened on an inconsistent basis. Thus, even though I continued to attend meetings through September of 2002, I was
able to observe Bellesmith a total of only eight times.⁹

In addition to meeting on an irregular basis, this group differed from Upton and York in another important way. Rather than being organized like a traditional support group, it functioned more as a sales seminar, with various individuals, such as a massage therapist, life insurance sales person, and a vitamin and herbal supplement store owner, giving presentations to the group. Participants were generally pressured to buy the products and services offered by those presenting, which is perhaps why the group was often sparsely attended (usually only 3-6 women came to meetings). Even so, Bellesmith had several members (at least two) who were loyal to the boutique owner (who facilitated and organized the group) and thus attended on a regular basis.

Because of the format of Bellesmith meetings, I was able to jot notes while in the field. I would then write full fieldnotes from these jottings soon thereafter. Due to the semi-commercial nature of these meetings, these notes included less data on how the women in the group responded to and coped with their disease.

The fourth group observed, Hogart, which was affiliated with a small-town (population <40,000) hospital, met once a month for one to two hours. The Hogart meetings were generally given over to presentations by doctors and other medical personnel. Between May, 2003, and June, 2004, the group heard presentations by two oncologists, a plastic surgeon, a patient advocate, a nutritionist, and another doctor. The group deviated from this format on two special occasions: Christmas and the anniversary of the group’s formation – when members met to socialize at a local restaurant. The women also used one meeting a year as a planning session, at which they discussed possible speakers for the upcoming
months. At the Hogart meetings (12 altogether), I took jottings and used them to construct full fieldnotes later.

Observing the groups allowed me to learn more about the difficult emotions evoked by breast cancer and how members worked together to develop strategies to cope with them. While the women in all four groups struggled with similar problems – for example, dealing with the stigma of losing a breast and the uncertainty of the future – they had different resources available to them to help them cope. This is one reason why I chose to observe the groups that I did. York and Upton, which were composed of mostly white, middle-class women complemented the (primarily) working-class groups, Hogart and Bellesmith, providing an opportunity to learn more about how class-based inequalities affect the ways women respond to and cope with breast cancer. Each group is described in more detail below.

The Groups

York. The group I call York was affiliated with a large urban hospital and its cancer support center. York members met in a conference room across the hall from one of the hospital’s oncology waiting rooms. Although group meetings started in the evening (7:00 p.m.), it was common to see patients moving about the area, many of whom appeared extremely ill and/or visibly upset. This gave a somber feeling to the setting, and served as a constant reminder (to me) that people being treated at the hospital suffered from serious illness, from which they could die. Even though members of the group risked seeing these patients if they arrived early, many did so, using the time to socialize informally before the meetings began.
Between ten and fifteen women typically attended the group. Almost all of them were white, ranged in age from mid-30s to mid-70s (although most were in their mid-50s), and were middle-class. The primary indicators of social class were education and occupation. Nearly all members of York had bachelor’s degrees, and some had professional degrees. Representative occupations were therapist, registered nurse, and realtor. The women’s husbands and partners had similar degrees and often higher-status jobs. Secondary indicators of class included designer clothing, luxury cars, international travel, and large suburban homes (where many of the interviews were conducted).

York, the only group in the study that was facilitated by a trained counselor, followed a traditional support group format. That is, members took turns introducing themselves and sharing problems with which they were currently struggling, while the facilitator attempted to guide discussions in therapeutic ways. New members, for example, often talked about the fear and anxiety evoked by a cancer diagnosis, and sought help in coping with these uncomfortable emotions. Those who were further along in the treatment process generally sought help for other kinds of problems, such as, coping with the disfigurement of their disease, and/or uncertainty about the future.

On occasion the facilitator would invite guest speakers to present to the group. During my observation period, a nutritionist, physical therapist, and two researchers who worked at the hospital and studied breast cancer treatment regimens presented information to the group. These presenters were asked, however, to use only half of the meeting time and then leave, so that the women could discuss their illness and problems associated with it, as they normally did.
Upton. The group I call Upton, like York, was affiliated with a large urban hospital and its cancer support center. It was facilitated by an oncology nurse, and met in the waiting room of a medical practice that was located in the hospital. Members of the group would rearrange the chairs in the area, forming them into a circle. The women, who generally numbered between ten and fifteen, would then, similar to members of York, introduce themselves and discuss their breast cancer diagnosis and treatment, as well as the emotional struggles they were experiencing. They talked, for instance, about the anxiety evoked by their disease, how they worried about the future of their health, and how they struggled to come to terms with what they had been through.

The leader of the group, unlike the York facilitator, did not attempt to guide these discussions in therapeutic ways. Instead, she used her experience and knowledge as a nurse to answer the women’s medical questions, and even encouraged them to discuss the disease in medicalized ways. The women were prepared to do so, because they gathered information about breast cancer and its treatment from the Internet, books, and medical journals, a practice they held in common with members of York. Seeking out such information, as later discussion will show, helped these women to feel better about their disease. It also allowed them to take advantage of the skills and resources that they had as predominantly (white) middle-class, college-educated, women.

Even though the Upton women were well informed about breast cancer and its treatment, they would, on rare occasions, like the members of York, invite guest speakers to present at their group. For example, a nutritionist, exercise consultant, and a physical therapist who worked with lymphedema patients all gave presentations to the group.¹¹ These
presenters, like those at York, were asked not to use all of the group’s time, so that the women would still be able to discuss their illness and any problems associated with it before meetings ended. Even so, speakers usually used more than their allotted time. Meetings in these instances usually ran long, lasting two hours or more.

**Bellesmith.** The group I call Bellesmith, as mentioned above, met in a boutique that sold wigs, prosthetics, and other aesthetic accessories for breast cancer patients. The group, which was organized and facilitated by the boutique owner, met sporadically, even though meetings were supposed to be held once a month. When the group met, members gathered in the back of the shop in a lounge area, where there were two small sofas, several matching chairs, and tables covered with magazines. Although meetings did not officially start until after the shop had closed, members often showed up early, using the time to socialize with one another. They would also look at merchandise in the boutique and talk to customers, who were often being fitted for wigs.

Typically, only four to six women attended the group, although on occasion there were as many as ten. Regular attendees were all white, predominantly working-class, and ranged in age from mid-30s to mid-80s. All but one had been diagnosed with breast cancer. The exception, a woman in her mid-80s, had been diagnosed with ovarian cancer several years prior. This woman, who faithfully attended the group, had forged a close friendship with the boutique owner, after being a customer in the store. The other women who regularly attended Bellesmith had developed similar social ties and obligations to the owner. Most of them, it appeared, came out of loyalty to her (because she had been kind to them when they
were ill and had need for items sold in the boutique), rather than any genuine interest in the speakers, who pitched their products and services during group meetings.

As noted earlier, a variety of sales people presented to the group, attempting to get members to purchase the products and services that they were offering. These sales pitches generally lasted for the entire meeting, and sometimes became antagonistic. For example, one presenter, an owner of a vitamin and herbal supplement store, suggested that some of her products could be used to prevent a future cancer recurrence, a claim which several of the women challenged. In this case and others like it, the boutique owner would intervene, reminding members that they must use their own best judgment when purchasing products. She, however, continued to invite these kinds of speakers to the group, and attendance seemed to suffer as a result.

**Hogart.** This group was affiliated with a small rural hospital. It met in a surgical waiting area adjacent to the emergency room, and was always well attended, with at least eighteen to twenty women coming to the group each month. About one-third of these women were African American. The rest were white. Almost all were working class.  

In addition, approximately one-third of the members of Hogart brought their partners or spouses with them. Before meetings started, the men and women, many of whom had become close friends through the group, would socialize with one another. Later, they would separate, with the men migrating to one side of the waiting room, continuing to talk with one another, while the women sat on the other side, listening to the guest speaker.

Guest speakers generally had medical backgrounds, and presented information that
was basic and often repetitive. One month, for example, a local oncologist spoke about risk factors, stages of breast cancer, treatment options, and recent research findings. Several months later, another doctor presented essentially the same information. Group members reported that this was common. Speakers were often recycled, despite the fact that the composition of the group rarely changed and many women had been attending meetings for at least three years.

Members of Hogart did not, however, appear to tire of the meeting format. They continued to attend group meetings, remained enthusiastic about inviting guest speakers to the group, and were always actively engaged in the question-and-answer sessions that followed presentations. But what the women seemed to enjoy most was the social nature of the group. Many arrived early so that they could socialize with one another. Others would remain after meetings officially ended, chatting and joking with one another, sometimes for as long as twenty minutes or more.

Additional Data Sources

In addition to participant observation, I conducted 35 intensive, open-ended interviews. In total, I interviewed 30 support group participants, 4 facilitators, and one counselor affiliated with the Upton cancer center (see Appendices A, B, and C for interview schedules). Most of the interviews took place in the women’s homes or on the site of the group meetings. Two interviews were conducted in restaurants and one by phone. All but one were tape-recorded and transcribed, as one woman requested that her voice not be recorded. Extensive notes, as near verbatim as possible, were taken for this interview.
Participant interviews were semi-structured and followed a loose interview schedule (see Appendix A), which was developed after identifying recurrent themes from group meetings. Topics covered included diagnosis and treatment, emotional responses to being sick, coping strategies, responses of friends and family members, and involvement in and satisfaction with the support groups. Interviews ranged from one to five hours in length, with an average length of two hours. Additional information was gathered in follow-up conversations at support group meetings. Occasionally, women approached me at support group meetings to add information that had come to mind after an interview.

Finally, I also collected data at events related to and/or sponsored by the groups and their members. For example, I attended an informational fair during breast cancer awareness month, a fly-fishing retreat for breast cancer survivors, two Race for the Cure events sponsored by the Komen Foundation, and several parties given by group members. These occasions provided opportunities for conducting numerous informal interviews. They also gave me the chance to learn more about the culture that has been created around breast cancer.

Analysis

Data were analyzed using a grounded theory approach (Charmaz 2001; Glaser and Strauss 1967). This involved simultaneously collecting and analyzing data by writing fieldnotes and notes-on notes, coding fieldnotes for emerging themes, and writing analytic memos to develop interpretations of observed patterns and processes. Initially, for example, I wrote fieldnotes and coded them for patterns of speech and behavior, paying special
attention to how the women talked about and reacted to their breast cancer diagnosis. This was followed by more focused coding that aimed to identify the strategies the women used to help one another cope with their disease. For instance, through this analytic process it became clear that information-seeking was a crucial part of coping with the emotional fallout of breast cancer. Other strategies were similarly identified. These included concealing disfigurement, joking, practicing a compensatory form of femininity, storytelling, taking on the identity of breast cancer survivor, and defining breast cancer as a blessing.

As these strategies were identified, I used subsequent fieldwork and interviewing to gather more focused data on them. For example, in their interviews, many of the women talked about the emotional pain evoked by the loss of a breast(s), a topic they generally avoided during group meetings. This led me to pay closer attention to the sexualized joking that took place in the groups, and how the women used this type of humor to deal with the discontent and insecurity that they experienced about their changed bodies. Similarly, I used data collected from the York and Upton groups to help me better understand the experiences of the Hogart women. It was clear, for instance, from observations of the former two groups that information-seeking was one way that the women dealt with the fear and anxiety evoked by a cancer diagnosis. When I started observing the Hogart group (over a year later), I thus paid particular attention to how these women gathered information about their disease, how these strategies differed from the ones used by the York and Upton women, and the consequences they had for how members of the group experienced their disease. This too helps to illustrate how the data analysis process for this project was a continuous one that evolved over time.
COPING WITH BREAST CANCER

Many researchers have studied how people cope with difficult life events, such as the diagnosis of a potentially life-threatening disease. Most of this work, as will be discussed below, has focused on individual coping strategies (see, for example, [Thoits 1995 and Pearlin 1989] for reviews of this literature). The present study departs from such a focus, examining collective coping strategies. What the women of Upton, York, Bellesmith, and Hogart did to manage the emotional fallout of their disease, they did together. They might have done much worse, it seems, had they not devised the collective coping strategies that this study attempts to explain.

Being diagnosed with breast cancer is a difficult life event that evokes intense feelings of fear and anxiety. For instance, the women in this study reported fears not only of dying, but leaving their families bereft; fears of disfigurement and loss of sexual attractiveness; confusion about etiology; uncertainty about the effects and effectiveness of treatment regimens; and, even if treatment worked in the short term, dread of recurrence (see also, McKenzie and Crouch 2004; Weihs 1996; Glanz and Lerman 1992). The disease thus profoundly disrupts women’s emotional equilibrium and feelings of control.

Those who study stress and the coping process have attempted to explain how people deal with the emotions evoked by such a difficult life event. For example, Pearlin (1989), Thoits, (1995, 1986), and others (Lazarus and Folkman 1984; Selye 1982; Holmes and Rahe 1967) have examined the types of resources that people draw upon to help them cope, including social support (i.e., the “social ‘fund’ from which people may draw when handling stressors [Thoits 1995:64]) a sense of control (feeling like one can master, control, or
effectively alter one's environment), and self-esteem (or feeling confident in one's abilities to
deal with the stress and strains of life). They have found that these resources serve to buffer
the deleterious effects of stress, and also influence the types of strategies that individuals use
to help them cope (Pearlin 1989; Thoits 1995, 1986; Lazarus and Folkman 1984; Berkman
1984).

For instance, Folkman (1984) and her colleague (Lazarus and Folkman 1984) report
that people who feel in control of difficult situations and are confident that they can cope
with them, are more likely to use problem-based strategies, that is, techniques that aim to
alter or eliminate the source of stress (Pearlin and Schooler 1978). Conversely, when
individuals feel less confident or perceive a problem to be outside of their control, they are
more likely to make use of emotion-based strategies, that is, strategies that allow them to
control the meaning of a problem or stressful event by neutralizing the threat of it (e.g., by
making positive comparisons or finding positive value in negative events [Lazarus and
Folkman 1984; Pearlin and Schooler 1978]). Other emotion-based strategies do not attempt
to change the meaning of an event directly. Rather, they help people “screen out” the
negative feelings associated with the source of stress (e.g., by avoiding the problem or
denying that it exists [Lazarus and Folkman 1984]). The general consensus among many in
the area is that these latter types of strategies are largely ineffective (Thoits 1995; Lazarus
and Folkman 1984; Pearlin and Schooler 1978). However, not all research has proven this to
be the case. Some studies have found that strategies such as avoidance and denial can be
useful for coping, at least in the short term (Thoits 1995; Aneshensel and Huba 1983).
Others have found that individuals often use these types of strategies in conjunction with
cognitive and/or problem-based ones (Clark 1994; Aneshensel and Huba 1983). People thus use different types of coping strategies, in different situations, with varying results.

While the literature on stress and coping provides a starting point for understanding how people deal with difficult life events, it has been criticized for ignoring the social nature of the coping process. This body of research does not, for example, give much insight into the ways people are able to manage their own and others’ emotions. Nor does it adequately consider how people work together to help one another cope. These are issues, however, that have been addressed, in part, by researchers in other areas. Those who study the sociology of emotions, for instance, have added to our understanding of the coping process, by showing how people learn to regulate and suppress their own and others’ emotions (James 1989; Hochschild 1979, 1983). Those who study support groups have built on this body of research, by examining how such groups allow people to cope with the difficult circumstances or events in their lives through interaction with others facing similar situations (Erickson 1997; Francis 1997b, Rieff 1987).

Francis (1997b), for example, in her research on divorce and bereavement support groups, has shown how such groups helped members to redefine the event of “spousal loss,” as well as fashion new identities for themselves. Wolkomir’s (2001) and Mason-Schrock’s (1996) work examines similar social processes, showing how support groups allow members to redefine themselves in favorable ways. Other researchers have studied groups more like those of the present study, including Sandstrom’s work on support groups for people living with HIV/AIDS (1996, 1990) and Karp’s (1992) study of a self-help group for those suffering from affective disorders. These researchers show how support groups, by bringing together
people who are in a similar health situation, allow members to reconstruct the meaning of their illness and thereby sustain desirable social identities (Sandstrom 1996, 1990; Karp 1992). Again, this helps to illustrate how support groups allow people to cope collectively with difficult life events and the uncomfortable emotions that they evoke, a process that Francis (1994, 1997a, 1997b) has labeled “interpersonal emotion management.”

The present study adds to these bodies of research by showing how support groups allow women who have been diagnosed with breast cancer to manage the emotional fallout of their disease. As will be discussed later, it illustrates how the York, Upton, Hogart, and Bellesmith groups allowed their members to cope with the uncertainty of their breast cancer diagnosis, deal with the stigma and uncomfortable feelings evoked by the disfiguring effects of their disease, and help one another make sense of what they had been through. It also shows how the women’s behavior was influenced and constrained by the mainstream breast cancer culture.

BREAST CANCER CULTURE

Women do not experience breast cancer in a cultural vacuum. Rather, how they respond to and cope with breast cancer is influenced by groups and organizations that have embraced and promoted a culture around the disease. While these groups and the philosophies that they represent are not homogeneous, they can be largely characterized as focusing on breast cancer awareness, emphasizing positive and upbeat attitudes for breast cancer patients, hiding the physical effects of the disease, and drawing attention to survival and “survivors” (Ehrenreich 2001). Against the background of this culture, breast cancer can
thus be seen as more than a medical issue. How women experience breast cancer greatly depends upon the values and beliefs promoted by the groups and organizations that have created a particular culture of disease.

In 1985, Zeneca Pharmaceuticals (now AstraZeneca) declared October “Breast Cancer Awareness Month” (Sellman 2005). Since (and even before) that time, many groups and organizations have worked hard to bring public attention to the disease. The most prominent of these is the Komen Foundation (Milden 2005; Ehrenreich 2001). This non-profit organization, the largest private funding source for breast cancer research and community outreach in the United States, was founded by Nancy Brinker in 1982 to honor her sister Susan Komen, who died of the disease (<http://komen.org>). Known for its sponsorship of “Race for the Cure” events (5K walk/runs that are held across the nation), the Komen Foundation has been largely responsible for shaping how the disease is framed in the public arena (King 2004; Ehrenreich 2001; Klawiter 2000, 1999).

As King has reported, the organization has worked hard to present the fight against the disease as one that “does – and should – take place on the terrain of science and medicine” (2004:476). This is best reflected in Komen's primary mission, which as reported on its website is, “to eradicate breast cancer as a life-threatening disease by advancing research, education, screening and treatment” (<http://www.komen.org>). Such a focus has led Komen and other mainstream organizations, such as the American Cancer Society and the Avon Breast Cancer Crusade, to promote “breast cancer awareness,” early detection, and the need for cutting-edge research, while virtually ignoring the persistently high incidence of the disease, its social and environmental causes, as well as the number of women that it kills.
every year (King 2004; Ehrenreich 2001). According to Ehrenreich (2001) and other researchers (King 2004; Klawiter 2000, 1999), this helps to explain how and why Komen and these other organizations have been so successful in creating an upbeat culture around the disease. By downplaying the suffering and death caused by breast cancer, they have been able to draw attention to survival and “survivors,” and thus promote an “overly bright and hopeful configuration of the disease” (King 2004:487).

This is also at least one reason why corporations have been so willing to sponsor and support organizations affiliated with the disease. Breast cancer has been promoted in a non-threatening and corporate-friendly way, and lacks the stigma associated with other diseases such as AIDS (King 2004). This is evidenced by the long list of “corporate partners” (over twenty companies identified on the Komen website) who have donated at least one million dollars to the organization, including, among others, Ford Division, Yoplait, Quilted Northern, Kellogg, KitchenAid, M & M’s Brand Chocolate Candies, and Lean Cuisine (<http://www.komen.org>). It is also illustrated by the way these companies have been able to successfully capitalize on the disease. As King (2004) has reported, these corporations, and others like them, have relied on philanthropy as a “profitable strategy” to market their products. In 2001, KitchenAid, for instance, created a campaign called “Cook for the Cure,” which raises funds for the Komen Foundation through sales of its long line of pink (the color associated with the disease) kitchen appliances and gadgets (<http://www.kitchenaid.com>). Other companies have followed in a similar vein, offering to support Komen and its mission by donating a portion of proceeds from sales of their products, which, like those sold by KitchenAid, are most often unrelated to the disease, but carry the image of the pink ribbon
that has become synonymous with “breast cancer awareness.”

The proliferation of these kinds of products, as well as the media attention that has been drawn by the disease, illustrates how ubiquitous breast cancer culture has become. It also shows how Komen, other organizations affiliated with the disease, and their “corporate partners” have been able to shape the meaning of breast cancer. Through the use of symbols such as the pink ribbon and carefully orchestrated events like the “Race for the Cure,” these companies and organizations have been able to dictate how the disease is publicly framed. In Fine and Ross’s (1984) terminology, Komen and others, through the use of “display” (i.e., performances or objects), have been able to form a “consensual understanding” of the symbolic meaning of breast cancer. But this has been well documented by other researchers, including Ehrenreich (2001), Klawiter (2000, 1999), and King (2004), who, as the above discussion has illustrated, have shown how a culture has been created around breast cancer, as well as how this culture has influenced public discourse about the disease.

What these authors have not considered, at least in any detail, is how the mainstream breast cancer culture has affected the ways women, especially those who participate in support groups, manage the emotional fallout of their disease. The present study is helpful in this regard. As the discussion in the following chapters will show, this project illustrates how the culture surrounding breast cancer has influenced and limited the ways women think and talk about, as well as cope with, their disease.
DISSENDERATION OVERVIEW

This study examines how women who participated in four breast cancer support groups learned to cope with the emotional fallout of their disease. Each chapter examines a particular problem with which the women struggled, and shows how they worked together to develop coping strategies to deal with it. These problems correspond to the progression of the women’s illness, and are discussed in the order in which the women experienced them.

Chapter two, for example, focuses on how members of the four groups dealt with the fear and anxiety evoked by their initial breast cancer diagnosis. More specifically, it examines how the women sought information to help mitigate feelings of unease. The analysis in this chapter also shows how class-based inequalities led the women to seek information about breast cancer in different ways. The women of York and Upton, who were mostly middle-class, had the resources to gather and interpret information on their own, in effect becoming lay experts on the disease. The working-class women of Bellesmith and Hogart lacked these resources, and thus collaborated in constructing their doctors as experts.

These divergent strategies, as chapter two will show, affected the women’s illness experiences. Members of York and Upton interacted more assertively with their care providers and were more satisfied with treatment decisions. Members of Bellesmith and Hogart, who were invested in trusting the expertise of their doctors, were subject to medical paternalism and pressured into making decisions that they later questioned.

Chapter three examines how members of the four groups learned to cope with the embarrassment, shame, and self-doubt evoked by the bodily manifestations of disease and treatment. In so doing, chapter three draws attention to how the women learned to conceal
their illness from others, joke about changes to their bodies, and practice compensatory femininity. As the analysis shows, these strategies helped the women to feel better about themselves and their bodies. These strategies, however, also inadvertently maintained gender inequality by reinforcing traditional standards of beauty. They also reinforced the mainstream breast cancer culture's depoliticized construction of the disease.

Chapter four analyzes how the women in the study dealt with post-treatment fallout. More specifically, it examines how members of the four groups learned to cope with the uncertainty of the future, as well as how they came to make sense of what they had been through. In so doing, it examines three strategies that the women used to view themselves and their illness in positive ways, including creating and sharing medicalized stories that narratively located their breast cancer diagnosis in the past, taking on the identity of breast cancer survivor, and redefining their illness experience as a blessing. This chapter also shows how these strategies served to reinforce a breast cancer culture that encouraged positive attitudes, rather than indignation and collective action in response to the disease.

Chapter five, the conclusion, discusses the implications of the findings of this project in greater detail, showing how they contribute to the larger bodies of literature on health, coping, and gender. More precisely, it examines how the findings and analysis from this project add to our understanding of how support groups can help people interactively cope with difficult and stigmatizing life events; how gender and gender inequality impact the ways in which support group participants are able to help one another cope; and how the emotion-work strategies that these individuals use to cope with illness can be influenced and constrained by a particular culture of disease. Finally, this chapter assesses the strengths and
weakness of the study, and discusses avenues for future research.
Chapter Two

COPING WITH A BREAST CANCER DIAGNOSIS

Almost all of the members of York, Upton, Hogart, and Bellesmith described being diagnosed with breast cancer as traumatic. The women reported being afraid that they might die, fearful over what might happen to their families, and anxious over what a future with cancer might hold. One woman, Betty, who participated in the York group, recalled what happened when her doctor called to say that her pathology report came back positive (for cancer cells), saying,

And I remember where I was sitting. Like at the little desk in the other house. In the kitchen, at that little desk – I was sitting down, and the doctor was talking [on the telephone]. This was when he had the path [sic] report back. And I wrote down [pause] “invasive carcinoma.” And, you know, it was real, but it wasn’t real. My life changed at that moment.

This sentiment was echoed by many of the women. Kim, a member of Upton, whose breast cancer diagnosis and treatment was different from most due to the size and location of lumps in her breast and under her arm, nonetheless serves as a good example of how overwhelming it was for the women to be to be told that they had cancer. In describing her first trip to the oncologist, Kim said,

So that was a brutal appointment. After that it was like, oh, shock.

And so she [the oncologist] is basically--is sitting down and then she’s starting to talk about, “Well, you need to do chemo[therapy]. You need to do this. You need to do that. I would consider doing a high dosage…” And she’s talking like this different language. It was all cycles and about drugs… And I was like, “Wait a minute! Wait a minute! We know nothing. We know absolutely nothing.” And I said, “Well, what makes you so sure?… What
makes you so sure? That I have cancer?”

Kim’s description of her initial visit to the oncologist’s office illustrates some of the common reactions the women had to being diagnosed with breast cancer. Most responded with shock, and then became overwhelmed with fear and anxiety. In response, the women sought ways to alleviate their fears and make sense of what was happening in their lives.

One such strategy was to seek information about breast cancer. The women in the four groups tended to do so, however, in different ways. Those participating in the predominantly middle-class groups, York and Upton, gathered information from a variety of sources, attempting to become lay experts on the disease. The women who participated in the mostly working-class support groups, Hogart and Bellesmith, relied on doctors and other professionals for the information that they received, and coped primarily by putting their trust in these experts. In this chapter I will discuss how the women used these two information-seeking strategies, “becoming experts” and “trusting the experts,” to mitigate the fear and anxiety that they experienced after being diagnosed with breast cancer. I will also show how these strategies had consequences for how the women experienced their disease.

**BECOMING EXPERTS**

As noted in the introduction, the York and Upton groups were affiliated with cancer centers at large urban hospitals, and consisted almost exclusively of middle-class, white women. A typical meeting for either group began with the women introducing themselves and summarizing their diagnosis, treatment, and health status. This could take the entire meeting, especially if ten or more women were in attendance. If extra time remained, the
women used it to discuss “what was going on with them” and/or any particular problems that they were currently experiencing. Sometimes this generated discussions about the women’s emotional responses to being sick, how family members were reacting to their illness, or even their reactions to medical personnel. More often, however, the extra time was spent discussing and sharing information related specifically to breast cancer and its treatment, especially at Upton, where the group was facilitated by an oncology nurse.

Few of the women had much prior knowledge about breast cancer. For example, before being diagnosed, most of the women were unfamiliar with the clinical stages of the disease, the surgical options available to breast cancer patients, or how treatment regimens were chosen or carried out. Many thus reported that the “first thing” they did after being diagnosed was to seek information about the disease. They did so in a number of ways, including borrowing books from public and university libraries, consulting Internet websites dedicated to breast cancer, requesting copies of their medical records, and conversing via online listservs with other women who had breast cancer. Four women who participated in the York and Upton groups serve as illustrative examples.

The first is Annette, a member of York, who had a master’s degree in one of the social sciences. During one support group meeting Annette explained that after being diagnosed she went straight from the doctor’s office to the public library, checking out as many books as was allowed per topic (breast cancer) and exchanging these for more after she finished reading the first batch. In addition, she consulted journal articles and “reputable” Internet sites, and even joined several online chat rooms, seeking information about breast cancer, possible options for treatment, and emotional support from others in similar
situations. Annette was not alone. Many of the York and Upton women reported searching for information in these and other ways.

Julie, a member of Upton, for example, requested copies of “everything” regarding her cancer diagnosis. This meant obtaining documentation of her pathology and laboratory reports, mammogram x-rays, medical files, and other personal medical information. Once she had these materials in her possession, Julie searched the Internet, comparing her particular case with general information about breast cancer that she found online. In an interview, she explained how she did this. She stated,

I did get on the Internet, and I definitely researched breast cancer. And I had the nurse fax a copy of the pathology report. Then I sat down with my pathology report, and I looked up various things. As I read my pathology report, I had some concerns. So, I made a long list of questions. It was twenty-five questions I went in with [to the doctor’s office].

Although Julie’s research resulted in several concerns and quite a few questions, it did provide her with much needed information. The same was true for Helen, a member of York.

Before committing to any surgical procedures, Helen visited several medical school libraries and read a variety of journal articles about breast cancer and its treatment. When asked how she deciphered some of the complicated information contained in these texts, Helen stated that she purchased a copy of Taber’s Cyclopedic Medical Dictionary and a Merck Manual (of Diagnosis and Therapy), and used them together to help her understand what she was reading. In her interview she explained that,

You use the dictionary to learn the jargon, then the Merck Manual to see what the standardized treatment strategies are. Then you can go on to the medical texts, taking your dictionary with you to read about all the words you don’t know, and read recent periodicals for
the most current research.

In this way, Helen learned more about breast cancer and the treatment options available to her as a cancer patient.

Although not every member of Upton and York pursued information as aggressively as the three described above, the majority of the women did make a concerted effort to seek it out. In addition, even those who initially chose not to gather information or sought little of it, often reported feeling pressured to do so after starting to attend support group meetings. For instance, Gladys, a woman who joined Upton about six months into my observation period, did not seek much information about breast cancer when first diagnosed. In fact, she vowed to read “only one book” about the disease. She quickly changed her mind, however, after attending several support group meetings. In her interview, Gladys explained why:

I felt really dumb --after going to the support group for a while and hearing everybody spiel off all their medical stuff. I thought, “Well, maybe I better go home and read up. Make sure what I got going here.” So, I did. [Laughing].

The above example illustrates that participants of York and Upton expected one another to be well informed about breast cancer and to able to discuss the particulars of their medical cases. And while individual members were rarely called to task if they could not, they did risk feeling, as Gladys described it, “dumb,” in front of other group members. The majority of the women in the two groups did not have to worry about this kind of stigma, however. Most sought information even before starting to attend group meetings. And those who did not, frequently went on to seek information not long after.

In other words, even though some of the York and Upton women, including Gladys,
might not have particularly enjoyed seeking information, they typically had the resources and capabilities to do it. Most were college educated, and had at least some experience locating and understanding informational materials geared to both lay and professional audiences. In addition, if they worked outside of the home, they usually had jobs or careers that allowed them to miss work, generally without hassle, so that they could deal with their illness.¹⁷

Julie, who was mentioned earlier, is an example. Although she was working a part-time job when she was diagnosed, Julie had previously been employed as a nurse. Her husband was a mid-level corporate manager. As a result, Julie was able to take off time from work while she was sick. The bulk of it was spent visiting doctors and recuperating from surgery and follow-up treatments. However, she also used the time to seek information about breast cancer. She tracked down copies of her medical files, searched for information on the Internet, and made lists of questions to ask her doctor.

At first glance perhaps Julie’s behavior does not seem all that impressive. But it does demonstrate the use of several important skills. To locate a copy of her pathology report, for example, she had to know whom to contact and what to ask for. To be able to receive the information quickly, she needed access to a fax machine, which she had at home. Next, Julie had to be able to understand basic information contained in a medical report. As a former nurse, she was able to do just that. When she was not able to comprehend something in the report, she was able to locate more information about it on the Internet, again conveniently at home. Finally, Julie was able to compare information regarding her particular case with general information that she found online, and make a list of twenty-five questions to ask her doctor.
As this would suggest, Julie collected a significant amount of information and developed a detailed understanding about breast cancer and its treatment. The same was true for the other members of York and Upton. They gathered information from a variety of sources and used it to become lay experts on the disease. More importantly, the women used the information they collected to help them cope with the emotional fallout of breast cancer. Gathering and sharing information helped to relieve fear and anxiety, for example, by informing them what radiation or chemotherapy would be like, which side effects were considered normal, and/or how the results of different reconstructive surgeries might look. For the women it also meant that they were knowledgeable and competent medical patients. These points will be discussed in greater detail, in the following sections.

**Alleviating Fear and Anxiety**

Being diagnosed with breast cancer created a mix of uncomfortable feelings for the Upton and York women. As mentioned earlier, they reported being afraid that they might die, fearful over what might happen to their families, and anxious over what a future with cancer might hold. Seeking information was thus one strategy that the women used to help them cope with being ill. And though it is not clear whether or not all of the women in the two groups sought information with the specific intent of feeling better about their illness, many of them did. In fact, several of the women spoke directly about the emotional benefits they gained from actively seeking information.

Annette and Julie, who were both mentioned earlier, serve as examples. For instance, in her interview, Annette told me,
I’m a reader. When I’m faced with any kind of problem, I find out as much information as I can about it. If I know what I’m dealing with, I can cope with it better.

Julie reported something similar. She said,

I’m big on researching things. That’s partly how I deal with anxiety about things. . . Even before I was diagnosed with the biopsy, I started researching different ways of having it done.

Although other members of York and Upton did not speak directly about how gathering information helped them cope with being sick, that it did so was still evident.

Consider Connie, a woman who participated in the York group. She was one of the few members of the group that did not seek breast cancer related information after being diagnosed and starting adjunctive treatment. When she came to her first support group meeting, she was already several weeks into radiation treatment and was extremely distraught, crying frequently as she described her situation to the group. She also explained how frightening treatment was for her because she did not know what to expect, or whether the radiation would target any remaining cancer cells in her breast. In describing her experience, Connie said,

On the day that it [her first radiation treatment] happened, it was horrible. When I heard that machine going GEERRRR [imitating noise of the radiation machine], it was like my mind went crazy. I hated it. I hated it. I didn’t know what it was doing, and I didn’t read about what it was doing. I didn’t want to because I was in denial. I said it wasn’t going to happen. For the first half of it I kept saying, “I’m doing this. My body is doing this but my mind is not doing this.”

After hearing about her experience, other group members shared some of the information that they had collected about radiation therapy. They also urged Connie to seek more information.
on her own.

At her next visit to the group, Connie reported that she had taken the women’s advice, checking out several books from the library and reading up on radiation as a form of cancer treatment. She also said that doing so made her feel better about the situation. She told the group,

I’m more convinced that they [radiation technicians] know what they’re doing. Before, I never knew if they were hitting the right place [in my breast] or not. But according to what I read, the markings are very precise. And I’m more convinced that it’s [radiation] going to work.

In addition, Connie reported feeling less anxious and emotionally distraught, which was also evident from the drastic change in her demeanor from one meeting to the next.

In this example, Connie was nervous about and afraid of having radiation therapy. She did not know what to expect when she went for treatment and was anxious about whether the radiation would work. Although other York and Upton women experienced similar kinds of fears and anxieties, they coped largely by seeking information. For example, by gathering information, women like Annette and Helen learned what to expect from the radiation treatment process, as well as how it worked to destroy stray cancer cells. During her first visit to the group, these two women shared what they had learned with Connie and encouraged her to seek more information on her own. As the above interview and fieldnote excerpts help to illustrate, following their advice helped Connie feel less anxious about the treatment process and increased her confidence that radiation would successfully treat her breast cancer.

Seeking information about breast cancer also helped Connie feel better about herself
as a medical patient. For instance, when asked about her first visit to the support group, Connie explained how she felt inadequate because she had not learned more about her disease. From her interview:

When Annette said she had gone to the library and gotten every book she could get and read everything in it, I felt dumb. You know, I felt like I went into denial, rather than to go into reading about everything, you know? It was like I felt—dumb is not the word. But I felt like I went at in sort of the wrong way. I just went and said, “Whatever, whatever they do, I’ll accept,” whereas I guess I should have researched. But I was in denial. How can you read when you are in denial?

Because she had not sought information about breast cancer and was unable to participate in detailed discussions about it, Connie, like Gladys, felt “dumb” when she attended her first group meeting. That both of the women felt this way helps to illustrate how having the ability to locate and discuss medical information during meetings became a source of status among members of York and Upton. For the women who attended the two groups being able to do these things also meant that they were “smart” (versus dumb) medical patients.

“Becoming experts,” thus helped the Upton and York women cope with the emotional fallout of breast cancer in at least two ways. First, by gathering information about the disease, the women learned what to expect from doctors and treatment, which reduced some of the uncertainty associated with being a breast cancer patient. As was illustrated with Connie’s radiation therapy experience, this, in turn, helped members of the two groups cope with the fear and anxiety they experienced as a result of being sick. Second, seeking information and discussing it during meetings helped the women feel well-informed about their disease and prepared for their encounters with the medical system. Mastering
information related to their disease, in other words, signified to the women that they were knowledgeable and competent patients. As will be discussed later, this also had consequences for how the women interacted with their physicians.

Sometimes, however, the York and Upton women’s strategy of seeking and sharing information did not work. Instead of making them feel better, engaging in such behaviors actually made them feel worse. For example, sometimes the women became overwhelmed by the kind of information with which they were faced. Other times they were upset by information that was contradictory or ambiguous. In the following section, I will discuss how the women’s strategy of “becoming experts” was not always successful for alleviating their fears and anxieties, as well as how the women dealt with this when it happened.

**Dealing with Unsettling Information**

At any given meeting, York and Upton members used group time to talk about their experiences with breast cancer. But most discussions, especially about chemotherapy, rarely went beyond a surface level. For instance, members might mention how many treatments they had (or had remaining), what drugs they were given, and some of the side effects they experienced. They did not typically discuss, at least in any detail, how much they disliked chemotherapy, how physically ill it made them feel, or how difficult the experience was for them emotionally. That chemotherapy was extremely hard, both physically and emotionally, was clear, however, as the women often talked about these things during interviews. Donna, a member of Upton, is an example. From her interview:
Jackie: Going back to the chemo and radiation, I know you said that that really sticks out to you. What was the hardest part about chemo?

Donna: Well I always say that the chemo and the reconstruction run hand in hand as the most difficult—that if I forget everything else, I’ll probably never forget those two things.

Jackie: What is it about chemo that you won’t forget?

Donna: How sick it made me those two times, because I swear I thought I was dying. I was so sick that I thought I was not going to make it.

Sandra, who attended York, described a similar experience. From her interview:

Jackie: What was the hardest thing about treatment for you?

Sandra: Chemo. Chemo was the pits.

Jackie: And specifically what made it difficult?

Sandra: . . . the chemo was so hard on my body. You know, getting sick and feeling just so 

As Donna and Sandra’s comments illustrate, chemotherapy was a physically and emotionally painful experience for the women. Yet, this was rarely discussed during group meetings.

One exception was during a York meeting when only two longstanding group members, Betty and Sandra, the leader, a hospital oncology nurse, and I were present. On this particular night, when asked by Deborah, the leader of the group, how she was doing,
Sandra responded,

I’ve been having a rough time lately. I think it’s because I’ve just now been able to acknowledge how much I hated chemo. I hated chemo. I hate what it did to my body. I hate that I have chemo-arthritis now. I hate how I feel like I’ve been robbed of a year of my life.

And I’m just now realizing how sick I actually was. I had to pretend that it wasn’t that bad, for my family and friends, because I didn’t want them to worry. I think I also had to pretend that it wasn’t so bad for myself, too. If I hadn’t, I don’t think I could have made it through.

Betty concurred, saying,

I thought it was awful, too. Chemo is much more difficult than we generally let on, even in the support group.

Why the women were reluctant to discuss such issues became clear at the next meeting, when Mary attended the group for the first time.

At the beginning of this meeting, Deborah made reference to the previous one, saying that, “The last meeting was one of the most memorable ones I’ve ever attended. I think it’s so important for us to acknowledge how difficult the cancer experience can be.” She then asked Betty how she had been doing since the last meeting. While Betty was answering the question, Mary, the new woman, entered the room and sat down at the table. As she settled in, Betty said, “I’ve been doing well. I think it was good for me to be able to share how hard chemo was.” She then backtracked for others who had not been present at the last meeting, saying,

I just talked about how awful chemo was. How sick and weak I felt. Eating when I felt terrible. Not liking to eat. Trying not to be around people that had germs and whatever. Toward the end of my chemo I could barely walk to the bathroom. I would lie in bed and have to go, and hold it as long as I could, so I’d have to get up as few times as possible.
And I couldn’t get downstairs to get food. It was awful. It really was.

Betty then started to tear up and said, “Now see, I’m going to start crying again.” She wiped a few tears from her eyes and then said, “But everything about my life is different now. I feel like I’ve gained a lot from the experience.”

While Betty was still speaking, Mary started to sob. When Deborah asked her what was wrong, the woman explained that she was starting chemotherapy the following week and was terrified of going.

While Deborah consoled Mary by patting her on the shoulder, Betty and the other women in attendance reassured her that she would be alright. They then spent the rest of the evening describing what it would be like to have her first chemotherapy treatment, and answered Mary’s questions about it. Betty described what the treatment room would look like and what would happen when she arrived, while Annette explained how Mary could prepare for treatments by eating a meal beforehand and having prescriptions for nausea medications filled several days in advance. Sharon, the oncology nurse, also provided Mary with tips on surviving her first treatment, and promised to look for her in the treatment room the following week. By the end of the meeting Mary appeared less upset, and thanked everyone for helping to prepare her for the upcoming treatment.

At this particular meeting, Betty shared how physically debilitating and emotionally difficult chemotherapy was for her. Normally, this kind of information would not have been discussed during group time, especially in front of a new member. However, Deborah encouraged Betty to do so, as follow-up to the discussion that took place at the previous meeting. In addition, Mary, the only new member in attendance, entered the room after the
meeting had officially started and Betty had begun to speak. Consequently, she heard information typically not shared with those just starting chemotherapy. When she became upset by what she heard, other members of the group felt obliged to calm Mary by sharing information and tips intended to make the experience less frightening and more manageable, such as Annette’s suggestion of eating a meal before going to treatment. In this way, group members attempted to relieve the additional anxiety created by Betty’s candid discussion of chemotherapy.

Mary’s first experience in the York group helps to illustrate how certain kinds of information about breast cancer and its treatment could create more emotional distress for the women, rather than less. In this case, hearing how physically debilitating and emotionally difficult chemotherapy was for Betty increased Mary’s anxiety about starting treatment the following week. The women dealt with the situation by moving the discussion away from the harsh side effects of chemotherapy and focusing instead on specific strategies Mary could use to avoid and/or cope with them. One way the York and Upton women therefore handled overwhelming information was to shift attention away from it by discussing practical solutions to the problem at hand. In this way, they redefined the situation, such that it was less threatening.

Members of York and Upton were able to largely avoid uncomfortable situations, such as the one described above, by refusing to discuss certain topics, at least in particular ways, for example, not typically talking about the debilitating nature of chemotherapy. However, the women could not entirely avoid discussing information that was upsetting to them. Such was the case when they found and/or discussed information that was
contradictory or ambiguous in nature. When this happened, the women attempted to deal with the information and the feelings it evoked by individualizing their discussion of breast cancer and its treatment. The following examples help to illustrate how they did this.

During one Upton meeting, Rhonda, a white woman in her early 40s, broached the topic of stem cell transplant. Having been diagnosed with an advanced stage of breast cancer, Rhonda was considering having the procedure as part of a clinical trial. She explained to the group how her doctor had recommended the treatment, and provided a vague description for other members of the group. She concluded by saying, “And then they give you back those stem cells, which are good and clean and haven’t been bothered with cancer cells! It’s supposed to be very successful.” Although Rhonda was excited about the transplant and hoped that it would work for her, her knowledge about the procedure seemed sketchy, at best.

In response to this, several members chimed in with additional information. One woman, Michelle, seemed especially concerned that Rhonda would consider having a stem cell transplant without knowing more about it. She also shared information that she had read about the procedure saying,

Actually, there is conflicting information about the success of stem cell transplants. There’s a recent study out of Johns Hopkins that shows there’s virtually no difference in survival rates between women who have the procedure and those who do not.

Kim, a scientist at a research university, added,

The study that reported stem cell rescue to be an effective treatment was later found to be fraudulent. There were five clinic trials about the high dose chemo and stem cell rescue. One was from South Africa. Some were from Belgium. One from the U.S. Most of them –four were
inconclusive. And one of them showed positive results. That was the South African one. But during my chemo it came out that the one positive trial was fraudulent. It was actually a fraud. Their data were fraudulent.

In response to these comments, Rhonda explained that her oncologist thought that she should go forward with the transplant and that she planned to follow her doctor’s recommendation. At this, several other members joined in to support Rhonda’s decision saying that “everyone is different,” “different things work for different people,” and “you have to do what is right for you,” to which almost everyone in attendance agreed.

The women’s response to the contradictory information on stem cell transplant was a common one. They individualized the discussion, putting the focus on Rhonda and her personal decision, instead of the conflicting data on the procedure. Doing so helped the women accomplish several things. First, it helped them avoid a potential argument over which information was correct. Second, it enabled them to support Rhonda and her decision to undergo the procedure, without actually having to take a stand on the stem cell transplant debate. Most importantly, claiming that “everyone is different” allowed the women to disregard information that they found threatening (i.e., stem cell transplants are ineffective in treating breast cancer), as well as combat some of the fear and doubt created by the suggestion that one of their members could possibly die from an advanced stage of the disease.22

The women responded in similar ways when they talked about chemotherapy, as its benefit to breast cancer patients was also unclear. For instance, Love writes that, in general, “Chemotherapy reduces the risk of recurrence by about a third” (2000:380). However, she
goes on to state that the figure is somewhat misleading, since patients who are at higher risk of recurrence also have a better chance of the treatment working for them. As an example, Love reports that,

If you have a 60 percent chance of recurrence, a one-third risk reduction means it will reduce it by 20 percent, but if you have a 9 percent chance of recurrence the one-third reduction in mortality is only 3 percent. This is an important concept to understand when trying to weigh risks and benefits (2000:381).

Members of York and Upton were familiar with these type of data from both their own research and discussions with their doctors. But for many of them the information was more unsettling than reassuring, especially since doctors could not tell them exactly what their chance of recurrence was.

Take, for example, how Kathleen, a member of York, talked about chemotherapy and the doubt she experienced over whether or not it would work for her. From her interview:

One day, I said to my oncologist, “I mean this chemo has got to be taking care of any cancer cells in this other breast, too. Right?”

She said, “Well, that’s our hope.”

And I said, “Well, on a scale of 1 to 10, where’s the hope?”

So she goes, “Well, it’s hard to quantify that.”

I almost flipped her the bird on that one.

Kathleen went on to say,

. . . I mean, even now [whispering] reading about chemo. I’m thinking, [whispering], “Did I really need to do this chemo?” When you read about, you know. [Laughing], again, it’s all a crap-shoot. It’s just amazing to me.

As Kathleen’s comments suggest, not knowing if chemotherapy would successfully treat her
cancer or not resulted in a significant amount of fear and doubt. The same was true of other York and Upton women.

How they and the leaders of their groups dealt with these feelings is best illustrated by what happened when Kathleen expressed her concern about the effectiveness of chemotherapy at one group meeting. From my fieldnotes:

Kathleen mentioned that she had just recently started chemotherapy.

When Cheryl, who was substituting for Deborah as the group facilitator, asked her how it was going, Kathleen said, “I don’t know. You know, they can’t tell you whether it’s going to work or not. The doctors tell me there’s about a 10-20 percent chance that this will keep the cancer from coming back. I’m hoping that it will work, but who knows?”

To this Cheryl exclaimed, “Well, you are not a statistic! You can’t go by just numbers. Everyone is different. We’re going to assume that the chemo will work for you.”

Connie chimed in and said, “Yeah. How can they tell you that? Everyone’s experience is different.”

Kathleen replied, “I’m going on the hope that it will work for me.”

As was the case with the stem cell transplant example described earlier, the women here resorted to individualizing their discussion of chemotherapy when they were faced with unsettling information about it. Even Cheryl, who frequently substituted as leader for the group and facilitated other breast cancer support groups at the hospital, encouraged the women to disregard certain information (how chemotherapy affects rates of recurrence) and instead focus on how each individual patient is different. Again, this allowed the women to deal with the uncertainty that they experienced as a result of being faced with contradictory and/or ambiguous information about their disease.
As the discussion in this section has shown, not all information affected the York and Upton women in the same way. Instead of reducing some of the uncomfortable feelings created by their illness, certain types of information increased their emotional distress. This was particularly the case when the women were faced with information that was overwhelming and/or contradictory in nature. When confronted with these situations, the women employed a number of strategies to help them cope, including focusing on practical solutions, which served to redefine the information in a less threatening way. They also individualized their discussions of breast cancer and its treatment, to help them feel better about contradictory or ambiguous information and the feelings it evoked. Therefore, their strategy of “becoming experts” usually helped them feel better about their disease and about themselves as patients.

Seeking information also helped the members of Hogart and Bellesmith cope emotionally with their disease. However, these women gathered information in a different way. Instead of seeking it on their own, they looked to medical experts to educate them about the disease and how it was treated, trusting that these professionals would tell them everything they needed to know. In addition, the information they gathered by “trusting the experts” had different meanings for them as breast cancer patients. Whereas for the York and Upton women being able to seek information and discuss it with one another during meetings meant that they were knowledgeable and competent patients, for the women of Hogart and Bellesmith, gathering information from the medical experts meant that they, as breast cancer patients, were being treated by knowledgeable and competent physicians. In the following sections I will briefly reintroduce these two groups of women, discuss the strategy they used
to gather information, and explain how it affected their disease experience.

TRUSTING THE EXPERTS

Unlike York and Upton, which met in local hospitals, Bellesmith meetings were held in a boutique that specialized in products and services for breast cancer patients. As discussed in the previous chapter, the group consisted of a small number (four to ten) of white, working-class women, who gathered to hear sales people talk about products and services that were, in some cases, only loosely related to breast cancer. Likely due to the relentless sales pitches and the frequency with which meetings were canceled, attendance was sporadic and the group lacked stable membership. For the regular attendees, friendship and loyalty to the shop owner were stronger attractions than the information provided about breast cancer. The Hogart group thus provides a better example of reliance on experts.

On any given month, approximately eighteen to twenty women met in a waiting room of a small-town (population less than 40,000) hospital for Hogart meetings. Like Bellesmith, participants were predominately working class, and were typically not college educated. Because they lacked many of the skills and resources of the York and Upton women, they relied on medical experts, particularly the few cancer specialists who practiced in the local community, to provide them with information about breast cancer and its treatment. These local medical experts provided most of the informational content at the group’s monthly meetings. The Hogart women rarely mentioned seeking information from other sources.

Anna, who was diagnosed with breast cancer at the age of 72, was a typical Hogart member. She did not seek information on her own, relying instead on doctors to provide
information and tell her what to do. From her interview:

Jackie: Did you have a lumpectomy, or did you have a mastectomy?

Anna: Mastectomy.

Jackie: Is that what the doctor recommended?

Anna: Yes. On account of my age, and my family history.

Jackie: When he recommended that you do that, did you talk to anyone else about it? Or look up any information about it?

Anna: No. ‘Cause I was kind of afraid. And I wanted to get it [cancer] out as quickly as I could, before it did any more damage than what it had already done.

Anna chose not to seek further information or get a second opinion. She also trusted that her doctor knew what was best for her as a patient, and decided to follow his advice to have a mastectomy. Her experience was common among other members of the Hogart group.

Even Bonnie, who was the leader of the group, and had more information than most of the other members, ultimately trusted physicians and other group presenters to tell her what she needed to know about breast cancer. In her interview she told me,

You have to put your trust in the doctor that he’s going to do the best thing for you. And you have to be part of the team.

. . . [you have to do] research on your own, so that when you go see your doctor, if he doesn’t touch on a question that you might have, then you can ask your own. If he doesn’t give you all the answers, then you can ask him a question that he hasn’t answered, or hasn’t already given the answer to it.

But most of the time my experience with the doctor that I have is that he explained everything, even before I needed to ask him any questions.

Bonnie says that patients should trust their doctors. She also invokes the rhetoric of being a
“team player,” suggesting that she understands, at least by mainstream middle-class values, that patients should play an active role in their medical care by seeking additional information and questioning medical experts.

However, Bonnie did not do this. Although she sought some information about breast cancer and was prepared to ask her doctor questions, she never did, because he preemptively “explained everything.” While it is possible that Bonnie’s doctor did tell her everything that she needed to know, it is more likely that she trusted that he had. After all, later in the interview she told me, “I had to trust what he was telling me, and trust that nothing else was needed.” Which, according to Bonnie, was why she decided to have a mastectomy without radiation or chemotherapy.

This example is an important one. It illustrates that even a Hogart member who was an “exception to the rule,” that is, one who sought information and tried to be a “team player,” was not that different from other members of the group. In fact, Bonnie’s experience shows that she was more like the women in her own group than those from York or Upton. In other words, despite her intentions to do otherwise, she trusted the experts to provide her with any information or medical advice that she might need.

The Hogart women depended on doctors in this way largely because they lacked the resources to gather information on their own. They did not have easy access to the Internet and medical libraries. They also lacked the skills required to use such resources, had they been readily available. Many of the women in the group had only high school educations, and thus lacked the advanced literacy skills that the York and Upton women took for granted. For example, when, Anna, introduced earlier, approached me and said she would like to be
interviewed, I asked her to write down her contact information. She demurred, asking me to do it for her, because her handwriting was “not too good.” Later, on the day of the interview, she apologized for taking so long to read the consent form, saying, “I read awful slow.”

Unfortunately, these kinds of deficiencies were common among the Hogart members. Throughout my project, many of these women made comments about their lack of writing and reading skills. Some confessed to having sloppy handwriting. Others described having difficulty understanding written materials, especially those medical in nature. Several even apologized for their inadequacies in these areas.

The women’s lack of skills in these areas limited the type and quality of information that they were able to acquire on their own and from their doctors. This was often evident in what the Hogart women could, and could not, tell me about their medical treatment. Judith and Marie are examples. When asked what chemotherapy drugs they were given, the women said that they did not know. When further questioned, however, both could give pieces of information like, “They gave me the red one that makes your hair fall out.” Or, “One of mine caused me to lose the feeling in my hands.” From details such as these, I was often able to figure out more about the Hogart women’s medical care. In these two cases, that the women likely took Adriamycin, a chemotherapy drug that is red and results in hair loss, and/or Taxol, a chemotherapy drug that often causes neuropathy.

When I asked Judith and Marie if these were the medications that they were given, they both recognized the names, and answered yes. This indicates that they either could not remember the names of the drugs on their own or, as some of the other Hogart women that I interviewed admitted, they were unsure of how to pronounce the names. Regardless of the
reason, the women knew few specific details about the medical procedures and treatments that they had endured. And compared to the York and Upton women, their knowledge of breast cancer and its treatment was thin.

Even so, the information that they gathered by “trusting the experts” still helped the women cope emotionally with their disease. It did so in at least two ways. First, hearing about current research and new forms of breast cancer treatment helped relieve some of the women’s fears about the possibility of a future recurrence. Second, it allowed the women to believe that they were being treated by knowledgeable and competent doctors. I will discuss these points next.

Alleviating Fear and Anxiety

As with the York and Upton women, members of Hogart reported being afraid when they were first diagnosed with breast cancer, nervous about treatment, and fearful over what might happen to them and their families. But because several years had passed since most of them had been treated for the disease, at least some of the these initial fears had waned. One that remained was the fear of recurrence.

That the Hogart women or even their York and Upton counterparts continued to experience these kinds of feelings should not be surprising. Cancer patients, in general, are often fearful and anxious long after they have been diagnosed and “successfully” treated for the disease. McKenzie and Crouch (2004) discuss this in greater detail, stating that:

Our research has shown that the self-understandings of these persons [cancer patients] involve a sense of being afflicted, not necessarily by the disease itself. . .but rather by its sinister nature and the possibility of its recurrence. The latter implies (a) that cancer may still be there,
[emphasis in original] dormant; and (b) that in the event of the disease’s recurrence, untimely death will become a certainty. Amid continuing manifestations of the pervasive fear of cancer in society generally, persons in this situation, even many years after their cancer episode, think of themselves as permanently branded by the disease (Pp. 139-140).

The Hogart women certainly experienced the kind of fear and doubt that McKenzie and Crouch (2004) describe, and continued to think of themselves as breast cancer patients, long after being diagnosed.

For example, Bonnie, the leader of the group, explained that even nine years later, she still thought of herself, and was seen by others, as a breast cancer patient. From her interview:

Just because you’ve gotten over cancer, doesn’t mean that you’re over the cancer. You know, you’re over the disease part, but you’re still considered a cancer patient for the rest of your life. Thirty years from now, I’m still going to be considered a cancer patient. I may not have the disease, but I’m still a cancer patient. And it doesn’t mean that I still can’t learn about the disease.

As Bonnie’s comment suggests, continuing to learn about breast cancer helped her cope with some of the uncertainty associated with having been a breast cancer patient.

The same was true of the other Hogart members. For instance, when asked what they liked best about the group, many of the women responded that the speakers were their favorite part. They especially liked hearing presenters talk about the “most recent” research on breast cancer. Christine serves as an illustrative example. In her interview, she said,

I think most of them [speakers] bring you good information. And with the oncologist you find out what’s happened since [you were treated]. ‘Cause they’re always doing clinical trials. And you get to know what things are new, and what options you have, if you have to go through this again.
The leader of the group concurred. In her interview, she said,

Bonnie: I just like hearing what they [doctors] have to say. . . .
You know, if there are progresses that have been made.
[For example], when I went through [treatment] they didn’t
have the sentinel node biopsy, but now they’ve got the sentinel
node biopsy. And that’s only been since 1995, so there are
changes. . . . And they are doing some testing now to find out if
there’s a gene that could be passed on. And there’s all the different
chemo drugs. There’s some drugs that are supposed to be for lung
disease and they ended up being used for breast cancer. But you
don’t hear about that unless you hear from the doctor.

Jackie: So you like keeping up with things, to see what’s going on?

Bonnie: Yeah. I may not retain it, but I like hearing it.

As these examples suggest, Christine and Bonnie, like most of the other Hogart
members, continued to attend support group meetings long after they were diagnosed and/or
experienced any cancer-related health problems. While part of their attendance can be
attributed to the social nature of the group, the women also enjoyed hearing about recent
advances in the treatment of the disease, as the two interview excerpts above illustrate. And
though they might not have articulated it as well as York and Upton members, having this
kind of information did help them cope emotionally. For instance, hearing about medical
advances helped to reduce some of the uncertainty that they experienced, especially
concerning the possibility of a cancer recurrence. As Christine pointed out, having this kind
of information helped the women know what to expect, “. . . if [they had] to go through this
again.”

Having doctors lecture about treatment strategies and current research also helped to
reassure the Hogart women that their medical providers were knowledgeable and skilled at
what they did. In fact, simply having the doctors speak to the group was often more important to the women than the actual information that they could gain by attending. Take, for instance, the women’s willingness to tolerate presentations that were repetitive from month to month or even one year to the next, as well as Bonnie’s earlier comment about enjoying the speakers but not being able to retain what they said. Both would suggest the women were less concerned about getting new information, than about having presenters who could speak authoritatively and knowledgeably about the disease and its treatment.

On the rare occasion that the Hogart women did not have a guest speaker present to the group, they spent group time reassuring one another that their doctors were “good” ones. During my observation period, for example, the women had two meetings where guest speakers either could not attend or cancelled at the last minute. One of these was used to plan speakers for the upcoming year. At the other, the women shared some of their breast cancer experiences, then ended the meeting early. At both, however, they dedicated a significant amount of time to discussing how “good” their doctors were.

At the planning meeting, Bonnie announced that she would try to get one of the local oncologists, Doctor Tate, to speak at a future meeting. Marie, a patient of this doctor, said,

We are very fortunate to have Dr. Tate and the other doctors in this practice. I don’t care what anyone says; these doctors and the treatment we get from them is better than any you would get at [nearby research hospitals].

Almost all of the other women in attendance agreed, adding complimentary statements of their own. They made similar kinds of comments during their interviews, as when, unsolicited, Renee told me, “I’ve had good doctors, very good doctors. I’ve been very
Talking about their doctors in these ways helped the Hogart women cope with the uncertainty of having breast cancer. It did so in several ways. First, emphasizing how good their doctors were reinforced the idea that their physicians were knowledgeable and skilled. This, in turn, helped the women trust that they were receiving proper medical care. Second, comparing their doctors to others, especially those practicing at (relatively) nearby research hospitals, enabled the women to believe that the doctors in their small town were as skilled as those who practiced in larger, more prestigious places. This too reinforced the belief that the medical treatment they were receiving was not only appropriate, but actually quite good. Given that there was only one oncology practice in the area and the women’s options for medical care were therefore limited, it was especially important that they be able to believe that this was the case.

CONSEQUENCES OF INFORMATION-SEEKING STRATEGIES

Trusting the experts helped members of Hogart believe that their physicians were knowledgeable and competent medical providers. However, the sense of trust that the women had in their physicians was often precarious, at best. Some of them, for instance, held a general distrust of those in authoritative positions. For others, their sense of trust was violated when physicians treated them in paternalistic ways and/or pressured them into making quick decisions regarding their medical care. In the following sections, I will discuss how the women’s strategy of “trusting the experts” had consequences for how they interacted with doctors, as well as how they went about making decisions about their breast cancer
treatment and care. I will also show how their experiences compared to the York and Upton women’s, who used the strategy of “becoming experts” to learn more about their disease.

Medical Paternalism

On the first night that I attended Hogart, a local oncologist, Dr. Norris, spoke to the group. During his approximately forty-minute talk, the doctor provided an overview of breast cancer and its treatment, focusing attention on risk factors of the disease, common surgical and treatment options, as well recent research findings. At the conclusion of his presentation, Dr. Norris opened the floor for questions. Many of the women raised their hands and were called on in turn. Several asked what could be done for the lymphedema symptoms they were experiencing, while others wanted to know why they were not “good candidates” for certain kinds of reconstructive surgeries. While Dr. Norris attempted to address the general issues at hand – how to diagnose and treat lymphedema, or how to choose between available reconstructive surgeries – he remained noncommittal and attempted to steer the conversation away from individual cases. The leader of the group then attempted to change the subject by asking about the results of a recent study pertaining to the effectiveness of self breast-exams.

The results of this particular study had been widely reported in mainstream media, and created quite a bit of controversy. Specifically, researchers found that self breast-examinations do not detect tumors early enough to reduce the risk of death from breast cancer, meaning that women who perform monthly breast-exams have no greater rate of breast cancer survival than those who do not (Thomas et al. 2002). Some took the study to
mean that teaching self breast-examination techniques to both doctors and women is a waste of time. This came on the heels of a much publicized debate concerning the effectiveness of mammograms in detecting malignant breast tumors (Gotzche and Olsen 2000). Both studies created confusion about whether or not women should perform monthly self-examinations and/or have yearly mammograms, and if so, how much faith they should put into the two tests for detecting breast cancer.

The leader of the Hogart group had Dr. Norris address the results of the self breast-examination study by asking whether he thought women should continue performing the exams. The doctor first briefly described the research and its findings for those who were unfamiliar with them. Then he recommended that group members continue performing self-examinations regardless of study results, because many women have detected their own breast cancer using the technique. After addressing these issues, Dr. Norris proceeded to use group time to vent his frustrations concerning the general public’s access to such information through news reports and the Internet. He also recommended that the women not seek breast cancer related information on their own, saying, “Most people don’t have the skills or training to interpret the results of clinical studies reported on the news or the Internet. To avoid any misunderstandings, they should just leave it up to their doctors to give them the information they need.”

As a cautionary tale, the doctor told a story about a young woman, a daughter of one of his patients, who had sought information when she learned that her mother had breast cancer that had metastasized to the brain. Unaware that tumors originating in the brain were treated differently from those that had spread from other sources, the daughter sought
information on “brain tumors,” making reference to it at her mother’s next medical appointment. According to Dr. Norris, seeking the information had created unnecessary distress for the patient and her family. Because of this and the average person’s lack of scientific knowledge, he again recommended that the women not seek any information on breast cancer. When the group leader challenged him, saying that patients had the right and responsibility to seek information and be their own advocates, the doctor said, “Your doctor should be your best advocate. You don’t need to advocate for yourself.”

To further strengthen his point, Dr. Norris gave a brief history of his educational and clinical experience, including the number of years he spent in college, medical school, residency, and working in his current practice. He also claimed that the average person had “no business” attempting to interpret or understand medical information. Instead, the doctor argued, such tasks should be left up to the experts. None of the women openly disagreed with him. Several even said that they agreed.

The women’s general silence should not, however, be taken to mean that they all agreed with Dr. Norris. In fact, incidents like these often served to increase some of the general distrust the women already had of those in authoritative positions. Renee, an African-American woman, who joined the group over a year after learning that she had breast cancer, illustrates this point. Like many of the other women, she explained how the early days of her diagnosis seemed like a whirlwind of activity. In the span of one week, a mammogram detected a lump in one of her breasts, a biopsy revealed that it was malignant, and she was scheduled for surgery, including a mastectomy with TRAM flap reconstructive surgery.
During her interview, I commented on how quickly events took place. In response, Renee said,

> It happened really fast. Because he talked to me. The surgeon talked to me that afternoon, and said that, “It is cancer.” That, “I think we need to go on and get it now.” . . . So that’s why he said, “Go on and do it then.”

It is not surprising that Renee’s surgeon wanted to move quickly, given that she was 38 years old when diagnosed, and breast cancer found in younger women is often more aggressive than that found in older ones (Love 2000).

What is disturbing is how her doctors interacted with her as a patient. For instance, when asked how her options were presented to her, Renee said,

> The plastic surgeon gave me the choice. Well, no. [pause] The surgeon said that it may be best to go on and have a mastectomy. And the plastic surgeon was saying, “Go on and have the TRAM flap.” So, everybody did it so fast. It was like they didn’t want me to have time to think about it.³⁹

In this case, the two surgeons recommended what they thought was best for Renee, a mastectomy and TRAM flap reconstruction. They also discouraged her from taking more time to think about the situation.⁴⁰ Somewhat reluctantly, Renee accepted their recommendations and agreed to have the procedures.

Although she would not openly criticize her doctors’ actions during her interview, that their paternalistic behavior and her reaction to it bothered Renee was evident. She appeared embarrassed that she had not taken a more active role in her medical care and angry that the doctors treated her with such little respect. For instance, when asked if she sought information of her own, Renee hesitantly admitted that, “No, I sure didn’t.” Later when
questioned about how it made her feel to be pressured to act so quickly, she said, “At the time, I was so scared, I was accepting anything.” But Renee went on to suggest that if she had seriously thought about what the doctors were saying, she would have reacted in a different way.

It is not surprising, however, that she did not. While her doctors’ behavior may have been insulting, Renee was willing to tolerate it largely because, as discussed earlier, she needed to believe that they were knowledgeable and skilled at what they did. To admit that the doctors behaved poorly would have challenged this notion and eroded her trust in their skills. The same could be said of the women listening to Dr. Norris’s presentation described above. Although many of them may have been offended by his arrogance, as well as distrustful of his authoritative stance, they were reluctant to speak out about such things, because, like Renee, they too had a vested interest in believing that the local doctors were competent and provided them with the appropriate care.41

Therefore, these women often tolerated behavior that the York and Upton women would have found difficult to ignore. Take, for example, Kathleen, a member of York mentioned earlier, who was the wife of a high-ranking university administrator. Like many of the other women from York and Upton, Kathleen requested a copy of the pathology report from her initial breast biopsy. However, when she insisted upon having one in her possession prior to meeting with the oncologist at her next medical appointment, she met with resistance. But Kathleen did not give up, she persisted until she got what she wanted. From her interview:

And I made it very clear to them that I wanted that pathology
[report] before I came in for my follow-up appointment. Because one of the things that I’ve learned is, on that day of the follow-up, of any kind of procedure, they’re not there to talk with you. They are there to give you the facts. To give your exam and say, “You know, you’ve had enough today.” [But] I’m ready to discuss it. And I didn’t want that little situation again.

Not only did Kathleen receive a copy of the pathology report before her follow-up appointment, she also pushed to have someone go over it with her, the day she picked it up.

She explained what happened:

I went and picked up my pathology report. And I was like, “I want to talk to somebody.” Again, I know a lot of people up there [hospital]. So, they sent someone down to talk to me. And I sat down with the P.A. [physician’s assistant], and she explained it all to me.

As this interview excerpt illustrates, Kathleen received individualized attention from the physician’s assistant, even when she did not have a scheduled appointment. Although this can be partially explained by her connection to the university and its hospital where she knew, “a lot of people up there,” she also asserted herself, demanding to get the information that she wanted, while showing little deference to medical personnel.

Lareau refers to such behaviors as displays of entitlement (2003:125). In other words, when Kathleen demanded a copy of her pathology report and insisted on “talking to somebody,” she assumed a certain set of rights. More precisely, she acted as if she should have access to medical records, as well as her doctors’ time and attention, when she wanted them, not when it was necessarily convenient for others, especially patients who were waiting for their scheduled appointments. As Kathleen’s behavior shows, the York and Upton women not only knew how to interpret medical information, they also knew how to use their
status to get it.

Note, too, the difference between Kathleen’s experience and those of the Hogart women. The latter group of women viewed their doctors as authority figures and typically deferred to their wishes. Members of York and Upton, on the other hand, usually saw medical professionals as their social equals. And they generally had no problem demanding extra attention, when they saw fit. These differences in experience help to illustrate that, as Waitzkin (1991) contends, doctor-patient interactions are “micropolitical situations” that serve to reinforce inequality not only between doctors and their patients, but also between the various social classes.

The former is evident in the types of interactions the Hogart women described having with their doctors, as when Renee was discouraged from taking more time to think about her medical care. The latter is made more clear when the Hogart members’ experiences are compared to those of women in the other two groups. For example, members of York and Upton, such as Kathleen, had access to breast cancer information that Renee and the other Hogart women did not. They were then able to use it to their advantage by demanding more individualized attention from their doctors, while the Hogart women were unable to do the same.

Lareau (2000) has described similar patterns in how middle- and working-class parents negotiate with teachers in their attempts to influence and improve their children’s educational experience. According to Lareau, middle-class parents take an active role in their children’s education, seeking additional resources and attention from teachers, especially when their children experience academic difficulties. Working-class parents, however, lack
the inside information and knowledge about the school system that middle-class parents often have and therefore tend to defer to those in authority, in this case teachers, trusting that these professionals will do what is best for them and their children. Lareau (2000) concludes that as a result of these differences middle-class children get a more customized education, while working-class children get a generic and often inferior one.\footnote{43}

It was much the same for the women in this study. The women from Upton and York sought information and used it, in conjunction with their status as mostly middle-class, white women, to get more customized care from their physicians. The predominantly working-class women from Hogart were not able to do the same. These women did not seek information on their own, and approached their doctors in a different way. They often held a general distrust of those in authoritative positions and consequently did not feel comfortable interacting with them, especially as compared to the York and Upton women. As a result, these women received care from their doctors that was far less individualized. In addition, they had to put more faith in their physicians, trusting that the treatment they were receiving was appropriate. This was not the case for the York and Upton women, who were typically more knowledgeable about the options available to them, and who were less likely to rely solely on their physicians when deciding what to do about their treatment.

In the following section, I will examine how the groups of women went about deciding what surgeries to have, and which, if any, follow-up treatments to consider. Here too the experiences of the groups of women were different. Attention will first be given to Hogart members. These women typically had little information on which to base their decisions and were often pressured by their doctors to make up their minds quickly. This is
in contrast to the experiences of the York and Upton women, who had plenty of information at their disposal, and were usually encouraged to take their time deciding what to do.

Decision-Making

When I first started observing the Hogart support group, I had already become well acquainted with the York and Upton women. In fact, I had been observing the latter two groups for approximately eighteen months before I learned of the Hogart group. By this time, I had grown accustomed to the way the York and Upton members read and discussed breast cancer related information. I had also seen how they used this kind of information to make decisions about their breast cancer treatment and care.

When I started attending Hogart meetings, I was surprised. Not only was the format of their meetings different – they had speakers instead of time for sharing individual experiences – but few of the women in the group could provide detailed information about the breast cancer care that they had received. Nor could they explain why they pursued one type of treatment instead of another, aside from saying that they did what their doctors recommended. This suggests that the women knew even less in the early days of diagnosis, a time when the illness was new to them and they needed to make important decisions about it.

Two decisions that the women often had to consider included choosing between a mastectomy or lumpectomy, and whether or not to have reconstructive surgery. Many also had to make decisions concerning the prophylactic removal of the remaining breast, and about adjunctive forms of treatment, such as radiation and chemotherapy. These were difficult and unpleasant choices to make. And the majority of the Hogart women were ill-
prepared to make them.

Anna and Renee, who were introduced earlier, serve as examples. They did not seek information on their own, and when first diagnosed were unable to talk to anyone else who had faced the disease. This led Renee to conclude, “It was like I was all alone. And [I] didn’t know what to do.” Although Anna was not as socially isolated, she experienced the same kind of uncertainty. When asked if she discussed her surgical options with her husband, she said,

No! He didn’t know no more than I did about it!
He said, “Do what you think is best.”

For Anna, “doing what was best,” meant following her doctors’ advice, and having the surgeries that they recommended. This was typically the case among Hogart members.

Even when the women did not rely solely on their doctors for recommendations, and/or wanted extra time to think about their decisions, they often reported feeling pressured by their physicians to make decisions quickly, as was alluded to earlier. Some of the Hogart women recalled times when their doctors used intimidation to try to influence their medical choices. Because the majority of these women did not have much information on which to base their decisions, or the confidence to go against their doctors, they were susceptible to these kind of tactics.

Renee is a good example. In an interview, she explained how her plastic surgeon pushed the idea of having reconstructive surgery. She tried to resist the pressure by telling him that she needed more time to decide. Upon hearing this, the doctor reportedly told her, “You don’t need to think about it. Just do what I’m telling you to do, before you change your
mind.” When Renee continued to waver, he became even more adamant, saying, “You don’t need to wake up and see yourself without a breast.”

In this case, the plastic surgeon pressured Renee to act quickly. First, he encouraged her to commit to reconstructive surgery, without taking time to seriously consider all aspects of the situation or seek additional information. Second, when she seemed uncertain about her decision, the doctor attempted to scare her, preying on fears of what she might look like without a breast. In response to this kind of pressure, Renee conceded to her doctor’s wishes and went ahead with the reconstructive surgery. As was mentioned earlier, when recalling the experience in her interview, Renee would not openly criticize her doctor’s actions. However, she appeared embarrassed that she had not taken a more active role in her medical care and angry that the doctors treated her with such little respect.

Although not all of the Hogart women described physician behavior as egregious as this, many did recall feeling pressured to make decisions quickly. Anna serves as another example. As previously mentioned, her doctor recommended a mastectomy. After agreeing to the procedure, she was referred to a plastic surgeon, who recommended that she get a breast implant. Like Renee, she felt pressured to follow his advice. When asked why this was the case, Anna said,

Anna: . . .it was kind of hasty, when that doctor knew it was cancer. And the plastic surgeon, he, uh, I got an implant. And if I had known, like I know now, I don’t think I would’ve gotten it. Because, I would’ve got just a prosthesis. . .

Jackie: . . .What made you decide to get an implant?

Anna: That doctor talked me into that.
Jackie: What did he say that talked you into it?

Anna: He said, “Well, if you get an implant, you won’t have to worry about getting a prosthesis.” And this thing and that thing. And, you know, and I said, “Well, . . .” [pausing] And when you’re kind of upset, things sound pretty good to you.

In this situation, the plastic surgeon influenced Anna’s decision to get an implant. He did so, in part, by comparing the advantages of having an implant to the disadvantages of wearing a prosthesis. Other factors, however, had a greater bearing on Anna’s decision to follow through with the surgical procedure. First, the plastic surgeon used his skills of persuasion to convince her that she should get an implant. Second, Anna had to trust that what the doctor was saying was true, since she had no other information to draw upon. Most importantly, she was in an emotionally vulnerable state, having just learned that she had cancer. And as Anna concluded, “when you’re kind of upset, things sound pretty good to you.”

In the above excerpt, Anna also acknowledged that she now would do things differently. This was true of other Hogart members, as well. Like Renee and Anna, other women in the group reported that feeling pressure to make decisions quickly led them to make choices that they later questioned. This was not typically the case with York and Upton members. Although a few of these women reported being dissatisfied with the decisions that they had made, it was a rare occurrence. When it did happen, it tended to be in particular situations, such as when the surgeries and treatments that they chose produced unexpected side effects or unusual problems. But again, these cases were unusual.

This is not to say that women in the latter two groups did not have a difficult time
making decisions. Indeed, many of them said that deciding how to treat their breast cancer was one of the most challenging problems they faced. For instance, when asked what was the most difficult part of her breast cancer experience, one member of Upton, Diane, replied,

> Aside from the initial shock of just knowing that I had breast cancer, the decision-making was the hardest part. The decision-making lasted longer [than the initial shock].

Diane therefore took longer than most, over a month, to decide whether to have a lumpectomy and radiation, or a mastectomy with reconstructive surgery. Eventually, she decided on the mastectomy and an implant.

Although most of the other York and Upton members did not take as long as Diane to make up their minds, they did admit to having difficulty making decisions. They also claimed that the pressure to make decisions quickly added to the stress of the situation. For most, the primary concern was removing the cancer before it spread to the lymph nodes or other parts of the body. Of only slightly less concern was deciding how to remove it (i.e., what surgical procedure/s to choose), and whether or not to seek further treatment. Investing their energy into finding breast cancer information proved to be helpful in this regard.

Building on a previous example helps to show how this was the case. Julie, as discussed earlier, requested copies of her medical documents and compared information in them to that which she found on the Internet. She also used the information to help her decide what to do about her breast cancer treatment. For instance, upon reviewing a copy of her initial breast biopsy report, Julie learned that the surgeon was unable to get clear margins. When she expressed concern about this, her doctor did not seem to be alarmed. In
fact, according to Julie, the doctor appeared quite optimistic. In her interview, Julie described the situation, saying,

    Everything she [doctor] indicated was not any big deal, you know? She would say, “That’s not anything per se to worry about.” And as I stood up to leave, she patted me on the shoulder, like this, [demonstrating], and said, “You barely have breast cancer.” Those were her words to me.

This incident, as well as her doctor’s reluctance to discuss surgical and/or treatment plans, prompted Julie to consider other options and seek a second opinion.

    After deciding to switch doctors, she learned that she had stage-two breast cancer. In her case, this meant that cancer cells had spread to several lymph nodes and possibly other parts of her body. It also meant that Julie needed to decide what kind of breast surgery to have, so that she could begin chemotherapy as quickly as possible. Reflecting on her experience, she said,

    And it [changing doctors] was the best decision I ever made. And I thank God I did. I mean, I honestly really believe it saved my life.

Because she sought information about breast cancer, Julie was able to question her original doctor’s assessment. She knew enough to be concerned that the surgeon had not gotten clear margins, and decided to find another doctor. As Julie pointed out in her interview, the decision to switch doctors likely changed her breast cancer experience in dramatic ways.

    Had one of the Hogart women, perhaps Renee or Anna, faced a similar situation, the outcome probably would have been different. Neither of the women, or even the majority of their other group members, had enough outside information to question their doctors’ medical assessments. And although conjecture, had they been in Julie’s situation, they
probably would not have sought a second opinion, trusting instead that what their doctor was saying was true, that is, that they, “barely had breast cancer.” In a case such as this, trusting the doctor and deciding not to seek another opinion could have had serious consequences. It might have meant the difference between surviving or dying from the disease.

Again, this is a hypothetical case. However, it helps to illustrate how the two information-seeking strategies had potentially serious consequences for how the women in the various support groups experienced breast cancer. By becoming lay experts on the disease, the York and Upton women were able to make difficult, yet informed, decisions about their medical treatment. The Hogart women, conversely, depended on their doctors for information, and made (equally difficult) decisions based on what they were told. As long as the information and recommendations that their doctors provided were accurate, this strategy was not necessarily problematic. Had their physicians been incorrect, however, the Hogart women would have likely suffered as a result, especially as compared to the York and Upton women, who, like Julie, often had the capabilities to catch such mistakes.

Medical correctness aside, class-based resources made a difference in how the women experienced their illness. The middle-class women from Upton and York were more confident in the choices they made; reported feeling a greater sense of control over their lives; and generally emerged from the experience with a more detailed understanding of what had happened to them.
CONCLUSION

As this chapter has shown, members of York, Upton, Hogart, and Bellesmith experienced feelings of fear, anxiety, and loss of control owing to uncertainty about their disease, treatment options, and prognosis. To cope with these uncomfortable emotions they sought information about breast cancer and its treatment. Women in the middle-class groups, York and Upton, had the resources to gather and interpret information on their own, in effect constructing themselves as lay experts on the disease. Women in the working-class group, Hogart, lacked these resources, and thus collaborated in constructing their doctors as experts.

These distinct strategies had consequences for the women’s illness experiences. Members of York and Upton used their lay expertise to interact more assertively and effectively with physicians and other care providers. Those from Hogart, who were invested in trusting the expertise of their doctors, were subject to medical paternalism and pressured into making decisions that they later questioned. These differences in illness experience show that, as Waitzkin (1991:8-10) contends, doctor-patient interactions are “micropolitical situations” that serve to reinforce inequality not only between doctors and patients, but also between social classes. The present study shows how these micropolitical situations can be shaped by a mesopolitical construction: the support group. Women who brought middle-class skills to these groups, and who could help each other gather, share, and interpret information, empowered each other. The working-class women, while no less interpersonally supportive of each other, derived comfort from affirming the power of those who already possessed it.
Chapter Three

COPING WITH A STIGMATIZED APPEARANCE

In a sexist society, a woman’s value as a human being is frequently measured by her physical appearance, a fact most women learn and internalize at a young age. This situation is problematic for all women, but especially for those with stigmatized bodies. Such is often the case with women who have had breast cancer. Mastectomies and lumpectomies are not only disfiguring, but also alter one of the most sexualized parts of a woman’s body, her breasts. This disfigurement, in combination with the physical effects of chemotherapy, such as hair loss and a sickly pallor, can drastically alter a woman’s physical appearance, often creating serious doubts and insecurities about her appearance and self-worth.

This was true for members of Upton, York, Bellesmith, and Hogart. The physical changes accompanying the women’s illness evoked feelings of embarrassment, shame, and self-doubt. In response, they developed strategies to help them cope emotionally and feel better about themselves as women. In this chapter I will discuss these strategies, including how the women concealed their illness from others, joked about changes to their bodies, and practiced a compensatory form of femininity. I will also compare these strategies to the ones the women used to deal with the loss of their hair, which many claimed was more upsetting than losing a breast(s). Finally, I will show how all of the strategies, while allowing the women to feel better about themselves and their bodies, helped to maintain gender inequality by reinforcing traditional standards of beauty and depoliticizing breast cancer as a social issue.
Once diagnosed with breast cancer, women in the support groups had to decide what surgical procedure(s) to have. For most, this meant choosing between having a lumpectomy, which involves the removal of the cancerous lump with a small area of normal tissue around it (Love 2000:680), or a mastectomy, i.e., the removal of the whole breast. While a lumpectomy is less surgically invasive, both procedures are disfiguring. The idea of losing part or all of a breast thus evoked fear and anxiety for women in all four support groups. The women’s greatest fear was that after surgery they would no longer be physically attractive. Many even questioned whether their current or future partners/spouses could love them without a breast(s).

The experiences of five women serve as illustrative examples. The first is Nedra, a 47-year-old member of York, who joined the group after her initial cancer diagnosis, but before having a mastectomy. At her first meeting she described how the lump in her breast had been found through a routine mammogram, hesitantly adding that she would soon be having a mastectomy. When she mentioned the upcoming surgery, Nedra began to sob uncontrollably. Through a choked voice she told the group, “I just can’t imagine not having a breast! What am I going to do?”

Many of the women in attendance seemed uncomfortable with this display of emotion. They averted their eyes and remained silent while Nedra continued to cry. A few offered platitudes such as, “Everything will be okay,” or “You’ll make it through this.” Another offered to show Nedra her breast implant after the meeting, saying, “It might be good for you to see what the plastic surgeons can do.” The leader of the group, Deborah,
added, “Having a mastectomy is difficult, but it’s necessary. It will probably save your life!”

The other women in attendance agreed.

The group’s response was common. The women typically did not discuss how losing a breast made them feel. And when someone like Nedra did broach the topic, most of them appeared to be uncomfortable with and reluctant to contribute to such discussions. Instead, the women usually reminded one another that having a mastectomy or lumpectomy was a “small price” to pay for their lives, as did Deborah in the above example. The topic would then be dismissed. This should not, however, be taken to mean that losing a breast was not upsetting to the women.

The topic did come up frequently in the women’s interviews. Donna, a member of York, who had bi-lateral mastectomies, in addition to chemotherapy and radiation treatment, is an example. Like many of the other women in the groups, she reported that seeing herself in the mirror served as a daily reminder of her illness and the physical trauma that she had endured. From her interview:

Donna: Well you know, it was obvious that I’d had the mastectomies. And my shower is just right where you can see yourself. When you come out of the shower, the mirror [is right there]. And you know, I could see just the little things, the burns and the marks [from radiation], and the scars from the mastectomies.

Jackie: I’ve heard several women say that taking showers was often when it would really hit them what had happened. What would you think when you saw yourself in the mirror?

Donna: To me it represented tragedy and sadness, because the scars just looked like lashes.

Jackie: So it looked like –
Equating the physical effects of breast cancer to an assault or attack suggests how traumatic losing a breast(s) was for Donna and the other women in the groups. That the “attack” was on one of the most sexualized parts of their bodies made the invasion even more distressing.

The women feared that their spouses/partners would no longer find them physically attractive. Bonnie, a member of Hogart, Sandra a member of York, and Betty, also a member of York, are examples. Bonnie, who had been married for over twenty years, claimed that all breast cancer patients felt insecure about their bodies and worried about how their husbands (or partners) would react to them. She said:

‘Cause one thing that a woman fears is, you know, what’s her husband going to think if she has one less breast? Every woman goes through that whether she’s 60 years old or whether she is 24 years old. [She asks herself,] “What am I going to do with just one breast?”

Like Bonnie, Sandra, who was divorced, but in a long-term relationship, expressed feelings of insecurity about her body. She doubted whether her partner could continue to love her. From her interview:

[And I thought], would he love me? Would he—you know, I mean, we're not married. Not that marriage, I mean [laughs], I know from experience that marriage doesn't guarantee anything. But you know, we're not married and so there's… [sighs] I've got to be careful how I say this because I don't mean it the way it sounds-- because we've got such an incredibly rock-solid relationship—but still there was that part of me, that [questioned] will he still love me? Will he stay with me? And maybe that doesn't make any difference whether you’re married or not. But I think knowing that you're not married might intensify that just a little bit. And I think some of that was going on throughout the whole [experience].

Despite being in long-term or “rock-solid” relationships, both Bonnie and Sandra felt
insecure about their changed bodies and feared that they would be rejected by their partners/spouses. Their fears were not unfounded.

Women in all four of the support groups had heard stories of breast cancer patients being abandoned by their partners or spouses after being diagnosed. Some had witnessed this happening to members of their groups, as was the case with Betty, whose husband filed for divorce shortly after she started chemotherapy. Like Bonnie and Sandra, Betty felt insecure about her appearance and doubted whether anyone could be sexually attracted to a woman who had lost her breasts. As she described them in her interview, these feelings were only intensified when her husband decided to leave. She said:

[Losing my breasts] is a big issue though. That’s one of the reasons I don’t wanna date or have a boyfriend or whatever is because I don’t have any breasts. And that feels –the rejection that I felt, being a woman in her 50’s with no breasts and no hair and being thrown away.

I mean it’s quite enough for women to think we’ve –you know, we don’t like our ears. We don’t like our hair. We don’t like this. We’re just so critical of ourselves anyway. So, I think had [my husband] said, “You are the most beautiful [person] –you are the most wonderful person. I’m just so glad to have you,” like some husbands do, I still would’ve had trouble adjusting to my self-image and body.

But, the way it was just [made it more difficult]. . . . [Now,] I don’t want men because I’ve been burned. But part of it is like, I think I will be rejected by them. Because that’s my experience. I’ve been rejected. I think, “Well, sure. Somebody might like to go out to dinner with me. Or something like that. That would be fun.” But then if they thought of anything more, who would want a no-breasted woman? Do you know what I mean?

As these five women’s experiences illustrate, being diagnosed with breast cancer and facing disfiguring surgeries left them feeling self-conscious about their bodies and insecure in their intimate relationships. These feelings were typical of other women in the support groups.
One way the women attempted to deal with such uncomfortable feelings was to conceal the physical effects of their illness. Many of them did so by having reconstructive surgeries and/or wearing prosthetic breasts. As the following discussion will show, however, doing these things did not always make the women feel better about their bodies. In fact, sometimes it made them feel worse.

Concealing Disfigurement

Like many breast cancer patients, the Upton, York, Hogart, and Bellesmith women attempted to disguise their disfigurement by having reconstructive surgeries such as the TRAM flap procedure or breast implants, or by wearing prosthetic inserts in their bras. For example, twenty-one of the women I interviewed had mastectomies. Of these, seventy-one percent (15 women) chose to have breast reconstructive surgery. The remaining six women (29 percent) all wore prostheses. These proportions were similar in all four groups. Virtually all of the women who had mastectomies also had reconstructive surgery or wore prostheses. Sometimes they did both.

As these data suggest, the women in the study chose to conceal the physical effects of their illness most often by having reconstructive surgery. The pressure to do so came from a variety of sources. Some of the women felt pressured by their friends and family. Others were strongly encouraged by their spouses/partners to have their breast(s) reconstructed. Many more were persuaded by doctors, particularly their plastic surgeons, who presented reconstructive surgery as both desirable and necessary.

Dr. Peters, a plastic surgeon who presented information on reconstructive surgery to
the Hogart women at one of their monthly meetings, is an example. At the beginning of his presentation, the doctor explained that reconstructive surgery was an individual choice, saying that each woman must decide what is right for her. However, he also emphasized the negative consequences of choosing not to have a breast reconstructed. From my fieldnotes:

> The most important thing for you to know, is that it’s okay to say, “I don’t need to have reconstructive surgery,” or “I don’t want to have it right now.” But keep in mind, it’s always possible that later on you’ll realize, “I didn’t think this would bother me. But it really does. Every time I take a shower, every time I take off my clothing, I’m reminded of losing my breast.” Then you may decide that you’re ready for reconstructive surgery.

Dr. Peters’s comments show how the women often received contradictory information about reconstructive surgery. While the plastic surgeon claimed that electing not to have a breast reconstructed was an acceptable decision, he later implied that doing so was likely a mistake, citing the emotional (or psychological) effects of living with the loss of a breast.51

Doctors, especially plastic surgeons, who had a vested interest in convincing the women to have reconstructive surgery, thus strongly encouraged the women to pursue such a “treatment” route. For example, after telling the Hogart women that reconstructive surgery was an “individual choice,” Dr. Peters gave a forty-five minute slide presentation promoting the idea of plastic surgery for breast cancer patients. In fact, the doctor opened his slide presentation with a picture drawing of the “ideal” or “perfect breast,” which he described as being round and perky, with a “protrusion of the nipple complex.” He also provided exact measurements of the “ideal breast,” including the distance from the top of the breast to the nipple, the slope of this area, and the distance from the nipple to the bottom of the breast. This information was followed by a series of photographic slides featuring women, not all of
whom were breast cancer patients, who had elected to have a variety of breast augmentation surgeries, like breast implants, the TRAM and Latissimus flap procedures, and breast reduction.

For each slide, the doctor presented pre- and post-operative pictures of the women’s breasts. These before-and-after photographs were accompanied by an account of why each woman was treated – a tumor or some other physical abnormality, or simply a desire for larger or smaller breasts. The doctor also provided a summary of the corrective procedure, and emphasized how the results of the surgeries, while not perfect, were better than doing nothing at all, especially in the case of breast cancer patients. According to members of the four groups, the doctor’s message was not unique. Indeed, it appeared to be the norm.

The experience that Elizabeth, a member of York, had with her plastic surgeon serves as another example. In her interview, Elizabeth explained how even after she rejected the idea of reconstructive surgery, her doctor scheduled an appointment with a plastic surgeon, encouraging her to at least consult with him before making her final decision. Upon meeting the plastic surgeon, Elizabeth was shown a variety of photographs, including some of women with mastectomies that had not fully healed. These were followed by photographs of women who had chosen to have reconstructive surgery, including saline implants, which the plastic surgeon recommended for Elizabeth. Ultimately, Elizabeth consented to the procedure, claiming that her decision to do so was based on the information she was given and her desire not to wear a prosthesis for “the next 30 or 40 years.”

Upon reflecting on the experience, however, Elizabeth admitted that the images she saw were shocking and probably influenced her decision to get an implant. From her
interview:

Yes, he showed me pictures. I saw the difference between not having it [reconstructive surgery] done and having it done. [But] they had some awful pictures. I don’t even think they ought to show some of them! All the skin that’s been brought together after a mastectomy, and it was a new wound. It was not one that over a period had healed some. So it’s kind of a stark awakening to see those pictures.

As this excerpt illustrates, Elizabeth’s plastic surgeon used aggressive means to convince her to have reconstructive surgery. His tactics worked.

Elizabeth’s experience, as well as Dr. Peters’s encounter with the Hogart women, show how plastic surgeons promoted the idea that breast cancer patients should seriously consider and choose to have reconstructive surgery. By focusing on the “ideal breast” and providing photographs of women who had chosen to have the various surgical procedures they could provide, these doctors also seemed to fuel the women’s feelings of inadequacy about their own bodies. This is best exemplified by Elizabeth’s decision to proceed with reconstruction after meeting with her plastic surgeon, even though she had initially decided not to have the surgery. It was also evident when some members of Hogart, who were years past treatment, expressed a desire (during the question-and-answer period following Dr. Peters’s presentation to the group) to pursue reconstructive surgery. These women, however, were in the minority, as most who decided to have reconstructive surgery did so at the time of their initial treatment.

Immediate reconstruction has come to be seen by many as beneficial (see, for example, Gross, Burnett, and Borrelli 1996) for reasons of cost and time efficiency. It is also advocated as a means to achieve faster emotional recovery, as Dr. Peters suggested at the
Hogart meeting described above. Yet in their review of literature on the emotional consequences of breast reconstruction, Harcourt and Rumsey conclude that, “Existing research into the psychological aspects of breast reconstruction is limited and not sufficiently conclusive to inform changes to policy and the provision of care” (2001:477). Put differently, available data do not substantiate doctors’ claims that reconstructive surgery helps breast cancer patients cope better with their disease. Regardless, the York, Upton, Hogart, and Bellesmith women largely bought into the idea of reconstructive surgery. As the previously mentioned data indicate, most of the women in all four groups actively pursued some form of reconstructive surgery and used it as one means of concealing the disfigurement resulting from their disease.

Even those who rejected the idea of reconstructive surgery and had misgivings about hiding the loss of their breast(s), felt pressured to do so. Michelle, a member of Upton, is an example. In an interview, she described how she decided not to have her breast reconstructed, after attending a seminar about the reconstructive procedures available to breast cancer patients. She said:

And I went [to the seminar] on reconstructive surgery. And I saw the pictures. And I saw the lines, the incisions. And I found out how many hours that it takes and that sort of did it for sure. I felt that, “I don’t think I want to be doing this. I don’t want to be that much longer in surgery.”

But the other thing is, Jackie, I have this kind of organic philosophy about life. And so for part of me, it’s like when that breast is gone, that breast is gone. And putting something else there isn’t going to make it different for me. And then I’m also kind of a radical feminist, so I had this other part of me which was like, are we reconstructing for the women or are we reconstructing for society? And so I think, you know, a part of me was kind of like this is who
I am. And this has been my experience. And the grieving that I’m going to do is about the loss, and replacing it [breast] with something is not going to change that.

But, you know, it is nice to have the prosthesis because if you don’t wear it, you do [stand out]. You become visible because people look at you like something is different.

Although few of the other women in the four groups rejected the idea of reconstructive surgery for the same reasons as Michelle, most felt pressured to conceal the disfigurement resulting from their disease. Even if they opted not to have reconstructive surgery, they chose to wear prostheses, especially in public, where going without might draw unwanted attention and evoke feelings of discomfort.

While reconstructive surgery and/or wearing prosthetic inserts in their bras might have helped the women feel less publicly visible or stigmatized, they still struggled with the physical disfigurement resulting from their disease. Having reconstructive surgery or wearing a prosthesis, in other words, might have buffered some of the trauma associated with losing a breast, but could not fully diminish the sense of loss accompanying a mastectomy or lumpectomy. The experience of one Upton member, Julie, serves to further illustrate this point. In her interview, Julie explained what it was like for a friend, who had never had breast cancer, to tell her that she could not “really know” what it was like to lose a breast, since she had had reconstructive surgery at the same time as her mastectomy. She explained:

Oh, people say stupid things to you. [A friend said to me],
“You don’t even know what it’s like to lose a breast, when you have an immediate TRAM flap.”

[I’m] sorry, but you do. Maybe there’s not an empty space, but there’s no breast. [uncomfortable laugh] It’s like, okay, you see the scars. And yes, you do know what it’s like to lose a breast. There’s no minute that
you ever kid yourself that [the reconstructed breast] is a breast.

I mean, I have pictures of --I have visions of my surgery and I’m picturing my breast sitting in the basement [of the hospital]. My whole breast is sitting in the basement. I know how much it weighed. You know, I know the dimensions of it cut off.

But still... I just, I needed to wake up and still feel whole, even though I knew it was not a breast, [I] still [needed to] feel whole.

As Julie’s comments show, having reconstructive surgery allowed her to cope with the loss of her breast, in part, by helping her to feel “whole.” Nonetheless, she never viewed her reconstructed breast as a real one, and continued to face emotional fallout from her surgery.

The same was true of the other women in the study. Despite having reconstructive surgery and/or wearing prosthetic breasts, they still faced the trauma associated with losing a part of their bodies that was often central to their identities as women. One of the ways members of York, Upton, Hogart, and Bellesmith attempted to cope with such a loss was to joke about their new bodies. As the following discussion will show, they frequently did so in quite sexualized ways.

**Sexualized Joking**

Several researchers have reported how various groups use humor to cope with uncomfortable emotions, such as fear and anxiety. Smith and Kleinman (1989), for instance, analyze medical students’ use of humor to mitigate uncomfortable feelings evoked by undesirable patients (e.g., those who are grossly overweight and/or unattractive), and invasive medical procedures. Similar phenomena have been described in studies of emergency personnel (Van Wormer and Boes 1997; Palmer 1983), funeral directors (Thompson 1991;
Hafferty 1988), and surgical teams (Goffman 1961). In these situations, humor allows people to acknowledge a problem and relieve tension, without having to directly address the source of either. It also helps them to save face and avoid appearing weak (Smith and Kleinman 1989).

Members of Upton, York, Hogart, and Bellesmith used humor in similar ways. On multiple occasions, members interrupted themselves and others to crack a joke, usually when group discussions turned somber. For example, on one occasion, Betty, mentioned earlier, expressed concern and sadness over her husband’s decision to file for divorce a few months after her breast cancer diagnosis. As she spoke, others offered words of encouragement, while a few even became tearful. Seeing that the mood of the group had turned melancholy, Betty then changed the subject, attempting to joke about the situation. From my fieldnotes:

Betty then said, “I’m going to take a trip to Florida to get away, and I’ve decided I’m going to make a commercial about my trip. It’s going to go something like this...” Imitating a television announcer’s voice, she then said, “[Betty Smith], you’ve lost your breasts. You’ve lost your husband. What are you going to do now?” Answering her own question, she exclaimed, “I’m going to Disney World!”

Initially, Betty’s joke evoked looks of doubt and even shock. By the completion of the punch-line, however, her parody of a popular television commercial featuring various championship sports stars got everyone laughing.

After the joke, nothing more was said about Betty’s situation. Rather, the tone of the discussion changed and remained light thereafter. This example illustrates how women in the groups used humor to defuse tense situations and interrupt potentially painful discussions. In this case, members of York avoided not only a discussion of Betty’s bleak situation, but also
a frank discussion of the implicit fears underlying her joke, including insecurities associated with an altered body or rejection by a loved one, as well as how these fears might pertain to other members’ lives. This example also shows how the other women collaborated with Betty by remaining silent and refusing to press for more details about what she was experiencing.

Other times, however, the joking was more interactive and extended. For instance, on one occasion at York, two of the women used the time preceding the meeting to joke about what their bodies looked like after breast cancer surgery. At this meeting, Betty, who frequently joked about her body, made reference to her “foobs,” i.e., “fake boobs.” Her comments encouraged another member, Hazel, to joke with her about how they both disliked the way their bodies looked. The other women in attendance participated by laughing at the women’s jokes, in essence encouraging Betty and Hazel to continue with their banter. From my fieldnotes:

Betty said to Hazel, “Check out my foobs! I just had my implant surgery last week. I’ve been calling them my foobs. They’re my fake boobs!”

Hazel replied, “You may have foobs, but I’ve got a penis.”

Everyone in the room, about six other women, stopped what they were talking about and looked at Hazel. Some laughed.

Hazel then continued, “The way they did my [implant] surgery. It looks like I have a penis on my chest now.” [Pointing to her chest.]

Even more of the women laughed.

Betty responded saying, “When they [surgeons] put my expanders\textsuperscript{55} in they finally asked me if I knew they weren’t normal. The plastic surgeon said they were lop-sided and too high and round.”
Hazel laughed and said, “Isn’t that what everybody wants? High and round?”

This comment received more laughter.

Betty said, “They may be high and round, but they looked deformed.”

Hazel replied in a deadpan voice, “Well, at least you don’t have a penis on your chest.”

Several of the women smiled, and everyone else laughed.

Betty then said, “The plastic surgeon kept filling them [implants] up with the [saline] injections. But they [breasts] were hard.”

Betty then paused and said to Hazel, “Hey! They could do that with your penis. Make it hard!”

There was more laughter from the other women in the room.

Hazel said, “Yeah. I’ve also got these two lumps [from surgery] under my arm [pointing to her right arm]. But they’re in the wrong place. They need to be closer to the penis.” [Pointing to her chest again.]

At this, the other women exploded in laughter.

When they stopped laughing, discussion turned to a member whose daughter had recently married. Deborah, the leader of the group, who was running late, then entered the room, and called the meeting officially to order.

In this example, Betty and Hazel joked about how their bodies looked “deformed,” even after having reconstructive surgery. The other women in the room encouraged the exchange by laughing at the two women’s jokes.

But none of them, even later in the meeting, broached the uncomfortable feelings underlying the previous joking. Instead of talking about how embarrassed and dissatisfied they were with their bodies, how sexually unattractive they felt, or even how they no longer felt like women (as when Hazel claimed to have a penis on her chest), the women stuck to
safer topics of discussion. They talked, for instance, about how quickly one member’s hair was growing back after chemotherapy, and about how many radiation treatments another member had remaining. Even so, it was clear that the women were distressed by the changes to their bodies. For example, underlying Betty’s jokes about having “fake boobs” and Hazel’s comments about having a penis on her chest, were implicit fears about having a “deformed” body, and no longer being sexually attractive, especially to men.

These same fears were evident in the type of humor the women described using outside of the groups. For instance, one member of Hogart, Renee, confessed to telling friends, “You know what? I don’t think I could be a topless dancer now!” Bonnie, another member of Hogart, who had always been large breasted before having breast cancer, liked to tease that after having a mastectomy and a saline implant she had a “Dolly Parton” on one side and a “Cindy Crawford” on the other. Both of these jokes illustrate how the women felt dissatisfied with their new bodies and feared that they were no longer sexually attractive. Like those previously described, the two women’s jokes also show how members of the various groups consistently joked about their bodies in sexualized ways.

That they did so is significant. Theoretically, the women could have joked about any number of things, in any number of ways. Yet they chose to joke most often about their bodies in sexualized ways. Doing so helped them to acknowledge the discontent and insecurity they experienced over losing a breast(s). It also provided them with a way to reassure one another that they were still sexual beings, despite what they had been through. At the same time, by making light of the situation, the women could avoid serious discussions about how losing a breast(s) made them feel sexually undesirable. It also helped
them **not** to appear deeply invested in something they feared they had lost.

Given the conditions under which they came together, it is not surprising that the women chose to cope with their illness in this way. With the exception of York, none of the groups were facilitated by a psychological counselor. Upton was led by an oncology nurse, Hogart by a former breast cancer patient, and Bellesmith by the owner of the shop in which the group met. Most of the leaders were thus not trained or equipped to facilitate their respective groups in any emotionally therapeutic way. Nor did they necessarily desire to see the groups move in that direction.

For example, in her interview, Mavis, who had led the Upton group for over seven years, explained how she was unprepared and unwilling to facilitate the group in the same way as the psychiatric nurse who had preceded her. She said:

> [When the other woman ran the group], it used to be a little bit more [pause] – to me it was more depressing. [She would] sort of draw out things from people. [pause] I did not make an effort to do that because I don’t have any training in that. And I don’t want to do more damage than good. So yeah, there was sort of a transition where we went from having more of psychotherapy feel to the group to having more of a social feel.

Mavis went on to explain how this change in focus influenced the emotional tone of the group. From her interview:

> I also am not the kind of person that deals well with [feelings]. I’ve heard rumors about some of the other support groups, that they’re very – I have a hard time coming up with the word – but, basically, depressing. The people leave feeling bad. And there’s a lot of crying. And I never wanted our support group to be like that; and it really hasn’t. There have been some sad times, but that’s pretty natural when you’re in an oncology sort of support group. But I think for the most part, it’s had sort of an upbeat mood.
As this excerpt shows, Mavis characterized therapeutic support groups as depressing, and sought to maintain a more “upbeat mood” for the Upton group.

The same was true of the other three groups. In fact, participants and leaders seemed invested in the belief that the groups were not places where breast cancer patients came primarily to cry and complain. At one York meeting, for instance, Deborah, the leader of the group, made a point of saying, “Many breast cancer patients tell me they don’t want to come to support group because they think it will be depressing and everyone will cry or complain the whole time. I always tell them to give it a try. They’ll be surprised how little of that goes on and how much the women laugh.” This was a message that Deborah repeated at several other meetings, and one to which group members always concurred.

The leaders’ and participants’ insistence that the groups have an upbeat tone makes sense given the constraints they faced. As noted above, only one of the facilitators in the study had training as a counselor. This made it hard for the women to delve into emotionally difficult discussions, at least with any certainty that they would be guided in a therapeutically meaningful way. This is one reason why the women relied on humor to help them cope with the physical disfigurement resulting from their disease. They generally lacked an environment in which they could successfully do otherwise. 57

In addition, the women also experienced pressure to be positive from the larger breast cancer culture. As discussed by Klawiter (1999) and Ehrenreich (2001), the majority of groups and organizations serving breast cancer patients, as well as those attempting to treat and prevent the disease, have created a culture of disease that emphasizes breast cancer awareness, positive and upbeat attitudes for breast cancer patients, the hiding of illness, as
well as the celebration of survival and survivors. Such a focus precludes serious discussion of the environmental or social causes of the disease, and the suffering and death associated with it. This has led Ehrenreich to remark that, “so pervasive is the perkiness of the breast cancer world that unhappiness requires a kind of apology . . .” (2001:48). This is another reason why the women in this study relied on humor to help them cope with their disease. It allowed them to acknowledge the disfigurement that they faced, without having to discuss the painful emotions that these changes brought forth.

As their treatment progressed, however, these uncomfortable feelings became increasingly difficult for the women to ignore. During adjunctive therapies, such as chemotherapy, their hair fell out and their skin often took on a sickly pallor. In short, the women started to look like “cancer patients.” Such changes to their appearance made it nearly impossible for the women or their loved ones to ignore the reality of their illness. In fact, these visible changes served as frequent reminders of the potential severity of their disease and the possibility that they could die.

In reaction to this new dilemma, the women developed strategies to help them cope. These included making games of losing their hair and practicing a compensatory form of femininity. Like those previously discussed, these strategies allowed the women to avoid examining and discussing more painful emotions associated with their illness, and ultimately served to reinforce traditional standards of beauty, as well as the invisibility of their disease.
VALIDATING A NORMAL SELF

In Rapunzel’s Daughters: What Women’s Hair Tells Us About Women’s Lives, Rose Weitz writes, “If you really want to understand the importance of hair, talk to a woman who doesn’t have any. You’ll quickly learn, as I did, that losing one’s hair can feel like losing one’s very self!” (2004:134). Many of the York, Upton, Hogart, and Bellesmith women felt the same. They expressed more despair over losing their hair than a breast(s), reporting that becoming bald was devastating not only because it changed their appearance, but also because it served as a visible sign of their illness to themselves and others.

Jasmine, a member of Upton, is an example. Before being diagnosed with breast cancer and starting chemotherapy, Jasmine had waist-length dark hair. After two rounds of chemotherapy, it started to fall out. Three days later her hair was gone, an experience she described as both traumatic and devastating. From her interview:

And in three days everything was gone. Everything was gone! And that was very devastating for me. Very devastating... I don’t know. It’s just, that was the hardest thing, losing my hair. I could not look at myself. I could not.

Later in her interview, Jasmine went on to say that she did not recognize herself in the mirror and refused to let anyone take her picture while she was ill.

Donna, mentioned earlier, reported a similar experience. Like Jasmine, she described the loss of her hair as devastating and tried to avoid seeing herself, if at all possible. From her interview:

Jackie: You said losing your hair was really hard.

Donna: It was devastating.
Jackie: A lot of the women I’ve talked to say that losing their hair was one of the hardest things.

Donna: Yeah.

Jackie: What was hard about it for you? I know that might sound like a stupid question, but…

Donna: No, it’s not. Well, just for the fact, you know, I can’t even explain it. I just remember that it was devastating. And to see yourself in the mirror, and I wouldn’t let anybody take my picture. . . I didn’t want anything reminding me, any pictures, nothing. Because I’ll never forget the mental image I had of myself during that time.

Donna’s and Jasmine’s experiences are representative of other women in the study who lost their hair during chemotherapy. Generally, the women experienced a great deal of distress over becoming bald, and were particularly sensitive about their appearance.

While losing their hair was upsetting, it was what such a loss came to signify that was of even greater consequence to the women. For most, the loss of their hair, along with the other physically debilitating effects of chemotherapy, became outward signs of their illness. This, in turn, forced the women to deal with the reactions of family and friends, who were frequently distressed by their sickly appearance and fearful of what it meant for the women’s chances of survival.58 One way the women attempted to cope with this new dilemma was to make a game of losing their hair. Often bittersweet in nature, these “hair games” allowed them to cope with the emotional distress associated with losing their hair, and helped them deal with family and friends who were often shaken by the experience and what it came to signify.
Hair Games

Coping with the loss of their hair was hard for women in all four of the groups. For those with young children, it was especially difficult. The women struggled with how to talk to their children about their illness, often putting the topic on hold until it could no longer be ignored. In many cases, this meant waiting until their hair was about to fall out before discussing the issue with their children. This is what happened with Grace, the mother of an eight-year-old son, and a member of York.

During one support group meeting, Grace discussed the impending loss of her hair, asking other members for ways to broach the topic with her son. From my fieldnotes:

Since the last meeting, Grace had started chemotherapy. She told the other women, “Everyone says that with Adriamycin your hair always falls out. I keep telling myself maybe I won’t really lose my hair.”

Several of the women murmured in disbelief. And then Deborah, the group facilitator, said, “Don’t tell yourself that. With Adriamycin, your hair will fall out.”

The other women nodded their heads in agreement.

Grace then said, “I know. Everyone says it will fall out. I just don’t want to think about losing my hair. Somebody said I should cut it short before it actually falls out, that it would make it easier to deal with.”

Deborah said, “There are many women that do that. They say it helps them feel like they’ve got some control over the situation. They’re not just waiting for it to fall out. It doesn’t make as big of a mess that way either. You don’t have hair falling out everywhere.”

Grace responded, “That sounds like a good idea. I’ve already got an appointment to get my hair cut shorter. But what I’m really worried about is how I’m going to tell my son.”

Annette asked, “How old is your son?”
Grace responded, “He’s eight.”

Deborah said, “The worst thing that you could do is to not talk to him about it. He’s going to know that something is going on. He’ll take his cues from you. If you talk to him and let him know that you’re okay with it, he’s going to handle it a lot better.”

Annette said, “I’ve read that it helps to let your children play an active role in the experience. You might want to let him help shave your head. That will also give you the opportunity to talk to him about your cancer.”

Betty said, “I’ve also heard about some women getting those washable markers and letting their kids draw on their bald heads. Maybe you should try that. I bet he would think it’s fun. Plus, it might help him to not be afraid.”

Grace responded, “That’s a good idea! I think he would love to draw on mom’s head. He’ll think that’s cool!”

At a later meeting, Grace reported that she did let her son draw on her bald head. She also thanked the group for the suggestion, saying that it helped initiate the topic of her illness with her son and consequently made them more at ease with her condition.

Donna, from Upton, faced a similar situation. When the tissue biopsies from her mastectomies revealed that she had an aggressive form of breast cancer, Donna was advised to have chemotherapy, which she did. Her sister and young niece were visiting her at home when she first realized that her hair was starting to fall out. Distressed by what she saw and concerned for how her two family members would react, Donna decided to make a game of pulling out her hair. From her interview:

Donna: And I remember when mine was falling out, my niece was here. And she was four at the time, and she said, “Look Aunt [Donna], if you just take a brush it’s all gone in that spot I just brushed.” And my sister, she and I, and my niece—I mean, all I had to do was this [running fingers through her hair] and hair was all around me. So we
just kind of pulled it out.

Jackie: Did you make kind of a game out of it?

Donna: For [my niece] we did. You know, because I was devastated. And, my sister, you could just see it on her face that she felt bad for me. But we kind of joked around about it. We grabbed handfuls of hair and pulled it out. I let my niece help pull out my hair.

In this particular example, Donna, although alarmed by the loss of her hair, attempted to put her sister and niece, as well as herself, at ease by making a game of pulling out her hair.

Other women in the four groups acted similarly, not only with their young children, but also with their older family and friends. For example, Sarah, a member of York who was in her early 50's when diagnosed, took a close friend with her to shop for wigs. Knowing that her friend was wary of how she would handle the situation, Sarah decided to make the experience “fun” by trying on a variety of wigs. She even had her friend bring a camera to take pictures of the event. From her interview:

We [my friend and I] went to look for my wig together. And we had a blast! She brought a camera. And we laughed. You know, I tried on a Dolly Parton wig. And I tried on the cornrows. I tried on all kinds of wigs.

Sarah went on to describe how she decided to buy several wigs, including one that was long, even though her hair had always been short. She said:

And I had always wanted that swish hair [long hair that swishes back and forth]. I always wanted that kind of hair. And I thought, “I’m gonna have it.” And so I got swish hair. And I had a lot of fun with that. Because I, you know, one day I’d come into work with hair sort of like this [short] and then the next day I’d come in with hair down to here [long hair]. And they [co-workers] would say, “Gosh!” And I’d say, “I’m bald! I’m bald! You wanna see?” [And they’d say], “No! No! That’s okay.” But people just got comfortable with it, because they knew that I was.
Like Donna, Sarah dealt with the loss of her hair by making a game of it. In so doing, she tried to make herself, as well as those around her, more comfortable with her hair loss.

As the above discussion illustrates, losing their hair and enduring other physical effects of chemotherapy was difficult for all of the women who faced this form of treatment. However, for most of them, the “hair games” they played helped them cope with the loss of their hair and some of the uncomfortable emotions associated with it. Such games also served as a way for the women to broach the topic of their illness with family and friends, helping to put both themselves and others at ease with the situation.

Another way the women attempted to make themselves and others more comfortable with their illness was by practicing a form of compensatory femininity. In addition to having reconstructive surgery or wearing prosthetic inserts in their bras, they often wore wigs or scarves and gave extra attention to other aspects of their physical appearance, such as their make-up and clothing. Doing these things, as the following discussion will show, helped the women to overcome some of the insecurity and embarrassment they felt about their appearance, and provided them with opportunities to reassure one another that their efforts were a success.

Compensatory Femininity

Sociologists generally agree that gender is a social construction that can take a number of forms. Connell, however, writes that for women, the most support, culturally and ideologically, is given to “emphasized femininity” (1987:187). This form of femininity, he argues, stresses being outwardly sociable, fragile, sexually receptive, and above all physically
attractive, i.e., thin, shapely, and “made up.” From these gendered expectations, women
learn not only that they will be viewed and evaluated, especially by men, as (sexual) objects,
but also to see themselves as such. As Sandra Bartky explains:

Knowing that she is to be subjected to the cold appraisal of the
male connoisseur and that her life prospects may depend on how
she is seen, a woman learns to appraise herself first. The sexual
objectification of women produces a duality in feminine
consciousness. The gaze of the Other is internalized so that [women]
become at once seer and seen, appraiser and the thing appraised
(1990:38).

With the cultural emphasis on near physical perfection, few women are content with their
personal assessments, and many believe that they do not measure up. As one consequence,
Bartky argues, women often spend tremendous time, energy, and money to alter and perfect
their physical appearance (1990:40-41).

Members of York, Upton, Hogart, and Bellesmith were no exception. Most of these
women devoted special attention to their physical appearance. This was especially the case
for the middle-class women from York. For example, at one of the first York meetings I
attended, I was struck by the meticulous attention the women seemed to have given to every
aspect of their appearance. From my fieldnotes:

Almost all of the women were dressed nicely. Betty looked very stylish,
wearing khaki capri pants, a fitted button-up rust-orange blouse, and
slip-on sandals. She had a very short haircut that appeared professionally
styled. She also carried an expensive-looking purse. Hazel wore a
designer khaki suit, quite a bit of make-up, and had several large diamond
rings on her fingers. Another woman, Anne, wore a matching skirt and
blouse. Like most of the other women in the group, her hair was also
carefully styled, as was her make-up.

The same was true of members of Upton, Hogart, and Bellesmith. Like those from
York, these women typically dressed up for meetings, wearing dresses, skirts and blouses, or matching pantsuits. They also usually had carefully done make-up and neatly styled hair (or wore wigs and scarves). And while many of them, especially those from Hogart, could not afford the designer clothing and expensive jewelry worn by members of York, it was still evident that the women spent considerable time on their appearance. What was unclear, especially in the early stages of the data collection process, however, was whether the women were just doing what they had always done, or if they were spending more time on their appearance, trying to compensate for the physical effects of their disease.

Observing the groups for an extended period of time was helpful in this regard. For example, with the York and Upton groups I was able to observe several of the women as they went through the process of being diagnosed with breast cancer, treated for the disease, and monitored for follow-up care. What stood out about this process was the special attention given to their appearance after losing their hair. During this time, for example, the women often wore carefully styled wigs or scarves and typically wore noticeably darker make-up, to cover the loss of their eyebrows and eyelashes, and their pale skin. Although the women generally dressed well, that they did so during this stage of their illness also stood out.

My impressions of the women’s behavior were corroborated by the interviews. Members of all of the groups reported spending extra time on their appearance after being treated for the disease. Bonnie, the leader of Hogart, for instance, discussed how she and her husband worked to make her clothing “look right” when she was recovering from her mastectomy and later when she got the tissue expander for her breast implant. From her interview:
My husband and I, we kept designing ways that I could wear clothes without the [drainage] tubes [from surgery] being visible and then with the [tissue] expander [for the implant]. I mean it [the expander] was just a big old long lump up here [on my chest]. And clothes just didn’t look right. But, I mean, I knew I was not going to look perfect, because I didn’t have a perfect body [before cancer]. I didn’t have a size 8 or 10 body. So, that was something that I had to learn to deal with. . . But I still worked hard to make my clothes look right.

Even while recovering from surgery, Bonnie expended considerable effort on her appearance.

The same was true of Julie, a member of Upton.

Julie, in fact, claimed that she spent more time on her clothing and make-up while she was sick than at any other point in her life. From her interview:

[During chemo], I dressed better, made-up better than I ever have in my entire life. I really did. I mean, [before I got sick], I did good to wear matching shoes. I’m just not a real foo-foo person. I’m more into wearing comfortable shoes [and clothes]. Forget matching. But I was in a real fashion mode during chemotherapy. And then I’m also [generally] really tight, so to spend money on clothes. . . [While I was sick], I bought more clothes. I got all these clothes. I took care of myself. 59

Betty’s and Julie’s experiences are representative of the other women in the study, most of whom reported that they worked hard to appear physically attractive during their illness.

Such data help to show that members of the groups were not just practicing an emphasized form of femininity when they devoted extra time and attention to their appearance. They were also trying to compensate for the physical effects of their disease. Doing so helped them cope with the insecurity and embarrassment they felt about their appearance. It also provided the women with opportunities to reassure one another that their efforts were a success.

They typically did so by exchanging compliments with one another during their
meetings. For instance, at the York meeting mentioned earlier, several members commented on Betty’s hair and outfit, telling her that she “looked good.” This seemed especially important to Betty, who, on this particular night, was attending the group for the first time without a wig since completing chemotherapy. Later in the meeting, Betty returned the favor by complimenting Ruth, who also revealed her post-chemotherapy hair to the group for the first time. From my fieldnotes:

Deborah, the leader, then turned to Ruth and said, “How about you, Ruth? How are you doing?”

Ruth replied, “I’m doing okay.” She then smiled and with a quick motion, jerked off her hat, saying, “I’m getting hair back! I had this [hat] on because my head was cold.”

When Ruth pulled off her hat, Betty said, “Wow. Look at your hair! It’s coming back! It looks good!”

Ruth smiled really big.

Although her hair was still extremely short and still patchy in places, the women continued to compliment her.

Deborah said, “It looks so good.”

Sarah said, “It does look good. Very stylish. What do they call it? It looks very chic, like you meant for it to be like that.”

Deborah said, “It does. You know, I see women that have styles like that, and they always look so stunning. And even if you didn’t mean for it to be like that, it still looks good. Cuts like that always look dramatic. Everyone I’ve seen them on, always looks good. It’s just that most people would never be brave enough to do that on their own.”

Ruth continued to smile and thanked the women for their compliments.

In this exchange, Ruth sought compliments from the other women by dramatically revealing her newly grown hair. The other women in attendance were generous in their responses,
reassuring Ruth that her hair was not only acceptable, but actually quite stylish and chic, even though it was still patchy and short. That they did so would suggest that they wanted not only to reassure Ruth that she looked attractive, but also to point out that she was exhibiting signs of recovery. Using compliments in this way gave the women hope that they were getting better and would survive their disease.

Similar incidents occurred in the other groups. For example, Donna, mentioned earlier, attended a York meeting only ten days after her bi-lateral TRAM flap. As she greeted other members, she repeatedly pulled her shirt tight across her breasts, stuck out her chest, and said, “Check out my profile.” The other women smiled and said that Donna’s new breasts looked good. Here again, members of the groups used their time together to compliment one another. Doing so helped to reassure them that they were still able to present an attractive image, despite the damage caused by cancer, surgery, and chemotherapy.

This was especially important because many of the women felt embarrassed and even ashamed of the way they looked after being treated for their disease. Sandra, a member of York, underscored this point in her interview: “When you go through this [breast cancer], especially chemotherapy, you are so vulnerable. And you need so much to be validated. I mean, there you are, bald, sick, and a lot of people gain weight. I mean, you are not your normal self.” The compliments the women paid one another thus served to acknowledge the efforts they put into their appearance, and reassure them that their efforts were a success.

Although exchanging these kinds of compliments might have made the women feel better, at least momentarily, they still struggled with the way that they looked. For example, in her interview, Ruth, who was mentioned above, explained that she did not feel human
without her eyelashes or eyebrows. She said:

    Ruth: I think what bothered me more [than losing my hair] was losing my eyebrows and eyelashes.

    Jackie: And what was it about it that bothered you?

    Ruth: It just made your face look terrible. I mean you just look real pale, like you’re from another world.

Being reassured by other group members that she still looked attractive helped Ruth feel better about herself, as the previous fieldnote excerpt illustrated. However, the realization of how sickly or “terrible” she looked kept Ruth from being entirely convinced by the other women’s words.

Put differently, Ruth and the other women knew that they looked unhealthy and unlike their normal selves during their illness. They also realized that after losing a breast(s) their bodies would never look the same. This did not mean, however, that the compliments that they shared with one another were empty or meaningless. Rather, these exchanges provided the women with opportunities to remind one another that, while they might not be as attractive as they been in the past, they were still making an effort to look good, and that they had not given up on themselves. This, in turn, served to reassure members of the groups that they were still worthwhile and valuable as women, despite what they had been through.

The women’s focus on their appearance also served another important function. It allowed them to avoid some of the more visible reminders of their illness, as well as the painful emotions such reminders could evoke. In other words, by practicing a compensatory form of femininity and spending their group time exchanging compliments with one another, members of the groups were able to divert attention from their sickly appearance and avoid
uncomfortable discussions related to it. Even so, many of the women recalled times, especially outside of the groups, when they realized how sick they looked. Such realizations often caused them considerable distress, leading them to wonder whether they would survive.

The experience that Sandra, a member of York, had at her last chemotherapy treatment is illustrative. At this appointment, Sandra was so weak that a friend had to bring her into the hospital in a wheelchair. While waiting to see the doctor, Sandra saw an older woman, who appeared extremely ill, being wheeled into the waiting room. Seeing this woman in a situation similar to her own caused Sandra to start crying. From her interview:

> And I cried, I remember I was with [my friend] and I was sitting in the chair beside her in the waiting room, waiting to go back to see somebody, [the oncologist], maybe. And they wheeled this lady in, in a wheelchair. And she was older, yes. But she looked so frail. And so ill. And I just burst out crying. And I said [to my friend], “I’m afraid I’m gonna get like that.”

> And she said, “No you won’t! No you won’t!”

. . . Well, I knew she was right. And I knew what it was. I knew it was just the gut, you know, that [sighs] that [sighs] [pause]. I can’t even exactly put myself back in that place again. But I just remember she looked just so awful. [pause] And sick. And I guess I really was afraid that that’s what I looked like. Or I think it was more like that’s what I’m gonna get like.

> . . . I’m not real clear on what that was. I just remember this lady coming in and it was just more than I could take.

For Sandra, seeing the older woman’s sickly appearance evoked fears about her own health and made real the possibility that she could die. Other women reported having similar kinds of experiences even after finishing treatment.

Donna, the member of Upton who had bi-lateral mastectomies with follow-up chemotherapy, is another example. Even before she lost her hair, Donna’s husband shaved
his head in solidarity, a gesture that she found touching. After her chemotherapy ended and her hair had started to grow back, however, her husband decided to shave his head again for the summer. Donna, unaware of his plans, was upset to see what he had done. From her interview:

My husband a couple months ago decided to shave his head again, and I didn’t know it. He walked out of the bathroom and came out here in the living room and I cried, because it wasn’t funny anymore. You know, like now you’re reminding me of being sick. It’s not funny anymore to do that. . . And so when he did it that time, I said, “Let that be the last of it. It just doesn’t mean the same anymore. And you can keep it short, but at least have some hair. Because now you look sickly.” But I did, I told him, “Don’t do it again because you look sick. People are going to think you lost your hair because you’ve got cancer.”

As this interview excerpt shows, a bald head, for Donna, came to signify illness and the possibility of death. Seeing her husband without hair thus not only reminded Donna of her own illness, but also the continued uncertainty that she faced as a breast cancer patient.

Experiences like Sandra’s and Donna’s conjured painful emotions. Realizing that they looked sick, or being reminded of being sick, often led the women to be fearful and anxious about their health and their future. As the above discussion has shown, this is at least partially why the women expended such effort on their appearance and frequently exchanged compliments during their meetings. They did not want to be reminded that their health might further decline or that they could die. Nor did they want to experience the uncomfortable emotions that such realizations might evoke.

Even if the women had wanted to discuss these painful emotions during their respective group meetings, they lacked the kind of environment that would have allowed them to successfully do so. As previously noted, only one of the leaders was a trained
counselor. The others lacked the skills to facilitate any complex group therapy. In addition, the women experienced pressure from the larger breast cancer culture to be positive and upbeat about their disease. Given these constraints, it makes sense that the women chose to use their time together in the ways that they did. Choosing to joke about and compliment one another on their physical appearance allowed the women to acknowledge the disfigurement that they faced as a result of their disease. At the same time, it provided them with ways to avoid talking about how upset they felt about these changes in their bodies.

CONCLUSION

Members of Upton, York, Hogart, and Bellesmith took great measures to conceal the physical effects of their disease. Many of them did so, in part, by having reconstructive surgeries, such as the TRAM and Latissimus flap procedures, or by getting breast implants. Others disguised the loss of a breast(s) by wearing prosthetic inserts in their bras. The women also practiced a compensatory form of femininity that served to hide the other physical effects of their disease. All of these strategies helped the women to appear normal, even while many were extremely ill.

As Strauss and Glaser (1975, 1984) have reported, such behavior is common among those with health problems. People with heart disease, arthritis, and multiple sclerosis often try to hide and compensate for their disease (1975: 58-65). In this regard, the women of Upton, York, Hogart, and Bellesmith were no different. As the previous discussion has illustrated, these women spent considerable time and energy attempting to hide the physical effects of their disease. What the current study helps to show, however, is how the disguising
of illness by the women in the four groups served to reproduce gender inequality and reinforce the invisibility of breast cancer.

For instance, by disguising the physical effects of their illness and practicing compensatory femininity, members of the support groups unwittingly perpetuated traditional standards of beauty. Given the cultural acceptance of emphasized femininity, as well as the stigma and rejection they likely would have faced had they not hidden their physical disfigurement, their decision to do so is certainly understandable. Even so, their behavior served to reinforce the idea that a woman’s value as a human being hinges on her physical appearance. Ultimately, this reinforced sexist ideas about women and helped to maintain gender inequality.

In addition, the women’s behavior contributed to the invisibility of their disease. For example, by buying into the idea that breast cancer patients should be upbeat, the women helped to obscure the suffering and death associated with their disease. This, in turn, served to depoliticize issues related to their illness. The women’s behavior reinforced a breast cancer culture that individualized the problem and encouraged positive attitudes rather than indignation and collective action. Acting upbeat, joking around, and sharing compliments with each other helped the women feel better, at least temporarily, but their behavior also played a part in maintaining larger inequalities.

Furthermore, as the analysis in this chapter has shown, the conditions under which the women met, and the subsequent strategies they used to cope with their physical disfigurement, led them to avoid talking about how changes in their bodies made them feel. While this too might have temporarily helped the women feel better about themselves and
more at ease during their meetings, it denied them the opportunity to cope with their illness in therapeutically meaningful ways. The strategies the women used also influenced how they came to understand their illness after completing treatment. As the next chapter will show, by focusing on the medical details of their diagnosis and avoiding emotionally upsetting discussions, the women were able to ultimately define their illness experience as a blessing. Although doing so helped them to justify and better understand the suffering and pain that they had endured, it also reinforced the mainstream breast cancer culture’s perspective of the disease.
Chapter Four

COPING WITH POST-TREATMENT FALLOUT

Breast cancer is marked by uncertainty. Even though there are known risk factors, such as having a high-fat diet, being obese, having a mother who had the disease, and/or using hormone replacement therapy, all women are susceptible to developing the illness, with this risk increasing as they get older (Love 2000). In fact, it is estimated that one in eight women will develop the disease in her lifetime (Ratner 1999). Furthermore, breast cancer can be present when lumps in the breast(s) are too small to detect by touch. So not only are all women vulnerable to the disease, but also many who are first diagnosed show few, if any, signs of being ill.

Women who have had breast cancer face even greater uncertainty. As discussed in chapter two, doctors rarely, if ever, declare cancer patients “cured” (Mackenzie and Couch 2004). Nor can they, with absolute certainty, predict which patients will have their cancer return. Women who have been treated for breast cancer therefore face the distinct possibility of recurrence, as well as the reality that they may one day die from the disease. As one result, they continue to experience fear and anxiety long after completing treatment.

Such was the case for the women in this study. Members of the four groups reported that following treatment they were plagued by a sense of fear and dread. They feared that their cancer would return, and, if it did, that they would die. They also reported feelings of powerlessness, even after completing treatment, because they no longer felt like they were actively fighting their disease. This led some to feel as if they had little control over their lives or the future of their health. As this implies, even the post-treatment women struggled
with the emotional fallout of their disease.

Several examples illustrate what the women went through. The first is Angie, a member of York, who often expressed frustration over not being able to “move on” with her life, after having breast cancer. At one group meeting, for instance, she described how she continued to live in fear, especially of recurrence. She said:

The other day, I told one of my friends that I feel like I’ve come a long way. But even so, there’s still that feeling in the pit of my stomach (pointing to her stomach.) *This fear*. And it just seems to me that no matter how far you seem to come, that feeling in the pit of your stomach is always there.

The other women attending the meeting agreed. They too reported that they worried about the future, fearing that their cancer would return.

Isabella and Betty, other members of the group, even compared the sense of fear and dread that they experienced to having a black cloud constantly hanging over their heads.

From my fieldnotes:

Isabella [responding to Angie’s earlier comments] said, I’m not sure it [the fear] ever goes away. Not totally anyway. Maybe the time between thinking about the cancer and the fear gets longer. But it’s still like a having a big black cloud hanging over your head.

Betty concurred. More hopeful, however, she concluded that, Well, over time the cloud may get smaller and less dark, but it never totally goes away. Maybe it’s grey and the sun can shine through, but it’s *always* there.

As these two women’s comments illustrate, members of the groups faced uncertainty about what the future might hold. They feared that they might face a recurrence, and many even worried that cancer cells might have already spread to other parts of their bodies, without their knowledge.
Sandra, a member of York, is another example. She explained that she never knew how to respond to family members and friends who asked how she was doing or if she was now well. From her interview:

Sandra: It is amazing how many people [ask], “How are you doing?” or “Are you cured?” Well, they don’t say it that way. They ask, “Did they get it all?”

Jackie: People will ask you this?

Sandra: Yes.

Jackie: Friends or…?

Sandra: Acquaintances. Even my brothers. You know, my brothers will say that. It is sort of what they want to know. It is like, “Did they get it all? Are you cured? Are you well?”

Sandra continued, My answer to them is always, “I don’t know. Time will tell.” Half of my brain says, “That is a real negative attitude.” And the other part of my brain says, “It is the truth.”

Jackie: You don’t know.

Sandra: Yes. I don’t know.

Sandra’s comments show how the women were forced to live with uncertainty. They did not know if “doctors got it all” or if they had been “cured.” Consequently, they continued to experience fear and anxiety about the future and their health.

For most of the women, these uncomfortable feelings intensified after they had completed surgery, chemotherapy, and/or radiation. Members of all four groups reported that during treatment they were focused on eradicating their cancer, and had little time or energy to focus on the future. After treatment, however, they were able to reflect on what they had been through, and what the future might bring. It was during this time, the women said, that
they started to feel less in control of their lives and began to worry about their cancer coming back.

Renee, a member of Hogart, said that after she completed treatment, visits from family and friends started to wane. Left with more time to herself, Renee started to worry about recurrence and even began to have panic attacks. From her interview:

Well, [during treatment], I had people around me. But then after a while, they stopped coming. And then I had anxiety attacks real bad one day. And I ended up in the hospital. So, I guess when, everybody’s gone, and you’re alone, you start thinking about things. I would get so depressed. And I would get this feeling where [whispering], I would think that I was gonna die. I don’t know. You think about the unknown. I was thinking about that a lot.

Renee’s experience shows how the time immediately following treatment proved to be a difficult adjustment period for the women. Family and friends often stopped visiting on a regular basis. The women also lacked the constant medical supervision to which they had become accustomed during chemotherapy and radiation treatment.

For example, at the York meeting mentioned earlier, several of the women discussed how often they visited their oncologists for follow-up appointments. A few even expressed a desire to visit their doctors more frequently, rather than less, saying that doing so made them feel as if they were being proactive in their care. From my fieldnotes:

Angie said, I would go back [to the oncologist] as often as they would let me. I think it’s like this, when you’re going through treatment you feel like you’re doing something.

Deborah said, I can see that. When you’re in treatment, you feel like you’re doing everything in your power to get better. You feel like you have some control over the situation.

Ruth said, That’s how I feel. That’s partially why I decided to go ahead
with the radiation. I’m hesitant to just stop doing something.

Angie said, I guess that’s how I feel, too. You do all your treatments, and then it feels like you’re not doing anything. But that feeling in your stomach [fear] is still there. At least when you’re doing your treatment you feel like you’re doing something.

During treatment the women felt as if they were actively fighting their disease. As Deborah, the leader of the group, pointed out, this allowed them to feel more in control of their cancer experience. After treatment, however, they did not see their doctors as frequently and played a less active role in their medical care. As the above fieldnote excerpts show, this led the women to feel less in control of their health and lives.

It also led them to experience increased fear and anxiety about any physical symptoms they experienced. Indeed, after finishing treatment, many of the women started to question even the most mundane of physical symptoms, such as headaches or muscle pain, taking them as signs that their cancer had returned. At another York meeting, for instance, Isabella, Betty, and Sheila discussed how easy it was to assume that any physical symptom was cancer related. From my fieldnotes:

Isabella said, After my chemotherapy, there was a time when I thought maybe there was a tumor in my brain. But then again, I had hit myself in the head with a hoe when I was gardening. (She then made a motion and thud sound, as if something had clunked her in the head.)

None of the women laughed. Several even nodded their heads, suggesting that they understood why Isabella might think such a thing.

Betty then said, I’ll think things like that, too. It’s hard not to. You get a headache and think, “Oh, no. Is it a brain tumor?” But then you say, “Okay. I took some aspirin. It went away. It was just a headache.” Or you go, “Hey, there was that time I hit myself in the head with the hoe.”

Sheila said, That’s like me. I got this new pillow. And for the next few
days I had this bad neck-ache. I kept thinking, “What if it’s cancer?” Then I thought about it and was like, “You just got a new pillow.” And then the pain went away a few days later. So, I knew that’s what it was. But you can’t help being afraid.

Members of all of the groups described similar experiences. Ailments, such as headaches and neck-aches, which would be little cause for alarm for non-cancer patients, caused these women considerable anxiety. Given their medical histories, this makes sense. Because the women had had cancer, they were at greater risk for developing it again. Therefore, they worried about unexplained aches and pains.

Unfortunately, these feelings of fear and anxiety came at a time when family and friends were often unwilling or unable to provide the women with the additional support that they needed. As illustrated by Renee’s experience described above, after treatment, family and friends generally stopped visiting, preparing meals, or offering other types of instrumental support that they had provided in the past. Emotional support was also frequently in short supply. Many of the women reported that after they completed treatment, family and friends seemed intolerant of their fears and anxieties about the future. Some were even told to “move on” with their lives.

Spouses and/or partners, the women said, were especially guilty of the practice, frequently dismissing their fears as unwarranted. For instance, at one York meeting, Isabella explained how frustrated her husband had become with her fear of recurrence. He did not understand, Isabella claimed, why she continued to worry about her cancer coming back, or why she contemplated what she would do if it did. She explained to the group:

   It’s like my husband, he gets aggravated with me. He says, “It’s done! It’s over!”
Isabella then said, He doesn’t understand why I keep thinking that it [cancer] could come back.

She continued, But the reality is, because I’ve had cancer, I’m at a higher risk of getting it again. It’s likely that I could get cancer again. Do I think about this everyday? No. But it’s always in the back of my mind. It’s not always the first thing on my mind when I get up. But it creeps in my head sometimes.

After confessing this to the group, Isabella went on to explain how she still received the American Cancer Society’s catalog and continued to look through it to see what new products were available to cancer patients. This, too, she said, aggravated her husband, who wanted to believe that her cancer would never return. From my fieldnotes:

And my husband will say, “Why are you looking at those things? You don’t need those anymore. It’s done. It’s over with. You’re not going to get cancer again.”

Isabella, lowering her voice, said, But I tell him, “It’s always a possibility.”

As these fieldnote excerpts illustrate, the fear of recurrence was never far from the women’s minds. However, like Isabella’s husband, many of the women’s family members and friends were not receptive to these concerns, even though, they surely knew that recurrence was a possibility.63

Even when the women suspected that their family and friends would be empathetic, they often chose not to share their concerns. Some claimed that they did not want to further burden their loved ones, many of whom, the women believed, had already been stretched to their emotional limits. Others chose not to confide in their family and friends, fearing that they would cause needless worry. For example, at the York meeting discussed earlier, Sheila explained how she never talked to her husband about the aches and pains she experienced or
about her fear of recurrence. She said:

If I told him [husband] things like that, he would just worry about them non-stop for at least a week. He wouldn’t let it go. So, I don’t tell him stuff like that. I don’t want him to worry. I would never tell him.

Many of the other women felt the same. Both in their meetings and interviews, members of all of the groups reported that, at least some of the time, they kept their fears and anxieties to themselves, despite the fact that they continued to worry about the possibility of recurrence.

This is at least one reason why the women continued to attend support group meetings long after completing treatment. As the analysis in chapter two showed, continuing to attend meetings helped members of Hogart, who lacked the resources and skills to gather information on their own, keep informed of the most recent advances in breast cancer treatment. It also increased their confidence in the competence of local doctors, who they believed could successfully treat any future recurrence. Continuing to attend meetings was thus one way members of Hogart dealt with the uncertainty of the future and their fear of recurrence.

Members of York and Upton coped with uncertainty in other ways. One was by learning to create and tell stories about their breast cancer diagnosis and treatment. As the following section with show, these stories allowed the women to talk about their cancer experience in emotionally detached ways and helped them to regain a sense of control over their lives.
STORYTELLING

Telling stories is a common way for people to cope with and better understand difficult life events. As Reissman (1990) shows, people who have been through divorce use storytelling as a way to make sense of the end of their marriages. Other researchers (Mishler 2004, 1985; Frank 1995; Charmaz 1991) explain how storytelling helps people cope with a variety of short- and long-term illnesses. For example, Williams (1984) and Bury (1982) show how those with rheumatoid arthritis use stories to help them understand what caused their illness, as well as account for the disruption it creates in their lives. Similar work has been done on other diseases and medical conditions, including ulcerative colitis (Kelly and Dickinson 1997), breast cancer (Langellier and Sullivan 1998; Mathews, Lannin, and Mitchell 1994), and disorders related to the temporomandibular joint (TMJ) (Garro 1994). In the case of illness, these researchers conclude that storytelling allows people to cope with the uncomfortable emotions associated with being ill (Mishler 2004, 1985; Charmaz 1991; Kelly and Dickinson 1997), refashion favorable images of themselves (Frank 1995), and redefine their illness in ways that are meaningful to them (Frank 1995; Charmaz 1991).

Members of York and Upton used storytelling in many of these same ways to help them cope with the fear and anxiety they experienced about the future. For example, by telling stories that focused on clinical details, the women were able to avoid discussing the emotionally painful aspects of their illness. More importantly, by sharing medicalized stories, women in the two groups were able to reassure one another that their disease was something over which doctors and science would ultimately prevail. This, in turn, helped the women to regain a sense of control over their health and lives, as the following discussion
Early in the data collection process, I noticed how storytelling played an important role in York and Upton group meetings. In fact, members of these two groups typically used their entire time together to share diagnosis and treatment stories with one another. These stories followed a format that included time of diagnosis, the stage and type of cancer they had, and any surgical procedures they had endured. In addition, the women usually described the kind and number of chemotherapy and/or radiation treatments that they had had, as well as any problems they had experienced with those treatments. Stories usually ended with the women explaining how they were currently faring with their illness and any special concerns they had about it.

Kim, a long time member of Upton, best illustrates this pattern. Whenever she shared her story with the group, Kim always used medical details to explain what she had been through. For instance, at one meeting, after introducing herself, Kim gave a detailed overview of her diagnosis and treatment regimen, and then reported on her most recent doctor’s visit. From my fieldnotes:

Kim said, My name is Kim. I was diagnosed with cancer in my left breast almost two years ago. My case was a little unusual because I had tumors in my breast and under my arm. When he biopsied the tumor in my breast, the surgeon removed two centimeters of it and still did not get clear margins.

Kim continued, Based on the size of the tumor and my age –I was forty when I was diagnosed –the doctor decided to do chemo first, instead of surgery. They wanted to try to shrink the tumors before removing them. So, I went every three weeks for four cycles of Adriamycin and Cytoxan, and then I finished with four cycles of Taxitere. Actually, I had one cycle of Taxol and three of Taxitere.
Kim then continued, After that, I had bi-lateral mastectomies, because they had also found microcalcifications in my other breast.

Kim went on, In the meantime, I started looking for clinical trials to be in, and found one in [a west coast city].

One of the new women in attendance looked impressed with Kim’s reference to the clinical study, and then asked, What was that about?

Kim replied, For the study I received vaccine shots for HER-2. That was for seven months and I just finished participating in the study a few months ago.

Mavis, the leader then said, It’s hard to believe it’s been almost two years. But you just finished with the clinical study, so it’s really only been several months since you’ve finished everything up.

Kim smiled and nodded her head. She then said, Now the whole thing is dealing with how chemo affects your body afterwards. Have any of you noticed that chemo changes your body?

Several of the other women nodded.

Kim then launched into a discussion of how chemotherapy had resulted in changes to her hormone levels, and provided the group with exact figures from her most recent laboratory results.

Kim’s account of her illness illustrates how the women often relied on the use of clinical details to relate their experiences to other members of their groups. For example, in her story Kim emphasized the specific size of the biopsy taken from her breast, the number and frequency of her chemotherapy treatments, and the exact findings from her laboratory blood work.

The other York and Upton women told their stories in similar ways. For instance, after completing treatment, Betty, a member of York, often gave the following account of her illness:
I’m the class of 2001. My cancer was found in a routine mammogram. I had a biopsy that came back positive for invasive ductal carcinoma. Had my surgery, bi-lateral mastectomies, on Valentine’s Day. Had reconstructive surgery in August. I also did chemotherapy, just to be on the safe side. Now I’m doing just fine.

Like Kim, Betty reduced her illness experience to a diagnosis date, the “class of 2001,” and a series of medical procedures. Obviously, however, there was much more to the women’s breast cancer experiences than this, as data from their interviews often illustrated.

Compare, for instance, how Kim talked about her diagnosis in the group to the way she discussed it in her interview. From her interview:

Kim: After [my husband and I] found out [that I had cancer], oh, we didn’t even move for a few minutes. We just got in the car and went, “Whoa! What was that?”

Jackie: Do you remember what you said to each other? Or what he said to you?

Kim: I don’t remember specifically. He just said something to the effect of [pausing] –I forget. [starting to whisper] And it sounded so profound when he said it. Something like that was the worst thing he’d ever experienced in his life. That, that was the most brutal thing he’d ever sat through. In his entire life.

And it was. It was brutal. It was like, just a total shock.

Whereas Kim gave the group a sanitized version of her diagnosis and treatment, in her interview she was more revealing. As the above excerpt illustrates, both she and her husband felt overwhelmed, shocked, and afraid when she was first diagnosed with cancer. Yet, during their meetings, Kim and the other women rarely talked about these emotional responses to being sick. Rather, they continued to tell stories that emphasized the clinical details related to their illness.
Why did they choose to tell their stories in such medicalized ways? In part because it helped them to quickly inform other group members, who were familiar with the medical lingo associated with the disease, about their breast cancer experience. More importantly, giving such detached accounts of their illness allowed the women to avoid discussing the painful feelings that accompanied their disease, especially the fear and anxiety associated with the future. That the stories functioned in this way became particularly apparent when someone, usually a new member, attempted to talk about her illness in other ways.

For instance, at the Upton meeting described above, Amanda attended the group for the first time. She arrived late, however, entering the room as Kim was wrapping up her story. After Kim finished, it was my turn to introduce myself. I did so and explained why I was attending the group. Mavis, the leader, then introduced herself and indicated that Amanda should go next, saying, “You can go ahead and introduce yourself and say a little about yourself.”

Looking as if she might cry, Amanda said who she was, then went on to explain why she had decided to attend the group that night. She confessed that she had recently been worried about recurrence, and asked the other members how they dealt with such fears. From my fieldnotes:

Amanda said, My name is Amanda, and it’s been about a year and a half since I was diagnosed with breast cancer. I guess what I’m wondering is how do you keep going on? When do you ever stop worrying about if the cancer’s going to come back? It’s like every little twitch you worry that it’s cancer.

Some of the other women nodded and then Amanda said, Do you ever get to the point that you just don’t think about it anymore?
Donna who had taken her turn before Amanda came in, responded by saying, With any health problems you have, you wonder if it might be cancer. I recently had some changes with my bowels, and, of course, my oncologist wanted to have it checked out. So I had to have a colonoscopy. I didn’t think it was anything, but you still worry about it.

Amanda then said, Right now, I have these raised bumps on my chest [pointing to the right side of her chest] and down my arm. It looks like a relief map.

Mavis, who was an oncology nurse, asked, Is it like a rash?

Amanda replied, No. It looks like it’s under the skin. It looks like there’s a rope under there, or a snake, or whatever.

Mavis probed for more details, asking, Have you been to a dermatologist?

Amanda said, Yes. He’s never seen anything like it.

Several of the women moaned in response.

Members of the group then spent some time clarifying what the bumps under Amanda’s chest and arm looked like.

Pressing the women to respond to her earlier question, Amanda then said, It’s always stuff like this. It [cancer] never leaves your mind. When do you stop worrying about it?

None of the women answered Amanda’s question. Instead, Elizabeth, a long standing member of the group, used the lull in conversation to introduce herself and start telling her diagnosis and treatment story.

Because Amanda entered the meeting late, she did not know and could not follow the standard script that regular members used when telling their stories. Lacking a model to emulate and being upset when she entered the room, she thus used her turn to ask how the other women coped with the uncertainty of their disease. The women did not, however, directly respond to Amanda’s questions. Instead, they quizzed her about the bumps she had under her chest and arm, attempting to medicalize the conversation, as they usually did.
When Amanda pressed the issue, they responded to her questions with silence.

The women reacted in similar ways when other members strayed from the traditional storytelling format by broaching other uncomfortable topics of discussion. For example, at another Upton meeting, Lucy, who had been diagnosed with stage-four breast cancer and only periodically attended the group, announced that her cancer had spread to her digestive system. She then explained how this latest development had resulted in more physical pain and caused her to focus on surviving from one day to the next, rather than looking ahead to the future. From my fieldnotes:

Lucy said, I thought I had been doing better, but actually I’ve gotten worse in the last several weeks. I just found out that the cancer cells have spread to my colon, as well as to my stomach. Actually, I just learned that the cancer cells have basically spread throughout my digestive system.

I looked around the group to see how the other women were taking this news. They seemed visibly disturbed, but none of them would look at Lucy. A few said “Oh, no!” or even moaned at the news, but no one said anything directly to Lucy or tried to console her.

Lucy then continued, Right now I’m still just taking the Tamoxifen. But I want to talk to my doctor about doing something else. The doctors say that it [the Tamoxifen] is still working. But after this, I feel like maybe I need to be taking something else with it, or something else instead of the Tamoxifen. I just don’t feel like the Tamoxifen is doing much to help me at this point.

Lucy looked at Mavis when she said this, and Mavis nodded her head yes.

Lucy then said, I was talking to [the counselor at the cancer center], and I told her, “Before, I was always trying to look ahead, but now I’ve just gotten to the point where I have to focus on making it one day. I can only look at things one day at a time now. I can’t look ahead. It’s enough to just make it through one day.”

Lucy continued, I thought I had been doing better. But right now with
the cancer being in my digestive system, [pointing to stomach], I’m having a lot of problems. Some days will be okay, but other days I have a lot of pain.

At this, Lucy just stopped talking. Although she did not cry, it was evident from her facial expressions that she was upset. No one, however, responded to these visible cues or what she had said.

After an awkward pause, Lucy nodded for the next woman to take her turn.

Given the almost certain outcome of her illness, i.e., death, the women perhaps did not know what to say to Lucy, or were afraid that what they might say would sound trite. It seemed more likely, however, that they avoided discussing Lucy’s situation because of how it made them feel. Not only did it remind them of the uncertainty of their disease, but also the possibility that they too might die. This is at least one reason why the women stuck to their storytelling format. It lent a predictability to their meetings. As long as they continued to give medicalized accounts of their illness, the women could feel confident that situations, such as those with Lucy and Amanda, could be avoided. They could also be assured that they would not often be emotionally upset during their meetings.

The established format, however, also guaranteed that the same stories would be repeated ad nauseam, and that the women would not likely delve into emotionally challenging territory. This was not lost on all of them. For example, when Barbara attended Upton for the first and only time during my observation period, she approached me after the meeting and pointedly asked, “So what happens next time? Does everyone tell their story again?” As this comment suggests, Barbara recognized the limitations of the storytelling format and questioned its usefulness.

Some of the regular attendees felt the same way. For instance, in her interview, Julie,
who had participated in the Upton group for over a year, explained how she did not like the storytelling format and thought that it was a waste of time. She said:

Now the second time I came, I thought, “Is this what we’re going to do every time? Go over the same thing of your story, the whole story, and nothing but stories? Or are we going to talk about what’s going on now?” And by the third time I came, I thought, “I’m not sure I’m going to come back, if I keep hearing the same damn stories every time.”

Julie did, however, continue to attend the group. She even tried to change how the women used their time together.

On several occasions, she and another member, Michelle, refrained from telling their stories and instead brought up issues with which they were currently struggling. The other women appeared to respond somewhat positively to their efforts, and it seemed, at least for a short time, that the meeting format was starting to change. Before long, however, the women fell back into their storytelling routine.

It was much the same with the York group. These women likewise shared diagnosis and treatment stories during their meetings. Although they were not as wedded to the storytelling format as the Upton women –sometimes, for example, they had thematic sessions, such as, “Taking care of yourself during treatment” or “How to cope during the holidays” – they still medicalized their discussions and avoided talking about the uncertainty associated with their disease. When someone ventured into that territory, the other women responded as did the Upton members. They either remained silent or attempted to change the subject.

For instance, at one meeting, Isabella, who had finished treatment but continued to
struggle with the emotional fallout of the disease, tried to engage the women in a discussion about the emotional pain that breast cancer inflicts on its victims. From my fieldnotes:

Isabella said, I was thinking about the other women that started about the same time that I did [giving some names as examples]. And they all seem to be doing fine. They’ve gotten on with things. You don’t see them still coming to support group. But, for me, sometimes I feel like I’m doing fine. Then there are these spots, they’re like open wounds, that are still there [pointing to her heart, like the wounds were on the inside]. It’s like they’re still open and they still hurt.

Some of the other women nodded in agreement, but did not say anything in response.

Isabella continued, And I look at the other women, and they seem to be doing fine, and I think, “What’s wrong with me? Why am I still coming to support group?”

Sarah then jumped into the conversation, saying, But, you know, I think you need to have some older people in the support group. It’s good to have people who are further along [in the treatment process or finished with treatment]. They give hope to others. We can give each other encouragement.

Deborah, the leader, agreed, saying, I think that’s true, although there are people who say you should have a support group with all women that were diagnosed at the same time.

Sarah, Deborah, and a couple of the other women then started reminiscing about old members, saying things like, “Oh, remember so-and-so?” and “Have you seen her recently?”

Once this got started, no one ever came back to Isabella’s concerns about coping with the “open wounds” associated with having breast cancer.

Although Isabella looked somewhat stunned that the women ignored her comments, she did not say anything about it. But she did stop attending meetings shortly thereafter.

As this would suggest, the groups did not work equally well for all of the women.
Some of them, like Julie, Michelle, and Isabella, grew tired of the storytelling format and pushed for the groups to move in a more therapeutic direction. However, as previously discussed, the groups generally did not have the resources to make such changes. The leader of Upton was an oncology nurse, not a trained counselor. She therefore lacked the skills and training to facilitate the group in a therapeutic way. The leader of York, while a psychological counselor, often lacked commitment to the group, frequently letting others facilitate, or cancelling meetings when she could not or did not want to attend. This likely contributed to the group’s high membership turnover, as well as to the women’s reluctance to invest emotionally in the group.

In addition, the cancer centers with which both Upton and York were affiliated segregated advanced-stage patients into separate groups. Members of the two groups thus rarely met with women (like Lucy) who were severely ill or likely to die of breast cancer. As later analysis will show, this helps to explain why these women were generally able to maintain such a positive perspective on their disease. They interacted primarily with women like themselves, who had favorable prognoses and were optimistic about recovery. For women like this, the storytelling format mostly worked. While it was sometimes boring, it allowed them to share their experiences with one another and enjoy the camaraderie of the groups, without being forced to discuss the uncomfortable emotions associated with their disease.

Storytelling therefore functioned like the sexualized joking discussed in the previous chapter. It allowed the women to avoid talking about painful emotions associated with their illness. In this case, storytelling helped them to avoid discussing the fear and anxiety they
experienced about recurrence and the possibility of death. More importantly, however, talking about their illness in clinical ways helped the women to view their disease as a series of medical procedures—over which they and their doctors could exercise control. Giving medicalized accounts of their illness was thus one strategy the women used to help them cope with the uncertainty of the future and regain a sense of control over their lives after having faced a life-threatening disease.

Storytelling also helped the women in other ways. For example, it allowed them to present their illness as something over which they had triumphed. By narratively locating breast cancer in the past, the women could embrace the identity of breast cancer survivor. Doing so helped them to see themselves not as victims of an unfair disease, but as women who had endured and overcome a traumatic life event. As the next section will show, however, the survivorship rhetoric was sometimes problematic. Some of the women questioned its usefulness, especially when all breast cancer patients were encouraged to take on the identity. Others struggled with what the term implied about women who had died from the disease.

**TAKING ON THE IDENTITY OF SURVIVOR**

In 1985 Zeneca Pharmaceuticals (now AstraZeneca) declared October “Breast Cancer Awareness Month” (Sellman 2005). Since that time, groups and organizations serving breast cancer patients, as well as those attempting to treat and prevent the illness, have created a culture around the disease. This culture, as discussed in previous chapters, emphasizes breast cancer awareness, positive and upbeat attitudes for breast cancer patients, and the hiding of
illness (Ehrenreich 2001; Klawiter 1999). It also honors those who have survived the disease (Ehrenreich 2001). In fact, “breast cancer survivors” are celebrated within the culture in a number of ways.

For instance, Komen Foundation-sponsored Race for the Cure events (5K walk/run events held to raise breast cancer “awareness” and money for breast cancer research) typically culminate in a celebratory survivors’ march. I attended my first Race for the Cure in the summer of 2002 and saw how the survivors’ march is used to publicly recognize and label women who have had the disease as “breast cancer survivors.” During this march hundreds of women paraded around a large field, as bystanders cheered them on. From my fieldnotes:

Sometime after most of the participants had completed the race, an announcement was made from the center stage. All “survivors” were asked to gather on one side of the field for a procession. Hundreds of women wearing pink t-shirts, which distinguished them from other race participants who had on white shirts, gathered together on one side of the field.

It took quite a while for all of the women to get organized, but eventually they started walking towards the center stage. As the line came by where I was standing, I noticed that the women were grouped according to when they had been diagnosed and treated for breast cancer.

Those in front, a few of whom had bald heads, which I assumed was a side effect from chemotherapy, had signs that read anywhere from 1-11 months. As the line progressed, I saw that there were signs for women who were 1-, 2-, 3-, or more year survivors. At the end of the line, there were even a few women who had been diagnosed as many as 30 years prior.

As the women passed by, many waved pink pom-poms that had been handed out earlier in the day. Spectators in the crowd also waved the pom-poms and clapped and cheered, especially when someone they knew walked by. Applause also increased when those at the end of the line (who were long-time survivors) walked past.
When the women finally made it to the center stage, the announcer congratulated them on their survivor status. She then requested a moment of silence, after which a number of doves were released into the air. At this, the women and the crowd began wildly cheering again.

As the description of this event illustrates, survivorship, at least within the mainstream breast cancer culture, is seen as worthy of honor and public celebration. Women who have been diagnosed and treated for the disease are thus encouraged to identify themselves as “breast cancer survivors” and keep track of the length of time that has passed since their initial diagnosis.

The women in this study, many of whom participated in the Race for the Cure event described above, were no exception. When members of York and Upton told their breast cancer stories, they were expected to report when they had been diagnosed and reveal how much time had since elapsed—just as at the survivors’ march. In addition, when they told their stories, many of the women identified themselves as six-month, one-year, or longer-term survivors. For example, whenever Kim, mentioned earlier, introduced herself to other members of the Upton group, she usually identified herself as a “breast cancer survivor,” as the following representative fieldnote excerpt shows.

When it was Kim’s turn to introduce herself, she said, I was diagnosed when I was 40 years old. Because of the type of tumors I had under my arm and in my breast, I had to have chemotherapy first. Then I had double mastectomies. After that, I participated in a clinical study, which I just finished recently. Now, I am a two-year breast cancer survivor.

As this example illustrates, Kim embraced the identity of survivor. Other women from Upton and York did the same.

The women also marked survivorhood by celebrating important days relative to their
diagnosis and treatment. For instance, at one York meeting, Mildred, a white woman in her early 50's, announced that the day marked the one-year anniversary of her diagnosis. After sharing this information with the group, she proclaimed, “I am a one-year breast cancer survivor!” This comment elicited cheers, applause, and congratulatory comments. Mildred, clearly pleased with the praise and (understandably) happy to be celebrating this milestone, smiled and nodded in response.

These two examples show how the rhetoric of survivorship was an accepted part of group meetings. Even I was expected to use it. For instance, I gained entry into all four support groups in part because the leaders and participants knew that my mother had been diagnosed with and treated for breast cancer. Therefore, I was generally introduced to new members as the daughter of a survivor\(^7\), and, especially at York, often expected to give a brief account of my connection to the disease. The following fieldnote excerpt serves as an illustrative example. From my fieldnotes:

Deborah then introduced me to the group. Seemingly for the benefit of the new members in attendance, she added, Jackie’s mother is a breast cancer survivor, which is how she got interested in studying the group.

She then added, Jackie, Why don’t you tell the new members about your mother?

Feeling somewhat put on the spot, I responded, Like Deborah said, my mother is a breast cancer survivor, which is one of the reasons why I got interested in studying breast cancer support groups.

Connie, one of the new women in attendance, then asked me, How is your mother doing now?

I replied, She’s doing fine. Actually, she just celebrated her eleven-year anniversary of being cancer-free.
A few of the women made comments, such as, “That’s great!” Then almost all of them started clapping.

I could feel my face turning red from the unwanted attention, and was particularly embarrassed by the clapping.

The women politely ignored my embarrassment and then Deborah said, She’s an eleven-year survivor? I didn’t realize it had been that long. That’s great.75

I replied, Yes. She’s an eleven-year survivor.

Similar incidents occurred at York and the other three support groups. In almost every case, I was usually prompted or felt obligated to refer to my mother as a survivor, even though I had misgivings about doing so.76

The rhetoric of survivorhood served several functions in the support groups. First, it allowed members to be recognized for triumphing over their disease. In other words, calling themselves survivors was a way for the women to signify that they had “won the breast cancer battle.” Second, the presence of women who proclaimed themselves survivors gave other women hope that they too would survive their disease. Any woman, whether a few months into treatment or many years beyond it, could be held up as a survivor. Non-survivorhood – death – was kept at a distance.

Some of the women, nonetheless, had misgivings about using the survivor rhetoric. Several voiced frustration over not knowing when they could embrace the identity. They questioned, for instance, at what point they could be considered survivors: Was it after being diagnosed? Only after completing treatment? Or did it have to be years after being cancer-free? Other women disliked the term because of what it implied about those who had died from the disease. For example, were these women’s struggles less important? Or were they
any less heroic for not having survived? Finally, at least some of the women did not like the label of survivor, as they did not want to be known by or saddled with it for the rest of their lives.

Several examples illustrate these points. The first comes from a discussion the York women had concerning exactly when a breast cancer patient becomes a survivor. As this excerpt shows, some of the women struggled with when (or even if) they should embrace the identity. It also illustrates how the leader of the group adopted and attempted to reinforce the mainstream breast cancer culture’s view of the issue: any woman who has been diagnosed with breast cancer is a survivor. From my fieldnotes:

Early in the meetings Deborah made an announcement about an upcoming event for breast cancer survivors taking place at the York cancer center. This caused the women to engage in a discussion about what constituted a “breast cancer survivor.”

After Deborah made the announcement, Connie said, I’ve always wondered what they mean by survivor. Who does that include? Do you have to have completed treatment to be a survivor?

Several of the women shook their heads no and then Annette responded, I don’t think you have to have completed treatment to go to the survivor’s events.

Connie replied, I know that. But I mean, when are you supposed to become a survivor? How do they determine that?

Helen joined in the conversation saying, Well, you often hear doctors say that you want to make it to that five year mark. If you can survive for five years, that’s supposed to mean that your chances of having a recurrence are decreased.77

Deborah then said, Yes. But I don’t think you have to wait five years to be a survivor. From the minute you are diagnosed you are surviving. Every woman who is diagnosed with breast cancer is a survivor. You are fighting the disease from the very beginning.
You are doing your best to survive.

Deborah continued, That’s like [a friend of hers, with whom the other women were familiar]. As long as I’ve known her, she’s been fighting the disease. She keeps having recurrences and it seems like she’s always in chemo. But she’s still a survivor. She’s doing everything she can to survive.

Betty then asked, But what about the women who die?

Deborah said, They’re survivors. They fight their disease until the end.

Betty, especially, seemed dissatisfied with this answer, but the women did not pursue the conversation further.

As this excerpt shows, the women wrestled with the meaning of survivor. And, at least some of them, such as Betty, did not like how the term diverted attention away from those who had died from the disease.

Barbara Ehrenreich (2001), who is critical of how the mainstream breast cancer culture honors survivors, often at the expense of ignoring those who have died, shares this concern. She writes:

For those who cease to be survivors and join the more than 40,000 American women who succumb to breast cancer each year – again no noun applies. They are said to have “lost their battle” and may be memorialized by photographs carried at races for the cure – our lost, brave sisters, our fallen soldiers. But in the overwhelmingly Darwinian culture that has grown up around breast cancer, martyrs count for little: it is the “survivors” who merit constant honor and acclaim (Ehrenreich, 2001:48).

Although Betty and some of the other women may have disliked the use of survivorship rhetoric, they were, unlike Ehrenreich, generally unable to articulate why they found it problematic.
For example, at another York meeting, Angie became agitated when Deborah and several other members of the group insisted on referring to women who had had breast cancer as survivors. Yet when pressed to explain why she did not like the term, she could not. Instead, she replied, “I don’t know why. I just know I don’t like it, and there are other people who don’t like it, too.” Some of the women in attendance seemed annoyed with Angie’s answer, rolling their eyes or sighing in response. Deborah then said that, “While the word may not be perfect, it’s the best we’ve got,” and suggested that Angie “learn to get used to it.”

One-on-one, where perhaps they felt free to be more candid with their views, a few of the women voiced other concerns about the survivorship rhetoric. For instance, some of them mentioned that they did not want to be stuck with the identity for the rest of their lives. Gladys, a member of Upton, is an example. In her interview, she explained how she did not want to wear the pink ribbons associated with “breast cancer awareness,” because she did not like the idea of being known primarily as a breast cancer survivor. She said:

And I haven’t wanted to wear one of the [pink breast cancer awareness] ribbons. And I can’t explain it. Other than to me it says that I’m a cancer survivor. But when are you really a survivor? After five years?

Gladys continued, My friend in Florida even sent me a real pretty little pink ribbon [pin] with the pink stones in it. But I really don’t wanna wear it. Then, I thought about it some more, and I even told the oncologist about it. And I said, [to him], “You know, it’s been a year now. I am a survivor. I may have only survived one year, but I can claim this acclaim to fame here.”

After a short pause, Gladys then said, But I have a different feeling about it. I guess I get hung up on funny little things. I just don’t want to wear one [pink ribbon] or be known that way [as a breast cancer survivor].

As this interview excerpt shows, Gladys, like the York women mentioned above, struggled
with the meaning of survivor. She questioned, for instance, when a cancer patient became a cancer survivor and doubted, even after a year, whether the identity truly applied to her. Yet even if the label of breast cancer survivor did rightfully belong to Gladys, she did not want to be viewed, at least by some audiences, as such. But, like Angie, she was unable to articulate exactly why she found the identity troublesome, concluding only that she did not want to be “known that way.” Given the pervasiveness of the survivorship rhetoric and how widely accepted it was within the mainstream breast cancer culture, including the groups in which these women participated, it is not surprising that this was the case. Gladys and other group members were generally discouraged from challenging the rhetoric. When they attempted to do so, they were often chastised by others, especially the leaders, who encouraged them to embrace the identity of survivor.

Taking on the identity of survivor still proved useful to most of the members of the groups. As the preceding analysis has shown, embracing the identity allowed the women to see themselves in a positive light. For example, by claiming the identity of survivor, members of the groups were able to view themselves as strong women who had overcome a traumatic life event. This image of themselves was far more favorable than some of the alternatives, such as, seeing themselves as victims of an unfair disease, or as “damaged” women who were no longer worthy of admiration, respect, or love. Redefining themselves as survivors was thus one strategy the women used to help them cope with a stigmatizing identity (i.e., breast cancer patient).

The leaders of the groups used the rhetoric in similar ways. As earlier examples illustrated, by referring to all group members as survivors, regardless of when they had been
diagnosed or if they were still completing treatment, the leaders reinforced the view that all breast cancer patients were to be admired and honored for what they had been or were going through. Should the women ever question this view, the leaders used the rhetoric in other ways. As earlier examples showed, they often held up long-term survivors as examples of women who had persevered and triumphed over the disease. The implication here was that members of their groups could hope to do the same.

As this would suggest, the survivorship rhetoric, although certainly problematic, helped the women to see themselves in a favorable light, after having faced a life-threatening and physically disfiguring disease. It also allowed them to reevaluate their breast cancer experience. For example, after completing treatment and realizing in all likelihood that they would survive, the women were able to redefine their illness in generally positive ways. As the following discussion will show, the women learned to view their disease as a blessing. This, in turn, helped them come to terms with what they had been through.

DEFINING BREAST CANCER AS A BLESSING

After completing treatment, the women in this study struggled to find meaning in their illness experience. Many questioned why they had to endure such pain and suffering, and sought ways to justify what they had been through. One way the women dealt with these problems was to redefine their illness as a blessing. Having had breast cancer, the women came to believe, made them stronger people with a fuller appreciation for life. It also led to other changes in their lives, they argued, that would have likely not happened otherwise.

Sarah, a long-time member of York, is an example. At one group meeting she...
explained how being sick forced her to take the time to notice the “small things” and better appreciate the life she had been given. From my fieldnotes:

Someone in the group then mentioned how being ill helps you to appreciate the small things in life. This led Sarah to tell the following story.

She said, When I was sick, a friend of mine gave me a journal and told me to write five things in it that I was grateful for everyday. This was after I had started chemo. And one day I was sitting on the patio pulling out my hair. (Sarah made motions like she was pulling out handfuls of hair.) And I was throwing it down, thinking, “Well, maybe the birds can use it.”

She and several of the other women laughed at this.

Sarah then continued, saying, And while I was sitting there, I looked down and started watching this little ant. And have you ever watched ants? They are incredible. They are these tiny little things and they carry and move things that are huge (making a motion with her arms wide apart). Ants carry things like crickets that are way bigger than they are. I mean ants are amazing.

While she was saying this, Deborah, the leader, apparently seeing where the story was headed, started to smile.

Sarah then went on, And I got to thinking if that ant can take on something so much bigger than it, so could I. So, I wrote that in my journal. And I just thought, if I hadn’t have been sick and sitting out there, I never would have taken the time to watch an ant.

Sarah concluded, There’s so many things to be grateful for, if we just take the time to notice them. Having been sick gave me the opportunity to really see how precious life is.

Deborah then said, Yes, it does make you reflect on and recognize the precariousness of life.

Sarah then said, And now everyday, I still try to write five things in my journal that I’m thankful for.

Being diagnosed with breast cancer forced the women to face their own mortality. While contemplating the possibility of death resulted in significant emotional suffering, as previous
discussion has shown, it also led many of the women, like Sarah, to reevaluate their lives and try to become better people, that is, women who did not take life for granted.

This was a theme that was repeated throughout many of the women’s interviews. For instance, Carol, a member of Hogart, also explained how her cancer diagnosis led her to be more appreciative of life. From her interview:

Carol: Getting cancer caused me to step back and really look at my life.

Jackie: In what sense?

Carol: It made me see that I took it [my life] for granted.

Jackie: I’ve heard a lot of women say that the experience really changes their perspective on life. Did you feel that way?

Carol: Yes. I took my life for granted. You don't think about it until you go through something like that.

Jackie: Are there specific ways you feel like it has changed your life?

Carol: Yes. [Before I had cancer], I would work two jobs and on my days off I wouldn’t even go outside. [And one day, when I was sick,] I was resting at my mom's house and through the window, I could see this tree. There's a big tree at the people's house across the street and the wind had it blowing back and forth. And as I watched that tree, God told me, “I gave you all of that and you have taken it for granted.”

So ever since then I don't care if there's snow on the ground, ice, I come outside. And I just take air in, you know, just breathe. Listen to the wind, the rain, because it is not promised to me.

As this excerpt illustrates, Carol came to see breast cancer as an experience through which she was able to transform her life. Like Sarah, she believed that, despite the pain and suffering she had been through, her illness had changed her life for the better. She claimed to no longer take life for granted, and learned to appreciate things she had previously ignored,
such as the wind blowing through the branches of a tree.79

Many of the other women reported learning similar lessons as a result of their illness. Some echoed Carol’s and Sarah’s sentiments, saying that having cancer made them more appreciative of life. Others claimed that having breast cancer led them to be more compassionate people, especially to others who were suffering. This is best illustrated by a conversation some of the Upton women had at one of their group meetings. From my fieldnotes:

After sharing her story with the group, Gladys said, Now that I’ve completed treatment and am starting to feel better, I’ve had time to think about how this experience has changed me.

She continued, I really think I’m starting to redevelop my sense of compassion. I mean, you go through all this, and you’re so thankful, and you’re so grateful for your friends, and for making it through. It changes how you see things. And you feel more compassion for other people who are suffering like you did.

Gladys then sighed and said, And I just pray that this is going to last. But we’re all human. So, you know it’s going to sluff off some.

Donna responded, I think once you’ve gone through something like this [breast cancer] you’ll always be a changed person. It makes you more compassionate for others, because you can imagine what they are going through.

Michelle joined in saying, I think so, too. It’s not that I would want to have cancer again, if I had things to do over, but I know that this experience has changed me, and I’m a better person for it.

While these women agreed that having breast cancer was one of the most difficult events of their lives, they also concluded that it had changed them in positive ways. As Gladys, Donna, and Michelle’s comments illustrate, the women believed that they had become better people
(i.e., more compassionate) as a result of their disease.

The women realized, however, that while these lessons were meaningful to them, they might seem obvious or clichéd to outsiders. For example, at one York meeting, Hazel declared, “These are all things we know. Life is precious. You should really live each day. Seize the moment.” She then went on to conclude, “The real test is if we change our lives in the long run, or if we just let things go back to the way they were before [cancer].”

Hazel’s comments help to illustrate that the women wanted their illness and the suffering it caused not to have been in vain. Therefore, they often emphasized the ways in which cancer had led to long-lasting, positive consequences in their lives. For example, Sarah, mentioned above, claimed that having breast cancer not only caused her to be more appreciative of life, but also served as a catalyst for other major life changes. More specifically, after being diagnosed with and treated for the disease, she and her husband retired from stressful jobs, relocated to be closer to family, and started spending more time with their daughter and grandchildren. According to Sarah, had she not been diagnosed with cancer, she would not have considered making these life changes at that point in time.80

Betty, another member of York, saw her illness in a similar way. It led to changes that, she argued, would not have occurred otherwise. For instance, after being diagnosed with breast cancer, Betty’s marriage, which had been unstable for years, finally came to end.81 Having married at a young age and been a stay-at-home mother for most of her adult life, she had never lived by herself, worked outside the home, or enjoyed much independence. All of this changed after her illness and divorce. She found a job, a new place to live, and started establishing a life on her own, changes which she saw as positive, albeit difficult, and directly
related to her cancer diagnosis.

While not all of the women experienced radical life changes such as these, almost all of them could point to specific ways that breast cancer had changed their lives for the better. And, like Sarah and Betty, many of them came to believe that these changes would have been unlikely had they not become ill. In other words, the women came to see these positive outcomes as direct consequences of having had breast cancer. This, in turn, helped them to believe that they had not suffered needlessly. It also, as the above discussion has shown, allowed them to conclude that breast cancer, had, in fact, been a blessing in their lives.

According to Sandstrom (1998) and Stanley (1999), this is a common reaction among people who experience life-threatening illnesses. The authors show, for example, how people with HIV/AIDS view their illness as a gift or blessing, as a way to justify the pain and suffering they have endured and to value the illness as a transformative experience. The women in this study used a similar strategy to redefine the meaning of breast cancer. By emphasizing how breast cancer resulted in positive life changes, they were able to believe that their disease had served a meaningful purpose in their lives. They were also able to see themselves as stronger, more appreciative people as a result.

CONCLUSION

As this chapter has shown, members of Upton, York, Hogart, and Bellesmith continued to experience emotional fallout long after completing treatment. They felt anxious about the future, fearing that their cancer would one day come back, and, if it did, that they would die. Unfortunately, they often lacked the kind of support from family and friends that
would have helped them deal with these uncomfortable emotions. Therefore, they turned to their support groups for help. Here, the women learned strategies for coping with the uncertainty associated with their disease, as well as ways to reconstruct their illness and themselves in a positive light.

These strategies included learning to create and tell medicalized stories about their breast cancer diagnosis and treatment, taking on the identity of breast cancer survivor, and redefining their breast cancer experience as a blessing. As the analysis in this chapter has shown, these strategies helped the women to regain a sense of control over their lives. For example, by telling stories that focused on the clinical details of their illness, the women were able to present their disease as something over which they and their doctors ultimately had control. Furthermore, by narratively locating breast cancer in the past, the women were able to embrace the identity of breast cancer survivor. Doing so helped them to see themselves not as victims of an unfair disease, but as women who had endured and overcome a traumatic life event. This, in turn, allowed them to eventually define their illness as a meaningful experience and themselves as better people for having gone through it.

At the same time, these strategies discouraged the women from seeing breast cancer as a social or political issue. By embracing the rhetoric of survivorhood, for example, members of the groups rendered invisible the over 40,000 women who die from the disease annually in the United States. The environmental causes of these deaths, also remained obscured. In addition, by redefining their illness as a blessing, the women diverted attention away from the suffering and pain associated with their disease. As Ehrenreich (2001) points out, these practices serve to create and reinforce a breast cancer culture that focuses on
individual survivors and their triumphs, rather than indignation and collective action in response to the disease.
Chapter Five

CONCLUSION

I began this project seeking to understand how women coped with the emotions evoked by breast cancer. My strategy was to study women in four breast cancer support groups to learn how they interactively managed their feelings. As my fieldwork progressed, I saw that what the women could do in their groups was limited in a number of ways. For example, the skills and resources that they brought with them influenced the kinds of coping strategies they were able to use. Cultural ideas about how women are supposed to look and act also affected how these women responded to and coped with their illness. Similarly, cultural norms concerning the presentation of emotions affected how the women expressed and dealt with the uncomfortable feelings they experienced. As the findings and analysis in previous chapters have shown, what the women did individually and collectively was very much shaped by a context of economic and gender inequality.

The women’s responses to their illness were also shaped by the mainstream breast cancer culture. As discussed throughout the preceding chapters, this culture, which has been created by organizations such as the Komen Foundation and others affiliated with the disease, discourages the expression of anger or indignation. By celebrating survivors, it also downplays the suffering and death associated with the disease. This too had an impact on how the women helped one another cope. Put differently, how they managed the uncomfortable emotions evoked by their illness was dependent, in part, on the values and beliefs embraced and promoted by groups and organizations that have created a culture around the disease.
In this chapter, I will discuss the implications of these findings in greater detail, and show how they connect to the larger bodies of literature to which they contribute. More precisely, I will explain how the findings and analysis from this project add to our understanding of (1) how support groups help people interactively cope with difficult and stigmatizing life events; (2) how gender and gender inequality affect how support group participants are able to help one another cope; and (3) how the emotion-work strategies that these individuals use to cope with illness can be influenced and constrained by a culture of disease. Finally, I will assess the strengths and weaknesses of this study, as well as discuss avenues for future research.

COPING WITH DIFFICULT LIFE EVENTS

The women in this study experienced intense feelings of discomfort as a result of their disease. When first diagnosed, they feared that they would die and worried about what would happen to their families if they did. As they underwent treatment, the women’s concerns shifted. After surgery, they struggled with the disfiguring effects of their illness, and feared that they were no longer physically or sexually attractive. Even after completing treatment, they continued to face the emotional fallout of their disease. The women struggled with the uncertainty of the future and tried to find meaning in what they had been through. As this would suggest (and as previous discussion has shown), being diagnosed with breast cancer is a difficult life event that profoundly disrupts women’s emotional equilibrium and feelings of control.

What can we learn from the foregoing analysis of how these women coped with the
emotional fallout of their disease? First, unlike previous research, which has focused almost exclusively on how individuals cope (see Pearlin [1989] and Thoits [1995] for reviews of this literature), the present study shows how support groups allow people to cope collectively with difficult life events. In so doing, it makes clear the social nature of the coping process. Second, the present study adds to our understanding of how gender can influence the ways women cope. More specifically, it shows how support group leaders, by embracing gender ideologies, can limit their participants’ success in dealing with difficult emotions. Finally, this study illustrates how the culture that has been created around breast cancer has served to trivialize the pain and suffering of the disease, and has thus constrained how women are able to respond to and cope with it. In the following sections, I will discuss these points in greater detail, showing how they add to existing literature on coping and our understanding of the coping process.

**Stress and Coping**

Psychologists and medical sociologists have long been fascinated with the concept of stress. Using the term to refer to environmental, social, or internal demands that evoke feelings of unease and cause individuals to readjust their usual behavior patterns (Thoits, 1995,1986; Pearlin 1989; Lazarus and Folkman 1984), these researchers have attempted to understand how individuals deal with difficult events or circumstances in their lives. Early work in the area focused on how people adjust to life changes, such as marriage, problems with a boss, or the death of a spouse (Selye 1982; Holmes and Rahe 1967). Later research attempted to categorize these events, recognizing that different sources of stress affect people
in different ways (Pearlin 1989). Pearlin (1989), for instance, identifies two types of 
sstressors, difficult life events (e.g., being diagnosed with a serious illness) and chronic strains 
(e.g., dealing with a difficult job). Other researchers (Thoits 1995; Kanner et al. 1981) 
include a third type, which they call the daily hassles of life (“mini-events” that occur through 
the course of a day, forcing a person to readjust in small ways, such as having to deal with 
heavy traffic).

Of these stressors, researchers have focused primarily on difficult life events and 
chronic strains (Young 2004; Thoits 1995). In so doing, they have sought to better 
understand how people cope with these challenging events and circumstances in their lives. 
They have also attempted to identify the types of resources that people draw upon to help 
them cope (Thoits 1995; House, Landis, and Umberson 1988; Cohen and Wills 1985; 
Folkman 1984; Berkman 1984; Lazarus 1966). Thoits (1995) describes these resources as 
the “social and personal characteristics” that make it easier or harder for people to deal with 
their problems. Much of the stress and coping literature has focused on three such resources. 
These include social support, a sense of control (or mastery over life), and self-esteem (Thoits 

Although defined and measured in many different ways, social support generally 
refers to the “social ‘fund’ from which people may draw when handling stressors” (Thoits 
1995:64). Most often discussed in the literature are the kinds of support that people are able 
to access from those around them, especially their family and friends. Berkman (1984), for 
example, identifies three types of support that can be exchanged between people, including 
emotional, instrumental, and financial support. She (Berkman 1984) and others (Thoits
1995; Cohen and Wills 1985; House et al. 1988; Caplan 1974) go on to explain that these kinds of resources serve to buffer the deleterious effects of stress, thus helping people to better cope. However, they do not discuss exactly how this is the case. Rather, these researchers seem more concerned with the positive outcomes that social support can have on physical and mental health (see for example, House et al. 1988; Cohen and Wills 1985; Berkman 1984; Caplan 1974).

The same has been true of those who study other coping resources, such as a sense of control (mastery over life) and self-esteem. These researchers have focused primarily on the positive effects that such resources can have on physical and mental well-being. Although, for example, there is some minor debate in the literature (see Thoits[1995], for a review), most researchers have found that a sense of personal control —that is, feeling like one can master, control, or effectively alter one’s environment — reduces the psychological distress associated with stressful events, and thus buffers the harmful effects that they can have on physical and mental health (Thoits 1995; Turner and Roszell 1994; Rodin 1986). Similarly, self-esteem, or feeling confident in one’s abilities to deal with the stress and strains of life, has been found to mediate their harmful effects (Thoits 1995; Turner and Roszell 1994; Kaplan, Robbins, and Martin 1983).

As Folkman (1984) and others (Lazarus and Folkman 1984; Pearlin and Schooler 1978) have discussed, the kinds of resources that people have to help them cope with the stress in their lives also influence the types of strategies they use to manage it. For example, these researchers argue that people who feel in control of difficult situations and are confident that they can cope with them, are more likely to use problem-based strategies
The literature on stress and coping, as the above overview illustrates, provides a starting point for understanding how people deal with chronic strains and difficult life events. It illustrates, for example, that the resources people have available to them influence how

(Folkman 1984; Lazarus and Folkman 1984), that is, techniques that aim to alter or eliminate the source of stress (Pearlin and Schooler 1978). When individuals feel less confident or perceive a problem to be outside of their control, they are more likely to make use of emotion-based strategies (Folkman 1984; Lazarus and Folkman 1984; Pearlin and Schooler 1978; Lazarus 1966). Some of these strategies are cognitive in nature, that is, they involve neutralizing a threat by changing its meaning (e.g., by making positive comparisons or finding positive value in negative events [Lazarus and Folkman 1984; Pearlin and Schooler 1978]).

Other emotion-based strategies do not attempt to change the meaning of an event directly. Rather, they help people “screen out” the negative feelings associated with the source of stress (e.g., by avoiding the problem or denying that it exists [Lazarus and Folkman 1984]). The general consensus among many in the area is that these latter types of strategies are largely ineffective (Thoits 1995; Lazarus and Folkman 1984; Perlin and Schooler 1978). However, not all research has proven this to be the case. Some studies have found that strategies such as avoidance and denial can be useful for coping, at least in the short term (Thoits 1995; Aneshensel and Huba 1983). Others have found that individuals often use these types of strategies in conjunction with cognitive and/or problem-based ones (Clark 1994; Aneshensel and Huba 1983). People thus use different types of coping strategies in different situations, with varying results.
they perceive and experience the stressful events and/or circumstances in their lives. It also shows how these resources affect the types of strategies that people use for coping, as well as how successful they are in using them. The experiences of the women in this study corroborate these findings. As discussed in earlier chapters, the resources that the women had available to them affected the types of coping strategies that they used, in addition to how well they were able to mitigate some of the uncomfortable emotions they experienced.

But this is only part of the analytic story. To understand how the women in this study dealt with such a difficult life event, it is important to recognize that they learned to cope collectively with their disease. And it is here that the stress and coping literature falls short. Existing research in the area does not give much insight into the processes through which people learn to help one another cope with the stressful circumstances or events in their lives. Although this has long been identified as a problem with this body of literature, it continues to be ignored. In an overview essay, Pearlin (1989), for example, argues that most of research in the area presents coping as taking place in a social vacuum, and goes on to implore researchers to remedy this problem. Even so, work in the area continues to be criticized for focusing more on the outcomes of various coping strategies than on the processes through which they occur (Young 2004; Thoits 1995).

In other words, because these researchers have been so myopically focused on outcomes, they have largely ignored the social processes through which people are able to manage the uncomfortable emotions evoked by the stressors in their lives. They have also failed to discuss, at least in any detail, exactly how people work together to help one another cope. These are issues, however, that have been addressed, in part, by researchers in other
areas. Those interested in the sociology of emotions, for example, have examined some of the processes through which people learn to manage their own and others’ emotions (Thoits 1996; Francis 1994; James 1989; Hochschild 1983, 1979). Those who study support groups have built on this body of research by showing how such groups allow people to cope with trouble through interaction with others in similar straits (Erickson 1997; Francis 1997a, 1997b; Rieff 1987). In what follows, I will show how my findings add to these bodies of research by yielding insight into the interactive management of illness-related emotions.

**Emotion Management**

Although their focus is not explicitly on stress or the coping process, many sociologists have studied how people deal with uncomfortable or undesirable emotions. Coming from an interactionist perspective, many of these researchers have drawn upon the early work of Arlie Hochschild (1979), who first introduced the concept of emotion work. Using the idea to refer to the act of “trying to change in degree or quality an emotion or feeling” (1979:561), the author developed a theoretical framework for understanding how people learn to shape or suppress their feelings. She then went on to apply her ideas to service workers, showing how airline attendants and bill collectors manage the uncomfortable feelings evoked by difficult customers, as well as how they learn to display “corporately mandated” feelings (Hochschild, 1983). Much of the research on emotion management has followed in this tradition, examining how employees manage their feelings as they interact with others in or connected to the workplace (see, for example, Sanders 2005; Harlow 2003; Fine 1996; Pierce 1995; Leidner 1993; Tolich 1993; Ghidina 1992; Paules
Subsequent work in the area has expanded upon Hochschild’s ideas. Other researchers, for example, have explained how people learn to regulate not only their own emotions but those of others. For instance, Cahill and Eggleston (1994) discuss how wheelchair users, in their attempts to negotiate their way through an able-bodied world, learn to manage their own and others’ feelings of embarrassment and anger. Additional studies have examined similar phenomena, including Smith and Kleinman’s (1989) study of medical students, Rafaeli and Sutton’s (1991) research on criminal investigators and bill collectors, and Lois’s (2001a, 2001b) work on a volunteer search and rescue team, among others (Schweingruber and Berns 2005; Garot 2004; Holyfield and Jonas 2003; Cahill 1999; Thoits 1996). Although these researchers studied different kinds of people, coping with different types of uncomfortable feelings, they reached a similar conclusion: that emotion management helps people to transform their own and others’ feelings of unease into ones that are less upsetting and less disruptive of tasks at hand.

Some situations, however, evoke such strong emotions that individuals are forced to seek professional help. Thoits (1986, 1985) and Francis (1997a, 1997b), for instance, discuss how people turn to support groups for help with coping, especially when the source of their uncomfortable feelings is largely beyond their control. For example, people are likely to seek out support groups when facing problems such as the death of a spouse (Francis 1997a, 1997b), divorce (Francis 1997a, 1997b), addiction (Rossol 2001; Denzin 1998), illness (Sandstrom 1996; Karp 1992), or other situations that threaten their sense of self (Wolkomir 2001a, 2001b; Taylor 2000; Mason-Shrock 1996). Such groups, according to Francis, allow
people to interactively manage the uncomfortable emotions that they are experiencing, a process that she has labeled “interpersonal emotion management” (1997a, 1997b).85

In her research on divorce and bereavement support groups, Francis uses the concept to show how such groups helped members to redefine the event of “spousal loss,” as well as fashion new identities for themselves (1997b). Wolkomir’s (2001b) and Mason-Schrock’s (1996) work examines similar social processes. The former discusses how participation in support groups allowed homosexual men to negotiate a gay-Christian identity, while the latter shows how being involved in such groups helped transsexuals to interactively redefine a “true self.” Other studies have looked at groups more like those of the present study, including Sandstrom’s work on support groups for people living with HIV/AIDS (1996, 1990) and Karp’s (1992) study of a self-help group for those suffering from affective disorders (depression and manic depression). These researchers show how support groups, by bringing together people who are in a similar health situation, allow members to reconstruct their illness and therefore sustain desirable social identities (Sandstrom 1996, 1990; Karp 1992).

Although the present study also shows how participating in their respective groups helped the women of York, Upton, Hogart, and, to a lesser extent, Bellesmith, reconstruct more favorable images of themselves and their illness, it adds to the aforementioned literature in other important ways. As will be discussed later, it illustrates how gender ideologies can limit how individuals express and manage their emotions in the process of redefining themselves. It also shows how the culture of a disease can limit the types of identities that individuals are willing to embrace and therefore claim for themselves. Before addressing these points, however, I will show, more explicitly, how the support groups allowed the

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women in this study to interactively manage their emotions. More specifically, I will discuss how the findings and analysis from the preceding chapters help to illuminate how the women used the groups to help them transform the meaning of illness, validate one another’s self-worth, and redefine themselves and their illness in favorable ways.

**Transforming the Meaning of Breast Cancer.** Like many people, the women in this study associated cancer with prolonged illness, suffering, and death. Subsequently, they experienced intense feelings of fear and anxiety after they were diagnosed. As the findings and analysis in chapter two showed, the women coped with these uncomfortable feelings, in part, by seeking information about breast cancer. The different groups of women, however, did so in fundamentally different ways. The members of Upton and York, most of whom were college educated, sought information by reading books, searching the Internet, and joining listservs for women who had been diagnosed with the disease. Members of Hogart, who lacked the skills and resources to seek information on their own, turned to their doctors. Not only did they seek information during their medical visits, but they also invited these doctors and other experts to present at their monthly meetings.

Seeking information allowed the women in all the groups to cope with the uncertainty of their cancer diagnosis. Having collected information about their disease and its treatment, for example, allowed the York and Upton women to feel knowledgeable and confident as they negotiated their way through the medical system. This, in turn, helped to assuage the feelings of fear and anxiety that they experienced after being diagnosed. Although the Hogart women gathered information in a different way, doing so also allowed them to feel better
about their cancer diagnosis. It reassured these women that their doctors were knowledgeable and competent, and could successfully treat them in the event of a recurrence.

What role did the support groups play in this process? The York and Upton women clearly had the skills and resources to seek information on their own. So why did they turn to support groups for help with coping, if gathering information about their disease could make them feel better? Similarly, why did the Hogart women continue to attend meetings long after completing treatment, especially when the medical experts presenting at their group often repeated the same information time and again? The answers to these questions lie in what the women were able to do collectively with the information that they gathered and/or heard.

For example, the York and Upton women, by sharing the information they had gathered, were able to change how they viewed their disease. Instead of viewing it as a potential death sentence, they came to see breast cancer as a disease over which they and their doctors could exert a degree of control. Seeking information also helped the Hogart women transform the meaning of their disease, although they did so in a slightly different way. Because these women did not seek information on their own, they had to trust that what their doctors were telling them was true. As the analysis in chapter two illustrated, this led members of the group to collaborate in constructing their doctors as experts. Doing so also helped these women to change how they viewed their disease. As was the case with the York and Upton women, members of Hogart went from seeing breast cancer as an unmanageable disease to one that could be controlled by those with the appropriate knowledge and skills. This, in turn, served to diminish the uncertainty that they experienced as a result of their
cancer diagnosis.

Transforming the meaning of breast cancer therefore represents one process through which members of the various groups were able to cope collectively with the emotional fallout of their disease. While Sandstrom (1996, 1990) and Karp (1992) have also shown how support groups help their members to transform the meaning of illness, these authors have not considered seriously the role that information-seeking and sharing play in this process. Sandstrom (1990), for example, focuses attention on how support groups enable those living with HIV/AIDS to reconstruct the meaning of their illness by engaging in forms of identity embracement (associational, identity, and ideological [see Snow and Anderson, 1987 for a more detailed discussion of these strategies]). Karp (1992), on the other hand, shows how support groups help those suffering from affective disorders to adopt rhetoric (in this case the rhetoric of biochemical causation) that enables them to legitimate their mental illness and thus transform how they view it and, consequently, themselves.

The present study adds to this body of literature by identifying another way that support groups enable their members to transform the meaning of illness. By seeking and sharing information on breast cancer and its treatment, the women of Upton, York, Hogart, and, to a lesser extent, Bellesmith, were able to reinterpret the meaning of their disease. They moved from their initial view of it, which emphasized the destructive and deadly nature of cancer, to one that was far less upsetting. That is, the women came to see breast cancer as a disease that could be controlled by doctors and the ever-changing drugs and technologies that were available to them. Redefining their disease in such a way helped to mitigate the uncomfortable feelings that they were experiencing, thus allowing the women to feel
somewhat better about their breast cancer diagnosis.

Changing how they viewed their disease, however, did not help the women feel better about the physically disfiguring effects of surgery, chemotherapy, and radiation. As discussed in chapter three, the women experienced intense feelings of embarrassment, shame, and self-doubt after losing part or all of a breast(s). Many of them also struggled with the uncomfortable emotions that were evoked by the loss of their hair. And no amount of clinical information could help the women feel better about these losses. They therefore had to find other ways to help one another cope. Members of the various groups dealt with these problems by validating each other’s self-worth as women. Doing so, as the findings and analysis in previous chapters would suggest, allowed them to collectively manage the uncomfortable emotions that they experienced after facing the physically disfiguring effects of their disease.

Validating Womanhood. In a sexist society, women are often viewed as objects and are thus valued primarily for how they look. While this is problematic for all women, it is especially troublesome for those with stigmatized bodies. Women who are over-weight, those who do not conform to traditional standards of beauty, as well as those who are physically disabled or deformed are likely to experience misgivings about their appearance and question their self-worth. Because the women in this study faced the loss of one of the most sexualized parts of their bodies, they experienced precisely these kinds of problems. They felt anxious about how their bodies looked, and many of them feared that they were no longer attractive or desirable to men.
This is at least one reason why these women continued to attend their respective support groups after completing treatment. They struggled with the uncomfortable feelings evoked by the changes to their bodies and sought reassurance from others that they were still valuable as women. The members of York, Upton, Hogart, and Bellesmith also turned to their respective groups for help in coping with these problems because they often lacked emotional support in their lives outside of the groups. As noted in earlier chapters, friends and family often tired of the women’s continuing emotional struggles, particularly after treatment was completed and the women were given favorable prognoses. Furthermore, compared to continued illness or the possibility of death, some family members and friends thought that the women’s concerns about their bodies were vain or even inappropriate.\(^86\)

This illustrates how members of the groups faced a troubling double bind. Like most women, they were expected to comply with traditional norms of feminine appearance. This meant showing concern for how they looked and making an effort to “look good.” At the same time, these women, like most, also faced potential stigma for worrying too much about their physical appearance. If they seemed too invested in it, they could be accused of being shallow or narcissistic. Unlike most women, however, women in the support groups faced an additional dilemma. As alluded to above, displaying too much concern about their bodies and how they looked after surgery and treatment meant risking being seen as ungrateful for having survived their disease.

The women therefore had to find ways to help one another feel better about their altered bodies, while not appearing to be too invested in how they looked. They also had to learn to show that they were appreciative of having survived their illness, despite the physical
disfigurement and emotional trauma it had caused. This was not easy. Indeed, the women worked hard to negotiate and cope with these conflicting problems.

As shown in chapter three, one way the members of the groups dealt with the disfiguring effects of their disease and the way these changes to their bodies made them feel was by concealment. Following the recommendations of their doctors and other members of their groups, they wore prosthetic inserts and/or had reconstructive surgeries (breast implants, the TRAM flap, or Latissimus flap procedures). They also worked hard to compensate for the disfiguring effects of their disease. Members of all four groups devoted meticulous attention to their clothing, make-up, and hair, especially while they were recovering from treatment. They also frequently complimented one another on their efforts to look better.

These strategies helped to reassure the women that they were still attractive, despite the disfigurement caused by their disease. They also allowed members of the groups to remind one another that they had not given up on themselves, and were still making efforts to look good. In these ways, members of the groups were able to conform to societal expectations that they, as women, should be concerned with and willing to work on their physical appearance. Given the obstacles that they faced in trying to present an attractive image, however, the women were also generally able to avoid being seen as overly concerned with how they looked. Disguising their illness and practicing a compensatory form of femininity thus helped the women to feel better about themselves and their bodies, as well as negotiate the double bind that they experienced as a result of the disfiguring effects of their disease.

Engaging in sexualized joking and redefining their illness as a blessing also helped
the women to manage these problems. Through the use of humor, for example, the women were able to acknowledge the discontent and insecurity that they experienced over losing (a) breast(s). Because they were willing to make fun of and joke about their altered bodies, they were also able to avoid appearing too invested in how they looked. Redefining their illness experience as a blessing was also helpful in this regard. Although this strategy served other functions, it also helped the women to appear grateful for having survived their disease, despite the disfigurement and discontent that it had caused.

Again, this shows how members of the groups were able to negotiate a double bind resulting from an illness that threatened their status as women. It also illustrates another way they were able to cope collectively with their disease. By using the strategies described above, the women were able to reassure one another that they were still attractive and desirable, despite the disfiguring effects of surgery, chemotherapy, and radiation. This, in turn, served to validate their self-worth as women, thus buffering some of the embarrassment, self-doubt, and anxiety that they experienced about their changed bodies.

The present study thus adds to our understanding of how support groups help people to cope with stigmatizing and difficult life events by allowing their members to validate one another’s self-worth. Other research has found support groups to function in similar ways. For example, Francis (1997b) has shown how support group participation can help the newly divorced feel better about themselves, even after being abandoned by those they have loved. The present study, however, adds to these findings in an important way. As the discussion in this and previous chapters has shown, it illustrates how gender and gender inequality can affect the ways support group participants go about validating one another’s self-worth. This
is clearly illustrated by how the women in this study relied on traditionally feminine ways to help one another feel better about themselves, namely by devoting considerable time and attention to their physical appearance and complimenting one another on their efforts to look better. While these strategies reinforced traditional standards of beauty and sexist ideas about women, they did help members of the four groups to feel better about themselves. Like transforming the meaning of their disease, validating womanhood therefore represents a social process through which members of York, Upton, Hogart, and Bellesmith were able to interactively manage some of the uncomfortable emotions caused by their disease.

Another way that the women worked together to manage the emotional fallout of their disease was by reconstructing how they viewed themselves and their illness experience. Doing so, as the following discussion will show, helped the women to restore favorable images of themselves after facing a stigmatizing and potentially life-threatening disease. It also allowed them to redefine their illness in positive ways.

Reconstructing Favorable Images of Self and the Illness Experience. During the data collection process, I witnessed many of the women attending their respective groups for the first time. Almost without exception these women, most of whom were newly diagnosed, appeared distraught and extremely anxious. Some cried openly as they introduced themselves and explained what brought them to their groups. Others appeared to be in shock. It was as if they could not believe that they had been diagnosed with breast cancer.

Although not all of these women continued to attend the support groups, those who did experienced a transformation. While they continued to struggle with their disease in
various ways, they became more confident and even proud about being or having been breast cancer patients. How the women sought information and used it to reinterpret the meaning of their disease partly accounts for these changes. So too do the ways in which they learned to create and share medicalized stories about their breast cancer diagnosis and treatment. These ways of coping helped the women to feel less anxious and more in control of their illness experience.

They do not, however, fully account for how the women learned to take pride in having been breast cancer patients. This is better explained in other ways, namely by how members of the groups came to see themselves as breast cancer survivors. As shown in chapter four, by telling stories that narratively located their breast cancer diagnosis in the past, the women were able to embrace such an identity. Doing so not only helped them to cope with the uncertainty of the future, it also allowed the women to reconstruct how they viewed themselves. Once afraid that they might become victims of breast cancer, members of the groups came to see themselves as strong women who had triumphed over a potentially life-threatening disease.

To be able to see themselves in such a positive light was important to these women, especially because their feelings of self-worth had been diminished by a disfiguring disease and its treatment. Taking on the identity of “breast cancer survivor” therefore allowed the women to deflect some of the stigma that they faced as a result of their disease. It also, as noted above, allowed them to see themselves in more socially desirable ways.

Redefining their illness as a blessing worked in a similar way. By focusing on how breast cancer had led them to be more fully appreciative of life, members of the groups were
able to see themselves not as women who had been damaged or embittered by their disease, but as better, stronger people, because of what they had been through. This, in turn, helped the women to conclude that the suffering they had endured had not been in vain. In fact, it allowed them to believe that their illness, albeit a difficult life experience, had served a meaningful purpose in their lives. In these ways the women of this study were able to reconstruct not only favorable images of themselves, but of their illness experience, as well.

Once again, this illustrates how participating in the support groups allowed these women to cope collectively with their disease. As Pearlin (1989) and Thoits (1995) have pointed out, this kind of perspective is largely missing in the literature on stress and coping. As discussed earlier, most of the research in this area centers its attention on individuals and the efforts that they make in trying to cope with the stressful events and circumstances in their lives. While such a focus has produced a useful body of knowledge, especially about the resources and strategies that individuals use to help them cope, it has also caused researchers in the area to be shortsighted in other ways. Most importantly, it has led them generally to ignore how people are able to help one another cope.

The current study helps to fill this void. Drawing upon Francis’s idea of interpersonal emotion management (1994, 1997a, 1997b) it shows how, through participation in their respective support groups, the women in this study were able to manage interactively the emotional fallout of their disease. More specifically, it illustrates three ways that the support groups functioned to help the women cope with the emotions evoked by their breast cancer diagnosis. First, it shows how support group participation allowed the women to transform the meaning of their disease. Although other researchers (e.g., Sandstrom 1996, 1990; Karp
have also found support groups to function in this way, the present study identifies another way it can occur, that is, by seeking and sharing medical information, and using it to redefine illness in less threatening ways. The present study also shows how support groups allow those who participate in them to feel better about themselves by validating their self-worth. While this too has also been reported in other research (e.g., Francis, 1997b), the present study shows how this process can be gendered in nature, and can serve to reinforce existing inequalities (a point discussed in further detail below). Finally, the present study adds to our understanding of how support groups help members work together to reconstruct favorable images of themselves and their illness. This too helps to illustrate how coping is a joint endeavor, rather than just the result of individual efforts to feel better, as previous research has suggested.

THE GENDERED NATURE OF COPING

The discussion in this chapter has thus far focused on how the members of York, Upton, Hogart, and Bellesmith were able to cope collectively with their disease. In doing so it has emphasized what these women, by working together, were able to accomplish in their respective groups. As the analysis chapters showed, however, the women faced obstacles in trying to cope with their disease. In what follows, I will consider what this tells us about how gender ideologies can affect coping. But first I will briefly review relevant literature on gender, emotions, and coping, with attention to what the literature says about the conditions under which people are likely to have difficulty coping or managing their emotions.
Constraining Coping: The Role of Gender Ideologies

It is widely believed that women are more emotional and emotionally expressive than men, and that these differences between the sexes are innate. According to Johnson (2005), such notions are deeply embedded in our culture and are reinforced through mainstream media, including popular books, such as John Gray’s (1992) *Men are from Mars, Women are from Venus* and Deborah Tannen’s (1990), *You Just Don’t Understand*. Empirical research has not, however, supported these popular notions of how women and men experience and express their emotions. Simon and Nath, for example, report that, “there is *little* [emphasis in the original] correspondence between men’s and women’s feelings and expressive behavior and gender-linked cultural beliefs about emotion” (2004:1166). Other researchers have found that while emotions and the ways in which they are expressed are gendered, that these differences, rather than being innate, are cultural, and are representative of the vast inequalities that exist between men and women (Johnson 2005; Erickson and Ritter 2001; Thoits 1989; Kemper 1978; Hochschild 1975).

For example, Hochschild (1975, 1979), in her early research on emotions, explains how cultural norms, which she calls “feeling rules,” prescribe when certain emotions are to be expressed, to what degree, where, and by whom. She (Hochschild 1983) and other researchers (Johnson 2005; Erickson and Ritter 2001; Smith 1990) have gone on to show how these norms are used to ensure that women and men display emotions in culturally distinctive ways. Women, for instance, are encouraged to convey feelings of happiness, warmth, and friendliness. At the same time, they are discouraged from displaying “negative” emotions, such as anger or indignation, and risk being stigmatized if they do (Erickson and
Ritter 2001; Pierce 1995; Smith 1990; Bartky 1990; Hochschild 1983). Men, on the other hand, have more freedom to display either anger or emotional detachment, and can even gain status from expressing themselves in such ways (Johnson 2005; Erickson and Ritter 2001; Seidler 1991).

As Kemper (1978), Hochschild (1975), and Thoits (1989) have argued, this helps to illustrate how inequality affects even the expression of emotions. As these authors have argued, those in subordinate positions, in this case women, are often forced to express themselves in deferential ways (for example, by displaying emotions that do not reflect how they truly feel). Those in subordinate positions are also, according to these researchers, often held responsible for others’ emotions. Because women tend to occupy such positions, especially in comparison to men, they are generally expected to perform this kind of emotional labor (Wharton and Erickson 1995; Smith 1990; Bartky 1990). Furthermore, because this kind of work is supposed to come naturally to them, they are expected to be good at it.

These ideas about and expectations for women influenced how the members of York, Upton, Hogart, and Bellesmith managed the emotional fallout of their disease. For example, rather than responding to their illness with anger or indignation, they reacted to it in ways deemed more appropriate for their gender. In accord with Hochschild’s (1983) and others’ (Erickson and Ritter 2001; Pierce 1995; Smith 1990; Bartky 1990) findings, the women often suppressed “negative” emotions, and instead tried to remain upbeat about their plight. As chapter three showed, one way they did this was to joke and laugh, especially about the disfigurement caused by their disease. Doing so not only helped them to feel better about
themselves and their changed bodies, but also allowed members of the groups to avoid appearing angry or bitter – feelings that certainly would have been justifiable, but seen as inappropriate because they were women.

Focusing on the positive outcomes of their disease helped the women in a similar way. By emphasizing how their illness had led them to be better people, and how it had served as a catalyst for changes that might not have otherwise occurred in their lives, they were able to express gratitude for, rather than anger about, what they had been through (a finding corroborated by Sandstrom’s [1998] work on HIV/AIDS patients). Wrestling positive value from such a difficult life event thus allowed members of the groups to display their emotions in culturally appropriate and traditionally gendered ways.

In the absence of professionally trained leaders and other forms of support, it makes sense that the women helped one another cope in such ways. As noted in earlier chapters, only one of the groups (York) was facilitated by a trained counselor. And even she took a laissez-faire approach to guiding the group. Similar to the leaders of Upton, Hogart, and Bellesmith, she assumed that the women would discuss issues of importance to them, and that they were capable of helping one another cope. For instance, at one group meeting, she commented that the women’s breast cancer support group was easier to facilitate than the men’s prostate cancer group that she also led. She went on to explain that the women “liked to talk about their problems,” while the men expected her to invite guest speakers, develop specific programs, and guide discussions for them. As this would suggest, members of York, although they could have benefitted from such additional resources just like the men, were assumed not to need them, because, they, as women, supposedly knew how to talk about and
cope with the difficult emotions evoked by their disease.

These kinds of assumptions were common and affected the resources that were made available to the other groups. Although Upton was affiliated with a large hospital and the cancer support center connected to it, the group received no financial support from these organizations. In fact, the facilitator, an oncology nurse who worked at the hospital, volunteered her services, and received no formal training or other support during the eight years that she had been involved with the group. When asked about this in her interview, she denied that it was a problem. She, like the leader of York, thought that group participants were capable of guiding themselves, because, they, as women, liked to “socialize” and help one another work through their problems.

This helps to illustrate how gender ideologies affected the ways the groups were organized, as well as what the women were able to accomplish in them. As the above discussion has shown, members of the groups were regularly left to their own devices, assumed to be equipped and able to help one another cope. Just because they were women, however, did not mean that they had the necessary skills. Indeed, most of the groups’ participants sought support precisely because they were having difficulty coping on their own. Without much guidance from the leaders or investment on the part of the sponsoring organizations, they were forced to help one another cope as best they could, generally expressing and managing their emotions in traditionally gendered ways.

While these ways of coping did help the women to feel better, they also led members of the groups to avoid talking about or dealing with some of the more uncomfortable or painful emotions evoked by their disease (for example, their fears of recurrence or death,
and/or the anger they experienced about what they had been through). The current study thus helps to illuminate some of the conditions under which emotion management is likely to be constrained. As reported elsewhere (Copp 1998), it shows how a lack of social support can make it difficult for people to express and manage their emotions openly. It also shows how support group leaders, by embracing gender ideologies, can limit their participants’ success in dealing with difficult emotions. Such groups, which are designed ideally to help people cope, can therefore, under certain conditions, actually constrain how and to what degree their members are able to express and manage their emotions.

**BREAST CANCER CULTURE AND COPING**

In the previous section I identified some of the obstacles that the women of York, Upton, Hogart, and Bellesmith faced in attempting to cope with their disease. In the following pages, I will continue with this theme, focusing attention on how their behavior was influenced and constrained by the mainstream breast cancer culture. Before doing so, I will briefly review literature that attempts to explain what this culture is, how it has been created, as well as the ways it has been transmitted to the general public. Then I will show how the present study helps us understand how cultures of disease can affect people’s illness experiences.
The Pink Cloud Effect

As noted in earlier chapters, Zeneca Pharmaceuticals (now AstraZeneca) declared October “Breast Cancer Awareness Month” in 1985 (Sellman 2005). Since (and even before) that time, many groups and organizations have worked hard to bring public attention to the disease. The most prominent of these is the Komen Foundation. This organization, with its emphasis on “breast cancer awareness,” early detection, and the need for cutting-edge research has been largely responsible for shaping how the disease is framed in the public arena (Milden 2005; Ehrenreich 2001; Klawiter 2000, 1999). In fact, by downplaying the suffering and death caused by breast cancer and drawing attention to survival and “survivors,” the organization and others like it, such as the American Cancer Society and the Avon Breast Cancer Crusade, have been able to create an upbeat culture around the disease, thus promoting an “overly bright and hopeful configuration” of it (King 2004:487).

This is at least one reason why corporations have been so willing to sponsor and support organizations affiliated with the disease. As discussed in chapter one, breast cancer has been promoted in a non-threatening and corporate-friendly way, and lacks the stigma associated with other diseases such as AIDS (King 2004). This, however, has been well documented by other researchers (for example, Ehrenreich 2001; Klawiter 2000, 1999; King 2004), who have shown how a culture has been created around breast cancer, as well as how this culture has influenced public discourse about the disease.

What these authors have not considered, at least in any detail, is how the mainstream breast cancer culture has affected the ways women, especially those who participate in support groups, manage the emotional fallout of their disease. The present study is helpful in
this regard. It shows how the culture surrounding breast cancer has influenced and limited the ways women think and talk about, as well as cope with, their disease.

For example, by situating breast cancer within the terrain of science and medicine, Komen and others have encouraged women to view the disease in a medicalized way. As shown in this study, the women used their time together to create and tell stories that focused on the clinical details of their breast cancer diagnosis and treatment. While this helped them to feel better by allowing them to view their illness as a series of medical procedures—over which they and their doctors could exercise control—it also led the women to avoid talking about the uncomfortable emotions that they were experiencing, and to downplay the pain and suffering that they had endured. Taking on the identity of breast cancer survivor had similar consequences. While this coping strategy helped the women to feel better about themselves and what they had been through (e.g., by allowing them to view themselves as strong women who had persevered over a difficult life event), it also led them to avoid talking about the pain and suffering caused by their disease.

As discussed in the previous chapter, at least some of the women were critical of these practices. For example, one member of York, Sandra, expressed concern about how members of her group refused to talk about the painful emotions evoked by their disease. She even went on (in her interview) to claim that most of the York women were “living under the pink cloud.” The phrase, which she borrowed from Alcoholics Anonymous (A.A.), generally refers to the period when newly recovering addicts are enthusiastic about becoming sober, but have yet to face or deal with many of the hardships and volatile emotions that accompany long-term recovery from addiction. By using the phrase in
reference to the York group, Sandra was suggesting that its members, because they refused to
discuss the painful emotions and negative consequences of their disease, had yet to “truly”
deal with them. While this might have been the case, it does not explain why the women
responded to their illness in the ways that they did.

This is better understood by examining the conditions under which they tried to cope
with their disease. The women experienced tremendous pressure from the mainstream breast
cancer culture to remain upbeat, even though they were facing a life-threatening disease that
evoked strong fears and anxieties. When combined with the other obstacles that the women
faced (namely the lack of trained counselors for facilitating the groups and societal pressure
to suppress “negative” emotions because they were women), they were left with few options
for coping with their disease. They therefore resorted to strategies (such as creating and
sharing medicalized stories about their breast cancer diagnosis and treatment, as well as
taking on the identity of breast cancer survivor) that admittedly helped to make them feel
better, at least temporarily, but did not allow them to fully express or cope with the difficult
emotions that they were experiencing. What these women were able to accomplish in their
groups was thus limited, especially by the mainstream breast cancer culture (another type of
pink cloud), which has consistently trivialized the suffering, death, and emotional pain caused
by the disease.

This culture has also influenced how others expect breast cancer patients to behave.
By celebrating survivorhood and survivors, the mainstream breast cancer culture downplays
the emotional fallout breast cancer patients continue to experience after completing treatment
for the disease. Consequently, many of the women in this study reported that their loved
ones, especially their partners and spouses, were less than sympathetic when they expressed uncertainty about the future and/or discontent about what they had been through. As “survivors,” they were expected to be strong, positive, and upbeat, not fearful or anxious, or too willing to complain about the aftermath of their disease. The women thus learned, both inside and outside their groups, to cover their uncomfortable emotions with a veneer of strength and courage. This too helps to illustrate how the culture that has been created around breast cancer has limited the range of emotions that women who have had the disease are able to express. It also illustrates another way that this culture has served to trivialize the pain and suffering evoked by the disease.

EVALUATION AND FUTURE DIRECTIONS

The present study shows how support groups can help people learn to cope with life-threatening disease. It offers several advantages over similar studies that have also attempted to analyze the collaborative nature of the coping process. For example, this project, unlike Sandstrom’s (1996, 1990) investigation of men living with HIV/AIDS, is based on direct observations of the support groups. The data gathered through these observations proved invaluable to understanding how members of the four groups helped one another cope with their disease. Indeed, without these observations it would have been virtually impossible to identify the processes that the women used to cope, especially since what they reported in their interviews was often an idealized version of what occurred in the groups.

The interview data do, however, complement the direct observations by providing insight into the problems the women faced, particularly ones that they did not openly discuss.
in the groups. In interviews, many of the women talked in detail about the emotional trauma that they experienced as a result of losing a breast(s). This provided a more accurate picture of what the women went through, and also revealed the importance of the sexualized joking that took place in the groups. Interviewing the women and directly observing the support groups in which they participated thus led to a more complex understanding of their illness and how they coped with it than could have been gained from using only one of these data collection methods.

The amount of time that I spent observing the groups also contributed to the quality of data that I was able to collect. Because I attended the four groups over an extended period of time (York and Upton for two years; Bellesmith and Hogart for 13 months), I was able to gain an in-depth understanding of how the women interacted with one another, how they learned to help one another cope, as well as how their coping strategies changed as their illness and the problems associated with it changed. Having such a long-term presence in the groups thus led to a more complete understanding of the women’s illness experience, particularly the problems that they faced after completing treatment for their disease.

My long-term commitment to the groups also allowed me to develop rapport and a strong sense of trust with the women. This was reflected in their willingness to not only be interviewed, but also to speak candidly to me about topics they often avoided discussing in the groups (e.g., the emotional pain evoked by the loss of a breast, and the frustration and hurt that they experienced when family members and friends refused to provide emotional support). Had I spent significantly less time observing the groups and developing relationships with the women in them, it is doubtful that I would have been able to gather this
Another strength of the project is the diversity that is represented by the four groups. Two of them (York and Upton) looked like most support groups that are included in academic studies (see Mechanic and Myer 2000 for a review); that is, members were predominantly white and middle class. But the other two groups, Hogart and Bellesmith, were significantly different. They were composed of women from mostly working-class backgrounds. In addition, approximately one-third of the women who participated in the Hogart group were African American. These differences in the composition of the groups made it possible to compare the experiences of the women. They also helped to illuminate how class-based inequalities affected the ways the women were able to cope with their disease.

Unfortunately, the groups lacked diversity in other ways, which resulted in several weaknesses in the study. All of the groups, for example, were composed primarily of women who had been diagnosed with stage-one or stage-two breast cancer, meaning that most of them could expect to recover from the disease. They therefore rarely, if ever, talked about the possibility of dying or the emotions that are evoked by a progressively advancing disease. These are issues that would have certainly been salient to women suffering from stage-four (or terminal) breast cancer. But because I was not able to gain access to a support group for such women, the current study cannot speak to how their experiences with the disease, as well as how they cope with it, might differ from those of women with less advanced stages.

Likewise, the study is not able to show how the experiences and coping strategies of women who participate in faith-based support groups might differ from those who attend
groups of a more secular nature. Although many of the women in the current project relied on faith to help them cope, this was not the focus of their respective groups. In fact, the leaders of the four groups generally steered discussions away from religion, perhaps fearing that some women would try to impose their beliefs on others. Faith-based support groups could thus prove a fruitful site for future research, providing an opportunity to examine how faith impacts the coping process. Studying such groups could also enhance our understanding of how religious ideologies affect the ways people understand and respond to a disease.

Another avenue for future research could include an investigation of support groups for men suffering from a comparable disease, such as prostate cancer. Such a study could help to further illuminate how gender ideologies affect the coping process. It could, for instance, lead to a better understanding of how social constructions of masculinity influence the ways men cope with a disease, especially one that threatens their identities as men and sexual beings. It could also serve as a point of comparison to the current study, showing how these coping processes differ from those of women facing a similarly stigmatizing disease. Furthermore, it could help to verify (or refute) several of the conclusions drawn from this study, namely that gender ideologies impact the ways support groups are organized and facilitated, as well as how their members express and manage the emotions evoked by a potentially life-threatening and stigmatizing disease.

Finally, the present study suggests that more attention should be given to the role that partners and spouses play in the coping process. The findings and analysis reported here suggest that many women with breast cancer do not receive the emotional support that they
need or desire from significant others in their lives. They also indicate that these women, 
even while extremely sick, are expected to tend to the emotional needs of others, especially 
those of their partners or spouses. Further research, then, could help to identify ways to 
alleviate this burden. This, in turn, could go a long way in helping women to cope better with 
the emotional fallout of breast cancer.
NOTES

1. However, as Love reports, the longer a breast cancer patient goes without a recurrence, the less likely she is to have one (2000:520).

2. White women of higher socioeconomic status are more likely to get breast cancer than poor women. Researchers speculate that this is because they tend to have their first child later in life, which is another risk factor for the disease. Even so, these women are less likely to die of the disease than poor women (Love 2000).


4. Examples of these include Bald in the Land of Big Hair (Rodgers 2001), Confronting the Cow: A Young Family’s Struggle with Breast Cancer, Loss and Rebuilding (Donner 2000), and Seeing The Crab: A Memoir of Dying (Middlebrook 1996).

5. All names herein are pseudonyms.

6. When I initially contacted the leader of York, she informed me of another group that she facilitated for women with advanced stages of breast cancer. I requested to attend and study this group. The leader, although hesitant, agreed to ask members if I could have access to the group. They declined, saying that they did not want an outsider to observe the group. In addition, the leader of York told me of a group for young women (participants were under 40) with breast cancer. Although I gained access to this group, it lacked stable membership and soon disbanded.

7. I never took notes during meetings, except when guest speakers presented to groups, which happened only rarely. On such occasions, most of the women took notes, and it was expected that I would do the same.

8. Even after meetings officially ended, members of the group often lingered, continuing to socialize and talk with one another. These informal conversations provided additional opportunities for gathering data. They also frequently resulted in opportunities to conduct impromptu, informal interviews. This was the case for the other three groups, as well.

9. I also observed the boutique several times during business hours.

10. During my observation period, one meeting was cancelled, one was cut short because the guest speaker was not able to attend, and a third was used to socialize at a restaurant because a speaker could not be arranged for that particular month.

11. Lymphedema refers to swelling (usually of the arm) that can occur after lymph nodes are removed for breast cancer surgery (Love 2000).
12. Most members of Bellesmith had only high school educations. Representative occupations were teacher’s aide, sales clerk, and homemaker.

13. Again, the primary indicators of social class were education and occupation. Members of the Hogart group typically had only high school educations. Representative occupations were nurse’s aid, secretary, prison guard, and homemaker.

14. For example, M & M’s has started to market a pink version of their candy to “help fight breast cancer,” while Quilted Northern offers toilet paper products marked with the pink breast cancer awareness ribbon (<http://cms.komen.org/komen/Partners/MillionDollarCouncil/index.htm>).

15. Underlined text indicates emphasis used by the respondent.

16. Many other members of the group did the same, as did the women of York.

17. There were two exceptions. After experiencing extended health problems, Joyce and Donna, both members of Upton, eventually lost their jobs due to long absences from work. In addition to being diagnosed with breast cancer, Donna was hospitalized and treated for severe depression. Joyce underwent two unexpected operations, including open-heart and back surgeries. Both women had worked for their respective employers for 15-20 years, when they were fired from their jobs.

18. Adjunctive therapies are those used in combination with surgery, such as radiation or chemotherapy (Love 2000).

19. Although not a common side effect of chemotherapy, many of the women complained of arthritic pain after completing treatment.

20. Betty’s husband of over 20 years left her not long after she diagnosed with cancer. Her life thus changed in many ways after being sick. She often attributed these changes to having cancer.

21. Similar to a bone marrow transplant, stem cell transplant or rescue involves removing stem cells from the body and storing them until time of replacement (or “rescue”). Prior to replacement the patient is given high-dose chemotherapy to kill cancer cells. After high-dose chemotherapy is given, the stem cells previously removed are put back into the body through a transfusion. The goal of the procedure is to restore normal blood production and prevent the production of additional cancer cells (Love 2000:383-385).

22. Acknowledging that Rhonda could possibly die of breast cancer also meant that the other women might have to consider that they too might not survive the disease.

23. For example, those with a family history of the disease, lymph node involvement, and/or aggressive forms of breast cancer are at higher risk for recurrence (Love 2000).
24. If individual women from these two groups did seek information on their own, they usually did not spend group time sharing it with other members.

25. The main exceptions were the leader, who reported feeling a responsibility to seek and share information with others in the group, and another member whose daughter was active in the Komen Foundation, the group that organizes Race for the Cure events across the United States and other countries.

26. It is also quite possible that Bonnie felt unprepared or too intimidated to ask questions, once she actually saw her doctor. In addition, she might have felt that, as a professional, he was better equipped to determine what was best for her. As will be discussed in greater detail later in this chapter these kinds of experiences are common among working-class patients (see Lareau 2003).

27. That she could actually read and understand the document was clear, as she read part of it aloud.

28. Refers to temporary or permanent nerve damage. Symptoms often include numbness or loss of feeling in the hands and/or feet (Love 2000).

29. Close to three-fourths of group members were at least three years out of treatment. For some, it had been seven to eight years since they had been diagnosed and treated for breast cancer. This is in contrast to York and Upton members, most of whom had been diagnosed and treated within the last six to eighteen months. The exception was Kim and Elizabeth, both members of Upton, who had been both been diagnosed 6-8 years earlier.

30. As McKenzie and Crouch point out, cancer patients are “rarely, if ever, pronounced ‘cured’, however ‘well’ they may appear to be after treatment has ceased” (2004:139). The women in this study were well aware of this, and I use the term “successfully” with this in mind.

31. Most breast cancer patients undergo an axillary lymph node dissection to see if cancer cells have spread from the tumor site to the lymphatic system. Removal of these nodes, however, can often lead to lymphedema, a condition that is characterized by extreme swelling of the hand and arm. A sentinel node biopsy is a relatively new procedure that allows surgeons to reduce the number of lymph nodes removed, and thus reduce the risk of lymphedema. In this procedure, radioactive dye is injected into the breast, near the site of the tumor. The dye travels naturally through nearby lymph nodes, identifying which ones (i.e., the sentinel nodes) would be most likely to carry any stray cancer cells. Those lymph nodes are then removed and biopsied. If they test normal (clear of cancer), typically no other nodes have to be removed (Love 2000:373-374). Although the procedure is gaining popularity, it is not always widely practiced, especially outside of research oriented hospitals.

32. As will be discussed later, it was also why they tolerated arrogant and/or offensive behavior from their physicians when the York and Upton women largely would not.
33. Hospitals approximately 1 ½ to 2 hours away, where many of the York and Upton women received their treatment.

34. This was the case even though only two or three members of the group received care outside of the area and/or were personally familiar with the type of care available at these two research hospitals.

35. I did not observe actual interactions between the women and their doctors during medical appointments. Analysis in this section is based on what the women said about these encounters, as well as the differences between the York and Upton women’s accounts and their Hogart counterparts. Analysis regarding the Hogart women is also based on observations of how physicians interacted with them at monthly meetings.

36. The doctor also implied that using appointment time to clear up confusion about such matters was a waste of his time. It could also be deduced from his comments that dealing with patients’ emotional distress, regardless of its source, made him feel uncomfortable and was outside his realm of treatment.

37. Even in follow-up conversations and interviews, I had difficulty finding anyone in the group who would criticize his comments. Even the leader who initially challenged the doctor in the meeting was reluctant to do so, although she did suggest that she was far from happy with them.

38. TRAM (transverse rectus abdominis muscle) flap surgery involves using skin and fat from the abdomen to reconstruct a breast. The surgery is touted as a “natural” way to reconstruct a breast, since it uses the woman’s own body tissue. Another added “benefit” is that the procedure works much like a “tummy tuck,” since it removes fat from the stomach area. This particular operation is, however, considered to be one of the more complicated and painful reconstructive surgeries available to breast cancer patients, and also results in more physical scaring, especially as compared to other reconstructive procedures (Love 2000).


40. This point will be discussed in more detail in the upcoming section on decision making.

41. As will be discussed later in this section, as members of the working-class, the women also felt a certain level of discomfort when they interacted with authority figures and often remained quiet and reserved in their presence.

42. Many of the women who participated in the York group belonged to social circles that included doctors. This was less likely to be the case with the women from Upton, although many of these women worked in medical settings, especially as nurses, and/or had friends who did the same.
43. Even when the two groups of children attend the same schools (Lareau 2000).

44. It is difficult to attribute Renee’s decision to have a TRAM flap operation only to the pressure she received from her plastic surgeon. As will be seen in chapter three, most breast cancer patients are strongly encouraged to have some kind of reconstructive surgery. However, none of the women in the other groups described experiencing the kind of pressure that Renee and other Hogart members did, especially when it came to making decisions regarding their general medical treatment and care.

45. Rhonda and Joyce, members of Upton are examples. Both women had TRAM flap reconstructive surgeries that eventually had to be reversed or repaired. The women later said that they regretted their decisions to have the surgery, and if given the chance, would choose a different option. However, Rhonda and Joyce both emphasized that they knew the risks associated with the procedure, and acknowledged that the complications that they experienced were out of the ordinary.

46. According to the women, doctors tended to focus on the latter, reassuring them that they had some time to contemplate their choices.

47. This meant that cancer cells were found near the margins of her biopsy incision, which would suggest that some malignant cells remained in her body.

48. The women’s past behavior does help to support this claim. Of the ten Hogart members interviewed, only one reported getting a second opinion about her diagnosis.

49. These figures are significantly higher than national statistics on breast reconstruction. According to the American Society of Plastic Surgeons, approximately 57,778 women had breast reconstruction surgery in the United States in the year 2005. This figure does not include women who got breast implants for purely cosmetic reasons or those who had breast reduction. (For more information, see, <http://plasticsurgery.org/media/statistics/loader.cfm?url=/commonspt/security/getfile.cfm&PageID=17870>). Although approximately 200,000 new cases of breast cancer were reported that same year, it is impossible to determine what percentage of those undergoing reconstructive surgery were actually new breast cancer patients. Other studies suggest that approximately 30% of women in the United States undergo reconstructive surgery at the time of mastectomy (Harcourt and Rumsey 2001:478).

50. Because their reconstructed breasts were often not the same size or shape as their natural ones, some of the women wore prosthetic inserts in their bras so that the two would “match.”

51. His message was common. Many of the women from York, Upton, and Bellesmith reported that their doctors encouraged them to have reconstructive surgery, claiming that breast cancer patients who do adjust better psychologically than those who do not. As will be discussed later, available data do not support this claim.
52. The Latissimus flap procedure involves taking a flap of skin and muscle from the back to reconstruct a breast (see Love 2000:447-461).

53. As this example illustrates, women who had mastectomies were typically presented with two choices: have reconstructive surgery or wear a prosthesis. Rarely, if ever, was choosing to do neither presented as a viable option.

54. Emphasis added.

55. Expanders, which are gradually filled with saline, are used to stretch the skin prior to final insertion of the implant(s) (Love 2000).

56. Although Bonnie made reference to a singer known for her large breasts, and a supermodel who is popular for her “sexy” body, the underlying message in her joke was that her breasts were of two very different sizes and were therefore not attractive or desirable.

57. In addition, a number of the women sought counseling services outside of the groups. For these women, attending group meetings seemed to serve more of a social function than a therapeutic one. In other words, they did not attend the groups to seek further counseling services.

58. As will be discussed later, being faced with such startling reminders of their illness also forced the women to face the possibility that they could die.

59. As this quote would suggest, Julie’s motives for buying more clothes were probably quite complex. It was not just about looking good while she was ill. It was also about allowing herself to enjoy nice things while she was still alive. Several of the women, in fact, reported that they spent extra money on clothing and other purchases while they were sick, saying that they might not have the opportunity to do so in the future. Such comments would suggest that the women knew that their health could get worse or that they might die of their disease.

60. According to the Centers for Disease Control (CDC), over 40,000 women die per year of breast cancer in the United States (<http://www.cdc.gov/cancer/breast/statistics/>). These data were rarely, if ever, discussed by the women in the support groups. Nor are they regularly discussed or critiqued by organizations associated with the mainstream breast cancer culture.

61. Although men can also develop breast cancer, it is rare. Breast cancer accounts for less than one percent of all cancers occurring in men (Love 2000:414).

62. Even so, most of the women were diagnosed with early stages of the disease and had generally positive prognoses.
63. As Ratner (1999) discusses, denying the possibility of recurrence is one way that family and friends cope with the uncertainty of cancer.

64. Generally the Hogart and Bellesmith groups had guest speakers. When they did not, they also sometimes told their breast cancer stories.

65. All four are commonly used chemotherapy drugs for breast cancer patients.

66. Microcalcifications are small deposits of calcium clustered together in the milk ducts (Love 2000).

67. Some women, like Kim, have tumors that “over express” the HER-2 gene. In this mutated form, the gene causes cells to divide and multiply faster than normal, which may lead to breast cancer (<http://www.imaginis.com/breasthealth/bc_drugs3.asp#Herceptin>). The clinical trial in which Kim participated was testing the effectiveness of a vaccine against the mutated HER-2 gene.

68. As Kim’s example illustrates, it was more difficult for the women to avoid such discussions in their interviews, where the setting was more intimate and the questions they were asked more direct.

69. Stage-four breast cancer means that cancer has metastisized to other bodies of the body and that the disease is considered terminal (Love 2000).

70. Tamoxifen is a prescription drug used to treat women who have had estrogen positive breast cancer, as well as women with advanced stages of the disease (Love 2000).

71. As will be discussed later, most of the Upton and York women had positive prognoses. However, as the data in this chapter have shown, they still faced considerable anxiety about the future, due to the uncertainty associated with their disease.

72. For example, the leader often missed meetings to attend collegiate sporting events and suggested that meetings be cancelled or be held less often during the summer months. Several members fought to have meetings in the summer. One even told the leader that, “People get diagnosed and have problems with cancer in the summer too, you know.”

73. As later discussion will show, the term “survivor” is problematic. Although it is most often used to refer to women who have completed treatment for the disease, it is also used to refer to the newly diagnosed and those still in treatment. In addition, the word has come to be used so loosely that the Komen Foundation has coined the term “co-survivor” to describe close friends and family members of those with the disease (<http://www.komen.org>).

74. Whenever they introduced me, the leaders of the groups also identified me as a researcher. However, my personal connection to breast cancer was often used to legitimate my academic interests in it.
75. Although Deborah was often forgetful, she knew that it had been a relatively long period of time since my mother had been diagnosed with and treated for breast cancer. As will be discussed later, she also, in this instance, as well as others, used my mother as an example of a long-term survivor.

76. Upcoming analysis will show why I and some of the other women had misgivings about using the term.

77. This five year figure is often referenced for many different types of cancers.

78. As noted earlier, part of the reason the women struggled with this issue was because of the uncertainty of their disease and the possibility that they may face a future recurrence.

79. The Hogart women’s accounts of their illness were more likely to have religious undertones than the York or Upton women. As Carol’s comments illustrate, these women often saw their illness not only as a blessing, but also as a gift from God.

80. At that time, both she and her husband were several years from retirement, and took cuts in their pensions to retire early.

81. Although Betty’s marriage probably would have ended eventually, she saw her illness as being the cause of her husband finally leaving.

82. Berkman (1984) and others (Thoits 1996; Wortman and Conway 1985; Wortman and Lehman 1985) also explain, however, that simply having connections to others does not guarantee that people will receive the kind of support that they need. In fact, Wortman and her colleagues report that family members are often the worst support-givers, since they are also affected by the stressful situation or event (Wortman and Conway 1985; Wortman and Lehman 1985). As was discussed in the previous chapter, this is at least one reason why many people turn to support groups for help in dealing with the stressful events or problems in their lives.

83. Antonovsky (1987) refers to these kinds of resources as, “generalized resistance resources,” and argues that they help people to develop a “sense of coherence.”

84. Pearlin and Schooler have argued that such strategies encourage “passive acceptance, withdrawal, an element of magical thinking, a hopefulness bordering on blind faith, and belief that the avoidance of worry and tension is the same as problem solving” (1978:7).

85. Lively (2000) has used the term “reciprocal emotion management” to describe a similar process.

86. Some of the women reported struggling with similar feelings.
87. The same was true for Hogart. Although the hospitals that sponsored the groups provided a space for the women to meet, they did not provide any training or support for the leaders of the group. Bellesmith’s situation was somewhat different, since the group met in a boutique owned by the leader. Like the leaders of Upton and Hogart, however, she had no formal training or background in counseling or facilitating a support group.

88. While she denied that it was an issue for members of the group, she found it problematic for herself, because she had difficulty finding someone else to take over leadership of the group.

89. AstraZeneca is the manufacturer of Tamoxifen, a drug used in follow-up treatment for breast cancer patients. It was also, until the year 2000, a leading producer of pesticides (Milden 2005; Ehrenreich 2001).
REFERENCES


APPENDIX A

PARTICIPANT INTERVIEW SCHEDULE

1. When did you first find out that there was a problem? (Probes: Who told you? What did they say? What was your first reaction?)

2. Who were the first people you talked to after getting the diagnosis? (Probe: What did they say? How did they react?)

3. If partner/spouse is not mentioned above: When did you tell your partner/spouse? How did they react?

4. If subject has children: Did you tell your children? What did you say? How did they react?

5. Did you tell your mother/father? What did you say? How did they react?

6. Who else did you talk to about the diagnosis? What did they say?

7. Who would you say has been most supportive? (Probe: What have they done for you?)

8. What kind of treatment did you decide to have? (Probe: Who did you talk to in deciding what kind of treatment to have?)

9. What was the hardest thing about the treatment? (Probe: Who did you rely on for support during treatment? How did you feel about the support they gave you?)

10. Did you have reconstructive surgery? (Probe: Who did you talk in deciding do it or not do it?)

11. What kinds of things have you had to tell yourself to get through all this?

12. Looking back on your experience now, are there any moments or events that strikes you as funny or absurd? (For example, something about treatment, hair falling out, something someone said...)

13. When people interact with someone who has cancer, they may feel awkward and not know what to say or do. Often what they do say may come out wrong, or their actions may seem offensive. Looking back on your experience, can you recall a time(s) when someone said or did something to you that was inconsiderate, hurt your feelings, or made you angry?

14. Did you or do you ever dream about having cancer?
15. How did you find out about the support group?

16. What was your first impression of the group? (Probe: Did anything surprise you about it? Did anything disappoint you?)

17. How long have you been attending the support group?

18. Did you or do you attend any other support groups?

19. What do you like best about the support group? What do you like least?

20. Is there anything you would change about the support group, if you could? (Probe: Is there anything that could be done differently to make it work better for you?)

21. Is there anything we have not talked about that is important for understanding your experience of breast cancer?
APPENDIX B

FACILITATOR INTERVIEW SCHEDULE

1. How did you get started facilitating the group? (Probe: When? Why? How long have you facilitated the group?)

2. What were your visions for the group? (Probe: What did you hope it would be like?)

3. Did you have any worries or concerns about facilitating the group before you got started?

4. Did the group work the way you had hoped that it would?

5. What do you like best about the group? What do you like least?

6. Have you ever had people that caused problems in the group? (Probe: What happened? What did you do? How did other members react?)

7. Has the group change over time? (Probe: In what ways? How do you feel about the changes?)

8. Has it gotten easier (or harder) for you to facilitate the group over time?

9. Have you ever felt upset after leaving a meeting? (Probe: What happened? What did you do afterwards? Did you talk to anyone about it? What did you tell yourself about it?)

10. One of the things that I have noticed in the meetings is that the women often do not talk about what they feel the most strongly about. (For example, being afraid of dying.) Do you ever get the sense that the women are afraid, or hesitant, to bring up an issue that is especially troubling emotionally? (Probe: What issues seem to be avoided? Would the group work better if the women shared their feelings about those issues?)

11. What kinds of problems have you experienced facilitating the group?

12. Have you ever felt like you made any mistakes, or wished that you had done things differently, in facilitating the group? (Probe: What would you do if you were starting over?)

13. Where appropriate: How did you decide to stop facilitating the group?
APPENDIX C

COUNSELOR INTERVIEW SCHEDULE

1. How did you get started working with cancer patients? (Probe: When? Why? How long have you worked with cancer patients?)

2. What were your visions for working with cancer patients? (Probe: What did you hope it would be like?)

3. Did you have any worries or concerns about doing this kind of work before you got started?

4. Has your job worked the way you had hoped that it would?

5. What do you like best about working with cancer patients? What do you like least?

6. Has your work with cancer patients changed over time? (Probe: In what ways? How do you feel about the changes?)

7. Has it gotten easier (or harder) for you to work with cancer patients over time?

8. Did you ever feel upset after working with a group or patient? (Probe: What happened? What did you do afterwards? Did you talk to anyone about it? What did you tell yourself about it?)

9. One of the things that I have noticed in the support group meetings is that the women often do not seem to deal with or talk about what they feel the most strongly about. (For example, their fear of dying.)

   Do you ever get the sense that patients are afraid, or hesitant, to bring up issues that are especially troubling emotionally? (Probe: What issues seem to be avoided?)

10. Many of the women in the group mention seeking counseling from you (and others). Do you think that there are particular needs that are not (or cannot) be met in a support group? (Probe: Do the women talk about the group? Do they talk about what might be lacking in the group? What do you think patients can gain from participating in a support group?)

11. What kinds of problems do you experience working with cancer patients?

12. Have you ever felt like you made mistakes, or wished that you had done things differently, in facilitating the groups/working with patients? (Probe: What would you do if you were starting over?)